

# STILLBIRTH RESEARCH AND EDUCATION

## Submission to the Senate Select Committee on Stillbirth Research and Education

29 June 2018



## About the Population Health Research Network

The Population Health Research Network<sup>1</sup> (PHRN) is a national data linkage infrastructure network. The PHRN commenced in 2009 and is funded by the Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS), with support from state and territory government agencies and academic partners. The University of Western Australia is lead agent for the PHRN. The PHRN's primary purpose is to build and support the operation of collaborative, nationwide data linkage infrastructure capable of securely and safely linking data collections from a wide range of sources including within and between jurisdictions and across sectors and providing access to linked data.

Through the support of the PHRN, Australia now has the facilities and capabilities to link and provide access to linked data in all jurisdictions. This infrastructure is of international significance. PHRN achievements include:

- Establishment of new data linkage units in Queensland, Victoria, Tasmania and South Australia
- Establishment of an accredited Commonwealth Integrating Authority at the Australian Institute of Health and Welfare (AIHW)
- New online application and secure data delivery systems which facilitate access to data
- Establishment of a remote access data laboratory (SURE) that enables researchers to access linked datasets in a secure environment from anywhere in Australia

The PHRN infrastructure supports the linkage of data collections from both the public and private sectors across a range of disciplines including health, education and social services e.g. hospital admitted patients, cancer registries and the Australian Early Development Census.

The PHRN and its participants have decades of experience in operating safe and secure, national data linkage infrastructure. More than 80% of research using linked data in Australia uses the PHRN infrastructure.

The PHRN is continuing to improve Australia's data linkage infrastructure, increase access to linked data and expand the use of linked data. Current PHRN projects include:

- Enduring/routine linkage of Commonwealth to Commonwealth data collections e.g. MBS and PBS and Commonwealth to state/territory data collections e.g. hospital to PBS
- Expansion of the number and type of data collections that are routinely linked at both the Commonwealth and state/territory levels
- Streamlining of application and approval processes required to access linked data
- Content data repositories such as the equivalent of the Custodian Administered Research Extract Server<sup>2</sup> in each jurisdiction to reduce the burden on data custodians and minimise the time to extract data for research and analysis

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<sup>1</sup> The Population Health Research Network. Perth WA (Aus). 2016 [cited 27/10/2017]. Available from <http://www.phrn.org.au>

<sup>2</sup> Eitelhuber and Davis Health Information Science and Systems 2014, 2:6 <https://link.springer.com/article/10.1186/2047-2501-2-6> [accessed 27/10/2017]

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### Recommendations

The PHRN supports further research into the causes and ways to prevent stillbirth. The following recommendations are made:

1. Researchers should be made aware of the linked data resources currently available for research into stillbirth.
2. States/territories to send high quality linkage variables with their national minimum dataset submissions.
3. Governments should ensure that data linkage units and data custodians are sufficiently resourced to meet both internal government and external researchers' data needs.

### 1. Introduction

In the years 2013 and 2014 the stillbirth rate in Australia was 7.1 per 1,000 births. This rate has remained relatively unchanged for decades (1995 and 2014).<sup>3</sup> Although the causes of most stillbirths are known approximately 15% of the deaths remain unexplained.<sup>4</sup> In order to address this significant health issue further research into the causes and ways to prevent stillbirth is required.

This submission addresses the first term of reference “consistency and timeliness of data available to researchers across states, territories and federal jurisdictions”.

### 2. Consistency and timeliness of data available to researchers across states, territories and federal jurisdictions

A wide range of research methods will be required to better understand how to prevent stillbirths including trials of models of care and prospective cohort studies. Analysis of existing data should be one of these methods as it is cost effective and can illuminate issues at the population level. Currently there are two main sources of data for research into stillbirth – death registrations and the perinatal data collected by midwives.<sup>5</sup> Both of these data sources are maintained by states and territories who provide data on to national death and perinatal data collections. A more detailed understanding of stillbirth can be gained by linking death and perinatal data with data from a range of other sources including hospital admissions, emergency department admissions and prescription pharmaceuticals.

In seven out of the eight states and territories perinatal and death data are already routinely linked to other administrative data collections by PHRN funded data linkage units.<sup>6</sup> This enables a range of research to be conducted at the jurisdictional level.

For national cross-jurisdictional or multi-jurisdictional research the PHRN provides a coordinated service for the application and linkage of data collections. This includes ad hoc linkage to the Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS)

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<sup>3</sup> Australian Institute of Health and Welfare 2018. Perinatal deaths in Australia: 2013–2014. Cat. no. PER 94. Canberra: AIHW.

<sup>4</sup> *ibid*

<sup>5</sup> ABS 3303.0 - Causes of Death, Australia, 2016. AIHW National Perinatal Data Collection (NPDC)

<sup>6</sup> <http://www.phrn.org.au/for-researchers/data-collections-available-by-jurisdiction/> (accessed 25/06/2018)

data. The linkage of researcher datasets e.g. clinical trial data to administrative data collections is also available.

The PHRN is currently funding a project to achieve routine linkages between the state/territory data collections and the Commonwealth data collections e.g. MBS and PBS through the Australian Institute for Health and Welfare. This should improve the timeliness of provision of linked data to researchers.

**Recommendation 1:** Researchers should be made aware of the linked data resources currently available for research into stillbirth.

Whilst there have been significant improvements in the number of linked data collections available for researchers in the last five years there remain several barriers/challenges:

- The application and approval processes remain burdensome. This is a result of the different legislation and policies in each jurisdiction.
- Some jurisdictions remain reluctant to share identifiers across borders to enable cross-jurisdictional linkage.
- The national minimum datasets are high quality and standardised data across jurisdictions. However, they are currently not linked. In addition, much more detailed data is available at the jurisdictional level and this is not nationally standardised.
- Increasing internal use of linked data by government departments may result in decreased access for non-government researchers as government use is prioritised.

The Government's response to the Productivity Commission's Report on Data Availability and Use may result in improvements in the barriers identified in first two dotpoints above. However, it is currently unclear how much impact the response will have at the state/territory level.

If the states/territories agreed to provide high quality identifiers with their national minimum dataset submissions this would enable high quality linkage of these standardised datasets. Ideally this linkage would be part of the cross-jurisdictional routine linkages currently being developed by the PHRN.

**Recommendation 2:** States/territories to send high quality linkage variables with their national minimum dataset submissions.

**Recommendation 3:** Governments should ensure that data linkage units and data custodians are sufficiently resourced to meet both internal government and external researchers' data needs.