DEADLY HEART TREK

Medical and educational visit to Indigenous communities in NT 2021 and QLD 2022

What is the Deadly Heart Trek?

The Deadly Heart Trek was developed as an opportunity to listen, learn, educate, diagnose and treat Aboriginal and Torres Strait Islander communities affected by rheumatic heart disease (RHD).

The project is led by a dedicated group of experienced doctors, local health workers and Indigenous leaders who are committed to progressing the prevention of rheumatic heart disease.

Principles of the Deadly Heart Trek

- Ensure Aboriginal and Torres Strait Islander leadership, engagement, and endorsement
- Maintain a culturally safe program: abiding by cultural protocols, adhering to cultural safety, and always acting with respect. All team members will have participated in a cultural session before going to community
- Adhere to community protocols, do no harm and work within ethical boundaries for Aboriginal and Torres Strait Islander communities
- Listen to the needs of each State/ Territory/community and deliver to their needs, with respect to RHD echo screenings, education, advocacy and treatment, and potentially upskilling local health workers
- Only work with communities that request support
- Monitor the COVID situation, ensure COVID safety and utilise the principles of the COVID hygiene education
- Adhere to the Endgame Strategy as per the END RHD Centre of Research Excellence

Where does the Trek go?

Initially, a warm-up Trek took place in the Northern Territory in September 2021 with several communities who were highly enthusiastic to invite the team to visit. Dr Bo Remenyi led a local medical delivery team and visited nine communities; five in the Big River Region and four in the Barkly region.

Once COVID travel restrictions were lifted completely, we recommenced plans for the National Trek, with QLD the first priority in August 2022. Dr Robert Justo and Dr Ben Reeves co-led the two trek delivery teams starting in Thursday Island and visited five communities across the Cape and Torres Strait regions.

There are now plans for Central Australia in 2023.

Who is involved?

The delivery team is a group of committed doctors, health workers, nurses and Indigenous community engagement leads, many are known in the community as they have worked in communities for decades on RHD. The two NT teams were all local, while the two QLD team included some team members outside QLD.

Governance: The Trek is governed by a National Steering Committee, members: leading paediatric cardiologists, an Aboriginal cultural engagement lead, social justice Aboriginal lawyer, and an independent philanthropic organisation. Both the delivery team and Steering Committee include Aboriginal and Torres Strait Islanders. Rigorous project management tools were used including a comprehensive risk matrix and checklists for pre, during and post the visits.

Key collaborators: The Snow Foundation, RHDAustralia, Champions4Change, Take Heart Project, HeartKids, RHD Control Programs, Heart Foundation Australia NT Cardiac, Orange Sky, One Disease, QLD Children's Hospital, Far North QLD Hospital Foundation.

Pre-visit community consultation, engagement and understanding

The Trek team included Aboriginal and Torres Strait Islander Community Engagement Leads who worked with the communities in advance. They sought permission and ensured the teams were invited to visit and then organised the logistics to prepare the communities. An informative 'Register your Interest' form was shared within communities, and they could select the activities they wanted. During this period, engagement with local health centres/clinics and Aboriginal Community-Controlled Organisations was established which provided vital support for the visit.

All members of the delivery team and the Steering Committee attended a mandatory cultural authority session with the Lead cultural advisor, Vicki Wade prior to the visits.

RHD CONTROL PROGRAMS QLD, NT, SA, WA

What happened in community?

Upon arrival, the teams were warmly welcomed by community members, including Traditional Owners and Elders where possible, and further discussions were held with local organisations to ensure community understanding and empowerment. The major focus of the Trek was education, and heart screenings so that RHD could be diagnosed and treated early.

A large part of the work was done in schools and some at youth and community centres or local organisations. Children were reviewed for healthy hearts and healthy skin, and general well-being. The local communities were extremely helpful, assisting with the coordination of consents, to maximise the number of kids' echo screenings.

Each evening and morning, the Trek team held briefing sessions, and discussed learnings of the day and prepared for the next day.

Education and awareness

Education sessions and activities were provided to students and teachers at the schools. Sessions varied by community with some communities, especially in the NT, holding specific educational and awareness events for the entire community such as BBQs, movie screenings of the Take Heart documentary and some fun soccer activities. Many youth service providers enjoyed these enabling them the opportunity to collaborate and support the Trek.

During school sessions, Trek team members presented an entertaining session on 'healthy heart' and 'healthy skin' and outlined the Echo screening process.

Songs produced by other communities called 'boom boom' and 'my heart keeps beating', were a real hit with the students in educating them on how to prevent RHD. Gift packs with sponsor-donated items such as socks and bracelets were a welcomed treat at the end of the sessions.

Treatment and follow-through during the visit

All children who were diagnosed with borderline or definite RHD were treated on the same day, following parental consent.

The new RHD patients were formally registered on the control program and linked to standard treatment and cardiology care.

A large number within the NT communities had various skin diseases and were treated immediately. Children with other health conditions were also treated on the same day and linked to health services for long-term management.

Results from the NT and QLD Communities

	NT	QLD
Communities visited	9	5
Hearts screened + skin checked	873	978
Healthy hearts	819	931
New RHD cases diagnosed and treated*	26	28
Known definite RHD	14	15
New congenital heart disease	14	8
Cases of scabies, skin infections**	75	low
% of children with definite RHD	2.9%	2.5%

*New RHD cases breakdown: definite 10 QLD & 11 NT; borderline 18 QLD & 15 NT

**Where skin infection was identified, all cases were treated and where needed referred to the health clinic

The regions visited have a very high burden of RHD with 2.9% for NT and 2.5% for QLD. The World Heart Federation considers a community where more than 0.1% of children have RHD, to be a high burden.

- All new cases appropriately reviewed and treated
- All previously known RHD cases were treated
- Skin – burden of scabies was high in NT, all children's skin was reviewed and treated

Education and increasing awareness of RHD, healthy hearts and healthy skin was a fundamental part of the Trek. Children and families participated, 1,500 in NT and 3, 000 in QLD (figures are an estimate)

Post-visit follow-up and feedback

Following the visits, standard medical follow-up will be carried out for all those new cases identified, who are now on the RHD register.

In addition, an online survey was sent directly to the communities to gain feedback across all aspects; community engagement, education/awareness, medical treatment and diagnosis, cultural appropriate and safe delivery.

Feedback from all NT and QLD communities was very positive, responding that they greatly benefited from the visits and would welcome the team back. They also reported they would recommend the Deadly Heart Trek team to other communities.

For the NT community data, the health boards of Barkly and the Big River Regions have their corresponding summary community data sets and all NT communities have their own set of data. For QLD communities, almost all have been given their own specific community data.

We are now writing to and meeting relevant Government members and stakeholders with the data findings and learnings. Aggregate data by region is being shared, not specific community data as this is the communities data.

"There was great preliminary communication in the lead up to the day which allowed us to share the information with our parents and the wider community. Follow-up communication with parents/ carers of students was excellent."

"It was amazing to have so many medical professionals visit our remote school in a coordinated activity that benefits and supports the health of so many students and community members. Thank you from the bottom of our happy, healthy pumping hearts!"

Learnings and benefits

The learnings from the NT Trek were integrated into the planning and delivery for QLD. Additional learnings are being discussed for further Treks. Below is a high-level insight into some learnings, many of these reaffirmed our principles and our community checklists:

- Community engagement and participation must be at the heart of the project for success. They're needed at every stage – pre, during, and after the Trek to ensure cultural safety, inclusiveness, comprehensiveness, and local ownership.
- Developing and maintaining mutual understanding and collaboration helps to create healthy communities and strong local public health systems.
- Critical to have Aboriginal and Torres Strait Islander members within the project team and delivery team, to ensure empowerment, leadership, appropriate project design, and proper community engagement.
- An Indigenous community lead within the delivery team increased the communities' trust, acceptance and understanding of the Trek team and the activities being delivered.
- Community engagement prior to the Trek and having a community lead within the team, has built up and strengthened partnerships between community and medical teams. The positive impact is huge. It not only improves the delivery of important medical activities but it breaks down systemic problems in health centres.
- The inclusion of some junior health workers and doctors on the delivery team helped upskill their knowledge and understanding of Indigenous health and Indigenous communities.
- A listening, learning, and flexible approach and listening to community with a positive, open, and responsive attitude is crucial. This includes caution around sorry business and amending plans when sorry business is taking place.
- Community engagement was done remotely prior to the Trek. For Future treks, a pre-visit in community by a Trek member would be beneficial, to ensure a greater understanding of activities, especially consent for the heart screenings. This could be a First Nations person and/ or a health worker.
- For future, ideally our Community engagement lead would meet with Traditional Owners/Elders well in advance of arrival (even a zoom), to become more familiar with the community and services provided and needed.
- Written consent for heart screenings continues to be challenging and having a key school lead with commitment and good processes made a huge difference, one junior school had almost their entire students consent prior to arrival. More engagement to identify the key school lead is important in order for more consent prior. However, each community is different. Consider including in general health consents for some communities who may be more educated on RHD but caution on ensuring true consent.
- The communities benefited greatly by having accessibility to doctors and health workers and providing a comprehensive view of their health.

Recommendation

Extra efforts need to be made to address RHD and scabies in these communities both Federally and by State and Territory.

We are pleased there has been a commitment from the Albanese Government to more than double the funding for the elimination of RHD in Australia, increasing from $6 million to $13.5 million nationally. We also urge each State and Territory to commit additional funds. By taking greater action and providing more funding, we can make a difference in the lives of the thousands of Aboriginal and Torres Strait Islander people living with RHD and meet our obligation to prevent and eliminate RHD by 2030 under the World Health Organisation's 2018 international resolution, to which Australia is a signatory.

We have a philanthropic partner, The Snow Foundation who is engaged and willing to contribute to a greater commitment.

The RHD Endgame Strategy Report clearly outlines what needs to happen to both prevent people from developing ARF and improve the quality of life of those living with RHD. The Report called for an initial investment of $40 million over 3 years for Phase 1 implementation to establish the national implementation unit, invest in community-level action and support jurisdictional action plans. This investment is needed now as a minimum to meet its 2030 target.

We recommend this listening and action work, by the Trek team, be business as usual for communities with a high burden of RHD and who don't have easy access to health workers. The Trek team is developing an overview of what this could look like, and it will include recommendations to include a First Nations health worker and/or community engagement lead as part of the team.

Future of the Deadly Heart Trek

A Trek to communities in Central Australia is being planned for March 2023, and further Treks to communities across the country are under consideration.

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Data

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