

Development and implementation of a national online application system for cross-jurisdictional linked data

Natalie Wray¹, Kate Miller², Katie Irvine³, Elizabeth Moore³, Alice Crisp⁴, Kathleen Bapaume⁵, Catherine Taylor⁶, Rob Smetak⁷, Nadine Wiggins⁸, Mikhalina Dombrovskaya¹, and Felicity Flack^{1,*}

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¹Population Health Research Network, University of Western Australia, Perth 6009, Australia

²Telethon Kids Institute, Perth 6009, Australia

³NSW Ministry of Health, Sydney 2065, Australia

⁴Australian Institute of Health and Welfare, Canberra 2601, Australia

⁵Victorian Department of Health, Melbourne 3000, Australia

⁶Queensland Department of Health, Brisbane 4001, Australia

⁷SA NT DataLink, University of South Australia, Adelaide 5000, Australia

⁸Menzies Institute for Medical Research, Hobart 7000, Australia

Abstract

The Population Health Research Network (PHRN) is an Australian national data linkage infrastructure that links a wide range of health and human services data in privacy-preserving ways. The data linkage infrastructure enables researchers to apply for access to routinely collected, linked, administrative data from the six states and two territories which make up the Commonwealth of Australia, as well as data collected by the Australian Government. The PHRN is a distributed network where data is collected and managed at the respective jurisdictional and/or cross-jurisdictional levels. As a result, access to linked data from multiple jurisdictions requires complex approval processes. This paper describes Australia's approach to enabling access to linked data from multiple jurisdictions. It covers the identification of, and agreement to, a minimum set of data items to be included in a unified national application form, the development and implementation of a national online application system and the harmonisation of business processes for cross-jurisdictional research projects. Utilisation of the online application system and the ongoing challenges of data linkage across jurisdictions are discussed. Changes to the data custodian and ethics committee approval criteria were out of scope for this project.

Keywords

linked data; cross-jurisdictional; application; approval

*Corresponding Author:

Email Address: felicity.flack@uwa.edu.au (Felicity Flack)



Introduction

Australia's Population Health Research Network (PHRN) was established in 2009 through funding from the Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS), co-funding from state and territory governments and academic institutions to build a nationwide data linkage infrastructure [1]. A key objective of the PHRN was to build the capability to enable efficient access to cross-jurisdictional linked sensitive data. Cross-jurisdictional linkage brings together data, from different sources in different jurisdictions, but relating to the same individual [2, 3]. This is a high priority for Australia as administrative data¹ pertaining to an individual is collected by state and territory governments (e.g. hospital admissions) and the Australian Government (e.g. prescribing data) [2, 4, 5]. In addition, Australia has a mobile population and there is significant cross-border health service use, particularly by people living along jurisdictional borders [6, 7].

By 2012, each of Australia's jurisdictions (including the Commonwealth) were supported by a PHRN data linkage unit (DLU), as well as the central PHRN office providing overall strategic leadership. This network of linkage units enabled researchers to access single jurisdictional linked data and linked data from all jurisdictions.

Between 2010 and 2016, several research projects designed to test the cross-jurisdictional data linkage infrastructure revealed that researchers were required to navigate complex application and approvals processes. Each jurisdictional data linkage unit had a unique data application form and approvals process. In addition, the data linkage units were at different stages of business maturity, and many had limited experience working with other data linkage units. Both the data linkage units and researchers found the cross-jurisdictional experience to be challenging [8–12], an experience which is not limited to Australia [13–16].

It was clear that a unified data application form and better coordination of the application and approval processes for cross-jurisdictional projects considering specific jurisdictional requirements, project-specific requirements and the resources available was required.

This paper describes Australia's unique approach to coordinating the application and approval processes for access to cross-jurisdictional linked data via a unified national application form and supporting harmonised business processes, as well as experience with implementation of the approach. Changes to the data custodian and ethics committee approval criteria were out of scope for this project. This paper may be of particular interest to organisations and countries who are building infrastructure to facilitate discovery of, and access to, cross-jurisdictional linked datasets for research.

Methods

This initiative had five phases. The Project Control Group (PCG) comprised one representative from each PHRN jurisdictional data linkage unit and one researcher (10

¹Administrative data - Data collections that are made up of information that is routinely collected during the delivery of a service, such as the provision of health care or education.

members) and was responsible for project deliberations and decisions in Phases 1, 2 and 3. A PHRN Project Coordinator was responsible for project management and provided secretariat support to the PCG.

Phase 1: A preferred model to support cross-jurisdictional research applications

The objective of Phase 1 was to engage with all Australian data linkage units to develop a preferred model to support, and simplify, the application process for researchers requesting access to administrative data from more than one jurisdiction. Strategic drivers, stakeholder concerns and learnings based on previous PHRN consultations with researchers and data linkage unit staff were considered. Four options for providing application services were identified as well as the risks, issues, advantages and disadvantages for each option. The identified options were:

- Process guidance website
- Process guidance and tracking website
- Unified national application model
- Pre-filled "paper" forms

A unified national application model was chosen as the preferred approach as it would simplify the application process for researchers and be flexible enough to address different jurisdictional requirements.

Phase 2: Selection of data items

The objective of Phase 2 was to describe the features and requirements to be used for the construction of a unified national application model. A two-day face-to-face workshop was facilitated by a software development company and attended by a representative from each jurisdictional data linkage unit and the PHRN Project Coordinator.

The group reviewed paper-based data application forms from each of the seven PHRN data linkage units and created a list of all data items from all the forms, classified into the following sections:

- Personnel details
- Project details
- Data services required
- Details of data collections for extraction
- Details of non-core data sets to be linked in
- Cohort definition
- Funding sources
- Other information

A list of data items, which included all sections from the above list – deemed essential or mandatory – was drafted for review by the PCG. The PCG also agreed on non-mandatory data items to be included or excluded from the features list. For each of the data items chosen for inclusion in the unified

national application model, the PCG agreed to the exact description of the data item.

Once all the data items for the unified national application model were agreed upon, each PCG representative was responsible for seeking the necessary jurisdictional approvals for use of the form.

Phase 3: Construction and implementation of the unified national application model

The software build was completed by the software developers within 11 weeks. An Agile approach was used with the PHRN Project Coordinator and the software developers meeting regularly to showcase the features to the PCG and to conduct preliminary testing of its functionality. Each jurisdictional data linkage unit was given the opportunity to conduct user acceptance testing to identify any bugs or issues with the software.

Phase 4: Harmonised business processes for cross-jurisdictional projects

The jurisdictional data linkage units recognised that in addition to the unified, online application form, a national approach was required for:

- The coordination of feedback on project feasibility
- The provision of cost estimates
- Information about approval requirements for each jurisdiction
- Monitoring of application progress from submission to approval for cross-jurisdictional applications

Each jurisdictional representative conducted a business analysis of their application and approvals processes which, when collated, highlighted jurisdictional variability. Jurisdictional representatives then participated in a one day facilitated face-to-face workshop to map out a more coordinated approach for cross-jurisdictional projects whilst still meeting each jurisdiction's approval criteria. This coordinated approach is referred to as the harmonised business processes in this paper. This included, as part of the evaluation process, some time-based key performance indicators such as number of cost estimates provided within 14 days of submission and number of project planning meetings held within 21 days of submission. Upon agreement of the harmonised business processes a six-month pilot period commenced.

Phase 5: Performance of the OAS, 2015–2020

The performance of the OAS was monitored from 2015–2020 by recording quantitative standard performance measures, as well as qualitative feedback from user satisfaction surveys regarding the system and processes.

Results

The web-based application form, named the PHRN Online Application System (OAS) (<https://oas.phrn.org.au>), was

deployed to the production environment. Prior to launching the OAS for researcher applications, the following activities were completed:

- Data for reference tables and drop-down lists entered
- Help bubble information written and entered
- OAS help document written and published on the PHRN website
- Training for each data linkage unit either online or face to face
- Researcher demonstrations in NSW and WA

The help section provided general information to users, explained the 'buttons' found on each page, instructions for completing the application form and troubleshooting/frequently asked questions.

The application form includes the modules and data items, information (help) bubbles and instructions to assist users in completing the application form. At the time of the launch, coordination of each cross-jurisdictional project was conducted by a self-nominated Lead Agent from one of the jurisdictions involved in the project.

The six-month trial of the harmonised business processes for cross-jurisdictional projects was completed. After an evaluation, all data linkage units agreed to continue with the harmonised business processes for the management of cross-jurisdictional projects. The key elements of the harmonised business processes are detailed in Figure 1. Prior to this project none of these elements were coordinated nationally, instead, researchers would apply separately to each jurisdiction for approval and receive separate feedback from each jurisdiction.

There has been ongoing effort by the PHRN to improve the utility of the OAS and its supporting harmonised business processes. To better support the work of the jurisdictional linkage units, the PHRN took on a central coordinating role based at the PHRN Program Office. The Expression of Interest (EOI) phase was separated from the application and approvals phase to clarify when the design and feasibility assessment of an application was complete, and it was ready to be considered for approval.

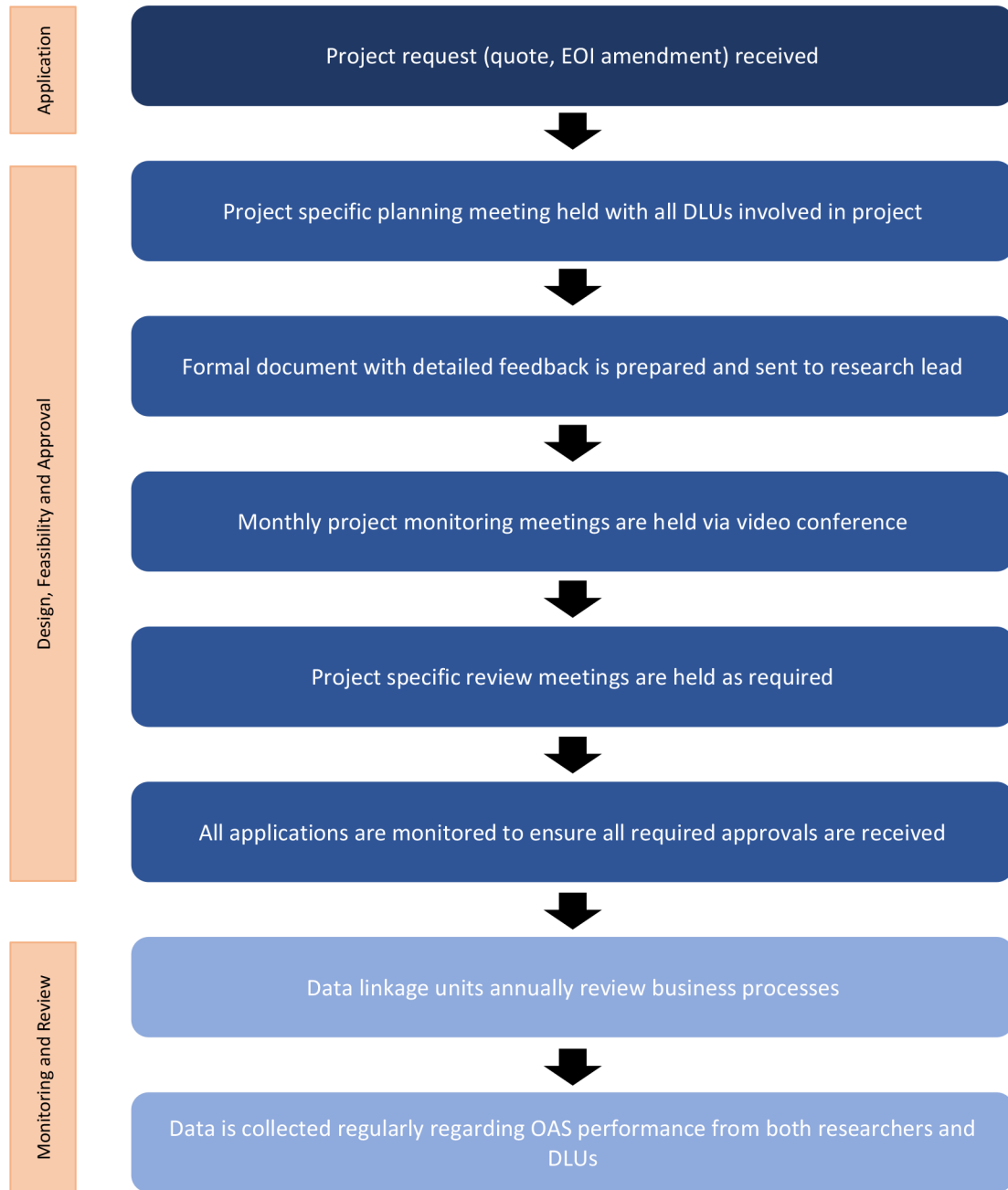
Performance of the OAS (2015 to 2020)

Researchers and data linkage units are registered users of the PHRN OAS. The number of registered users of the PHRN OAS increased annually from Year 1 (2015) to Year 6 (2020). The biggest increase in the number of users was in Year 6 (2020) when the PHRN OAS recorded 125 additional registered users compared with Year 5 [See Figure 2].

In Year 1 (2015) of the PHRN OAS being available to researchers, 19 cross jurisdictional projects were submitted. The number fell to 8 in Year 2 (2016). This may be due to initial reluctance and a learning curve by the researchers and DLUs, and then steadily rose over the following years. The highest number of cross-jurisdictional projects submitted to the PHRN OAS was in 2020 with a total of 35 [See Figure 3].

A total of 110 cross-jurisdictional projects were submitted to the PHRN OAS between February 2015 and 31 December 2020. Out of these 110 projects, 41 projects requested a cost

Figure 1: Cross-jurisdictional harmonised business processes



estimate only. The remaining 69 were full project applications. Twenty of these projects were later withdrawn, discontinued or paused indefinitely. Reasons for projects being withdrawn, discontinued or paused included:

- Projects were not funded or did not have adequate funding
- Projects were not technically and/or practically feasible
- Researchers were waiting for changes in legislation or data availability before progressing the project
- Projects were de-scoped from cross-jurisdictional to single-jurisdiction projects

Out of the 49 active project applications, 24 had all their approvals in place by 31 December 2020.

Discussion

The approval requirements for access to linked data from multiple jurisdictions with different legal, regulatory and policy environments are complex. This project has demonstrated that it is possible to simplify and coordinate the application process for researchers requesting access to linked cross-jurisdictional administrative data in Australia. This was achieved with the support of jurisdictional linkage units and data custodians leading to the introduction of a national, web-based application form and supporting harmonised business

Figure 2: Number of registered users of the PHRN online application system by year

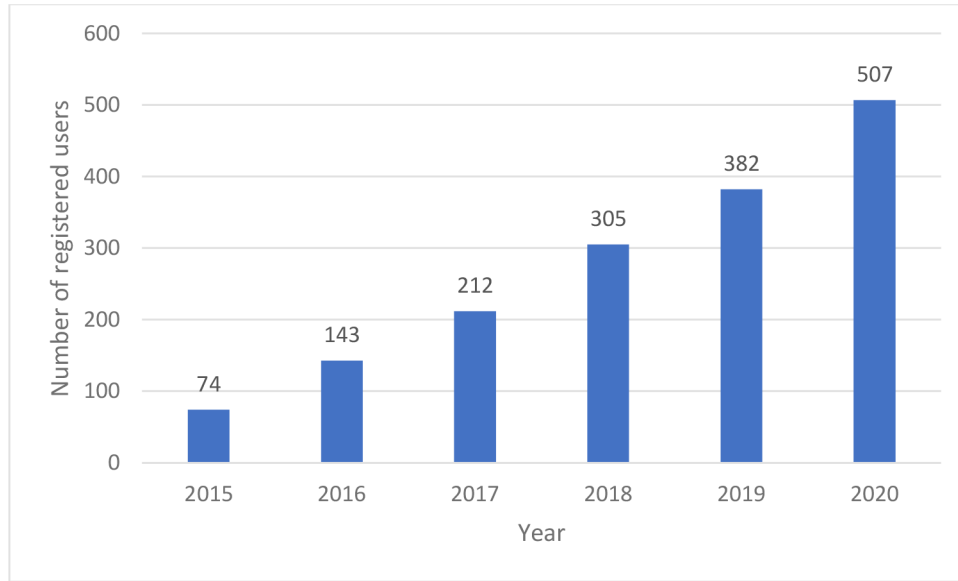
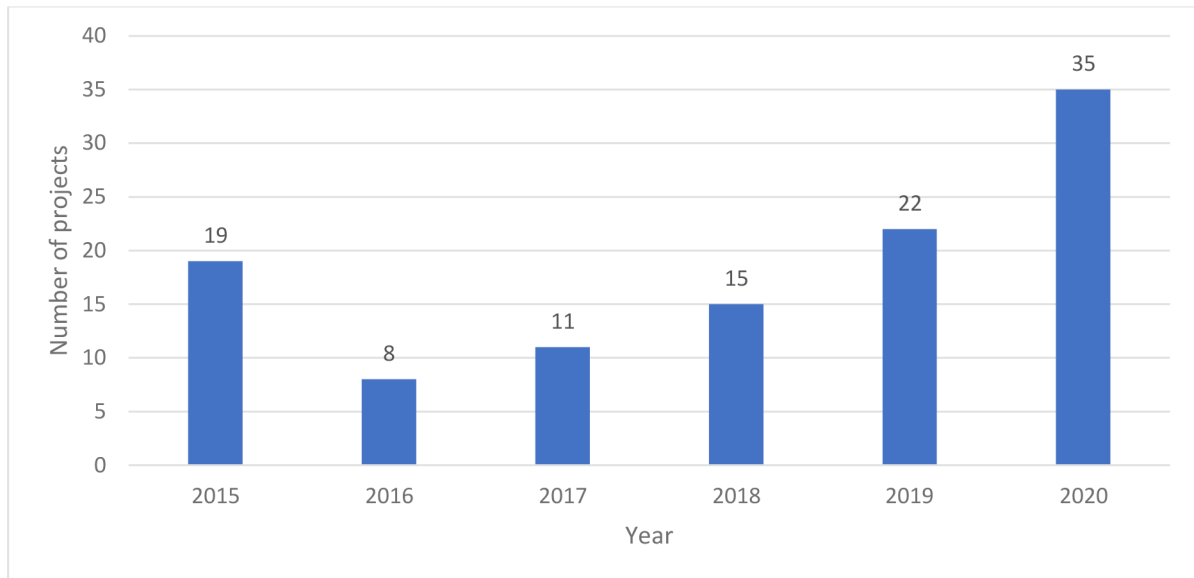


Figure 3: Number of cross-jurisdictional projects submitted to the PHRN online application system, by year



processes. Prior to the project, the process was inefficient requiring researchers to apply separately to each individual data linkage unit. Applications and feedback on applications were not coordinated.

When this project commenced, there was no single national application process for researchers to request access to linked cross-jurisdictional administrative data and there was no organisational basis to develop and implement a coordinated application process. The establishment of the PHRN to lead and provide this organisational basis was essential to enabling this project and address a national problem. Therefore, a consultative and flexible approach with stakeholders which included researchers and data custodians was integral to the success of the project.

There were several factors that contributed to the successful development and implementation of the PHRN OAS. Whilst it was possible to reach agreement on all the data items for a unified national application form, the web-based application system and associated harmonised business

processes had to be sufficiently flexible to accommodate the varying legislative and policy requirements of multiple stakeholders.

This flexible approach enabled data linkage units from different jurisdictions, with different organisational structures, governance accountabilities and regulatory requirements, to agree to use the system. Further, it enabled researchers to know the project costs sooner and have a better understanding of the scheduled delivery of the project.

This flexible approach was demonstrated in the improved harmonisation of business processes for cross-jurisdictional projects. With more harmonised, supportive business processes in place, one of the barriers and risks to timely cross-jurisdictional linkage projects was mitigated and most likely contributed to the observed increases in the number of registered OAS users and the number of applications submitted.

Other factors including the promotion of the cross-jurisdictional application process on the PHRN website and

via webinars in the latter years of operation may also have contributed to the increase of registered users and cross-jurisdictional projects submitted.

The PHRN OAS could not have been developed and implemented without significant consultation with all stakeholders over several years. There will be ongoing need for flexibility and consultation with stakeholders. In a federated country like Australia, a balanced approach is required to ensure:

- All nine jurisdictions continue to use the PHRN OAS to coordinate cross-jurisdictional linked data applications.
- All seven data linkage units continue to use the PHRN OAS and participate in project planning and project monitoring meetings.
- Researchers continue to apply for access to cross-jurisdictional linked data via the PHRN OAS.

Despite the success of the OAS, the time from submission to approval remains highly variable between applications and generally long. There are reports of long time frames for national linkages in other countries but it is difficult to make direct comparisons when the definitions of submission and approval pathways may be different [17, 18]. Some of the time variability may be explained by the variation in level of completeness of applications on submission. During this project it was noted many applications are actually expressions of interest or preliminary ideas and require considerable planning and preparation before they are ready to be considered by data custodians and ethics committees for approval. This design and planning phase can take many months and extend the time from submission to approval to a year or more. A range of factors may also contribute, many of which are outside of the scope of the OAS, including data custodian approval requirements and differences in legislation and policy across jurisdictions. However, there are improvements that can be made to the OAS. Further refining and streamlining of the OAS and the harmonised business processes along with education and training for researchers on how to design and apply for cross-jurisdictional linked data projects is an ongoing requirement.

The PHRN has commenced a review of the effectiveness of the OAS with the aim of updating the system and further simplifying the process for researchers.

Limitations

This project was subject to budgetary and time restrictions. The differing legislation, regulation and policy requirements across jurisdictions limited the options for a completely unified approach.

Conclusion

This project has demonstrated that a coordinated application process for all nine (six states, two territories and the Commonwealth) Australian jurisdictions is both necessary and possible despite the differing policy, governance and regulatory environments. Its establishment is a significant achievement and Australia is the first federated nation to implement a

coordinated application process for researchers to apply for access to cross-jurisdictional linked data in all jurisdictions.

The key elements required for the success of the project were:

- Funding and resource support for the consultation and software development
- A willingness from all stakeholders to identify and address the challenges
- Keeping a focus on improving the researcher experience whilst meeting legislative, regulatory and policy requirements

The PHRN has demonstrated its ability to work with multiple stakeholders across multiple jurisdictions to reach agreement on the best way to mitigate the risks and mediate the challenges associated with coordinating access to data from multiple jurisdictions. A consultative and flexible approach has been integral to the success of the project especially given that at the beginning of the project there was no reference point to develop and implement a coordinated application process. The study findings may be relevant to other countries such as Canada, the United States of America, Germany and Brazil, who may attempt cross-jurisdictional data linkage.

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Statement on conflicts of Interest

Natalie Wray, Kate Miller and Felicity Flack were employed by the University of Western Australia with funding from the Australian Government's National Collaborative Research Infrastructure Strategy via the Population Health Research Network during the development and implementation of the OAS.

Ethics statement

Ethics approval was not required for this work as it is a description of the development of software and administrative processes and did not involve collecting data on human or animal participants.

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Abbreviations

DLU:	Data Linkage Unit
NCRIS:	National Collaborative Research Infrastructure Strategy
NSW:	New South Wales
PCG:	Project Control Group
PHRN:	Population Health Research Network
OAS:	Online Application System
WA:	Western Australia

