



Rheumatic Fever Co-design Initiative: Tāmaki Makaurau, 2020–2023

Reflections on the initiative



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Acknowledgements

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

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

We acknowledge the families that have been impacted by rheumatic fever, and we acknowledge those who are no longer with us as a result of rheumatic fever.

We acknowledge the work of those who have preceded this initiative and whose work we have built upon, and we acknowledge the work that continues today to bring light to the darkness of rheumatic fever.

We acknowledge the hundreds of people who have generously contributed to and championed this initiative. This included families, communities, community leaders, health professionals, system stakeholders and, of course, the three design teams: Te Tima Māori, Samoa Team, and Lomipeau. And finally, we acknowledge Te Whatu Ora who have shown courage, conviction and resolve to support a power-sharing approach.

Introduction

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 pūkawatia 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
 Internalize it, externalize 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!

E ngā mana, e ngā reo, e rau rangatira mā. Tēnā koutou, tēnā koutou, tēnā koutou katoa.

The karakia above, named Te Kura ā Rongo and created by Te Amohanga Rangihau specifically for this kaupapa, signals hope for the future and an intention of a new reality. It is an honour to be able to recite this karakia at the commencement of this report.

The three design teams (Te Tima Māori, Samoa Team, and Lomipeau) have each created a final report. These reports speak to what has been achieved from the perspectives of the teams, expressed in their own words and focusing on what has mattered most to them and their communities as they have gone about their work.

In addition, Dovetail (and partners) have undertaken a developmental evaluation process and have created an evaluation report. The report you are now reading is not intended to replace, supersede or override any of these reports. It is intended to supplement these reports by providing reflections from the perspective of ThinkPlace, who were the overall contract holder to deliver this initiative and who have worked in partnership with the three design teams and Te Whatu Ora.

To write a report that reflects on this unique initiative comes with a weight of responsibility that is not held lightly. The initiative was defined by a genuine intent to shift power to Māori, Samoan and Tongan communities and the practical expression of that intent. The approach taken by each of the teams has clearly been authentic and true to each cultural context, as evidenced by the depth of insights, the quality of engagement, the uptake of the prototypes, and the overwhelming desire of people to be part of the movement.

We are proud to have played a role in this initiative and are humbled to have been trusted with that responsibility. We wish to celebrate what has been achieved by each of the three design teams—they have gifted so much of themselves to this initiative in the interests of improving outcomes for Māori, Samoans and Tongans.

We know there is still much to do in the collective effort to free Aotearoa New Zealand from the impacts of rheumatic fever, but we are confident that the foundations have been significantly strengthened by this initiative.

Thank you for taking the time to read this report.

Ngā mihi nui

The ThinkPlace Project Team

Background and process

Causes of Rheumatic Fever

Group A streptococcus (Strep A) is a bacterium that can cause infections in the throat (strep throat) and the skin (impetigo, cellulitis). Strep A infections are contagious and can be spread by coughing and sneezing or sharing food or drinks. Fortunately, the low-cost antibiotic penicillin is still very effective at killing strep infections.

Scientists believe that Acute Rheumatic Fever (rheumatic fever) happens because our immune system gets “tricked” by the bacteria. This sets off an inflammatory process that can cause sore and 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.

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 A infection, some 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 the full 10 day course can reduce the risk.

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

Context for the Co-Design Initiative

Significant effort has been made over many years to improve rheumatic fever outcomes in Aotearoa New Zealand. Despite the gains that have been made, rheumatic fever persists at unacceptably high rates. Rheumatic fever disproportionately impacts Māori and Pacific Peoples.

In 2018, a series of engagements with stakeholders from across the rheumatic fever system identified the need for community-led solutions. In 2019, a budget bid was approved as part of Budget 19 and additional funding was allocated to:

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

In 2020, the Ministry of Health undertook a procurement process and appointed ThinkPlace and partners to deliver the co-design initiative. The initiative commenced in November 2020.

Intent of the Initiative

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.



The visual identity we've used in this document references the many hands involved in the Rheumatic Fever Co-design Initiative. The design teams described their relationship as being separate but together—much like the fingers of a hand. Each team worked in the context of their own communities, but learned from each other while working toward the same overall goal.

Phases of the initiative

The initiative was undertaken in four distinct phases:

- Phase 1: System Discovery and Opportunity Exploration
- Phase 2: Learning and Prototype Development
- Phase 3: Embedding System Changes and Evaluation
- Phase 4: Reflection and Reporting.

The duration, intent and activities of each phase are summarised on this page and the next.



Reflections on what we have collectively learned (**how** the work was undertaken) are included in the later section titled 'Reflections on the approach'. The remainder of this section of this report summarises the insights, opportunities and prototypes that emerged (**what** we did).



Phase 1: System Discovery and Opportunity Exploration

1 November 2020 – 31 December 2021

- We established the foundational values and ways of working for this initiative so that safe places were created for whānau/families and communities to engage and share their experiences, beliefs and aspirations.
- We engaged with people across the sector to understand the current landscape of rheumatic fever and to identify opportunities for collaboration.
- We formed three ethnic-specific design teams (Māori, Samoan and Tongan) to develop and lead culturally-specific ways of approaching this work.
- We established ongoing relationships with whānau/families that were built on trust and respect.
- We spent time with whānau/families to understand their experiences of rheumatic fever prevention and management, and to understand their hopes and aspirations for the future.

Phase 2: Learning and Prototype Development

1 January 2022 – 30 June 2022

- From the insights and opportunity areas surfaced during Phase 1, we identified possible areas of intervention (i.e. opportunities) that are 'new to the system'.
- We tested our thinking with families, health professionals, and other stakeholders to uncover the specific actions, interventions, or concepts that might make a significant and positive difference to whānau/families.
- We identified the attributes of those solutions that are most critical for ensuring they achieve their intended purpose.
- We defined what 'excellent' looks like from the perspective of whānau/families and began building a qualitative evidence base of the likely impact of the potential solutions.

Phase 3: Embedding System Changes and Evaluation

1 July 2022–30 June 2023

- We reflected on the learning from Phase 2 to identify high-potential concepts that have supporting qualitative evidence of potential impact.
- We iteratively tested elements of the concepts with stakeholders to progressively arrive at a refined solution. We had a focus on overcoming barriers to implementation and ensuring maximum uptake.
- We determined pathways to scaling 'excellence' and determined the key champions from across the system to support this embedding and scaling.
- We worked with the champions to understand how we could overcome barriers, moving from a view of what 'excellent' looks like to demonstrating how it can be delivered in practice.

Phase 4: Reflection and Reporting

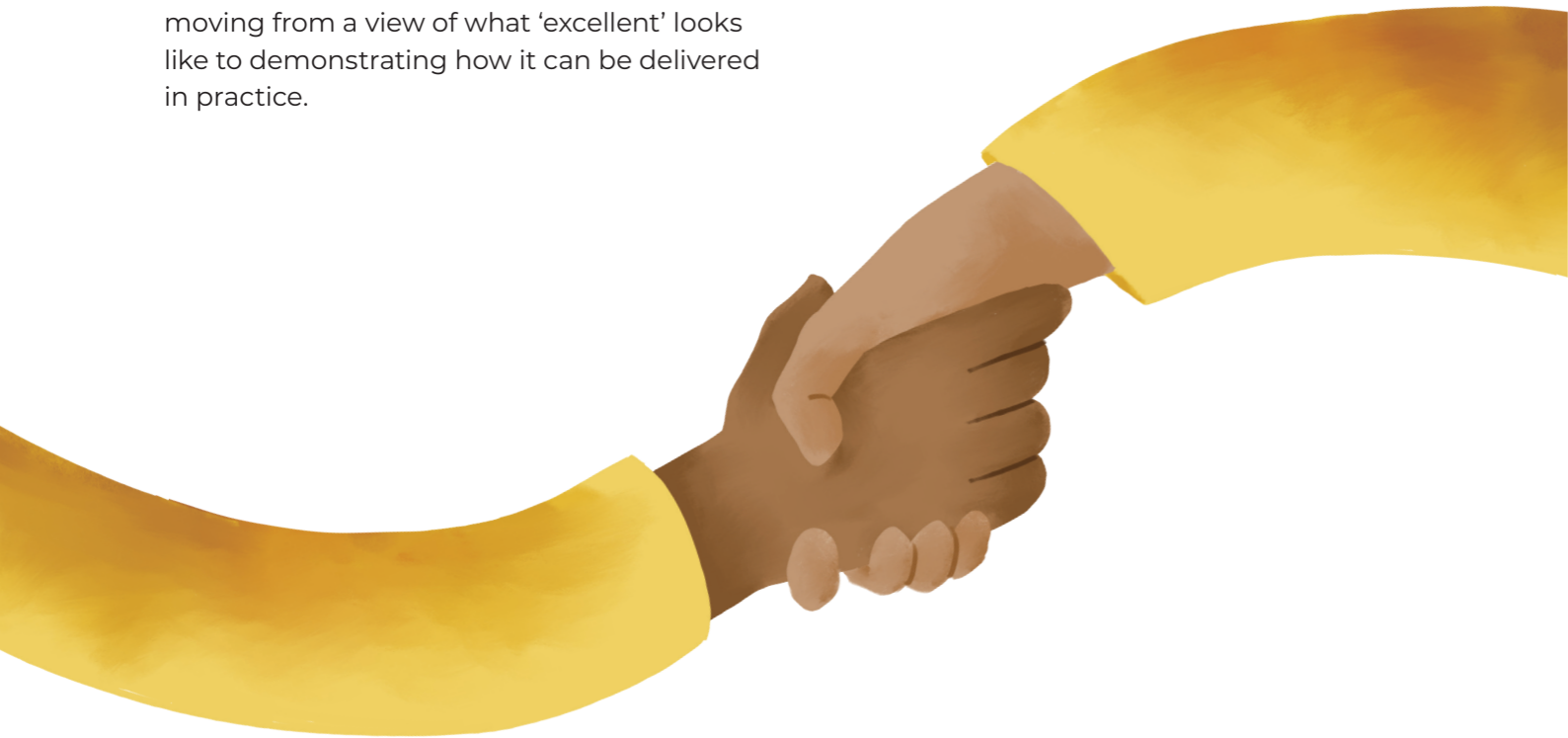
1 July 2023–31 December 2023

- We reflected on what has been learned in Phase 3 and identified what is needed to ensure sustainability.
- We created our final reports for each team, as well as the evaluation, exploring and documenting what we had learned across the previous three phases.
- We ensured the champions had the resources they needed to extend the work.
- We acknowledged the contributions of whānau/families and stakeholders who had contributed to the process for each team.

Insights Summary (Phase 1)

During Phase 1, each team surfaced a range of insights from their discovery activities that involved families, community members, health practitioners, and other stakeholders. The following 13 high-level insights were summarised based on those inputs. For more detailed and ethnic-specific insights, including the cultural context in which they are contained, please refer to the individual team reports.

1. Māori, Samoan and Tongan ways of being, thinking and acting are not affirmed by the rheumatic fever prevention and management system.
2. The language of rheumatic fever perpetuates negative stereotypes and is disconnected from family aspirations.
3. When an individual experiences rheumatic fever, it affects the whole family.
4. Children and young people who have been diagnosed with rheumatic fever frequently experience shame and embarrassment.
5. Families who have experienced rheumatic fever have found the journey to be traumatic, confusing and disempowering, and have expended a lot of emotional energy.
6. Family members of a child diagnosed with rheumatic fever frequently feel shame and guilt and think they were responsible for the disease.
7. The language and stories of rheumatic fever hold little relevance for families because they are disconnected from traditional narratives, language and beliefs.
8. The relationship between family members and the health practitioners is critical and can set the tone, positively or negatively, for what follows.
9. 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.
10. The best information people often get is from other families who have had similar experiences.
11. 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.
12. Despite insitutional barriers, Māori and Pacific practitioners are doing what is required to support their communities but the work is tiring.
13. For a disease that disproportionately impacts Māori and Pacific people, the extent of Māori and Pacific influence over the rheumatic fever system is constrained.



Opportunity Identification (Phase 1)

To close out Phase 1, we identified several areas of opportunity that were linked to the insights. Each of these opportunity areas have a point of difference to things that have been implemented previously, creating the potential for them to positively impact the experience and outcomes for Māori, Samoan and Tongan 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 and 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 rangatiratanga for Māori and equity and self-determination for all through **choice and control**.
- Reducing **barriers to access** for both the prevention (including treatment of Strep A infections) and the management (including 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 and 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 and career pathways** for Māori and Pacific people.
- Lift **cultural capability** right across the system.



What each team created

Prototype development (Phases 2 and 3)

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:

- Where is there energy from communities and stakeholders? We wanted to go with what feels right and was impactful to people.
- 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.

This section summarises the core prototypes that each team created, tested and began the process of embedding. The descriptions draw from each team's final report and more detail is contained in these reports.



Te Tīma Māori

Te Tīma Māori developed three core prototypes that are grounded in tikanga.

Te Kura ā Rongo

The karakia (named 'Te kura ā Rongo', and used to open this report) was an emergent prototype that was developed in response to the sacredness of the stories that were shared with the team by whānau. The team needed protection of these stories; for whānau who were sharing the stories with the team, and for the team members who were hearing the stories.

The karakia was written specifically for this kaupapa by Te Amohanga Rangihau, a member of Te Tīma Māori, and was relied upon for everything that Te Tīma Māori did. As the work continued, the team saw the potential for the karakia to be a form of koha to whānau and professionals that they engaged with. It was then that Graham Tipene and Jono Cole, further members of Te Tīma Māori, designed a mahi toi (Māori art) to sit alongside the karakia so that, together, they could be framed and provided as koha.

From this, the team then saw the potential for the karakia to offer protection of the stories and people more widely across the rheumatic fever prevention and management system. The karakia was gifted to Te Whatu Ora for inclusion in the Rheumatic Fever Roadmap (2023–2028) and a framed copy was gifted to the Associate Minister of Health. It was also relied upon to open and close the kiriata (videos) created in the next prototype.

The team's aspiration is that the karakia will continue to be used by whānau, clinicians and other stakeholders into the future, helping to place tikanga at the heart of how we engage with each other. The prototype highlighted the benefits and importance of valuing tikanga to ensure people are supported and protected

through design processes and health service provision. It also highlighted how solutions to challenges experienced by Māori exist within Te Ao Māori.

Ko tō Manawa, ko tōku Manawa

The series of three kiriata/videos (named 'Ko tō Manawa, ko tōku manawa', which translates to 'your heart, my heart') were created specifically for tamariki Māori by acclaimed Māori production agency, Long White Cloud Productions.

The kiriata are centred around the whakapapa pūrākau of Papatūānuku and Ranginui and how their tamariki brought light to a world of darkness. This is a metaphor for how tamariki can do the same with rheumatic fever. The kiriata are filled with Te Reo Māori, karakia, waiata and positive messaging that equips tamariki and their whānau with the knowledge they need to be safe from rheumatic fever.

The team wanted to harness the power of storytelling because this is what feels natural to Māori and is how knowledge is shared between generations. Whānau are familiar with traditional cultural narratives and find them interesting, and they hold true over many generations.

The team identified an opportunity to design the videos for tamariki under the age of 5 years old. While it is rare for tamariki this young to experience rheumatic fever, it is the age where they are most open and can be positively influenced. The team wanted to get the stories and the knowledge into the minds, hearts and mouths of young tamariki to start the process of generational change.

Te Tīma Māori are grateful to have had the support of Toi Tangata and the Kohanga Reo National Trust who are using the kiriata as a resource for their tamariki. It is through organisations like this that real change that benefits Māori can occur.

The aspiration of the team is for others across the system to use the kiriata in similar ways. The prototype also provides inspiration to those in the health and social sectors who are communicating with whānau Māori; this is what communication can look like when Māori develop the resources from start to finish.

Kōrero Whakamana

The language guidelines are a resource for media and health professionals to support them to talk to whānau Māori about rheumatic fever in a mana-enhancing way. It provides practical alternatives to the negative words and phrases currently used so that we can remove the stigma around rheumatic fever.

When talking with whānau and Māori health professionals, the team heard that language typically used by media and health professionals had a strong bearing on how whānau felt about themselves. Commonly-used language includes things like 'a third world condition', 'a condition of poverty', and 'a Māori condition'.

The team identified that this language implies that rheumatic fever is an immovable part of life for whānau and there is nothing they can do to escape it or change things. The team saw an opportunity to support whānau to dream of a future without rheumatic fever, and different language is needed to support that.

The team created a simple flow chart (the language guidelines) that shows people what alternative language choices are that uplift whānau. They also identified that a critical stakeholder was media; media hold mana and are often seen by whānau as trustworthy or experts. So the team prioritised the places speaking directly to whānau Māori, and that is Māori media.

The aspiration of Te Tīma Māori is that this insight and tool will be used by media, clinicians, policy makers, and others. That they will change the language they use and help whānau Māori experience less shame about how they are spoken to.

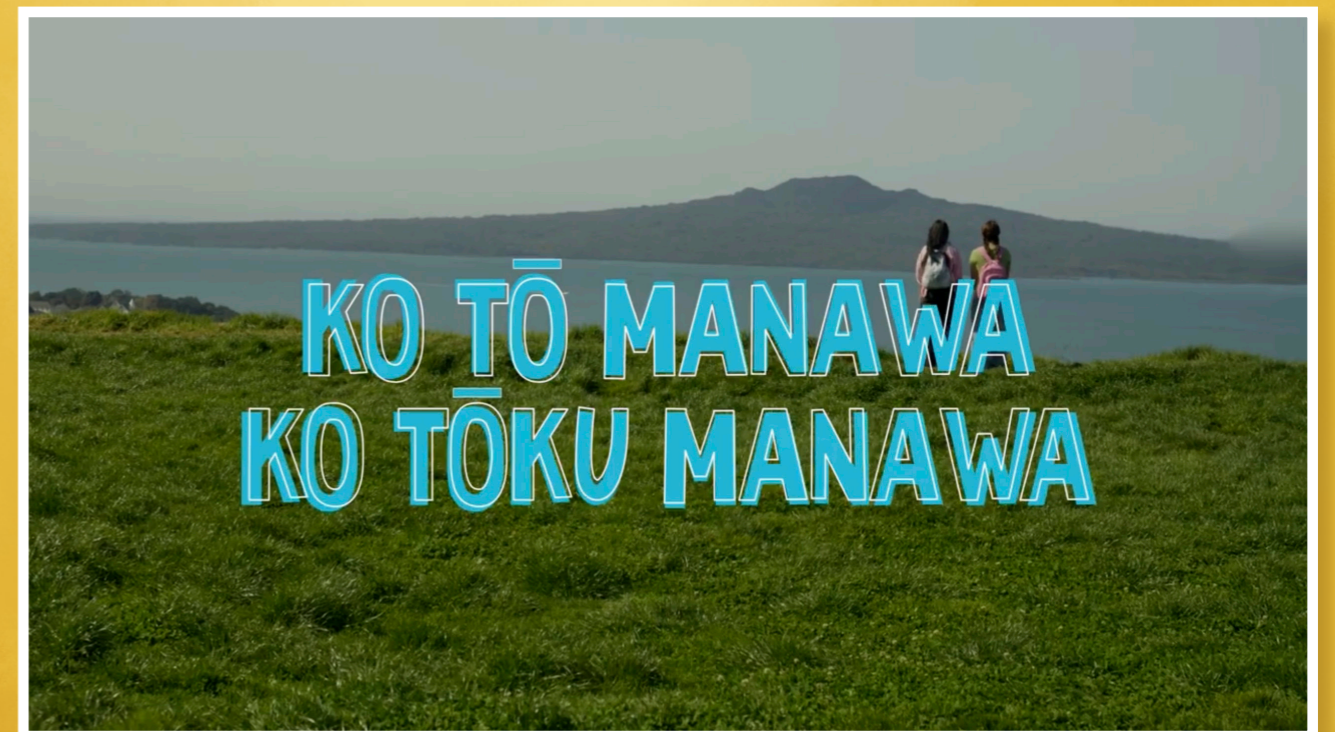
Opposite page, top right: Te Kura ā Rongo, written by Te Amohanga Rangihau. Mahi toi (artwork) by Graham Tipene and Jono Cole.

Opposite page, bottom right: Still from title sequence of kiritia (video) 1, *Ko tō Manawa, Ko tōku Manawa*, by Long White Cloud Productions.

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!



Team Samoa

The Samoa Team's approach was based on a foundation of 'E ui ina sui faiga, ae tumau pea fa'avae | Though the approaches may change, the foundations remain the same'. A key part of the team's approach was the intentional leveraging of Samoan relational capital to enable and empower 'extension partners' (people who are able to champion particular prototypes) who played a critical role in designing, testing, iterating and embedding the prototypes.

The team developed six core prototypes.

Soālaupule Family Meeting Guide

The Soālaupule Family Meeting Guide is a tool designed for health practitioners who need stronger communication and better engagement with patients to ensure they have better healthcare.

Families told the Samoa team they didn't know or understand what rheumatic fever is even after being diagnosed. Their healthcare experiences do not affirm Samoan values and ways of relating. Meanwhile, healthcare workers told the team that they need help to better communicate and engage with Samoan patients particularly regarding their diagnosis and its severity. They see the challenges that families experience but lack the confidence and know-how to respond.

The guide outlines an inclusive decision making process between patients and their families with health professionals. From beginning to end of the Soālaupule meeting process, the Fa'asamoa way of doing things is applied and power dynamics are shared. The guide applies values like *ava fatafata* (mutual respect), *fa'aaloalo* (respect), *fa'amaoni* (faithfulness) and *alofa* (love), alongside clinical best practice.

Soālaupule provides a foundation for non-Samoan health professionals to improve their healthcare practice. The guide complements clinical best practice. The tools are being further

developed and made available through the Goodfellow Unit. This prototype has practically demonstrated how clinicians can balance the power in clinical interactions.

Soālaupule Capability Building Workshop

The Soālaupule Capability Building Workshop is a learning and development module for health professionals that explains and demonstrates the value of applying Samoan principles of dialogue, consensus building, and power sharing, through the application of Soālaupule in health. It is particularly helpful in decision making, resource allocation, and engaging families in determining appropriate support and care for families with rheumatic fever.

Families told the team that their healthcare experiences do not affirm Samoan values and ways of relating. The team heard that non-Samoan health professionals find it challenging to traverse the complexities of Samoan families' social, spiritual, political, and cultural values. They also lack understanding of how these values influence family health decisions and frame their understanding of quality healthcare.

After a period of exploration, development and testing, the team agreed with co-design participants on a capability building module for non-Samoan clinicians, based on Soālaupule. The team created and socialised a Soālaupule learning guide with organisations that have an interest in workforce capability.

The team have worked with several organisations to roll tools out through their networks (e.g. the Goodfellow Unit, Pasifika GP Network, Pasifika Chapter of the Royal New Zealand College of GPs, etc.). Several other organisations have already aligned their practice with Soālaupule.

The development of the Soālaupule Capability Building module becomes a model for how ethnic-specific and culturally competent training of the health workforce can happen in ways that immediately increase the capability of the workforce.

Rheumatic Fever Infographic and Glossary

The glossary prototype was inspired by insights and discussions with Samoan families dealing with rheumatic fever. Even after experiencing rheumatic fever / rheumatic heart disease, many families did not know what rheumatic fever is or how it came to be in their family. Specifically, they did not understand the terms and words used to describe rheumatic fever symptoms and treatment by health professionals. One of the key issues amongst Samoan people was that they could not connect a sore throat to a potentially damaged heart.

The glossary is a bilingual visual tool for Samoan and non-Samoan clinicians to have conversations about rheumatic fever with families in a way that Samoan families can understand. The resource has been represented and translated in a way that helps to bridge a language barrier between a Samoan patient and a clinician with little grasp of the Samoan language.

The infographic and glossary was prepared for a specific context: a child is experiencing a sore throat, and the family visits a GP. You can imagine how the infographic and glossary can be used by the GP in that situation to explain what is happening in a way that supports understanding for the family. It visually explains the impacts of strep throat and rheumatic fever on the heart and also describes the journey of the strep throat bacteria.

In particular, the prototype demonstrates two things that are more widely applicable to rheumatic fever health communications with Samoan families:

1. How a clinical process can be explained visually.
2. How translations and consistent terminology can help explain medical terms.

The tool is being used by various stakeholders within role play settings and within their practice.

Youth 'Let's Talk Rheumatic' Information Event

This prototype trialled ways to raise awareness of rheumatic fever among Samoan youth. Instead of being targeted by a 'campaign', young people preferred to have the opportunity to share stories and experiences together as a group of young people, supported with pastoral care to create safety.

Messaging about rheumatic fever and rheumatic heart disease doesn't resonate with Samoan young people; Samoan young people told us they weren't receptive to the current information about rheumatic fever. As a result, young people have low awareness and understanding of rheumatic fever. This prototype aimed to specifically engage young people to attend information evenings that would be meaningful for them.

This prototype has implications for anyone who wants to work together with young people to engage and empower other youth to learn and take ownership of rheumatic fever prevention in the community. Samoan young people are often characterised as disinterested and 'hard to reach'. But when supported with adequate resources and safety, they were inspired to share important messages with their peers in a relatable and engaging way. This prototype is proof of concept

that by engaging youth in a supported manner, rather than running another campaign, puts them in control and enables community-led awareness raising of rheumatic fever.

Pharmacy Based Rheumatic Fever Prevention

The Samoa team supported the President of the Pacific Pharmacies Association to explore how pharmacies might play a strengthened role in community-based prevention and care of rheumatic fever. While this is not a new idea, the team were specifically looking at the application of the idea to a South Auckland context and how the approach could be community-led.

The working group developed a pilot concept for a pharmacy and community partnership to test pharmacy-based sore throat checks and prescription of antibiotics, as well as community-led communications and engagement.

It is not always easy or practical for families to access a doctor or health practitioner to get a sore throat checked for strep. The time and cost to see a doctor for a sore throat is a problem for many families. When families do not get a sore throat checked, it is a missed opportunity for prevention of rheumatic fever.

Pharmacies played a critical role in their local communities during the COVID-19 pandemic and Pacific community-led engagement and events were successful during the COVID-19 pandemic. This provided inspiration about how those successes could be leveraged for rheumatic fever prevention.

Through the co-design initiative, we explored with community in South Auckland the potential for a South Auckland pharmacy pilot and identified needs and conditions that will help it succeed.

Top right: An extract from the Glossary prototype.

Systems mapping for Le Afio'aga o Aotearoa (Ōtara-Papatoetoe Locality)

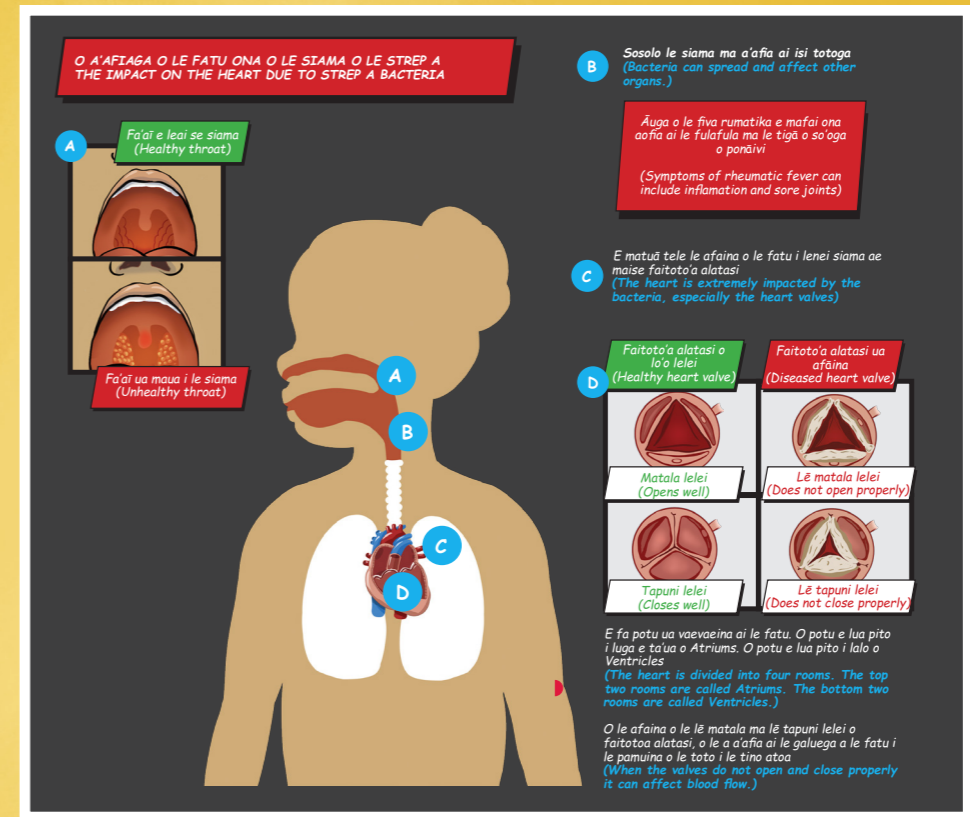
During the discovery phase, the Samoa Team learned that rheumatic fever data specifically related to Samoans is not readily available. Given the prevalence of data generally, it could be assumed that extracting Samoan-specific data would be straightforward and would provide new insights into the experiences of Samoan families.

The Samoa Team commissioned research experts, Pacific Perspectives Ltd. (led by Dr Debbie Ryan and Dr Gerard Sonder) to undertake further research and analysis that built on prior work that they had done with Le Afio'aga o Aotearoa (Ōtara-Papatoetoe Locality — refer to the Samoa Team report for details about the locality). Specifically, Dr Ryan and Dr Sonder focused on the implementation of rheumatic fever control in primary care at a locality level, that encompasses primordial, primary and secondary prevention.

Pacific Perspectives discovered that existing data about Samoans and rheumatic fever is fragmented, siloed, and hard to piece together in a meaningful way. This highlights an opportunity to strengthen the data management foundations across the system so that interventions that impact Samoan families can be data-informed and validated.

Dr Ryan and Dr Sonder prepared a summary report of their findings, which is included in the Samoa team's final report.

Bottom right: The Soālaupule learner workbook cover and journey map that is part of the Soālaupule Capability Building Workshop prototype.



Lomipeau

The Tongan team adopted the name Lomipeau after a famous double-hulled canoe. The name means ‘the wave cutter’ and is a metaphor for cutting through the waves of rheumatic fever to take Tongans to a destination of good health and wellbeing.

Lomipeau developed four core prototypes.

RF Champs Programme

The RF Champs programme is a culturally-responsive and whole-of-kāinga peer-to-peer programme that creates safe places for young people and their families to heal from their trauma related to rheumatic fever.

The team learned that Tongan families who had experienced rheumatic fever had also experienced significant trauma. This was not only from the disease itself, but also from their interactions with the health system. Kāinga identified that they would benefit from experiences that enabled healing from that trauma.

When explored further with kāinga, they identified the benefits of creating safe spaces for them and other kāinga to come together and share stories and experiences with each other. Together with kāinga, Lomipeau developed and piloted a peer-to-peer network that operated in a way that aligned with Tongan values, cultural practices, and family dynamics.

There are several defining features of the RF Champs Programme that make the programme what it is and distinguishes it from previously implemented peer-to-peer groups that haven’t achieved the impact they desired. An important feature is creating a space for young people and different spaces for mums, dads and the older generation, while paying attention to when gender-specific engagement is best. Another feature is having people from within the group (a champion) nurture the wider group, so that

the group benefits from being supported by someone relevant and consistent.

Below is a summary of how Lomipeau structured the various events. This model is relevant to all age groups, however the precise activity or topic will vary depending on which age-group is involved.

1. **Haohaoā** (refer to the next prototype) underpins the model and guides the design of everything within the programme. Short term interactions (hao) explicitly link to longer term outcomes (haoā).
2. **Activities together** act as an attractor to bring people together, and create a conducive environment for forming connections, trust and safety.
3. **Pastoral care** is an important part of the group time. It is built on the trust that has already been developed and helps maintain the vā. It creates the space for healing and mutual support. This also extends to family members if and when appropriate. For example, when picking up or dropping off young people, the team would make time to connect with parents and grandparents using the notion of tauhi va māfana.
4. **Hot topics** that are relevant to the groups can be explored because of the safety that has been created. For example, for parents it might be how to talk to their child about body image in relation to scarring.
5. **Clinicians** can provide a specific rheumatic fever focus once the other building blocks are in place. Bringing in clinicians to share correct information and to shift perceptions of clinicians is important. Mental wellbeing and pastoral care elements are critical prevention and management tools. It also ensures relevant health communication that is not condescending.

6. **Culture & identity:** the programme supported kāinga to connect with Tongan culture and grow their confidence. The team learned that celebration of being ‘Tongan’ was very important for young people, especially those of mixed ethnicities. Young people valued having a safe space to unpack cultural aspects that could be perceived as barriers, e.g. intersection of multiple cultural identities (mixed ethnicities, New Zealand-born Tongan, gender diverse young people, etc.).

The pilot is ready to be expanded to cover more sites across Auckland.

Haohaoā model

The Haohaoā model is a Tongan co-design model that Lomipeau created to be the basis of Lomipeau’s work and which can be used for future co-design initiatives that involve Kāinga Tonga.

Lomipeau created a video, featuring Lomipeau team member Reverend Ifalame Teisi, that explains the thinking behind Haohaoā and how it relates to Kāinga Tonga in terms of preventing and managing rheumatic fever. The video makes the thinking accessible to others. The team also created a Haohaoā guide based on the video of Reverend Ifalame Teisi.

The team identified that there is a mismatch between the response of the health system and the Tongan communities’ mindsets and attitudes (nonoa’ia | complacency) towards the symptoms of rheumatic fever. In order to overcome the nonoa’ia mindsets and attitudes, the team wanted to leverage existing Tongan values and frameworks that have the ability to capture the hearts and minds of the Tongan peoples and make them move collectively and immediately. This capitalises on the Tongan sense of cultural collectivism.

The Haohaoā Tongan framework is one that has the sufficient cultural weight to transform the mindsets and attitudes of nonoa’ia throughout the Tongan community. The Haohaoā concept can be described as the transmission of cultural knowledge across Tongan families to keep future generations safe by avoiding known dangers experienced by the previous generations. A Tongan maritime concept, it was originally used during the navigation and settling of the Pacific to pass vital information back to those who were still in transit or still to come.

The aspiration of the team is that Haohaoā enables self agency and autonomy for kāinga (hao) and how to achieve and sustain positive life outcomes (haoā). They hope that the Haohaoā model will be used by other Tongan groups working on co-design initiatives and that it will continue to be developed in order to benefit Kāinga Tonga.

Faiva (performance), videos and posters

The faiva, videos, and posters are awareness raising and health communications collateral and tools that are based on peer-to-peer dissemination of knowledge and draw on traditional Tongan customs for communicating important messages.

The team learned how mainstream health communications don’t resonate with Kāinga Tonga, and that they sometimes created confusion. They heard that kāinga didn’t know many of the basics of rheumatic fever, even if they had experienced it. This inspired Lomipeau to create a uniquely Tongan approach to rheumatic fever awareness raising.

The team were inspired by the learning that kāinga might think that rheumatic fever is gone when the awareness raising work or campaign finishes. They wanted to ensure this

didn't happen with this co-design initiative so they created performance pieces (faiva). These were developed with kāinga and featured the young people from the RF Champs Programme and their siblings. The performances use faiva faka-Tonga (performing arts) that is aligned with traditional Tongan ways of transferring knowledge intergenerationally.

The song that was created and performed is titled 'Nofo 'I Lelenga' | 'To dwell in a state of apprehension'. It is an original composition by Samiukatoa Uatahausi and written by Rev. Ifalame Teisi. The lyrics speak of the range of emotions experienced by families once rheumatic fever has set upon the lives of young people and their families, and the last verse seeks to depict the freedom they have experienced since overcoming rheumatic fever, although forever bound by on-going treatments and the effects.

Inspired by the learning that the best people to hear health messages from are your friends and family who have lived experience, Lomipeau also created a series of four videos that feature the young people from the RF Champs Programme. The videos talk about some of the key messages that young people and their families need to know about rheumatic fever.

Another medium for sharing knowledge with kāinga is through posters that were displayed during the Faiva / Performance evening. This was a way to distill some of the key messages that kāinga wanted to or needed to hear from other kāinga who had also experienced rheumatic fever. Through the use of imagery and stories, the posters show kāinga that they are not alone.

Tool for non-Tongan Clinicians

The team worked with Tongan GPs to develop a tool that supports clinicians to provide Haohaoā in practice, showing how this contributes to short-term and longer-term outcomes for kāinga.

The team heard how clinicians have a critical role to play in reducing the trauma experienced by kāinga, but often they don't understand Tongan culture and practices.

Lomipeau worked with Tongan clinicians to develop and test an easy to use tool for non-Tongan clinicians to provide care that is affirming to kāinga. The tool has its foundations in the stories from kāinga, was developed with Tongan clinicians, and was tested with GPs, nurses and other health professionals.

Top right: The Haohaoā framework underpinning the phases of the Tongan co-design methodology.

Bottom right: A tool for clinicians to apply a kāinga-centred approach through application of the Haohaoā framework.



Reflections on the approach

As we conclude the co-design initiative, we have reflected on six topics that we wanted to share our thoughts about. This is focused more on the 'how' of the initiative and the prototype development, and we hope that this learning and insight is useful for other initiatives and activities that are undertaken.



Summary of reflections on the co-design initiative

Reflection 1 — Drawing on existing cultural knowledge to inspire innovations that are new to the system

Reflection 2 — It takes a village to disrupt a persistent consequence of health inequities

Reflection 3 — Building relationships and walking alongside families, rather than researching families

Reflection 4 — Widening our view of who the critical change champions are

Reflection 5 — Widening our view of embedding and scaling

Reflection 6 — Configuring the initiative for success

Reflection 1— Drawing on existing cultural knowledge to inspire innovations that are new to the system

Drawing on existing cultural knowledge that spans generations is not new; it is a practice that sits at the heart of Māori, Samoan and Tongan social systems.

Yet, to date, the rheumatic fever prevention and management system hasn't received the full value of drawing on existing cultural knowledge. This was an innovation territory that we deeply explored in this initiative. The initiative tested how cultural knowledge is brought into the rheumatic fever space: how does it show up, in what ways can it be useful, and in what ways can it unlock the greatest value?

The necessary pre-requisite to draw on existing cultural knowledge was the depth of cultural knowledge and relationship capital that was held by design team members and, through that relationship capital, by advisors and guides that existed outside of the design teams. The way the initiative and the teams were structured allowed the team members to fully express their cultural identity in their work. For many of the team members, it was the first time in years or even decades that their participation in a large government-commissioned project had enabled that full expression.

Each team genuinely believed that the work being done was special and sacred, and this care and vision attracted others in their networks to be part of the initiative. This created a chain of relationships and an extended network that opened up new opportunities and new system stakeholders. Many of the team members were not already embedded in the health system

and this distance allowed the teams to step outside current paradigms and to look beyond the status quo.

The 'separate but together' approach mentioned earlier played out in how the three design teams related to each other and to the other partners in ThinkPlace and Te Whatu Ora. It is common for projects to target outcomes for Māori and Pacific Peoples with the result that activities are homogenised and don't necessarily work for any cultural grouping. This initiative was unique in that there was a specific focus on each of Māori, Samoan and Tongan communities (the 'separate' part) and yet there was a sense of togetherness, collectivism and encouraging each other (the 'together' part) that came with undertaking the individual work streams within a single co-design initiative. We saw the value of creating space for Māori to be Māori, for Samoans to be Samoans, and for Tongans to be Tongans; the freedom for each team to be guided by the traditional wisdom that is unique to their culture in exploring how it might influence the rheumatic fever prevention and management system.

Each team had a strong team identity and each individual felt safe and proud to be part of their respective teams. While working within their own cultural contexts kept a healthy degree of separation between the teams — the space to be themselves — they were also very much together by sharing, supporting, and encouraging each other, and by taking inspiration from each other. Each team had specific ways in which it was leading the overall initiative, trying something

new or achieving a breakthrough that would then provide inspiration to the other teams to adapt what they saw to their own work and cultural context.

A feature of the co-design initiative is that it spans a vast system — from the family and community level of lived experience all the way through to the mechanics of the rheumatic fever prevention and management system, from cultural concepts through to western medical concepts, etc. Those different parts of the system use different language and ways of communicating, and so a significant part of what the three design teams, ThinkPlace and Te Whatu Ora were doing through the initiative was finding ways for the different parts of the system to understand each other and to map to each other (or not).

The nature of this initiative involved a level of translation between different systems and worldviews. For example, conventional notions of health literacy, health communications and health promotion began to look very different when placed in the context of traditional Māori, Samoan and Tongan modes of communicating, sharing knowledge and taking collective action. There is a risk that the mainstream system discounts the significance of these cultural approaches and views a cultural dance, for example, as a type of entertainment and misses the immense potential as a communication tool that is culturally grounded, understood and relevant. This was a significant area in which the design teams challenged assumptions about how communities consume information.



Reflection 2— It takes a village to disrupt a persistent consequence of health inequities

The initiative started with Te Whatu Ora, ThinkPlace and three design leads for each of the Māori, Samoan and Tongan streams. As the initiative progressed, the need for broader design teams was identified and the three teams—Te Tima Māori, Samoa Team and Lomipeau—were established. From there, the group of stakeholders, participants and champions grew to include families, communities, community leaders, health professionals from the three ethnic communities, broader system stakeholders (funders, health delivery, social services, NGOs, etc.) and others.

This collective approach that was taken is significant and ultimately is what opened up the wide range of innovation possibilities. It is the coming together of individual perspectives and experiences and the exploring of what sits between them that takes us out of continuing to try the same things and, instead, being able to see a vast sea of innovation potential that hasn't yet been explored.

To illustrate this further, to the right are some of the key participants across the initiative with a summary of their unique contribution. This demonstrates that collective action is required to disrupt persistent consequences of health inequities.

The people that it is all about

Families and communities

- Shared stories of lived experience.
- Helped us understand what aspects mattered most.

- Contributed to decision making around where to focus our efforts.
- Provided insight and feedback on the suitability of ideas.
- Contributed relationship capital by connecting us with their family and friends.
- Contributed inspiration and ideas about what works in other contexts and what could be done differently.

The people delivering the co-design initiative

Te Tima Māori, Samoa Team, and Lomipeau

- Created a robust cultural basis for undertaking the work and safely bringing families into the work.
- Listened to and understood their communities' aspirations, will, and needs, and where the focus needs to be to make a difference.
- Leveraged their relationship capital to invite people into the work and to open up new innovation potential.
- Played a governance and quality assurance role to ensure all potential solutions were culturally aligned and meeting the aspirations of families.
- Contributed technical expertise such as research, design, communications, strategy, etc.

ThinkPlace

- Knowledge of undertaking large projects and provision of back-office support (planning, reporting, budgets, etc.) so that the design teams could focus on the core work.
- Understanding of innovation practices and complex system dynamics to support the design teams with frameworks, conceptual models, insight generation and innovation potential.
- Experience of co-design initiatives to bring confidence across the entire initiative that the approach was sound.
- Stepping back from the work to look at the opportunities to leverage what each team was doing across the initiative and broader.

Te Whatu Ora

- Provided funding.
- Helped us understand how the system is configured and why.
- Helped us understand what has been tried before.
- Held knowledge and relationships across the health and social systems and provided referrals and advice.
- Understood how the system is configured and what the barriers are so they were able to identify opportunities to disrupt the system or work within its constraints.

The people who will be playing a role beyond the co-design initiative

Māori, Samoan and Tongan health professionals

- Contributed understanding of the realities of healthcare for impacted families and their clinicians.

- Contributed cultural knowledge to help us understand how the system barriers and constraints play out within a cultural context.
- Supported the testing of prototypes among other health professionals and with families.
- Shared clinical knowledge.

Other health professionals

- Shared clinical knowledge.
- Ensured prototypes were consistent with clinical best practice.
- Contributed an understanding of the wider system, what has been tried before and what works.
- Identified barriers and blockages in the system that prevent the desired experience for families from being delivered.

Delivery and extension partners

Examples of delivery and extension partners include Kohanga Reo, Scorpions Rugby League Club, and The Goodfellow Unit. Collectively, these partners:

- Provided access/reach to target audiences.
- Leveraged relationship capital and existing programmes to bring focus on rheumatic fever prevention and management.
- Identified effective, sustainable and scalable ways to extend the prototypes and achieve impact.
- Contributed own resources to support the initiative.

Reflection 3— Building relationships and walking alongside families, rather than researching families

Because of the make-up of the three design teams, engagement with families and community stakeholders was able to happen in ways that worked for them rather than being imposed upon them. Rather than following a set or predetermined process, the three teams relied on principles and values for engagement: caring, listening, no judgement, strengths-based, and safe.

Each team was determined to make the engagements a positive experience for the families who participated. The result of this focus on building trust and relationships was a core and consistent group of families who participated at multiple points throughout the initiative because they found the experience rewarding, they felt respected, they believed in the work, and they wanted to contribute to other families having improved experiences.

What started initially as ‘research’ activities — built upon team members using their relationship capital — quickly evolved into deeper relationships and the invitation for families to participate more deeply in the co-design process. The shape of this varied by team and by family that was being engaged with; the teams met families where they were at and how they wanted to contribute. For example, the Samoa Team facilitated a process where families would attend a series of workshops to discuss, dream, innovate, and reflect — co-designing with families. Meanwhile, Te Tīma Māori took an approach of understanding the intent of whānau, holding and responding to that intent through proposed solutions, and checking back with whānau to ensure that they were on the right track — co-deciding with whānau.

What is evident in this discussion is that there is no singular model for ‘co-design’, and this initiative provided the space for each team to work out what the best model was for them and their community. Co-design isn’t always about asking people with lived experience to design or do everything; changing systems requires a range of people to play a role. Across all three teams, the team members played a vital role in championing for families; they relieved the burden that is often placed on families of needing to know how the system works or knowing what needs to happen next in the design process. This allowed families to be present, contributing their expertise, and influencing the direction of the work. The design teams walked alongside community, creating a space where power was shared and where respective strengths and skills were leveraged. This placed families in the driver’s seat without the unreasonable burdens that often come with that.

Each team took a multi-generational approach by considering the children who have experienced rheumatic fever, their siblings (who play a vital support role), their parents, their grandparents, as well as other significant people (e.g. teachers, relatives, neighbours, church ministers). The teams identified that preventing and managing rheumatic fever is a collective effort and designed their engagements to suit. For example, the Lomipeau RF Champs Programme had the main group for young people but also had parallel groups and activities for mums, dads, and grandparents.

The three teams were mindful of demands they were placing upon families to participate in the co-design process. Many families who have experienced rheumatic fever have experienced significant trauma because of it: disempowerment, guilt, shame, body-image issues, etc. Sometimes families still don’t know what rheumatic fever is, even after their child had experienced heart valve replacement surgery. There is a heaviness that wraps itself around these families, and they can feel as though there is no safe space for them. Not only does this impact that family, but it also prevents them being able to provide peer-to-peer support to

other families and vice-versa. The response taken by the teams was to create safe places to talk, share and design together, as well as alleviating the physical barriers to engagement (e.g. transport, child care, expenses).

For several of the design teams, the appropriate starting point was engaging with families who have experienced rheumatic fever. This naturally surfaced opportunities to improve the management side of the rheumatic fever system, and as the initiative progressed the teams moved further back into the prevention side of the system.



Reflection 4—

Widening our view of who the critical change champions are

We began with a relatively narrow view of who were the key agents within the rheumatic fever prevention and management system. It consisted of the expected health system candidates: health funders / commissioners, hospitals, GPs, health clinics, school nurses, etc. As the initiative progressed, and as families shared their stories and experiences, it became apparent that there were promising opportunities for innovation by partnering with stakeholders who are not typically viewed as being part of the health system.

Here is an example. Previous rheumatic fever initiatives have mostly focused on children aged between 5 and 18, because this is the age range where risks of getting rheumatic fever are highest. However, Te Tima Māori saw an opportunity to start much earlier by getting the stories and practices around rheumatic fever prevention into the hearts and minds of under-5's so that they are prepared. This resulted in the Kohanga Reo movement emerging as the ideal partner to lead the scaling and embedding of the prototypes (karakia and videos), under the leadership of The Kohanga Reo National Trust and Toi Tangata.

Similarly, the teams identified stakeholders and champions at the edges of the formal health system. For example, the Samoa team observed the vital pastoral care work that is undertaken by the Scorpions Rugby League Club in Ōtara and this provided inspiration for how health communications and promotion can best work with Pacific young people. The Scorpions club has access to the young people, is trusted by them, and holds a position of leadership within the community. The capacity of these types of

organisations is there to play a significant role in preventing and managing rheumatic fever, and we would do well to reposition our view of the boundaries of the system. Another example is the church network, particularly for Samoan and Tongan communities.

Another example is the Goodfellow Unit: they have championed the inclusion of the Samoa Team's Sōalāupule capability framework in their calendar of professional development for GPs around the country. We heard a strong message that clinicians know that cultural competency and culturally-responsive care are not where they need to be, but they lack the necessary tools and guidance to practically lift the standard. The reception to the various tools and frameworks that the teams have created has been incredibly positive.

Despite these examples, it would seem that we have only just scratched the surface in terms of possibilities around partnerships to prevent and manage rheumatic fever. We have observed how this initiative has re-energised parts of the wider system that may have been feeling despondent but are now seeing hope because there is significant untapped innovation territory across the system. The initiative has shown that we are far from having tried everything, and, collectively, we should take a renewed energy into the next phase of efforts to reduce the rates of rheumatic fever. As the evaluation report has stated, there are emerging signs of the potential for systems change evident in the work and these will require ongoing nurturing to translate potential to real and sustained systems change.



Reflection 5— Widening our view of embedding and scaling

The aim of this project was to **identify** and **embed** innovative and sustainable system improvements to prevent and manage rheumatic fever for Māori, Samoan and Tongan people in Tāmaki Makaurau.

A significant area of exploration with the community and stakeholders was related to the topic of scalability. Often, when considering scaling of innovation there is an assumption that ‘scaling out’ is what is needed, i.e. increasing the numbers of people who experience a ‘thing’.

An alternative model¹ for thinking about scaling is:

- **Scaling out** – replicating prototypes into pilots and programmes and increasing the reach of the solution (i.e. rolling out to more people).
- **Scaling up** – embedding changes in policies and processes that results in trickle-down effects (i.e. changing system structures).
- **Scaling deep** – the change that happens in people’s mental models and belief systems (i.e. creating readiness and conditions for change).

All three types of scaling were explored during this codesign initiative, as the primary expression of embedding. The individual prototypes often featured multiple forms of scaling.

Some examples involving different kinds of scaling are discussed below.

¹ Lindsay Cole & Penny Hagen (2023) Scaling deep through transformative learning in public sector innovation labs — experiences from Vancouver and Auckland, Public Management Review, DOI: 10.1080/14719037.2023.2254776

Prototype: Ko tō Manawa, ko tōku Manawa (Te Tīma Māori)

- **Scaling out:** the kiriata/videos were launched at Te Kōhanga Reo ki Puhinui. Toi Tangata and the Kohanga Reo National Trust are leading the embedding of the kiriata across the national Kōhanga Reo network.
- **Scaling deep:** the way in which the kiriata have been developed has created a new view of what ‘good’ looks like in terms of communicating with whānau Māori. The acknowledgement of the Kōhanga Reo movement as a key stakeholder is an example of changing mental models about how best to innovate.
- **Scaling up:** the strengths-based language used in the kiriata provided a demonstration of what affirming language looks like and this has been incorporated into other workstreams with potential for trickle-down effects.

Prototype: Soālaupule Capability Workshop (Samoa Team)

- **Scaling deep:** the prototype has demonstrated the value to families of taking a Soālaupule approach, and this has impacted the mindset and behaviour of health professionals.
- **Scaling out:** the partnership with the Goodfellow Unit has been all about leveraging these insights and the tools across the network of general practitioners that the Goodfellow Units supports.

Prototype: RF Champs Programme (Lomipeau)

- **Scaling deep:** much thought, consideration and trust-building was undertaken to create deep engagement with young people and their families. This helped to shift assumptions for families about what it means to be involved in a ‘peer-to-peer’ group as well as for health professionals around how to overcome the barriers to participation.
- **Scaling out:** the team developed and tested the conceptual model for how additional programmes could be structured and commissioned, creating a high-level blue-print for scaling out to occur.

Lessons learned

A learning from this co-design initiative is that it is not necessarily clear at the outset what types of scaling will be most effective or most necessary given the targeted outcomes of a prototype. The scaling potential was highly emergent.

A related learning is that all three types of scaling are necessary to create sustained system change and, ideally, the scaling types should be integrated or work together. An evident risk is that by focusing solely on scaling out, the benefits of scaling deep and up may not be realised, and the benefits of scaling out are not sustained over the longer term.

There is also a time factor that became evident when exploring and activating deep scaling. Whilst scaling out can happen relatively quickly, scaling deep is related to relationships, trust, insight and engagement and can be impaired by trying to move too quickly.

The formation of new networks and relationships is another example of how deep scaling has been activated within this initiative. Those relationships

are mutually valuable and impactful beyond the rheumatic fever prevention and management system.

A final reflection on this topic is that scaling deep, up, and out each require different capabilities, relationships and stakeholders. The complexity of a co-design initiative pursuing a portfolio of all three is that many stakeholders need to be involved to cover the broad range of organisations, capabilities, relationships and resources that are needed to succeed. While pursuing one type of scaling makes things simpler, the sustainability of the initiative may be compromised.

Reflection 6 — Configuring the initiative for success

There are several enabling conditions that were created by Te Whatu Ora (the initiative was commissioned by Manatū Hauora and then transitioned to Te Whatu Ora following the creation of Te Whatu Ora) that were essential for the co-design initiative.

Enabling condition 1: duration of the initiative

One of these conditions was the duration of the initiative of approximately 3 years. Time is needed to build trust, to identify and agree new approaches, and to take families and stakeholders on the journey with us. Co-design happens at the pace of relationships and trust. By not having an artificial constraint such as a 6-12 month project meant that the teams could focus on the relationships and take the necessary time to build those.

This was significant. As can be seen from the quality of the prototypes, and the linkages to cultural values and practices, this depth would not have been achieved in a truncated period. The duration gave each of the design team leaders the opportunity to assess the initiative and the landscape, before handpicking their team members who had the necessary experience and expertise.

The duration allowed the design teams the time and space to enter the rheumatic fever system, to understand it, to see the less visible connections, and to explore the places in the system where intervention had the potential to improve rheumatic fever outcomes.

A risk with this longer duration is that there would be team member attrition and a loss

of initiative knowledge as a result. However, team member departures have been minimal in number and have resulted from changes in personal or employment circumstances. Once established, the teams ultimately stayed in tact and committed to seeing the initiative succeed. This is significant, especially given the team churn that exists in many organisations and on many longer projects.

Enabling condition 2: geographic focus

Another enabling condition was the geographic focus on Tāmaki Makaurau. Even within a single city, we learned that the stakeholder landscape is vast because rheumatic fever transcends sectoral boundaries. To have taken an ‘all of Aotearoa’ approach within this co-design initiative would have spread the initiative thin and would have resulted in more ‘transactional’ engagement (i.e. less depth and longevity to the engagements).

Enabling condition 3: flexibility to adapt

A further enabling condition was the flexibility created within the brief for the project approach to adapt to the context and what was being uncovered. Conventional logic is for projects to be fully planned at the outset, but this can limit the ability of the project team to respond to what they are learning and sensing. While the co-design initiative had several overarching phases, with defined objectives, within this framework there was sufficient freedom to adapt the approach.

An example of how we adapted our approach was with the creation of the design teams. This was not conceived of in the initial approach prepared by ThinkPlace—we had envisaged that the work would be undertaken by the three design team leads and supported by ThinkPlace. Once underway, we saw the opportunity to stand up three standalone design teams—Māori, Samoan and Tongan—and resource was shifted from ThinkPlace to those teams. It was this shift in approach that created the conditions for the depth and quality of work we have seen.

Recommendations for future co-design initiatives

Lastly, below are several recommendations for future co-design initiatives based on our learning from this initiative:

1. **Include a ‘project stand down’ phase.**

While it takes time to stand up a co-design initiative and build relationships, it also takes time to stand the initiative down in ways that reflect the importance of those relationships and that maximises the learning from the initiative. While initially scheduled to finish in June 2023, the final phase of the initiative wasn’t concluded until December 2023, with the additional time period acting as a ‘stand down’ or consolidation phase.

2. **Factor in further evaluation activities into the future.**

The evidence of system change will naturally take time to be apparent; it therefore makes sense to undertake evaluation activities 2-5 years into the future. We recommend committing to this at the same time the co-design initiative is commissioned.

3. **Set aside funding to nurture what comes out of the co-design initiative.**

The realities of innovation in complex systems is that high potential innovations need ongoing care, nurturing and resourcing to ensure those innovations progress into mainstream delivery. It makes sense to allocate a portion of funding for the time period of 3-5 years beyond the end of the co-design initiative to ensure that the progress made by the co-design initiative is maintained and enhanced.

4. **Contract for equity.**

Contractual mechanisms are one of several tools for holding or equalising power. In this initiative, power was intentionally equalised through the contractual mechanisms in several ways. One was through the way Te Whatu Ora configured the contract, with flatline monthly funding of expenses. This meant that design team members didn’t experience delays in having their expenses covered. Another was through the role ThinkPlace played in ensuring that the teams had sufficient budget to do what they needed and wanted to do, and supporting the teams with budget management so they could focus on the work and not be personally exposed to contract and budget risks. Another was by providing monthly retainers to the design team members. This breaks out of the western construct of timesheeted hours or standard working hours and acknowledged that, in many cases, team members were working during evenings, weekends or during family / community time. The effect of this was shifting the power by clearly signalling to team members that all that they contributed (ideas, time, wisdom, cultural knowledge, expertise, relationship capital)

was recognised and valued. It also gave team members consistency of income so they could focus on the work.

5. A team of part-time experts brings diversity and depth.

Instead of having a small number of people working exclusively on this initiative, we opted for a larger number of people who worked part time only. While this created some constraints (e.g. more effort to take everyone on the journey, harder to align schedules, etc.), the benefits were extensive: we had more brains in the game, with a wider group of perspectives, more skills, and a larger relational network we could draw upon. Also, the fact that the teams sat outside the sector enabled them to bring a fresh perspective and act autonomously to attempt to disrupt the status quo.

6. A funder is more than a funder.

A funder / commissioner has much more to contribute than the financial resources. Te Whatu Ora played multiple roles, including champion, connector and insight gatherer. The team within Te Whatu Ora held relationship capital across the rheumatic fever prevention and management system and were able to identify opportunities and constraints that were not on our radar. This was an important role and it would be ineffective in a co-design initiative for the funder to revert to merely a contract management role. It's a team effort, and the funder needs to be part of that team.

We're grateful for the role that the team at Te Whatu Ora played and how they continually nurtured the enabling conditions.

7. The value derived is broader than the immediate project.

A benefit of co-design initiatives is that the value delivered and derived is applicable across multiple spaces. They also create community-system connections and relationships that have the potential to having lasting value. A challenge that comes with that is in justifying the investment given that much of the benefit is associated or spills over. The imperative, then, is to intentionally maximise those spill-over benefits by sharing the insight and work more widely than the immediate sector that is being worked within.



Conclusion

As we conclude this report and the co-design initiative, we reflect on the aspiration that sat behind this initiative. Many policies, plans and strategies speak of a desire to be family-centred, to be culturally responsive, and to be community-led. The Rheumatic Fever Co-Design Initiative was established to move beyond aspiration and into reality; this was bold and new.

This initiative has shown what is possible when Māori, Samoan and Tongan communities are placed in a position of leadership and equipped with the resources and mandate to design with their communities. The result is not more of the same; it surfaces new innovation potential and new possibilities, even if it may have previously felt like all available options had been exhausted.

The initiative has also shown that there is a wider group of champions and delivery partners than we might realise, and by working in partnership we can unlock new possibilities.

The prototypes that were developed are robust; they were developed for community by community and with community. But this is just the beginning. The prototypes have given a clear marker for what excellent looks like but further work is needed right across the system to grow, evolve, expand and embed these prototypes so that the rheumatic fever prevention and management system operates differently and achieves different results.

We conclude our role within this initiative with the knowledge and confidence that, together, we are journeying to a future where Aotearoa is freed from the shackles of rheumatic fever.

And we again acknowledge all those who have contributed to the progress that has been made through this initiative.



