

The burdensome logistics of data linkage in Australia – the example of a national registry for congenital heart disease

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ABSTRACT

Objective. Data linkage is a very powerful research tool in epidemiology, however, establishing this can be a lengthy and intensive process. This paper reports on the complex landscape of conducting data linkage projects in Australia. **Methods.** We reviewed the processes, required documentation, and applications required to conduct multi-jurisdictional data linkage across Australia, in 2023. **Results.** Obtaining the necessary approvals to conduct linkage will likely take nearly 2 years (estimated 730 days, including 605 days from initial submission to obtaining all ethical approvals and an estimated further 125 days for the issuance of unexpected additionally required approvals). Ethical review for linkage projects ranged from 51 to 128 days from submission to ethical approval, and applications consisted of 9–25 documents. **Conclusions.** Major obstacles to conducting multi-jurisdictional data linkage included the complexity of the process, and substantial time and financial costs. The process was characterised by inefficiencies at several levels, reduplication, and a lack of any key accountabilities for timely performance of processes. Data linkage is an invaluable resource for epidemiological research. Further streamlining, establishing accountability, and greater collaboration between jurisdictions is needed to ensure data linkage is both accessible and feasible to researchers.

Keywords: congenital heart disease, data linkage, epidemiology, ethics, population health, registry.

Introduction

Data linkage is a valuable research tool, which involves the bringing together of information from various sources, creating a new, more comprehensive dataset.¹ Linked data is thus a very powerful resource in epidemiological research, and its benefits have been widely reported.^{2–6} Data linkage allows for the study of disease groups across a population.^{7–9} Matching records from the same individual across different data sources allows researchers to capture a ‘whole of life’ picture of a patient’s journey through a healthcare system.

The Australian Government reported on the substantial advantages of utilising linked administrative data in health research as part of the National Research Infrastructure Roadmap in 2006.¹⁰ This Roadmap also proposed the development of a coordinated national data linkage framework, resulting in the establishment of the Population Health Research Network (PHRN) in 2009.¹¹ The PHRN facilitates a network of the seven data linkage units (DLUs) representing the Australian states and territories, and a national DLU, the Australian Institute of Health and Welfare (AIHW), supporting researchers who wish to access linked population data. Multi-jurisdictional research projects are advised to apply via the PHRN.

Most administrative health service datasets involve hospital-based health care, such as admitted patient data. Much data on outpatient care can be obtained via linkage with the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS) data.

Linking of registry data to administrative datasets allows for analysis of the economic burden of disease, access to and patterns of care, and assessment of outcomes in a contextualised manner – taking into consideration the impact of health determinants such as ethnicity, remoteness, and socioeconomic status.¹²

In 2020, we were awarded an Australian Government Medical Research Future Fund grant, to analyse the burden of congenital heart disease (CHD) in Australia. The project involves the establishment of a National CHD Registry and includes funding for data linkage.¹³ The aim of our linkage project is to understand the burden of CHD from a health-care provision perspective, and to provide more accurate monitoring of healthcare utilisation for CHD.

The study population consists of patients with a diagnosis of CHD derived from the 10 major CHD referral centres across Australia. The total cohort was defined as either Cohort 1, consisting of patients known to the clinics contributing to the Registry, or Cohort 2, patients not already known to the centres, but identified as having CHD by the DLUs through patient encounters associated with CHD diagnosis codes.

We have previously described the major bureaucratic inefficiencies in the establishment of a national disease registry in Australia.¹⁴ In this companion paper, we now examine the process of attempting to obtain data linkage for such projects.

The process of data linkage is currently complex and lengthy. For a national study, it can take >3 years to gain all required approvals, involving up to 8 DLUs, over 10 ethics committees, and numerous data custodians.¹⁵ This linkage project commenced at the end of 2021, with linkage unlikely to commence until early 2024. Although linked health data is an invaluable asset for researchers, the process of obtaining the necessary approvals is a major burden to applicant resources. This paper provides insight into the process of undertaking multi-jurisdictional data linkage in Australia.

Methods

Data collection

We reviewed the processes, required documentation, and applications required to conduct multi-jurisdictional data linkage across Australia.

Applying for multi-jurisdictional data linkage was a step-wise process (Table 1, Fig. 1). The first stage of the multi-jurisdictional linkage application process commenced with submission of an expression of interest (EOI) to the PHRN, via their online system. Once the DLUs are satisfied that the project is feasible, the project can proceed to jurisdiction-specific applications. Approval must be granted from each DLU linking the dataset, the data custodian governing the

database, and the relevant ethics committee, and any other required bodies before linkage can commence.

The AIHW National Hospital datasets are compiled from data previously supplied to the AIHW by state and territory health authorities. The Northern Territory (NT) does not participate in National Mutual Acceptance (NMA) for data linkage, and therefore NT data required a direct application to SA-NT Datalink and submission to a NT Human Research Ethics Committee (HREC). Also of importance to our study aims was the Victorian Cost Data Collection maintained by the Centre for Victorian Data Linkage. This dataset is not covered under the AIHW HREC, requiring submission to an additional NMA-participating accredited HREC.

The Western Australia (WA) DLU underwent major reform over 2022–2023, resulting in major delays and an extended closure of services. Due to these lengthy delays, Western Australian linkage was put ‘on hold’ until WA Research Data Service recommenced. The team re-engaged the WA linkage team in June 2023, although the WA DLU had a substantial backlog of requests, and our application has not yet been addressed at the time of writing and hence data pertaining to this process is not included in the results.

Analysis

We analysed our experience in completing our PHRN EOI and various jurisdiction-specific applications. Time from initial EOI, to progression to jurisdiction-specific applications, to receiving approvals was calculated.

Results

Our EOI was first submitted to the PHRN on 1 December 2021. This commenced the consultation phase (Table 1). The project was authorised to commence jurisdictional ethics and governance applications on the 26 July 2022 (238 days from submission of the EOI), and the consultation and review phases were deemed complete on 13 March 2023 (468 days from submission of EOI).

Each DLU has its own processes within the application phase, as outlined in Fig. 1. The entire process took a total of 605 days from initial submission to final approval from all ethics committees.

Data linkage framework

Much of the consultation and review phases was spent developing and editing the data linkage framework, or data flow, of the linkage project (Fig. 2). This dataflow was complex, given that the project involved not only linkage of individuals in Cohort 1 whose identifiers were to be provided to DLUs, but also of the unknown Cohort 2. The data flow also had to be tailored to each state/territory DLU that was involved. The data flow went through several rounds of feedback with the DLUs. This feedback was

Table 1. An overview of the data linkage application phases undertaken in the Congenital Heart Alliance of Australia and New Zealand Registry Data Linkage Project.

Consultation	<ul style="list-style-type: none"> Submission of an expression of interest via the PHRN's online application system. Outline of the linkage project including aims, methodology, data flow, funding, any conflict of interests, consumer consultation, the research team, cohort selection, datasets of interest, data management and security, privacy and consent details, and an analysis plan Documents included: AIHW Technical Assessment, Registry study protocol, CHAANZ data dictionary, data linkage flowchart, and various jurisdiction-specific documents as outlined in Table 3.
Review	<ul style="list-style-type: none"> The PHRN meets with representatives of all involved data linkage units to discuss the project and review the expression of interest and associated documents. Feedback is given to the research team, and the expression of interest form is released for editing and resubmission. Submission of research team responses to each query raised by the PHRN and DLUs. Revision of expression of interest form and associated documents to address feedback.
Application	<ul style="list-style-type: none"> Preparation and submission of data linkage application/s and human research ethics application/s.
Approvals	<ul style="list-style-type: none"> Obtaining data custodian, ethics, and other necessary approvals (e.g. <i>Public Health Act 2005</i> (Qld) approval for Queensland Health data, Public Interest Certificate for MBS/PBS data)
Data linkage	<ul style="list-style-type: none"> Data linkage units coordinate linkage of the approved data sets before delivery of data to the research team.

CHAANZ, Congenital Heart Alliance of Australia and New Zealand; DLU, Data Linkage Unit; PHRN, Population Health Research Network.

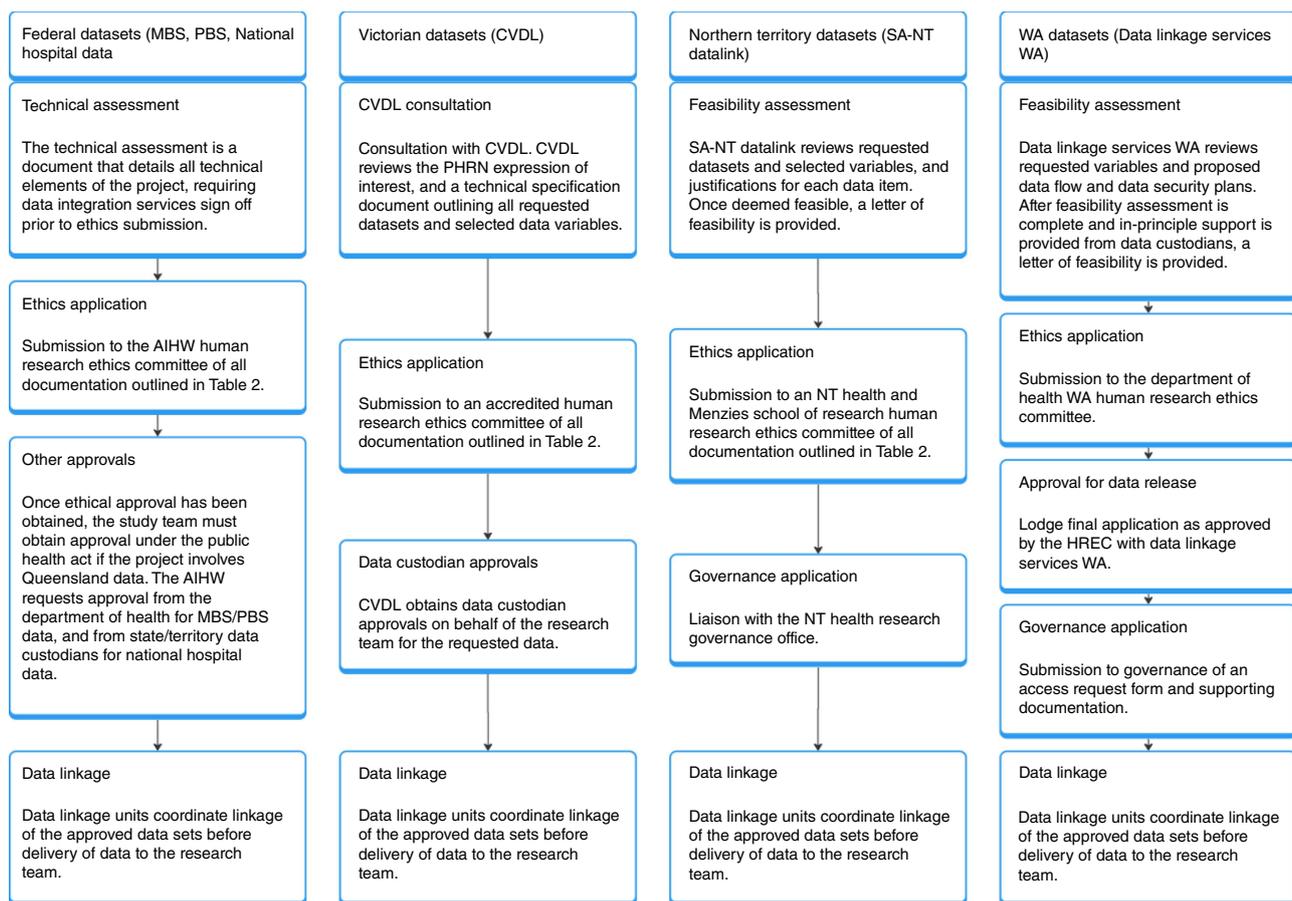


Fig. 1. Flowchart of the application phase for all linkage units involved in the CHAANZ CHD Registry Data Linkage project. AIHW, Australian Institute of Health and Welfare; CVDL, Centre for Victorian Data Linkage; HREC, Human Research Ethics Committee; NT, Northern Territory; PHRN, Population Health Research Network; MBS, Medicare Benefits Schedule; PBS, Pharmaceutical Benefits Schedule; SA, South Australia; WA, Western Australia.

seldom through the central PHRN feedback, with numerous requested changes being made via direct email or phone calls. Each time the data flow methodology changed, all

documents involving the data flow had to be updated in the PHRN online system, as well as the direct communications being had with each DLU and ethics committees.

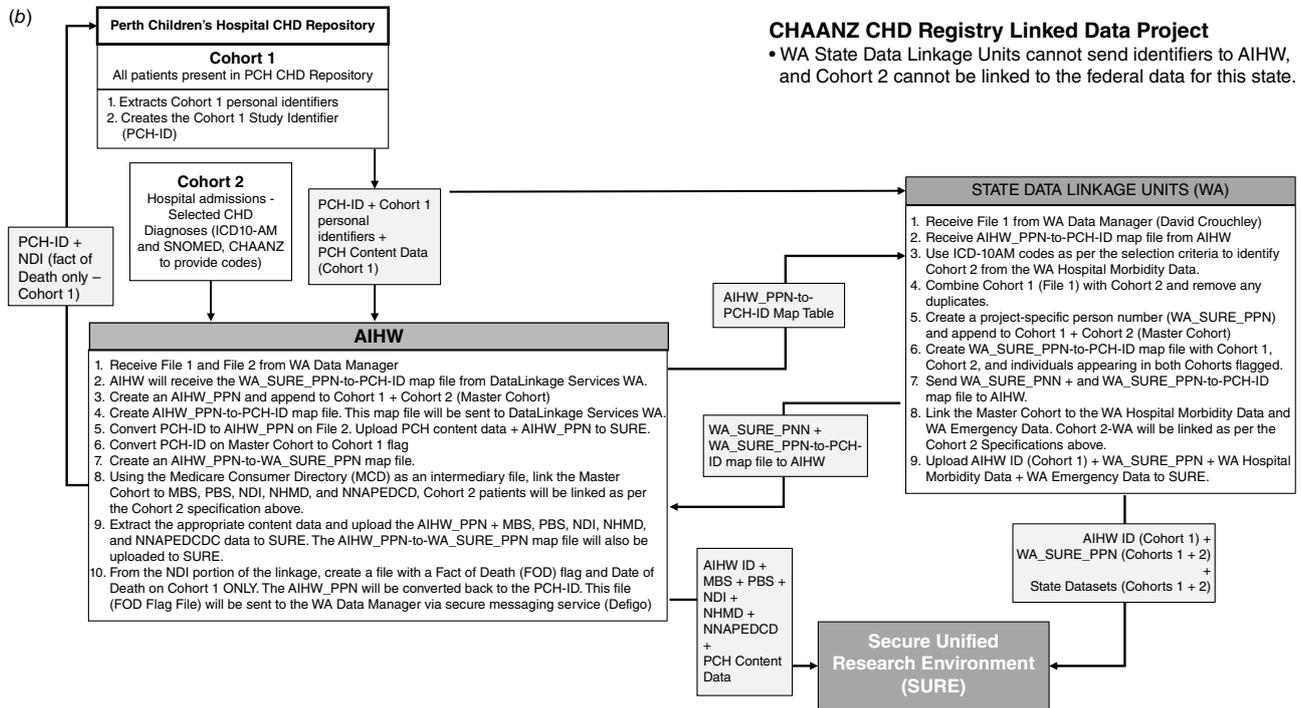
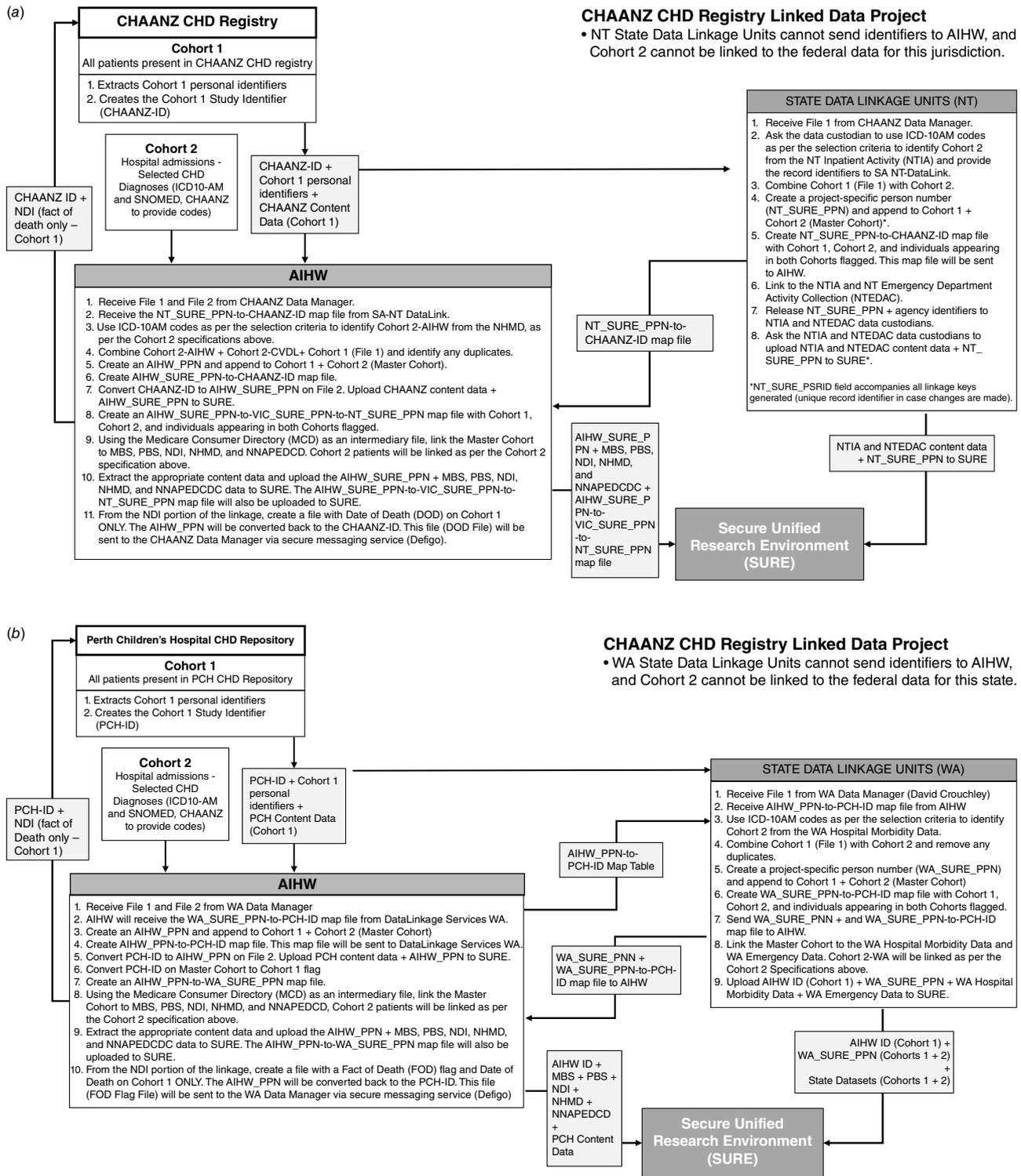


Fig. 2. The data linkage framework required for data linkage for the CHAANZ CHD Registry linkage project. (a) Outline of the data flow for linkage with the AIHW and the Northern Territory DLU, (b) outline of the data flow for linkage with the AIHW and the Western Australian DLU, and (c) outline of the data flow for linkage with the AIHW and the Victorian DLU. AIHW, Australian Institute of Health and Welfare; CHAANZ, Congenital Heart Society of Australia and New Zealand; CHD, Congenital Heart Disease; CVDL, Centre for Victorian Data Linkage; FOD, Fact of Death; ID, identification; MBS, Medicare Benefit Scheme; MCD, Medicare Consumer Directory; NDI, National Death Index; NHMD, National Hospital Minimal Dataset; NNAPEDDC, National Non-Admitted Patient Emergency Department Data Collection; NT, Northern Territory; NTDL, Northern Territory Data Linkage; PBS, Pharmaceutical Benefit Scheme; PPN, Person Project Number; SURE, Secure Unified Research Environment; VAED, Victorian Admitted Episode Database; VCDC, Victorian Cost Data Collection; VEMD, Victorian Emergency Minimum Dataset.

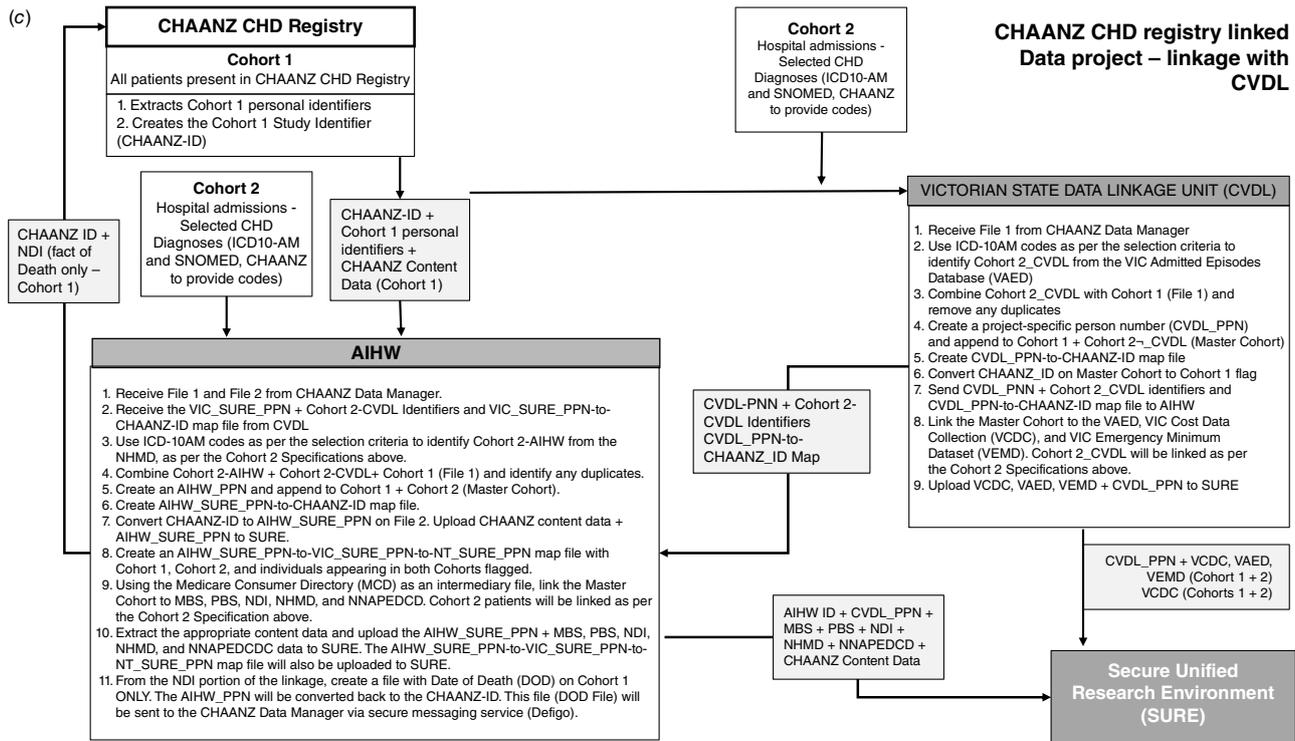


Fig. 2. (continued)

Table 2. Pros and cons of using the National Hospital Data over linking administrative hospital data with each state data linkage unit.

Pros	Cons
Streamlined application process, reducing number of data linkage unit applications required from 7 to 3, and ethics applications from 5 to 3.	As most of the data linkage is funnelled through the AIHW DLU and their ethics team, progression of linkage is limited by their response/approval time.
Uniform variable list for datasets across states and territories.	Loss of some variables of interest from some datasets.
Presumably lesser cost, however, as accurate quotes were not obtained from DLUs once decision to take National Hospital data route was made, this cannot be verified.	Significantly increased cost of AIHW linkage from initially budgeted amount.

Ethics approvals

Grant reporting timelines were greatly challenged by the coronavirus disease 2019 (COVID-19) pandemic. In the interest of meeting already delayed reporting milestones, the team opted to collect hospital inpatient and emergency department data via the AIHW National Hospital datasets, as compared to the alternative option of applying to each state and territory DLU and their associated ethics committees and data custodians. This decision streamlined the application process significantly, reducing the DLU applications required from 7 to 3, and ethics applications from 5 to 3. There were other considerations involved in this decision, summarised in Table 2.

The application for NT data linkage ethical approval was submitted to the NT Health and Menzies School of Research HREC on 16 January 2023, with approval received on 7 March 2023 (51 days). This application consisted of nine

documents (Table 3), and went through one additional round of review, wherein the ethics committee asked for additional information regarding data collection, recruitment, and stakeholder involvement.

Application to the AIHW HREC was submitted on 23 March 2023, with approval received on 28 July 2023 (128 days). This application consisted of 25 documents (Table 3) and went through five additional rounds of feedback prior to the HREC meeting. This feedback involved revisions to the Technical Assessment, queries about study personnel, and updates to the proposed data flow.

Application to the NSW Population and Health Services Research Ethics Committee (PHSREC) was submitted on 29 May 2023, with approval received on 18 July 2023 (52 days). This application consisted of 22 documents (Table 3) and went through one additional round of feedback prior to the HREC meeting, and one round of review post-meeting. This feedback involved recommendations for consultation with

experienced data linkage researchers, and queries about requested variables.

Delays in submission to the relevant HRECs were experienced during the approval stage outlined in Table 1, due to lengthy response times from DLUs. For example, with all other documentation prepared, a requirement for one signature from a data custodian for the Victorian Cost Data delayed application to the PHSREC by 60 days.

Other approvals

After the relevant ethical approvals had been obtained, additional approvals were required prior to linkage. For Queensland hospitals' data, it is required that an application for data release under the *Public Health Act 2005* (Qld) (PHA) be approved by each data custodian relevant to the project and the Director General of Queensland Health. This was fortunately swift for our project, as we had obtained data custodian signatures whilst awaiting ethics approval. The PHA application was submitted on 29 August 2023, with approval received on 6 September 2023 (9 days).

Lastly, when we thought that all the appropriate approvals for the project had been obtained, after 646 days, we received an email from the AIHW informing us of a further and unforeseen delay. The AIHW National Hospitals' team obtains the remaining jurisdiction's data custodian approvals on the research team's behalf once AIHW ethics is approved. In the meantime, the AIHW was to submit the approved project to the Department of Health and Aged Care for them to issue a Public Interest Certificate (PIC) for the use of MBS/PBS data. The AIHW estimated that it would be a few weeks until they submitted that request, owing to the Department being 'understaffed recently and unable to progress new requests'. At that point, the time estimate was a further 3–4 months for the PIC to be issued. Only then could linkage begin.

Discussion

There are obvious important advantages of data linkage for national or state-based Registry projects, as this enables a complete picture of patient interactions with the healthcare system. This information is invaluable for patients, families, healthcare providers, systems planners, and governments. In this paper, we describe the continuing and substantial bureaucratic hurdles to data linkage in Australia, 15 years after the establishment of a centralised body which aims to streamline this process. These delays frustrate researchers but also, importantly, reduce Australia's ability to generate meaningful data and reduce our international competitiveness in epidemiological research.

Without national data linkage capabilities, research cannot make use of cross-jurisdictional data linkage. Data linkage infrastructure has progressed since its inception,¹⁶

however, much duplication and complexity in the application process remains. Conducting research involving national data linkage in a timely manner is thus virtually impossible.

The difficulty in establishing cross-jurisdictional linkage problems lies, in part, within the complex multi-jurisdictional nature of Australia's health system. Australia's federal, state and territory, and local governments share responsibility for the health system, and consequently health data is not held centrally. Navigating the legal framework governing these systems, while achieving standardisation of data and linkage methodology across jurisdictions, is complicated.

Although all efforts were made to expedite our linkage applications, expected timelines were pushed back repeatedly. The PHRN online cross-jurisdictional application form was designed to enable a more centralised application process, but it is unclear if this system streamlines applications as intended. The central EOI process meant DLUs had some familiarity with the project once we progressed to the application phase, but nevertheless we had to undertake the same processes outlined by each individual DLU for single jurisdictional linkage (Fig. 1), not circumventing any steps after the lengthy consultation and review period.

The application phase involved substantial duplication of effort. Each time the data flow or application documentation was amended during consultation with individual DLUs, these changes had to be uploaded to the PHRN online form. This also occurred in the other direction, with changes in the PHRN form needing to be relayed back to DLUs. Multiple places to update versions led to confusion amongst the team and DLUs about document versions and changes to data flow.

Another limitation of this centralised process is that the progression of the consultation and review process is limited by the availability of all parties to meet and discuss the project. Feedback was not released to the research team until all DLUs had provided their feedback; this was thus limited by the slowest party. Significant delays were experienced due to the WA DLU undergoing reform, with the WA portion of the linkage eventually being placed on indefinite hold. This extended closure highlights the need for lasting resources to ensure the longevity of Australia's linkage infrastructure. Unpredictable responsiveness added further delays to the project, with no expected response time outlined by most DLUs.

The research team was responsible for developing the data flow (Fig. 2), at times feeling like guesswork via many iterations of data flow documentation. It seemed counterintuitive that the data flow was not initially proposed to us by the DLUs conducting the linkage, who were the experts in data linkage, and were charging considerable dollar amounts for the linkage.

Other groups have also found that, although data linkage in Australia has overcome some challenges in developing

Table 3. Documentation involved in each ethics submission in the application phase of data linkage project.

Data Linkage Unit or Ethics Committee	Documents
Australian Institute of Health and Welfare (AIHW) Human Research Ethics Committee	<ul style="list-style-type: none"> – Ethics approval for the main registry project – Independent Peer Review Report – Technical Assessment approved by the AIHW Data Integration Services Centre – Confidentiality agreements signed by all research team members – Victoria Specific Module (required for applications involving Victorian data) – CHAANZ Registry study protocol – <i>Public Health Act</i> signed by Queensland data custodians – Participant Information and Consent Forms
NT Health and Menzies School of Research Human Research Ethics Committee	<ul style="list-style-type: none"> – Cover letter – NT HREC application form – Letter of Feasibility provided by SA-NT Datalink after review phase completed – SA-NT Datalink Data Elements Specification Form – CV of chief investigator – Data Linkage Protocol – Registry Study Protocol – RGO Authorisations of sites involved in Registry project
The NSW Population and Health Services Research Ethics Committee (PHSREC)	<ul style="list-style-type: none"> – Cover letter – Human Research Ethics Application – Victoria Specific Module – Data Linkage Protocol – Privacy Form applying for a waiver of consent – Variable List – Data Custodian Approval from CVDL – Independent Peer Review Report – CVs of all researchers – CHAANZ CHD Registry study Protocol – CHAANZ CHD Registry study HREA – CHAANZ CHD Registry study participant information sheet and opt-out form – CHAANZ CHD Registry study parent/guardian information sheet and opt-out form – CHAANZ content data variable list – Commonwealth (AIHW) variable lists

CHAANZ, Congenital Heart Alliance of Australia and New Zealand; CHD, congenital heart disease; CVDL, The Centre for Victorian Data Linkage; CV, curriculum vitae; HREA, Human Research Ethics Application; HREC, Human Research Ethics Committee; NSW, New South Wales; NT, Northern Territory; SA, South Australia.

the infrastructure for cross-jurisdictional data linkage, national data linkage projects are hindered by the complexity of the process.^{15,17} A recent publication by Dutch researchers reported on obstacles similar to those faced in the Australian data linkage landscape.¹⁸ There is an urgent need for a truly streamlined application process with reduced duplication and greater consistency of procedures.^{7,15,17,19}

Improving Australia's data linkage infrastructure requires greater homogeneity and simplification of the legislative framework governing health data. The Australian Government 2017 Productivity Commission inquiry report noted a risk-averse culture has led to 'overly cautious interpretation of relevant legislation ... and complex and lengthy approval processes' (p. 55).²⁰ The 2017 report also noted a lack of national leadership and longwinded bureaucratic processes for data release.²⁰ While protecting patient privacy and ensuring ethical conduct is undoubtedly a critical element of research, the current approval process is a source of major inefficiency and limits the accessibility of data linkage.

Greater oversight from the PHRN could be considered. The PHRN provided excellent resources on navigating the

complicated application phase, however, the requirements themselves were oftentimes unclear. One common application, such as the existing online PHRN EOI form, could be utilised by all DLUs, centralising the process.

The AIHW has been developing new data asset initiatives that should address some of the issues faced in accessing cross-jurisdictional health data, by integration of existing linked AIHW datasets to enable access in a more timely manner.²¹ This initiative is underway, with assets such as the National Integrated Health Services Information available for application, and the National Disability Data Asset being finalised.²²

Ultimately, the establishment of the data linkage project was a lengthy and intensive process. Access to linked data is invaluable to a National Registry, allowing for longitudinal analysis of population groups, however, the costly and time-consuming process of achieving the necessary approvals remains a challenge to both grant funding and timelines. Further streamlining, key accountabilities, and greater collaboration between jurisdictions is needed to ensure data linkage is feasible to researchers.

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