

# Australian National Standards of Care for Childhood-onset Heart Disease

Draft for Public Consultation 31 October 2021

## Foreword: Co-Chairs

The journeys for patients with Childhood-onset Heart Disease (CoHD), their families and carers are often challenging and confronting, and for many are lifelong. The National Strategic Action Plan for Childhood Heart Disease (NSAP 2019) mandated the development of national Standards of Care as the first and central step in the progressive transformation of care for those impacted by CoHD in this country.

The Australian National Standards of Care for CoHD (CoHD Standards) are the culmination of over a decade of advocacy from the combined voices of HeartKids Ltd, patients, families and carers, and CoHD healthcare providers. The development process has been a rewarding collaboration between healthcare providers, key planners, and patients, families and carers to whom we offer our thanks. This will be a model for continuing engagement and renewal of the CoHD Standards over time. Our project incorporates the development of key National Clinical Practice Guidelines, scientific Statements regarding care and services, and infrastructure and workforce needs which will be completed after publication of the CoHD Standards. We are especially grateful for the support of the Federal Government for this project, and productive engagement with State and Territory Health Departments.

This is a critical time for us all, confronted by the important challenges of climate change for our environment, lives and health, and the stark reminder provided by the COVID-19 pandemic of our shared international vulnerabilities. Working with our community of CoHD patients, families, carers and healthcare providers with a confident and coherent path forward to achieving our lead objective of living well has seemed more important than ever.



Gary Sholler AM



Lisa Selbie

# Acknowledgements

The Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) Steering Committee acknowledges the Traditional Owners across this land and pays respects to Elders past, present and emerging. We recognise the strength, resilience and capacity of Australia's Aboriginal and Torres Strait Islander peoples and acknowledge their connection to culture, land, and sea.

We write these CoHD Standards with deep respect and concern for the land and the adverse impact of climate change, and for the lives and wellbeing of the patients and families whose care is the focus of this document.

## CoHD Standards of Care Steering Committee

**A/Prof Gary Sholler AM<sup>1,2,3</sup>** MBBS, FRACP, FCSANZ, FACC  
*Paediatric & Fetal Cardiology & Project Co-Chair*

**Dr Lisa Selbie<sup>4,5</sup>** PhD  
*HeartKids Research Advisory Committee Chair & Project Co-Chair*

**A/Prof Luke Burchill<sup>6,7</sup>** MBBS, PhD, FRACP  
*ACHD Cardiology*

**Prof Michael Cheung<sup>8</sup>** BSc, MBChB, MRCP, MD, FRACP  
*Paediatric Cardiology, Chair of Paediatric Cardiology Council CSANZ*

**Ms Shakira Donovan<sup>9</sup>** BSc (Psych)  
*Patient Representative from CoHD Community*

**Ms Caitlin Elliott<sup>8</sup>** NPC, RN, MANP(NP), PgD, BNS  
*Nursing*

**Ms Fiona Ellis<sup>4</sup>** BA, MTourMgt  
*HeartKids CEO*

**Prof Nadine Kasparian<sup>10</sup>** PhD, MAPS  
*Psychology, Neurodevelopment & Allied Health*

**Ms Jessica Keating<sup>4</sup>** RN, MHA, MPH  
*HeartKids Action Plan Project Manager*

**Ms Kristie Molloy<sup>11</sup>** LLB/LP, BSc (Psych)  
*Parent Representative from CoHD Community*

**Dr Mary Tallon<sup>4,12</sup>** RN, RM, MScN, PhD  
*HeartKids CoHD Standards Project Coordinator*

**A/Prof Prem Venugopal<sup>13</sup>** MBBS MS FRACS (CTH)  
*Paediatric Cardiac Surgery*

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### Affiliations

1 Sydney Children's Hospitals Network, NSW

2 Heart Centre for Children, Westmead, NSW

3 University of Sydney, Camperdown, NSW.

4 HeartKids Ltd, Parramatta, NSW

5 School of Biotechnology & Biomolecular Sciences UNSW, Advanced Academic Program in Biotechnology, Johns Hopkins University, Maryland, USA

6 Royal Melbourne Hospital, Parkville, VIC

7 University of Melbourne, Parkville, VIC

8 Royal Children's Hospital, Parkville, VIC

9 The University of Notre Dame, Fremantle, WA

10 Heart Institute and Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital, OH, USA

11 College of Business, Government and Law, Flinders University, Adelaide, SA

12 School of Nursing, Curtin University, Bentley, WA.

13 Queensland Paediatric Cardiac Services, Children's Health Queensland Hospital and Health Service, South Brisbane, QLD

The CoHD Standards Steering Committee would like to acknowledge the many people who contributed to developing the CoHD Standards, especially the members of the Advisory Committee and Working Groups for their commitment and contribution to the CoHD Standards (Appendices A and B). Their ongoing dedication has been instrumental in creating standards that provide a framework to inform the development of quality service delivery that supports those affected by CoHD to live well.

The Steering Committee acknowledges the integral role of HeartKids Ltd as facilitators and contributors to the first Australian National CoHD Standards. HeartKids Ltd, the only national not-for-profit organisation solely focussed on supporting and advocating for all people impacted by childhood-onset heart disease, provided an important voice for all patients, families and carers across Australia.

Development of the CoHD Standards was funded by the Australian Government Department of Health from 2019–2023 as part of the Government’s support of the 2019 National Strategic Action Plan for Childhood Heart Disease (NSAP 2019). The views expressed are those of the CoHD Standards Steering Committee, Advisory Committee and Working Group members and do not necessarily reflect those of the Australian Government. The Commonwealth of Australia does not warrant or represent that the information contained in this publication is accurate, current, or complete. To the extent permitted by law, the Commonwealth of Australia does not accept any legal liability or responsibility for any loss, damages, costs, or expenses incurred by the use of, reliance on, or interpretation of the information contained in this publication.

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# Executive Summary

These first Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) have been developed to inform the healthcare requirements for enabling all Australian patients, families and carers impacted by CoHD to live their best and healthiest lives – to live well.

The CoHD Standards provide the clarity and certainty to deliver excellent, comprehensive, inclusive and equitable care across Australia for patients, families and carers, and offer an iterative roadmap to the future of these services.

Paediatric CoHD Services (described as Type 3, Type 2, Type 1) and adult congenital heart disease (ACHD) Services describe the organised programmes delivering care, and consider the impact of Australian geography and population distribution, with measures to share supportive links to bring care closer to home. The CoHD Standards identify the unique needs of priority populations including Aboriginal and Torres Strait Islander peoples, the many Australians living in regional, rural and remote areas, and young adults transitioning to the adult healthcare system. The key elements of mental health and neurodevelopmental care are highlighted as essential to whole-of-life care. Enabling of coordinated multidisciplinary and collaborative research is recognised as important in providing new and improved opportunities for future healthcare delivery.

This **framework** for the key requirements and expectations for whole-of-life, holistic and connected CoHD-informed healthcare service delivery, have been developed as a first phase of a suite of resources for nationally-agreed standardised care, and will be used to evolve comprehensive CoHD clinical practice guidelines, scientific position statements and roadmaps (Phase 2) and workforce and infrastructure plans (Phase 3) to meet the CoHD Standards, and the health needs of the CoHD community.

To enable these CoHD Standards, and effectively guide future care planning the following embedded national CoHD structural and leadership modifications are recommended:

- (1) The CoHD Standards are to be the primary reference source for developing and maintaining CoHD services in Australia across all Health jurisdictions.
  - a. In the event current services do not meet these Standards, a maximum period of three years (until 2025) is permitted to achieve full compliance.
- (2) An Australian National CoHD Standards Oversight and Management Committee be created to manage future review and enhancement of the CoHD Standards.
  - a. To be actioned within 6 months of the final publication of the CoHD Standards (2023).
  - b. Nationally coordinated support should be provided to maintain this Committee.

- (3) National Discipline-Specific CoHD Networks be created to facilitate coordinated Australian service delivery (by 2023).
  - a. Networks should consider integrated national care delivery and will be closely involved in contributions to ongoing updated CoHD Standards.
  - b. Individual or collective networks should be developed for CoHD/ACHD Cardiologists, Cardiac Surgeons, Nurses, Perfusionists, Transition Planning.

*These networks may be created separately or within existing relevant professional or State bodies.*
  - c. Accreditation of key CoHD health providers across all State and Territory Health jurisdictions should be implemented to support workforce and CoHD Standards requirements.
- (4) A National CoHD/ACHD Research Council be created to facilitate national multicentre research projects with significant research impact by 2023.
- (5) Training and Accreditation pathways be established across key CoHD Health disciplines to ensure adequate training and education, and verification of all CoHD professionals.
  - a. It is expected that relevant training bodies, professional Colleges and associations, and accrediting bodies will contribute to this process.
  - b. CoHD disciplines should be identified to inform where this process requires implementation.
  - c. Identified professional groups should complete this process within 3 years (by 2025) with initial focus on paediatric CoHD cardiac surgeons, ACHD cardiac surgeons, paediatric and ACHD / CoHD perfusionists.
- (6) A National CoHD Multidisciplinary Advisory Collaborative be established to allow formalised interaction between representatives of CoHD patients and families, carers, healthcare providers, healthcare planners, and CoHD advocacy groups.
- (7) Implementation of key comprehensive CoHD clinical practice guidelines, scientific position statements and roadmaps (Phase 2) and workforce and infrastructure plans (Phase 3) be completed by 2023.

# Abbreviations & Acronyms

ACHD	Adult Congenital Heart Disease
AHPRA	Australian Health Practitioner Agency
ASD	Atrial Septal Defect
CALD	Culturally and Linguistically Diverse
CoHD	Childhood-onset Heart Disease
CT	Computed tomography
ECMO	Extracorporeal Membrane Oxygenation
EP	Electrophysiology
FTE	Full Time Equivalent
ICU	Intensive Care Unit
IT	Information technology
KPI	Key Performance Indicators
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NDIS	National Disability Insurance Scheme
NICU	Neonatal Intensive Care Unit
NSAP	National Strategic Action Plan for Childhood Heart Disease
PDA	Patent Ductus Arteriosus
PFO	Patent Foramen Ovale
PICU	Paediatric Intensive Care Unit
QA	Quality Assurance
QI	Quality Improvement
RACHS	Risk Adjustment for Congenital Heart Disease
RACP	Royal Australian College of Physicians
RHD	Rheumatic Heart Disease
24/7	Twenty-four hours, seven days per week

*A Glossary of Terms is provided in Appendix C.*

# Introduction: Supporting the CoHD Life Journey

Childhood-onset Heart Disease (CoHD), which includes congenital heart disease and acquired heart disease diagnosed in childhood, places a significant burden on the over 65,000 Australian children and adults living with CoHD and the even larger number of family members and carers.<sup>1</sup> The significant impacts of CoHD on Australia's healthcare system, educational institutions, the workforce, and the broader economy and community challenge the many professionals and members of the community who strive to provide the best care and support for those affected.

The CoHD life journey begins with diagnosis of a heart condition, and whilst diagnosis of CoHD may occur during pregnancy, the majority of CoHD is diagnosed after birth.<sup>2</sup> Whether CoHD is congenital heart disease (including structural lesions of the heart tissues or valves), arrhythmias, cardiomyopathies (functional abnormalities of the heart muscle mediated by a person's genetics), or acquired as a consequence of other paediatric disease or medical therapy,<sup>3</sup> many patients will experience lifelong challenges to their health and wellbeing.<sup>4</sup> CoHD represents a wide spectrum of disease severity and thus, requires a range of services to align with the complexity needs of diverse patient groups. Patients with CoHD can experience mild to moderate disease and require a level of service that is distinct from the highly involved service delivery required for those with more complex disease (Appendix D).

The cardiac care trajectory is different for every individual and their family. It may include, but is not limited to, diagnosis, hospitalisation, critical care, medical procedures, initiation of treatments, hospital discharge, transition from paediatric to adult health care, changes in health status, transplantation pathways, death and dying, and grief and bereavement. It encompasses periods of wellness (for some conditions, wellness is the predominant state) and poor health, periods of developmental, educational, relational and occupational transition, and periods of uncertainty, medical decision-making, information processing, adversity, and adjustment.

In 2019 the Minister of Health the Hon. Greg Hunt MP launched The National Strategic Action Plan for Childhood Heart Disease (NSAP 2019) and committed funding to help implement its recommendations, including the development of nationally agreed upon standards of care for CoHD.<sup>5</sup> The standards were recommended to inform the development and provision of high quality, seamless, patient-centric lifelong care for all Australians impacted by CoHD.

# Purpose

## Why do we need CoHD Standards?

Australian healthcare providers to date, have relied on domestic expert knowledge and relevant local guidelines and international best practice standards<sup>6–13</sup> to inform current informal models of cardiac care and services in Australia. Current services provide quality care in many parts of the health system; however, there remain some limitations to access, challenges for building resilient services for the future, impediments to the delivery of holistic care which meets the unique needs of priority populations, and the impacts of geography on regional services.<sup>14,15</sup>

The purpose of this first Australian National CoHD Standards (CoHD Standards) is to provide a coherent national framework to define key requirements in the delivery of care which will reduce the burden of CoHD on all those affected and be inclusive and equitable in supporting people living their fullest and best lives.

The CoHD Standards aim to be aligned with a whole-of-life, holistic approach and focus on those diagnosed with CoHD, and their families and carers, and to incorporate strong and meaningful input from patients, families, carers, healthcare providers and healthcare planners.

To achieve improved equitable and inclusive healthcare for all Australians, the CoHD Standards address the health disparities experienced by Aboriginal and Torres Strait Islander peoples and those from other priority populations, including people living in regional, rural and remote areas, and young adults transitioning to the adult healthcare system.<sup>15</sup>

As well as outlining best quality service provision, the CoHD Standards also embed requirements for mental health and neurodevelopmental care for patients, families and carers from the beginning of the cardiac journey and as an essential service throughout all stages of life.

Planning and delivery that are informed by nationally agreed Australian National CoHD Standards can:

- enhance the well-established collaborative bonds between CoHD services that focus on providing coordinated and complete care for patients and families within and between States and Territories;
- ensure that neurodevelopmental and mental health care are embedded in cardiac care and services;
- reduce variation in care by improving access and equity of priority populations to specialty services across Australia;
- capture comprehensive information through data collection and surveillance of CoHD incidence, treatment, outcomes and variations in care;
- enable optimal systems planning to build capacity in health and other services;
- facilitate collaborative research that will inform earlier interventions and improved therapies and health outcomes; and
- enable sharing of best practice, as Australian health providers increasingly engage with global collaborations.

## What is the scope of the CoHD standards?

To provide all Australians impacted by CoHD with lifelong and holistic care and support now and in the future, the CoHD Standards provide clear requirements for care planning and care delivery to support patients, families and carers. They have been developed as the first phase of an ongoing process of providing nationally-agreed standardised care.

The CoHD Standards address cardiac care, surgery, nursing, psychology and allied health support for metropolitan and regional/rural patients, families and carers, and recognise the unique needs of Australia's priority populations. In addition, the CoHD Standards include augmented elements of mental health and neurodevelopmental care. As well, the CoHD Standards recognise the critical role of research in providing new opportunities for care.

It is important to note that these CoHD Standards offer a robust framework for care delivery, with detailed clinical practice guidelines and position statements (Phase 2), and infrastructure and workforce requirements (Phase 3) to form the subsequent phases of this project, and which will secure, if implemented, continuing improvements to service delivery for the future.

## How will the CoHD Standards be used?

The CoHD Standards are written for patients, families and carers, healthcare providers, researchers, healthcare planners and policy makers using, delivering and developing services across Australia. The term 'patients, families and carers' used throughout this document refers to the infants, children, adolescents, and adults living with CoHD and their parents, siblings, partners, and family and carer networks who support them.

Patients, families and carers can gain a clear understanding of the standards of care they should expect and be empowered to advocate for this standard if it is not provided. The CoHD Standards also encourage them to participate in decisions regarding their own health, as well as supporting patient, family and carer participation to inform service improvements, research and advocacy.

For healthcare providers and researchers, the CoHD Standards will identify the elements of excellent clinical services and discovery and translation of impactful research programmes, and promote engagement with the patient, family, carer and wider community.

For healthcare planners and policy makers, the CoHD Standards offer a blueprint for best practice frameworks in conjunction with clinical practice guidelines, scientific statements, workforce and infrastructure plans, and will provide for a common language for future collaboration, advocacy, and planning with healthcare providers and patients.

# Development of the CoHD Standards

## The Lead Principle and Values

To enable development and adoption of CoHD Standards that are relevant and accessible for all those impacted by CoHD, significant engagement and consultation was sought from patient and family representatives, healthcare providers, researchers, and healthcare planner communities (Appendices A and B). The CoHD Standards are written using terminology and language considered and selected by the healthcare providers and patient, family and carer participants (Appendix C).

Engagement and collaboration were reflected through the development of the Lead Principle and key Values intrinsically linked to the provision of quality person-centred, whole-of-life healthcare. The main aim of the collaborative efforts of the community involved in developing these CoHD Standards was to enable all those impacted by CoHD to achieve their best health for a full and rewarding life.

## Living Well

### Lifelong best health throughout life.

The principle leading these CoHD Standards is to achieve the best possible health for those touched by CoHD,<sup>16</sup> which is characterised as **living well** throughout life.

Health is defined as *'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'* (WHO, 1946). *Health reflects the complex interactions of a person's genetics, lifestyle and environment. Generally, a person's health depends on 2 things: determinants (factors that influence health) and interventions (actions taken to improve health, and the resources required for those interventions).*<sup>17</sup>

- The patient, family and carers are at the centre of care planning and delivery
- Patients, families and carers are supported and encouraged to partner in their care planning.
- Care planning incorporates a long term, whole-of-life perspective.
- Care planning incorporates a focus on achieving good health and wellbeing,<sup>16</sup> and the degree to which this may exist for all CoHD patients.

Care planning and counselling should recognise the variation in CoHD creating the correct level of care tailored to the complexity and severity of an abnormality.

Avoiding misinterpretation of the consequences of specific CoHD abnormality reduces the possibility of inappropriate restrictions and limitations, and interventions, and so contributes to good health and wellbeing.

Physical activity and appropriate exercise and sporting involvement is promoted for all CoHD patients.

Quality of life measures should be incorporated into care planning.

- Comprehensive support: Care planning identifies action measures to address the medical, social, psychological, educational, and neurodevelopmental needs of CoHD patients.
- Comprehensive support incorporates trauma informed care, and recognises the impact of significant abnormality on patients, family, carers and healthcare providers.<sup>18,19</sup>

# Values

Values	Statements
Excellence	<ul style="list-style-type: none"> <li>• Excellence is considered best practice, high quality, consistent, and coordinated care for patients, families and carers.</li> <li>• Excellence remains central to all aspects of service planning, delivery, and evaluation.</li> <li>• Excellence requires reliable, purpose specific and common data across constituencies.</li> <li>• Excellence is supported by performance measures benchmarked nationally and internationally.</li> </ul>
Patient- and Family-Centred Care	<ul style="list-style-type: none"> <li>• Patients, families and carers, affected by CoHD are at the centre of all care and care planning.</li> <li>• Patients, families and carers, are involved, supported, and empowered to be partners in their care planning and delivery, and sensitive to their needs.</li> <li>• The requirements of Aboriginal and Torres Strait Islander peoples and populations at disadvantage are sensitively addressed, with measures implemented for equitable access.</li> </ul>
Dignity and Respect	<ul style="list-style-type: none"> <li>• Care is developed and delivered with openness and integrity, and undertaken with respect for, and engagement with patients, families, carers and within healthcare teams.</li> <li>• Care is sensitive, honest and responds to culture, the impacts of distance and regionality, social circumstances, and the role of our environment on psychological and physical wellbeing.</li> </ul>
Empathy and Compassion	<ul style="list-style-type: none"> <li>• Care is provided with compassion and an understanding that the lived experiences of patients, families and carers impacted by CoHD are unique, and influenced by a range of physical, emotional, developmental, cultural, and social factors.</li> </ul>
Knowledge	<ul style="list-style-type: none"> <li>• Care is developed and delivered by healthcare providers with recognised training, current knowledge, and evidence-based practice experience in CoHD.</li> <li>• Care is informed by the best local, national and international research that is facilitated, shared, and integrated across all CoHD services with resources to support discovery, innovation, and future translational care options.</li> <li>• Knowledge focusses on the causes, care and short term impacts of CoHD including social, psychological and neurodevelopmental consequences</li> <li>• Knowledge should be enhanced to end health disparities in Australia.</li> </ul>
Collaboration	<ul style="list-style-type: none"> <li>• Care planning and delivery for patients, families and carers is collaborative to ensure that everyone is well-informed, and care is accessible, inclusive, and offered as close to home as possible.</li> <li>• Collaboration between healthcare providers involves a shared commitment to strengthen the quality of care through rich interactions with a wide range of individuals involved in CoHD, and with networked partnerships between specialist healthcare and support services across metropolitan, regional, rural, and remote areas.</li> <li>• Collaboration recognises the need for strong national and international relationships with CoHD healthcare providers, researchers and the CoHD community. This sustains and evolves longstanding working relationships, such as that between the CoHD communities in Australia and New Zealand.</li> </ul>

## The process of the CoHD Standards development

Development of the CoHD Standards involved nationwide engagement, participation and collaboration with patient, family and carer representatives, interdisciplinary healthcare providers, and other key stakeholders. This process was facilitated by HeartKids Ltd, as described in Appendix E, and guided by the CoHD Standards Steering Committee (Appendix A).

Discipline-specific working groups focussing on the whole-of-life approach were established and included 132 memberships from twelve specialities including: Provision of Services (Large and Small Centres), Regional Care, Cardiology, Cardiac Surgery, Adult Congenital Heart Disease, Transition to Adult Care, Consumers (patient, family, carer representatives from the CoHD Community), Nursing, Mental Health and Psychology, Neurodevelopment, Priority Populations and Research (Appendix B). Through frequent iterative engagement, working groups developed recommendations informed by published evidence, relevant international best practice and expert knowledge of working group members on the current capacity and capability of CoHD care in Australia. A draft of the CoHD Standards is available for public consultation from November to December 2021.

### *CoHD Standards: A living document*

The CoHD Standards are a living document, will be subject to regular review, and are for use by patients, families and carers, healthcare providers, healthcare planners and National and State Governments to guide practice improvements, workforce and infrastructure requirements, service-based decision-making, education, research, and advocacy. The CoHD Standards are to be maintained and reviewed regularly by the Australian National CoHD Standards Oversight and Management Committee and relevant healthcare providers and professional groups, CoHD patients, families and carers and other key stakeholders. Attention will be directed to key aspects of clinical practice, education, research, and accreditation procedures that may be relevant in New Zealand to reflect the strong partnership with the patient, clinical and research communities between both countries.

# Key Recommendations arising from the CoHD Standards

## Structural Change and Leadership

- (1) The CoHD Standards are to be the primary reference source for developing and maintaining CoHD services in Australia across all Health jurisdictions.
  - a. In the event current services do not meet these Standards, a maximum period of three years (until 2025) is permitted to achieve full compliance.
- (2) A National CoHD Standards Oversight and Management Committee is to be created to manage future review and enhancement of the CoHD Standards.
  - a. To be actioned within 6 months of the final publication of the CoHD Standards (2023).
  - b. Nationally coordinated support should be provided to maintain this Committee.
- (3) National Discipline-Specific CoHD Networks be created to facilitate coordinated Australian service delivery (by 2023).
  - a. Networks should consider integrated national care delivery and will be closely involved in contributions to ongoing updated CoHD Standards.
  - b. Individual or collective Networks should be developed for CoHD/ACHD Cardiologists, Cardiac Surgeons, Nurses, Perfusionists, Transition Planning.  
*These networks may be created separately or within existing relevant professional or State bodies.*
  - c. Accreditation of key CoHD healthcare providers across all State and Territory Health jurisdictions should be implemented to support workforce and CoHD Standards requirements.
- (4) A National CoHD/ACHD Research Council be created to facilitate national multicentre research projects with significant research impact by 2023.
- (5) Training and Accreditation pathways be established across key CoHD Health disciplines to ensure adequate training and education, and verification of all CoHD professionals.
  - a. It is expected that relevant training bodies, professional Colleges and associations, and accrediting bodies will contribute to this process.
  - b. Groups should be identified where this process requires implementation.
  - c. Identified professional groups should complete this process within 3 years (by 2025) with initial focus on paediatric CoHD cardiac surgeons, ACHD cardiac surgeons, paediatric and ACHD / CoHD perfusionists.
- (6) A National CoHD Multidisciplinary Advisory Collaborative be established to allow formalised interaction between representatives of CoHD patients and families, carers, healthcare providers, healthcare planners, and CoHD advocacy groups.
- (7) Implementation of comprehensive CoHD clinical practice guidelines, scientific position statements and roadmaps (Phase 2) and workforce and infrastructure plans (Phase 3) be completed by 2023.

## CoHD Standards Phase 2

### Clinical Practice Guidelines, Scientific Position Statements, and Road Maps

As part of this project, supplementary clinical practice guidelines, scientific position statements, and road maps will be produced to further develop the content and application of the CoHD Standards. Established CoHD Standards Working Groups will play a central role in this together with relevant CoHD community and professionals. Consolidation and publication of the initial key documents will take place over the next two years.

## CoHD Standards Phase 3

### Workforce and Infrastructure

As part of this project, supplementary workforce and infrastructure recommendations highlighted in the NSAP 2019 will be produced. This will have particular relevance to planning services, and it is expected that this may be developed in conjunction with Government and Health Authorities. Key considerations will include resilience, succession planning, professional training and education and research. This should meet the needs of patients, families and carers, and the professional requirements of the health teams and practitioners delivering CoHD care. Physical infrastructure will be considered with provision for regular maintenance and updating. It is anticipated that these requirements be met within three years from publication of the CoHD Standards. Details on necessary physical infrastructure will be considered with provision for regular maintenance and updating. It is anticipated that these requirements be met within three years from publication of the CoHD Standards.

## Measuring the outcomes of the CoHD Standards

The CoHD Standards will be assessed through identification of available resources, services and infrastructure at publication and at three- and six-years post-publication. This should be under the direction of the CoHD Standards Oversight and Management Committee. Metrics will include, but not exclusively, evidence that Standards are being met, clinical guidelines and relevant position statements and roadmaps have been developed and implemented, workforce and infrastructure needs have been assessed and plans to address identified gaps are developed. Metrics will include evaluation of patients, families and carers' perceptions of improvements with regard to access to services and available information, and contribution to their best health and wellbeing.

Effective adoption of the CoHD Standards into care practices will enable patients, families and carers impacted by CoHD to receive care of consistently high quality that is sustainable for the future.

# Paediatric and Adult CoHD Services

## Standard 1

**Living well throughout life, and irrespective of the length of life, informs the CoHD Standards, and provides guidance for planning across all Standards.**

Standard One describes the range of CoHD paediatric and adult congenital heart disease (ACHD) healthcare services. Larger scale CoHD service providers are at the core of CoHD care delivery and the means of securing care excellence and high quality outcomes, in particular for patients with complex and moderate CoHD (Appendix D).

CoHD and ACHD services share established supportive links to bring care closer to home for patients and pathways of referral to centralised specialist multidisciplinary services when needed.

Paediatric CoHD Services are described as being Type 3, Type 2, Type 1, and include healthcare for a range of congenital and acquired conditions (CoHD). Adult services which focus on CoHD congenital structural heart abnormalities are generally referred to as adult congenital heart disease (ACHD) services. These Services exist in a range of clinical settings.

In Services providing complex care, the strong relationship between volume of experience and successful outcomes is widely recognised. Wherever possible, the principle of centralisation of high complexity, low volume services into a comprehensive integrated unit to achieve clinical excellence should be adhered to. This facilitates the goal of achieving excellent CoHD surgical, procedural, and medical outcomes with adequate and sustainable provision of expertise in surgical, interventional, anaesthetic, perfusion, and intensive care disciplines. This strategy also recognises prudent deployment of the specialist health workforce. This principle is the main driver to centralise CoHD and ACHD cardiac surgery and complex invasive cardiology procedures to a single comprehensive centre within each State.

The geographical considerations and population distribution in Australia create challenges of travel and disruption for patients, families, and carers, however preserving excellence and the best possible outcomes counterbalance the impediments and difficulties caused by the distances as well as the social dislocation involved in accessing highly complex services. Measures to deliver some key elements of care and surveillance close to home for patients outside the capital cities are incorporated into CoHD Service planning.

- 1.1 CoHD and ACHD Services are central to care delivery for patients with CoHD throughout life, and in particular deliver medical and supportive care when interventions, specialised investigations, and complex conditions are treated. Strong, properly resourced, and expertly led and staffed services are essential to provide education, training, research, innovation and sustainability of excellent care across all disciplines engaged in supporting patients.**

- 1.1.1** CoHD Services (Paediatric and ACHD) provide patients with excellence in care (planning, care delivery and communication).

## Standard 1: Paediatric and Adult CoHD Services continued

- 1.1.2** Larger, multidisciplinary CoHD Services should ideally offer a hub and spoke framework of care delivery to allow centralisation, and sustainable optimisation of expertise and resources of highly specialised elements of care.
- 1.1.3** Patients and families have timely and reliable access to CoHD and ACHD dedicated services throughout life.<sup>1,20</sup>
- 1.1.4** CoHD Services (Paediatric and ACHD) have dedicated governance and leadership focussing on the delivery of excellent, best-practice services in line with the Australian National CoHD Standards.
  - 1.1.4.1** CoHD Services are led by suitably trained experts in CoHD/ ACHD.<sup>21</sup>
  - 1.1.4.2** Within CoHD and ACHD Services with multidisciplinary teams, a lead in each stream, major service offering and professional domain should be identified.

*Leads should be responsible for coordination and guidance of that service stream including professional or stream specific, education, development and management. Leads should form part of a multidisciplinary collaborative leadership group in that Service to offer voice to the various Service offerings.*
  - 1.1.4.3** Service governance structure is documented and transparent and with focus on patients, families and carers.
- 1.1.5** All CoHD Services (Paediatric and ACHD) and governing entities of those Services, incorporate the Lead Principle, Values, and Standards of the Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards).
- 1.1.6** CoHD Services consider the special and culturally appropriate requirements of Aboriginal and Torres Strait Islander peoples and other priority populations (see Standard 10).
  - 1.1.6.1** To enable Aboriginal and Torres Strait Islander peoples to have access to culturally appropriate care timely referral will be made to Aboriginal Torres Strait Islander Health Workers / Indigenous support services. In the case of other members of priority populations relevant and culturally appropriate support should be engaged when needed.
- 1.1.7** All staff employed by CoHD and ACHD services have training in CoHD/ ACHD care.
  - 1.1.7.1** For healthcare providers, training commences during basic (university, technical college) medical education, and educational bodies involved in medical, nursing, psychology, and allied health training include some exposure to CoHD educational resources.<sup>22</sup>

## Standard 1: Paediatric and Adult CoHD Services continued

- 1.1.7.2 Specialty and advanced training (medical colleges, nursing, psychology, and allied health) should work with CoHD/ACHD experts to incorporate CoHD educational materials relevant to that training.<sup>21,22</sup>
- 1.1.7.3 Providers of CoHD/ACHD services have appropriate accreditation and credentialing provided through relevant employing bodies and training organisations.
- 1.1.7.4 Administrative and support staff predominantly involved in services delivering care to CoHD patients should have role appropriate orientation and training in relevant aspects of CoHD and the needs of patients and families.

### 1.2 Paediatric CoHD Services Type 3 provide coordinated multidisciplinary care, with cardiac surgery, located in a Tertiary Paediatric Hospital.

This includes paediatric cardiac surgery, cardiac diagnostic and interventional catheterisation, advanced and appropriate cardiac imaging (including cardiac MRI/CT), electrophysiology, pulmonary hypertension services, and advanced heart failure management. Type 3 centres will be at the centre of a managed clinical network of services for complex CoHD at appropriate locations across each state and territory. This may include satellite centre(s) for provision of some specialist cardiology services and collaboration with local health care facilities to provide close to home outreach cardiology services as appropriate.

- 1.2.1 Paediatric CoHD Services Type 3 work with specialty providers to support remote assessment and management of acute cases and transport through the retrieval service established in the State.
- 1.2.2 Paediatric CoHD Services Type 3 are supported by multidisciplinary teams.
  - 1.2.2.1 The team includes dedicated and integrated CoHD full time equivalent staff for support of cardiology and cardiac surgery, advanced practice nursing, psychology, genetic counselling, neurodevelopmental screening, social work, allied health, and appropriate administrative support.
- 1.2.3 Paediatric CoHD Services Type 3 must have a dedicated Paediatric Intensive Care Unit (PICU), Neonatal Intensive Care Unit (NICU), with relevant cardiac ICU expertise and training.
  - 1.2.3.1 Paediatric Intensive Care Units will be designated as Paediatric Cardiac Surgical Intensive Care training sites if the hospital has a dedicated cardiac surgical department and manages complex cardiac surgery (including Risk Adjustment for Congenital Heart Surgery (RACHS category 5 and 6) with a sufficient CoHD ICU case load (minimum 250 cases per year) and case mix.

## Standard 1: Paediatric and Adult CoHD Services continued

- 1.2.4** Anaesthetic services for paediatric CoHD interventions must be available.
- 1.2.5** Paediatric CoHD Services Type 3 provides specialist paediatric clinical follow-up, screening and surveillance care in regional remote areas and capacity to organise timely coordinated care to Type 3 Paediatric CoHD Services when the need arises.<sup>23</sup>

*This may involve collaboration with Paediatric CoHD Type 1 Service providers.*
- 1.2.6** Paediatric CoHD Services Type 3 are supported by dedicated echocardiography staff,<sup>24</sup> advanced practice nursing support,<sup>25</sup> psychology, allocated medical trainee(s), and allied health staff allocated to CoHD services.
- 1.2.7** Paediatric CoHD Services Type 3 have a lead role in medical specialist training for CoHD and education across the multidisciplinary team.
- 1.2.8** Paediatric CoHD Services Type 3 collaborate with materno-fetal medicine programmes to provide capabilities for rapid transfer of patients if required.<sup>24</sup>
  - 1.2.8.1** Capability for on-site and/or co-located facilities to manage relevant cases is available or under planning review for CoHD Services Type 3.
- 1.2.9** Paediatric CoHD Services Type 3 are staffed to ensure sustainable on-call rostering of specialist medical consultants and all teams needed to support CoHD clinical care, including surgical and interventional catheter care.<sup>9</sup>
  - 1.2.9.1** It is expected that senior medical general paediatric cardiology staff will operate at no more than an average 1:4 rostering, and cardiac surgery senior medical staff no-more than an average 1:3 rostering, with other staff who are expected to return to the hospital acutely to be rostered no more than 1:3.
- 1.2.10** Paediatric CoHD Services Type 3 have cardiac inpatient and outpatient facilities appropriate to patient and family requirements.
  - 1.2.10.1** Inpatient cardiac beds allow for 24/7 admission of all cardiac surgery cases, acute cases, and should allow for a triaged patient admission as required for care delivery.
  - 1.2.10.2** Outpatient services are triaged and patients prioritised according to need for a high-level multidisciplinary service capability in the event suitable alternative arrangements are not available.
- 1.2.11** Paediatric CoHD Services Type 3 are appropriately staffed and resourced to have integrated and dedicated time allocated to senior medical specialist continuing education, junior medical staff training, and training and development of the multidisciplinary team.

## Standard 1: Paediatric and Adult CoHD Services continued

- 1.2.12** Paediatric CoHD Type 3 Services have well developed audit and case review meetings on a weekly basis to oversee invasive and complex case planning.
  - 1.2.12.1** Attendance involves all senior medical staff, and key members of nursing staff and other members of the multidisciplinary team and key partners involved in patient care.
  - 1.2.12.2** Comprehensive and centralised case discussion summaries are maintained and readily available to team members for the purpose of optimising direct care delivery.
  - 1.2.12.3** Regular audit of mortality and complications takes place.
- 1.2.13** Paediatric CoHD Services Type 3 have embedded research programmes, and integrated links with relevant higher education facilities to promote the development and translation of innovation in CoHD.
- 1.2.14** It is expected that paediatric CoHD Services Type 3 are appropriately staffed and resourced to have integrated and dedicated time allocated to the multidisciplinary team to participate in research activities led by the embedded programmes as relevant to their roles.<sup>8,24,25</sup>
- 1.2.15** Paediatric CoHD Services Type 3 have embedded education programmes aimed at CoHD staff, relevant health staff, trainees, and students.
  - 1.2.15.1** The educational programmes are available for a range of individuals including, but not exclusively
    - o patients, carers, and the community serviced
    - o CoHD professionals, with relevant activities for students and trainees
    - o tailored and relevant materials should be available across the whole multidisciplinary team.
  - 1.2.15.2** Paediatric CoHD Services Type 3 are appropriately staffed and resourced to provide these educational services through internal and linked resources.
- 1.3 Paediatric CoHD Services Type 2 provide coordinated multidisciplinary care, without cardiac surgery, located in a Tertiary Paediatric Hospital.**
  - 1.3.1** Under normal circumstances Paediatric CoHD Services Type 2 will not provide cardiac surgery (see Standard 1.3.5).
  - 1.3.2** Paediatric CoHD Services Type 2 incorporate all elements of a Paediatric CoHD Service Type 3 with some selected medical sub-specialties omitted.



## Standard 1: Paediatric and Adult CoHD Services continued

- 1.5 Paediatric CoHD Outreach is provided by a visiting paediatric cardiologist connected with a Paediatric CoHD Service Type 3, Type 2, or Type 1.**
  - 1.5.1** Outreach services include an intermittent visiting CoHD clinic and will involve a paediatric cardiologist and may involve additional CoHD personnel.
  - 1.5.2** Outreach Services require close collaboration with local medical services, and ideally have a local medical champion to optimise integration into local medical and support services.
  - 1.5.3** Adequate workforce and infrastructure is provided to offer a sustainable Paediatric CoHD Outreach service.
  - 1.5.4** Telehealth is available to aid management of patients, when the distance required for review and timing of specialist in-person assessment impede necessary care and surveillance. (See Standard 12).
  - 1.5.5** Paediatric CoHD Outreach services engage with local medical, nursing and allied health staff as needed, and provide care to those requiring such services.
- 1.6 ACHD Services (Comprehensive) are supported by multidisciplinary teams.**
  - 1.6.1** The team includes dedicated and integrated, CoHD full time equivalent staff for support of cardiology and cardiac surgery, advanced practice nursing,<sup>26</sup> psychology, genetic counselling, social work, allied health and appropriate administrative support.
  - 1.6.2** ACHD Services (Comprehensive) provide coordinated multidisciplinary care to patients with Adult Congenital Heart Disease (ACHD) in a tertiary adult hospitals.<sup>7,22</sup>
    - 1.6.2.1** Medical services includes congenital heart disease cardiac surgery, cardiac diagnostic and interventional catheterisation, advanced cardiac imaging (including cardiac MRI/CT), electrophysiology, pulmonary hypertension service, advanced heart failure management.<sup>22,27</sup>
  - 1.6.3** ACHD Services (Comprehensive) provide for access to 24/7 on call ACHD specialist advice.
    - 1.6.3.1** Services include the provision of specialist ACHD advice for non-cardiac surgery (including dental) for ACHD patients with moderate or complex ACHD.  
Sustainable rostering of at least 1:3 cardiologists is required.
    - 1.6.3.2** ACHD Services (Comprehensive) have well developed audit and case review meetings on a regular basis to oversee invasive and complex case planning.
    - 1.6.3.3** ACHD Services (Comprehensive) will manage ACHD Cardiac Catheterisation and Intervention.



# Care in Regional Australia

## Standard 2

The CoHD Standards relevant to regional Australia are developed to support whole-of-life care that is culturally sensitive and culturally respectful and empowering for patients, families and carers. The CoHD Standards for regional Australia align with a network model of care and collaborative multidisciplinary care.<sup>15,25,26</sup>

Australia has a wide geographical distribution with over 28 percent of the general population living in regional or remote areas of the country beyond 100km of Paediatric CoHD Services Type 2 or Type 3 or Comprehensive ACHD Services. The CoHD Standards recognises the unique challenges and requirements of regional Australia.

- 2.1 Regional CoHD and ACHD services are provided as close to home as possible, where possible, to minimise travel requirements.**
  - 2.1.1** Regional CoHD care is provided through close collaboration between local medical and nursing care services and paediatric cardiologists / CoHD services.<sup>20,28,29</sup>
  - 2.1.2** Service requirements for regional areas are identified and local CoHD and ACHD services tailored to those requirements.
    - 2.1.2.1** Assessment of requirements are developed by local health care planners, healthcare providers, patients, families and carers, and providers of CoHD and ACHD services.
    - 2.1.2.2** Services may be provided by individual paediatric or ACHD cardiologists (collaborating with a relevant Paediatric CoHD Service Type 2 or Type 3, or an ACHD Service (Comprehensive)), or through multidisciplinary CoHD teams as needed.
- 2.2 Patients and families have appropriate and coordinated access to tertiary services including timely state-wide and interstate retrieval to a CoHD Type 2 / 3 Service or ACHD Services (Comprehensive) when required.**
  - 2.2.1** Planning and documentation of services are available for review as required.
  - 2.2.2** Funding for services in regional Australia recognises and accommodates the requirements involved in providing CoHD / ACHD care.
    - 2.2.2.1** Appropriate funding structures are based on Service planning.
    - 2.2.2.2** Funding is available to care providers (including workforce) and for support of travel & accommodation for patients and families.<sup>5,15</sup>
- 2.3 A local clinical lead is designated for each major regional area with CoHD or ACHD Outreach services.**
  - 2.3.1** It is expected that the role would be part-time and the medical skills for such a role would require distinct paediatric and adult leads.

## Standard 2: Care in Regional Australia continued

- 2.3.2** The clinical lead role(s) is supported by separate paediatric and adult coordinators as required.
- 2.3.3** Paediatric CoHD services / ACHD services identify a contact person to assist with co-ordination matters.
  - 2.3.3.1** In the event the regional service is provided by a CoHD Services Type 1 with an individual service linked paediatric cardiologist, that individual may act as the contact.
- 2.3.4** The rural and regional services nominate clinical specialised cardiac nurses with relevant knowledge to assist with support of patients and families affected by CoHD.<sup>22,25,26</sup>
  - 2.3.4.1** Given the distinct knowledge and care requirements it is expected that two roles will be required, one for CoHD (paediatric nursing) and one for ACHD (adult nursing) with fraction dependent on case load and requirements.<sup>25,26</sup>
  - 2.3.4.2** The roles will incorporate activities to foster strong links with CoHD/ACHD nurses in advanced practice and specialised nursing roles.<sup>25,26</sup>
- 2.4** **The CoHD service or supporting paediatric cardiologist, and/or ACHD Centre collaborates with rural and regional services to develop and facilitate mentorship and appropriate professional development.**
  - 2.4.1** There are opportunities for nominated key regional team members to join joint multidisciplinary CoHD and ACHD patient review meetings as required.

# Paediatric CoHD Cardiology Care

## Standard 3

Paediatric Cardiology is the primary driver of the diagnosis and delivery of long term care to CoHD patients until transition. The benefits of high quality care provided by sub-specialty experts is well understood. Securing excellent outcomes for paediatric patients will involve the continuing involvement of a paediatric cardiologist. Sub-specialty paediatric cardiologists (e.g. interventional cardiac catheterisation, paediatric arrhythmia, fetal cardiology, complex heart failure) provide a range of supplementary key services. Paediatric cardiology clinicians and researchers play an important part in research into CoHD. Maintaining a secure, highly qualified, sustainable paediatric cardiology profession should be priority for care planners.

**3.1 Paediatric CoHD Cardiology care is provided to patients below the age of 15–18 years by paediatric cardiologists.<sup>8</sup>**

**3.1.1** Paediatric cardiologists play a central role in cardiac assessment, planning and surveillance of patients with CoHD and work collaboratively with other healthcare providers including psychology, allied health, nursing, and primary health care.<sup>8,25</sup>

**3.2 Paediatric Cardiologists have qualifications and training verified and registered through the appropriate pathways of the RACP and AHPRA.<sup>8</sup>**

**3.2.1** Sub-specialty skills within paediatric cardiology require relevant additional training, experience, and long-term delivery of services in those sub-specialty areas. Relevant areas include cardiac catheterisation with intervention, paediatric electrophysiology, advanced cardiac imaging (MRI, CT), and heart failure and cardiac transplantation, pulmonary hypertension, and fetal cardiology.

**3.3 National credentialing of paediatric cardiologists, including specific credentialing of sub-specialty paediatric cardiology disciplines, is implemented.**

# Paediatric Cardiac and ACHD Surgery

## Standard 4

Paediatric Cardiac surgery and ACHD Cardiac surgery are highly specialised sub-specialties of Cardiac Surgery. Delivering excellence in CoHD cardiac surgery is a central requirement for CoHD Services Type 3 and for ACHD Services (Comprehensive). Geographically isolated Type 2 Services may implement carefully selected cardiac surgical procedures, the number of sites providing cardiac surgery nationally should be limited, so that the resources and expertise required to achieve outcome excellence are not diluted, the balance of case complexity is preserved, and the cardiac surgical workforce can function sustainably, maintaining high levels of CoHD/ACHD surgical volume.

**4.1 Paediatric cardiac surgery and adult congenital heart surgery is performed in cardiac surgical centres with onsite access to all necessary CoHD (or ACHD surgery) infrastructure, services, and specialised personnel including dedicated CoHD operating theatres, cardiac catheter and catheter intervention laboratories and staff, CoHD and / or ACHD capable ICU.**

**4.1.1** Paediatric cardiac surgery is performed in a Paediatric CoHD Services Type 3 or geographically-isolated Type 2 with continuous 24/7 direct on-site access to paediatric cardiology, paediatric diagnostic and interventional catheterisation, the full multidisciplinary CoHD team, and with other relevant sub-specialty services.

**4.1.1.1** The paediatric ICU include suitably trained and experienced staff.

**4.1.1.2** Centres performing paediatric cardiac surgery have 24/7 access to expertise in paediatric interventional cardiac services, diagnostic cardiac imaging, complex arrhythmia management, pulmonary hypertension management and mechanical circulatory support.

**4.1.2** Adult congenital heart surgery is performed in an ACHD Services (Comprehensive) with continuous access to ACHD specialty services.<sup>21</sup>

**4.1.2.1** Adult ICU include suitably trained and experienced staff.

**4.1.2.2** Centres performing ACHD cardiac surgery have 24/7 access to expertise in interventional cardiac services, diagnostic cardiac imaging, complex arrhythmia, pulmonary hypertension and mechanical circulatory support.<sup>7</sup>

**4.1.2.3** Where simple congenital heart lesions are managed outside such a centre and by a non-ACHD cardiac surgeon, the pre-surgical case review should involve an ACHD cardiologist and ACHD cardiac surgeon.

## Standard 4: Paediatric Cardiac and ACHD Surgery continued

**4.1.2.3.1** A list of relevant lesions and procedures, inclusions and exclusions should be prepared within three years of publication of these Standards through collaborative engagement between ACHD cardiac surgeons and non-ACHD cardiac surgeons.

**4.2 Assessment for heart transplantation for congenital heart disease (including ventricular assist device as a bridge transplant) is conducted at a designated Paediatric Congenital Cardiac Transplant Centre or Adult Transplant Centre with relevant ACHD experience and skills.**<sup>30–32</sup>

**4.2.1** All patients who may benefit from transplantation, including with failing univentricular circulation, must undergo a centralised uniform assessment with the same national criteria by a cardiac surgeon and cardiologist with expertise in both surgical management of univentricular circulation, and complex transplantation in patients with repaired congenital heart disease, as well as durable ventricular assist devices.<sup>32,33</sup>

**4.2.2** Where transplant services are not available, services may be developed where assessment and / or the majority of workup can be conducted in the patient / family's home state.<sup>31</sup>

**4.3 Paediatric cardiac and ACHD surgical service centres have an ECMO programme including provision for an ECMO retrieval service.**<sup>11</sup>

**4.4 Paediatric cardiac / ACHD surgical services have dedicated paediatric / ACHD cardiac theatre capability.**

**4.4.1** Operating theatres have 24/7 access to staff trained and experienced in the requirements for paediatric / ACHD cardiac surgery.

**4.4.2** Access to theatre and ICU beds for non- elective cases, proportionate to local CoHD/ACHD caseload requirements are facilitated with an understanding that non-elective surgical cases make up a substantial part of the cardiac surgical case load.

**4.4.3** On the day cancellation of elective cases for non-clinical reasons are kept to below 5% of total cases per year.

**4.5 Paediatric cardiac and ACHD surgery is performed by an appropriately trained congenital cardiac surgeon.**<sup>34</sup>

**4.6 Paediatric cardiac surgeons and adult congenital cardiac surgeons have formal training in congenital cardiac surgery following their initial training in Adult Cardiac Surgery.**<sup>34</sup>

**4.6.1** Training Programmes for paediatric and adult cardiac surgeons should include experience at one or more recognised\* CoHD cardiac surgical centre(s) for a duration of at least two years, followed by formal mentorship (named mentors) at a surgical centre that is endorsed by the Royal Australian College of Surgeons.<sup>34</sup>

*\*A recognised cardiothoracic surgical service is one that includes a trainee cardiothoracic surgical position that is endorsed by the Australian College of Surgeons.*



## Standard 4: Paediatric Cardiac and ACHD Surgery continued

### 4.9.2 Criteria for assessment should include:

Comparative outcome measures comprised of, but not limited to:

- o Mortality
- o Major morbidities
- o Volumes of congenital / complex congenital cases
  - o a minimum case volume of 100 congenital cases / year surgeon averaged over 3 years.

*Some variation to these numbers is addressed in Standard 4.10.*

- o Management and review of surgical data
- o Collaborative linkage with national colleagues
- o Adequate support for the surgical team including cardiology services, radiology, PICU, anaesthetics, specialist nursing and access to sub-specialties.

**4.9.2.1** A standardised assessment matrix should be developed within three years of publication of these standards of care.

### **4.10 Cognisant of Australia's large geography and population distribution, congenital cardiac surgery may be provided in suitably equipped and audited, geographically isolated Paediatric CoHD Centres Type 2 performing smaller case volumes. Additional safety provisions will apply.**

**4.10.1** Collaborative collegiate support and planning must be implemented for surgeons functioning in isolation to manage surgeon wellbeing.

**4.10.1.1** Upgraded surveillance, formal external Australian peer review and Quality Assurance (QA) requirement will be required.

**4.10.1.2** Where this is not immediately available, a set of reviewable criteria will be produced within three years by the CoHD/ACHD cardiac surgery community together with oversight bodies.

# CoHD Transition to Adult Care

## Standard 5

Patients who have been cared for by Paediatric CoHD Services require considered transition to adult services, whether ACHD Services for congenital heart disease, or other adult cardiology services. The specifics of this process may vary according to the cardiac abnormality and patient needs, and considers patient-specific lifelong consequences of CoHD. The consequences of loss to follow-up may pose serious threats to safety, and robust efforts should be made to secure appropriate service delivery for all children transitioning to adult cardiac care.

- 5.1 Transition is transdisciplinary, holistic, individualised, flexible, and carefully planned to provide seamless, uninterrupted, and supportive care.**<sup>37-40</sup>
  - 5.1.1** CoHD patients with congenital or structural heart disease have transition to ongoing follow-up at an ACHD Service and review by an ACHD cardiologist and have a relevant transition plan.<sup>40</sup>
  - 5.1.2** CoHD patients without congenital or structural abnormalities have ongoing follow-up by a general or sub-specialty adult cardiologist or centre as required and have a relevant transition plan.
    - 5.1.2.1** The appropriate cardiology surveillance strategy can be tailored to the underlying lesion, condition, and severity.
- 5.2 Transition is patient- and family-centred, empowers patients and parent/ carers to be actively involved in the transition planning and delivery process.**<sup>40-42</sup>
- 5.3 Transition commences during early adolescence, considers individual and developmental readiness and capacity, and continues into adulthood following successful engagement with adult congenital cardiology care.**<sup>37,43</sup>
- 5.4 Transition comprises multiple sessions throughout adolescence and young adulthood to promote understanding about their CoHD, enable meaningful goal setting, tracking of progress of developmental tasks and allowing for screening for other concerns. This includes an emphasis on health/treatment compliance, mental health, social, educational/vocational goals.**<sup>44-47</sup>
- 5.5 Dedicated CoHD transition clinics are present in all CoHD Services Type 3 and Type 2, and accessible to CoHD Services Type 1 as well as regional, remote, and disadvantaged patients.**<sup>48</sup>
  - 5.5.1** Transition care is provided by dedicated staff and infrastructure to support transition.
  - 5.5.2** Transition is facilitated jointly by paediatric CoHD and ACHD practitioners and teams<sup>48-50</sup> and where possible, primary care.<sup>51,52</sup>
  - 5.5.3** Pathways are available to secure the transition process and share information and recall information between the paediatric and ACHD / adult cardiology phases of care.

## Standard 5: CoHD Transition to Adult Care continued

- 5.5.3.1** Transdisciplinary transfer involves strong collaboration between paediatric CoHD and ACHD services, and where possible, an individualised joint transfer process to introduce the ACHD team in partnership with the paediatric team.<sup>49,53,54</sup>
- 5.5.3.2** A centralised comprehensive patient database with intrinsic systems to highlight patients at higher risk of loss-to-follow-up, and the personnel to monitor patient progress and arrival to ACHD services is recommended in order to minimise patient loss-to-follow-up.<sup>50</sup>
- 5.5.3.3** A transdisciplinary communication system is required to ensure coordinated care throughout the whole-of-life.
- 5.5.4** Early intervention and preventative care for Aboriginal and Torres Strait Islander peoples includes consideration of, and is adapted to, a person's gender and role in the community.  
*For an Aboriginal and Torres Strait Islander person, adolescence is a time when cultural identity is critical to development.*<sup>55</sup>
- 5.5.5** Transition education and support is tailored to the developmental stage of the patient inclusive of learning and intellectual disabilities where additional barriers to accessing appropriate health care is addressed.<sup>55,56</sup>

# Adult Congenital Heart Disease (ACHD) Cardiology

## Standard 6

ACHD cardiologists provide healthcare for adults with congenital or structural heart disease. They may be involved in transition care which begins in late high school (age 15 years and above). This Standard identifies the nature and role of an ACHD Cardiologist, and should be read with ACHD Services in Standard 1.

Other forms of CoHD acquired or appearing in childhood are transitioned to appropriate cardiology or sub-specialty cardiology services. A whole-of-life approach, links to network models of care and seamless transition are emphasised in the follow standards of care.

**6.1 Adult Congenital Heart Disease patients should have care provided by an ACHD Cardiologist.<sup>7,21</sup>**

**6.1.1** ACHD cardiologists play a central role in assessment, planning and surveillance of patients with congenital heart disease and work collaboratively with other healthcare providers including Allied health, Nursing, Psychology, and Primary Health Care.<sup>7,22</sup>

**6.2 ACHD cardiologists should have a path for formal recognition by relevant national colleges and registering bodies (AHPRA).**

**6.2.1** In the absence of such training, accreditation, and registration pathways, these should be established in Australia.

**6.3 An ACHD cardiologist is part of the evaluation and decision-making team when cardiac surgery is planned for an ACHD patient.<sup>21,22</sup>**

# Nursing Care for the patients with CoHD and their families

## Standard 7

CoHD and ACHD nursing staff play a central role in care of patients and families and supporting them to be active participants in all aspects of their care, coordination and surveillance. Advanced Practice and specialised nursing roles facilitate delivery of evidenced based practice and excellence in cardiac CoHD/ACHD nursing care for patients, families and carers. Members of CoHD/ACHD nursing teams maintain close links with local services and provide an equitable nursing model across all aspects of patients and families continuum of care.

**7.1 The specialist cardiology service will have Advanced Practice Nurses and specialised nursing roles to facilitate delivery of evidence-based practice and excellence in cardiac nursing care.**

**7.1.1** CoHD and ACHD sub-speciality nursing services are led by Advanced Practice Nurses. Advanced Practice Nurses include Clinical Nurse Consultants and Nurse Practitioners and Nursing Unit Managers.<sup>25,57,58</sup>

**7.1.2** Inpatient cardiac services have a nominated lead nurse/s with responsibility for the service, providing professional and clinical leadership and support a team of nurses providing care to children with CoHD.

*While titles and descriptions of additional nursing roles vary across Australian States and Territories, additional nursing roles can include cardiac nurses in specialised roles such as Care Coordinators, Clinical Nurses and Clinical Nurse Specialists.<sup>25</sup>*

**7.2 Nursing staff providing care for CoHD/ACHD patients and families have appropriate CoHD/ACHD education with upskilling appropriate for their role.<sup>25,26</sup>**

**7.2.1** Sub-specialty areas of CoHD/ACHD are staffed by appropriate education, clinical expertise, and professional levels to match those roles.<sup>25,26,57,58</sup>

**7.3 Within CoHD and ACHD services, experienced and appropriately trained nursing staff are available for support and care of CoHD/ACHD patients at all stages and within all sub-specialty areas of care delivery (including cardiac surgery and cardiac catheterisation/intervention).**

**7.3.1** Appropriate staffing is provided to support the requirements of general cardiac care within CoHD Type 3 or Type 2 / ACHD services, and some suitably structured CoHD Type 1 services.

**7.3.2** Appropriate staffing is provided to ensure each sub-specialty area in a Type 3 or Type 2 Service or Comprehensive ACHD Service has a dedicated CoHD/ACHD of at least Advanced Practice level.

## Standard 7: Nursing Care for the patients with CoHD and their families continued

- 7.3.3 Nursing staff are incorporated into and play a central role in care coordination, liaison, communication, and care delivery as an inpatient and outpatient in collaboration with the multidisciplinary team.
- 7.3.4 Specialist cardiac surgical nursing care includes support during the preoperative, intraoperative, postoperative inpatient, and post discharge from hospital phases.
  - 7.3.4.1 Specialist cardiac surgical intraoperative nursing care includes proficiency in perioperative instrumentation and theoretical knowledge of CoHD and intraoperative care.<sup>25,58</sup>
  - 7.3.4.2 The intraoperative nursing services provide procedural support when needed across peri-operative specialties, including interventional cardiac catheter procedures, extra corporeal life support and inter-hospital retrieval programmes (where transplant services are established).
- 7.4 **A CoHD/ACHD specialised nurse and/or Advanced Practice Nurse is readily available in CoHD Service Type 3 and Type 2 and ACHD outpatient clinics and at key stages of interaction with CoHD services and ACHD services including some suitably structured CoHD Type 1 Services.**
  - 7.4.1 Provision of nursing resources are informed by the coordinated care and expert multidisciplinary collaboration required to support patients, families and carers during key stages of their CoHD journey.<sup>25,58</sup>
  - 7.4.2 Key areas of interaction include fetal cardiac services, planned admission for procedures and treatment, sub-specialty clinics, transition and specialist ACHD nursing care and support.<sup>59</sup>
- 7.5 **Patients with complex needs have an Advanced Practice Nurse / specialised nurse team responsible for coordinating their care.**
  - 7.5.1 Patients and families have timely access to appropriately coordinated palliative care and/or bereavement services that work collaboratively with the treating cardiology team, including a consistent Advanced Practice Nurse / specialised nurse.<sup>25</sup>

# Mental Health and Psychological Care

## Standard 8

Mental health, broadly defined, encompasses our emotional, psychological, social, cultural, and spiritual wellbeing. Our mental health affects how we feel, think, and act. It influences our sense of self, how we manage stress and adversity, relate to others, and make choices.

Children, adolescents, and adults with CoHD value empathy, choice, and continuity in their medical, developmental, and psychological care. People with CoHD, and their families and carers recognise the importance of their mental health and prioritise opportunities to access mental health care in ways that deeply respect and align with their cultural beliefs.

Embedding mental health professionals within specialised CoHD services is a key component of comprehensive care delivery, and can normalise emotional responses to cardiac challenges, reduce stigma associated with seeking mental health treatment, and improve timely access to appropriate mental health care from experienced providers. This allows for a comprehensive approach to patient and family care, creating a healing environment to support and strengthen patients, families and carers.

**Access to specialised mental health care is essential for patients with CoHD and their families and carers throughout the whole-of-life, from fetal or postnatal cardiac diagnosis through to end-of-life and bereavement care. Patient- and family-centred mental health care must be integrated into routine paediatric and adult CoHD care, be equitable and inclusive of all, and delivered in accordance with the principles of trauma-informed care, emphasising patient and family choice, dignity, empathy, compassion, psychological safety, and healing.**

- 8.1 Infants, children, adolescents, and adults with CoHD and their families and carers have equitable and inclusive access to high quality, evidence-based mental health care, information, and support from the point of diagnosis, throughout cardiac care, and across the whole-of-life.**
- 8.2 Knowledge about the widespread effects of trauma and adverse childhood experiences, the diverse pathways to recovery and resilience, and principles of trauma-informed care is integrated into CoHD care practices, procedures, and policies.**

*Trauma-informed care recognises that many people, including patients with CoHD, their families, carers and health professionals, have a history of trauma. A trauma-informed approach to cardiac care: (a) emphasises personal choice, control, dignity and empowerment, (b) creates a physically and emotionally safe environment for discussion of trauma experiences, (c) recognises and responds to trauma symptoms in a respectful, compassionate and supportive way, (d) emphasises strengths, resiliency and the importance of benevolent experiences, (e) fosters trust, transparency and partnership*

## Standard 8: Mental Health and Psychological Care continued

*between patients, families, and health professionals, (f) demonstrates sensitivity to triggers that may risk re-traumatisation, (g) recognises that potential added anxiety or distress for patients with CoHD when pandemics or other impactful global health events occur, (h) values therapeutic engagement, and (i) promotes healing, recovery and wellbeing.*

### **8.3 CoHD / ACHD services include specialised mental health roles to provide education, screening, assessment, intervention and treatment, and excellence in mental health care for patients with CoHD and their families and carers.**

*Members of the mental health team include psychologists, social workers, child life therapists, occupational and music therapists, and psychiatrists – all with specialised training and credentialing in their discipline. Mental health professionals work in strong collaboration with people with CoHD, their families and carers, and interdisciplinary care team, including medical specialists, nurses, primary care doctors (local GPs), allied health professionals, and palliative care specialists, as well as a range of local, community and educational services, including schools.*

**8.3.1** Within hospital settings, mental health professionals will actively participate in regular medical and developmental care rounds, case conferences and meetings, provide input within complex cardiac subspecialties, and lead and participate in dedicated psychosocial rounds to facilitate collaborative, integrated mental health care for patients and their families.

### **8.4 Patients with CoHD and their families and carers have access to up-to-date, evidence-based information and education related to disease, treatments, procedures, hospitalisation, acute and long-term effects, risk and resilience factors, developmental care and neurodevelopment, psychological and social adaptation, mental health and wellbeing across the lifespan, and the interconnectedness of physical and mental health, provided in formats that are culturally and developmentally appropriate, and in accordance with trauma-informed care principles.**

*Relevant, up-to-date information will be made available in multiple formats, languages, and literacy levels to ensure equitable access throughout cardiac care.*

### **8.5 CoHD / ACHD services provide routine screening and assessment, led by mental health professionals using standardised measures, to identify and respond to patient and family psychological and social needs.**

*It is essential that CoHD/ACHD care includes early and ongoing conversations with patients, families and carers about their mental health and psychosocial needs. The language used during these conversations will be culturally and developmentally appropriate and will serve to normalise and destigmatise mental health care.*

## Standard 8: Mental Health and Psychological Care continued

- 8.5.1** Screening will be offered at regular intervals across the cardiac care journey to capture potential changes in patient and family psychological and social needs over time.

*Screening will include questions about (a) psychological distress (e.g., anxiety, depression, traumatic stress, isolation), (b) social needs (e.g., financial hardship, homelessness), (c) risky health behaviours (e.g., substance misuse, non-adherence with medical recommendations), (d) safety and adverse experiences (e.g., abuse, neglect, exposure to violence), and (e) resilience factors (e.g., healthy coping, social support, engagement with support services).*

- 8.5.2** Assessment will be offered by mental health professionals to comprehensively define the nature of any difficulties, identify risk and resilience factors, determine a diagnosis (if appropriate), and develop personalised care recommendations. For infants, children, adolescents, and adults with ongoing daily care needs, this should include assessment of their relationship with primary caregivers, as well as the needs of the carers themselves.

- 8.5.3** Screening and assessment findings are routinely documented, openly and empathically discussed with patients, families and carers, communicated (as appropriate) with members of the interdisciplinary care team, and used to directly inform care recommendations.

- 8.6 Patients with CoHD and their families and carers have opportunities to develop personalised, collaborative mental health care plans, shared with their treating team and which highlight their strengths and offer pathways to address risks and difficulties, in accordance with the individual's and family's beliefs, values, goals, and needs.**

*CoHD/ACHD services have clear referral and treatment pathways, including links with local, community-based services and resources, and will provide an equitable model of mental health care across all aspects of the cardiac patient and family continuum of care, inclusive of patients and families of all backgrounds, genders, cultures, languages, and abilities.*

- 8.7 Patients with CoHD and their families and carers have timely and ongoing access to high quality, evidence-based psychological interventions, psychotherapies, and pharmacotherapies throughout the whole-of-life.**

- 8.7.1** Siblings of patients with CoHD will be provided with appropriate support services, including opportunities to share their experiences and express their worries, frustrations, and needs. Families, carers and health professionals will have access to mental health professionals who can advise on ways to anticipate and meet siblings' needs, especially during hospital visits, when siblings are unable to visit the hospital regularly, or when they are cared for by family or friends.

## Standard 8: Mental Health and Psychological Care continued

**8.7.2** End-of-life care for neonates, infants, children, adolescents, and adults with CoHD will be psychologically-informed and must include access to specialised, patient- and family-centred mental health care in addition to specialised palliative care services.

*Bereaved families and carers must have opportunities to process their grief and loss, with ongoing and long-term access to specialised psychological care, social work support, and bereavement services aligned with their cultural, religious, and spiritual beliefs and readiness for support.*

**8.8** Throughout cardiac care, infants, children, adolescents, and adults with CoHD have access to developmentally appropriate play, music and art-based therapies, and opportunities for social interaction, including peer-to-peer connection.

*These opportunities should be facilitated by a mental or allied health professional in collaboration with caregivers and the healthcare team, taking into careful consideration the individual's needs, preferences, age, abilities, and health status. Where possible, these opportunities should take place in an environment designed, staffed, and equipped to meet the child, young person, or adult's needs.*

**8.9** Patients with CoHD/ACHD and their families and carers have access to appropriate social and cultural services and resources.

*Early referral to government and charitable support services including, but not limited to, disability, legal, financial, food, transportation, childcare, educational, employment, housing, and family and parenting services, will be facilitated by specialised social workers and other members of the health care team, as needed.*

**8.10** CoHD/ACHD services ensure their mental health professionals have access to patient medical records and that mental health information is seamlessly integrated into the electronic medical record, as appropriate.

**8.11** CoHD/ACHD services prioritise and cultivate the mental health and wellbeing of its health professionals.

*Burnout, compassion fatigue, moral distress, and poor physical and psychological health are all common among health professionals working in paediatric and adult healthcare settings. Self-care is necessary but insufficient to support the mental health and wellbeing of health professionals. System-level policies and initiatives, co-designed with health professionals, must include regular review of work demands and caseloads, tailored education and skills-based training to promote mental health literacy and professional quality of life, regular opportunities to openly communicate challenges and difficulties, and access to confidential peer and professional support.*

**8.12** Specialist CoHD/ACHD services have an identified mental health lead with responsibility for management of the dedicated cardiac mental health programme.

# Neurodevelopmental Care

## Standard 9

Developmental, behavioural, and psychological difficulties are among the most prevalent consequences of CoHD. As a group, children with complex congenital heart disease<sup>60</sup> are at increased risk of developmental delay, disorders, or disabilities<sup>61</sup> compared to those with simple or no congenital heart disease. This does not mean that “all” patients with complex CoHD have these difficulties (in fact, many do not), but the number of infants, children, adolescents, and adults with complex CoHD and developmental challenges is significantly higher than in the general population. These difficulties can profoundly affect educational and employment opportunities, relationships, physical and mental health, and overall quality of life. A significant proportion of children with complex CoHD require specialised habilitative services, supportive therapies, and educational supports into adulthood. Early identification and intervention for developmental concerns are critical to the wellbeing of children with CoHD and the responsibility of health professionals as an integral function of healthcare.<sup>60</sup>

**Access to individualised, patient- and family-centred neurodevelopmental care is essential for patients with CoHD throughout the whole-of-life. Comprehensive and coordinated developmental surveillance, screening, evaluation, re-evaluation, interventions, therapies, and ongoing management must be integrated into routine CoHD care, be equitable and inclusive, and emphasise early initiation of evidence-based therapies to support infants, children, adolescents, and adults with CoHD in reaching their full potential. There must also be recognition that a person’s level of neurodevelopmental risk or neurocognitive functioning can change over time, thus continued monitoring is critically important.**

*(1) Surveillance is “the process of recognising children who may be at risk for developmental delay”; (2) Screening is “the use of standardised tools to identify and refine that recognised risk”; and (3) Evaluation is a complex process to identify specific developmental delays, disorders, or disabilities that affect an individual.<sup>61</sup>*

‘Developmental disorder’ and ‘developmental disability’ refer to “a childhood mental or physical impairment or combination of mental and physical impairments that result in substantial functional limitations in major life activities”<sup>62</sup>

## Standard 9: Neurodevelopmental Care continued

**9.1 From the time of diagnosis, and throughout the whole-of-life, patients with CoHD and their families and carers must have access to high quality, up-to-date information and education on neurodevelopment and neurocognitive functioning, tailored to their heart condition and provided in formats that are culturally, linguistically, and developmentally appropriate, and in accordance with trauma-informed care.**

**9.2 During hospitalisation, all patients with CoHD will receive individualised, evidence-based, patient- and family-centred developmental care to minimise the stress of the hospital setting, support child-parent and sibling-sibling bonding and attachment, and provide an optimal environment for brain development.**

*An individualised approach must be taken toward all caregiving interactions, with continual responsiveness to each infant or child's individual competencies, vulnerabilities, and thresholds, with the goal of promoting development and autonomic, motor, and state organisation through positive touch, holding, skin-to-skin contact, positioning, sleeping, settling, pain management, feeding, and appropriate sensory stimulation. Parents are encouraged to have maximum involvement in decision-making for their child and are supported to engage in cue-based cares, cuddles, skin-to-skin contact, settling, feeding, or bathing, as well as talking, reading, and singing to their child. Parents are also supported to make decisions regarding their presence or involvement during their child's procedures or resuscitative interventions.*

**9.3 Inpatient CoHD services will include regular developmental rounds to support early identification of patients at risk of developmental delay or disorder, provide anticipatory guidance, promote family engagement, facilitate a coordinated and efficient approach to interdisciplinary care, and provide a model of developmental care training for all clinical staff.**

**9.4 All patients with CoHD have access to periodic, age-specific, developmental surveillance and formal screening using standardised, reliable, and valid developmental screening instruments.**

*Prompt and accurate identification of, and response to, developmental delay or disorder is essential in the comprehensive care of children.<sup>61</sup>*

**9.4.1** Formal screening involves administration of standardised, age-appropriate, developmental screening instruments at regular intervals throughout infancy and childhood, and for relevant adult patients. Developmental concerns elicited on surveillance at any age should be followed by standardised developmental screening or direct referral for formal evaluation or intervention and specialty medical and developmental care.

**9.5 All patients with CoHD at high risk for developmental delay or disorder must be referred for and have access to standardised, age-specific developmental and medical evaluation and re-evaluation over time.**

## Standard 9: Neurodevelopmental Care continued

*Patients with CoHD who are at high risk for developmental delay or disorder (as specified in the introductory section) undergo periodic, formal developmental and medical evaluation beginning in early infancy and repeated at age 12-18 months, 3-5 years, 11-12 years, and 15-17 years, as well as after transition to adult care and at any time that developmental concerns are identified, to ensure optimal interventions, therapies, supports, and outcomes.*

**9.5.1** Performance-based neurodevelopmental testing must encompass all the major domains of age-relevant functioning.

**9.6** All adults with CoHD who are at high risk for neurocognitive disorder must have access to standardised, performance-based neuropsychological evaluation and re-evaluation over time.

**9.7** All infants, children, adolescents, and adults with CoHD and developmental delay or disorder must have access to individualised, evidence-based interventions, therapies, supports, and services, including specialised habilitative, special education, and disability services.

*This includes access to appropriate supports and services during times of developmental, educational, and occupational transition, provided by professionals with training and experience working with patients with CoHD and their families.*

**9.8** All patients with CoHD will have access to a coordinated model of care, including individualised care plans developed through partnership and co-management between primary care providers, specialists, the patient with CoHD, their family and carers, to implement a specific, shared management plan as an organised team.

**9.9** Patients with CoHD and developmental delay, disorder, or disability, their families and carers, should have access to social and financial services and resources, as needed.

*Early referral to governmental and charitable support services including, but not limited to, childcare, educational, disability, legal, financial, food, transportation, employment, housing, parenting and early intervention services, and the National Disability Insurance Scheme (NDIS), will be facilitated by developmental specialists, social workers, and other members of the health care team, as needed.*

**9.10** The CoHD service must include, or directly partner with, specialised capabilities in the provision of lesion specific information, education, screening, evaluation, interventions and therapies, and excellence in individualised developmental or neurocognitive care for patients with CoHD throughout the whole-of-life.

*Because patients with CoHD can manifest difficulties in multiple areas of neurodevelopment, evaluations require an interdisciplinary team approach. The composition of the team should be tailored to best address the individual*

## Standard 9: Neurodevelopmental Care continued

*needs of the patient and their caregivers and include health professionals with expertise in genetics, neurology, developmental paediatrics, neuroimaging, psychology, and pharmacotherapy, as well as developmental professionals in speech and language therapy, physiotherapy, occupational therapy, and child life therapy, and a range of community and educational services. Education specialists play an important role in coordinating educational and outreach services and assisting to maximise school (or educational) support.*

**9.11 Magnetic resonance imaging (MRI) is the imaging modality of choice for the detection of neonatal brain injury, including stroke in congenital heart disease at the time of publication of these CoHD Standards. Consideration should be given to performing MRI both pre-operatively and post-operatively in neonates with congenital heart disease requiring surgery, for the highest yield in detecting brain injury including stroke.**

**9.11.1** In preterm infants (<37 weeks gestation at birth), routine cranial ultrasound may supplement MRI for detection of intraventricular haemorrhage.

**9.11.2** If neuroimaging is indicated in congenital heart disease, and where MRI is contraindicated (e.g. extracorporeal life support), CT and ultrasound should be undertaken in place of MRI.

**9.11.3** An individual approach to the care of patients with congenital heart disease and neurological signs should be additional to background recommendations and there should be a low threshold for neurology input throughout the whole-of-life.

# Care for Priority Populations

## Standard 10

Priority populations include Aboriginal and Torres Strait Islander children and adults, those with refugee backgrounds,<sup>63</sup> and patients, families and carers (inclusive of children and adults) living in disadvantage with limitations in access to health care services. CoHD/ACHD care should recognise these factors and evolve a culturally respectful, compassionate, responsive approach, to ensure equitable access to healthcare services, and optimal cultural, social and environmental support. Flexible interdisciplinary strength-based frameworks should be developed that are grounded in patient empowerment, and allow for adapted services that deliver care most effectively.

- 10.1 Protocols are developed by CoHD and ACHD services to identify the needs of, and improve CoHD and ACHD care delivery to infants, children, adults, families and carers from priority populations, Aboriginal and Torres Strait Islander people, and refugee backgrounds.**<sup>18, 64–66</sup>
  - 10.1.1 Protocols are developed in conjunction with National, State, Territory and regional authorities and representatives from priority populations and Aboriginal and Torres Strait Islander communities, including patients, families and carers.
  - 10.1.2 Protocols identify and provide solutions to provide equitable access to services.
  - 10.1.3 Protocols consider the impact of social, relocation and intergenerational trauma.
  - 10.1.4 Protocols provide specific prioritised triage, assessment and management pathways.
  - 10.1.5 Protocols are sensitive to the cultural and social requirements of priority populations.
- 10.2 A healing strength-based approach is used. Frameworks are grounded in patient empowerment and an openness to do things differently.**<sup>18</sup>
  - 10.2.1 Environmental health assessments are a central part of care.<sup>18</sup>
- 10.3 For families with limited English proficiency, professional interpreters are used for all consultations to ensure equitable health communication and health education.**<sup>67</sup>
  - 10.3.1 Care protocols and service planning for patients and families from culturally and linguistically diverse (CALD) backgrounds with CoHD centres around their participation as equal partners in treatment and management and ensure equitable health communication, health education and health literacy.<sup>68</sup>
  - 10.3.2 Information is communicated through professional interpreters (when applicable) with relevant and culturally appropriate written, verbal, and audio-visual materials.<sup>67</sup>

## Standard 10: Care for Priority Populations continued

**10.3.3** Information is understandable for the child, adolescent, adult, family and carers in a way that is culturally sensitive and offered with appropriate support.

**10.4** Development of care protocols incorporates specific considerations of safety when appropriate.<sup>14,29,55</sup>

# Research

## Standard 11

The national CoHD research goals are directed toward discovery, translation of evidence into practice, reducing the burden of disease, and improving outcomes and the delivery of care for patients of all ages with CoHD and their families and carers.

CoHD research facilitates clinical and academic links among and between institutions. Scientists and researchers of all backgrounds can collaborate with and deliver improved outcomes through connections and planning with clinical staff, patients and families.

**11.1 CoHD research in Australia is supported by a sustainable funding stream secured at the National level.**

**11.1.1** CoHD research should focus on understanding the causes, triggers and mechanisms of disease, and optimising outcomes for patients. This is achieved through multidisciplinary research and translation at all stages of care, from initial diagnosis and counselling, through interventions, and towards optimised life-long wellbeing and health economic and societal benefit.

**11.1.2** Barriers to, and enablers of, high quality collaborative research should be identified and addressed.

**11.2 Research in CoHD encompasses a whole-of-life approach, from fetal life to death, from bench to patient, and is inclusive of the spectrum of basic, health and medical research disciplines. It includes genetic considerations, quality of life, measures of mental health, neurodevelopment and neurocognitive function, social health and the outcomes of specific interventions.**

**11.2.1** Patient, family and carer engagement should be actively sought.

**11.2.2** These data, systematically collected, will offer the potential for data linkage and research to enhance health outcomes, educational outcomes, resource allocation, social services use, and to inform policy change.

# Health Information and Digital Communication Technology

## Standard 12

Continuing improvements in health information and digital communication technology combined with the rapid increase in health data informs and enables high quality, safe healthcare. The use of improved and accessible electronic health records, My Health Record applications, surveillance approaches, including disease and intervention-specific registries and other digital health measures all support the essential ongoing, systematic collection, analysis and interpretation of health-related data that is essential to the planning, implementation, and evaluation of health practice.

**12.1 Telehealth CoHD and ACHD services develop and adopt protocols and implement workforce and infrastructure to deliver telehealth services. These services particularly, but not exclusively, respond to the geographical demands of a regional population.**

- 12.1.1 Telehealth takes place in collaboration with, and supported by area health services, State and Federal Health authorities, and with input from patients, families and carers affected by CoHD with the objective of providing seamless delivery of care, where appropriate.<sup>69</sup>
- 12.1.2 Telehealth is to be considered a basic, integrated infrastructure and workforce requirement for CoHD services and ACHD services.<sup>5</sup>
- 12.1.3 Workforce implications are considered and supported with implementation of these services.
- 12.1.4 Telehealth is prioritised for patients, families and carers who are dislocated / separated from family and /or lands, to have regular communication with family, carers and healthcare providers locally.
- 12.1.5 CoHD-specific health information delivered through digital technologies enables patients, families and carers, regardless of their geographical location, to access, understand and use health information to benefit their health.
- 12.1.6 Telehealth protocols are developed and implemented for upskilling of regional and local health services to facilitate assessment and investigation of CoHD and ACHD where possible.<sup>69</sup>
- 12.1.7 Telehealth protocols take place in collaboration with, and supported by area health services, State and Federal Health authorities, and with input from patients and families affected by CoHD with the objective of providing seamless delivery of care, where appropriate.
- 12.1.8 Appropriate funding strategies are implemented through State and Federal Governments and health services and Medicare to support CoHD and ACHD telehealth.

**12.2 A complete medical record should be maintained by all Services for all patient contacts and across all disciplines within the multidisciplinary team.**

## Standard 12: Health Information and Digital Communication Technology continued

**12.2.1** Health jurisdictions and governing bodies managing area health services should ensure that the relevant electronic medical record provides rapid access to easily identifiable CoHD data, and allows for data entry of records by all members of the multidisciplinary service within institutions, such as hospitals and community based health services.

*This provides for the right information to be available at the right time and to the right healthcare and/or service providers.*

**12.3 Large scale, secure, cloud-based data transfer capabilities for large data volumes between CoHD and ACHD within and outside of each State are provided.**

Protocols are developed and implemented for upskilling of regional and local health services to facilitate assessment and investigation of CoHD and ACHD where possible.<sup>62</sup>

**12.3.1** Data transfer capabilities support transfer of patient data and investigations including CT scans, MRI scans and echocardiographic studies in uncompressed original format directly required for timely patient care.

**12.3.2** Data transfer is accessible within and outside institutions (for approved personnel) for externally accessible and secure.

**12.4 A National, cross-jurisdictional, combined CoHD and ACHD Database (Registry) for both day-to-day patient management, transition management, quality assurance activities, and verified research into CoHD is implemented and maintained (by 2025).**

*\*A CoHD Database would include patient registries to collect information on disease- and intervention-specific outcomes, as well as clinical quality registries to monitor the quality of healthcare.*

**12.4.1** The CoHD Database is designed to secure and deliver excellence in patient care.

**12.4.2** The CoHD Database incorporates stratified consent, security, and access, and is maintained centrally.

**12.4.3** The COHD Database provides information to assist with governance and quality assurance activities, including procedural performance.

**12.4.4** The CoHD Database is managed collaboratively with centralised IT support and management.

# Appendices

## Appendix A: CoHD Standards Steering Committee Members

### CoHD Standards Steering Committee

**A/Prof Gary Sholler AM<sup>1,2,3</sup>** MBBS, FRACP, FCSANZ, FACC  
*Paediatric & Fetal Cardiology & Project Co-Chair*

**Dr Lisa Selbie<sup>4,5</sup>** PhD  
*HeartKids Research Advisory Committee Chair & Project Co-Chair*

**A/Prof Luke Burchill<sup>6,7</sup>** MBBS, PhD, FRACP  
*ACHD Cardiology*

**Prof Michael Cheung<sup>8</sup>** BSc, MBChB, MRCP, MD, FRACP  
*Paediatric Cardiology, Chair Paediatric Council CSANZ*

**Ms Shakira Donovan<sup>9</sup>** BSc (Psych)  
*Patient/Family/Carer Representative from the CoHD Community*

**Ms Caitlin Elliott<sup>10</sup>** NPC, RN, MANP(NP), PgD, BNS  
*Nursing*

**Ms Fiona Ellis<sup>4</sup>** BA, MTourMgt  
*HeartKids CEO*

**Prof Nadine Kasparian<sup>11,10</sup>** PhD, MAPS  
*Psychology, Neurodevelopment and Allied Health*

**Ms Jessica Keating<sup>4</sup>** RN, MHA, MPH  
*HeartKids Action Plan Project Manager*

**Ms Kristie Molloy<sup>11</sup>** LLB/LP, BSc (Psych)  
*Patient/Family/Carer Representative from the CoHD Community*

**Dr Mary Tallon<sup>4,12</sup>** RN, RM, MScN, PhD  
*HeartKids Project Coordinator*

**A/Prof Prem Venugopal<sup>13</sup>** MBBS MS FRACS (CTH)  
*Paediatric Cardiac Surgery*

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#### Affiliations

1 Sydney Children's Hospitals Network, NSW

2 Heart Centre for Children, Westmead, NSW

3 The University of Sydney, Camperdown, NSW.

4 HeartKids Ltd, Parramatta, NSW

5 School of Biotechnology & Biomolecular Sciences UNSW, Advanced Academic Program in Biotechnology, Johns Hopkins University, Maryland, USA

6 The Royal Melbourne Hospital, Parkville, VIC

7 The University of Melbourne, Parkville, VIC

8 The Royal Children's Hospital, Parkville, VIC

9 The University of Notre Dame, Fremantle, WA

10 Heart Institute and Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital, OH, USA

11 College of Business, Government and Law, Flinders University, Adelaide, SA

12 School of Nursing, Curtin University, Bentley, WA.

13 Queensland Paediatric Cardiac Services, Children's Health Queensland Hospital and Health Service, South Brisbane, QLD

## Appendix B: CoHD Standards Advisory Committee and Working Group Chairs

### CoHD Standards Advisory Committee / Working Group (WG) Chairs and invited WG Members

Name	Qualification	Speciality	Working Group/s*
A/Prof Nelson Alphonso <sup>5,16</sup>	MBBS, FRACS, FRCSI	Paediatric Cardiac Surgery, QLD	Cardiac Surgery, Research
Dr David Ray Andrews <sup>1, 33</sup>	MBBS, FRACS, FCSANZ	Paediatric Cardiac Surgery, WA	Cardiac Surgery, Adult CHD
Dr Julian Ayer <sup>8, 13</sup>	MBBS, FRACP, PhD	Paediatric Cardiology, NSW	Co-Chair Research, Transition, Regional
Dr Julia Baezinger <sup>8, 13, 44, 45</sup>	MSc Psychology, PhD Health Sciences, Grad Dip in Pub Hlth	Clinical Psychology, NSW	Mental Health, Neurodevelopmental Care
Prof Nadia Badawi AM <sup>8, 13</sup>	MBBCh (Hons I) DCH MSc PhD FRCPI FRACP	Neonatology, NSW	Mental Health, Neurodevelopmental Care
Dr David Baker <sup>13, 14</sup> Ms Charlotte Barr <sup>1</sup>	MBBS, FRACP BPhysio, PGCert Paed Phys, MPhysio	ACHD Cardiology, NSW Physiotherapy, VIC	Transition Mental Health, Neurodevelopmental Care, Cardiac Surgery
Mr Daniel Beard <sup>3</sup>	Cert Media and Comms	Patient / Family representative, WA	Consumer (Patient/Family/ Carer representative from CoHD Community)
Prof Christian Brizard <sup>1, 10</sup>	MS, MD	Paediatric Cardiac Surgery, VIC	Advisory Committee Member
Dr Andrew Bullock <sup>11, 33</sup>	MBBS	Paediatric and ACHD Cardiology, WA	Advisory Committee Member
Prof David Stephen Celermajer AO <sup>8, 13, 14, 32</sup>	MBBS (Hons), MSc (Oxon), PhD (London), DSc (Sydney), FAA, FAAHMS, FRACP, FCSANZ, FAHA, FHKCC (Hon)	ACHD Cardiology, NSW	ACHD
Ms May M Chan <sup>1</sup>	RN BNurs, Science Post Grad. Peri Operative	Intraoperative Nursing, VIC	Cardiac Surgery
Dr Julia Charlton <sup>1, 2, 10, 48</sup>	MBBS, FRACP, Grad Dip Mental Health Sc, PhD	Neonatology, VIC	Mental Health, Neurodevelopmental Care
Ms Emily Chapman <sup>8</sup> Clinical A/Prof Sarah Cherian <sup>11, 35, 36</sup>	BNurse, MAdvN MBBS(Hons) FRACP PhD	Nursing, NSW Paediatric Refugee Health, WA	Transition Priority Populations
Prof Michael Cheung <sup>1, 2, 10</sup>	BSc MBChB MD FRCP(UK) FRACP	Paediatric Cardiology, VIC	Chair Large Centres, Small Centres, Regional, Cardiology, Cardiac Surgery, ACHD
Ms Beth Chidlow <sup>11</sup>	BSc Nursing, MN (Nurse Prac)	Nursing, WA	Advisory Committee Member
A/Prof Rachael Cordina <sup>13, 14</sup>	MBBS PhD	ACHD Cardiology, NSW	Deputy Chair Adult CHD, Mental Health, Neurodevelopmental Care, Cardiology
Ms Evelyn Culhane <sup>1</sup> Ms Shakira Donovan <sup>3, 49</sup>	BEd Hon BPysch	Nursing, VIC Patient / Family representative, WA	Chair Transition Chair Consumer (Patient/ Family/Carer representative from CoHD Community)
Mrs Marjorie Doyle <sup>3</sup>	Post Grad Cert Community Welfare	Patient / Family representative, VIC	Priority Populations Consumer (Patient/Family/ Carer representative from CoHD Community)
Ms Karen Eagleson <sup>4, 5, 16</sup>	RN MHSt	Nursing, QLD	Mental Health, Neurodevelopmental Care, Nursing, Research
Dr Lucas Jon Eastaugh <sup>1, 2</sup>	MBBS FRACP FCSANZ	Paediatric Cardiology, VIC	Deputy Chair Cardiology, Regional ACHD
Ms Caitlin Elliott <sup>1</sup>	NP, RN, MANP(NP), PgD, BNS	Nursing, VIC	Chair Nursing

Miss Mia Evangelellis	BEEd	Patient / Family representative, WA	Consumer (Patient/Family/ Carer representative from CoHD Community)
Ms Erin Ferguson <sup>46</sup>	BNurs	Nursing, Regional QLD	Nursing, Regional, Priority Populations
Prof Marino Festa <sup>8</sup>	MBBS MRCP(UK) FCICM MD(Res)	Paediatric Intensive Care, NSW	Large Centres
Mrs Annabel (Kirsten) Finucane <sup>7,39</sup>	MBChB FRACS General Surgery FRACS Cardiac Surgery	Paediatric Cardiac Surgery, NZ	Cardiac Surgery
Prof Jeffrey Fletcher <sup>28,29</sup>	BSc (Hons) MBBS DCH FRACP PhD	Paediatric Nephrology, Regional NSW	Deputy Chair Regional, Research
Dr Tom Gentles <sup>7,42</sup>	BHB, MB ChB, DCH, FRACP, FCSANZ	Paediatric Cardiology, NZ	Cardiology
Ms Kate Harley <sup>1</sup>	BNurs	Nursing, VIC	Nursing
Ms Rebecca Henderson <sup>8</sup>	MBA	Cardiac Research, NSW	Mental Health, Neurodevelopmental Care
A/Prof Christine Jeffries-Stokes <sup>37,38</sup>	MBBS, B Med Sc, MPH, FRACP, PhD	Paediatrics, Regional WA	Priority Populations, Regional
A/Prof Rob Justo <sup>4,5,16</sup>	MBBS FRACP FCSANZ	Paediatric Cardiology, QLD	Chair Cardiology, Regional, Priority Populations, Mental Health, Neurodevelopmental Care
Prof Nadine Kasparian <sup>17,44</sup>	BA Psych (Hons I), PhD, MAPS	Psychology, Neurodevelopment, Allied Health, NSW & USA	Chair Mental Health, Neurodevelopmental Care, Research
Dr Andrew Kelly <sup>9</sup>	MBBS DCH(Adel.) FRACP FCSANZ	Paediatric Cardiology, SA	Deputy Chair Small Centres
Prof Igor Konstantinov <sup>1,10</sup>	MD, PhD, FRACS	Paediatric Cardiac Surgery, VIC	Cardiac Surgery, Research
Ms Karen LeClair <sup>8</sup>	RN MN	Nursing, NSW	Mental Health, Neurodevelopmental Care, Nursing, Transition
Dr Suzanne Long <sup>3</sup>	BPhysio(Hons), PhD	HeartKids, Allied Health, VIC	Mental Health, Neurodevelopmental Care
Ms Rachel Maree <sup>47</sup>	BA	Patient / Family representation, QLD	Consumer (Patient/Family/ Carer representative from CoHD Community), Mental Health, Neurodevelopmental Care
Dr Fiona MacFarlane <sup>4</sup>	MD, ANZCA	Paediatric Anaesthetics, QLD	Cardiac Surgery
Ms Ros Marsden	BA	Patient / Family representation, VIC	Mental Health, Neurodevelopmental Care
Mr Jonathan Mackley	M Comm	Patient/Family representation, NSW	Consumer (Patient/Family/ Carer Representative from CoHD Community)
Dr Jacob Matthew <sup>1,2,10</sup>	MBBS FRACP	ACHD Cardiology, VIC	Cardiology
Ms Kenya McAdam <sup>27</sup>	Cert II Business	ATSI Patient / Family representation, NT	Priority Populations
Mr Patrick McConville <sup>3,47</sup>	BA (Hons), MBioethics	Patient / Family representation, VIC	Mental Health, Neurodevelopmental Care, Consumer (Patient/Family/ Carer representative from CoHD Community)

Ms Lindsay Meltz <sup>8</sup>	BNurse MNurse	Nursing, NSW	Regional
Dr Johnny Millar <sup>1,2,10</sup>	MChB, PhD	Paediatric ICU	Large Centres
Ms Kristie Molloy <sup>50</sup>	LLB/LP, BSc (Psych)	Patient / Family representation, SA	Consumer (Patient/Family/Carer representative from CoHD Community)
Ms Gemma Moon <sup>29</sup>	BNurse, CNS Mental Health	Patient / Family representation, NSW	Mental Health, Neurodevelopmental Care
Ms Katherine Morlidge <sup>11</sup>	BSc Nursing(Hons), Grad Cert Child/Adolescent Health Nursing), Dip Child Nursing	Nursing, WA	Nursing
Ms Dominique Morsman <sup>1</sup>	RN, BNurs, Post Grad Dip Cardiac Care, Post Grad Cert Paed, Intensive Care	Nursing	Deputy Chair Nursing
Dr Jim Morwood <sup>4</sup>	MBBS, FRACP, FCSANZ	Paediatric Cardiology, QLD	Cardiology
A/Prof Mugur Nicolae <sup>5,16</sup>	MD FRACP FRCPC FCSANZ	ACHD Cardiology, QLD	Chair Adult CHD, Cardiology, Research, Cardiac Surgery
Mr Killian O'Shaughnessy <sup>8</sup>	CCP(Aust)	Paediatric Perfusion, NSW	Cardiac Surgery
Ms Diane Oake <sup>8</sup>	BA(Hons) Psych., MPsych	Clinical Psychology, NSW	Mental Health, Neurodevelopmental Care
Dr Yishay Orr <sup>8,40</sup>	MBBS BSc(med) Hon PhD FRACS	Paediatric Cardiology, NSW	Deputy Chair Large Centres, Cardiac Surgery
Ms Jennifer Orchard <sup>4</sup>	RN, BHScience (Nurs), M Hlth Prac in Child Hlth	Nursing, QLD	Cardiac Surgery
A/Prof Georgia Paxton <sup>1,10</sup>		Paediatric Refugee Health, VIC	Priority Populations
Ms Shelley Paine <sup>4</sup>	Bachelor of Nursing, Grad Dip Nursing	Nursing, QLD	Nursing, Transition, Regional
Ms Elle Pendrick <sup>3</sup>	BA MIH	Patient / Family representation, Regional NSW	Deputy Chair (Patient/Family/Carer representative from CoHD Community), Regional, Mental Health, Neurodevelopmental Care
Dr Madeleine Pidcock <sup>8,17</sup>	BSc(Psych) Hons I, PhD (Clinical Psych)	Clinical Psychology, NSW	Mental Health, Neurodevelopmental Care
Dr Nick Piggot <sup>8</sup>	MB BS	Paediatric ICU, QLD	Large Centres
A/Prof Enzo Porello <sup>2,10</sup>	PhD	Medical Research, VIC	Research
Ms Tania Quinn <sup>8</sup>	Aboriginal and Torres Strait Islander Health Worker	Aboriginal Health representation, Palliative Care & Chronic and Complex Needs	Mental Health, Neurodevelopmental Care

Dr James Ramsay <sup>11</sup>	MBBS	Paediatric Cardiology, WA	Chair Small Centres, Cardiology, Regional, Priority Populations
Dr Benjamin Reeves <sup>43</sup>	MBBS FRACP	Paediatric Cardiology, Regional QLD	Regional, Priority Populations
Dr Bo Reményi <sup>22,23</sup>	MBBS	Paediatric Cardiology, NT	Chair Priority Populations, Regional, Cardiology
Ms Sonia Riley <sup>4</sup>	BOccThy (Hons)	Occupational Therapy, QLD	Mental Health, Neurodevelopmental Care
Dr Cameron Seaman <sup>11</sup>	MBBS FRACP	Paediatric Cardiology, WA	Small Centres
Dr Megan C Sherwood <sup>8</sup>	MBBS FRACP FCSANZ	Paediatric Cardiology, NSW	Cardiology
Prof Jon Skinner <sup>7,8</sup>	MD	Paediatric Cardiology, NSW	Research
Ms Jessica Suna <sup>5,28</sup>	BNurse, BAS, GradCert Clinical Trial Management, MHSc (Research)	Research, QLD	Research
A/Prof Prem Venugopal <sup>1,5</sup>	MBBS, FRCS(CTh), FRACS	Paediatric Cardiac Surgery, QLD	Chair Cardiac Surgery, Cardiology, Large Centres, Small Centres, Adult CHD
Ms Michelle Vink <sup>9</sup>	RN, BNurse, Post Grad Dip Advanced clin nurs	Nursing, SA	Nursing
Ms Vicki Wade <sup>27</sup>	MSc (Nursing) MPH	RHD Australia, NT	Priority Populations
Ms Lynette Ward <sup>8</sup>	Bach App Sc (OccThy)	Occupational Therapy, NSW	Mental Health, Neurodevelopmental Care
Ms Karen Weir <sup>8</sup>	BTch(0-5)	Child Life Therapist, NSW	Mental Health, Neurodevelopmental Care
Prof Robert Weintraub <sup>1,2,10</sup>	MBBS (Hons) FRACP FACC FCSANZ	Paediatric Cardiology, VIC	Chair Research
Dr Gavin Wheaton <sup>9,26</sup>	MBBS FRACP FCSANZ	Paediatric Cardiology, SA	Chair Regional, Transition, Priority Populations, Cardiology
Mrs Holly Williams <sup>3</sup>	B Eng	HeartKids & Patient / Family representation, QLD	Transition, Mental Health, Neurodevelopmental Care, Consumer (Patient/Family/Carer representative from CoHD Community)
Ms Carlie Willock <sup>3</sup>	BNScience	Patient / Family representation, Regional QLD	Consumer (Patient/Family/Carer representative from CoHD Community)
Ms Laura Yeates <sup>14,30,31</sup>	BSc(Hons), Grad Dip Gen Couns FHGSA (Genetic Counselling)	Genetic Counselling, NSW	Mental Health, Neurodevelopmental Care, Research
A/Prof Dominica Zentner <sup>10,41</sup>	MBBS(Hons) FRACP PhD	ACHD Cardiology, VIC	Adult CHD

\*Advisory Committee Members who accepted a Working Group Chair role are identified as Chair / Co-Chair / Deputy Chair.

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## Affiliations

1. The Royal Children's Hospital, Parkville, VIC
2. Murdoch Children's Research Institute (MCRI), Parkville, VIC
3. HeartKids Ltd, Parramatta, NSW
4. Queensland Children's Hospital, South Brisbane, QLD
5. The University of Queensland, Herston, QLD
6. National Women's Hospital, Greenlane, NZ
7. Starship Children's Hospital, Greenlane, NZ
8. Sydney Children's Hospital Network, NSW
9. Women's and Children's Hospital, North Adelaide, SA
10. The University of Melbourne, Parkville, VIC
11. Perth Children's Hospital, Nedlands, WA
12. Melbourne's Centre for Cardiovascular Genomics and Regenerative Medicine, MCRI, Parkville, VIC
13. The University of Sydney, Westmead, NSW
14. Royal Prince Alfred Hospital, Camperdown, NSW
15. University of Lucerne, Luzern, Switzerland
16. Queensland Paediatric Cardiac Research, Children's Health Queensland, South Brisbane, QLD
17. University of New South Wales Sydney, Camperdown, NSW
18. Mater Hospital Services, Brisbane, QLD
19. Princess Alexandra Hospital, Brisbane, QLD
20. The Prince Charles Hospital, Chermside, QLD
21. Australian National University, Canberra, ACT
22. Menzies School of Health Research, Charles Darwin University, Darwin, NT
23. Royal Darwin Hospital, Darwin, NT
24. Johns Hopkins University, Maryland USA
25. Royal Brisbane and Women's Hospital, Herston, QLD
26. University of Adelaide, Adelaide, SA
27. Rheumatic Heart Disease (RHD) Australia, Darwin, NT
28. The Tweed Hospital, Tweed Heads, NSW
29. Queensland Paediatric Specialists, Southport, QLD
30. Agnes Ginges Centre for Molecular Cardiology, Centenary Institute, Sydney NSW
31. Clinical Genomics Laboratory, Centre for Population Genomics, The Garvan Institute of Medical Research, Darlinghurst, NSW
32. Heart Research Institute, Sydney, NSW
33. Fiona Stanley Hospital Murdoch, WA
34. Sir Charles Gairdner Hospital Nedlands, WA
35. The University of Western Australia, Perth WA
36. Telethon Kids Institute, Perth, WA
37. Kalgoorlie Hospital, Kalgoorlie, WA
38. Rural Clinical Schools of Western Australia, University of WA,
39. World Society of Pediatric and Congenital Cardiac Surgery (Global)
40. Western Sydney Local Health District (Westmead Hospital), Westmead, NSW
41. The Royal Melbourne Hospital, Parkville, VIC
42. The University of Auckland, Auckland, NZ
43. Heart Rx Cardiology, Cairns North, QLD
44. Cincinnati Children's Hospital, OH, Cincinnati, USA
45. University of Cincinnati College of Medicine, Cincinnati, OH USA
46. Cairns Hospital, Cairns, QLD
47. Australia and New Zealand Fontan Advocacy Committee, AU and NZ
48. Mercy Hospital for Women, Heidelberg, VIC

## Appendix C: Glossary of Terms

**Access to care** is having the timely use of healthcare services to achieve the best health outcomes.

**Acyanotic heart disease** is a form of congenital heart disease where oxygen levels in the body circulation is normal. There is considerable variability in severity from simple (mild) to complex abnormalities. In newborns with some forms of acyanotic, complex congenital heart disease the oxygen levels in the body circulation may be temporarily lower than normal.

**Adult congenital heart disease (ACHD)** is congenital heart disease in adults who have undergone treatment during childhood and have transitioned from paediatric CoHD care. This also includes adults diagnosed with a congenital heart defect in adulthood.

**Advanced Practice Nurse (APN)** Nurses practising at an advanced practice level incorporate professional leadership, education, research and support of systems in their field of health care.

**Cardiac sonographers** Cardiac sonographers (scientific staff dedicated to ultrasound imaging) are specially trained to perform echocardiograms, or ultrasound imaging, to evaluate different aspects of the heart. In the case of CoHD, they have specific experience and training, and this information is then reviewed by a CoHD /ACHD cardiologist.

**Care continuum** is a concept involving an integrated system of care that guides and tracks a patient over time through a comprehensive array of health services.

**Carer** is a person who provides unpaid care and support to a family member or friend who has a health condition or disability.

**Childhood-onset Heart Disease (CoHD)** includes congenital and acquired conditions affecting the heart in childhood. These abnormalities might be detected prior to or after birth. For the majority of patients with onset of an abnormality in childhood this will persist lifelong, with the consequences ranging from trivial to complex and involved.

**Congenital heart disease** is a problem with the structure of the heart, heart valves or heart vessels that is present from birth. Congenital heart disease impacts the functioning of the heart which can be evident at birth or evolve over time. A common abbreviation for congenital heart disease is CHD; this abbreviation has not been used in the CoHD Standards to avoid confusion with childhood heart disease, childhood-onset heart disease and cardiovascular heart disease.

**Consumer engagement** in research means consumers, community members, researchers and research organisations working in partnerships, to improve the health and wellbeing of all Australians through health and medical research.

**Culturally and linguistically diverse (CALD)** is an acronym used to describe the many Australian communities that are originally from another country. The CALD population is defined by the country of origin, language spoken, English proficiency.

**Culture** is the combination of knowledge, beliefs, values and behaviours people and includes personal identification, language, thoughts, communications, actions, customs, beliefs, values, and institutions that are often specific to ethnic, racial, religious, geographic, or social groups.

**Culturally appropriate services** are broadly defined as care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals.

**Cyanosis / cyanotic heart disease** is where the oxygen level in the body circulation is lower than normal, leading to a blue tinge often seen in the skin, mucous membranes, nail beds, etc. There are some abnormalities where oxygen levels are reduced, but not to a level where it is detectable to the eye, and in this situation oxygen sensors (oximeters) can be helpful. Abnormalities with cyanotic heart abnormalities are usually considered complex.

**Disability** is any continuing condition that restricts everyday activities. Disability may relate to physical, intellectual, cognitive, neurological, sensory or psychiatric, impairment or a combination of those impairments which may be ongoing and / or episodic.

**Disparities** in health refer to differences in the burden of disease, injury, and the opportunity to achieve optimal health for people due to social and economic disadvantage. Disparities in health are influenced by social determinants of health including race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location.

**Echocardiography** (or cardiac ultrasound) uses standard two-dimensional, three-dimensional, and Doppler ultrasound to create images of the heart.

**Electrocardiogram** may be abbreviated as ECG, which is a recording of the electrical activity of the heart. Electrocardiography should not be confused with a cardiac ultrasound.

**Evidence-based practice(s)** is the conscious, that health care practices should be based on scientific evidence.

**Family** includes those who are considered to be family by the individual with CoHD and may extend beyond the traditional nuclear and extended family. The term 'patients and families', used throughout this document, refers to the infants, children, adolescents, and adults living with CoHD and their parents, partners and family and carer networks who support them.

**Fetus / fetal heart disease** is heart disease, such as CoHD, which is recognised before birth, resulting in patients requiring a range of unique management plans and services plans.

**Genetics** is the study of how individual genes or groups of genes are involved in health and disease. Genes determine physical characteristics such as gender, blood type, eye colour. Some health conditions and diseases are carried in our genes. Understanding genetic factors and genetic disorders is important for understanding causation, promoting health and preventing disease.

**Healthcare costs** Direct costs are those costs borne by the healthcare system, community, and patients' families in addressing an illness. Indirect costs are mainly productivity losses to society caused by the health problem or disease.

**Health literacy** is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

**Heart murmur** is a sound produced by the heart. This sound may reflect a normal heart or may be characteristic of certain characteristics. Heart murmurs are usually detected with a stethoscope.

**Infrastructure for CoHD** refers to the service and resource requirements needed to deliver quality care for people with CoHD who may have complex health needs and require lifelong care from workforce operating from a range of institutions, both public and private.

**Mental health and wellbeing** can mean different things to different people depending on beliefs, values, perspectives, and experiences. In the CoHD Standards, mental health includes consideration of developmental abilities and emotional, relational, behavioural, cognitive and cultural, aspects.

**Mental health care** in CoHD is defined as integrated, specialised and evidence-based care that focusses on reducing mental health burden and optimising emotional and psychological wellbeing for all those impacted by CoHD and their families. There is emphasis on prevention and early intervention through evidence-based screening, assessment, prevention, intervention and treatment, as part of routine cardiac care.

**Mental health professionals** are members of the mental health team and include psychologists, social workers, child life therapists, occupational and music therapists, and psychiatrists; all with specialised education and formal training and accreditation in their discipline.

**Morbidity** refers to the adverse consequences of having a disease and includes medical problems caused by treatments.

**Multidisciplinary team**, which may be abbreviated as MDT, involves a range of healthcare providers working together to deliver comprehensive patient care. They usually are focussed on specific conditions or groups of conditions, and vary according to patients' needs, patient load, organisational constraints, resources, clinical setting, geographic location, and professional skills.

**Neonate** is a newborn baby in the first 28 days of life. Neonatal care will often continue until the equivalence of term gestation or weight is reached.

**Neurodevelopmental care** is defined as integrated, specialised and evidence-based care to promote and enhance development and prevent or minimise neurodevelopmental or neurocognitive impairment in infants, children, young people, and adults with CoHD. There is an emphasis on early intervention, ongoing surveillance, and specialised intervention, therapies and habilitative services, as indicated.

**Patients and families** 'patients and families', used throughout this document, refers to the infants, children, adolescents, and adults living with CoHD and their parents, partners and the family and carer networks who support them.

**Patient registries** are organised systems that use observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure and that serves predetermined scientific, clinical, or policy purpose(s).

**Peer support** occurs when people provide knowledge, experience, emotional, social, or practical assistance to each other. Peer support is distinct from other forms of social support in that the source of support is a peer; a peer can offer support by virtue of relevant, lived experience.

**Person-centred and family-centred care** is defined as healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that healthcare decisions are respectful of, and responsive to, the preferences, needs and values of patients, and that they have the education and support they need to make decisions and participate in their own care.

**Prevalence** is the proportion of a population which has (or had) a specific characteristic at a given time. In medicine, this is typically proportion of the population that experiences an illness, a condition, or a risk factor.

**Primary healthcare** for most patients is provided by a primary care clinician who will be their first point of contact in the Australian health system. A primary care clinician may be a doctor, dentist, nurse, allied health professional or a pharmacist. This level of care may be provided in a general practice, community, or allied health centre or Aboriginal and Community Controlled Health Services. It may also include health promotion, health education or prevention. Depending on the person's health condition, they may be referred on to secondary or tertiary care.

**Priority populations** are specific groups within our population who also experience disadvantage and reduced health outcomes and include Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse populations who have specific, in particular refugee patients and families, people who live in rural and remote areas.

**Quality of Life** describes individuals' views about their lives in the context of culture, values, expectations, physical functioning, and emotional and social wellbeing.<sup>70</sup>

**Refugee(s)** the term 'refugee' is used to refer to people who have been found to be refugees under the United Nations Refugee Convention and hold an Australian or New Zealand humanitarian visa, and also people of 'refugee-like' background who have entered under other migration streams. 'Refugee-like' acknowledges that people may have had refugee experience in their countries of origin, but do not have formal refugee status.<sup>63</sup>

**Research impact** is the contribution that research makes to the economy, society, environment, or culture, beyond the contribution to academic research.

**Spiritual health** recognises the significance of spirituality and includes belief in a supreme being and / or unity with a greater force. It can include transcendence and actualisation of different dimensions and capacities of human beings.

**Surveillance** is a system of ongoing health checks.

**Telehealth** A telehealth service is a health care activity supported at a distance by information and communication technology service(s). Telehealth services can describe healthcare disciplines such as tele-pathology, support modes of video communication supported by devices and applications and include a range of functions such as direct healthcare, mentoring, specialist opinion, case conferences and / or education.<sup>69</sup>

**Transdisciplinary** describes collaboration that extends beyond the disciplinary boundaries of the multidisciplinary team integrating theoretical knowledge from the health, natural and social sciences to advance approaches to care.<sup>71</sup>

**Transition** refers to planning, coordinating and implementing continuity of healthcare from one healthcare service / setting to another. Transition of care also refers to transitions between home and hospital, and other transitions related to development such as home to school. Transition encompasses clinical aspects as well as the experiences, views and needs of patients and families.<sup>37</sup>

**Trauma-informed care** is a framework for healthcare service delivery that is based on knowledge and understanding that traumatic experiences influence physiology and recognises the signs and symptoms of trauma in patients, families and colleagues. Trauma informed care integrates knowledge and about trauma into healthcare and focusses on avoiding re-traumatisation.<sup>18</sup>

## Appendix D: Childhood-onset Heart Disease

### Childhood-onset Heart Disease (CoHD)

Childhood-onset Heart Disease (CoHD) is a general term for a range of cardiac conditions that affects infants, children, adolescents, and adults who experience ongoing impact throughout their life. CoHD includes both congenital and acquired heart disease of childhood.<sup>73</sup> Congenital heart disease predominantly refers to structural lesions involving the heart tissues or valves. In some classifications, spontaneous arrhythmia, myopathies, and genetically mediated functional abnormalities of the heart, or primary pulmonary hypertension will be included under congenital heart disease; though these may also be considered independently as abnormalities with onset in childhood.<sup>3</sup>

Acquired heart disease with onset in childhood is included under the term CoHD, and consists of, but not exclusively, myocarditis, Rheumatic carditis, Kawasaki Disease, and cardiac disease which occurs as a complication secondary to chronic paediatric diseases or medical therapy.<sup>72</sup>

### CoHD Prevalence

Congenital heart disease is the most common type of birth defect<sup>73</sup> and is a leading cause of hospitalisations and death of Australian babies.<sup>74,75</sup> About half of all babies born with congenital heart disease will require surgical or interventional procedures at some stage of their lives, while one third will require surgical intervention in their first year.<sup>76</sup> The combined prevalence of congenital and acquired forms of CoHD in Australia represents a significant burden on the health and wellbeing of children and their families with the number of Australians (newborn to adult) living with CoHD estimated to be far greater than estimated 65,000 with congenital heart disease.<sup>1</sup> Currently, the large and growing population of adults living with CoHD outnumber children with the disease.<sup>73</sup>

Aboriginal and Torres Strait Islander peoples continue to be disproportionately impacted by CoHD, and experience higher incidences of congenital and acquired heart disease and a higher infant mortality.<sup>77</sup>

### CoHD Spectrum of Severity

CoHD is a chronic condition with no cure that for many patients requires complex, specialised care across the life course. CoHD exhibits a spectrum of structural and functional severity at first recognition, may evolve and change, and carries a risk of ongoing functional abnormality and complications in some patients.<sup>3</sup>

There are three common functional domains of interest for CoHD, with a fourth domain related to causation.

#### (1) Structure

There is no universally accepted categorisation of severity; however, a common characterisation is mild (simple), moderate and complex abnormality. This principally relates to the physical characteristics of the heart abnormality.

#### (2) Function

The functional implications of CoHD should be considered separately, and range from no

functional impact to significant interference with heart function and efficiency; metrics range from determining the impact on day-to-day activities to objective assessments of function such as formal exercise testing.

### (3) Complications

Complications of a heart abnormality relate to the nature of the abnormality, how it has been managed (including surgery), and the natural behaviour of the abnormality over time. This is best considered on a case by case basis.

### (4) Causation

The causes of CoHD are not completely understood but may have impacts on the timing and manifestations of abnormality. Genetic research has advanced considerably in the last 15 years (to the time of the initial publications of the Standards), and genetic factors can be recognised in up to a third of congenital heart disease, and more frequently in some myopathies and arrhythmias.<sup>75</sup>

Children with **mild (simple) congenital heart disease** often require no intervention whatsoever and are very unlikely to suffer adverse impact from their cardiac abnormality. Depending on the abnormality there may be a small risk of complications over time. These patients are likely to require ongoing, but often infrequent surveillance through life.

Children with **moderate congenital heart disease** are likely to require some form of intervention and may require one or sometimes more than one surgical or catheter intervention to improve heart function. Depending on the abnormality there may be varying risk of complications over time. In some cases, the repair / intervention itself produces changes in the heart that may require focussed consideration. These patients require surveillance tailored to their abnormalities throughout life.

Children with **complex congenital heart disease** will have an abnormality requiring surgical or catheter intervention in the newborn period and/or first year of life or may require multiple procedures in a programme of staged procedures or may have significant functional cardiac impairment from their abnormality or it's surgical or catheter management. These abnormalities may include cyanotic congenital heart disease (conditions where the oxygen level in the body circulation is lower than normal) and some forms of acyanotic heart disease (conditions with circulations able to produce normal oxygen levels, but sufficiently complex to require early interventions). Functional impact may persist after interventions, and loss of life occurs more frequently in this group of patients. These patients and their carers have the highest risk of medical complications, and have the highest requirements for medical, nursing, psychological, neurodevelopmental and social surveillance and support. Regular and sometimes frequent surveillance with be needed through life.<sup>62</sup>

Functional impact of heart abnormality varies widely, with focus placed on the degree to which an abnormality of the heart alters day to day heart function compared with a normal heart. Functional impact often forms the dominant consideration in care planning and may be associated with symptoms of heart abnormality. Variations in heart function from normal may not be apparent yet be important in anticipating / avoiding future health difficulties. This forms an important basis for surveillance. For some patients there may be little or no impact throughout life, whilst for others, some

limitations in physical activity and performance may need to be considered. This is best individualised. For most patients a close to full range of physical activity should be encouraged, in adults, commonly used functional categories such as the New York Heart Association Classification<sup>78</sup> can be used to classify the degree of overt functional impact, however in babies and children these manifestations need to be age-adapted.<sup>60,61</sup>

The spectrum of CoHD complications is influenced by specifics of the heart abnormality, the type of repair / intervention that has taken place, heart function and the natural evolution of specific abnormalities (and repaired abnormalities) over time. Complications may relate directly to the heart, however, may also have significant impact on many aspects of health. Children with complex CoHD are at increased risk of neurodevelopmental problems following cardiac surgery in infancy and childhood. Quality of life can be impacted with implications for the emotional and developmental wellbeing of the whole family that can have far reaching effects through the lifetime.<sup>20,79,80</sup> Neurodevelopmental, genetic and psychological impacts may significantly erode the benefits of successful heart intervention and should be kept in focus during surveillance.<sup>81</sup> Support in these areas should be part of normal care. There are also compounding impacts of lifestyle, social and economic factors and climate change on the outcomes for patients.

Services should be available and tailored to the needs of patients and families that address distinctions in severity of the condition and requirements for specific services.

## Appendix E: CoHD Standards Development

The approach to CoHD Standards development was participatory and collaborative with input from patients, families, carers, healthcare providers and relevant stakeholders and facilitated by HeartKids Ltd and the CoHD Standards Steering Committee. An Advisory Committee and Working Groups were established and included members with expert knowledge, practice and / or lived experience in CoHD (members listed in Appendices A and B). Development of the CoHD Standards was guided by qualitative mapping of values shared during discussions and embodied in the process.

The drafting of the CoHD Standards was led by the Project Co-Chairs and guided by the Steering Committee of nine members (Appendix A) representing medical, paediatrics, adult congenital heart disease (ACHD), nursing, psychology, neurodevelopment, patient, family and carer representatives.

An Advisory Committee of twenty-five members (Appendix B) was asked to establish performance measures to guide the process and support completion of CoHD Standards in keeping with the project goals, to incorporate Mental Health and Neurodevelopmental Standards, provide a governance framework for development of clinical practice guidelines, and outline workforce and infrastructure plans that align with the CoHD Standards. Priority domains of CoHD healthcare were identified and 12 discipline-specific working groups focussing on the whole-of-life approach were established. There were 132 memberships across working groups from a number of specialities: Cardiology, Cardiac Surgery, Adult Congenital Heart Disease, Nursing, Mental Health and Psychology, Neurodevelopment, Research, Transition, Priority Populations, Regional Care, Patients, families and carers, and Provision of Services from Large and Small Centres (Appendix B).

Draft CoHD Standards development was guided by regular working group discussions which were Chair-led and documented. The content was examined and summarised, themes were identified, and reported back to members to guide further discussion, generate new ideas, and establish consensus. Regular meetings between the coordinating team, Standards Co-Chairs and Working Group Chairs and Co-Chairs to help support with the iterative development process.<sup>82</sup> Some areas of discussion and review were captured to inform future development of clinical practice guidelines workforce and infrastructure plans. Principal statements for quality care for CoHD were informed by published evidence, relevant international best practice standards, expert knowledge of members, expert consensus-based recommendations on the current capacity and capability of CoHD care in Australia, and best practice approaches to address gaps and future needs.

Draft CoHD Standards were mapped against relevant published Australian and international standards and guidelines to highlight areas of alignment and distinction.

The CoHD Steering Committee with the support of HeartKids Ltd is initiating public consultation on the Draft CoHD Standards from November to December 2021. These CoHD Standards will be a living document, with plans to allow regular review, to integrate practice improvements, education, and research. Once agreed and adopted by the relevant health organisations, CoHD Standards should be managed and reviewed collaboratively by relevant health professionals and professional groups, CoHD patients and families, and key stakeholder representatives (See recommendation 2, Structural Change and Leadership). Attention will be directed to key aspects of clinical practice, education, research, and accreditation procedures that may be applicable to New Zealand.

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