

# Supporting the long-term developmental needs of children with congenital heart disease and their families

A companion document to *'Understanding the Development and Participation of Children with Significant Health Needs'*



A service translation initiative delivered in partnership by the Queensland Paediatric Cardiac Service (QPCS) and Queensland Child and Youth Clinical Network (QCYCN) 2016 - 2018

## **Supporting the long-term developmental needs of children with congenital heart disease and their families.**

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# Acknowledgements

First and foremost, we extend our appreciation and gratitude to the parents and caregivers statewide who contributed to this project, with special mention to our consumer representatives. They generously shared their time, experience and valuable learnings of navigating the health care system to help us understand their journeys and the lived experience of families of children with congenital heart disease. They bravely shared the challenges and frustrations of accessing developmental services and supports for their children, while showing humility and appreciation of the support they have received in order to help future families. For this we are very grateful.

This project was conducted across three pilot Hospital and Health Services (HHS) and would not have been possible without the dedication of the leads and stakeholders from health services within CHQ Metro, Cairns and Hinterland and West Moreton HHSs, as well as the support from the respective Chief Executives.

The steering committee, sponsored by Children's Health Queensland (CHQ) executive, included representation from each of the pilot HHSs, as well as the Queensland Child and Youth Clinical Network (QCYCN), Child Development Subnetwork (CDSN), Queensland Paediatric Cardiac Service (QPCS), Congenital Heart Disease Long-term Improvements in Functional hEalth (CHD LIFE) Program, GP Liaison/Integrated Care Team, Innovation Change and Redesign Excellence (iCARE) program, HeartKids and consumers. The committee's guidance, commitment and belief in the work enabled project outcomes to be realised. With the committee's support, the project team worked tirelessly to maintain the energy, progress the work, seek avenues for sharing the learnings and outcomes and harness opportunities for ongoing work. The project team's dedication, passion and desire to "dream big" realised project outcomes far beyond those initially anticipated.

Finally, this project would not have been possible without the funding support provided by the Healthcare Improvement Unit (HIU) through the Clinical Excellence Division, Queensland Health.

***Miranda Campbell***

Principal Project Officer (on behalf of the steering committee)



## Dedication

This book is dedicated to the infants, children and young adults living with CHD. Your strength, courage and integrity inspire us to continue to improve health and developmental services, to support you to develop, participate and achieve to the best of your ability.

# Foreword

## *A word from the Executive Sponsor*

It has been a privilege to be Executive sponsor and to be part of ‘*At the Heart of the Matter*’ the joint Children’s Health Queensland - Paediatric Cardiac Service (QPCS) and Queensland Child and Youth Clinical Network (QCYCN), service quality and redesign initiative. This piece of work has been underpinned by a shared vision, common understanding and a set of shared ‘can do’ values which have been brought to life through a commitment to working in partnership. I want to pay tribute to everyone involved, including the Queensland Department of Health – Clinical Excellence Division, Health Improvement Unit who have provided financial assistance and in particular to clinicians, consumers and families who have shared their expertise and experiences with the aim of improving the system of care for others yet to come. Health system change can be challenging, however, we know from our recent experience that with thoughtful reflection, a consumer focus, a commitment to partnering and a passion for doing the right thing much can be achieved. ‘*At the Heart of the Matter*’ is a perfect example of how we can deliver on promise when these core elements are recognised, harnessed and focused.

I trust you enjoy reading this report and find our learning helpful in informing your own improvement and redesign initiatives. I look forward to seeing this work implemented across the State of Queensland and to hearing how it contributes to improving the lives of children and families who have contact with our health system.

### **Frank Tracey**

Executive Director, Clinical Services, Children’s Health Queensland

## *Partnerships supporting statewide work*

The QPCS and QCYCN partnered to progress the ‘*At the Heart of the Matter*’ project, a service translation initiative to improve the neurodevelopmental care and ultimately quality of life outcomes for children having cardiac surgery before 12 months of age. This partnership married the clinical expertise of our cardiac surgeons, cardiologists, intensive care physicians, nurses and allied health clinicians, child development experts, paediatricians, primary care experts, community partners and consumers, with a statewide reach driven by the needs of children, families and young people themselves. We have all learnt a great deal together that will feed system change through building knowledge, understanding, linkages and pathways. It is the passion of the collective, our families and clinical champions that has driven this work through inevitable challenges to deliver what ultimately has been a labour of love, ‘*At the Heart of the Matter*’.

### **Associate Prof Dr Robert Justo**

Director Cardiology, Queensland Paediatric Cardiac Service

### **Dr Kerri-Lyn Webb**

Co-Chair Queensland Child and Youth Clinical Network

## **CHD LIFE program evolution**

When the QPCS established what is now the CHD LIFE (Long-term Improvement in Functional hEalth) Neurodevelopmental Long-term Follow up Program in partnership with the Child Development Service in 2013, our mission was clear - to improve the long-term outcomes of children with congenital heart disease at risk of adverse outcomes and their families by screening for deviations, diagnosing impairments, raising awareness, facilitating early intervention, conducting research and training professionals. *'At the Heart of the Matter'* has enabled us to expand our partnerships with clinicians, services and families and improve our understanding of the lived experience of congenital heart disease, what is important to families and what is possible when we come together with a focused vision. CHD LIFE Program is committed to continue this work into the future, to share our experience and contribute to the broader body of knowledge to improve the lives of those living with CHD in and beyond our care.

### **Karen Eagleson**

Clinical Nurse Consultant - Cardiac Maternal Fetal Medicine/CHD LIFE Program

## **HeartKids partnership, project and beyond**

HeartKids is the only national charity dedicated to supporting Australians of all ages impacted by congenital/childhood heart disease, the leading cause of infant death in Australia and a complex chronic disease requiring lifelong treatment. For over forty years, HeartKids has provided timely support to infants, young people and adults living with congenital/childhood heart disease all across Australia. We also fund life-saving research, provide reliable and evidence-based information and advocate for the needs of impacted families. Our support is a commitment for life.

We are proud to have been involved in *'At the Heart of the Matter'* a project that was outcome focused and demonstrates real impact for our families and for the community. One of the specific aims of the HeartKids research program has been to gain a better understanding of the consequences of CHD and its treatment including the neurological, cognitive or social impacts on children affected by CHD and how these issues are addressed. *'At the Heart of the Matter'* has enabled HeartKids to play an active role in delivering on our aim. We are excited to extend our partnership to the CHD LIFE Program and continue to advocate for the needs of people impacted by CHD, provide quality information to guide families through their life long journey and deliver high quality support services.

### **Holly Williams**

HeartKids Limited – QLD State Manager

## **Integrating care for all children**

*'At the Heart of the Matter'* is an important integrated care initiative which will benefit all children at increased risk of adverse neurodevelopmental outcomes. The issues identified and solutions developed are applicable beyond children who undergo early cardiac surgery, and will inform the care of many other groups of children requiring long-term surveillance and transition to adult care.

It is my hope that the principles of coordinated, collaborative care articulated in this document become the norm in the care of all children and families.

### **Dr Dana Newcomb**

Medical Director Integrated Care, Children's Health Queensland Hospital and Health Service

## *Harnessing the voice of consumers*

I can't believe that I have been a part of something that is going to make such a huge difference for families going forward and I'm proud of what we've contributed. I firmly believe that the solutions and outcomes are going to make a massive difference for families in the future. I am also truly grateful for the new friendships that I've formed. I've learnt so much along the way, especially how powerful and important collaborative relationships are. I've also been quite blown away by how many people are so passionate about their work. It's so encouraging to see how this achieves great outcomes but also a greater understanding for all involved.

### ***Pam***

Project consumer

Being part of the team who co-designed this valuable book was an opportunity I felt so passionately about. Having "lived" the experience, I had the knowledge and understanding that could help others. It was my way of helping other families better navigate the system in the community and in the hospital, understand the jargon and help the services see the perspective of a family living and breathing the journey. I found the experience extremely rewarding. The team was well led by someone just as passionate about gaining positive outcomes.

### ***Karen***

Project consumer

Image supplied by HeartKids Limited.



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# Document purpose

## *What is the purpose of this document?*

The purpose of this document is to assist services providing developmental supports to children and families across the care continuum, to contextualise project outcomes to services within their hospital and health service.

## *How should services use this document?*

Services are encouraged to use this document to:

- Understand the expected long-term developmental outcomes for children with congenital heart disease who undergo open heart surgery before 12 months of age.
- Understand the issues faced by children and families accessing developmental supports along the care and developmental continuum across Queensland.
- Understand how international best practice guidelines have been contextualised to the Queensland health care system.
- Localise the recommended long-term care pathway, to assist families to access the right services, in the right place, at the right time.

## *What's included in this document?*

- An executive summary providing a concise overview of this service translation initiative.
- The recommended long-term care pathway, including an example of how this has been contextualised to Cairns and Hinterland HHS to assist other HHSs to localise the pathway within their service models.
- A snapshot of key points at the beginning of each section.
- A comprehensive literature review in Part 3, for services interested in understanding the developmental outcomes of this high-risk population in more depth.



## Executive summary

# Executive summary

## *Background*

Congenital heart disease (CHD) is one of the most common birth defects and is the biggest single cause of child mortality and early childhood hospitalisation. In Australia, the prevalence of CHD is 7.8 cases per 1,000 births. Nearly one third of infants with CHD require surgical intervention. As surgical interventions are improving, mortality rates have significantly decreased. Children with CHD are surviving, but many are left with substantial physical, intellectual, psychological and social difficulties, leading to an increased burden upon families, health care systems and educational facilities. These difficulties can be very subtle in young infants and the extent of impairment can be overlooked or not fully recognised until more complex developmental skills are expected, such as at entry to formal schooling.

Prior to this project, there was no reliable model of care to meet the neurodevelopmental needs of all children with CHD who undergo open heart surgery before 12 months of age in Queensland. The Queensland Paediatric Cardiac Service (QPCS) CHD LIFE (Long-term Improvements in Functional hEalth) Program provided robust developmental surveillance based on international best practice guidelines to a select high risk group of infants. However, it was centralised at Lady Cilento Children's Hospital (LCCH) and did not include neurodevelopmental follow up to all infants undergoing surgery before 12 months as recommended.

It is widely reported that an absence of early monitoring of neurodevelopment can delay identification of developmental concerns or even developmental disability, which in turn may delay access to early supports or intervention and limit children from achieving their full potential. The American Heart Association (AHA) recommends developmental surveillance of all children with CHD, including those who have undergone open heart surgery. These children will likely require access to support, from screening and developmental enrichment, through to specialist intervention.

To address the disparity in statewide service provision and ensure best practice implementation, the QPCS partnered with the Queensland Child and Youth Clinical Network (QCYCN) to undertake a service translation initiative, to establish a statewide approach to the developmental support needs of children with CHD in Queensland. Service redesign methodology support was provided through a partnership with Children's Health Queensland's Innovation Change and Redesign Excellence (iCARE) Program.

## *Project aims*

The primary aim of the project is that the developmental support needs of children with congenital heart disease and their families, provided by Queensland Health services across the care continuum within Brisbane Metro, West Moreton and Cairns and Hinterland regions, will be met by the right people, at the right time, in the right place.

## *Method*

This service translation initiative utilised a clinical service redesign (CSR) methodology to support the change journey across trial sites. Phases of the project included planning, diagnostics, solution design, implementation and sustainability. An important element of this methodology is the focus on consumer co-design.

The project had Executive sponsorship through Children's Health Queensland (CHQ), a strong governance structure led by QCYCN and CHQ, a steering committee representing service along the care

continuum and across trial sites and a dedicated project team. Representation from services across trial sites supported localisation and implementation of solution strategies.

### ***Project scope and limitations***

The in-scope cohort included infants with CHD who undergo open heart surgery in the first year of life, from the three pilot sites: CHQ Metro; Cairns and Hinterland; and West Moreton Hospital and Health Services (HHS). Targeted health services were those providing developmental support to in scope children and families across the developmental continuum, including primary through to quaternary level care, from the three pilot sites.

Limitations included out of scope children (surgery after 12 months of age or acquired heart disease) and services providing developmental support outside the health care sector, including education and disability providers and private practitioners.

### ***Summary of issues with accessing developmental supports***

Quantitative data relating to service provision and expected growth and qualitative data gathered from workshops, surveys and patient journey mapping, was collated and themed. Issues were identified under three themes, relating to the provision of care across the continuum.

#### **Theme 1: Service provision throughout the child's journey**

*Issue 1.1: There are currently no clinical pathways in Queensland Health that focus on the neurodevelopmental needs of at-risk infants.*

*Issue 1.2: It is difficult for GPs to determine their role in supporting a child with CHD and their family after early open heart surgery.*

*Issue 1.3: Centralising neurodevelopmental follow-up services at LCCH is costly and unsustainable.*

*Issue 1.4: There is variability in eligibility criteria and referral requirements to access health services that support neurodevelopment across Queensland.*

*Issue 1.5: There is variability in what health services provide families across the trial sites.*

*Issue 1.6: It is difficult for families to access neurodevelopmental interventions in a timely way.*

*Issue 1.7: There is a lack of well co-ordinated care within and across services.*

#### **Theme 2: Caregiver knowledge and skills**

*Issue 2.1: Families are not consistently supported to build their knowledge and skills to understand and support their child's development and participation.*

*Issue 2.2: Information about neurodevelopment and CHD are not easily found on websites.*

#### **Theme 3: Patient and family centred care**

*Issue 3.1: Services do not always communicate with families in a patient and family centred way.*

*Issue 3.2: The mental health and well-being of families, an important part of supporting neurodevelopment and participation of children, is not always adequately supported.*

## **Summary of solutions to improve access along the care continuum**

Stakeholders were engaged across the three trial sites, inclusive of consumers, to identify solutions and strategies to solve the issues realised during the diagnostic phase. A risk/benefit matrix was utilised to prioritise feasible strategies for implementation within the scope of the project.

Six guiding solutions were identified that would enable the aims of the project to be realised:

- 1. The QPCS CHD LIFE Program will partner and engage with key services to provide well co-ordinated services and supports for early neurodevelopment from antenatal diagnosis along the inpatient care journey.*
- 2. Partnerships and integrated care pathways between services across trial sites will support long-term neurodevelopment along the care continuum.*
- 3. The Queensland Paediatric Cardiac Service CHD LIFE Program will drive statewide advocacy, capability building and service improvement through service partnerships to support long-term neurodevelopment along the life course.*
- 4. Neurodevelopmental support needs of families will be met within their local area.*
- 5. Families will be actively supported to build their knowledge, skills and motivation to understand and support their child's development and participation.*
- 6. The mental health and wellbeing of families will be well supported while in hospital and in their local area.*

## **Localisation and implementation of project solution strategies**

Solution strategies were localised within trial sites by local work groups, made up of representatives from services across the care continuum and supported via videoconference with trial sites. This included facilitation to contextualise the long-term care pathway and plan coordination of care between Lady Cilento Children's Hospital and trial site services.

The CHD LIFE Program will continue to drive statewide education and training to build local capabilities, to support sustainability of the long-term care pathway.

## **Project outcomes**

Engagement with stakeholders and consumers across trial sites enabled a broad range of project outcomes to be realised, as outlined in Chapter 3, including:

- an integrated, statewide, long-term care pathway, enabling developmental surveillance and timely linkages to services for assessment and evaluation as required
- improved co-ordination of care between and across services
- improved early neurodevelopmental support and caregiver activation from antenatal diagnosis and throughout inpatient admission
- keeping parent-infant mental health and caregiver wellbeing on the neurodevelopmental agenda, from antenatal diagnosis through to discharge to community
- CHD LIFE Program driving long-term, statewide capability and capacity building, enabled by ongoing partnerships and a centralised database.

## *Future recommendations*

Undertaking a project of this duration with strong partnerships and collaborations has brought valuable learnings about the lived experience of families with a child with CHD, as well as service provision and redesign. It has not only identified areas for ongoing improvement but has provided valuable recommendations for future statewide work.

**Strength in partnerships**, to support statewide work and ongoing implementation of project outcomes to all HHSs across Queensland.

**Consumer driven health care**, by recognising the value in including consumers lived experience through consumer co-design.

**Integration of care**, by recognising the value in maximising universal services such as primary care as consistent through the child's journey including supporting transition to adult services.

**Transferability of project outcomes**, to other high risk cohorts to provide the same principles of co-ordinated, integrated, family-centred care along the life course.

**Support transitions for children and families**, through key education transitions and into adult services, enabled through partnerships with education providers and HeartKids.

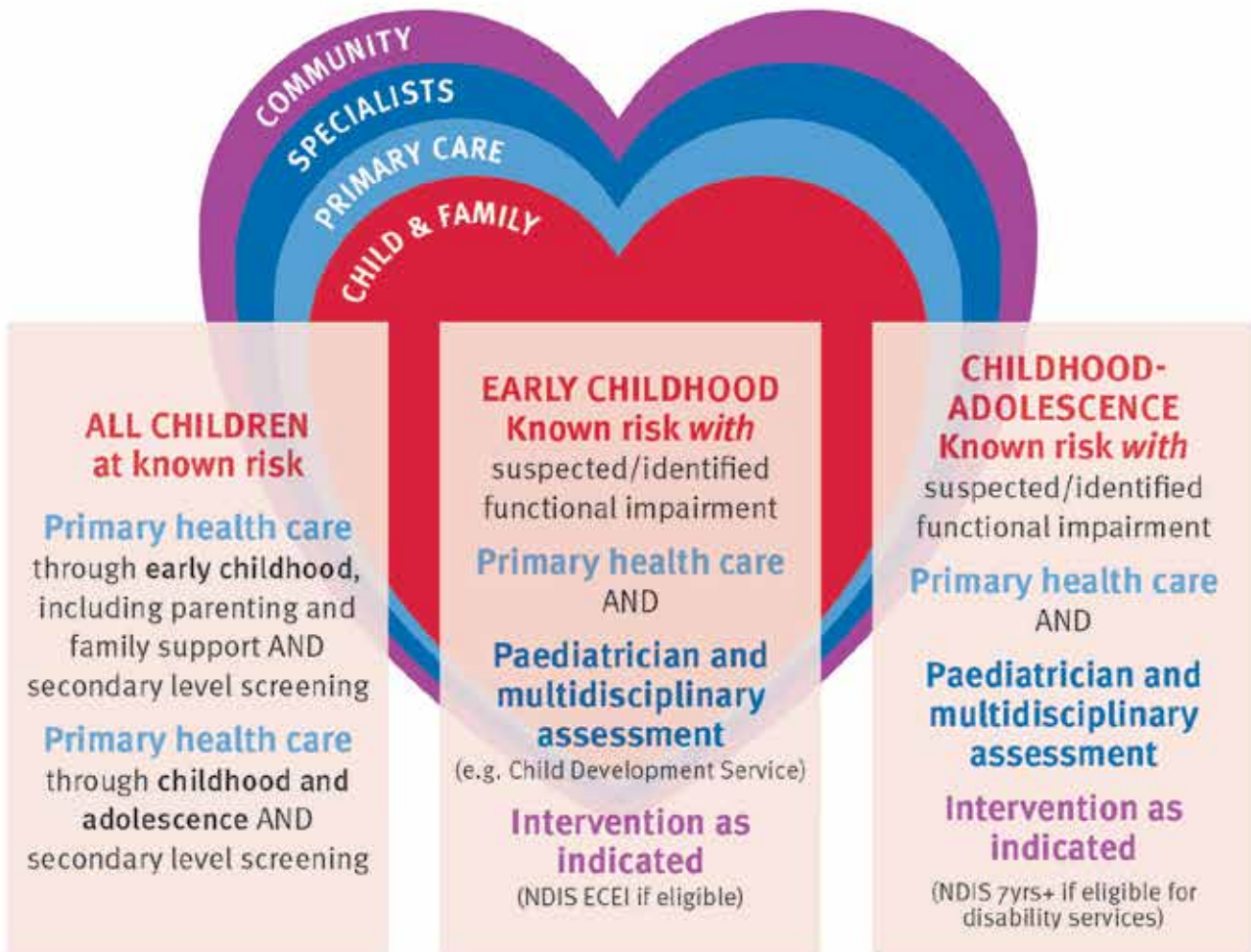
A newborn baby is lying in a hospital bed, wrapped in a pink blanket with a heart pattern. The baby is wearing a white diaper and has a white bandage on their right wrist. A stethoscope is being used to listen to the baby's chest. The background shows a hospital room with a yellow sign on the wall and medical equipment.

## Part one : Long-term care pathway



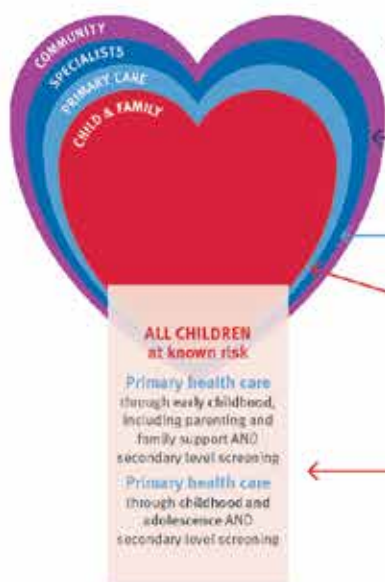
# Part one: Long-term care pathway

## Long-term care pathway for children with congenital heart disease following open heart surgery before 12 months of age



- KNOWN RISK** Children undergoing open heart surgery for congenital heart disease under 12 months of age are at high risk for neurodevelopmental deficits.
- FAMILY-CENTRED** Services and supports should be family-centred, and provided by the right people, in the right place, at the right time. GPs provide important support to the family throughout the lifespan, including supporting transition to adult services as required
- LONG TERM** Surveillance, screening or assessment into adolescence at recommended age points is required as deficits may emerge over time. Long term outcomes and statewide service needs will be well understood through meaningful, collaborative data collection

# Long-term care pathway for children with congenital heart disease following open heart surgery before 12 months of age



All families are encouraged to access services within their community that support growth and development (e.g. Education system, non-health services).

Most children will have a Cardiologist monitoring cardiac care through the lifespan. Children may also have a General and/or Developmental Paediatrician, or other medical/allied health specialists.

All families are encouraged to link with a local General Practitioner (GP) for overall health management, including supported transition to adult services.

The child and family are at the centre of care.

**Early childhood: 0 to 8 years | Childhood-Adolescence: 9 to 18 years**  
**Primary health care:** Families may access primary health care through their GP, a child health service or indigenous health service. Rural and remote families may access services through alternative providers as available within the Hospital and Health Service (HHS).  
**Secondary level screening:** In addition to use of *Parental Evaluation of Developmental Status*, secondary level screening using the *Agas and Stages Questionnaire* is recommended for targeted screening given known clinical risk (can be used for children under 5 1/2 yrs).

**EARLY CHILDHOOD**  
 Known risk with suspected/identified functional impairment  
 Primary health care AND  
 Paediatrician and multidisciplinary assessment (e.g. Child Development Service)  
 Intervention as indicated (NDIS FOD eligible)

**CHILDHOOD-ADOLESCENCE**  
 Known risk with suspected/identified functional impairment  
 Primary health care AND  
 Paediatrician and multidisciplinary assessment  
 Intervention as indicated (NDIS 7yrs+ if eligible for disability services)

**Primary health care:** Ongoing links with primary care is recommended throughout childhood and adolescence, particularly with a GP for wellbeing support and transition to adult services as required.

**Formal assessment:** It is recommended assessments are selected based on functional presentation of the child in line with best evidence. Further information about recommended assessments are outlined in the *Pink Book*. Multidisciplinary assessment may include General or Developmental Paediatrician review, and may occur through a Level 4 paediatric hospital outpatient department, a child developmental service, a Level 5/6 paediatric hospital (e.g. Lady Cilento Children's Hospital (LCH)) or private practice, depending on availability of service within the HHS and eligibility criteria.

**Intervention:** Intervention may be provided through Level 4 paediatric hospital outpatient department, a child developmental service, National Disability Insurance Scheme (NDIS) provider, a Level 5/6 paediatric hospital (LCH), or private practice, depending on availability of services within the HHS and eligibility criteria.

**KNOWN RISK**  
 Children undergoing open heart surgery for congenital heart disease under 12 months of age are at high risk for neurodevelopmental deficits.

**FAMILY-CENTRED**  
 Services and supports should be family-centred, and provided by the right people, in the right place, at the right time.  
 GPs provide important support to the family throughout the lifespan, including supporting transition to adult services as required

**LONG TERM**  
 Surveillance, screening or assessment into adolescence at recommended age points is required as deficits may emerge over time.  
 Long term outcomes and statewide service needs will be well understood through meaningful, collaborative data collection

**Known risk:** Information outlining why these children are at risk, typical neurodevelopmental profile and recommended developmental domains to monitor can be found in the *Pink Book*.

**Family-centred:** Where possible, families should be encouraged to access formal and informal services and supports within their local community that provide developmental support.

**Long term:** Key time points for screening/assessment: 6mths, 12mths, 18mths, approx. 2yrs, 4-5yrs, 11-12yrs, 15+yrs (based on international guidelines and in line with current primary care health check schedule). Families should be encouraged to access surveillance at key time points, even if no concerns were identified at earlier screening.

**Recommendations re: developmental domains and standardised tools** are available in the *Pink Book*. Screening and assessment results should be documented and/or scanned into iEMR (where available) and local providers may be contacted to provide results where parents have consented.

The CHD LIFE Program database collects routine clinical care data on the neurodevelopmental and functional health outcomes of children undergoing OHS before 12 months of age and their families. This data will improve understanding of long term outcomes and how they may change over time. It can also be shared with local health care providers to support service development.



**Part two: *'At the Heart of the Matter'*  
service translation initiative**

# Part two: ‘At the Heart of the Matter’ service translation initiative

## Chapter 1 Introduction

This chapter provides a detailed overview of the project, including background, aim, methods and limitations.

### Snapshot

- The 2012 American Heart Association scientific statement recommended long-term neurodevelopmental surveillance for all children with CHD post early OHS.
- An independent study commissioned by HeartKids Australia in 2011 into the clinical and community needs of children and adolescents with CHD identified quality of life outcomes have not been supported by access to treatment and support services. Recommendations included enhancing services to support better health through screening, neurodevelopmental assessment, psychological support, access to allied health services and parental support.
- The QCYCN Child Development Subnetwork document “[Understanding the Development and Participation of Children with Significant Health Needs](#)” highlighted infants who undergo cardiac surgery in early life as one high risk cohort with significant health needs requiring focus on understanding their development and participation.
- The CHD LIFE Program identified the need to establish a sustainable, statewide, family-centred approach to the long-term follow-up of infants after early cardiac surgery, through a partnership with the Queensland Child and Youth Clinical Network.

### Background

Congenital heart disease (CHD) is one of the most common birth defects, accounting for 28 per cent of all major congenital anomalies.<sup>1</sup> In Australia, the prevalence of CHD for the general population has been reported at 7.8 cases per 1,000 births and is the biggest single cause of child mortality and early childhood hospitalisation.<sup>2</sup> Nearly one third of infants with CHD require surgical intervention.<sup>3</sup> As surgical interventions are improving, mortality rates have significantly decreased.<sup>4</sup> As a result, more children with CHD are surviving into adulthood,<sup>5</sup> but many are left with substantial physical, intellectual, psychological and social difficulties, leading to an increased burden upon families, health care systems and educational facilities.<sup>6-9</sup>

Neurodevelopmental disabilities are the most common and potentially the most significant sequelae of complicated childhood disease,<sup>10</sup> including for infants who undergo surgery in the neonatal period.<sup>11,12</sup> Survivors demonstrate a specific pattern of neurodevelopmental sequelae and behavioural impairments, including mild cognitive impairments, social and language deficits, inattention, hyperactivity and impulsivity, visual perceptual deficits, impaired executive functioning and motor impairments.<sup>6,8,9,11,13</sup> Neurodevelopmental sequelae of CHD are often very subtle in young infants and the extent of impairment can be overlooked or not fully recognised until specific cognitive and higher executive functioning skills are developmentally expected.<sup>13</sup> Neurodevelopmental and psychosocial morbidity related to CHD has lasting negative impacts on educational achievement, lifelong earning potential and quality of life for survivors.<sup>11</sup>

Given the spectrum of neurodevelopmental risk, the American Heart Association (AHA) recommends developmental surveillance of all children with CHD.<sup>11</sup> Children whose neurodevelopmental needs are understood have a greater chance of reaching their full potential later in life, thus significantly decreasing the burden potentially placed upon many families.<sup>6,9,14</sup> There is a risk that an absence of caregiver activation and monitoring of neurodevelopment can delay referral to early supports and intervention services, which may negatively impact developmental outcomes and limit children from achieving their full potential.<sup>7,11,13,15</sup>

Despite the well-documented presence of additional neurodevelopmental vulnerability amongst children with CHD,<sup>6,7,9,10</sup> there are currently no practice guidelines for the evaluation and management of these children in Queensland. In 2013, the Queensland Paediatric Cardiac Service (QPCS) established a Neurodevelopmental Long-term Follow up pilot Program – now the CHD LIFE (Long-term Improvements in Function hEalth) Program - in partnership with the Child Development Service (CDS) at Lady Cilento Children’s Hospital (LCCH). The Program targeted three patient groups identified as being at high risk for poor developmental outcomes - infants who have undergone an arterial switch operation, a Norwood procedure and/or those treated with extracorporeal life support (ECLS),<sup>11</sup> with early developmental outcomes consistent with international reporting for these children. With increasing service demands in cardiology and a drive for integrated, family centred care, a service translation initiative was required to develop a statewide approach to the developmental support needs of this population in Queensland.

A partnership between QPCS and the Queensland Child and Youth Clinical Network (QCYCN) was established to undertake a service translation initiative, with funding provided by the Health Improvement Unit. Previous work of the QCYCN and the Child Development Subnetwork (CDSN) identified the unique interface between health and developmental services across the care continuum, as outlined in the [“Act now for a better tomorrow”](#)<sup>16</sup> document. Of particular note was the imperative to address the needs of vulnerable populations of children, such as those with medical co-morbidities. The CDSN further developed this work to understand the development and participation needs, perceptions and priorities of families of children with significant health needs, including congenital heart disease requiring early surgery. Recommendations were outlined in the [“Understanding the development and participation of children with significant health needs,”](#)<sup>17</sup> which provided guidance to this project, to address the developmental support needs of children with CHD and their families.

## **Project aims**

The primary aim of the project is that the developmental support needs of children with congenital heart disease and their families, provided by Queensland Health services across the care continuum within the Brisbane Metropolitan area, West Moreton and Cairns and Hinterland regions, will be met by the right people, at the right time, in the right place.

## **Method**

### **1.1.1 Methodology**

This project followed a Clinical Service Redesign (CSR) methodology, with a strong focus on consumer co-design. Clinical Services Redesign (CRS) methodology is founded on issues based problem solving, data driven hypothesis testing and change driven by the value added from the customer perspective. Critical to the CSR framework is engagement with clinicians, support staff, management, patients and their families and the broader community. This co-design approach ensures service change initiatives are informed by the needs of stakeholders. The contributions of patients, parents and carers allows for true patient and family centred innovation and improvement that can not only influence the patient journey, but also clinical governance in a practical and safe way that is meaningful for everyone. The phases and key activities of the CSR methodology are outlined below.



**Diagram one: Clinical services redesign methodology**

### 1.1.2 Planning: project team and steering committee

The project team responsible for administration of project activity and project deliverables included the Principal Project Officer, CNC – Cardiac Maternal Fetal Medicine/CHD LIFE Program, CDSN Principal Project Officer, Director of Cardiology, QCYCN Co-Chair, HeartKids representative and Consumer representative.

The steering committee provided overall leadership, decision making and accountability and included representation from QPCS, QCYCN, CDSN, Primary Care, Cairns and Hinterland HHS, West Moreton HHS, HeartKids, consumers and iCARE. The steering committee was chaired by the CHQ Executive project sponsor.

### 1.1.3 Partnerships: trial sites

Three sites were selected as pilot sites as a representative sample of the 16 Hospital and Health Services across Queensland. These were carefully selected and leads invited to join the steering committee. Support of leads and endorsement of inclusion in the project was received by the Chief Executives of each trial HHS -

Children’s Health Queensland HHS (CHQHHS):

- all surgeries performed at Lady Cilento Children’s Hospital (LCCH)
- LCCH provides statewide quaternary and local tertiary services, with focus on provision of early neurodevelopmental support and coordination of care statewide
- challenges for a quaternary service providing developmental surveillance to whole state, including the CHD LIFE program clinic were identified
- approximately 38 per cent of in scope surgeries performed at LCCH are on infants living in CHQ’s direct service delivery catchment area.

Cairns and Hinterland HHS (CHHHS):

- dedicated Paediatric Cardiologist
- services providing outreach to Torres and Cape HHS
- distance to travel to LCCH for specialist services

- Aboriginal and Torres Strait Islander representation
- approximately 10 per cent of in scope surgeries performed at LCCH are on infants from CHHHS.

West Moreton HHS (WMHHS):

- close proximity to LCCH, with many families in WMHHS living closer to LCCH than those living in CHQHHS. Families often prefer to return to LCCH to access services (not just specialist services)
- approximately 15 per cent of in scope surgeries performed at LCCH are on infants from WMHHS.

Inclusion of these three HHSs as pilot sites covers more than 60 per cent of the total in scope cohort of infants with CHD undergoing open heart surgery in the first 12 months of life.

#### **1.1.4 Ethics and governance**

This project received ethics approval from the Children’s Health Queensland Human Research Ethics Committee 10th October 2016 (HREC/16/QRCH/337) for Children’s Health Queensland, West Moreton Hospital and Health Service and Cairns and Hinterland Hospital and Health Service.

Multi-site governance approval coordinated by CHQ Research Governance Office, including:

- Children’s Health Queensland (SSA/16/QRCH/345)
- Cairns and Hinterland HHS (SSA/16/QCH/134 – Lead 257 LR)
- West Moreton HHS (SSA/16/QWMS/50).

Overall project governance was provided in partnership by CHQ and QCYCN (see Appendix 2).

#### **1.1.5 Diagnostics – establishing the problem**

A robust diagnostic phase was undertaken over a six month period to establish the problem with how the developmental needs of children with CHD after early open heart surgery are met by services and supports across the three trial sites. This included a literature review outlining why children with CHD are at risk of poor neurodevelopmental outcomes after early open heart surgery and recommendations for follow-up. A detailed literature review is included in Part 3.

Data relating to clinical services provision was also analysed, inclusive of:

- expected demand based on population growth
- cost to CHQ of centralised clinic provision
- cost to HHS of supporting centralised clinic attendance.

Stakeholder workshops with health services across the care continuum providing developmental supports to this cohort – 77 stakeholders representing 20 services attended 3 workshops across 3 trial sites.

A statewide GP survey was distributed via email. Details of the survey are summarised in outcomes and a copy of the survey is included in the Appendices (see Appendix 3). A total of 33 responses were received and analysed as part of the diagnostic phase.

A statewide caregiver survey was distributed via the CHQ Facebook page and HeartKids email database. Results of the survey are summarised in outcomes and a copy of the survey is included in the Appendices (see Appendix 4). A total of 163 eligible responses were received from families statewide.

This included responses from families:

- living across Queensland (12 of the 16 HHSs with 58 per cent from the three trial sites)
- of children and young people of a range of ages (from infants aged three months through to families of young adults up to 34 years of age)
- identifying as Aboriginal or Torres Strait Islander (seven per cent of responders).

Targeted patient journey mapping was undertaken with project consumer representatives from each of the three trial sites – 21 year old “HeartKid”, mother of a six year old, mother of a two year old. Mapping included service access, referral processes and waiting times and consumer experiences at each key time point.

Collation of quantitative and qualitative data from all diagnostic activity identified three key themes:

1. Service provision throughout the child’s journey.
2. Caregiver knowledge and skills.
3. Patient and family centred care.

### **1.1.6 Solution design – identifying solution strategies**

Stakeholder workshops including consumer representation to identify solution strategies for issues identified. Eighty people attended a total of 8 workshops across the 3 trial sites, with consumers present at 5 of the 8 workshops. Focus groups were also held to target stakeholders unable to attend workshops, including Paediatric Intensive Care Unit (PICU) and cardiac ward nursing staff and CHD LIFE Program clinic staff, ICT project staff and integrated care staff. Total interactions throughout solution design phase included 30.8 per cent allied health, 24.3 per cent administration, 16.6 per cent nursing, 11.2 per cent medical, 17.2 per cent consumers.

A risk/benefit matrix was completed and driver diagram developed to map and prioritise solutions and identify feasible strategies for implementation.

### **1.1.7 Implementation – contextualising and implementing solutions**

Work groups were established with representation from services targeted for each solution, inclusive of consumer representatives. Five work groups were established with representation from services across the care continuum from each of the trial sites. Workshops, focus groups and meetings resulted in 190 engagements with nursing, allied health, medical, administration and executive staff, as well as consumers. Consumer input at workshops and direct consultation was undertaken to develop and review project documents and deliverables. Videoconferencing was utilised with all three trial sites to prepare for and support localisation of project outcomes.



## Project scope and limitations

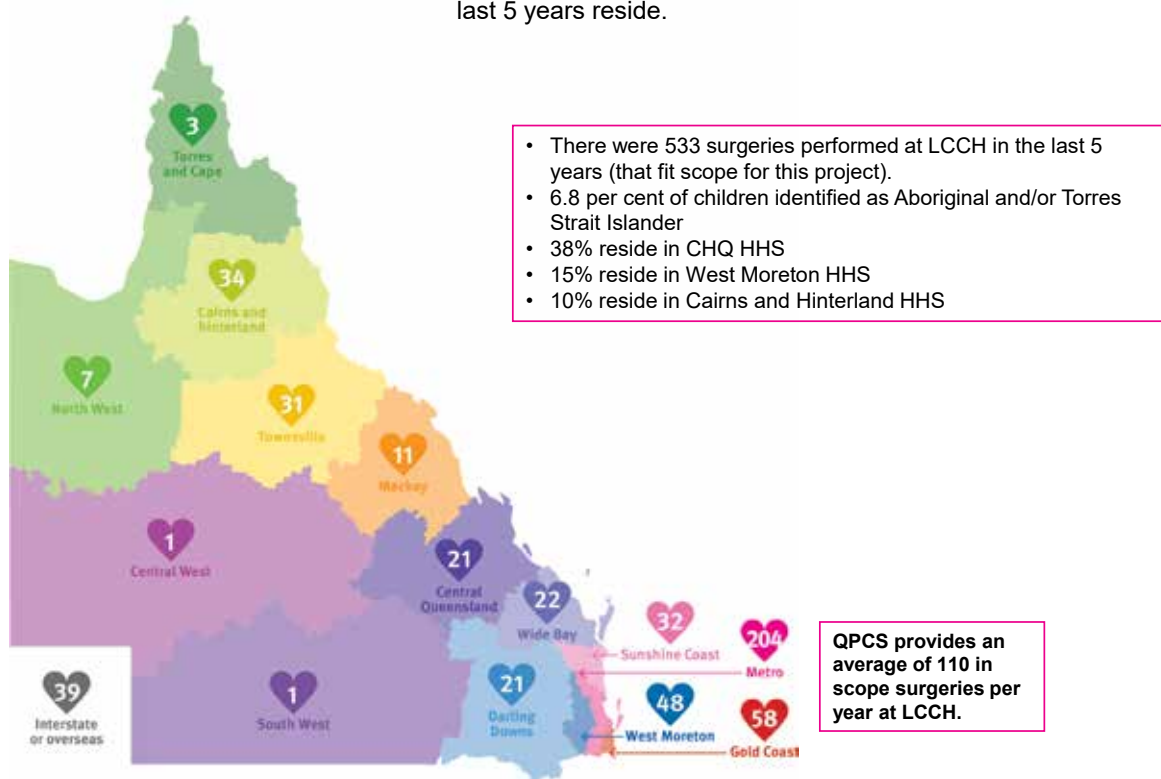
### 1.1.8 Scope

Infants with CHD who have undergone open heart surgery before 12 months of age at LCCH, from CHQ Metro, CHHHS, WMHHS.

There are 110 surgeries performed at LCCH every year on infants under 12 months of age. In the last 5 years:

- 6.8 per cent of children identified as Aboriginal and/or Torres Strait Islander
- 38 per cent resided in CHQ HHS
- 15 per cent resided in West Moreton HHS
- 10 per cent resided in Cairns and Hinterland HHS.

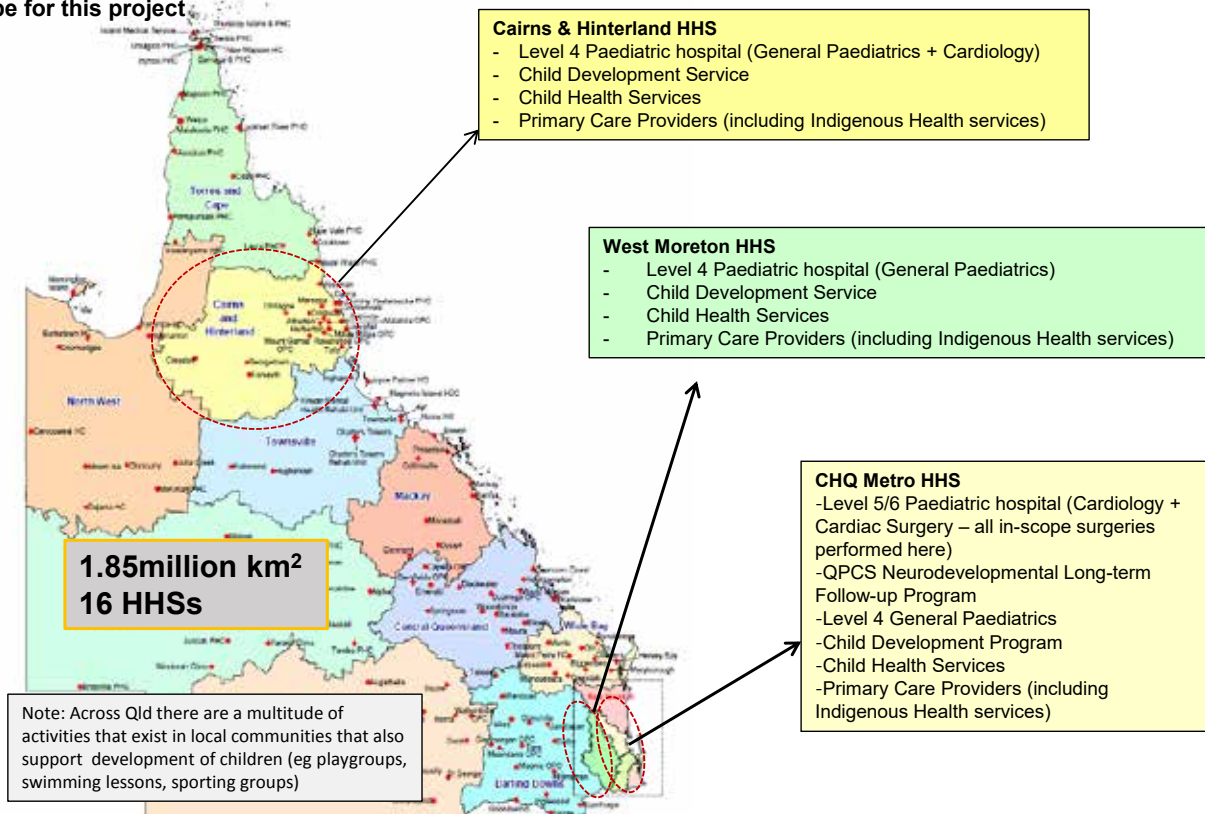
This map shows where children with CHD who have had open-heart surgery before 12 months of age in the last 5 years reside.



Health services providing developmental supports to this cohort from the three trial sites including:

- Level 5/6 paediatric hospital (Cardiology, Cardiac Surgery, General/Developmental Paediatrics)
- Level 4 paediatric hospitals (General Paediatrics and Cardiology)
- Child Development Services
- Child Health Services
- Primary Care providers (including indigenous health services and GPs).

This map shows health services within the trial sites that provide formal developmental supports to children within scope for this project.



### 1.1.9 Limitations

This project was unable to include infants undergoing surgery after 12 months of age, acquired heart disease, or other high risk medically complex cohorts (identified need for transferable project outcomes). While every effort was made to include education providers as key stakeholders, this proved to be a challenge. It has been identified that future work facilitated by partnerships with education providers is required, with particular focus on supporting transitions into primary and secondary school, as well as transition from school to vocation/training.

Implementation of project outcomes had to be possible within existing resources, as no additional funding was available to enable increased capacity or capabilities.

## Chapter 2 Establishing the problem – summary of issues identified with accessing developmental supports along the care continuum

This chapter provides a detailed summary of the themes and issues identified as a result of the rigorous diagnostic activity undertaken.

### Snapshot

- Living with CHD impacts the health and wellbeing of families, including early bonding/attachment, routines and experiences, developmental milestones and participation in roles along the life course.
- Parents need to be “experts” but finding information, navigating systems and accessing services is difficult.
- Services and supports are required across the care continuum and along the life course, but aren’t always available at the right time or in the right place and aren’t always well co-ordinated, integrated, or family centred.

### Theme 1: Service provision throughout the child’s journey

#### Issue 1.1: There are no clinical pathways in Queensland health that focus on the neurodevelopmental needs of at-risk infants

Clinical Pathways are standardised, evidence-based multidisciplinary management plans, which identify an appropriate sequence of clinical interventions, timeframes, milestones and expected outcomes for identified patient groups. They aim to support the implementation of evidence-based practice, improve clinical processes by reducing risk, reduce duplication through the use of a standardised tool and reduce variation in health service process delivery.

Despite international best practice guidelines for long-term follow-up of this cohort, these have not been contextualised to Queensland or the public health system.

*“There is no visibility and clarity of pathway for children with developmental concerns and medical co-morbidities.” (Service provider)*

*“There is no consistent referral pathway - each service has different criteria across the continuum.” (Service provider)*

*“The last few weeks before we went home I remember feeling like everyone had forgotten about him...I felt no one really knew what to do with us.” (Caregiver)*

#### Issue 1.2: It is difficult for GPs to determine their role in supporting a child with CHD and their family after early open heart surgery

GPs are recognised as the primary point of contact for many families. Care is often handed back to GPs for long-term monitoring, including ongoing developmental surveillance and referral to other services if required. Standard 12 of the EQulP National Guidelines<sup>16</sup> states: “GPs also have a vital role to play in all aspects of chronic disease management and in providing by way of referral, any and all information that will impact upon the subsequent management of the consumer/patient’s care.”

Within Queensland Health there are referral guidelines, Clinical Prioritisation Criteria (CPC) and GP HealthPathways to assist GPs and their delegates to make referrals to healthcare services to enable the provision of safe, timely and quality care. However, these are not specific for children with CHD following early open heart surgery.

*65 per cent of GP respondents reported neutral or low confidence in their knowledge of the risk of CHD and early open heart surgery on a child's development. (Source: GP survey)*

*52 per cent of GP respondents across QLD said referral/health pathways would assist them to support developmental surveillance of children with CHD. (Source: GP survey)*

*"If an infant goes home and then develops issues with development or feeding and presents to the GP there is no direct referral pathway to LCCH allied health." (LCCH Allied Health)*

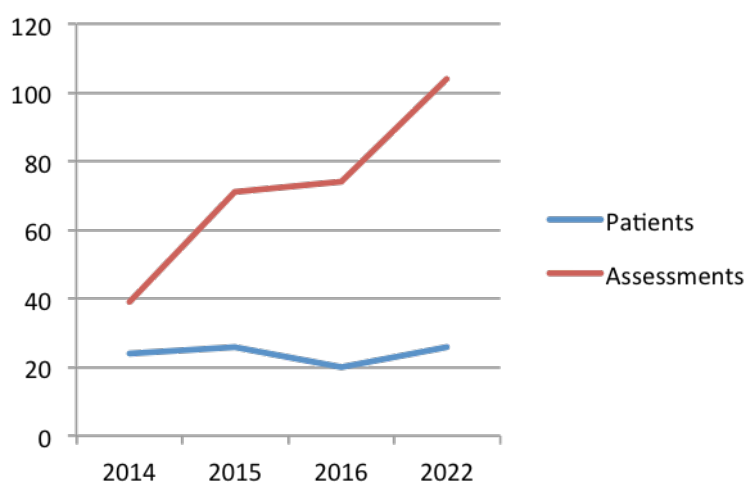
### **Issue 1.3: Centralising neurodevelopmental follow-up services at LCCH is costly and unsustainable**

In 2013 the QPCS CHD LIFE (Long-term Improvements in Functional hEalth) Program was established to provide multidisciplinary assessment to infants considered to be at the highest risk for poor developmental outcomes. This was limited to infants who had undergone an arterial switch operation, a Norwood procedure or treatment with extracorporeal life support (ECLS). The protocol was based on the AHA recommendations and included assessment at 6m, 12m, 2y, 4y, 8y, 11y, 16y.

Data analysis of this clinical service provision identified the cost incurred by LCCH, the home HHS and families for one patient to attend LCCH for one clinic appointment from Cairns was up to \$3,595 and from West Moreton/Brisbane Metro was \$2,067.

This does not include unquantifiable costs including missed work, care for additional siblings and meals, or the burden for families with missed work, school, extra-curricular activities, social disruption and loss of family routine. It should also be noted that this does not take into consideration benefits or outcomes gained through this robust method of clinical service provision.

Projected growth in numbers of children with CHD who will have open heart surgery before 12 months of age and who meet the criteria for QPCS CHD LIFE Program clinic was calculated based on ABS population growth data for Queensland (approx 1.2 per cent) and CHD incidence data. This predicted that within five years, the clinic would go from administering about 70 to over 100 assessments per year.



## Issue 1.4: There is variability in eligibility criteria and referral requirements to access health services that support neurodevelopment across Queensland

We know that children with CHD in Queensland who have surgery before the age of 12 months receive cardiac surgery at LCCH and will have to engage with a number of other support services in their local contexts. This includes those services that can support neurodevelopment from the primary level of care such as General Practitioners and Child Health services through to more specialist levels of developmental service such as Child Development Services and Clinical Service Capability Framework (CSCF) Level 4, 5 and 6 Hospital based services.

A review of health services providing developmental supports to this cohort identified variation in eligibility, intake processes and age cut-offs across the state and within health services themselves and difficulties from service providers and caregivers in knowing which services were appropriate and/or available.

*“After surgery, infants often need onward allied referral BUT they often do not meet inclusion criteria for community/local services.” (LCCH Allied Health)*

*“Each allied health service has different criteria across the continuum.” (Multiple services across all three trial sites)*

*“It was obvious that my child really needed physiotherapy, however after a 7 month wait our referral from our neurologist was rejected by child development services because my child was not “disabled” enough.” (Caregiver)*

## Issue 1.5: There is variability in what health services provide families across trial sites

In a state as geographically large and diverse as Queensland, the need for services for families is varying and widespread. More than 60 per cent of infants who undergo open heart surgery before 12 months of age reside outside the Brisbane metropolitan area (Source: QPCS database Dec 2016). For those living in rural and remote areas access to non-specialised, primary and secondary care level services can be challenging. It has been identified that challenges are also evident in metropolitan areas with over 50 per cent of caregivers reporting that accessing services in their local communities was difficult in Metro North, Metro South and West Moreton. (Source: Parent Survey Dec 2016)

Child Development Services	Eligibility & Referral criteria	Level 4 Hospital Allied Health based services	Eligibility & Referral Criteria	Level 4 Hospital General Paediatrics	Eligibility & Referral criteria
West Moreton CDS	Referral from parent, GP, Gen Paed Developmental concerns, those born <K32 or with neurological risk factors	West Moreton	No hospital based allied health services (In-reach provided by CDS)	West Moreton General Paediatrics	Referral from GP or other medical specialists
Cairns & Hinterland CDS	Referral through access unit from GP or CH Infants at risk of developmental delay 0-5 years (prior to commencing prep)	Cairns Hospital	Referral from Specialists, GPs, nurses or other AHPs only (no self referral)	Cairns Hospital General Paediatrics	Referral from GP or other medical specialists
Children's Health Qld CDS	Referral from GP, Paed or medical specialist 0-16 years (new); 0-18 years (existing) Significant developmental and/or learning difficulties impacting on daily life across multiple settings; or Children with developmental delays and co-morbid complex medical conditions (eg. VCFS).	LCCH	Referral from Cardiologist, Specialist or health professional Infants 0-12months with complex medical needs requiring multiple team involvement Referral from Cardiologist/Specialist for issues associated with cardiac diagnosis – referral to infant team or CDS if required	LCCH – General Paediatrics (Level 4, 5, 6)	Referral from Paediatrician or other medical specialist
Child Health Services	Eligibility and Referral Criteria	Caboolture Hospital	0-16 years (new) 17 years (existing) Referral from GP, internal referral from CHN, RM, RN, Paed, AH Infants in SCN with known high risk CHD (HLHS)	Caboolture Hospital – General Paediatrics	Referral from GP or other medical specialists
Child Health CHQ HHS	Referral from any source (including parents) 0 to 8 yrs	Redcliffe Hospital	<6yrs main cohort, >6yrs from Gen Paed for Ax for diagnosis/pre-school readiness (OT/SP) Referral from GP, Gen Paed, Specialist, AHPs At risk infants	Redcliffe Hospital – General Paediatrics	Referral from GP or other medical specialists
Child Health - Cairns & Hinterland	Referral from any source (including parents) 0 to 18 yrs	Prince Charles Hospital	0-16 years Must be under care of Gen Paed Psych – No Ax for <6yr – would refer to CDS. Will see <6 for Rx.	Prince Charles Hospital General Paediatrics	Referral from GP or other medical specialists
Child Health - West Moreton	Referral from any source (including parents) 0 to 12 yrs (hearing screening to 18yrs)	Redlands Hospital	0-16 years Referral from GP, specialists, AHPs Sub-acute only – referral to CDS for ongoing input	Redlands Hospital – General Paediatrics	Referral from GP or other medical specialists
		Logan Hospital	0-16 years Referral from GP, specialists, AHPs Sub-acute only – referral to CDS for ongoing input	Logan Hospital – General Paediatrics	Referral from GP or other medical specialists

A review of responses from the caregiver survey and the service workshops identified that access to local services is dependent on whether there are the right professionals with the right knowledge available to meet their needs in their local region. 78 per cent of parents/caregivers reported difficulties accessing the services they required locally, with 44 per cent reporting a lack of paediatric and/or cardiac specific services locally and needing to travel or pay for private services.

*“There are limited outpatient services in Cairns and limited developmental outreach services.” (Service provider, Cairns)*

*“There is a lack of education of local staff supporting children with CHD and their families.” (Service provider, Cairns)*

*“We had appointments in Brisbane but that is 1600kms away and it took a fair while to get a local appointment which was a waste of time really.” (Caregiver)*

*“He was still being spoon fed liquid. There was no way we could go without therapy. I contacted DSQ... We had our assessment and he qualified for services but they didn’t have a speech pathologist.” (Caregiver)*

### **Issue 1.6: It is difficult for families to access neurodevelopmental interventions in a timely way**

Queensland public health services utilise prioritisation categories for inpatient and outpatient services, determined by the severity of the presenting condition and urgency for appointment. These categories have consequent waiting times for accessing services at level 4/5/6 hospital and child development services.

Families rely on timely referrals being made by service providers to other services e.g. GP to Paediatrician, hospital to community services. Children with learning, developmental and behavioural difficulties often meet the criteria for Category 2 to 3 as the nature of these conditions is more chronic than acute, with an associated waiting time frame of up to 12 months. It should be noted that 12 months is a substantial proportion of time in an infant or young child’s life, when significant developmental skill acquisition is expected.

Our statewide caregiver survey found 33 per cent of respondents commented on the long waiting times to access developmental services following discharge from hospital.

*“Since being discharged it’s taken four to six weeks to get appointments once the referrals were submitted.” (Caregiver)*

*“Developmental issues may be triaged as Category 2 or 3 for allied health services therefore there are long wait lists for service.” (CHQ service provider)*

### **Issue 1.7: There is a lack of well co-ordinated care within and across services**

The statewide caregiver survey and patient journey mapping identified that children with CHD and their families may require support from a number of professionals and a range of service providers across the life course. Families who receive an antenatal diagnosis of CHD may receive input from multiple professionals across multiple services and facilities. Following open heart surgery, families receive intensive support from the critical care and cardiac teams, including cardiac nurse care co-ordinators and for some, the connected care service. Following discharge, infants may require consistent and ongoing follow-up throughout childhood from services within the community. Others may benefit from intermittent support to understand their developmental needs over time or later in childhood, commonly at key transition periods such as starting school.

In a state as geographically large as Queensland, with 16 HHSs, services and supports are spread across a vast area and governed separately. For a family transitioning between services, well co-ordinated care is important to ensure safe, effective care. Within Queensland Health there are guidelines and standards to ensure the safe provision of care. Standard 12 of the Equip National Standards<sup>18</sup> states: “The quality and timeliness of information provision should facilitate transitions of care within and beyond, the organisation. Good record keeping and the sharing of health records, particularly when enabled by electronic transfers of information, are needed for safe transition between services and healthcare providers.”

Responses from service providers across the 3 trial sites regarding barriers to providing optimal support to this cohort highlighted that there is a lack of co-ordinated care for CHD patients and their families. Common themes were identified across services within trial sites, as well as across HHSs. These themes, which were also commonly reported by parents/caregivers statewide, are outlined below:

1. There is not always consistent communication within and between services, making transition between services difficult for families. Some differences were noted across trial sites, however all sites reported inconsistent communication/MDT handover and linkages between hospitals, GPs, General Paediatricians and local services.

*“There was no one person co-ordinating the discharge. There could have been more support to plan for discharge.” (Caregiver)*

*“They said they could only offer 6 weeks of therapy then he would be referred back to community... We’d just come from community and there was no one there for us to see.” (Caregiver)*

*“I only found out the child had been discharged home when I saw it on Facebook.” (Referring doctor, Cairns)*

*“Information regarding surgery and acute care goes to the GP rather than the Paediatrician...this sends a message to family that the Paediatrician is not important.” (Paediatrician, WMHHS)”*

2. There are no formal processes to support the transition of adolescents to adult services.

Transition between services and into adulthood are key times where effective co-ordination of care is imperative. The burden of chronic illness in adolescents with CHD can lead to a significantly greater rate of mental health or social problems, including anxiety, depression and behavioural problems compared to the general population.

*“There is no defined transition process for adolescents into adult services.” (all 3 trial sites)*

*“If there are services available to assist with this we have not been made aware of them.” (Caregiver)*

3. There is no central database for co-ordinating information and reporting on outcomes.

There is currently no platform available to all services for accessing and/or sharing information regarding care provided to children with CHD. A review of systems currently being used by services identified multiple systems but no consistent access for services within the trial sites. |

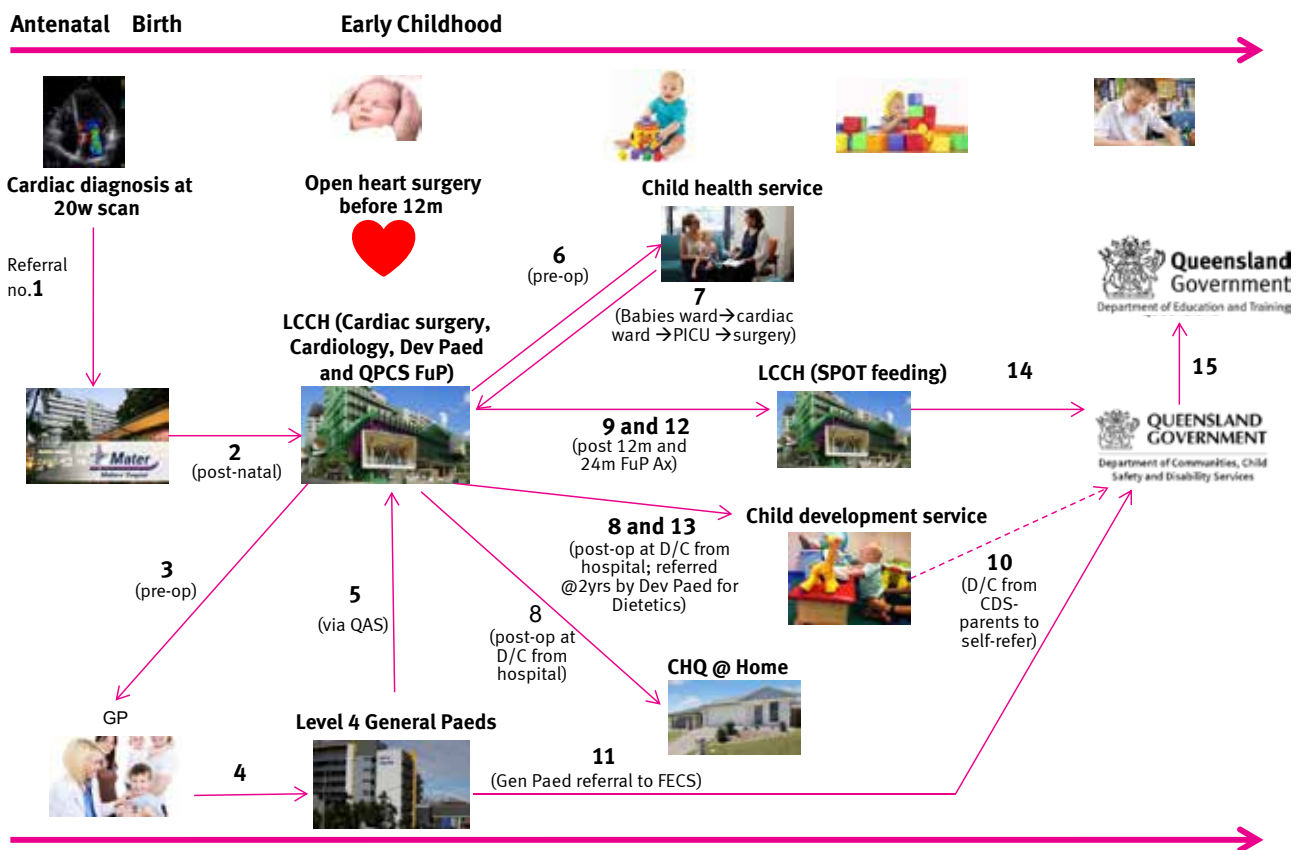
A national CHD registry is being developed but is still in its infancy. It is unclear how this will interface with health services in Queensland.

*“There is a lack of communication to community health...this may improve with access to ieMR.”  
(Child Health, CHQ)*

*“Lack of central co-ordination and reporting. We need feedback and data for quality assurance and service improvement. Not all children get captured.” (PICU, CHQ)*

*“Living in Cairns...I found it hard to give them accurate information on him when all his records were in Brisbane and not accessible by health professionals.” (Caregiver)*

This patient journey demonstrates how the lack of co-ordination of care can result in a complicated and confusing service journey for the family. (Source: Patient journey mapping with consumer, Dec 2016)  
The numbers represent each time a referral was made to a service. There were 15 referrals made to 9 different services within a 24 month timeframe. Five of these services existed within the one health service.





## Theme 2: Caregiver knowledge and skills

### Issue 2.1: Families are not consistently supported to build their knowledge, skills and motivation to understand and support their child's development and participation

High quality care is associated with informed decision-making, therefore ways to assess and improve the knowledge of consumers concerning their healthcare is critical. "Activation" is one term used to operationalize consumer-directed healthcare decision-making. Consumers who are "activated" with the knowledge and skills to understand and support their child's needs are more effective in healthcare management.

In the paediatric setting, parent activation is important for direct positive health outcomes of their children. Activation also serves to enable stronger peer supports and links in local communities. Planetree criteria III.A<sup>19</sup> states: "During their care, patients and families are provided education and access to a wide range of information in a manner that they understand, to support them in making informed choices."

One of the challenges for service providers in this clinical cohort is assessing the readiness of parents/caregivers to receive information about the long-term neurodevelopmental outcomes associated with CHD. At time of diagnosis, be it ante- or post-natal, many caregivers may not have capacity to take on additional information and may be focused on decision making and/or survival of their fragile infant. The need for a more consistent approach to neurodevelopmental counselling at antenatal diagnosis has been identified in the literature, with inconsistent practice identified within centres internationally.

Once infants are stable post operatively, it is important that parents are supported to provide developmentally enriched environments for their infants and encouraged to support their development and participation.

*"Cardiology finds that parents do not always have readiness to understand the depth of information re developmental outcomes and impact which impacts on what we provide" (Cardiologist)*

*"I remember thinking the Cardiologist didn't talk to us at all about neurodevelopment...I think it would have been too much to digest. We were just thinking about survival. You get through hospital, you're trying to feed a baby with an NGT." (Caregiver)*

The caregiver survey results strongly reinforced the importance of 'their activation' in supporting their child's development and participation. 68 per cent of caregivers said that their best source of support to help their child develop and participate to their full potential is their own knowledge and problem solving.

*"Being supported to have a role in his care - knowing I could go and get the bath, get the towels and sheets - I felt like I was a member of the team. Knowing I could pick him up and talk to him like a normal baby." (Caregiver)*

Challenges identified with information provision included information provision being dependent on: timing and severity of diagnosis; readiness of caregivers to take on information; and which professionals are involved at key time points of care. Additional challenges were identified with inconsistency with the provision of written information and documentation of what information has been provided to caregivers.

### Issue 2.2 Information about neurodevelopment and CHD is not easily found on websites

Parents are the consistent caregivers and advocates for their child throughout their journey. They are important members of the health care team, required to make decisions regarding their child's

care and to support their development and participation beyond the healthcare environment. In order to be activated caregivers, access to information along the developmental continuum is important to build health literacy. In this era of digital and social media, the internet is parents' most accessible and readily available tool for accessing information and resources to support their child's neurodevelopment.

It has been acknowledged that parents may not be ready for information at time of diagnosis, or during their infant's hospital admission. It is therefore important that they can easily access the information and resources they require after hospital discharge.

Planetree criteria III.B<sup>19</sup> advocates that: "Patients and families are provided with information and support needed to be as involved as they choose in coordinating their care across settings, among multiple providers and across discrete episodes of care."

Only 17 per cent of caregivers in the three trial sites found online information helpful in supporting their child's development and participation. (Source: Caregiver survey, Dec 2016)

### *Theme 3: Patient and family centred care*

#### **Issue 3.1 Services do not always communicate with families in a patient and family centred way**

Patient-centred care is health care that is respectful of and responsive to, the preferences, needs and values of patients and consumers. The widely accepted dimensions of patient-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers and access to care. Patient-centred care is the core of a high quality health care system and a necessary foundation for safe, effective, efficient, timely and equitable care.

Communication is one of the key requirements and should be open, direct and compassionate. Key time points for families where communication is vital:

- diagnosis – what it means, what to expect
- surgery – risks, procedure, recovery, outcomes
- discharge planning – when, what needs to happen prior, expectations, requirements
- referral to a new service/changing services – who, waiting times, process, what will they offer, what information will be shared
- transition to adult services – ongoing needs, available services, what to expect, differences in adult facilities.

A common theme from the survey responses was the lack of satisfaction with the communication between health professionals and parents/caregivers and the impact that can have on families.

Parents reported that their experiences were affected negatively by a lack of patient and family centred care, including not feeling well informed and not feeling respected as a valuable member of the health care team. Common concerns included:

- an overuse of technical and medical language during what is a stressful time
- a lack of clarity regarding the role and purpose of a professional's visit
- communication that was not family centred, sensitive and/or informative
- intervention that does not consider the child within the context of the family
- a lack of communication and information sharing within and between services

- not always being given choice or control over decision making
- not feeling kept informed about eligibility for services, waiting times, expected service delivery.

*“I need any medical talk to be in easily understood language for the initial advice that there is a problem or medical situation.” (Caregiver)*

*“Being told to do “therapy” rather than supported to do “normal” things like movement and tummy time. It needs to be worded in a way that it’s not an exercise or a duty, it’s everyday activity just in a different environment.” (Caregiver)*

*“His dad knew that the stoma wouldn’t be forever but I didn’t. He probably understood the language but I didn’t. I felt better about learning how to change the stoma once I knew it wasn’t permanent.” (Caregiver)*

### **Issue 3.2: The mental health and wellbeing of families, an important part of supporting neurodevelopment and participation of children, is not always adequately supported**

Maternal stress and the risk of Post Traumatic Stress Disorder (PTSD) in mothers of infants with CHD is well reported in the literature. Many parents acknowledge that their mental health and wellbeing is crucial to enable them to support the developmental and participation needs of their children. Many commented on the trauma of what they experienced in the early years around diagnosis and surgery and felt that while a lot of focus was on the health of their baby, there was a lack of attention to parental wellbeing. Social-emotional support for families has been documented to lower the impact of CHD on the family, consequently families with lesser social support networks may have the greatest need for professional supportive interventions to prevent negative impacts.

A review of services providing psychosocial support to parents/caregivers of children with CHD across the care continuum from antenatal diagnosis through to post-discharge was conducted and summarised. Challenges identified with supporting the mental health and wellbeing of parents/caregivers included:

- no clear pathway for the provision of social-emotional support to families
- variation in support needs of families from emergency/practical/reactive input, through to proactive/supportive input
- limited resources within the acute phase to provide proactive, supportive input
- inconsistency with onward referral to community supports
- inconsistency with documentation of what support has been provided to caregivers.

Parents/caregivers were asked to identify their best supports to enable their child’s optimal development and participation:

- 24 per cent identified their own formal supports such as their GP, counsellor or psychologist
- 52 per cent identified family
- 33 per cent identified friends.

*“Health professionals (especially the doctors), I feel may need to approach parents in a more “holistic” manner and consider the many aspects of life (especially the mother’s head space) – not just medical.” (Caregiver)*

## *Chapter 3 Identifying the solution - developing a statewide approach to the developmental support needs of children with congenital heart disease in Queensland*

This chapter provides details of the overarching solutions that were identified for each of the issues recognised during the diagnostic phase.

### **Snapshot**

- The QPCS CHD LIFE program will partner and engage with key services to provide well co-ordinated services and supports for early neurodevelopment from antenatal diagnosis along the inpatient care journey.
- Partnerships and integrated care pathways between services across trial sites will support long-term neurodevelopment along the care continuum.
- The QPCS CHD LIFE program will drive statewide advocacy, capability building and service improvement through service partnerships to support long-term neurodevelopment along the life course.
- Neurodevelopmental support needs of families will be met within their local area.
- Families will be actively supported to build their knowledge, skills and motivation to understand and support their child's development and participation.
- The mental health and wellbeing of families will be well supported while in hospital and in their local area.

Strategies were identified via workshops and targeted consumer consultation. The implementation of solution strategies was undertaken under key areas as listed below, and was facilitated by work groups inclusive of stakeholders and consumers.

### *Implement processes to support early neurodevelopment, from diagnosis throughout inpatient admission*

1. Established allied health meetings in PICU.
2. Completed application for funding to introduce developmental care practices into PICU including Family and Infant Neurodevelopmental Education Program, with aim to introduce developmental care ward rounds.
3. Commenced neurodevelopmental messaging to staff through PICU weekly bundle and cardiac ward newsletters, white boards and screen savers.
4. Commenced consistent delivery of timetables in PICU.
5. Continued presentation of neurodevelopmental outcomes at Cardiology workshops targeted at medical, nursing and allied health staff.
6. Completed staff survey to identify need and plan inclusion of supporting early neurodevelopment in PICU in nursing training and education.
7. Established 'neurodevelopmental committee' to support ongoing work in this area. Includes support from Executive Director of Allied Health, collaboration with the Children's Hospital

at Westmead who have implemented developmental care ward rounds into their PICU and collaboration with the PICU Liberation<sup>20</sup> group. (see Appendix 1 for further information regarding PICU Liberation).

*Provide caregivers with education, training, information and resources along the care continuum to prepare them and support their involvement in care*

1. Screensavers in PICU parent lounge used for family messaging.
2. Parent education groups on ward.
3. 'Caring for your sick child' booklet now made available in antenatal and inpatient setting.
4. List of volunteer services displayed on ward and within welcome pack.
5. Recognised need for educational materials designed to support parents to support their infant's/ child's neurodevelopment. Additional funding required.
6. Support parents to be involved in care where clinically possible – introduction of developmental care ward rounds would enhance this pending funding.
7. Education and consistent messaging re key time points for developmental screening and accessing services – supported by post card and sticker in Personal Health Record.

*Keep parent-infant mental health and caregiver wellbeing on the neurodevelopmental agenda*

1. Family resource created consolidating community mental health support services.
2. LCCH parent infant mental health resource created defining services and referral methods, including accessing volunteer services to support wellbeing.
3. Review of antenatal support services provided by CNC –Cardiac Maternal Fetal Medicine/CHD LIFE Program and Social Work through antenatal care journey to ensure consistency, including education relating to trauma response.
4. Parent self-care included as regular parent education group on ward established by cardiac Social Work and HeartKids.

*Implement processes that support co-ordinated discharge and referral*

1. Review of cardiac ward allied health meeting and establishment of agenda inclusive of discharge planning and recruitment to long-term care pathway.
2. Multidisciplinary referrals inclusive of caregiver input, using standard referral forms (Child Health Service, CDS, Interagency or Inter-hospital transfer).
3. Appointment of discharge coordinator for each child/family and identified key contact at home HHS.
4. Copy of long-term care pathway and supporting document to be included with each referral to support local implementation.
5. Develop letter re long-term care pathway to accompany patients transferring back to local hospitals or CDS.
6. Detailed medical letter to accompany discharge summary and sent to referring specialist (e.g. Paediatrician) with copy to families.

*Develop an integrated long-term care pathway, contextualised to each trial site, to support the needs of each infant/family*

1. Develop integrated long-term care pathway contextualised to each HHS.
2. Develop postcard and sticker for the Personal Health Record (in QLD the “Red Book”) to support parents to access developmental surveillance at key time points and flag for secondary level screening (ASQ-3).
3. Develop companion document to accompany the care pathway, to support contextualisation of recommendations within services across HHSs.
4. Contribute expert clinical knowledge to development of the “Heart Murmurs” and “Developmental Delays” GP HealthPathways™ to include CHD and surgery before 12 months as a high risk cohort with linkages to the care pathway and referral process.
5. Develop a centralised database to monitor care pathway compliance and long-term functional health outcomes including identifying a minimum required dataset and SMS reminder capabilities.
6. Distribute presentations to services to communicate the care pathway.

*CHD LIFE program will lead statewide education and training utilising existing platforms and networks*

1. Establish centralised database to enable audit of care pathway and evaluation of long-term functional health outcomes.
2. Identify minimum data set required for database.
3. Continue to support inpatient work, supporting early neurodevelopment and care-giver wellbeing.
4. Quaternary level responsibility to drive statewide advocacy and awareness, service improvements, education and training through engagement and partnerships within the hospital and across all levels of primary, secondary and tertiary health care.
5. Advocate for timely access for families to required local services to support their child’s development along the continuum inclusive of key transition points and middle/schooling years.
6. Contribute to the broader body of knowledge to improve the lives of those living with CHD beyond our care.

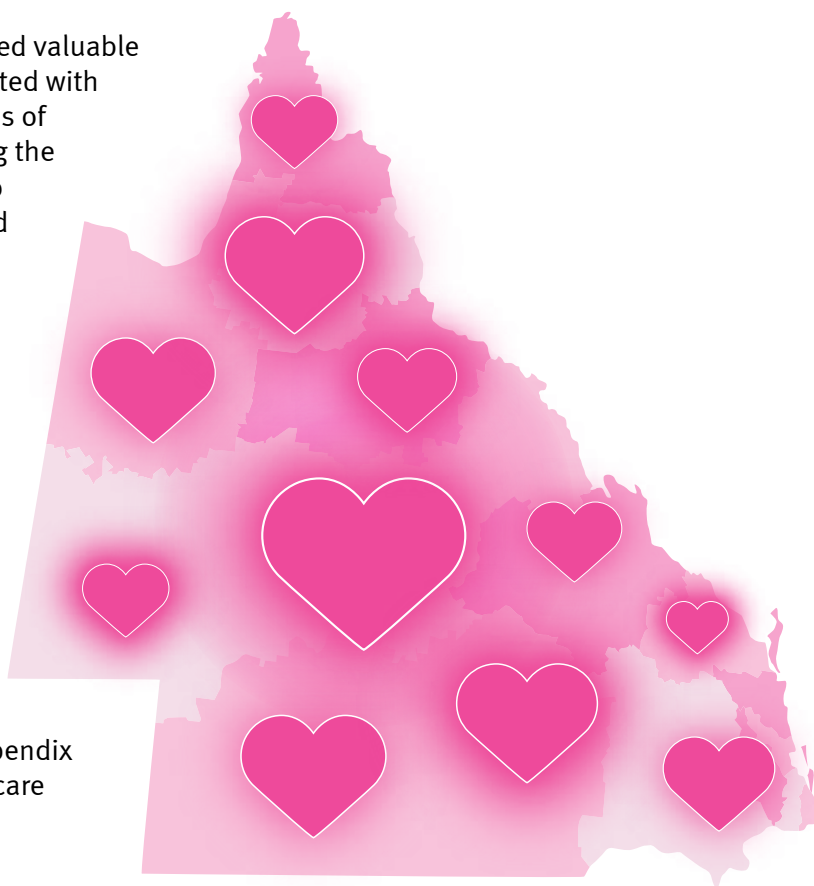
## Chapter 4 Statewide implementation

This chapter outlines the long-term care pathway and provides resources to support the implementation of best practice guidelines within HHSs across Queensland.

### Snapshot

- The long-term care pathway provides an evidence-based guideline for developmental surveillance and support along the life course.
- The companion document provides more detail to support HHSs to contextualise the pathway to services within their local area.
- Post card and sticker for Personal Health Record flags secondary level screening.
- GP HealthPathways™ supporting GPs to manage children with CHD.
- Minimum dataset maintained by CHD LIFE Program.

Engaging three HHSs as pilot sites provided valuable information about the challenges associated with meeting the developmental support needs of children with CHD and their families along the life course. This provided opportunities to develop strategies and outcomes targeted to the needs of families and services, in line with international best practice guidelines. The resulting long-term care pathway is the recommended approach to the developmental surveillance and management of children with CHD after early open heart surgery and services within all HHSs Queensland wide are encouraged to adopt this pathway as “business as usual” for this high risk cohort. Supporting documentation, including Personal Health Record supports (Appendix 5), GP HealthPathways (Appendix 6) the recommended minimum dataset (Appendix 7) and an example of the contextualised care pathway (Appendix 8) are included in the Appendices.



## Chapter 5 Summary and conclusions

The CHD LIFE Program identified the need to develop a statewide, integrated, family centred approach to the developmental needs of children and families receiving care through the Queensland Paediatric Cardiac Service. International best practice recommendations advocate for co-ordinated, integrated developmental surveillance along the life course, however the application of this framework is challenging in a decentralised health service in a state as geographically large as Queensland. The partnership with QCYCN provided the opportunity to marry expert clinical knowledge with expert knowledge about statewide work across service contexts, to enable successful implementation of outcomes.

The ‘*At the Heart of the Matter*’ project outcomes have contextualised best practice clinical guidelines within the unique structure of statewide Queensland health services, building on previous work of the QCYCN. The “[Act now for a better tomorrow 2013 to 2020](#)”<sup>16</sup> document highlighted the need for an understanding of child development within the Queensland health care sector, with particular focus on vulnerable populations such as children living with medical co-morbidities. The “[Understanding the Development and Participation of Children with Significant Health Needs](#)”<sup>17</sup> document identified children with CHD who had undergone early surgery as one of these vulnerable population groups requiring a coordinated approach to developmental support across the life span. Considerations outlined for child development in Queensland provided guidance for expected project outcomes, including:

- development of care pathways for priority populations
- growing partnerships with internal and external stakeholders
- statewide consumer engagement
- support for service review and evaluation
- standardisation of data collection and reporting
- active participation in policy and strategy formation and implementation.

Of significant importance to the success of this project was the co-design with consumers. The “[Understanding the Development and Participation of Children with Significant Health Needs](#)”<sup>17</sup> document synthesised key messages from parents, which were considered throughout this cardiac project to maximise outcomes. Consumer engagement through this project highlighted that families need to be engaged, listened to and considered part of the multidisciplinary team and feel empowered to be advocates for their child.

We know that there is still much to be done to understand and improve the functional health outcomes for the children we care for. The CHD LIFE Program is dedicated to continuing to drive initiatives to improve the functional health of this high-risk cohort. Just as children and families live within their homes and the community, as a quaternary cardiac service, we also recognise it is essential to work in partnership within the hospital and across all levels of primary, secondary and tertiary health care. Ongoing partnership with stakeholders and consumers, including QCYCN and HeartKids, will support an integrated service model where patient and family-centred care is business as usual and the development and participation of children with CHD is maximised.



## *Chapter 6 Recommendations for the future*

This chapter provides an overview of recommendations for this cohort as identified throughout the project journey, as well as for other vulnerable populations.

### **Snapshot**

- Statewide implementation of project outcomes – “business as usual”.
- Long-term evaluation of pathway and functional health outcomes.
- Ongoing partnerships with CHD LIFE Program, QCYCN and HeartKids.
- Transferability of project outcomes to other high risk cohorts.

### *Achieving statewide implementation of project outcomes through partnerships*

Ongoing partnerships between the CHD LIFE Program, QCYCN and HeartKids will support the implementation of project outcomes statewide. Under the governance of the CHD LIFE Program, proposed activity will include:

- recruitment to the CHD LIFE Program and consent for data collection
- auditing long-term care pathway use
- evaluating long-term functional health outcomes
- supporting implementation of “business as usual” within non-trial HHSs
- driving statewide advocacy and capability building and contributing to statewide/national guidelines.

### *Recommendations for ongoing work*

A number of solution strategies were identified by stakeholders and consumers, which require additional funding, or need to be undertaken as part of broader pieces of work within and/or across the organisation. Considerations for ongoing work include:

- a digital platform (patient portal or application) to assist families to access information and coordinate their child’s care
- information available online via handouts or videos, accessible via the above platform
- Project ECHO series to build capabilities - Cardiac identified as one high risk cohort that should be considered in a broader neurodevelopmental ECHO series.

### *Transferability to other high risk cohorts*

The application of learnings regarding the challenges faced by families accessing developmental supports across the continuum is important for other vulnerable populations. Transfer of project outcomes including the long-term care pathway to all high risk infant cohorts is recommended, to support an integrated, family centred approach to the developmental support needs of children and families statewide.



## Part three: Literature review

## Part three: Literature review

This chapter provides a detailed overview of CHD including prevalence, risk factors for poor functional health outcomes, recommended assessments and implications for practice. It aims to provide an understanding of this high risk cohort and why a specific lens is required to support the development and participation of these children and families along the life course.

### **Snapshot**

- 1 in 100 babies are born with CHD. More than half will require surgery before the age of 12 months.
- Mortality rates have decreased with improvements in surgical intervention, but morbidity has increased.
- Infants with CHD are often born with neurological changes due to abnormal fetal circulation associated with their heart structure.
- Peri-operative management associated with life-saving surgical and pharmacological interventions can impact brain development and long-term neurodevelopment.
- Children may present with functional health difficulties at difference points along the developmental continuum.
- Long-term developmental surveillance is recommended at key time points, such as transition to school.
- Integrating care along the service continuum and supporting families to understand how to optimise their child's development and participation is recommended.

### **Introduction**

Congenital heart disease (CHD) refers to abnormalities in the heart's structure or function that arise before birth.<sup>21</sup> Nearly one third of infants with CHD require surgical intervention,<sup>3</sup> and improved surgical interventions has led to more children surviving into adulthood,<sup>5</sup> many are left with adverse functional health outcomes requiring services and supports from families, health care systems and educational facilities.<sup>6-9</sup>

Neurodevelopmental disabilities are the most common and potentially the most significant sequelae of complicated childhood disease,<sup>10</sup> particularly for infants who undergo surgery in the neonatal period.<sup>11,12</sup> Congenital heart disease survivors demonstrate a specific pattern of neurodevelopmental sequelae and behavioural impairments,<sup>6,8,9,11,13</sup> which are often very subtle in young infants. The extent of impairment can be overlooked or not fully recognised until specific cognitive and higher executive functioning skills are developmentally expected.<sup>13</sup> Neurodevelopmental and psychosocial morbidity related to CHD can have lasting negative impacts on educational achievement, lifelong earning potential and quality of life for survivors.<sup>11</sup>

Given the spectrum of neurodevelopmental risk, the American Heart Association (AHA) recommends developmental surveillance of all children with CHD.<sup>11</sup> Children whose neurodevelopmental needs are identified and addressed prior to reaching three years of age have a greater chance of reaching their full potential later in life, thus significantly decreasing the burden potentially placed upon many families.<sup>6,9,14</sup> It is widely reported that an absence of early monitoring of neurodevelopment can delay

referral to early intervention services, which may negatively impact developmental outcomes and limit children from achieving their full potential.<sup>7,11,13,15</sup>

Despite the well-documented presence of neurodevelopmental delays amongst children with CHD,<sup>6,7,9,10</sup> there are currently no practice guidelines for the evaluation and management of these children in Queensland or nationally. With increasing service demands in cardiology and a drive for integrated, family centred care, a service translation initiative was required to develop a statewide approach to the developmental support needs of this population in Queensland.

## **Definition and prevalence**

Congenital heart disease refers to abnormalities in the heart's structure or function that arise before birth<sup>21</sup> that can or potentially have functional significance.<sup>22</sup> Congenital heart disease is one of the most common birth defects, accounting for 28 per cent of all major congenital anomalies.<sup>1</sup> The incidence of CHD in Australia has been reported as 7.8 per 1000 live births and is the biggest single cause of child mortality and early childhood hospitalisation.<sup>2</sup> Congenital heart disease can be categorised into two main diagnostic groups:<sup>23,24</sup>

- cyanotic heart disease (including univentricular and biventricular)
- acyanotic heart disease.

The most common cyanotic CHD subtypes reported worldwide include pulmonary stenosis (PS), Tetralogy of Fallot (TOF), coarctation of the aorta (CoA), transposition of the great arteries (TGA) and aortic stenosis (AoS). In the acyanotic CHD subtypes, the most common lesions include ventricular septal defects (VSD), atrial septal defects (ASD) and patent ductus arteriosus (PDA). More severe cyanotic lesions such as hypoplastic left heart syndrome (HLHS) or truncus arteriosus, are relatively rare compared with these more common defects.<sup>1,25</sup>

Survival of infants born with CHD is dependent on the complexity of disease, associated non-cardiac malformations and perinatal complications, as well as the quality of surgery and post-operative care.<sup>26</sup> Up to 95 per cent of infants born with major CHD will not survive childhood without lifesaving surgical intervention.<sup>27</sup> Some lesions, however, such as a small patent ductus arteriosus or a small muscular VSD may resolve spontaneously without the need for surgery.<sup>25</sup> It is reported that 30 to 50 per cent of infants with CHD will require open heart surgery in the neonatal period.<sup>3,23</sup> Advances in surgical techniques have led to more corrective rather than palliative operations,<sup>27</sup> and increased survival for infants with diagnoses previously considered fatal.<sup>28</sup> In addition, advances in cardiac catheterisation, intensive care, non-invasive imaging and medical therapies have also contributed to a reduction in mortality rates in the CHD population.<sup>11</sup>

With ongoing improvements in surgical interventions over the past decades, mortality in children with CHD has decreased significantly and more than 90 per cent of children with CHD are now expected to survive into adulthood.<sup>29</sup> Long-term morbidity however, is an ongoing concern for this population,<sup>30</sup> and neurodevelopmental outcomes and quality of life for survivors of CHD have been well documented.<sup>11</sup> Children with CHD are at risk of substantial physical, intellectual, psychological and social difficulties, leading to an increased burden on families, health care systems and educational facilities.<sup>6,7,9</sup> The neurodevelopmental and psychosocial morbidity associated with CHD has a lasting negative impact upon educational achievement, lifelong earning potential and quality of life, for the individual, as well as their carers and families.<sup>11,15,31</sup>

## **Risk factors for poor developmental outcomes**

A number of studies have sought to identify risk factors for poor neurological, neurobehavioural, cognitive and motor outcomes in infants following open heart surgery.<sup>6,10,32-34</sup> Length of hospital stay,

number of open heart procedures, genetic or other medical conditions, prematurity, cardiopulmonary bypass (CPB) time, deep hypothermic cardiac arrest (DHCA) time, single versus two ventricles, seizures, growth and maternal education have all been found to have a statistically significant relationship with delay on later neurodevelopment.<sup>6,11</sup> Historically there has been greater focus on intra-operative risk factors such as length of CPB or DHCA and noxious pharmaceutical interventions such as anaesthesia.<sup>35</sup> Improvements in surgical management including decreased use of CPB and reduced length of DHCA, however, has not seen dramatic improvements in neurodevelopmental outcomes.<sup>35,36</sup> Predicting long-term outcomes is difficult, given the multifaceted risks associated with CHD and consequent management,<sup>37</sup> including non-modifiable risk factors such as type of CHD, gender and genetic disorders,<sup>38</sup> and modifiable factors such as hospital length of stay.<sup>35,39</sup> With increased awareness of these modifiable factors, improvements in perioperative management of infants with CHD may see improved long-term neurodevelopmental outcomes.

### *Patient characteristics*

Genetic disorders such as trisomy 21 and 22q11 deletion are common in infants with CHD and with improvements in genetic testing more genetic comorbidities are being diagnosed.<sup>40</sup> Approximately one third of infants with CHD requiring surgery have a comorbid genetic disorder,<sup>29,40</sup> placing them at increased risk of poorer developmental outcomes than those without comorbidities, particularly cognitive functioning and IQ.<sup>10,11,38</sup> Variations of apolipoprotein E (APOE), most commonly the APOE e2 allele, responsible for cholesterol metabolism and lipid transport in the brain to support post-operative neuro-resiliency and repair, has gained increasing focus due to association with neurodevelopmental impairment in the CHD population.<sup>41,42</sup> In addition to genetic disorders, other comorbidities such as extracardiac anomalies have also been associated with poorer developmental outcomes.<sup>10</sup>

The type of cardiac lesion can also impact developmental outcomes and the reasons are multifaceted, including abnormal fetal circulation and oxygen saturation, brain dysmaturational, surgical course and the need for post-operative support such as extracorporeal membranous oxygenation.<sup>35,43</sup> Cyanotic defects have been well reported as being associated with poorer developmental outcomes.<sup>44</sup> In particular, single ventricle physiology such as HLHS, has been associated with cognitive, motor and language deficits across the developmental continuum.<sup>45-47</sup> Acyanotic lesions, although often less complex, have been associated with fine and gross motor deficits in infancy.<sup>33</sup>

Other patient characteristics such as lower birth weight,<sup>47,48</sup> gestational age,<sup>49</sup> male gender,<sup>10</sup> and lower maternal education<sup>10,50,51</sup> have been found to be predictors of poorer cognitive and motor outcomes.<sup>10</sup>

### *Peri-operative risk factors*

Infants with CHD commonly present with smaller, structurally less mature brains at birth, similar to those seen in preterm infants.<sup>52,53</sup> Pre-operatively, reduced brain volume, brain dysmaturational and abnormal cerebral microstructures are common,<sup>54,55</sup> likely due to altered fetal circulation and decreased oxygen delivery in utero.<sup>55,56</sup> Studies utilising pre-operative magnetic resonance imaging (MRI) have shown that a term-aged infant with CHD may present with an up to one month delay in brain maturation, increasing the vulnerability for neurologic injuries such as periventricular leukomalacia.<sup>42,53</sup>

In addition to structural abnormalities, infants with CHD who require surgery in the first month of life are at a high risk for preoperative brain injury regardless of type of CHD.<sup>57</sup> Up to 40 per cent of infants with CHD have identified brain injury on MRI preoperatively and new injuries may be detected in up to 30 per cent of infants post-operatively.<sup>57-61</sup> It is proposed that pre-operative brain injury may be due to vulnerability of the structurally immature brain, or as a sequela of altered cerebral blood flow.<sup>57</sup> Particularly in infants born with TGA or HLHS, disordered circulation of oxygen rich blood can lead to reduced brain oxygenation and therefore a higher risk of cerebral damage.<sup>25,56,58,62</sup>

The clinical presentation of neurological comorbidities may include hypotonia, poor feeding, seizures and poor state regulation, most commonly seen in infants with cyanotic lesions.<sup>58,63</sup> Significant associations have been found between perioperative neurodevelopmental status and persisting neurologic abnormalities, microcephaly, gross and fine motor impairments and developmental delay.<sup>33,34</sup> While the effect of brain injury severity on long-term neurodevelopmental outcomes is not well known,<sup>57</sup> the high incidence of white matter injury in infants with CHD has been associated with an increased prevalence of perceptual impairments, attention deficit disorder and developmental delay, suggesting the lesions are of clinical importance.<sup>42,60</sup>

Intra-operative risk factors have been the focus of mortality and morbidity studies for many years. Improvements in surgical techniques and the introduction of bypass has led to more complex surgeries being undertaken.<sup>27,28</sup> Infants with complex physiology previously managed via a palliative course are now undergoing staged surgical palliation, with many surviving into adulthood.<sup>28,29</sup> Complex surgeries and associated intra-operative management present additional risks, further complications and consequent neurodevelopmental sequelae.<sup>35,61,64</sup>

### *Post-operative risk factors*

Advancement in the post-operative management of infants with CHD has significantly reduced mortality, however the impact on morbidity has become an increasing focus.<sup>11</sup> Early experiences of the post-operative infant in the paediatric intensive care unit (PICU) can impact early neurodevelopment and later outcomes. Of particular risk to medically fragile infants are post-operative complications such as seizures,<sup>65,66</sup> higher lactate levels,<sup>46,48</sup> or the need for life saving but potentially noxious interventions, including inotropic support<sup>39,48</sup> and Extracorporeal Life Support (ECLS).<sup>10,35</sup> Infants with CHD requiring ECLS should also be considered at particularly increased risk of neurological impairment and developmental delay.<sup>11</sup> Extracorporeal life support may be required pre- and/or post-operatively to sustain cardiopulmonary function in critically ill newborns and infants with potentially reversible cardiac and/or respiratory failure.<sup>67,68</sup> In infants with CHD undergoing heart surgery, indicators for ECLS treatment may include low cardiac output, inability to wean from cardiopulmonary bypass (CPB), refractory arrhythmias, pulmonary hypertension and inotrope-refractory cardiogenic shock.<sup>67</sup> The need for ECLS is not only associated with high mortality but also high rates of disability,<sup>69</sup> acute neurological injury<sup>49</sup> and impaired quality of life<sup>68</sup> in survivors. For infants with CHD requiring postoperative ECLS, it is estimated that only 13 per cent survive completely intact, with 50 per cent presenting with suspect or abnormal cognitive outcome and 28 per cent with suspect or abnormal neuromotor outcome.<sup>70</sup>

Post-operative complications and high acuity support requirements are not only indicative of medical complexity, but also contribute to increased length of hospital stay. Post-operative length of PICU and hospital stay has been significantly associated with reduced cognitive and motor performance.<sup>10,32,33,46</sup> A higher number of subsequent hospital admissions have also been associated with gross and fine motor delays.<sup>34</sup>

Routine follow-up of infants following open heart surgery has found patients requiring supplemental tube feeding at discharge from hospital have lower cognitive, language and motor composite scores on the BSID-III than those who feed orally.<sup>6</sup> It is suggested that the need for tube feeding may correlate with disease severity, which also correlates with hospital length of stay.<sup>6</sup>

### *Neurodevelopmental outcomes*

Current literature indicates that many infants who undergo open heart surgery in the neonatal period demonstrate a pattern of neurodevelopmental sequelae, including impairments of behaviour, cognition, social skills and language, visual perception, executive function, motor skills, inattention, hyperactivity and impulsivity.<sup>6,9,11,13</sup> Specifically, infants with CHD who have undergone open heart surgery have

been found to be at the highest risk for neurodevelopmental delays.<sup>11,12</sup> Delays may be very mild or absent in the early years and go undetected, with issues arising later in childhood with higher level skill acquisition.<sup>37</sup> A typical neurodevelopmental profile may include early motor difficulties, which may improve in the early years,<sup>71</sup> language and communication difficulties emerging at pre-school age, behavioural and learning difficulties presenting at school age,<sup>37,72</sup> and executive functioning and mental health difficulties in adolescence.<sup>72,73</sup> Impairments are typically seen across developmental domains, impacting skill acquisition, peer interaction and learning.<sup>11,72</sup>

### *Post-operative/early infancy outcomes*

The incidence of neurological abnormalities is high for infants with CHD following early open heart surgery,<sup>3,55</sup> particularly those with single ventricle physiology requiring palliative procedures.<sup>74</sup> Neurological abnormalities and consequent major developmental disabilities have been reported in up to 69 per cent of infants following palliative surgery,<sup>23</sup> compared with 24 per cent following corrective surgery.<sup>3,56,75</sup> Post-operative brain injury, such as white matter injury,<sup>61</sup> haemorrhages and infarcts,<sup>63</sup> may be present in up to 50 per cent of infants. Neurological and neurobehavioural abnormalities may be identified, including seizures, altered tone, reduced consciousness, restlessness and agitation.<sup>58,63</sup> This can lead to functional implications such as delayed motor development, feeding difficulties and poor state regulation,<sup>58,63</sup> impacting care giving practices and early attachment.

In early infancy, delays may be most significant post-operatively,<sup>76,77</sup> however at 12-15 months of age mild to severe impairments may be seen across multiple developmental domains in up to 44 per cent of infants.<sup>6,12,78</sup> Delays in motor skills are most commonly reported,<sup>6,12</sup> ranging from mild in 63 per cent to significant in 37 per cent of infants.<sup>10</sup> In studies of infant development up to 15 months of age, between 43 and 63 per cent of infants present with motor skills  $>1SD$  below the mean when evaluated using standardized developmental assessments such as the Bayley Scale of Infant Toddler Development-2nd Ed (BSID-II),<sup>10</sup> Ages and Stages Questionnaire-3rd Edition (ASQ-3)<sup>78</sup> and Alberta Infant Motor Scales.<sup>79</sup> A systematic review undertaken by Snookes et al., (2010) also substantiated that at one year of age, the risk of gross motor delay was greater than the risk of delays in cognition for infants who had undergone open heart surgery before six months of age.<sup>31</sup>

Infants with HLHS have significantly higher risk of neurodevelopmental delays at 12 months of age than children with biventricular heart defect and healthy control subjects.<sup>50,75,80</sup> At 12 months of age, developmental delays may be seen in up to 63 per cent of infants following palliative surgery compared with only 19 per cent following corrective surgery.<sup>3</sup> Children with HLHS are more likely to present with hypotonia (64 per cent), poor posture (23 per cent), minor neurological dysfunction (23 per cent), reduced gross motor skills (36 per cent) and reduced fine motor skills (41 per cent).<sup>31</sup> Significant motor delays  $>2SD$  below the mean have been reported in 11 per cent of infants at 12 months<sup>71</sup> and up to 44 per cent at 14 months<sup>10,47</sup> of age.

### *Early childhood/pre-school outcomes*

Early childhood is an important period of significant developmental growth and skill acquisition critical for the developmental trajectory and lifecourse. For children with CHD, skill acquisition may be impaired by neurological deficits, particularly those who have undergone multiple interventions and surgeries in their early childhood, such as those with HLHS and other single ventricle physiology.<sup>81</sup>

At two years of age, neurological impairment may be seen on MRI in up to 36 per cent of children with CHD.<sup>81</sup> Mild delays ( $>1SD$  below mean) may be present in up to 32 per cent and moderate to severe delays ( $<2SD$  below mean) in up to 9 per cent of children with CHD in at least one developmental domain of the Bayley Scale of Infant Toddler Development-3rd Ed (BSID-III).<sup>14,46,77</sup> By the age of two

years, gross motor skills have often improved, however cognitive and language difficulties are likely to emerge and delays are typically more pronounced in children with single ventricle physiology.<sup>46,50,77</sup> Motor outcomes in this cohort are worse in infants who have been treated with ECMO post Norwood, or have had additional hospitalisations following second stage surgery.<sup>82</sup>

During three to four years of age, higher level cognitive, motor and language skills are typically developing, however delays are common for children with CHD.<sup>11</sup> Neurological impairment may be found in 21-30 per cent of children with TGA,<sup>83,84</sup> leading to developmental difficulties including poor balance and coordination, decreased attention span and oromotor apraxia.<sup>83</sup> Children with single ventricle physiology also experience more difficulties than other CHD cohorts. Significant developmental delay has been reported in approximately 33 per cent of children with single ventricle compared to 21 per cent of children with biventricular CHD,<sup>71</sup> including gross and fine motor delays in 30 per cent and 35 per cent respectively, communication delays in 20 per cent and problem solving difficulties in 24 per cent.<sup>45</sup> Children with single ventricle lesions may also present with substandard cognitive skills,<sup>81,85</sup> worse processing speed, inattention and impulsivity,<sup>86</sup> and behaviour in the at-risk or clinically abnormal range.<sup>45</sup>

### *School age outcomes*

At school age, children who have undergone open heart surgery in early infancy are at increased risk of poorer neurocognitive, functional and health outcomes.<sup>87</sup> Deficits may vary in severity from mild to severe and may be seen across functional areas. Lower than average self-care skills have been reported in 30 per cent,<sup>88</sup> and moderate to severe disability in up to 22 per cent<sup>34</sup> of school aged children following early open heart surgery. Functional limitations due to motor and cognitive impairments may be exhibited in up to 20 per cent of children,<sup>34</sup> with neurological abnormalities and functional limitations twice as likely in boys than girls.<sup>89</sup> Many of these children require services such as tutoring, special education and therapy including physiotherapy, occupational therapy and speech therapy.<sup>11</sup>

The neurodevelopmental profiles of children with CHD at school age indicate an ongoing high incidence of abnormal neurological assessment<sup>34</sup> and delayed motor performance.<sup>84,90</sup> Long et al (2016) found motor ability at four months and two years to be associated with motor proficiency at five years.<sup>91</sup> Gross motor delays including balance deficits may be identified in up to 50 per cent of school aged children.<sup>34,89,91</sup> Fine motor delays have been detected in up to 28 per cent of girls<sup>89</sup> and between 40 and 50 per cent of boys.<sup>34,89</sup> Chronic neuromotor disability, commonly unilateral spastic cerebral palsy, has been reported in six per cent of school aged children with biventricular and ten per cent with univentricular CHD.<sup>48</sup> This has been associated with higher rates of other impairments such as intellectual impairment, autism spectrum disorder, epilepsy and visual impairment.<sup>48</sup> Significant independent risk factors for poor motor outcomes include genetic disorders, increased ICU stay, low birth weight, post-operative seizures and low socio-economic status.<sup>90</sup>

At school age, many children who have undergone surgery for CHD in infancy have executive functioning difficulties<sup>92,93</sup> leading to poorer academic achievement than average students.<sup>94</sup> Cognitive performance measured by intelligence quotient (IQ) varies in school aged children with CHD. Most children demonstrate normal to low average skills,<sup>90,95</sup> however 5 – 18 per cent may present with significant intellectual impairment.<sup>90,96,97</sup> Children with TGA are at increased risk of delay in the areas of intelligence, academic achievement, executive functioning, language and motor skills.<sup>83,98</sup> Children with single ventricle physiology such as HLHS are the most at risk for neuropsychological difficulties, including reduced working and long-term memory capacity,<sup>51</sup> attention and information processing speed,<sup>72</sup> and executive functioning compared to healthy control subjects.<sup>95</sup>

Motor dysfunction and behavioural problems frequently coexist in school-age children with CHD.<sup>99</sup> Estimated rates of attention deficit and hyperactivity disorders have been reported in 40-50 per cent of



children with TGA, which is significantly higher than the general population.<sup>11</sup> Behavioural difficulties and impairments in social interactions in school age children with TGA have been associated with post-operative seizures.<sup>65</sup> Children with single ventricles have been reportedly at heightened risk for internalising and externalising problem behaviour and experience more problems at school.<sup>72</sup>

### *Adolescent outcomes*

Improvements in surgical techniques have led to an increase in the population of adolescents and adults with CHD.<sup>100</sup> Neurodevelopmental and behavioural impairments seen in childhood can continue into adolescence, impacting daily living skills, communication and adaptive behaviour.<sup>36,87,98</sup> Difficulties with adaptive behaviour, including learned skills in conceptual, practical and social domains, can impact on everyday functioning. These difficulties can have a negative impact on quality of life, self-esteem and behaviour, the ability to form relationships and adjustment to vocation.<sup>11,36</sup>

As with early neurodevelopmental sequelae, severity of developmental and behavioural difficulties in adolescents is difficult to predict and there is limited information regarding risk factors for neurological changes and the impact on neurodevelopmental outcomes.<sup>101</sup> Adolescents with CHD, particularly cyanotic CHD, have smaller brain volumes compared to the general population, which correlates with lower IQ and cognitive function.<sup>100</sup> Preoperative acidosis, hypoxia and post-operative seizures are associated with worse neurodevelopmental outcomes in adolescents.<sup>36,101</sup> Boys with CHD report reduced levels of physical activity and lower self-esteem during adolescence compared with girls.<sup>89</sup>

Adolescents with TGA, TOF or VSD reportedly have reduced school performance and an increased prevalence of internalising behaviour (such as anxiety and depression), externalising behaviour (such as attention and aggression) and social difficulties.<sup>11</sup> Increasing academic and psychological demands placed on adolescents may see twice the frequency of impairment in adolescents with TGA than reported at 5 years of age.<sup>36</sup> Neuropsychological assessment results at 16 years have reported IQ scores close to the population mean but higher rates of impairments in gross and fine motor, speech and language and executive function. Special services, including tutoring, early intervention, occupational therapy, special education and counselling may be accessed by up to 65 per cent of adolescents with TGA.<sup>36</sup>

Adolescents who have undergone a Fontan operation are also at high risk of worse executive function and problems in behaviour, mental health, self-esteem and psychiatric disorders.<sup>73,102,103</sup> Rates of lifetime psychiatric diagnoses such as anxiety and attention deficit and hyperactivity disorder (ADHA) have also been reported in 65 per cent of the SV population, compared with 22 per cent of the healthy population. The prevalence of ADHD is higher in adolescents born in the early preterm period.<sup>102</sup>

The burden of chronic illness in adolescents with CHD can lead to a significantly greater rate of mental health or social problems, including anxiety, depression and behavioural problems compared to the general population.<sup>104</sup> The use of psychiatric medications in adolescents with TGA is up to four times more frequent than the healthy population.<sup>36</sup> In order to prepare adolescents for transition to adulthood, Marino et al (2012) recommend counselling for educational or vocational options to maximise potential.<sup>11</sup>

### *Measuring long-term functional health outcomes*

#### *Postoperative risk stratification*

Post-operative neurodevelopmental status of infants with CHD is an important indicator of later neurologic, motor and global developmental outcomes.<sup>33</sup> Identification of developmentally at risk infants in the CHD population allows for implementation of individualised developmental care in

the perioperative period,<sup>105,106</sup> and informs referral to early intervention services to mitigate long-term neurodevelopmental sequelae.<sup>8,74,107</sup> In order to identify at risk infants postoperatively, valid and reliable assessment measures that screen neurological and neuromotor performance of fragile and unstable infants are needed.<sup>108</sup> Spittle, Doyle and Boyd (2008) reported on the benefits of infant neuromotor assessments, including their use as discriminative, predictive and evaluative tools.<sup>109</sup> They acknowledged that the first year of an infant's life is a critical period for brain development. A subsequent systematic review of neonatal assessments for use with preterm infants up to 4 months corrected age, found Prechtl's assessment of General Movements (GMs)<sup>110</sup> and the Test of Infant Motor Performance (TIMP)<sup>111</sup> to have the strongest psychometric properties.<sup>108</sup>

### *Longitudinal developmental surveillance*

Developmental screening at key transition points in childhood such as early infancy, prior to school entry and transition to high school is imperative for early identification of developmental difficulties and referral to early intervention or support services.<sup>3,11,34</sup> Marino et al (2012) recommend screening at nine, 18, 30 and 48 months of age, with specific autism screening recommended between 18 and 24 months.<sup>11</sup> Screening behaviour at 2.5 and four years is important for early identification of learning and behavioural difficulties common in school aged children. Developmental screening across developmental domains at four years is also recommended to assess development, social and emotional readiness for school. Developmental domains that should be assessed in early childhood include cognitive, gross and fine motor, communication, adaptive skills and social and behavioural interaction.<sup>11</sup>

The Ages and Stages Questionnaire – 3rd Edition (ASQ-3)<sup>112</sup> is a screening system composed of questionnaires designed to be completed by parents or primary caregivers at any point for a child between one month and 5½ years of age. The questionnaires can accurately identify infants or young children who are in need of further assessment.<sup>113</sup> Items are organised into five areas: communication, gross motor, fine motor, problem solving and personal-social. Scores range from 0 (below cut-off) to 60 (above cut-off) with age normed cut-offs in each of the five developmental areas. Questionnaires take 10-15 minutes to complete and 1-5 minutes to score. The ASQ-3 has proved highly accurate in identifying children with developmental delays, with excellent sensitivity and specificity and was standardised on a large research sample.<sup>112</sup> It has been used in a number of studies to evaluate developmental performance after open heart surgery.<sup>45,77,78</sup>

In order to understand the impact of CHD on quality of life, behaviour and family functioning, a number of checklists and questionnaires are commonly reported in the literature. Frequently reported tools include the Pediatric Quality of Life Inventory (PedsQL),<sup>114</sup> Impact on the Family Scale (IOF),<sup>115</sup> Parenting Stress Index (PSI),<sup>116</sup> Parent Behavior Checklist (PBC)<sup>117</sup> and Child Behavior Checklist.<sup>118,119</sup>

### *Longitudinal developmental assessment*

In school aged children and adolescents with CHD, developmental surveillance may indicate the need for further assessment to establish an understanding of impact on function. Developmental assessment should be guided by functional presentation identified through screening, considering motor, behaviour, communication, social, cognitive/learning and executive function domains. In adolescence, neuropsychological assessments are recommended, including tools that assess academic achievement, memory, executive functions, visual perception, attention and social cognition.<sup>36</sup> Screening at key transition points such as primary school, high school entry and senior school is important due to the increased demand in the complexity and types of developmental tasks required.<sup>11</sup> Suggested assessment tools include:

- *Bayley Scale of Infant Toddler Development – Third Edition*<sup>120</sup>
- *Wechsler Individual Achievement Test – Second Edition*<sup>121</sup>

- *General Memory Index of the Children's Memory Scale*<sup>122</sup>
- *Delis-Kaplan Executive Function System*<sup>123</sup>
- *Behaviour Rating Inventory of Executive Function (BRIEF)*<sup>124</sup>
- *Beery Test of Visual Motor Integration (VMI)*<sup>125</sup>
- *Test of Visual-Perceptual Skills (TVPS)*<sup>126</sup>
- *Sense of Direction Scale*<sup>127</sup>
- *Connor's attention deficit and hyperactivity disorder (ADHD) scale*<sup>128</sup>
- *Reading the Mind in the Eyes Test – Revised*<sup>129</sup>
- *Adult Autism Spectrum Quotient*<sup>130</sup>

While this is not an exhaustive list of screening tools and assessments used to evaluate neurodevelopmental outcomes in children and adolescents with CHD, it gives a general overview of assessments commonly referenced in the CHD literature.

### **Support needs for children and families – the role of health services across the care continuum**

Evidence suggests that children whose developmental needs are identified and addressed prior to reaching three years of age have a greater chance of reaching their full potential later in life, thus significantly decreasing the burden subsequently placed upon many families.<sup>6,9,14</sup> Within the first year of life, up to 51 per cent of infants with CHD may be receiving early intervention services, including occupational therapy, physiotherapy and speech therapy.<sup>6,47</sup> As children progress through childhood and higher level skill acquisition is expected, emerging difficulties place increasing demand on early intervention and special education services,<sup>90,94,131</sup> particularly from the HLHS cohort.<sup>95,132</sup>

There is growing concern that an absence of developmental monitoring and routine follow-up programs may preclude the identification of many children with CHD in need of intervention, thus delaying referral to early intervention services.<sup>7,11,13,15</sup> It is important that caregivers are educated about the impact of CHD on long-term outcomes and the importance of long-term follow-up.<sup>37</sup> Close monitoring of children with CHD at school age is strongly recommended, as the demands of higher level cognitive functioning increased with age and educational demands,<sup>88</sup> and specific learning difficulties become more evident.<sup>50</sup>

Given the spectrum of neurodevelopmental risk, the American Heart Association (AHA) recommends developmental surveillance of all children with CHD, including those who have undergone open heart surgery and those with cyanotic heart lesions not requiring early surgery.<sup>11</sup> The AHA advocates for surveillance, screening, evaluation and management and indicates that the following groups should be considered high risk for neurodevelopmental delay; (1) neonates or infants requiring open heart surgery, (2) children with other cyanotic heart lesions not requiring open heart surgery in the neonatal or infant period, (3) children with CHD and other comorbidities, (4) other conditions to be determined at the discretion of the medical providers.<sup>11</sup> Variability in developmental outcome and difficulty predicting long-term developmental outcomes highlights the importance of routine screening for this population,<sup>6</sup> and consistent data collection via regional and national registries to inform practice.<sup>37</sup>

Despite the well-documented presence of neurodevelopmental delays and participation challenges experienced by children with significant health needs such as those with CHD,<sup>6,7,9,10</sup> there are currently no practice guidelines for and no systematic approach to the evaluation and management of these children in Australia. Health services are well placed to understand the medical, developmental and psychosocial needs of children concurrently through provision of integrated multidisciplinary services

delivered by professionals with a specialist skill set. Partnering with families throughout the patient journey, from birth across the life course, supports their understanding of their child's needs and how best to support and maximize their development and participation in life. The QCYCN's "[\*Act now for a better tomorrow 2013 to 2020\*](#)"<sup>16</sup> document highlighted the need for development of care pathways for priority populations, through partnering with internal and external stakeholders, as well as engaging with consumers statewide. Effective engagement and partnerships enable rigorous service review and evaluation, standardisation of data collection and reporting, active participation in policy and strategy formation and successful implementation of best practice care pathways.

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# Appendices

## *Appendix 1: Abbreviations and definitions*

ASQ-3 – Ages and Stages Questionnaire-3rd Edition – is a screening system composed of questionnaires designed to be completed by parents or primary caregivers at any point for a child between one month and 5 and a half years of age. The questionnaires can accurately identify infants or young children who are in need of further assessment. The ASQ-3 is offered by Child Health Services statewide as part of standard care for infants and children requiring secondary level screening.

CDS – Child Development Service – a specialist public health service that works with families, communities and professionals to understand the needs of children and young people who are experiencing developmental problems, by providing multidisciplinary, diagnostic assessment and intervention.

CDSN – Child Development Sub Network – a sub network providing clear apolitical advice through cooperation and collaboration on matters regarding child development services in Queensland Health HHSs.

CHD – Congenital Heart Disease – abnormalities in the hearts structure or function that arise before birth

CHD LIFE – Congenital Heart Disease Long-term Improvements in Functional hEalth Program - a multidisciplinary partnership Program designed to improve long-term neurodevelopmental and functional health in children with congenital heart disease at risk of adverse outcomes and their families by monitoring and reporting long-term outcomes, raising awareness, facilitating early intervention, conducting research, and training professionals.

CHQ – Children’s Health Queensland – a specialist statewide hospital and health service dedicated to providing the best possible family-centred health care for every child and young person in Queensland.  
CPB – cardiopulmonary bypass – a technique that temporarily takes over the function of the heart and lungs during surgery, maintaining the circulation of blood and the oxygen content of the patient’s body.

CPC – Clinical Prioritisation Criteria – clinical decision support tools that were developed to help ensure referrals to public specialist outpatient services in Queensland are triaged according to their clinical urgency in a safe, consistent and equitable manner.

CSCF – Clinical Service Capability Framework – outlines the minimum support services, staffing, safety standards and other requirements required in both public and private health facilities to ensure safe and appropriately supported clinical services. It serves two major purposes: 1) To provide a standard set of capability requirements for most acute and sub-acute health facility services provided in Queensland by public and private health facilities and 2) To provide a consistent language for health care providers and planners to use when describing health services and planning service developments.

CSR – Clinical service redesign – a research methodology founded on issues based problem solving, data driven hypothesis testing and change driven by the value added from the customer perspective.

DHCA – deep hypothermic cardiac arrest – a surgical technique that involves cooling the body to temperatures below 20°C and stopping blood circulation and brain function for up to one hour.

ECEI – Early Childhood Early Intervention – providing support early in life to reduce the effects of disability and to improve the person’s functional capacity.

ECLS – Extracorporeal Life Support – refers to a type of life support that involves using a machine outside the body to replace the work of the heart and/or lungs. Extracorporeal means ‘outside the body’ and when a patient is on ECLS, their blood is removed and then returned into their body. ECLS is used when the heart

and/or lungs are failing, despite all other treatments. This type of life support allows the injured organ(s) the opportunity to rest and recover. ECLS is used on infants and children with severe, but reversible heart or lung disorders that have not responded to the usual treatments of extra oxygen, intravenous medications and mechanical ventilation.

HHS – Hospital and Health Service – Public health services in Queensland are provided through 16 Hospital and Health Services (HHS). These are statutory bodies, each governed by a Hospital and Health Board.

HREC – Human Research Ethics Committee – play a central role in the Australian system of ethical oversight of research involving humans. HRECs review research proposals involving human participants to ensure that they are ethically acceptable and in accordance with relevant standards and guidelines.

LCCH – Lady Cilento Children’s Hospital – is the major specialist children’s hospital for families living in Queensland and northern New South Wales. The hospital provides care to the state’s sickest and most critically injured children who need highly specialised care. Lady Cilento Children’s Hospital is also the local children’s hospital for families who live in the catchment area in inner Brisbane.

NDIS – National Disability Insurance Scheme – an insurance scheme that takes a lifetime approach, investing in people with disability early to improve their outcomes later in life. The NDIS supports people with disability to build skills and capability so they can participate in the community and employment.

OHS – open heart surgery – surgery in which the heart is exposed and the blood made to bypass it.

PICU – Paediatric Intensive Care Unit – a special ward for children and young people who are seriously ill or recovering from major surgery.

PICU Liberation – The Society of Critical Care Medicine’s ICU Liberation initiative aims to liberate patients from the harmful effects of pain, agitation and delirium in the intensive care unit (ICU). The ICU Liberation initiative is focused on assessing, treating and preventing pain, agitation and delirium and implementing early mobility strategies that can help reduce the risk of long-term consequences from an ICU stay. Guidelines and resources are available under Bundles including:

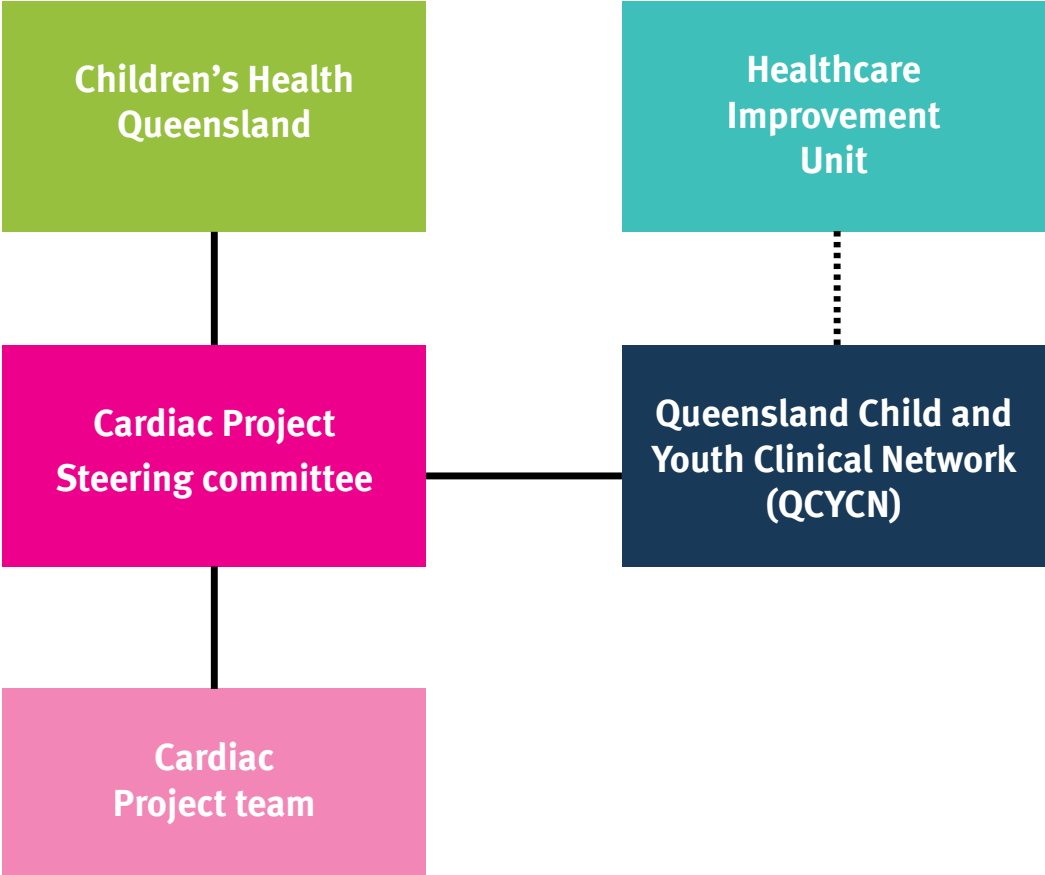
- A – Assess, prevent and manage pain
- B – Both spontaneous awakening and spontaneous breathing trials
- C – Choice of analgesia and sedation
- D – Delirium: assess, prevent and manage
- E – Early mobility and exercise
- F – Family engagement and empowerment.

QCYCN – Queensland Child and Youth Clinical Network – an independent, Queensland Health body that works through collaboration and partnerships to drive service improvements in the area of children and young people’s health, to achieve better health outcomes for children and young people across Queensland. The QCYC is funded by the Healthcare Improvement Unit, hosted by Children’s Health Queensland.

QPCS – Queensland Paediatric Cardiac Service – provides care and treatment for children with heart disease across Queensland.

SSA – Site Specific Assessment – required by each participating site to determine the level of support and suitability of a research study to be conducted and completed at a site, whether that study is multi-centre or single-site.

*Appendix 2: 'At the Heart of the Matter': governance structure*



## Cardiac Project questionnaire

The Queensland Child & Youth Clinical Network and the Queensland Paediatric Cardiac Service are undertaking a joint project to establish a statewide model of care to meet the developmental support needs of children with congenital heart disease (CHD) who have surgery before 12 months of age.

We are interested to investigate how well the developmental and support needs of these children are understood within our stakeholder groups, including GPs. This will help us to plan what information and resources are required to support this population group.

We would appreciate it if you could take a moment to complete the following brief survey. It should take no more than 2 minutes:

Name (optional): \_\_\_\_\_ Suburb of practice: \_\_\_\_\_

1. How confident are you in your knowledge of the risk of CHD and early open heart surgery on a child's development and how this may impact development and participation in age appropriate daily activities from birth through to adulthood. Please circle.

Very confident \_\_\_\_\_ Somewhat confident \_\_\_\_\_ Neutral \_\_\_\_\_ Not confident

2. What do you use in your practice to screen development and participation in age appropriate activities with this population group?
- a. Nothing
  - b. Informal questions/observations
  - c. Formal screening tools eg. PEDS-Parents Evaluation of Developmental Status, ASQ-Ages & Stages Questionnaire (please list)

\_\_\_\_\_

- d. Other (please list)

\_\_\_\_\_

3. How confident are you in your knowledge of what services are available to support development and participation in age appropriate activities, and how to refer to these services.

Very confident \_\_\_\_\_ Somewhat confident \_\_\_\_\_ Neutral \_\_\_\_\_ Not confident

4. What, if anything, would assist you to support the developmental surveillance of children with CHD? For example access to screening tools, referral pathway so for local services, access to information about CHD & development. Please describe.

\_\_\_\_\_

\_\_\_\_\_



Return to [dana.newcomb@health.qld.gov.au](mailto:dana.newcomb@health.qld.gov.au) or [karen.eagleson@health.qld.gov.au](mailto:karen.eagleson@health.qld.gov.au)

## Appendix 4: Parent survey

### Cardiac Project Parent Survey 2016

#### Your child's development

1. Can you tell us what it means to you when a health professional talks about your child's "development"? Can you give examples?
2. How do you think your child's cardiac condition has affected their development, if at all?
3. How do you think your child's cardiac condition might affect their development as they get older, if at all?

#### Some general information about your child

4. In what year was your child born?
5. What is your child's gender?
  - a. Male
  - b. Female
  - c. I'd prefer not to answer this question.
6. Other (please specify).
7. What is your postcode?
8. What languages are spoken in your child's home? (specify more than one if appropriate)
  - a. English
  - b. Other (please specify).
9. Does your child identify as being of Aboriginal and/or Torres Strait Islander origin?
  - a. Yes, Aboriginal
  - b. Yes, Torres Strait Islander
  - c. Yes, Aboriginal and Torres Strait Islander
  - d. Yes, Other
  - e. No
  - f. I'd prefer not to answer this question.
10. Does your child attend formal education? (you can select more than one option).
  - a. No
  - b. Yes, Child Care Centre/Family Day care
  - c. Yes, Kindergarten/Preschool
  - d. Yes, Special Kindergarten/Preschool
  - e. Yes, Primary School
  - f. Yes, Special Primary School
  - g. Yes, High School
  - h. Yes, Special High School
  - i. Yes, TAFE or other Vocational Education
  - j. I'd prefer not to answer this question
  - k. Other (please specify).

## Your child's health

11. What is your child's primary cardiac diagnosis (eg. Transposition of the great arteries (TGA), Hypoplastic Left Heart Syndrome (HLHS), Tetralogy of Fallot (TOF)?
12. Does your child have additional non-cardiac diagnoses (including genetic conditions) or health issues? Please list.
13. How many cardiac surgeries has your child had?
  - a. 1
  - b. 2
  - c. 3+.
14. How old was your child at the time of their first cardiac surgery?
15. How old was your child at the time of their most recent cardiac surgery?
16. How many non-cardiac related surgeries has your child had?
  - a. 1
  - b. 2
  - c. 3+.
17. What is the longest hospital admission your child has ever had? Make your best guess if you can't remember the exact details.

## Your child's development journey so far

For the next questions, please consider your child's **development** as the skills they learn to do daily activities.

- For an infant this may be feeding, sleeping, settling and interacting.
  - For a toddler this may be talking, playing, eating, toileting, dressing.
  - For a child this may be playing, making friends, thinking and learning.
  - For a teenager this may be making friendships, concentrating, learning, starting work.
18. Do you remember having concerns about your child's development:
    - a. During their inpatient stay (before or after surgery).
      - i. Yes (go to ii)/No/I can't remember.
      - ii. What were your concerns?
      - iii. Did you receive services/supports to address these concerns?
        - 1.Yes.
          - a. General Paediatrician
          - b. Developmental Paediatrician
          - c. Music Therapist
          - d. Occupational Therapist
          - e. Physiotherapist
          - f. Psychologist
          - g. Social Worker
          - h. Speech Pathologist
          - i. Other
        - i. What was your experience accessing these services? Please give details regarding finding suitable services, the referral process, waiting times, availability of required therapists etc.

2. No.
  3. I can't remember.
- b.** At time of discharge from hospital.
- i. Yes (go to ii)/No/I can't remember/My child is still an inpatient.
  - ii. What were your concerns?
  - iii. Did you receive services/supports to address these concerns?
    1. Yes.
      - a. General Paediatrician
      - b. Developmental Paediatrician
      - c. Music Therapist
      - d. Occupational Therapist
      - e. Physiotherapist
      - f. Psychologist
      - g. Social Worker
      - h. Speech Pathologist
      - i. Other.
        - i. What was your experience accessing these services? Please give details regarding finding suitable services, the referral process, waiting times, availability of required therapists etc.
    2. No.
    3. I can't remember.
- c.** In the first year after discharge from hospital?
- i. Yes (go to ii)/No/I can't remember/My child has only just been discharged from hospital.
  - ii. What were your concerns?
  - iii. Did you receive services/supports to address these concerns?
    1. Yes.
      - a. General Paediatrician
      - b. Developmental Paediatrician
      - c. Music Therapist
      - d. Occupational Therapist
      - e. Physiotherapist
      - f. Psychologist
      - g. Social Worker
      - h. Speech Pathologist
      - i. Other.
        1. What was your experience accessing these services? Please give details regarding finding suitable services, the referral process, waiting times, availability of required therapists etc.
    2. No.
    3. I can't remember.
- d.** During transition to primary school or during primary school years?
- i. Yes (go to ii)/No/I can't remember/My child hasn't started school yet.
  - ii. What were your concerns?
  - iii. Did you receive services/supports to address these concerns?
    1. Yes.
      - a. General Paediatrician
      - b. Developmental Paediatrician
      - c. Music Therapist
      - d. Occupational Therapist
      - e. Physiotherapist



- f. Psychologist
  - g. Social Worker
  - h. Speech Pathologist
  - i. Other.
    - i. What was your experience accessing these services? Please give details regarding finding suitable services, the referral process, waiting times, availability of required therapists etc.
  - 2. No.
  - 3. I can't remember.
- e.** During transition to high school or during high school years?
- i. Yes (ii)/No/I can't remember/My child hasn't started high school yet.
  - ii. What were your concerns?
  - iii. Did you receive services/supports to address these concerns?
    - 1. Yes.
      - a. General Paediatrician.
      - b. Developmental Paediatrician
      - c. Music Therapist
      - d. Occupational Therapist
      - e. Physiotherapist
      - f. Psychologist
      - g. Social Worker
      - h. Speech Pathologist
      - i. Other.
        - i. What was your experience accessing these services? Please give details regarding finding suitable services, the referral process, waiting times, availability of required therapists etc.
    - 2. No.
    - 3. I can't remember.
- f.** Currently?
- i. Yes (go to ii)/No/I'm not sure.
  - ii. What are your concerns?
  - iii. Do you receive services/supports to address these concerns?
    - 1. Yes.
      - a. General Paediatrician
      - b. Developmental Paediatrician
      - c. Music Therapist
      - d. Occupational Therapist
      - e. Physiotherapist
      - f. Psychologist
      - g. Social Worker
      - h. Speech Pathologist
      - i. Other.
        - i. What was your experience accessing these services? Please give details regarding finding suitable services, the referral process, waiting times, availability of required therapists etc.
    - 2. No.

There are a number of ways to support a child to develop and achieve their full potential. This might include activities through community or church supports, music or swimming lessons, library sessions, mother's groups or playgroups, parenting courses and many others.

19. Can you tell us the supports that you have accessed in your local community that have been helpful to you, your family and/or your child? (These might be formal organisations and programs or informal supports (eg. Library sessions, church groups).
20. Generally speaking, how easy was it to find and access these supports?
- easy
  - difficult
  - not sure
  - mixed (please describe).
21. Does your child currently have any issues with (select all relevant):
- sleep and/or settling
  - feeding (infants)
  - learning
  - behaviour
  - expressing themselves
  - understanding what is said
  - washing, dressing, toileting, eating
  - moving around/Playing sport
  - using their hands to write, draw, dress
  - using technology
  - keeping their mind on the job (if applicable)
  - making friends/Getting on with others.
22. What are your CURRENT best sources of support to help your child develop and participate to their full potential?
- my own knowledge and problem solving
  - my own formal supports (eg. Counselling, GP, Psychologist)
  - other families with a child with similar needs (in person or online)
  - general community groups not specifically related to my child's needs
  - my family
  - my friends
  - my child's medical team
  - my child's therapist/s
  - my child's childcare centre/school/TAFE
  - online information/resources/supports.
23. Which things would you like to HAVE MORE OF to help your child reach their full potential? (choose as many options as you like)
- my own knowledge and problem solving
  - my own formal supports (eg. Counselling, GP, Psychologist)
  - other families with a child with similar needs (in person or online)
  - general community groups not specifically related to my child's needs
  - my family
  - my friends
  - my child's medical team
  - my child's therapist/s
  - my child's childcare centre/school/TAFE
  - online information/resources/supports.
24. Looking back on your journey, what do you wish you knew (if anything) about helping your child develop and reach their full potential?

25. What services or supports do you think would have helped your child develop and reach their full potential?
26. If your child could tell you what has made the biggest difference/helped them.
27. Is there anything else you would like to tell us?
28. We may conduct interviews or workshops in the future to gather more information about families' experiences. If you would be interested in participating in these, please provide your contact details below. Please note information gathered in this survey will remain de-identified.

**Name:** \_\_\_\_\_


**Best contact: Email:** \_\_\_\_\_ **Phone:** \_\_\_\_\_

## Appendix 5: Personal Health Record supports

Postcard and sticker for the Personal Health Record prompting key touchpoints and secondary level screening (ASQ-3) as “business as usual.”

Children’s Health Queensland Hospital and Health Service

### Developmental screening for children with congenital heart disease who have undergone open heart surgery



**Open heart surgery before 12mths**

**6mth**  
Ages and Stages + health check

**12mth**  
Ages and Stages + health check

**18mth**  
Ages and Stages + health check

**2.5-3.5yrs**  
Ages and Stages + health check

**4-5yrs**  
Start primary school  
Ages and Stages + health check

**11-12yrs**  
Start high school  
GP

**15yrs+**  
Finish high school and transition to adult services  
GP

**Children undergoing open heart surgery for congenital heart disease before 12 months of age are at an increased risk of delays in reaching their developmental milestones.**


While your baby/child may not have delays right now, these can appear over time. It is important to have your child’s development regularly checked to pick up on subtle changes early. We know that early support for infants and children leads to the best outcomes.

It is recommended that your child has extra developmental screening when you attend your local primary health care provider (e.g. Child health, GP, Indigenous health services).


For children aged birth to five years, the *Ages and Stages Questionnaire (ASQ-3)* is the recommended screening tool to be used as part of the already scheduled health checks in your child’s Personal Health Record (Red Book).

For children aged six years and older, please speak with your GP or specialists about options for checking your child’s development.

If your child receives support for their development (e.g. speech, occupational or physiotherapy) and is then discharged, it is important to continue attending your local primary health care provider for developmental screening.



Updated: February 2018.




Every infant who has surgery before 12 months of age will have a sticker (pictured left) and postcard (pictured above) placed in their Personal Health Record (Red Book) to support caregivers to access developmental surveillance at key timepoints and support Child Health Services to implement secondary level screening (ASQ-3).

## Appendix 6: GP HealthPathways

The CHQ HealthPathways team are developing paediatric pathways that will be available for localisation to each HHS, to support GPs to manage infants/children with CHD as per the care pathway.

### HealthPathways

HealthPathways is a website intended primarily for GPs to access current evidence-based clinical pathways. The pathways written by GPs or GPs include point-of-care guidance for the assessment and management of medical conditions, as well as referral information.

The Clinical Excellence Division (CED) has partnered with Children's Health Queensland (CHQ) Hospital and Health Service (HHS) to jointly-fund the development of clinical content for paediatric pathways. These pathways will include Clinical Prioritisation Criteria (CPC) guidelines where available.

Regions around the state will then have the option of adopting these paediatric pathways and going through a process of 'localisation'. This will allow regions to adopt the pathways to include their local resources, service profiles and referral pathways. GPs will then access the pathways in their own region's website, to ensure consistency of use.

### Paediatric HealthPathways to be developed by CHQ include:

- Otitis media
- Headaches in children
- Heart murmur
- Children's eye conditions
- Constipation in children
- Food hypersensitivity
- Behavioural problems in children
- Developmental problems in children
- NDIS Service Page.

## Appendix 7: CHD LIFE Database- Minimum dataset (Database governed by Queensland Paediatric Cardiac Research (QPCR))

Queensland  
Paediatric  
Cardiac Research  
*'little hearts matter'*

Lady Cilento Children's  
Hospital  
Cardiac Services  
Level 7f Clinical  
Directorate  
Stanley Street  
South Brisbane  
QLD 4101  
AUSTRALIA

**Directors**  
**Nelson Alphonso**  
Cardiac Surgery

**Ben Anderson**  
Cardiology

### QPCS CHD LIFE PROGRAM DATABASE

Queensland Paediatric Cardiac Service (QPCS) CHD LIFE (Congenital Heart Disease Longterm Improvements in Functional hEalth) Database

- DATA COLLECTION

THE FOLLOWING PARAMETERS WILL BE COLLECTED:

#### DEMOGRAPHIC DATA

Last name (only visible to Database researchers)

First name (only visible to Database researchers)

Date of birth

Gender

Race

Postcode

Parental education

Family members

#### BASELINE PATIENT DATA (AT ENROLMENT)

Gestational age

Birth anthropometrics - height, weight, head circumference

Antenatal diagnosis

Primary diagnosis

Primary procedure

- Type of operation
- Date of operation
- Pre-operative risk factors
- Cardiopulmonary bypass time
- Surgical complexity - Aristotle score
- Duration of mechanical ventilation
- Post-operative complications
- Length of stay – PICU, hospital
- Hospital length of stay

Extracorporeal Life Support – total hours

Previous operations; number, type and date

Presence and type of comorbidities, including genetic

Presence of developmental disability in first degree family member

Healthy hearing test (neonatal hearing screening) – attended and result

At discharge from first hospitalisation –

- Feeding
- O<sub>2</sub> saturations
- Developmental support services referred to
- General Practitioner

#### NEURODEVELOPMENTAL/FUNCTIONAL HEALTH DATA AT KEY TIME POINTS MAY INCLUDE -

##### All ages -

Service type for screening or assessment accessed

Anthropometrics – height, weight, head circumference

Presence and type of comorbidities

Developmental/learning supportive service type - currently accessed, referred to

Attending School/Preschool/Day Care

Parental –

- Identified concerns and strengths
- Understanding of child's development

Age appropriate standardised screening/assessment tools results for identified developmental domains. Dependent on local availability and routine care, these may include, and are not limited to –

##### 6 and 12 months –

Screening –

- General Development - *Ages and Stages Questionnaire, Third Edition (ASQ-3) inclusive of ASQ Social and Emotional*

Assessment –

- General Development - *Bayley Scale of Infant Development, Third Edition (Bayley-III)*

##### 2 years

Screening – (18 months and 2 ½ - 3 years)

- General Development - *Ages and Stages Questionnaire, Third Edition (ASQ-3) inclusive of ASQ Social and Emotional*

Assessment –

- General Development - *Bayley Scale of Infant Development, Third Ed. (Bayley-III)*
- Behaviour and Emotion - *Child Behaviour Check List (CBCL 1.5-5yrs)*
- Adaptive Behaviour - *Adaptive Behaviour Assessment Scale, Third Ed. (ABAS-3)*

##### 4-5 years –

Screening -

- General Development - *Ages and Stages Questionnaire, Third Ed. (ASQ-3) inclusive of ASQ*

*Social and Emotional (to 60 months)*

Assessment -

- Intelligence/Cognition - *Wechsler Preschool and Primary Scale of Intelligence, Third Ed. (WPPSI-III)*
- Executive Functioning - *Behaviour Related Inventory of Executive Functioning (BRIEF)*
- Behaviour and Emotion - *Child Behaviour Check List (CBCL 1.5-5yrs)*
- Adaptive Behaviour - *Adaptive Behaviour Assessment Scale, Third Ed. (ABAS-3)*
- Speech and Language - *Clinical Evaluation of Language Fundamentals (CELF-P); Sutherland Phonological Awareness Test (SPAT)*
- Health-Related Quality of Life - *Paediatric Quality of Life Inventory (Peds QL)*

**8-12 years –**

Assessment –

- Intelligence/Cognition - *Wechsler Intelligence Scale for Children – Fifth Ed. (WISC-V)*
- Academic Achievement - *Wechsler Individual Achievement Tests (WIAT-II); Woodcock Johnson Test of Achievement (WJ-IV)*
- Executive Functioning/Attention - *Behaviour Related Inventory of Executive Functioning (BRIEF); Connors, Third Ed. (Connors 3); Test of Everyday Attention for Children (TEA-Ch)*
- Memory – *Children’s Memory Scale*
- Behaviour and Emotion - *Child Behaviour Check List (CBCL)*
- Attention - Adaptive Behaviour - *Adaptive Behaviour Assessment Scale, Third Ed. (ABAS-3); Vineland 3*
- Speech and Language - *Clinical Evaluation of Language Fundamentals (CELF-4/5); Sutherland Phonological Awareness Test (SPAT)*
- Health-Related Quality of Life - *Paediatric Quality of Life Inventory (Peds QL)*

**16 years –**

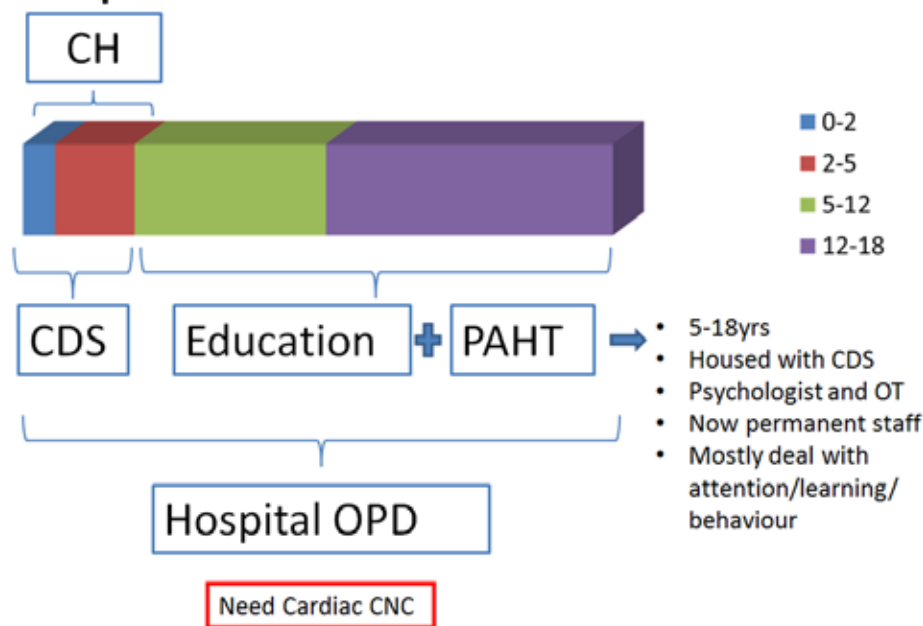
Assessment –

- Intelligence/Cognition - *Wechsler Adult Intelligence Scale (WAIS-IV)*
- Executive Functioning - *Behaviour Related Inventory of Executive Functioning (BRIEF)*
- Memory – *Children’s Memory Scale*
- Adaptive Behaviour - *Adaptive Behaviour Assessment Scale, Third Ed. (ABAS-3)*
- Behaviour and Emotion - *Youth Self Report (adolescent CBCL)*
- Health-Related Quality of Life - *Paediatric Quality of Life Inventory (Peds QL)*



## Appendix 8: Example of contextualised care pathway in Cairns and Hinterland HHS

### Proposed surveillance structure



#### Referral process:

1. All referrals to be sent to Child Youth and Families (CYF) Access Unit:  
[Referrals.Comm-CYandFHSCairns@health.qld.gov.au](mailto:Referrals.Comm-CYandFHSCairns@health.qld.gov.au)
2. Book clinic appointment for Paediatric Cardiologist.
3. Book clinic appointment for Paediatrician.
4. Notify GP.
5. Send referral to CDS – Neurodevelopmental support.
6. Send referral to Connected Care or Nurse Navigator.
7. Send referral to Community Health for Child Health follow up:
  - care coordination
  - home visit family – Ages and Stages at 4mths 6mths 12mths 18mths 2yrs 3yrs and 4yrs
  - ensure immunisation are up to date
  - involve Indigenous health worker if indigenous client
  - hearing and Vision screening at 4 years of age.
8. Discuss NDIS if eligible.
9. When no longer eligible for CDS – referral via CYF Access Unit to Paediatric Allied Health Team.
10. Maintain data base as per CHD LIFE Program.

#### Proposed surveillance structure:

- ALL patients <1 year with open heart surgery referred.
- Add to local Excel database and note if consent given for CHD LIFE Program centralised database.

- Include demographic and baseline patient data gained from referral as part of usual clinical care.
- Facilitate data sharing with CHD LIFE Program centralised database where families have given consent through:
  - advising CHD LIFE Program when developmental review has occurred (as able)
  - clear documentation of standard Cardiac developmental follow up information and any screening or assessments undertaken in ieMR
  - scanning of all developmental and functional health screening and assessments into ieMR
  - provision of developmental and functional health information to CHD LIFE Program when requested by Program or families.
- Standard Cardiac follow-up:
  - anthropometric data, Comorbidities (referral to General Paediatrician for all in group), what service referred to, school status, parental concerns re development.
- Options for follow-up:
  1. Cairns Hospital Allied Health Team:
    - option for specialised MDT follow up for feeding, O2 management, developmental surveillance etc. and transitioning from hospital to community (as deemed appropriate)
    - access to MDT feeding Clinic for those with severe and long-term feeding and nutritional issues
    - follow up with the team and family whilst an inpatient at CH during step down from LCCH
    - scar management through OT if required (written referral required)
    - referral to local regional services within the CHHHS if required.
  2. Community Child Health: Provide home visits, family care and support, update contact details, immunisations and developmental surveillance. Ages and Stages assessments may be included here to support regular engagement with the service. Indigenous health workers liaise with Child Health Service nurses.
  3. Child Development Service - Established Level 4 multidisciplinary family -centred service model. Community based, specialist child developmental assessment for children aged 0-5. Would require referral through Child Youth and Families Access Unit.
  4. PAHT: (5-18 yrs) Multidisciplinary assessment by OT and psychologist. Regular liaison with school Guidance Officers. Current caseload primarily for attention, learning and behaviour disorders. Would require referral through Child Youth and Families Access Unit for reassessment.
  5. Education (State v Catholic v Private) – assessment for educational and learning skills.
- Identified challenges:
  - coordination and local database entry. Need to identify where a regular review schedule is to be maintained
  - change with NDIS – access to private assessment for NDIS plan
  - small regional centres access to CDS via limited outreach. Families may need to travel to Cairns. Limited access for school/adolescent allied health – access through GP plan. Younger children access to NDIS ECEI
  - transition to adult care
  - base for Cape and Torres HHS – impact for base providing services and families requiring access.





**Queensland**  
Government