Population Health Research Network Response to the call for submissions: A review of data linkage capabilities in Western Australia to enhance the next generation of whole-of-Government data linkage

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1. Population Health Research Network

The Population Health Research Network (PHRN) welcomes the opportunity to contribute to the review of data linkage capabilities in Western Australia to enhance the next generation of whole-of-Government data linkage.

The PHRN is Australia's national data linkage network and was established in 2009. The PHRN is funded by the National Collaborative Research Infrastructure Strategy (NCRIS). The PHRN is the only NCRIS capability led from Western Australia.

The original purpose of the PHRN was to expand, build and/or evaluate infrastructure for the probabilistic linkage of data relevant to the health and wellbeing of the Australian population. The PHRN now supports a network of state data linkage units which provide services for Australian states and territories, national data linkage units which conduct cross-jurisdictional linkage and a number of national eResearch tools and services to assist researchers to access linked data efficiently and securely. Further information on PHRN is available at www.phrn.org.au.

From 2008-09 through to 30 June 2017, the PHRN has been allocated $46.6 million from NCRIS. The University of Western Australia (UWA) as the Lead Agent for the PHRN has entered into successive funding agreements with the Australian Government Department of Education and Training and taken responsibility for implementing the PHRN investment plans. UWA sub-contracts with all of the PHRN's Participant Organisations to build and implement the agreed data linkage infrastructure.

2. Barriers and challenges for WA involvement in cross-jurisdictional data linkage and the PHRN

2.1 Funding

The main barriers to WA Department of Health (WADOH) involvement in the PHRN appear to be a reluctance to accept Australian Government funding through UWA and an inability to negotiate funding agreements in a timely fashion.

The Western Australian Data Linkage Branch (WADLB) was well established when the PHRN commenced in 2009 and was the model for the new PHRN-supported data linkage units. WADLB and the Centre for Health Record Linkage (CHeReL) in NSW which started in 2006 did not receive funding for establishing a data linkage unit through the first NCRIS Funding Agreement. However, WADOH was allocated funding to coordinate the PHRN Proof of Concept (POC) Collaborations which were to assess the ability of the new data linkage infrastructure to perform cross-jurisdictional linkage of data and provide linked de-identified data in a form that can be used for research studies. An amount of $2.25 million was originally allocated to cover the costs of the research projects and coordination of the projects by the WADOH. This

included $1 million of PHRN NCRIS funds. WADOH led the first PHRN POC Collaboration and remained responsible for PHRN POC coordination until 2013-14. Difficulties in negotiating a mechanism to provide funding was one of the reasons that WADOH ceased coordinating the PHRN POC Collaborations.

The second round of funding available to the PHRN was the Education Investment Fund - Super Science Initiative. WADOH were allocated $536,000 to build/support the Custodian Administered Research Extract Server (CARES). CARES has been a successful initiative which has reduced the burden on data custodians for project by project data extraction. Other PHRN data linkage units are planning to establish similar systems. Negotiation of the funding agreement with WADOH for the PHRN EIF-SSI funds was lengthy (in excess of two years). This was longer than the negotiations required in any other Australian jurisdiction.

Since the EIF-SSI funding the PHRN has had three more funding rounds. Over $0.5 million which was allocated to WADOH from these rounds was not taken up and the funds have since been re-distributed to other PHRN participants. WADOH has also missed out on the opportunity to be included in the PHRN proposal to the NCRIS 2015 Agility Fund. $13 million is available for allocation through this fund.

PHRN has also provided funding for other WA groups. From 2008 to 2017, UWA and Curtin University have each received over $7 million of PHRN NCRIS funding to host the national coordinating office of the PHRN (UWA) and the Centre for Data Linkage (Curtin). The total Commonwealth Government PHRN NCRIS/EIF-SSI investment in WA to date is over $15 million. The WA Government cash co-investment is around $1.1 million.

In the 2015-16 Federal Budget $150 million a year (indexed) over ten years from July 2017 was announced for the NCRIS capabilities. The PHRN is working hard to ensure that it participates in this long term funding opportunity. The PHRN is keen to support data linkage in Western Australia and to discuss how the WA Government and academic institutions can continue to be involved in the development of Australia's national data linkage infrastructure.

2.2 Participation in cross-jurisdictional projects

One of the key activities for the PHRN is to establish the capability for cross-jurisdictional data linkage in Australia. Cross-jurisdictional linkage is important because in Australia different governments collect different health information e.g. states collect hospital data and the Commonwealth collects Pharmaceutical Benefits Scheme data. Cross-jurisdictional linked data can be used to:

- Increase statistical power for research on rare conditions or outcomes
- Ascertain complete patient pathways, care and outcomes
- Understand cross-border service use
- Obtain accurate data for longitudinal studies
- Evaluate state-based variations in hospital and health care.

The WADLB has been involved in cross-jurisdictional linkage prior to the PHRN, having previously negotiated a Memorandum of Understanding with the Commonwealth for linkage of Medicare and Pharmaceutical Benefits Scheme data to WADOH data. A number of important studies using this data were completed and their results contributed to the business case for the Commonwealth investment in national cross-jurisdictional linkage infrastructure. Unfortunately, the WA arrangement has been discontinued and other approaches such as those supported by PHRN will be required for linkage of WA and Commonwealth data.

The PHRN has now funded four POC Collaborations to demonstrate the feasibility and value of cross-jurisdictional linkage using its infrastructure. The four projects are summarised below:

Table 1: Summary of the four PHRN Proof of Concept Collaborations.

Title	Jurisdictions	Comments	Endorsed
POC1: In-hospital and post-discharge mortality: learning about quality of care using data linkages from Australian states	WA, NSW, SA, QLD	First cross-jurisdictional project to utilise the CDL as national linkage unit	May 2010
POC2: Burden and cost of injury-attributable health care use and mortality in Australia	NSW, QLD, SA	First cross-jurisdictional project to use a case-control design involving electoral roll data	July 2012
POC3: Perinatal outcomes and child development (risk and protective factors)	WA, NSW, SA, NT, C'wealth	First cross-jurisdictional project to involve linkage of perinatal and local education and the national Australian Early Development Census (AEDC)	July 2012
POC4: Linkage of the Australian Childhood Immunisation Register (ACIR) and state-based registers to evaluate and inform Australia's immunisation program	WA, NSW, C'wealth	First cross-jurisdictional project to use an accredited Commonwealth Integrating Authority (the AIHW) and a remote access data facility (the SURE) for the linkage of a C'wealth collection with state health data	August 2012

Western Australia was invited to participate in all four POC Collaborations. WA hospital and death data was provided for POC Collaboration 1 (POC1). This project has resulted in three publications to date[1,2,3] and demonstrated that cross-jurisdictional data linkage could be conducted safely and securely. It also demonstrated the importance of understanding cross-border health service use.

WA data was also provided for POC Collaboration 4 (POC4) following lengthy negotiations. Agreement could not be reached for linkage variables from the WADOH data collections to be sent to the AIHW for linkage. However, the WA Registrar agreed for linkage variables from the birth register to be sent to AIHW for cross-jurisdictional linkage which enabled WA to participate via a two-stage linkage approach. WADOH health data was only available to researchers following state-based linkage, which restricted the ability of the study to track cross-border health service use.

Approvals from WADOH were not received in time for WA to be included in POC Collaboration 2 (POC2) and Collaboration 3 (POC3). POC2 proceeded without WA data and POC3 was not completed. One of the significant barriers to accessing data for POC2 was the WADOH requirement for the researcher to write individually to every hospital in the state for approval. This involved preparation of 108 separate applications.

Another substantial difficulty faced by the research teams involved with PHRN POC2, POC3 and POC4 was that following project endorsement, there was a policy change within WADOH which translated into a reticence to provide linkage variables to a national data linkage unit (Curtin University or AIHW)[4]. The outcome of this change in policy means that other cross-jurisdictional linkage projects cannot include WA health data.

[1] Boyd JH et al. Accuracy and completeness of patient pathways--the benefits of national data linkage in Australia. *BMC Health Serv Res. 2015 Aug 8;15:312*
[2] Rosman D et al.Multi-jurisdictional linkage in Australia: proving a concept. *Aust N Z J Public Health. 2016 Feb;40(1):96-7*
[3] Spilsbury K et al. Cross border hospital use: analysis using data linkage across four Australian states. *Med J Aust. 2015 Jun 15;202(11):582-6.*
[4] http://www.health.wa.gov.au/circularsnew/attachments/914.pdf (Cited 7 June 2016).

3. Comparison of WA Data Linkage Branch to other Australian State/Territory Data Linkage Units

WADLB was the first systematic data linkage unit established in Australia. It took a further 10 years for the second data linkage unit to be established in NSW. Therefore, WA has been building its master linkage file for ten or more years longer than all the other DLUs in Australia. However, the data linkage capability in all other states and territories is rapidly catching up with, or has passed, the WA capacity. All state/territory data linkage units now have their core health data collections linked and at least 10 years of linked hospital data. Some states also have a wide range of non-health data collections in their Master Linkage File (MLF) e.g. South Australia. The majority of these data linkage units now process similar or greater numbers of new project requests each year than the WADLB. The larger states (NSW, QLD and VIC) have the advantage of significantly larger populations than WA.

4. How can WA be part of the national data linkage agenda?

To leverage its mature infrastructure and to assist in its long-term sustainability and responsiveness to evolving researcher demands, the WA system needs to be able to articulate with data linkage systems in other jurisdictions i.e. the Australian government, other states and territories. This may involve release/receipt of linkage variables to/from other jurisdictions. As explained above, this has become an issue for WA in recent years.

The recently passed amendments to the *Hospitals and Health Services Act (1927)* allow for the WADOH to disclose information for "health related research, whether that research is conducted by persons who are staff members of a health service provider or persons employed or engaged in the Department or other persons." This would seem to enable WA to participate in cross-jurisdictional research projects that involve health data. However clear interpretation of the legislation to confirm this would be useful. There may be barriers for the disclosure of linkage variables from non-health data collections which may require legislative solutions.

The current 'Conditions of Use' for access to WA Health data require that '… all projects require at least one investigator based in WA to ensure results are distributed to the WA community.'[5] This represents a significant impediment to researchers in other jurisdictions wishing to conduct studies involving national data linkage. The research team for PHRN POC2 encountered this issue and were required to seek a waiver from the WADOH HREC for access to WA data. This issue needs to be addressed to remove additional logistical barriers for outside researchers and encourage national studies to include WA data with the anticipation of their results directly benefiting the WA community.

More efficient application, approval and data extraction processes will be required for WA to participate in the national data linkage system and meet the anticipated increasing demand from the research community. Currently the WADLB must manage both the internal government needs for linked data and the research community's demands. Internationally, the best data linkage systems are usually based on collaborations between government and the academic sector. For example, out-sourcing client services and content data extraction for research projects to a University has been done in Wales[6] and Manitoba[7] and would be a solution to the competing demands of government and researchers. Data linkage (the matching of identifiable variables from different data collections) should remain within government.

[5] http://www.datalinkage-wa.org.au/access-and-application/access-linked-data (Cited 7 June 2016).
[6] http://www.saildatabank.com/
[7] http://umanitoba.ca/faculties/health_sciences/medicine/units/community_health_sciences/departmental_units/mchp/