

# IMPROVING ACCESS TO AND LINKAGE BETWEEN HEALTH DATA SETS HELD BY COMMONWEALTH ENTITIES

Response to the invitation by the Senate Select  
Committee into Health

December 2015

## About Research Australia

Research Australia is an alliance of 160 members and supporters advocating for health and medical research in Australia. Research Australia's activities are funded by its members, donors and supporters from leading research organisations, academic institutions, philanthropy, community special interest groups, peak industry bodies, biotechnology and pharmaceutical companies, small businesses and corporate Australia. It reflects the views of its diverse membership and represents the interests of the broader community.

Research Australia's mission is to make health and medical research a higher priority for the nation. We have four goals that support this mission:

- A society that is well informed and values the benefits of health and medical research.
- Greater investment in health and medical research from all sources.
- Ensure Australia captures the benefits of health and medical research.
- Promote Australia's global position in health and medical research.

### **Elizabeth Foley**

CEO & Managing Director  
02 9295 8547  
elizabeth.foley@researchaustralia.org

### **Greg Mullins**

Head of Policy  
03 9662 9420  
greg.mullins@researchaustralia.org

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**RESPONSE TO THE INVITATION BY THE SENATE SELECT  
COMMITTEE INTO HEALTH, DECEMBER 2015**

## INTRODUCTION

Research Australia welcomes the Committee's decision to hold an inquiry into improving access to and linkage between health data sets held by Commonwealth entities.

The health data sets held by Commonwealth entities have the potential to be an important resource for health and medical research, and for this research to be of enormous benefit to the community. This benefit can only be fully realised if the data is as complete and comprehensive as possible; is made available for research purposes; and each data set can be linked to others.

Indeed, even greater benefit can be achieved by linking the health data sets of Commonwealth entities to other Commonwealth datasets (eg. social security records) and to data sets held by the States and Territories (eg. hospital admissions and immunisation records). While respecting the focus of the Committee's current inquiry, Research Australia urges the Committee to consider the benefits of linking datasets from a broader range of sources.

## HEALTH DATA SETS AS A RESOURCE FOR RESEARCH AND BETTER HEALTH

The potential for the better development and use of health data sets to provide benefits to individual patients, healthcare providers and the broader health system and community are well recognised, including by the Council of Australian Governments.

### ***Building the evidence base and improving data collections***

*There is a need to continue research and data development to improve our collective knowledge and understanding of mental health and wellbeing, the many factors contributing to it, their interaction, and effective ways to improve and maintain mental health for people across the population.*

*For example, current Australian mental health and broader health data collections are inadequate in their description of the mental health and social and emotional wellbeing of Aboriginal and Torres Strait Islander people. Improvement of national data collections in these areas will be critical to the design and refinement of services and supports, and to the identification of service gaps. Similarly, evidence of systematically effective approaches to suicide prevention is scarce, but there is an imperative for governments, service providers and the community to perform better in this area. Suicide is a complex phenomenon and in 2010 was the leading cause of death for men aged 16–44.*

*New opportunities are enabling us to increase our knowledge of risk and protective factors for mental health in the early years, using data being collected through the national rollout of the Australian Early Development Index and associated research. Work is also starting on the measurement of social and emotional wellbeing and development in middle age. The value of these collections will increase as data accumulates over time and is linked to other data collections.<sup>1</sup>*

The recent consultation paper for the development of the Australian National Diabetes Strategy has proposed that data linking should be a key element of the strategy, and has clearly articulated the benefits of doing so.

### ***Data linking***

*Healthcare policies relating to chronic diseases such as diabetes should be informed by robust evidence generated for the Australian setting. Since 1992, every Australian who has consulted a doctor, had a medical test or been prescribed a medication has contributed to recorded health data. As a result, there are a number of existing datasets and databases, including the NDSS, the National Diabetes Register, the National Gestational Diabetes register, the Pharmaceutical Benefits Scheme, Medicare records, the AIHW, PCEHR, hospitals, and birth and death registries. Within the recognised legislative and privacy requirements, de-identified aggregate data derived from these linked datasets have the potential to provide valuable information about how people develop diseases (including diabetes); how diseases progress under different preventive and treatment strategies; and how health dollars can be more efficiently and effectively focused.<sup>2</sup>*

While the above statements were made specifically in respect of mental health and diabetes respectively, the same opportunities to deliver better healthcare, improve health systems and inform prevention exist for all areas of health.

<sup>1</sup> COAG, The Roadmap for National Mental Health Reform 2012–22, page 41

<sup>2</sup> National Diabetes Strategy Advisory Group, A Strategic Framework for Action, Consultation paper for the Australian National Diabetes Strategy, 2015 page 32

The Productivity Commission has highlighted a role for the better use of data to help improve the efficiency of Australia's health system.

*More generally, administrative data — including performance data, patient health records and government-held datasets on patients' use of medications or procedures — can support development of a more rigorous evidence base on the clinical and cost effectiveness of health interventions. Among other things, these data (subject to appropriate privacy safeguards) enable researchers to investigate the burden of disease, access to health care across the community, and the effectiveness of specific health interventions. This can help health care providers to choose the best treatments for individual patients. It also helps governments and insurers to make better overall funding decisions by directing funding to where the greatest health benefits can be achieved (including to preventive health measures), and away from interventions with low or no clinical value.<sup>3</sup>*

## Improving care and reducing cost

While the health needs of Australians are broadly the same across the nation and the National Health Reforms have established a broad national framework and a set of targets, the practices adopted by individual Australian hospitals and other healthcare providers vary significantly. Some of this variation is evidence of the adoption of innovative healthcare practices in particular locations; other variation is evidence of a failure to adopt best practice. Data is essential to understanding what is happening where, and why.

Several reports of the National Health Performance Authority have highlighted the variation in performance by individual hospitals and health providers across Australia.<sup>4</sup> More recently, The Australian Commission on Safety and Quality in Health Care has collaborated with the Australian, state and territory governments, specialist medical colleges, clinicians and consumer representatives to develop the *Australian Atlas of Healthcare Variation*.

*This is the first time that data from the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS) and Admitted Patient Care National Minimum Data Set (APC NMDS) have all been used to explore variation across different healthcare settings.<sup>5</sup>*

While the NHPA reports have highlighted the differences and are a valuable resource, they do not identify what needs to be done to improve performance. The Atlas goes a step further and makes some recommendations for change.

Despite the existence of these reports, there is an ongoing need for the comprehensive and routine collection, linkage and analysis of health data in electronic formats. Only then will we be in a position to identify the key areas for improvement. The role of data goes beyond identifying problems; it can also point to potential solutions. And when changes are made to health practice and delivery, the prospective analysis of can be used data to evaluate the effect of the changes.

While some of the pieces are currently in place, and some datasets can be compiled and linked, we are not yet in a position to make optimal use of the data that is currently collected and stored by a range of government departments and agencies across the Commonwealth, States and Territories.

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<sup>3</sup> Productivity Commission 2015, *Efficiency in Health*, Commission Research Paper, Canberra. p.75

<sup>4</sup> National Health Performance Authority, *Hospital Performance: Time patients spent in emergency departments in 2011–12; Healthy Communities: Avoidable deaths and life expectancies in Australian Communities, 2009-2011; Hospital Performance: Length of stay in public hospitals in 2001-12* <http://www.myhospitals.gov.au>

<sup>5</sup> Australian Commission on Safety and Quality in Healthcare 2015, *Australian Atlas of Healthcare Variation*, 2015, p.9

## A NEW FRAMEWORK FOR THE COLLECTION, USE AND LINKAGE OF HEALTH DATA SETS

As the Productivity Commission has noted in the extract quoted above, data can be used by researchers to identify new and improved ways of delivering health services and improving health outcomes, but there is currently a range of impediments to the use of health data sets in this way. We need a new national framework for the collection, storage and use of data which recognises that:

1. Data sets are a valuable and expensive national resource
2. Data should be collected and stored in a manner which enables the use and linkage of data for research purposes.
3. Research is a legitimate purpose for which information can be collected, used and disclosed.
4. Access to data for appropriate research purposes should be facilitated by the owners/operators of data sets.

### **1. Data sets are a valuable and expensive national resource**

While the data within health datasets can also be extremely valuable if utilised properly, the collection and storage of data comes at a significant cost to the community; It is therefore incumbent on governments to ensure that they maximize the value. This can be done by designing data sets so as to ensure the interoperability of databases, the reusability of data and the availability of data for research.

### **2. Data should be collected and stored in a manner which enables the use and linkage of data for research purposes.**

Data are most valuable when data sets are able to be linked, and data linking has multiple purposes. It can support individual patients and practitioners, ensuring that up to date information about a patient from various sources is available when and where it is needed. It is necessary for effective research, to help understand the extent and nature of the problem, inform research and identify which solutions work. Data linkage is also needed to support the effective monitoring of the performance of the health system in treating and preventing disease (particularly chronic disease) and understanding the impact of disease on patients and the community. Individual data sets cannot provide the richness needed to achieve these objectives; it can only be achieved when numerous data sets are linked.

To provide the clearest picture of the social and economic impacts of disease, the linking of data sources needs to incorporate socioeconomic and demographic data as well as health data.

Data sets must be created with the expectation that they will be linked to other data sets. Furthermore, data sets need to be linked in ways that support future expansion and usability- so that, for example, as research identifies further conditions that are diabetes related, health information on these conditions can be included and linked to data on diabetes, including patient records.

### **3. Research should be specifically recognised as a purpose for which information can be collected, used and disclosed.**

Legislation is required to recognise that research is a legitimate purpose for which health data can be collected, stored and used; and to appropriately balance this use with concerns relating to data security and individual privacy. Recent experience provides an example of the need to explicitly recognise research as a purpose for which data is collected and stored.

The Personally Controlled Electronic Health Records Act (PCEHR Act) establishing the Personally Controlled Electronic Health Record (now 'My Health') was passed by Parliament in 2012. The legislation specifically provides that the provision of data for research or public purposes is allowed, and makes provision for rules to be made for these purposes. This is useful, and to some extent a model for all legislation establishing data sets. However, rules can only be made in relation to the provision of 'de-identified data.'

Putting aside the finer technical debates about 'deidentified' and 'reidentifiable' data, Research Australia acknowledges that researchers rarely need to know the identity of individuals, and that these exceptions typically relate to research activities such as clinical trials where the individual's consent to the provision of their health information can be obtained as part of their consent to participation in the trial. The real difficulty with the requirement that only de-identified data can be provided is the limitation this imposes on the ability to link data from the data set with other data.

The Population Health Research Network (PHRN) has been established by the Australian Government to build a nationwide data linkage infrastructure capable of securely and safely managing health information from around Australia. The PHRN is developing and testing leading-edge technology to ensure the safe and secure linking of data collections whilst working to protect individuals' identity and privacy<sup>6</sup>. It is also developing mechanisms for the secure exchange of linkable data between those who hold the data collections (Data Custodians) and the researchers who receive approval to analyse the linked data. A key aspect of these arrangements is that the linked datasets provided to researchers do not contain the identifying information of the individuals whose data is included in the dataset, thus protecting their privacy.<sup>7</sup>

As the PCEHR Act is currently drafted, the PCEHR Operator can only provide de-identified data for research purposes, effectively preventing identified data in the PCEHR system from being provided to the PHRN (or any other agency) for linking to other data sources.

The PCEHR Act and the enacting legislation for other Commonwealth data sets need to be amended to explicitly recognise research as a purpose for which data is collected, stored and used, **and to provide for the provision of identified data to approved data linkage agencies**. In 2010, Australian Government Portfolio Secretaries endorsed seven high level principles for data integration as well as a supporting set of governance and institutional arrangements.<sup>8</sup> Adherence to this framework could be a condition for approval as a data linkage agency.

#### **4. Access to data for legitimate research purposes should be facilitated by the operators of data sets**

The linking of data requires the manipulation of datasets to facilitate the extraction of data and the linking process. This activity takes time and effort and may require specific skills and tools. In many cases the operator of the data set is best placed to undertake the manipulation of the data and the provision of the dataset to the researcher or a data linking agency in a format that enables the linking to be undertaken. (In some cases the operator may be the only person or entity capable of doing this.)

Research Australia submits that the operators of Commonwealth Health data sets should be appropriately resourced so as to be able to undertake the activities required to facilitate the use of the data sets for research purposes.

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<sup>6</sup> [www.phrn.org.au/about-us/privacy](http://www.phrn.org.au/about-us/privacy)

<sup>7</sup> Disclosure: Elizabeth Foley, CEO of Research Australia, is a member of the Board of the PHRN.

<sup>8</sup> <https://statistical-data-integration.govspace.gov.au>



## DATA, LINKAGE AND PRIVACY

As noted earlier, the Productivity Commission has recently looked at Australia's health system and identified the capacity to make much greater use of data, including through linking of data sources. The Commission also recognised that the current legislative and regulatory requirements in relation to Privacy are unreasonably restricting the ability to use data for research and other purposes.

*'Political will is often needed to address privacy concerns in a way that allows data to be released. Policy makers need to make trade offs between a high level of confidentiality and the consequences of not making data available. Concealing data can mean that patients receive ineffective (or even harmful) care, adverse effects of drugs go undetected, or significant money is spent on interventions that do not improve health outcomes (rather than on interventions that do). It can also make it difficult to hold health care providers to account for their performance.'*

*Importantly, moving towards releasing more data does not need to mean releasing all data: releasing some data (with appropriate safeguards) is still better than releasing none. As a general principle, the onus should be on those who wish to withhold data to make a strong case for doing so.'*<sup>9</sup>

Research Australia agrees with the Productivity Commission's position that sensible reforms of the current privacy and confidentiality regime are possible which would facilitate better access for research purposes while providing appropriate protection to individuals. Research Australia urges the Committee to support the Productivity Commission's call for reform in this area.

## MAKING EFFECTIVE USE OF DATA

While linking data is critical we also need to ensure that Australia has the data management capability to undertake the linking effectively, and the data analysis capability to make the best use of the data. The need for greater capability in this area, preferably through shared infrastructure and resources available to all research groups needs to be recognised.

More health services research needs to be undertaken to improve the implementation of evidence based care, and we need to build the capacity of the health services research workforce. This includes the capacity of the individuals working within the health system to analyse and interpret data to evaluate the delivery of healthcare in their own workplaces.

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<sup>9</sup> Productivity Commission 2015, *Efficiency in Health*, Commission Research Paper, Canberra. pp.85-86

## CONCLUSION

Research Australia is pleased that the Committee has recognised the scope for better linkage of health data sets and greater access to data, particularly for research purposes.

Research Australia conducts annual opinion polling on a range of issues and questions related to health and medical research. This opinion polling consistently shows that the Australian community values health and medical research. Australians support greater Government expenditure on health and medical research and contribute financially themselves. Australians also support research in more tangible ways; in the most recent polling, only 4% of Australians reported that they were unwilling to share their health information for research purposes.<sup>10</sup>

Research Australia strongly supports initiatives to more routinely collect and store health data electronically and to make this data available for research purposes. Doing so has the scope to improve the care provided to individuals, the health of the overall community, and the efficiency of our health system. The linking of health data sets provides the opportunity to address bigger and more complex questions more effectively and quickly, and providing enabling legislation to permit the linking of datasets as well as the resources to undertake this work should be a high priority for Commonwealth, State and Territory governments grappling with how to provide a world standard health care system while constraining the growth in expenditure.

If you require any further information, please contact Greg Mullins, Head of Policy, on 03 9662 9420 or at [greg.mullins@researchaustralia.org](mailto:greg.mullins@researchaustralia.org).

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<sup>10</sup> Research Australia, Australia Speaks! Research Australia Opinion Polling Volume 13, page 8

**RESEARCH AUSTRALIA LIMITED**

384 Victoria Street Darlinghurst NSW 2010

**T** +61 2 9295 8546 **ABN** 28 095 324 379

[www.researchaustralia.org](http://www.researchaustralia.org)