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## MULTI-JURISDICTIONAL LINKAGE IN AUSTRALIA: PROVING A CONCEPT

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### DATA LINKAGE SERVICES

A distributed network of jurisdictional and national data linkage services has been established through the Population Health Research Network (PHRN) to enhance health-related research in Australia [1]. Service providers have adopted strong data governance frameworks, best practice linkage principles and secure data exchange processes to ensure data protection [1, 2]. Data governance regimes include project-specific ethics approvals, data access agreements, and separated data linkage and analysis phases. These processes minimise risks to privacy but place considerable administrative and logistical burden on researchers, data custodians and linkage units [3, 4]. The burden of this workload can escalate significantly when information is sourced from multiple agencies [5].

The maturity of jurisdictional data linkage services varies markedly across Australia. Services have been operating in WA since 1995 and in NSW/ACT since 2006 [3, 6], while newer services in other states/ territories only embarked on development since 2009 with funding from the national and state/territory governments [7]. National linkage hubs at the Centre for Data Linkage (CDL) at Curtin University and the Australian Institute of Health and Welfare have also been supported through these funding initiatives [1].

### PROOF OF CONCEPT PROJECTS

Early in the PHRN development process, four “Proof of Concept” (PoC) projects were initiated to test different aspects of the linkage infrastructure especially in relation to timelines for approvals, complexity of data flows, linkage capabilities within and between jurisdictions and data delivery mechanisms. A diary of all of the administrative and logistical activities was maintained for each of the projects to monitor progress and for later review. A dedicated Coordinator was also appointed to proactively broker approvals and agreements between parties and to maintain project momentum.

Each PoC project had different epidemiological objectives and study design. PoC1 investigated hospital related mortality across four Australian states - WA, NSW, SA and QLD. This novel study documented the extent of cross border hospital movement patterns and cross border hospital-related deaths in Australia at an individual patient level [8]. PoC2 examines the burden and cost of injury-attributable health care use and mortality in Australia. It uses a case control study design, with controls sourced from electoral records of individual states. The third PoC project investigates perinatal outcomes and child development using the Australian Early Development Census 2009 cohort linked to a wide range of data sources. PoC4 is a linkage of the Australian Childhood Immunisation Register and state-based registers to evaluate and inform Australia’s immunisation program. National linkages for the first three projects were conducted by the CDL [1], while linkages for PoC4 were conducted by the AIHW. The PoC1 project has recently been completed; remaining projects are still in progress.

### FINDINGS

The first PoC project required approvals from multiple data custodians and ethics committees. The study required two data sources from each of the four jurisdictions. A total of five data applications, five ethics submissions and nine data transfer agreements were needed. The staged linkage component involved matching over 44 million records.

The Gantt chart (Figure 1) illustrates the number and complexity of tasks, many of which occurred in parallel across jurisdictions. The greatest delays were in developing agreements between data

providers and gaining approvals for national linkage. Overall, the approvals stage(s) took more than two years; each linkage phase took six months; while the extraction and supply of data to the researcher took a further three months. Although data analysis and reporting of results extended over a 24 month period, this was not continuous.

## CONCLUSION

While the utility of linked data and the productivity of jurisdictional linkage centres is evidenced through thousands of publications from linked data research projects [3], the linkage of data across jurisdictions has not previously been attempted in Australia or elsewhere. The PHRN PoC work described here shows that multi-jurisdictional data linkage in Australia is feasible but complex, and some streamlining of processes is required.

For multi-jurisdictional data linkage to become practical and efficient in Australia, the number and complexity of inter-agency data exchange agreements need to be reduced and researcher access approval processes need to be simplified. This may be difficult to achieve in Australia's federated environment where laws and regulatory frameworks differ between jurisdictions. The experience in some states suggests that efficiencies could also be achieved through the creation of enduring linkage maps and development of data custodian support systems [9].

As the infrastructure adapts and improves from these learnings, it will be important for multi-jurisdictional research projects to have flexible funding and be supported through strong coordination, structured custodian involvement and sympathetic researcher participation.

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