

TREASURY PRE-BUDGET SUBMISSION

2022 – 2023



HeartKids



Acknowledgement

HeartKids acknowledges the Traditional Custodians of Country throughout Australia and the ongoing and important wisdom shared through their continued connection with the land, waters and community.

We respectfully recognise the Elders of the past and present and support the children who will become future Elders.

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Purpose

In 2019 the Honourable Greg Hunt MP Minister for Health announced \$6 million funding for the six-year [HeartKids Project](#) (Appendix 1) to help implement the recommendations of the [National Strategic Action Plan for Childhood Heart Disease](#) (Appendix 2). This funding covered two three-year phases as confirmed by the Assistant Director of Chronic Disease Policy Section in 2019 (Appendix 3).

The purpose of this submission is to:

1. Confirm the committed funding for Phase Two of the HeartKids Project. The further \$3.3 million is required to continue, expand and complete the already well-established work on the [National Strategic Action Plan for Childhood Heart Disease](#).
2. Seek additional funding for HeartKids Cardiac Care Coordinators to coordinate and case-manage regional, rural and remote patients and families, including a focus on Aboriginal and Torres Strait Islander peoples and adolescent/young adult patients, in line with the National Strategic Action Plan for Childhood Heart Disease.

Background

The National Strategic Action Plan for Childhood Heart Disease

The National Strategic Action Plan for Childhood Heart Disease 2019 – Beyond the Heart: Transforming Care (the Action Plan) was launched by the Honourable MP, Minister for Health Greg Hunt in February 2019 with an aim to reduce the impact of Childhood Heart Disease (CHD) in Australia and achieve the goal that people with CHD live longer, healthier and more productive lives through effective management of CHD across the life course.

The Action Plan focuses on three main objectives; to improve the lifelong management, care and support of people with CHD and their families, to support communities through education and awareness and research.

Implementation of the Action Plan delivers:

- The first ever Australian standards of care for CHD, including world-first neurodevelopmental and mental health standards
- More specialist CHD health professionals and specialist CHD centres to provide access to CHD-relevant health and allied health services and support through all of life for all Australians impacted by CHD irrespective of where they live
- Increased awareness of CHD and its unique challenges and improved access to information, support and resources for all people impacted by CHD
- Research evidence that will inform earlier interventions and improved therapies to reduce the burden of CHD on all those affected
- Monitoring and surveillance of the implementation of the Action Plan to ensure benefit for those impacted by CHD and the wider community.

HeartKids

HeartKids Limited (HeartKids), the national not-for-profit organisation solely focused on supporting and advocating for all people impacted by congenital or childhood-acquired heart disease, coordinated the development and implementation of the National Strategic Action Plan for Childhood Heart Disease.

HeartKids is the only charity providing national lifelong support for over 65,000 Australian babies, children, teens and adults and their families and carers affected by Childhood Heart Disease (CHD), one of the largest causes of infant death in Australia.

HeartKids' Vision

Every child, teenager and adult in Australia with congenital or childhood-acquired heart disease has a fighting chance to live a long, healthy and fulfilling life.

HeartKids is the only national Australian charity to:

- Support, inform and educate families throughout their whole CHD journey; and
- Advocate for the needs of all people impacted by CHD; and
- Drive funding to unite researchers, clinicians, heart kids, families and communities through world-leading research and action programs; and
- Harness the passion of the CHD community for greater impact.

Governed by a Board of Directors, HeartKids has a proven track record of more than 40 years in delivering programs and services to help those impacted by CHD lead the most fulfilling life possible and reach their personal goals. Our work is evidence-based and outcome-focused, demonstrating real impact for people with CHD, their families and the community. Our programs and services, focused on advocacy, information, research and support, align with the objectives of the Public Health and Chronic Disease Program. We work closely with a large community of clinicians, researchers, policymakers, organisations and consumers in developing and delivering our programs and services.

Childhood Heart Disease

Childhood Heart Disease (CHD), which includes congenital heart disease and childhood acquired heart disease, places a significant burden on over 65,000 children and adults living with CHD, and their family members and carers.¹ These conditions significantly impact Australia's healthcare system, educational institutions, the workforce and the broader economy. CHD is one of the leading causes of death and hospitalisation of infants.^{2,3,4} CHD is a chronic condition that, for many patients, requires complex, specialised care across the life course.¹

CHD survival rates have improved dramatically due to medical advances. Most people with CHD now survive into adulthood, and currently adults living with CHD outnumber children with the condition.^{5,6,7,8}

The longer survivorship of people with CHD means we are now looking beyond childhood and focus on whole-of-life care and the impact this has on patients, the health system, the workforce and the national economy.

HeartKids Project Phase One

April 2020 to March 2023

The initial \$3 million for Phase One was awarded to HeartKids in April 2020 under the Childhood Heart Disease – Consumer Awareness, Education and Standards of Care Grant 2020–2023.

The agreed intended outcomes of Phase One are:

- Build on existing print and digital resources and develop new print and digital resources to provide evidence-based information on CHD and available support services that is easy to understand and interpret
- Actively promote and disseminate evidence-based information on CHD to consumers through multiple platforms
- Develop a digital strategy, in consultation with CHD consumers
- Develop evidence based clinical practice guidelines for health professionals to support best practice diagnosis, care, and management of CHD, in collaboration with the Congenital Heart Alliance of Australia and New Zealand (CHAANZ), CHD specialists and clinicians
- Obtain endorsement of the clinical practice guidelines by the National Health and Medical Research Council
- Develop evidence-based standards of care, including neurodevelopmental and mental health standard
- Develop training and education resources for health professionals through suitable avenues, including online-training programs, face-to-face training, or printed materials
- Obtain accreditation of training and education resources, where required and obtainable by relevant colleges, for example the Royal Australian College of General Practitioners and the Royal Australian College of Physicians
- Collect, monitor and evaluate the utilisation of resources and the effectiveness of grant activity.

A key focus across all deliverables in Phase One has been an ongoing commitment to the specific needs of priority populations including Aboriginal and Torres Strait Islander people, young people transitioning from paediatric to adult care and people located in rural and remote areas of Australia.

HeartKids Project Phase One Outcomes

HeartKids has successfully delivered all scheduled outputs of Phase One in 2020 and 2021, with all remaining initiatives on track for implementation in 2022 and early 2023. Feedback from health professionals, health planners and consumers impacted by Childhood Heart Disease (CHD) has all been exemplary, with the noted impacts of the work already evident.

The outcomes to date of Phase One are documented below:

Standards of Care

- Development of the National Australian Standards of Care for Childhood-onset Heart Disease Draft One (Appendix 4) in collaboration with a Steering Committee and series of Working Groups with over 130 members from cardiology, cardiac surgery, general paediatrics, adult congenital heart disease (ACHD), nursing, psychology, and importantly parents and patients from diverse cultural backgrounds and geographical locations
- Publication of the National Australian Standards of Care for Childhood-onset Heart Disease for public consultation in October 2021.

Health Professional Education

- Creation of a central database of over 250 existing Australian and International health professional education and training resources that relate to CHD or the management of CHD across the lifespan
- Development of a Gap Analysis Report that compares the existing CHD education resources and the workforce priorities and deficits identified in a Learning Needs Assessment completed by over 100 health care professionals working with patients with CHD to determine key priorities for future education.

Consumer Resources

- In consultation with over 900 consumers impacted by CHD, development of new consumer-focused, evidence-based education resources initially targeting priority areas including teen transition and resources for Aboriginal and Torres Strait Islander people impacted by CHD including Indigenous storytelling, a podcast series, teen focused resources and “Heart Story” videos
- All existing HeartKids CHD resources were reviewed and updated to reflect best practice health literacy principals and community preferences and priorities.

UpBeat Teen App

- Development and pilot of UpBeat, a smartphone app that supports young people during the difficult period of transitioning from paediatric care to adult care and to better manage their condition and engage with their health care more independently.

Note: See Appendix 5: UpBeat Case Study for further information on UpBeat.

CHD Directory

- Development of a dedicated, Australian, CHD specific online directory for consumers and health care professionals that lists CHD specific health care professionals, health care organisations and support groups/networks.

HeartKids Helpline

- HeartKids Helpline has been enhanced to a service that is staffed with a dedicated coordinator with predefined workflows, policies and procedures and a collated library of evidence-based support resources that provided support and resources to over 500 requests in 2021.

Teen Camp

- A teen camp for Aboriginal and Torres Strait Islander teens aged 13 to 18 with congenital or acquired heart disease was held on 10-12 December on the Sunshine Coast.

Note: See Appendix 6: Teen Camp Case Study for further information on Teen Camp 2021.

HeartKids Project Phase Two

HeartKids are seeking to confirm the further \$3.3 million (inclusive of annual indexation), as agreed by the Minister and Department of Health in 2019, to continue, expand and complete the already well-established work on the National Strategic Action Plan for Childhood Heart Disease into 2023, 2024, 2025 for Phase Two of the project.

Working with the existing governance structures and partnerships HeartKids has established with clinicians, researchers, government, consumers impacted by CHD and the broader CHD community, we will deliver Phase Two of the HeartKids Project.

Phase two includes the below initiatives:

- Produce the final prioritised national clinical practice guidelines, position statements and models of care for childhood heart disease including neurodevelopmental and mental health and transition
- Complete the suite of clinical education modules and support resources for health professionals
- Produce and deliver awareness and education resources for non-health professionals including schools, childcare centres, universities, workplaces and sporting clubs
- Increase CHD patient and family support by funding HeartKids Support Coordinators in the currently underserved areas of Tasmania, Far North Queensland and the ACT
- Evaluate current specialist outreach services for regional and remote communities, including remote Indigenous communities, and provide recommendations for funding outreach services where significant gaps exist
- Investigate options for reducing barriers to accessing care and supporting people with CHD and their families
- Establish a National Transition Coordinator role to focus on teen transition to reduce the number of young people lost to care at this key stage
- Provide metro and regional teen camps for young people with CHD to facilitate ongoing connection with peers and build self-management skills
- Engage a health economist to prepare a consensus model for measurement of the economic burden of CHD (both direct and indirect costs)
- Fund an annual national CHD survey to collect data from people with CHD, including their healthcare use and experiences, and the health, social and economic impact of living with CHD
- Ongoing provision of the CHD Directory and HeartKids Helplines Services to continue to meeting community needs

Phase Two Budget

HeartKids Project Phase Two	Year One 2022-2023	Year Two 2023-2024	Year Three 2024-2025	TOTAL
Budget	\$972,000	\$1,172,000	\$1,162,000	\$3,306,000

Announced by The Hon Greg Hunt MP, Minister for Health and Aged Care on 14 February 2019 (Appendix 1).

Further detail is set out in Phase Two Deliverables and Costings (Appendix 7).

HeartKids Cardiac Care Coordinators

An additional opportunity for further support exists within the scope of the National Strategic Action Plan for Childhood Heart Disease that would see the implementation of CHD Cardiac Care Coordinators in each major children's hospital in Australia.

HeartKids Cardiac Care Coordinators would be based on the very successful model of the McGrath Foundation's Breast Care Nurses. They would be highly skilled and experienced clinicians employed by HeartKids to coordinate and case-manage regional, rural and remote patients and families, including a focus on Aboriginal and Torres Strait Islander people and adolescent/young adult patients.

The role would focus on:

- Provision of services at specialist outreach clinics
- Coordination of surgery and interventional procedures
- Development of care pathways, including transition pathway
- Reducing failure to attend rates and improving transition to adult cardiac care
- Providing education to young people with CHD and their families and the health workforce.

HeartKids requires an additional \$1.56 million of funding to deliver this outcome as documented in the Complete Funding Request on the next page.

Complete Funding Request

Phase Two Funding Confirmation

HeartKids Project	Year 1 2022-2023	Year 2 2023-2024	Year 3 2024-2025	TOTAL
Phase Two	\$972,000	\$1,172,000	\$1,162,000	\$3,306,000

Additional Funding Request

HeartKids Project	Year 1 2022-2023	Year 2 2023-2024	Year 3 2024-2025	TOTAL
Cardiac Care Coordinators	\$312,000	\$624,000	\$624,000	\$1,560,000
TOTAL FUNDING REQUESTED				\$5,092,000

References

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- ² AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (2017). "Heart, stroke & vascular diseases." Retrieved June 2018, from <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/heart-stroke-vascular-diseases/overview>.
- ³ AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (2018). "Deaths in Australia." Retrieved June 2018, from <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/life-expectancy>.
- ⁴ DAVIES, S., HOFER, A. & REEVE, C. (2014). "Mortality attributable to rheumatic heart disease in the Kimberley: a data linkage approach." *Internal Medicine Journal* 44: 1074-1080.
- ⁵ KHAIRY, P., IONESCU-ITTU, R., MACKIE, A. S., ABRAHAMOWICZ, M., PILOTE, L. & MARELLI, A. (2010). "Changing mortality in congenital heart disease." *Journal of the American College of Cardiology* 56: 1149-1157.
- ⁶ LEGGAT, S. (2011). *The 2011 Childhood Heart Disease in Australia White Paper. Childhood heart disease in Australia: Current Practices and Future Needs. A report for HeartKids and Paediatric and Congenital Council of the Cardiac Society of Australia and New Zealand.* Pennant Hills, NSW, Australia, HeartKids Australia.
- ⁷ LE GLOAN, L., MERCIER, L., DORE, A., MARCOTTE, F., IBRAHIM, R., MONGEON, F., ASGAR, A., MIRO, J., POIRIER, N. & KHAIRY, P. (2011). "Recent advances in adult congenital heart disease." *Circulation* 75: 2287-2295.
- ⁸ WINLAW, D. (2007). "Congenital heart disease in the 21st century." *Critical Care and Resuscitation* 9: 270-274.

Appendix 1: Media Release

[The HeartKids Project: \\$26 million to tackle childhood heart disease](#)

The Australian Government will establish the HeartKids Project with \$26 million to tackle childhood heart disease, which affects more than 65,000 Australians.

Date published:

14 February 2019

Media type:

Media release

Audience:

General public

The Liberal National Government will establish the HeartKids Project with \$26 million to tackle childhood heart disease, which affects more than 65,000 Australians.

Today, on international day for congenital heart disease, our Government will provide \$20 million for medical research into congenital heart disease.

This funding from the Medical Research Future Fund will support our best and brightest researchers to translate their vital work into real health benefits – better diagnosis, treatment and prevention of congenital heart disease.

The funding is for an open grant round aimed at better understanding the disease’s genetic causes and prevention and treatment options.

Unlike other cardiovascular problems, which commonly present in adults over 45 years, congenital heart disease has its greatest impact on the young.

Congenital heart disease is the leading cause of deaths for Australian infants and the second leading cause of death for children.

Sadly, eight babies are born with congenital heart disease every day, with four passing away each week. There is currently no known cure.

In Australia, of the approximately 300,000 births each year, 2,400 to 3,000 babies are born with a form of congenital heart disease.

For the first time, there are now more adults than children living with congenital heart disease – and this large and growing population requires lifelong and highly specialised medical care.

Our Government will also provide up to \$6 million to help implement the recommendations of the National Strategic Action Plan for Childhood Heart Disease by supporting HeartKids with \$1 million per year over six years.

We announced the National Strategic Action Plan for Childhood Heart Disease a year ago along with \$150,000 for the organisation HeartKids to jointly developed the plan.

The Action Plan will guide improvements for the care of thousands of patients, and save lives.

It will coordinate policy action for tackling the disease across the nation and drive collaboration in management, care and support, research and community awareness.

The Action Plan targets three priority populations that are disproportionately affected by childhood heart disease — Aboriginal and Torres Strait Islander people, adolescents and young adults who are moving from paediatric to adult cardiac health services and people living in remote, or rural and regional locations.

HeartKids' role in progressing the Action Plan's recommendations will include addressing the standards of care for people impacted by childhood heart disease and increasing the availability of quality, relevant information about childhood heart disease.

A particular focus will be to help young people impacted by childhood heart disease as they move into adulthood.

We are committed to doing more to support people battling this dreadful disease – and the HeartKids Project will help us chart the most effective way forward.

Since 2013, the Coalition has provided \$662 million for research into forms of cardiovascular disease including \$45.7 million for congenital heart disease research.

We have also provided \$7.7 billion to subsidise medicine to treat cardiovascular disease on the Pharmaceutical Benefits Scheme (PBS).

Appendix 2: National Strategic Action Plan for Childhood Heart Disease

National Strategic Action Plan for Childhood Heart Disease



NATIONAL STRATEGIC ACTION PLAN FOR CHILDHOOD HEART DISEASE

February 2019

BEYOND THE HEART : TRANSFORMING CARE

Appendix 3: Confirmation of Phase One and Two Funding

From: PIPER, Kate <Kate.Piper@health.gov.au>
Sent: Wednesday, 10 April 2019 8:53 AM
To: Rob Lutter <Rob.Lutter@heartkids.org.au>; THOMPSON, Kevin <Kevin.Thompson@health.gov.au>
Cc: lisaselbie <lisaselbie@gmail.com>; BRUNKER, Robyn <Robyn.Brunker2@health.gov.au>; PHILLIPS, Ellen <Ellen.Phillips@health.gov.au>; GUNADASA, Erika <Erika.Gunadasa@health.gov.au>; Mark, Tanya <Tanya.Mark@health.gov.au>
Subject: RE: National Strategic Action Plan for CHD 2019 (Reference ID: 4500127188) [SEC=UNOFFICIAL]

Good morning Rob,

My apologies for the delay in responding to your email, unfortunately I have been off work for a number of weeks due to a neck injury and am currently only able to work restricted hours.

I haven't had a chance to review the Financial Report attached to your email of 2 April, however I will do this and let you know if anything further is required.

With regard to the next steps for the implementation of aspects of the Action Plan. The following should help to outline the process:

- The \$6 million funding allocation to implement aspects of the CHD Action Plan will be provided via two separate funding agreements (as the funding is available through two different sources within the Department). The first funding agreement will be for activities conducted in the financial years 2019-20 to 2021-22, with a second funding agreement established later on for the second three year funding term (2022-23 to 2024-25).
- Grant Opportunity Guidelines (GoGs) for the first three year phase (2019-20 to 2021-22) will be drafted and published on the GrantConnect website. GrantConnect is the Commonwealth Government's whole-of-government grant information system. It is a centralised web-based facility for publication of grants information on Forecast Opportunities (upcoming grants) and Grant Opportunities (current grants, open for application). It will take a number of weeks for the GoGs to be finalised and published, so at this stage it is expected they won't be available until early in the 2019-20 FY – I will keep you informed of this process and the associated timeframes.
- These GoGs will describe the grant activity, and in this circumstance will be restricted to HeartKids Pty Ltd to submit a response.
- HeartKids will need to provide the Department with a response to the GoGs. While this cannot be formally completed until the GoGs have been issued on GrantConnect, HeartKids can start to prepare a proposal based around TWO areas as follows:
 - **PACKAGE A** – This package is related to '*standards of care*'. It includes the development of clinical practice guidelines for CHD; and the development of education and training materials for healthcare professionals. Activities should align with Recommendations:
 - 1.3 - Develop authoritative national clinical practice guidelines on childhood heart disease for health services and health practitioners throughout Australia.
 - 2.3 - Deliver education, training and support for health professionals.
 - 2.4 - Support the management of childhood heart disease in primary care.
 - **PACKAGE B** – This package is related to '*consumer awareness and education*'. It includes activities to increase the availability of quality, relevant information for those affected by CHD and their families/carers, as well as for the wider population; and the development of strategies to assist young people impacted by CHD as they transition into adulthood. Activities should align with Recommendations:
 - Part of 3.1 – Increase access to quality, relevant information, education and support through a range of approaches, phone, face to face and digital (i.e. building on existing resources, invest and implement a digital strategy that provides a web-

- based CHD education portal, linkages to key parent sites, developed in consultation with CHD consumers).
- 3.3 - Increase the number of young people engaged with transition and ongoing specialist CHD care.
- Given the 6 year duration of the overall commitment, it is expected that an assessment/evaluation of activities should be included as part of the first funding agreement (2019-20 to 2021-22) to inform the second 3 years funding period (2022-23 to 2024-25).

The last steps in the finalisation of the Action Plan itself, is for it to be progressed to the Clinical Principal Committee (CPC) and then to the Australian Health Ministers' Advisory Council (AHMAC) for noting. This will ensure the health departments of each state and territory are aware of, and have access to, the *National Strategic Action Plan for Childhood Heart Disease*. This is an important step, as many of the recommendations outlined in the Action Plan impact or are the responsibility of state/territory government.

I will stay in touch with you regarding the timeframe for the publication of the GoGs, however if you have any queries in the meantime, please do not hesitate to send me an email.

Kind regards,

Kate

Kate Piper

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From: Rob Lutter <Rob.Lutter@heartkids.org.au>
Sent: Tuesday, 2 April 2019 11:53 AM
To: PIPER, Kate <Kate.Piper@health.gov.au>; MCDONALD, Jacinta <Jacinta.McDonald@health.gov.au>; THOMPSON, Kevin <Kevin.Thompson@health.gov.au>
Cc: lisaselbie <lisaselbie@gmail.com>
Subject: National Strategic Action Plan for CHD 2019 (Reference ID: 4500127188) [SEC=No Protective Marking]

Hi Kate,
Just checking on what our next steps are now that you have received everything (Financial Report attached).
Can we please start to look at a new contract to implement the CHD action plan over the next 6 years. We would like to get started as soon as possible.
Look forward to your reply.

Kind regards

Rob Lutter
Chief Executive Officer
HeartKids Limited

HeartKids Infoline: 1800 432 785

M: 0437 023 756

Appendix 4: National Standards of Childhood-onset Heart Disease

Australian National Standards of Care for Childhood Heart Disease

Australian National Standards of Care for Childhood-onset Heart Disease

Draft for Public Consultation 31 October 2021

Appendix 5: UpBeat Case Study

Case study: UpBeat

An app designed to help heart kids transition to adult life and care.

Problem identification: Bumpy transitions

Currently, it is estimated over half of Australians with childhood heart disease (CHD) are being 'lost to care.'^{1 2} This can be due to a disconnect during the transition period. This has associated consequences for the management of their disease, mental health, wellbeing and ultimately their life expectancy.



As part of the National Strategic Action Plan for CHD Focus Area 3.3: 'Increase the number of young people engaged with transition and ongoing specialist CHD care', HeartKids surveyed over 150 young Australians with CHD to find out what they think the biggest barriers to transition are.

They identified the following challenges:

- Concern about the burden of responsibility of managing their condition, such as organising appointments
- Experiencing worry and fear that they won't know their health care team
- A lack of information on the process of moving teams
- Feeling lost in the system -- like a number, not a person
- A lack of specialised mental health support.



Up Beat

Technology & transition

The survey results also indicated that technology may be able to assist young people as they transfer from paediatric to adult care. A follow-up survey targeting clinicians and support workers directly involved in teen transition that tested the ideas and results of the young person survey indicated similar support for a technology solution to support teen transition. A market review of available smartphone applications (apps) and a literature search show that internationally, apps have been beneficial in the teen transition process.


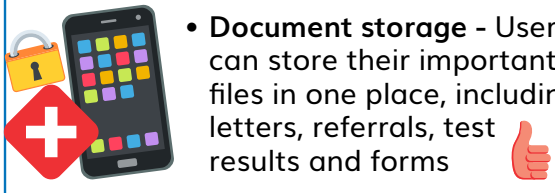
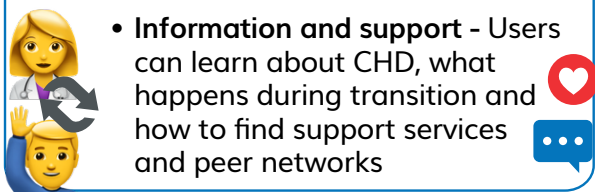
Talking to stakeholders

The challenges identified above are in-line with the priority areas of the Standards of Care for CHD Transition Working Group. Additionally, consultation with key stakeholder groups including RHD Australia, Australian Institute of Clinical Innovation, Royal Children's Hospital Transition Support Services Territory Education Departments has further validated these insights.

Solution: UpBeat

UpBeat is an app designed for young heart kids (15 to 19 years) who are starting to manage their lives and health care more independently. It is a tool that helps users to engage with the transition process and the self-management of their condition, while connecting them to relevant support services and resources.

The key features of UpBeat are:

- **A medical summary.**- Users can organise their key health information, including medication details, care team contacts and appointments notes 
- **Document storage** - Users can store their important files in one place, including letters, referrals, test results and forms 
- **Information and support** - Users can learn about CHD, what happens during transition and how to find support services and peer networks 

Challenge: Making UpBeat relevant for everyone

CHD is a general term for a range of conditions that affect the way the heart works. There is a broad spectrum of severity across conditions and people. As such, there are many different experiences of CHD.

Adding further complexity, UpBeat is designed to be used on a national level, across many different care and service environments. This includes users in regional and remote areas who may not have access to a formal transition program through their hospital, as well as complementing the transition experience for users who are part of coordinated transition programs. This is in contrast to

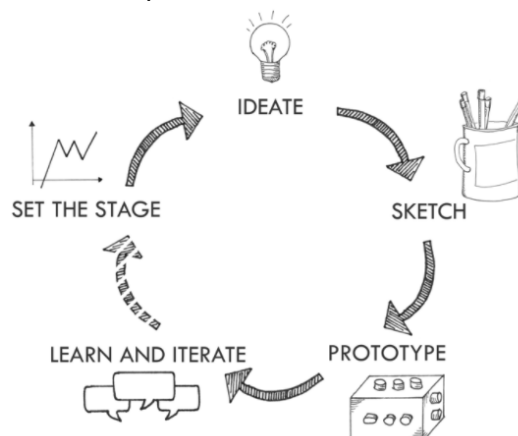
many of the apps we identified during our research, which are tied to one hospital, transition program or region. UpBeat has also been developed to continue to function without a reliable internet connection, as this may not be available in some of Australia's regional locations and remote communities.

Each user will use the app differently based on their condition, location and varied needs. While some users will want to log multiple surgical procedures in UpBeat, other users may not have had any surgeries. Some users may use UpBeat mainly to keep on top of their medications, whereas others will not. Some users will already know a lot about transition, whereas others will need greater access to this education.

We were confronted with the challenge: **How do we make an app that covers the broad range of use cases for such a diverse community?**

Answer: Innovating through co-design

To ensure that UpBeat is accessible, relevant and useful to the broadest range of users possible, we have adopted co-design principles. This has meant working with consumers throughout each of the key stages of app design and development, thereby giving equal value to expertise by lived experience, and expertise by profession, education and technical experience.



Model: Co-design process for app design and development, incorporating regular user testing.

Young Persons' Digital Advisory Group

To facilitate this continual flow of user input, we created a Young Persons' Digital Advisory Group to oversee the project.

This group consists of a range of young consumers, as well as a handful of clinical and technical experts. It is purposefully made up of consumers and clinicians from around the country to represent different experiences and perspectives of the transition process. The young people are all different ages and at different stages of transition.

User testing

Throughout the app build, we have conducted facilitated user testing every two weeks to validate design decisions and identify opportunities for design enhancements. These testing sessions have involved Advisory Group members as well as other consumers. We have conducted over 10 hours of user testing with 15 different users. This diverse user input has allowed us to explore many different use cases and user flows. Their feedback and decisions have been invaluable in improving the app.

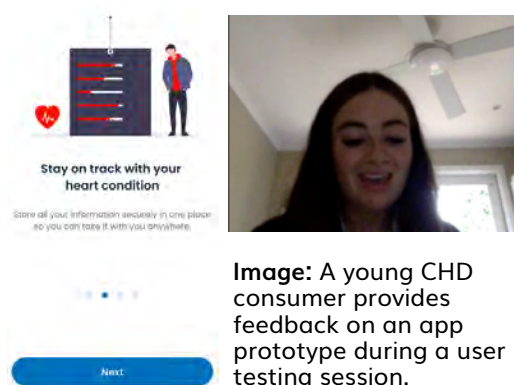
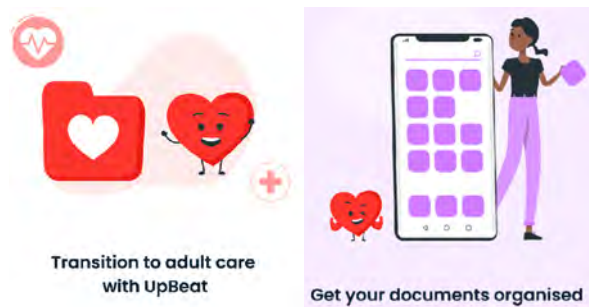


Image: A young CHD consumer provides feedback on an app prototype during a user testing session.

Next steps: Pilot

We are running a four-month pilot from July – November 2021 to further improve upon the app through co-design principles. Around 50 young heart kids from around the country will participate and provide their feedback. UpBeat will officially launch in January 2022.



Images: Screenshots from the pilot version of UpBeat. This version adopts friendlier and younger styles based on feedback from users that the imagery in the prototype version was too clinical.

Consumer resources

Concurrently, we are creating new educational resources to sit alongside UpBeat. Young people want to learn about transition in different ways. A key theme that keeps coming through in our consultation is that young people want to hear 'stories from other people like me.'

The first video is in our MyHeart: Transition Stories series is available to watch now, with further videos and written stories to follow throughout 2021. These stories will explore the key transition concerns and themes identified in our consultation with young people, through the lens of a young person drawing upon their first-hand experience.



References

¹ NICOLAE, M., GENTLES, T., STRANGE, G., TANOUS, D., DISNEY, P., BULLOCK, A., GRIGG, L., CHEN, S.S.M., PRESSLEY, L., CORDINA, R., HORNUNG, T., O'DONNELL, C. & CELERMAJER, D.S. (2019). "Adult Congenital Heart Disease in Australia and New Zealand: A Call for Optimal Care." *Heart, Lung and Circulation*. 28: 521-529

² KEMPNY, A., TUTAREL, O., DIMOPOULOS, K., UEBING, A., SHIINA, Y., ALONSO-GONZALEZ, R., LI, W., SWAN, L., BAUMGARTNER, H., GATZOULIS, M. & DILLER, G. (2016). "Meeting the challenge: The evolving global landscape of adult congenital heart disease."

Appendix 6: Teen Camp Case Study

Case Study: Teen Camp

In December 2021, HeartKids ran a Teen Camp for Aboriginal and Torres Strait Islander teens with heart conditions.

Problem Identification: Teens lost to care

It is estimated over half of Australians with childhood heart disease (CHD) are being 'lost to care.'^{1 2} In our Aboriginal and Torres Strait Islander population, this number is likely to be even higher due to barriers to accessing health care.³

Aboriginal and Torres Strait Islander teens with CHD are living in every state and territory in Australia. Australia's Indigenous population has among the highest rates of Rheumatic Heart Disease (RHD) diagnosis worldwide, which causes grief and heartache for many families and communities. Many teens with CHD face a lifetime of complicated and painful treatments and surgeries, which can contribute to them feeling isolated from other teens due to their health condition.⁴

Solution: Teen Camp

The Aboriginal and Torres Strait Islander Teen Camp was created in response to this need, with all expenses covered by HeartKids.

The three-day camp was designed to provide Aboriginal and Torres Strait Islander teens with heart conditions an opportunity to connect with other young people with similar conditions. Camp activities provided an opportunity for them to explore culture and identity, whilst building confidence, independence and knowledge surrounding their physical and mental health.



Background

Stakeholder and community engagement

To ensure that the camp was a medically safe and culturally responsive experience for all campers, extensive community and stakeholder engagement was undertaken.

This included consultation with:

- Health professionals who identify as Aboriginal and/or Torres Strait Islander and others working closely with this population group, including a Paediatric RHD Clinical Nurse Consultant
- Organisations and services including NACCHO, RHD Australia, Australian Institute of Clinical Innovation and the Royal Children's Hospital Transition Support Service
- Young people who had attended HeartKids camps in the past
- HeartKids' Health and Clinical Advisory Committee
- The Standards of Care for CHD Working Groups, especially those focused on priority populations, transition and consumers.

Campers

Campers were recruited through promotion on HeartKids social media and newsletters, via RHD Australia, through brochures in Aboriginal Community Controlled Health Centres, by cardiologists and cardiac nurses and Indigenous liaison officers in hospitals.

Campers provided extensive information on their medical histories, as well as social and emotional considerations. Each camper was signed off by their cardiologist or GP as being physically able to complete the planned activities.

Volunteers

The success of the camp can be attributed to the voluntary support we received from nine individuals with experience in nursing, cardiac care, Indigenous health and youth work. Overwhelmingly, all volunteers felt the camp was a wonderful experience.

HeartKids is incredibly grateful for their time, compassion and leadership.



Challenge: COVID-19

COVID-19 presented unprecedented challenges in the planning and delivery phases of Teen Camp 2021.

State border closures restricted any campers, volunteers or HeartKids staff from Victoria, New South Wales and South Australia from attending camp. The evolving situation meant that plans were changing weekly in the lead up to camp.

Solution: Communication, Flexibility and Expert Health Advice

The safety of our campers was the most important consideration in planning.

All aspects of camp were reviewed with a 'covid lens.' Flexible approaches were developed for different scenarios. A comprehensive Risk Management Plan was prepared which outlined potential COVID-19 risks, consequences and controls.

We engaged the HeartKids Health and Clinical Advisory Committee to provide expert health advice throughout the planning phases. As per their advice, all volunteers were fully vaccinated against COVID-19.

To ensure campers and their parents and guardians felt prepared for camp in light of the changing circumstances, the Project Coordinator had ongoing contact with them, via phone, email and a Zoom session that was scheduled. This communication was key to ensuring an attendance rate of 100%, as campers and their families felt prepared, confident, safe and enthusiastic about all aspects of the camp program.



The Camp Weekend

Campers and volunteers travelled from all over Australia to the Sunshine Coast, including from very remote communities. Campers participated in a range of physical, cultural and health-related activities.

The activities provided opportunities for campers to gain confidence and independence, and feel connected to others and their culture. All campers participated enthusiastically across all activities.

Both incidental and formally collected feedback indicates that campers not only enjoyed their experiences but felt as though the weekend enabled them to develop connections and ongoing friendships with other young people living with CHD.

Impact

Highlights include:

- Campers participating in vital health education, e.g. learning how to check and control their INR using a Coagucheck, with one camper taking one home as this was something she did not have access to
- Half the campers seeing the ocean for the first time, and all trying (and succeeding at!) surfing and paddle boarding
- The friendships established between the campers, formed through supporting each other in the physical activities, sharing their individual heart health journeys and as a product of the laughs and joy of being on camp
- The life skills and confidence gained by campers, especially those travelling from remote communities, including navigating airports and flights, catching Ubers, meeting new people from varying backgrounds, being away from family and friends and the independence that this brings.

100% of campers indicated that they would like to attend another HeartKids camp in the future.



Feedback

Campers

'All heart kids should go to camp because it's deadly!'

'Go on camp because it's really good and you will make friends.'

'Come on camp and meet with kids with heart conditions, make new friends, listen to others tell their story.'

'It was great. Make the camp longer!'

'It was the best thing I've done in my life.'

Volunteers

'It was a fantastic experience; I would love to volunteer again.'

'My favourite part of camp was seeing the kids encouraging each other and laughing and smiling and trying new things.'

'So many laughs and I have never seen them smile so much. I am so proud of them all.'

Parents

'Everyone in community was very excited for my child, she would like to attend again! Meeting other young people and making new friends was the best part.'

'It was a fantastic experience for my child because they had the chance to try things they have never tried before. Also, the ability to do these things around people who were aware of their condition. My child felt safe. They had an amazing time.'

References

¹ NICOLAE, M., GENTLES, T., STRANGE, G., TANOUS, D., DISNEY, P., BULLOCK, A., GRIGG, L., CHEN, S.S.M., PRESSLEY, L., CORDINA, R., HORNUNG, T., O'DONNELL, C. & CELERMAJER, D.S. (2019). "Adult Congenital Heart Disease in Australia and New Zealand: A Call for Optimal Care." *Heart, Lung and Circulation*. 28: 521-529

² KEMPNY, A., TUTAREL, O., DIMOPOULOS, K., UEBING, A., SHIINA, Y., ALONSO-GONZALEZ, R., LI, W., SWAN, L., BAUMGARTNER, H., GATZOULIS, M. & DILLER, G. (2016). "Meeting the challenge: The evolving global landscape of adult congenital heart disease." *International Journal of Cardiology*. 168: 5182-5189

³ HAYNES, E., MITCHELL, A., ENKEL, S., WYBER, R., BESSARAB, D. (2020). "Voices behind the Statistics: A Systematic Literature Review of the Lived Experience of Rheumatic Heart Disease." *International Journal of Environmental Research and Public Health*. 17(4): 1347.

⁴ AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (2013). *Rheumatic heart disease and acute rheumatic fever in Australia: 1996–2012. Cardiovascular disease series.* Canberra, ACT, Australia, Australian Government.



Appendix 7: Deliverables and Costings

Action Plan Focus Area 1: Standards of Care			
Action Plan Action	Deliverables	Itemised costs	Total cost
1.2 Develop authoritative national clinical practice guidelines on CHD for health services and health practitioners throughout Australia	<ul style="list-style-type: none"> Continue work with Standards of Care Steering Committee and Working Groups to produce the final prioritised national clinical practice guidelines, position statements and models of care for childhood heart disease including neurodevelopmental and mental health and transition Note, this work will be inclusive of Action Plan Actions: <ul style="list-style-type: none"> 2.5 Disseminate best practice information and approaches throughout services in Australia 4.3 Establish clear models of care for Neurodevelopmental care for CHD. 	0.8 FTE Project Coordinator \$324,000 Design and admin costs \$20,000 Technical writer/editor \$30,000 TOTALS Year 1: \$158,000 Year 2: \$108,000 Year 3: \$108,000	\$374,000
Action Plan Focus Area 2: Infrastructure			
Action Plan Action	Deliverables	Itemised costs	Total cost
2.3 Deliver education, training and support for health professionals	<ul style="list-style-type: none"> Ongoing preparation, promotion and evaluation of CHD education material, resources and support materials for health professionals 	0.8 FTE Project Coordinator (two years) \$180,000 Hosting and licensing \$90,000 Development \$40,000 TOTALS Year 1: \$140,000 Year 2: \$140,000 Year 3: \$30,000	\$310,000

Action Plan Focus Area 3: Awareness and Education

Action Plan Action	Deliverables	Itemised costs	Total cost
<p>3.2 Increase access to ongoing support by funding inpatient and outpatient community (peer) support team members</p>	<ul style="list-style-type: none"> Establish new HeartKids Support Coordinators based in hospital and community settings in currently underserved areas (Tasmania, Far North Queensland and the Australian Capital Territory) to provide support to individuals and families working alongside the clinical team to: <ul style="list-style-type: none"> Provide face-to-face support to families ensuring connected care before and after hospital admissions Facilitate connection to HeartKids community, peers as mentors, parents as advocates Provision of HeartKids programs and services tailored to family/community need Liaison between CHD cardiac coordinators and health service providers and cardiac social workers Establish the HeartKids “Reaching the Regions” Program with two regional based HeartKids Support Coordinators in Western Australian and the Northern Territory to Support specific high-risk areas and priority populations within the CHD community e.g., Rheumatic Heart Disease (RHD), geographically isolated areas, high needs teens and young adults heart kids and high-risk families suffering post-traumatic stress syndrome 	<p>5 x .6 FTE HeartKids Support Coordinators \$378,000</p> <p>Year 1: \$100,000</p> <p>Year 2: \$150,000</p> <p>Year 3: \$250,000</p>	<p>\$500,000</p>
<p>3.3 Increase the number of young people engaged with transition and ongoing specialist CHD care</p>	<ul style="list-style-type: none"> Deliver three HeartKids teen camps in 2023, four teen camps in 2024 and five teen camps in 2025 with a focus on including teens from priority populations and rural and remote regions. 	<p>0.6 FTE Teen Camp Project Coordinator \$180,000</p> <p>\$20,000 per metro camp</p> <p>\$30,000 per regional camp</p> <p>TOTALS</p> <p>Year 1: \$110,000</p> <p>Year 2: \$150,000</p> <p>Year 3: \$170,000</p>	<p>\$430,000</p>

3.4 Deliver awareness and education for non-health professionals	<ul style="list-style-type: none"> Working with subject matter experts, develop and deliver a suite of evidence-based, quality information and education materials and policy guidance for professionals working outside the health system to allow them to better support people with CHD in the community. This includes resources for: <ul style="list-style-type: none"> Childcare centres Education settings including schools and universities Community groups Sporting clubs Workplaces Deliver a community-based awareness campaign to improve understanding of CHD and its impact across the whole lifespan. 	0.4 FTE Communications Project Co-ordinator (two years) \$80,000 Material development and awareness campaign costs \$40,000 TOTALS Year 1: 60,000 Year 2: 60,000 Year 3: 0	\$120,000
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Action Plan Focus Area 5: Priority Populations

Action Plan Action	Deliverables	Itemised costs	Total cost
5.3 Evaluate current specialist outreach services for regional and remote communities, including remote Aboriginal communities, and fund outreach services where significant gaps exist	<ul style="list-style-type: none"> Coordinate the preparation of a comprehensive gaps report that includes service review and gaps analysis: <ul style="list-style-type: none"> To evaluate current specialist outreach services for regional and remote communities, including remote Aboriginal and Torres Strait Islander communities That provides recommendations for funding in outreach services to reduce barriers to accessing services due to geographical disparity in services 	Independent review and report preparation Year 1: \$0 Year 2: \$100,000 Year 3: \$150,000	\$250,000

5.4 Establish models of care for the transition of patients from paediatric to adult cardiac health services, including investment in transition nurses	<ul style="list-style-type: none"> Fund a HeartKids employed National Teen and Young Adult Transition Program Coordinator to: <ul style="list-style-type: none"> Form partnerships with primary care and emergency departments to identify young adults who are lost to follow-up and reconnect them with specialist CHD care Facilitate access to teen peer support and develop programs for teen personal growth, self-management and leadership. 	0.6 FTE National Teen and Young Adult Transition Program Coordinator role Year 1: \$0 Year 2: \$60,000 Year 3: \$60,000	\$120,000
5.5 Investigate options for reducing barriers to accessing care and supporting people with CHD and their families	<ul style="list-style-type: none"> Comprehensive report with actionable recommendations prepared including: <ul style="list-style-type: none"> Reviewing available support for people with CHD and their families and the experience of navigating existing services and government support including Carers Allowance, NDIS and Centrelink Review disability and carer payments to ensure children and adults with CHD can access required support. Investigate a national patient travel and accommodation assistance scheme (PATS) to overcome jurisdictional differences in eligibility and operation. 	Independent review and report preparation Year 1: \$60,000 Year 2: \$60,000 Year 3: \$0	\$100,000

Action Plan Focus Area 7: Surveillance

Action Plan Action	Deliverables	Itemised costs	Total cost
7.2 Invest in an economic burden of CHD report	<ul style="list-style-type: none"> Engage a health economist to prepare a consensus model for measurement of the economic burden of CHD (both direct and indirect costs) and to update this report every two years to monitor the impact of the Action Plan. 	Preparation of economic burden model and report Year 1: \$50,000 Year 2: \$50,000 Year 3: \$100,000	\$200,000
7.3 Invest in funding of the annual national CHD survey	<ul style="list-style-type: none"> Administer an annual national CHD survey to collect data from people with CHD, including their healthcare use and experiences, and the health, social and economic impact of living with CHD. 	Preparation and distribution of annual survey Year 1: \$66,000 Year 2: \$66,000 Year 3: \$66,000	\$198,000

Project Management and Administration

Action Plan Action	Deliverables	Itemised cost	Total cost
Project management and administration	<ul style="list-style-type: none"> Management and administration of Phase Two of the HeartKids Project 	Application of the industry standard 20% of project cost to cover management and administration overheads Year 1: \$228,000 Year 2: \$228,000 Year 3: \$228,000	\$683,000

HeartKids Cardiac Care Coordinators

Task	Deliverables	Itemised costs	Total cost
5.1 Fund CHD cardiac coordinators in each jurisdiction	<ul style="list-style-type: none"> Cardiac Care Coordinators employed by HeartKids located in each major children's hospital in Australia will coordinate and case-manage regional, rural and remote patients and families, including a focus on Aboriginal and Torres Strait Islander people and adolescent/young adult patients. CHD cardiac coordinators will focus on: <ul style="list-style-type: none"> Provision of specialist outreach clinics Coordination of surgery and interventional procedures Development of care pathways, including for transition Reducing failure to attend rates and improving transition to adult cardiac care Providing education to young people with CHD, their families and the health workforce. 	A total 6.5 FTE: <ul style="list-style-type: none"> Northern Territory 2.0 FTE based in Darwin and Alice Springs Western Australia 1.5 FTE based in Perth and Kimberley Queensland 1.5 FTE based in Cairns and Brisbane South Australia, New South Wales/ Australian Capital Territory, Victoria/ Tasmania 0.5 FTE each Year 1: \$312,000 Year 2: \$624,000 Year 3: \$624,000	\$1,560,000