

Addressing rheumatic fever inequities in Aotearoa New Zealand: a scoping review of prevention interventions

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ABSTRACT

Introduction. Rheumatic fever is a preventable illness caused by untreated Group A Streptococcus (GAS) infection. Despite reductions in most high-income countries, rheumatic fever rates remain a concern in Aotearoa New Zealand. Pacific and Māori people are inequitably affected, with risk of initial hospitalisation due to rheumatic fever 12- and 24-fold more likely, respectively, compared to non-Māori and non-Pacific people. **Aim.** This scoping review aims to explore the range of interventions and initiatives in New Zealand seeking to prevent GAS and rheumatic fever, with a particular focus on Pacific and Māori. **Methods.** Databases Scopus, Medline, EMBASE and CINAHL, along with grey literature sources, were searched to broadly identify interventions in New Zealand. Data were screened for eligibility and the final articles were charted into a stocktake table. **Results.** Fifty-eight studies were included, reporting 57 interventions. These targeted school-based throat swabbing, awareness and education, housing, secondary prophylaxis, improving primary care guidelines and diagnosis of sore throats and skin infections. Some interventions reported short-term outcomes of improvements in awareness, a reduction in rheumatic fever risk and fewer hospitalisations. Evaluation outcomes were, however, lacking for many initiatives. Pacific and Māori people primarily served only in an advisory or delivery capacity, rather than as partners in co-design or leadership from the beginning. **Discussion.** Although positive outcomes were reported for some interventions identified in this review, rheumatic fever rates have not shown any long-term reduction over time. Co-designing interventions with affected communities could ensure that strategies are better targeted and do not contribute to further stigma.

Keywords: inequity, intervention, New Zealand, Pacific, Pasifika, Māori, rheumatic fever, rheumatic heart disease.

Introduction

Rheumatic fever (RF) is an autoimmune condition that occurs typically in children aged 5–14 years as a result of an untreated Group A Streptococcus (GAS) infection, via a sore throat or skin infection.¹ If regular intramuscular benzathine penicillin injections are not administered every 28 days for 10 years, damage to heart valves can result in rheumatic heart disease and, in some cases, death.¹ RF rates have reduced dramatically in most high-income countries since the 1970s due to improvements in hygiene and living conditions; however, rates remain high in Aotearoa New Zealand (NZ), which is influenced by socioeconomic deprivation, housing conditions and barriers to health care.² Risk of initial hospitalisation for RF is 24- and 12-fold more likely for Pacific and Māori people, respectively, compared to Europeans/other ethnicity.³ In Auckland, risk for acute RF is 240-fold greater for Pacific children and 87-fold greater for Māori children, compared to non-Māori and non-Pacific people.⁴ Although rates of acute RF appear to show a downward trend since 2020, the potential impacts of the coronavirus disease 2019 (COVID-19) pandemic and lockdown restrictions in NZ should be considered.^{2,5} Given that rates of RF are yet to show a lasting, long-term reduction, it is critical that

WHAT GAP THIS FILLS

What is already known: Although many interventions have been tried, rheumatic fever remains a significant issue in Aotearoa New Zealand, particularly for Pacific and Māori populations.

What this study adds: This scoping review identified a need for more community-led interventions, particularly by and for Pacific and Māori people, that undertake rigorous evaluation processes.

action is taken to address inequities and ensure that case numbers do not rise, particularly as restrictions ease and mobility within the community increases.

Environmental risk factors linked with acute RF include overcrowding, mould and damp housing, consumption of sugary beverages and inadequate health care.⁶ A lack of cultural safety and racism, both personal and institutional, are also barriers to RF health services, with Māori and Pacific families describing negative and unsafe experiences within the health system.⁷ Access to adequate and timely treatment is critical for treating initial GAS infections and preventing the development of RF. In 2011, the NZ government established the Rheumatic Fever Prevention Programme, investing NZD\$65 million into addressing this disease burden. However, its goal of reducing the national RF incidence to 1.7 per 100 000 was not achieved by the programme's end in 2017, and inequities for Pacific and Māori people remained, currently sitting at 2.2 per 100 000 nationally and 8.9 and 8.0 per 100 000 for Pacific and Māori people, respectively.^{5,6} Several reviews published over the last 10 years have explored interventions aimed at preventing or controlling RF, and assessed their effectiveness in the NZ context.^{8–11} Despite the significant burden of acute RF and rheumatic heart disease among Pacific people, there is limited information regarding the breadth of interventions focused on, and led by this population.

This scoping review aims to broadly provide a stocktake of primordial, primary and secondary prevention interventions used in NZ to reduce RF, with a particular focus on the role of Pacific and Māori people throughout the development and implementation of these interventions. For this review, we used a broad definition of 'intervention' to include all programmes, initiatives, guidelines and delivery of treatments aimed at preventing RF from a primordial, primary and/or secondary prevention lens.

Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Extension for Scoping Reviews guidelines was followed (see Supplementary file S1).¹²

Eligibility criteria

Documents were included in this review if they explored an intervention or initiative aimed at primordial, primary or secondary prevention of RF in the NZ context. We excluded interventions solely focused on treatments or care for rheumatic heart disease. In order to capture a broad range, no limits were applied for the year of publication (up until the date of search, 3 March 2022) or the type of record.

Data sources and search strategy

Data sources included both databases for peer-reviewed articles and grey literature sources such as government reports, websites, and news articles. A database search was conducted across Scopus, Medline, EMBASE and CINAHL using a search model with the following three key elements: (1) RF; (2) intervention; and (3) NZ context, adjusting search strings and medical subject heading (MeSH) terms. For example, the search via Scopus used the keywords: rheumatic OR 'rheumatic fever' OR 'group A strep*' AND interven* OR reduc* OR prevent* OR manag* OR evaluat* OR strateg* OR initiative AND 'New Zealand' OR Aotearoa OR NZ, with no limits on publication date or type of article (for the full search strategy, see Supplementary file S2). In order to identify grey literature, a snowball method was used (following up references found in documents), in addition to general searches of news websites, Google and government and organisation websites.

Study selection

Database results were extracted into the Endnote 20 (Clarivate) reference management software, where duplicates were removed. Two researchers (ST, SO) independently screened titles and abstracts of articles and grey literature sources for eligibility over several rounds, comparing findings after each round, and this was followed by full-text reviews of the remaining articles. A high level of agreement (92%) was achieved throughout the screening rounds. Conflicting responses were discussed between the two authors, ST and SO, with adjudication by a third author (FGS) when required. In some cases, a single report identified a number of different interventions. Conversely, in cases where multiple sources reported the same intervention; for example, review articles, either the source with the most complete information was selected or in some cases, up to two sources were identified if both reported differing but relevant information.

Data charting and synthesis

Data from the final articles were charted into a stocktake table. Data points extracted and charted for each intervention included: the author(s) and/or leading organisation(s); the title of the intervention or article; region; target population;

intervention type; description of the intervention; date established/published; and reported evaluation or outcomes. Information on 'Pacific or Māori focus' was also charted from included articles, and described the level of involvement by Pacific and/or Maori experts, advisory groups, and communities, throughout the intervention's design, development, or implementation. The charted data presents information that was publicly available and easily accessible. Due to the broad nature of this review and the wide range of interventions identified, no contact with authors or organisations was initiated for more information.

Results

A total of 583 documents were identified from the databases and 53 from grey literature. After eligibility screening, 58 documents were included in the final review (Fig. 1) including 23 journal articles, 17 District Health Board (DHB) reports, eight Ministry of Health reports/websites, six organisation reports/websites, two general websites and one newsletter and news article. Of these included documents, 57 interventions were identified, and summary characteristics are

presented in Table 1. Almost half (47%) of interventions began during the 2013–17 period, a majority were based in Auckland (37%) and approximately half (47%) were primarily based in or intended for clinical settings.

Supplementary file S3 presents the full stocktake table of interventions, programmes and plans identified, including approaches that span across upstream factors, awareness and education, diagnosis, treatments, and medication adherence.

Primordial prevention

Our review identified 13 interventions that targeted primordial prevention, including national government programmes and regional DHB plans.^{13–28} The Rheumatic Fever Prevention Programme ran from 2011 to 2017 to address housing, health literacy and rapid diagnosis of sore throats.¹⁹ As part of this programme, the Ministry of Health's 'Healthy Homes Initiatives' were established in DHBs to conduct housing assessments and provide support such as heating, insulation and curtains, to create warmer, drier homes and reduce avoidable hospitalisations.¹³ An evaluation estimated approximately 160 fewer hospitalisations and 990 fewer visits to

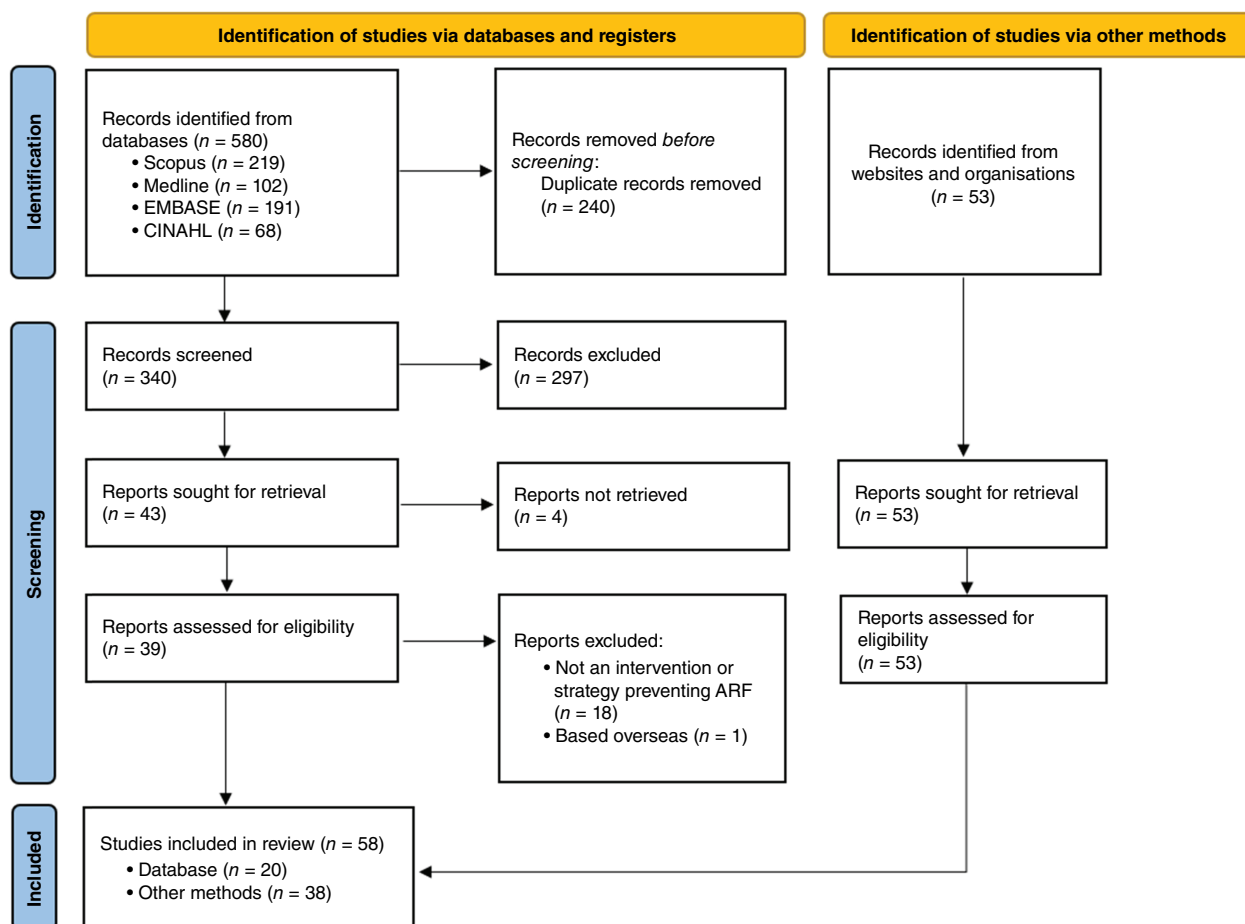


Fig. 1. PRISMA diagram of databases and grey literature sources. Note: ARF refers to acute rheumatic fever.

Table 1. Summary characteristics of interventions.

Characteristics	Interventions	
	<i>n</i>	%
Intervention start date ^A		
Prior to 1998	1	2
1998–2002	4	7
2003–07	1	2
2008–12	19	33
2013–17	27	47
2018–22	5	9
Region ^B		
Nationally	12	20
Auckland	22	37
Bay of Plenty	9	15
Hawkes Bay	3	5
Manawatu/Whanganui	1	2
Northland	6	10
Taranaki	1	2
Waikato	2	3
Wellington	3	5
Primary setting of intervention ^C		
Clinical	27	47
Community	15	26
School	15	26
Total	57	100

^AIntervention start date may also refer to date published or estimated start date.

^BMore than one region may be identified for one intervention.

^CPrimary setting of intervention refers to the primary location where the intervention was based or where it was primarily intended for use.

general practitioners than in the year prior to the intervention within a sample population.²⁴ In terms of intervention delivery, interviews with 25 whānau reported positive experiences with the assessors, and although the number of Pacific and Māori assessors was not explored, Pacific and Māori whānau discussed feeling more comfortable with assessors of their own culture due to shared understandings about their situation.¹³

Primary prevention

We identified five interventions related to developing, improving or evaluating primary care guidelines for the diagnosis, management and secondary prevention of RF.^{1,10,29–31} The development of evidence-based guidelines was intended to present the standard of care that should be available to all people and ensure consistency across services.¹ However, audits conducted by Shetty *et al.* in Northland

general practices showed that management of GAS infections for young people remained substandard over time.^{30,31} They identified inequities in care, with one in five Māori participants with GAS pharyngitis not receiving recommended antibiotics compared to 1 in 10 non-Māori participants.³¹ Prescribing for Pacific people was not specifically explored in this study.

Interventions also targeted rapid and accessible diagnosis of GAS infections and RF, such as access to sore throat clinics in the community,^{32,33} improving GAS diagnosis tools,^{34,35} and a range of school-based throat swabbing programmes.^{17,36–45} Mana Kidz is a school-based programme in Counties Manukau run by a Māori-led primary health organisation who practice a Kaupapa Māori approach. Over 34 000 children consented (approximately 50% Pacific and 39% Māori) from 88 primary and intermediate schools.⁴³ Fifty-nine schools have a nurse and whānau support worker in school each day and 29 schools have a nurse once a week, providing assessments and treatments for sore throats, skin infections, headlice and more. Between February 2013 and September 2014, 11% of throat swabs taken at schools were GAS positive and 97% of these were treated.⁴³ A significant reduction of >60% was found in first presentations of acute RF after the programme was introduced.⁴⁴ A national evaluation of sore throat management in NZ reported 46% effectiveness (95% CI 16–66%) for the programme in Counties Manukau during 2012–16, whereas school-based services in other regions were not found to be effective.⁴⁶ The evaluation concluded that school-based sore throat programmes could be effective in preventing acute RF in regions within densely populated high-risk settings, but that different approaches may be needed for low-risk or dispersed populations.

With emerging research identifying links between skin infections and RF, interventions were adapted to provide skin infection management such as referrals for antibiotics.^{41–43,47,48} The Kiri Ora/Healthy Skin project based in schools within Eastern Bay of Plenty provides healthy skin packs to children, consisting of soap, plasters, nail clippers and nit combs.^{47,48} It also provides a health literacy resource focused on messaging of the need to 'clean, cut, cover and check'. Strong parental support was found for this programme, outlining how it developed children's health literacy and the school-based nature of it removed healthcare cost and travel barriers for families.⁴⁷

One report also explored adherence to medications treating the initial GAS-positive infection. A series of trials in schools tested different ways of administering the standard 10-day course of oral amoxicillin by comparing directly observed therapy, blister packing medication and using text communication reminders.⁴⁹ Directly observed therapy showed a significant improvement in adherence, whereas no difference was identified for blister packs or text communications. The feasibility and acceptability of offering intramuscular penicillin as a treatment for GAS-positive school children was also explored, resulting in 100% antibiotic

adherence and 83% of parents reporting they were happy with how the treatment was administered to their child.⁴⁹

Secondary prevention

We identified seven studies exploring treatments and secondary prophylaxis.^{49–55} Studies showed the safety and efficacy of penicillin injections every 28 days for patients diagnosed with RF,⁵² and the effectiveness of community-based nurses delivering this programme.⁵¹ Ways of improving adherence to regular penicillin injections included offering incentives in the form of mobile phone credit or supermarket vouchers⁵⁵ and the use of an app to provide timely reminders and help to schedule appointments.⁵⁴

DHB initiatives prompted by the government's prevention programme were also identified, including plans to ensure appropriate management of RF cases.^{14–16,18,20,22,23,25–28,56} This included ensuring timely notification of cases, updating regional registers, delivery of secondary prophylaxis on time, referrals to housing and social services, and reviewing system failures.

Awareness and education

In this scoping review, 37 of the total 57 interventions (65%) reported some component of awareness or education. Seven strategies were aimed at a national scale,^{19,46,57–61} including the Winter Rheumatic Fever Awareness Campaigns. Stories of Pacific and Māori families affected by RF were broadcast via television, radio and printed materials, aiming to promote links between sore throats and RF, the importance of getting sore throats checked by health professionals and completing a full course of antibiotics.⁵⁷ After the 2014 Winter Awareness campaign, a survey was conducted with 800 parents or caregivers of children aged 4–18 years. The evaluation found that the campaign had reached 76% of the target audience, and had a high recall among Pacific respondents on television (73%), at a healthcare provider (53%) and on radio (32%).⁵⁷ An evaluation of the 2015 campaign found that 81% of families recognised that a sore throat can cause RF, whereas 91% acknowledged that it can damage your heart. However, more support was needed to promote the importance of antibiotic adherence with just over one-third of focus groups identifying that a full antibiotics course is needed to prevent sore throats from developing into RF.⁵⁸

Regional strategies have focused on engaging Pacific and Māori communities in particular.^{21,25,61–65} The Bro'town project is one example, conceptualised by a group of Pacific nurses from Counties Manukau DHB, which serves a primarily Pacific and Māori population.²¹ Using the Samoan characters from the popular comedy cartoon, Bro'town, a series of hard copy comics targeted at Pacific and Māori youth were produced covering sore throats, the RF hospital journey and how to prevent future attacks of RF.²¹ The comics were trialled in low decile schools in South

Auckland and the Waikato; however, this review was unable to identify any published evaluation outcomes. Alliance Health Plus, a Pacific-led primary health organisation, also leads a range of awareness campaigns focused on Pacific people in South Auckland.^{61,64} This includes delivering education sessions at Samoan and Tongan churches and encouraging youth to produce video content spreading the message.

Pacific and Māori involvement

Because Pacific and Māori communities experience the greatest burden of RF, we explored the level of involvement by these groups in the interventions. Involvement was determined by publicly accessible information, and a significant proportion (26%) of interventions remain unknown. Almost half of interventions (47%) acknowledged input from Pacific and/or Māori organisations, communities and experts solely in an advisory role or involvement in the delivery of an intervention. Leadership collaborations or co-designed interventions by Pacific and Māori people were less common (26%).

Discussion

This scoping review identified 57 interventions aimed at reducing GAS and RF by addressing upstream factors, increasing public awareness, and improving diagnoses, treatments and adherence to medication. The government-initiated Rheumatic Fever Prevention Programme targeted a number of these areas, including healthy housing, sore throat clinics, awareness campaigns and health service improvements.¹⁹ Similar multiyear prevention programmes have been conducted in Cuba, Costa Rica and Tunisia.^{66–68} Each has reported successes in reducing RF incidence, due to a range of factors including decreased poverty, improving healthcare providers' expertise, general public awareness and focusing on strong primary healthcare services to identify, register, refer and follow-up cases. A study in Baltimore, USA, showed the impact of affordable, comprehensive healthcare programmes, with a 60% decline in RF in areas with the programme compared with no change in other parts of the city.⁶⁹ Shifting from 10 days of oral antibiotics for a GAS infection to a one-off benzathine penicillin injection was also reported as contributing significantly to prevention efforts in both Costa Rica and Tunisia,^{66,68} and was similarly identified by one NZ study as an acceptable way to ensure antibiotic adherence.⁴⁹

Some of the school-based throat swabbing initiatives identified in this review reported significant reductions in rates of positive GAS swabs, such as the Mana Kidz programme.⁴³ However, an evaluation of the Ministry of Health's sore throat management initiatives showed variable coverage and uptake across regions and priority populations.⁴⁶ Evaluations of the national Winter Rheumatic Fever Awareness campaign series showed high recall among Pacific

and Māori participants, and a recognition that the advertisements, which featured stories predominantly from Pacific and Māori families, spoke to people like them.⁵⁷ However, Anderson and Spray argue that such campaigns contribute to further stigmatisation and structural violence of Pacific and Māori people, failing to acknowledge the inequitable historical and structural conditions that have created these environments and instead placing the blame and responsibility on individuals.⁷⁰ These factors should be carefully considered in the development of future interventions to ensure that inequities are not maintained or reinforced. Initiatives conceptualised and led by Pacific and Māori communities themselves may have the potential to be better focused, more effective and avoid stigmatisation.

Many interventions identified in this review failed to report evaluation outcomes. Evaluations may assess the process, implementation and/or effectiveness of an intervention, and a failure to do this can result in time-intensive and costly programmes that may not achieve the intended impact. Incidence rates of RF in NZ continue to show inequitable burdens, particularly for Pacific children,⁵ and although many interventions explicitly target or have a focus on Pacific communities, outcomes have not been publicly reported in many cases. Although Pacific organisations, experts and community members were often acknowledged in initiatives on an advisory capacity, far fewer reported active leadership and direction from the outset. Communities involved in leadership and decision-making within research and in the development of interventions from the beginning have shown potential to result in community-led action and positive outcomes,⁷¹ and could be beneficial for addressing RF in NZ.

The strength of this scoping review is that it provides a broad overview of the range of interventions, initiatives and plans undertaken in NZ to address the RF burden, sourced from both peer-reviewed and grey literature. It has focused identified a key gap in how Pacific and Māori people are involved or leading interventions related to them. However, it is important to note that a limitation is that the review includes only information that is publicly available and accessible, as author groups and organisations were not contacted for further detail.

Conclusion

There is a need for greater recognition of the complex determinants that continue to contribute to health inequities in NZ. Interventions should reflect these factors and ensure that appropriate evaluation systems are built in to ensure effectiveness and sustainability. A report from the Office of the Prime Minister's Science Advisor outlines that 'going forward, the approach to rheumatic fever/rheumatic heart disease prevention and control should be holistic, collaborative, Māori and Pacific-led and underpinned by a national

strategy' (p. 8).² This review highlights the need for more community-led interventions, particularly by and for Pacific people.

Supplementary material

Supplementary material is available [online](#).

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