

Rheumatic Fever Co-Design Initiative | Update (31 July 2022)

INITIATIVE INTENT

Co-design with communities and other system stakeholders to identify and embed innovative and sustainable system improvements to prevent and manage rheumatic fever for Māori, Samoan and Tongan people in Tāmaki Makaurau.

WHAT HAVE WE DONE?

Phase 1: System Discovery and Opportunity Exploration

1 Nov 2020 – 31 Dec 2021

Established 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.

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



We formed three ethnic-specific design teams to develop and lead culturally-specific ways of approaching this work.

We established ongoing relationships with whānau/families to understand their experiences of rheumatic fever and to build engagement going forward.

We engaged with people across the sector to understand the current landscape of rheumatic fever and to identify opportunities for collaboration.

Within the opportunity areas, we're identifying new approaches and concepts and are testing elements of these with families and stakeholders.



Phase 2: Learning and Prototype Development

1 Jan 2022 – 30 Jun 2022

From the insights and opportunity areas surfaced during Phase 1, we framed possible areas of intervention (i.e. opportunities). We've tested the thinking with families/stakeholders/contributors to clearly identify the elements and attributes of a solution that make a positive difference for families/communities. In other words, we defined what 'excellent' looks like and began building a qualitative evidence base of the impact of the potential solution.

Identified systemic and experiential insights and opportunity areas to affirm cultural ways of being.

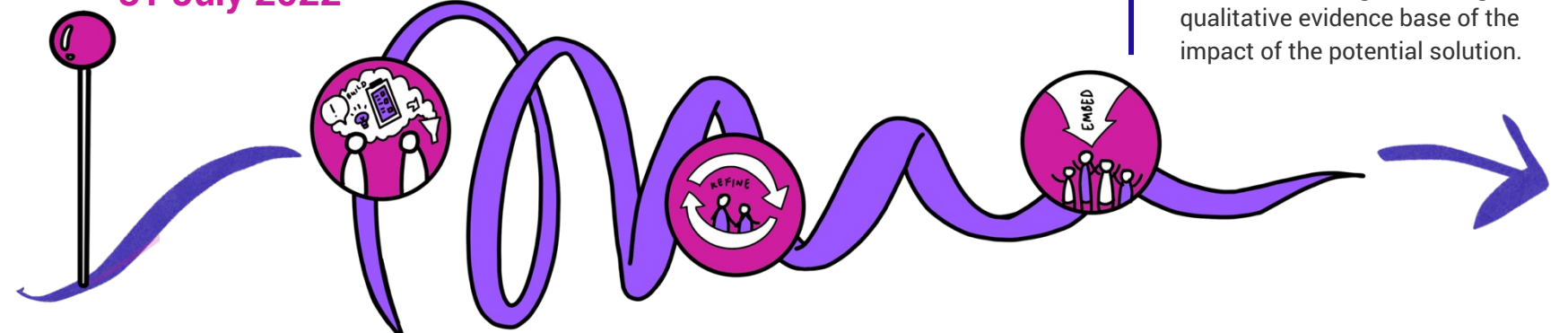
WHAT HAPPENS NEXT?

31 July 2022

Phase 3: Embedding System Changes and Evaluation

1 July 2022 – 31 July 2023

Phase 3 is about finding ways to successfully embed and scale (in part) what we have learned about what 'excellent' looks like. We will work with stakeholders to understand the barriers to embedding/scaling, and to identify and test possible solutions to those barriers. This is about moving from a view of what 'excellent' looks like to demonstrating how it can be delivered in practice.



We will reflect on the learning from Phase 2 to identify high potential concepts that have supporting qualitative evidence.

We will continue to test elements of the concepts with stakeholders, with a focus on overcoming barriers to implementation.

We will reflect on what has been learned in Phase 3 and will identify what is needed to ensure sustainability.

What do we mean by...

'Prototype'?

Prototypes are small-scale concepts that we can use to test ideas for solutions in a low-risk, low-cost way before we invest too much time in developing full solutions.

A prototype is not a pilot of an entire programme. A prototype will typically focus on testing specific critical elements so we can rapidly receive feedback about whether the concept actually has the potential to make a difference, and have a short feedback loop.

'Qualitative evaluation'?

We are taking a developmental evaluation approach because this method is well-matched to reflecting, monitoring and evaluating complex environments such as the rheumatic fever system. This evaluation approach is iterative; it prioritises active learning and engaging early to understand how the innovation and its context is interacting over time.

Phase 1 (Discovery)

INSIGHTS

What we learned (at a high-level) from the three communities we engaged with during Phase 1:



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



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



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



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



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



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



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



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



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.



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



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



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

OPPORTUNITIES

Areas that we identified for exploration in Phase 2:



OPPORTUNITY #1

Leveraging community-led protective factors

This is about creating safe spaces and building support for families to learn about, share, and heal from their rheumatic fever experiences. This might take the form of karakia, peer-to-peer networks, supporting the use of cultural capital as a protective factor or building upon existing hubs like schools, churches or marae to become protective hubs for families.

OPPORTUNITY #2

Taking a culturally affirming approach to health communications

Designing health communications from a Māori, Samoan and Tongan perspective and that connect with traditional narratives and cultural beliefs. This includes using channels that communities use (e.g. Tongan radio) and taking a strength-based approach to counter the dominant deficit narrative painted about families.

OPPORTUNITY #3

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

Creating opportunities for culture to co-exist within the Western health system. This includes taking steps to settle mauri during clinical interactions, shifting to a family-oriented view of the health journey, enabling tino rangatiratanga through offering more choice and control, enabling a space for traditional healing practices and providing continuity of care to work via relationships.

OPPORTUNITY #4

A rheumatic fever system that sustainably affirms cultural ways of being

Finding ways for Māori and Pacific leaders to influence the design of the system, showcasing the stories of people in the system that illuminate the importance of cultural ways of being in the system, investing in leadership pathways for Māori and Pacific people, and lifting cultural capability across the system.

Phase 2 (Prototype Development)

INTRODUCTION

During Phase 2, the design teams took the high-level opportunity areas that emerged in Phase 1 and explored these more deeply with families, communities, and stakeholders via conversations and workshops. We were looking to uncover the specific actions, interventions, or concepts that might make a significant and positive difference to families.

The next two pages summarise the key learnings and next steps for each of the opportunity areas that the design teams identified during Phase 1.

During Phase 3 we are looking to widen the reach and deepen the impact of these initiatives. In some cases, this means delivering a specific project. In others, it means continuing to co-create and support collective action. It also means co-creating with stakeholders from right across the rheumatic fever prevention and management system to identify how we can successfully embed, scale and sustain these initiatives. We are also working with evaluation partners to consider the wider impacts of the initiatives, with an evaluation report to be prepared at the end of Phase 3.

Our goal for the end of the contracted period (30 June 2023) is for the rheumatic fever prevention and management system to be continually evolving and learning how to create safe, inclusive and culturally responsive experiences that ultimately reduce the rates of rheumatic fever.

DECIDING WHERE TO FOCUS

The opportunities identified in Phase 1 were inspired by hundreds of conversations. During Phase 2, we tested our thinking further through hundreds more. Two main principles guided our decisions about where to focus our efforts, energy and resources during Phase 3:

1. *Where is there energy from communities and stakeholders?* Go with what feels right and impactful to people.
2. *What is not already happening?* If there is already work happening, then we're best to support that work rather than doing something that might be a duplication.

TE TIMA MĀORI

3 core exploratory areas:



- 1 **Te Kura ā Rongo.** Mahi toi and karakia that is a repository of knowledge to support intergenerational dissemination of knowledge to and from whānau.

LEARNING:

- Tikanga keeps us all safe: Māori and non-Māori.
- This mahi toi acts as a repository of knowledge that will carry knowledge through generations as this piece is kept within whānau and handed down.
- Having the ability to open source this karakia has been important.

NEXT STEPS:

- Gifting to a wider group of whānau and stakeholders.
- Wider socialization of Te Kura ā Rongo to achieve wide uptake and regular use.
- Seek opportunities for Te Kura ā Rongo to protect and uplift other mahi (e.g. Rheumatic Fever Action Plan / Roadmap).



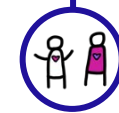
- 2 **Kōrero Whakamana: there is power in words.** Language guidelines to support key stakeholders across the system to eradicate language that doesn't serve Māori.

LEARNING:

- The language guidelines show manaakitanga to whānau by highlighting kōrero that doesn't serve Māori.
- Whānau turn off when they hear jargon; it takes away their ability to feel included and belong, as well as the opportunity for learning and sharing.

NEXT STEPS:

- Finalise and disseminate guidelines to key stakeholders.
- Work with Māori media to embed in their criteria and storytelling processes.



- 3 **Video resources created for Māori by Māori** that create connections and tell better stories that resonate with whānau as aspirational and mana-enhancing.

LEARNING:

- Current videos are not targeted at whānau and don't resonate.
- Ideally, videos show emotion and help whānau overcome barriers. Show Māori who are happy and strong.
- Cartoon videos are best for kids. For adults, documentary-style featuring actual whānau is best.

NEXT STEPS:

- Work with Te Whatu Ora, Pū Manawa, schools, Māori media agencies and whānau to develop and embed videos.

Please refer to Te Tima Māori Phase 2 report for full details.

Additional areas of interest:



- 4 **Increased cultural capability.** Investment into the attraction and retention of Māori practitioners and building of the cultural capability of funders, commissioners and deliverers.

LEARNING:

- Cultural capability is something that should be part of everything, not just a 'training' element. This is done by leading with tikanga and creating space for people to engage.
- The karakia creates opportunities for conversations that build cultural capability.

NEXT STEPS:

- Wrap capability component around all activities with Opp. 1, 2 & 3.



- 5 **Whakatau Wairua** through whanaungatanga and tino rangatiratanga. Creating settling experiences for tamariki / rangatahi by ensuring that tikanga is being followed.

LEARNING:

- Giving whānau choice is a way they can assert tino rangatiratanga.
- Te Kura ā Rongo provides a tikanga-based way to whakatau wairua.
- There are opportunities via other initiatives (e.g. RF register, clinical guidelines) to encourage changes in clinical practice.

NEXT STEPS:

- Support the development of the RF register and identify ways that whānau can be given choice and control over their RF experience.
- Input to clinical guidelines workstream to ensure that opportunities to whakatau wairua are maximised.



- 6 **Strengthening foundations:** unlocking the potential of kura / schools to play a key role of leveraging what is already being done in some places.



- 7 **Community hubs** via schools / kura to cater to those not connected to iwi / marae in Tāmaki.

LEARNING:

- These areas are covered in part by other initiatives. The role we can play is bringing together a broad of people to identify and act on new opportunities to support and amplify.

NEXT STEPS:

- Continue seeking opportunities to connect Māori and non-Māori who are operating in different parts of the system.

Phase 2 (Prototype Development)

LOMIPEAU

Please refer to Lomipeau Phase 2 report for full details.

3 core exploratory areas:



- 1** How might we develop experiences that **enable healing from family trauma** developed through previous RF/RHD experiences, so that families can determine their own journey and can support others? E.g. Peer-to-peer networks (Tongans supporting Tongans).

LEARNING:

- Tongan young people want safe spaces that foster peer-to-peer connections around rheumatic fever, to support healing and to allow autonomy to lead a health life.
- Build rheumatic fever understanding into other activities so it doesn't feel too heavy. Have an informality to it.
- Involve clinicians who can connect with young people and make the messages simple without dumbing it down.
- Include a wider range of cultures as many young people are mixed ethnicity.
- Kāinga Tonga are living in conditions where they can only focus on the day-to-day and have limited bandwidth to make choices that affect their long-term realities.

NEXT STEPS:

- Extend informal peer groups and explore ways to sustain these and remove system barriers that limit commitment and consistency in service delivery.
- Aligning with health providers that are running peer groups for young people to leverage the learning and better cater for Tongan youth.



- 2** How might we develop a **Tongan understanding of RF/RHD** and communicate in ways that are consistent with this understanding? E.g. Health communications that resonate with Tongans and are accessible.

LEARNING:

- Negative experiences and the siloed nature of services makes it hard for Tongan families to access information / support.
- The conventional 'mofi hui' name for rheumatic fever is misleading; 'mofi lumetika' resonates better with families.
- Medical practitioners need to be relatable and health information needs to be easy to understand.
- Apps can be short term solutions but there needs to be more efforts made in terms of offline experience. E.g. there is a preference to have reminders conducted in person in order to tauhi or nurture the vā between kāinga and practitioner.

NEXT STEPS:

- Addressing the siloed nature of health and social services through tauhi vā māfana that enables folau tau'atāina.
- Surfacing and embedding insights about information flow (offline and online).
- Feeding online aspects into relevant existing workstreams (e.g. Fight the Fever app, RF 'register'), etc.



- 3** How might we develop a model of care and **healthcare journey that reflects our Tongan communities?** E.g. Tongan-youth-specific models of care that cater for the whole family.

LEARNING:

- A family-centric approach is needed, not an individualistic one.
- Families are looking for a wider network of support from health to social services under one roof.
- Health professionals need to genuinely understand Pacific ways of being to provide cultural safety for all.
- An integrated approach to service and funding is needed to address siloed approaches and funding barriers.

NEXT STEPS:

- Running alongside the peer-to-peer service pilot.
- Creating connections with Tongan clinicians and experts.
- Co-design with kāinga and stakeholders the key components of health communications and 'virtual hub' models.

SAMOA TEAM

Please refer to Samoa Team Phase 2 report for full details.

6 core exploratory areas:



- 1** **Myth busting** (working title). Development of rheumatic fever prevention messages that resonate with Samoan people's values, beliefs and lived realities.

LEARNING:

- Samoan families identified a lack of clear and simple communication of the very basics of rheumatic fever.
- When given the opportunity, families 'translated' clinical jargon into simple everyday concepts and messages for each other.

NEXT STEPS:

- Feature refinement with community.
- Identifying testing opportunities by connecting with other work.



- 2** **Let's talk rheumatic** (working title). Proof of concept that an entirely different approach to communications is required (e.g. social media, story telling instead of facts, etc.).

LEARNING:

- Young Samoans do not ask questions or even complain.
- Fact-based, health-focussed information that is out there is not relevant to everyday realities of young people.
- Several organisations are operating in this space; we want to align.

NEXT STEPS:

- Develop requirements brief.
- MVP content.
- Evaluation to understand experience and impact of communications.



- 3** **The Fa'asamoa way** (working title). Capability framework that can be used by stakeholders when working with Samoan people.

LEARNING:

- Inequities for Samoans within wider health system play out in the rheumatic fever system.
- Families feel alienated from decision-making.
- Most service / care providers have little knowledge of what matters for Samoans.

NEXT STEPS:

- Develop capability framework (MVP).
- Partner with key community / system stakeholders to propagate framework.



- 4** **Delivering better quality primary care** through supporting tools, capability build modules, and use of quality improvement mechanisms to embed best practice.

LEARNING:

- Professionals identified limited understanding of the Samoan holistic system of wellbeing.
- Primary care best practice guidelines are not always accessed or adhered to.

NEXT STEPS:

- Develop and test MVP of capability building module.
- Mapping quality improvement mechanisms.



- 5** **Mapping the rheumatic fever system for a locality.** Testing that a more intentional focus on data will provide insight into where system intervention is necessary and impactful.

LEARNING:

- The health and social system is fragmented.
- Data is held in different places by different agencies for different purposes, creating an incomplete picture of what the system is delivering, its impact, and its return on investment.

NEXT STEPS:

- Align with a locality prototype (Ōtara-Papatoetoe).
- Leverage existing systems mapping and overlay rheumatic fever lens.



- 6** **Pharmacy-based rheumatic fever prevention.** Pharmacy-based sore-throat management and rheumatic fever prevention model.

LEARNING:

- Following the COVID-19 vaccination programme, communities are increasingly using pharmacies as 'go-to' places for basic diagnosis and preventative actions.
- Visiting a GP can be a barrier to getting strep throat diagnosed.

NEXT STEPS:

- Learn from pharmacy-based model in Te Taai Tokerau.
- Identify partner pharmacies to test the model.