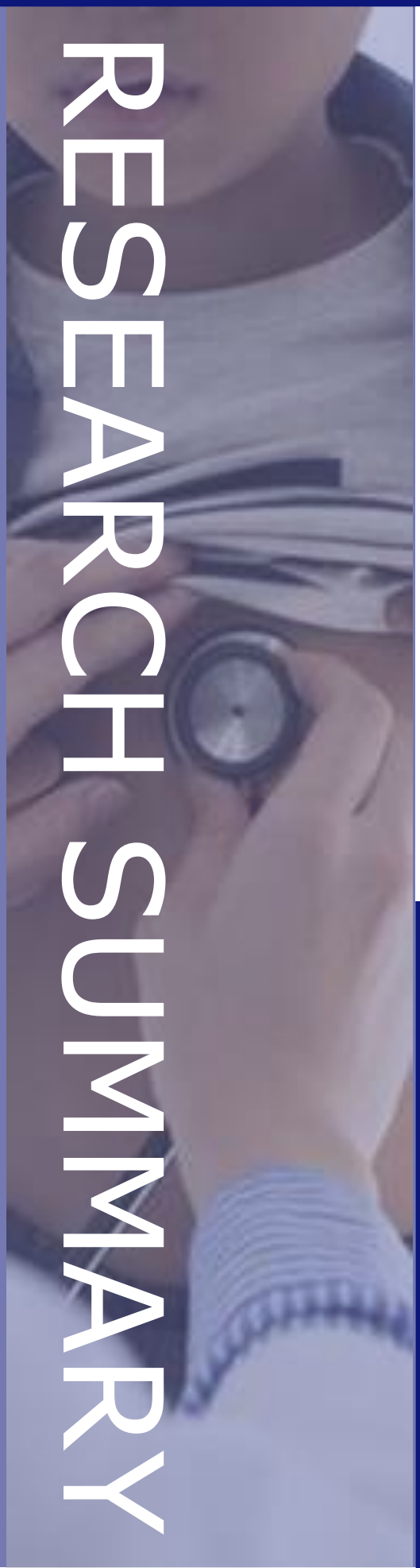
Multisectoral and Decolonial Approaches to Prevent Acute Rheumatic Fever in Aotearoa

RESEARCH SUMMARY



Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) are preventable diseases associated with poverty, inadequate housing, and household crowding. Most common in low-income countries, ARF and RHD are also prevalent in Aotearoa, New Zealand where Māori and Pacific children experience the greatest burden of disease. Despite government attention, public health initiatives and extensive research, rates of new ARF diagnoses remain high in Aotearoa compared to other high-income countries.

ARF and RHD are inequitable conditions. Existing research recognises multisectoral influences on rates of disease including poverty, poor housing conditions and access to services. Previous studies describe that collaborative action across sectors is needed to reduce and eventually eradicate ARF and RHD from Aotearoa. Existing research does not explain what multisectoral policy responses and holistic approaches look like in practice and does not investigate how organisations are working collaboratively to address this issue. In what ways are non-government organisations (NGOs) and government organisations collaborating to address the causes of ARF and RHD? What are the factors that drive or constrain multisectoral action in the response to ARF and RHD in Aotearoa?

This research project recruited 22 professionals involved in ARF/RHD prevention across non-government and government organisations. It sought to understand perceptions of current initiatives, listen to stories of collaborative action occurring between organisations and individuals across sectors, and identify barriers to multisectoral action. This research summary highlights the context for this research, findings and recommendations for further research and action.

KEY MESSAGES

- ARF and RHD are multisectoral issues concerning health, housing, and social sectors.
- Māori and Pacific children have the highest rates of disease in Aotearoa, with Māori children 36 times and children of Pacific descent 80 times more likely to develop ARF compared to children of European/other descent.
- Many organisations are working across housing, health, education, and social sectors to address ARF/RHD. Multisectoral initiatives and policy responses are needed to reduce and eventually eradicate ARF and RHD from Aotearoa.
- Multisectoral action is hindered by misaligned values, racist contracting arrangements, and competition between individuals and organisations.
- Barriers preventing multisectoral collaboration must be addressed for the implementation of holistic, culturally responsive prevention initiatives.

CONTEXT

ARF is caused by a group A streptococcus (GAS) infection of the throat or skin which can lead to an unusual immune response causing RHD. RHD is a chronic disease with long-term consequences including the need for heart surgery and premature death.

RHD is estimated to affect 40.5 million people globally but not frequently seen in nations where there is a high standard of living. Rates of ARF and RHD declined in high-income countries in the 20th century because of improved living standards and access to healthcare. Despite being a high-income nation, ARF and RHD have remained prevalent in Aotearoa. The ongoing impacts of colonisation on Indigenous Māori and Pacific Peoples has perpetuated inequities in living standards and accessibility of healthcare, resulting in disparate rates of ARF and RHD. The main risk factor for ARF is household crowding increasing the spread of GAS. Recent research has linked new diagnoses of ARF to scabies and the consumption of sugary drinks.

Government organisations and NGOs are dedicating time and resources to addressing ARF/RHD, with ongoing research and investment into public health responses and prevention campaigns. Although studies have identified overcrowding as the greatest modifiable risk factor for ARF, prevention efforts to date have centred around throat swabbing programmes in areas of relative socio-economic deprivation, aiming to catch GAS infections before they progress to ARF. A current focus of research funding is on the development of a GAS vaccine. Westernised, biomedical responses to social issues have resulted in interventions inadequately addressing the underlying social determinants of health causing ARF and RHD.

RESEARCH METHODS

The questions guiding this research are,

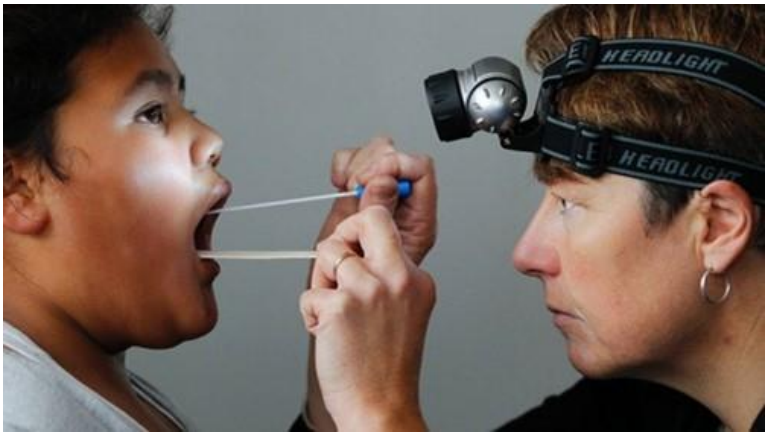
• In what ways are NGOs and government organisations collaborating to address the causes of ARF and RHD in Aotearoa?

• What are the factors that drive or constrain multisectoral action in the response to ARF and RHD in Aotearoa?

This study reviewed transdisciplinary literature and employed qualitative research techniques to answer the research questions. The study recruited 22 professionals working across a spectrum of organisations, all with a common goal of preventing or treating ARF and RHD. Organisations represented in these research findings include the Ministry of Health (MoH), Auckland District Health Board (ADHB), the National Hauora Coalition (NHC), Starship Foundation, Habitat for Humanity Northern Region (HFHNR) and Matakohe Architecture as well as housing and health researchers.

Research methods included interviews, focus group discussions (FGDs) and participant observation. These tools were used to understand participant involvement with ARF/RHD prevention initiatives, analyse the collaborative relationships that exist across sectors and identify the ways forward for impactful multisectoral action. As this research took place during the COVID-19 pandemic under lockdown restrictions, all interviews and FGDs but one took place using virtual meeting software.

"To curb high rates of ARF and RHD, New Zealand must address increasing social and ethnic inequalities."
(Bennett, Zhang, et al., 2021, p. 37).



RESEARCH FINDINGS

INSIGHTS AND PASSIONS

Research participants told unique and deeply personal stories explaining what led them to become involved in ARF and RHD prevention efforts. Dame Tariana Turia and the late Dr Diana Lennon were credited as being influential drivers of action in the ARF/RHD prevention space. Turia ensured that ARF/RHD were recognised at a political level, and Lennon, a renowned researcher and paediatrician, led ARF/RHD research projects.

> *"We can't get it done if we treat it just as a health condition. We have to address the wider determinants of health. We have to address poverty, we have to address housing, and we have to acknowledge the history of racism and colonisation. If we don't do that, we're going to end up with a wagging finger of the mainstream health system telling us we've put our kids in harm's way".*
>
> - Dr Rawiri Jansen, Clinical Director of the NHC

INEQUITY AND STRUCTURAL VIOLENCE

Research participants commonly credited historical injustices, poverty, and barriers to accessing the social determinants of health as factors that influence inequitable rates of new ARF diagnoses in Pacific and Māori communities.

The racist nature of the response to ARF/RHD is recognised by participants. If this were a disease impacting affluent communities with different skin tones and histories, the response to ARF/RHD would be far more resourced and impactful. ARF and RHD are issues of poverty and markers of inequity. Existing research and interventions tend to hold whānau accountable for negative health outcomes, placing responsibility on the victims of ARF/RHD create a sense of stigma for whānau.

Racism perpetuates colonial ideologies and arrangements, seen in western systems designed to benefit Pākehā, and results in poor outcomes for Māori and Pacific people. This research recognised that language in the media and public health promotional material uses deficit jargon such as "*vulnerable*" or "*predisposed*" to discuss issues like ARF/RHD that predominantly impact Māori and Pacific people. This places the blame onto Māori and Pacific people without recognising structures and contextual factors that determine health outcomes.

NOT ADDRESSING THE ROOT CAUSES

Participants identified that many existing interventions do not address the root causes of ARF/RHD. A confidential participant shared their opinion about ARF in Aotearoa, "*It shouldn't be in New Zealand. I think it's going to be more than increasing throat swabbing or a vaccine... We're going to need to address housing*". Participants identified the overly medicalised focus of ARF/RHD prevention interventions that "*don't address those primordial determinants of health*" as well as the lack of investment in holistic, culturally responsive healthcare services and multisectoral initiatives.

MULTISECTORAL PREVENTION CASE STUDIES

Three case studies of multisectoral initiatives seeking to address ARF/RHD in Aotearoa were highlighted in the research findings, the Rheumatic Fever Prevention Programme (RFPP), the Healthy Homes Initiative (HHI), and Pū Manawa.

The government-led RFPP commenced in 2012 with a goal of reducing new ARF diagnoses by two-thirds. The central foci of the RFPP were to establish sore throat swabbing clinics in schools located in high-risk communities, provide education on ARF/RHD to healthcare professionals, raised awareness through health promotion campaigns, and implemented programmes to reduce household crowding. The RFPP failed to reach its targets and ended in 2017.

The HHI, born out of the RFPP, was repeatedly mentioned by participants. Another government-directed initiative, the HHI addresses housing inequities by focusing on the provision of warm, dry, healthy housing for whānau. This initiative sees health and housing focused organisations working closely together to deliver interventions including insulation retrofitting, curtains, and winter warmer packs. Chronically underfunded and reactive rather than proactive, the HHI relies on the resources and connections of NGOs to deliver interventions to communities, and often fails to intervene before a child becomes unwell.

Pū Manawa is a recently established collaborative non-profit organisation with multisectoral representation, consisting of patients, clinicians, researchers, and scientists. Pū Manawa pulls together ARF/RHD prevention experts to advocate for systems change in Aotearoa and though they are recognised by the government, they do not receive government funding.

MULTISECTORAL ACTION

The impacts of ARF/RHD are wide-reaching and severe, and the solutions are multisectoral. Traditional biomedical responses to ARF/RHD seen in past programmes like the RFPP have not been entirely impactful. These have not addressed the complex socio-economic conditions which underlie ARF rates. Multisectoral approaches are required to address this complex, disparate condition.

BARRIERS TO MULTISECTORAL ACTION

Participants identified various reasons that multisectoral action is either not pursued or is not successful in ARF/RHD prevention. These reasons ranged from macro-level issues with siloed government ministries and funding mechanisms to micro-level interpersonal relationships, lack of transparency, and competition.

The siloed separation of societal sectors and government systems prevent multisectoral collaboration even when goals are shared. A Starship Foundation representative explained that the "*HHI is one of the most contentious things that we fund because there's a question of whether we have moved out of health*". Even when the HHI has significant positive impacts for child health and has been shown to keep children out of hospital. Organisations are encouraged to stay in their domain, and divisions intended to simplify systems result in inability to think holistically.

Current interventions are led by Pākehā voices from a western perspective, not by te ao Māori and those with lived experience. This lack of cultural representation and leadership is a barrier to designing and implementing impactful solutions.

Participants discussed how government contracts limit the self-determination of Māori organisations and communities. The focus of community initiatives becomes contract-driven, not community-driven, because of the structure of funding mechanisms and the demanding nature of contracts. The contract-driven space of health and social services is highly competitive. Often organisations with the same values and aligned vision for their community are pitted against one another because they compete for funding sources. Interpersonal competition across academic, research and multidisciplinary spaces, described by participants as "*territorial behaviour*" silences new voices. Competition inhibits collaboration and prevents organisations from sharing information and resources.

ENABLERS OF MULTISECTORAL ACTION

Participants reported hopeful markers of progress. One participant, Dr Nigel Wilson, commented, "*if you'd written [this thesis] up until 2018, you could have titled it: Lack of intersectoral collaboration is associated with the inability to control and manage ARF and RHD*". Many organisations and initiatives are looking holistically, building capacity, and creating culturally responsive interventions. Examples include HFHNR working with iwi Māori groups, and the NHC working within communities and designing by Māori, for Māori solutions to address ARF and RHD.

INSIGHTS: MULTISECTORAL COLLABORATION

- ***Siloed Systems**: produce interventions that do not have a holistic approach, affecting funding and service availability.*
- ***Cultural leadership:** is required to design impactful solutions that are by Māori, for Māori and of Māori.*
- ***Competition:** stifles collaboration.*
- ***Capacity building:** enables other individuals and organisations to design and deliver ARF/RHD prevention programmes that are responsive to community needs.*
- ***Opportunity:** with health system reform, there is the potential for increased holistic, multisectoral action.*

RISKS AND OPPORTUNITIES

In a time of change, with the 2022 health system reform, the creation of a new health system, Te Whatu Ora, and a Māori health authority, Te Aka Whai Ora, there are opportunities for systemic transformation. Participants expressed a sense of hope that the reforms will reduce the number of whānau that fall through the metaphorical gaps of a deeply flawed system that privileges Pākehā. Perhaps the new health system will be open to criticism, adapted to observe the links between health outcomes and social determinants to cultivate multisectoral responses to multifaceted issues like ARF/RHD.

A risk of increased multisectoral action, as noted by one participant, is that "*if you say it's everybody's problem, you can make it nobody's problem*". Making ARF/RHD a multi-sector priority may transform it into no sector's priority as there may be less clarity of roles and responsibilities of each organisation and sector involved.

COVID-19 LEARNINGS

Conducted in the context of COVID-19 lockdowns and seemingly unrestricted government spending, the concept of scarcity, which health and social organisations are incessantly socialised to, has been disproven. The resourced reaction to COVID-19 has revealed that scarcity rhetoric, saying that there is no money for ARF/RHD prevention initiatives, is untrue. Funds are available, however, interventions targeting privileged population groups are prioritised, over ARF/RHD interventions that address issues that impact disadvantaged groups.

One impact of COVID-19 is organisations working together across sectors. Participants told stories of how organisations collaborated, sharing resources and knowledge, during the COVID-19 response. NGOs notions of territory or influence were cast aside to meet the needs of communities.

HEALTH IN ALL POLICIES

For siloed, disunified, competition-driven structures to be addressed, a Health in All Policies (HiAP) approach is called for. HiAP is an approach to multisectoral policy-making that considers the consequences of policies on the social determinants of health, recognising that health is determined by many factors, not only health sector programmes. HiAP may be correlated with Durie's Māori framework of health, te Whare Tapa Whā in that it recognises all aspects of life to have impacts on the social, mental, emotional, and spiritual health of people. Additionally, HiAP is a conceptual tool that can help to address the synergistic nature of intersecting epidemics (syndemics, see above), GAS, household crowding, the consumption of sugary drinks and scabies leading to ARF/RHD in Aotearoa.

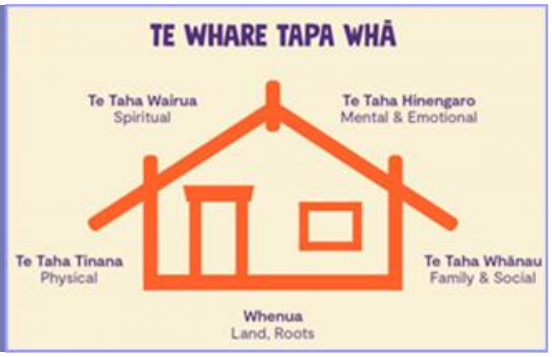
INNOVATIVE APPROACHES

A SYNDEMIC APPROACH

A syndemic occurs when two or more diseases adversely interact in the context of social inequality. Moving away from siloed medical approaches, the syndemic approach observes interrelated health conditions that arise in inequitable conditions. A syndemic analysis concentrates on the underlying drivers of the syndemic to enable the creation of targeted interventions that address the root causes of disease (figure below). This research identified a synergy between GAS infections and other factors including scabies and the consumption of sugary drinks in the context of a housing crisis with high rates of household crowding, leading to new diagnoses of ARF. There are multiple systemic drivers of this syndemic including racism, medicalised health systems and housing policies that further increase inequities. Housing policies in Aotearoa serve the interests of wealthy landowners and homes are not built to accommodate intergenerational family structures. Inadequate, overcrowded housing is an outcome of racist systems that disempower families. A syndemic analysis promotes collaboration, joining up silos of thinking, to address common systemic drivers of inequity.

"If the health system… understood the impacts of housing on health, then we'd have a very different looking health system".

- Confidential participant



INDIGENOUS LEADERSHIP AND TE WHARE TAPA WHA

Initiatives are moving away from western, medicalised responses to ARF/RHD, increasingly recognising the need for Māori and Pacific leadership to design and implement culturally-centred solutions. In the past, government organisations have responsibilised Māori for the problems that impact them; however, they are reluctant hand over the direction and ownership of solutions. Government organisations may consider turning to NGOs such as the Starship Foundation and the NHC for advice to give autonomy to Māori and Pacific-led organisations. The government may consider adopting cultural models for housing and health policies, such as the Pacific housing model, Lolo Na'ati, and Te Whare Tapa Whā model of Māori health.

Te Whare Tapa Whā is a framework for the conceptualisation of health that disrupts the standardised biomedical model, providing space for te ao Māori perspectives to transform the health sector. Developed by Sir Mason Durie in 1994 and translated from te reo as "the house with four sides", te Whare Tapa Whā is a framework that uses the whare (house) as a metaphor to represent the four dimensions of an individual's hauora. Critiqued for being too simplistic, with awareness of diversity and connection to whenua and whānau, Whare Tapa Whā is a useful model for healthcare workers and policy-makers alike for a holistic conceptualisation of health.

RECOMMENDATIONS

Rates of new ARF diagnoses are a stark reminder that socio-political structures in Aotearoa are not equitable. This study asks why existing interventions have not addressed high rates of new ARF diagnoses in Aotearoa and how multisectoral approaches may provide a path forward for change. This research incorporated the knowledge and experience of 22 experts in the ARF/RHD prevention space with literature from various academic fields in a transdisciplinary approach. The following recommendations for future research and action are intended to build upon work that has already been done in the ARF/RHD prevention space.

RECOMMENDATION ONE: AUTONOMY FOR MĀORI AND PACIFIC LEADERSHIP IN HEALTH REFORMS

Māori and Pacific authority is necessary for creating and implementing solutions by, for and of Pacific and Māori people. This research has identified that homes in Aotearoa are not designed to cater to intergenerational family structures and communal ways of living. Recognising the exceptional work already conducted by Māori and Pacific researchers, this research calls for more Māori- and Pacific-led ethnographic research into the living situations of Māori and Pacific communities, investigating the impact of housing on health, and the decolonisation of housing design. This will inform the creation and instigation of culturally responsive policies.

RECOMMENDATION TWO: INVESTIGATION INTO THE GAS, OVERCROWDING, SCABIES, NUTRITION, ARF SYNDEMIC

More research is required to investigate the relationship between scabies, the consumption of sugary drinks, household crowding and GAS causing ARF/RHD. An in-depth analysis should be undertaken considering the biological synergy of these conditions in the context of deprivation, involving Māori and Pacific communities. Further research should involve families with lived experience of ARF/RHD.

RECOMMENDATION THREE: A NATIONAL ARF/RHD STRATEGY

Aotearoa's response to ARF/RHD is fragmented. A national strategy to address ARF/RHD is required to unite provider organisations and assist them in moving away from talking about collaboration to pooling their resources for impactful multisectoral initiatives

RECOMMENDATION FOUR: RESTRUCTURING GOVERNMENT CONTRACTS AND RESOURCE PROVISION

Government-provider contracts must be restructured to reduce competition, encourage partnerships between organisations, and foster multisectoral collaboration. The government must better resource initiatives to cover the baseline costs of interventions and not taking advantage of passionate community-led and -funded organisations so that services can reach more families. The government must reflect on funding mechanisms, ensuring these align with te Tiriti o Waitangi.

RECOMMENDATION FIVE: HEALTH IN ALL POLICIES (HIAP) AND CULTURAL MODELS

For the adoption of te Whare Tapa Whā model of health and the Lolo Na'ati Pacific model of housing, and HiAP approaches to integrate health considerations into all policy spaces.

RECOMMENDATION SIX: LEARNING FROM COVID-19

Recognising that resource scarcity in the provision of social and health services is a myth, the government must adequately resource the response to ARF/RHD. Primarily, a national ARF/RHD register should be urgently developed.

This research summary has been prepared for research dissemination. It is based on the following material: Trace, A. (2022). Multisectoral and Decolonial Approaches to Prevent Acute Rheumatic Fever in Aotearoa. (Unpublished Masters Research Thesis, The University of Auckland). Refer to the Masters thesis for the unabridged research and a complete list of reference material.

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