

Bridging the gap between science and indigenous cosmologies: Rheumatic Heart Disease Champions4Change

Vicki Wade^{A,*} and Maida Stewart^A

For full list of author affiliations and declarations see end of paper

***Correspondence to:**

Vicki Wade
Rheumatic Heart Disease Australia,
Menzies School of Health Research,
Charles Darwin University, Darwin, NT,
Australia
Email: vicki.wade@menzies.edu.au

ABSTRACT

Australia has articulated a commitment to eliminate rheumatic heart disease (RHD) by 2031. Business as usual will not achieve this goal. Diverse sectors need to work together in implementing complementary strategies towards this ambitious target. Rheumatic Heart Disease Australia's 'Champions4Change' program is one important element that provides a novel and vital approach. Champions4Change is a culturally safe program of people living with acute rheumatic fever (ARF) and rheumatic heart disease (RHD). The Champions support each other, advocate for ending RHD, design education and awareness programs and inform resource and program development through their lived experiences. New approaches that acknowledge the complex and challenging environments in which ARF/RHD exist are required to eliminate RHD and improve care for those living with ARF/RHD. Approaches taken by the program include local engagement, improved capacity and opportunities for Champions and their communities to make self-determined decisions based on culturally informed information. This paper highlights success stories using culture and locally appropriate approaches to improve community knowledge and awareness of RHD. We describe the rationale, development and purpose of Champions4Change, illustrating how this is far more than a peer-support group, and provides benefits for health services and researchers, as well as empowering community members.

Keywords: acute rheumatic fever, culturally appropriate care, indigenous health, peer support, rheumatic heart disease.

Introduction

Group A Streptococcus can result in post-infectious sequelae including acute rheumatic fever (ARF), and rheumatic heart disease (RHD). The link between streptococcal pharyngitis and impetigo, and the diverse manifestations of ARF – chorea, sore joints and damaged heart valves – can be very challenging to explain and understand. This is compounded in Australia's high-risk settings (remote areas, poor housing and infrastructure) where there might be language barriers and diverse cultural knowledges relating to illness causation and germ theory. Breaking down these complexities for communities is a critical part of disease prevention, empowerment and health literacy.

The Champions4Change program is an Australia-wide network of community members affected by acute rheumatic fever (ARF) or rheumatic heart disease (RHD), established in 2018 by Rheumatic Heart Disease Australia. Champions are people with ARF or RHD, or someone caring for them. Champions share personal stories and insights, and inspire others whose lives are affected by ARF/RHD. The name was chosen to describe who champions are and what they represent: 'Champions4Change – sharing, caring and inspiring'. Champions4Change is the first program of its kind in Australia. It aims to privilege and promote the voices of its Champions, acknowledge and respect Aboriginal cosmologies (world views), support Champions in their lives and work, and put culture, country and community at the centre of responses to RHD.

The value of peer support

Chronic disease peer support programs have demonstrated a wide range of benefits including high levels of satisfaction by participants, increased health knowledge, improved social support and social connectedness, emotional wellbeing and reductions

Received: 19 July 2022

Accepted: 12 September 2022

Published: 3 October 2022

Cite this:

Wade V and Stewart M (2022)
Microbiology Australia
43(3), 89–92. doi:[10.1071/MA22030](https://doi.org/10.1071/MA22030)

© 2022 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of the ASM. This is an open access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License ([CC BY-NC-ND](https://creativecommons.org/licenses/by-nc-nd/4.0/))

OPEN ACCESS

in patient care time required by health professionals.¹⁻³ Within Australia, Aboriginal community and family support programs have been implemented across diverse care settings and health conditions including cancer, diabetes, asthma, child and maternal health and drug and alcohol and sexual health.⁴⁻⁷

Among Aboriginal people in the Northern Territory, where language diversity is amongst the highest in the world, there is a real need to provide accessible information and more support for ARF and RHD.^{8,9} In Uganda, a RHD peer-support program showed improved health-related quality of life scores improving social connectedness.¹⁰

In Australia a small, pilot peer group of young Aboriginal people from the Darwin area brought participants closer, feeling supported by each other.¹¹

The need for new approaches

Conventional health promotion messages sometimes assume that information is enough to modify behaviour. There is now considerable evidence demonstrating that health promotion in Aboriginal contexts is most effective when based on principles of self-determination including co-design and community-focused actions. Moving beyond standard principles of health promotion, Champions4Change draws on cultural cosmologies – that is, an appreciation of diverse Aboriginal world views and understanding of the functions of the universe – to provide a strengths-based approach. This supports and activates existing strengths, and develops abilities and critical thinking skills to facilitate action for change and a greater sense of control.¹²

Improving access to information, support and self-management capacity are important in improving the lived experience of ARF and RHD.¹³ In a study promoting delivery of penicillin for secondary prevention of ARF, positive community engagement was recognised as a key required strategy to achieve success.⁸

Champions have the potential to play a critical role in closing the gap in health care for Aboriginal and Torres Strait Islander peoples with ARF or RHD. The Champions share and translate the meaning of health from an Aboriginal perspective into ways that allow service providers to understand what it is like to be living with ARF or RHD. This two-way learning drawing on ‘lived experience’ both empowers the community and benefits the health service, providing critical insights for healthcare providers into the everyday realities of ARF/RHD.

Embedding culture and connectedness into RHD care

Our approach with Champions4Change is to look beyond the biomedical model to the cultural, political and environmental factors that underpin these medical conditions.

The Champions developed a model, ‘Keeping Our Campfires Burning’ (Fig. 1), to describe the vision and implementation of the program. They wanted a clear message about staying strong in culture and feeling connected, to look after



Fig. 1. Keeping our Campfires Burning model.

themselves, their families and communities. The model has seven elements representing the whole, in keeping minds and bodies connected and strong. We are all connected to the fire like embers rising from the fire. These elements keep our fires alive and burning.

To work effectively with Aboriginal and Torres Strait Islander communities, acknowledgement and understanding of the unique cultures of First Nations peoples is needed. As some of the oldest living cultures on this planet, the richness, diversity and complexities of our cultures needs to be appreciated in a respectful and competent way. It is also necessary to acknowledge the impacts that colonisation has had, and continues to have, on the health and wellbeing of Aboriginal and Torres Strait Islander peoples.¹⁴

Champions4Change draw on their cultural knowledge to bring a richer understanding of what it truly means to be living with ARF and RHD. Champions, comprising culturally diverse Australian First Nations community members, draw strength from their own complex social structures which define roles and responsibilities to keep communities functioning safely. These roles include passing on and sharing knowledge, a process at the heart of traditional Aboriginal culture based on the kinship system.

Despite recent advances in the biomedical treatment of RHD, the associated health benefits at a population and community level have not been fully realised for Aboriginal and Torres Strait Islander peoples. Devastating health outcomes still occur in young people. Many of the barriers to better health sit outside the biomedical domain, driven by cultural, political and environmental factors. These challenges – the legacies of colonisation – require a shift in public health and research imperatives to generate healthy societies.¹⁵

Shaping health messages: the power of personal stories

There is significant power in the ability of personal stories to create understanding and change minds. For many years data showing high morbidity and mortality associated with ARF and RHD were presented in the medical literature

and at conferences. The figures roll off the tongue like a mantra. The Champions provide an opportunity to put a face to the statistics, telling first-hand the stories of being diagnosed with and living with ARF or RHD: stories about caring for a young child with the condition; the challenges of interacting with the healthcare system; critical insights that healthcare providers, policy makers and politicians need to hear. In a clinical environment, patients lack empowerment or opportunity to provide their story as they are rushed through a list of questions about signs and symptoms and whether they are adhering to treatment. Champions4Change provide an avenue to redress the balance. They are regularly invited to address health conferences at which moving experiences of the devastating impacts of these conditions are shared.

Success stories: champions in action

Chief among their efforts, Champions make sure that culture, language and understandings shape local health messaging. This is critical, for example, in places like Maningrida in the NT, one of the most linguistically diverse communities in the world, with 15 languages spoken and a high burden of RHD. Acknowledging the achievements of Champions in developing innovative multi-lingual education and awareness programs, Champions4Change was featured as an 'Aboriginal and Torres Strait Islander-led transformation' in the 2022 Close the Gap report.¹⁶

The Dillybag project

Champions4Change identified the need for culturally appropriate resources they can use within their communities. We developed, co-designed and attracted seed funding for a project currently underway called The Dillybag Project. The resources being developed, in English and selected Aboriginal languages, will help fill the gap in essential information about ARF and RHD. Content is fully designed for and by the communities living with, and at risk of ARF and RHD. Educational workshops will support the use of resources in communities for the Champions. The Dillybag project is designed to:

- Improve awareness and knowledge of what causes ARF and RHD and how to prevent ARF and RHD reflecting best practice care.
- Improve confidence and capability of individuals and communities to make informed decision about their care.
- Produce resources to improve community and health professional education and training.
- Be the foundation of a health promotion campaign.

Using hip hop and music

Champion Anne-Marie from Barunga worked with a leading national children's entertainer, Justine Clarke, and school children in her community, to create a music video called 'Boom Boom' (<https://www.youtube.com/watch?v=X7HqzJafAr8>). The video contains RHD prevention messages and was made

in partnership with Skinnyfish music, END RHD, Menzies School of Health Research and Bupa Foundation. It has been shared widely on social and mainstream, receiving positive local feedback.¹⁷

Lúrra RHD project, Maningrida, East Arnhem land

The Lúrra RHD project arose during a medical research project in which community echocardiographic screening of children was being conducted in Maningrida and surrounding homelands.¹⁸ Recognising the need for local language resources, a set of lessons on RHD for school students was developed by the school's Language and Culture Team, an experienced community health educator, and locally based Champions4Change, to create a curriculum of lessons on core RHD primary health messages in local languages. The units cover body systems such as the circulatory and immune systems, and germ theory of disease. Key primary and environmental health care messages are embedded throughout.

Future aspirations

In Australia, RHD is a First Nations health issue. Solutions must be informed by First Nations peoples. Champions4Change provides a unique mechanism to bridge the divide between community needs and knowledge, and Western medical approaches to ARF and RHD prevention and management. Two-way learning that informs health services and empowers community members is a crucial part of the journey towards RHD elimination. Programs such as Champions4Change have been shown, both internationally and nationally, to assist hard to reach communities with complex social and cultural needs. Achievements of Champions4Change to date highlight the unique role community members with lived experiences of RHD can play. Sustained funding to continue and expand our work is a priority.

References

1. Walker C, Peterson CL (2021) Where does value lie in peer support? An exploratory discussion of the theories and methods underpinning effective research in peer support. *Qual Health Res* 31, 218–227. doi:10.1177/1049732320964173
2. Fisher EB *et al.* (2018) Peer support in prevention, chronic disease management, and well-being. In *Principles and Concepts of Behaviour Medicine*. pp. 643–677. Springer, New York, NY. doi:10.1007/978-0-387-93826-4_22
3. Zimmerman CT *et al.* (2022) The roles of quality of life and family and peer support in feelings about transition to adult care in adolescents with gastroenterology, renal, and rheumatology diseases. *J Pediatr Nurs* 62, 193–199. doi:10.1016/j.pedn.2021.04.032
4. Duley P *et al.* (2017) The Strong Family Program: an innovative model to engage Aboriginal and Torres Strait Islander youth and Elders with reproductive and sexual health community education. *Health Promot J Aust* 28, 132–138. doi:10.1071/HE16015
5. Liaw ST *et al.* (2016) Safe and effective cultural mentorship in general practice. *Aust Fam Physician* 45, 431–436.
6. Bentley M (2008) *Evaluation of the Peer Education component of the Young Nungas Yarning Together program*. South Australian Community Research Unit, Flinders University.
7. Munns A *et al.* (2016) The emerging role of the urban-based aboriginal peer support worker: a Western Australian Study. *Collegian* 23, 355–361. doi:10.1016/j.colegn.2016.08.007
8. Read C *et al.* (2018) Qualitative evaluation of a complex intervention to improve rheumatic heart disease secondary prophylaxis. *J Am Heart Assoc* 7, e009376. doi:10.1161/JAHA.118.009376

9. Belton S *et al.* (2018) Rheumatic heart disease in pregnancy: how can health services adapt to the needs of Indigenous women? A qualitative study. *Aust N Z J Obstet Gynaecol* **58**, 425–431. doi:10.1111/ajo.12744
10. Scheel A *et al.* (2018) The impact of a peer support group for children with rheumatic heart disease in Uganda. *Patient Educ Couns* **101**, 119–123. doi:10.1016/j.pec.2017.07.006
11. Leda S *et al.* (2021) Improving the well-being for young people living with rheumatic heart disease: a peer support pilot program through Danila Dilba Health Service. *Health Promot J Austr* **33**, 696–700. doi:10.1002/hpja.533
12. McPhail-Bell K *et al.* (2015) 'We don't tell people what to do': ethical practice and Indigenous health promotion. *Health Promot J Austr* **26**, 195–199. doi:10.1071/HE15048
13. Haynes E *et al.* (2020) Voices behind the statistics: a systematic literature review of the lived experience of rheumatic heart disease. *Int J Environ Res Public Health* **17**, 1347. doi:10.3390/ijerph17041347
14. Hinchliffe S *et al.* (2018) Healthy publics: enabling cultures and environments for health. *Palgrave Commun* **4**, 57. doi:10.1057/s41599-018-0113-9
15. Mohamed J *et al.* (2022) Close the Gap Campaign Report 2022. Transforming power: voices for generational change. In *A report prepared by the Lowitja Institute for the Close the Gap Steering Committee*. <https://humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/close-gap-2022>
16. Knowles R (2019) Heartfelt song beats back infection. *National Indigenous Times*. 16 July. <https://nit.com.au/heartfelt-song-beats-back-infection/>
17. Francis JR *et al.* (2021) Single-view echocardiography by nonexpert practitioners to detect rheumatic heart disease: a prospective study of diagnostic accuracy. *Circ Cardiovasc Imaging* **14**, e011790. doi:10.1161/CIRCIMAGING.120.011790
18. Mitchell AG *et al.* (2021) Using community-led development to build health communication about rheumatic heart disease in Aboriginal children: a developmental evaluation. *Aust NZ J Public Health* **45**, 212–219. doi:10.1111/1753-6405.13100

Data availability. Data sharing is not applicable as no new data were generated or analysed during this study.

Conflicts of interest. The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Declaration of funding. This research did not receive funding.

Acknowledgements. We thank Professor Anna Ralph for editorial assistance.

Author affiliation

^ARheumatic Heart Disease Australia, Menzies School of Health Research, Charles Darwin University, Darwin, NT, Australia.

Biographies



Vicki Tooditj Wade is a Noongar woman from the Gorenj, Minang, Bibelmen and Wadjari tribes in the south west of Western Australia. Vicki has worked for over 40 years in health and during that time has held many senior positions at state and national levels. Vicki has spent many of these years working in improving the heart health of her people. Vicki sits on the Close the Gap steering committee, as well as several research and health committees across Australia. For her efforts, Vicki has received two prestigious awards: first, the CSANZ achievement award for working with First Nations people in heart health; and second, the Sidney Sax medal for her outstanding contribution to the health system in Australia. Vicki is the Director for RHD Australia and hopes one day her long-time efforts will have contributed to closing the gap for her grandchildren and their children.



Maida Stewart is a Wemba Wemba/Wergaia woman who has lived in the Northern Territory for over 29 years. For the past 18 years, Maida has been working as an Aboriginal Health Practitioner with the [Danila Dilba Health Service](#) in Darwin, Northern Territory, where she provided culturally appropriate and responsive health care to Aboriginal and Torres Strait Islander communities in the greater Darwin region. Maida has extensive experience in primary health care practice, and in health education and promotion. She's worked in the areas of women's health, child and maternal health, acute healthcare, mobile outreach and has been employed as a chronic disease coordinator. In 2018, Maida was awarded a [Churchill Fellowship](#) that focused on examining healthy housing in relation to primary prevention of ARF/RHD, which took her to Auckland on Aotearoa's (New Zealand) North Island in early 2020 to investigate the [Healthy Homes Initiative](#). Starting with RHD Australia in March 2021 as the Champions4Change Project Coordinator, Maida is the main point of contact for the Champions4Change program. She works closely with senior cultural advisor, Vicki Wade to develop, coordinate, and implement strategies and resources that provide training and education to Champions in the program. By establishing and building meaningful relationships and encouraging networking between individuals and communities, Maida will work with Champions to prioritise their social and emotional well-being, and support their capacity building, community education, and health promotion activities.