

WORLD CONGRESS ON RHEUMATIC HEART DISEASE

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Title: DEADLY HEART TREK: COMMUNITY-CONSULTATION AND CULTURE DRIVEN CARE INITIATIVES TO ENHANCE RHEUMATIC HEART DISEASE ELIMINATION IN REMOTE & REGIONAL COMMUNITIES IN AUSTRALIA

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Background & Aims: Australia has some of the highest rates of acute rheumatic fever and rheumatic heart disease (ARF/RHD) in the world. Most are Aboriginal and Torres Strait Island children and youth living in remote regional communities. The Deadly Heart Trek, a community-led healthcare collaboration, created by paediatric cardiologists, First Nations leaders and philanthropy in 2021 has improved the way RHD programs can listen, learn, and respond to First Nations communities. The Deadly Heart Treks are a collaborative, culturally safe community focused preventative model for ARF/RHD developed to address these alarmingly high rates in First Nations children of Australia.

Methods: The Treks are predominately prevention responses to ARF/RHD complementing diagnostic and medical intervention. The program responds to and supports communities with education on heart and skin, early diagnosis and treatment. Teams include First Nations Cultural Leaders and Educators, Paediatric Cardiologists, Infectious Disease Specialists, Sonographers and Nurses. Prior to and throughout the Trek, community consultation and permissions occur with First Nations and government leaders, land-councils, traditional landowners, health clinics, schools and community members. The teams are invited to visit remote regional communities across Australia. Prior to entry, cultural messaging and safety practices are shared daily. Teams use a variety of resources in language to educate children and community including prevention, Strep A infections. Children are screened for RHD and skin disease. Successful engagement includes classroom education, barbeques, films, songs, and sports. Qualitative interviews and post-program survey analysis with community and Trek teams are used to assess the program's ongoing improvement.

Results: First Nations leadership and community voices were critical to its success.

First Nations children aged 3-16 years in 36 regional and remote Central and Northern Australian communities were provided heart screening, skin checks and education between 2021-2023.

Approximately 2, 700 children had their hearts and skin checked. All children and some teachers, family members, and community engaged with heart and skin educational activities.

Raised awareness of causes of ARF and RHD and how to prevent ARF.

All activities enhanced community empowerment, trust and self-determination.

Post survey results demonstrated meeting key success measures of 'community invitation to return' in 100% of communities. Furthermore, 100% of communities recommended the program to other communities enhancing projected reach for future projects. Experienced healthcare and community members provided direct feedback about culturally appropriate and safe delivery of the program leading to sustained knowledge about RHD.

Conclusions: RHD remains endemic in remote First Nations communities in Australia. The Deadly Heart Trek has successfully delivered RHD prevention and intervention strategies. First Nations leadership, cultural knowledge and consultation have been the foundational priorities ensuring the success of Deadly Heart Treks. These critical elements must be central to community initiatives going forward to enable success and ongoing feedback pathways to and from community.

Culturally safe education, early detection, and improved surveillance for First Nations Australian children is essential to tailor a public health response that empowers a community-led response to address the high burden of heart and skin disease.