New Zealand Government
Te Kāwanatanga o Aotearoa

MINISTRY OF HEALTH
MANATŪ HAUORA

RESEARCH AGENDA:
Rheumatic fever and rheumatic heart disease

2026

Public Health Agency & Mental Health Group
and Health Science, Strategy Policy Group

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Background and context

Background and context

In 2018, the World Health Assembly (WHA) adopted resolution WHA 71.14 calling for the World Health Organization (WHO) to launch a coordinated global response to rheumatic heart disease (RHD) and rheumatic fever (RF) (WHO 2018). In 2024, the WHO published the *WHO Guideline on the Prevention and Diagnosis of Rheumatic Fever and Rheumatic Heart Disease* (WHO 2024). Here it estimated that in 2021, 55 million people around the world had RHD and that RHD caused 360,000 deaths.

Over the last 25 years, the incidence of RF and prevalence of RHD has declined substantially in most high-income countries in Europe and North America. The WHO has calculated that globally age-standardised mortality rates decreased by 28% from 2000 to 2021. The same decrease has not been seen in Sub-Saharan Africa, the Middle East, Central and South Asia, tropical Latin America and the South Pacific, including Australia and New Zealand, continue to have much higher rates of RF and RHD. In addition, the prevalence of RHD among women is higher across nearly all world regions (WHO 2024).

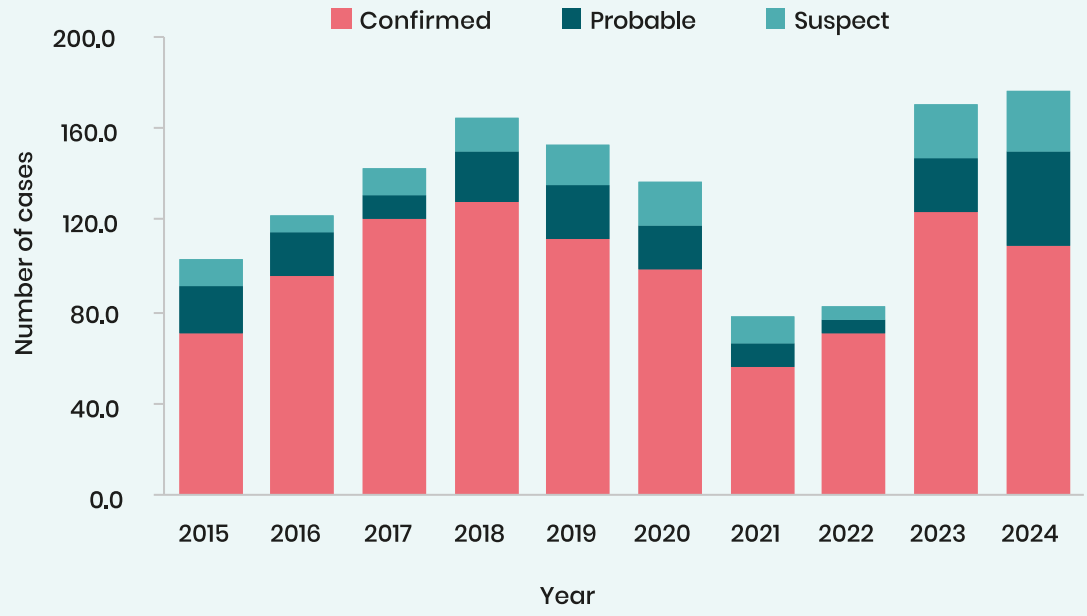
New Zealand researchers have been heavily involved in global efforts to manage the disease and research important gaps in knowledge, due to the expertise that they have developed over several decades of research on and clinical attention to RF and RHD. In 2021 the National Heart, Lung, and Blood Institute, within the US National Institutes of Health, convened a global stakeholders' workshop entitled 'Eradication of Rheumatic Heart Disease: Assessing Research Challenges and Opportunities', which included New Zealand research leaders. The proceedings from this workshop led to several papers identifying global priorities for RF and RHD research across the prevention and treatment continuum (Baker et al 2023; Fulurija et al 2023; Karthikeyan et al 2023; Rwebembera et al 2023; Vervoort et al 2023).

While global priorities were forming, the Ministry of Health – Manatū Hauora (joined later by Health New Zealand – Te Whatu Ora (Health NZ)) worked closely with the sector to produce the *Rheumatic Fever Roadmap 2023–2028* (roadmap) (Health NZ 2023). The purpose of the roadmap is to:

- reset and refocus efforts to prevent, identify and manage RF and RHD
- identify specific priorities for action over the next five years – including work currently under way and new priority areas.

One of the priority actions in the roadmap was to coordinate an RF research agenda specific to New Zealand (as item 3.4) (Health NZ 2023, p 33). Since the roadmap has been completed, Health NZ has also significantly updated the clinical guidelines for managing RF and RHD (Health NZ 2025). The roadmap and the clinical guidelines are providing strategic and clinical guidance for the health sector. The RF research agenda is intended to add to these important system-level responses.

FIGURE 1. Number of initial episode rheumatic fever cases by year, 2015–2024



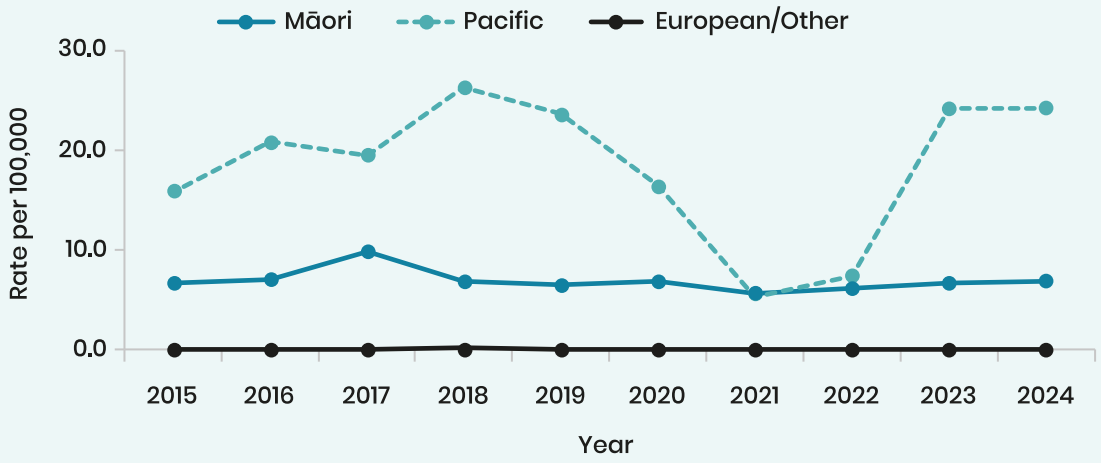
Source: PHF Science (2026)

Current case rates of rheumatic fever

The latest Institute of Public Health and Forensic Science (PHF Science) report shows that 149 people were identified as having 'probable' or 'confirmed' RF for the first time in 2024 (PHF Science 2026). This is the highest number of rheumatic fever cases notified in the past 10 years (Figure 1).

In New Zealand, the ethnic groups who are overwhelmingly impacted by RF and RHD are people who identify as Māori or Pacific peoples. The PHF Science (2026) report assigns people to ethnic groups based on prioritised ethnicity classification rather than total response. As a result, it may undercount the number of Pacific peoples with RF and RHD because an increasing number of Pacific peoples also identify as Māori (and so, under the prioritised system, are counted as Māori rather than Pacific peoples).

FIGURE 2. Initial episode rheumatic fever rates by prioritised ethnicity, confirmed and probable cases, 2015–2024



Source: Source: PHF Science (2026)

In 2024, the overall incidence for first episode of RF was 2.8 per 100,000 people. By ethnicity, however, the case rate was 24.1 per 100,000 for Pacific peoples, 6.9 per 100,000 for Māori and 0.1 per 100,000 for European or other ethnicities (Figure 2).

In 2024, most (124 out of 149) confirmed and probable cases were in children (5–14 years) and young people (15–24 years). Of these, only three cases were of European or other ethnicities, and the rates were highest among the 5–14 years age group, especially for Pacific children at 76.7 per 100,000 (Table 1).

There is currently no national reporting of recurring RF cases. RHD prevalence, including first-episode RHD cases, is not nationally reported either because RHD is not a notifiable disease.

New Zealand research to date

New Zealand has invested substantially in RF and RHD research for several decades through the Health Research Council (HRC),[1] not-for-profit organisations and other funders. Along with Australia, New Zealand has undertaken much of the leading research dedicated to RF and RHD

1. In its latest impact report, HRC (2025b) details the impact of a decade of HRC funding for RF research. In particular, it notes:
   - international collaborations have developed and promoted echocardiographic screening protocols and criteria for diagnosing RHD
   - evidence shows that skin infections caused by group A streptococcus (GAS) bacteria can increase the risk of acute rheumatic fever, in the same way that a GAS sore throat or 'strep throat' is a risk factor for acute rheumatic fever
   - acute rheumatic fever is strongly associated with modifiable risk factors, notably household crowding, barriers to accessing primary care, and consuming sugary drinks
   - extensive links and research partnerships exist between Pacific communities and researchers in New Zealand and across Pacific nations
   - evidence-based and inclusive science communication and engagement campaigns for RF have been conducted
   - researchers who have led or contributed to the University of Otago rheumatic fever research group have received over $4.2 million in HRC funding to study rheumatic fever since 2013.

TABLE 1. Initial episode rheumatic fever cases and rates by prioritised ethnicity, age group and year, confirmed and probable cases, 2015–2024

	Māori				Pacific peoples[2]				European or Other			
	5–14 years		15–24 years		5–14 years		15–24 years		5–14 years		15–24 years	
Year	Cases	Rate[3]	Cases	Rate[3]	Cases	Rate[3]	Cases	Rate[3]	Cases	Rate[3]	Cases	Rate[3]
2015	34	27.6	4	3.6	37	57.7	8	13.4	0	0.0	0	0.0
2016	34	27.2	6	5.3	41	63	16	26.4	1	0.2	2	0.4
2017	43	33.7	14	12.3	43	64.8	14	23.1	2	0.5	1	0.2
2018	42	24.5	11	7.6	47	75.2	28	44.7	3	0.7	3	0.7
2019	39	22.4	10	6.9	58	91.4	14	22.5	2	0.5	0	0.0
2020	45	25.5	5	3.4	38	58.9	10	16.1	3	0.7	0	0.0
2021	42	23.7	4	2.8	13	20.1	4	6.6	0	0.0	0	0.0
2022	45	25.4	2	1.4	15	23.3	3	5.0	0	0.0	0	0.0
2023	39	21.8	13	8.9	53	81.1	17	27.5	3	0.7	1	0.2
2024	46	25.5	6	4	51	76.7	18	28.2	1	0.2	2	0.4

Source: PHF Science (2026)

prevention and treatment, including in the current development of a *Streptococcus pyogenes* vaccine (Wirth et al 2022).

In addition to the traditional funding sources, in 2023 the Government allocated a one-off $10 million package for the development of the Streptococcus pyogenes vaccine. This funding has resulted in substantial partnerships with Australian and other international research and industry entities (Rapua 2025). Health NZ also supports clinical research and evaluations of other substantial programmes of work that are contributing to the body of evidence for RF prevention, case management, diagnosis and treatment (Dennison 2023; Health NZ 2025).

Reforms to the health research landscape

New Zealand's science, innovation and technology system is currently undergoing its most significant reform in decades. Strategic prioritisation, favouring collaboration over competition and emphasising advanced and emerging technologies for economic growth, is the driver for the reform. The Prime Minister's Science, Innovation and Technology Advisory Council held its first meeting on 18 July 2025 to start identifying strategic priorities to guide future funding decisions (MBIE 2025b). Key research fund-holders for RF and RHD research that are affected by these changes are PHF Science and the HRC.

2. Use of prioritised ethnicity in analyses undercounts cases in Pacific peoples in particular. Using total ethnicity response increases the total number of cases in Pacific peoples to 662, compared to 613 when using prioritised ethnicity (an 8% increase).

3. Rate per 100,000 population. The denominator data used to determine disease rates for ethnic groups is based on the proportion of people in each ethnic group from the usually resident 2018 census population to the mid-year population estimates for 2015–2024.

Notably PHF Science has become a public research organisation. An investment of $75 million over eight years was awarded to PHF Science in late 2025 as a continuation of Te Niwha, the infectious disease and pandemic preparedness research platform funded by the Ministry of Business, Innovation and Employment (MBIE) over 2023–2026 (MBIE 2025a). RF and group A streptococcus (GAS) research was included in several Te Niwha projects (Te Niwha 2025).

In the past, HRC has been the principal funder of health research and works directly with the Minister of Health (administering the Health Research Council Act 1990) and Minister of Science, Innovation and Technology (for funding). In October 2025, the Government made the in-principle decision to transfer health research funding from the HRC to Research Funding New Zealand, which MBIE will administer. From there, the funding will be divided and allocated based on advice from the Prime Minister's Science, Technology and Innovation Advisory Council. The transition to Research Funding New Zealand will be phased in over the next two years, while HRC will continue to administer all existing contracts and manage funding rounds through to 2028 (HRC 2025c).

HRC continues to prioritise RF research in its funding grants. It has recently awarded a large team of leading researchers[4] just under $1.4 million for a 42-month project, Whitia Kia Ora-Manawa Ora: Co-creating a Māori-centred model of RHD care (HRC 2025a).

New Zealand health system: roles and responsibilities

Three key national agencies have overlapping responsibilities for RF.

- The Ministry of Health is the lead advisor to the Government on health. Its three core functions are policy, regulation and monitoring. The Public Health Agency and Mental Health Group (PHAMH) sits within the Ministry of Health and leads the Ministry's work on public and population health.
- Health NZ is responsible for delivering and improving services and health outcomes across the health system.
- PHF Science provides national monitoring and surveillance of notifiable diseases including RF and invasive group A streptococcus (iGAS).

4. Associate Professor Anneka Anderson, Associate Professor Matire Harwood, Dr Rochelle Ellison-Lupena, Mr Shannon Leilua, Dr Rachel Brown, Professor Nigel Wilson, Associate Professor Mona Jeffreys and Ms Elizabeth Tilton.

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Ministry of Health rheumatic fever work programme

Ministry of Health rheumatic fever work programme

Working alongside Health NZ, the Director of Public Health and Director of Pacific Health (within the PHAMH) have developed a work programme to support priority actions identified in the roadmap. Most of the actions in the roadmap sit within Health NZ's responsibilities. The PHAMH has a role in this programme at strategic and systems levels and as part of its core monitoring function.

These roles are being delivered through six focus areas:

1. **social determinants of health**
2. **coordinating a national research agenda**
3. **surveillance and data**
4. **community care**
5. **accountability and monitoring**
6. **Māori Health Directorate collaboration.**

Developing a nationally coordinated research agenda

This project drew on the WHO guidance for developing a research agenda. The following definition provided the overarching objectives.

> A research agenda is a strategic plan that outlines the goals, priorities, and areas of investigation for future research endeavours. It serves as a roadmap, guiding researchers toward meaningful and impactful work. In the context of WHO, a research agenda identifies priority areas and gaps in health information and research, shaping new avenues for investigation and innovation for public health. A research prioritization document ranks the agenda to provide the most pressing areas to focus efforts.
>
> **(WHO 2025a)**

The WHO has also detailed this systematic process to follow.

1. Identify the objectives, what is the public health need?
2. Understand the research landscape
3. Plan the methodology to be used
4. Collating stakeholders with a broad range of experience to be involved in the prioritization process
5. Hold consultations or surveys to identify research areas or questions, and then to prioritize them
6. Publish and disseminate the priorities
7. Implement the research priorities
8. Monitor and evaluate the outcome eg on funding, product development or public health outcomes
9. Determine when the research priorities need to be updated

(WHO 2025b)

The project team took a pragmatic approach to applying this guidance. For details on the sector experts we engaged with and the methodology we followed, see Appendices 1 and 2.

03

A national research agenda for rheumatic fever

A national research agenda for rheumatic fever

Through the process of developing a research agenda, it became clear that, in addition to priorities for the research itself, there were equally urgent actions that central government and the health system needed to take to enable the research findings to be used. This section describes those actions as system responsibilities.

1

RF and RHD whānau at the centre

Placing whānau at the heart of research ensures that lived experiences, cultural values and community needs guide the design, delivery and evaluation of clinical care, access to services and interventions.

2

Shared accountability

Cross-sector collaboration for clinical, system and research alignment. Conducting research with and across agencies, sectors and communities addresses RF and RHD collaboratively, rather than in silos, and leads to system-level learning and accountability.

3

Knowledge translation

Sharing research findings to translate new knowledge into policy and action. It promotes interaction among researchers, clinicians and other producers and users of research as they explore ways to make research insights accessible, actionable and relevant. Explicitly prioritising research on how to move evidence from knowledge to action should involve the use of implementation science to guide the adaptation and sustainability of evidence-based interventions across community, clinical and system domains.

4

Long-term cross-agency policy impact

Generating and supporting research on system-level change, including how evidence is moved from knowledge into policies and clinical practices that can be implemented to have the greatest impact on addressing RF and RHD.

Research priorities

We have identified the following topics and subtopics as the main priorities for our research agenda. These priorities span the causes of RF and RHD, access to primary care, early detection, clinical management and long-term outcomes, recognising that RF is a life-course and systems-driven (syndemic) condition. There remain gaps in knowledge across the prevention and treatment spectrum from primordial prevention to tertiary-level care.

PRIORITY 1

Better understanding and improving life outcomes for individuals who develop RF or RHD

PRIORITY 2

Clinical practice and health services

PRIORITY 3

Anti-stigma and wellbeing

PRIORITY 4

System investment and economic evaluation

PRIORITY 5

Research collaboration and mapping across Pacific communities

PRIORITY 1

Better understanding and improving life outcomes for individuals who develop RF or RHD

(a) Longitudinal studies of RF and RHD across the life course (including palliative care) to develop integrated models of care across the health and social support system.

(b) Understanding the long-term economic impacts of RF and RHD on whānau, communities and the health system.

(c) Community-led research that co-designs locally relevant interventions and solutions across primary health care and the prevention, diagnostic and treatment continuum

(d) Research that builds on existing evidence to refine and evaluate targeted interventions and clinical practices for tamariki, rangatahi and pregnant women.

(e) Exploring methods to integrate community-sourced data into real-time surveillance and clinical decision-making systems. This data should include lived experience narratives, whānau-reported outcomes, and locally generated service and environmental data.

PRIORITY 2

Clinical practice and health services

(a) Strategies to improve long-term secondary prophylaxis adherence, as well as post-surgical follow-up and warfarin management.

(b) Identification of biomarkers to support the diagnosis of acute rheumatic fever (ARF) and earlier identification of those who are most at risk.

(c) Development of cost-effective imaging tools for early detection of RHD in populations most affected by RF and RHD.

(d) Investigating the scope and pathways of GAS transmission.

(e) Researching the role of skin infections in GAS transmission, carriage and RF epidemiology with a focus on whether interventions to prevent skin infection reduce RF incidence.

(f) Effective methods for training and education of local professionals in RF and RHD management.

PRIORITY 3 Anti-stigma and wellbeing

(a) Understanding how service design and policy settings can actively uphold mana and support wellbeing to enable successful prevention and treatment of RF and RHD and drive equitable life outcomes for Māori and Pacific whānau.

(b) Strategies to amplify upstream conditions across systems (eg, coordinated approaches to housing, income, education, access to health care) that protect the wellbeing of whānau affected by RF and RHD and support them to thrive.

(c) Development of strategies that foster trust in and the cultural acceptability of vaccination, along with informed choice, to support people's readiness for and uptake of a future GAS vaccine.

PRIORITY 4 System investment and economic evaluation

(a) Comprehensive cost–benefit analyses of prevention and treatment interventions across the life course, including the opportunity and treatment costs of RHD.

(b) Analysis of the economic costs that GAS transmission adds to the health system including the economic benefits of preventing RF and other ambulatory sensitive (potentially avoidable) hospitalisation conditions such as skin infections, cellulitis and respiratory conditions.

(c) Cost–benefit analyses of cardiology service models in resource-limited settings.

(d) Modelling the long-term economic cost and impacts of RF elimination strategies.

PRIORITY 5

Research collaboration and mapping across Pacific communities

Note: Pacific communities include New Zealand, Australia and Pacific Island nations.

(a) Mapping of approaches to RF, RHD and GAS prevention, diagnosis and treatment across the Pacific region.

(b) Use of whole genome sequencing, including strain types and skin infection patterns, to investigate GAS transmission dynamics across the Pacific region.

(c) Exploration of an all-of-Pacific RF and RHD strategy.

(d) Assessing the feasibility of an integrated data system for Pacific-wide RF and RHD surveillance and reporting system.

(e) Design and identification of methods to publicly report and disseminate RF and RHD research findings in an accessible way across Pacific communities.

(f) Strategies to incorporate Pacific worldviews and cultural diversities in RF and RHD research methodologies.

(g) Strategies to address known barriers to vaccine uptake in populations across the Pacific region, in preparation for the GAS vaccine.

System responsibilities

The Ministry has a key role in setting strategic direction and monitoring system-level performance across the continuum of prevention, diagnosis, treatment and long-term care for RF and RHD. The following three areas and actions points are priorities for the Ministry.

1. Effective leadership and accountability for health system performance

(a) Monitor and evaluate the roadmap and research agenda to support subsequent strategies and action plans that work towards an elimination strategy.

(b) Strengthen leadership and governance structures for RF and RHD to advance progress on the roadmap.

(c) Develop an elimination strategy.

(d) Strengthen surveillance systems for RF, RHD and GAS.

2. Supporting knowledge sharing and implementation

(a) Convene and support forums to strengthen research networks and translate the knowledge gained from research into policy and operational systems and clinical services.

(b) Support regular public reporting of data from RF monitoring and surveillance as part of meeting government measures and targets.

3. Cross-agency coordination

(a) Support research collaboration to align with long-term policy objectives.

(b) Apply systems thinking approaches to policy in order to support evidence-based institutional- and practice-level changes.

(c) Develop processes for cross-sector information-sharing to support partner agencies in decision-making.

Next steps

The completed research agenda will be shared with the sector and funding bodies. A high-level action plan for the Ministry will be developed to support the research agenda. This will include a plan for monitoring and evaluating the impact of having a centralising research agenda.

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Appendix 1: Experts who informed the research agenda

RF researchers in New Zealand consist of a relatively small network of experts spanning multiple disciplines, including clinical, public health, social sciences, policy and health systems. Māori and Pacific and lived experience perspectives also contribute to the research landscape. We approached the following key informants and peer reviewers as known leaders in the sector.

Associate Professor Anneka Anderson, Pūmanawa, National Hauora Coalition, University of Auckland

Bronwyn Petrie and Hayley Buchan, Starting Well, Planning, Funding and Outcomes, Health NZ

Dr Corina Grey, [then] Ministry for Pacific Peoples

Professor Dianne Sika Paotonu, University of Otago

Dr Florina Chan-Mow, Paediatrician, Counties Manukau, Pūmanawa

Dr Gerard Sonder, Pacific Perspectives

Health Gain Development Team, Planning Funding and Outcomes, Health NZ

Professor Jason Gurney, University of Otago

Dr John Malcolm, Emeritus Paediatrician, Bay of Plenty

Dr Josephine Aumea Herman, [then] Chief Clinical Advisor Pacific Health, Ministry of Health

Katie Te Amo, **Ezra Schuster**, **Nelson Sheridan**, Ministry of Social Development

Professor Matire Harwood, University of Auckland

Professor Michael Baker, University of Otago

Dr Monleigh Ikuia, Pūmanawa, University of Auckland

Professor Nikki Moreland, University of Auckland

Phillippa Anderson, **Melissa Kerdemekidis**, Population Health Team, Manawa Taki, Health NZ

Associate Professor Rachel Webb, Starship Hospital, University of Auckland, Pūmanawa

Dr Samuela Ofanoa, **Dr Siobhan Tu'akoi**, **Dr Amio Matenga-Ikihele**, Moana Research, Auckland

Shannon Leilua, National Hauora Coalition

Dr Willy-John Martin, Māori Science Lead, MBIE

Invitations to submit feedback

We sent invitations to attendees at two workshops to submit feedback on written drafts of this document. The workshops were:

- **National research priorities for group A streptococcus diseases**, Te Niwha Summit, November 2024
- **Group A streptococcus wānanga**, Hamilton, November 2025.

Appendix 2. Methodology

We took a pragmatic approach to applying the WHO steps for developing a research agenda.

1. What is the public health need?
2. Understand the research landscape
3. Plan the methodology to be used
4. Collating stakeholders with a broad range of experience to be involved in the prioritization process
5. Hold consultations or surveys to identify research areas or questions, and then to prioritize them
6. Publish and disseminate the priorities
7. Implement the research priorities
8. Monitor and evaluate the outcome eg on funding, product development or public health outcomes
9. Determine when the research priorities need to be updated (WHO 2025b)

Below we describe Steps 1 to 6 in detail. Steps 7 to 9 are planned for the next phase of this project.

1 What is the public health need?

The *Rheumatic Fever Roadmap* (Health NZ 2023) has been developed in response to the public health need of Pacific and Māori populations. Part of this response is to develop a coordinated national research agenda.

2 Understanding the research landscape

A high-level scan of research undertaken over the last 50 years has compared New Zealand research activities with the global RF and RHD priorities published by the National Heart, Lung, and Blood Institute in 2023. A Ministry of Health librarian undertook the stocktake by conducting a dedicated literature search, which also involved collaborating with Health NZ and reviewing the HRC-funded projects from 2013 to 2025.

A workshop at the 2024 Te Niwha infectious diseases and pandemic preparedness summit was held at the beginning of the project. Then in November 2025 a GAS research wānanga was held adjacent to the following Te Niwha summit. These two workshops provided intelligence about the research landscape and increased awareness of parallel research activity under way. The Ministry of Health's Chief Science Advisor also provided input to this aspect of the project with his wider-ranging networks and links to academia and health research.

The research and science environment in New Zealand has been undergoing significant reforms. Where possible, we have referred to these developments in the introduction section of this agenda.

3 Methodology used

The methodology was developed recognising the disproportionate impact of RF on Māori and Pacific peoples, and the need for Māori and Pacific leadership, worldviews and health aspirations to underpin the agenda. It involved three methods:

1. conducting key informant interviews and creating multiple opportunities to engage with and provide subject-matter expertise in order to collect a wide range of perspectives and knowledge
2. a high-level scan of New Zealand and indigenous research activities as compared with the global priorities for RF and RHD published in 2023 to understand general trends in publication topics
3. synthesising the information from the two methods above to identify research gaps for New Zealand (for the findings, see Appendix 4).

4 Collating stakeholders with a broad range of experience to be involved in the prioritisation process

Collating stakeholders involved purposefully selecting 20 key informants, holding two workshops with research leaders in 2024 and 2025, and undertaking three rounds of written feedback with these and other recommended experts. We prioritised gaining strong representation of Pacific and Māori research and clinical leadership and deliberately sought out social sector and policy perspectives.

Through the interview process, key informants shared many insights and feedback that overlapped with and reinforced similar views about RF and RHD research and the research environment in New Zealand. Interviewees, regardless of their research disciplines and backgrounds, reported encountering many of the same challenges and highlighted the need for a more coordinated approach to research on preventing and reducing ARF and RHD and better supporting people living with these conditions.

We asked key informants the following questions.

1. What do you think the main aims of a nationally coordinated research agenda for rheumatic fever should be? How do we (Ministry of Health) ensure this is something purposeful and useful?
2. Do you have a view on which aspects of eliminating rheumatic fever (eg, prevention, diagnosis, treatment, epidemiology, management) require more focused research efforts?
3. What do you think the main gaps in rheumatic fever research are for Aotearoa, either in your particular area, and/or more broadly?
4. Can you see opportunities to reduce barriers to research, evaluation or implementation activities which would help coordinate and align national efforts to fill these gaps?
5. How can a nationally coordinated research agenda build on the progress already made toward Māori and Pacific leadership in rheumatic fever research?
6. From a systems level, what role could a nationally coordinated research agenda play in knowledge translation, linking strategy to policy to implementation/practice?
7. How can the Ministry better translate research findings into effective policies to better support research and health outcomes at local, regional and national levels?

The interview process identified several barriers and weaknesses across the system that were perceived to be holding back research coordination and collaboration as well as effective policy that was sustainable over time. These insights informed the development of the four pillars as underpinning common themes (Appendix 3). A strong message was that research needs to span the full continuum of prevention and care for RF and RHD, particularly at the primary health and community levels. This advice aligns with the intention of the *Rheumatic Fever Roadmap* (Health NZ 2023) as well as many of the recommendations in the Chief Science Advisor's report, *Group A Streptococcus and Acute Rheumatic Fever in Aotearoa New Zealand* (Office of the Prime Minister's Chief Science Advisor 2021) and the research gaps identified in the *Evidence Brief: Invasive group A streptococcus and skin infections* (Ministry of Health 2024).

5 Hold consultations or surveys to identify research areas or questions, and then prioritise those findings

After the key informant interviews and first researcher workshop in 2024, the three Ministry co-leads conducted an initial prioritisation. Priorities were continually refined as further feedback was received and following the second researcher workshop. The final priorities were settled on after three rounds of feedback.

6 Publish and disseminate the priorities

The Ministry has published the research agenda on its website and widely disseminated it across the sector. Active participation in science and health research funding forums, with Health NZ and the research community, will be ongoing to implement the research priorities.

7–9 Implement the research priorities; monitor and evaluate the outcomes; determine when to update the research priorities

The system responsibilities have been adopted as key actions for the ongoing RF work programme sitting within the Public Health Agency. Progress on these will be communicated through Health NZ's RF newsletter, the Public Health Agency newsletter and other external communication opportunities.

Appendix 3: How key informant themes align with the underpinning pillars

Pillar	Suggested research topics that key informants identified
RF and RHD whānau at the centre	› Capture tamariki, rangatahi and whānau perspectives on RF through qualitative and longitudinal research. › Model RF as a life-course condition and integrate lived experience into research design. › Conduct research on the intergenerational and psychosocial impacts of RF on whānau and communities. › Explore stigma associated with RF and design culturally responsive anti-stigma interventions. › Develop participatory research frameworks that centre lived experience and community leadership.
Shared accountability	› Map RF research and implementation efforts to identify duplication, gaps and opportunities for integration. › Investigate governance models and stewardship structures for RF accountability and coordination. › Conduct policy research on cross-agency coordination mechanisms for RF prevention and care. › Create RF research registries or knowledge-sharing platforms to improve the visibility of research findings and reduce silos. › Evaluate strategies to grow Māori and Pacific RF research leadership and workforce capability. › Develop transnational RF research collaborations across Pacific regions.
Translating knowledge	› Study barriers to and enablers for implementing RF research findings at scale. › Assess the relationship between RF research investment and health outcomes in New Zealand. › Design equitable and sustainable funding models for RF research, including community-led initiatives. › Expand implementation science to include mapping, evaluation and scaling of RF interventions.
Long-term cross-agency policy impact	› Explore pathways to eliminating RF in New Zealand, including through changing social norms and public health framing. › Take systems-level approaches to preventing RF, by integrating structural determinants and societal change. › Evaluate the effectiveness of RF prevention strategies over time and identify barriers to their impact. › Advance basic science research on GAS transmission, carriage and autoimmune mechanisms. › Investigate the epidemiology and prevention of GAS skin infections as precursors to ARF. › Conduct health economics research on RF prevention and treatment across the life course.

Appendix 4: Findings of the gap analysis

To analyse the key informants' advice against the body of New Zealand and indigenous research, a senior Ministry librarian conducted a high-level and inclusive scan of published literature (n = 220). Each paper was coded against the 22 global research priorities identified by the National Heart, Lung, and Blood Institute (NHLBI) for RF and RHD, with coding to multiple priorities if appropriate (see Baker et al 2023; Fulurija et al 2023; Karthikeyan et al 2023; Rwebembera et al 2023; Vervoort et al 2023).

The librarian calculated the total number of publications for each of the primordial, vaccine, and primary-, secondary- and tertiary-level priorities. When there were under 10 publications in the 50-year period, they highlighted these in red as a major gap (Table 2). These clusters were then compared against the topics the key informants had identified and the underpinning pillars that led to the four research priorities. The absence of system-related research in the NHLBI priorities was also considered a notable gap.

TABLE 2: Comparison of New Zealand and indigenous research (1975–2025) with global RF and RHD priorities

Global priorities in the five NHLBI publications (2023)	Number of publications 1975–2025
1. Research priorities for the primordial prevention of acute rheumatic fever and rheumatic heart disease by modifying the social determinants of health	**93**
1.1 Global analysis of disease incidence, prevalence and SDH characteristics	34
1.2 Global assessment of legacy primordial prevention programmes	6
1.3 Scalable primordial prevention interventions	24
1.4 Improved access and equity across the RHD continuum	29
2. Research opportunities for the primordial prevention of rheumatic fever and rheumatic heart disease – streptococcal vaccine development	**80**
2.1 Basic science studies of disease pathogenesis	41
2.2 Group A streptococcus vaccine pipeline and correlates of protection	30
2.3 Global network for surveillance, trials, manufacturing	5
2.4 Equitable access to vaccines	4
3. Research opportunities for the primary prevention and management of acute rheumatic fever and rheumatic heart disease	**92**
3.1 Epidemiology of superficial GAS infection	27
3.2 Diagnosis of superficial GAS infections	16
3.3 Scalable and sustainable primary prevention models	36
3.4 Downstream effects of primary prevention scale-up	13

Global priorities in the five NHLBI publications (2023)		Number of publications 1975–2025
4.	**Research priorities for the secondary prevention and management of acute rheumatic fever and rheumatic heart disease**	**184**
4.1	RHD epidemiology to guide programmes and policies	72
4.2	Strategies to find and diagnose ARF and RHD	44
4.3	Tools to manage ARF and slow RHD progression	38
4.4	Integration of technologies into healthcare systems	25
4.5	Economic evaluations of primary prevention	5
5.	**Tertiary prevention and treatment of rheumatic heart disease**	**61**
5.1	Surgical and catheter-based intervention guidelines	32
5.2	Unmet need for surgical correction in low- and middle-income countries	8
5.3	Development of lower-cost surgical technologies	0
5.4	Research on lower-cost procedures and access	1
5.5	Comprehensive tertiary care and innovation	20

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