

Ending rheumatic heart disease in Aboriginal and Torres Strait Islander communities: A systematic review of prevention programs in Australia

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Abstract

Purpose Australia has one of the highest incidences of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in the world, with a disproportionate disease burden on Aboriginal and Torres Strait Islander communities. This systematic review aimed to explore the effectiveness and cultural responsiveness of prevention programs to prevent, reduce and control RHD, to improve quality of life, and prioritise community engagement and empowerment.

Methods A systematic review was conducted involving a comprehensive search of three databases (PubMed, Embase and CINAHL) and grey literature from Australian Indigenous websites and Google Scholar. Articles met inclusion criteria if they evaluated prevention programs, targeted ARF/RHD and centred Aboriginal and Torres Strait Islander communities in Australia. Data were extracted by three reviewers, and results were descriptively analysed. Study quality was appraised via the Mixed Methods Appraisal Tool and the Aboriginal and Torres Strait Islander Quality Appraisal Tool.

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Main findings Eleven peer reviewed articles were included. Prevention programs varied in their effectiveness and cultural responsiveness to reduce ARF and RHD. Overall, the studies scored higher for generalised methodological quality determined by the Mixed Methods Appraisal Tool than the measurement of cultural responsiveness via the Aboriginal and Torres Strait Islander Quality Appraisal Tool. Research engagement with Aboriginal and Torres Strait Islander communities addressed ways to improve screening strategies to identify ARF, awareness of RHD adherence to penicillin prophylaxis, community-led education and training, environmental health and community-centred traditional language to convey culturally responsive health messaging.

Principal conclusions Further research is urgently needed in the provision of effective and culturally responsive prevention programs to reduce the incidence of ARF and RHD. Studies that centre Indigenous-led and community-based prevention programs that value self-determination, community agency and autonomy to advance holistic health and wellbeing for Aboriginal and Torres Strait Islander peoples offer promise in the elimination of ARF and RHD.

Keywords: Acute rheumatic fever; Rheumatic heart disease; Community-based programs; Decolonising paradigms; Indigenous health; Health equity

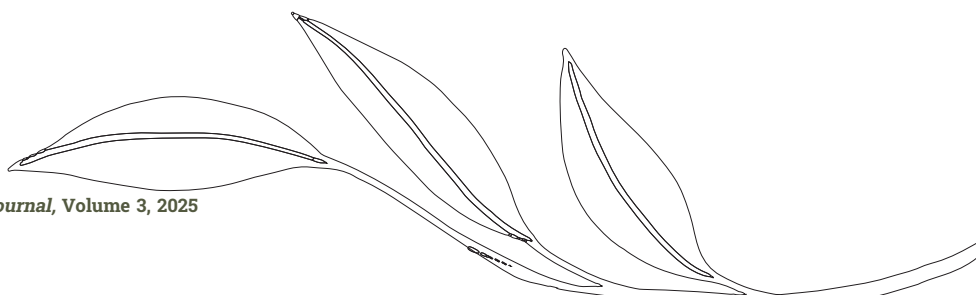
Highlights

- The rheumatic heart disease (RHD) endgame strategy in Australia seeks to eliminate RHD by 2031.
- To eliminate RHD by 2031, collective and urgent action is required that prioritises Indigenous-led and community-based prevention programs.
- A focus on addressing health inequities and the political, social and cultural determinants of health is essential for the prevention of ARF and RHD in Aboriginal and Torres Strait Islander communities.
- Culturally responsive programs that empower community development will create sustainable and beneficial strategies to eliminate RHD.

Introduction

More than 40.5 million cases of rheumatic heart disease (RHD) currently exist worldwide; it is one of the most acquired yet preventable heart disease conditions (Watkins et al. 2017). Characterised by permanent myocardial valvular damage, evidence suggests that RHD is the consequence of a single episode or repeated episodes of acute rheumatic fever (ARF). Acute rheumatic fever is triggered by an autoimmune response in susceptible individuals and caused by *Streptococcus A* (Strep A) infections of the

throat (pharyngitis) or skin (impetigo) (Carapetis et al. 2016). Untreated RHD can cause severe complications – including endocarditis, heart failure and stroke – contributing to life-long disability, morbidity and premature mortality (Zühlke et al. 2017). Despite significant global reductions in disease prevalence in the last quarter of a century, RHD remains a major public health concern in lower-income and middle-income countries (Ruan et al. 2023). The high prevalence of RHD is almost exclusively seen in poorly resourced settings due to overcrowding, insufficient





hygiene infrastructure and other socio-environmental factors that directly lead to the pathogenesis of Strep A infections and resultant ARF and RHD (Coffey et al. 2018; Ghamari et al. 2022).

In Australia, Aboriginal and Torres Strait Islander peoples (respectfully referred to as Indigenous peoples and Indigenous communities henceforth) are disproportionately burdened by this preventable disease. Notably, Australian data derived from 2022 reported that Indigenous communities accounted for 78% of all RHD cases and 92% of all ARF cases, underscoring the critical health disparity within Indigenous communities (Australian Institute of Health and Welfare [AIHW] 2024). The age-standardised rate of RHD among Indigenous peoples in Australia is 60 times higher than in non-Indigenous Australians (Katzenellenbogen et al. 2020). The Northern Territory (NT) in Australia exhibits a ten-fold higher population of Indigenous peoples compared with non-Indigenous Australians. The NT demonstrates one of the highest documented prevalence rates of RHD worldwide with 3,005 in 100,000 cases attributed to Indigenous peoples residing in this region (AIHW 2024). Acute rheumatic fever and RHD are potent markers of social disadvantage and health disparity driven by inequitable access to wealth and healthcare compounded by the continued negative impacts of colonisation, systemic failures and injustice experienced by Indigenous peoples (Haynes et al. 2022).

Rheumatic heart disease is a complex chronic condition with devastating impact on Indigenous children, adolescents, families and communities (Mitchell et al. 2018). Recent qualitative research shed light on the lived experience of RHD in Indigenous communities and the voices behind the statistics (Haynes et al. 2020). Collective trauma is prominent within communities affected by RHD, attributable to

disease-specific challenges and also the need to endure long-term painful penicillin injections to prevent recurrent ARF. More broadly, the ongoing negative impacts of colonisation and institutional racism continue to contribute to the widening gap in Indigenous peoples' health outcomes and healthcare experiences in Australia (Australian Government 2024; Haynes et al. 2020; Parter et al. 2021). For example, the health-adjusted life expectancy gap between Indigenous and non-Indigenous Australians was 15.5 years for males and 14.7 years for females in 2018 (AIHW 2022). Collective trauma, marginalisation, health and social inequities are further intensified by a Western biomedical approach that continues to dominate mainstream health service provision. This poses significant barriers to accessing culturally safe primary healthcare for Indigenous peoples impacted by RHD and its precursor ARF (Mitchell et al. 2022; Toombs et al. 2023).

Culturally safe healthcare can only be defined as 'culturally safe' by the recipients of the healthcare provided (Ramsden 2002). In contrast, culturally unsafe practice is defined as any omission or action that disempowers, demeans or diminishes the cultural identity and wellbeing of a patient and/or individual (Papps and Ramsden 1996). Indigenous worldviews and ways of knowing need to be recognised; valuing traditional culture and languages as strengths within Indigenous communities has the potential to disrupt the dominant deficit discourse in the Indigenous health narrative (Fforde et al. 2013; Moreton-Robinson 2015; Parter et al. 2023; Stoneham et al. 2014). Therefore, it is imperative to understand and address persistently high rates of RHD using a sociological lens and decolonising methodologies that prioritise the needs and values of Indigenous peoples (Haynes et al. 2021; Smith 2021; Wyber et al. 2020a).





Primary healthcare is a whole-of-society approach that supports the interrelated principles of 'equity, access, empowerment, community self-determination and intersectoral collaboration' with a commitment to the fundamental human right of individuals and communities to attain the highest level of health possible (Public Health Association of Australia 2023). Primary healthcare strategies to prevent RHD are categorised into three tiers, targeting the different stages of disease genesis and progression: primordial prevention, primary prevention and secondary prevention (RHD Australia 2020). Primordial prevention aspires to address upstream social determinants of health, including poor housing conditions and insufficient hygiene facilities to limit Strep A transmission. Primary prevention involves regular screening and timely treatment of Strep A infections across various settings to prevent ARF. Furthermore, the delivery of prophylactic penicillin injections is a key part of secondary prevention, with an aim to reduce the recurrence of ARF and further progression to RHD. There has been renewed attention and momentum in RHD research globally to identify programs and strategies that are effective in reducing the burden of disease (WHO). Recently published systematic reviews examining RHD prevention programs across the globe have highlighted the importance of integrating RHD prevention into existing health systems and implementing comprehensive strategies that target all levels of prevention (Abrams et al. 2020; Shimanda et al. 2024). The Australian Government has set the goal to eliminate RHD by 2031; approaches to achieve this include funding important research to implement the RHD endgame strategy and updating guidelines for RHD prevention, diagnosis and management (RHD Australia 2020; Wyber et al. 2020b). However, it remains unclear what programs have been implemented to prevent RHD in Indigenous

communities and whether they have been effective and culturally responsive.

Given the urgency of the elimination target and the need to identify ARF and improve RHD care for Indigenous communities, a systematic review focusing on the Australian context was warranted. It is imperative to identify evaluated prevention programs undertaken in Indigenous communities to inform future research, policy and program delivery.

Methods

Protocol and registration

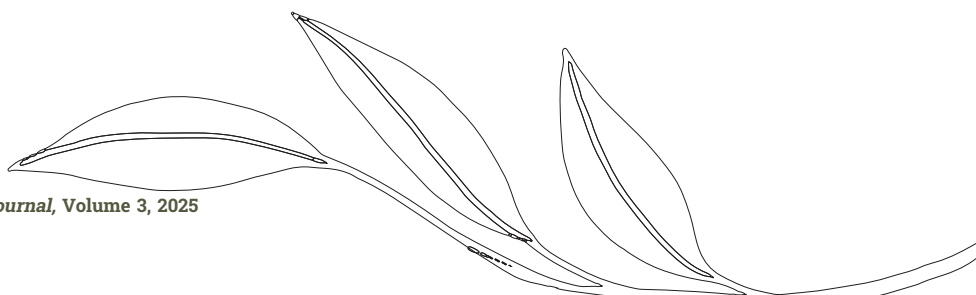
This systematic review adhered to the reporting guidelines in the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) 2020 statement (Page et al. 2021); see Supplementary Table S1 for the PRISMA-SR checklist. A protocol was prospectively registered with Open Science Framework (OSF) on 15 January 2024 (Registration DOI: <https://doi.org/10.17605/OSF.IO/XKF6Y>).

Research questions

1. How effective are the available programs in preventing acute rheumatic fever and rheumatic heart disease in Aboriginal and Torres Strait Islander communities in Australia?
2. How culturally responsive are the available prevention programs?

Inclusion and exclusion criteria

Published peer review articles and grey literature were eligible for the study, including original research of all study evaluation types, except for systematic reviews or general reviews. Eligibility was extended to both quantitative and qualitative studies. No restrictions were imposed on the study design, age, gender, language or publication date.





Information sources

Three electronic databases were systematically searched (PubMed, Embase and the Cumulative Index to Nursing and Allied Health Literature [CINAHL]) by the first author (YC). Database searches were conducted on 16 January 2024. Reference lists of included studies were manually searched by the lead author (YC), and grey literature was searched from Australian Indigenous HealthInfoNet, Lowitja Institute, National Aboriginal Community Controlled Health Organisation (NACCHO), Coalition of Peaks, Google Scholar, Open DOAR, OALster, Research Registry, PROSPERO, JBI Systematic Review Register and RHD Australia. See [Supplementary Table S2](#) for the full strategy applied to PubMed.

Search strategy

The search strategy was developed by YC, LH and an expert librarian (JM). The search strategy was trialled and tested by authors (YC, LH) and the librarian (JM), and reviewed by authors (LD, DL, AU, MTa, JC, KT) during an iterative process, which incorporated adjustments to improve results. Text words in the search strategy used Boolean operators and extensive synonyms that included (Aboriginal and Torres Strait Islande* OR Aboriginal OR Indigenous....) AND ("Rheumatic Fever" OR "Rheumatic Heart" OR ARF OR RHD....) AND (Program* OR Interven* OR Therap*....). See [Supplementary Table S3](#) for a copy of the search terms applied to each database.

Selection process

Search results were directly uploaded to Covidence (Veritas Health Innovation, Melbourne, Australia), where duplicates were removed by one author (YC). Title/abstract and full-text screening were independently completed by two reviewers (YC and LH), and an independent third reviewer (LD) was introduced to resolve discrepancies. Studies met inclusion criteria if they were: 1) conducted in Australia,

2) evaluated programs, interventions or initiatives to prevent ARF/RHD, 3) Aboriginal and Torres Strait Islander peoples and communities, and 4) available in English. No restrictions were placed on the year of publication, participant characteristics or study design. Studies were excluded if they were: 1) global studies, 2) prevalence studies, 3) reviews of all types and 4) studies exploring tertiary interventions for the treatment of known RHD (e.g. hospital surgeries). Fifteen studies were piloted to reach consensus regarding the inclusion and exclusion by four authors (YC, LH, LD, DL).

Data extraction

A standardised form was developed that included key study elements (i.e. author, date, study location, program aim, research design, study setting, participant characteristics, length of follow-up, methods of data collection, findings and implications). This was designed, piloted and applied through data extraction conducted by three authors (YC, LH, LD).

Synthesis method

While a meta-analysis was proposed, a narrative synthesis was ultimately selected as the identified studies were clinically heterogeneous ([Bland 2015](#)) with regard to the types of clinical research questions, study designs, research participant sampling, interventions and outcome measures that were used. A narrative synthesis was also considered to be well-suited to the task of critically exploring and enriching understanding of research approaches and determining the cultural responsiveness of prevention programs ([Greenhalgh et al. 2018](#)). However, descriptive and inferential statistics from each study, where available, were summarised within the data extraction tables to compare outcome measures for specific ARF/RHD prevention strategies. Selected studies were categorised into clinic-based, community-based and school-based programs and discussed narratively.



Assessment of methodological quality

The quality of the included studies was assessed using the Mixed Methods Appraisal Tool (MMAT) Version 2018. The MMAT is a validated and widely used tool that enables the quality assessment of studies with a wide range of methodologies including qualitative, quantitative and mixed methods (Hong et al. 2018). Two preliminary screening questions were applied to all included articles to define whether they were empirical. Each study was then critically appraised based on the methods used and the corresponding category of assessment questions. The methodological quality criteria evaluated many factors, including: whether the participants in each study were representative of the target population; whether appropriate measurements were conducted in relation to the outcome and intervention; the completeness of the outcome data; consideration of confounders and the appropriate administration of the intervention. Each criterion was rated with a 'yes', 'no', or 'can't tell' and the percentage of questions responded with a 'yes' determined the overall quality of the study. Three authors (YC, MTa, AU) independently assessed all included studies. Differences in ratings were resolved by discussion.

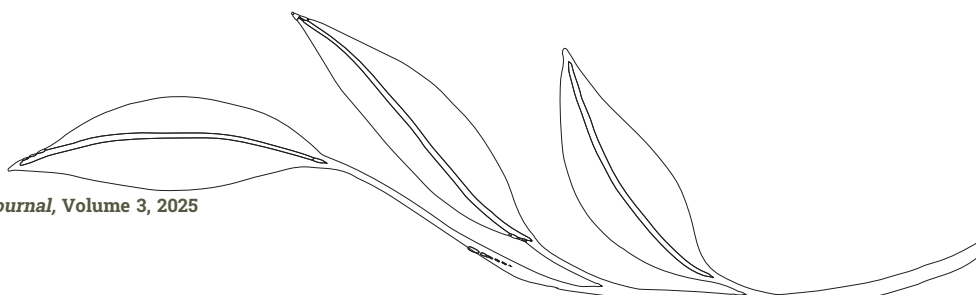
In conjunction with MMAT, the Aboriginal and Torres Strait Islander Quality Appraisal Tool (QAT) was used to assess the quality of health research from an Indigenous perspective. Developed by the Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE), the tool consists of 14 questions reflecting the values, principles, priorities and epistemologies of Aboriginal and Torres Strait Islander peoples (Harfield et al. 2020). The companion document offers additional guidance on how to understand each assessment question and was therefore consulted in the quality appraisal process. Complementary to MMAT, which assesses

quality of health research through a Western lens, Aboriginal and Torres Strait Islander QAT explores aspects of research that are not commonly prioritised by health researchers. Several factors are important to Indigenous communities involved in research when determining the cultural responsiveness of research practices, including: community engagement and consultation; research leadership and governance; adherence to community protocols; protection of the intellectual and cultural property rights of Indigenous peoples; the collection and management of research material; Indigenous research paradigms; a strength-based approach; the translation of findings into policy and practice; benefits to participants and communities involved; and capacity strengthening and two-way learning. The tool enables the critical evaluation of research quality through prioritising and privileging Indigenous ways of knowing and the voices and rights of Indigenous communities (Harfield et al. 2020). To determine the final score out of a possible total of 14, the allocation of points was calculated according to the following: yes (Y) = 1; partially (P) = 0.5; no (N) = 0; unclear (U) = 0. Four authors (YC, DL, KT, KM) independently assessed all studies. Differences in ratings were resolved with discussion.

Results

Study selection

Database and grey literature searches identified 786 records. After the removal of 309 duplicates, 474 records underwent title and abstract screening. A further 441 articles were excluded, leaving 33 full-text articles for eligibility assessment. Of these, 12 articles were excluded as they were conference abstracts. No other records were retrieved by searching reference lists and other methods. In total, 11 studies met eligibility criteria and were included in the review for analysis and synthesis of findings. Figure 1 illustrates



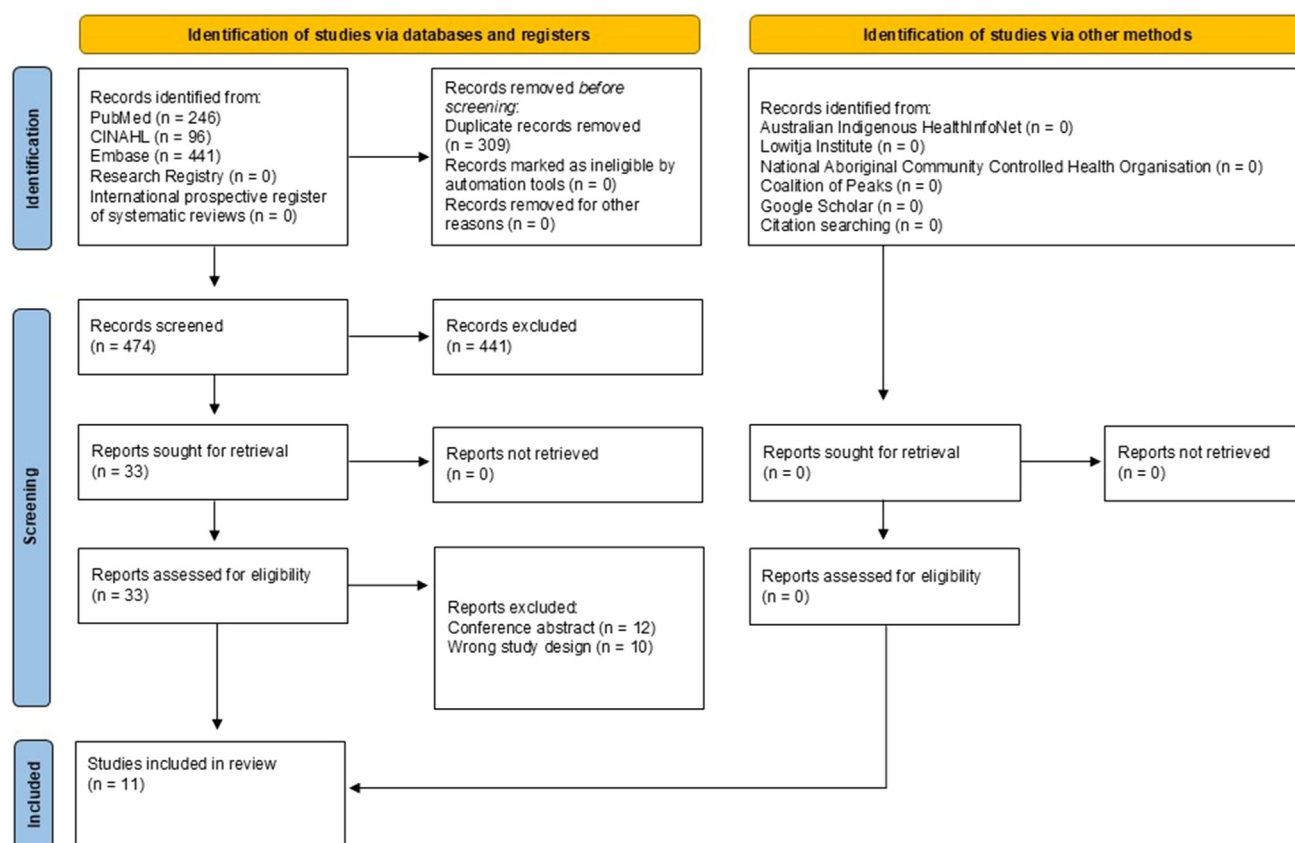


Figure 1: PRISMA flowchart illustrating the number of articles identified and screened, assessed for eligibility, and the final number included in the systematic review (Page et al. 2021) <http://www.prisma-statement.org/>.

the included studies in accordance with a PRISMA flowchart (Page et al. 2021).

Summary of study characteristics and findings

The included studies were published between 1993 and 2023. One study was published before the 2000s (Neilson et al. 1993). The included studies originated from three states and territories in Australia, including Queensland (n = 1; Neilson et al. 1993), the NT (n = 9, Haynes et al. 2019; Kearns et al. 2010; Kerrigan et al. 2021; Mitchell et al. 2021; Ralph et al. 2018; Ralph et al. 2013; Ralph et al. 2022; Read et al. 2018; Wyber et al. 2021) and Western Australia (n = 1; Pickering et al. 2023).

The 11 studies in the review had various research designs, including qualitative (n = 4), quantitative (n = 5) and mixed methods (n = 2). Included programs adopted a variety of study approaches inclusive of cross-sectional, descriptive, stepped-wedge randomised control and ethnographic. Participant samples ranged from a single remote Aboriginal community to up to 10 remote Aboriginal communities affected by RHD. See [Supplementary Table S4](#) for full details of the study and participant characteristics of the program evaluations. See [Supplementary Table S5](#) for methods of data collection and key findings of the program evaluations.



Quality of methodological reporting Mixed Method Assessment Tool

Overall, the quality of the included articles was deemed acceptable, with clearly stated research questions. Despite the varying methodological quality of studies ranging from 40% to 100%, no studies were excluded due to limited evidence retrieved concerning evaluation programs of ARF and RHD. Three qualitative studies scored 100%, as the required methodological descriptions met every criterion (Haynes et al. 2019; Kearns et al. 2010; Read et al. 2018). The qualitative study by Mitchell et al. (2021) scored 40% for failing to clearly describe data collection methods, and effectively interpret and explain the results. Two quantitative studies received a score of 60% (Ralph et al. 2013; Wyber et al. 2021) and the remaining three quantitative studies scored 80% (Neilson et al. 1993;

Ralph et al. 2018; Ralph et al. 2022). The scores related to quantitative studies were reduced for varying reasons, including: outcome assessors were not blinded (Ralph et al. 2018); inadequate participant sampling strategy (Ralph et al. 2013); inappropriate variable measurements (Wyber et al. 2021); existing risk of non-response bias (Neilson et al. 1993; Wyber et al. 2021); and the confounders were not accounted for (Ralph et al. 2022). One mixed method study scored 70%, with reduced scoring as a consequence of an inadequate participant sampling strategy, existing risk of non-response bias and inappropriate statistical analysis (Pickering et al. 2023); the other mixed method study met all criteria and scored 100% (Read et al. 2018). See Supplementary Table S6 for the MMAT Quality Appraisal Scores (Hong et al. 2018). Figure 2 provides a visual representation of the MMAT scores

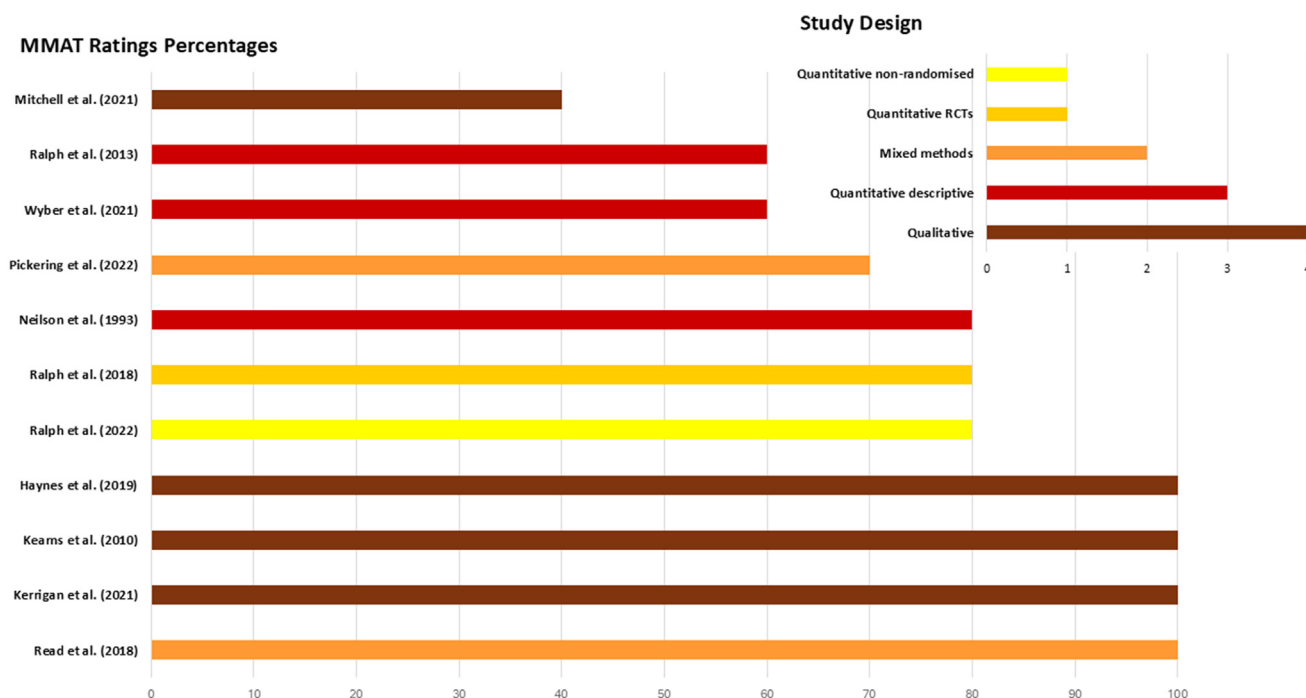
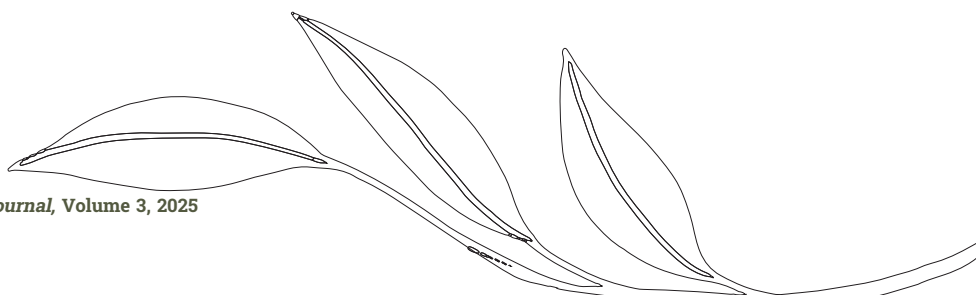


Figure 2: Visualisation of Mixed Methods Appraisal Tool (MMAT) scores and study designs. Brown, quantitative non-randomised studies; red, quantitative randomised controlled trials (RCTs); orange, mixed methods studies; light orange, quantitative descriptive studies; yellow, qualitative studies.



and the different colours were used to distinguish the different study designs employed by the included studies (quantitative non-randomised, quantitative randomised controlled trials (RCTs), mixed methods, quantitative descriptive, qualitative).

Aboriginal and Torres Strait Islander Quality Appraisal Tool

Overall assessment scores as per the Aboriginal and Torres Strait Islander QAT were generally low, yet variable, ranging from 2 to 12.5 out of a total of 14, with an average score of 6.54. [Ralph et al. \(2018\)](#) obtained the lowest score of 2 out of a possible 14. The highest score of 12.5 was obtained by [Haynes et al. \(2019\)](#). In summary, over 70% of studies met or partially met the following five criteria: respecting and following community protocols (8 of 11, 72.7%; criterion 5); the translation of findings into sustainable changes in policy and/or practice (9 of 11; 81.8%; criterion 11); research was of benefit to participants and Aboriginal and Torres Strait Islander communities (11 of 11; 100%; criterion 12); research demonstrated capacity strengthening for Aboriginal and Torres Strait Islander individuals (9 of 11; 81.8%; criterion 13); and everyone involved in the research had an opportunity to learn from each other (9 of 11; 81.8%; criterion 14). In contrast, six criteria were met or partially met by $\leq 46\%$ of the studies. Four of 11 studies (36.3%) met criterion 1 (research responded to a need or priority determined by the community). Criterion 2 (community consultation and engagement appropriately inclusive) was met or partially met by 5 of 11 (45%) studies. Criterion 6 (rights of access to existing intellectual and cultural property) was not met or partially met by any studies (0%). Criterion 7 (created intellectual and cultural property) was partially met by one of 11 ($\leq 1\%$) of studies. Criterion 9 (use of an Indigenous research paradigm) was met by one of 11 ($\leq 1\%$) studies. Criterion 10 (used a strengths-based approach) was met by five

of 11 (45.4%) studies. See [Supplementary Table S7](#) for the scores of the Aboriginal and Torres Strait Islander QAT to determine the cultural responsiveness of research conducted ([Harfield et al. 2020](#)). [Figure 3](#) provides a visual representation of the cultural responsiveness of the research conducted, with the darker shade of blue representing higher cultural responsiveness.

Programs and performance

Three types of prevention programs were identified targeting primordial prevention, primary prevention, secondary prevention and a combination of prevention strategies. From the 11 studies that met inclusion criteria, the identified programs were clinic-based, community-based and school-based.

Clinic-based programs (n = 4)

In the NT, a clinic-based approach was adopted with a focus on enhancing the delivery of prophylactic antibiotic injections to prevent the recurrence of ARF, namely improving secondary prophylaxis of RHD. [Ralph et al. \(2013\)](#) utilised participatory action research methods to support clinic staff in identifying and addressing system barriers by designing and implementing continuous quality improvement (CQI) activities. The aim was to facilitate clinician adherence to national ARF/RHD guidelines and promote evidence-based best practices. The study reported a significant improvement in the delivery of care at the participating clinics, which was indicated by an increased proportion of people receiving $\geq 40\%$ of their scheduled benzathine benzylpenicillin G (BPG) injections. Additionally, improved clinical documentation, and increased scheduling and attendance to regular reviews by a medical specialist, were observed ([Ralph et al. 2013](#)). However, the proportion of clients with ARF receiving $\geq 80\%$ of scheduled BPG did not change ([Ralph et al. 2013](#)).

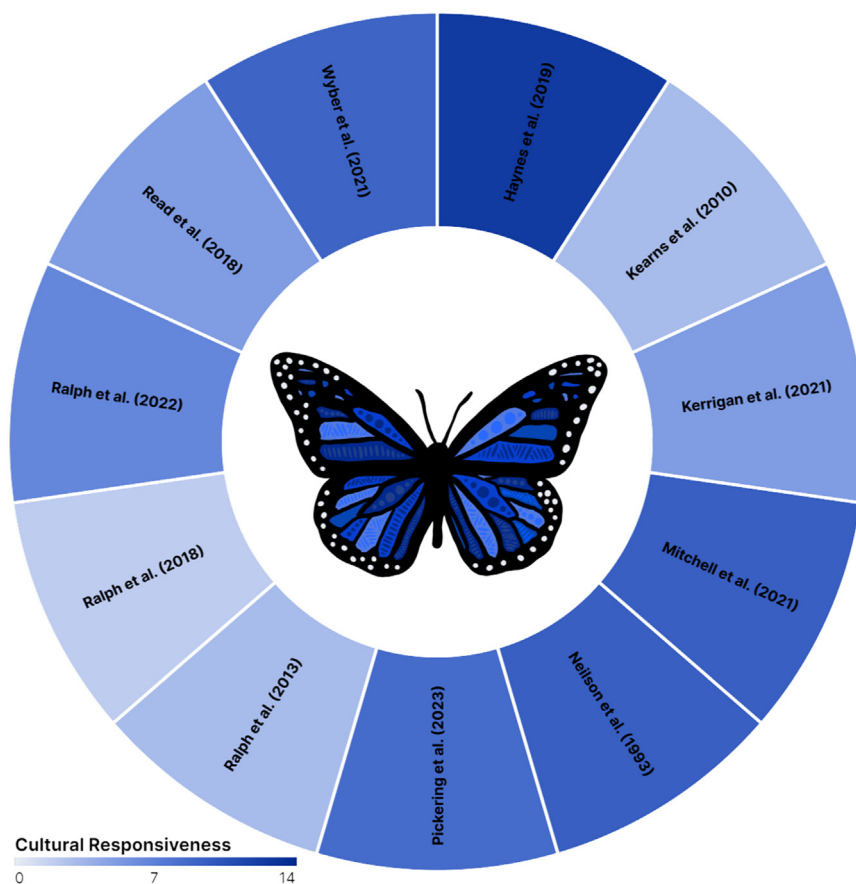
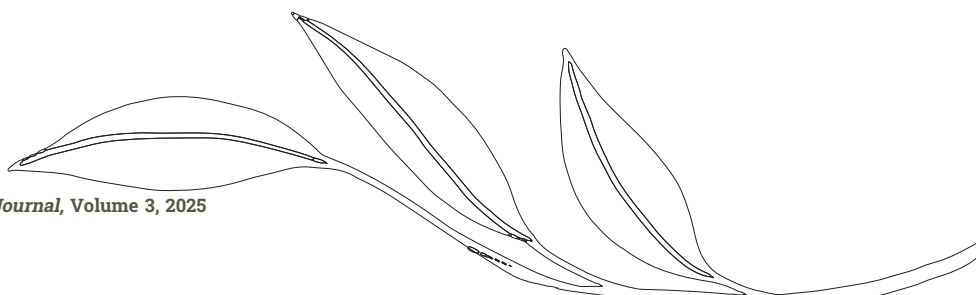


Figure 3: Visual representation of culturally responsive research based on the Aboriginal and Torres Strait Islander Quality Appraisal Tool. Acknowledgement of © digital artwork by Wagiman artist Tara-Rose Gonebale.

The study conducted by [Ralph et al. \(2013\)](#) provided evidence and optimism for a larger-scale, stepped-wedged randomised control trial involving 10 Aboriginal community health clinics in the NT ([Ralph et al. 2018](#)). All participating clinics received a multifaceted intervention supporting CQI action items to improve BPG delivery, aligned with the chronic care model. The study did not show improvement in client adherence to secondary prophylaxis. Regardless, a positive impact was observed on the attitudes of some clinic staff towards the management of RHD ([Ralph et al. 2018](#)). A further study in the NT that conducted qualitative analysis of the program revealed that the

study had limited efficacy and impact due to complex challenges at the project design, implementation and contextual levels ([Read et al. 2018](#)). The program’s short timeframe was insufficient for achieving sustainable impact on RHD control through a CQI approach. There was a lack of attention to the community linkage and self-management support themes of the chronic care model. Additionally, the project failed to account for challenges associated with high staff turnover and complex cultural-linguistic aspects of care delivery that characterised the local environment. Overall, the activities undertaken within the program were perceived by both clinic staff and





the local community as not meeting their needs ([Read et al. 2018](#)).

In contrast, a mixed methods study carried out by [Pickering et al. \(2023\)](#) in Western Australia achieved better community engagement in the concurrent assessment of Strep A pharyngitis and impetigo. In partnership with an Aboriginal community controlled health organisation primary healthcare clinic in Western Australia, the research team developed a culturally appropriate sore throat questionnaire through yarning circle conversations with Aboriginal caregivers. The questionnaire was trialled and validated for the assessment of Strep A pharyngitis and impetigo alongside other established assessment tools, including serological and microbiology testing. The set of tools was proven to be feasible, practical and acceptable to participants ([Pickering et al. 2023](#)).

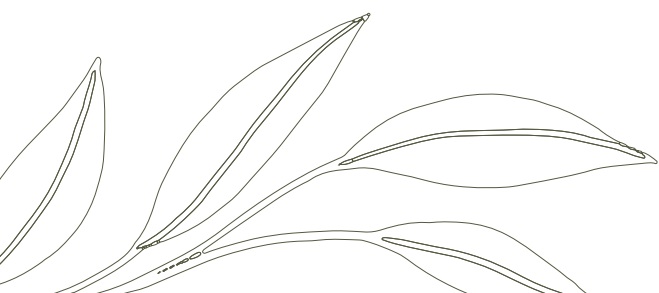
Community-based programs (n = 6)

The community-based programs identified and included in this review aimed to strengthen primordial prevention and primary prevention of ARF by addressing social and environmental determinants of health and by the early detection and treatment of Strep A infections, respectively. It is believed that [Neilson et al. \(1993\)](#) published the first ever study evaluating a community-led RHD primary prevention initiative in north Queensland. In 1985, the Yarrabah Community Council decided to undertake community surveys and a sore throat screening program in response to a high level of suspected RHD in the community. Following an intense public education campaign coordinated by the Department of Aboriginal Affairs film crew, the local Aboriginal community health team implemented the screening program to identify and treat new ARF cases. Eighty-nine per cent of community members participated in the first survey and received throat swabbing and

appropriate treatment. Children aged 4 to 16 years were deemed vulnerable and received throat swabbing three times a year for six years. Aboriginal health workers were employed to keep the council and community informed through monthly reports. A significantly lower proportion of the community participated in the second survey in 1991 in the absence of a health education campaign, but 87% of the vulnerable group were screened and one new case of ARF was identified. The program offered a relatively simple yet cost-effective and efficient model for primary prevention attributable to the successful community education campaign ([Neilson et al. 1993](#)).

[Kearns et al. \(2010\)](#) reported on the evaluation of the full moon strategy introduced in Central Australia in 2006 as part of the NT RHD control program to improve community awareness of ARF and secondary prophylaxis uptake. Clients and healthcare workers were encouraged to use the full moon as a cue for the timing of the four-weekly prophylactic penicillin injection. Additional media campaigns and health promotion materials were developed and implemented in collaboration with the Department of Health and Families. Two years after the program was introduced, there was a 10% absolute increase in prophylaxis uptake, but not during the week of the full moon. However, uptake of penicillin prophylaxis was more consistent compared with pre-intervention ([Kearns et al. 2010](#)).

A qualitative study by [Haynes et al. \(2019\)](#) conducted in the NT aimed to co-design, implement and evaluate the 'On Track Watch' program for RHD primordial and primary prevention underpinned by principles of community-based participatory action research and two-way learning. The project was enabled by collaboration and shared leadership between community researchers (CRs) and external





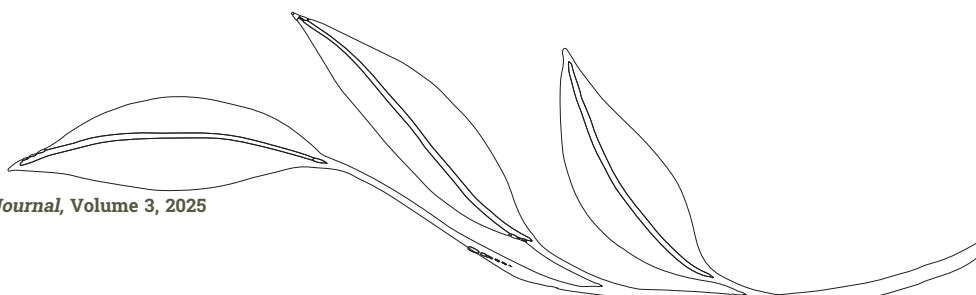
researchers or facilitators. Sixteen adult CRs participated in a free, practical, competency-based Certificate II course to deliver a range of activities that were aligned with the needs voiced by the community, including a community throat swabbing day, a school lunch program and outreach to a related homeland to engage with teenagers. The project emphasised Yolŋu ways of knowing, being and doing. The study explored locally meaningful metaphors to deliver culturally safe health messaging, and offered an opportunity for institutional researchers to be invited into an Aboriginal community to co-create strategies for RHD elimination (Haynes et al. 2019). Program outcomes were empowering and multifaceted, including the development of RHD educational materials that drew on Yolŋu metaphors and traditional knowledge systems. Increased health-seeking behaviour in the community was observed owing to enhanced awareness and agency regarding RHD prevention. Moreover, the project facilitated capacity building of the CRs through research training, enabling them to develop practical skills, address regional and national Indigenous health conferences and drive other locally meaningful RHD prevention initiatives.


Another community-based program that incorporated both primordial and primary prevention of RHD was reported in three different evaluation studies conducted in the NT (Kerrigan et al. 2021; Ralph et al. 2022; Wyber et al. 2021). The program aimed to address upstream social and environmental determinants of health in the causal pathway of ARF and RHD through the employment and training of Aboriginal community workers (ACWs). The formative evaluation of the program concluded that it had been accepted by the Aboriginal families involved and had the potential for ongoing development (Wyber et al. 2021). The qualitative evaluation of the program reported that ACWs were best placed to support two

of the six domains of primordial and primary prevention: housing and environmental health support and health navigation through trusting relationships with families and the authority attributed to ACWs through the project (Kerrigan et al. 2021). The ACWs improved health literacy and supported awareness and empowerment; however, this was limited by disease complexities. Consequently, ACWs requested more training to address knowledge gaps and improve knowledge transfer to families. Additionally, ACWs perceived their capacity and authority was insufficiently empowered within the project timeframe to provide health professionals with the necessary education regarding the complexities of ARF/RHD (Kerrigan et al. 2021). A further quantitative evaluation of the program also saw an encouraging decrease in numbers of new ARF diagnoses during the four years of the study from six in one year to none (Ralph et al. 2022). The program model holds promise for sustainable RHD control through larger rollouts across more communities.

School-based program (n = 1)

The program reported by Mitchell et al. (2021) in the NT was the only program that explored a school-based model seeking to embed RHD prevention in a primary education curriculum. Responding to local data of high RHD prevalence in remote community Maningrida, Aboriginal teachers were driven by a sense of urgency and responsibility to create culturally relevant lessons to teach children about RHD in their home languages. The Lŭrra RHD project involved extensive collaboration between local Aboriginal and Western workers from the disciplines of health, education, community development and linguistics. Extensive collaboration resulted in the production of a culturally meaningful narrative of RHD that drew on local traditional knowledges and metaphors. Principles of community-led development were used to evaluate the program.





The major outcomes or impacts included children's new responses and attitudes to skin infections and their RHD treatment, staff adopting more culturally responsive health communication styles, and the dissemination of knowledge related to RHD prevention through kinship networks (Mitchell et al. 2021).

Discussion

Despite Australia having an enviable standard of living globally, it seems that achieving the goal to eliminate RHD by 2031 may be out of reach. This is reflected in this review, which identified limited research concerning programs to prevent ARF and RHD in Indigenous communities. Eleven program evaluations were identified, in which varying research designs were conducted in the clinic, community and school settings that aimed to strengthen primordial, primary or secondary prevention. Varying research designs were conducted in the clinic, community and school settings that aimed to strengthen primordial, primary or secondary prevention. One RCT was identified and analysed by this review, which is partially reflective of the longstanding challenges around conducting RCTs in Indigenous community settings in relation to cultural acceptability and appropriateness (Esgin et al. 2023; Ralph et al. 2018).

The MMAT quality appraisal of studies indicated that most studies (8 of 11, 72%) were of sound methodological quality and met 70% to 100% of the established criteria. In contrast to the MMAT, the cultural responsiveness of the conducted research studies was very poor. This was determined by applying the Aboriginal and Torres Strait Islander QAT (Harfield et al. 2020), in which the average score of studies was 6.54 out of 14. The narrative synthesis of the program's performance and the key findings of studies outlined in [Supplementary Table S5](#) reveal varying research approaches and outcomes to

address ARF/RHD. However, RHD registers and RHD guidelines that have been implemented across Australia and follow strict biomedical approaches have failed to address the disproportionate rates of ARF/RHD that persist in Indigenous communities. It is therefore clear that greater community ownership and collaborative interdisciplinary partnerships with Indigenous communities is crucial to the success of RHD elimination efforts (Biles et al. 2022; Harfield et al. 2020). This is enabled by decolonising approaches and culturally responsive research practices that focus on community development as well as disease prevention (Biles et al. 2022; Harfield et al. 2020; Smith 2021). It is vital that external researchers commit to cultural humility and be willing to promote two-way learning and position themselves as co-learners and co-designers who prioritise and privilege local Indigenous voices (Haynes et al. 2019).

The research conducted by Haynes et al. (2019) reflects a decolonising paradigm to eliminate RHD through community development aligned with the six National Health and Medical Research Council (NHMRC) principles: Spirit and integrity, Cultural continuity, Equity, Reciprocity, Respect and Responsibility (NHMRC 2018a, 2018b). Decolonising approaches have the potential to disrupt power imbalances exerted by domineering Western medical and research paradigms that oppress and control rather than empower and enable equality and autonomy (Haynes et al. 2019; Smith 2021). It is essential for Indigenous community members to lead RHD prevention strategies to drive sustainable change and design solutions that are welcomed within their community (Biles et al. 2022; Harfield et al. 2020; NHMRC 2018a, 2018b). Crucially, community ownership is reflected in Indigenous peoples having the agency and control over the direction of RHD reduction projects to align with local priorities and needs that are

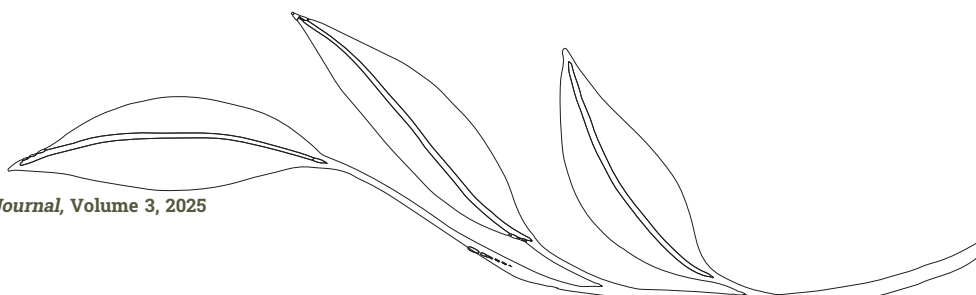



determined by the community (Biles et al. 2022; Harfield et al. 2020; NHMRC 2018a, 2018b). Programs undertaken by Haynes et al. (2019) and Neilson et al. (1993) were assessed to be authentically community initiated and originating from local aspirations to address high burdens of RHD, therefore meeting criterion 1 of the Aboriginal and Torres Strait Islander QAT (Harfield et al. 2020). Haynes et al. (2019) described the willingness and flexibility of non-Indigenous researchers to modify pre-defined project objectives to better meet community needs and ensure that local visions are empowered, especially around improved nutrition and engaging with teenagers with RHD. The current review was able to identify early evidence of true community leadership in the study conducted by Neilson et al. (1993). The prevention program implemented in the Yarrabah community in the 1990s demonstrated local Indigenous leadership and widespread community participation. The program achieved the development and dissemination of the education campaign and video production, and the design of program responses.

Based on these findings, communities were galvanised into intensive action when presented with local epidemiological data. Local Elders and leaders were driven by a shared responsibility to safeguard the wellbeing of the younger generations against the suffering attributed to RHD (Haynes et al. 2019; Mitchell et al. 2021). However, community empowerment, to address ARF/RHD, is impeded as access to Government- and clinic-controlled RHD data and RHD registers is restricted to community members (Mitchell et al. 2021). This highlights the importance of creating meaningful partnerships between the local community, Aboriginal community controlled health organisations, and the mainstream public health system to show respect for Indigenous peoples' rights

to access their own data (Biles et al. 2022; UN 2007). Indigenous data sovereignty is key to an effective prevention program that empowers local action, ownership and autonomy regarding health and wellbeing (Biles et al. 2022; Kickett-Tucker 2017). According to Harfield and colleagues (2020), Indigenous control over the collection and management of research materials is essential for research with Indigenous communities. Six out of 11 studies included in this review provided adequate or partial evidence for this requirement.

Further, genuine Indigenous leadership and governance needs to be supported in all stages and aspects of research and evaluations of programs to avoid tokenistic consultation with community stakeholders by external research institutions (Kickett-Tucker 2017; NHMRC 2018a, 2018b). This means that trusting and respectful partnerships need to be established to empower local Indigenous peoples to co-design project plans, deliver research activities, and collect, analyse and interpret data according to their own values, understandings and knowledges. Importantly, project plans and processes require Indigenous oversight provided by Elders or community leaders at all stages. Additionally, effective collaboration with community is necessary when communicating research progress and findings back to the community whilst valuing and taking on the feedback provided (Kickett-Tucker 2017; NHMRC 2018a, 2018b). There is some evidence in the included studies that formal agreements were negotiated, and written forms of endorsement were sought from local leadership groups during pre-project consultation. However, community consultation was inconsistent across studies and often neglected and is often not included and prioritised in Western biomedical research reporting styles (Biles et al. 2022; Harfield et al. 2020). Furthermore, agreements to protect the





existing and new intellectual and cultural property created through research were not negotiated; all studies failed to provide insufficient details to meet this standard.

Most studies provided evidence that research had been beneficial to participating communities and strengthened the capacity of local community members. An exemplar of this was demonstrated through the Lúrra project, which was led by local Aboriginal teachers and co-designed with non-Indigenous researchers to deliver a culturally relevant RHD story (Mitchell et al. 2021). The delivery of health promotional lessons, resources and materials was embedded in the local school curriculum. The curriculum content was provided in local Indigenous languages and integrated with locally meaningful metaphors to optimise effectiveness in promoting health literacy around the causal pathways of ARF and RHD (Mitchell et al. 2021). The success of this prevention program was achieved by the delivery of empowering and strengths-based health communication and messaging (Mitchell et al. 2021). Valuing Indigenous traditional languages is not only a practical way to overcome language barriers in increasing RHD awareness, it is also critical for respecting and responding to different conceptualisations of the disease underpinned by Indigenous epistemologies (Biles et al. 2022; Harfield et al. 2020; NHMRC 2018a, 2018b). A further example of beneficial research and community capacity building was reported by Neilson et al. (1993). This project established successful collaboration amongst the Yarrabah Community Council, Aboriginal community health team, and the Department of Aboriginal Affairs film crew. The key learning is that when programs are led by local Indigenous people and guided by their unique experience and cultural knowledge, RHD prevention strategies have the potential to mobilise

the entire community to take collective action, be involved in designing local solutions and disseminate strategies to kinship networks (Biles et al. 2022; Harfield et al. 2020; Neilson et al. 1993; NHMRC 2018a, 2018b). Empowering Indigenous knowledge and ways of being and doing, alongside culturally responsive approaches, will also result in sustainable and meaningful changes embedded into policy or practice (Parter et al. 2023).

In stark contrast to Indigenous-led initiatives, the full moon strategy, which was a clinic-centred program, employed a top-down and government-led approach (Kearns et al. 2010). The program disseminated RHD promotional materials that typified health education imposed by external academic or government agencies, which heightened existing patriarchal power imbalances. Disempowering research approaches serve to perpetuate colonial practices and intensify feelings of mistrust and marginalisation (Smith 2021). An international exemplar that moved away from top-down approaches by resourcing school health clinics to prevent the first presentations of ARF was conducted in New Zealand (Lennon et al. 2017). It is important to discuss this study, given the similar health disparities experienced by New Zealand's Indigenous peoples in comparison with Indigenous peoples in Australia concerning prevalence rates of ARF and RHD (Lennon et al. 2017). The combination of Indigenous Māori and New Zealanders of Pacific Island descent make up one-third of New Zealand's youth population who are aged <20 years. In Māori and Pacific Islander communities, by the time a child reaches 13 years, the cumulative risk of hospitalisation with ARF is approximately 1 in 150. Identifying the urgent need to reduce the incidence of ARF, Lennon et al. (2017) established a school-based sore throat clinic program staffed by nurses and community health workers between 2010 and 2016. The program



received a high consent and participation rate and achieved success through throat swabbing, bacterial cultures, and treatment with oral penicillin for 10 days. A 58% reduction in first presentation ARF was achieved, coinciding with an 11% decline in Strep A pharyngitis. The New Zealand context offers lessons to be learned regarding the sustainability of school-based programs to eliminate RHD, as school nurses are supported in delivering penicillin prophylaxis in this setting.

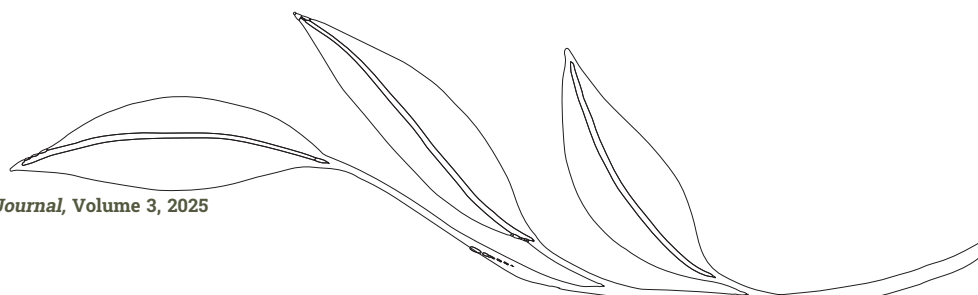
Strengths and limitations

The strength of this review lay within the nuanced urgent prioritisation regarding the need to prevent ARF and RHD in Indigenous communities. Therefore, to highlight evidence specific to Indigenous peoples in the Australian context it excluded global studies reporting on RHD prevention programs outside Australia. Conversely, not accommodating global studies may have also been a limitation. However, global evidence was sourced and referenced throughout the study and a New Zealand school-based prevention program was outlined in the discussion section of the review. A further limitation was associated with the small number of included studies and heterogeneity among their outcomes; therefore, a meta-analysis was unable to be performed to ascertain the relationship between program design and health outcomes. However, it is acknowledged that this heterogeneity is expected for place-based, community-driven prevention programs, as each of them is tailored to the socio-cultural context and needs of a particular community. Lastly, the exclusion of prevalence studies in this review, which utilised population-based handheld echocardiographic screening approaches to detect RHD cases in Indigenous communities, limited the discussion concerning the benefit of this diagnostic procedure to identify RHD (Francia et al. 2024; Francis et al. 2020). However, the systematic review by Francia

et al. (2024) reinforces the continued significant challenges related to access and adherence to BPG prophylaxis nationally and globally, which justifies the need for the combination of empowered community development strategies and portable echocardiographic screening approaches to gain traction to prevent and control RHD in Indigenous communities.

Future directions

The RHD endgame strategy marked a major shift in paradigm from a strong emphasis on delivering secondary prophylaxis in clinics staffed by non-Indigenous people to a comprehensive approach incorporating active screening and outreach-based programs driven by local Aboriginal communities (Wyber et al. 2020a; Wyber et al. 2020b). A sociological perspective is mandated to address indirect causal contributors to RHD, which are intricately linked to environmental and social determinants of health (Marmot 2017; Marmot and Wilkinson 2006). Concerted and collaborative efforts across government departments and community groups are imperative for a comprehensive elimination strategy (Kickett-Tucker 2017). It is necessary to partner with the community to scale up effective programs to achieve transformative change and impact (Biles et al. 2022; Harfield et al. 2020; Kickett-Tucker 2017; NHMRC 2018a, 2018b). This could potentially lead to improvement in a range of chronic condition outcomes beyond RHD and its precursor diseases. Efforts to improve housing (Marmot 2017; Marmot and Wilkinson, 2006) and access to culturally safe primary healthcare is imperative (Toombs et al. 2023). Cultural responsiveness is essential for systemic transformation in healthcare; it involves individual practitioners delivering and sustaining culturally safe and effective care. This transformative process demands a holistic approach encompassing





knowledge, self-awareness and action. It is about engaging with patients respectfully, applying learned insights to practice, and fostering open dialogue to enhance care and outcomes. Ultimately, cultural responsiveness is the cornerstone of achieving and maintaining cultural safety within healthcare systems (Indigenous Allied Health Australia 2019). Additionally, improved efforts by the higher education sector need to occur to recruit, retain and nurture an adequate representation of Aboriginal and Torres Strait Islander Health workers, nurses, midwives, academics and policy advisors (CATSINaM 2022).

Future studies should explore the potential utility of RCTs to assess the effectiveness of community-based RHD prevention programs, striving to fulfil both scientific rigour and cultural integrity through the integration of exploratory, interpretive and participatory qualitative approaches. Such studies need to be underpinned by strong community control and engagement and focus on centring the voices of Indigenous peoples with lived experience of RHD/ARF. Future programs involving communities must also be guided by national and Aboriginal and Torres Strait Islander ethics and standards applicable to research with Indigenous peoples (NHMRC 2007, 2018a, 2018b).

During the global pandemic of COVID-19, collective urgent action was seen worldwide to produce a vaccination to stem morbidity and premature mortality, and global economies invested billions of dollars in the race to curtail a virus that did not discriminate according to ethnicity or social class (Wood and Schulman 2021). On the other hand, RHD is pronounced as a disease of poverty and social and health inequity but has not received the same urgent investment. It is with hope that the advancement of vaccination to protect children from Strep A infections under current development is nearing implementation

(Ajay and Dorfmueller 2023; Dale and Walker 2020).

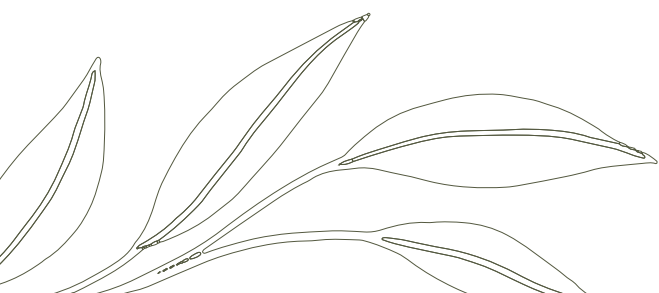
The establishment of the *Streptococcus A* Vaccine Initiative in 2019, in response to progress made through WHO and the World Health Assembly, holds significant promise for expediting the production of a Strep A vaccine (Fulurija et al. 2024).

Conclusion

This review underscores the urgent need to reduce preventable suffering, morbidity and consequent premature mortality associated with RHD that disproportionately impacts the lives of Indigenous peoples. Collective and urgent action is required by state, territory and Commonwealth governments of Australia to address political, social and cultural determinants of health and wellbeing to prioritise the implementation of the RHD endgame strategy. To achieve the elimination target by 2031, it is necessary that systemic social justice advocacy and anti-racism sentiment is embedded within all political, educational, social, health and research agendas and policies to achieve sustainable health equity for all Indigenous peoples. As a wealthy and compassionate society, Australia should be investing in authentic Indigenous-led community development that privileges Indigenous knowledge and voices to prioritise community-identified needs. Decolonising and culturally responsive approaches to eliminate RHD in Australia will embrace Indigenous ways of knowing, being and doing to promote wellbeing and healing, and the ability to thrive in society beyond the survival of colonial harmful systems that predicate ill-health.

Author contributions

All authors contributed to the conceptualisation of the study. Y. Cai and L. Holland drafted the manuscript. All authors provided editing and revisions of the manuscript. All authors have approved the final manuscript for submission.





Declaration of interests

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CRedit author statement

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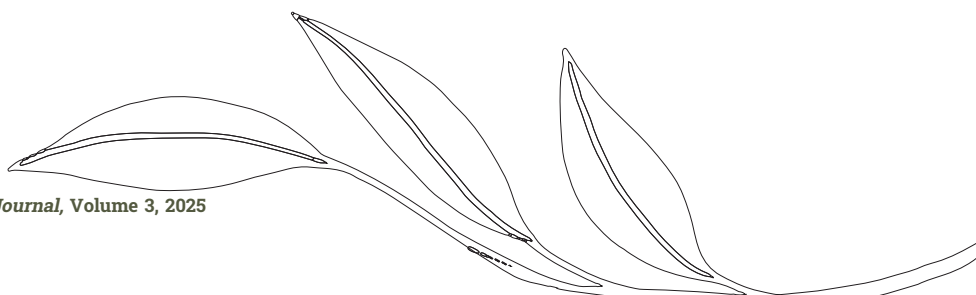
Jane Moore: Conceptualisation, Methodology, Writing - Review and Editing

Catherine Kilgour: Conceptualisation, Writing - Review and Editing

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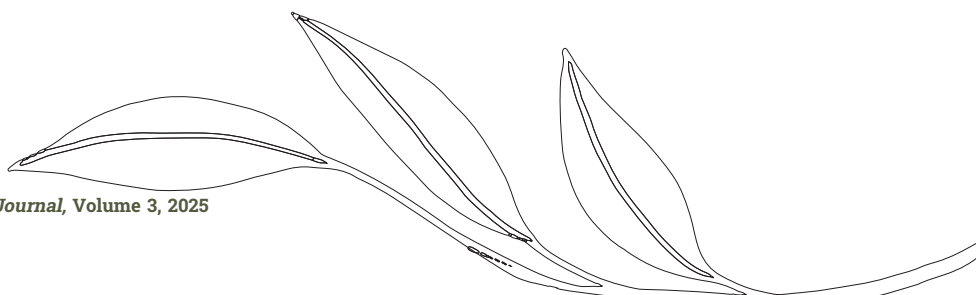
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Supplementary material

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.fnhli.2024.100040>.

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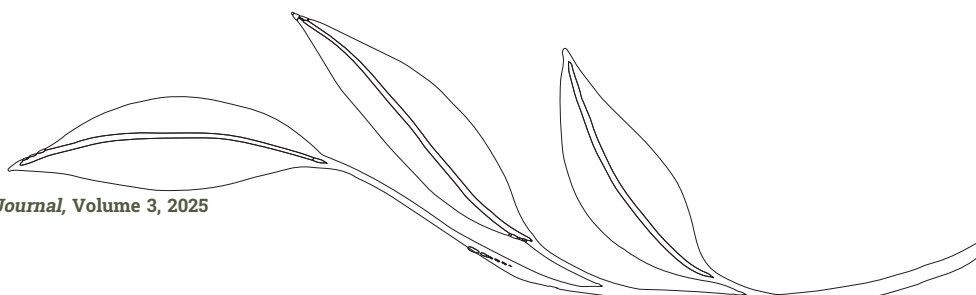


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