

## **Submission in response to the Productivity Commission’s Issues Paper, Data Availability and Use (April 2016)**

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The purpose of this submission is to provide an insight to help address the questions posed by the Commission in the issues paper. The evidence presented in this submission highlights several issues identified by the Commission as recurring data-related themes from previous reports (Box 2, p8 of Issues Paper – Data Availability and Use) which include insufficient data sharing between agencies, insufficient dataset linkage and limited data access for research purposes.

### **Data linkage – an invaluable tool in health services research**

Health research and in particular health services research is primarily driven by the availability of quality data. Health services in Australia including hospitals routinely collect a vast amount of patient information for administrative purposes with such data collection core to their operations. The ability to link this administrative data to specific datasets such as mortality and births registries or to governmental databases such as the Pharmaceutical Benefits Scheme (PBS), Medical Benefits Scheme (MBS), Police Road Traffic Accident reports or other cohort data can provide valuable information at the population level that can be used to better inform public policy. Linked administrative health data is an important resource in helping researchers answer specific population health research questions, assisting with the planning and evaluation of health services and can also serve as crucial evidence to inform health policies. Linked hospital data can be used to study populations which are generally hard or expensive to recruit. Examples of Australian studies that have made use of linked hospital data include: Assessing the morality in the aboriginal population from rheumatic heart disease (1); Studying disease aetiologies in children (2); Examining rare diseases such as meningococcal disease in children (3).

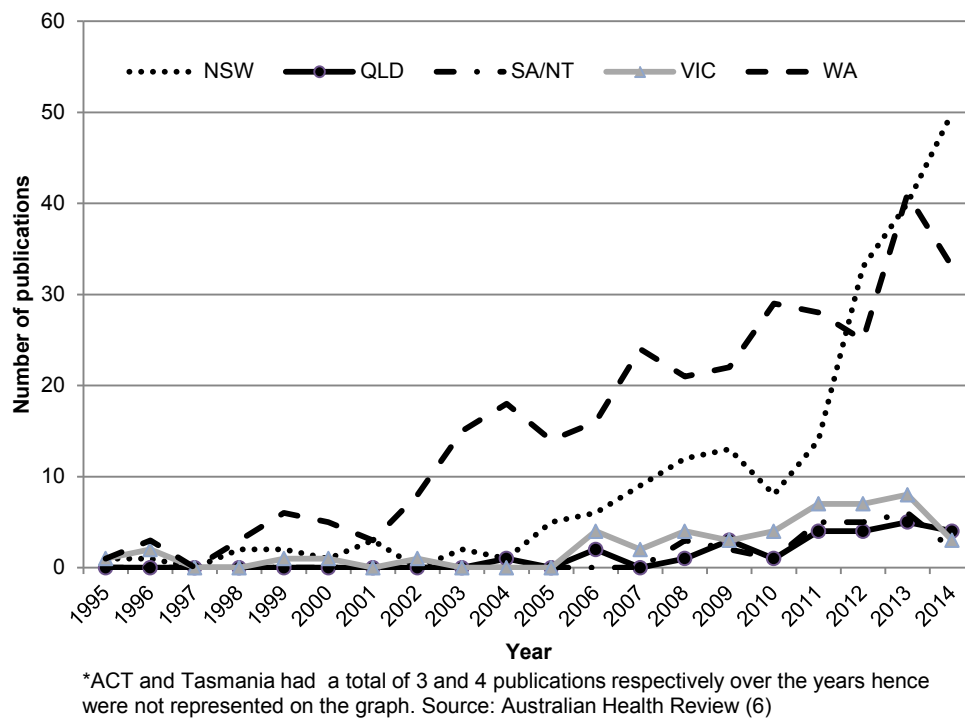
Data linkage has also played an important role in extending the value of studies such as the 45 and Up Study. Through linking cohort data to hospital, pharmaceutical and Medicare administrative data researchers were able answer a variety of important questions on topics such as hospitalisations due to specific infections (4) and use of general practice and healthcare cost at end of life (5). Linked administrative data have also been used to enhance numerous costing and economic evaluations as well as to evaluate the impact of health service delivery on patient outcomes. The advantages of such approaches are the large sample size, accuracy of data compared to self-reported information, the complete capture of data (overcoming limitations of patient loss to followup), and the ability to capture both historical and prospective information. It also represents an efficient and cost-effective approach for the long-term follow up of patients in trials or exposed to policy changes and health service improvement more generally because data are acquired from routinely collected information at a small additional cost but with great additional benefit. While there is some use of linked administrative health data in Australia, this is minimal compared to other countries such as the UK and Sweden.

### **Linked hospital data use in Australia**

Our submission is largely based on a systematic review that provides evidence on the level and type of use of linked hospital data which conducted by authors of this submission (6). It provides much needed insight into the level of current and past data availability for Australian researchers. This submission summarises several main findings from the systematic review. There has been an observable growth in the availability of data and its use through data linkage for health research. The number of research outputs (peer-reviewed publications) based on research that uses linked hospital data has increased significantly since the establishment of the first data linkage service in Western Australia two decades ago and the subsequent establishment of data linkage units in each Australian state. However our results show significant variations in research outputs across Australia indicating a great unevenness in the use of linked administrative hospital data in Australia as shown in Figure 1 below. It is evident that two states, New South Wales (NSW) and Western Australia (WA), contributing to more than 80% of publications have clearly outperformed the other states. This difference is highly unlikely to be driven by the health needs of the population, nor the availability of able researchers to use such data, but is much more likely to reflect data access issues. Our results also show that research areas between NSW and WA are quite different as research using data linkage in WA for example focused more on the circulatory system whereas NSW has shown a greater emphasis on mother and child health.

The practical issues and barriers of conducting cross-jurisdiction research was also highlighted in our findings as our results show only 10 publications using linked data from multiple states which is likely to grossly underestimate the potential to contribute to important cross jurisdictional questions. Although there have been considerable improvements in Australia's data linkage infrastructure, largely due to the substantial investments of more than \$90 million in the Population Health Research Network (PHRN), it is recognised that researchers continue face significant barriers in gaining access to data through the current data linkage process. Health data is held by different custodians which means that researchers need to approach different organisations or levels of governments to request access and link the necessary databases. Further, differences in legislative protocols surrounding confidentiality between ethics committees and operating procedures between linkage units can create discord in research progress and adds significant additional time to an already pressing timeline. The lack of a streamlined process and excessive duplication of process and effort necessitates a significant time investment from the researchers on top of possible financial barriers.

Figure 1: Number of publications utilising hospital data linkage by State from 1995-2014.



As a result of significant infrastructure support and investment, all Australian states have established data linkage units with the capacity to provide population-wide data. However during the course of our research we directly contacted each state data linkage unit for information and found significant variation across the states in the policies regarding provision of linked data in terms of whether they link all hospitals, and the provision of private and emergency data. Few hospitals provide quality outpatient data and not all data linkage units are able to link to private hospitals. The most productive data linkage units such as those from NSW and WA, charge for their data linkage services, which may indicate that resourcing is required to support research in a timely and consistent manner. The more productive units at supporting research using linked hospital data all have clear and established guides and processes for researchers available online. This may help explain the significant disparities in publication output across states.

Furthermore, the comparable reporting of outcomes by all data linkage units will facilitate comparison across different jurisdictions. Ultimately, we believe the performance of data linkage units should be assessed by quantifying resource inputs in relation to research and other outputs which make use of the data. One potential measure is to quantify the cost per publication, which would facilitate the ongoing evaluation of data linkage units in contributing to health and medical research in Australia. Moving to some type of outcome based funding (e.g. paying data linkage units based on the publications produced) could also be considered.

Linked administrative health data in Australia have been recognised as an important resource for health services research and informing health policies. It is a huge untapped resource that remains under-utilised. Therefore steps towards minimising the barriers of accessibility would be beneficial to improve data availability and its use to researchers. It may be beneficial for data custodians of government data to be semi-independent bodies rather than the government itself to reduce potential conflicts of interest that may arise where government officials look for ways to block or delay data access to minimise their own personal reputational risk of undesirable findings being made public. A

better process may be to have standardised timeframes where researchers provide the government with their findings pre-public release so that the government have time to prepare a considered public response. There also needs to be coordination within each data linkage unit with regards to the processes and documentation required from the researcher as well as between data linkage units to avoid unnecessary duplication of processes. There needs to be clear procedural guidelines and timelines available to which researchers are able to gauge the feasibility of using linked data services. Beyond developing the infrastructure for comprehensive administrative datasets, there is clearly a need to provide training and funding for analysis if data linkage is to translate into research outcomes and further impact.

Thank you for the opportunity for us to submit our response.

### References

1. Davies SB, Hofer A, Reeve C. Mortality attributable to rheumatic heart disease in the Kimberley: a data linkage approach. *Intern Med J* 2014; 44: 1074–80. [doi:10.1111/imj.12540](https://doi.org/10.1111/imj.12540)
2. Moore HC, de Klerk N, Keil AD, Smith DW, Blyth CC, Richmond P, Lehmann D. Use of data linkage to investigate the aetiology of acute lower respiratory infection hospitalisations in children. *J Paediatr Child Health* 2012; 48: 520–8. [doi: 10.1111/j.1440-1754.2011.02229.x](https://doi.org/10.1111/j.1440-1754.2011.02229.x)
3. Gibson A, Jorm L, McIntyre P. Using linked birth, notification, hospital and mortality data to examine false-positive meningococcal disease reporting and adjust disease incidence estimates for children in New South Wales, Australia. *Epidemiol Infect* 2015; 143: 2570–9. [doi:10.1017/S0950268814003355](https://doi.org/10.1017/S0950268814003355)
4. Chen Y, Liu BC, Glass K, Kirk MD. High incidence of hospitalisation due to infectious gastroenteritis in older people associated with poor self-rated health. *BMJ Open* [Internet] 2015;5(12):e010161. [doi:10.1136/bmjopen-2015-010161](https://doi.org/10.1136/bmjopen-2015-010161)
5. Tran, B, Falster MO, Girosi Federico, Jorm L. Relationship between use of general practice and healthcare costs at the end of life: a data linkage study in New South Wales, Australia. *BMJ Open* [Internet] 2016;6(1):e009410. [doi: 10.1136/bmjopen-2015-009410](https://doi.org/10.1136/bmjopen-2015-009410)
6. Tew, Michelle, Dalziel, Kim M., Petrie, Dennis J., and Clarke, Philip M. (2016). Growth of linked hospital data use in Australia: a systematic review. *Aust. Health Review*, <http://dx.doi.org/10.1071/AH16034>