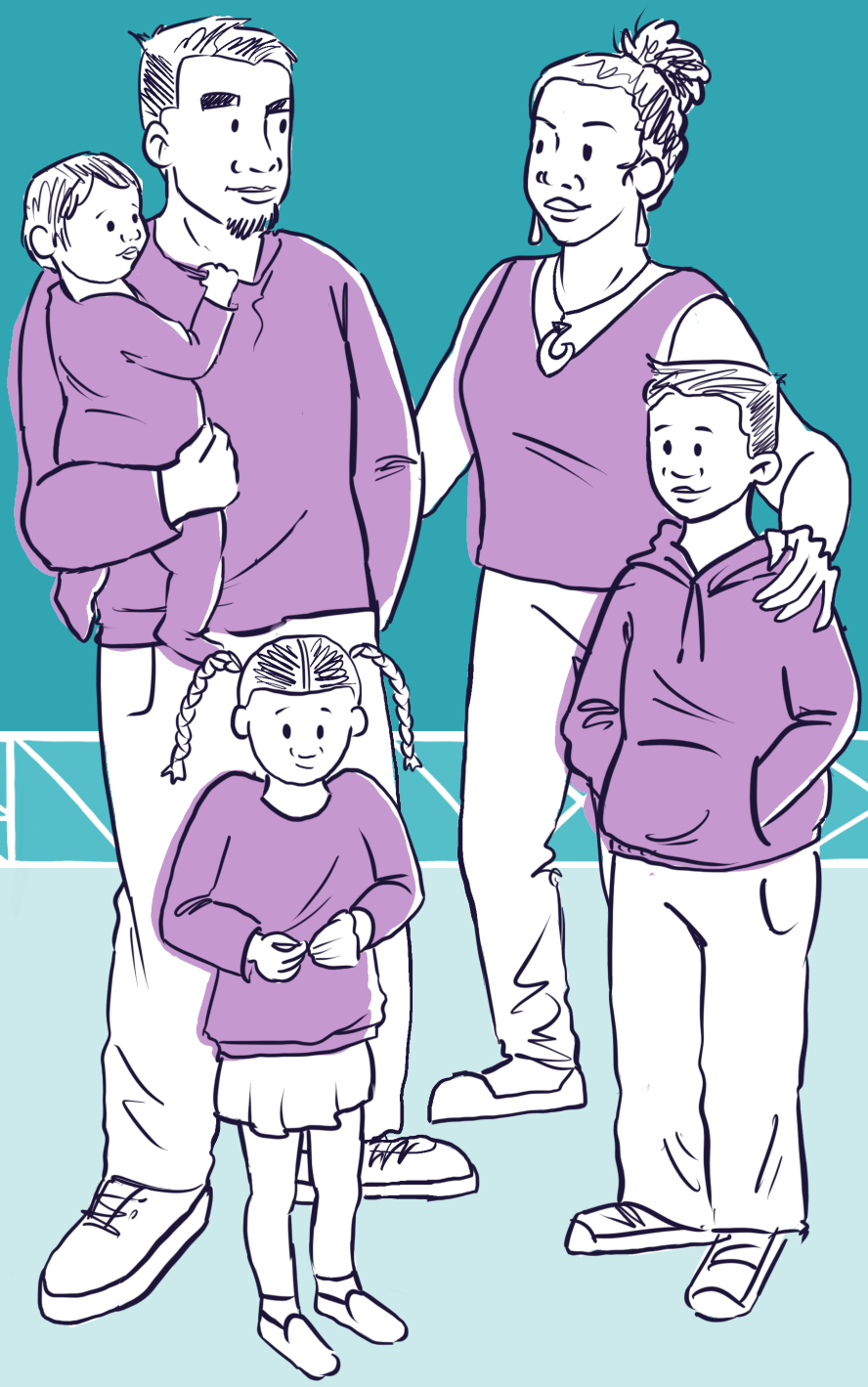
Rheumatic Fever Roadmap



A roadmap for the prevention and management of rheumatic fever and rheumatic heart disease from 2023–2028

Te kura ā Rongo

Manawa nei e, te huaki rangi
Manawa nei e, te huaki papa
Hohou nuku te kokonga whare kia kitea
Hohou rangi te kokonga ngākau kia rongohia
Kauae rungatia, kauae rarotia
Kia pūkuwatia te mānehurangi
Mō Hine-ngākau, mō Tama-ngākau
Hei oranga tinana, hei oranga wairua
Tau te Mauri!
Tau hā, tau ana!

Heartfulness in the subconscious
Heartfulness in the conscious
To stimulate further what we understand
To foster further what is yet to be understood
Internalise it, externalise it

So that it may imbue a new reality
For her soul, for his soul
For physical and spiritual wellbeing
Contentment in life anew
Bring forth vitality!

Me mihi ka tika ki te hunga whai wāhi mai ki tēnei kaupapa. Ki a koutou e whakapau kaha nei ki te whai māramatanga ora mō tēnei mea te Rūmātiki. Engari, mātua rā me mihi atu ki ngā huhua tāngata me ngā whānau i manawanui mai ki te tuku i ō rātou whakaaro me ō rātou kōrero. Me kore ake tēnei kaupapa i a koutou, mōkori anō ngā mihi whakamānawa ki a koutou katoa.

Tau hā, tau ana!

Kua whakaritea mai tēnei taonga karakia, arā, ko Te Kura ā Rongo, nā ō pūrākau e pā ana ki ngā whānau, ā, nā Graham Tipene rāua ko Jono Cole ngā ataata e whakaatu atu nei.
Ko tō mātou nei karakia nā Te Amohanga Rangihau i tito, tō mātou urupare hei tiaki i te reo pūrākau me te reo kōrero, e aratakina ana mā ngā tikanga Māori, me te tuku ihotanga o te mātauranga.

Purutia tēnei taonga kia tata ki tō ngākau, ki tō hinengaro anō hoki, hei tukunga māu, hei tiaki i ngā whānau, hei kaupare atu i te rūmātiki.

It is only right that we acknowledge those who have made space for this kaupapa. To those of you who work tirelessly to seek understanding about Rheumatic Fever. But most importantly, we must acknowledge the many contributors and whānau who have dedicated their thoughts and stories. This kaupapa would be nothing without you all. It is with great privilege that we honour you all.

Bring forth vitality!

This taonga and karakia, Te Kura ā Rongo, has been brought together by the stories of whānau, and visually presented by Graham Tipene and Jono Cole. Our karakia composed by Te Amohanga Rangihau is our response to protecting stories and voice, leading through tikanga Māori, and intergenerational dissemination of knowledge.

Please keep this gift close to your heart and mind as you make your contribution to protecting whānau from rheumatic fever.

Te Tima Māori
Rheumatic Fever Codesign Initiative

Mihi

Ka mihia te rāngai me a mātou rangapū mahitahi (kua whai wāhi ki te tautoko i ngā tāngata, i ngā whānau me ngā hāpori) mo ō rātou tāpaetanga ki tēnei māhere huarahi mo te aukatinga o te Rūmātiki e waewae kai pakiaka ai ngā whānau puta noa i Aotearoa. Matahiapo nei to rātou mātangatanga, tō rātou tohungatanga me tō rātou ū ki te kaupapa. Ka mihia hoki ngā wheako whaiaro o ngā tāngata me ngā whānau kua pāngia e te Rūmātiki. Kua tītia ngā kōrero me ngā wheako a ngā tāngata whaiaro ki te ngākau, ā, ko tōna tikanga ka kitea hoki i roto i te mahere huarahi, i roto hoki i tōna whakatīnanatanga.

Rārangi maunga tū te ao, tū te pō, rārangi tangata ka ngaro.
Tēra ia ngā tai o te hāpori māori me te hāpori o ngā moutere e whawhati nei i te rironga o Ahorangi Diana (Dinny) Lennon. Ko ia ra te aumāngea i tautoko nui i ngā whānau māori me ngā whānau o ngā motu. Nāna ngā mahi nunui kia mana te noho o te Rūmātiki hei mate e mōhiotia whānuitia ana i ngā rau tau 80, na āna mahi kua noho tahi te Rūmātiki me ngā mate nunui. Ka mihia a Dinny te kairangahau, i te Rūmātiki, pai rawa i ngā tau 30 kua hori.

Tiwhatiwha te pō, tiwhatiwha te ao.
Tīhei Mauri ora!

E te Tīma Māori, tena koutou i to koutou whakaaronui kia tākoha mai rā te karakia mo te māhere huarahi ōtira na koutou i manaaki i te taha māori ma te tirohanga māori e tau ai ngā huarahi kei mua i a tātou.

Kei te rōpu tuhituhi, mo koutou i arataki i te whakawhanaketanga o te mahere huarahi. He huanui tō tautoko, ko te huanga o tēnei tuhinga hei arahi, hei aronga tahitanga ki te whakahaerenga o te aukatinga o te rūmātiki i Aotearoa nei mo ngā tau e rima nei, haere ake nei te wā.

Tena koutou Pū Manawa, nā koutou i tākoha mai te ingoa o te mahere huarahi, me to koutou arahitanga i roto i ngā mahi whakawhanake i te puna mo te rūmātiki.

Acknowledgements

Mauri ora ki a tātou

Ngā mihi nui, Fa'afetai tele lava, Mālō 'aupito, Fakafetai lahi lele, Fakaaue lahi oue tulou, Meitaki atupaka, Fakafetai lasi, Vinaka vaka levu, Fọiȧkse'ea, Kam rabwa and thank you from Te Whatu Ora.

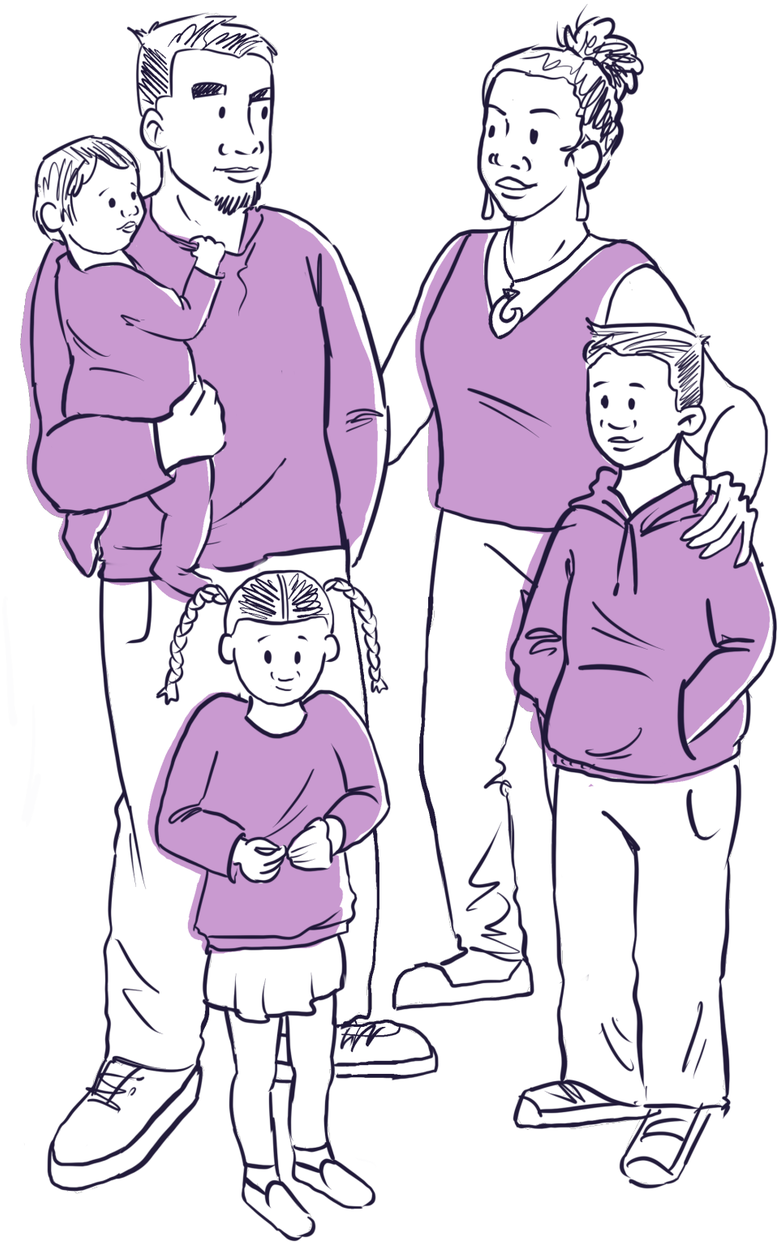
We would like to acknowledge the sector and key partners (who engage and support patients, whānau and communities) for their contribution to this roadmap. Their knowledge, expertise and commitment to this mahi are invaluable.

We also want to acknowledge and value the lived experiences of people and their whānau who experience rheumatic fever and/or rheumatic heart disease. The views, experiences and insights from patients and their whānau have been embedded and should be visible throughout the roadmap and its implementation.

Preface about the imagery

Triangle motifs are used in this roadmap document to graphically convey important concepts. These triangle motifs are inspired by, and reflect, the visual cultures across the Pacific. The triangle can also be used to represent an uppercase delta character used in mathematics to mean "change".

Contents



Foreword

Rheumatic fever prevention is a focus for the Government.

In Aoteroa New Zealand, the incidence of rheumatic fever is much higher compared to other high-income countries. It almost exclusively affects our Māori and Pacific children and young people aged 4-19 years old.

The consequences of rheumatic fever and rheumatic heart disease are significant for whānau, often resulting in significant time off school or work, restricted physical activity and regular prophylaxis injections to prevent recurrence. People with rheumatic heart disease also experience an increased risk of health complications and, for some, early death. The impact of a diagnosis extends beyond the physical effects, recognising the psychological and emotional impact a diagnosis can have on people who live with rheumatic fever or rheumatic heart disease and their whānau.

Rheumatic fever is potentially preventable. Addressing the impacts of socioeconomic inequities, improving the quality of housing and ensuring access to timely and appropriate healthcare is critical if a reduction in rheumatic fever is to be seen in Aotearoa New Zealand.

In 2018, the World Health Assembly adopted a Global Resolution for all Member States, as the first global policy on rheumatic fever and rheumatic heart disease to be endorsed by all governments. The resolution initiated a coordinated global response to renew global efforts for the prevention and management of rheumatic fever and rheumatic heart disease.

This roadmap is an important component of our response to the Global Resolution. It is part of our actions to reset, renew and amplify efforts to tackle rheumatic fever and rheumatic heart disease.

Under this plan, we have a strong focus on eliminating inequities, meeting our commitments to Te Tiriti o Waitangi, ensuring timely access to quality care and placing the needs of people with lived experience of rheumatic fever and rheumatic heart disease at the heart of our efforts.

We are grateful to everyone who has contributed to this roadmap and look forward to working together to prevent, improve the management and experience of people with rheumatic fever and rheumatic heart disease.

I am confident that the outcomes of this roadmap will contribute more broadly to achieving Pae Ora: healthy futures for our tamariki and rangatahi.

Hon Barbara Edmonds
Associate Minister of Health

Introduction

Rheumatic fever is rare in most high-income countries however, Aotearoa New Zealand has a relatively high incidence in comparison. In Aotearoa New Zealand rheumatic fever almost exclusively affects Māori and Pacific children and young people aged 4-19 years living in the North Island.

When adjusted for age, sex and socioeconomic deprivation, hospitalisation rates for rheumatic fever are 23.6 times higher for Pacific peoples and 11.8 times higher for Māori compared to European and other ethnicities.[1]

The exact reasons for inequities of rheumatic fever incidence between Pacific peoples and Māori, compared to New Zealand European and other ethnicities are multifaceted; social determinants of health including systemic racism and privilege, socioeconomic deprivation, poor quality housing, household crowding, and barriers to accessing health care are thought to be important drivers. The risk of developing rheumatic fever can also be associated with other factors such as familial history or the specific type of Group A streptococcal (GAS) bacteria that is present.

Rheumatic fever prevention has been a focus for the Government, the Ministry of Health and other partners since 2011, with dedicated investment for prevention initiatives. Following an initial investment, there was an apparent impact on the rates of rheumatic fever. However, due to the range of initiatives put into place, it was difficult to understand if it was one initiative alone, a combination of initiatives that led to this stabilisation and decrease, or if it was due to the natural variation of rheumatic fever cases year-on-year due to small numbers. Despite these efforts, rates of rheumatic fever remain high in Aotearoa New Zealand compared to other high-income countries and there is growing awareness of a large number of people affected by chronic rheumatic heart disease.[2]

It is timely to **reset, renew and amplify** our efforts in Aotearoa New Zealand to tackle rheumatic fever and rheumatic heart disease and critically to learn from what has been tried.

What are rheumatic fever and rheumatic heart disease?

Rheumatic fever is an autoimmune response to a Group A streptococcal (GAS) throat infection. In some cases, the inflammation caused by rheumatic fever can cause rheumatic heart disease, where there is scarring of the heart valves. Rheumatic fever is preventable. To prevent a recurrence, secondary prophylaxis with the antibiotic benzathine penicillin is required. This is provided monthly by intramuscular injection for 10 years or until age 21, whichever period of time is longer.

Rheumatic heart disease is a condition in which heart valves have been permanently damaged by rheumatic fever. It can occur as the result of a first acute presentation of rheumatic fever. It is more likely to occur with recurrent episodes of rheumatic fever.

[1] *Bennett J, Zhang J, Leung W et al 2021. Rising Ethnic Inequalities in Acute Rheumatic Fever and Rheumatic Heart Disease, New Zealand, 2000–2018. See https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7774562/*

[2] *Tilton E, Mitchelson B, Anderson A et al 2022. Cohort profile: methodology and cohort characteristics of the Aotearoa New Zealand Rheumatic Heart Disease Registry. See https://bmjopen.bmj.com/content/12/12/e066232*

The purpose of the roadmap is to:

1. reset and refocus efforts around rheumatic fever and rheumatic heart disease prevention, identification and management

2. identify specific priorities for action over the next five years – including work currently underway and new priority areas.

In November 2021, the Office of the Prime Minister's Chief Science Adviser (OPMCSA) released an evidence review summarising what is known about GAS and acute rheumatic fever in Aotearoa New Zealand.[3] This review and evidence within it have been used throughout this roadmap and has played an important role in shaping many of the priority areas identified in this document.

There is a naturally healthy tension of ensuring that evidence-based approaches are used when preventing and managing rheumatic fever and rheumatic heart disease whilst upholding the commitment of the recent health reforms to be responsive to the needs of whānau and community and what they say is needed.

Ensuring whānau are central to this work includes an ongoing commitment to ensure cultural perspectives of health and wellbeing for priority groups are upheld, recognised and valued by the health sector concerning the patient and whānau journey through the health system.

It is hoped this roadmap has been able to strike a balance to uphold both scientific research and evidence and patient and whānau voice.

[3] *Office of the Prime Minister's Chief Science Adviser (OPMCSA) 2021. Group A Streptococcus and Acute Rheumatic Fever in Aotearoa New Zealand: A summary of current knowledge in Aotearoa New Zealand. See https://www.pmcsa.ac.nz/topics/antimicrobial-resistance-and-infectious-disease/rheumatic-fever/*

Rheumatic fever data

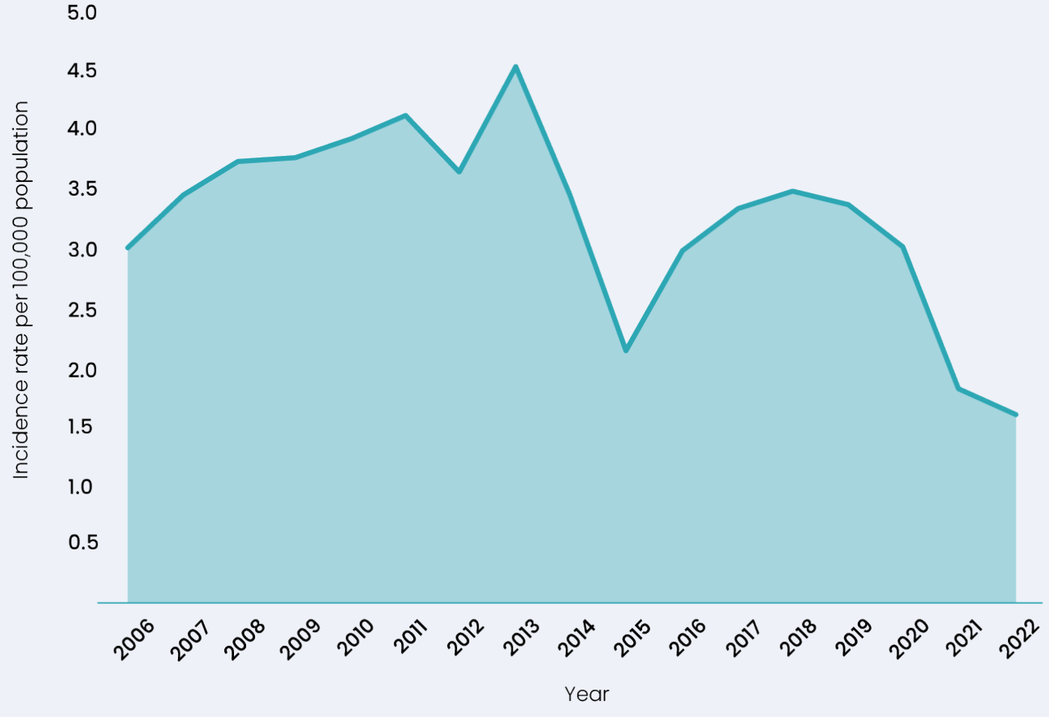
The majority (approximately 70 percent) of rheumatic fever cases in Aotearoa New Zealand occur in school-aged children.

The latest data available at the time of publishing shows that in the 12 months ending on 31 December 2022, there were 82 people admitted to hospital for the first time with rheumatic fever (1.6 per 100,000) in Aotearoa New Zealand. This is a decrease from 93 people in the 12 months ending 31 December 2021 (1.8 per 100,000).[4]

The graph below shows the rate of people admitted to hospital with rheumatic fever for the first time from calendar years 2006 to 2022.

The graph below shows that the hospitalisation rate for the first episode of rheumatic fever was stable between 2006/07 and 2012/13. A reduction in this rate was seen between 2013/14 and 2016/17. The incidence of hospitalisations for first admission for rheumatic fever then rebounded somewhat but not back to pre-2012/13 levels.

First episode rheumatic fever hospitalisations, annual rate per 100,000, New Zealand, 2006-2022[5]



[4] *National rheumatic fever data is provided by the Ministry of Health biannually and made available online at https://www.health.govt.nz/our-work/diseases-and-conditions/rheumatic-fever/reducing-rheumatic-fever*

[5] *Source: Service Analysis and Modelling Evidence, Research and Analytics, Manatū Hauora. ICD codes used include; ICD-10-AM diagnosis codes: I00, I01, I02 (Acute rheumatic fever); ICD 9 CM-A diagnosis codes: 390, 391, 392 (Acute rheumatic fever); ICD-10-AM diagnosis codes: I05-I09 (Chronic rheumatic heart disease) and ICD 9 CM-A diagnosis codes: 393-398 (Chronic rheumatic heart disease).*

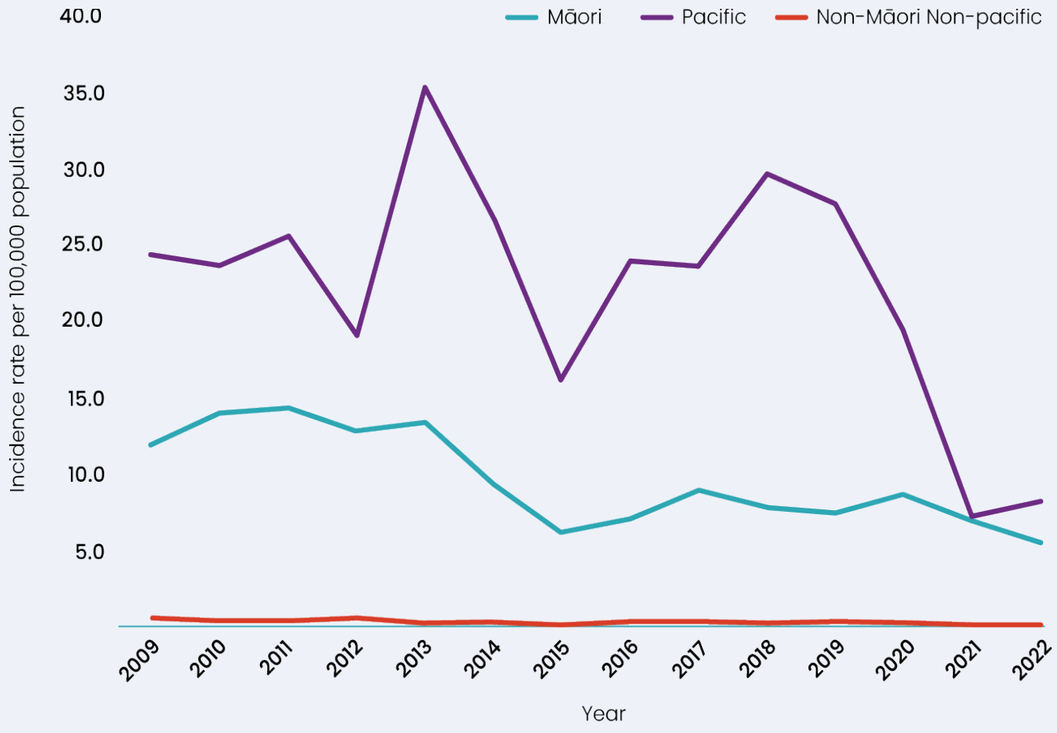
Since 2019/20, there has been a significant decrease in first-episode rheumatic fever hospitalisations. This coincided with the widespread implementation of public health mitigation measures to control the COVID-19 pandemic. However, this decrease is not distributed equally for Māori and Pacific people.

Following a decrease in hospitalisation for Māori between years 2011 to 2016, there has been a stabilisation in the rate since 2017. In contrast, there has been a large decrease in the incidence for Pacific in 2020 and 2021, particularly in Counties Manukau.

The graph below shows the rate of Māori and Pacific people admitted to hospital with rheumatic fever for the first time between 2009/10 and 2021/22.

As a result of the recent decrease, the Auckland region now accounts for approximately one third of all hospitalisations (compared to approximately two thirds in previous years).[7] There have been some increases and decreases in hospitalisations in other districts which may be due to the variability of small numbers of cases which can fluctuate year to year.

First episode rheumatic fever hospitalisations, annual rate per 100,000, by ethnic group, New Zealand, 2009/10 – 2021/22[6]



[6] *Source: Service Analysis and Modelling Evidence, Research and Analytics, Manatū Hauora. ICD codes used include; ICD-10-AM diagnosis codes: I00, I01, I02 (Acute rheumatic fever); ICD 9 CM-A diagnosis codes: 390, 391, 392 (Acute rheumatic fever); ICD-10-AM diagnosis codes: I05-I09 (Chronic rheumatic heart disease) and ICD 9 CM-A diagnosis codes: 393-398 (Chronic rheumatic heart disease).*

[7] *We recognise that Auckland's experience of the public health mitigation strategies for COVID-19 outbreaks was different to the rest of the country. Of note there was a significant outbreak in the Pacific community in August 2021 and Auckland also experienced longer periods in Alert Levels 3 and 4 compared to the rest of the country. These factors will be included in the Insight Project (see action 3.1a).*

Work is underway *(see action 3.1a)* to understand the contributing factors that have led to this decrease, largely driven by a reduction in hospitalisations for Pacific People in Counties Manukau, Auckland. Specifically, it is crucial to understand any factors working well at present in rheumatic fever prevention, that can be sustained going forward during the implementation of the roadmap.

Possible factors for this decrease include:

- the decrease is due to the natural variation of rheumatic fever cases year-on-year due to small numbers
- the impact of COVID-19 on increasing the demand for health services, leading to decreased access other services such as primary and emergency care for sore throat management
- that the impact of COVID-19 public health measures has resulted in a decrease in rheumatic fever during 2020 and 2021 i.e., regional/national lockdowns since March 2020 and extended absence from school breaking the chain of transmission
- adherence to COVID-19 related public health messaging contributing to the decrease i.e., demonstration of correct hand washing, staying home if you're unwell, social distancing, mask wearing and the importance of getting tested
- the border closure between the Pacific Islands and Aotearoa New Zealand preventing different GAS strains from travelling across borders.

Our role in the global response to rheumatic fever and rheumatic heart disease

The 2018 World Health Assembly adopted a Global Resolution for all Member States, as the first global policy on rheumatic fever and rheumatic heart disease to be endorsed by all governments. The resolution launched a coordinated global response to rheumatic fever and heart disease and renewed global efforts for its prevention and control, including the call to:

- accelerate multisectoral efforts toward reducing poverty and improving socioeconomic determinants
- implement and resourcing of programmes that foster multisectoral work and focus on prevention
- improve surveillance and good-quality data collection and analysis
- strengthened national and international cooperation to address rheumatic fever and rheumatic heart disease
- continue advocacy on behalf of communities at risk
- facilitate timely, affordable and reliable access to existing and cost-effective new medicines and technologies for prevention and management
- support research and development, including greater understanding around epidemiology and pathogenesis of rheumatic fever and rheumatic heart disease.[8]

This roadmap is one element of the health sector's commitment to renewed efforts for rheumatic fever prevention and control.

[8] *World Health Assembly 2018, May 26. Rheumatic Fever and Rheumatic Heart Disease, WHA 17.14. See https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R14-en.pdf*

Te Tiriti o Waitangi

As set out in Whakamaua: Māori Health Action Plan 2020-2025, the text of Te Tiriti, including the preamble and the three articles, along with the Ritenga Māori declaration, are the enduring foundation of our response to Māori for rheumatic fever and rheumatic heart disease.

Te Pae Tata – Interim New Zealand Health Plan is also a foundation to ensure that our priority actions recognise Te Tiriti and improve Māori health outcomes. Te Pae Tata holds account for the health system to be responsive and affirms the role of improvement and equity as everyone's responsibility across the health system. Specifically, this roadmap makes a strong and purposeful effort to embed Te Tiriti o Waitangi across the rheumatic fever sector, and places whānau at the centre of the health system as it relates to rheumatic fever and rheumatic heart disease.

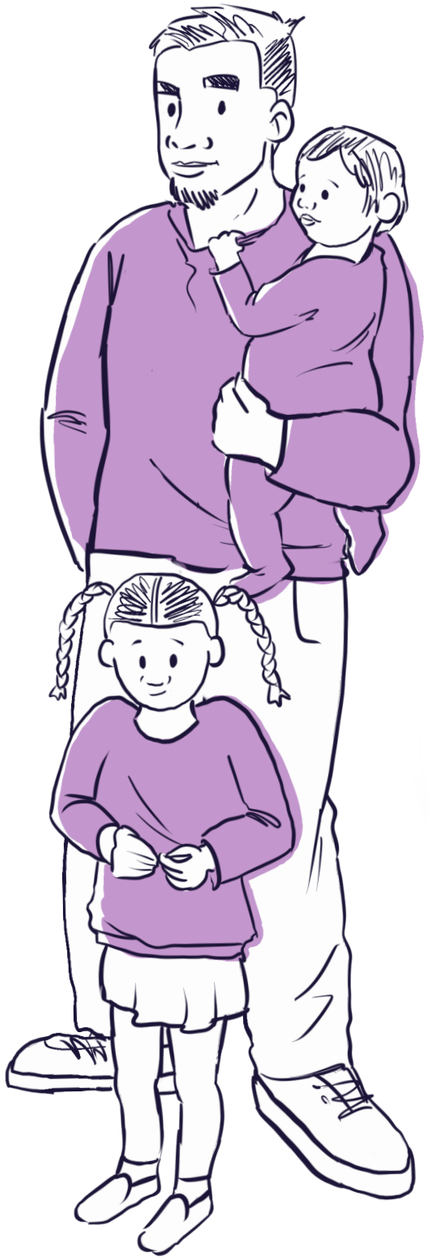
The 2019 Hauora Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry identified five Te Tiriti o Waitangi principles (listed below) that need to apply when addressing inequities for Māori. These principles with the articles above have been considered and incorporated into this roadmap.

Table 1. Te Tiriti o Waitangi principles

tino rangatiratanga	autonomy, self-determination, and sovereignty
active protection	a requirement to act to the fullest extent possible to achieve equitable outcomes for Māori and priority groups
partnership	requiring the Crown and Māori to work in partnership in the governance, design, delivery, and monitoring and evaluations of health and disability services
equity	a commitment to equitable care access, services, and health outcomes for Māori and priority population groups
options	requiring provision for properly resourcing Kaupapa Māori health and disability services, and ensuring all health and disability services are provided in a culturally appropriate way which recognises and supports the expression of hauora Māori models of care

In practice for this roadmap, this means:

- partnering with and enabling leadership of Māori agencies, experts, communities and whānau when planning, designing, and delivering initiatives and services related to rheumatic fever prevention and management
- designing and prioritising initiatives that see the devolution of power and resources to Māori communities
- achieving equity for Māori through prioritisation of actions that will make significant health and well-being gains for Māori around rheumatic fever and rheumatic health disease
- communicating with providers the expectation that health services will be designed and delivered in partnership with Māori to meet the expectations and autonomy of Māori hapori, hapū and iwi
- supporting and funding for kaupapa Māori services and kaupapa Māori initiatives where possible
- ensuring the roadmap and initiatives in the roadmap are meaningful to whānau.



Equity

In Aotearoa New Zealand, people have differences in health outcomes that are not only avoidable but unfair and unjust.[9]

There is a purposeful effort to ensure a Pacific equity focus in the roadmap by including Pacific ethnic-specific approaches and evidence-based research that informs us where there is an opportunity for the greatest Pacific health gains in the context of rheumatic fever and rheumatic heart disease.

The roadmap has been designed so that actions will contribute to reducing inequities in rheumatic fever and rheumatic heart disease in Aotearoa New Zealand for Māori and Pacific communities.

In practice for this roadmap, this means:

- ensuring approaches to improve equity are described with specificity for each priority population (ethnic-specific)
- designing the roadmap in collaboration with representatives from priority communities
- considering the four system levers in Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025, when developing the roadmap and implementing the actions. These are: Pacific leadership; health and disability workforce; organisational and infrastructural capacity; and funding and investment
- considering the Pacific Health Enablers in Ola Manuia: Interim Pacific Health Plan during the development and implementation of the roadmap. These are: population health and intersectoral collaboration; community and lived experience voice; data and insights; commissioning; provider development; and workforce development
- ensuring all actions in this roadmap are designed to improve outcomes for Māori and Pacific peoples. This will include consideration of socio-political economic determinants, the intersectionality of equity issues, and service level barriers such as transport, cost, clinic location etc
- co-designing initiatives with priority communities so that initiatives have a connection to communities, localities, and whānau. This includes using insights and guidance from whānau with lived experience of rheumatic fever. This also means in practice "doing with, not doing to" and acknowledging rheumatic fever is not the community's problem to solve, it is an all-of-government system issue to solve[10]
- using models of health and wellbeing that resonate with priority groups (such as Te Whare Tapa Whā, Te Pae Māhatonga, Te Wheke & Fono Fale, Ta Vaka Atafaga and Mana Moana).

[9] https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity

[10] Ministry of Health 2022. Rheumatic Fever Co-design Initiative Phase 1 (Discovery) Report.

Values guiding the roadmap

This roadmap is guided by the values below. These are the values that health agencies[11] commit to working when developing and implementing the actions. Values guide behaviours, attitudes, and mindsets.

Te Tiriti o Waitangi and improving equity are at the core of this roadmap (as reflected in the sections above). It is important to note that while improving equity is a value, giving effect to the articles and principles of Te Tiriti is a requirement rather than a value. However, the values intersect with Te Tiriti articles and principles (e.g. equity) and support meeting Te Tiriti commitments, such as being accountable for achieving equitable outcomes and through meaningful engagement of priority groups.

Values	
Whānau-focused	We recognise that Māori, as Te Tiriti o Waitangi partners, and Pacific peoples are central in developing an effective and ongoing response. We recognise that a one-size-fits-all approach does not work and our focus should include 'what matters to whānau'. This may include delivering whānau and person-centred care and/or using mātauranga Māori and Pacific driven models of care.
Manaakitanga	We uphold the mana of people this roadmap is working to support. We show care, inclusion, respect, support, trust, safety and kindness to each other.
Equity[12]	We commit to improving equity across all rheumatic fever/ rheumatic heart disease outcomes. We recognise that different and better approaches are needed across diverse communities and focused resources are needed to get equitable health outcomes. This includes culturally safe community/sector engagement and meaningful involvement of priority groups. Community leadership engagement and consumer voices are vital in this process.

[11] The relevant health service agencies - Te Manatū Hauora | Ministry of Health, Te Whatu Ora | Health New Zealand and Te Aka Whai Ora | Māori Health Authority.

[12] https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity for the full Ministry of Health equity statement.

Whānaungatanga	We commit and work together collectively towards a common purpose. We will be clear about responsibilities and accountabilities and rights. We will learn and share. The leadership around rheumatic fever prevention and rheumatic heart disease management will be visible and reflect the voices of those most affected by rheumatic fever and rheumatic heart disease. Our capacity and capability will be organised in the right way to deliver advice and support collaborative working, with relevant communities across the sector and across government priorities.
Va/va'a/vaha	We acknowledge the traditional Pacific notion of va that describes the sacred spatial and relational context within which relationships unfold. Appreciating the va deepens our cultural understanding and appreciation for the space within relationships; both personal and professional. In the context of the roadmap, the va is about prioritising, valuing, and nurturing the relationships we hold as a health sector with patients, aiga/kainga/families, colleagues, and other Pacific stakeholders. The outcomes of this are reciprocity, respect, and mutual trust.
Evidence, knowledge and outcomes	We commit to evidence-based policy and programmes recognising different forms of knowledge including mātauranga Māori and knowledge of those who have had rheumatic fever or are living with rheumatic heart disease. We have a focus on outcomes, not outputs. We recognise the value of innovation but also the need to evaluate to ensure we are effective in reaching our goals.

Framework for the roadmap

Addressing rheumatic fever and rheumatic heart disease will require holistic, whānau-centred, wellness approaches across the prevention spectrum including:

- primordial prevention (addressing the socioeconomic determinants of health)
- primary prevention (preventing and treating GAS infections)
- secondary prevention (including early detection/diagnosis and preventing recurrences which can lead to rheumatic heart disease)
- tertiary prevention (improving quality of care and health service experiences for people with rheumatic fever and rheumatic heart disease).

Figure one, on the next page, outlines the framework underpinning the roadmap. It takes a programme logic approach, meaning delivery against the priority actions (detailed in tables 1-3) will contribute to the desired outcomes.

Priority groups

The framework contains the priority groups for the roadmap. Specifying priority groups helps focus priority actions and contributes to achieving the outcomes of the strategy.
The priority groups are identified based on meeting Te Tiriti o Waitangi obligations and epidemiology of rheumatic fever and rheumatic heart disease in Aotearoa New Zealand.

Priority groups for this roadmap are:

- Māori children and young people, and their whānau
- Pacific children and young people, and their aiga/kainga/families.

We acknowledge the diversity among Māori hapori, hapū and iwi and that Pacific peoples are not one people, and that ethnic-specific approaches are required.

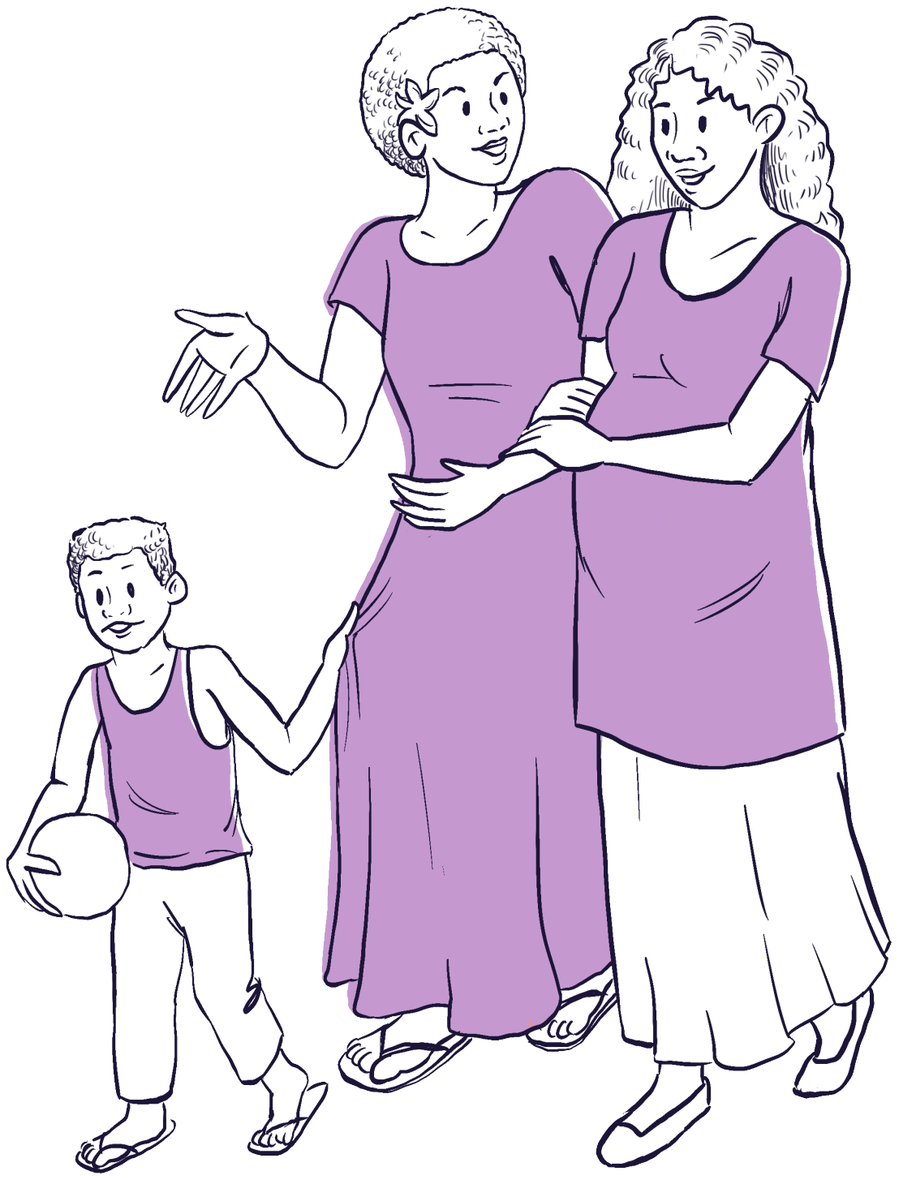
To reach priority groups there needs to be a focus on priority settings such as whānau and community settings in addition to primary and secondary care.

Framework for the roadmap

Values, Te Tiriti, and Equity

Research, evaluation and monitoring

Guiding Documents	Whakamaua	Te Tiriti o Waitangi	Ola Manuia
Vision	Pae Ora (healthy futures) for tamariki and rangatahi by preventing rheumatic fever and ensuring those with rheumatic fever (RF) and rheumatic heart disease (RHD) and their whānau are supported to live well.		
Goals	To improve Māori health and wellbeing	To prevent new and recurrent cases of rheumatic fever	To improve hauora for those with rheumatic fever and rheumatic heart disease	Improved equity for Māori and Pacific communities concerning RF and RHD
Focus Areas	**Whānau Ora** Determinants of well-being and primary prevention	**Tāngata Ora** Quality health care and improved experiences for those with RF and RHD	**Kōkiri Ngātahi** System readiness, leadership and collective action
Immediate Outcomes	1.1 Increase in warm, dry and healthy homes for priority groups 1.2 Focused cross-sectoral work to address other socioeconomic determinants (privilege, racism, socioeconomic deprivation, housing) 1.3 Whānau feel empowered and can inform and access the knowledge they need about prevention 1.4 Improved access to culturally safe and high-quality sore throat (and skin infection) management for priority groups	2.1 Improved access, continuity and coordination of age-appropriate care for those with rheumatic fever and rheumatic heart disease 2.2 Increased knowledge and training of the workforce about the management of rheumatic fever and rheumatic heart disease 2.3 Increased capability of the workforce around tikanga and cultural safety and provision of services that support whānau Māori 2.4 Increased capability of the workforce around ways of being, cultural safety and provision of services that support Pacific families	3.1 Enhanced data and information about the prevention and management of rheumatic fever and rheumatic heart disease in Aotearoa New Zealand 3.2 Increased integration and coordination of the rheumatic fever prevention and management system 3.3 Amplify and elevate the leadership and role of Māori and Pacific communities, experts and health professionals. 3.4 Support a nationally coordinated research agenda
Priority Groups	Māori tamariki and rangatahi and their whānau	Pacific children and young people and their families	



Focus areas and priority actions

The three tables in this section contain the priority actions for rheumatic fever and rheumatic heart disease for the next five years, 2023-2028. They are grouped into three focus areas:

1. **WHĀNAU ORA**
(determinants of wellbeing and primary prevention)

2. **TĀNGATA ORA**
(quality health care, and improved journey through the health system for those with rheumatic fever and rheumatic heart disease)

3. **KŌKIRI NGĀTAHI**
(system readiness and change).

The focus areas are designed to take a multifaceted approach: addressing socio-economic determinants; prevention; high quality and acceptable health services; and system change. A coordinated and multifaceted approach is needed if rheumatic fever is to be prevented and for those with rheumatic fever and rheumatic heart disease and their whānau to be supported to live well.

Each focus area includes how the actions will meet Te Tiriti obligations and achieve equitable rheumatic fever outcomes. The priority actions listed in the tables have been designed and prioritised so that they will meet Te Tiriti obligations and contribute to achieving equity in rheumatic fever outcomes. The actions have been developed to support whānau leadership – focusing on resourcing, support and advocacy for patient/whānau leadership.

Some priority actions are already being funded and are underway. These will be summarised in a separate document and will be kept up-to-date. Other actions are new and have emerged during the development of this roadmap, including through analysis of the co-design insights and discussion with experts and sector workshops. Further ideas and initiatives will likely emerge over time, and will be incorporated where possible.

An implementation plan will be developed to sit alongside the roadmap, updated annually, providing detail on implementation, leadership and accountability against the priority actions within each focus area.

Focus area one: Whānau Ora

Determinants of wellbeing and primary prevention

Primordial and primary prevention aim to keep people well by intervening before health effects occur to prevent disease. This is often referred to as an upstream approach.[13]

For rheumatic fever and rheumatic heart disease, prevention can be achieved by improving the determinants of health and well-being (e.g., working across agencies, housing and health/social systems that privilege non-Māori and non-Pacific people), and early and appropriate access to sore throat management of GAS infections.

Actions in this focus area have been informed by the co-design insights and are strengths-based. Any future or additional solutions need to focus on te ao Māori, the use of Māori and Pacific peoples' models of wellbeing, and a continued focus on strengths-based language (including when discussing rheumatic fever rates).

The outcomes for this focus area are:

- ensuring whānau live in warm, dry, and healthy homes that meet their needs
- cross-sectoral work to address other socioeconomic determinants (privilege, racism, socioeconomic deprivation, housing)
- whānau feel empowered and can inform, access, and use the knowledge they need about prevention
- improved access to culturally safe and high-quality sore throat (and skin infection) management for priority groups.

Context and insights

- Aotearoa New Zealand currently has a shortage of quality housing stock, and many homes are cold, damp and are not always designed for larger family units nor diverse spatial use of homes.
- Many policies and programmes that contribute to the socio-economic determinants of well-being sit outside the health sector. There needs to be wider ownership and leadership of this issue by other sectors and agencies.[14] Likewise, health needs to advocate for its inclusion and prioritisation within other sectors.
- There needs to be a more targeted approach to prevention with a focus on priority groups, for example, whānau and families with a family history of rheumatic fever.
- Whānau need to be involved when developing actions to prevent rheumatic fever, for example when creating resources, whānau and communities need to be engaged to ensure the messages are relatable, including being age appropriate.
- There are barriers to accessing quality health care which include racism.
- There is a need to increase the knowledge of clinicians (especially for overseas–trained medical professionals) on the risk factors for rheumatic fever in the New Zealand context, including the importance of sore throat management in priority populations, as part of rheumatic fever prevention.
- There is a need to increase the knowledge and skills of clinicians, so they can engage in a culturally safe way with whānau Māori and Pacific aiga/kainga/families.

[13] *WHO 2014. The case for investing in Public Health. Geneva: World Health Organization. See https://www.euro.who.int/__data/assets/pdf_file/0009/278073/Case-Investing-Public-Health.pdf*

[14] *Insights from The Samoan Team of the Auckland Rheumatic Fever Co-design Initiative*

Table One: Priority actions for focus area one: whānau ora (Determinants of wellbeing and primary prevention)

Outcomes	Priority actions
1.1 Ensuring whānau live in a warm, dry and healthy home that meets their needs	**Existing work underway:** a. Continue to fund and deliver the Healthy Homes Initiative[15] (now a nationwide programme).
1.2 Increase in cross-sectoral work to address other socioeconomic determinants	**Potential new actions:** a. Strengthen cross-sector working and partnerships focusing on issues such as housing and other determinants *(see immediate outcome 3.2)*. For example: • explore actions that align with objectives of 'all-of-government' strategies e.g. Ministry for Pacific Peoples' Pacific Well-Being Strategy—Weaving all of Government—Progressing Lalanga Fou. • leverage off the infrastructure and role of the Social Wellbeing Board to ensure alignment of efforts across agencies. • collaborate with other sectors to address social determinants of rheumatic fever and rheumatic heart disease (health, housing, education, work and income etc.)
1.3 Whānau feel empowered and can inform and access the knowledge they need about prevention	**Potential new actions:** a. Explore and develop social marketing campaigns to raise awareness about RF prevention that is whānau-led, whānau-centred, strengths-based and evidence-based. b. Develop communications resources with priority populations that can be adapted locally. c. Ensure whānau and priority communities (with lived experience of RF and RHD) have opportunities to increase their autonomy and gain more influence in the decisions that affect them.
1.4 Improved access to culturally safe high quality sore throat and skin infection management for priority groups	**Existing work underway:** a. Support and encourage a focus on RF and embed prevention and management at a district/regional level. b. Update and disseminate the Group A Streptococcal (GAS) Sore Throat Management Guideline[16] so the workforce has up-to-date information on clinical care for the management of GAS sore throats. c. Support the Mana Kidz nurse-led school-based programme providing comprehensive primary healthcare (including RF prevention) to children in the Counties Manukau district.

[15] *https://www.tewhatuora.govt.nz/keeping-well/new-content-page-13/healthy-homes-initiative*

[16] *https://www.heartfoundation.org.nz/resources/group-a-streptococcal-sore-throat-management*

Focus area two: Tāngata ora

Quality health care and improved journey through the health system for those with rheumatic fever and rheumatic heart disease

Repeat Group A Streptococcal (GAS) infections increase the risk of rheumatic fever. Recurrent episodes of rheumatic fever increase the risk or severity of rheumatic heart disease.

This focus area aims to improve the diagnosis, management, and experience for people with rheumatic fever and rheumatic heart disease, in order to reduce the risk or severity of rheumatic heart disease in those who have had rheumatic fever, and improve the outcomes for those living with rheumatic heart disease (secondary and tertiary prevention).

To ensure these actions meet Te Tiriti commitments and achieve equitable outcomes for rheumatic fever, services need to be governed, designed, implemented and continually evaluated by Māori and Pacific people to ensure they are whānau centred and culturally responsive.[17]

The outcomes for this focus area are:

- improved access, continuity, and coordination of care for those with rheumatic fever and rheumatic heart disease
- increased knowledge in the workforce about the diagnosis and management of rheumatic fever and rheumatic heart disease
- increased capability in the workforce around tikanga Māori, cultural safety, and how to provide services that are of value to and support whānau, including building knowledge and awareness around Te Tiriti, models of care and approaches for wellbeing, and about settling of mauri.

[17] *Insights from Te Tīma Māori of the Auckland Rheumatic Fever Co-design Initiative*

Context and insights

Improved access to quality healthcare

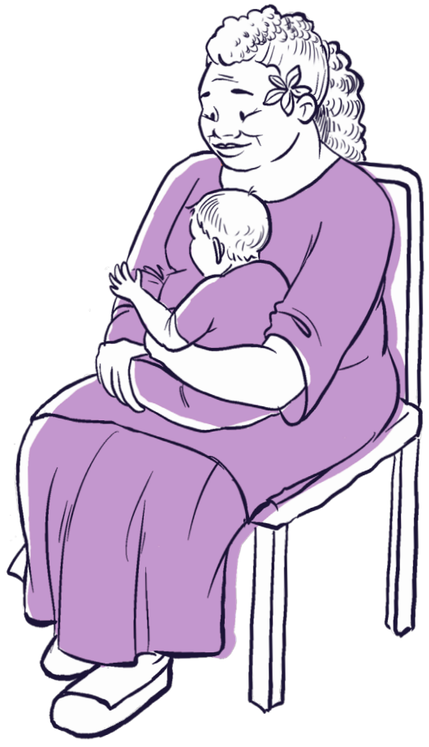
- Currently, there are numerous different regional 'registers' used to track and deliver prophylaxis, meaning people can be lost to follow-up or have delayed prophylaxis injections if they move around Aotearoa New Zealand. This can lead to an increased risk of a recurrent attack with no antibiotic cover remaining.
- Prophylaxis is a challenge for young people. This can be because of embarrassment, injection pain, a lack of access to good age- and culturally-appropriate services and resources, the timing of service with other commitments, and understanding of the disease.
- Patient-centred and age-specific approaches to delivering prophylaxis need to be developed that works for individuals and whānau e.g., new methods of formulation and delivery of antibiotics, more autonomy for patients and whānau/ caregivers about how and when prophylaxis is provided.
- Poor oral health increases the risk of bacterial endocarditis, a bacterial infection affecting heart valves damaged by rheumatic fever and/or rheumatic heart disease. Therefore, access to dental care for people with RF/RHD should be improved.
- There is currently no mechanism to audit service delivery against best practice recommendations contained within national guidelines. Best practice guidelines also need to be updated to reflect best practices and be specific to ensure consistency of management from district to district.
- The transition between paediatric and adult services needs to be strengthened. Limited transition/youth focused services, means some young people are lost/do not engage in care when they leave paediatric services.
- The coordination of care between secondary and tertiary health services needs to be improved.
- The health system is poorly integrated regarding rheumatic fever and rheumatic heart disease. Better support/coordination is needed for people with valve replacements to ensure they can access services and receive appropriate warfarin management and support.
- There needs to be holistic approaches including recognising psychosocial stressors that impact on well-being issues relating to the diagnosis and the complexity of the healthcare needed for this lifelong illness. This may mean existing services are resourced to provide more wrap-around care.

Cultural safety and appropriateness

- Peer-to-peer services are needed to support tamariki and rangatahi and their whānau to enable healing.[18]
- Health services are not always culturally safe or supportive of whānau and are not always patient-centred.
- A health system that is health literate plays an important role in shifting the current narratives for our priority groups, whānau and families. More work can be done to ensure our health system is health literate and culturally responsive. This can be measured against the recommendations in Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025 about health literacy.
- There are issues with systemic racism with Māori and Pacific whānau reporting they receive poor quality health care compared to non-Māori and non-Pacific patients due to health professionals' biases and a health system that is often misaligned with Māori and Pacific values and expectations of health. Racism is also evident in the quality of health information provided. Communities feel that some clinicians assume that because a family may be Pacific/Māori they know what rheumatic fever is and the process for treatment. Families need appropriate support and guidance to understand the impact of diagnosis and the journey from diagnosis to management based on their knowledge of the disease. Sometimes people report the best information they receive about rheumatic fever has been from another parent.[19]

Increase in workforce knowledge, capacity and capability

- There is limited understanding of rheumatic fever and rheumatic heart disease amongst primary care health practitioners, particularly those trained overseas or new to high prevalence areas that need to be specifically addressed. This includes knowing when to refer for an investigation of rheumatic fever and how to best support the management of rheumatic fever once a diagnosis is made by hospital clinicians.
- There needs to be support of health services and training for health professionals in cultural safety and anti-racism training, and how to develop family-centred models of care.[20]



[18] *Insights from Lomipeau (The Tongan Team) of the Auckland Rheumatic Fever Co-design Initiative*
[19] *Insights from Lomipeau (The Tongan Team) of the Auckland Rheumatic Fever Co-design Initiative*

[20] *Insights The Samoa Team of the Auckland Rheumatic Fever Co-design Initiative*

Table Two: Priority actions for focus area two: tāngata ora (quality health care and improved journey through the health system for those with rheumatic fever and rheumatic heart disease)

Outcomes	Priority actions
2.1 Improved access and coordination of care for those with rheumatic fever and rheumatic heart disease	**Existing work underway:** a. Develop and implement a national Rheumatic Fever Care Coordination System that will allow health providers to keep track of secondary prophylaxis as well as manage the movement of patients across areas. This will be piloted in 2023 and rolled out nationally (with training and support) by 2024. b. Improved access to dental care for people aged over 18 years living with rheumatic heart disease. We will review the current service provision of dental care in early 2023 and ensure implementation of improvements for greater access during 2024. c. Continue and extend the enhanced nursing prototype for models of care in Counties Manukau – this model focuses on age appropriateness and cultural competency of services and delivering holistic responses that meet the health needs of young people. **Potential new actions:** d. Work with clinicians and patients/whānau to provide greater whānau support during diagnosis and early management, focussing on: • culturally specific and/or language-specific resources; peer support; more options and autonomy on how/when they receive their prophylaxis injection and ensuring a family-centred model of care. e. Work with clinicians and patients/whānau to explore ways to improve access and experience of care focuses on: • the transition between paediatric and adult services; barriers for patients/whānau navigating the health system; supportive wrap-around care for rheumatic heart disease patients with valve replacements; with particular attention to warfarin monitoring and support.

2.2 Increased knowledge of the workforce about the management of rheumatic fever and rheumatic heart disease

2.3 Increased capability of the workforce around tikanga Māori and cultural safety and how to provide services that are of value to and support Māori whānau

2.4 Increased capability of the workforce around cultural safety and how to provide services that are of value and support Pacific families.

Existing work underway:

a. Update the New Zealand Guidelines for Acute Rheumatic Fever and Rheumatic Heart Disease. This will be completed by mid-2024 and will provide clinicians with evidence-based best practice guidelines on the diagnosis, management and secondary prevention of acute rheumatic fever and rheumatic heart disease.

Potential new actions:

b. Work with clinicians and patients/whānau to update e-learning and other opportunities that contribute to workforce development e.g.:
   - explore options to build health promotion knowledge
   - align workforce development initiatives with the National Public Health Service, Te Uru Kahikatea (TUK)[21] Public Health Workforce Development Plan
   - support work to address cardiac sonographer workforce shortages
   - support work for obstetric/maternity service providers to improve the detection of rheumatic heart disease for at-risk pregnant people.

c. Update consumer evaluations to monitor outcomes such as improvements in culturally safe services. This may need to link with wider work on the cultural safety of health services and other cultural safety resources i.e. the Hui process, Meihana Model.[22]

[22] *https://www.health.govt.nz/our-work/public-health-workforce-development/te-uru-kahikatea*

[22] *https://www.psychology.org.nz/journal-archive/Pitamaetal_NZJP36-3_pg118.pdf*

Focus area three: Kōkiri Ngātahi

System readiness and change

This focus area, Kōkiri ngātahi, is about ensuring the whole rheumatic fever/rheumatic heart disease prevention and management system is working together in a coordinated and integrated way. This is to ensure that the most effective interventions are being implemented in a high-quality manner.

The system for rheumatic fever and rheumatic heart disease prevention and management includes policymakers; central government (including those outside the health sector who are addressing wider determinants of health and wellbeing); Māori and Pacific leaders and communities; rheumatic fever and rheumatic heart disease patients and whānau, NGOs; public health units; primary and secondary care; and academia.[23]

To ensure actions in this focus area meet Te Tiriti commitments and achieve equitable rheumatic fever outcomes there needs to be a focus on addressing institutional privilege and racism. Decision-making needs to be made by and in partnership with Māori and Pacific leaders and designing, delivering and evaluating solutions needs to be done by Māori and Pacific communities.

The focus area is cross-cutting and will contribute to the other two focus area outcomes. It will also contribute to the following outcomes:

- enhanced data and information about rheumatic fever and rheumatic heart disease in Aotearoa New Zealand
- increase integration and coordination of the rheumatic fever prevention and management system and stakeholders
- amplify and enhance the leadership of Māori Iwi Partnership Boards, Māori and Pacific experts, health professionals and communities around rheumatic fever and rheumatic heart disease
- support a coordinated national research agenda.

[23] *Kania, J., Kramer, M. and Senge, P. (2018). The Water of Systems Change. Foundation Strategy, NonProfits.NGOS, Systems Thinking. https://www.fsg.org/resource/water_of_systems_change/*

Context and insights

- It is important to have a coordinated research agenda.
- There are gaps in evidence for rheumatic fever in Aotearoa New Zealand including:
  - role of nutrition in rheumatic fever risk[24]
  - mechanisms that determine individuals' susceptibility to developing rheumatic fever
  - how best to support healthy weight in this population.
- There is an association between GAS skin infections and rheumatic fever. More research is needed to understand if this is a causal relationship and if so, whether there are treatment regimens for GAS skin infections that reduce the risk of rheumatic fever.[25,26]
- There is some evidence that there are missed opportunities for health encounters to identify those with unrecognised rheumatic heart disease and further research is needed to determine the utility and cost-effectiveness of enhanced case-finding in high-risk population groups.
- The monitoring and surveillance requirements for rheumatic fever need to be evaluated and improved if required.[27]
- There is current research underway into the feasibility of developing GAS vaccine for Aotearoa New Zealand.
- Structural issues are at play in the high rates of rheumatic fever and rheumatic heart disease in Aotearoa New Zealand including housing, access to primary care, and racism.
- The system needs to learn from what has been tried previously. This needs to be followed by scaling up and improving what is working, stopping what isn't and identifying other opportunities to learn from.
- Opportunities to add to knowledge through evaluation of interventions and monitoring of outcomes.

[24] *Insights from Lomipeau (The Tongan Team) of the Auckland Rheumatic Fever Co-design Initiative*

[25] *Baker, M.G., Gurney, J., Moreland, N.J., et al. Risk factors for acute rheumatic fever: a case-control study. Lancet Reg Health West Pac, 2022.*

[26] *Bennett, J., Moreland, N.J., Oliver, J., et al. Risk factors for group A streptococcal pharyngitis and skin infections: A case control study. Lancet Regional Health - Western Pacific, 2022.*

[24] *Insights from Lomipeau (The Tongan Team) of the Auckland Rheumatic Fever Co-design Initiative*

Knowledge gaps and supporting research

Kōkiri ngātahi is about ensuring the health system is working together in a coordinated and integrated way to ensure positive outcomes for whānau. This includes the approach to supporting scientific research and understanding knowledge gaps for rheumatic fever and rheumatic heart disease.

A significant amount of research has been undertaken or is currently underway relating to rheumatic fever and rheumatic heart disease. However, further research is needed to build evidence and understanding around rheumatic fever and to support collective efforts in the Aotearoa New Zealand context.

The number of recent studies have provided increasing evidence that GAS skin infections may play a role in developing acute rheumatic fever.[28,29] An association between rheumatic fever and GAS skin infections is significant, and further work is underway to determine whether treating GAS skin infections (and how best to treat these infections) will lead to a reduction in rheumatic fever incidence.

In addition to the evidence around the role of GAS skin infections, the OPMCSA review on GAS and rheumatic heart disease[30] identified several areas where further research is required to better understand emerging evidence, such as:

- the association of rheumatic fever with eczema and skin infection
- the specific role of within household transmission of GAS
- the role of genomics in tracing transmission pathways
- carriage rates for GAS
- the true prevalence of rheumatic heart disease and how this influences future interventions, i.e. for pregnant women
- a greater body of research about lived experiences with a strong social science lens leading to more strengths-based findings to inform new approaches
- indigenous-led research to critique current Western approaches and provide more culturally responsive and safe interventions
- how to intervene to reduce the risk associated with a family history of rheumatic fever or rheumatic heart disease without stigmatising whānau
- a better understanding of the outcomes from different heart repair methods, including how surgeons choose their approach and what's happening on a national level in Aotearoa New Zealand.

[28] *Baker, M.G., Gurney, J., Moreland, N.J., et al. Risk factors for acute rheumatic fever: a case-control study. Lancet Reg Health West Pac, 2022.*

[29] *Bennett, J., Moreland, N.J., Oliver, J., et al. Risk factors for group A streptococcal pharyngitis and skin infections: A case control study. Lancet Regional Health - Western Pacific, 2022.*

[30] *https://www.pmcsa.ac.nz/topics/antimicrobial-resistance-and-infectious-disease/rheumatic-fever/*

There is a tension between scientific research and using evidence-informed approaches balanced with responding to the needs of whānau and community and what they say is needed. Both aspects are important in ensuring that approaches to rheumatic fever and rheumatic heart disease prevention and management are evidenced but are equally responsive to patient voice.

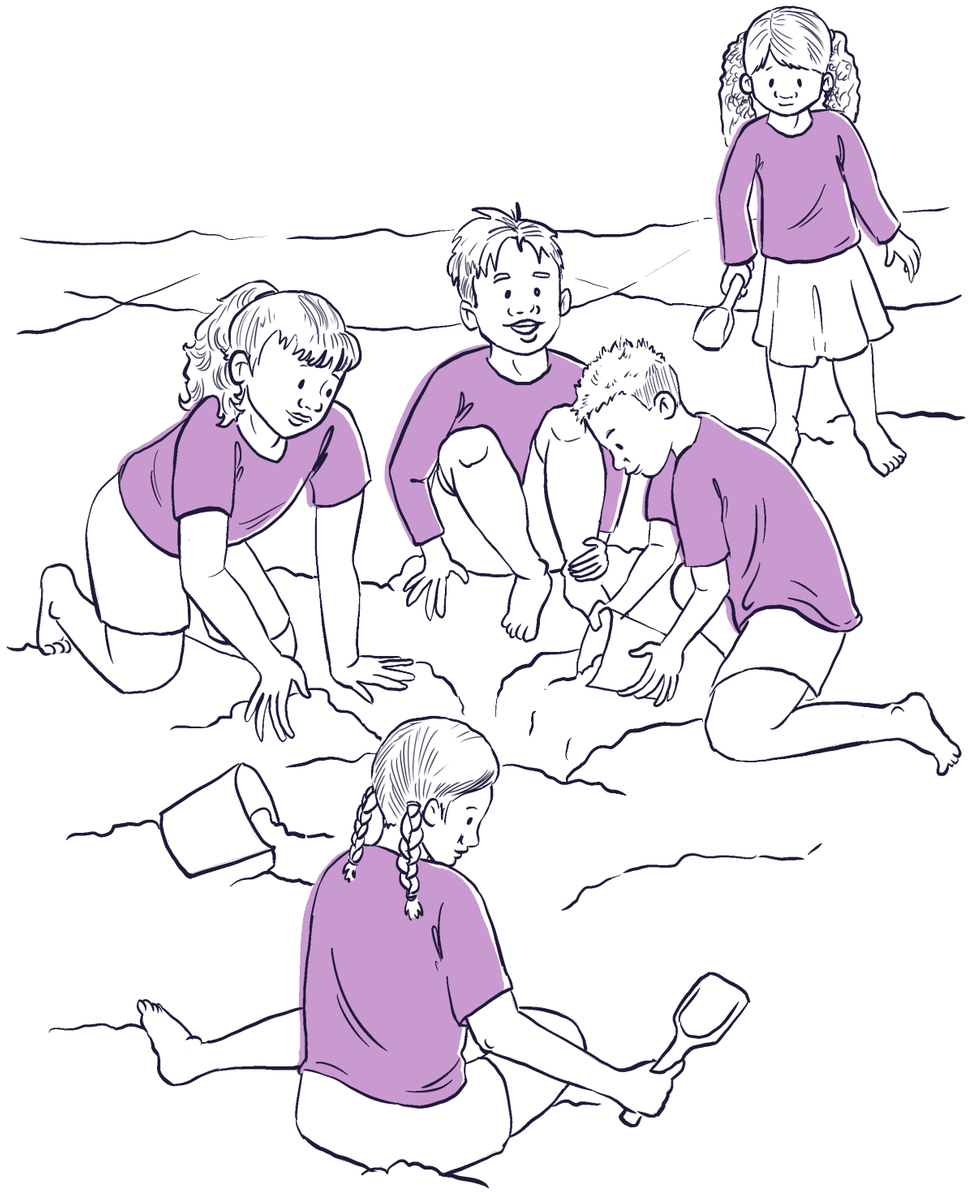
The framework (Figure 1), for this roadmap, demonstrates that **research, evaluation and monitoring** play an important role in ensuring the goals and vision set out within this roadmap are met, in balance with the values and commitment to Te Tiriti and equity.

Evaluation of initiatives is important in supporting and establishing an evidence base for rheumatic fever, and what works or is not working well. Evaluation of existing and new priority actions will be incorporated to measure against the desired outcomes and progress of the priority actions over the next five years. Further detail relating to evaluation will be incorporated into the implementation plan of the roadmap, to be updated annually as progress is tracked.

Table Three: Priority actions for focus area three: kōkiri ngātahi (Systems readiness and change)

Outcomes	Priority actions
3.1 Enhanced data and information about the prevention and management of rheumatic fever and rheumatic heart disease in Aotearoa New Zealand	**Existing work underway:** a. Understand the causal factors of the recent decrease in RF first-time hospitalisations (report due December 2023) and implement any learnings/insights. b. Complete the research and development around the feasibility of a Group A Streptococcal (GAS) vaccine with a focus on Māori and Pacific children and implement any learnings/insights. This work is underway until late 2025. c. Review of the evidence for echocardiographic case-finding and screening for undetected RHD – with the intention to design and undertake a demonstration pilot if the evidence supports this approach, focussing on tamariki and rangatahi in school and community/health settings. This work started in January 2023. **Potential new actions:** d. Improve monitoring and surveillance of GAS infection, rheumatic fever and rheumatic heart disease to better describe the current burden and epidemiology of the disease, monitor trends and identify changes (increases) in incidence.
3.2 Increase integration and coordination of the rheumatic fever prevention and management system. **3.3 Amplify and elevate the leadership and role of Māori and Pacific communities, experts and health professionals.** **3.4 Support a nationally coordinated research agenda.**	**Existing work underway:** a. Embed the learnings from the Rheumatic Fever Co-design Initiative (Budget 19) into services and the system. b. Embed the learnings from the three former Auckland DHBs and Alliance Health + PHO short-term, high-impact initiatives into services, future models of care and the wider health system. c. Work alongside Pū Manawa to ensure coordination of efforts for rheumatic fever prevention and management.[31] d. Continue to share innovation/learnings within and across the sector – developing better and different ways of achieving this. **Potential new actions:** e. Consider and implement ways to embed whānau/patient voice into the rheumatic fever and rheumatic heart disease work programme. f. Explore options to amplify and elevate the leadership and role of Māori and Pacific in the oversight and leadership around rheumatic fever, including Māori Iwi Partnership Boards, Māori and Pacific experts, health professionals and communities. g. Support the development of the Māori and Pacific health workforce, including recruitment and development, to address the quality and responsiveness of health care. h. Support the development of a nationally coordinated research agenda.

[31] *Pū Manawa is the Rheumatic Fever Network, Aotearoa New Zealand. The network is co-chaired by Dr Anneka Anderson (co-chair Māori) and Dr Malakai Ofanoa (co-chair Pacific) and its members work in a variety of research, clinical and academic settings.*



Next steps

The implementation of the priority actions in this document (Section 7) will contribute to the outcomes, objectives, goals and ultimately the vision of the roadmap. This includes meeting Te Tiriti o Waitangi commitments regarding rheumatic fever and meeting goals regarding equity. However, it will require a coordinated and quality improvement approach to ensure actions are effective.

An implementation plan will sit behind this roadmap, to be finalised in mid-2023. The implementation plan will include a monitoring framework that will include performance measures developed to track progress in delivering the actions, and indicators to measure whether outcomes, objectives, and goals are being achieved. Indicators specifically related to improving Māori health and well-being and improving equity for priority groups will be included. An annual update will be provided against the implementation plan – using the monitoring framework.

This roadmap lays out some actions that are already happening and others that need to start. Not all the actions outlined will be implemented in the short term as actions will be prioritised and phased. Further ideas and initiatives will likely emerge over the life span of this roadmap, and these will be included in implementation plans where appropriate.

A Te Tiriti partnership approach will be taken to implement the roadmap including through partnerships held by Te Aka Whai Ora with the Iwi Māori Partnership Boards. Health agencies[32] will work together to implement the actions and will have shared accountabilities.

It is also recognised that in order to make impactful change involving other sectors and systems that influence the wider determinants of health, and impact on rheumatic fever and rheumatic heart disease, health agencies need to work closely and set clear expectations with leaders who hold cross-sectoral partnerships and close the loop between strategy, policy, whānau and outcomes.

[32] *The health service agencies (Te Manatū Hauora | Ministry of Health, Te Whatu Ora | Health New Zealand (HNZ) & Te Aka Whai Ora | Māori Health Authority)*