

REPLY

Reply: Resetting policy and practice for prevention of acute rheumatic fever among Aboriginal and Torres Strait Islander people

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FULL ARTICLE:

Dear Editor

The clonidine case study published in *Rural and Remote Health* describes an endeavour by an Aboriginal Community Controlled Health Service to address pain-related distress in Aboriginal children with acute rheumatic fever (ARF)¹. It is written from a biomedical perspective, and the off-label use of a medication it discusses must only be seen as a stopgap while the critical work of preventing ARF in the first instance is undertaken.

ARF research has historically been framed from non-Indigenous and biomedical perspectives, reflecting the power difference between Indigenous and non-Indigenous people. However, more non-Indigenous researchers are gaining understanding of cultural safety and are willing to work with Indigenous researchers as equals incorporating a desire to learn, and Indigenous researchers are providing leadership around choice of topic, research

questions and ways that studies are designed and conducted.

Recent collaborative work confirms this change in direction as seen in the work of Kerrigan et al² reporting the first multi-site effort in Australia to strengthen prevention in a community-based program led by Aboriginal Community Workers. Further culturally aligned activities include community-led development incorporating Indigenous knowledge, languages and, importantly, collaborative leadership, to build health messaging around ARF and training for Aboriginal community members in health research^{3,4}. The first attempt to understand the lived experience of Aboriginal families who are prescribed the penicillin regimen revealed how privileging a biomedical perspective for this condition may do harm by continuing the stance of colonisation^{5,6}. Importantly, the 2020 RHD Endgame Strategy to eliminate ARF in Australia recommends a priority action area 'to resource an Aboriginal and Torres Strait Islander-led National Implementation Unit to coordinate rheumatic

heart disease elimination efforts across Australia⁷. These activities aim to reset policy and practice for health and wellbeing around ARF. Yet this is a sensitive task with inherent vulnerabilities due to the requirement for those in power to listen to Aboriginal and Torres Strait Islander leaders and communities and to genuinely work together, to courageously take new paths to remove social and economic inequalities and to accept that the journey to a reset will be an uncomfortable one for those with power and privilege⁸.

Evidence for effectiveness of penicillin as secondary prophylaxis (SP) has been accumulating since Manyemba and Mayosi recommended randomised control trials to determine the best doses and routes⁹ and any deviation from the current recommended prescription could be harmful. SP adherence, long known to be difficult, is starting to improve in some locations and ARF recurrences are dropping¹⁰. An ARF management plan must be a partnership with patients and their family, and the treatment pathway must be their choice, whether injected penicillin, oral penicillin, no penicillin, or rotation between these choices over time. However, we know that lack of meaningful health communication prevents such choice. Families deserve access to information using effective health communication, which in turn requires partnering with local people. When families are provided

opportunities to ask questions around disease conditions in a safe space and using two-way learning and the language they think in, questions will arise that are invariably different from those medical scientists or ethnographers, or health promotion officers ask about a disease. Working collaboratively under Indigenous leadership to create health messaging that answers the questions that people have will always be superior.

Complexities of the policy and practice context for ARF, along with the historical and political forces that perpetuate the conditions for this disease, mean the forward moves to eliminate ARF in Australia hang on a knife edge. In one remote Australian community, more than 10% of children were registered for SP in 2020 highlighting the urgency for action¹¹. When Indigenous leaders are free to lead, they do things differently, they work from different perspectives and through understanding their own people and situations. Will mainstream health providers and policymakers listen and will they tolerate the discomfort inherent in standing with Indigenous leaders and allowing them to lead? I look forward to hearing outcomes of further Indigenous-led projects to eliminate ARF and to sharing in further action to prevent this condition in Australia.

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