

Community leadership and empowerment are essential for eliminating rheumatic heart disease

Jonathan R Carapetis¹, Alex Brown^{2,3}

The major impediments to control are lack of commitment, funding and coordination, not lack of knowledge

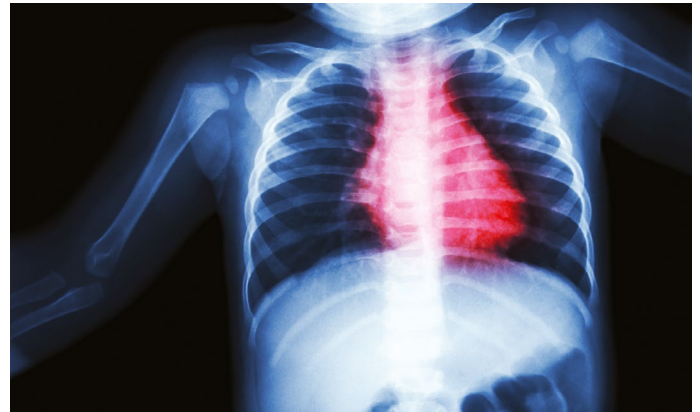


It has been a long time coming, but Australia is starting to understand the tragedy and injustice of rheumatic heart disease (RHD) in Aboriginal and Torres Strait Islander people. No condition is more emblematic of “the gap”: in Australia, the burden of RHD is borne almost exclusively by Indigenous people, with rates among the highest in the world. It is a disease with social determinants, including poverty and overcrowded housing, it starts in childhood but stretches into adulthood, it kills people prematurely, and, most devastatingly, it is preventable. The major impediments to its being controlled or even eliminated are lack of commitment, funding and coordination, not lack of knowledge.



Over the past five years, a network of researchers and service providers has come together in the National Health and Medical Research Council-funded End Rheumatic Heart Disease Centre of Research Excellence. The Centre is about to publish *The RHD Endgame Strategy: The blueprint to eliminate rheumatic heart disease in Australia by 2031*. It has already modelled what will happen if we fail to alter course in RHD control: more than 10 000 Indigenous Australians will develop RHD over the next 11 years, of whom 563 will die and 1370 will require heart surgery as a direct consequence of RHD. More than \$317 million would be needed for their medical care alone.¹

Hearteningly, END RHD, a coalition of organisations led by the Aboriginal Community Controlled Health Organisation (ACCHO) sector, has formed to support communities at greatest risk of RHD, to advocate implementation of the Endgame Strategy, and to educate Australians about the role they can play in ending RHD. END RHD is co-chaired by the chief executive officer of the National Aboriginal Community Controlled Health Organisation, Ms Pat Turner AM, and includes representatives from ACCHO peak bodies in each of the jurisdictions in which RHD is a major problem. END RHD embodies the essential elements of what is needed to rid Australia of this devastating disease: Indigenous leadership, community empowerment, and a primary focus on the social determinants of disease, in addition to strategies targeting streptococcal A skin and throat infections and care for people with established RHD.



A study in this issue of the *MJA*² highlights RHD care, other elements needed to implement the Endgame Strategy, and some of the challenges in doing so. Francis and colleagues report a cross-sectional echocardiographic screening survey of children and young people in the remote Northern Territory community of Maningrida. They found an extraordinarily high prevalence of definite RHD (5.2% of screened people aged 5–20 years), of whom 62% had previously been undiagnosed and 25% had severe disease.

This project had many admirable elements that could inform activities in other communities. The focus on education and health promotion in local languages, intense community engagement, and local leadership were exemplary, to which the very high participation rate is testament.

However, a range of questions remain unanswered. Why, for instance, are the reported results so different from the findings of the gECHO study,³ conducted a decade earlier? In this study, in which almost 4000 Indigenous children aged 5–15 years in remote communities across northern and central Australia were screened, the prevalence of definite RHD was 0.86%; 53% of cases were previously undiagnosed, and only one in 18 new cases was severe. While the prevalence of definite RHD was highest in the Top End of the NT (1.5%), where Maningrida is located, the threefold difference in prevalence between the two studies is remarkable. A single community may not be representative of an entire region, but if the Maningrida findings are to stimulate consideration of more widespread screening, how one identifies communities in which it is warranted is critical.

The difference in prevalence found by the two studies is difficult to explain. There is no evidence that socio-economic determinants of group A streptococcal infections and RHD had dramatically worsened in this region over the past 10 years to a degree that would explain such discordance. However, four years prior to the study by Francis and colleagues, a large cluster of acute rheumatic fever (ARF) cases was identified in Maningrida: more than 1.5% of 5–14-year-old children developed ARF over a 6-month period.⁴ As most people with RHD in the NT do not

¹ Telethon Kids Institute, Perth, WA. ² South Australian Health and Medical Research Institute, Adelaide, SA. ³ University of Adelaide, Adelaide, SA. ✉ Jonathan.Carapetis@telethonkids.org.au
 • doi: [10.5694/mja2.50695](https://doi.org/10.5694/mja2.50695) • See Research (Francis).
 Podcast with Jonathan Carapetis available at mja.com.au/podcasts

have known histories of ARF, and ARF can be very mild or even asymptomatic, it is likely that a substantially greater proportion of Maningrida residents had ARF at this time.⁵ Such a significant outbreak has rarely, if ever, been reported for an Indigenous community, and the study of Francis and colleagues may have included a number of RHD cases related the ARF outbreak four years earlier.

Francis and his co-authors also point out that auscultation is still used in child health checks in NT Indigenous communities. This approach, however, is less accurate than flipping a coin for diagnosing RHD, and should therefore be abandoned for this purpose.⁶

We commend the authors for the careful wording of their recommendations. They recognise that echocardiographic screening may have obvious benefits; besides detecting new cases of RHD and facilitating life-saving treatment and secondary prevention, it is an excellent tool for motivating a community to focus on RHD, which, together with education about prevention and related activities, can enhance engagement. But it is also intensive and costly: hence the need to focus on more practical methods for implementation, as the authors point out, but also to ensure that communities are advised about a threshold for screening in accordance with established criteria. They must also be provided with adequate technical support and advice before embarking on such screening programs.

Australia has a rare opportunity to eliminate RHD by implementing the Endgame Strategy. In so doing, we will make an important step towards closing the health gap between Indigenous and non-Indigenous Australians, not only by reducing the burden of RHD but also the burdens of other diseases that share

similar social determinants. But success depends on communities being supported to direct local strategies that comprehensively address streptococcal A infections, ARF and RHD at many levels. Maningrida is a perfect example.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

© 2020 AMPCo Pty Ltd

- 1 Cannon J, Katzenellenbogen JM, Wyber R, et al. The cost of inaction on rheumatic heart disease: technical report of the predicted human and economic toll of rheumatic heart disease for Aboriginal and Torres Strait Islander people by 2031. Perth: Telethon Kids Institute, 2018. <https://endrhdt.telethonkids.org.au/siteassets/media-docs---end-rhd/research-docs/the-cost-of-inaction-on-rheumatic-heart-disease---technical-report.pdf> (viewed June 2020).
- 2 Francis JR, Fairhurst H, Hardefeldt H, et al. Hyperendemic rheumatic heart disease in a remote community: a prospective study using echocardiographic screening to determine disease burden. *Med J Aust* 2020; 213: 118–123.
- 3 Roberts K, Maguire G, Brown A, et al. Echocardiographic screening for rheumatic heart disease in high and low risk Australian children. *Circulation* 2014; 129: 1953–1961.
- 4 Francis JR, Gargan C, Remenyi B, et al. A cluster of acute rheumatic fever cases among Aboriginal Australians in a remote community with high baseline incidence. *Aust N Z J Public Health* 2019; 43: 288–293.
- 5 Hardie K, Ralph AP, de Dassell JL. RHD elimination: action needed beyond secondary prophylaxis. *Aust N Z J Public Health* 2020; <https://doi.org/10.1111/1753-6405.13002>.
- 6 Roberts KV, Brown AD, Maguire GP, et al. Utility of auscultatory screening for detecting rheumatic heart disease in high-risk children in Australia's Northern Territory. *Med J Aust* 2013; 199: 196–199. <https://www.mja.com.au/journal/2013/199/3/utility-auscultatory-screening-detecting-rheumatic-heart-disease-high-risk> ■