REVIEW ARTICLE

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The Australia and New Zealand Congenital Outcomes Registry for Surgery (ANZCORS): methodology and preliminary results

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Abstract

Background: Analysis of multi-institutional data and benchmarking is an accepted accreditation standard in cardiac surgery. Such a database does not exist for congenital cardiac surgery in Australia and New Zealand (ANZ). To fill this gap, the ANZ Congenital Outcomes Registry for Surgery (ANZCORS) was established in 2017.

Methods: Inclusion criteria included all cardiothoracic and extracorporeal membrane oxygenation (ECMO) procedures performed at five participating centres. Data was collected by data managers, validated by the surgical team, and securely transmitted to a central repository.

Results: Between 2015 and 2019, 9723 procedures were performed in 7003 patients. Cardiopulmonary bypass was utilized for 59% and 9% were ECMO procedures. Fifty-seven percent ($n = 5531$) of the procedures were performed in children younger than 1 year of age. Twenty-four percent of procedures ($n = 2365$) were performed in neonates (≤28 days) and 33% ($n = 3166$) were performed in children aged 29 days to 1 year (infants). The 30-day mortality for cardiac cases ($n = 6572$) was 1.3% and there was no statistical difference between the participating centres ($P = 0.491$). Sixty-nine percent of cases had no major post-operative complications (5121/7456). For cardiopulmonary bypass procedures ($n = 5774$), median stay in intensive care and hospital was 2 days (IQR 1, 4) and 9 days (IQR 5, 18), respectively.

Conclusion: ANZCORS has facilitated pooled data analysis for paediatric cardiac surgery across ANZ for the first time. Overall mortality was low. Non-risk-adjusted 30-day mortality for individual procedures was similar in all units. The continued evaluation of surgical outcomes through ANZCORS will drive quality assessment in paediatric cardiac surgery across ANZ.

Introduction

Every year, in Australia and New Zealand approximately 3000 children are born with congenital heart disease (CHD).[1] Half of these babies are expected to require surgical intervention at some point in their lives. Surgery for CHD is inherently complex. Several studies from North America have shown significant variation in morbidity and mortality after congenital cardiac surgery across different

hospitals.[2,3] These variations were greater for complex operations.[2] In the 1990's a high incidence of death in babies after cardiac surgery made headline news across the world, and came to be known as the Bristol Heart Scandal. Implementation of reforms from the subsequent investigation led by Professor Ian Kennedy resulted in a dramatic improvement in paediatric cardiac surgical outcomes across the United Kingdom. By 2010, the 30-day mortality rate had fallen from 4.3% in 2000 to 2.6%.[4,5]

Analysis of multi-institutional data and benchmarking between units is an accepted accreditation standard for all adult cardiac surgical services in Australia, adult/paediatric intensive care units in Australia and British and North American paediatric cardiac surgical programs.[6–8] However, such a process does not exist for paediatric cardiac surgery in Australia and New Zealand (ANZ). Clinical evidence in paediatric cardiac surgery generally stems from retrospective, single or multi-institutional series. With the aim of bridging this knowledge gap and after consultation with all relevant stakeholders, we established the Australia and New Zealand Congenital Outcomes Registry for Surgery (ANZCORS) in 2017. The analysis and presentation of results from the ANZCORS database will be performed and presented in four stages. This report delineates the aims, methodology and results of Phase 1.

Methods

Aims

(1) Establish a comprehensive, binational paediatric cardiac surgery outcomes Registry.
(2) Undertake benchmarking of 30-day mortality between institutions for specific procedure groups for paediatric cardiac surgery in ANZ.
(3) Identify significant variations (if any) in these outcomes.

Study sites

At present, five centres undertake paediatric cardiac surgical procedures in ANZ. These include: (1) Auckland—Starship Children's Hospital, (2) Brisbane—Queensland Children's Hospital, (3) Melbourne—Royal Children's Hospital, (4) Perth—Perth Children's Hospital and (5) Sydney—Children's Hospital at Westmead.

Inclusion criteria

All cardiothoracic or extracorporeal membrane oxygenation (ECMO) procedures performed at any of the five centres were included in the Registry. This included all patients with childhood heart disease, those with a congenital heart defect, as well as those without a congenital heart defect (infective endocarditis and rheumatic heart disease).

Ethics approval

Extensive legal consultation was undertaken to ensure adequate compliance for participating institutions, clinicians, and participants. A collaboration agreement was drafted to allow sharing of registry data for the purposes of quality improvement (QI). Ethics approval was waived in New Zealand as the activity was considered 'quality assurance' and local requirements did not mandate ethical approval. However, New Zealand did need to provide a Privacy Impact Assessment (PIA) to the Information, Security and Risk Committee for approval. The PIA outlined ANZCORS systems for data transfer, data storage/security, data management and ANZCORS compliance with New Zealand's Health Information Privacy Code (HIPC). Subsequently ANZCORS was granted national ethics approval (HREC/19/QCHQ/49534) in Australia and has a fully executed Network Agreement is in place to permit ongoing data sharing.

Governance structure and steering committee

Data and project management for the ANZCORS database are provided by the Queensland Paediatric Cardiac Research (QPCR) group of the Queensland Paediatric Cardiac Service (QPCS). The offices are located within the Child Health Research Centre (CHRC) at the Queensland Children's Hospital site in Brisbane. The team coordinates and supports the collection, preparation, validation, analysis, and reporting of ANZCORS data.

Oversight is provided by a binational Steering Committee with representation from each participating institution. The Steering Committee also includes representation from the two professional bodies in the region—Cardiac Society of ANZ (CSANZ) and ANZ Society of Cardiothoracic Surgery (ANZCTS). The Steering Committee consists of voting and non-voting members. All manuscripts are also reviewed by the wider ANZCORS Collaborative (Appendix 1).

Data collection

ANZCORS data was retrieved from the hospital cardiac database system at each site by a designated local data manager. Data is validated regularly by the surgical team at each site. The initial data transfer was collated in 2020. Prospective data will be transferred securely at 6 monthly intervals. The dataset includes 65 variables (encompassing 196 diagnoses, 279 procedures, 40 risk factors, 56 complications and 33 anaesthetic adverse events).[9]

The unit of observation collected by the ANZCORS database is the surgical procedure, rather than the episode of care (i.e., multiple rows per patient episode depending on the number of procedures performed). One major purpose of ANZCORS is its use as a resource to test for specific-cause variation in 30-day mortality across the five surgical centres (benchmarking). For this purpose, the unit of observation is the 30 days following the first operation in an episode of care. Within this 30-day window, death is attributed to the primary (initial) operation, regardless of any additional procedures performed in this window.

Study design

Data analysis will be conducted in 4 phases

Phase 1: Clinical outcomes (non-risk-adjusted; 2015–2020). The first annual report on clinical outcomes was produced by analysis

of ANZCORS data from 4 centres over the 5-year period from 2015 to 2019. A summary of the main findings is presented below. From 2021, the annual report will be tailored for presentation to different stakeholders including families, cardiac clinicians, non-cardiac clinicians, and hospital administrators. The report will use a 5-year rolling period for comparison of outcomes to account for the small number of complex operations in several procedure groups. ANZCORS also aims to present its findings every year at the annual scientific meetings of the ANZ Society of Cardiothoracic Surgery (ANZCTS) and the Cardiac Society of ANZ (CSANZ).

Phase 2 (a): Implementation study (2021–2022). HeartKids is the only not-for-profit organization in Australia founded by parents of children with childhood heart disease to help navigate their lifetime journey and help them lead the most fulfilling life possible. Educating families and supporting research is a key pillar of their charter. HeartKids together with members of the clinical teams across Australia played a large role in establishing the *National Strategic Action Plan for Childhood Heart Disease* with the Australian Federal Government.[10]

We have partnered with HeartKids to pilot consumer co-designed dissemination of information to parents, clinicians, and health service providers. Implementation will be guided by the principles of the Consolidated Framework for Implementation Research (CFIR),[11] acknowledging that presentation of results directly impacts upon the effectiveness of dissemination and consumer satisfaction. This will provide an in-depth understanding of factors influencing successful implementation. We will establish a working group of health professionals, parents, technology specialists, implementation science experts and service delivery leaders to provide governance and allow for an iterative approach of continuous improvement.

Stakeholder interviews. The ANZCORS team in Brisbane conducted several stakeholder interviews in Queensland to evaluate consumer attitudes and expectations regarding ANZCORS benchmarking and reporting. The stakeholders included: cardiac surgeon ($n = 1$), cardiac surgery fellow ($n = 2$), cardiac surgery clinical nurse consultant (CNC) ($n = 1$), cardiology CNC ($n = 2$), cardiologist ($n = 3$), intensivist ($n = 2$), anaesthetist ($n = 2$), hospital administrator ($n = 1$) and parents ($n = 5$). The interviews were both audio-recorded and transcribed. Two researchers conducted qualitative analysis of the transcripts using an interpretive description approach. Framework analysis using CFIR was used to categorize barriers and enablers. Open-ended questions were used to examine priorities for communication of surgical outcome data. Overall, all stakeholders expressed a need for this information and viewed it as a positive learning opportunity. Parents requested contextualisation and clarity in communication. Health professionals expressed a need for (1) detailed information to counsel families, ensuring the standardization of messaging regarding risk, and (2) the ability to evaluate local performance against a national average to ensure that local practice was at an optimal standard.

Co-design workshops. Before implementation, we will hold two co-design workshops to address (1) how to communicate information about performance benchmarking to stakeholders (both clinicians and consumers) and (2) how to communicate information from the personalized risk profiling to families. These workshops will be led by two facilitators: an implementation researcher and experienced clinical research nurse. The workshops will include a broad cross section of clinical and consumer stakeholders, including consumers from the Aboriginal/Torres Strait Islander, Māori and rural population groups. At both workshops, we will elicit feedback from attendees on example information reports from the risk analysis.

The workshop for reporting information to families will aim to determine:

- What long-term outcomes do families prioritize?
- When families prefer to receive this information (e.g., in clinic)?
- The preferred format of information for families
- Who is the best person to convey the information?

Phase 2 (b): Health economic analysis (2022–2023). The data collected will be used to measure the long-term economic burden following surgery for CHD. Economic impact will be measured from a health system perspective. Resource use will be based on activity, duration of ventilation, intensive care unit (ICU) stay, and hospital stay. Unit costs will be obtained from hospital records or from expert opinion. Health impact will be assessed using Quality Adjusted Life Years (QALY), with quality of life based on Patient Reported Outcome Measures (PROMS) to calculate a national assessment of the burden of disease of CHD. Although international studies have assessed the long-term burden of disease of CHD in terms of QALYs,[12] there is limited evidence specific to the ANZ population.

Phase 3: risk modelling and benchmarking (2021–2024).

Primary and secondary outcomes. The primary outcome is 30-day mortality. This is the same primary outcome used in the ANZSCTS adult cardiac database and the CCAD NICOR database in the United Kingdom.[5,13] Secondary outcomes include (a) mortality during the same hospital admission, (b) length of mechanical ventilation, (c) length of ICU and hospital stay, and (d) morbidity including stroke with new neurological deficit on discharge, heart block requiring permanent pacemaker, mechanical ventilation >7 days, post-operative bleeding requiring reoperation, deep wound infection/mediastinitis, renal failure at discharge, unplanned reoperation, extracorporeal life support. Models will include pre-defined risk factors such as diagnostic and procedural factors, gestational age, age and weight at surgery, syndromes, and non-cardiac malformations. Modelling will also be informed by a range of socioeconomic and demographic variables, including:

a Hospital databases: marital status of parents, residential postcode.

b From postcode: socioeconomic status at birth will be derived based on scores from the Index of Relative Disadvantage from the Socio-Economic Indexes for Areas (SEIFA) produced by the Australian Bureau of Statistics, and the New Zealand Index of Deprivation 2018 (Department of Public Health, University of Otago).

c The 2006 Australian Bureau of Statistics Remoteness Structure will be used to classify each patient's residential postcode as (i) Major City of Australia, (ii) Inner Regional Australia, (iii) Outer Regional Australia, (iv) Remote Australia or (v) Very Remote Australia. For New Zealand the Urban Accessibility Index will be used to provide similar information.

The predictive modelling will undergo several iterations using existing ANZCORS data and newly acquired prospective data.

Other sequentially added secondary outcomes include 1, 5- and 10-year mortality including analysis of specific sub-groups such as Aboriginal/Torres Strait Islanders, Māori, lower socioeconomic and rural and remote populations.

Risk adjustment model. The retrospective 2013–2019 dataset will be split into development (70%) and independent validation (30%) cohorts. Multivariate logistic regression will be used to build the statistical model. Separate risk models will be required for each outcome (mortality and each type of morbidity). Within the development sample we will use 25 by 5 cross-validation (with random splits stratified by year and surgical site), with model performance assessed using the Akaike Information Criterion (AIC) and the Area under the receiver operating curve (AUC-ROC). The best performing model will then be tested in the independent validation dataset.

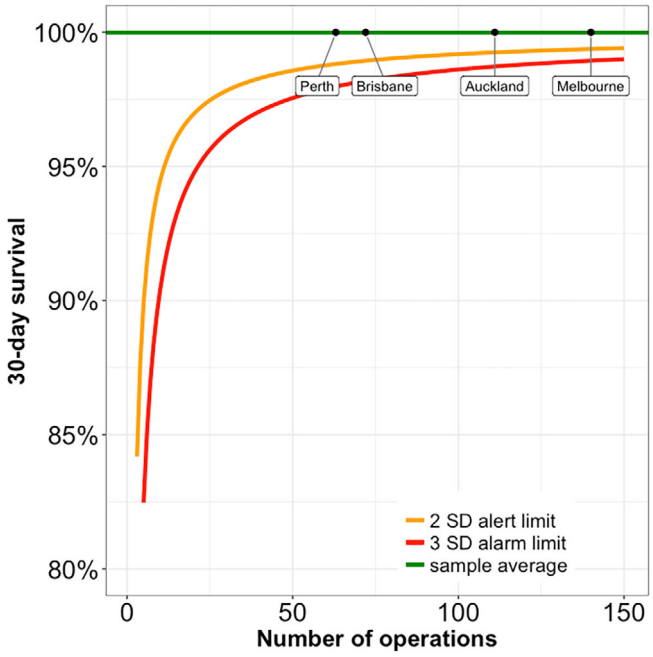

Fig. 1. Shows a comparison of the 30-day survival for tetralogy of Fallot amongst the four surgical units (Perth, Brisbane, Auckland and Melbourne) as a horizontal green line (30-day survival on the *y*-axis and number of operations on the *x*-axis). Two control limits are shown: An alert limit [orange line, 2 standard deviations (SD) below average] and a warning limit [red line, 3 standard deviations below average]. If a unit's symbol is above the solid line, then their performance is 'no different' from the national average. If a unit's survival is below the orange line or red line, it will be investigated locally in accordance with ANZCORS Management of Outliers policy and closely monitored in subsequent years.

Subsequently we will perform external validation using the projected 3000 procedures accrued between 2020 and 2022. We will update the risk prediction model by including the 2023 data in the development model, which will then be used in the subsequent year as the risk adjustment for the new report based on 5-year rolling data from 2019 to 2023.

Benchmarking using unadjusted data. Unadjusted 30-day mortality was compared between four participating centres for 30 different cardiac surgical procedures between 2015 and 2019 using funnel plots. No outliers were identified for any procedure. A sample funnel plot for Tetralogy of Fallot is presented in Figure 1 and the list of surgical procedures is given in Appendix 2.

Benchmarking using risk adjustment. Once validated, the risk adjustment model will predict each patient's probability of mortality at 30 days. The predicted probabilities will be summed within surgical sites and compared with the observed outcomes to identify outliers. In 2024 we will undertake the first external validation of risk adjusted benchmarking using our own ANZ model on procedures accrued between 2020 and 2023.

Phase 4: Morbidity analysis (2022–2024). Statistical models will also be developed to evaluate major morbidity. Morbidity outcomes include stroke with new neurological deficit on discharge, heart block requiring permanent pacemaker, mechanical ventilation >7 days, postoperative bleeding requiring re-exploration, deep wound infection/mediastinitis, renal failure at discharge, unplanned reoperation and need for ECMO. These outcomes will be compared between participating institutes to identify outliers. Further analysis will then be undertaken to identify specific procedures associated with a higher mortality and compared between participating hospitals.

Results (phase 1)

Clinical outcomes

Data on 18 869 patients from 2013 to 2020 has already been collated from all five centres in the ANZCORS database (Table 1). Additionally, data from Royal Children's Hospital, Melbourne is available from 2008 onwards, from Perth Children's Hospital from 2010 onwards and the Queensland Children's Hospital for 2012 onwards.

The initial data analysis was based on the 5-year period from 2015 to 2019. Patient and procedure data from the Children's Hospital at Westmead was collected in a format different to the other 4 units. The data is presently undergoing mapping and has not been included for analysis in the present report.

Table 1 ANZCORS database 2013–2020

Centre	Auckland	Brisbane	Melbourne	Perth	Sydney	Total
Neonates 0–28 days (*n*)	951	900	1356	214	1368	4789
Infants 29–365 days (*n*)	1211	1186	1838	431	1703	6369
Children 1–16 years (*n*)	1537	1275	1980	431	1556	6779
>16 years (*n*)	561	161	158	19	33	932
Total procedures (*n*)	4260	3522	5332	1095	4660	18 869

2015–2019 (5 years)

Surgical procedures

Between 2015 and 2019, a total of 9723 procedures were performed in 7003 patients across four centres in ANZ. The different types of procedures and the 30-day survival is listed in Table 2.

Table 2 30-day survival (2015–2019)

Procedure sub-groups	Number of patients $n = 7003$	Survival %
Anaesthetic procedures	1	100
Anomalous systemic venous connection	6	100
Aortic aneurysm	14	92.9
Aortic valve disease	560	98.4
AP window	13	100
ASD	452	100
AV septal defects	254	98.4
Glenn procedure (bidirectional cavopulmonary shunt)	227	99.6
Cardiomyopathy	44	97.7
Coarctation of aorta and aortic arch hypoplasia	617	99.2
Conduit operations	139	98.6
Conduit stenosis/insufficiency	153	99.3
Congenitally corrected TGA	8	100
Cor triatriatum	6	100
Coronary artery anomalies	43	100
DORV	32	100
Electrophysiological†	263	98.9
Fontan procedure	203	100
Hypoplastic left heart	123	93.5
Interrupted arch	19	100
Interventional cardiology procedures	17	94.1
Lung disease	12	100
LV to aorta tunnel	2	100
Mechanical support	268	81
Miscellaneous procedures	230	96.1
Mitral valve disease	271	99.6
Palliative procedures–single ventricle‡	380	96.8
Partial anomalous pulmonary venous connection	87	100
Patent ductus arteriosus	168	97.6
Pectus excavatum, carinatum	78	100
Pericardial disease	62	95.2
Pulmonary atresia	55	100
Pulmonary valve disease	79	97.5
Pulmonary venous stenosis	21	95.2
RVOT obstruction, IVS pulmonary stenosis	175	99.4
Sinus of valsalva aneurysm	6	100
Systemic venous obstruction	1	100
Tetralogy of fallot	392	100
Total anomalous pulmonary venous connection	116	97.4
Tracheal stenosis	22	100
Transposition of the great arteries	407	99
Tricuspid valve disease and ebstein's anomaly	90	100
Truncus arteriosus	45	95.6
Vascular rings and slings	142	100
VSD	700	99.9

Abbreviations: AP, aorto-pulmonary; ASD, atrial septal defect; AV, atrio-ventricular; DORV, double outlet right ventricle; IVS, intact ventricular septum; LV, left ventricle; RVOT, right ventricular outflow tract; TGA, transposition of the great arteries; VSD, ventricular septal defect.

†Systemic-pulmonary artery shunts, pulmonary artery bands.

‡Pacemaker and implantable cardioverter-defibrillator procedures.

Twenty-four percent of procedures were performed in neonates (0–28 days old), 33% of procedures were performed in infants (29–365 days) while 38% of procedures were performed in patients between 1 and 16 years of age. Overall, 57% of procedures were performed in patients younger than 1 year of age. Table 3 shows procedures stratified by case category. Fifty-nine percent of procedures required the use of cardiopulmonary bypass. Extracorporeal membrane oxygenation (ECMO) accounted for 9% of the procedures over the 5-year period.

Unadjusted mortality

The overall 30-day mortality for all cardiac procedures including ECMO was 1.8%. When ECMO procedures not related to cardiac surgery and non-cardiac ECMO were excluded, the overall mortality reduced to 1.3% (Table 4). There was no difference in 30-day mortality between the 4 centres (Fisher P-value = 0.491). Mortality in patients who required cardiopulmonary bypass and those who did not was similar (1.2% versus 1.3%, p = 0.880). Amongst the different case-category groups, cardiac ECMO not related to cardiac surgery had the highest mortality (28%; P-value <0.001). Mortality in patients who required ECMO for reasons other than after cardiac surgery was no different from patients who needed ECMO for other reasons [23% (47/176) versus 14% (5/35), $P = 0.272$].

Table 5 shows 30-day mortality by year of surgery in 6572 patients undergoing cardiac procedures. There was no difference in the mortality over the 5-year period ($P = 0.345$). Table 6 shows 30-day mortality stratified by age in 6572 patients undergoing cardiac procedures. Amongst the different age-groups, neonates had the highest 30-day mortality (3.1%; Fisher P-value <0.001).

Major adverse events

Table 7 shows the incidence of major adverse events. Across all four centres and every procedure sub-group, 69% of patients did not have any major adverse event. The overall incidence of a neurological deficit including stroke was 1.2%. The incidence of deep wound infection and mediastinitis were 0.5% and 0.3%, respectively. Less than 5% of patients required mechanical ventilation for more than 1 week.

Length of stay

The median stay in the ICU for procedures requiring cardiopulmonary bypass excluding ECMO was 2 days

Table 3 Procedures stratified by case category (2015–2019)

Case category	*N*	%
Cardiopulmonary bypass	5774	59
Non-cardiopulmonary bypass	1682	17
ECMO	835	9
Delayed sternal closure	811	8
Thoracic	402	4
Other	219	2
Total	9723	100

Abbreviation: ECMO, extracorporeal membrane oxygenation.

Table 4 30-day mortality stratified by case category[†] (2015–2019)

Case category	Total Patients	30-day mortality	%
Cardiopulmonary bypass	5420	64	1.2
Non-cardiopulmonary bypass	1117	14	1.3
Post cardiac surgical ECMO	35	5	14.3
Cardiac ECMO not related to cardiac surgery[‡]	46	13	28.3
Non-cardiac ECMO	130	28	21.5
Total 30-day mortality	6748	124	1.8
Total 30-day mortality excluding cardiac ECMO not related to cardiac surgery and non-cardiac ECMO	6572	83	1.3

[†]Excludes delayed sternal closure and thoracic procedures.

[‡]Includes predominantly arrhythmia and cardiomyopathy.

Table 5 30-day mortality stratified by year of surgery (2015–2019) for cardiac procedures with cardiopulmonary bypass, cardiac procedures without cardiopulmonary bypass and post cardiac surgical ECMO[†]

Year of surgery	Total patients	30-day mortality	%
2015	1328	14	1.1
2016	1418	13	0.9
2017	1356	26	1.9
2018	1350	15	1.1
2019	1120	15	1.3
Total	6572	83	1.3

[†]Excludes non-cardiac ECMO, cardiac ECMO not related to cardiac surgery, delayed sternal closure and thoracic procedures.

Table 6 30-day mortality stratified by age group (2015–2019) for cardiac procedures with cardiopulmonary bypass, cardiac procedures without cardiopulmonary bypass and post cardiac surgical ECMO[†]

Age group	Total patients	30-day mortality	%
0–28 days	1259	39	3.1
29–365 days	2089	21	1.0
1 yr-16 years	2872	20	0.7
≥16 years	352	3	0.9
Total	6572	83	1.3

[†]Excludes non-cardiac ECMO, cardiac ECMO not related to cardiac surgery, delayed sternal closure and thoracic procedures.

Table 7 Distribution of morbidity (major adverse events) in 7456 cardiac procedures with and without cardiopulmonary bypass (2015–2019)

Major adverse event	*n*	%
None	5121	69
Arrhythmia necessitating permanent pacemaker	58	0.8
Bleeding requiring reoperation	106	1.4
Cardiac arrest	129	1.7
Requirement for post-operative mechanical support (ECMO)	166	2.2
Mechanical ventilation >7 days	351	4.7
Neurological deficit including stroke	91	1.2
Unplanned cardiac reoperation	225	3
Wound infection—Deep	36	0.5
Wound infection—Mediastinitis	26	0.3

(IQR 1, 4). The median hospital stay for procedures requiring cardiopulmonary bypass excluding ECMO was 9 days (IQR 5, 18).

Discussion

We describe the creation, governance structure and preliminary results of a multi-centre, combined prospective and retrospective, binational outcomes registry comprising all patients undergoing paediatric cardiac surgery in Australia and New Zealand. The geographic proximity and similar healthcare systems in ANZ have facilitated strong clinical and academic partnerships between the two countries. Universal publicly funded health care in both countries ensures effective and streamlined follow-up thereby ensuring robust data collection.

The initial 5-year data analysis from four centres in ANZ has demonstrated that the early outcomes are uniform across all centres in the two countries. There were no outliers when risk-unadjusted 30-day mortality was compared between the four centres for all the different procedure groups using funnel plots. Overall mortality was 1.3% which is comparable to the results reported by CCAD NICOR and the STS database.[2,5]

The principal objective of ANZCORS is to create a sustainable, binational model for reporting, analysis and risk adjusted benchmarking of paediatric cardiac surgical outcomes. Historically, outcome data from ANZ has only been collected in a European database without any direct quality control benefit for children in ANZ. In 2019 the Australian Commission on Safety and Quality in Health Care highlighted cardiac surgery as a high-cost, high-volume clinical domain in which such information is currently insufficient.[14]

Accurate risk prediction in paediatric cardiac surgery is a vital tool to aid clinical decision making, counselling of families, informed consent, benchmarking between units for quality control and planning of service delivery. Identifying children at higher risk will provide parents with a 'starting point' to engage with clinicians, educators, and support services to enable targeted early intervention. The risk modelling will also be used to study outcomes in vulnerable groups like Indigenous children, Māori, Pacific Islander and lower socioeconomic and rural and remote patients.

As mortality after paediatric cardiac surgery improves, the focus globally is shifting to reducing morbidity. By comparing uniformly defined morbidity outcomes across the five sites in ANZ, clinicians will be able to identify procedures with higher morbidity and collectively and constructively implement potential solutions. This has important implications for reducing ICU and hospital length of stay and the longer-term burden of CHD on society.

Registries are well-recognized as efficient, cost-effective tools to improve clinical outcomes.[15,16] Registry reports, however, are often detail-heavy and directed towards a narrow readership group with limited flexibility to contextualize information to the requirements of different stakeholders.[17,18] Different recipients have different information needs. The needs of each are no less important than the other, and each must be individually addressed.[17,19]

The inaugural 2015–2019 ANZCORS report was tailored for cardiac surgeon consumption. However, we quickly recognized that information needed to be contextualized to all stakeholders, particularly parents and families and completed a series of pilot interviews with Queensland stakeholders. This is in line with positive deviance theory, a strength-based approach that focuses on the opportunities for learning from successful behaviours and strategies from others in similar contexts.[20] The interviews highlighted the mixed viewpoints and differing needs of parents and health professionals. Phase 2 of the project aims to tailor ANZCORS reports to individual stakeholders' requirements through consumer co-design using principles of implementation science. We will pilot dissemination of individualized reports in a Queensland cohort and educate parents and families regarding risk and cardiac surgical outcomes. Given the heterogeneity of this population, our study represents the first step in exploring personalized medicine in this group of patients.

From a research standpoint, ANZCORS will create a unique population-based multicentre CHD dataset which will serve as a rich data source for other teams conducting population-based research in patients with CHD. Furthermore, large and ever increasing patient numbers represent 'big data' and facilitates analysis utilizing newer non-conventional artificial intelligence methodologies like machine learning and deep neural networks.[21]

Conclusions

ANZCORS facilitated pooled data analysis for paediatric cardiac surgery across ANZ for the first time. Between 2015 and 2019, over half the procedures required the use of cardiopulmonary bypass. Nearly 60% of all procedures were performed in children younger than 1 year of age. Overall mortality was low (1.3%). Non-risk-adjusted 30-day mortality for individual procedures was similar in the 4 units analysed. Different stakeholders had mixed viewpoints and differing needs about the content of the annual report and the report must be adapted to individual stakeholder needs through consumer co-design. We project that this approach to the evaluation of surgical outcomes through ANZCORS will foster continued education, quality improvement and better delivery of health services in paediatric cardiac surgery across ANZ.

Author contributions

Supreet P. Marathe: Methodology; project administration; validation; writing – original draft; writing – review and editing. **Jessica Suna:** Conceptualization; data curation; investigation; methodology; project administration; resources; supervision; validation; writing – original draft; writing – review and editing. **Kim S. Betts:** Formal analysis; validation; writing – review and editing. **Greg Merlo:** Methodology; resources; validation; writing – review and editing. **Igor E. Konstantinov:** Investigation; methodology; resources; writing – review and editing. **Ajay J. Iyengar:** Methodology; validation; writing – original draft; writing – review and editing. **Prem Venugopal:** Investigation; methodology; project administration; resources; supervision; validation; writing – review and editing. **Nelson Alphonso:** Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; supervision; validation; visualization; writing – original draft; writing – review and editing. **ANZCORS Collaborative:** Data curation; methodology; project administration; resources; supervision; validation; writing – review and editing.

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Conflict of interest

None declared.

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Supporting information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1 Supporting Information