

Information for Patients, Families and Carers impacted by Childhood-onset Heart Disease



About the Australian National Standards of
Care for Childhood-onset Heart Disease

What are standards of care?

Standards of care describe treatment that is accepted by medical experts as appropriate and high quality for a certain health condition. Sometimes these are called best practice, standard medical care, or standard therapy.

Standards of care are widely used by health professionals. They should be available to all patients, families and carers. Standards of care describe what high quality healthcare services look like. They align with professional regulations and are guided by the best research evidence available.

Many people can be involved in developing standards of care. These often include:

- healthcare professionals with expertise and experience in the specialist area
- patients and family members with lived experience
- people who advocate for improved care and access to support
- researchers
- health service leaders
- representatives from professional organisations.
- government bodies coordinating healthcare

Standards of care are developed and agreed to after a lot of discussion. This is to ensure they are clearly explained, and equitable and accessible for everyone. It is also important to report on these standards and to measure the difference they make for healthcare.

Standards of care should remain up to date. This means they continue to be reviewed. Key representatives from those involved in the development of the standards are part of this process. Reviewing standards of care is usually done under the guidance of a leading professional organisation.

The Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) were developed in this way. Patients, families and carers are at the centre of all parts of the CoHD Standards including materno-fetal, paediatric and adult congenital heart disease (ACHD) services. The CoHD standards are also centred around living well and are supported by six values:

- Excellence
- Patient- and Family-Centred Care
- Dignity and Respect
- Empathy and Compassion
- Knowledge, and
- Collaboration.

The CoHD Standards are based on the below values and lead principal



What is CoHD?

Childhood-onset heart disease (CoHD) is a general term that covers all types of heart abnormalities that begin in childhood. This includes both congenital heart disease and heart conditions acquired after birth. CoHD often has implications throughout whole of life.

The word 'congenital' refers to a condition or trait that is present from birth. Congenital heart disease happens when the heart does not develop properly during pregnancy. This can involve:

- the vessels that travel to and from the heart
- the size of the heart chambers, and/or
- one or more of the valves that control the flow of blood through the heart.

Any problem with the heart can make it harder for the heart to work. Sometimes this is only mild, and in other cases it has a bigger impact on health. For babies with congenital heart disease this can affect growth and development.

Congenital heart disease is mostly diagnosed following birth. It can also be diagnosed in pregnancy. Sometimes it is diagnosed later in childhood and occasionally in adulthood.

CoHD also covers conditions affecting the rhythm of the heart, or other conditions related to the heart muscle itself. Sometimes a genetic cause can be found for these conditions.

Acquired heart disease develops after birth, usually during childhood. Acquired heart disease can be caused by infection, inflammation or toxins, or by other health conditions. For example, some infections can trigger an abnormal inflammatory response which can damage the heart.

Each new diagnosis of CoHD should be confirmed by a specialist cardiologist. This is usually confirmed using an ultrasound scan called an echocardiogram. Sometimes extra pictures and tests are required.

Some people with CoHD will only need to see their medical CoHD specialist infrequently during their lives. Others may need coordinated care involving more regular appointments. This may or may not include medical and/or surgical intervention. Care may also involve nurses, allied health professionals and psychologists. These health professionals can provide information and support for patients, families and carers to help achieve the best possible health outcomes throughout life.

It is important that patients, parents, carers and families impacted by CoHD receive information that is clear, easy to understand and specific to their heart condition. Learning about a heart condition is a process of information sharing

between the healthcare providers who have knowledge and skills in CoHD, and the person with CoHD and their family. This includes talking with one or more members of the CoHD healthcare team and asking questions as often as needed.

Why do we need CoHD Standards?

The Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards) provide important information about organising and delivering high quality CoHD healthcare.

They outline the requirements for doctors, nurses, allied health staff, psychologists and all health professionals involved in CoHD healthcare services in Australia. This will help to ensure high quality specialist care requirements are consistent and accessible for all Australians affected by CoHD.

The CoHD Standards help patients, families and carers to know more about what to expect when it comes to their CoHD healthcare.

This helps when making decisions about their health and healthcare. The CoHD Standards help patients, families, carers and their healthcare providers to tailor care to their needs, including where they live. The COHD Standards take a broad and long term view of necessary services. This includes mental health and recognition of possible impacts on learning. The CoHD Standards consider how patients move from childhood to adulthood, including old age, and what services may be needed throughout life.

The CoHD Standards are unique to Australia, its people, the vast distances of the land and how healthcare is structured across the country.

How can the CoHD Standards be used?

The CoHD Standards inform healthcare providers what they need to do to provide high quality CoHD healthcare services.

This includes the knowledge, expertise and access to the equipment and space they need to provide this care.

The requirements for high quality healthcare outlined in the CoHD Standards help patients, families and

carers plan for their care. They also help people ask questions about the types of services available to them, and to make decisions that best suit them and their family.

The CoHD Standards address important areas of healthcare for Aboriginal and Torres Strait Islander peoples, refugee populations, and people living in regional, rural and remote locations across Australia.

“The Standards of Care allow those affected by CoHD to understand what excellent physical and mental health care should look like.”

Parent of a child with CoHD

How do the CoHD Standards help me? They...

Outline what's needed to provide high standard CoHD care in Australia

These needs are based on the best knowledge, expert opinion and research evidence available as well as diverse lived experiences.

Are unique to Australia's health system and the people who live here

They are tailored to patients, families and carers to support their best health throughout life.

Help patients, families and carers to 'live well'

They take into account a person's physical, mental health, neurodevelopmental and social health.

Focus on 12 priority areas that support whole of life CoHD care in Australia

These priority areas provide information about the different CoHD healthcare services available and the healthcare professionals who deliver them. They also address the needs of priority populations including Aboriginal and Torres Strait Islander peoples, refugee populations, and young people who are transitioning to adult CoHD healthcare services.

Have the ability to measure the effectiveness of CoHD care in Australia

This will help guide the review of CoHD Standards to ensure continued improvements in healthcare.

Are continually updated, which means it will improve over time

The first edition of the CoHD Standards provides a current reference point for CoHD healthcare services in Australia.

Belong to all members of the CoHD community

They will continue to be updated, guided by collaboration based on the best available knowledge, practice and evidence.

The CoHD Standards

Each CoHD Standard refers to an aspect of CoHD healthcare. Some are about the types of CoHD healthcare services and healthcare professionals in Australia. Some describe the requirements for CoHD healthcare at specific times in life. Others address the needs of priority groups including Aboriginal and Torres Strait Islander Australians and refugee populations.

What each of the CoHD Standards covers

STANDARD 1 CoHD Services	Requirements for high quality CoHD healthcare services in Australia, including: <ul style="list-style-type: none">– types of CoHD healthcare services available in Australia– training and education required for CoHD specialists– the range of healthcare professionals who provide specialist CoHD healthcare.
STANDARD 2 Regional CoHD Care	Healthcare services in regional areas, covering: <ul style="list-style-type: none">– 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.
STANDARD 3 Paediatric Cardiology	Requirements for paediatric cardiologists, including: <ul style="list-style-type: none">– specialist CoHD knowledge and skills in diagnostic imaging– care during pregnancy– family genetic assessment and counselling– interventional cardiac catheter procedures in childhood– conditions impacting heart rhythm– specialist care for heart failure.

STANDARD 4**Paediatric
Cardiac 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.

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.

STANDARD 6**ACHD Cardiology**

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

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

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.

STANDARD 8**Mental
Health and
Psychological
Care**

Mental health care 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.

STANDARD 9**Neuro-
developmental
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.

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 support for patients, families and carers.

STANDARD 11**Research**

The role of research. Involvement in CoHD national and international research should:

- be driven by discovery
- involve the whole of life
- be guided by patient experience.

STANDARD 12**Health
Information
and Digital
Communication
Technology**

High quality CoHD services across Australia through secure technology to improve collaboration on, and communication of patient care details including:

- telehealth
- databases
- digital communication tools and
- establishment of peak craft groups.

Development of the CoHD Standards

The CoHD Standards were developed with input from over 130 members of the CoHD community. Feedback has been included from specialist doctors, nurses, psychologists, social workers, physiotherapy and occupational therapists, early education specialists and government representatives. Importantly, young people, adults, parents, advocates and carers impacted by CoHD, have also provided input.

The CoHD Standards were developed through best evidence, expert opinion and lived experience.

They will continue to be assessed under the guidance of a leading professional organisation, and will be updated to reflect improvements and advances in CoHD healthcare knowledge, services and research.

“I am excited to know that the CoHD Standards have been developed by merging patient perspectives and lived experiences with expert knowledge and evidence-based research... they prioritise the human at the centre of that disease, and the unique needs, goals, and values accompanying them.”

Adult with CoHD

Acknowledgement of Country

The Australian National Standards of Care for Childhood-onset Heart Disease 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.