

# Briefing paper

for the national priority setting  
meeting in cardiac  
neurodevelopmental care

October 2025



**CHD LIFE +**

**Co-designing sustainable cardiac  
neurodevelopmental models of care**

# Briefing paper

## About the briefing paper

The CHD LIFE+ program of research aims to evaluate existing and potential models of care for CHD neurodevelopmental support to inform future practice.

CHD LIFE+ is a partnership between those listed on page 22 and led by a core management committee. It is funded by a MRFF Cardiovascular Mission Congenital Heart Disease Grant (ARGCHDG0035) 2020-2025.

A national priority setting meeting will be held as a culminating event of the CHD LIFE+ program.

This briefing paper starts by outlining the event and then explains why it is needed. It is intended to cover the status quo, acting as a springboard for the meeting to start from. The meeting is then free to be future focused.

## Briefing paper authorship

The national priority setting meeting is organised and led by the CHD LIFE+ management committee, and this briefing paper has been written and prepared by the CHD LIFE+ management committee.

- ♥ Steven McPhail
- ♥ Robert Justo
- ♥ Karen Eagleson
- ♥ Ben Auld
- ♥ Will Parsonage
- ♥ Bridget Abell
- ♥ Thomasina Donovan
- ♥ Nicole White
- ♥ Pakhi Sharma
- ♥ Alison Farrington
- ♥ Jenna English
- ♥ Jessica Keating

# CHD LIFE+ partners and project teams



Australian Centre for Health Services Innovation  
Queensland University of Technology

Professor Steven McPhail  
Professor William Parsonage  
Professor Adrian Barnett  
A/Professor Sanjeewa Kularatna  
A/Professor Nicole White  
Dr Bridget Abell  
Dr Pakhi Sharma  
Dr Thomasina Donovan  
Alison Farrington  
Jenna English



Murdoch Children's Research Institute, VIC

Professor Michael Cheung  
Dr Julia Charlton  
Professor Amanda Wood  
Dr Lorna Ginnell



Child and Adolescent Health Service, WA

Dr Stephen Shipton  
Dr Cameron Seaman  
Dr Mary Tallon



Women's and Children's Health Network, SA

Dr Andrew Kelly  
Dr Karina Laohachai  
Dr Rishi Agrawal  
Annette Sargent



Queensland Children's Hospital

A/Professor Robert Justo  
Dr Karen Eagleson  
Dr Ben Auld  
Dr Nelson Alphonso  
Dr Kerri-Lyn Webb  
Dr Prem Venugopal  
Sonia Riley  
CHD LIFE project team



HeartKids Ltd  
Holly Williams  
(until 2023)  
Jessica Keating



Mater Research Ltd, QLD  
A/Professor Samudragupta Bora



The Sydney Children's Hospitals Network, NSW

Professor Nadine Kasparian  
A/Professor Gary Sholler  
Professor Nadia Badawi  
Dianne Swinsburg  
Dr Natalie Fairbairn



Top End Health Service  
Dr Bo Remenyi  
Dr Simone Martin  
Cecelia Antunes  
Gladys Ngugi

# Contents

<b>Briefing paper .....</b>	<b>2</b>
About the briefing paper .....	2
Briefing paper authorship.....	2
<b>CHD LIFE+ partners and project teams .....</b>	<b>3</b>
<b>Neurodevelopmental care for CHD children and their families in Australia .....</b>	<b>5</b>
<b>National priority setting meeting cardiac neurodevelopmental care.....</b>	<b>6</b>
Meeting goals .....	6
<b>CHD LIFE+ findings .....</b>	<b>7</b>
Health services & delivery of neurodevelopmental follow-up care .....	7
Follow-up care pathways .....	8
Factors influencing health service delivery .....	11
Opportunities to improve delivery and sustainment of services .....	13
National collaboration .....	14
Community of practice.....	14
Jurisdictional projects .....	14



# CHD LIFE+

Congenital Heart Disease - Long-term Improvement in Functional hEalth+  
Family-centred care models supporting long-term neurodevelopment

A MRFF Congenital Heart Disease Grant (ARGCHDG000035)

# Neurodevelopmental care for CHD children and their families in Australia

Congenital Heart Disease (CHD) is one of the most common conditions children are born with, affecting about one in every hundred babies. As children with CHD grow, many face challenges with learning, movement, speech, and social skills. Some also have trouble focusing or managing tasks and emotions. Even when these difficulties are mild, they can still affect how well a child does at school, makes friends, stays healthy, and feels good emotionally.

That's why it's important to check early for any signs of developmental delays. Doctors and specialists should regularly monitor children who are at higher risk, using check-ups and special tests to track their development. If any concerns are found, families should be supported with timely access to care and treatment.

Although experts agree this kind of follow-up care is important, it doesn't always happen as it should. Common challenges include not having enough trained staff, families needing to travel long distances, limited awareness among healthcare providers, and financial issues like insurance and service costs.

The American Heart Association has published helpful guidelines for follow-up care for children with CHD. However, these guidelines can be hard to apply in other countries because healthcare systems vary.

To help improve care for children with CHD in Australia, we explored what supports good care and what gets in the way. We looked at how follow-up care is

provided internationally, across Australia, and in local communities. We also studied the Queensland model of care to understand its impact on families, healthcare providers, and costs.

Using what we've learned, we plan to meet with key people from across Australia to discuss future priorities and explore which ones can be addressed at a national level.

The next page provides a summary of the meeting. The rest of this document explains in more detail what we've learned from our research so far.

To find out more about other pathways around the world and the common problems read our [research article](#):

*Abell, B., et al. Implementing neurodevelopmental follow-up care for children with congenital heart disease: A scoping review with evidence mapping. Developmental Medicine Child Neurology (2023).*

# National priority setting meeting cardiac neurodevelopmental care

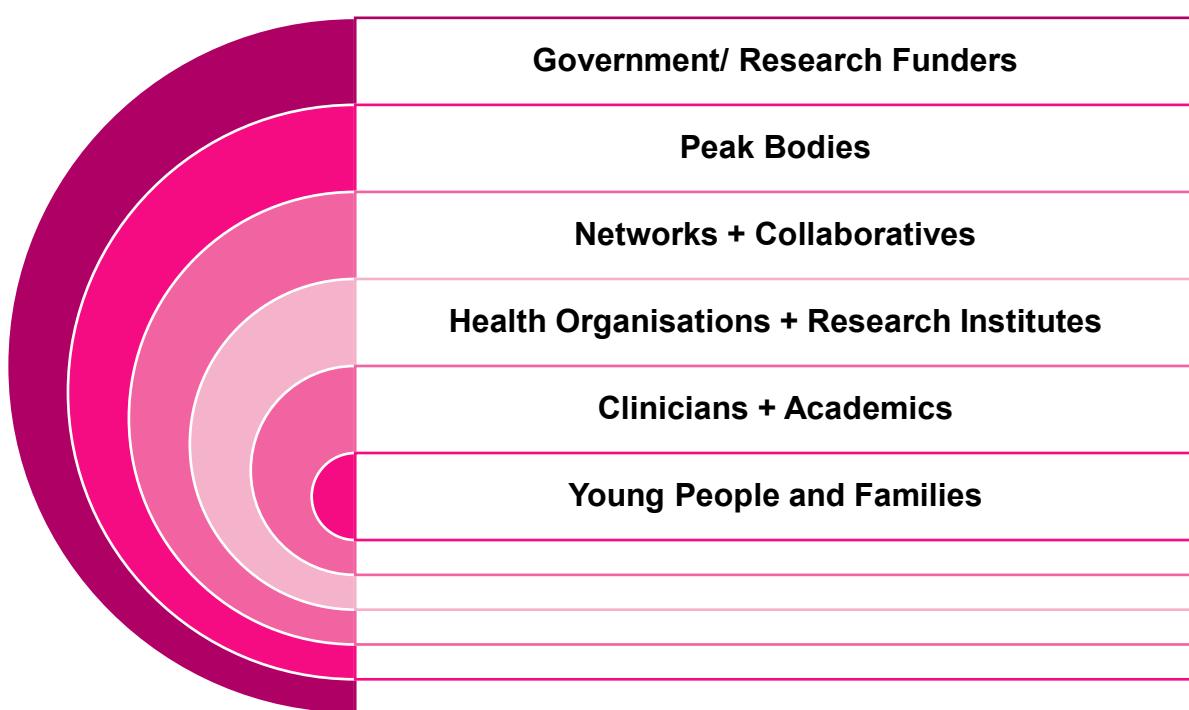
The national meeting will bring together around 60 key people from across Australia that have an interest or role in improving care outcomes for children. These participants will represent a range of groups, as shown in the figure below.

The meeting will begin with presentations from the CHD LIFE+ team, followed by interactive activities and group discussions designed to gather bold ideas and practical solutions.

Insights shared during the meeting will help shape a final report that outlines the most important next steps for care and research across Australia. A creative visual summary will also be developed to capture the key themes and outcomes from the day.

## Meeting goals

- ♥ Extend and sustain collaborative networks beyond the life of the CHD LIFE+ study.
- ♥ Provide a platform for lived experience and expert input into co-designing context relevant priorities for improving neurodevelopmental care for children with CHD in Australia.



# CHD LIFE+ findings

## Health services & delivery of neurodevelopmental follow-up care

Children who receive open heart surgery before the age of 1 are at greater risk of neurodevelopmental delays. One option is to provide the neurodevelopment follow-up care they need at the hospital which conducted the surgery. However, these follow-up teams are usually at specialised tertiary hospital centres which can present challenges for accessing follow-up care. For example:

### In Queensland

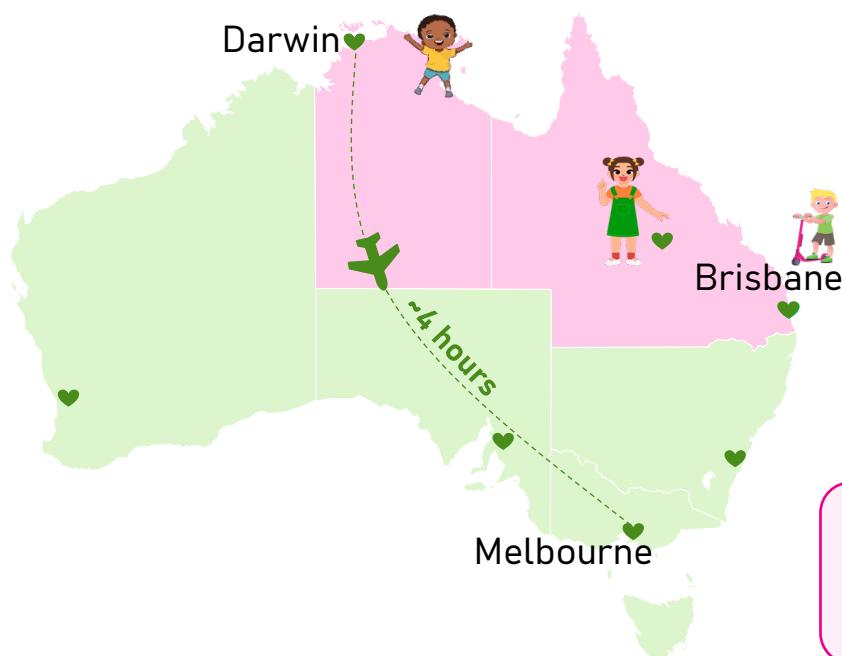
• 70% of families impacted by surgery or intervention for CHD live in the urbanised southeast of the state, near Brisbane. These families, typically live 34kms from the surgical centre. The typical drive time for this destination was 36mins. However, 25% of these

metro/regional families still live further than 60kms away, a drive time longer than 50mins typically.

• The remaining 30% of Queenslanders typically live 947kms from the surgical centre. The typical drive time would be 11 hours. For 25% of rural families the time was longer than 15 hours because they lived more than 1,350kms away from the hospital, meaning that air travel would likely be needed.

### In Northern Territory

• Families have to fly interstate, mostly to Melbourne, to receive cardiac surgery because it can't be done locally.  
• This presents challenges for follow-up care for both families navigating different systems and providers keeping track of families returning.



This is why we need to **deliver care differently**, not just at the surgical centre, but using a **range of solutions** that address local needs.

To find out more [read](#): Auld et al., *International Journal for Equity in Health*, 2023

## Follow-up care pathways

We spoke to service providers around Australia and often found that there wasn't a specific pathway for children with CHD to receive follow-up neurodevelopmental care.

*"We don't have a dedicated or separate cardiac model for developmental follow-up. So, we access general services here for those purposes." [Paediatric Cardiologist].*

*"Not at this stage, we don't have a specific pathway, or any specific clinic set up for children with CHD. So, there's no really structured pathway." [Allied Health Staff].*

Instead, we found that most children with CHD receive neurodevelopmental follow-up by **accessing a combination of existing services** across primary, secondary and tertiary care.

As a result, each child follows a **unique pathway** based on their circumstances. The figure on the following page summarises all the services Australian families currently access to receive neurodevelopmental follow-up care including ongoing surveillance and screening, once-off assessment and diagnosis, and services that provide access to supports, therapies and interventions.

See how children like Evie, David and Sally move through the health system to receive care and the pathways they form.

1. Evie met criteria to be part of a neonatal follow-up program while she was in hospital. She received all neurodevelopment follow-up care appointments by returning to this program at the hospital.  

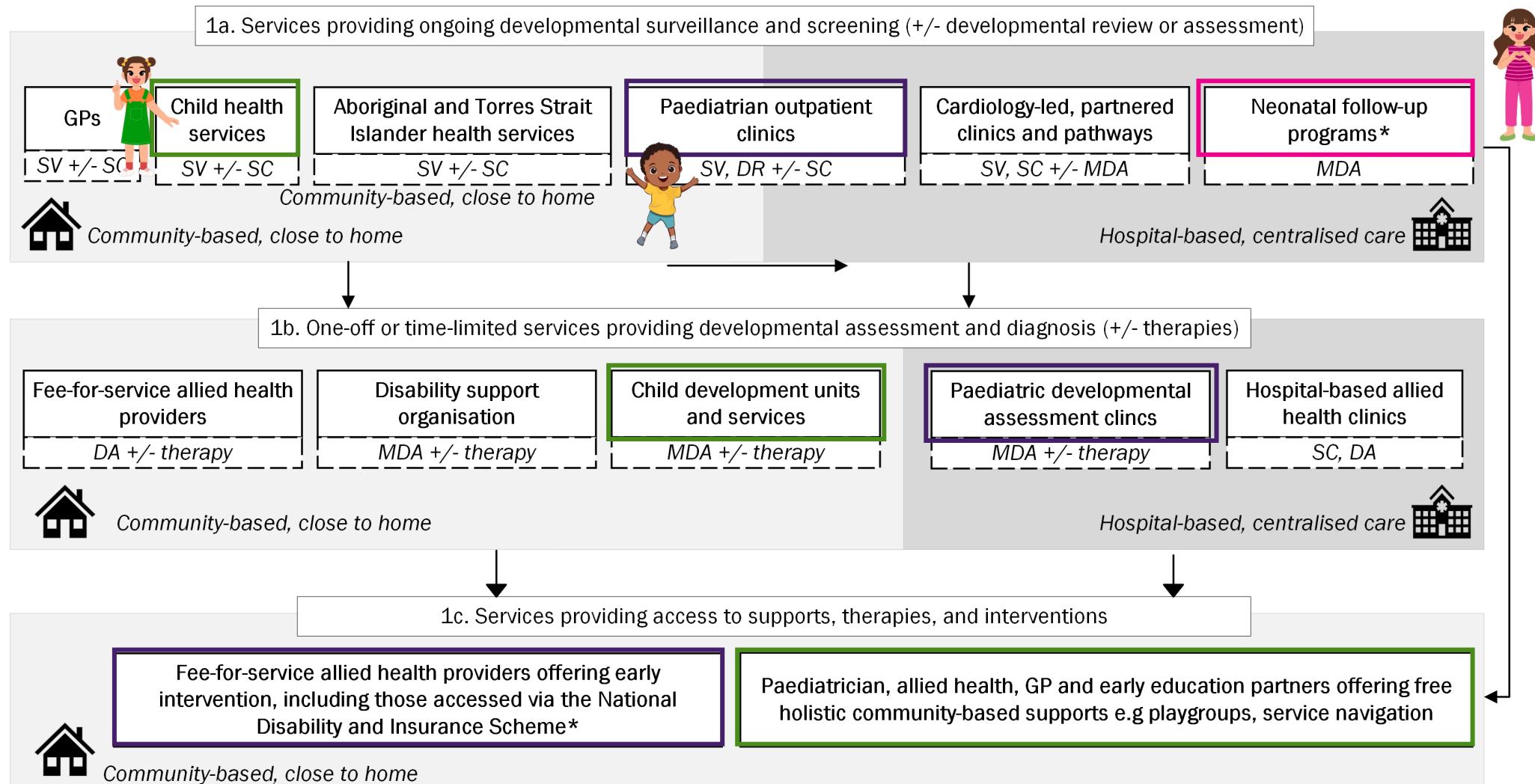

2. Sally gets her neurodevelopmental screening at her local child health service. When a concern was identified, she was referred to the child development unit/service for formal assessment. This did not confirm a diagnostic delay but Sally was referred to free community developmental supports such as play-groups and day-care assistance and continued screening at child health.  


3. David went to his paediatrician for a check-up which included developmental review. When a concern was identified, he was referred to a hospital-based developmental assessment clinic. A delay was found so his family takes David to services that provide support/ therapy/ interventions at a cost. They are waiting to see if they qualify for the NDIS to reduce costs.  


To find out more about Australian follow-up care pathways & providers read our [research article](#):

*Abell, B., et al. Neurodevelopmental follow-up care pathways and processes for children with congenital heart disease in Australia. Pediatric Research (2024).*

**Figure 1.** Graphical overview of the services and care pathways that support neurodevelopmental follow-up for children with congenital heart disease in Australia, annotated with examples. Adapted from Abell et al., *Pediatric Research*, 2024 with permission.



GP: general practitioner, SV: service offers surveillance, SC: service offers screening with tool, DR: service offers developmental review without standardised assessment tools, MDA: service offers multidisciplinary developmental assessment using recognised tools, DA: service offers developmental assessment using recognised tool(s), +/-: this is not offered by all services in all regions, \*: not all children with CHD are eligible for these services, →: referral pathways across services and community/hospital-based care

## Costs

We know a fair bit about the costs of caring for children with neurodevelopmental disorders, including attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). However, we still don't know much about the costs of caring for children with CHD who also have neurodevelopmental concerns or delays.

We reviewed studies on costs of caring for children with neurodevelopmental disorders and found that:

- ♥ Helping children with neurodevelopmental delays or disabilities was worth the money and improved their quality of life.
- ♥ It's still hard to model the full picture of neurodevelopmental care, especially when health problems are connected and treatments involve many different professionals.
- ♥ We know these conditions affect more than physical health, they also impact caregiver well-being. Yet, none of the studies we reviewed considered the costs related to these impacts. Future economic evaluations should recognise this impact and include caregiver-related outcomes.

To learn more about the costs of caring for children with CHD who also have neurodevelopmental concerns or delays, we looked into the **out-of-pocket costs families face**. Out-of-pocket costs are expenses families experience that are not covered by insurance or public healthcare programs. This can include costs for doctor visits, treatments, medicine and travel. It can also involve indirect costs, including parents taking time off from their jobs to attend appointments.

Out-of-pocket costs can become a big financial burden for families of children with CHD who need long-term neurodevelopmental follow-up. This can limit the care these children receive, which may impact their development and well-being.

We found that even with the support of Australia's universal healthcare system, families still face large out-of-pocket costs. Moving care services closer to home may help reduce direct travel costs, but it won't fully solve the problem of lost work time for caregivers. These findings could help policymakers create better strategies to help affected families.

To find out more about health economic methods used to assess the costs of caring for children with ND disorders read our [research article](#):

*Kularatna S, et al. **The Cost of Neurodevelopmental Disability: Scoping Review of Economic Evaluation Methods. Clinicoecon Outcomes Research** (2022).*

## Factors influencing health service delivery

When speaking to service providers around Australia, they talked about what makes it hard or easy to give good follow-up care to kids with CHD. We grouped their responses into six categories.

Each category had both **barriers** (things that made care harder) and **strengths** (things that helped care happen). The figure on the next shows what we found.



Some problems were connected to each other. For example, if there aren't enough workers, it can also be harder to get services, and there might not be enough money to fix it. These three things (access to care, funding, and staff shortages) were the most common concerns shared by everyone.

### Embedding follow-up into existing services can improve access, but it's not without its own challenges.

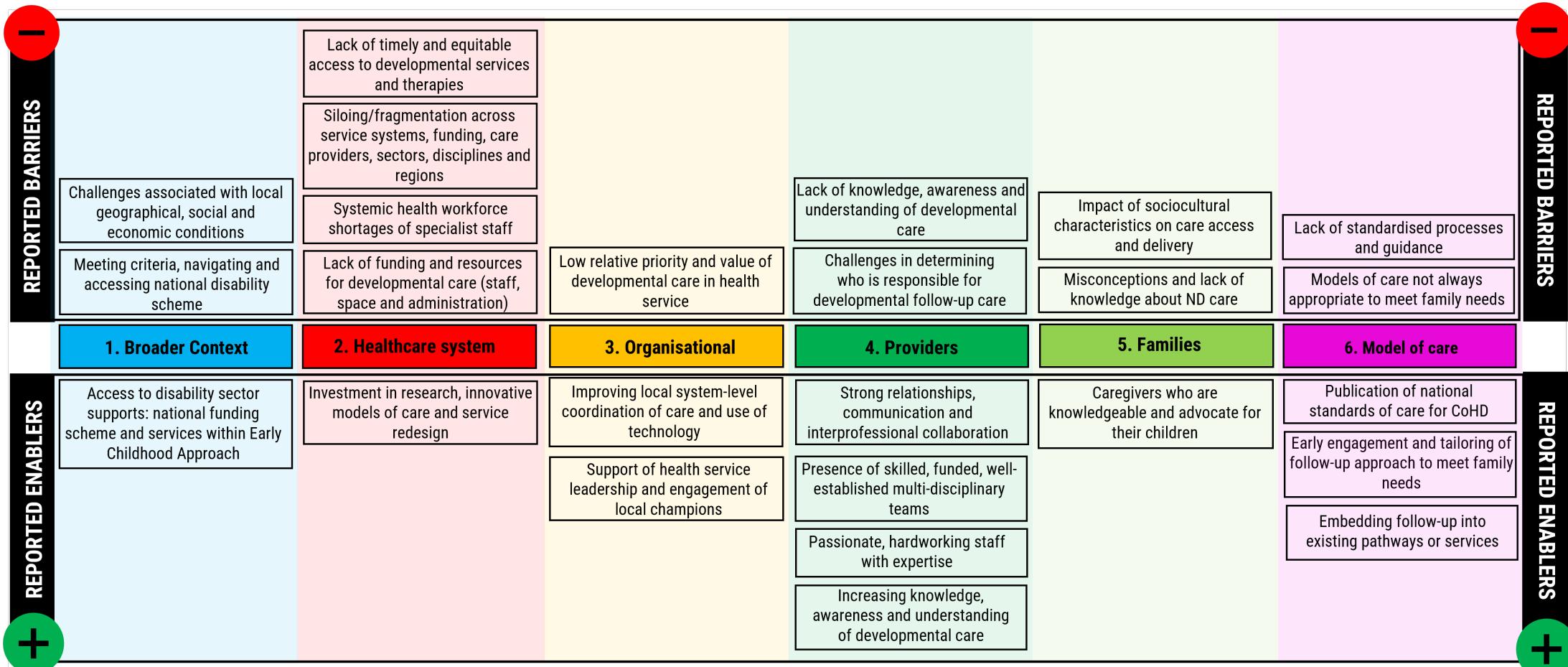
It was considered appropriate to use existing services to overcome resourcing and geographical challenges. However, systematic coordination of care pathways to ensure eligible children are not lost to follow-up was generally lacking.

Currently neurodevelopmental “*follow-up care for children with CHD in Australia is largely unfunded, fragmented, inconsistent, uncoordinated*” (Badawi et al., *Pediatric Research*, 2025). Of particular note was the finding that coordination of follow up was often left to the family to manage and that infants received follow up only if problems were detected.

The above quote comes from a commentary paper on our research article. Read it [here](#).

The most common problems were in the healthcare system like not enough services, not enough money, and not enough staff. But the biggest strengths came from the people working in healthcare, like doctors, nurses and allied health providers who worked well together and had strong skills.

**Figure 2.** Perceived barriers (top) and enablers (bottom) to implementing and delivering neurodevelopmental care for children with CHD in Australia, grouped by colour-coded higher-order theme. Taken from *Abell et al., Frontiers in Pediatrics*, 2024 with permission.



## Opportunities to improve delivery and sustainment of services

Ideas were shared on how to improve follow-up care for kids with CHD in Australia. Some ideas helped fix problems, and others made good use of things that were already working well.

The picture below shows how these ideas were sorted into six big groups. Each group connects to different parts of the health system. For example, building partnerships helped solve problems in the healthcare system and also made use of enablers at the provider level.

To find out more about the current Australian context for delivery neurodevelopmental follow-up care read our [research article](#):

*Abell B, et. al., (2024), “It’s more than just a conversation about the heart”: exploring barriers, enablers, and opportunities for improving the delivery and uptake of cardiac neurodevelopmental follow-up care.*

*Frontiers in Pediatrics*

**Figure 3.** Suggested strategies for improving neurodevelopmental follow-up of children with CHD in Australia. Numbers represent higher order barrier or enabler theme the category maps to. Taken from *Abell et al., Frontiers in Pediatrics, 2024* with permission.

<b>Build partnerships to break down silos</b> Build and maintain partnerships between health, education, disability and research sectors for cross sector navigation and advocacy; foster partnerships between regional and metro teams of practitioners for capacity building; partner better with those delivering care in the community (GPs, child health nurses, allied health and indigenous health) via case management, telehealth and care planning; develop a state-based or national collaborative	<b>Generate evidence to advocate for need and value</b> Generate evidence to support long-term value and payoff of early investment in developmental care (including quality of life and cost savings); perform research investigating implementation and outcomes of different models of developmental care; develop and implement national guideline and benchmarks for developmental care; create or leverage national/international collaborations with other services for data and advocacy
<b>Increase funding and resourcing</b> Increase funding for research in the field; invest funds in advocacy and education within the health sector; increase funding for local community-based developmental services; consider system-level health funding opportunities (e.g., Medicare items/eligibility, NDIS)	<b>Grow capacity of specialist developmental workforce</b> Provide education to primary care and community services about how to perform opportunistic screening/developmental assessment and refer children to specialist services; develop simple screening tools; provide accessible, low-cost training for pediatricians in developmental assessment; provide incentives, leadership and specialist training opportunities to attract pediatricians, allied health staff and psychologists to the field
<b>Adapt the care provided to meet family needs</b> Expand developmental services to older children and key transition points; develop culturally appropriate resources; provide mental health and peer support to families; provide education and coaching to families including service navigation and advocacy; implement cardiac developmental care navigators or resources to help families access services and bridge care; integrate telehealth into hybrid models of developmental care; co-design with families; consider a developmental one-stop-shop of co-located disciplines and services to provide holistic care; consider a hub and spoke model of developmental services with central care coordination	<b>Better integrate data and leverage existing systems</b> Increase data integration and decrease barriers to data sharing across systems within and beyond health; better integrate workforce data across agencies and systems; consider data linkage of developmental outcomes with existing cardiac outcomes databases; create a national developmental follow-up database or pathway; create opportunities for family input into health records; embed developmental follow-up into cardiology workflows; integrate follow-up with existing hospital-based neonatal programs

## National collaboration

### Community of practice

Established June 2024, meets monthly:

- ♥ Ongoing dialogue, collaboration, and sharing of ideas between jurisdictional project teams
- ♥ Open communication between the academic project team and national partners
- ♥ Ongoing capacity building of clinicians and services
- ♥ National partnerships for sustainability of ongoing work in this space
- ♥ The generation of collective national project outputs and learnings to inform future priorities



### Jurisdictional projects

The CHD LIFE+ partners from six children's heart centres across Australia wanted to design better ways to support kids with CHD as they grow. Each centre did its own project to figure out what kind of care would work best in their local area. Below is a quick summary of their projects and what we've found so far from the early results.

Future work is needed to help fill gaps in our findings, including perspectives from Tasmania and the Australian Capital Territory.

### Why?

- ♥ Actioned two key context-specific opportunities to improve CHD follow-up care at both local and national level
- ♥ How we can work together to break down silos and generate evidence for change
- ♥ Address barriers and enablers across multiple levels

**Figure 4.** Summary of research methods across the six jurisdictional projects.

Victoria	Western Australia	New South Wales	Northern Territory	South Australia	Queensland
 <p><b>murdoch children's research institute</b></p> <p><b>Database audit</b> of access to allied health or ND clinics. </p> <p><b>Survey</b> providers and parents of children with complex forms of CHD. </p> <p><b>Interview</b> providers and those with lived experience, parents, carers &amp; kin to identify unmet ND needs. </p>	 <p><b>Child and Adolescent Health Service</b></p> <p><b>5-year retrospective database review</b> to understand ND service access. </p> <p><b>Survey</b> parents to understand availability and accessibility of ND services. </p> <p><b>Interviews/ focus groups</b> with key stakeholders to better understand experiences of providing the ND pathway. </p>	 <p><b>2-year retrospective database review</b> of ND service use, referrals for therapies, and NDIS access. </p> <p><b>Comprehensive audit</b> of services &amp; interrogation of cardiac service database. </p> <p><b>Survey</b> clinicians to explore ND practices, confidence and barriers to engaging families in conversations about ND. </p>	 <p><b>TOP END HEALTH SERVICE</b></p> <p><b>10-year retrospective database review</b> of ND screening rates and outcomes. </p> <p><b>Geographic, ethnocultural and linguistic mapping</b> of at-risk populations. </p> <p><b>Develop resources</b> in collaboration with HeartKids to improve communication with families. </p>	 <p><b>Women's and Children's Health Network</b></p> <p><b>Retrospective database review</b> to understand ND service access and outcomes. </p> <p><b>Survey</b> families of children with complex forms of CHD. </p> <p><b>Quality assurance recall</b> of developmental screening for those who have not accessed ND services. </p>	 <p><b>Environmental scan/ audit of existing resources</b> and international cardiac ND program websites. </p> <p><b>Prioritise</b> resources for inclusion in a repository. </p> <p><b>Develop and collate</b> a suite of prioritised resources in consultation with consumers and healthcare providers. </p>

## Preliminary national findings

- Heart Around 30-40% of young children with CHD in Australia are being regularly followed up in neonatal programs, developmental clinics or community-based primary care services depending on the jurisdiction
- Heart A large proportion of children have visited allied health providers or paediatricians at least once in early childhood
- Heart Unmet needs remain: many children need recall for missed follow-up, are lost to follow-up, or may not have been offered developmental follow-up at all

## Call to action from jurisdictional projects

### Coordinated service delivery

- Establish clear pathways
- Co-design pathways and services
- Triage care needs
- Consider navigators

### Quality data capture

- Set-up registries
- Enable use for research

### Education and awareness

- Child health book inserts
- Information packages
- Narrative scripts

### Supports

- Peer support groups for families
- Mental health support
- Peer groups for providers

Costs of service

Public waitlists

Travel times

Lack of childcare

Regional service availability

Lack of clinical pathways

Coordination gaps/silos

Lack of service awareness

Lack of education about ND

Parental burden

## Queensland CHD LIFE+ Project Summary

### What was done in the project?

For many years, the Queensland team have been working to make sure children with heart problems who have heart surgery as babies get the right help to develop well. Queensland is a huge state, and many families have to travel long distances for care. The Queensland team have created a special plan called a care pathway which helps parents and health care providers across the state know what to do for children with heart disease. The recent review of this care pathway found ways to make it better for families and health care providers. The team have now started a new project to build a website or online place where families and health care providers can easily find information about heart disease and development, and the care pathway.

### What were the key findings?

The team knows it can be hard for families and health care providers to easily find good information online about heart disease and how it affects children's development. The team are checking lots of websites from Australia and other countries and many don't have enough details or are hard to work through and understand. The team are working with health care providers and families (in a process called co-design) and talking with hospital bosses and HeartKids to plan and develop useful resources and the website.

### What are the next steps?

The next steps are to finish building the online resource hub with help from families and health workers, and to make sure it's easy to use. They want to include more people from regional areas and from different health services in Queensland, like GPs and Indigenous Health Services, so the project reaches everyone who needs it. They'll keep working with families and other experts to make the resources even better.

They're also looking at new projects to improve care, working with different groups to make sure everyone's efforts fit together and help as many kids and families as possible. The group wants to keep learning from others around Australia and share what works well.

### Team

- ♥ Mrs Sonia Riley
- ♥ Dr Karen Eagleson
- ♥ Dr Rob Justo
- ♥ Dr Ben Auld
- ♥ Dr Bronagh McAlinden
- ♥ Katie Walker-Smith
- ♥ Dr Prem Venugopal
- ♥ Jess Keating

### Further information

- ♥ Read [here](#) about the recent review of Queensland's care pathway which helps parents and health care providers know what to do for children with heart disease.

## New South Wales CHD LIFE+ Project Summary

### What was done in the project?

The study team at The Sydney Children's Hospitals Network in NSW wanted to learn how many babies with CHD get help to check how they are growing and developing after heart surgery. The goal of this study was to find out if some babies were missing this important care and how we could prevent them from missing out.

To do this, the study team looked at hospital records from 2022 to 2023. They also asked the hospital team who care for these babies to fill out a survey. The survey asked how confident the hospital team felt talking with parents about their baby's growth and development and what made it hard for them to talk about this.

### What were the key findings?

- ♥ Not all babies with CHD who needed follow-up care got it. At 12 months old, only 39% of babies had a check for their development.
- ♥ Less than half of the hospital team (44%) asked parents about their mental health often and 59% talked often about babies' growth and development.
- ♥ The reasons the hospital team did not talk about these things were not having enough time, not speaking the same language as parents, and not knowing where families who need extra help can turn to.
- ♥ Babies who had surgery younger, who stayed in the Newborn Intensive Care Unit, or who were diagnosed with CHD before birth were more likely to get development checks.

### What are the next steps?

The project team will now work on making sure babies get the development checks they need.

They are:

- ♥ Making a list to keep track of babies who need check-ups.
- ♥ Giving the hospital team better tools and ways to talk with families.
- ♥ Making a clearer path to care for babies with CHD and their families.

### Team

- ♥ Ms Dianne Swinsburg
- ♥ Dr Natalie Fairbairn
- ♥ Prof Gary Sholler
- ♥ Prof Nadine Kasparian

## **Victoria CHD LIFE+ Project Summary**

### **What was done in the project?**

The Victorian team wanted to learn about how children with CHD get help with their development after surgery. They talked to parents and health workers, ran surveys and interviews, and checked hospital records at the Royal Children's Hospital in Melbourne. They looked at children who had surgery in their first six months of life and included families from different age groups and places, including rural areas.

### **What were the key findings?**

- ♥ Most families (68%) worried about how their child's development was going. About 80% had used support services like speech therapy or occupational therapy, but 20% said their child needed more help than they were getting.
- ♥ Families often used services for more than two years, showing that long-term support is needed.
- ♥ Just over half of the families were happy with the help they got, but younger children's parents were more satisfied than those with older children.
- ♥ Parents found it hard to organise all the care their children needed, especially after leaving hospital. Sometimes, parents had to do the coordination themselves, which could be overwhelming.
- ♥ There was not enough communication between different health services and between services and families.
- ♥ Families said there was no easy way to talk about developmental worries

during their regular check-ups, and some didn't know what support was available.

- ♥ Social and emotional problems were common concerns parents/caregivers had for their children.

### **What are the next steps?**

The team plans to review and improve the new follow-up service to make sure it works well. They want to connect better with doctors and families in country areas, finish a mental health education resource, and build a system to keep track of children's information. They're also working with teams in other states so that children who move or need care in different places don't miss out on important checks. Their goal is to give all children with CHD fair and ongoing support, no matter where they live.

### **Team**

- ♥ Dr Lorna Ginnell
- ♥ Prof Michael Cheung
- ♥ Dr Bryn Jones
- ♥ Dr Leah Hickey
- ♥ Prof Amanda Wood

## **South Australia CHD LIFE+ Project Summary**

### **What was done in the project?**

The team wanted to find out what is happening in South Australia for children with CHD when it comes to checking their development and brain function. They looked at records from children aged birth to five years who had heart problems and needed surgery or treatment. They checked different databases to see how many children were getting development checks, did surveys with parents, and reached out to families who hadn't had an age appropriate health check to offer them a child health and development check in the community.

### **What were the key findings?**

- ♥ Many children with heart problems were not getting regular checks on their development.
- ♥ Out of 289 children, 111 needed an age appropriate child health and development check.
- ♥ Only about 65 of these 111 children were up to date with their checks.
- ♥ Some families didn't know much about the community health services available or didn't understand how important these development checks were.
- ♥ Barriers included missing appointments because of other health issues and thinking the heart doctor was checking everything.
- ♥ About 39% of parents said their child's heart problem made it harder to bond with them because they were always worried about their child's health.

### **What are the next steps?**

The South Australian team has made a special information pack for families about heart care and is working on an improved clinical pathway and research paper. They have created stickers and information pages for the child health record book, and are working with HeartKids for extra resources and support. They've given training to Child and Family Health Nurses throughout the state of South Australia to help them understand the importance of checking development in children with heart conditions. There are plans to start a support group for families with children who have complex medical needs. The team has also designed a new, more organised way of caring for these children, which includes better communication between hospital nurses and special nurses in the community. This new plan is ready and waiting for future funding so it can be put into action.

### **Team**

- ♥ Dr Karina Laohachai
- ♥ Dr Andrew Kelly
- ♥ Dr Rishi Agrawal
- ♥ Annette Sargent CPC
- ♥ Sami Glastonbury, Consumer Advocate

## Western Australia CHD LIFE+ Project Summary

### What was done in the project?

The team in Western Australia wanted to find out how well children with CHD were getting help for their brain and development (neurodevelopment) after heart surgery. They looked at records over a six year period for children who had heart surgery in their first year of life. They also asked parents to do an online survey about the help their children received and any problems they faced with accessing help or attending appointments for their child's neurodevelopment. In addition, they talked to healthcare workers in focus groups and interviews to understand what it's like giving this kind of care, and to consider some practical better ways to plan neurodevelopmental care.

### What were the key findings?

- ♥ Out of 313 children who had heart surgery, about 30% were included in a special follow-up program for babies at high risk, but nearly 28% were not offered any neurodevelopmental follow-up at all.
- ♥ Most children lived in the city, but there were kids from all over Western Australia, including very remote areas.
- ♥ Many parents were aware of the risks to their child's development, but about a quarter didn't know about these risks.
- ♥ Over half of parents had concerns about their child's development, but some said they didn't get enough information or support.
- ♥ The biggest problems families faced were long waitlists, costs, and the distance they had to travel to get help.

- ♥ Some parents felt relieved when issues were found and help was given, but others were frustrated about not getting help quickly.
- ♥ Healthcare workers said there needs to be more awareness and education about development problems, more funding, and better ways to track and share information between different services. They also said it's harder for kids in country areas to get help.

### What are the next steps?

The team wants to use what they've learned to put in place a more practical plan to help children with CHD get the support they need for their development.

The team wants to make sure everyone understands how important it is to check on kids' development, not just their heart. They plan to add more education and awareness for families and staff, improve how information is shared, and look for ways to get more resources.

They also want to get approval for a registry to keep better track of kids and submit a plan to support more local help.

### The team

- ♥ Dr Mary Tallon
- ♥ Dr Cameron Seaman
- ♥ Dr Steve Shipton

## Northern Territory CHD LIFE+ Project Summary

### What was done in the project?

The team in the Northern Territory looked at children with CHD. Because the Northern Territory has only a small number of these kids each year, the team wanted to understand their health and development better. They checked medical records from 2012 to 2022 for kids who needed heart surgery in their first year of life and collected information about their health, where they live, and what kind of care they received.

### What were the key findings?

- ♥ For every 1000 children born in the Northern Territory, about 3 children are born with a congenital heart problem needing early surgery each year. Just under half the children affected identify as Aboriginal and/or Torres Strait Islander.
- ♥ Many of these kids have other health issues too, 3 out of 5 had a neurodevelopmental disorder (like learning or developmental delays), and 2 in 3 had other medical problems.
- ♥ Lots of families live very far from Darwin, some more than 1,000 km away, making it hard to get regular check-ups.
- ♥ Nearly half of the children were “lost to follow-up”, meaning they didn’t have regular appointments with doctors or specialists after leaving hospital.
- ♥ Language and cultural differences, as well as the long distances to travel for care, make it even harder for families to get support.

### What are the next steps?

The team wants to make things better by:

- ♥ Creating resources in local languages and making videos so families who don’t speak English or read well can still get important information.
- ♥ Helping doctors learn more about watching out for developmental problems in these kids.
- ♥ Working with local communities to design care that is safe, respectful, and meets the needs of families from different backgrounds.
- ♥ Continuing to improve follow-up for these children, especially those living far away, so none are missed.

### Team

- ♥ Dr Simone Martin
- ♥ Mrs Cecelia Antunes
- ♥ Dr Bo Remenyi
- ♥ Ms Gladys Wambui Ngugi
- ♥ Ms Leanne O’Neil
- ♥ Dr Ari Horton
- ♥ Professor Anna Ralph
- ♥ Dr Hilary Harderfeldt

**Co-designing national priorities will help everyone continue working together and build on the strong partnerships and progress made through the CHD LIFE+ research program.**



Australian Centre  
for Health Services  
Innovation



Child and Adolescent  
Health Service



**Government of South Australia**  
Women's and Children's  
Health Network



A MRFF Congenital Heart Disease Grant  
(ARGCHDG000035)

**Co-designing sustainable cardiac  
neurodevelopmental models of care**