SUBMISSION TO THE PRODUCTIVITY COMMISSION:

INQUIRY INTO DATA AVAILABILITY AND USE

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INTRODUCTION

The National Heart Foundation welcomes the opportunity to make a submission to the Productivity Commission's Inquiry into Data Availability and Use. As an organisation dedicated to reducing suffering and death from heart, stroke and blood vessel disease in Australia, the Heart Foundation acknowledges the important role data availability and use plays in improving health care. The Heart Foundation generates and translates research evidence to help all Australians achieve better heart health. Through the strategic collection and use of data, we identify information gaps and analyse the heart health needs in the community. Our research program funds world-class cardiovascular research and focuses on supporting early to mid-career researchers to ensure Australia continues to grow much needed capacity to address cardiovascular health issues.

The focus of this submission relates to health-related data and datasets. We aim to identify high value data and the benefits that can be realised if data and/or datasets are to be made available and/or data linkages enhanced.

The Heart Foundation undertakes and funds important cardiovascular research and holds the view that with improved data linkages and availability of large datasets, this will create efficiencies by reducing duplication amongst researchers along with reducing costs and resources associated with conducting research (i.e. clinical trials). It would also improve the effectiveness of research by providing a more accurate picture of health and wellbeing.

Improving data quality requires a change in clinical and managerial practices as well as good design of health information systems that embed accurate documentation into workflows. There also needs to be a focus on the safety and quality of patient-centred care.[1] This submission focuses on the key themes of data availability, timely access to data and data linkages. Examples of benefits derived from increased availability and linkage of data within the cardiovascular setting are provided.

Creating a new, sustainable and accessible source of nationally linked data is a priority for health and health research. It will provide both efficiency and effectiveness across the health and research sector, enabling researchers' streamlined, timely and secure access to data to inform policy and program initiatives that can improve the health outcomes of the population.

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[1] Liaw ST and de Lusignan S. *An integrated health neighbourhood framework to optimise the use of EHR data*. J Innovations in Health Informatics 2016 (in press).

DATA AVAILABILITY

High value data within the health system include datasets that are routinely used by governments and healthcare providers to monitor the health and treatment of Australians, as well as healthcare expenditure. Ideally, these datasets have high completion rates and contain standard definitions and reliable data. Such data includes hospital separation, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Schedule (PBS), births, deaths, health practitioner registration and disease notifications. Increased access to and linkages between these data would improve efficiencies and effectiveness for health and research.

For example, hospital separation and morbidity data should be pooled nationally and linked with the death index, the MBS and PBS datasets in a more efficient manner than at current. By doing so, it will be possible to get an objective assessment of outcomes and variations in care nationally.

Registries are varied within the health field, in particular, with cardiovascular disease. Device, procedure and quality registries are high-value datasets that can provide a rich source of information to clinicians and researchers alike.

Clinical quality registries should be prioritised and harmonised where they exist. In the cardiovascular disease setting, one example is the Australasian Cardiac Outcomes Registry (ACOR).[2] This is a national procedures registry, and should be contributed to by state-based registries.

Other high value data that should be available and linked includes:

- General practice

- Private health insurance data

- Community services data

- Aged care

- Research data, including government, nonprofit and private

- Pathology and imaging laboratories

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[2] http://acor.net.au/

Timely access to data

Timely access to and availability of cross-jurisdictional linked data are essential to health researchers to influence policy and practice to improve public health and wellbeing of communities, in particular those National and State priority areas such as cardiovascular disease.

Timeliness of data access is a significant obstacle to Australia achieving an improved system of health data integration. For example, delays in linked State-based data provision have become commonplace in a number of State jurisdictions over recent years. Research groups have experienced delays of multiple years in the provision of data in some instances. Such delays place competitively funded projects at risk of not being completed to the level that was specified in the grant proposal. Also, access to Commonwealth data is largely impractical with current delays ranging from two to six years, leading to important research not being undertaken or even attempted.[3,4,5.]

DATA LINKAGES

Data linkages are vital to understanding the complete picture of health, health outcomes and treatment. Current data linkages are state-based, limiting the usefulness of the data at a national level. Cross-jurisdictional linkage is essential to provide a more complete understanding of health than would be possible utilising State-based data alone. Furthermore, linking health data with other public sector data such as aged care, community services, housing and the environment sector would allow population health policy and planning to be more integrated.

Improved processes and timelines for data linkage between Australian States with Commonwealth data collections (e.g. MBS, PBS) are needed. Processes around ethics and governance for access to big data also needs to be simplified. A key solution would be to adopt a national policy for a streamlined application process to access data. A centralised (government) approach, such as the Integrating Authority[6], offers a more assured and efficient linkage of a greater range of data collections across multiple sectors and jurisdictions.

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[3] Population Health Research Network. *2013 Independent Panel Review Findings and Recommendations.* 17 April 2014. Accessed on 28/07/2016. Available at: http://www.phrn.org.au/media/80607/phrn-2013-independent-review-findings-and-recommendations-v2-_final-report-april-17-2014-2.pdf

[4] Menzies Foundation. *Public Support for Data-based Research to Improve Health.* 16 August 2013. Accessed on 28/07/2016. Available at: https://www.lowitja.org.au/sites/default/files/docs/10-Menzies-Foundation-Public-support-data-based-research.pdf

[5] McLaughlin, D and Dobson, A. *Women's health Australia – Submission to PHRN Review.* The Australian Longitudinal Study on Women's Health. Accessed on 28/07/2016. Available at: http://www.phrn.org.au/media/80591/australian-longitudinal-study-of-womens-health.pdf

[6] http://www.nss.gov.au/nss/home.nsf/pages/Data%20Integration:%20Accredited%20Integrating%20Authorities

BENEFITS

The benefits of increased access to and linkage of high-value datasets are many and varied. Specific examples are provided below, but overall benefits include:

- All of population research and monitoring of health outcomes can be achieved to inform policy and programs,

- Routinely collecting standardised data and establishing simplified processes for its release will ensure ongoing savings and efficiencies are created, and

- Longitudinal studies will be more feasible.

Example: Outcomes Research

The Case for Action proposal to the NHMRC by Zeitz and Beltrame gives an example of where using outcome measurements and assessment criteria standardised across Australia can lead to health improvements. The proposal describes Outcomes Research as "comprehensive, collaborative and essential to the improvement of future health care".[7] To enable quantitative assessment of clinical outcomes, measurements are derived from many sources, including administrative datasets (e.g. hospital morbidity data, Medicare, birth/death registries), adverse event reporting, clinical registries and data linkage. These measurements can then be used to assess and benchmark clinicians'/health services. The proposal suggests that establishing clinical registries and adopting the key principles of outcomes research may improve cardiovascular healthcare in three ways:

1. Improved outcomes (e.g. compliance with guidelines will see improvements in care),

2. Reduced healthcare costs (e.g. guidelines adherence reduces events and hospital admissions and more appropriate use of cardiovascular investigations results in costs savings), and

3. Clinician engagement (e.g. feedback to clinicians is imperative for clinical practice to change and allows for innovation).

Routinely undertaking standardised outcome measures and applying performance criteria will benchmark clinicians and health systems and foster improvements in health care delivery. These

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[7] Zeitz C, Beltrame J. *Case for Action proposal: Appropriateness and performance in the management of cardiovascular disease in Australian hospitals.* Submitted by the NHMRC Research Translations Faculty Cardiovascular Health and Stroke Steering Group; October 2014, p. 8. Available at: www.nhmrc.gov.au/research/research-translation/research-translation-faculty/ideas-research-translation-faculty-cases.

outcome measures must be collected, analysed and reported back to the clinicians'/health system for clinical care improvements to be facilitated.

Example: Data Linkages in the United Kingdom

Several studies based in the United Kingdom (UK) have shown the benefits of data linkage in regards to a specific cardiovascular condition (Atrial Fibrillation). [8,9,10] These studies were conducted using the UK Clinical Practice Research Datalink (CPRD), the Hospital Episodes Statistics (HES) and the Central Mortality data of the Office for National Statistics (ONS).

The CPRD contains the complete primary care medical records for more than 11.7 million people enrolled in 684 general practices representative of the UK population. The CPRD includes demographic and lifestyle data, full primary care medical symptoms and diagnoses, laboratory tests and referrals. Furthermore, prescriptions issued by general practitioners are automatically transcribed into computer records.

The HES include ethnic origin, dates of hospital admission and discharge, primary and other main reasons for treatment, and surgical operations and procedures performed during hospital stay. The ONS data consists of date and cause of death as recorded in death certificates.

Through the availability and linkage of this data, one of these studies was able to describe the current main epidemiological features of a very large cohort with incident non-valvular atrial fibrillation in the UK, and the temporal trends of standardised atrial fibrillation incidence over the last 13 years.

It used very recent data derived from a source population of 6.1 million patients, and included primary care and hospital discharge information.[11] Another study was able to identify the number of patients with atrial fibrillation who remained on anticoagulant therapy after one year of commencement. This greater therapy persistence to one medication over another could lead to fewer cardioembolic strokes.[12] The third study provided[13] was the first study of incidental detected

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[8] Martinez C, Katholing A, Wallenhorst C and Freedman SF. *Therapy persistence in newly diagnosed non-valvular atrial fibrillation treated with warfarin or NOAC – A cohort study.* Thrombosis and Haemostasis 115.1/2016. August 2015.
[9] Martinez C, Katholing A, Wallenhorst C, Granziera S, Cohen AT and Freedman SB. *Increasing incidence of non-valvular atrial fibrillation in the UK from 2001 to 2013.* Heart 2015 101: 1748-1754 originally published online August 25, 2015. doi: 10.1136/heartjnl-2015-307808
[10] Martinez C, Katholing A and Freedman SB. *Adverse prognosis of incidentally detected ambulatory atrial fibrillation - A cohort study.* Thrombosis and Haemostasis 112.2/2014. June 2014.
[11] Martinez C, Katholing A, Wallenhorst C, Granziera S, Cohen AT and Freedman SB. *Increasing incidence of non-valvular atrial fibrillation in the UK from 2001 to 2013.* Heart 2015 101: 1748-1754 originally published online August 25, 2015. doi: 10.1136/heartjnl-2015-307808
[12] Martinez C, Katholing A, Wallenhorst C and Freedman SF. *Therapy persistence in newly diagnosed non-valvular atrial fibrillation treated with warfarin or NOAC – A cohort study.* Thrombosis and Haemostasis 115.1/2016. August 2015.
[13] Martinez C, Katholing A and Freedman SB. *Adverse prognosis of incidentally detected ambulatory atrial fibrillation - A cohort study.* Thrombosis and Haemostasis 112.2/2014. June 2014.

ambulatory atrial fibrillation and followed a very large cohort for three years. It found that incidental ambulatory atrial fibrillation is common and is associated with a serious risk of stroke, death and myocardial infarction compared to controls. Based on this study, the authors argue for more comprehensive targeted screening to reduce the burden of stroke and premature death associated with atrial fibrillation.

Example: An 'Integrated Health Neighbourhood' Framework to Optimise the Use of EHR Data[14]

This paper describes a vision of an integrated health neighbourhood underpinned by a community wide health information exchange. It uses a model of multilevel integration of data, information, clinical practice and disciplines to support inter-professional coordinated care across primary, secondary and tertiary care settings. The study used an electronic data repository, which links and manages data extracted from admissions, emergency department and diabetes clinics at one hospital with ten general practices. The authors suggest that replicating this model across the health system, nationally and globally, will enable comparative effectiveness research to be done logically and cost effectively.

Example: Acute Coronary Syndrome Care Across Australia and New Zealand: The SNAPSHOT ACS Study[15]

This study was the first comprehensive combined Australia and New Zealand audit of Acute Coronary Syndrome (ACS) care. It identified variations in the application of the ACS evidence base and varying rates of in hospital clinical events. Once identified, these variations incentivised some jurisdictions to focus on the development of electronic data collection within the Electronic Medical Record.

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[14] Liaw ST and de Lusignan S. *An integrated health neighbourhood framework to optimise the use of EHR data*. J Innova-tions in Health Informatics 2016 (in press).
[15] Chew D, French J, Briffa TG, Hammett CJ, Ellis CJ, Ranasinghe I, Aliprandi-Costa BJ, Astley CM, Turnbull FM, Lefkovits J, Redfern J, Carr B, Gamble GD, Lintern KJ, Howell TEJ, Parker H, Tavella R, Bloomer SJ, Hyun KK and Brieger DB. Acute coronary syndrome care across Australia and New Zealand: the SNAPSHOT ACS study. Med J Aust 2013; 199 (3): 185-191.