

AUSTRALIAN CHRONIC DISEASE PREVENTION ALLIANCE



Submission to the Productivity Commission Inquiry Data Availability and Use July 2016

About ACDPA

The Australian Chronic Disease Prevention Alliance (ACDPA) is an alliance of five non-government health organisations who are working together in the primary prevention of chronic disease, with particular emphasis on the shared risk factors of poor nutrition, physical inactivity and overweight and obesity.

The members of the Alliance are:

- Cancer Council Australia
- Diabetes Australia
- Kidney Health Australia
- National Heart Foundation of Australia
- National Stroke Foundation.

ACDPA welcomes the opportunity to provide comment on the Productivity Commission Issues Paper on Data Availability and Use.

Our comments focus on the availability and accessibility of high quality data on chronic disease and associated risk factors, in order to understand disease burden, monitor population trends over time, identify research gaps, and inform strategies and investment in the prevention and management of chronic disease.

Context

Chronic disease is recognised as Australia's greatest health challenge.¹ Chronic diseases are the leading cause of illness, disability, and death in Australia, accounting for 90% of all deaths in 2011.² Around one in two Australians has a chronic disease and around 20% have at least two chronic illnesses or conditions.³

However, much chronic disease could be prevented through the elimination of common risk factors. At least 80% of all heart disease, stroke, and type 2 diabetes, and over 40% of cancer could be prevented.⁴

National Strategic Framework for Chronic Conditions

A new National Strategic Framework for Chronic Conditions is currently in development through the Australian Health Ministers' Advisory Council's Community Care and Population Health Principal Committee. In the Framework, *Data and Information* is identified as a key Enabler to inform policies, strategies, actions and services that will support people with, or at risk of developing, chronic conditions:

"Data and Information - the use of consistent, quality data and real-time data sharing enables monitoring and quality improvement to achieve better health outcomes".⁵

Specifically the Framework highlights the importance of data collection, linkage and sharing across health settings, services and sectors to:

- Promote health and improve management of risk factors
- Improve performance and health outcomes
- Identify and better target priority populations
- Strengthen the evidence base and support new and innovative solutions
- Avoid duplication of effort and fragmentation
- Inform design, innovation and continuous quality improvement of services and policy.

The collection, availability and coordination of high quality data will contribute to a greater understanding of the health, social and economic impacts of chronic disease, as well as informing strategies for effective prevention and management.

As such, the Productivity Commission's Inquiry should consider and align with the data priorities identified in the National Strategic Framework for Chronic Conditions.

International chronic disease prevention

On a global scale, the 'WHO Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020' urges governments to set targets, develop multisectoral national chronic disease plans in order to reach these targets, and measure results.⁶ Consistent with this, national data collection and reporting on progress towards targets, actions and indicators is important to determine improvements and reflect Australia's international commitment to address chronic disease.

Australia's healthcare system

Medicare is Australia's universal health insurance scheme. This Commonwealth government program provides access to medical and hospital services to Australian citizens at no, or a reduced cost. The Medicare Benefits Schedule lists all services for which there is a benefit and the Pharmaceutical Benefits Scheme lists medicines available at a subsidised cost.

As healthcare is delivered in a mix of private and public services, and in some disease areas there is a high interaction between the two sectors, access to comprehensive and meaningful public and private sector data is necessary to inform evidence-based, system wide health interventions.

Improving the availability of public sector data

The concept of open data is gaining momentum internationally, with the United States and United Kingdom providing precedents for making health data more accessible, usable and useful for a range of audiences. The US National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) open data portal contains 103 chronic disease datasets totalling over 33 million rows of data (at October 2015), to promote greater openness, interoperability and innovation through accessible and usable chronic disease data.⁷

Increasing openness and accessibility of public health data reduces time from data collection to dissemination, and broadens the reach and uses of public health data. Greater data availability and linkage have the potential to promote innovation and target investment in the prevention and management of chronic disease.

From a health and medical research sector perspective, it is not possible to provide a comprehensive list of all public sector datasets that should be considered high value. Rather, the assumption should be that all public sector datasets that can be linked, on an individual basis, with health records, are potentially high value. This includes birth, marriage, death, Medicare Australia, hospital, employment, education and welfare records, as well as individually identified records from population surveys conducted by government agencies such as the National Health Survey, conducted by the Australian Bureau of Statistics (ABS).

While it is not possible to list all public sector datasets that should be considered high value, there are characteristics that define these datasets:

- the data are accurate, with known level of accuracy and completeness
- the dataset contains individually-identified records that can be linked to other datasets
- the dataset is comprised of all eligible individuals in a population (such as Medicare Australia data), rather than smaller, ad hoc datasets

Some high value datasets relevant to chronic disease have been identified below, which could be linked to enable better informed health policies and more efficient use of health resources:

- National health surveillance data, including the 2011-12 Australian Health Survey which collected self-reported data on health status, risk factors, and health service use, and physical and biomedical measures of nutritional status and chronic disease markers
- National disease registries and related clinical databases, where available
- Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Schedule (MBS) data
- Australian hospital inpatient data
- Electronic health records, i.e. My Health Record, which provides an online summary of an individual's health and medical history.

Gaps in public sector data

National collection and linkage of data on risk factors, health determinants, diagnosis, treatment, care pathways and outcomes would inform monitoring and surveillance of chronic diseases. Further, improvements in data completeness, quality and availability would provide a stronger evidence base on emerging issues, current and planned interventions, and future trends.

Regular collection and availability of national health surveillance data, including physical, biomedical and environmental measures, enable monitoring of chronic disease risk factors over time and assessment of the effectiveness of preventive health strategies.

While national health surveys record some chronic disease markers, national disease registries are required to capture clinical data. National cancer registries record incidence and mortality data; however there are no national registries recording the incidence and prevalence of cardiovascular disease (including heart disease and stroke), diabetes and chronic kidney disease. In the absence of population-level registry data, national survey data and proxy measures are currently used to estimate incidence of these diseases.

Limited data are also available for certain groups of the population, including Aboriginal and Torres Strait Islanders. Chronic diseases occur more often and account for two-thirds of the

gap in death rates between Indigenous and non-Indigenous people.⁸ Regular and quality collection and reporting on the incidence and prevalence of chronic disease amongst Aboriginal and Torres Strait Islander populations are crucial to assess health status, monitor changes over time, and inform prevention and treatment strategies.

Improving the availability of private sector data

In Australia, health and medical services are delivered through a combination of public and private providers. Data from publicly funded healthcare is generally available, although with some room for improvement; however the ability to access comprehensive and accurate private sector data would itself be considered high value data. Linking public and private sector data and standardisation of data collection across the public and private health sectors would be of great benefit.

Further, vast amounts of individual health data (including potential risk factors and health outcomes) are collected by the private sector on a daily basis through wearable technologies and smartphone apps. New technologies are beginning to enable cost-effective analyses of this type of big data, combined with electronic records, private insurance and pharmaceutical records.^{9,10} Analyses at the population-, subpopulation-, and personal-levels have the potential to identify correlations between risk factors and disease, and determine the most effective approaches for disease prevention for various subgroups. 'Precision health' has the potential to provide an 'evidence-based' approach to targeted, predictive and personalised care through the analysis of large datasets, which inform predictions of individual disease risk and strategies for maintaining health.

Key considerations in the potential of precision health are consent, confidentiality, access and oversight when such large datasets are combined and analysed, in order to maintain the privacy and security of individual health data.

Considerations

There are a number of factors that are currently restricting the availability of data, including: legislative, logistic and other administrative problems in transferring and exchanging data; policies and restrictions on the release of data; lack of funding for the development of advanced data systems and infrastructure; and complexities in ensuring the security and privacy of confidential health data.

It is acknowledged there will be workforce and financial pressures that the delivery of open data will impose on data custodians; however, the cost to government departments and agencies are small compared with the economic benefits that more accessible data will drive. In Australia, the estimated economic value of open government datasets ranges from \$500 million to \$25 billion per year.¹¹ A report by McKinsey & Co suggests that open data may help create \$3 trillion a year of value in the global economy.¹² How much governments will need to invest will depend on what infrastructure and expertise is already in place, how much data has already been collected, which datasets are published, and which policies are put in place to support the open data ecosystem.

A significant consideration for government is the cost associated with anonymising data. Departments such as Health and Social Services hold enormous amounts of data; however, much of it is highly confidential. Anonymising this data requires a degree of expertise that

not all government agencies and departments will have, and as such, there may need to be some investment in capacity building within government. It will also be important to develop processes for updating data once it is anonymised.

In addition to developing cost-effective ways of anonymising and continuously updating datasets, other cost considerations include legal costs to comply with open data legislation, and potential liability costs.

As mentioned earlier, one of the key concerns with linking multiple datasets is the protection of individuals' privacy. Therefore, it is critical that government continues to fund initiatives such as the Population Health Research Network (PHRN), which is developing and testing leading-edge technology to ensure safe and secure linking of data collections whilst protecting identity and privacy.¹³

Summary

There is great potential for open health data to inform chronic disease prevention and management through the collection, availability and analysis of high quality health data on risk factors, disease burden and health outcomes over time.

However, privacy and security of individual health data are crucial considerations in progressing the potential of open health data.

Contact

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