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POSITION STATEMENT

Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards). 1st Edition

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These first Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) have been developed to inform the healthcare requirements for CoHD services and enable all Australian patients, families and carers impacted by CoHD (paediatric CoHD and adult congenital heart disease [ACHD]) to live their best and healthiest lives.

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

The CoHD Standards provide a framework for excellent CoHD care, encompassing key requirements and expectations for whole-of-life, holistic and connected healthcare service delivery.

The CoHD Standards should be implemented in health services in conjunction with the National Safety and Quality Health Service Standards developed by the Australian Commission on Safety and Quality in Health Care. All healthcare services should comply with the CoHD Standards, as well as working to their organisation's or jurisdiction's agreed clinical governance framework, to guide the implementation of structures and processes that support safe care.

Contents

Introduction

These first Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) have been developed to inform the healthcare requirements for CoHD services and enable all Australian patients, families and carers impacted by CoHD (paediatric CoHD and adult congenital heart disease [ACHD]) to live their best and healthiest lives.

The CoHD Standards are designed to provide the clarity and certainty required for healthcare services to deliver excellent, comprehensive, inclusive, and equitable CoHD 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, and Type 1) and Adult Congenital Heart Disease (ACHD) Services describe the organised programs delivering care. The structure of both types of Service is influenced by geography and the population distribution of Australia, with measures to share supportive links to bring care closer to home. The 12 CoHD Standards (Table 1) identify the unique needs of priority populations including Aboriginal and Torres Strait Islander peoples, those of varied cultural backgrounds, 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, and targeted CoHD research is recognised as important in providing new and improved opportunities for future healthcare delivery.

The CoHD Standards provide a framework for excellent CoHD care, encompassing key requirements and expectations for whole-of-life, holistic and connected healthcare service delivery, and has been developed as Project 1, the first of a suite of resources for nationally agreed CoHD standardised care. It will be used to inform workforce and infrastructure planning (Project 2) and evolve comprehensive CoHD clinical practice guidelines, scientific position statements and roadmaps (Project 3) to meet the CoHD Standards and the health needs of the CoHD community.

The CoHD Standards are designed:

- for patients, families and carers, healthcare providers, researchers, healthcare planners and policymakers using, delivering and developing services across Australia;
- to be the primary reference source for developing and maintaining CoHD services in Australia across all health jurisdictions;
- to apply to all Australian CoHD Services (Paediatric and ACHD); and,
- to set the expected quality of CoHD care processes to achieve the best possible outcomes for patients and families.

The CoHD Standards should be implemented in health services in conjunction with the National Safety and Quality Health Service Standards developed by the Australian Commission on Safety and Quality in Health Care. All healthcare services should comply with the CoHD Standards, as well as working to their organisation's or jurisdiction's agreed clinical governance framework, to guide the implementation of structures and processes that support safe care.

Table 1 Summary of the Australian National CoHD Standards

The CoHD Standards are a framework to provide for excellent care and a holistic approach. In the context of these Standards, excellent care* is defined as safe, patient/family-centred, effective, and coordinated care. The CoHD Standards are organised under 12 priority domains. The CoHD Standards are developed to inform the requirements for CoHD healthcare and enable patients, families and carers affected by CoHD to live their best and healthiest lives. The CoHD Standards are guided by the lead principle of Living Well and are supported by six key values derived from consultation and group discussions: Excellence, Patient- and Family- Centred Care, Dignity and Respect, Empathy and Compassion, Knowledge, and Collaboration.

Standard 1	**CoHD Services (Paediatric and ACHD)** The provision of comprehensive coordinated care across CoHD healthcare service types for all Australians.
Standard 2	**Regional CoHD Care** The provision of coordinated and improved access to CoHD healthcare services in regional Australia.
Standard 3	**Paediatric Cardiology** The provision of specialist CoHD healthcare by paediatric cardiologists including subspecialties.
Standard 4	**Paediatric Cardiac and ACHD Surgery** The provision of specialist CoHD cardiac surgery for CoHD patients at all ages, and their families and carers.
Standard 5	**Transition to Adult Care** The provision of transition from paediatric to adult CoHD care which commences early, is carefully planned, holistic, and individually tailored for patients, families, and carers.
Standard 6	**ACHD Cardiology** The provision of comprehensive coordinated congenital heart disease care for adults by ACHD cardiologists.
Standard 7	**Nursing** The provision of excellent CoHD nursing care by specialist Advanced Practice Nurses, and specialised CoHD nurses.
Standard 8	**Mental Health and Psychological Care** Access to specialised mental health care for patients, families and carers that is integrated into CoHD healthcare throughout life, inclusive of end-of-life and bereavement care.
Standard 9	**Neurodevelopmental and Neurocognitive Care** Access to comprehensive coordinated developmental surveillance, screening, evaluation and re-evaluation for patients, families, and carers throughout the whole of life.
Standard 10	**Priority Populations** Equitable access to coordinated CoHD healthcare for patients/families and carers that is culturally respectful, compassionate, responsive, grounded in empowerment and optimises cultural, social, and environmental support.
Standard 11	**Research** The provision of CoHD research, focused on improved outcomes and discovery, encompassing the whole of life, that is collaborative, sustainable, and nationally and internationally benchmarked, and integrated into CoHD Services.
Standard 12	**Health Information and Digital Communication Technology** Access to telehealth CoHD Services, provision, and maintenance of accessible CoHD electronic health records, and large-scale data transfer capabilities.

*Definition of excellent care is derived from the Australian Commission for Safety and Quality in Health Care. National Model Clinical Governance Framework. Sydney: ACSQHC; 2017. http://www.safetyandquality.gov.au

Section One. Journey, Purpose and Development of CoHD Standards

Supporting the CoHD life journey

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

The CoHD life journey begins with a diagnosis of a heart condition, and while diagnosis of CoHD may occur during pregnancy, particularly with complex congenital heart disease, most CoHD is diagnosed after birth [2]; (Appendix C). 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, infection, environmental factors, or medical therapy [3], many patients will experience lifelong challenges to their health and wellbeing [4].

CoHD represents a wide spectrum of disease severity and so requires a range of services to align with the complex needs of diverse patient groups. Some patients with CoHD can experience mild disease with minimal long-term health consequences.

Others may experience moderate disease requiring treatment with most patients achieving a favourable outcome and requiring a level of service that is distinct from the highly involved service delivery needed for those with more complex disease (Appendix D).

The cardiac care trajectory is different for every person, their family, and carers. It may include, but is not limited to, diagnosis, hospitalisation, critical care, medical procedures, initiation of treatments, hospital discharge, transition from paediatric to adult healthcare, 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.

The CoHD Standards were recommended to inform the development and provision of high-quality, seamless, patient-centric and lifelong care for all Australians impacted by CoHD [5].

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, in the past, now and in the future, whose care is the focus of this document (see Acknowledgement to Country (Box 1) and the Co-Chair's Foreword (Box 2).

Box 1. Acknowledgement of Country

The Australian National Standards of Care for Childhood-onset Heart Disease (CoHD) authors and contributors acknowledge the Aboriginal and Torres Strait Islander peoples of this land. We acknowledge them as the Traditional Custodians of the country throughout Australia, where the CoHD Standards were written. We recognise their strength, resilience and their connection to the land, culture, and community. We celebrate their longest continuous living culture and acknowledge the important contributions Aboriginal and Torres Strait Islander people have and continue to make in Australian society. We pay respects to all Elders past and present, and thank the Aboriginal and Torres Strait Islander people who contributed to this document. We acknowledge the importance of supporting health for all peoples and generations now and in the future.

Purpose of the CoHD Standards

Why do we need CoHD Standards?

The purpose of the CoHD Standards is to provide a coherent national framework that defines key requirements in delivering care to reduce the burden of CoHD on all those affected and be inclusive and equitable in supporting people living their fullest and best lives —"living well" throughout life.

Australian healthcare providers have relied on domestic expert knowledge and relevant local guidelines and international best practice standards [6–13], to inform local models of cardiac care and services. 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 delivering holistic care that meets the unique needs of priority populations, and the impacts of geography and regional services [10,11]. The CoHD Standards align with a whole-of-life, holistic approach and focus on those diagnosed with CoHD, and their families and carers. To this end, they 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 those living with disadvantage, people living in regional, rural and remote areas, those from refugee backgrounds and young adults transitioning to the adult healthcare system [10].

Box 2. Foreword from the Co-Chairs

The journeys for people with Childhood-onset Heart Disease (CoHD), their families and carers are often challenging and confronting, and for many are lifelong. The 2019 Plan for Childhood Heart Disease mandated the development of national standards of care as the first and central step in transforming care for people affected by CoHD.

The Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) are the culmination of more than 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 planned work also incorporates the identifying workforce and infrastructure status and developing key National Clinical Practice Guidelines, and scientific statements regarding care and services, which will be completed after these CoHD Standards are published. We are especially grateful for the support of the Federal Government for this project and productive engagement with State and Territory Health Departments. The publication of the CoHD Standards 1st Edition will mark the beginning of implementation and advocacy.

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 on a confident and coherent path forward to achieving our lead principle of 'living well' seems more important now than ever.

Gary Sholler AM and Lisa Selbie

As well as describing excellent care [12], and service provision, the CoHD Standards also embed requirements for mental health and neurodevelopmental care for patients, families and carers from the beginning of the patient journey, and as an essential service throughout all stages of life.

Care planning and delivery informed by nationally agreed CoHD Standards will:

- enhance the well-established collaborative bonds between CoHD Services (Paediatric and ACHD) that focus on providing coordinated and complete care for patients and families within and between States and Territories;
- ensure neurodevelopmental and neurocognitive care, 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 collaboration.

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 requirements for care planning and delivery to support patients, families and carers.

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. The CoHD Standards also include augmented elements of mental health and neurodevelopmental care.

Importantly, 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 information regarding infrastructure and workforce (Project 2), and clinical practice guidelines and position statements (Project 3) to follow publication of the CoHD Standards 1st Edition (Project 1). With effective implementation, these will secure continuing improvements to service delivery and outcomes 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 policymakers using, delivering, and developing services across Australia. The term 'patients, families and carers' used throughout this document refers to the fetus, infants, children, adolescents, and adults living with CoHD and the parents, siblings, partners and family and carer networks who support them.

The CoHD Standards enable people with CoHD, families and carers to gain a clear understanding of the standard of care they should expect and be empowered to advocate for this standard if it is not provided. The CoHD Standards also encourage patients, families and carers to take part in decisions about patient 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 identify requirements for excellent clinical services, and discovery and translation of impactful research programs, as well as promoting engagement with patients, families, carers, and the wider community.

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

The CoHD Standards can be accessed publicly on a dedicated webpage, with links also available through relevant government and professional organisational websites. Links to the CoHD Standards can also be included on fact-sheet information about CoHD that are provided to patients, families, and carers at specialist CoHD healthcare services.

How will the implementation of the CoHD Standards be assessed?

The CoHD Standards should be implemented in health services in conjunction with the National Safety and Quality Health Service Standards developed by the Australian Commission on Safety and Quality in Health Care. All healthcare services must incorporate the CoHD Standards, as well as working within their organisation's or jurisdiction's agreed clinical governance framework, to guide the implementation of structures and processes that support safe care.

In the event services do not currently meet these CoHD Standards, the expectation is that substantial progress will be made towards compliance within three years of publication of the CoHD Standards 1st Edition.

The Standards themselves will be reviewed for their effectiveness in supporting and driving 'excellent CoHD care'. To support effective implementation of the CoHD Standards, and to guide future care planning, a range of clinical, national, and jurisdictional structural, governance and leadership infrastructure are to be recommended.

Compliance with the CoHD Standards and the impact of their effectiveness will be assessed by identifying available CoHD resources, services, and infrastructure at publication and at 3 and 6 years after publication. This will be under the guidance of the CoHD Standards Management Committee. Metrics will include, for example:

1. Comparisons of implementation of institutional- and jurisdictional-relevant CoHD Standards;
2. Metrics based on Workforce and Infrastructure data already collected as part of the CoHD Standards Preparation, and to be collected in the future;
3. Application of selected established Key Performance Indicators (KPIs); and,
4. Evolution of new KPIs as appropriate.

How are the CoHD Standards structured?

The introduction at the beginning of each standard describes its rationale and context. The specific sub-standards and criteria then follow. The information in italics provides additional guidance (contextual observations and considerations beyond the assessable requirements of the CoHD Standards).

Development of the CoHD Standards

Lead principle and values

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

Engagement and collaboration were reflected through developing a Lead Principle and key Values, intrinsically linked to providing 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'.

Living Well

"Best health throughout life"

The lead principle for these CoHD Standards is to achieve the best possible health for those impacted by CoHD, which is characterised in these Standards 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' [12]. Health reflects the complex interactions of a person's genetics, lifestyle, environment, culture, and beliefs. Generally, a person's health depends on two things: determinants (factors that influence health) and interventions (actions taken to improve health and the resources required for those interventions) [13]. For the purposes of the CoHD Standards, Living Well requires that:

- Patients, 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; and,
- Care planning incorporates a long-term, whole-of-life perspective and a focus on achieving good health and wellbeing [13], and the degree to which this may exist for all CoHD patients, including:
  - recognising the variation in CoHD, creating the correct level of care tailored to the complexity and severity of an abnormality;
  - identifying action measures to address the medical, social, psychological, educational and neurodevelopmental needs of CoHD patients;
  - maintaining good health and wellbeing, with a conscious effort to avoid inappropriate restrictions and limitations;

- o promoting physical activity and appropriate exercise for all CoHD patients
- o incorporating quality-of-life measures into care planning; and,
- o providing comprehensive support that incorporates trauma-informed care and recognises the impact of significant abnormality on patients, family, carers and healthcare providers [14,15].

The Values underpinning the COHD Standards are presented in Table 2.

The process of developing the CoHD Standards

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

Discipline-specific working groups focusing on the whole-of-life approach were established and comprised 91 participants from 12 key domains including: Paediatric CoHD Services (large and small centres) and ACHD Services, Regional Care, Paediatric Cardiology, Cardiac Surgery, Adult Congenital Heart Disease Cardiology, 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 and 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. Two public consultation periods on the draft CoHD Standards were completed by December 2022 followed by publication of the CoHD Standards 1st Edition in 2024.

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 Federal and State Governments. They will guide practice improvements, workforce and infrastructure, service-based decision-making, education, research, and advocacy. The CoHD Standards will be maintained and reviewed regularly by an Australian CoHD Standards Management Committee and relevant healthcare providers and professional groups, CoHD patients, families and carers and other key stakeholders.

Key aspects of clinical practice, education, research, and accreditation procedures outlined in the CoHD Standards may be relevant in New Zealand, reflecting the strong partnership between the patient, clinical and research communities in both countries.

Table 2 Values underpinning the CoHD Standards.

Excellence	For the purposes of the CoHD Standards, 'Excellence' in care is defined as safe, patient/family-centred, effective, and coordinated care [68]. Excellence remains central to all aspects of service planning, delivery, and evaluation. Excellence requires reliable, purpose-specific, and common data across constituencies. Excellence is supported by performance measures benchmarked nationally and internationally.
Patient- and Family-Centred Care	Patients, families, and carers affected by CoHD are at the centre of all care and care planning. Patients, families, and carers are involved, supported, and empowered to be partners in their care planning and delivery which is sensitive to their needs. The requirements of Aboriginal and Torres Strait Islander peoples, those of differing cultural backgrounds and populations at disadvantage are sensitively addressed, with measures implemented for equitable access.
Dignity and Respect	Care is developed and delivered with openness and integrity, and is undertaken with respect for, and engagement with, patients, families, carers and within healthcare teams. 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.
Empathy and Compassion	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.
Knowledge	Care is developed and delivered by healthcare providers with recognised training, current knowledge, and evidence-based practice experience in CoHD. Care is informed by the best local, national, and international research that is facilitated, shared, and integrated with resources to support discovery, innovation, and future translational care options. Knowledge focuses on the cause, care and short- and long-term impact of CoHD including social, psychological, and neurodevelopmental consequences. Knowledge is shared throughout the CoHD community. Knowledge is enhanced to end health disparities in Australia.
Collaboration	Care planning and delivery for patients, families and carers is collaborative and focuses on everyone being well informed. Care is accessible, inclusive, and offered as close to home as possible. Collaboration between healthcare providers involves a shared commitment to strengthen the quality of care through rich interactions with a wide range of people involved in CoHD, and with networked partnerships between specialist healthcare and support services across metropolitan, regional, rural, and remote areas. 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 those between the CoHD community in Australia and New Zealand.

Section Two. Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards)

Living Well: *Living well throughout life informs the Childhood-onset Heart Disease (CoHD) Standards.*

Standard 1. CoHD Services (Paediatric and ACHD)

Standard 1 describes the provision of comprehensive coordinated care across Paediatric CoHD 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 (refer to Appendix D).

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

Paediatric CoHD Services are described as being Type 3, Type 2 or Type 1, and include healthcare for a range of congenital and acquired conditions. Adult services that focus on CoHD congenital structural heart abnormalities are generally referred to as Adult Congenital Heart Disease (ACHD) Services [16]. 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 centralising high-complexity, low-volume services into a comprehensive integrated unit to achieve clinical excellence should be prioritised. 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 Services (Paediatric CoHD and ACHD) are central to care delivery for patients with CoHD throughout life. The Services deliver comprehensive cardiac medical and supportive care. 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 excellent care that is patient/family-centred, safe, effective and coordinated.

Larger, multidisciplinary CoHD Services (Paediatric and ACHD) 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.

1.1.2 Patients and families have timely and reliable access to dedicated CoHD Services throughout life [1,7,17].

1.1.3 CoHD Services (Paediatric and ACHD) have dedicated governance and leadership teams that focus on delivering excellent, best-practice services in line with the CoHD Standards.

- 1.1.3.1 CoHD Services are led by suitably trained experts in CoHD/ACHD [18,19]
- 1.1.3.2 Within CoHD and ACHD Services with multidisciplinary teams, a lead in each stream, major service offering, and professional domain is identified.

  Leads are responsible for coordinating and guiding that service stream including professional or stream-specific, education, development and management. Leads form part of a multidisciplinary collaborative leadership group in that service to offer voice to the various service offerings [20,21].
- 1.1.3.3 The Service's governance structure is documented and transparent and focuses on patients, families, and carers.

1.1.4 All CoHD Services (Paediatric and ACHD) and governing entities of those Services incorporate the Lead Principle, Values, and Standards of these CoHD Standards.

1.1.5 CoHD Services (Paediatric and ACHD) consider the special and culturally appropriate requirements of Aboriginal and Torres Strait Islander peoples and other priority populations (refer to **Standard 10**).

- 1.1.5.1 To enable Aboriginal and Torres Strait Islander peoples to have access to culturally appropriate care, timely referral will be made to Aboriginal and Torres Strait Islander Health Workers or Practitioners and/or support services [22]. In the case of other members of priority populations relevant and culturally appropriate support should be engaged when needed.

1.1.6 All staff employed by CoHD Services (Paediatric and ACHD) have training in relevant CoHD / ACHD care.

For healthcare providers, training starts 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.

1.1.6.1 Providers of CoHD Services (Paediatric and ACHD) have appropriate accreditation and credentialing provided through relevant employing bodies and training organisations.

1.1.6.2 Administrative and support staff predominantly involved in services delivering care to CoHD patients have role-appropriate orientation and training in relevant aspects of CoHD and the needs of patients and families.

1.1.7 CoHD Services (Paediatric and ACHD) provide the right staffing level and skills mix relevant to clinical demand, including subspecialty care, within each program.

1.1.7.1 Where high acuity-related after-hours medical rostering is required, services should provide a minimum of two, but preferably three, appropriately skilled medical staff.

1.1.7.2 Services reflect and provide the right support and guidance for staff, patients, families, and carers regarding diversity of gender, culture, and the breadth of ethnic backgrounds.

1.1.8 CoHD Services (Paediatric and ACHD) highlight to patients and families any areas of healthcare that could impact their short and long-term wellbeing.

Common relevant health domains include mental health, neurodevelopment, genetic associations of cardiac abnormality, physical activity, dental care, obesity, vaccination and management of cardiovascular risk factors.

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), arrhythmia management, pulmonary hypertension services, and advanced heart failure management. Paediatric CoHD Services Type 3 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 providing some specialist cardiology services and collaboration with local healthcare 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 permanent staff to support cardiology and cardiac surgery, advanced practice nursing, psychology, genetic counselling, neurodevelopmental screening, social work, allied health, and appropriate administrative support.

1.2.2.2. Access to geneticists with advanced knowledge of CoHD.

Genetic services are a key component of CoHD management and counselling. Familial CoHD, including structural, cardiac functional and cardiac rhythm abnormality, have an increasingly recognised genetic basis. Personalised medicine will become increasingly important for patient care. Access to geneticists with advanced knowledge of CoHD or staffing with cardiologist/geneticists is essential.

1.2.3 Paediatric CoHD Services Type 3 have a dedicated Paediatric Intensive Care Unit, Neonatal Intensive Care Unit (NICU), with relevant cardiac Intensive Care Unit (ICU) expertise and training.

1.2.3.1 Paediatric Intensive Care Units are 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).

1.2.4 Anaesthetic services for paediatric CoHD interventions are available.

1.2.5 Paediatric CoHD Services Type 3 provide specialist paediatric clinical follow-up, screening and surveillance care in regional remote areas and have the capacity to organise timely coordinated care for Paediatric CoHD Services Type 3 when the need arises [15,20,23].

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 [23], advanced practice nursing support [23,24], psychologists [24,25], allocated medical trainee(s) and allied health staff allocated to CoHD Services [25].

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 have expert medical, nursing and allied health support staff in fetal cardiology and collaborate with materno-fetal medicine programs to provide capabilities for rapid transfer of patients if required [26–28].

Fetal cardiologists (subspecialty-trained paediatric cardiologists) play a key role in prenatal diagnosis, management, and coun selling for patients with a pre-birth diagnosis of cardiac abnormality (or suspected cardiac abnormality). Collaboration *with materno-fetal medicine programs is essential for best practice care when needed and will be a key area of capability for Paediatric CoHD Services Type 3.*

1.2.8.1 Capability exists for on-site critical case delivery and/or co-located facilities to manage relevant cases (or is in planning review) for Paediatric 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 [18,19,29].

1.2.9.1 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 and acute cases.

1.2.10.2 Outpatient services are triaged, and patients prioritised according to need.

1.2.11 Paediatric CoHD Services Type 3 are appropriately staffed and resourced to have time allocated to senior medical specialist continuing education, junior medical staff training, and training and development of the multidisciplinary team.

1.2.12 Paediatric CoHD Services Type 3 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, key members of the 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.

1.2.12.4 Key audit data are integrated with a National Congenital Heart Disease Registry (CHD Registry), subject to privacy requirements.

1.2.13 Paediatric CoHD Services Type 3 have embedded research programs and integrated links with relevant higher education facilities to promote the development and translation of innovation in CoHD care.

1.2.14 Services Type 3 are appropriately staffed and resourced to have integrated and dedicated time allocated to the multidisciplinary team to take part in research activities as relevant to their roles [16,17,28].

1.2.15 Paediatric CoHD Services Type 3 have embedded education programs aimed at CoHD staff, relevant health staff, trainees, and students.

1.2.15.1 The education programs are available for a range of individuals including:

- patients, carers, and the community serviced.
- CoHD professionals, with relevant activities for students and trainees.
- 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.

Geographically isolated Paediatric CoHD Services Type 2 may implement a carefully selected subset of cardiac surgical procedures. The number of sites providing cardiac surgery should be limited so 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 whilst maintaining high levels of CoHD/ACHD surgical volume.

1.3.1 Paediatric CoHD Services Type 2 will not provide cardiac surgery except when significant geographical considerations allow (refer to **Standard 1.3.2**).

1.3.2 For geographically isolated Paediatric CoHD Services Type 2, cardiac surgery may be provided under the provisions of **Standard 4.10.**

1.3.3 Paediatric CoHD Services Type 2 incorporate most elements of a Paediatric CoHD Service Type 3, with some selected on-site CoHD subspecialties omitted.

1.3.3.1 A Paediatric CoHD Service Type 2 includes specialist paediatric cardiac services with variable inclusion of cardiac surgery (where required by geographical considerations [refer **Standard 4.10**]), cardiac diagnostic and appropriate interventional catheterisation (modified according to the absence of cardiac surgery), invasive, advanced heart failure management, specialised paediatric pulmonary hypertension and fetal cardiology services and embedded research programs [7,30,31].

1.3.4 All Paediatric Services Type 2 have clear referral pathways to a linked Paediatric CoHD Service Type 3 to rapidly manage cardiac surgery or medical subspecialties that are unavailable.

1.3.4.1 Dedicated and funded pathways to Paediatric CoHD Services Type 3 are identified where these specific capabilities are not available internally.

1.3.5 Paediatric CoHD Services Type 2 have embedded research programs and links with relevant higher education facilities to promote the development and translation of innovation in CoHD.

1.3.5.1 Paediatric CoHD Services Type 2 tailor research to expertise and infrastructure and may participate in research through multicentre studies and collaborations.

1.4 Paediatric CoHD Services Type 1 are designed to offer local CoHD surveillance and coordination of patient care. Paediatric CoHD Services Type 1 may be provided:

(a) ***by a small centre with a CoHD cardiologist and a small number of dedicated CoHD support staff to assist with long-term care, or***

(b) ***by a single CoHD cardiologist to manage short- and long-term assessment and care with relevant support.***

Individual CoHD small centres and cardiologists should collaborate with a Paediatric CoHD Service Type 3 or Type 2.

1.4.1 Paediatric CoHD Services Type 1 are provided by individual paediatric cardiologists who may be supported by full- or part-time personnel with relevant training in CoHD.

1.4.1.1 Access to high-quality paediatric echocardiography (cardiologist or CoHD sonographer) and other primary investigations is accommodated [23].

1.4.1.2 Support includes access to nursing, psychology and allied health staff [19,20,23,32]

1.4.2 Paediatric CoHD Services Type 1 have established links to Paediatric CoHD Services Type 2 and/or Type 3 to allow seamless access to appropriate CoHD multidisciplinary services when needed with documented roles and responsibilities.

1.4.3 Paediatric CoHD Services Type 1 should contribute to local education in relation to CoHD.

1.5. Paediatric CoHD Outreach is provided by a visiting paediatric cardiologist connected with a Paediatric CoHD Service (Type 3, 2 or 1).

1.5.1 Paediatric CoHD Outreach Services include an intermittent visiting CoHD clinic, involve a paediatric cardiologist and may involve additional CoHD personnel.

1.5.2 Paediatric CoHD 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 (refer also to **Standard 12**).

1.5.5 Paediatric CoHD Outreach Services engage with local medical (general practitioners and relevant specialists), nursing and allied health staff, and the primary health multidisciplinary team as needed, and coordinate care to those requiring such services.

Through triage of case demand, this brings quality care close to home (refer to **Standard 10***) for those in need.*

1.6 ACHD Services (Comprehensive) are supported by multidisciplinary teams.

1.6.1 The team includes dedicated and integrated CoHD full-time equivalent staff to support cardiology and cardiac surgery, advanced practice nursing [24,33] psychology [25,34] genetic counselling [24,35] social work, allied health and appropriate administrative support [32,36].

1.6.2 ACHD Services (Comprehensive) provide coordinated [16,19,24,30,36,37] multidisciplinary care to patients with ACHD in tertiary adult hospitals [15,30].

1.6.2.1 Medical services include Childhood-onset Heart Disease, Cardiac Surgery, Cardiac Diagnostic and Interventional Catheterisation, Advanced Cardiac Imaging (including cardiac MRI/CT), Electrophysiology, a Pulmonary Hypertension Service and Advanced Heart Failure Management.[18,19,29,38]

1.6.3 ACHD Services (Comprehensive) provide access to 24/7 on-call ACHD specialist advice.

1.6.3.1 Services include 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.

1.6.3.3.1 Cardiac catheterisation and intervention studies in ACHD patients are performed in ACHD Services (Comprehensive) by accredited and credentialed ACHD cardiologists or ACHD structural interventional cardiologists.

1.6.3.3.2 In the absence of such accreditation and credentialing pathways, these should be established.

Interventional closure of simple ASD/PFO's may be performed at other large *centres by an experienced Interventional Cardiologist. Discussion with ACHD Structural Interventional Cardiologists prior to performing transcatheter procedures in ACHD patients is recommended.*

1.7 ACHD Services (Regional) are available in regional centres in each Australian state and territory and are provided by one or more ACHD cardiologist(s) with at least 12 months of training spent in a dedicated ACHD Fellowship [16,17].

1.7.1 ACHD Services (Regional) require access to ACHD nursing support with dedicated staff to the service.

1.7.2 ACHD Services (Regional) require established links to an ACHD Service (Comprehensive) with articulated and documented roles and responsibilities.

For geographically isolated services, a collaborative paediatric cardiology/ACHD hybrid model may be considered as an interim measure pending establishment of an ACHD Service (Regional) capability.

1.8. ACHD Outreach is provided by a visiting ACHD cardiologist connected with an ACHD Services (Comprehensive) or ACHD Services (Regional).

Outreach services require close collaboration with local medical services, and ideally have a local medical champion of the Service to optimise integration into local medical and support services, with relevant financial support for services and staff.

1.8.1 For patients beyond 100 km of an ACHD Service, telehealth is considered as an alternative to in-person review.

1.8.1.1 This review is subject to cardiac abnormality, clinical condition and local medical review collaborations.

1.8.2 Adequate workforce and infrastructure is provided to offer a sustainable ACHD Outreach Service.

Implementation Pathway

Implementation will be managed by relevant health professionals, relevant hospitals, State Health Jurisdictions, and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress towards or,achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 2. Regional Care

The CoHD Standards relevant to regional Australia are developed to support coordinated care and improved access to CoHD healthcare in regional Australia. The CoHD Standards for Regional Australia 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 [1,14,20,23,26,39].

Australia has a wide geographical distribution, with more than 28 per cent of the population living in regional or remote areas beyond 100 km of Paediatric CoHD Services Type 2 or Type 3 or ACHD Services (Comprehensive). The CoHD Standards recognise the unique challenges and requirements of regional Australia.

2.1. Regional CoHD care is provided as close to home as 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 or CoHD Services [14,15,26].

2.1.2 Service requirements for regional areas are identified and local CoHD Services tailored to those requirements.

2.1.2.1 Service providers take part in service planning with local healthcare planners, healthcare providers, patients, families and carers, and providers of CoHD and ACHD care.

2.1.2.2 Care may be provided by individual paediatric or ACHD cardiologists (collaborating with a relevant Paediatric CoHD Service Type 2 or 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 Service Type 2 or 3 or ACHD Service (Comprehensive) when required.

2.2.1 Planning and documentation of services are available for review as required.

2.2.2 Funding is available to care providers (including the workforce) and for travel and accommodation for patients and families.

2.3. A local clinical lead is designated for each major regional area with CoHD or ACHD Outreach Services.

2.3.1 The clinical lead role(s) is supported by separate paediatric and adult coordinators as required.

2.3.2 Paediatric CoHD Services or ACHD Services identify a contact person to assist with coordination.

It is expected that the role would be part-time. The medical skills for such a role would require both paediatric and adult clinical leads. In the event the regional service is provided by a CoHD Services Type 1 with an individual service linked *paediatric cardiologist, that individual would act as the contact.*

2.3.3 Rural and regional services nominate clinical specialised cardiac nurses with relevant knowledge to assist with supporting patients and families affected by CoHD [23,26,33].

2.3.3.1 The nursing roles incorporate activities to foster strong links with CoHD/ACHD nurses in advanced practice and specialised nursing roles [8,33,40].

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 [24,33].

2.4. The CoHD Service or supporting paediatric cardiologist and/or ACHD Service collaborates with rural and regional services to develop and facilitate mentorship and appropriate professional development.

Nominated key regional team members should participate in relevant discussions in joint multidisciplinary CoHD and ACHD patient review meetings as required.

2.4.1 Models of service delivery should be reviewed.

Implementation Pathway

Implementation will be managed by relevant health professionals, relevant hospitals and regional services, relevant Colleges, State Health Jurisdictions, and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 3. Paediatric Cardiology

Paediatric CoHD cardiology care standards describe the provision of specialist CoHD healthcare by paediatric cardiologists including subspecialties.

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 subspecialty experts are well understood. Securing excellent outcomes for paediatric patients will involve the continuing involvement of a paediatric cardiologist.

Subspecialty paediatric cardiologists (e.g., interventional cardiac catheterisation, paediatric arrhythmia, fetal cardiology, complex heart failure) provide a range of key supplementary services. Paediatric cardiology clinicians and researchers play an important part in research into CoHD. Maintaining a highly qualified, sustainable paediatric cardiology profession should be a priority for healthcare planners.

Paediatric cardiologists may focus in one or more special domains:

a. Cardiac Imaging
    I. Echocardiography
    II. MRI imaging
    III. CT imaging

Echocardiographic imaging of the heart is a core capability for all paediatric cardiologists; however, advanced capabilities and training in echocardiography will offer enhanced options for cardiac evaluation. MRI and CT scanning are distinct skills requiring extra training and accreditation, and form key capabilities for CoHD Services Type 3 and Type 2. In CoHD Services Type 2, these capabilities may be delivered through appropriate partnerships.

b. Cardiac Catheterisation and Intervention

Cardiac catheterisation is a diagnostic tool for angiographic and haemodynamic evaluation and forms part of core training for all paediatric cardiologists. However, Type 3 and Type 2 units will have nominated individuals with advanced skills to deliver these services. Interventional procedures to modify cardiac anatomy via a catheter pathway requires additional training and capabilities, with the range of procedures dependent on capabilities of the operators and resources for back-up, including paediatric cardiac surgery.

c. Cardiac Arrhythmia and Pacing
    I. Electrophysiology
    II. Familial/Genetic Cardiology

Cardiac arrhythmia management focusses on abnormalities of the cardiac conduction system, which may be structural or genetic and may evolve with time. Understanding of basic care is part of core paediatric cardiology training; however, advanced knowledge and skills for diagnosis and care requires specific training. Some paediatric cardiac arrhythmia specialists will have further capabilities in catheter evaluation and therapy for cardiac arrhythmia. CoHD Services Type 3 will have dedicated *cardiac arrhythmia subspecialists, and CoHD Services Type 2 will have designated collaborations to provide services at levels appropriate to the skills and expertise of the collaborators.*

d. Fetal Cardiology

Fetal cardiologists (subspecialty-trained paediatric cardiologists) play a key role in prenatal diagnosis, management and counselling for patients with a pre-birth diagnosis of cardiac abnormality (or suspected cardiac abnormality) in the fetus. Collaboration with materno-fetal medicine programs is essential for best practice care when needed and will be a key area of capability for CoHD Services Type 3.

e. Heart Failure
f. Transplantation
g. Pulmonary Hypertension

Heart failure, transplantation and pulmonary hypertension care will be provided by suitably trained subspecialists, and advanced capabilities will generally be delivered in CoHD Services Type 3.

h. Genetic Cardiology

Genetic services are a key component of CoHD management and counselling.

i. Familial CoHD

Structural, cardiac functional, and cardiac rhythm abnormality have an increasingly recognised genetic basis. Personalised medicine will become increasingly important in patient care. Access to geneticists with knowledge of CoHD, or staffing with cardiologist/geneticists, is essential.

3.1. Paediatric CoHD Cardiology care is provided to patients below the age of 15–18 years by paediatric cardiologists [19].

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 in psychology, allied health, nursing and primary health care [19,24,29,32,33].

3.2. Paediatric Cardiologists have qualifications and training verified and registered through the appropriate pathways of the Royal Australian College of Physicians (RACP) and Australian Health Practitioner Regulation Agency (Ahpra) [19].

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

Implementation Pathway

Implementation will be managed by relevant health professionals, National and State accrediting bodies, relevant Colleges, State Health Jurisdictions, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 4. Paediatric Cardiac and ACHD Surgery

The CoHD Standards for Paediatric Cardiac and ACHD surgery outline the requirements for providing specialist CoHD cardiac surgery for CoHD patients at all ages, and their families. Paediatric cardiac surgery and ACHD cardiac surgery are highly specialised subspecialties 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 CoHD Services Type 2 may implement carefully selected cardiac surgical procedures. The number of sites providing cardiac surgery should be limited so 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 whilst maintaining high levels of CoHD/ACHD surgical volume.

4.1. Paediatric cardiac surgery and adult congenital heart surgery are performed in cardiac surgical centres with on-site 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 and a CoHD- and/or ACHD-capable ICU.

4.1.1 Paediatric cardiac surgery is performed in Paediatric CoHD Services Type 3 or geographically isolated CoHD Services Type 2 with 24/7 on-site access to paediatric cardiology, paediatric diagnostic and interventional catheterisation, the full multidisciplinary CoHD team, and with other relevant subspecialty 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 ACHD Services (Comprehensive) with continuous access to ACHD specialty services [16,31,41].

4.1.2.1 Adult ICUs 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 [16].

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 surgeon.

4.2. Assessment for heart transplantation (including a ventricular assist device as a bridge to transplant) is conducted at a designated Paediatric Congenital Cardiac Transplant Centre or Adult Transplant Centre with relevant ACHD experience and skills [42–44].

4.2.1 All patients who may benefit from transplantation, including those with failing univentricular circulation, 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 [45,46]. *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 [44,46].

4.3. Paediatric Cardiac and ACHD Surgical Service centres have an extracorporeal membrane oxygenation (ECMO) program including provision for an ECMO retrieval service [47].

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, is 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 is kept to below 5 per cent of total cases per year.

4.5. Paediatric Cardiac and ACHD Surgery is performed by an appropriately trained congenital cardiac surgeon [48,49].

4.6. Cardiac surgeons have formal training in congenital cardiac surgery, following their initial training in adult cardiac surgery [48].

Training programs 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 Australasian College of Surgeons* [50].

*A recognised cardiac surgical service is one that includes a trainee cardiac surgical position that is endorsed by the Royal Australasian College of Surgeons.

4.7. All patients and families requiring cardiac surgical interventions have access to Advanced Practice Nurses and specialised nursing care who have specialist knowledge and skills in CoHD and/or ACHD.

4.7.1 This includes access to specialised nursing care during the preoperative, intraoperative and postoperative inpatient and post-discharge phases.

4.7.2 Specialist cardiac surgical intraoperative nursing care includes demonstrated proficiency in perioperative instrumentation and theoretical knowledge of CoHD and intraoperative care.

4.8. Perfusionists supporting paediatric cardiac and ACHD patients hold current certification with the appropriate professional body such as the Australasian Board of Cardiovascular Perfusionists (ANZCP) [51].

4.8.1 Paediatric and ACHD perfusionists perform a minimum of 40 cardiopulmonary bypass procedures per year as primary perfusionists outlined by the Australian and New Zealand College of Perfusionists [51].

4.8.2 Perfusionists supporting paediatric and ACHD cardiac surgery must hold current certification with the appropriate professional body such as the Australasian Board of Cardiovascular Perfusionists and be trained and credentialed in CoHD/ACHD perfusion [51].

4.9. Evaluation of paediatric cardiac and ACHD surgery performance is required on at least an annual basis [48–50].

4.9.1 All centres performing paediatric cardiac and ACHD surgery contribute to a national data registry allowing individual unit outcomes to be benchmarked against national outcomes and international best practice [49,50]. Clinical governance is in place for managing outcome outliers.

Criteria for assessment include:

Comparative outcome measures comprised of, but not limited to:

- mortality;
- major morbidities;
- volumes of congenital/complex congenital cases;
  - a minimum case volume of 100 congenital cases/year per surgeon averaged over 3 years.

  Some variation to these numbers is addressed in ***Standard 4.10****. Where a case is being mentored, the case is included for both the surgical mentor and the mentee.*
- management and review of surgical data;
- collaborative linkage with national colleagues; and,
- adequate support for the surgical team including cardiology services, radiology, paediatric intensive care unit, anaesthetics, specialist nursing and access to subspecialties.

4.10. Due to Australia's large geographic and population distribution, congenital cardiac surgery may be provided in suitably equipped and audited, geographically isolated Paediatric CoHD Services 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.

Implementation Pathway

Implementation will be managed by relevant health professionals, National and State accrediting bodies, relevant Colleges, State Health Jurisdictions, and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 5. Transition to Adult Care

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

The CoHD Standards for transitioning to Adult Care describe the requirements for providing transitional care that starts early and is carefully planned, holistic and individually tailored for patients and families.

5.1. Transition to Adult Care is transdisciplinary, holistic, individualised, flexible and carefully planned to provide seamless, uninterrupted and supportive care [52–54].

5.1.1 CoHD patients with congenital or structural heart disease have ongoing follow-up at an ACHD Service and review by an ACHD cardiologist and have a comprehensive transition plan [52,55,56].

5.1.2 CoHD patients without congenital or structural abnormalities have ongoing follow-up by a general or subspecialty adult cardiologist or centre as required and have a relevant transition plan.

  5.1.2.1 The appropriate cardiology surveillance strategy is tailored to the underlying lesion, condition and severity [57].

5.2. Transition to Adult Care is patient- and family-centred and empowers patients and parents/carers to be actively involved in the transition planning and delivery process [52,53].

5.2.1 Transition planning is aligned with **Standard 1.**

5.3. Transition starts during early adolescence, considers individual and developmental readiness and capacity, and continues into adulthood following successful engagement with adult congenital cardiology care [52,58].

5.4. Transition comprises multiple sessions throughout adolescence and young adulthood to promote understanding about their CoHD, enables meaningful goal setting, tracks the progress of developmental tasks and allows for screening for other concerns. This includes an emphasis on health/treatment compliance, mental health and social and educational/vocational goals [54–57,59].

5.5. Dedicated CoHD transition clinics are present in all Paediatric CoHD Services Type 3 and Type 2 and are accessible to Paediatric CoHD Services Type 1 as well as regional, remote and disadvantaged patients [52,54–57,60].

5.5.1 Transition care is provided by dedicated staff and infrastructure to support transition [52,57].

5.5.2 Transition care is facilitated jointly by paediatric CoHD and ACHD practitioners and teams [52,58,61–63]; and, where possible, primary care [64].

5.5.3 Pathways are available to secure the transition process and share information and recall information between the paediatric and ACHD or adult cardiology phases of care.

Transdisciplinary transfer involves strong collaboration between CoHD Services (Paediatric and ACHD) and, where possible, an individualised joint transfer process to introduce the ACHD team in partnership with the paediatric team [63,65].

5.5.3.1 Patients at higher risk of loss to follow-up have their arrival to ACHD Services and their progress monitored to minimise patient loss to follow-up [58,62,63,66].

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.

5.5.3.2 Whole-of-life coordinated care is supported by clear transdisciplinary communication [52,58,59].

5.5.3.3 A transdisciplinary communication system is required to facilitate 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 [65].

5.5.5 Transition education and support are tailored to the developmental stage of the patient, considering any learning and intellectual disabilities, where additional barriers to accessing appropriate healthcare is addressed [63–67].

Implementation Pathway

Implementation will be managed by relevant health professionals, hospitals, relevant Colleges, State Health Jurisdictions, and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 6. ACHD Care

ACHD cardiologists provide comprehensive coordinated 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 older). This Standard identifies the nature and role of an ACHD Cardiologist and should be read in conjunction with **Standard 1**.

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

6.1. Adult Congenital Heart Disease patients have care provided by an ACHD Cardiologist [16,17].

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 providers [16–18].

6.2. An ACHD Cardiologist is part of the evaluation and decision-making team when cardiac surgery is planned for a patient with ACHD [16,17,68].

Implementation Pathway

Implementation will be managed by relevant health professionals, National and State accrediting bodies, relevant Colleges, State Health Jurisdictions, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 7. Nursing

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

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 [40,69].

7.1.1 CoHD and ACHD subspeciality nursing services are led by Advanced Practice Nurses. Advanced Practice Nurses include Clinical Nurse Consultants and Nurse Practitioners [24,33,40].

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

While titles and descriptions of additional specialised nursing roles vary across Australian states and territories, additional specialised cardiac nursing roles can include cardiac nurses in specialised roles such as Care Coordinators, Clinical Nurses and Clinical Nurse Specialists [24,33].

The CoHD Standards acknowledge the important roles nurses/midwives play in the caregiving and referral to specialist cardiac nursing services for patients with CoHD and their families.

7.1.3 The Nursing Lead should ideally be part of the Service leadership team.

7.2. Nursing staff providing care for CoHD (Paediatric and ACHD) patients and families have appropriate education for their role(s) [24,33,40].

7.2.1 APNs and specialised nurses providing care in subspecialty areas of CoHD (Paediatric and ACHD) have the appropriate education, clinical expertise, and professional levels to match those roles [24,33,40].

7.3. Experienced and appropriately trained nursing staff are available for support and care of CoHD patients at all stages and within all areas of care delivery (including cardiac surgery and cardiac catheterisation/intervention).

7.3.1 Appropriately trained staff are provided to support the requirements of general cardiac care within CoHD Services Type 3 or Type 2 or ACHD Services, and some suitably structured CoHD Services Type 1.

7.3.2 Each subspecialty area in a CoHD Service Type 3 or Type 2 or ACHD Service (Comprehensive) has a dedicated CoHD nurse of at least Advanced Practice level.

7.3.3 Nursing staff play a central role in care coordination, liaison, communication and care delivery as an inpatient and outpatient in collaboration with the multidisciplinary team. They lead and participate in CoHD research to enhance knowledge and care delivery.

7.3.4 Specialist cardiac nursing care includes support during the preoperative, intraoperative, postoperative inpatient and post-discharge phases.

7.3.4.1 Specialist cardiac surgical intraoperative nursing care includes proficiency in perioperative instrumentation and theoretical knowledge of CoHD and intraoperative care [33].

7.3.4.2 Intraoperative nursing services provide procedural support when needed across perioperative specialties including interventional cardiac catheter procedures, extracorporeal life support and inter-hospital retrieval programs (where transplant services are established) [33].

7.4. A CoHD specialised nurse and/or Advanced Practice Nurse is readily available in Paediatric CoHD Services Type 3 and Type 2 and ACHD outpatient clinics and at key stages of interaction with CoHD Services including some suitably structured CoHD Services Type 1.

The allocation of nursing resources is informed by the coordinated care and expert multidisciplinary collaboration required to support patients, families and carers during key stages of their CoHD journey.

Key areas of interaction include fetal cardiac services, planned admission for procedures and treatment, subspecialty clinics, transition and specialist ACHD nursing care and support [26,28,70,71].

7.5. Patients with complex needs have an Advanced Practice Nurse/ specialised nurse team responsible for coordinating their care throughout the whole of life including end of life [24,33,40,72].

Implementation Pathway

Implementation will be managed by relevant health professionals, National and State accrediting bodies, relevant Colleges, State Health Jurisdictions, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 8. Mental Health and Psychological Care

The CoHD Standards for Mental Health and Psychological Care outline the requirements for access to specialised mental health care for patients, families and carers, integrated into CoHD healthcare throughout life, inclusive of end-of-life and bereavement care.

Mental health, broadly defined, encompasses our emotional, psychological, social, cultural, and spiritual wellbeing. Our mental health affects how we think, act, and feel (both emotionally and physically). It influences our sense of self, how we manage stress and adversity, how we learn and work, relate to others, make decisions and contribute to our community.

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 wellbeing, and prioritise opportunities to access mental health care in ways that deeply respect and align with their values, preferences and cultural beliefs [4]. Embedding mental health professionals within specialised CoHD Services (Paediatric and ACHD) is part of comprehensive care delivery and can normalise emotional responses to cardiac challenges, reduce stigma associated with seeking mental health care, optimise healthcare coordination, and improve timely access to appropriate mental health services from experienced providers [73,74]. This allows for a comprehensive approach to patient and family care, creating a healing environment to support and strengthen patient and family wellbeing.

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 all stages of treatment and transitions, to end-of-life and bereavement care [28,73]. Patient- and family- centred mental health care must be integrated into routine paediatric and adult CoHD care, be equitable and inclusive of all, and be delivered in line with the principles of trauma-informed care, emphasising patient and family choice, dignity, empathy, compassion, psychological safety and healing [32,75].

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, and across the whole of life [4].

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 [4,76,77].

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 to discuss 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 between patients, families, and health professionals, (f) demonstrates sensitivity to triggers that may risk re-traumatisation, (g) recognises the potential additional distress for patients with CoHD and their families and carers when pandemics or other impactful global health events occur, (h) values therapeutic engagement, and (i) promotes healing, recovery and wellbeing [78].*

8.3. CoHD Services (Paediatric and ACHD) include specialised mental health professionals to provide education, screening, assessment, intervention and treatment, and excellence in mental health care for patients with CoHD and their families and carers [79].

Members of the mental health team include psychologists, social workers, child life therapists, occupational, art 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 the interdisciplinary care team, including medical specialists, nurses, primary care doctors (local GPs), allied health professionals and palliative care specialists. They also work closely with a range of local, community and educational services, including Aboriginal and Torres Strait Islander Health Workers and Health Practitioners and schools [80,81].

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 [82,83].

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 life span, and the interconnectedness of physical and mental health. These are provided in formats that are culturally and developmentally appropriate and in accordance with trauma-informed care principles [84].

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 Services (Paediatric and ACHD) provide routine mental health screening and assessment, led by mental health professionals using standardised measures, to identify and respond to patient and family needs [74].

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

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 [85].
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, risk of harm), and (e) resilience factors (e.g. healthy coping, social support, engagement with support services) [86].

8.5.2 Assessment will be offered by mental health professionals to 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 an assessment of their relationship with primary carers as well as the needs of the carers themselves [71].

8.5.3 Screening and assessment findings are routinely documented, openly and empathically discussed with patients and family members, communicated (as appropriate) with members of the interdisciplinary care team and used to directly inform care recommendations [71,85].

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. These plans highlight strengths and offer pathways to address risks and difficulties in line with the person's and family's beliefs, values, goals and needs.

CoHD Services (Paediatric and ACHD) 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 the cardiac patient and family continuum of care. This includes 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 their lives [25,32,74,87].

8.7.1 Patients and family members, including siblings have 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.

8.7.2 End-of-life care for infants, children, adolescents and adults with CoHD will be psychologically informed and 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 [88].

8.8. Throughout cardiac care, infants, children, adolescents and adults with CoHD have access to developmentally appropriate play, music therapy, art-based therapies, and opportunities for social interaction, including peer-to-peer connection [80,85,87].

These opportunities should be facilitated by a mental or allied health professional in collaboration with caregivers and the healthcare team, taking into 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 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 healthcare team, as needed [*89*].*

8.10. Mental health professionals have access to patient medical records, and mental health information is seamlessly integrated into the electronic medical record, as appropriate [84].

8.11. CoHD Services (Paediatric and ACHD) prioritise and cultivate the mental health and wellbeing of 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 often insufficient to support the mental health and wellbeing of health professionals [*90*].*

8.12. CoHD Services (Paediatric and ACHD) have an identified mental health lead with responsibility for managing the dedicated cardiac mental health program.

The Mental Health Lead should ideally be part of the Service leadership team.

Implementation Pathway

Implementation will be managed by relevant health professionals, relevant Colleges, State Health Jurisdictions, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 9. Neurodevelopmental and Neurocognitive Care

The CoHD Standards for Neurodevelopmental and Neurocognitive Care describe the requirements for comprehensive, coordinated neurodevelopmental and neurocognitive surveillance, screening, evaluation and re-evaluation for patients with congenital heart disease throughout life, and their families and carers.

Developmental, behavioural, and psychological difficulties are among the most prevalent comorbidities of CoHD. As a group, children with complex congenital heart disease are at increased risk of neurodevelopmental delay, disorders, or disabilities [70,71,91], compared with those with milder or no congenital heart disease. This does not mean all patients with complex congenital heart disease have these difficulties (in fact, many do not), but the number of infants, children, adolescents, and adults with complex congenital heart disease and neurodevelopmental or neurocognitive challenges is significantly higher than in the general population. These difficulties can profoundly affect physical and mental health, educational and employment opportunities, relationships, and overall quality of life. A significant proportion of children with complex congenital heart disease require specialised habilitative services, supportive therapies, and educational supports into adulthood. Early identification of, and intervention for developmental concerns is critical to the wellbeing of children with CoHD and the responsibility of health professionals as an integral function of health care [92,93].

Access to individualised, patient- and family-centred neurodevelopmental care or neurocognitive evaluation and 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. It must be equitable, 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, therefore continued monitoring is critically important [93,94].

Surveillance is *'the process of recognising individuals who may be at risk for developmental delay, disorder or disability*'.*

Screening is *'the use of standardised tools to identify and refine that recognised risk'.*

Evaluation is *'a complex process to identify specific developmental delays, disorders or disabilities that affect an individual'* [95].

*'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" [92].

9.1. From the time of diagnosis, and throughout the whole of life, patients with CoHD and their carers must have access to high-quality, up-to-date information and education on neurodevelopment and neurocognitive functioning. This information must be tailored to their heart condition and provided in formats that are culturally, linguistically and developmentally appropriate, and in line with trauma-informed care [93,95]. In the context of fetal cardiac diagnosis, provision of information and education to caregivers may begin as early as during pregnancy.

9.2. During hospitalisation, patients with CoHD receive individualised, evidence- based, patient- and family-centred developmental care to minimise the stress of the hospital setting. This must support child–parent and sibling–sibling bonding and attachment and provide an optimal environment for brain development [96].

An individualised approach must be taken towards all caregiving interactions, with continual responsiveness to each infant or child's individual competencies, vulnerabilities and thresholds. The goal is to promote 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 and carers are encouraged to have maximum involvement in decision-making for their child and are supported to engage in cue-based care, 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 about their presence or involvement during their child's procedures or resuscitative interventions.

9.3. Inpatient CoHD Services (Paediatric and ACHD) 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 [93,94].

9.4. Infants, children and adolescents 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 [93,94,97].

9.4.1 Formal screening involves administering standardised, age-appropriate developmental screening instruments at regular intervals throughout infancy, childhood and adolescence. 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 infants, children and adolescents with CoHD at risk of developmental delay or disorder are referred for and have access to standardised, age-specific developmental and medical evaluation and re-evaluation over time [93,95,97].

Patients with CoHD who are at high risk of developmental delay or disorder undergo periodic, formal developmental and medical evaluation beginning in early infancy and repeated at age 6 months, 12–18 months, 3–5 years, 11–12 years and 15–17 years, as well as after transitioning to adult cardiac care and at any time that developmental concerns are identified. This will 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. Adults with CoHD who are at risk of neurocognitive difficulties or disorder have access to standardised, performance-based neuropsychological evaluation and re-evaluation over time [89,91,97,98].

9.7. Infants, children, adolescents, and adults with CoHD and neurodevelopmental delay, disorder or disability have access to individualised, evidence-based interventions, therapies, supports, and services, including specialised habilitative, special education, and disability services [97,99,100].

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. Patients with CoHD 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, have access to social and financial services and resources, as needed [93,96,99].

Early referral to government and charitable support services including, but not limited to, childcare, education, 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 healthcare team as needed.

9.10. The CoHD Services (Paediatric and ACHD) includes, or directly partners with, specialised professionals and services to provide specific information, education, screening, evaluation, interventions and therapies, and excellence in individualised neurodevelopmental or neurocognitive care for patients with CoHD throughout the whole of life [91,93,99,100].

Because patients with CoHD can manifest difficulties in multiple areas of neurodevelopmental or neurocognitive functioning, evaluations require an interdisciplinary team approach. Team composition should be tailored to best address the individual 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. Educational 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 detecting neonatal brain injury including stroke in congenital heart disease at the time of publishing the CoHD Standards 1st Edition [101].

MRI both pre-operatively and post-operatively should be considered in neonates with congenital heart disease requiring surgery, for the highest yield in detecting brain injury including stroke.

Implementation Pathway

Implementation will be managed by relevant health professionals, relevant Colleges, State Health Jurisdictions, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress/achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 10. Priority Populations

The CoHD Standards for Priority Populations outline the requirements for equitable access to coordinated CoHD healthcare for patients/families and carers that is culturally respectful, compassionate, responsive, grounded in empowerment and optimises cultural, social and environmental support. Priority populations include Aboriginal and Torres Strait Islander children and adults, those with refugee backgrounds and patients, families and carers (including children and adults) living in disadvantage with limitations in access to healthcare services. Flexible interdisciplinary strengths-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 Services (Paediatric and ACHD) to identify the needs of, and improve CoHD care delivery to, children, adults, families and carers from priority populations including Aboriginal and Torres Strait Islander peoples and refugees [10,102–104].

10.1.1 Protocols are developed in conjunction with the broader health service to identify and provide solutions to provide equitable access to services.
10.1.2 Protocols consider the impact of social, relocation and intergenerational trauma.
10.1.3 Protocols provide specific prioritised triage, assessment and management pathways.
10.1.4 Protocols are sensitive to the cultural and social requirements of priority populations.
10.1.5 Protocols identify key drivers to CoHD health risks, with a focus on common conditions affecting priority communities including rheumatic heart disease (RHD).

10.2. Environmental health assessments are a central part of care [102].

A healing, strengths-based approach is used. Frameworks are grounded inpatient empowerment and an openness to do things differently [14].

10.3. For families with limited English proficiency, professional interpreters are used for all consultations to ensure equitable health communication and health education [103,105].

10.3.1 Care protocols and service planning for patients and families from culturally diverse backgrounds, and who have CoHD, centre around patient, family and carer participation as equal partners in treatment and management and ensure equitable health communication, health education and health literacy [102,105,106].
10.3.2 Information is communicated through professional interpreters (when applicable) with relevant and culturally appropriate written, verbal and audio-visual materials [102,104,105,107].
10.3.3 Information is available and understandable for the child, adolescent, adult, family and carers.

10.4. Care protocols incorporate specific considerations of safety [11,65,102,104].

This includes access to social work support for patients and families and community Aboriginal Health Care Workers/Practitioners for Aboriginal populations and bicultural workers for refugee-background populations.

Cultural safety is a primary consideration, including clarification and understanding of family, kinship and cultural protocols. These elements extend across all areas of cardiac care including procedural consent.

Implementation Pathway

Implementation will be managed by relevant health professionals, regional services, relevant Colleges, State Health Jurisdictions, and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress / achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 11. Research

The CoHD Standards for Research focus on improved outcomes, encompassing the whole of life, that is collaborative, sustainable, nationally and internationally benchmarked and integrated into CoHD Services (Paediatric and ACHD).

The national CoHD research goals are directed towards discovery, translating evidence into practice, reducing the burden of disease [107], and improving outcomes and the delivery of care for patients of all ages with CoHD and their families and carers.

11.1. Scientists and researchers of all backgrounds collaborate to deliver improved outcomes through connections and planning with clinical staff, patients, families and carers.

11.1 Services facilitate and engage in research to improve knowledge, care processes and patient and family outcomes.

11.2 Services facilitate and engage in research that encompasses a whole-of-life approach from fetal life to death, from bench to patient, and includes 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 [108].

11.3 Services demonstrate how they embed research and evidence into their practice.

Implementation Pathway

Implementation will be managed by relevant health professionals and researchers, National and State funding bodies, relevant Colleges, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress / achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Standard 12. Health Information and Digital Communication Technology

Continuing improvements in health information and digital communication technology combined with the rapid increase in health data inform and enable 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 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 for CoHD Services (Paediatric and ACHD) [21]. 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 is supported by, area health services and State and Federal health authorities, with input from patients, families and carers affected by CoHD with the objective of providing seamless delivery of care [20,23].

12.1.2 Telehealth is implemented and used as a basic, requirement for CoHD Services (Paediatric and ACHD) [21,23].

12.1.3 Telehealth skills and capacity are included in CoHD Services (Paediatric and ACHD).

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 [109].

12.2. Coordinated care is supported through a digitally enabled medical record that is maintained by all services for all patient contacts and across all disciplines within the multidisciplinary team [21].

12.2.1 The electronic medical record provides rapid access to easily identifiable CoHD-relevant data and allows for data entry of records by all members of the multidisciplinary team 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.

Implementation Pathway

Implementation will be managed by relevant health professionals, relevant National and State bodies, relevant independent funding bodies, State Health Jurisdictions, and National and State Governments. Reference to consumers will be important through this process. Outcomes should be managed based on progress / achievement of targets as outlined in the relevant Standard. The CoHD Standards Management Committee will assist with coordination and facilitation.

Section Three. Appendices

Appendix A. CoHD Standards Steering Committee Members

CoHD Standards Steering Committee Members are listed in Table 3.

Table 3 **CoHD Standards Steering Committee Members**

Name	Qualifications	Professional Role
Prof. Gary Sholler AM[1-3]	MBBS, FRACP, FCSANZ, FACC	Paediatric and fetal cardiologist; **Co-Chair National CoHD Standards**
Dr Lisa Selbie[4,5]	PhD	Medical researcher, Chair HeartKids Research Advisory Committee; **Co-Chair National CoHD Standards**
A/Prof. Luke Burchill[6-8]	MBBS, PhD, FRACP	Adult Congenital Heart Disease (ACHD) cardiologist
Prof. Michael Cheung[9]	BSc, MBChB, MRCP, MD, FRACP	Paediatric Cardiologist and Chair of Paediatric and Congenital Council, CSANZ
Dr Shakira Donovan[10]	BPsych, MD	Doctor of Medicine and adult with CoHD
Ms Caitlin Elliott[9]	BNS, NPc, PGDipNP(Paed), MC-ANPN	Paediatric cardiac nurse practitioner
Ms Lesley Jordan[4]	Dip App Sc(Nursing), CM, MHM, GAICD	HeartKids CEO
Prof. Nadine Kasparian[1,11]	PhD, MAPS	Psychologist and Director of Heart and Mind Wellbeing Center and Heart Disease and Mental Health Research
Ms Jessica Keating[4]	BN, MHA, MPH	HeartKids Action Plan Project Manager
Ms Kristie Molloy[12]	LLB/LP, BSc(Psych)	Barrister and parent of a child with CoHD
Dr Mary Tallon[4,13,14]	BN, RM, MScN, PhD	HeartKids CoHD Standards project coordinator Paediatric cardiology clinical nurse specialist
Ms Elsa Van Wijk[4,15]	LLB/BIntBus, GAICD	Board Member, Heartkids and parent of a child with CoHD
A/Prof. Prem Venugopal[16,17]	MBBS MS FRACS (CTH)	Paediatric Cardiac Surgeon

[1] Sydney Children's Hospitals Network, Sydney, NSW, Australia (AUS)

[2] Heart Centre for Children, Sydney, NSW, AUS

[3] The University of Sydney, Sydney, NSW, AUS

[4] HeartKids Ltd, Parramatta, NSW, AUS

[5] School of Biotechnology & Biomolecular Sciences, University of NSW, Sydney, AUS; Advanced Academic Program in Biotechnology, Johns Hopkins University, Baltimore, MD, USA

[6] The Royal Melbourne Hospital, Parkville, Vic, AUS

[7] The University of Melbourne, Parkville, Vic, AUS

[8] Mayo Clinic, Rochester, New York, NY, USA

[9] The Royal Children's Hospital, Parkville, Vic, AUS

[10] The University of Notre Dame, Fremantle, WA, AUS

[11] Heart Institute and Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital, Ohio, OH, USA

[12] College of Business, Government and Law, Flinders University, Adelaide, SA, AUS

[13] School of Nursing, Curtin University, Bentley, WA, AUS

[14] Perth Children's Hospital, Nedlands, WA

[15] Australian Institute of Company Directors, NSW, AUS

[16] Queensland Children's Hospital, South Brisbane, Qld, AUS

[17] The University of Queensland, Herston, Qld, AUS

Appendix B. Working Group Chairs and Members

CoHD Working Group Chairs and Member are listed in Table 4.

Table 4 Working Group Chairs and Members

Name	Qualifications	Specialty and State	Working Group(s)*
A/Prof. Nelson Alphonso[5,16]	MBBS, FRACS, FRCSI	Paediatric Cardiac Surgery, QLD	Cardiac Surgery, Research
Dr David Ray Andrews[11,33,34]	MBBS, FRACS, FCSANZ	Paediatric Cardiac Surgery, WA	Cardiac Surgery, Adult CHD
Dr Julian Ayer[8,13]	MBBS, FRACP, PhD	Paediatric Cardiology, NSW	Co-Chair Research, Transition, Regional
Dr Julia Baezinger[8,13,15,44,45]	MScPsych, PhD HlthSci, GradDip PubHlth	Clinical Psychology, NSW	Mental Health, Neurodevelopmental Care
Prof. Nadia Badawi AM[8,13]	MBBCh (Hons I) DCH, MSc, PhD, FRCPI, FRACP	Neonatology, NSW	Mental Health, Neurodevelopmental Care
Dr David Baker[13,14]	MBBS, FRACP	ACHD Cardiology, NSW	Transition
Ms Charlotte Barr[1]	BPhysio, PGCert PaedPhys, MPhty	Physiotherapy, VIC	Mental Health, Neurodevelopmental Care, Cardiac Surgery
Mr Daniel Beard[3]	CertMediaCmn	CoHD Patient Community WA	Consumer
Prof. Christian Brizard[1,10]	MS, MD	Paediatric Cardiac Surgery, VIC	Advisory Committee Member
Dr Andrew Bullock[11,33]	MBBS	Paediatric and ACHD Cardiology, WA	Advisory Committee Member (2019-2020)
Prof. David Celermajer AO[8,13,14,32]	MBBS (Hons), MSc (Oxon), PhD (London), DSc (Sydney), FAA, FAAHMS, FRACP, FCSANZ, FAHA, FHKCC (Hons)	ACHD Cardiology, NSW	ACHD
Ms May M Chan[1]	RN, BN, PostGrad Sci, PeriOp	Intraoperative Nursing, VIC	Cardiac Surgery
Dr Julia Charlton[1,2,10,19]	MBBS, FRACP, GradDipMentHlthSc, PhD	Neonatology, VIC	Mental Health, Neurodevelopmental Care
Ms Emily Chapman[8]	BN, MAdvN	Nursing, NSW	Transition
Clinical A/Prof. Sarah Cherian[11,35,36]	MBBS (Hons), FRACP, PhD	Paediatric Refugee Health, WA	Priority Populations
Prof. Michael Cheung[1,2,10]	BSc, MBChB, MD, FRCP (UK), FRACP	Paediatric Cardiology, VIC	Chair Large Centres, Small Centres, Regional, Cardiology, Cardiac Surgery, ACHD
Ms Beth Chidlow[11]	BScN, MN (NursPrac)	Nursing, WA	Advisory Committee Member (2019-2020)
A/Prof. Rachael Cordina[13,14]	MBBS, PhD, FRACP	ACHD Cardiology, NSW	Deputy Chair Adult CHD, Mental Health, Neurodevelopmental Care, Cardiology
Ms Evelyn Culnane[1]	BEd (Hons)	Education, VIC	Chair Transition
Dr Shakira Donovan [3,6]	BPsych, MD	CoHD Patient Community, WA	Chair Consumer
Mrs Marjorie Doyle[3]	PostGradCertCommWel	CoHD Patient Community, VIC	Priority Populations, Consumer
Ms Karen Eagleson[4,5,16]	RN, MHSt	Nursing, QLD	Mental Health, Neurodevelopmental Care, Nursing, Research
Dr Lucas Jon Eastaugh[1,2]	MBBS, FRACP, FCSANZ	Paediatric Cardiology, VIC	Deputy Chair Cardiology, Regional, ACHD
Ms Caitlin Elliott[1]	NPc, RN, MC-ANPNP, PGDipNP(Paed), BNS	Nursing, VIC	Chair Nursing
Ms Mia Evangelellis[3]	BEd	CoHD Patient Community WA	Consumer
Ms Erin Ferguson[25]	BN	Nursing, Regional QLD	Nursing, Regional, Priority Populations

Table 4. **(continued).**

Name	Qualifications	Specialty and State	Working Group(s)*
Prof. Marino Festa[8]	MBBS, MRCP (UK), FCICM, MD (Res)	Paediatric Intensive Care, NSW	Large Centres
Mrs Annabel (Kirsten) Finucane[7,24,39]	MBChB, FRACS General Surgery, FRACS Cardiac Surgery	Paediatric Cardiac Surgery, NZ	Cardiac Surgery
Prof. Jeffrey Fletcher[28,29]	BSc (Hons) MBBS, DCH, FRACP, PhD	Paediatric Nephrology, Regional NSW	Deputy Chair Regional, Research
Prof. Tom Gentles[7,42]	BHB, MBChB, DCH, FRACP, FCSANZ	Paediatric Cardiology, NZ	Cardiology
Ms Kate Harley[1]	BN	Nursing, VIC	Nursing
Ms Rebecca Henderson[8]	MBA	Cardiac Research, NSW	Mental Health, Neurodevelopmental Care
A/Prof. Christine Jeffries-Stokes[37,38]	MBBS, BMedSc, MPH, FRACP, PhD	Paediatrics, Regional WA	Priority Populations, Regional
A/Prof. Rob Justo[4,5,16]	MBBS, FRACP, FCSANZ	Paediatric Cardiology, QLD	Chair Cardiology. Regional, Priority Populations, Mental Health, Neurodevelopmental Care
Prof. Nadine Kasparian[8,17,21,44,45,47]	BAPsych (Hons I), PhD, MAPS	Psychology, Neurodevelopment, Allied Health, NSW & USA	Chair Mental Health, Neurodevelopmental Care, Research
Dr Andrew Kelly[9]	MBBS, DCH (Adel) FRACP, FCSANZ	Paediatric Cardiology, SA	Co-Chair Small Centres
Prof. Igor Konstantinov[1,10]	MD, PhD, FRACS	Paediatric Cardiac Surgery, VIC	Cardiac Surgery, Research
Ms Karen LeClair[8]	RN, MN	Nursing, NSW	Mental Health, Neurodevelopmental Care, Nursing, Transition
Dr Suzanne Long[3]	BPhysio (Hons), PhD	HeartKids, Allied Health, VIC	Mental Health, Neurodevelopmental Care
Ms Rachel Maree[20]	BA	CoHD Parent Community, QLD	Consumer, Mental Health, Neurodevelopmental Care
Dr Fiona MacFarlane[4]	MD, ANZCA	Paediatric Anaesthetics, QLD	Cardiac Surgery
Ms Ros Marsden[3]	BA	CoHD Parent Community, VIC	Mental Health, Neurodevelopmental Care
Mr Jonathan Mackley[3,20]	MComm	CoHD Patient Community, NSW	Consumer (2020-2021)
Dr Jacob Matthew[1,2,10]	MBBS, FRACP	ACHD Cardiology, VIC	Cardiology
Ms Kenya McAdam[27]	CertIIBus	CoHD Patient Community, NT	Priority Populations
Mr Patrick McConville[3,20]	BA (Hons), MBioethics	CoHD Patient Community, VIC	Mental Health, Neurodevelopmental Care, Consumer
Ms Lindsay Meltz[8]	BN, MN	Nursing, NSW	Regional
Dr Johnny Millar[1,2,10]	MBChB, PhD	Paediatric ICU, VIC	Large Centres
Ms Kristie Molloy[46]	LLB/LP, BSc (Psych)	CoHD Parent Community, SA	Consumer
Ms Gemma Moon[29]	BN, MMhN	CoHD Patient Community, NSW	Mental Health, Neurodevelopmental Care
Ms Katherine Morlidge[11]	BScNurs (Hons), GradCert Child/AdoleHlthNurs, DipChildNurs	Nursing, WA	Nursing
Ms Dominique Morsman[1]	RN, BN, PostGradDip CardiacCare, PostGradCert Paed, Intensive Care	Nursing, VIC	Deputy Chair Nursing
Dr Jim Morwood[4]	MBBS, FRACP, FCSANZ	Paediatric Cardiology, QLD	Cardiology
A/Prof. Mugur Nicolae[5,18]	MD FRACP FRCPC FCSANZ	ACHD Cardiology, QLD	Chair Adult CHD, Cardiology, Research, Cardiac Surgery

Table 4. **(continued).**

Name	Qualifications	Specialty and State	Working Group(s)*
Mr Killian O'Shaughnessy[8]	CCP (Aust)	Paediatric Perfusion, NSW	Cardiac Surgery
Ms Diane Oake[8]	BAPsych (Hons), MPsych	Clinical Psychology, NSW	Mental Health, Neurodevelopmental Care
Dr Yishay Orr[8,40]	MBBS, BSc (Med) (Hons), PhD, FRACS	Paediatric Cardiac Surgery, NSW	Deputy Chair Large Centres, Cardiac Surgery
Ms Jennifer Orchard[4]	RN, BHSci (Nurs), MHPracChildHlth	Nursing, QLD	Cardiac Surgery
A/Prof. Georgia Paxton[1,10]	BS, MBBS, MPH	Paediatric Refugee Health, VIC	Priority Populations
Ms Shelley Paine[4]	BN, GradDipN	Nursing, QLD	Nursing, Transition, Regional
Ms Elle Pendrick[3]	BA MIH	CoHD Patient Community NSW	Deputy Chair Consumer, Regional, Mental Health, Neurodevelopmental Care
Dr Madeleine Pidcock[8,17]	BScPsych (Hons I), PhD (ClinPsych)	Clinical Psychology, NSW	Mental Health, Neurodevelopmental Care
Dr Nick Piggot[8]	MBBS	Paediatric ICU, QLD	Large Centres
A/Prof. Enzo Porello[2,10,12]	PhD	Medical Research, VIC	Research
Ms Tania Quinn[8]	Aboriginal and Torres Strait Islander Health Practitioner	Social Work, Palliative Care/ Chronic & Complex Needs, NSW	Mental Health, Neurodevelopmental Care
Dr James Ramsay[11]	MBBS, FRACP	Paediatric Cardiology, WA	Chair Small Centres, Cardiology, Regional, Priority Populations.(2019-2021)
Dr Benjamin Reeves[25,43]	MBBS, FRACP	Paediatric Cardiology, Regional QLD	Regional, Priority Populations
Dr Bo Reményi[22,23]	MBBS, FRACP	Paediatric Cardiology, NT	Chair Priority Populations, Regional, Cardiology
Ms Sonia Riley[4]	BOccThy (Hons)	Occupational Therapy, QLD	Mental Health, Neurodevelopmental Care
Dr Cameron Seaman[11]	MBBS, FRACP	Paediatric Cardiology, WA	Small Centres
Dr Megan C Sherwood[8]	MBBS, FRACP, FCSANZ	Paediatric Cardiology, NSW,	Cardiology
Prof. Jon Skinner[7,8]	MD	Paediatric Cardiology, NSW	Research
Dr Stephen Shipton[11]	MB, ChB, MRCP,FCPaed, MMed, FRACP	Paediatric Cardiology, WA	Co-Chair Small Centre (Current)
Ms Jessica Suna[5,28]	BN, BAS, GradCert Clinical Trial Management, MHSc (Research)	Research, QLD	Research
A/Prof. Prem Venugopal[4,5]	MBBS, FRCS (CTh), FRACS	Paediatric Cardiac Surgery, QLD	Chair Cardiac Surgery, Cardiology,
Ms Michelle Vink[9]	RN, BN, PostGradDip AdvClinNurs	Nursing, SA	Nursing
Ms Vicki Wade[27]	MScNurs, MPH	RHD Australia, NT	Priority Populations
Ms Lynette Ward[8]	BAppSc (OccThy)	Occupational Therapy, NSW	Mental Health, Neurodevelopmental Care
Ms Karen Weir[8]	BTch (0–5)	Child Life Therapist, NSW	Mental Health, Neurodevelopmental Care
Prof. Robert Weintraub[1,2,10]	MBBS (Hons), FRACP, FACC, FCSANZ	Paediatric Cardiology, VIC	Co-Chair Research
Dr Gavin Wheaton[9,26]	MBBS, FRACP, FCSANZ	Paediatric Cardiology, SA	Chair Regional, Transition, Priority Populations, Cardiology
Mrs Holly Williams[3]	BEng	CoHD Parent Community, QLD	Transition, Mental Health, Neurodevelopmental Care, Consumer
Ms Carlie Willock[3]	BNSci	CoHD Parent Community QLD	Consumer

Table 4. (continued).

Name	Qualifications	Specialty and State	Working Group(s)*
Ms Laura Yeates [14,30,31]	BSc (Hons), GradDipGen Couns FHGSA (Genetic Counselling)	Genetic Counselling, NSW	Mental Health, Neurodevelopmental Care, Research
A/Prof. Dominica Zentner[10,41]	MBBS (Hons), FRACP, PhD	ACHD Cardiology, VIC	Adult CHD

[1]The Royal Children's Hospital, Parkville, VIC, Australia (AUS)
[2]Murdoch Children's Research Institute (MCRI), Parkville, VIC, AUS
[3]HeartKids Ltd, Parramatta, NSW, AUS
[4]Queensland Children's Hospital, South Brisbane, Qld, AUS
[5]The University of Queensland, Herston, Qld, AUS
[6]University of Notre Dame, Fremantle, WA, AUS
[7]Starship Children's Hospital, Greenlane, NZ
[8]Sydney Children's Hospital Network, Sydney, NSW, AUS
[9]Women's and Children's Hospital, North Adelaide, SA, AUS
[10]The University of Melbourne, Parkville, Vic, AUS
[11]Perth Children's Hospital, Nedlands, WA, AUS
[12]Melbourne's Centre for Cardiovascular Genomics and Regenerative Medicine, MCRI, Parkville, Vic, AUS
[13]The University of Sydney, Sydney, NSW, AUS
[14]Royal Prince Alfred Hospital, Camperdown, NSW, AUS
[15]University of Lucerne, Luzern, Switzerland
[16]Queensland Paediatric Cardiac Research, Children's Health Queensland, South Brisbane, Qld, AUS
[17]University of New South Wales, Kensington, NSW, AUS
[18]Mater Hospital Services, Brisbane, Qld, AUS
[19]Mercy Hospital for Women, Heidelberg, Vic, AUS
[20]Australia and New Zealand Fontan Advocacy Committee, AUS and NZ
[21]Heart Institute and Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital, Ohio, OH, USA
[22]Menzies School of Health Research, Charles Darwin University, Darwin, NT, AUS
[23]Royal Darwin Hospital, Darwin, NT, AUS
[24]Trustee and Surgeon of Heart4Kids Organisation, NZ
[25]Cairns Hospital, Cairns, Qld, AUS
[26]University of Adelaide, Adelaide, SA, AUS
[27]Rheumatic Heart Disease (RHD) Australia, Darwin, NT, AUS
[28]The Tweed Hospital, Tweed Heads, NSW, AUS
[29]Queensland Paediatric Specialists, Southport, Qld, AUS
[30]Agnes Ginges Centre for Molecular Cardiology, Centenary Institute, Sydney NSW, AUS
[31]Clinical Genomics Laboratory, Centre for Population Genomics, The Garvan Institute of Medical Research, Darlinghurst, NSW, AUS
[32]Heart Research Institute, Sydney, NSW, AUS
[33]Fiona Stanley Hospital, Murdoch, WA, AUS
[34]Sir Charles Gairdner Hospital, Nedlands, WA, AUS
[35]The University of Western Australia, Perth, WA, AUS
[36]Telethon Kids Institute, Perth, WA, AUS
[37]Kalgoorlie Hospital, Kalgoorlie, WA, AUS
[38]Rural Clinical Schools of Western Australia, University of WA, WA, AUS
[39]World Society of Pediatric and Congenital Cardiac Surgery (Global)
[40]Western Sydney Local Health District (Westmead Hospital), Westmead, NSW, AUS
[41]The Royal Melbourne Hospital, Parkville, Vic, AUS
[42]The University of Auckland, Auckland, NZ
[43]Heart Rx Cardiology, Cairns North, Qld, AUS
[44]Cincinnati Children's Hospital, Cincinnati, OH, USA
[45]University of Cincinnati College of Medicine, Cincinnati, OH, USA
[46]College of Business, Government and Law, Flinders University, Adelaide, SA, AUS
[47]Heart Centre for Children, Sydney, NSW, AUS
*Advisory Committee Members who accepted a Working Group Chair role are identified as Chair/Co-Chair/Deputy Chair

Appendix C. Glossary of Terms And Abbreviations

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 are 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) is a nurse practising at an advanced practice level incorporate professional leadership, education, research and support of systems in their field of healthcare. (Also see Nursing roles).

Allied health professionals use evidence-based practices to prevent, diagnose and treat various conditions and illnesses. They often work in multidisciplinary health teams to provide specialised support to suit an individual's needs. In Australia, allied health professionals have a university-level qualification in a recognised allied health field that is accredited by their relevant national accreditation body or national professional organisation with clearly defined membership criteria and national entry- level competency standards and assessment processes, autonomy of practice and a defined scope of practice.[110]

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 imaging 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 most patients with onset of an abnormality in childhood, this will persist throughout life, with the consequences ranging from trivial to complex and involved.

CoHD services refers to any service that contributes to the improved health of an individual, family or carer and is not limited to medical or healthcare services. Examples of these services can include health education, health promotion, peer-support, recreation, financial, housing or sanitation services.

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 affects the functioning of the heart and 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/participation 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 diverse describes the many Australian communities that are originally from another country. This population is defined by the country of origin, language spoken and English proficiency.

Culture is the combination of the knowledge, beliefs, values and behaviours of 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 people.

Cyanosis/cyanotic heart disease is where the oxygen level in the body's 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 complex.

'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" [92]. (See also High Risk for developmental disorder and developmental delay).

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 that 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 is the consensus that healthcare practices be based on scientific evidence.

Excellent care is, for the purposes of these CoHD Standards, defined as care that is safe, person/family-centred, effective and coordinated.

Family includes those who are considered to be family by the person with CoHD and may extend beyond the traditional nuclear and extended family. The term ‘patients and families and carers’ 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, that is diagnosed before birth, resulting in patients requiring a range of unique management plans and service 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 and 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.

High Risk for ‘**developmental disorder**’ or ‘**developmental disability**’

The following groups should be considered at high risk for Developmental Delay.

a. Infants requiring open heart surgery (cyanotic and acyanotic)
b. Children with other cyanotic heart lesions not requiring open heart surgery in infancy.
c. Children with any combination of CHD and other co-morbidities
d. Other conditions determined at the discretion of the medical providers [83].

Healthcare costs are those costs borne by the healthcare system, community and patients (or their 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 people have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.

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 a workforce operating from a range of institutions, both public and private.

Jurisdictions in Australian healthcare represent various geographical boundaries with allocated responsibility for administration, legislation and regulation of healthcare practice and services across Australia. Jurisdictional structures include Australian Federal Government, State and Territory Governments [111], area health services, and other officially designated health and social organisations.

Mental health and wellbeing can mean different things to different people depending on beliefs, values, perspectives and experiences. In these 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 focuses on reducing mental health burden and optimising emotional and psychological wellbeing for all those affected 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 involves a range of healthcare providers working together to deliver comprehensive patient care. They usually focus 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 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 needed.

Nursing roles include Advanced Practice Nurses (APN) who are *specialist* nurses with extensive knowledge and experience. APN roles consist of Clinical Nurse Consultants (CNC) and Nurse Practitioners (NP). CNCs provide expert clinical consultancy and leadership in specialist clinical practice and education. NPs are autonomous practitioners in advanced clinical nursing in a specialist area. *Specialised* nursing roles include, but are not limited to, Clinical Nurses (CN), Clinical Nurse Specialists (CNS) and Care Coordinators. CNs, CNSs, and Care Coordinators are registered nurses who provide senior nursing leadership in service delivery, care coordination and education. All nurses working in CoHD Services hold current registration with the Australian Health Practitioner Regulation Agency (Ahpra) and hold qualifications and experience deemed appropriate for their positions by state and territory health jurisdictions.

Patients, families and carers, 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 serve 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- and family-centred care is defined as healthcare that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure healthcare decisions are respectful of, and respond 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 that has (or had) a specific characteristic at a given time. In medicine, this is typically the proportion of the population that experiences an illness, condition or risk factor.

Primary health care for most patients is provided by a primary care clinician who will be their first point of contact in the 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 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 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 diverse populations (including refugees).

Quality of life describes people's views about their lives in the context of culture, values, expectations, physical functioning and emotional and social wellbeing [112].

Refugee(s) refers 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 a refugee experience in their country of origin but do not have formal refugee status [104].

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 is a healthcare activity supported at a distance by information and communication technology service(s). Telehealth services can describe healthcare disciplines such as telepathology, 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 education [21,23].

Timely care requires using a patient's clinical presentation, the best available information and the CoHD diagnosis as key information to assess risk and therefore the appropriate ideal time for review by CoHD specialists and key medical partners, with a view to maintaining patient wellbeing and stability. This represents a best estimate and will vary according to clinical and social circumstances.

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.

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 [67].

Trauma-informed care is a framework for healthcare service delivery based on the 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 about trauma into healthcare and focuses on avoiding re-traumatisation [14,82].

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. These conditions may first become evident prenatally. CoHD includes both congenital and acquired heart disease of childhood. 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 [3].

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 that occurs as a complication secondary to chronic paediatric diseases or medical therapy [113,114].

CoHD Prevalence

Congenital heart disease is the most common type of birth defect [114], and is a leading cause of hospitalisations and death of Australian babies [1,36,113].[1] 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 [105]. 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 the estimated 65,000 with congenital heart disease [1]. Currently, the large and growing population of adults living with CoHD outnumber children with the disease [115].

Aboriginal and Torres Strait Islander peoples continue to be disproportionally affected by CoHD and experience higher incidences of congenital and acquired heart disease and a higher infant mortality [11,114,116].

As time passes there will be increasing demands for care adaptations for older Australians affected by CoHD. These services will increasingly involve geriatric medicine and the management of complex co-pathology.

CoHD Spectrum of Severity

CoHD is a chronic condition with no cure that for many patients requires complex, specialised care across the life course [1]. 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 [3].

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 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 past 15 years (to the time of publication of the CoHD Standards 1st Edition), and genetic factors can be recognised in up to a third of congenital heart disease, and more frequently in some myopathies and arrhythmias [36].

Children with mild (simple) congenital heart disease often require no intervention and are unlikely to suffer adverse effects 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 throughout life.

Children with moderate congenital heart disease are likely to require some form of intervention and may require one or more surgical or catheter interventions 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 focused 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. They may require multiple procedures in a program of staged procedures or may have significant functional cardiac impairment from their abnormality or its 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 will be needed throughout life.

The 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, while 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 [117] can be used to classify the degree of overt functional impact; however, in babies and children, these manifestations need to be age-adapted [96].

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 throughout the lifetime [83]. Neurodevelopmental, genetic and psychological impacts may significantly erode the benefits of successful heart intervention and should be kept in focus during surveillance. 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 at all ages.

Appendix E. CoHD Standards Development

In 2019, the Minister for Health launched a National Strategic Action Plan for Childhood Heart Disease, committed funding to a range of projects and prioritised the development of Standards of Care.

The approach to CoHD Standards development was participatory and collaborative with input from patients, family members, carers, healthcare providers and relevant stakeholders. It was 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 values shared during the engagement and collaboration discussions. The leading principle of living well throughout life and key values were embodied in the process.

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

An Advisory Committee of 25 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 focusing on the whole-of-life approach were established. Membership across working groups included 91 participants 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 [118]. Regular meetings between the coordinating team, Standards Co-Chairs and Working Group Chairs and Co-Chairs to help support the iterative development process. 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 has completed two public consultation periods on the Draft CoHD Standards by December 2022 and publication of the CoHD Standards 1st Edition in 2024. These CoHD Standards are a living document, with plans to allow regular review, to integrate practice improvements, education, and research. Agreed and adopted by the relevant health organisation, CoHD Standards is managed 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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Statement of Competing Interests

The authors declare no known competing interests.

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