

Compendium B- National Strategic Action Plan for Childhood Heart Disease (CHD) 2019

Current Activities and Resources Stocktake

Review of Current Activities and Resources Available for the Australian Childhood Heart Disease (CHD) Community

During the development of the National Strategic Action Plan for CHD 2019, activities, initiatives, programs and resources were identified, consulted and collected for community reference. This stocktake helped inform the identification of gaps, needs and opportunities to develop improved support for the CHD community. These resources informed consideration of the Action Plan Priorities: **MANAGEMENT CARE AND SUPPORT, SUPPORTIVE COMMUNITIES and RESEARCH** and the development of key recommendations.

Priority - Management, Care and Support

Focus Area 1: Standards of Care

Opportunity

Develop first Australian Standards of Care for CHD to build on existing international and Australian resources.

Identified Gap

Australia does not currently have standards of care for CHD across the lifetime continuum. There is only limited and in some cases no significant mention of CHD or its management in State-based cardiac services frameworks or general clinical frameworks.

Recommendations

- 1.1 Develop authoritative national clinical practice guidelines on CHD for health services and health practitioners throughout Australia
- 1.2 Develop national standards of care for CHD
- 1.3 Establish a CHD taskforce to oversee the development of standards of care for CHD

Sources of information and relevance

Standards of Care Sources	Relevance
CSANZ 2013 Adult CHD Recommendations for Standards of Care Position Statement	Recommend review for relevance, currency and applicability.
CSANZ 2016 Adult CHD Recommendations for Standards of Care Position Statement	Recommend review for relevance, currency and applicability.

<u>2018 AHA/ACC Guideline for the management of Adults with Congenital Heart Disease (August 2018) (USA)</u>	Recommend review for relevance, currency and applicability.
<u>Australian Consensus Framework for Ethical Collaboration in the Health Care Sector</u>	Recommend review for relevance, currency and applicability.
<u>Scottish Standards of Care</u>	Recommend review for relevance, currency and applicability.
<u>Adult Congenital Heart Association strategy (USA)</u>	Recommend review for relevance, currency and applicability.
ANZ Fontan Consensus Statement 2019 (in development by Dr D Zentner and Prof Y d'Udekem)	Recommend review for relevance, currency and applicability.

Guideline Sources	Relevance
<u>ACC/AHA 2008 Guidelines for the Management of Adults with Congenital Heart Disease: Executive Summary</u>	A decade old but comprehensive across many areas including research.
<u>ARF RHD Guidelines</u>	Includes standards of care and references the need for high risk populations to have access to the same standard of care as other Australians. This might be relevant across CHD more broadly.

Cardiology Framework Sources	Relevance
VICTORIA	
<u>Victorian Cardiology Framework – Design, service and infrastructure plan for Victoria's cardiac system</u>	No significant consideration of CHD/Identified gap.
<u>Heart Health: Better outcomes and improved services</u>	This paper details congenital anomalies including congenital heart disease in Victoria.
QUEENSLAND	
<u>Queensland Aboriginal and Torres Strait Islander cardiac health strategy 2014-2017</u>	No significant consideration of CHD/Identified gap.
<u>Qld Cardiac Services Framework</u>	CHD considered in the context of cardiac rehabilitation only.

SOUTH AUSTRALIA	
<u>SA Clinical Services Capability Framework</u>	CHD considered in the context of cardiac rehabilitation only.
NEW SOUTH WALES	
<u>Cardiac Models of Care</u>	No significant consideration of CHD/Identified gap.
AUSTRALIAN CAPITAL TERRITORY	
	No cardiac framework could be sourced.

TASMANIA	
Rebuilding Tasmania's Health System, Tasmanian Role Delineation Framework	Cardiology Service involves the prevention, investigation, diagnosis, treatment and management of a range of cardiac diseases, e.g. coronary artery disease, valvular heart disease, arrhythmias, heart failure and adult congenital heart disease. Services can range from emergency care, to acute care, surgery, rehabilitation, ongoing care for chronic conditions, and palliative care. Paediatric liaison service at Royal Children's Hospital RCH) and shared care model with Royal Melbourne Hospital for Adult Congenital Heart Disease.
<u>Cardiac Clinical Advisory Group – Response to Green Paper and Tasmanian Role Delineation Framework – Cardiology Services</u>	The Royal Hobart Hospital (RHH) meets a number of criteria for a Level 6 Cardiology service but does not provide full range of services. Currently only basic care for congenital heart disease can be provided by a Level 6 Cardiology Service, so a significant number of patients are required to travel to the Royal Melbourne Hospital every six months to receive care. The Cardiac Clinical Advisory Group Response to Green Paper and Role Delineation Framework proposes that basic care continues to be provided by the RHH and more complex care continues to be provided interstate. A share-care adult congenital heart disease service in both RHH and Launceston General Hospital (LGH), in conjunction with Royal Melbourne Hospital, would reduce the need for patients to travel interstate for services that can be provided locally, reducing the need for patients to travel interstate for care to only once a year. Such a service model could be achieved through clinical redesign and would not necessarily require additional resources. This is a potentially more cost-effective model than currently in place as it would reduce the number of patients seeking financial assistance through Patient Travel Assistance Scheme (PTAS). Development of Nationally consistent Standards of Care would greatly benefit this type of arrangement and could be reviewed/piloted as to demonstrate and test this type of model
NORTHERN TERRITORY	
<u>Cardiac Rehabilitation and Secondary Prevention: A framework for the Northern Territory</u>	No significant consideration of CHD/Identified gap.
WESTERN AUSTRALIA	
<u>Clinical Framework - whole of services mapping</u>	No significant consideration of CHD/Identified gap.
<u>National Strategic Framework for Chronic Conditions</u>	No significant consideration of CHD/Identified gap.

Focus area 2: Infrastructure and Workforce

Opportunity

Australia will have its first Infrastructure and workforce plan to ensure lifelong care is provided to people with CHD and their families. Health professionals will have the necessary skills and succession planning will enable continuity of care. This will enable those impacted to receive the best possible care, in a timely manner, regardless of where they live.

Identified gap

There is a shortage of specialist adult CHD services and clinics across the country.

Recommendations

- 2.1 Develop a CHD infrastructure and workforce plan
- 2.2 Invest in technological infrastructure
- 2.3 Deliver education, training and support for health professionals
- 2.4 Support the management of CHD in primary care
- 2.5 Disseminate best practice information and approaches throughout services in Australia

Sources of information and relevance

Infrastructure and workforce sources	Relevance
Nil	No planning reports or documents related to CHD were identified. This area is a clear gap that impacts on services as demonstrated by the Action Plan and Compendium C – Evidence.

Information on adult CHD (ACHD) clinics, centres and services	Relevance
QUEENSLAND	
Rockhampton Hospital Townsville Hospital	Regular outpatient clinics are conducted for ACHD patients.
The Prince Charles Hospital Mater Health Services	Heart and Lung Clinic is available. Dr Mugur Nicolae conducts adult congenital cardiology outpatient clinics.
NEW SOUTH WALES	
Dr Rachael Cordina, Adult Cardiologist in NSW – Adult outpatient clinics	There are plans to commence outpatient clinics for ACHD in NSW and other locations in 2019 - location and dates to be confirmed at time of writing.
Royal Prince Alfred Hospital Sydney Heart Centre	At Sydney Heart Centre, cardiologists see patients with a wide range of adult heart disorders in consultation including coronary disease, hypertension, heart failure, cardiomyopathy (dilated and hypertrophic), valvular heart disease, aortic disease including Marfan syndrome, heart rhythm disorders (clinical electrophysiology), and familial and congenital heart disease.
St Vincent's Hospital	St Vincent's Hospital Sydney is recognised as a leader in the provision of cardiac services, including cardiac transplantation.
Westmead Hospital	Provides adult cardiology service.
ACT	
Calvary Public Hospital, Bruce	General Cardiology Department only.
NORTHERN TERRITORY	
Royal Darwin Hospital	Royal Darwin Hospital Cardiology.
SOUTH AUSTRALIA	
Royal Adelaide Hospital	Teen transition and adults with CHD – weekly outpatient clinics.
Women's and Children's Hospital	Transition clinic 1-2 per month
TASMANIA	
Royal Hobart Hospital Launceston General Hospital	Patients requiring surgery are transferred to Royal Children's Hospital or Royal Melbourne Hospital depending on age.
VICTORIA	
MonashHeart	Older children and adults are treated at Monash.

Royal Melbourne Hospital	Young adults and adults are treated at Royal Melbourne Hospital.
Epworth Hospital	Adult Care Private hospital (includes repairs, valves and vessels).
The Alfred Hospital	Heart transplants are carried out at The Alfred Hospital.
Royal Women's Hospital	Antenatal facilities.
St Vincent's Hospital	Mild to moderate CHD is catered for, with more severe cases referred to Royal Melbourne Hospital.
<u>GP Health Pathway for CHD in VIC</u>	The Pathway informs primary care practitioners of care recommendations and referral pathways for CHD and is currently available for all GPs in the North Western and Eastern regions in Victoria.
WESTERN AUSTRALIA	
Sir Charles Gardiner Hospital – Adult Congenital heart disease Service	Adult Congenital Heart Disease Clinic (Fridays all day clinic and consultations as required). The service includes 0.5 FTE and 3 cardiologists.
Royal Perth Hospital	Cardiology services.
King Edward Memorial Hospital (KEMH)	Monthly ACHD and RHD service for Pregnancy Management (ACHD Cardiologists)

Cardiac Rehabilitation Services	Relevance
<u>Cardiac Clinical Services</u> Services across the country can be found at this link. It is updated annually.	Many people having surgery will need to access rehabilitation services. For young people including young adults this may mean attending services aimed at much older patients, who access services due to cardiovascular disease or coronary heart disease. This can be a major barrier for CHD patients as goals are likely to differ vastly from elderly age group. With increased awareness of CHD in the health professional sector there is an opportunity to tailor programs to make them more relevant and appealing to young people.

Priority - Supporting communities

Focus area 3: Awareness and Education

Opportunity

Adequately funded services will enable increased reach and support of people impacted by CHD regardless of where they live or are in their CHD journey. This includes different approaches, e.g. web-based, phone and virtual support, reading materials, information and support packs. Organisations could efficiently expand their use of HeartKids-provided information, rather than developing resources separately. Standardisation of patient information nationally may be of benefit where appropriate. Increase support of young people transitioning working directly with young people and their clinical setting and providers.

Identified Gap

There is a lack of awareness of CHD and limited capacity to provide effective awareness and education for patients, their families and carers as well as the range of healthcare professional working with CHD patients and their families and carers.

Recommendations

- 3.1 Increase access to quality, relevant information, education and support through a range of approaches, phone, face to face and digital.
- 3.2 Increase access to ongoing support by funding inpatient and outpatient community (peer) support team members
- 3.3 Increase the number of young people engaged with transition and ongoing specialist CHD care
- 3.4 Deliver awareness and education for non-health professionals

Sources of information and relevance

Awareness and Education Sources	Relevance
HeartKids (only consumer facing organisation that works to support individuals, families and carers impacted by CHD) <u>HeartKids Website</u>	Service limited by private donations only. Support services focussed in hospital setting, not allowing wider community support once people leave hospital setting. Minimal education provided to community (National series of education days conducted twice per year in 5 or 6 major centres). Quality consumer information however limited range and access e.g. languages, formats. Limited funding impacts specialist programs for example supporting young people to engage in their transition. Key areas of work include advocacy, information, support and research.
<u>National Heart Foundation of Australia Website</u>	Provides quality information on the common heart conditions which impact Australian adults and the Supporting Young Hearts program (https://www.heartfoundation.org.au/programs/support-and-information-for-young-hearts), but does not provide specific description of congenital heart

	disease and information and support for the impact of CHD on children and their families.
Paediatric hospitals such as Royal Children’s Hospital, Melbourne and Queensland Children’s Hospital, Brisbane	Royal Children’s Hospital provides quality information focussed on the nature of the conditions and what treatment should be anticipated. The information is broadly focussed on the hospital stay, preparation for surgery and related situations, such as Outpatient clinics, and the RCH Transition Support Service has also developed specific transition resources/information for adolescent CHD patients and for Fontan patients. Queensland Children’s Hospital also provides information to patients and families focused on patient journey. Standardisation of patient information nationally may be of benefit where appropriate.
State and Territory Health Departments	VIC State Government provides information on congenital heart disease https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/heart-abnormality-birth-defects . WA State Department of Health provides information supported by HeartKids (https://healthywa.wa.gov.au/Articles/A_E/Congenital-heart-defects) and this could be expanded to other organisations.

Focus area 4: Neurodevelopmental and Mental Healthcare

Opportunity

People with CHD and their families will experience improved mental health, cognitive outcomes and quality of life as a result of world first neurodevelopmental and mental health standards. (Relates to Focus area 1: Standards of Care).

Identified Gap:

There are limited services and support to meet the mental health and neurodevelopmental needs of people with CHD and their families and carers; improved support can be developed from existing models in NSW and QLD.

Recommendations

- 4.1 Develop standards of mental healthcare for CHD
- 4.2 Develop standards of neurodevelopmental care for CHD
- 4.3 Establish clear models of care

Sources of information and relevance

Strategies, Frameworks, Plans and Programs Sources	Relevance
<u>Psychology Service at the Heart Centre for Children, The Children's Hospital at Westmead</u>	Psychologists at the Heart Centre for Children provide emotional care for babies, children, young people and families affected by all types of heart disease.
<u>Australian Centre for Heart Health, Melbourne</u>	Provides programs to assist parents of children with congenital heart disease, and with HeartKids support, has developed the HeartKids Family Coping Program.
<u>"At the Heart of the Matter" Queensland Children's Hospital</u>	A project conducted across three pilot Hospital and Health Services (HHS) in Queensland, to provide information to assist services providing developmental supports to children and families across the care continuum, to contextualise project outcomes to services within the hospital and health service. There is an opportunity to expand this project to assist other State hospital services.
CHD LIFE Program, Queensland Children's Hospital	The CHD LIFE (Long term Improvement in Functional hEalth) This program provides quaternary level state-wide guidance and advocacy and has developed a state-wide model of care to meet the developmental needs of these children, which may be applicable and expanded to other States. The CHD LIFE database is a centralised platform that collects developmental and functional health data primarily from usual clinical care.
Early developmentally supportive care programs such as: Circle of Care Optimising Outcomes for Newborns (COCOON), The Royal Children's Hospital, Melbourne - <u>COCOON Care Guide</u> and <u>The Newborn Individualised Developmental Care and Assessment Program (NIDCAP), Grace Centre for Newborn Intensive Care, Sydney</u>	The focus of these programs are developmentally-supportive practices in intensive care that incorporate developmental care and infant and parent mental health. Preliminary NIDCAP training has occurred in The Queensland Children's Hospital Intensive Care Unit
CSANZ Mental Health and Developmental Care Working Group	A multidisciplinary working group, operating under the auspices of CSANZ, bringing together professionals in the field to build a strong network to discuss, develop, implement and advocate for services, initiatives and strategies to reduce the psychosocial and neurodevelopmental burden of CHD for infants, children and adults with all forms of CHD and their families, and support and nurture the health professionals who provide CHD care.
<u>WHO: Mental Health Action Plan 2013-2020</u>	The Plan is not specific to CHD however calls for provision of comprehensive, integrated and responsive mental health and social care services in community-based settings. Highlights the need for evidence and investment in research in mental health area which aligns with National Strategic Action Plan for CHD.

<u>National Mental Health and Suicide Prevention Plan</u>	Provides Australian context and highlights the importance of local, community-based approaches. The plan has a focus on regional and Aboriginal and Torres Strait Islander populations which are a shared priority population with CHD.
Neurodevelopmental Outcomes in Children With Congenital Heart Disease: Evaluation and Management: A Scientific Statement From the American Heart Association (USA, 2012)	AHA/AAP scientific statement that includes recommendations to optimise neurodevelopmental outcomes in the pediatric congenital heart disease (CHD) population. The CHD LIFE Cardiac developmental long-term care pathway contextualises these recommendations to the Queensland healthcare and geographic landscape.
Comprehensive evidence relating to the need for these standards is presented within the Action Plan and Compendium C - Evidence	Discusses mental health and neurodevelopmental issues and challenges faced by people with CHD and their families and the need for nationally consistent standards of care.

Focus area 5: Priority populations – Aboriginal and Torres Strait Islander people, people living outside of a major city and young people transitioning from paediatric to adult healthcare systems.

Opportunity

Currently available services highlight the gaps in required services for Aboriginal and Torres Strait Islander people, paediatrics, teens, young adults and adults with CHD, as well as their families and carers. While current plans and reports do not adequately address the needs of people with CHD, future plans and services can include increased consideration of CHD and implement strategies to improve support for Priority Populations, regardless of where they live. The National Strategic Action Plan for CHD carefully considers the support required of people impacted by RHD and recognises the importance of working alongside relevant agencies in this space to develop services based on best practice models.

Identified Gap

Even with documents addressing Aboriginal and Torres Strait Islander people’s health, the impact of CHD on individuals and their families is not recognised.

Recommendations

- 5.1 Fund CHD cardiac coordinators in each jurisdiction
- 5.2 Fund cardiac sonographers and a portable echo machine in each jurisdiction
- 5.3 Evaluate current specialist outreach services for regional and remote communities, including remote Aboriginal communities, and fund outreach services where significant gaps exist
- 5.4 Establish models of care for the transition of care from paediatric to adult cardiac health services, including investing in transition nurses
- 5.5 Investigate options for reducing barriers to accessing care and supporting people with CHD and their families

Sources of information and relevance

Strategies, Frameworks and Plans - Aboriginal and Torres Strait Islander People	Relevance
<u>National Aboriginal and Torres Strait Islander Health Plan 2013–2023</u>	No significant consideration of CHD/Identified gap.
<u>NACCHO - Aboriginal Control Community Health Organisations</u>	No significant consideration of CHD/Identified gap.
<u>Uluru Statement from the Heart 2017</u>	No significant consideration of CHD/Identified gap.
<u>Commonwealth of Australia, Department of the Prime Minister and Cabinet, Closing the Gap Prime Minister’s Report 2018</u>	No significant consideration of CHD/Identified gap.
<u>Better Cardiac Care for Aboriginal and Torres Strait Islander People</u>	No significant consideration of CHD/Identified gap.
<u>WHO Statement on RHD</u>	The National Strategic Action Plan for CHD is committed to supporting those impacted by RHD. The Plan’s strategic focus is the provision of cardiac services and support to families impacted and to work alongside END RHD and RHD Australia.
<u>National Partnership Agreement on RHD</u>	As above.
<u>National Partnership Agreement on Rheumatic Fever Strategy – continuation and expansion</u>	As above.
<u>Queensland Aboriginal and Torres Strait Islander Rheumatic Heart Disease Action Plan 2018-2021</u>	The Governance Committee of this Plan oversees implementation of strategies designed to reduce prevalence of RHD and improve care of children and adults already impacted by this disease
South Australian Aboriginal Heart and Stroke Plan 2017-2021	Strategy - Enhance care for the identification, acute and ongoing care of children and adolescents with heart disease and stroke by paediatric cardiology services, with effective transition pathways into adult cardiology services Strategy – Maintain and expand the existing SA Rheumatic Heart Disease Control Program
SA Rheumatic Heart Disease Control Program	SA Health program with federal funding, linked to Rheumatic Heart Disease Australia

Strategies, Frameworks and Plans – Rural and Regional	Relevance
<u>National Strategic Framework for Rural and Remote Health</u>	Whilst there is no specific mention of CHD, this framework supports and is consistent with many of the National Strategic Action Plan for CHD recommendations and is a critical document for consideration in development of services in rural and regional areas.

Strategies, Frameworks and Plans – Young People Impacted by CHD	Relevance
ANZ Fontan Consensus Statement 2019 (in development Dr D Zentner and Prof Y d’Udekem)	Recommend review for relevance, currency and applicability of a specific section on transitioning from paediatric and adult cardiac healthcare.

<u>GP Health Pathway for CHD in Victoria</u>	The Pathway informs primary care practitioners of care recommendations and referral pathways for CHD – these GP Health Pathways exist for a number of other conditions as transition has been involved in informing the pathway patients with intellectual disability and/or Autism, in partnership with the North Western Melbourne PHN. This pathway is currently available for all GPs in the North Western and Eastern regions in Victoria, and would be applicable to be modelled and expanded in other regions.
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Access to Paediatric Services	Relevance
AUSTRALIAN CAPITAL TERRITORY	
Canberra Hospital	In Canberra, there is no Paediatric Treatment Centre. Families travel to Sydney and paediatric cardiologists visit outpatients monthly over 3 days.
NEW SOUTH WALES	
Westmead Children's Hospital, Sydney Children's Hospital Network	Major specialist centre with centre of excellence in the mental health space. The Westmead Hospital model is highly applicable model for adaption in other major centres.
John Hunter Hospital	Outpatient clinics are conducted every second month at the following locations: Armidale, Port Macquarie, Tamworth, CHD Randwick, Hamilton, Maitland, Muswellbrook, Taree, Moree.
NORTHERN TERRITORY	
Royal Darwin Hospital	Dr Bo Remenyi is the Paediatric Cardiologist in the Royal Darwin Hospital. Patients requiring treatment may be transferred to Women's & Children's Hospital, Royal Children's Hospital, Melbourne or Queensland Children's Hospital, Brisbane. Patients requiring surgery are transferred to Royal Children's Hospital, Melbourne or Queensland Children's Hospital, Brisbane. Outpatient clinics are conducted twice weekly. Visiting cardiologists from Women's and Children's Hospital Adelaide provide outpatient services 3 monthly at Royal Darwin Hospital and Katherine District Hospital.
Alice Springs Hospital	Visiting cardiologists from Women's and Children's Hospital Adelaide provide outpatient services (3 monthly) in the Alice Springs Hospital. Patients requiring treatment may be transferred to Women's & Children's Hospital or Royal Children's Hospital, Melbourne. Patients requiring surgery are transferred to RCH Melbourne.
QUEENSLAND	
Queensland Children's Hospital	Tertiary paediatric cardiology and cardiac service which provides outreach services to Toowoomba, Sunshine Coast, Hervey Bay, Bundaberg, Mackay, Townsville, Mt Isa, Doomadgee and Mornington Island.
Cairns Base Hospital	Paediatric Cardiology and outreach to Thursday Island, Palm Island, Weipa, Aurukun.
Gold Coast University Hospital	Paediatric Cardiology
<u>Connected Care and Nurse Navigator Programs, Children's Health Queensland Hospital and Health Service</u>	This new service represents a model that supports the Action Plan recommendation regarding Nurse Coordinators.

Cardiac Care Coordinators, Queensland Paediatric Cardiac Service, Children's Health Queensland Hospital and Health Service	<p>The position of Cardiac Care Coordinator (CCC) is a statewide role responsible and accountable for the provision of specialised knowledge and advanced clinical practice for coordinated and integrated care across the continuum for cardiac patients and their families, including at the point of transition.</p> <p>Children's Health Queensland does not have a specific CHD Transition Service.</p>
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SOUTH AUSTRALIA	
Women's and Children's Hospital, Adelaide	Women's and Children's Hospital is the major children's hospital in South Australia. The Cardiology Department provides a state-wide service. Outreach clinics are conducted at Flinders Medical Centre, Port Augusta, Mount Gambier, Alice Springs, Darwin and Katherine. Patients requiring surgery are referred to Royal Children's Hospital Melbourne.
Port Augusta Hospital	Dr Andrew Kelly provides inpatient and outpatient Cardiology services at the Port Augusta Hospital (monthly).
Flinders Hospital	Dr Andrew Kelly provides inpatient and outpatient Cardiology services at the Flinders Medical Centre.
TASMANIA	
Royal Hobart Hospital Launceston General Hospital	<p>No specific services are provided for CHD in Tasmania. Children treatment is provided at Royal Children's Hospital, Melbourne as relevant.</p> <p>Outpatient clinics are provided by Royal Children's Hospital clinicians and health professionals in four Tasmanian towns every 6 weeks to 3 months for paediatric patients only.</p>
VICTORIA	
Royal Children's Hospital, Melbourne	This is a key centre in Australia for most advanced surgeries, including transplants Newly opened facility. Outpatient clinics conducted at regional areas – Sale, Wangaratta, Geelong, Shepparton.
MonashHeart, Monash	Older children and young adults are treated at Monash. MonashHeart is an adult and paediatric clinic located at Melbourne.
Royal Melbourne Hospital	Young adults are treated at Royal Melbourne Hospital.
The Alfred Hospital	Heart and lung transplants are carried out at The Alfred Hospital. Paediatric lung transplants and heart/lung transplants, and adult heart transplants are performed.
Royal Women's Hospital	Young person's heart transplant clinic conducted twice/year. Antenatal service is provided.

WESTERN AUSTRALIA	
Perth Children's Hospital	Perth Children's Hospital (PCH) is the major children's hospital in WA; it replaced Princess Margaret Hospital in June 2018. Families from all over WA are sent to PCH for assessment and intervention if required. There are currently six paediatric cardiologists that provide comprehensive public inpatient and outpatient cardiac services through PCH, King Edward Memorial Hospital, including fetal, cardiac problems in pregnancy and neonatal cardiology programs, Sir Charles Gardiner Hospital for ACHD program. Outpatient clinics are conducted in Regional Centres including the West and East Kimberley, Karratha, Roebourne, Port Hedland, Kalgoorlie, Albany and Geraldton. Some adult regional patients with congenital heart disease are seen in the Regional Clinics. About 45 days of Regional Clinics are provided by PCH Cardiologists.
King Edward Memorial Hospital for Women	This hospital provides services for antenatal, high risk pregnancies statewide. The Fetal Cardiology Service is part of the Materno-fetal Medicine Program. Two paediatric cardiologists from PCH provide this service. Mothers deliver newborns here prior to transfer to PCH.

Teen Transition Services	Relevance
NEW SOUTH WALES	
Trapeze and Agency for Clinical Innovation Transition Network	Trapeze is a free service to help young people manage their condition better as they make the leap from their children's hospital to adult health care services. Trapeze works in collaboration with the Agency for Clinical Innovation (ACI) Transition Care Network to provide comprehensive services to young people with chronic conditions in NSW. ACI Transition Care Coordinators (TCC) are located in three adult tertiary hospitals in NSW: Westmead Hospital, Royal Prince Alfred Hospital and John Hunter Hospital. NSW Health does not have a specific CHD Transition Service.
<u>Chronic Illness Peer Support Program (ChIPs), Sydney Children's Hospitals Network</u>	This service is available in some States and is completely philanthropically funded. While it is not CHD specific, it provides a model for expansion of services to other regions.
QUEENSLAND	
<u>Connected Care and Nurse Navigator Programs, Children's Health Queensland Hospital and Health Service</u>	This new service represents a model that supports the Action Plan recommendation regarding Nurse Coordinators.
SOUTH AUSTRALIA	
Royal Adelaide Hospital	Teen transition and adults with CHD – Weekly outpatient clinics.

VICTORIA	
<u>RCH Transition Support Service</u>	The Transition Support Service provides young people and their parents/carers with information and resources. Some of these topics will include information about transition, self-management tips, health and wellbeing issues for young people, educational/vocational supports, as well as links to other services. This service is not CHD specific. This Service has informed Action Plan recommendations on FTE for transition nurse role across every service in Australia required to meet demand of CHD patients.
Youth Support Coordinator (HeartKids) 0.2 FTE	HeartKids Youth Support Coordinators provide support to young people in Royal Children's Hospital, facilitate Youth Advisory Councils in Victoria. There is limited capacity to deliver services due to 0.2 FTE staff. This service is currently not replicated across the country.
<u>Chronic Illness Peer Support Program (ChIPs), Royal Children's Hospital</u>	This service is available in some States and is completely philanthropically funded. While it is not CHD specific, it provides a model for expansion of services to other regions.
WESTERN AUSTRALIA	
Starting high school support through Perth Children's Hospital	Perth Children's Hospital clinical nurses provide support for students starting high school. Students starting high school may request a letter for the school detailing their condition and any requirements related to their health that might need to be managed. Clinical nurses can assist with this, but it may take 2 weeks to access the service. There is a specific transition program for adolescents who have congenital heart disease that will require long term follow up through the ACHD Program at SCGH. PCH and SCGH is now on the same campus.

Travel Assistance Schemes	Relevance
AUSTRALIAN CAPITAL TERRITORY	
<u>Interstate Patient Travel Assistance Scheme ACT</u>	These schemes are utilised by CHD patients, however there is not consistency between them and they do not take into account cancelled services or the real cost of having to access services interstate as an only option for many families.
NSW	
<u>Isolated Patients Travel and Accommodation Assistance Scheme NSW</u>	As above.
NORTHERN TERRITORY	
<u>Patient Assistance Travel Scheme NT</u>	As above.

QUEENSLAND	
<u>Patient Travel Subsidy Scheme QLD</u>	As above.
SOUTH AUSTRALIA	
<u>Patient Assistance Transport Scheme SA</u>	As above.
TASMANIA	
<u>Patient Travel Assistance Scheme TAS</u>	As above.
VICTORIA	
<u>Victorian Patients Transport Assistance Scheme VIC</u>	As above.
WESTERN AUSTRALIA	
<u>Patient Assisted Travel Scheme WA</u>	Families who are required to have surgery, interventional cardiology procedures, arrhythmia management or specialised consultations e.g pulmonary hypertension or heart failure assessment interstate receive support from the WA Health Department. This will usually provide support for two parents and include airfares, accommodation and daily subsistence allowances. Some antenatal patients with complex heart problems may travel interstate at around 34 weeks. They receive support again form the WA Health Department.

Priority – Research

Focus area 6: Research

Opportunity

To create and build research evidence that will inform earlier interventions and improved therapies to reduce the burden of CHD on all those affected.

Identified Gaps

Refer to National Strategic Action Plan for CHD and Compendium C – Evidence for further details on how these recommendations were formed to address gaps in international research and data in relation to CHD, and the critical role of consumer engagement determining research priorities and measuring the impact of research outcomes on benefits for consumers and improved efficiency in the delivery of the health system.

Recommendations:

- 6.1 Understanding the genetic causes of and predisposition to CHD to provide support for those impacted by CHD
- 6.2 Preventing neurodevelopmental and mental health complications
- 6.3 Understanding the impact of prenatal and postnatal factors affecting the health of children born with CHD and their families
- 6.4 Undertaking longitudinal impact and informed practice with the National Congenital Heart Disease Registry
- 6.5 Exploring the role of exercise and increased activity in reducing the impact of CHD

Sources of information and relevance

Consumers in Research and Sources to Inform Research Priorities	Relevance
<u>Consumer and Community Involvement in Health and Medical Research 2016 NHMRC Guidelines</u>	This is highly relevant to the HeartKids Project CHD Research funding to be available through The Mission for Cardiovascular Health in 2019, and will provide best practice for consumer engagement identifying and assessing the impact of CHD Research in the future.
<u>Congenital Heart Alliance of Australia and New Zealand (CHAANZ) Website</u>	CHAANZ is a consortium of CHD researchers from Australia and New Zealand who support CHD research and facilitate and manage the first bi-national CHD registry, a key resource to support the key research priorities identified by the sector.
<u>Australia and New Zealand Fontan Registry Website</u>	The Fontan Registry gathers information from children and adults who have had the Fontan operation to treat forms of CHD, and is available for researchers to address key research priorities. The clinicians, researchers and health professionals participating in the both the Fontan Registry and CHAANZ represent a significant proportion of the clinical and research CHD community in Australia and New Zealand.

<p><u>Australian Genomics Health Alliance (AGHA) Cardiovascular Genetic Disorders Flagship</u></p>	<p>The Flagship investigates current models of care for genetic heart disease families to develop a unified “best practice” approach to cardiac genetic testing. The establishment of an Australia-wide database of genetic variants found in patients with inherited cardiomyopathies and primary arrhythmia disorders will be a valuable resource to support collaborations with the CHD research community.</p>
<p>Key peer-reviewed scientific articles and evidence (referenced in the accompanying Evidence Compendium C)</p>	<p>Key research priorities were developed from the current evidence base available in the peer-reviewed published scientific literature as well as from consultation and consensus of the Expert Working Group on Research during the Action Plan development. The Expert Working Group on Research as well as the members of both CHAANZ and the Fontan Registry comprise a significant proportion of those performing CHD research in Australia and New Zealand, and have the necessary expertise to identify research priorities and opportunities to achieve research impacts with international significance.</p>

Focus area 7: Surveillance

Opportunities

Commence monitoring and surveillance of the implementation of the Action Plan to ensure benefit for those impacted by CHD and the wider community. Create and build data for CHD to inform understanding, build evidence and assist with planning, infrastructure, costings and reporting in the future.

Identified Gaps

There is limited standard data collection across Australia for CHD. The National Strategic Action Plan for CHD is a valuable resource pulling together all available data, research and leading thinking on the state of CHD in Australia. HeartKids funding of Congenital Heart Alliance of Australia and New Zealand (CHAANZ) endeavours to collect data in a registry format to better understand and track clinical care, interventions, treatments, surgery and impact of CHD on individuals both retrospectively and into the future and is an Australian first.

Recommendations

- 7.1 Invest in the Congenital Heart Alliance of Australia and New Zealand (CHAANZ) Registry
- 7.2 Invest in an economic burden of CHD report
- 7.3 Invest in funding of the annual national CHD survey
- 7.4 Develop an evaluation framework that includes production of an annual report card to monitor progress against this Action Plan

Sources	Relevance
<u>Congenital Heart Alliance of Australia and New Zealand (CHAANZ) Website</u>	<p>Highly relevant to understanding of congenital heart disease, it's impacts and understanding treatment through development of registries, and research opportunities.</p> <p>CHAANZ has published several papers cited in Compendium C – Evidence</p> <p>The National CHD Survey conducted through CHAANZ measures the self-reported burden of CHD.</p> <p>The CHD Registry developed and managed by CHAANZ will enable data collection in major CHD centres across the country.</p>
<u>Australia and New Zealand Fontan Registry Website</u>	Information stored in database which will allow comparisons with the CHAANZ CHD Registry.
<u>Queensland Paediatric Cardiac Service (QPCS)</u>	<p>QPCS has collected detailed data on all surgical procedures performed since 1995 and catheter procedures since 2001. Catheter outcomes benchmarked internationally with IMPACT Registry.</p> <p>Information stored in database which will allow transfer to CHAANZ CHD Registry.</p>