

Implementation Plan

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



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Acknowledgement of Country

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

The Australian Government Department of Health and Aged Care has provided funding for the Childhood Heart Disease – Consumer Awareness, Education and Standards of Care project. The Implementation Plan is a complementary document to the *Australian National Standards of Care for Childhood-onset Heart Disease 1st Edition*, and reflects the views of the authors and not necessarily the views of the Australian Government Department of Health and Aged Care.

Introduction

Childhood-onset heart disease (CoHD), which includes congenital heart disease and acquired heart disease with initial presentation during childhood, places a significant burden on the children and adults living with CoHD and their family members and carers. CoHD is one of the leading causes of death and hospitalisation of infants.

Current population-based estimates suggest between 200,000 and 250,000 Australians are living with CoHD, and more than a million Australians are impacted by this (parents, carers, siblings, extended families). An estimated 100,000 individuals have needed surgery or intervention, with some currently lost to high-level, specialised follow-up.

CoHD survival rates have improved dramatically due to medical advances, with most people with CoHD now surviving into adulthood. Despite the longer survivorship of people with CoHD, this can remain an important chronic medical condition. Specialised care and surveillance are required throughout life.

The *Australian National Standards of Care for Childhood-onset Heart Disease 1st Edition* (CoHD Standards) are the primary reference source for developing and maintaining CoHD services in Australia across all Commonwealth, state and area health services, hospitals and dedicated CoHD services (paediatric and ACHD).



The purpose of the CoHD Standards is to provide a coherent national framework and reference point that defines key requirements for delivering excellence in CoHD care. The CoHD Standards outline the fundamental building blocks for creating high quality and sustainable health services for the CoHD community now and into the future.

Effective adoption of the CoHD Standards into care practices will provide patients, families and carers impacted by CoHD with consistent, high quality, inclusive and equitable care, with the aim of reducing the burden of CoHD on all those affected and supporting people living their fullest and best lives – ‘living well’ throughout life.



The Plan

OBJECTIVE

This Implementation Plan (Plan) aims to guide effective implementation of the CoHD Standards and should be read in conjunction with the CoHD Standards, which form the primary reference. The priorities and actions described in this Plan should be incorporated into planning by healthcare providers, healthcare service directors, health service planners, and state and territory jurisdictional service leads.

Scope

The Plan outlines:

- priority areas to underpin implementation of the CoHD Standards
- governance of the CoHD Standards and related activities
- broad implementation and indicative evaluation measures for each Standard

- how health services can evaluate their performance against the CoHD Standards evaluation and maintenance of the CoHD Standards.

The Plan indicates areas and activities that can be developed, expanded or modified by (or for) the target audience to produce tangible improvements in the provision of CoHD care.

Implementation

Implementation of the CoHD Standards will involve Commonwealth and state and territory governments and health departments, hospitals and healthcare services, professional regulatory and representative bodies, and health professionals. Reference to, and engagement with, consumers will also be important throughout this process.

Implementation will take into account the National Safety and Quality Health Service Standards, from the Australian Commission on Safety and Quality in Health Care (ACSQHC), with reference to national and international published evidence and relevant global position and consensus statements.

Implementation priorities

The following priorities have been identified to enable overall implementation of the CoHD Standards. These include structural changes, to be driven by existing leaders and key stakeholders in CoHD, to lead CoHD care into the future. The priorities are relevant for multiple or all the CoHD Standards and are noted where relevant to specific Standards.

- 1** Workforce capability – develop formal training and accreditation pathways across CoHD medical specialties and health disciplines (where absent) to ensure adequate training and education.
- 2** Workforce capacity – support the growth of the workforce with specific CoHD training to enable health services to meet the standard of care detailed in the CoHD Standards and growing demand for CoHD services.
- 3** Professional networks – establish national discipline-specific networks for professionals working in CoHD (within existing professional organisations or independently) for collegiate sharing and supporting standardised approaches to CoHD care delivery and coordination.
- 4** Clinical guidance – develop comprehensive clinical guidance (clinical practice guidelines, scientific position statements, roadmaps, treatment pathways etc.) to enable health professionals to apply the CoHD Standards and provide excellence in care delivery.
- 5** Patient information – develop accessible patient information to support and empower patient and family participation in healthcare processes, enabling greater and more informed participation in decision making.

Governance of the Standards

Implementation pathways will be established progressively, along with oversight and funding mechanisms, through appropriate government, health service and professional organisations. The CoHD Standards Committee will assist with advocacy and facilitation, with primary implementation to be driven by special interest groups, organisations, and health services and jurisdictions.

The CoHD Standards Committee comprises an Executive Group and Advisory Sub-Committee. The CoHD Standards Committee will initially operate as a sub-committee of the Paediatric and Congenital Council of the Cardiac Society of Australia and New Zealand (CSANZ). Additional sub-committees will address and guide recommendations for standard-specific priorities, including development of clinical guidance documents. Members of the CoHD Standards Committee and sub-committees will include key health professionals, relevant not-for-profit groups, and consumers (patients, parents and carers).

Advocacy at all levels by the CoHD community (patients, families and professionals) will assist in timely transition of the CoHD Standards into practice.

Dissemination and engagement

The key dissemination objectives are to raise awareness of the CoHD Standards, including:

- their role as the key reference for reviewing and developing CoHD services in Australia
- how they apply to health service design and delivery, health policy and health workforce planning
- how they provide a resource for patients and families to understand what they can expect as part of their CoHD care.

Promotional and educational activities supporting dissemination of the CoHD Standards include:

- sharing the new Standards document (and any updates) and links to the hosting website with key stakeholders
- sharing information about the Standards on social media
- delivering educational material tailored for healthcare professionals about the CoHD Standards
- working with key agencies and organisations to support the implementation of the CoHD Standards.

Evaluation and review

Engagement with the Standards

Effective dissemination of the CoHD Standards and engagement of CoHD clinical and patient communities with the CoHD Standards will be evaluated using the following information:

- Activity on the CoHD Standards website including visitor traffic, the number of times documents are accessed via the website and the number of enquiries regarding the Standards submitted via the website.
- Feedback from professional bodies and consumer groups.

Meeting the Standards

Health services are encouraged to evaluate their own progress towards meeting the Standards using:

- prescribed measurement indicators and additional metrics
- a self-evaluation tool (available on request, refer to the [CoHD Standards website](#)) to record if and how individual Standards have been met.

Measures include, but are not limited to, evidence that:

- service delivery Standards are being met
- workforce and infrastructure needs have been assessed and plans to address identified gaps developed
- patients, families and carers, and their feedback on services and information (access, quality and impact), are included in service design and improvement.
- KPIs relevant to CoHD are being met*.

Where health services do not initially meet the CoHD Standards, strategies to support implementation of the CoHD Standards should be developed, and included in plans for future service development if not immediately practicable.

Health services should aim to incorporate the CoHD Standards while also working within their organisational or jurisdictional clinical governance framework.

Implementation and impact of the Standards

The CoHD Standards Committee – through its relationships with relevant government and professional bodies, plus national and international CoHD organisations – will seek to understand successes and barriers regarding implementation and uptake of the CoHD Standards.

The impact of the CoHD Standards on driving the delivery of excellent CoHD care will be evaluated using outcomes data, including available data regarding the CoHD burden on social, economic and health systems following the publication of the CoHD Standards.

The CoHD Standards Committee will manage review of the CoHD Standards document, initially at three years after publication. As with the development of the first edition of the Standards, future reviews and any updates to the Standards will involve the broader CoHD community. This will include public consultation, email communications about progress and any amendments to the Standards, and all relevant documents and information being maintained on a dedicated website.

* The CoHD Standards Committee may facilitate determination of further metrics as part of its collaborative facilitation role.



Implementation and evaluation of CoHD Standards

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STANDARD 1

CoHD Services (Paediatric and ACHD)

Requirements for high quality CoHD healthcare services in Australia, including:

- types of CoHD healthcare services available in Australia and their role
- the workforce and infrastructure required to provide healthcare for different CoHD services.

Objective	Target audience	Activities/Strategies	Evaluation
CoHD services (paediatric and ACHD) provide patients with excellent care that is patient-centred, safe, effective and coordinated.	<ul style="list-style-type: none"> – Governments through health departments – Hospitals and area health services – Medical colleges – Other healthcare professional representative and regulatory bodies – Tertiary education providers – Health service accrediting bodies 	Services at all levels of care	
		<ul style="list-style-type: none"> – Review case volume and workforce/infrastructure needs ^{1 2}. – Establish professional accreditation for CoHD specialties and subspecialties where currently absent ¹. (See also Standards 3 & 4) – Specialty and advanced training professionals (from medical colleges, nursing, psychology and allied health) work with CoHD (paediatric and ACHD) experts to incorporate CoHD educational materials relevant to that training. – Utilise or develop national collaboratives for CoHD/ACHD health professionals to facilitate: <ul style="list-style-type: none"> • collegiate sharing of specific CoHD/ACHD knowledge • national CoHD/ACHD initiatives • advocacy for implementation of the CoHD Standards ³. 	<ul style="list-style-type: none"> – Patients and families have timely and reliable access to dedicated CoHD services. – CoHD services are led by suitably trained experts in CoHD/ACHD. – All staff employed by CoHD services (paediatric and ACHD) have training in relevant CoHD/ACHD care. – Providers of CoHD services (paediatric and ACHD) have appropriate accreditation and credentialing provided through relevant employing bodies and training organisations. – CoHD/ACHD knowledge and skills are disseminated nationally and staff expertise meets the needs of the relevant teams in CoHD/ACHD healthcare services at all levels.
		Comprehensive care centres (Type 3 paediatric and ACHD)	
		<ul style="list-style-type: none"> – Centralise high complexity, low volume treatments (i.e. surgical and complex catheter interventions) in Type 3 centres. – Support comprehensive centres to take a lead role in training of health professionals working in/towards CoHD roles ¹. – Introduce service accreditation for key CoHD healthcare providers nationally. 	<ul style="list-style-type: none"> – Comprehensive (Type 3) centres contribute to the relevant clinical care network, models of care and training for statewide CoHD services (paediatric and ACHD).

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

1

Workforce capability

2

Workforce capacity

3

Professional networks

STANDARD 2

Regional CoHD Care

Healthcare services in regional areas, covering:

- provision of coordinated high quality care close to home where possible
- information sharing between regional CoHD/other healthcare providers and CoHD specialists from large city services.

Objective	Target audience	Activities/Strategies	Evaluation
CoHD services in regional, rural and remote areas provide care close to home, overcoming barriers to access associated with centralised specialist services e.g. travel time and costs, limited family facilities, lack of access to respite care.	<ul style="list-style-type: none"> – Governments through health departments – Hospitals and area health services, particularly with regard to CoHD outreach and support – Medical colleges – Other healthcare professional representative and regulatory bodies – Tertiary education providers – CoHD Services providing regional care and support 	<ul style="list-style-type: none"> – Evaluate existing models of care, service delivery (including access to CoHD cardiac investigations), and workforce, in larger regional centres^{1 2}. – Undertake planning, including workforce planning, with local CoHD service providers^{1 2}. – Funding for services in regional Australia recognises and accommodates the requirements involved in providing CoHD/ACHD care. – Utilise or develop national collaboratives for health professionals involved in regional CoHD/ACHD care to facilitate: <ul style="list-style-type: none"> • collegiate sharing of specific CoHD/ACHD knowledge • national CoHD/ACHD initiatives • advocacy for implementation of the CoHD Standards³. – Establish pathways for mentorships and education programs between regional and tertiary services¹. – Create local lead roles for coordinating services delivering care to CoHD patients¹. – Improve frameworks informing timely and appropriate access to specialist advice for local healthcare teams 24/7 via the cardiology consultant or senior cardiology trainee on call⁴. – Develop and implement telehealth protocols and workforce to support health professionals using telehealth to deliver CoHD and ACHD services⁴. (See also Standard 12) – Improve processes to guide secure and efficient access to investigative data between regional/remote and tertiary facilities via information systems and telehealth consultation. (See also Standard 12) 	<ul style="list-style-type: none"> – Appropriate funding structures are based on service planning and address staffing and equipment requirements. – CoHD services are led by local leads who are suitably trained experts in CoHD/ACHD. – CoHD/ACHD knowledge and skills are disseminated nationally and staff expertise meets the needs of the relevant teams in CoHD/ACHD healthcare services at all levels.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

- 1 Workforce capability
2 Workforce capacity
3 Professional networks
4 Clinical guidance

STANDARD 3

Paediatric Cardiology

Requirements for specialist paediatric cardiologists who care for unborn children, children and adolescents with CoHD, including:

- subspecialist CoHD knowledge and skills
- comprehensive care for patients, families and carers.

Objectives	Target audience	Activities/Strategies	Evaluation
<p>Credentialling processes provide standardised competencies/proficiencies for assessment and verification for professionals involved in paediatric cardiology subspecialties.</p> <p>Workforce planning includes paediatric cardiology subspecialty training.</p> <p><i>Paediatric cardiologists working in subspecialty fields (e.g. fetal cardiology, arrhythmias, genetics) are highly specialised.</i></p>	<ul style="list-style-type: none"> — Governments through health departments — Hospitals and area health services — Medical colleges — Other healthcare professional representative and regulatory bodies — Tertiary education providers — Paediatric cardiologists 	<ul style="list-style-type: none"> — Review workforce/ infrastructure needs according to service level^{1 2}. Consider workforce training opportunities. — Establish a pathway for credentialling of subspecialty paediatric cardiology disciplines¹. — Develop subspecialty specific curricula. — Develop clinical practice guidelines and position statements leading to excellence in care of CoHD patients in Australia, based on national and international CoHD guidelines⁴. 	<ul style="list-style-type: none"> — A plan is in place to meet future workforce needs, including specific training for paediatric cardiologists working in subspecialty fields. — Credentialling processes are established and recognised by relevant regulatory and accrediting bodies.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

1 Workforce capability

2 Workforce capacity

4 Clinical guidance

STANDARD 4

Paediatric Cardiac Surgery and ACHD Surgery

Congenital cardiac surgery for children and adults, including:

- specialist knowledge and training requirements for paediatric and adult congenital heart surgeons
- specialist knowledge, skills and training for CoHD anaesthetists and perfusionists
- access to specialist nurses for patients and families
- requirements when assessing the need for heart transplantation
- how services are evaluated.

Objective	Target audience	Activities/Strategies	Evaluation
<p>Formal training and credentialing pathways ensure standardised competencies/proficiencies for assessment and verification for professionals involved in paediatric and ACHD cardiac surgery.</p> <p><i>Paediatric cardiac surgery and ACHD cardiac surgery are highly specialised subspecialties of cardiac surgery.</i></p>	<ul style="list-style-type: none"> — Governments through health departments — Hospitals and area health services — Medical colleges — Other healthcare professional representative and regulatory bodies — Health service regulatory bodies — Established CoHD/ACHD surgeons 	<ul style="list-style-type: none"> — Review case volume and workforce/ infrastructure needs ^{1 2}. — Establish upgraded surveillance; formal, external peer review; and quality assurance for Type 2 paediatric CoHD services that are: <ul style="list-style-type: none"> • geographically isolated • performing smaller case volumes • suitably equipped and audited. — Establish a pathway for training and national recognition (accreditation and registration) of paediatric cardiac and ACHD surgeons ¹. — Develop a standardised performance matrix for paediatric cardiac and ACHD surgeons ¹. — Develop a list of relevant lesions and procedures, inclusions and exclusions for paediatric cardiac, ACHD and non-ACHD adult cardiac surgeons. — Develop clinical practice guidelines and position statements leading to excellence in care of CoHD/ACHD patients in Australia, based on national and international guidelines ⁴. 	<ul style="list-style-type: none"> — Training pathways and credentialing processes are established and recognised by relevant regulatory and accrediting bodies.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

- ¹ Workforce capability
² Workforce capacity
⁴ Clinical guidance

STANDARD 5

Transition to Adult Care

Transitioning from paediatric to adult CoHD care, including:

- the importance of starting transition early
- a carefully planned process
- transitions that are individually tailored for patients, families and their carers.

Objective	Target audience	Activities/Strategies	Evaluation
Transition services supporting patients and families from paediatric to adult CoHD care enable a transition process that is carefully planned, holistic, individually tailored for cardiac abnormality and patient/ family needs.	<ul style="list-style-type: none"> – Governments through health departments – Health services – Medical colleges – Other healthcare professional representative and regulatory bodies – Tertiary education providers 	<ul style="list-style-type: none"> – Review workforce/ infrastructure needs ^{1 2}. – Develop improved systems to prevent loss of follow up for patients in the transition from paediatric to adult care, including comprehensive and informative transition planning. – Establish dedicated CoHD transition clinics with appropriate staffing and infrastructure in all paediatric CoHD services, with equitable access for patients in regional and remote areas and those experiencing disadvantage. – Establish referral pathways and collaborative networks to ensure availability of, and access to, ACHD or other specialist adult cardiology services for all patients with CoHD ⁴. – Develop clinical practice guidelines and position statements to support successful transition of CoHD patients from paediatric to adult congenital cardiology services ⁴. 	<ul style="list-style-type: none"> – CoHD transition clinics are available and provide equitable access for patients in regional and remote areas, and those experiencing disadvantage. – Staffing for transition clinics meets the needs of the relevant services. – Pathways for transition of care are developed.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

1

Workforce capability

2

Workforce capacity

4

Clinical guidance

STANDARD 6

ACHD Cardiology

Requirements for specialist cardiologists who care for adults with congenital heart disease (ACHD), including:

- specialist knowledge and training
- comprehensive care for patients, families and carers.

Objectives	Target audience	Activities/Strategies	Evaluation
<p>Formal training, credentialling and accreditation pathways ensure standardised competencies/proficiencies for assessment and verification for professionals involved ACHD cardiology.</p> <p><i>ACHD cardiology is a highly specialised subspecialty of adult cardiology.</i></p>	<ul style="list-style-type: none"> — Governments through health departments — Medical colleges — Other healthcare professional representative and regulatory bodies — Established CoHD/ACHD specialists 	<ul style="list-style-type: none"> — Review workforce/infrastructure needs^{1 2}. — Develop a pathway to formal recognition for ACHD cardiologists¹. — Develop clinical practice guidelines and position statements leading to excellence in care of ACHD patients in Australia, based on national and international ACHD guidelines⁴. 	<ul style="list-style-type: none"> — Providers of CoHD services (paediatric and ACHD) have appropriate accreditation and credentialling provided through relevant employing bodies and training organisations. — CoHD Services are led by suitably trained experts in CoHD/ACHD. — 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.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

1 Workforce capability

2 Workforce capacity

4 Clinical guidance

STANDARD 7

Nursing

High quality CoHD nursing care for paediatric and adult patients delivered by:

- Specialist Advanced Practice Nurses, and
- Specialised CoHD nurses who have knowledge, training and skills in caring for patients, families and carers.

Objective	Target audience	Activities/Strategies	Evaluation
Evidence-based practice and excellence in cardiac/ CoHD nursing is facilitated through collegiate sharing of knowledge and opportunities.	<ul style="list-style-type: none"> — Governments through health departments — Health services — Nursing professional bodies — Other healthcare professional representative and regulatory bodies — Tertiary education providers 	<ul style="list-style-type: none"> — Conduct a review of Advanced Practice Nurse resourcing to ensure resource allocation meet requirements for the delivery of excellent care, as well as supporting the health and wellbeing of staff ^{1 2}. — Establish a national collaborative for CoHD/ ACHD nurses to facilitate: <ul style="list-style-type: none"> • collegiate sharing of specific CoHD/ACHD nursing knowledge and experiences • national CoHD/ACHD nursing initiatives • advocacy for implementation of the CoHD Standards ³. — Develop standard nomenclature for Advanced Practice nurses. — Develop clinical practice guidelines and position statements relevant to CoHD nursing to support excellence in CoHD care in Australia ⁴. 	<ul style="list-style-type: none"> — Advance Practice Nurse staffing meets the needs of the relevant teams in CoHD/ACHD healthcare services.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

- ¹ Workforce capability
² Workforce capacity
³ Professional networks
⁴ Clinical guidance

STANDARD 8

Mental Health and Psychological Care

Mental health and support for patients, families and carers, including:

- care that begins at diagnosis
- care that is integrated into CoHD healthcare
- end-of-life and bereavement care.

Objective	Target audience	Activities/Strategies	Evaluation
Mental health care within specialised CoHD services provides access to, and normalises people seeking, mental health support from experienced providers.	<ul style="list-style-type: none"> — Governments through health departments — Health services — Relevant healthcare professional representative and regulatory bodies — Tertiary education providers — Mental health and psychologists with principal interest in CoHD 	<ul style="list-style-type: none"> — Establish a national information register of coordinated community mental health resources for CoHD support⁵. — Develop a library of resources on mental health and CoHD for patients and families⁵. — Review workforce/infrastructure needs^{1 2}. — Develop clinical practice guidelines and position statements on mental health care in paediatric and adult CoHD in Australia⁴. 	<ul style="list-style-type: none"> — Mental health professional staffing meets the needs of the relevant services.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

- 1 Workforce capability
 2 Workforce capacity
 4 Clinical guidance
 5 Patient information

STANDARD 9

Neurodevelopmental and Neurocognitive Care

Neurodevelopmental and neurocognitive care including:

- supporting development through infancy, childhood, adolescence and adulthood
- neurodevelopmental and neurocognitive screening, evaluation and care
- responding to developmental needs both in and outside the hospital.

Objective	Target audience	Activities/Strategies	Evaluation
Neurocognitive evaluation and access to individualised, patient- and family-centred neurodevelopmental care or is an integral part of care for patients with CoHD throughout the whole of life.	<ul style="list-style-type: none"> — Governments through health departments — Health services — Relevant healthcare professional representative and regulatory bodies — Tertiary education providers — Neurodevelopmental and neurocognitive experts with a principal interest in CoHD & development of CoHD neurodevelopmental screening and intervention services 	<ul style="list-style-type: none"> — Establish a national information register of community neurodevelopmental and neurocognitive resources for CoHD⁵. — Review workforce/ infrastructure needs^{1 2}. — Provide planned infrastructure and access for at-risk patients. — Develop Australian clinical practice guidelines and position statements on neurodevelopmental and neurocognitive care in congenital heart disease⁴. 	<ul style="list-style-type: none"> — Neurodevelopmental and neurocognitive care professional staffing meets the needs of the relevant services. — Physical resources and access for neuroimaging relevant to CoHD patients are sufficient to meet the CoHD Standards requirements. — Comprehensive and coordinated developmental surveillance, screening, evaluation, re-evaluation, interventions, therapies and ongoing management must be integrated into routine CoHD care.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

- 1 Workforce capability
 2 Workforce capacity
 4 Clinical guidance
 5 Patient information

STANDARD 10

Priority Populations

Equitable access to coordinated CoHD healthcare for:

- Australia's Aboriginal and Torres Strait Islander peoples
- those with refugee backgrounds
- those with limited access to healthcare.

CoHD healthcare should:

- be sensitively planned
- be culturally respectful
- be compassionate
- emphasise the importance of knowledge of the impact of trauma
- improve cultural, social and environmental supports for patients, families and carers.

Objectives	Target audience	Activities/Strategies	Evaluation
<p>CoHD services support equitable access to individualised patient- and family-centred care which is culturally appropriate.</p> <p>Systems of care provide effective delivery to CoHD patients and their families and carers.</p>	<ul style="list-style-type: none"> – Governments through health departments – Health services – Regional and community service providers – Healthcare professional representative and regulatory bodies – Tertiary education providers – Community representative groups and leaders from priority populations – Healthcare professionals involved in providing care to priority populations affected by CoHD 	<ul style="list-style-type: none"> – Develop protocols to support CoHD health professionals identify specific care needs of priority populations, including Aboriginal and Torres Strait Islander peoples and people from culturally diverse backgrounds⁴. – Provide pathways to ensure equitable access. – Develop responsive strategies to meet priority population cultural needs. – Work with communities to identify and activate programs to meet priority population needs. – Develop clinical practice guidelines and position statements leading to excellence in care of CoHD patients in Australian priority populations, based on national and international guidelines⁴. 	<ul style="list-style-type: none"> – Equitable access to coordinated CoHD healthcare is available for patients/families and carers that is culturally respectful, compassionate, responsive, grounded in empowerment, and optimises cultural, social and environmental support. – An understanding of the social determinants of health is embedded in assessment and healthcare and is relevant for understanding both the patient and family context.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

4 Clinical guidance

STANDARD 11

Research

The role of research in CoHD at the national and international collaborative level should:

- be driven by discovery
- encompass a whole-of-life CoHD perspective
- be informed by patient experience.

Objective	Target audience	Activities/Strategies	Evaluation
Research data, systematically collected, provides the opportunity for data linkage with state and national datasets and for research to enhance health outcomes, educational outcomes, resource allocation and social services use and to inform policy change.	<ul style="list-style-type: none"> — National funding agencies and grant providers for medical research — CoHD research programs — National professional bodies — Commonwealth Government and state governments — CoHD researchers 	<ul style="list-style-type: none"> — Establish an Australian National CoHD/ACHD Research Council to facilitate national multicentre research projects with significant research impact. — Identify key research priorities for CoHD in Australia. — Identify barriers and enablers of high-quality, collaborative research in CoHD and develop strategies to address/support these. — Develop guidance on consumer engagement in fields related to CoHD and participatory approaches to quality improvement projects. — Grow the number of researchers and research publications in the field of CoHD ^{1 2}. 	<ul style="list-style-type: none"> — CoHD research is collaborative, sustainable, and nationally and internationally benchmarked, and integrated into CoHD Services. — Consumer/patient/family engagement is embedded in research on CoHD service delivery. — Number of funded research scholarships and grants focusing on CoHD increases. — Research findings and publications positively impact CoHD practice, policy or health outcomes.

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

1

Workforce capability

2

Workforce capacity

STANDARD 12

Health Information and Digital Communication Technology

CoHD care and research are facilitated across Australia, through high-quality, secure technology to improve collaboration on, and communication of patient care details, including:

- telehealth
- databases
- digital communication tools, and
- establishment of peak [digital health] craft groups.

Objectives	Target audience	Activities/Strategies	Evaluation
<p>Improved use of electronic health records (including My Health Record, disease and intervention-specific registries, other digital health measures) supports ongoing systematic collection, analysis and interpretation of health-related data to inform planning, implementation, and evaluation of health practice.</p> <p>Patient information on disease and intervention-specific outcomes, care pathways (including transition from paediatric to ACHD care) is available to the community and CoHD services.</p> <p>Improved capacity for telehealth where appropriate for patient and family care.</p>	<ul style="list-style-type: none"> — Governments through health and other relevant departments — Relevant professional representative and regulatory bodies — Health services — Health service regulatory bodies — Relevant research and higher academic bodies — Relevant CoHD providers and services 	<ul style="list-style-type: none"> — Create a digital network enabling transfer of patient data between CoHD and ACHD centres. These networks should: <ul style="list-style-type: none"> • connect interstate CoHD and ACHD centres • be capable of secure, large-scale, cloud-based data transfer • support transfer of clinical imaging in addition to patient data • make data available for clinical and research use • only allow limited, secure access to approved personnel within and outside the connected centres/institutions. 	<ul style="list-style-type: none"> — Funding for digital technologies needed for CoHD and ACHD service delivery is embedded in federal and state health programs, including Medicare support for CoHD and ACHD telehealth services. — Regional and local health services are upskilled to facilitate remote assessment and management of CoHD and ACHD (e.g. telehealth, remote monitoring). — Processes are developed to guide secure and efficient information sharing between relevant institutions/facilities.

Objectives	Target audience	Activities/Strategies	Evaluation
		<ul style="list-style-type: none"> – Establish a national database/ registry for all patients with CoHD (paediatric and adult patients) to monitor the quality of healthcare. The registry would: <ul style="list-style-type: none"> • enhance day-to-day patient management and transition management • support quality assurance activities, including procedure performance assessment, and help to deliver excellence in patient care • monitor patient involvement with CoHD research • be secure and maintained collaboratively with centralised IT support and management. – Identify and prioritise patient information needs and develop a suite of patient education resources, to be made available nationally⁵. – Develop and implement telehealth and new technology protocols to support health professionals using telehealth to deliver CoHD and ACHD services⁴. (See also Standard 2) – Develop clear processes to guide secure and efficient access to investigative data between regional/ remote and tertiary facilities via information systems and telehealth consultation⁴. (See also Standard 2) 	

Superscripts indicate implementation priorities addressed by activities/strategies for this Standard:

⁴ Clinical guidance

⁵ Patient information

