

Ministry of Health

Rheumatic Fever Co-Design Initiative Phase 1 Report

Context and Overview

April 2022

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Tuia ki runga
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Tuia ki te here tangata
Ka rongo te pō
Ka rongo te ao

Tiheī mauri ora.

E ngā iwi, e ngā mana, e ngā uri whakatipu
e noho mai nā i ngā rohe maha huri noa i
Aotearoa nei, tēnā koutou, tēnā koutou,
tēnā koutou katoa!

E ngā mate whānui o te motu, hoki atu ra
ki te ūkaipō o te tangata.

Tau mai ngā mihi ki a tātou ngā
waihotanga, ki a tātou e ora tonu ana.

Mauri ora ki a tātou.

Part One

Introduction



Purpose of the co-design initiative

This report summarises the work completed **during Phase 1** of the Ministry of Health's Rheumatic Fever Co-Design Initiative.

The report is intended to be read together with the end-of-phase reports for each of the ethnic-specific design teams (Māori, Samoan and Tongan):



Te Tīma Māori: Rheumatic Fever Co-Design Initiative 2020 – 2023, Discovery Report Āperira 2022



Rheumatic Fever Co-design Initiative: Samoa Team Report, Phase 1, April 2022

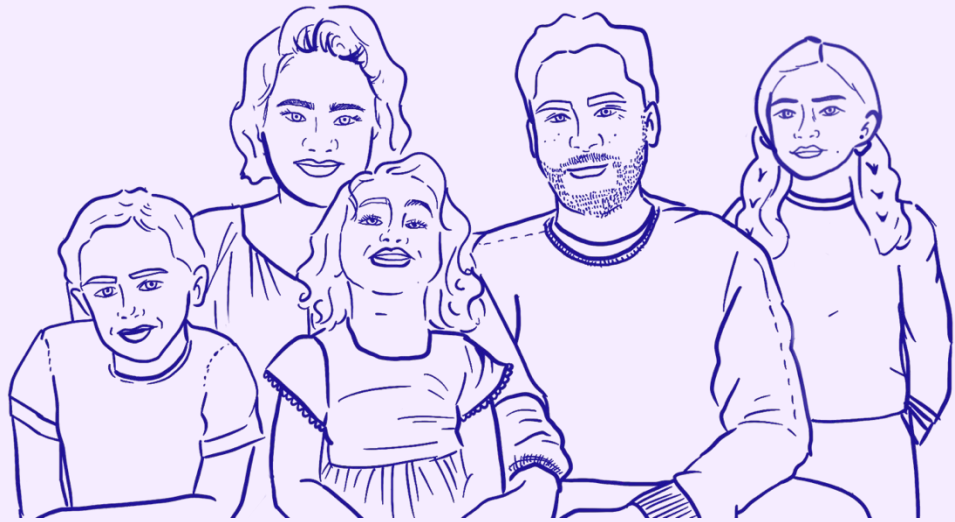


Rheumatic Fever Co-Design Initiative, Discovery Phase Report, April 2022: Lomipeau (Tongan Co-Design Team)

The purpose of this summary report to provide high-level orientation to the initiative.

The work done by the three ethnic-specific design teams has occurred within the relevant cultural contexts. To summarise this work and to remove the cultural context has extreme limitations.

For depth of insight, please refer to the individual reports.



Acknowledgements

We acknowledge and affirm Te Tiriti o Waitangi as providing the foundations of partnership between Māori and the Crown.

We acknowledge the wisdom, knowledge and experience that exists within Māori, Samoan and Tongan communities across Aotearoa New Zealand.

We acknowledge the families that have been impacted by rheumatic fever. We acknowledge those that have passed as a result of rheumatic fever.

We acknowledge the work of those who have gone before us, whose work we are building on.

We acknowledge everyone who has generously contributed to this initiative, including communities, stakeholders and the project teams.

Terminology



Rheumatic fever

Throughout this report, the term *rheumatic fever* is used to include acute rheumatic fever and rheumatic heart disease. The term *sore throats* relates to potential Group A streptococcal infections.

Samoan and Tongan

Through this report, the terms *Samoan* and *Tongan* are used to represent anyone who identifies as having Samoan or Tongan ancestry and who lives in Aotearoa New Zealand, irrespective of their place of birth.

Purpose of the co-design initiative

The stated purpose or scope of the rheumatic fever co-design initiative is:



This scope is both **broad** and **targeted**.

The **targeted** elements include a focus on three specific ethnic communities (Māori, Samoan and Tongan) and a focus on a geographic region (Tāmaki Makaurau/Auckland). The focus areas reflect that the majority of new rheumatic fever diagnoses occur within those demographics.

The **broad** elements of the scope include the full breadth of both **prevention** (i.e. preventing new occurrences of rheumatic fever) and **management** (i.e. managing existing cases of rheumatic fever and rheumatic heart disease), and the system-wide focus that includes communities and system stakeholders.

How the co-design initiative came about

The Ministry of Health, District Health Boards and NGO health providers have funded and implemented many initiatives to improve the rheumatic fever outcomes in Aotearoa New Zealand. Despite these efforts, and despite gains that have been made, rheumatic fever persists at unreasonably high rates.

2018

A series of engagements with stakeholders from across the rheumatic fever system identified the need for community-led solutions.

2019

A budget bid as part of Budget19 was approved and additional funding was allocated to:

- 1 The co-design initiative with Māori, Samoan and Tongan communities in Auckland.
- 2 High-impact, short-term initiatives with Auckland and Waitemata DHBs, Counties Manukau DHB, and Alliance Health Plus.
- 3 Funding for Healthy Homes Initiative providers to implement the findings of a process evaluation.

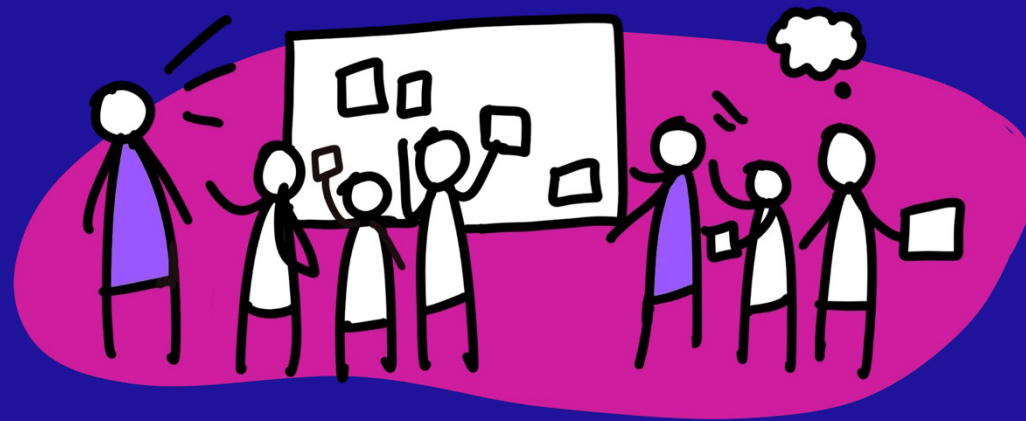
2020

In May 2020, the Ministry of Health undertook a procurement process using the All of Government consulting services panel. The proposed contract was for approximately 3 years to 'co-design innovative approaches to improve the prevention and management of rheumatic fever and rheumatic heart disease in Auckland'.

ThinkPlace submitted a proposal, in partnership with other organisations/ individuals, and was awarded the contract by the Ministry of Health. The contract commencement date was 1 November 2020, with a completion date of 30 June 2023.

Part Two

Context



Causes of rheumatic fever



The bacteria

Group A streptococcus is a bacterium that can cause infections in the throat (strep throat) and the skin (impetigo, cellulitis). Fortunately, the low-cost antibiotic penicillin is still very effective at killing strep infections. Erythromycin is used if someone is allergic to penicillin. If someone has a strep throat infection, it's important they take the whole 10-day course of antibiotics to completely kill the bacteria.

Strep A infections are contagious and can be spread by coughing and sneezing or sharing food or drinks. When a person starts antibiotics for a strep throat infection, they need to be careful not to spread the infection for at least 24 hours.



The disease


Acute rheumatic fever can be difficult to diagnose as it presents as a collection of symptoms. There isn't one definitive test that tells doctors that a child has the disease. After a strep throat infection, a few people will go on to get rheumatic fever. There is no way to know for sure who will get rheumatic fever, although children who have someone else in their family with rheumatic fever have the highest risk. Getting treatment quickly with antibiotics and taking all 10 days can reduce the risk.

Scientists believe that rheumatic fever happens because our immune systems get “tricked” by the bacteria. This sets off an inflammatory process that can cause sore, swollen joints, fevers, skin rashes, jerky body movements (due to brain involvement) and damage to the heart valves. Although the brain and soft tissue involvement resolves with rheumatic fever, the damage can settle in the heart valves. The damage to the heart valves can limit heart function and sometimes requires heart valve replacement surgery.

If someone gets rheumatic fever, it is important that they do not continue to get strep throat infections because the inflammation process can begin again, damaging the heart further. Ensuring that people do not get any more strep infections is the best way of protecting the heart.

This means a person who has had rheumatic fever should have an injection of penicillin (prophylaxis) every 28 days for at least 10 years to prevent strep infections from occurring again. This treatment takes a very committed approach from the patient's families.

What we know about the rheumatic fever system and experiences



The Office of the Prime Minister's Chief Science Advisor released a report in November 2021 titled:

'Group A Streptococcus and acute rheumatic fever in Aotearoa New Zealand: A summary of current knowledge in Aotearoa in New Zealand'.

This review aims to summarise what we know about the processes that lead to group A Streptococcus infection, acute rheumatic fever and rheumatic heart disease in Aotearoa New Zealand.

Included on the following pages are some of the findings from the report that have stood out for us and have influenced our approach. This summary provides context for the current state of the rheumatic fever system and provides support for the findings from our discovery phase.

Having said that, only limited research has been undertaken into the experiences of Māori, Samoan and Tongan families who experience rheumatic fever, and the findings from our discovery phase provide deeper insight into aspects of those experiences.

We encourage you to read the report, found here:

<https://www.pmcsa.ac.nz/topics/antimicrobial-resistance-and-infectious-disease/rheumatic-fever/>

1

New Zealand experiences high rates of rheumatic heart disease with inequitable distribution.

- Approximately 150 people per annum are hospitalised for a first episode of acute rheumatic fever.
- Māori are three times and Pacific peoples around five times more likely than other ethnicities to develop rheumatic heart disease, and both are around 11 times more likely to die from rheumatic heart disease. Even these figures mask some of the inequities because rheumatic fever was more common across non-Māori populations in the 1950s.
- Rheumatic fever causes significant emotional, health, social and economic stress for individuals and whānau, with longer term negative flow-on effects for wellbeing. People with rheumatic heart disease identify difficulty accessing employment and education opportunities as a result of their health condition.

2

There are several key factors that appear to contribute to acute rheumatic fever and rheumatic heart disease.

- Socioeconomic and living conditions (e.g. crowding, poor housing, transient housing, etc.) impact rheumatic fever risk.
- People with family/whānau history of rheumatic fever are more at risk.
- School-aged children are most affected by acute rheumatic fever (especially ages 5 – 14).
- Boys are at higher risk of developing acute rheumatic fever, something that appears unique to Aotearoa New Zealand.
- Undiagnosed early episodes of acute rheumatic fever (e.g. evidence shows a significant proportion of people presenting with rheumatic heart disease never presented with acute rheumatic fever.)

This page contains some of the findings from the report by The Office of the Prime Minister's Chief Science Advisor in November 2021 titled: 'Group A Streptococcus and acute rheumatic fever in Aotearoa New Zealand: A summary of current knowledge in Aotearoa in New Zealand'.

3 There are known barriers to preventing and managing the disease.

- It is not readily apparent to some people how untreated strep throat infections can ultimately cause rheumatic heart disease.
- Not completing initial course of antibiotics for sore throats.
- Barriers related to accessing healthcare include wait times, transport challenges, childcare or work commitments, moving between healthcare providers, traumatic experiences, etc.
- Not all children with acute rheumatic fever report having recently had a sore throat or skin infection.
- People don't know or are unable to present to hospitals for assessment.
- Monthly prophylaxis injections are not always being consistently received due to factors such as level of understanding of the importance of the treatment, the pain of the injections, difficulty scheduling appointments, shame for receiving injections at school, location and timing of injections are not ideal, etc.

4 There are risk factors that should be explored further to understand the role they play (if any).

- Strep A skin infection prevention and management and other strep infections that may prime the immune system.
- Health and nutrition factors, including sugary drinks.
- Travel between Pacific islands and New Zealand.
- Other strep infections that may prime the immune system.
- Inability to access healthcare as a result of childcare challenges for other children.

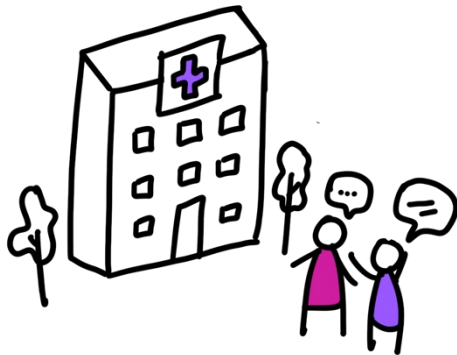
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5

There are some risk factors that have no supporting evidence that they influence development of rheumatic fever.

- There is no evidence to support health awareness alone being sufficient to prevent acute rheumatic fever. However, an understanding of sore throats, acute rheumatic fever and rheumatic heart disease is still important for the experience of an individual and their whānau when diagnosed. Health communications in the past have also created anxiety and internalised blame, shame, guilt and stigma for those whose children become sick.
- There is no evidence to support a relationship between pets in the home and acute rheumatic fever risk.



6

A new approach is needed.

- What is needed is a holistic, collaborative, Māori- and Pacific-led approach that accounts for unique community needs, which is supported by a national strategy that is flexible enough to include local context.
- The complexity of rheumatic fever must be matched with a systems approach and multi-pronged solutions. One intervention alone is unlikely to significantly reduce the incidence of Strep A and acute rheumatic fever. There are examples overseas of where a multi-pronged approach has positively shifted outcomes.

This page contains some of the findings from the report by The Office of the Prime Minister's Chief Science Advisor in November 2021 titled: 'Group A Streptococcus and acute rheumatic fever in Aotearoa New Zealand: A summary of current knowledge in Aotearoa in New Zealand'.



7

Promising developments to reduce the rates of rheumatic fever

- Research into possible vaccine for Strep A strains in Australia and Aotearoa New Zealand.
- Research, development and reformulation of drugs to support acute rheumatic fever prevention.
- Free prescriptions and GP visits for children under 13 years old.
- A national patient register for rheumatic fever is being explored. Research is underway to develop a better diagnostic tool for acute rheumatic fever.

This page contains some of the findings from the report by The Office of the Prime Minister's Chief Science Advisor in November 2021 titled: 'Group A Streptococcus and acute rheumatic fever in Aotearoa New Zealand: A summary of current knowledge in Aotearoa in New Zealand'.

8

Opportunity areas

Preventing Strep A exposure

- Greater prevention of threats (e.g. focus on housing)

Preventing acute rheumatic fever

- Improving antibiotic adherence when prescribed for a possible Strep A infection.
- Adapting clinical guidelines to screen for skin infections as well as throat infections.
- Improving how Strep A is coded and notified to achieve consistency across practitioners and detect recurrent cases of Strep A.

Preventing rheumatic heart disease

- Improving access to secondary prophylaxis and specialist appointments.
- Improving patient tracking.

Minimising complications arising from rheumatic heart disease.

- Active case finding (e.g. proactive echocardiography imaging).





Improving the experience of individuals and whānau throughout.



- Wraparound support to improve rapport, communication and create continuity of care.
- Small group discussions in communities (e.g. online support, churches and talanoa).
- Culturally safe and relevant health promotion campaigns across multiple media.
- Cultural safety training and evaluation for healthcare practitioners.
- Reducing access barriers via lived experience-informed and ethnic-specific insights.



Interventions that have been tried



This table shows some of the factors associated with rheumatic fever, what is being done to help, and things that can get in the way of maximum effectiveness in eliminating the disease in Aotearoa.



We developed this list of factors by reviewing available literature. It is not intended as an exhaustive list but provides a quick reference to many of the commonly identified factors. It is important to remember there are many unknowns with rheumatic fever and not everyone agrees on the most relevant factors.

Factors associated with RF	Things being tried or are helping	Barriers to effectiveness
 Cold, damp housing	<ul style="list-style-type: none"> • Healthy Homes Initiative 	<ul style="list-style-type: none"> • Housing supply • Substandard housing stock • Lack of money for heating
 Overcrowded housing	<ul style="list-style-type: none"> • Healthy Homes Initiative 	<ul style="list-style-type: none"> • Housing crisis • Families doubling up to get by • Lack of affordable large homes, especially for multi-generational living
 Family history	<ul style="list-style-type: none"> • Early / active treatment of other family members who have sore throats 	<ul style="list-style-type: none"> • Inconsistent relationship with one health provider • Inability to track families in one database • Children in different schools with different nurses • Disjointed health and social services that don't holistically treat whānau/families
 Bed sharing	<ul style="list-style-type: none"> • Bunk bed programmes • Messages to "top and tail" • Healthy Homes Initiative 	<ul style="list-style-type: none"> • Poverty • Hot bedding • Cultural, personal preference • Lack of sheet-washing facilities

Factors associated with RF	Things being tried or are helping	Barriers to effectiveness
 <p>Group A strep infections</p>	<ul style="list-style-type: none"> • Sore throat management in schools • Giving antibiotics for high-risk patients without waiting for test results • Sore throat 'drop in' clinics (rapid response clinics) • Free throat testing and free antibiotics • Trials of a vaccine • Penicillin is still effective at killing it, and it is a cheap, available antibiotic (erythromycin is used for penicillin allergies and is slightly less effective) • Probiotic trial 	<ul style="list-style-type: none"> • Not seeking help for sore throats, minimising their seriousness • Children do not always know how to identify a sore throat • Around half the cases of acute rheumatic fever don't have a sore throat history • The possibility that skin infections are linked to rheumatic fever and the challenges with prescribing antibiotics for both strep and staph infections • Doctors not treating sore throats with antibiotics in priority populations • Waiting for the next school nurse visit rather than visiting GP • Patients being dismissed without treatment when they present with sore throats
 <p>Adherence to medicine for Group A strep</p>	<ul style="list-style-type: none"> • Penicillin injection instead of 10-day oral antibiotics • Antibiotics given on-site rather than a script that must be filled • Free medication • Initiatives to increase medicines adherence • Having a school nurse to administer medicines each day helps but is expensive 	<ul style="list-style-type: none"> • Some estimates are that 1/3 do not finish medication, and 1/3 do not fill prescriptions • Medicines are shared with others • Lack of understanding as to why it's important to take the full course • Blister packs/apps have shown little effectiveness

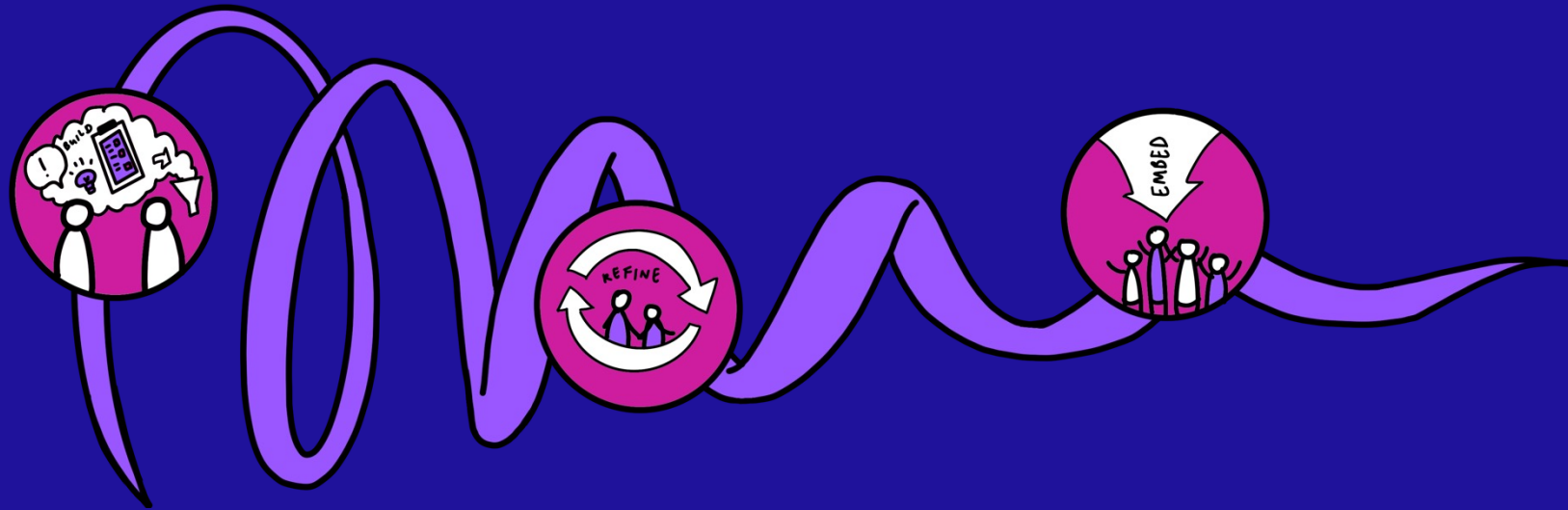
Factors associated with RF	Things being tried or are helping	Barriers to effectiveness
 <p>Adherence to long-term prophylaxis</p>	<ul style="list-style-type: none"> • Research into less painful, longer lasting subcutaneous penicillin injections • Good injection techniques, ice packs, Buzzy, lignocaine • Nurse injector home visits 	<ul style="list-style-type: none"> • Losing track of children as they transition from paediatric to adult services • No national register to track patients with ARF • Getting injections on day 28 each month due to other life events / priorities • Young adults drop off as they don't prioritise their health • Unskilled or impatient injectors put families off coming again • Difficulties getting to health clinics
 <p>Lack of public understanding of rheumatic fever</p>	<ul style="list-style-type: none"> • General public health campaigns • Pū Manawa website • HPA website for education • MoH website • Local parent groups • Heart Kids (for RHD) 	<ul style="list-style-type: none"> • A sense of victim blaming • Burden of prevention on marginalised parents • Guilt, fear of strep throat • Medical jargon, complicated disease to understand • Language barriers • Misunderstanding of the connection between sore throat and ARF • Mismatch between when information is provided and when people are ready to receive/absorb it

Factors associated with RF	Things being tried or are helping	Barriers to effectiveness
 <p>Lack of health professional understanding of rheumatic fever</p>	<ul style="list-style-type: none"> • MoH online course • Pū Manawa website • HPA website for campaign/educational materials • MoH website • The Heart Foundation guidelines • Health Pathways which support GPs to make the diagnosis 	<ul style="list-style-type: none"> • Primary care is stretched • It is a relatively rare condition that many GPs will never see and the diagnosis is not always obvious • Tensions between primary and secondary care (result of the system's design) • Lack of leadership/champions • Dismissing patients who come in for sore throats • Dismissing patients who are told they have the flu even when they are seeking help due to ARF symptoms
 <p>Lack of trust in health providers</p>	<ul style="list-style-type: none"> • Knowing the whole whānau well • Seeing the same GP/nurse to build rapport • Cultural match/choice of health care providers • Youth clinics (Rotovegas clinic) 	<ul style="list-style-type: none"> • Lack of ethnic concordance • Feeling judged • Bad health care experiences • Racial slurs • Mispronouncing names • Low/no cultural competency • Violating tapu • Language barriers • Families feeling like there is nowhere to complain about substandard medical care

Factors associated with RF	Things being tried or are helping	Barriers to effectiveness
 <p>Structural racism/health inequality</p>	<ul style="list-style-type: none"> • MoH strategies to address health inequalities (including Whakamaua: Māori Health Action Plan 2020-2025, and Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025) • Co-design project to distribute solutions to the communities of interest 	<ul style="list-style-type: none"> • Victim blaming • Discounting cultural beliefs about health and wellbeing • Microaggressions • Low cultural knowledge of Pacific/Māori family structures
 <p>Barriers to accessing health providers</p>	<ul style="list-style-type: none"> • Free GP visits for children • Low-cost clinics in high-deprivation areas • Having specialists come to GP clinics rather than patients go to hospitals 	<ul style="list-style-type: none"> • Limited transport options • Long wait times at GP clinic • Having debt with GP so won't go back • Short consultation time slots • Language barriers • After hours costs too much • Lack of flexibility of employers to allow time off work • Bad experiences so opting not to engage • Lack of cultural safety for patients

Part Three

The Co-Design Initiative



The overall phases of the initiative



Note: These phases are not discrete and will have activities that overlap. The nature of designing within complex systems is fluid, meaning we need to respond and adapt to changes as they happen. Changes will be communicated to the Ministry in our reporting.



Phase 1: System Discovery and Opportunity Exploration

1 November 2020 – 31 December 2021

Establishing the foundational values and ways of working for this initiative so that safe places are created for families and communities to engage and share their experiences, beliefs and aspirations.

Understanding the wider ecosystem of rheumatic fever and forming connections and trust with people from right across the system.



Phase 2: Learning and Prototype Development

1 January 2022 – 30 June 2022

From the insights and opportunity areas surfaced during Phase 1, framing possible areas of intervention (i.e. opportunities) and working alongside stakeholders and contributors to test the thinking to identify what makes a successful solution.



Phase 3: Embedding System Changes and Evaluation

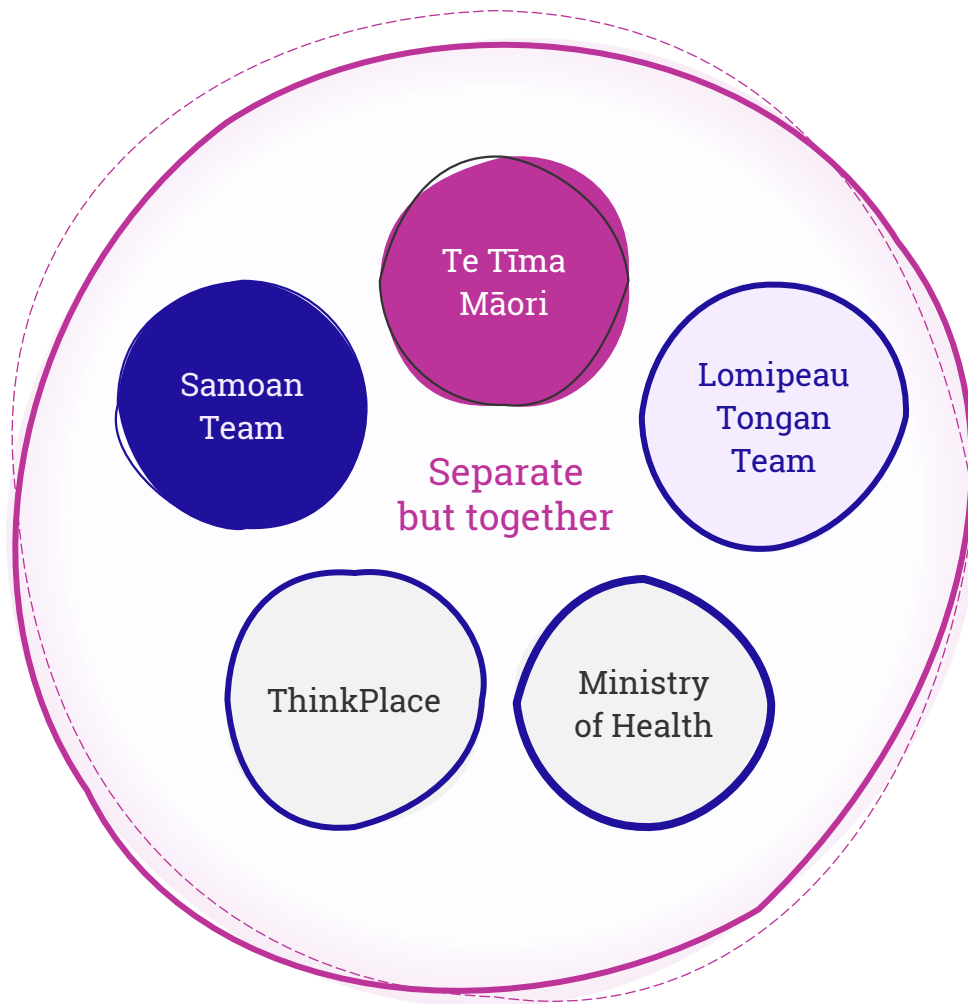
1 July 2022 – 30 June 2023

Prioritising the possible areas of intervention in Phase 2 based on qualitative evidence of what makes a difference to people, and working with stakeholders to uncover and identify possible solutions to the system barriers that prevent implementation or scaling of the solutions.



The core team

A way of viewing the core team's structure is through the phrase 'separate but together'. Three autonomous ethnic-specific teams were formed: a Māori team, a Samoan team, and a Tongan team. Together with ThinkPlace and the Ministry of Health the three teams take a collective and connected approach to the initiative.



The 'separate' element is essential as it creates the environment for each team to approach the work in ways that are culturally appropriate and that draw on existing cultural values, knowledge, practices and frameworks. The culturally-specific element is what makes this initiative unique, and the value of this approach can be seen in the depth of insight presented in the team-specific reports.

The 'together' element is essential as it provides encouragement and support to each team and helps to identify key opportunities at a systemic level. Also, the rheumatic fever system is generally not structured to account for ethnic-specific approaches so a collective effort is needed to influence changes across the system.

Each team has leadership from a **'co-design lead'**, and has 4-6 additional team members who contribute leadership, knowledge, relationship capital and technical skills (i.e. research practice, co-design methodology, visual design, etc.).

ThinkPlace, as the contract holder with the Ministry of Health, provides **behind-the-scenes support** to each of the co-design teams (i.e. contract management, project management, methodology support, stakeholder engagement, etc.).

The approaches taken

Each team's approach consists of different elements, reflecting the communities they serve and the cultural contexts in which they operate.

Each team has conceptualised the co-design initiative in relevant cultural terms. Rather than starting with traditional Western frameworks and methodologies, the teams have started with traditional cultural values, frameworks and approaches and supplemented those with traditional Western frameworks and methodologies if appropriate and useful.

This focus on 'doing things in the way they are meant to be done in our culture' has been a critical ingredient in creating experiences that are uplifting and value-contributing for the families and communities that have engaged in the initiative.

Ethical frameworks and research methodologies that support the family engagement activities have also been developed taking inspiration from cultural practices and frameworks.

The co-design initiative is not a point-in-time research project. Engagement with families and people with lived experience has been conducted within a relational framework, where ongoing engagement and participation is sought.

Because the scope of the co-design initiative is broad (i.e. both prevention and management of rheumatic fever), we have engaged with families with experience of rheumatic fever as well as families with no experience of rheumatic fever.

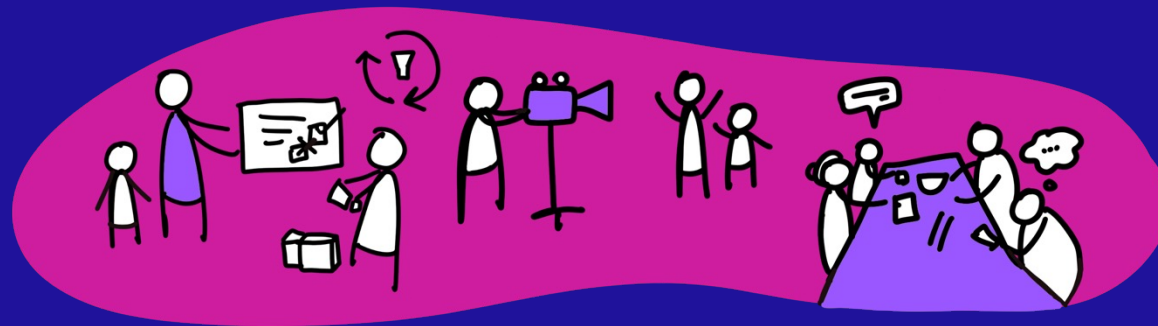
Within the framework of ethnic-specific co-design streams, the teams have engaged a broad range of people and perspectives from across each of the three ethnic communities. This includes young people, their families, community leaders, faith leaders, cultural leaders, health leaders, support workers, educators, etc. Again, this is a unique aspect of the work – the ability to look right across the support system through a cultural lens.

Finally, each team has placed high importance on culturally appropriate and affirming processes. This includes giving the opportunity for families and other stakeholders who were engaged to review what has been created before it is more widely shared.



Part Four

Findings and opportunities



Summary of our findings



The following findings have been identified through conversations with families, community members, health practitioners, and other stakeholders during Phase 1 of the initiative.

For more detailed and ethnic-specific insights, including the cultural context in which they sit, please refer to the individual team reports.



Māori, Samoan and Tongan ways of being, thinking and acting are not affirmed by the rheumatic fever prevention and management system.

Notwithstanding the instances of services, organisations and individuals that are culturally responsive, the rheumatic fever system as a whole is not affirming of Māori, Samoan and Tongan ways of being. People experience a lack of consideration of whanaungatanga, maintaining va, wairua and spiritual aspects, holistic wellbeing, traditional healing practices, and engaging the family collective rather than just the individual. The impact is significant; people experience a rheumatic fever system that signals that their culture and values are irrelevant.

The language of rheumatic fever perpetuates negative stereotypes and is disconnected from family aspirations.

Across media and the health and social sectors, the language associated with rheumatic fever is frequently deficit-based or reinforces negative stereotypes. Examples include ‘rheumatic fever is a Māori and Pacific disease’, ‘rheumatic fever is a disease of poverty’, ‘it’s a third-world condition’, ‘you must be overcrowding’, etc. For Māori, Samoans and Tongans, the language is stigmatising and blaming and is disconnected from their aspirations for their family.

When an individual experiences rheumatic fever, it affects the whole family.

In the context of Māori, Samoan and Tongan family structures, the experience of rheumatic fever is carried by all generations within the family. Yet health interventions frequently target the person diagnosed with rheumatic fever and not the wider family who play a critical support role. The knowledge needs of different family members can vary widely. For example, a grandparent for whom English is not their first language and doesn’t have a phone, compared with a sibling for whom English is their first language and are active on social media.



Children and young people who have been diagnosed with rheumatic fever frequently experience shame and embarrassment.

Young people who experience rheumatic fever have to navigate the implications of the disease, including monthly bicillin injections, at the same time as managing the complexities of being a young person. It can be embarrassing to leave school for the injection. Young people find that their peers know very little about rheumatic fever, leading to misconceptions such as being worried that they will catch rheumatic fever from their friend.

Families who have experienced rheumatic fever have found the journey to be traumatic, confusing and disempowering, and have expended a lot of emotional energy.

It is common for families to have very little knowledge of rheumatic fever, including its causes and implications, at the point of diagnosis. Many of these knowledge gaps continue well beyond the time of diagnosis. Navigating the experience takes a lot of emotional energy from everyone in the family. Family members frequently find the journey to be traumatic and often don't have a way to unpack or process the experience.

Family members of a child diagnosed with rheumatic fever frequently feel shame and guilt and think they were responsible for the disease.

Families carry a heavy emotional burden after the child is diagnosed, and often blame themselves. The words and actions of health practitioners and other people can fuel the cycle of self-blame. It is common for families to not fully understand how the disease developed, and this confusion is often filled by families with thoughts of their own actions or inactions.



The language and stories of rheumatic fever hold little relevance for families because they are disconnected from traditional narratives, language and beliefs.

Families experience health information and promotional communication as being full of complicated technical information that causes confusion. Levels of awareness of rheumatic fever and its causes and implications are lower than expected. The te reo Māori and Samoan and Tongan language that is used is often misleading or incorrect. Māori and Pacific people have a long history of oration and communicating important concepts through myths, legends and stories; previous and current rheumatic fever communications fail to make a connection into this.

The relationship between family members and the health practitioners is critical and can set the tone, positively or negatively, for what follows.

Whilst the rheumatic fever healthcare system delivers a largely clinical experience, families are looking for relational experiences that are defined by safety, trust, nurturing, continuity and free of judgement. The rheumatic fever journey lasts decades, and a poor or traumatising experience in the early phases of the journey can set the tone for the remainder of the journey.

Choice of healthcare options is more than a nice to have; it is an essential tool for achieving tino rangatiratanga for Māori, and equity and self-determination for all.

Given the significant inequities that rheumatic fever highlights, providing what may seem like small instances of choice and control to families can make a big difference to families. Positive examples that have been shared with us include being offered a course of oral antibiotics or a penicillin injection so the family can decide which treatment works best for their lifestyle; and being able to choose the day of the week or weekend for the monthly injection so that it minimises the impact on the young person and their family.



The best information people often get is from other families who have had similar experiences.

We heard of the important role that family, friends, teachers, spiritual leaders and other people play in terms of supporting families to prevent rheumatic fever or to navigate the rheumatic fever journey. In other words, relationship capital is a vital protective factor for families. Also, families who have experienced rheumatic fever desire having safe places to share their experiences.

There is a need for shared responsibility when tackling the causes of rheumatic fever, supporting families to assert their power without asking families to solve the problems caused by the system.

A principle of shared responsibility is evident in contexts where the rheumatic fever prevention system appears to be working well. In other contexts, there are extremes from families not being given the opportunity to assert their own power (e.g. framing rheumatic fever as a clinical issue that families lack knowledge about) and families being expected to solve the problems caused by the system (e.g. judgemental views toward overcrowding imply that the family is at fault for the housing challenges). A healthy rheumatic fever prevention and management system is one that is characterised by shared responsibility to each other.

Despite insitutional barriers, Māori and Pacific practitioners are doing what is required to support their communities but the work is tiring.

We heard stories of amazing people providing critical support to families in culturally relevant and affirming ways. But often these people are acting outside the system or their role descriptions, rather than being supported by the system. They leverage their cultural and relationship capital to provide what is needed, but at great personal cost and with the risk of burnout and lack of recognition.

For a disease that disproportionately impacts Māori and Pacific people, the extent of Māori and Pacific influence over the rheumatic fever system is constrained.

Despite the best efforts of people over the years, the extent of Māori and Pacific influence over the system is less than is needed. Many decisions appear to be made without input and influence from these communities, and without consideration of the cultural context and belief systems that these communities operate within.



Emerging opportunity areas



The earlier summarised report by the Office of the Prime Minister's Chief Science Advisor identified several opportunity areas based on the existing research and documented knowledge about rheumatic fever.

The co-design initiative has intentionally sought to connect into knowledge bases that don't frequently feature in research; that is, understanding the cultural context in which families make decisions and experience the rheumatic fever prevention and management system so we can identify **how** to do things differently.

We have identified several opportunity areas as the culmination of our discovery phase. Based on the work to date, our view is that each of these opportunity areas has a point of difference to things that have been implemented before and has the potential to positively impact the experience and outcomes for Māori, Samoan and Tongan families.

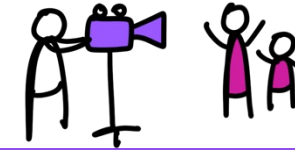
In Phase 2, we will work with communities and stakeholders to explore these further. We will develop and test specific concepts and assess the evidence that they make a difference to the experience for families.



Opportunity #1 Leveraging community-led protective factors

Specific elements of this can include:

- Growing awareness, connection and protection via sharing of **karakia**.
- Providing safe spaces for families impacted by rheumatic fever to process and **heal** from their journey.
- Families supporting other families (**peer-to-peer**) with a tailored approach to different sub-groups (gender, age, role in family)
- Building **hauora tikanga** and health confidence from a young age. Normalising a positive outlook on being healthy.
- Supporting the use of **cultural capital** as a protective factor.
- Support schools/churches/marae to be protective **hubs**.



Opportunity #2 Taking a culturally affirming approach to health communications

Specific elements of this can include:

- Aligning the storytelling with **cultural narratives**.
- Taking a **strengths-based approach** that pushes back against the deficit language of 'poverty', etc. Align with family aspirations.
- Communicate via the **channels** where people are (e.g. churches, marae, schools, Tongan radio, Māori TV, etc.).
- Designed first in **Te Reo Māori and Samoan and Tongan language**, with culturally appropriate and understandable terminology and tone of voice.



Opportunity #3

A health journey model of care that affirms cultural ways of being

Specific elements of this can include:

- Taking steps to allow people's **mauri to settle** during clinical interactions.
- Creating space for the **whole family** to contribute to the health journey, and catering for changing dynamics (e.g. transition from child service to adult service).
- Focus on **relationships**, whanaungatanga and va.
- Enabling tino rangitiratanga (for Māori) and equity and self-determination for all through **choice and control**.
- Reducing **barriers to access** for both the prevention (incl. treatment of Strep A infections) and the management (incl. prophylaxis treatment) of rheumatic fever.
- Creating 'and-and' approaches where **traditional healing practices** can exist alongside Western medical practices.
- Providing **continuity of care** and culturally-affirming care from frontline health practitioners.

Opportunity #4

A rheumatic fever system that sustainably affirms cultural ways of being

Specific elements of this can include:

- Enabling and allowing **Māori/Pacific leaders and communities** to influence the design of the system.
- Develop **empathy experiences** for people working within the system that illuminate the importance of the system affirming cultural ways of being.
- Invest in **leadership/career pathways** for Māori/Pacific people.
- Lift **cultural capability** right across the system.

