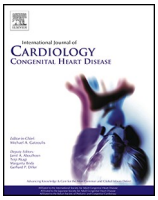
International Journal of Cardiology Congenital Heart Disease 17 (2024) 100538

Contents lists available at ScienceDirect

International Journal of Cardiology Congenital Heart Disease

journal homepage: www.journals.elsevier.com/international-journal-of-cardiology-congenital-heart-disease



A national Australian Congenital Heart Disease registry; methods and initial results

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A B S T R A C T

Background: Although several National Data Registries for Congenital Heart Disease (CHD) exist, few are comprehensive and contemporary. A National Australian CHD Registry has been developed that aims to redress this by creating the first comprehensive data collection for CHD children and adults, initially across Australia.
Methods: We defined and collected a minimum dataset of demographics, diagnoses, and procedures from people with CHD presenting at participating quaternary CHD services Australia-wide. Data were collected from a range of clinical data sources. Diagnoses and procedures were standardised to the European Paediatric Congenital Code – Short List. Methodological limitations were carefully documented.
Results: From 8 participating institutions, an initial 359,084 patient records were assessed for eligibility and 68,234 unique individuals with structural CHD have been included in the current dataset. There were 20,395 (30 %) people with mild CHD, 25,157 (37 %) with moderate CHD, and 13,530 (20 %) with severe CHD (6 % unknown complexity). The most common diagnoses were Ventricular Septal Defect (16,781, 25 %), Atrial Septal Defect (6,607, 10 %), Aortic Valve Disorders (5516 8 %), Coarctation of the Aorta (5,321, 8 %), Tetralogy of Fallot (4,489, 7 %), Transposition of the Great Arteries (4,009, 6 %).
Conclusion: The data presented here represents the most comprehensive cohort collected for the Australian CHD population thus far and is comparable with the largest contemporary CHD registries around the world. This Registry represents a key resource for improved understanding of the CHD population and will drive better care and outcomes for people living with CHD.

1. Introduction

Registries have become a key resource for Congenital Heart Disease (CHD) research around the world. These help to uncover the characteristics of a CHD population with continuously changing demographics, due to improved survival over the last several decades [1]. CHD Registries can contribute to improving the equity and accessibility of CHD healthcare, and provide key information required to drive research and improve patient outcomes. Whilst administrative health data has been a growing area in health research, these sources often lack the specificity and accuracy in reporting of CHD cases to act as the sole resource used in understanding this population [2,3]. Dedicated CHD

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https://doi.org/10.1016/j.ijcchd.2024.100538
Received 21 August 2024; Accepted 23 August 2024
Available online 24 August 2024

registries are particularly important to ensure the detail within the complexity of this field is captured, as the underlying conditions are often multiple and heterogeneous.

Surgical and medical intervention for CHD over the last 70 years has been a great success story, with survival to 16 years for children with complex CHD now at 87 % [4]. This has created a new and growing population of people surviving to adulthood with CHD [5]. Consequently, the life expectancy for mild and even moderate CHD patients quite closely approximates that of the general population [6]. This success leads to the next great challenge in CHD care; understanding and caring for this growing and evolving population. Global estimates of the birth prevalence of CHD is about 8–10 in 1000 live births [7,8] and the prevalence of adults living with CHD is about 3000 per 1 million adults [9]. The characteristics of the contemporary CHD population must be understood to deliver adequate care to these patients; this requires specialist care to minimise preventable complications and mortality [10, 11]. Service delivery can be improved with the insights available in large population-level datasets, such as using geographic analyses, for example, to inform resource allocation for services [12].

CHD Registries, either lesion specific or general, have been developed around the world over the past two decades. The National Australian CHD Registry, with the goal of registering all patients with CHD in Australia, aims to facilitate focused research, promote the need for greater resources and to build a lifelong continuum of care for all people with CHD.

Here we provide the details of the governance and data structures of the National Australian CHD Registry, outline the data collection and recruitment procedures, and detail the Registry's initial data collection from over 68,000 individuals CHD.

2. Methods

2.1. Australian context

The Australian Healthcare system has a "two level" funding model, where a federal government funded public health insurance scheme provides basic healthcare coverage, especially for services outside hospitals. Management of public hospitals, including inpatient and outpatient services and emergency care, is funded separately by each of the 8 Australian states and territories (New South Wales (31 % of the Australian population), Victoria (25 %), Queensland (20 %), Western Australian (11 %), South Australia (7 %), Tasmania (2 %), Australian Capital Territory (2 %), and Northern Territory (1 %)) (Fig. 1) [13]. The federal government manages direct payment to healthcare practitioners for primary health care, some specialist care, and subsidies for medications. Some of these services (hospitals, primary health care, specialist care) are also available through privately funded models [14]. Australia's population was 26.9 million in June 2023, and with a population density of 3.4 people per square kilometre, its distribution is highly urbanised (72 % living in major cities) with a small, low density regional population (26 % in regional areas and 2 % in remote areas) [15,16]. The most common ancestries in Australia are English (33 %), Australian (30 %), Irish (10 %), Scottish (9 %) and Chinese (6 %) [17]. In 2021, there were 983,700 Aboriginal and Torres Strait Islander people in Australia (representing 3.8 % of the population) [18].

CHD care and management generally involves a 'hub and spoke' model where large quaternary services located in urban centres support smaller regional clinics. These regional clinics allow for outpatient services to be delivered closer to regional/rural patients. CHD services are organised at the state (2nd tier government) level, with quaternary services (in both paediatric and adult hospitals) existing in the capital cities of the 5 most populous states.

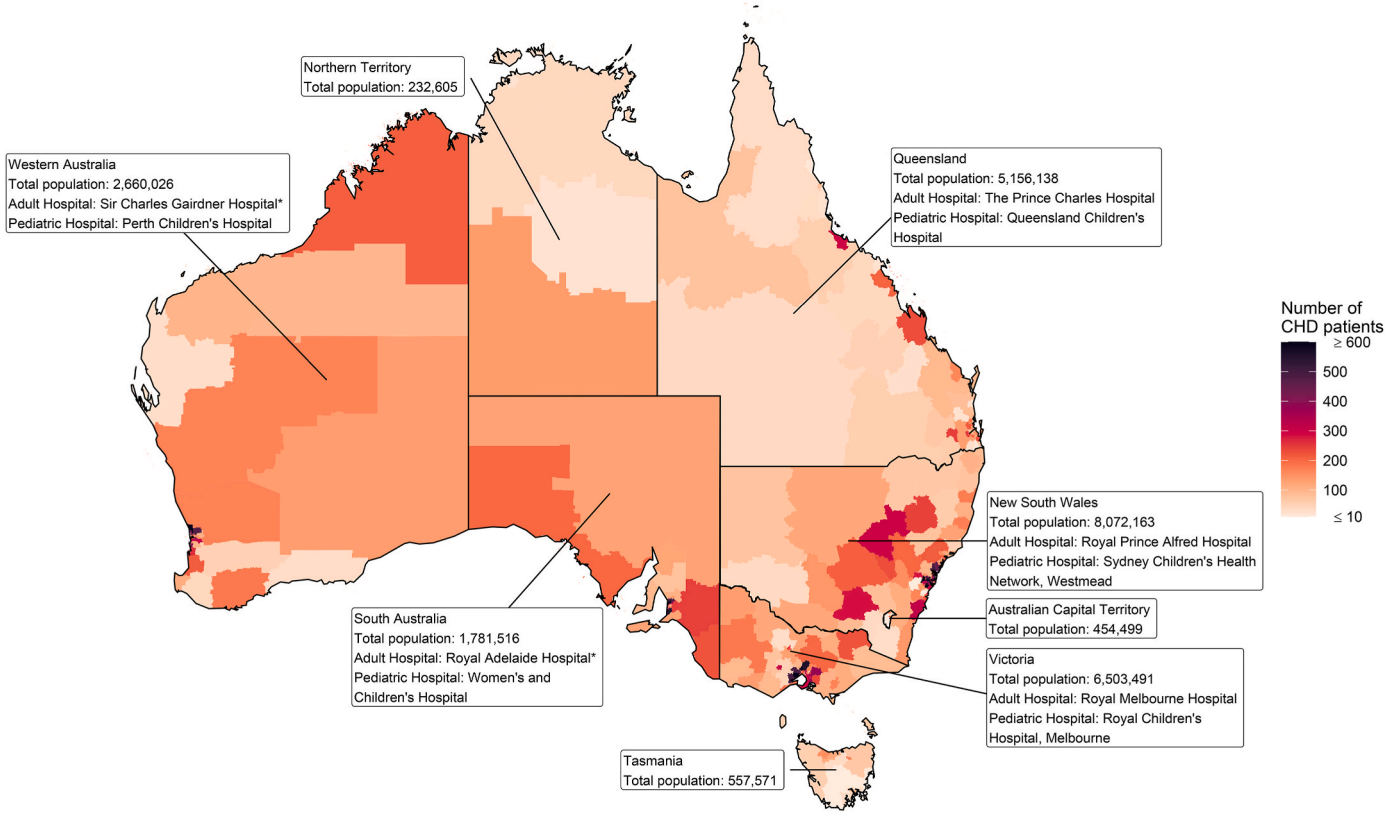

Fig. 1. The Australian context and participating hospitals. Map of Australia, black line shows the state boundaries, and the heat map shows the number of structural CHD patients included in the Registry in each Statistical Area Level 3. The labels show the state names, total state population and hospitals that are participating in the Registry. *Hospitals that have do not have data included in this report.

2.2. Collaborators and governance

Development of the Registry was initiated by Heartkids Australia, a not-for-profit non-government organisation, after the need for a Registry was recommended following an extensive national review of CHD management [19]. The hub and spoke structure of CHD care in Australia allows the Registry to cover all the CHD services by collaborating with each of the country's main hubs. In total there are 10 hospitals across Australia that are participating; there is one tertiary-level paediatric cardiac surgery service and one main adult hospital for adult congenital services in New South Wales, Victoria, Queensland, South Australia, and Western Australia (Fig. 1). Whilst the smaller Australian states and territories are not directly represented here, the current participating hospitals also provide services to these regions, allowing their inclusion in the current data capture.

The Registry is governed by a Steering Committee and Executive Committee that includes representatives from the cardiology department of each participating institution, other key CHD clinicians, Heartkids Australia, consumer representatives, and project managers. These committees provide guidance on data collection, data quality, finance, and review submissions for research projects.

2.3. Registry structure and minimum dataset

The Australian CHD Registry is a Filemaker Pro Database (V20.3.1.31) with a person-centric structure. A main demographics table is related to several secondary tables that detail an individual's medical record. These table include Diagnosis, Procedures, Catheter Tests, Echocardiography Test, Medications, Blood Tests, Hospital Events, Follow Up Visits and Miscellaneous Tests. This structure allows each person record to be related to multiple events, interventions, and diagnoses. Each participating hospital is organised as a "tenant" group, and each person record is assigned to one tenant. Duplicate records between hospitals are detected based on name and date of birth matches. Demographics details from the most recent record (based on last follow up date) are used for duplicate records in this report.

The minimum dataset collected includes key variables from the Demographics, Diagnosis and Procedure Tables (Table 1) and aims to collect from a date range starting from the beginning of 2010. Both Diagnosis and Procedure coding in the Registry use a subset of the European Paediatric Congenital Cardiology (EPCC) code – short list, as described previously [20].

Current data collection aims to complete an individual's record in a tiered structure; the first tier seeks to identify those being treated for CHD and collect the minimum data set, the second tier will collect retrospective data related to their medical investigations (catheter, echo, etc) and the third tier will include ongoing, prospective data collection of current individuals' medical journeys and new participants, using the available tables.

Table 1
The minimum dataset for the Registry.

Table	Variable
Patient	Date of Birth
	Gender
	Address
	Phone
	Mortality Status
	Medical Record Number
	Last Date of Care
Diagnosis	Diagnosis Code (EPCC)
	Diagnosis Name (EPCC)
	Diagnosis Code (Source)
	Diagnosis Name (Source)
	Diagnosis Date
Procedure[a]	Procedure Code (EPCC)
	Procedure Name (EPCC)
	Procedure Code (Source)
	Procedure Name (Source)
	Procedure Date

[a] Procedure Table not mandatory data.

2.4. Data sources

Each hospital has a unique context. Data sources that contain the CHD populations and their minimum dataset were identified on a case-by-case basis. Adult hospitals typically have smaller populations whose data are manually managed in dedicated, local Adult CHD databases, allowing for direct exports from these single sources. Paediatric hospitals often have much larger populations, many of whom are do not have CHD and require filtering. The minimum dataset is often found across multiple data sources, requiring consolidation.

The data presented here includes near completion of tier one data for eight of the current participating hospitals in Australia. Gaps include two hospitals' data that are still outstanding, one hospital that has half of the minimum date range complete and no procedure data, and one hospital with missing procedure data. These cases are due to a lack of coded, clinical data sources, requiring manual data collection, often from clinicians' letters and other free text sources. The data sources for each participating hospital's retrospective data collection, and any specific methodological challenges, are outlined in detail in Supplementary Material 1.

For all hospitals, data was prepared through an extract, transform, and load process. Once data sources were identified, they were extracted from local hospital systems. Data were transformed into standardised formats, matching the Registry's data dictionaries. Where required, diagnosis and procedure codes were translated into the EPCC short list used in the Registry. With standardised diagnosis and procedure codes, patient records were able to go through the participant selection process described below, removing those who do not meet the eligibility criteria. The final standardised and filtered datasets were loaded into the Registry.

2.5. Study population selection

The Registry's inclusion criteria includes participant of any age, with an attendance at a participating hospital and a diagnosis of CHD. The Registry defines CHD as any person born with structural heart defect that persists after 12 months of life or has had their condition rectified in the first 12 months of life.

As a first step, a large retrospective cohort of all individuals who attended the cardiology service at each participating hospital was collected from the identified data sources. To identify the eligible CHD population from these large retrospective cohorts, conditional algorithms were applied to individuals' EPCC codes to identify which have CHD. Each EPCC code is marked as a CHD code or a non-CHD code. In some cases, the presence of a code alone is not enough to determine eligibility and further, contextual rules to determine relevant procedures, sequelae, or follow up are required. Five True/False flags are created for each individual to determine their CHD status.

The first flag, "Diagnosis or Procedure Present", in the selection process identifies people with a diagnosis or procedure code present in the data, cases that lack the minimum dataset are excluded. Individuals who have only a diagnosis code noting a normal anatomy, such as normal heart (01.01.00) or atrial situs solitus (01.03.00), were excluded in this stage.

The second and third flags, "CHD Diagnosis Present" and "CHD Procedure Present", classifies people with at least one CHD code in their diagnosis or procedure list. There are some cases where it is not clear whether a diagnosis code was congenital or acquired, and contextual rules were applied to determine the "CHD Diagnosis Present" flag. For example, isolated Mitral Stenosis (06.02.92) was considered congenital if the data was acquired from a paediatric hospital, but not at an adult hospital (where acquired mitral stenosis is a likely confounder).

Furthermore, isolated valve disorders and cardiomyopathies that were associated with Rheumatic Heart Disease codes (10.05.01, 10.05.21, 10.05.30, 10.05.31, 10.05.33) or Kawasaki disease codes (10.09.01, 10.09.02, or 10.09.08) were not considered congenital.

Since the EPCC codes do not provide detail on severity or complexity of a condition, it can be difficult to determine eligibility of some cases using the codes alone. For example, the diagnosis of Persistent Arterial Duct (09.27.21), does not distinguish between a severe case requiring surgery and a transient case that spontaneously closes in the neonatal period. We sought to exclude isolated transient circulatory features that were recorded as a diagnosis in neonatal investigations but did not persist later in life. The fourth flag, "Transient Conditions with no Follow Up", identifies people with an isolated transient condition with no follow up after 12 months of life.

The Registry also applied contextual rules to certain types of genetic conditions that potentially involve cardiac complications, including Marfan syndrome, Williams syndrome and Loeys-Dietz syndrome. These are conditions who were included in the Registry if they contained associated cardiac codes. For example, both the code for Marfan syndrome (14.04.85) and the code for Ascending Aorta Dilation (09.16.09) are ineligible when they occur in isolation but an individual with both codes together will be eligible. The final flag, "Genetic Condition with Cardiac Involvement", identified people with a relevant genetic condition who also have an associated cardiac condition.

These flags are combined to create a final determination of eligibility, first all individuals with no CHD-related diagnosis or procedure are excluded. Next a "Baseline Eligibility" flag is determined using the following logic:

Baseline Eligibility = *("CHD Diagnosis Present" = TRUE AND "Transient Conditions with no follow up" = FALSE) OR ("CHD Procedure Present" = TRUE)*

This will identify all CHD cases, excluding potential transient conditions without follow-up after 12 months, unless there is a CHD procedure present. Finally, people with genetic conditions with associated cardiac conditions were included with the following logic:

Final Eligibility = "Baseline Eligibility = TRUE" OR "Genetic Condition with Cardiac Involvement = TRUE"

2.6. Data quality audit

Random samples of the minimum dataset were sent to 7 of the 8 participating hospitals to conduct a data quality audit. Identified cases were stratified by CHD complexity using an algorithm based on the European Society of Cardiology's 2020 guidelines for Adult Congenital Heart disease [21–23]. Ten individuals were sampled from Mild, Moderate, Complex, and Unknown categories for review. The audit assessed four points; first to check that the individual is correct, in that their demographic information matches their medical record number. Second and third, that the diagnosis and procedure lists had been checked for completeness (all the codes in the source data were present in the Registry) and correctness (the codes in the Registry are present in the source data). The fourth check was whether each individual was eligible for the Registry.

The results of this case-review of 240-individuals was fed back into data standardisation to improve the eligibility selection and data cleaning. A further 120 cases were then selected (20 from each hospital) to examine 'post-review' changes following the updated data standardisation process.

2.7. Ethics and consent

Human Research Ethics Approval was obtained from the Sydney Local Health District Ethics Review Committee (RPAH Zone) (EC00113). The number for this ethics protocol is 2019/ETH07472. Due to the large number of individuals involved and the low-risk nature of the research, a waiver of consent was granted by the Human Research Ethics Committee to collect retrospective data. Prospective data collection is approved via an opt-out consent process.

Prospective data collection begins at each hospital on a case-by-case process. When retrospective collection is completed and prospective collection processes are ready to begin, the Ethics committee is notified of the date that a participating hospital moves to prospective data collection. There are two methodologies that can be used to undertake opt-out consent. First is via a mail out, where participants are sent a letter with the study information and an opt-out form via mail or e-mail after attending an outpatient clinic. Second, the study information and opt-out form are provided during the clinic visit with the participant's cardiologist. Paper versions of the Opt-out form are available; however, an online version was developed to allow those captured by the registry to access the study information and opt-out form via the Registry's website. The online version can be delivered via a business card with a QR code, or a URL link.

2.8. Data security and Privacy

The Registry is hosted on a virtual private server stored on a cluster of servers located in a secure data centre in Australia. The data centre has 24 × 7 × 365 on-site security with CCTV monitoring and alarm systems. Physical access to servers will be restricted to escorted visits by authorised staff only. Logical access to the data in the Registry is controlled by a proprietary role-based security system. Authentication and authorisation are on a per user basis. Local clinicians will then only have access to the identifiable data about individuals entered at their site under their care. There is no public or unauthorised access to the Registry. All network traffic is encrypted using SSL (Secure Sockets Layer). The virtual private server is password protected and nightly back-ups performed and saved in a separate location.

2.9. Software and data analysis

All data were cleaned, prepared for the Registry, and analysed for reporting using R Statistical Software (v 4.3.0) and the tidyverse package (v 2.0) [24,25]. Since there are often multiple diagnoses and procedures per person, and the primary diagnosis was often not available in the source data, individuals needed to be categorised into a single diagnostic category. Where there were multiple CHD diagnoses, a purpose-designed hierarchy was applied, where an individual would be placed into the category corresponding to the most severe diagnosis or procedure in their list. Shape files used for mapping were from the Australian Geographic Statistical Standard and population data was taken from the 2021 census using the Table Builder tool, both provided by the Australian Bureau of Statistics [26,27].

3. Results

3.1. Patient selection

Patient records were collected from 8 hospitals around Australia and processed to determine eligibility (Fig. 2). In total, 359,085 records were collected from clinical data sources and 228,935 had no diagnosis, no procedure, or documented normal anatomy (almost all of these had been seen for "innocent murmur"). The remaining 130,150 records were considered for eligibility and 51,158 were determined ineligible for inclusion in the Registry. There were 41,086 records with no CHD diagnosis, 10,072 with fetal circulatory features but no continued follow up or procedures that were considered to have transient circulatory features only. A total of 78,992 records were selected as Registry eligible and 91 of these had opted out through the consent process, leaving 78,901 records included in the Registry.

Of the two atypical, non-structural CHD groups, there were 3376 with an isolated patent foramen ovale, and 1472 with an isolated genetic cardiac condition but with no structural cardiac condition listed. After

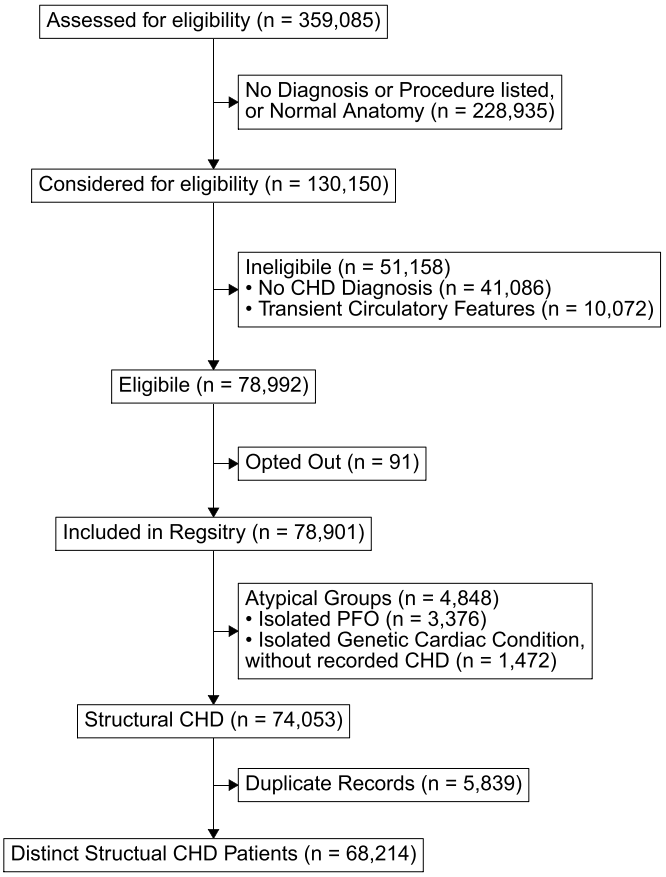

Fig. 2. The patient selection flowchart outlining the eligibility selection process for the Registry.

exclusion of these groups, there were 74,053 records in the Registry with structural CHD.

Since data were collected from multiple hospitals, name and date of birth matches were checked to identify duplicate records and find the total number of distinct participants (Fig. 3). After exclusion of duplicated records, there were 68,214 unique individuals with structural CHD. Most duplicates were seen between the adult and paediatric hospital pairs in each state and between paediatric hospitals where patients are transferred to another site, for surgery. Since only deidentified data were collected from Western Australian hospitals, the duplicates between Perth Children's Hospital and other hospitals were unable to be identified.

3.2. Structural CHD – cohort Description

The demographic overview of the 68,214 people with structural CHD is shown in Fig. 4. There were 20,395 (30 %) people with mild CHD, 25,157 (37 %) with moderate CHD, 13,530 (20 %) with severe CHD and 9132 (13 %) whose severity could not be classified with automated methods. There were 6838 (10 %) people born before 1980, 23,980 (35 %) were born between 1980 and 2000, and 36,964 (54 %) were born after 2000. Participants were collected from across Australia, 22,387 (36 %) from New South Wales, 15,088 (24 %) from Victoria, 8449 (14 %) from Queensland, 7167 (11 %) from Western Australia, 6650 (11 %) from South Australia, 1210 (2 %) from Tasmania, and 779 (1 %) from the Northern Territory. There were 779 individuals from outside Australia. 31,318 (46 %) of participants were female, 4518 (6 %) had a missing or unknown gender and 3886 (6 %) participants were recorded as having died in the clinical source data. The median time from the last recorded encounter with the cardiology service to data capture was 12 years (IQR 3–23 years).

The top 10 diagnosis categories in the data were Ventricular Septal Defect (16,781, 25 %), Atrial Septal Defect (6,607, 10 %), Aortic Valve Disorders (5516 8 %), Coarctation of the Aorta (5,321, 8 %), Persistent Arterial Duct (4,847, 7 %), Tetralogy of Fallot (4,489, 7 %), Transposition of the Great Arteries (4,009, 6 %), Pulmonary Valve Disorders (4,004, 6 %), Univentricular Heart (Not Fontan) (3,498, 5 %), and Atrioventricular Septal Defect (3,221, 5 %) (Fig. 5). The full list of diagnosis categories is available in Supplementary Material 2.

3.3. Data quality audit

A total of 280 participants across seven hospitals were reviewed for the first round of data quality audit. All 280 Registry participants were correctly matched against the source data. 261 (93 %) had a diagnosis list that was both complete and correct. 254 (91 %) had a procedure list that was both complete and correct. There were 264 (94 %) people who were marked as eligible when manually checked in the data quality audit. A second sample of 20 participants each from six hospitals were reviewed once data processing edits were implemented after the first round of results were reviewed. This time 120 Registry participants were correct, 111 (93 %) had a complete and correct diagnosis list and 117 (98 %) had a complete and correct procedure list. There were 117 (98 %) people who were eligible (Fig. 6).

4. Discussion

The National Australian CHD Registry represents the first efforts to collect a comprehensive cohort of people living with CHD in Australia. With 68,214 unique individuals with structural CHD currently identified, this cohort is already larger than the previously largest CHD registries, worldwide. These include the Swedish National Registry of Congenital Heart Disease with 58,604 reported in 2022 [28,29], German National Registry of Congenital Heart Disease with 52,582 CHD reported in 2021 [30,31] and The Quebec Congenital Heart Disease Registry with 43,542 reported in 2024 [32]. Indeed, this initial cohort is expected to grow when new data sources from two hospitals from South Australia and Western Australia are included. We also have a process underway to capture the same information for New Zealand.

Whilst some differences occur, frequencies of key CHD lesions are broadly similar between all these registries. As a percentage of the total cohort, these registries report Ventricular Septal Defect (17 %–22 %), Atrial Septal Defect (6 %–13 %), Persistent Arterial Duct (6 %–9 %), Tetralogy of Fallot (2 %–9 %), and Transposition of the Great Arteries (1 %–7 %). The National Australian CHD Registry reports 25 %, 10 %, 7 %, 7 %, and 6 % of the total cohort respectively. It should be noted that for participants with more than one CHD diagnosis, only the "most complex" was presented in this paper, rather than the "multiple diagnosis" groups being presented separately. We are currently performing further validation of this classification system and future reports may present different diagnostic categories, based on the outcomes of this work.

There are still some important limitations in the current dataset, including gaps in collection from some sources and collection still outstanding for other sources. Currently, the average yearly birth prevalence from these data is 6 in 1000 live births which is lower than current global estimates of 8–10 in 1000 live births [7,8]. This difference may be due to incomplete data collection reported here, rather than representing a truly lower prevalence. There are also likely gaps in the current collection of interventions in this cohort, noted by the large number of seemingly unrepaired lesions. With large proportions of people with Aortic Valve Disorders (80 %), Atrioventricular Septal Defect (59 %), and Transposition of the Great Arteries (40 %) who have not had a repair (Supplemental Material 2). This is unlikely to be a true reflection of the rates of repair for these (and possibly other) lesions but reflect ongoing data collection efforts and gaps in the current data collection.

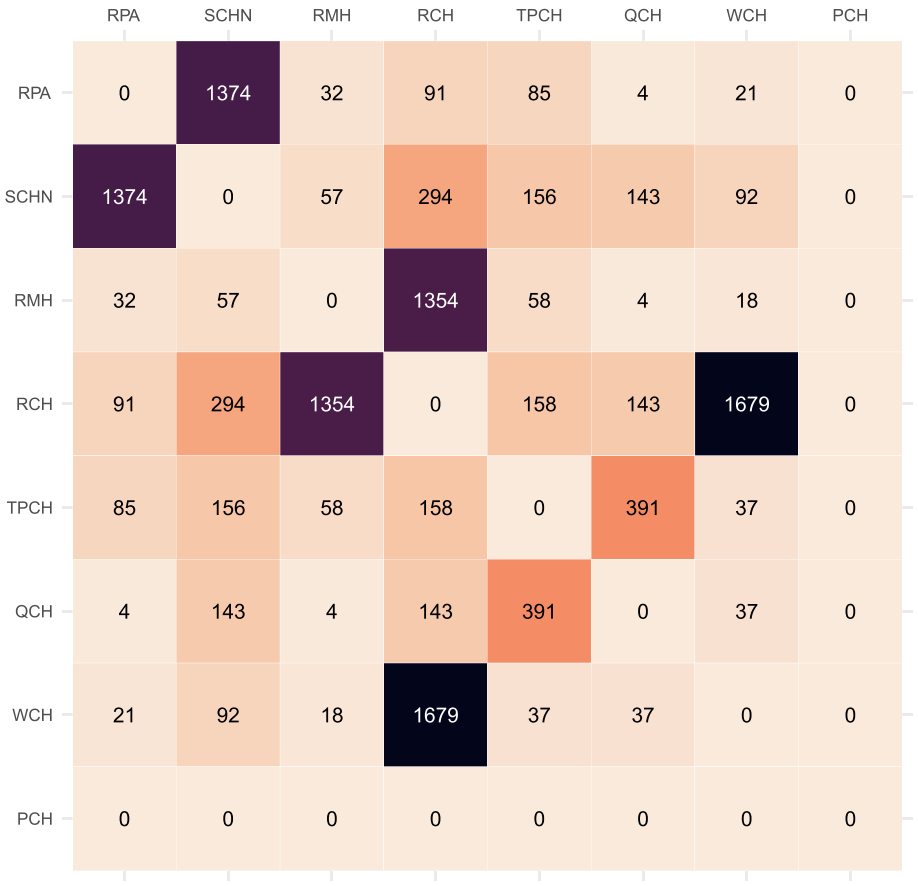

Fig. 3. A cooccurrence plot outlining the duplicate patients across the participating hospitals in the Registry. Royal Prince Alfred Hospital (RPA); Sydney Children's Hospital Network, Westmead (SCHN); Royal Melbourne Hospital (RMH); Royal Children's Hospital (RCH), The Prince Charles Hospital (TPCH); Queensland Children's Hospital (QCH); Women's and Children's Hospital (WCH); Perth Children's Hospital (PCH).

These gaps are likely due to the methodological challenges in data collection, as described. The impact of the data missing from the outstanding Australian hospitals is likely to be small, since these are smaller hospitals whose CHD populations will have been largely covered by large cohorts collected from the corresponding paediatric hospitals in these states. We also aim to supplement the primary data collection with comprehensive data linkage to administrative health data sources. By identifying people with hospital admissions associated with CHD, any Australians with CHD missed in primary data collection will be included, and all interventions since 2010 will also be collected. These linkages will also provide data on 10 years of healthcare interactions for this population, including inpatient admissions, emergency department presentations, outpatient healthcare and medication dispensing.

This dataset and the upcoming linkage will be a key source for future of international CHD research. The collaborative efforts of the CHD community in Australia have enabled the existence of this large, contemporary CHD cohort. Coupled with the long-standing and high-quality administrative health data available in Australia [33], The National Australian CHD Registry will provide a new benchmark for population research in CHD. The opportunity that this infrastructure will unlock will not only help to uncover the true burden on CHD in Australia but also provides the largest and most contemporary cohort to contribute to the global understanding of CHD.

4.1. Conclusions

The National Australian CHD Registry aims to become an enduring resource for CHD research, with comprehensive data collection from specialist CHD services countrywide, linked to key sources from administrative health data and other relevant collections. Here, we outline the data collection methodology for the minimum data for the Registry from clinical data sources and provide an overview of the initial data collected. Whilst some data collection is still ongoing, this already represents the largest and most contemporary data collection in the world. Planned linkage to Australian administrative health data will enrich the minimum data to provide a truly novel resource for CHD research.

This data will drive key outcomes in CHD care, including addressing gaps in service delivery at a population level, uncovering and understanding the cost burden of delivering care, investigating lesion and intervention specific outcomes, providing larger cohorts for rare conditions, and contributing to the global understanding of living with CHD.

Disclosures

Prof David Celermajer and A/Prof Rachael Cordina are Editorial Board Members of the International Journal of Cardiology Congenital Heart Disease and played no role in the Journal's evaluation of the manuscript.

CRediT authorship contribution statement

Calum Nicholson: Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Visualization, Writing – original draft. **Geoff Strange:** Conceptualization, Methodology, Project administration, Supervision, Writing – review & editing. **Julian Ayer:** Conceptualization, Data curation, Writing – review & editing. **Michael**

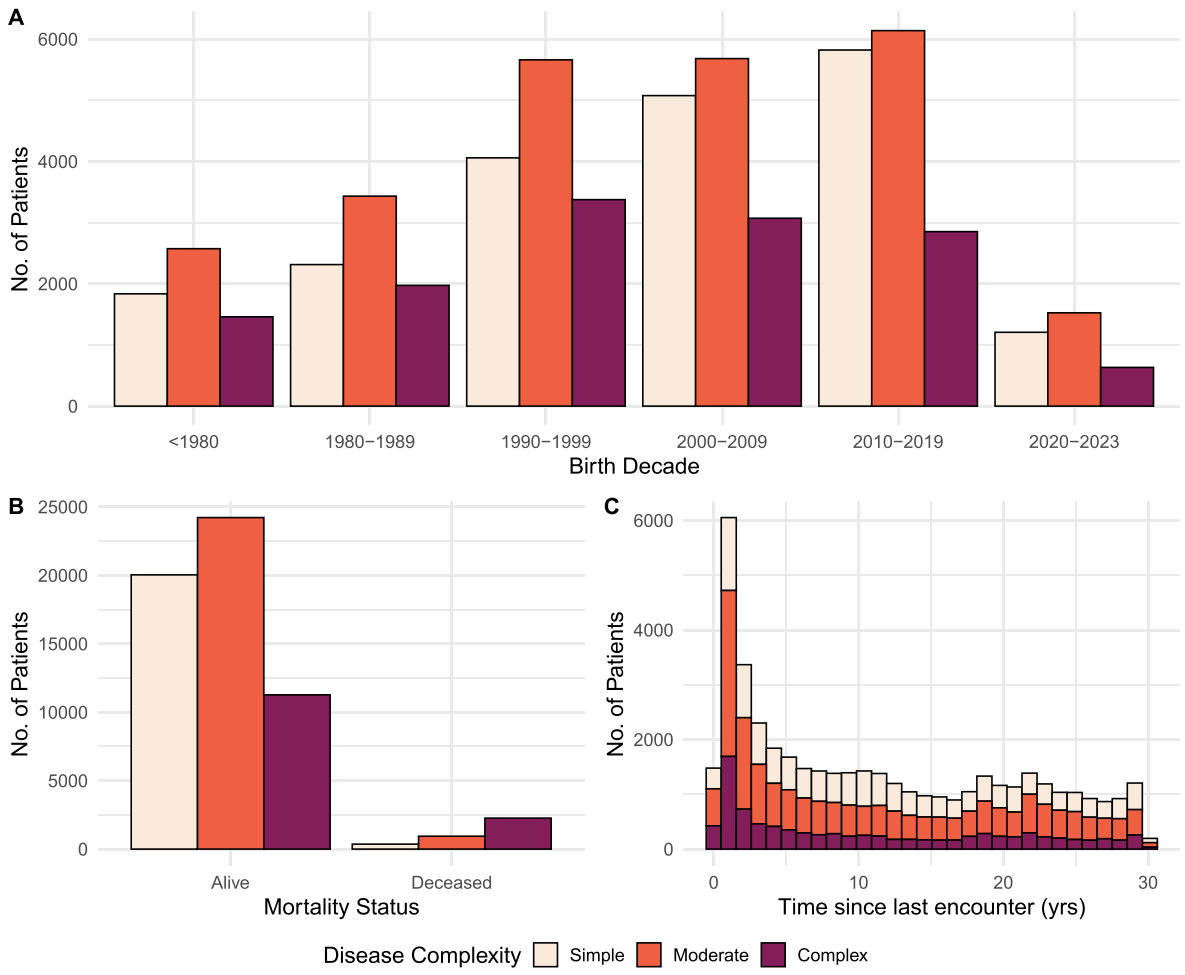

Fig. 4. Demographic summary of the structural CHD cohort. Birth Decade (A), Mortality Status (B), and Time since last follow up (C) stratified by CHD complexity, patients with unknown complexity excluded (n = 9132). Patients with follow up greater than 30 years (n = 4627) or who have died (n = 3569) were excluded from the Time since last follow up figure (C).

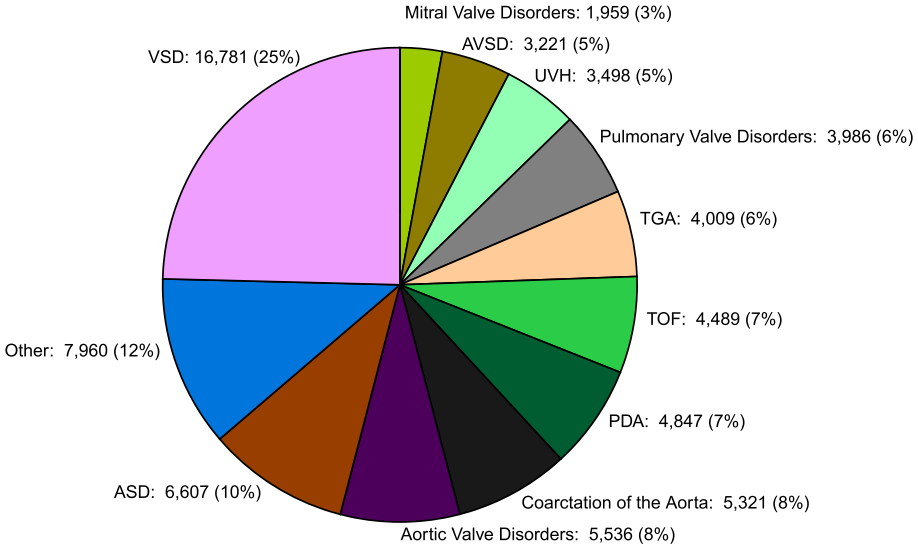

Fig. 5. Structural CHD Patients, grouped by Diagnostic Category. VSD - Ventricular Septal Defect, ASD - Atrial Septal Defect, PDA - Persistent Arterial Duct, TOF - Tetralogy of Fallot, TGA - Transposition of the Great Arteries, UVH - Univentricular Heart (not Fontan), AVSD - Atrioventricular Septal Defect.

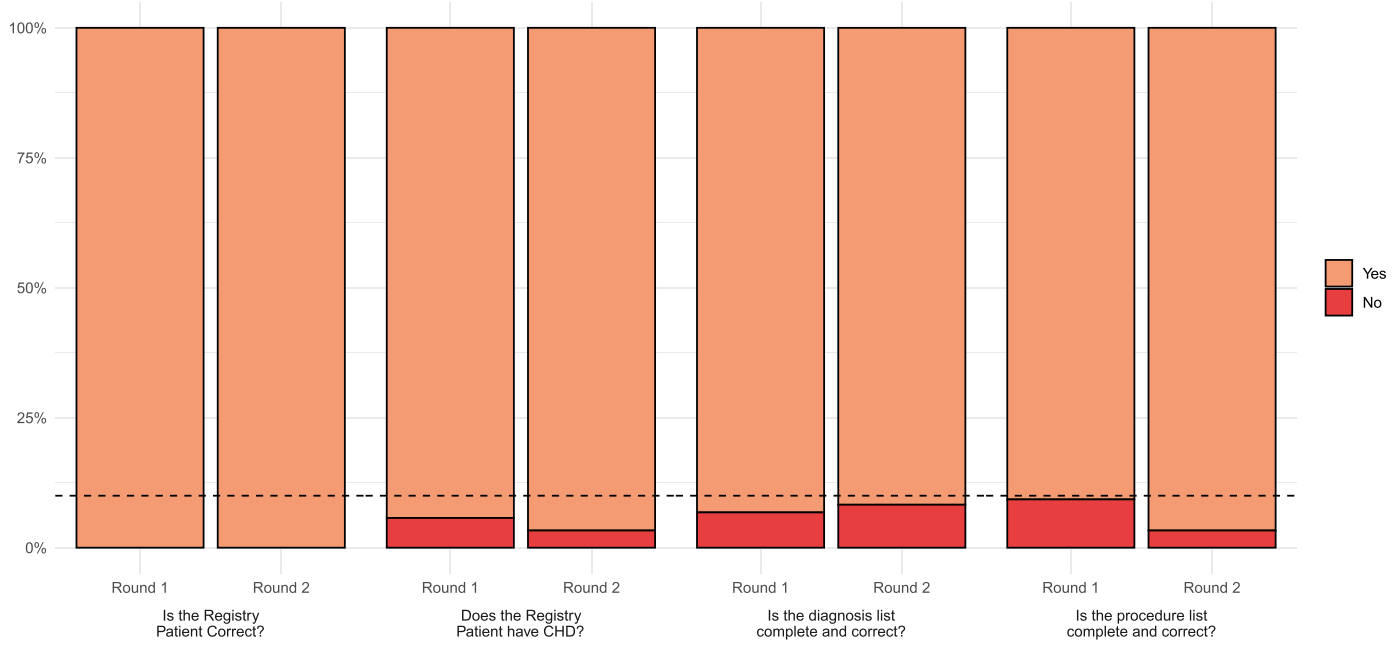

Fig. 6. Results from the Data Quality Audit. Registry data were checked against clinical data sources at 7 participating hospitals to ensure data were collected properly. The first round of review was conducted on 280 patients, the second round was conducted after edits to data processing were implemented based on the results of round one and was conducted on 120 patients. Data are presented as a proportion, dotted line is at 10 %.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

The National Australian Congenital Heart Disease Registry is a collaborative effort whose development has been a result of contributions from various individuals and organisations. The Congenital Heart Alliance and Australia and New Zealand is a collaborative group of key clinicians and researchers who work in CHD across both countries. From conception to data collection, this group has provided advice, expertise, and data to the development of this registry. Funding for the initial establishment of the Registry came to Heartkids Australia (a key consumer representative body, and charity, for childhood heart disease) from several donors including the Pinnacle Charitable Foundation and the Kinghorn Foundation. Heartkids Australia continues to play an important role in providing consumer representation and input in the Registry. Currently, the Registry is funded by a Medical Research Futures Fund Grant, Accelerated Research Grants Program, Congenital Heart Disease Opportunity (ARGCHD000028), provided by the Australian Federal Government. This grant is administered by the University of Sydney.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijcchd.2024.100538.

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