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Sydney Children's Hospitals Network

NSW Paediatric Cardiac Model of Care – FINAL



Document Control

Document Title:	Sydney Children's Hospitals Network NSW Paediatric Cardiac Model of Care: FINAL	Copies and Distribution:
Prepared By:	Jenny Sheehan	SCHN
Reviewed By:	SCHN	
Revision:	Version 0.4.3 post Panel review comments	
Date of Issue:	19/02/2021	
File No:	A113	
Server Location:	Advisory/A113 SCHN Cardiac Services MoC /Outputs and Deliverables/ 6.1 Project Reports/ 6.1.5 Final	



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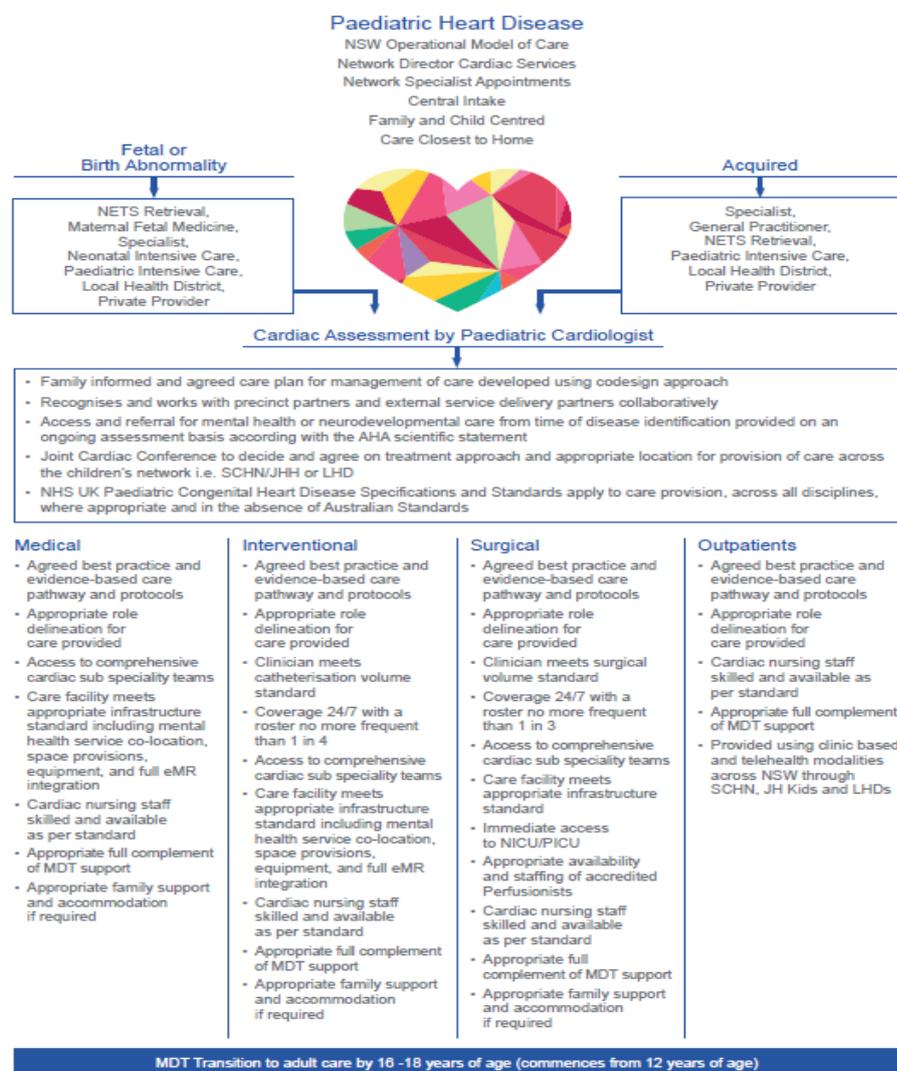
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Paediatric Cardiac Services NSW

The paediatric cardiac model of care reflects a value based, networked healthcare model. Documentation of the model has occurred within the context that there is no significant increase in childhood cardiac incidence anticipated and therefore demand for paediatric cardiac surgery in NSW is not expected to significantly increase. However, there is a growing trend of increased sub specialisation in cardiology providing emerging new treatment and care options, along with an increasing proportion of interventional cardiology and increased emphasis on neurodevelopmental and psychological wellbeing. This means a cohesive, collaborative, model of care is required for paediatric cardiac services across the spectrum of professional medical, nursing and allied health staff delivering care for babies through to adolescents and their families.

Figure 1 - Paediatric Cardiac Services Operational Model of Care at a Glance



The model of care is family and child centred and has been developed consistent with international best practice. The model of care ensures that as much care and treatment will be provided as close as possible to home and that travel to, and within the networked services, only occurs when essential, ensuring timely access for care and the best possible outcomes. This facilitates equitable access for families and children across NSW.

To develop a safe and sustainable paediatric cardiac services program there needs to be collaboration with interdependent services and organisations. This involves both internal and external providers along the patients' care pathway, to deliver the best care possible to infants and children with childhood heart disease in NSW.

Finally, studies of successful or 'great' cardiac institutions highlight strong leadership and mutual professional respect, embedded in its culture as the key to excellence. This attribute facilitates shared learning, interdisciplinary collaboration and clinical experience, which enables sustainability in excellence and performance, supports robust succession planning and sets in place openness to adopt and implement contemporary practice models. The NSW Paediatric Cardiac model of care has been developed to foster this culture in excellence and collaboration.

Congenital Heart Disease

Congenital Heart Disease (CHD) is any defect of the heart structure or major blood vessels that is present at birth. CHD is a leading contributor to the burden of disease among infants, being the biggest single cause of child mortality and early childhood hospitalisation. CHD is not a single disease but a general name for malformations of the heart, heart valves or major blood vessels which are present at birth. There are approximately 40 identifiable birth anomalies and syndromes that are classified as CHD.

CHD is a chronic condition that for many patients requires complex, specialised care across the life course (Celermajer, 2016) although acknowledging that this is often episodic. It is fundamentally different from heart disease diagnosed in adult life, which typically occurs as arteries become blocked and heart valves deteriorate with age, often related to lifestyle factors. CHD is unrelated to lifestyle.

Acquired heart disease refers to conditions developing in the heart which appears structurally and functionally normal at birth.

Novel genetic techniques, such as whole exome and genome sequencing, can accelerate gene discovery and assist in identifying causes of diseases of previously unknown aetiology, such as CHD (Gillian M Blue, 2012). However, currently there is no evidence for effective interventions to prevent CHD and no cure; treatment which can reduce the impact of the disease is available for most congenital heart defects. More than half of all children with a heart defect have a condition that is serious enough to require treatment.

In Australia the prevalence of CHD for the general population has been reported at around 6-8 cases per 1,000 births with over 2,000 babies affected each year and has remained fairly stable at that level for a number of years. Most cases are diagnosed in infancy and early childhood, but diagnosis can also happen later in life. While one third of cases of CHD can be attributed to chromosomal anomalies and gene disorders, there are known risk factors for CHD, which include:

- family history
- maternal illnesses, such as rubella
- misuse of alcohol, illicit drugs and over-the-counter or prescription medicines
- maternal health factors, such as early-onset pre-eclampsia and poorly controlled diabetes.

Defects can range from simple to complex and can occur alone or in groups, depending on how the heart has developed. The disorders include:

Congenital Heart Defects - Less complex

- Patent Ductus Arteriosus
- Coarctation of Aorta
- Atrial Septal Defect
- Ventricular Septal Defect
- Aortic Valve Disease
- Pulmonary Valve Disease

Congenital Heart Defects - Complex

- Atrioventricular Septal Defect
- Tetralogy of Fallot
- Transposition of Great Vessels
- Pulmonary Atresia
- Single Ventricle Pathology

Congenital Heart Defects - Disorders of Rhythm

- Supraventricular Tachycardias
- Ventricular Tachycardias
- Long QT Syndrome
- Complete Heart Block

Acquired Heart Disease

- Rheumatic Heart disease
- Kawasaki Disease
- Dilated Cardiomyopathy
- Coronary Artery Disease

Scanning for critical CHD is standard practice during second trimester (around 14 weeks) ultrasound assessments. This early detection provides more time for planning and preparing for treatment after birth. Pulse oximetry and observation of vitals (such as Apgar) after birth while still in hospital are essential in both detecting and monitoring symptoms of CHD.

CHD deaths also comprise a substantial proportion of perinatal deaths. Perinatal deaths refer to stillbirths (fetal deaths) and deaths of infants within the first 28 days of life (neonatal deaths). In Australia in 2017, there were 119 perinatal deaths with CHD as the main condition, of which 70 were fetal deaths and 49 were neonatal deaths. Congenital heart disease was responsible for 4.8% of all perinatal deaths in 2017 (ABS, 2018).

Due to advances in technology and treatment, there has been a significant increase in the number of children born with, or acquiring heart disease, that are surviving through to adulthood. It is important to note that while the intensity of intervention is required through childhood there is a need to consider episodic whole of life care (Australian Government Department of Health, 2019).

Determining a cause for CHD is important from a psychosocial perspective for the patient and family, but also in regard to family planning for both the parents and the affected child, as he or she approaches reproductive age. With the growing adult CHD population, information on recurrence risks and aetiology will become increasingly relevant. Understanding the aetiology of CHD will also benefit clinical management of the patient. As an extension, psychological morbidity remains prevalent within the CHD population. Reported prevalence of anxiety is higher than depression, both of which have been generally found to exceed population norms, ranging from 15 to 33 per cent in patients of all ages (Kasparian N. W., 2016).

Children with complex CHD (including those who need surgical intervention in the first year of life and those with other, co-morbid physical conditions) are at increased risk of neurodevelopmental impairment and disability. The risk and severity of neurological impairment increase with greater CHD complexity, the presence of a genetic disorder or syndrome, and greater child and family psychological stress (Marino, 2012).

Surgery for CHD results in an enormous financial burden for most families at a very vulnerable time. Significant out-of-pocket costs exist for patients and their families, including travel and accommodation for families required to travel to the designated specialist centres. This burden is particularly high for families in rural and remote locations including Aboriginal and Torres Strait Islander families (Australian Government Department of Health, 2019).

The Congenital Heart Alliance of Australia and New Zealand (CHAANZ) is developing the Australia and New Zealand Congenital Heart Disease Registry which will inform the future needs of the CHD patients and the healthcare system. The Registry, once established, will lead to an accurate measure of the burden of CHD in Australia and New Zealand, enable the development of an evidence-based needs assessment tool, provide a means for young adults from being lost to follow-up care, and be a resource for the appropriate recruitment of subjects for clinical trials (HeartKids, 2019).

Paediatric Cardiac Services

Paediatric cardiac care extends from the time of diagnosis (which may be during the antenatal period) through to infancy and childhood and eventual transition to adult services for a number of patients.

Cardiac procedures are part of management for many children with severe CHD and will require interventional treatment such as heart surgery and/or catheterisation. This treatment will be provided either immediately after birth or within the first few months of life (Blue GM, 2012), and there are another group of children who do not require procedural intervention until later in childhood years (e.g. ASD, isolated valvular disease, etc.). A small number of children with more complex problems require multiple surgeries or procedures over their lives.

The Australian Institute of Health and Welfare (AIHW) reported in 2019 that there were almost 5,000 CHD hospitalisations in Australia in 2016–17, with 1 in 3 among infants aged under 1 year, and 1 in 5 among children aged 1–14 years. In NSW inpatient paediatric cardiac care totals around 950 episodes annually, averaged over the last 20 years.

Unlike other cardiovascular conditions, the number and rate of hospitalisation for CHD declines with age. About half of all babies born with CHD will require surgical or catheter-based interventions at some time, with one-third needing these interventions in the first year of life (Kasparian N. P., 2011). In 2016–17, where CHD was the principal or additional diagnosis, procedure rates for infants aged under 1 year were 105 per 100,000 children for atrial septal defect, 99 per 100,000 children for ventricular septal defect and 124 per 100,000 children for patent ductus arteriosus. CHD was the underlying cause of 152 deaths (0.1% of all deaths) in Australia in 2017 (AIHW, 2019).

Cardiology

Paediatric Cardiology involves the management of the fetus, neonates, infants, children and young adolescents with heart disease. Cardiac lesions and their implications differ considerably from those that are seen in adult cardiology. In the last decade the strategies and techniques for evaluation and care have expanded significantly. Practitioners who do not have specific training/expertise in this area and for whom the management of congenital heart disease is not their core work, would find it very difficult to maintain adequate skills to reliably assess and advise regarding the significance and management of heart problems in infancy and childhood (The Cardiac Society of Australia and New Zealand, 2016).

Cardiology Care includes general cardiology as well as a number of specialty areas including pulmonary hypertension, electrophysiology, outpatient care of heart transplant patients, Imaging (CT and MRI), echocardiography, fetal cardiology, heart failure/functional cardiology and transplant. Interventional Cardiology is also used for diagnostic procedures and increasingly for treatment of cardiac conditions. Cardiology sub speciality services comprise:

- General Cardiology
- Interventional
- Heart Transplant and Heart Failure
- Pulmonary Hypertension
- Arrhythmia service
- Fetal Medicine service
- Research (Integrated research program across all aspects of care to support excellence in clinical practice and Translational research program).

Cardiac Surgery

Cardiac surgery is undertaken to either repair or palliate CHD and can be planned and elective, or unplanned and either urgent (during hospital admission) or emergent (<24 hours). Paediatric cardiac surgical procedures are performed in patients from birth to 18 years of age and can be categorised as follows:

- Neonate (≤ 28 days post-term) – all defined as **high complexity** cardiac surgery due to patient fragility peri-operatively, anatomic and physiologic variability and operative complexity. Includes surgery for hypoplastic left heart syndrome.
- Infant (>28 days & < 1 year of age) – range of high, moderate and low complexity procedures required including:
 - **Low complexity:** e.g. ASD, VSD, aortic coarctation repair
 - **Moderate complexity:** e.g. complete AVSD repair, Tetralogy repair, Single ventricle palliative procedures
 - **High complexity:** e.g. Ross procedure, Rastelli, Nikaidoh, Double switch, Yasui, DORV/AVSD (complex biventricular intracardiac repairs)
- Childhood (1 to 12 years)
 - **Low to moderate complexity:** e.g. ASD repair, partial AVSD repair, subaortic membrane resection
 - **High complexity:** e.g. Redo surgery after previous biventricular repair or single ventricle palliation
- Adolescence (>12 to 18 years)
 - Low complexity: e.g. ASD repair, Valvular surgery (AVR, MVR)
 - Moderate complexity: e.g. Ross procedure, RV-PA Conduit change

Non-cardiac thoracic surgery is performed by both cardiac and general paediatric surgeons and includes trauma services, complex airway surgery (collaborative with ENT), spine surgery (collaborative with orthopaedics) and general thoracic surgery.

Special Programs: Hypoplastic left heart program. Paediatric Heart Transplant (PHT) and Ventricular Assist Devices (VAD) which are currently not provided in NSW.

The Extracorporeal Membrane Oxygenation (ECMO) program in NSW is currently supported by the cardiac surgeons and the perfusion team. ECMO occurs post-cardiac surgery and to support cardiac and respiratory failure. Additionally, non-cardiac ECMO is used to support patients in the Intensive Care Units (NSW Agency for Clinical Innovation., 2020).

Psychological and Psychosocial Care

Mental Health

Mental healthcare for CHD is defined as integrated, specialised and evidence-based care that focuses on reducing mental health burden and optimising emotional and psychobiological wellbeing for affected fetus, infants, children, young people, adults and their families. There is an emphasis on prevention and early intervention, through evidence-based screening, assessment and psychological care and treatment, as part of routine cardiac care which can be delivered through a number of allied health services including psychiatry, psychology, developmental paediatrics, social work, speech, physiotherapy, audiology and Occupational Therapy.

Neurodevelopmental

Neurodevelopmental care for CHD is defined as integrated, specialised and evidence-based care to prevent or minimise neurodevelopmental or neurocognitive impairment in infants, children, young people and adults with CHD, with an emphasis on early intervention, ongoing surveillance and specialised intervention, as indicated.

Transition to adult care

Poorly planned transition from young persons to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. When children and young people who use paediatric services are moving to access adult services these should be organised so that all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

Paediatric Cardiac Care Staff

All patients should have access to the multidisciplinary team at all stages along the patient care pathway. The workforce required to deliver high quality paediatric cardiac services involves a broad range of clinical professions. The Paediatric Cardiac Service team comprises:

- Cardiac surgeons, cardiologists, sub specialist cardiologists, developmental paediatricians, anaesthetists, paediatric intensivists, neonatologists, Child and Adolescent psychiatrists, cardiac physiologists, doctors in training: cardiology, cardiac surgery fellows, paediatric registrars and residents
- Nursing: nurse practitioners (NP); clinical nurse consultants (CNC), nursing across: recovery; theatres; catheter laboratory; NICU; PICU; wards
- Cardiac allied health (AH): psychologists; sonographers; perfusionists; physiotherapy; social work; speech pathology; occupational therapy; audiology; chaplains; child life therapy; music therapy; nutrition and dietetics; orthoptics; pharmacy; and exercise physiology.
- Other key clinicians: biomedical engineering; pathology; medical imaging (catheter laboratory radiography; sonography; MRI and CT)
- Clinical support: administration staff, data support staff
- Researchers.

Paediatric Cardiologists (Medical, Interventional)

Paediatric cardiologists are subspecialty paediatricians with special expertise in the diagnosis and management of congenital and acquired cardiac disorders and multisystem disorders. They are able to coordinate patient care and work within the multidisciplinary team to optimise health outcomes for individuals and groups. The paediatric cardiologist has a breadth of expertise extending across acute hospital and ambulatory settings. The paediatric cardiologist manages patients in contexts which meet their care needs.

The Cardiac Society of Australia and New Zealand (CSANZ) recommends in the Paediatric Cardiology Standards of Practice that where a cardiology opinion is requested, for infants and children in whom there is a strong suspicion of congenital or acquired heart disease, this should be provided by a paediatric cardiologist, in order to ensure that appropriate advice is provided to the patient's family and management is optimised (The Cardiac Society of Australia and New Zealand, 2016).

In addition to general cardiology the areas of specialty practice to be covered are Electrophysiology, Interventional Cardiology, Pulmonary Hypertension, Imaging, ECHO, Fetal, and Heart Transplant/failure/functional.

Paediatric Cardiac Surgery

Paediatric Cardiac Surgeons are subspeciality cardiac surgeons who have experience and training in the techniques of congenital heart surgery. They provide pre, intra and post-operative care to individuals requiring cardiac surgery for the management of underlying acquired or congenital heart disease in the paediatric population. The cardiac surgeons are a care team both inside and outside of the operating theatre, as well as, participating in clinical decision making and care planning, being present on ward rounds and involvement in teaching, research and quality improvement.

Paediatric Cardiac Nurse

The paediatric cardiac nurse is often the first to identify subtle changes in the assessment of the complex cardiac patient. They play an essential role in interdisciplinary rounds, where the continuity of care is family and child centred. The paediatric cardiac nurse plays a key role in delivering care to cardiac patients with specialist cardiac nurse practitioners and clinical nurse consultants integral to care coordination and continuity.

Cardiac Clinical Nurse Consultant Service

The paediatric cardiac clinical nurse consultant (CNC) service comprises of expert nurses who are an integral part of the multidisciplinary team in providing holistic, family-centred cardiac care for children and young people with cardiac conditions and their families. A key component of this role is care coordination for families with complex care needs from diagnosis through to transition to adult services. The cardiac CNC offers a unique perspective of the family's journey and acts as a bridge between home, community and hospital, ensuring continuity of care and effective communication throughout the child/young person's cardiac care pathway. The team work closely within the multidisciplinary team to provide individualised care plans that meet the requirements of the patient and their family within the hospital and wider community setting. The cardiac CNC service advocate for the needs of families and aim to provide a compassionate, accessible, reliable and equitable service for all patients and their families with congenital and acquired heart disease.

Cardiothoracic Nurse Practitioner service

The cardiothoracic nurse practitioner (NP) service provides expert clinical care to children and their families throughout the cardiothoracic surgical pathway. A key component of the service is advocacy, case management and education for children and their families. The cardiothoracic NP service also offers educational support for the wider multidisciplinary team.

Perfusionists

Perfusionists are vital members of the cardiovascular surgical team because they are responsible for running the heart-lung (cardiopulmonary bypass) machine during cardiac surgery and other surgeries that require cardiopulmonary bypass to manage the patient's physiological status. Their main work is performed within a cardiac operating theatre, but they also work in intensive care units to set up, initiate and help manage and maintain ECMO circuits for support of cardiac or respiratory failure in patients in the ICU; general, orthopaedic, vascular and neurosurgical operating theatres; cardiac catheter laboratories and research laboratories. Virtually all heart operations require the services of a perfusionist to operate the heart-lung bypass machine. Some perfusionists specifically train to work in paediatrics.

Paediatric Cardiac Technical and Allied Health Team

Children with congenital and acquired heart disease are at risk of developmental, social, psychological, feeding, nutrition and physical problems, requiring significant Allied Health input, during most facets of their journey from infancy to adulthood (and beyond). To enable them to maximise their potential and participation in life, allied health professionals are vital members of a cardiac service in supporting these children. The requirement for Allied Health services increases with increased size of the service, increased patient complexity, acuity, and severity of the developmental issues, as well as the introduction of new treatment options (e.g. Transplantation and LVAD).

Allied health disciplines providing services to paediatric cardiac patients and their families include: Audiology, Child Life Therapy, Exercise Physiology, Genetics Counsellors, Medical Radiation Scientists (Medical Imaging and Sonographers), Music Therapy, Nutrition and Dietetics, Occupational Therapy, Orthoptics, Orthotics, Pharmacy, Physiotherapy, Psychology, Social Work, Speech Pathology and Chaplains.

Congenital heart health requires an integrated, life course approach — with equal emphasis on the physical and the psychological — beginning before birth, through infancy to adulthood. Cardiac Psychologists have become an integral part of the care team throughout its continuum. Psychological assessment and intervention for infants, children and families affected by heart disease across the lifespan is provided; that is from fetal diagnosis to transition. Care is provided on an inpatient and outpatient basis. Referrals are received through a range of different sources, cardiac nurses, cardiologists, and self-referrals from families are accepted.

Standards of Care

Australia has never had nationally agreed standards of care for CHD, and as such a significant gap exists. Without standards of care, risks to patients include: inconsistency of practice and resourcing of patient care, particularly disadvantaging people in rural, remote and isolated communities; fragmented care in responding to immediate needs rather than continuity in care for the life of the person; lack of alignment between workforce and infrastructure planning and resourcing; and CHD patients being 'lost to care', and suffering associated consequences for mental health, well-being and life expectancy (HeartKids, 2019).

The National Action Plan for Childhood Heart Disease (Australian Government Department of Health, 2019) recommends a framework for action and a range of activities regarding research and surveillance to set priorities and guide health policy and strategies that concentrate on childhood-specific care. A focus area is the development and implementation of the first CHD Australian standards of care and service specifications that cover the entire patient pathway, from prevention, diagnosis, treatment, in-home care to end-of-life care. The standards will also incorporate Mental Health and Neurodevelopmental standards.

The Australian Standards of Care for Childhood-onset Heart Disease Project commenced in May 2020 with funding from the Commonwealth Department of Health and will be developed over a three-year period. At completion, the Standards will be managed by one or more peak professional bodies with regular review to ensure currency, high quality and appropriate professional, stakeholder and government input (HeartKids, 2020).

Current international examples of standards of care for CHD practice include:

- National Health Service (NHS) UK Congenital Heart Disease Standards and Specifications (2016)
- Specialist Congenital Heart Disease standards for children and adults in Scotland
- AHA/ACC Guideline for the Management of Adults with Congenital Heart Disease (August 2018) (USA)
- Adult Congenital Heart Association Strategy (USA).

The Cardiac Society of Australia and New Zealand (CSANZ) also have in place a small number of Guidelines and Position Papers related to paediatric cardiac care. These cover areas such as paediatric cardiac catheterisation and recommend that paediatric cardiac catheterisation should only be undertaken in centres which have appropriate cardiac catheterisation laboratories and personnel for the paediatric age group. In regard to credentialing this should be undertaken in paediatric cardiac centres that perform at least 150 cases per year and have at least one experienced interventional cardiologist. The NHS UK standard suggest cardiologists performing catheterisation in children and young people with congenital heart disease must be the primary operator in a minimum of 50 procedures per year.

Guidelines for standards of practice in Paediatric Echocardiography have also been developed by CSANZ and outline the special considerations, minimum exposure cases in the paediatric age group and training of operators for paediatric patients with CHD and Fetal Echocardiography (The Cardiac Society of Australia and New Zealand (CSANZ), 2016).

Following the development of standards of care, a CHD taskforce will work with experts to devise a roadmap and priorities for the development of national clinical practice guidelines. The development of the national clinical practice guidelines for CHD will follow NHMRC guideline standards. The development of clinical practice guidelines (affirmed by CSANZ) will include a review of existing international clinical guidelines such as the American College of Cardiology/ American Heart Association's Guidelines for the Management of Adults with Congenital Heart Disease and other international guidelines on CHD for the feasibility of their adaption and adoption and for consideration in the Australian context (Australian Government Department of Health, 2019).

In the absence of Australian CHD Standards, NHS UK standards and existing CSANZ guidelines will be used to guide clinical specialist practice for this model of care. These interim standards in regard to tertiary services should include the

following elements while also aligning with the Paediatric cardiac care principles (Appendix A) developed by the NSW Paediatric Cardiac Services Model of Care Panel, working with the Australian Commission on Safety and Quality in Health Care (ACSQHC).

Surgeons

- Surgical teams must consist of a minimum of four consultant congenital cardiac surgeons per team (with a full complement to be achieved over a five-year period). This allows for sustainable rostering, leave, professional development and participation in the running of the unit as a whole including education and research.
- Out-of-hours arrangements must take into account the requirement for surgeons to undertake procedures for which they have the appropriate competence.
- 24/7 surgical care across the spectrum of neonatal and paediatric surgical emergencies (with the exception of cardiac transplantation) should be available, with a Consultant call to bedside response time of 30 minutes.
- congenital cardiac surgeons must be able to operate together on complex or rare cases.
- Each congenital cardiac surgeon must perform a minimum of 125 first operator congenital cardiac (paediatric and adult CHD) surgical procedures year, averaged over a three-year period.

Cardiologists

- Interventional cardiology cover must be 24/7 with a roster no more frequent than 1 in 4. Congenital interventionists based at other hospitals may participate in this roster. Each consultant congenital interventionist must be primary operator in a minimum of 50 congenital procedures per year, averaged over a three-year period.
- Provide 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover, with rosters no more frequent than 1 in 4 and ensuring a Consultant call to bedside response time of 30 minutes.
- There must be a designated lead interventionist who must be primary operator in a minimum of 100 procedures per year, averaged over a three- year period.
- The service must be staffed by a minimum of one expert electrophysiologist experienced in paediatric cardiac disease with appropriate arrangements for cover by a competent person.
- The service will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- The service will have a lead for congenital echocardiography (RANZCR accredited or retrospective equivalent experience).
- The service will have a lead for fetal cardiology who has fulfilled the training requirements for fetal cardiology. This will require more than one cardiologist with training in fetal cardiology to meet the requirements of the fetal cardiology standards.

Paediatric Cardiac Anaesthetists

- The service will have a continuous, immediate and documented availability of specialised cardiac paediatric anaesthetists with full training (in accordance with the Australian and New Zealand College of Anaesthetists (ANZCA), Guideline for the provision of anaesthesia care to children (PS29) and competence in managing paediatric cardiac cases including a specialist paediatric cardiac on-call roster, which is separate from the intensive care roster.

Paediatric perfusionists

- Paediatric perfusionists should be certified by the Australia and New Zealand College of Perfusionists (ANZCP) and have undergone subspecialist training in paediatric perfusion

Paediatric Intensive Care Units

- Paediatric Intensive Care Unit (PICU) Intensivists with appropriate skills in paediatric cardiac critical care must be available to the PICU on a 24/7 basis.

Cardiac nursing

- Nurse Manager who will provide professional and clinical leadership to the nursing team across the network.
- Sufficient clinical cardiac nurse educators to deliver competency-based programs for nurses across the network.

National Health Service United Kingdom Paediatric Congenital Heart Disease Specification

The National Health Service (NHS) implemented standards of care for congenital heart disease across the United Kingdom (UK) in 2016. The aim of these standards was that every patient should be confident that their care is being delivered by a hospital that is able to meet the required standards, and the NHS would only commission services that were able to meet those standards. These NHS standards for Paediatric Cardiac Surgery encompass the whole patient journey. The Standards of Care are based on the principle of a Network Model - fetal, paediatric and adult services working together to deliver care.

The NHS UK has established their outcomes framework using domains (Figure 2) to inform a quality dashboard with a number of outcome care measures. These measures complement the standards and will be used to measure outcomes for this paediatric cardiac model of care.

Figure 2 - NHS UK Outcomes Framework

Domain 1: Preventing people from dying prematurely

Domain 2: Enhancing quality of life for people with long term conditions

Domain 3: Helping people to recover from episodes of ill health or following injury

Domain 4: Ensuring people have a positive experience

Domain 5: Treating and caring for people in safe environment and protecting them from avoidable harm

Evidence for care

Current practice: international and national

A summary and review of literature regarding quality and standards of CHD care, based on local and international studies has been undertaken. The Royal Australasian College of Surgeons (RACS) have also undertaken a review of Paediatric Cardiac Services with a report finalised December 2020. The themes identified inform the discussion and development of the model of care. Common themes from the review include:

- mortality rates of paediatric cardiac surgery are not a standalone measure of outcomes and should be measured to include patient-level factors (age and STAT category score) as these factors make a greater contribution to mortality rate differences.
- volume is not the only consideration for good outcomes, with other issues of sustainability of services, numbers of support staff, infrastructure and frequency of on-call commitments being other factors to consider.
- European guidelines regarding the caseload per surgeon are similar to United Kingdom (UK) recommendations. Those guidelines propose a minimum of 2 surgeons and an optimal case load of 250 per annum (125 cases per surgeon), while accepting both the validity of smaller units and the value of adult case load as a surrogate for paediatric cases. In the UK, the National Health Service (NHS) standards for congenital heart interventions are that the surgeon be the primary provider of a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period along, with a minimum of a 1 in 3 on call roster (ideally at least 1 in 4).
- ongoing debate in regard to a mixed adult/paediatric versus paediatric exclusive cardiac surgery model. Benefits for both models are discussed such as a mixed model providing valuable input with adoption of innovative practices from the adult sector and care of adult congenital cases and an exclusive model providing availability, flexibility and focus in delivering a paediatric cardiology program.
- paediatric cardiac program components need to have institutional strategies to improve the capacity of the workforce and ensure the required infrastructure to provide quality care. Delivery of high-quality cardiac care involves a broad range of clinical professionals and supporting teams (including: Allied Health (AH), Intensive Care (CICU, PICU and NICU), Theatres, Nursing, Wards, Anaesthetics, Perfusion, Physiology and clinical support staff).
- an ethical Paediatric cardiac program supports care and structure of the service as patient centred and informed by transparency of reporting outcomes to inform parent and doctor shared decision-making processes though the patient journey.
- key elements of success for a paediatric cardiac program is strong leadership, a positive collaborative culture and innovation.
- children with CHD are surviving into adulthood and therefore a comprehensive program should include a formal transition service that establishes strong links between the paediatric and adult programs.

A review of recent published information on various topics relating to paediatric cardiac surgery has been undertaken by RACS and presented to the NSW Paediatric Cardiac Services Model of Care Panel, who have been working with the Australian Commission on Safety and Quality in Health Care (ACSQHC). The work to inform this detailed Report comprised two discreet components - data analysis and rapid reviews. The overall conclusion is that Paediatric cardiac surgery services are very complex and there is no one factor which has a major influence on outcomes. The Report is available at <https://www.schn.health.nsw.gov.au/news/articles/2021/01/cardiac-services-announcement>

Future Cardiac Patient Characteristics

There is an increasing trend for heart disease to be diagnosed prenatally or in the new born nursery; increased numbers of infants and children surviving complex cardiac surgery; and more intensive surveillance of at-risk groups has resulted in earlier treatment and reduction in long-term morbidity and mortality. Current and future cardiac patients will share many characteristics:

1. They are likely to have had a diagnosis of CHD made in fetal life. In the future more patients with a fetal diagnosis will have undergone a fetal intervention and such interventions will require close fetal monitoring.
2. They are likely to have surgical repair or catheter intervention in the newborn period. The “modern” era of cardiac surgery is for a single stage “repair” in the newborn period or in early infancy to normalise or stabilise the circulation. This is in sharp contrast to a previous era where children with CHD would have undergone multiple palliative procedures prior to a more definitive procedure in later infancy or early childhood.
3. When treated by well supported multi-disciplinary teams they are likely to have excellent survival. Currently and into the future, the success of a program will not be determined by survival statistics but by neurodevelopmental outcomes and psychological well-being, minimising reinterventions and optimising functional capacity.
4. They are likely to have hybrid procedures involving both surgery and catheter-based techniques. This is becoming standard of care and demands a close functional relationship between the operating suite and the cardiac catheter laboratories.
5. They are likely to have patient specific therapeutics, with operative interventions and catheter interventions planned from 3D printed heart modelling and grafts or conduits bioengineered from the patient’s own cells, for example.
6. They will include a small but growing number of children with heart disease who live with poor heart function or pulmonary hypertension. To achieve an optimal quality of life, these children will require advanced medical and surgical therapeutics including heart and/or lung transplantation and ventricular assist devices.
7. They are likely to live well into adult life, requiring reinterventions as adults. Infrastructure and personnel that span across the paediatric to the adult service will be vital in ensuring continuity of care.
8. They and their families will continue to demand innovation and research both for themselves and for the next generation.

Current Context

Across NSW there are approximately 17 paediatric cardiologists working in both metropolitan and rural health services. Tertiary paediatric cardiology services are delivered across both the Children’s Hospital Westmead (CHW) and Sydney Children’s Hospital Randwick (SCH) campuses as part of the Sydney Children’s Hospitals Network (SCHN), and limited services are provided at John Hunter Children’s Hospital in the Hunter New England Local Health District (HNELHD).

The paediatric cardiac services are underpinned by four pillars: inpatient care, ambulatory services, regional/remote service delivery and research as part of a network based state-wide service.

The SCHN Cardiac Service comprises cardiologists, cardiac surgeons, specialist nursing, doctors in training, allied health, physiologists, psychologists, sonographers, perfusionists, clinical support staff and researchers who work across both sites (CHW and SCH) within the SCHN. Elective and emergency cardiac surgery is provided along with a range of non-invasive investigations including ECG and Holter monitoring are available. Echocardiography is available in conjunction with cardiac consultation. The Cardiac Services team from the SCHN provides outreach services around NSW.

The Heart Centre for Children, at CHW, incorporates cardiology, cardiac surgery, cardiac research and the Edgar Stephens Ward at CHW whose services comprises:

- Paediatric cardiology for inpatients and outpatients
- Paediatric cardiothoracic surgery
- Congenital Heart Clinic, both paediatric and adolescent
- Outreach services
- NSW Fetal Cardiac Service
- Family support including psychological care for patients and families.

The services provided at SCH include consultative, diagnostic and procedural services for children with congenital and acquired heart diseases. The team also provide services in other hospitals, such as the Royal Hospital for Women, assessing the heart health of unborn children via the Cardiology Fetal clinic.

The following table provides a summary of the current infrastructure for CHD across the SCHN.

Table 1 - SCHN Infrastructure for Paediatric Cardiac Surgery and Interventional Cardiac Services as at 2018

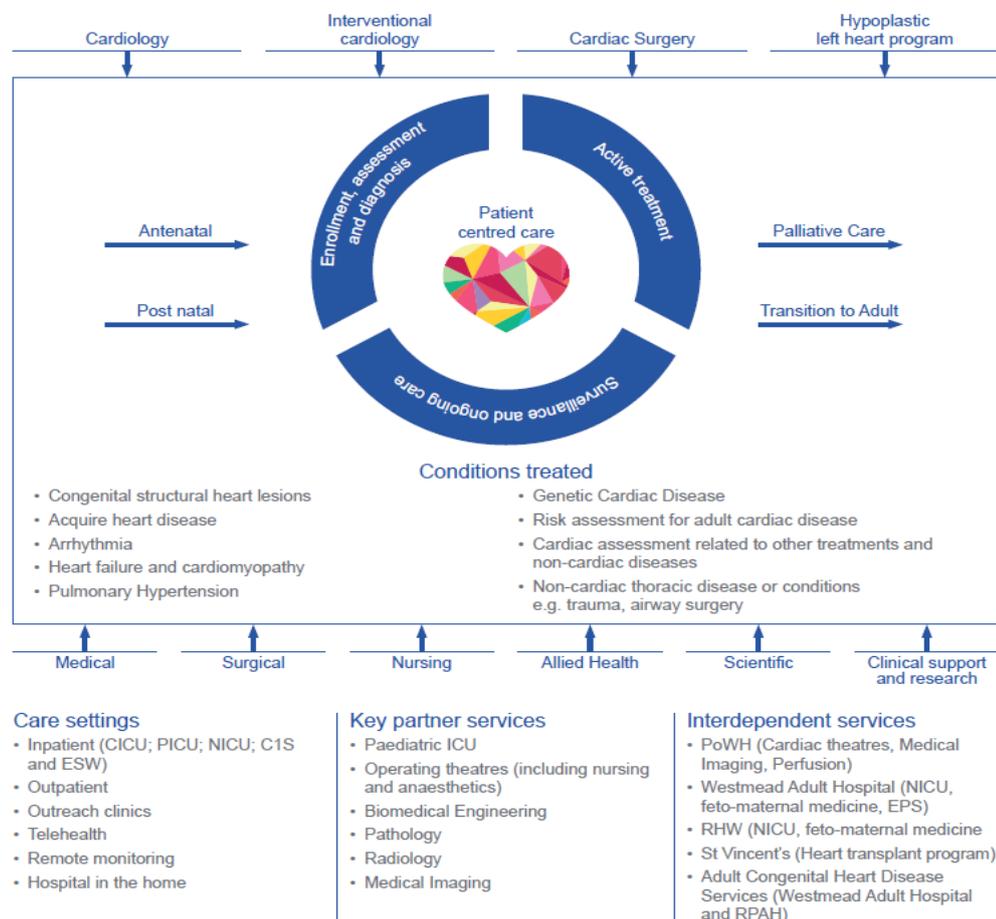
Current State Infrastructure ¹	CHW	SCH
Number of operating theatres	1 allocated theatre, utilised 5 days a week 1 further equipped theatre (not currently allocated) 1 equipped Cath lab (suitable for hybrid operating)	2 equipped cardiac theatres (RCOS), allocated 3 days per fortnight
Number of ICU beds	NICU beds – 23 (10 utilised as ICU beds) PICU beds – 21; COU beds – 6	Children’s Intensive Care Unit (CICU) beds – 13 NICU beds – 4 (contained within the CICU footprint)

¹ Source: Cardiac Planning Committee – Report to the CEO (2018) Page 16 (Reid, 2018)

Number of ward beds (NB: not all beds are utilised for cardiac services at all times)	Edgar Stephen Ward 20 bed spaces (18 staffed)	Ward C1 South 16 beds
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The wards in which the cardiac patients are accommodated are C1 South Ward at SCH and the Edgar Stephen Ward at CHW. The Grace Centre at CHW provides the Neonatal Intensive Care Unit (NICU). Under the shared services agreement with South Eastern Sydney LHD Prince of Wales Hospital (PoWH) are responsible for the operation of the Randwick Campus Operating Suite (RCOS). The paediatric cardiac theatres are within the RCOS, located in the PoWH building. The theatre utilised for paediatric cases is within the adult hospital theatre complex in PoWH; there are dedicated paediatric operating theatres at CHW.

Figure 3 - Paediatric Cardiac Service Delivery Model, SCHN²



² Source: October 2018. Cardiac Planning Steering Committee: Report to the CEO FINAL (amended graphic)

The need for change

Aiming to improve health care performance and outcomes, the Australian Government has committed to system-wide reform, including increased transparency and accountability (Australian Government Department of Health and Ageing, 2010). Clinicians have a duty to engage in creating “the right organisational environment”, despite this being “one of the most difficult challenges they face in the modern era” (Royal College of Physicians, 2005).

The NSW Government and Ministry of Health have committed to the ongoing provision of cardiac services from both CHW and SCH.

The implementation of the model should acknowledge the need to support precinct partners maternity services such as Royal Women’s Hospital (RHW) and Westmead Hospital (WH) in recognition of the increasing levels of maternal fetal services. The model should also address the need to maintain staff skill levels across the Network, and include strategies to ensure a sustainable two site, one network service.

For NSW to become a recognised leader in paediatric services, nationally and internationally, the Henry Review, completed in December 2019, considered that both Sydney Children’s Hospitals sites must work together effectively as a networked service to deliver on this vision.

Consultation also identified a number of areas of change to support the implementation of this model of care (see Appendix D for List of Participants). These include:

- the development of a bespoke paediatric cardiac coding system based on international coding system – this would be a national database to allow comparison and benchmarking based on Australian conditions and population. The International Paediatric Cardiology Code (IPCC) comprises 5,600 diagnostic and procedural codes thereby enabling international standardisation and comparison of CHD data, with additional categories for describing the complexity of CHD. The database repository would also store intake information and referrals - a true patient management system supporting communication between practitioners and also families.
- a centralised intake process to promote equity of service access
- a dedicated Network Director for paediatric cardiac services, predominantly a management/leadership role supported by networked appointments
- one transparent governance arrangement for paediatric cardiac services across the SCHN
- PICU and NICU to be included as part of the comprehensive cardiac service, while they are standalone entities, they are an integral part of the service in NSW
- a more streamlined, formalised Joint Cardiac Committee meeting format to discuss more patients requiring both surgical and/or interventional care supported by improved technology capability to manage and include all relevant participants
- Cardiac Clinical Nurse Consultants taking on a greater care coordination role providing a conduit to link to the services and care available for families and children. This could take the form of a formalised referral service – future planning to investigate the feasibility to have these linkages available across NSW. However, this needs to be undertaken in collaboration with local providers particularly in rural and regional areas
- greater focus placed on ensuring the child’s care journey progresses to transitional care, facilitated by MDTs involving telehealth, virtual care and linking in with the statewide program – Trapeze
- recognising the emerging importance of psychological and psychosocial support with evidence mounting that early intervention and ongoing assessment lead to improved outcomes for the child and family. Multiple articles have been produced documenting developmental delays, importance of neurodevelopmental care, early intervention and long-term surveillance

- recent work undertaken by allied health disciplines has highlighted that paediatric cardiac services requires the input of a wide variety of multidisciplinary allied health teams (16 allied health professions as listed earlier in this document), and that many professions were under-resourced to support cardiac services at SCHN. Particular consideration needs to be given to planning for critical allied health services (e.g., perfusionists) when planning robust cardiac services (SCHN, August, 2018)
- fetal cardiology assessment and diagnosis occurring much earlier in the pregnancy, as adopted in other States and internationally. The fetal cardiology model of care is best when centred on the woman and baby, with fetal screening occurring at 14 weeks. The proposed model is an integrated model where the fetal cardiologist travels to each tertiary maternity service and embeds their practice with the individual Maternal Fetal Units in the metropolitan area, linked in and working collaboratively with the Obstetrician as part of the service delivery model
- the current Arrhythmia service delivery model is being changed to be a truly networked service to set up clinics in collaboration with adult specialists also the team we can see the whole family adults and paediatrics in the one clinic. This will be an MDT family centred approach
- there is currently limited neurodevelopmental care available for children and families beyond 3 years of age and in early primary school age. Neurodevelopmental care should occur throughout the life of the child through to adulthood
- greater opportunity to develop a formal peer support program that supports the family and child through similar lived experience to assist with guidance, support and connection with other families
- involve a consumer co-design component in the model of care to ensure families are access the right care for them. This includes involvement of the design of the formalised care planning process and working in partnership with families and consumers to provide an optimal service
- e-health record is currently available but there are issues regarding sharing of information between services. The idea being discussed involves the development of an App as a health passport that holds the medical history for the individual
- address the issue that the medical information collected antenatally regarding the fetus be linked to the maternal medical record to provide a full history
- telehealth and virtual care model of care approaches should include an education component that upskills rural and regional clinicians that indicate an interest in the provision of cardiac care locally and enhances the service offerings regionally. Examples include real time ECG imaging involving a collaboration of sonographer, paediatrician and cardiologists reducing the need to travel and enhancing delivery of care closer to home
- need to consider how paediatric services are expanding in the outer metropolitan hospitals such as Campbelltown or regionally such as Wollongong or Shoalhaven and work with them to develop their cardiac care capacity with interested clinicians locally as part of the model of care and the Network rather than as an outreach service – consider opportunities and strategies that support shared care and collaborative arrangements for children and families in those outer metropolitan areas.

The Model of Care

Description of the model of care

The model of care delivers all aspects of specialised care and treatment of children and young people with congenital/acquired heart disease and delivering services and is a collaborative model for all children with heart problems. The model of care will ensure that all paediatric cardiac care is carried out only by appropriately trained cardiac specialists (including advanced investigation, cardiology and surgery). The model has been informed by extensive evidence-based studies undertaken in the United Kingdom, United States, Canada and Australia (Queensland and Victoria). These reports and studies have been referenced to ensure that families and children requiring cardiac care in NSW will have access to the best possible, evidenced based care framework, regardless of where they live.

The care for some patients with Childhood Heart Disease (congenital and acquired heart disease) will require episodic, whole lifetime care including prenatal diagnosis, maternity and obstetric services, children's services, transition to adult congenital cardiac services and palliative care. The cardiac specialist service will work closely with other relevant services including fetal services, maternity services and intensive care services to ensure a joined-up approach with treatment continuity.

The model of care is built on frameworks developed internationally such as the *Paediatric Congenital Heart Disease Specification, NHS 2016*, and *The Journey Towards Excellence for the Queensland Paediatric Service 2020 – 2024*. It is also informed by CSANZ Paediatric Guidelines, Position Papers and the *NSW Paediatric Capability Framework* to ensure the model of care supports the provision of high quality, safe and timely care for infants, children and adolescents as close to home as possible – '*the right care in the right place at the right time*'.

Objectives of the NSW Paediatric Cardiac Services Model of Care

The NSW Paediatric Cardiac Services Model of Care (MoC) objectives are to:

1. Deliver child and family centred care to ensure all patients receive high-quality comprehensive and individualised care.
2. Enable timely access to the multidisciplinary team for every patient.
3. Advance delivery of ambulatory care through outreach including virtual and telehealth to support regional families and their paediatric teams.
4. Ensure consistent care pathways and protocols across all sites of paediatric cardiac care delivery (Sydney Children's Hospitals Network, John Hunter Kids, Local Health District partners and outreach services).
5. Be a sustainable model that is not dependent on individual practitioners.
6. Promote collaboration, openness, respect and empowerment through all the clinical teams.
7. Build and grow a professional, skilled and caring workforce.
8. Undertake ongoing monitoring of clinical outcomes, provide quality assurance and have strong clinical governance.
9. Incorporate research and innovation into every stage of the inpatient and outpatient journey.
10. Be guided by robust, collaborative leadership that drives development, innovation and progress in the Cardiac Service.

Operationalising the model

- Establish Network Clinical Director of Cardiac Services and Network Nurse Manager roles; implement a rostering system to ensure 24/7 coverage across the SCHN; networked specialist appointments; initiatives that strengthen existing partnerships and provide opportunity for collaboration across NSW; adequate complement of MDT comprehensive support across the SCHN and linked with partner LHDs.
- Install and maintain a central intake service; implement a paediatric cardiac coding system based on an international coding system; establish database repository to support inpatient and outpatient care across clinical services, benchmarking, health outcomes, performance reporting and robust discharge planning and referral.
- Provide appropriate IT equipment and space for virtual/telehealth care; develop 'health passport'; interprofessional education and training across SCHN and linked with key LHD partners.

Key elements of the model

The model of care centres on a network of evidence based care meeting the individualised need, linked to antenatal and maternal fetal programs, cardiology and surgical provision, and transitional care as a collaborative paediatric cardiac service across the SCHN and NSW. Components of the service include primary, secondary, tertiary and quaternary elements with the services organised and delivered through integrated pathways of care provided as close to home as possible when appropriate.

Surgery, interventional procedures and cardiology are the three elements of a complex network of services for children with congenital and acquired heart disease that begins with prenatal screening and continues through to transfer to adult services.

Every surgical intervention case passes through a joint cardiac conference and is a mandatory component of the model of care. This is a fundamental process where experts provide opinions about care and the appropriate care pathway required by the individual infant or child. This may be expanded to cover fetal care planning, psychological and neurodevelopmental care in the future. Research is another fundamental component of the model as it formalises the process of understanding patient outcomes.

Delivery of care by the cardiac team will occur across a number of care environments including hospital, and a number of ambulatory settings: outpatients, outreach clinics, hospital in the home, remote monitoring, telehealth and always with the objective of providing care close to home for the family and child.

Once the child has received definitive intervention the care going forward, unless the patient has been discharged from ongoing cardiac follow-up, will require the child to see a cardiologist at ongoing regular intervals as defined by the treating cardiologist - sometimes for the rest of their life. The paediatric cardiologists are the primary care leaders working collaboratively with nursing staff at this point in the patient journey.

Transition to adult care will commence for children from the age of 12 years and carry through in preparation for transition to adult cardiac services at the age of 16 - 18 years. Transition has to be a multidisciplinary team and comprises input from nurses and allied health including psychosocial support. There is a nurse led transition model being implemented as a pilot, which will inform ongoing practice. The objective is that this will link in with Trapeze.

The delivery of care will:

- reflect nationally and internationally accepted operator volume requirements for currency of practice where surgical or endovascular interventions are being undertaken. That includes sufficient case numbers of all complexity to maintain expertise in the management of all types of congenital heart disorders

- be provided in a safe environment for cardiac surgery, with appropriate infrastructure (paediatric operating theatre, paediatric heart-lung machines and monitoring platforms, etc), personnel (appropriately trained surgeons, perfusionists, anaesthetists and nursing staff) and support facilities such as access to urgent paediatric cardiac catheterisation, specialist imaging and post-operative support services
- collect patient data that can measure the effectiveness and impact on patient outcomes
- manage referrals through a central intake
- be supported by a written care plan developed following diagnosis and agreed to by family/carers and care providers
- recognise a consultation and liaison service to support other clinical sub specialities
- exist within the framework of a network providing comprehensive access to all paediatric sub-specialties
- have appropriate staffing levels to ensure expert provision of care 24 hours per day, 7 days a week, with staffing plans to ensure a sustainable program in the future, comprising a network wide 24/7 roster
- adhere to clinical protocols and pathways of care based on best evidence and contemporary practice, consistent with the service being delivered
- have a close relationship with all maternity and fetal medicine services
- include access to neurodevelopmental care and mental health care from an early stage in the disease process
- ensure transition to adult-oriented health service is seamless to reduce loss to follow-up and decrease risk of non-adherence, this will require collaboration with the ACHD service based at Royal Prince Alfred Hospital with outreach facilities at Westmead Hospital and regional centres
- involves consumer engagement and co-design
- be delivered via all available modalities including telehealth, enabled by facilitating access to patient records and imaging systems across the network.

Governance arrangements

A robust governance process will support and enable the ongoing monitoring and evaluation of the paediatric cardiac service delivery components such as out of hours, clinical skill levels and critical workload levels. As the model of care has a statewide component, governance arrangements should also facilitate the process for the development of, and encouragement towards standardised clinical approaches based on best evidence and sharing of data/patient information.

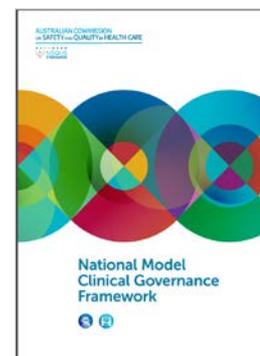
For the model of care to be implemented and successful, the management and decision-making structures need to develop as a formal network arrangement and shift from the single hospital model. This can be enabled through the appointment of a Network Clinical Director who will provide clinical leadership across the network and be responsible for the network's service. The establishment of transparent governance structures that align the operational and clinical management across the two Sydney Children's Hospitals Network hospitals will ensure everyone is accountable. This will require a broader overarching strategy that engages and communicates with all service providers in the broader "network" of paediatric care in NSW, including John Hunter Kids Hospital (Hunter New England Local Health District) and relevant LHDs which also includes sharing of patient and outcomes data across the system, shared incident reporting for cardiac services, network appointments (within SCHN) and joint collaborative meetings to determine pathways for care.

The ACSQHC has developed a National Model Clinical Governance Framework (Clinical Governance Framework) for public and private healthcare organisations in the acute sector (Australian Commission on Safety and Quality in Health Care, 2017). The development and subsequent implementation of this framework ensures the provision of safe and high-quality healthcare, delivering the best possible outcomes for patients in the clinical environment.

The Clinical Governance Framework has five components:

- Governance, leadership and culture
- Patient safety and quality improvement systems
- Clinical performance and effectiveness
- Safe environment for the delivery of care
- Partnering with consumers.

As highlighted in international studies, strong leadership overseeing the embedding and a positive and collaborative culture is key to a great service. Once in place this enables the adoption of transparent decision making, supports accountability and reporting structures that ensures that everyone is accountable, and the delivery of paediatric cardiac services are safe, effective, high quality and continuously improving.



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Table 2 - Paediatric Cardiac Governance Framework

Dimension	Elements to guide the operational framework of the paediatric cardiac model of care
Governance, Leadership and Culture	Identified clinical lead to support clinicians to understand their delegated safety and quality responsibilities in provision of care to patients; common culture, clear organisational structure; robust accreditation processes; code of conduct; collaborative research and service delivery across all disciplines; clear demarcation of roles and responsibilities; agility and adaptability of leadership to meet the needs of a changed or emerging situation; clear communication, negotiation and conflict resolution processes.
Patient safety and quality	Standardised clinical pathways and a formal mechanism to review compliance; access to best-practice guidelines, integrated care pathways, clinical pathways and decision support tools relevant to clinical practice; clear patient criteria; documented referral pathways and policies; clear process for managing critical incidents; care delivery is centred on children and family.
Clinical performance and effectiveness	Endorsed evidence based patient healthcare standards based on international and national best practice; scope of clinical practice is defined and reviewed regularly; rigorous measurement of performance and clinical audits to progress to manage risk and drive improvement in the quality of care; regular access to training, CPD and education resources to maintain and upskill; regular review of approach to care; robust recruitment and retention strategies.
Safe environment for delivery of care	Availability of infrastructure informed by College and/or Society Practice Guidelines and Position Papers; formalisation of multidisciplinary teams; maintenance of buildings, plant, equipment, utilities, devices and other infrastructure so they remain fit for purpose.
Partnering with consumers	Patient satisfaction survey; openness in disclosure; formal consumer engagement policy; ensure enough information is in place to allow parents and/or carers the capability to make fully informed decisions around patient care; formal complaints management approach; develops a charter of patient rights; consent and confidentiality comply with legalisation and best practice.

Patient selection criteria

The paediatric cardiac service is accessible to:

- pregnancy with either suspected fetal heart disease or at high risk of fetal heart disease
- all patients (including patients with congenital heart disease and inherited/ acquired conditions) before the sixteenth birthday at referral, with suspected or confirmed heart disease.

The paediatric cardiologists also provide support and care to adults with congenital heart disease, if requested.

Patients enter the paediatric cardiac pathway through:

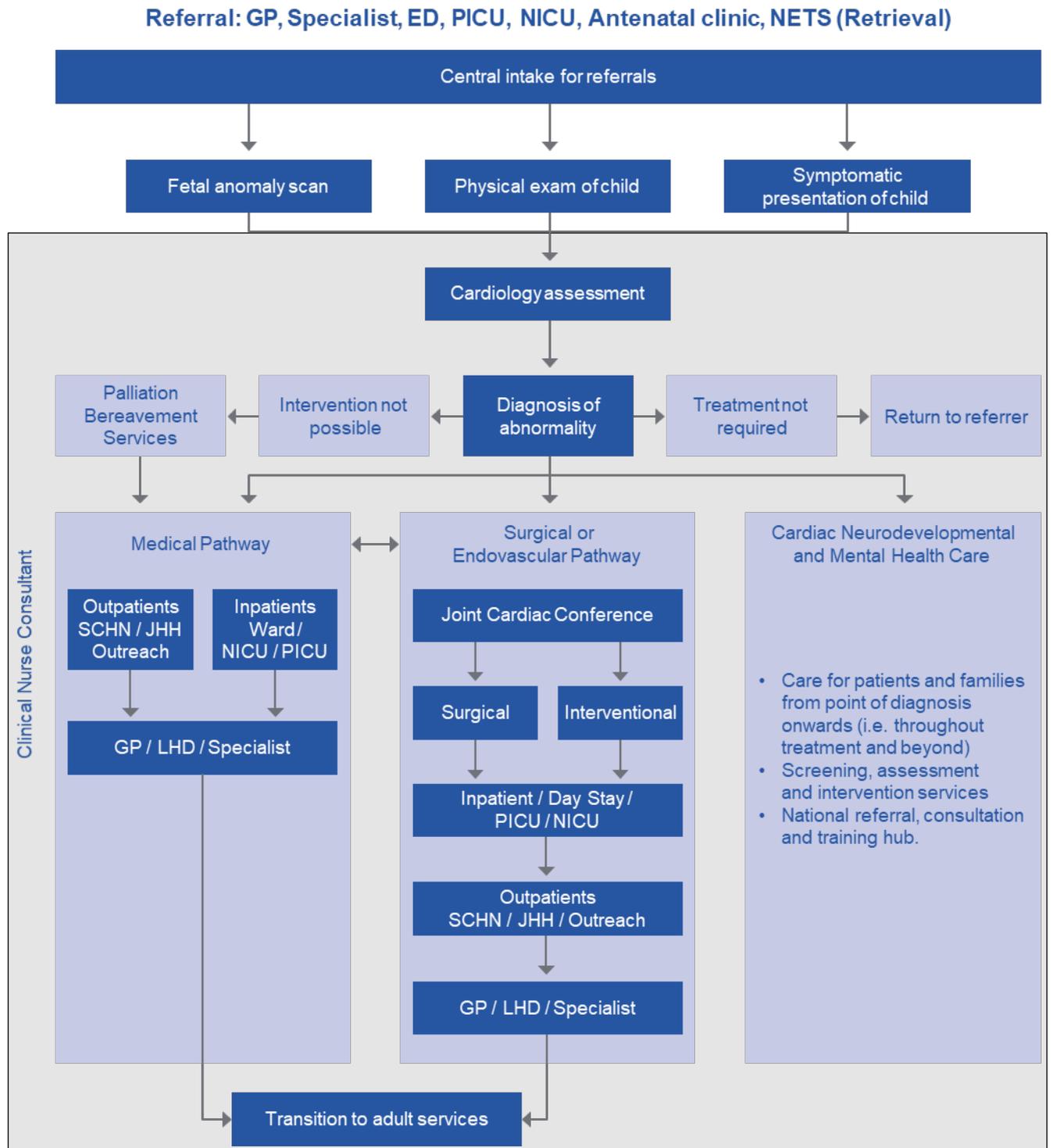
- prenatal diagnosis
- physical examination of an asymptomatic infant or child
- symptomatic infant or child.

There are four main patient types that enter the service and are described as follows:

1. Fetus diagnosed antenatally. If there is a suspicion of a defect the mother is automatically referred to Maternal Fetal Medicine (MFM). When a diagnosis is made, children with critical CHD, where neonatal intervention is likely needed to be born at Westmead Hospital or at the Royal Woman's Hospital, Randwick, and streamed from there to the paediatric cardiac service. Cardiologists are involved antenatally. Many cases of antenatally diagnosed CHD can be born in their local facility with appropriate follow up arranged antenatally. The majority of babies born may not need immediate surgery, but they will be kept in the Neonatal Intensive Care Unit (NICU) at the hospital where they are born and then streamed back into the cardiology service. The decision for those children is then made where they receive their care / surgery.
2. No antenatal diagnosis. These cases are picked up by a GP or paediatrician as part of routine assessment. These patients are sent to a cardiologist (public or private provider) for an opinion, or if in a rural or regional area they can be referred to an outreach service e.g. Canberra, Wagga, etc. where the cardiologist is providing an outreach service. From that consultation decisions are made regarding the type of intervention and the timeframe for provision.
3. Arrhythmia problem. While this is much more common in adults there is a small paediatric population who enter the service this way.
4. Acquired cardiac problems. This is a varied patient cohort who have acquired cardiac problems resulting from another illness or disease such as cancer, acute rheumatic fever, rheumatic heart disease, drug induced cardiac problems (myopathy), as a result of infection (myocarditis). The acquired subgroup also includes those with congenital problems - they may need a transplant. The number of patients in this group is very small and is complemented with good support early which prevents children from reaching this stage.

Patient care pathway

Figure 4 - Paediatric Cardiac Patient Journey



Clinical pathways

The model of care, to be successful, will rely on documented and standard clinical protocols and pathways of care that are in place so that the NSW Paediatric Cardiac Service will:

- Achieve a high quality of care at all stages of a seamless pathway in accordance with the model of care
- facilitate the development of as much non-interventional care and treatment as close as possible to home
- facilitate access to second opinions and referrals to other LHDs / services
- address how the specialist paediatric cardiac service will work, including with other clinical services
- have specific protocols for the transfer of children and young people requiring interventional treatment
- address how the cardiac service will communicate effectively with colleagues across the wider service to care for patients requiring non-cardiac interventions
- recognise the importance of partnerships with both internal and external providers delivering integrated and collaborative care.

Outcomes framework and measures

Variability in clinical practice leads to higher costs without achieving better patient outcomes. Identifying and communicating opportunities to raise the standards of care for patients help hospitals and clinicians drive up the quality of care, measuring processes and outcomes against achievable standards or benchmarks. This ensures that high quality services are maintained (quality assurance) but provides a means to raise the standards of care over time by identifying changes in the way care is provided (quality improvement). These changes can then be monitored to determine whether outcomes or the perceived quality of care are improved for patients or whether healthcare can be provided more efficiently.

Measures should be evidence based and could include the following:

- time to treat measures
- process measures (e.g. protocol adherence rates)
- clinical outcome measures (e.g. complications and mortality)
- neurodevelopmental and mental health measures including family functioning factors
- patient and provider reported outcome and experience measures (e.g. quality of life, experience of care)
- effectiveness and efficiency measures (e.g. service utilisation, appropriateness, resourcing and sustainability)

The following metrics will be used as part of the monitoring of the implementation of this model of care:

- Post Procedural Mortality: 3 year validated partial risk adjusted 30-day mortality after paediatric cardiac surgery
- 1-year rolling unvalidated partial risk adjusted 30-day mortality after paediatric cardiac surgery
- 30 day unplanned re intervention rate following congenital cardiac surgery and catheter intervention
- cancellations on day of operation for non-clinical reasons
- complexity of cases in the ICUs on each site
- post catheter intervention complication rate
- mothers with suspected Childhood Heart Disease in fetus seen by an obstetric ultrasound specialist and a fetal cardiology specialist within 3 days of referral
- mothers with suspected Childhood Heart Disease in fetus seen by specialist cardiac nurse on the day of diagnosis
- waiting time (in days) for elective congenital cardiac surgery
- patient reported outcome and experience data.

Implementation

This is the most resource intensive stage. Implementation of the elements described in the paediatric cardiac model of care will improve provision of care across the patient journey. However, this model of care will only be realised if it is supported by all those involved in providing cardiac care.

There are components within this model of care that will drive significant change, as well as development opportunities for longer term and ongoing system improvement to paediatric cardiac services in NSW. The first action will be to establish a transparent governance process across the Network. This will require the establishment of a formal Paediatric Cardiac Services Network which will be facilitated by the appointment of a Network Director of Cardiac Services, and appointment of a Network Nurse Manager supported by an MDT representative committee, including family and consumer representatives, responsible for all aspects of implementation and agreed actionable strategies. These strategies will require prioritisation dependent on available resources and funding. This structure will provide greater opportunities for improved communication, adoption of the interim NHS UK standards for paediatric cardiac care, the development of evidence-based treatment guidelines leading to standardised approaches to care, and create links to encourage clinicians to work together across facility, geographical and discipline boundaries.

Table 3 - Implementation Approach and Actions

Implementation Elements of the NSW Paediatric Cardiac Networked Model of Care
SCHN and the Ministry work together through the resource allocation process to better use and support the paediatric capacity in hospitals outside SCHN and within the SCHN
The appointment of a Network Director of Cardiac Services, and appointment of a Network Nurse Manager
Establish an MDT representative committee, including family and consumer representatives, responsible for all aspects of implementation and agreed actionable strategies to implement the model of care
Adoption of the appropriate NHS UK standards for paediatric cardiac care as an interim approach for quality standards
Strategies and resources required to implement the volume of care standards and roster requirements
Design and implement a central intake process using the Queensland model as a template
Identify infrastructure upgrades to facilitate care provision across the SCHN
Adopt and implement paediatric coding system
Establish and maintain a paediatric cardiac services data repository
Formalise and develop protocols for the Joint Cardiac Committee meeting format supported by improved technology capability to manage and include all relevant participants
Work with internal service providers to incorporate their operational models of care into this overarching model
Greater focus on ensuring the child's care journey progresses to transitional care, facilitated by MDTs involving telehealth, virtual care and linking in with the statewide program – Trapeze
Utilisation of consumer co-design approach in service planning and protocol development to ensure families and patients perspective and needs are understood and recognised
Support changes to the Arrhythmia service delivery model to be a truly networked service in collaboration with adult specialists

Support changes to the fetal cardiology model of care

Support and plan for the Cardiac Clinical Nurse Consultants to take on a greater care coordination role providing a conduit to link to the services and care available for families and children

Support further development of transitional care model

Support further development of neurodevelopmental care provision throughout the whole patient journey

Develop a formal peer support program that supports the family and child through similar lived experience to assist with guidance, support and connection with other families

Development of an App as a health passport that holds the medical history for the individual

Support enhancement and development of additional psychological and psychosocial support for the child and family

Continue to support and develop appropriate levels of allied health disciplines as identified in work undertaken in 2018 to ensure access both pre and post admission

Provide appropriate IT equipment and physical space for virtual/telehealth care at all locations

Ensure the telehealth/virtual care model includes an educative component that upskills rural and regional clinicians and facilitate true collaborative care delivery

Establish formal service linkages and collaborative approaches in shared care where appropriate in the outer metropolitan hospitals such as Campbelltown or regionally such as Wollongong or Shoalhaven. This would include upskilling or linking them into key committees to work with them to develop their cardiac care capacity

Continuous development, review and evaluation of clinical protocols and pathways of care based on best evidence and contemporary practice, consistent with the service being delivered

Oversight and operationalise the elements identified in the Paediatric Cardiac Governance Framework

Develop a reporting framework for outcomes measures and performance metrics for paediatric cardiac services

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Appendix A – Paediatric cardiac care principles

Paediatric cardiac surgery and complex cardiology require a range of governance, service and workforce elements to be in place to ensure safe, quality services. Foundation principles developed by the Australian Commission on Safety and Quality in Health Care for the effective conduct of complex Paediatric Cardiology and Cardiac Surgery include:

- Ensure the best available evidence underpins the delivery of safe and quality health services.
- Promote a patient-centred model of care, including access to appropriate consumer information and resources.
- Ensure that models of care, clinical care pathways, and workforce considerations also inform the development of service models and service delivery.
- Establish an integrated, well-coordinated multi-disciplinary care pathway, including an effective interface with referring practitioners and in the post-care phase, which may also include telehealth.
- Utilise an appropriate Services Capability Framework or Role Delineation document, to ensure that not only the cardiology and cardiac services include the most appropriate workforce and equipment, but that the appropriate support services are also in place (diagnostics, intensive care, etc).
- Appropriate clinical and corporate governance arrangements need to be established, formalised and transparent, particularly in the case of networked services.
- Ensure a system is established to review and validate the appropriate credentialing and continuing professional development that defines and manages the scope of clinical practice for the clinicians involved in provision of these services. There are a broad range of clinicians that need to be considered in this process, including: surgeons, perfusionists, anaesthetists, intensivists, interventional cardiologists, other medical, nursing and allied health staff.
- That the appropriate range of support services and equipment are maintained, including: intensive care, diagnostic services, cardiac catheterisation laboratories, biomedical engineering, and other specialised equipment.
- Ensure there are established systems and support for monitoring clinical outcomes and volume of procedures so that a critical threshold is sustained to ensure comprehensive and safe services for the full range of cardiology and cardiac surgery services provided.

These principles rely on a number of key elements being in place and implemented to support the sustainability of the paediatric model of care.

Appendix B – Guiding Principles of a Model of Care (ACI)

Models of care mean different things to different people. A model of care is guided by overriding statements and principles and defines the parameters or scope of the service. They provide continuity of care throughout the organisation.

The Agency for Clinical Innovation (ACI) guiding principles of a MoC are that it:

- is patient centric
- has localised flexibility and considers equity of access
- supports integrated care
- supports efficient utilisation of resources
- supports safe, quality care for patients
- has a robust and standardised set of outcome measures and evaluation processes
- is innovative and considers new ways of organising and delivering care, and
- sets the vision for services in the future.

Appendix C – Vision of the NSW Paediatric Cardiac Services Model of Care

The vision embodies 'Children First and Foremost' through:

- Equitable access to care
- Care that is evidence based delivering excellence in cardiac outcomes
- Quality of care that is national and international best practice
- Care delivered to the right patient by the right team at the right time in the right place
- Child and family centred care committed to providing clinical care, psychological care and supporting emotional health and wellbeing.

Appendix D – Consultation Participants

Participants involved in Consultation for the Model of Care

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Appendix E – Glossary

Term	Meaning
ACSQHC	Australian Commission on Safety and Quality in Health Care (Commission) leads and coordinates key improvements in safety and quality in health care across Australia
AH	Allied Health
ANZICS	Australian and New Zealand Intensive Care Society Paediatric Group
Antenatal	care received during pregnancy
CSANZ	Cardiac Society of Australia and New Zealand is the professional body for cardiologists and those working in the area of cardiology including researchers, scientists, cardiovascular nurses, allied health professionals and other healthcare workers.
CHD	Congenital Heart Disease
cardiology	study and medical treatment of disorders of the heart and the blood vessels
Cardiac catheterisation	is a procedure used to diagnose and treat certain cardiovascular conditions
CICU	Children's Intensive Care Unit which is the Sydney Children's Hospital nomenclature for their Paediatric Intensive Care Unit
Clinical Guidelines	Systematically developed reviews of evidence to assist health professionals and people with specific conditions to make decisions in respect of their care
ECMO	Extracorporeal membrane oxygenation (ECMO) is an advanced form of life support – focused on the heart and lungs. Usually delivered in an intensive care setting, there are two main types of ECMO – venovenous and venoarterial. Both provide respiratory support, but only venoarterial ECMO provides haemodynamic support
EPS	Electrophysiology (EPS) studies test the electrical activity of the heart to find where an arrhythmia (abnormal heartbeat) is coming from.
ECG	an electrocardiogram (ECG) is a medical test that detects cardiac (heart) abnormalities by measuring the electrical activity generated by the heart obtained by using ultrasound.
Family and Child Centred Care	an approach to care in which people share management of their illness with their health professionals. The three elements defining family and child centred care are communication; partnerships; and a focus beyond the specific condition to health promotion, healthy lifestyles and quality of life.
FTE	Full Time Equivalent
Interventional procedure	endovascular treatment to a patient provided in a vascular laboratory, such as a cardiac catheterisation laboratory
JHH	John Hunter Hospital, Newcastle
LHD	Local Health District
MDT	Multidisciplinary Team - having access to MDT has demonstrated reduced hospital admissions and better quality life for patients and their families. The team makeup comprises medical, nursing and full complement of allied health professions working together to deliver comprehensive patient care.
MoC	Model of Care

Term	Meaning
NETS	NETS is a state-wide service of NSW Health and provides expert clinical advice, clinical co-ordination, emergency treatment and stabilisation and inter-hospital transport for very sick babies and children up to the age of 16 years.
NP	Nurse Practitioner (NP) is a Registered Nurse (RN) experienced in their clinical specialty, educated at Masters Level, and who is endorsed by the Nurses and Midwives Board of Australia (NMBA) to provide patient care in an advanced and extended clinical role.
NICU	Neonatal Intensive Care Unit
On-call rostering	Available for emergency consultation for the period of on-call. Surgeons are required to be on-site within 30 minutes of notification.
Perinatal	the period immediately before and after birth
Procedural	non-surgical treatment
PICU	Paediatric Intensive Care Unit
Physiologists	Specialises in the study of the normal functions and activities of the body, including all physical and chemical processes
PoWH	Prince of Wales Hospital, Randwick
Randwick Campus Operating Suite	Under the shared services agreement with South Eastern Sydney LHD PoWH are responsible for the operation of the RCOS. The paediatric cardiac theatres are within the RCOS, located in the PoWH building. The theatre utilised for paediatric cases is within the adult hospital theatre complex in PoWH.
RACS	Royal Australasian College of Surgeons
RWH	Royal Women's Hospital, Randwick
SCHN	Sydney Children's Hospitals Network – two tertiary children's hospitals of Children's Hospital Westmead and Sydney Children's Hospital, Randwick
Surgical	Invasive technique to patients undertaken in an operating theatre
VAD	Ventricular Assists Devices