

Rheumatic Fever Co-Design Evaluation

Report for Te Whatu Ora

Adrian Field PhD
Alicia Crocket PhD
Amanda Hunter
Kate McKegg
Nadine Metzger
Georgia Parslow
Laurie Porima
Janet Tupou PhD

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Karakia

Manawa nei e, te huaki rangi	Heartfulness in the subconscious
Manawa nei e, te huaki papa	Heartfulness in the conscious
Hohou nuku te kokonga whare kia kitea	To stimulate further what we understand
Hohou rangi te kokonga ngākau kia rongohia	To foster further what is yet to be understood
Kauae rungatia, kauae rarotia	Internalise it, externalise it
Kia pūkuwatia te mānehurangi	So that it may imbue a new reality
Mō Hine-ngākau, mō Tama-ngākau	For her soul, for his soul
Hei oranga tinana, hei oranga wairua	For physical and spiritual wellbeing
Tau te Mauri!	Contentment in life anew
Tau hā, tau ana!	Bring forth vitality!

Our karakia composed by Te Amohanga Rangihau is our response to protecting stories and voice, leading through tikanga Māori, and intergenerational dissemination of knowledge.

(Te Tīma Māori, from the introduction to Rheumatic Fever roadmap; this karakia was also the starting point for all cross-team hui as the co-design progressed.)

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We would like to acknowledge all participants in this research, including the young people, whānau and kainga, clinical advisors and programme leads who offered their time, thoughts and reflections. Your critical input to this research is gratefully received.

Ngā mihi nui ki a koutou katoa

Fa'afetai lava

Malo 'aupito.

Executive summary

Background and approach

This evaluation details findings from a co-design initiative commissioned by Te Whatu Ora – Health New Zealand to provide innovative approaches to rheumatic fever prevention and management, working with Māori, Samoan and Tongan communities. Three phases of activity were commissioned:

- **Phase 1: System Discovery and Alignment (November 2020–December 2021):** Defining, empathising and ideation for the overall initiative.
- **Phase 2: Learning and Prototype Development (January 2022–June 2022):** Designing, implementing and evaluating prototypes.
- **Phase 3: Embedding System Changes and Evaluation (July 2022–June 2023):** Actions to embed community-led, sustainable system improvements to prevent and manage rheumatic fever.

ThinkPlace Ltd was awarded the contract and built on existing networks, as well as establishing new linkages, with Māori, Samoan and Tongan co-design leaders. After a year, ThinkPlace adapted its lead implementation role to take a more guiding and enabling approach (while retaining responsibility for delivery), and devolved developmental activity to three teams, each with a respective focus on Māori, Samoan and Tongan communities, and led by designers from these communities.

This report explores overall findings from the initiative, and findings specific to the three co-design teams: Te Tīma Māori (Māori team), Lomipeau (Tongan team) and Samoa Team.

Enabling community-led prototypes that offer innovative new approaches to preventing or managing rheumatic fever

The co-design process enabled the development and prototyping of a range of initiatives that complemented existing practices, were strengths-based and grounded in the cultural fabric of the communities most affected by rheumatic fever.

The co-design process led to the creation of ideas and initiatives that are specific to Māori, Samoan and Tongan communities, and these ideas and initiatives offer a new framing for rheumatic fever responses for the health system more generally. Furthermore, each co-design team offered responses that were based

on the unique strengths of each team: tikanga Māori for Te Tima Māori, system leadership for Samoa Team, and youth engagement for Lomipeau; each are outlined below.

Three central prototypes drive the mahi of Te Tima Māori. Firstly, Te Kura o Rongo, a resource that is principally based on a karakia composed by Te Amohanga Rangihau, as a koha to whānau, and an opportunity to share kōrero about this kaupapa to eradicate rheumatic fever (prefacing this report). Secondly, rheumatic fever communication to whānau with whānau, through developing guidelines on the language of rheumatic fever that is whānau-facing, and avoids falling into the stigma-associated terms such as poverty. Thirdly, Te Kiriata, Kaupapa Māori-based rheumatic fever visual resources, offer a series of videos, which create connection, and resonate with whānau Māori. Connected to these are a series of system-focused prototypes to enable greater activation of the core approaches.

Samoa Team centred their activities on activating the system of different stakeholders in the development of a Soālaupule framework and accompanying resources; these are designed to support more responsive engagement with Samoan families in the health system, and for Samoan families to engage with rheumatic fever prevention in community settings. The open-source nature of the framework and resources opens their potential to wider scaling and adoption.

Lomipeau undertook an intensive process with Tongan kainga, that explored the experience of rheumatic fever and the potential responses. The intention was to develop a culturally grounded Tongan approach that reflected histories, customs, and language. The centrepiece of Lomipeau activity was a youth peer-to-peer network, called Youth Champs, that provided a place in which young people and their kainga could gather and gain support, identity, hope and healing through their shared experience.

Early signals of system impacts from co-design

Te Tima Māori offered innovative approaches grounded in Te Ao Māori, that were built directly from the whānau lived experience of rheumatic fever. The work of Te Tima Māori is widely reflected in the Rheumatic Fever Roadmap, from the inclusion of the karakia through to the acknowledgement of the Māori aspirations for health. Te Tima Māori resources provide important platforms for more responsive services for Māori and showcase effective engagement with whānau to the wider sector.

The work of Samoa Team in the Soālaupule framework is offering early-stage signals of systems influence. The Goodfellow Unit at the University of Auckland, the Royal New Zealand College of General Practitioners (RNZCGP), and the Health, Quality and Safety Commission are all exploring the potential of the framework to support capacity building and resources for health practitioners in working with Samoan and other Pacific families.

The Youth Champs peer network led by Lomipeau has gained attention from health funders and funding has been earmarked for its expansion into other areas. It offers a fresh, culturally-grounded and youth-focused vehicle for engagement on rheumatic fever, and providing a healing space that current systems lack.

Whilst independent of the co-design, all three co-design teams had significant input into the development and review of the roadmap. In itself, this signals value of the co-design as a learning platform for wider policy development which complements the more common sector engagement that often accompanies strategy development.

Learning about scaling and sustainability of the prototypes

Bringing each of the prototypes to fruition required a longer process through the first phases of discovery, learning and prototyping than was anticipated. As a result, at the time of writing, the embedding aspiration has not been achieved to the degree anticipated at the outset of the co-design. The process of bringing the teams together, then the recalibration to devolve activity to three leads all took longer than anticipated, and at least two of the teams encountered capacity challenges at different points.

The scaling issue is therefore less where they have scaled to, and where their potential for scaling lies, noting also that there are some early signals emerging of leverage. The co-design has emerged with some important and innovative prototypes that have the potential for wider scaling, in terms of scaling out (expansion of an innovation and/or its replication); scaling up (ensuring there are institutional and systemic conditions in place to support the changes needed for the innovation to succeed); and scaling deep (deepening change beyond the surface structures and procedures to the beliefs, underlying assumptions, norms, and cultures). These will however be reliant on ongoing investment to embed, sustain and ultimately scale.

Learning from the co-design process

Learning from Te Tima Māori highlights the value of providing space for Te Ao Māori-grounded solutions, built on strong and trusted relationships. The holistic and intergenerational approach of Māori is an important foundation for resources that resonate with Māori. The value of culturally-grounded design processes and the importance of relational capital were also important to the Samoan and Tongan streams.

A challenge that emerged during the co-design process was having significant responsibility and investment in a sole design lead for each team, and the loss of key team members at critical times also slowed progress. Future investment in co-design should factor in a team approach, including writers, to both recognise the different skills required, and to manage risk.

Designing new ideas and approaches, in partnership with communities, and moving from ideas into prototyping takes time. The process of devolving to each team, engaging community and whānau networks in a meaningful way that builds trust, and developing prototypes were intensive processes. Maintaining connection across three independent providers was also an ongoing challenge, but also meant that the prototypes reflected and resonated with the communities from which they were developed.

At the same time, deliverables anticipated in initial contracting can challenge the imperative to engage communities fully, respectfully and meaningfully in the co-design and iteratively develop new approaches. Ultimately the design teams' decision to hold true to the community-led design meant that the extent to which prototypes were embedded at the conclusion of the co-design was at a much earlier stage than envisaged.

The Samoa Team identified a range of lessons for creating change within the rheumatic fever prevention and management system, which we believe have wider system applicability, including centring work on families and their experiences; relational capital as an enabler of engagement with Samoan families; acknowledging and addressing power imbalances; acknowledging intergenerational and cultural wisdom; and the value of both community-led and health system-building approaches.

Lessons for the wider health system from the co-design

For the health system, the key value of Māori, Samoan and Tongan-led processes is that they reveal responses that the mainstream system has been unable to uncover, through being grounded in the cultural knowledge and networks of each community. The Māori, Tongan and Samoan teams were able to proactively uncover new and innovative responses that indicates the value of entrusting those with the knowledge of their communities, and their lived experience of long-term conditions to develop responses that can create positive change.

The co-design also highlights the opportunity to value different forms of input into a programme or service design. The co-design initiative explicitly reached out to the wisdom of elders and community leaders, and drew on the relationship capital of the three co-design leads. These are only possible because of the prior work, trust and relationships each held in their communities, and helped ensure that the contribution of a range of sector and community leaders is valued and acknowledged in the process.

Commissioning practice for the future should look to contract directly with Māori, Tongan and Samoan leadership and organisations to themselves deliver such co-design packages, and directly entrust those with direct connections to their communities to lead responses, and allow Māori and Pacific champions in the space to be experts in their own communities.

A common shortfall of many co-design initiatives is that the intensity of effort that goes into the design and prototyping stage is often not matched by the effort to embed and sustain. This is a challenge that has similarly plagued pilot/trial models, where communities have been left disappointed and disempowered after expending significant effort and raising expectations. Notably, the co-design specifically included an embedding phase, but the time and resource required to develop the prototypes meant that the planned embedding phase is still in progress. Ongoing resourcing of many of the prototypes to sustain their impact beyond the initial embedding period should be considered.

Conclusions

The rheumatic fever co-design reveals the value of surfacing new approaches that are grounded in the cultures and experiences of affected communities, in a way that mainstream services are unable to fulfil. Each co-design team was able to work from its strengths to develop new and innovative solutions, that challenge professional practice and build community knowledge and capability to prevent and manage rheumatic fever.

PART 1:

Overall co-design insights

Background to the co-design

Rheumatic fever in Aotearoa

Rheumatic fever is widely acknowledged as a significant health concern that disproportionately impacts Māori and Pacific families. New Zealand experiences high rates of rheumatic heart disease with inequitable distribution. Māori are three times and Pacific peoples around five times more likely than other ethnicities to develop rheumatic heart disease, and both are around 11 times more likely to die from rheumatic heart disease. There have been many interventions tried, with a multitude of barriers to their effectiveness found, but there are still many unknowns with rheumatic fever.

As part of a multi-faceted programme to address disparities in rheumatic fever incidence and impact, an initiative was launched in late 2020 to 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. Centring Māori and Pacific world views and practices is a significant transformation for a system that is grounded in euro-centric models but is an approach being called for across sectors (Hagen et al 2021).

To deliver on this initiative, a Māori design team, a Tongan design team, and a Samoan design team each worked on innovative approaches to addressing rheumatic fever in their respective communities, led by ThinkPlace Ltd (referred to from this point as ThinkPlace).

Origins and development of the co-design

The co-design initiative was commissioned by the Te Whatu Ora – Health New Zealand¹ to provide innovative initiatives in rheumatic fever prevention and management, working with Māori, Samoan and Tongan communities and system stakeholders. A ‘braided river’ approach was envisaged from the outset, one that brings together different streams of knowledge and different ways of thinking and perceiving, to reach a shared understanding and framework for action.²

ThinkPlace was awarded the contract and built on existing networks, as well as establishing new linkages, with Māori, Samoan and Tongan co-design leaders. In the first year, activity was primarily led by ThinkPlace with guidance and expert input from the three cultural advisors, whilst relationships and trust between parties were established.

1. Initially the contract was with the Ministry of Health but transferred to Te Whatu Ora – Health New Zealand following health system changes.
2. See for example: www.sciencelearn.org.nz/videos/2153-he-awa-whiria-braided-rivers.

Three phases of activity were commissioned:

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This process of relationship building was acknowledged to have taken time to develop, and was essential to the delivery success that unfolded. Notably however, after a year, and with constructive relationships forged across the teams, ThinkPlace adapted its lead implementation role to take a more guiding and enabling approach (while retaining responsibility for delivery), and devolved developmental activity to three teams, each with a respective focus on activating networks in Māori, Samoan and Tongan communities, and led by designers from these communities. As the co-design unfolded, each emerged with their own identities: Te Tima Māori, Samoa Team, and Lomipeau.

Co-design teams

Te Tima Māori

Te Tima Māori approach is fundamentally grounded in tikanga, expressed through its design principles, ethical frameworks and process. Their work draws on an “in-depth exploration into the narratives of litany surrounding the human heart that seeks to understand them in their current state, with the overall purpose of providing clarity to better articulate and measure the true context of health and wellbeing for our whānau, hapū, iwi and communities” (Te Tima Māori, 2022).

The approach of Te Tima Māori draws on whānau-based ways of achieving aspirations, including tuakiritanga (identity); wairuatanga (faith); ūkaipō (belonging in place); whanaungatanga (connections and relationships); te reo me ono tikanga (connection to language and voice); kahukura (community leaders); manaakitanga (upholding mana of the collective); pūrākau (connection to narrative); and whakapapa.

Three central prototypes drive the mahi of Te Tima Māori:

1. Creating a karakia (Te Kura ā Rongo) as a taonga that disseminates intergenerational knowledge and captures the cultural integrity of Te Tima Māori and whānau
2. Developing a series of kiriata (videos) titled ‘Ko tō Manawa, ko tōku Manawa’ for tamariki Māori about rheumatic fever prevention and management for kōhanga reo and kura kaupapa
3. Developing language guidelines for media (Kōrero Whakamana) as a resource for media and health professionals to support them to talk to whānau Māori about rheumatic fever in a safe mana-enhancing way.

Samoa Team

The Samoa Team’s approach focussed on a potential shift in the dynamics of the rheumatic fever system and the ability for Samoans to influence this change. To do this, the team centred their work on the experiences and Fa’asamoa solutions of Samoan families and practitioners. Through the leveraging of Samoan relational and cultural capital, a network was formed, uniting individuals with lived expertise, clinical knowledge, system knowledge, and leadership skills. Placing Samoan families and their aspirations at the core of the initiative allowed for the identification and testing of innovative solutions believed to provide optimal healthcare and contribute to reducing rheumatic fever rates among Samoan families.

By the conclusion of the co-design process, prototypes developed by the Samoa Team focused on:

1. **Soālaupule Family Meeting Guide:** A helpful communication tool to facilitate better engagement between healthcare professionals and Samoan families to manage their diagnosis, grounded in the ‘Fa’asamoa way’ in which power dynamics are shared.
2. **Soālaupule Capability Building Workshop:** A training module designed for healthcare professionals to illustrate the importance and practical application of Soālaupule and Samoan principles in fostering dialogue, building consensus, and sharing power through the Soālaupule process.
3. **Rheumatic Fever Infographic and Glossary:** Development of a visual glossary to describe the journey of strep throat bacteria to the heart and its subsequent impact on the body, bridging the language barrier for healthcare professionals with little grasp of the Samoan language when consulting with Samoan families.
4. **Youth “Let’s Talk Rheumatic” Information Event:** A talanoa evening was organised by young people to engage their peers with healthcare professionals and Samoan youth impacted by rheumatic fever; empowering Samoan young people with the knowledge to reduce and prevent the disease in their local community.
5. **Pharmacy Based Rheumatic Fever Prevention:** Assisting the President of the Pacific Pharmacies Association to examine the potential for pharmacies to enhance their role in community-based prevention and care of rheumatic fever, using a community-led approach in South Auckland.
6. **Systems Mapping for Le Afio’aga o Aotearoa (the Ōtara-Papatoetoe area Locality):** Support for Dr Debbie Ryan and Dr Gerard Sonder (Pacific Perspectives Ltd.) to undertake further research and analysis on the implementation of rheumatic fever control in primary care at a locality level, that encompasses primordial, primary and secondary prevention.

Lomipeau

The Tongan team applies the Lomipeau metaphor to its work – a type of double-hulled canoe, where Lomipeau translates as ‘the wave cutter or suppressor’, as a way of “finding solutions and ways to cut through the peau, taking our people to a destination of good health and wellbeing.”

The faka hao-haoā model embodies safety in the short and long-terms, to bridge different frames of thinking, particularly, clinical and Tongan systems. The approach is intended to navigate towards a safe harbour that protects people from mofi lumetika (rheumatic fever).

A range of interlinked concepts further build the hao-haoā model:

- The Tongan concept of Tau’ataina (being free from harm) is linked to the traditional Tonga vaka (boat) and the protection offered by the Taula (anchor). The Taula provides safety for the vaka when it is stationary, however during voyage the responsibility of the Taula is placed upon the navigators to protect the vaka to its destination.
- Taula for this rheumatic fever journey is in the Faa’i Kavei Koula which are values that encompass the Tongan way of life, through Faka’apa’apa (respect), Tauhi vaha’a (nurturing relationships), Mamahi’i me’a (devotion) and Lototō (humility).
- Anchoring the approach in these values provides both the freedom of exploration and protection from damage or harm. (Lomipeau 2022a)

The central prototype underpinning Lomipeau is to develop experiences that enable healing through peer-to-peer support networks for young people and families, and providing greater autonomy over their journey/stories. Encompassing this is the development of a Tongan-based understanding of rheumatic fever that resonates with Tongan families. Earlier work in the initiative also explored developing an app to navigate rheumatic fever services and a family-centred model of care; these emerged as less feasible and work primarily focused on the youth peer networks.

Evaluation methods

Evaluation objectives and key evaluation questions

The evaluation objectives are as follows:

- Articulating the work that has undertaken — the approach more generally, as well as specific prototype areas
- Identifying evidence of wider system change
- Identifying the opportunities and challenges associated with embedding and sustaining the changes.

From these objectives, and from feedback in discussions, the following key evaluation questions (KEQs) guided the evaluation and form the underlying structure for this report:

- KEQ1: To what extent has the co-design initiative enabled community-led prototypes that offer innovative new approaches to preventing or managing rheumatic fever?
- KEQ2: What are the early signals of system impacts emerging from the co-design initiatives, and what is the potential for system change in the future?
- KEQ3: What are we learning about scaling and sustainability from the prototypes?
- KEQ4: What have we learned from the co-design process to support future innovation in rheumatic fever prevention and management with Māori, Samoan and Tongan communities?
- KEQ5: What have we learned from the co-design process for ways of working in the wider health system?

Developmental evaluation

The underlying approach applied to this work is developmental evaluation. Developmental evaluation (DE) is an approach that is suited to complex environments where ideas and initiatives are being developed and tested. The use of DE can support effective innovation and, at the same time, be an important risk mitigation strategy. The DE is intended to ‘walk alongside’ the co-design initiative as it learns from prototype implementation and seeks to bring about systems change.

Developmental evaluation builds critical reflection into the development process. This ensures key assumptions, actions, motivations, decisions and outcomes are critiqued and questioned, so that their contribution, or otherwise, to the change and development process becomes explicit and transparent.

A complexity perspective and a requirement for systems thinking are imperative to successfully reveal emergent possibilities and directions. A commitment by those working on the initiative to collaborative ways of working and thinking together throughout helps to ensure that a learning environment is created, grounded on relational trust. This relational grounding is essential for deep learning and change processes to succeed, and genuine continuous improvement to be embedded (Patton, McKegg and Wehipeihana 2016).

In practice, DE is often embedded at the outset of an initiative, so that evaluative thinking can co-inform prototype design and system transformation. We acknowledge however that for Te Tīma Māori and Lomipeau, the evaluation occurred at a later point with the co-design, and with reporting due some 12 months following contracting, our developmental approach in part involved a degree of taking stock of work to date, and then working alongside co-design teams.

The Samoa Team evaluation approach was more explicitly developmental, with an evaluator embedded in the team from an early stage and able to assist with sense-making at weekly meetings. The key evaluation outputs used case studies, enabling storytelling as a means to convey the project's outcomes from participants' experiences and viewpoints.

Three principles emerged that represent our journey in the evaluation process:

- Whanaungatanga (tauhi vā) — the importance of relationships. This involves creating a mana-orite relationship where there is acknowledgement and recognition of each other's capabilities and roles in this relationship. Time is taken to make connections and develop trusted relationships between the co-design teams and evaluators, and for the evaluators to build an understanding of the co-design journeys to date. This creates the conditions for evaluative thinking and learning together.
- Whakamana, working with each team, supporting them to lead on what might be the most appropriate ways to undertake their learning journey. Through this, we emphasise that developmental evaluation is a collaborative process and that making mistakes is a normal part of the learning cycle and should be seen as indicators for making progress. Support for each team to develop their own culturally grounded, ethnic specific, systems-oriented models of evaluation.
- Open and regular communication is critical to an enduring DE relationship, and provides opportunities for active participation by all parties in the evaluation to have input, and builds trust.

Data collection

A range of data collection approaches informed this evaluation report:

- Analysis of reporting from each phase of the co-design
- Regular weekly meetings between the Samoa Team leadership and their commissioned evaluator to explore and co-create responses
- Interviews with programme leads in Lomipeau in September and March 2023
- Interviews with kainga of young people participating in Lomipeau Youth Champs in July/August 2023
- Interviews with ThinkPlace project leadership, Te Whatu Ora leads, clinical advisors/stakeholders in the initiative, and other project stakeholders from mid-2022 to late 2023
- Hui with Te Tima Māori leads in November 2023.

Insights from the co-design

To what extent has the co-design initiative enabled community-led prototypes that offer innovative new approaches to preventing or managing rheumatic fever?

From the outset, the co-design was focused on initiatives to both prevent and manage rheumatic fever: prevention being critical to reducing the incidence and impact; and management to support those for whom rheumatic fever has lifetime consequences and requiring ongoing engagement with the health system.

The co-design process enabled the development and prototyping of a range of initiatives that offer departures from and complement existing practices. Many initiatives to date have tended to be deficit-focused and health service oriented, and are only rarely grounded in the cultural fabric of the communities most affected by rheumatic fever.

The co-design process led to the creation of ideas and initiatives that are specific to Māori, Samoan and Tongan communities and grounded in each culture, and these ideas and initiatives offer a new framing for rheumatic fever responses for the health system more generally. Furthermore, each co-design team offered responses that were based on the unique strengths of each team: tikanga Māori for Te Tima Māori, system leadership for Samoa Team, and youth engagement for Lomipeau.

Each team was able to draw on clinical advisors from within their communities, all of whom at various stages over time came to appreciate the significance of the work and the departure they offered from existing models. The importance of culturally-specific approaches that transcended a blanket view was highlighted by a clinical advisor to the initiative:

Even though we're Pan Pacific, they've asked for the ethnic specific Pacific as well because even though we're similar there are quite distinct differences between the different island groups... There's little intricacies to our ethnic specific cultures that differ that also bond us and to help us connect. [clinical advisor]

The work of Te Tima Māori signals a range of innovative approaches, including being Kaupapa Māori-led and guided from the outset, underpinned by the karakia and extending into tailored resources and communications for whānau and clinicians. Their approach was based on deep engagement with whānau, one that acknowledged and honoured the lived experience of rheumatic fever, and which provided lessons for the health sector.

Te Tima Māori applied tikanga and intergenerational knowledge or traditional ways of communicating, to reframe communications on the rheumatic fever discussion, and provide a cultural grounding that has resonance for Māori. A specifically-designed karakia provides a reference point that anchors the wider communications strategy. Communications are similarly reo- and tikanga-based, and are designed to reach children and whānau at the pre-risk age groups, such as in kōhanga reo, to lay a foundation in te reo for preventative action, and rapid responses to early warning signals.

Samoa Team centred their activities on activating the system of different stakeholders in developing a Soālaupule framework and accompanying resources; these are designed to support more responsive engagement with Samoan families in the health system, and for Samoan families to engage with rheumatic fever prevention in community settings (for example, prototypes were developed and trialled at a local rugby league club). The resources were visually based and accompanied by videos and storyboards in English and Samoan to model responsive approaches in clinical settings. The approach was one that was intended to shift the locus of control to a more equal partnership between families and clinicians. This included:

- Meeting families at the door
- Inviting families to open with a prayer
- Using terms that are more comprehensible, engaging and enables decision-making by the family.

A workshop that introduced the framework and resources acted as a prototypical capability building session, one where the Royal College of General Practitioners (RNZCGP) and the Goodfellow Unit at the University of Auckland were quick to see the potential for their use. The open-source nature of the framework and resources opens their potential to wider scaling and adoption.

Lomipeau undertook an intensive process with Tongan kainga, even with the disruption of COVID-19 lockdowns, that explored the experience of rheumatic fever (often as one of many challenges facing these families) and the potential responses. The intention was to develop a culturally grounded Tongan approach that reflected histories, customs, and language. In their talanoa, the Lomipeau team took an empathetic approach, building a safe space for families and trusting relationships.

What emerged from the co-design activity of Lomipeau was the need for an approach that acknowledged the challenge of the rheumatic fever experience, the ongoing stigma and burden that it places for young people and kainga. At the same time, the approach needed to be strengths-based, culturally resonant and provided a degree of psychological healing that supported young people in their ongoing management of rheumatic fever.

The centrepiece of Lomipeau activity was a youth peer-to-peer network, called Youth Champs, that provided a place in which young people and their kainga could gather and gain support, identity, hope and healing through their shared experience.

In parallel, Lomipeau recognised that traditionally, knowledge is transmitted in Tongan societies through song and dance (faiva). The challenge, journey and healing process that are encompassed by rheumatic fever were communicated through a commissioned song, which was performed at a celebration event for Lomipeau in July 2023.

What are the early signals of system impacts emerging from the co-design initiatives, and what is the potential for systems change in the future?

Connection of people with lived experience

An important dimension of the co-design was the active engagement of people with lived experience in the initiative, and the development of interventions that acknowledged their needs. All prototypes engaged with whānau and explored their experiences and aspirations.

Just as mental health services are appreciating and embracing the role of lived experience as a valid part of system responsiveness through peer support services, its emergence in the co-design similarly acknowledges the role that peer connection can play in supporting people on the rheumatic fever journey. The sustained involvement of whānau across all three teams in the discovery, design and prototyping similarly signposts the value that lived experience offers to health service development.

Community networks and capability

All three initiatives highlight the important contribution that community networks can play in enabling connections and building understanding of rheumatic fever prevention and management.

Te Tima Māori was able to draw on its deep connections with Te Kōhanga Reo movement and kura, and health promotion networks such as Toi Tangata, as a distribution model for rheumatic fever communications. Lomipeau, through its leadership based in the Village Collective, had a ready-made network to reach through and draw in a community that had experienced rheumatic fever, and respond to the psychosocial needs of young people. Samoa Team was able to work through a local rugby league club to share knowledge, engage community local leadership and build community-level understanding.

We've seen a broadening in how we would define the rheumatic fever prevention and management system and who plays a role, such as the kōhanga reo... I think that's the significance is we've actually just significantly broadened out who it is and therefore it's opened up entirely new forms of intervention, cos when it's the old players, it's just well what have we got? We've got clinical care and we've got awareness campaigns. [programme lead]

The application of established relationships and networks by co-design leadership in Māori, Tongan and Samoan communities offer a clear direction for health initiatives to leverage greater outreach, particularly where the leaders themselves play a key role in an initiative's development.

Expansion of prototypes

The work of Samoa Team in the Soālaupule framework is offering early-stage signals of systems influence. The Goodfellow Unit at the University of Auckland, the RNZCGP and the Health, Quality and Safety Commission are all exploring the potential of the framework to support capacity building and resources for health practitioners in working with Samoan and other Pacific families.

The Youth Champs peer network led by Lomipeau has quickly gained attention from health funders and funding has been earmarked for its expansion into other areas. It offers a fresh, culturally-grounded and youth-focused vehicle for engagement on rheumatic fever, and providing a healing space that current systems lack.

Rheumatic Fever Roadmap

In parallel with the co-design, Te Whatu Ora led the development of a Rheumatic Fever Roadmap, launched in June 2023. Six values underpin the roadmap: whānau-focused, manaakitanga, equity, whanaungatanga (common purpose), va/va'a/vaha (sacred relational space in Pacific contexts), and evidence, knowledge and outcomes. The roadmap sets out the following key goals:

- To improve Māori health and wellbeing
- To prevent new and recurrent cases of rheumatic fever
- To improve hauora for those with rheumatic fever and rheumatic heart disease
- Improved equity for Māori and Pacific communities concerning rheumatic fever and rheumatic heart disease.

These are driven by three focus areas: Whānau ora (focusing on determinants of wellbeing and primary prevention), Tangata ora (quality healthcare and improved experiences for those with rheumatic fever), and Kōkiri Ngātahi (system readiness, leadership and collective action).

Whilst independent of the co-design, the co-design teams have had significant input into the development and review of the roadmap. All three design leads appreciated being involved in the design of the roadmap from the outset to be able to draw on direct learning from each initiative, their engagement with whānau/families and community leaders and their cultural knowledge.

In itself, this signals value of the co-design as a learning platform for wider policy development which complements the more common sector engagement that often accompanies strategy development.

A range of elements were identified as significantly influenced by learning from the co-design:

- Use of the karakia developed by Te Tīma Māori to introduce and frame the document, and inclusion of the lyrics to the faiva (song) developed by Lomipeau; these both highlight the importance of traditional cultural approaches to transmit knowledge intergenerationally.
- System readiness actions in amplifying and elevating the leadership and role of Māori and Pacific communities experts and health professionals
- Ensuring age-appropriate interventions, which has parallels with the Youth Champs initiative developed by Lomipeau.
- Increase capability of the workforce around tikanga and cultural safety, which aligns with the work of both Samoa Team and Te Tīma Māori in developing more culturally resonant approaches, and in the case of Samoa Team, activating leadership at multiple levels.

- Social marketing campaigns to raise awareness about rheumatic fever prevention that is whānau-led, whānau-centred, strengths-based and evidence-based, aligning with the communications approaches being developed by Te Tīma Māori.
- Proposed actions to provide more culturally specific and/or language-specific resources; peer support; more options and autonomy, and ensuring a family-centred model of care; all of which emerged from learning in co-design development, and in the case of peer support, through prototyping by Lomipeau.

The design of the roadmap was also informed by the insights of the co-design, offering a strengths-based view of Māori and Pacific families and avoiding stereotypes.

Māori and Pacific leadership in health strategy

A potential signal of system change from the initiative is the central role that Māori and Pacific health leaders have played in the design and development of the initiatives, to the extent that this subsequently became a critical element of the Rheumatic Fever Roadmap. The roadmap was noted by one interviewee as marking a shift from the usual largely Pākehā-oriented strategy design, to one where Māori and Pacific leaders took a central role.

The co-design also highlights the opportunity to value different forms of input into a programme or service design. The co-design initiative explicitly reached out to the wisdom of elders and community leaders, and drew on the relationship capital of the three co-design leads. These are only possible because of the prior work, trust and relationships each held in their communities, and helped ensure that the contribution of a range of sector and community leaders is valued and acknowledged in the process.

Cultural responsiveness

Reflections on the co-design signal an openness to cultural frameworks, language and communication as a tool for better engagement with and buy-in from communities. The development of the Soālaupule framework and te kiriata have reportedly been well received by clinicians and other stakeholders, and are seen to offer practical and accessible resources that can improve practice (Soālaupule) and raise awareness from a fresh perspective (te kiriata).

What are we learning about scaling and sustainability from the prototypes?

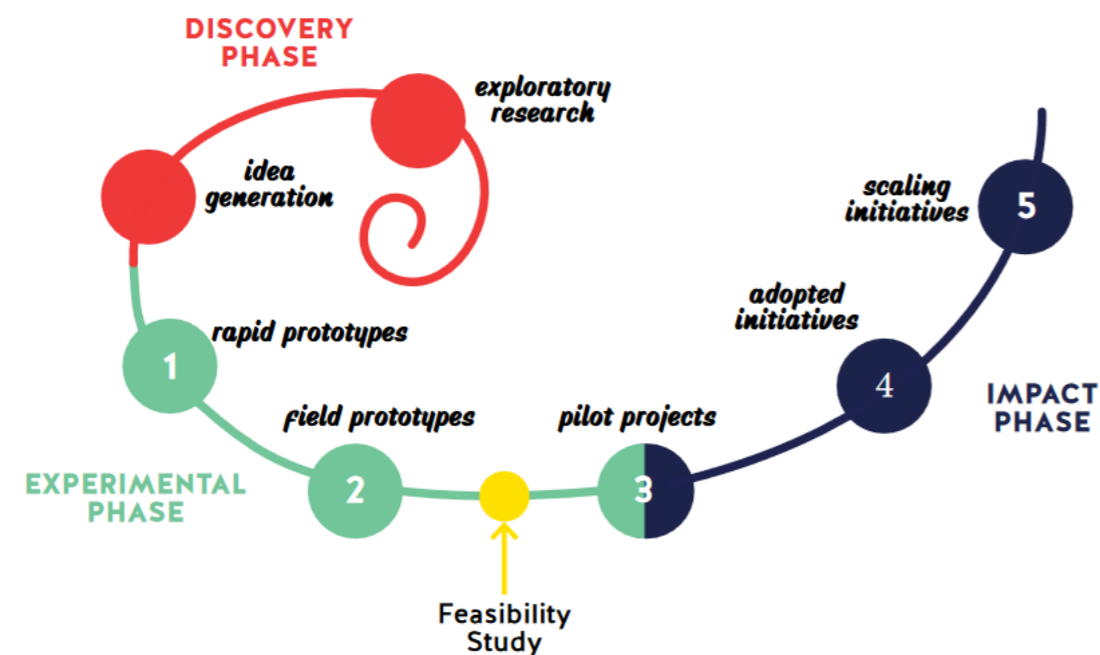
The challenge and complexity of scaling

Scaling is often assumed to be the natural outcome of a social innovation process, that it is something that will happen towards the end of an innovation cycle, and that scaling signifies a successful innovation.

However, scaling social innovation is complex and is often a fraught process that frequently doesn't realise funders' intentions and hopes. Those involved need to carefully consider a range of issues, including the justification for scaling, the trade-offs involved, the relational and operational issues, the ethics and the

decision-making context for scaling, as well as the nature and levels of support and assessment required for learning, adaptation and success. Further, it is only if conditions are favourable should some form of scaling be considered (McLean and Gargani, 2019).

FIGURE 1: Innovation swirl



Innovation Swirl adapted from NESTA by Mark Cabaj, Here to There Consulting (2020)

Scaling can also take a number of forms. One of the most common assumptions is that the initiative being scaled will be spread out to other locations or that the number of people who can access and participate in the programme or initiative will be increased (Ridell et al, 2015). This is typically called **scaling out**, and refers to the expansion of an innovation and/or its replication and adaptation in different contexts. Scaling out an initiative is a complex endeavour. It involves the transfer of understanding about the initiative, the development of know-how so that it can be implemented, and the building of motivation to take it on and sustain the changes to new groups of people (Coburn, 2003).

However, reproducing or adapting an initiative in more places with more people might never address the kind of changes needed to systems that are doggedly holding social problems in place. So, rather than relying on a process of scaling out, many initiatives also consider **scaling up** to achieve greater impact. This involves a focus on ensuring there are institutional and systemic conditions in place to support the changes needed for the innovation to succeed. This might be things such as advocating for changes in policies or regulations/laws, and influencing key relationships, resource flows and practices.

To effect deep and consequential change, a different type of scaling is needed. One that is not necessarily synonymous with growth. This has come to be known

as **scaling deep**. This means focusing on deepening change beyond the surface structures and procedures to the beliefs, underlying assumptions, norms, cultures and “hearts and minds” of people, organisations, systems or communities (Coburn, 2003). The other purpose of having a focus on scaling deep is so that change might be sustained beyond the initial rollout and implementation phase. It is common for new programmes and initiatives to create lots of enthusiasm and energy early on, but over time this can dissipate, and hard-won progress is lost as people return or ‘snap back’ to old ways of doing things. (Cabaj, 2015).

Recently, an innovative initiative in Tairāwhiti decided to look to tribal mātauranga, whakapapa, tohunga and to kuia, kaumatua and rangatira for guidance about what scaling might mean in an indigenous context. Rather than defaulting to definitions that come from another worldview, the process privileged tribal knowledge, stories, conversations, and concepts. They looked for examples where Māori have nurtured, grown, expanded and scaled movements like kōhanga reo and kura kaupapa. Common to these examples was that what was being scaled was a *kaupapa* grounded in community. Following a process of critical reflection with many across the tribe, over several months, many miles and cups of tea, and guided by the principles of āta (as developed by Ngāti Porou knowledge keepers), the concept of **Te Koha** emerged.

Te Koha is a set of culturally grounded Māori principles that frame scaling as a system of exchange with mutual accountabilities and responsibilities. The core principles include:

- aroha — love, affection
- humārie — humility
- rangatiratanga (and mana) — chieftainship, tribal decision-making authority
- whakapapa — kinship, connections, and history
- tauutu — reciprocal obligations
- whanaungatanga — relationships and context.

Te Koha represents a culturally grounded approach to scaling through a system of exchange with mutual accountabilities and responsibilities. When scaling is reconceptualised as koha, we must have regard for relationships and for context. We need to act with humility and reciprocity, and above all else, we need to ensure we are operating from a place of love or aroha (Wehipeihana et al. 2022).

Reflections on scaling with the co-design

The co-design has emerged from three years of activity with some important and innovative prototypes that have the potential for wider scaling. Some signals have emerged from Te Whatu Ora and/or Te Aka Whai Ora of investment intention to support wider adoption (such as the youth peer network); and interest from influential sector organisations for dissemination of the Soālaupule framework and resources.

The prototypes have developed responses that the mainstream system has been unable to uncover through business-as-usual activity, and which have particular resonance for the communities they work with. The stage that the prototypes have reached in the scaling process, referring back to **Figure 1** above, are the end of the second, experimental phase, where prototypes are in the field and

learning is ongoing. The scaling issue is therefore less where they have scaled to, and where their potential for scaling lies, noting also that there are some early signals emerging of leverage. The individual chapters on each co-design initiative discusses this in more detail, and potential areas of scaling are summarised in **Table 1** below.

TABLE 1: Potential key areas of scaling for Te Tīma Māori, Lomipeau and Samoa Team

Scaling type	Te Tīma Māori	Lomipeau	Samoa Team
Scaling out	Distribution and promotion of kiriata to kōhanga, kura and community networks. Distribution and promotion of language guidelines to clinical services and sector leaders.	Broadening number and reach of peer networks. Extension of songs and videos to communicate knowledge.	Extending reach of Soālaupule framework to healthcare professionals and related organisations. Broadening community-based communications and engagement on rheumatic fever. Culturally-tailored systems mapping resources for communities.
Scaling up	Principles of whānau and lived experience engagement as a model for wider service planning and development. Support for guidelines by sector leadership to enable greater engagement by clinicians and service leads.	Gaining policy leverage for their wider use (signalled by Rheumatic Fever Roadmap).	Embedding learning resources in learning modules for healthcare professional learning and development.
Scaling deep	Karakia as a cultural underpinning for rheumatic fever activities across the sector. Kiriata and guidelines offering approaches to changing knowledge, perceptions and practice.	Broadening connection families as well as young people with rheumatic fever prevention and management. Faiva as a mechanism for transmitting intergenerational knowledge.	Challenging professional understanding of how health advice is given and received and embedding more culturally-responsive approaches.
Te Koha	Provision of resources that can enrich knowledge and practice, and ensure people are not receiving information in a way that is harmful and disengaging.	Enduring culturally-grounded relationships that connect with kainga.	Ensuring system responses that acknowledge and embrace fa'asamoa approaches.

A common shortfall of many co-design initiatives is that the intensity of effort that goes into the design and prototyping stage is often not matched by the effort to embed and sustain into business-as-usual activities. This is a challenge that has similarly affected pilot/trial models, where communities have been left disappointed and disempowered after expending significant effort and raising expectations (Palmer et al 2019).

In contrast, an established aim of the co-design was to embed system changes by the end of the third year of the initiative. However, for many reasons, the time and resource required to develop the prototypes meant that the planned embedding phase is still in its early stages. There was also a view expressed that some of the innovations need to have a period of time to reflect and recalibrate to be ready for wider dissemination/scaling. For the value of the prototypes to be realised, some ongoing resourcing of many of the prototypes to realise and sustain their impact beyond the initial embedding period should be considered.

At the time of writing, the health system was working through a sustained change process, offering both risk and opportunity. Some interviewees raised concerns of the potential for fragmentation of existing rheumatic fever clinical networks in the restructuring, and if this would undermine momentum for change. Alternatively, others argued that the process of allowing the change process at Te Whatu Ora to settle may ultimately have all elements in a better position to scale further.

A further view on the change process was that the system as currently configured had so far failed to yield health gains in the rheumatic fever space. The restructuring could offer an opportunity for a more responsive system that is better able to embrace and scale the innovations of the co-design:

It's connecting them all up together and that's all about those new health changes, that we're not working in silos anymore and working together and knowing where to refer people to who can get the right support which works for them and at the moment there isn't a lot of avenue from the clinical point of view. [clinical advisor]

If the health system restructure does create a more integrated system that is able to absorb and adapt learning, then the prototypes may have an opportunity to gain more traction and support system improvements.

What have we learned from the co-design process to support future innovation in rheumatic fever prevention and management with Māori, Samoan and Tongan communities?

Enabling new and innovative solutions

A relatively unconstrained and open approach to the co-design process allowed a variety of 'out of the box' potential solutions to the prevention and management of rheumatic fever to emerge from participating communities, that otherwise may not have occurred if existing mindsets and approaches had been used. The range of ideas and intervention prototypes that emerged reinforced the importance and value of preventative approaches, to reduce the flow into

the sector of rheumatic fever cases, and novel approaches to rheumatic fever management, that support people in their ongoing contact with the condition:

how do we make sure we maintain, wrap the safety around those who are diagnosed and I think that's part of the youth being empowered to understand their diagnosis and being in charge of their healthcare from the youth to their family ... to have that longitudinal [view] so they don't drop off, stop taking the injections when they're supposed to stay on them and then still engage with the health sector [clinical advisor]

Resourcing and team support

A challenge that emerged during the co-design process, was having significant responsibility and investment in a sole design lead for each team, built into the design of the model by ThinkPlace and collaborators. In practice, teams were exposed on occasion with the loss of a key team member. The part-time nature of the co-design leads may also have constrained the opportunity for systematic effort given pressures of other commitments. A team approach needs to be factored in, to both recognise the different skills required, and to manage risk:

The key learning is one person's not enough. That's tough. Like you've got the weight of your people on your shoulders, that's just not fair. So it has to be more than one and the other key learning is what are the skills that we're looking for. So you look at those teams and there are some technical skills, traditional kind of design, research, systems thinking, ... but more it's about the relationship skills, the cultural skills, the mana, the status that people hold...[programme lead]

Challenges of prototyping and embedding

Designing new ideas and approaches, in partnership with communities, and moving from ideas into prototyping takes time. Although embedding was an established aim of the initiative by its third year, it has taken the full three years of the initiative for the prototypes in each team to emerge, and while there are clear signs of promise, embedding is clearly at an early stage.

Timeframes are a huge pressure point. This stuff just takes so much longer than you ever imagined you would. [programme lead]

The process of devolving to each team, engaging community and whānau networks in a meaningful way that builds trust, and developing prototypes were intensive processes. Maintaining connection across three independent providers was also an ongoing challenge, but also meant that the prototypes reflected and resonated with the communities from which they were developed.

At the same time, deliverables anticipated in initial contracting can challenge the imperative to engage communities fully, respectfully and meaningfully in the co-design and iteratively develop new approaches. Ultimately the design teams' decision to hold true to the community-led design meant that the embedding of the prototypes started later than originally anticipated.

Balancing system and community demands

Only a few elements of the prototypes were focused on the existing parts of the health system, instead working on areas untouched by current service provision to better meet the needs of Māori and Pacific peoples, a key area of system failure to date. In the early stages of the initiative, there was seen to be pressure-to meet system needs of delivering new and innovative approaches,

and the design teams needed to maintain a constant sense of purpose and accountability back to the communities they were working with, and to ensure trusting and enduring relationships.

... it was there more in the early days is who, it's almost like who do we need to please, who do we need to satisfy, who are we answering to and for the first year to two years, it was very much it's the clinicians, it's the pākehā, palagi and the system who hold the power, it's the people there working in the space and a small number of people and we've got to have them onside and it's all about what do they need and we need to communicate to them. [programme lead]

It was noted however that a more collaborative approach and openness to new ways of working had emerged by the end of the initiative, and an appreciation of the innovations developed.

Acknowledging expert and community input

A repeated theme across interviews was the importance of acknowledging the input of community and expert stakeholders through kai and koha/putea; this is a given in leading edge co-design practice where participants are reimbursed fully. Payments made to community members taking part in the co-design were received as a welcome acknowledgement — and that this was rare:

She's like "You know that this is the first project that we've been honoured," and she used that word, "That we've been honoured for our story this way and normally it's a full day and I get a \$100 petrol voucher," but we were like "Okay, we're going to do petrol voucher," one per family and then we're going to give the koha, \$500 for the four workshops, cos it's heaps, we're asking a lot. [team member]

Similarly, a payment made to the Pasifika chapter of the RNZCGP was hugely appreciated as a mark of honouring time and knowledge, and yet there is reportedly an expectation in many engagement practices that their input is generally unpaid. This acknowledgement of time, effort and reflection is often undervalued and yet is a critical point of exchange and mark of respect.

Nurturing Māori and Pacific leadership in the co-design space

The co-design model that emerged, with leadership coming from within the Māori, Samoan and Tongan teams to undertake the co-design was acknowledged by the project lead as a far better solution than the original approach of a consulting company-led model. However, as noted earlier, the process of relationship building across the teams and ThinkPlace was one that necessarily took time, and it remains relatively rare for a consulting lead to delegate leadership of an entire initiative to grassroots partner organisations. This experience lays a challenge to wider consulting practice, to invest in building genuine relationships with the communities they are seeking to support, and to leverage their social and financial capital to gain resources for Māori and Pacific leadership of alternative solutions; effectively to awahi and support this kind of development.

However, the fact that ThinkPlace felt the need to do so may also signal a challenge to commissioning practice for the future, that instead of seeking out established mainstream organisations to lead a co-design in ethnic-specific communities, a more responsive commissioning approach may be to contract

directly with Māori, Tongan and Samoan leadership and organisations to themselves deliver such packages. Such an approach would directly entrust those with direct connections to their communities to lead responses, and allow Māori and Pacific champions in the space to be experts in their own communities.

You have to have the people in there from the outset and genuinely give them some decision-making authority or otherwise we're just stuck in the old model [programme lead]

Principles of engagement

Samoa Team identified a range of specific conditions that must be met to enact meaningful and equitable change within the rheumatic fever healthcare system, that can have wider system applicability, including the following:

- **Centring work on whānau and their experiences:** Giving acknowledgement to the perspectives, knowledge and lived experience of families enriched the co-design process and enabled new solutions to be uncovered.
- **The importance of relational capital:** Establishing safe, comfortable, and beneficial engagement with Samoan families provided a place where interaction could occur.
- **Addressing power imbalances:** Acknowledging the contribution and value of everyone involved, creating a space of equal standing, and foster meaningful conversations, shared decision making.
- **Acknowledging intergenerational and cultural wisdom:** Multiple forms of knowledge exist that alongside clinical knowledge can inform and support multi-faceted responses to rheumatic fever and other health conditions.
- **The value of both community-led and health system-building approaches:** Both community-led and health service-oriented solutions are needed to address health inequities.

What have we learned from the co-design process for ways of working in the wider health system?

For the health system, the key value of Māori, Samoan and Tongan-led process is that they will reveal responses that the mainstream system has been unable to uncover. The co-design teams developed responses to rheumatic fever prevention and management that offer directions that challenge established system responses, including:

- Culturally-specific and strengths-based communications of rheumatic fever
- Building strengths-based approaches that give whānau skills and legitimacy in preventing and managing rheumatic fever, and signposting more culturally responsive practice for health systems
- Acknowledging the experience and stigma of managing the disease and providing a space of holistic healing
- Activating leadership in different settings to provide comprehensive responses to rheumatic fever.

Each of these offers challenges to existing practice and mindsets.

So having the youth who have rheumatic fever being able to share that information the way the youth understand will be useful and for them to have that awareness of what they need to look out for. I think it's quite a powerful tool because it's not something us as adults and us as adults who are sitting in the GP clinic have at all, to be honest. We like to think we have the power, the knowledge and the education and the treatments and stuff but that alone hasn't fixed the problem that we've seen in the last 10, 20 years. [clinical advisor]

Furthermore, it is not simply that these prototypes have wider health system application. It is that Māori, Tongan and Samoan teams were able to proactively uncover new and innovative responses that indicates the value of entrusting those with the knowledge of their communities to develop responses that can create positive change.

Promotion, awareness in the community to prevent it from happening in the first place and being empowered to say actually I want the other treatment, I don't want the tablets, I know there's another one. So then it's not only just the clinician who has the information and knowledge, that actually the patients, the community know what they're supposed to have and not have and actually ask for it and so it's more of a relationship rather than a one way [clinical advisor]

There was also the acknowledgement that other Māori and Pasifika experts and community leaders had also worked on rheumatic fever initiatives in the past. Early on in the forming stage, there was some underlying concerns of not wanting to 'step on the work that had already been done' and to keep the va, moving forward into the future but giving credit to their past collective efforts, whilst still breaking new ground with the co-design.

The work undertaken with community members was acknowledged by one co-design lead:

Now we gain their trust and I think now they're living with expectation that we're going to continue this to suppress those waves that they become buried under them, we will continue to make it happen. I think that's what we are dealing with right now. [team member]

Co-design approaches such as The Southern Initiative based at Auckland Council are a rare exception to this and notably occur where the co-design function is itself embedded within a lead organisation (Hagen et al. 2021).

Overall conclusions from the co-design

The rheumatic fever co-design reveals the value of surfacing new approaches that are grounded in the cultures and experiences of affected communities, in a way that mainstream services are unable to fulfil. Each co-design team was able to work from its strengths to develop new and innovative solutions, that challenge professional practice and build community knowledge and capability to prevent and manage rheumatic fever.

We can see clear signals of value being found by communities and practitioners in the prototypes developed by all three co-design teams, and potential for scaling. The extent to which that value and potential is realised will depend on how the health system is able to embed, sustain and grow these innovations.

The experience of the co-design highlights the importance of ceding leadership to those with cultural and community knowledge and networks; and in the process, to work alongside and awahi the teams to enable them to succeed.

Building new and innovative solutions outside of the mainstream system takes time, and these prototypes remain at an early stage. They are not yet at a point where their impact can be measured; we expect however that the process of further embedding the prototypes will lay the foundations for future monitoring of impact and value.



PART 2:

Findings from Te Tīma Māori

Te Tīma Māori approach

Te Tīma Māori used a Kaupapa Māori approach for the co-design that was deeply grounded in Te Ao Māori. The team came from a range of backgrounds, holding a range of skills and expertise that strengthened the co-design process. For example, “tikanga, community (hapori) and Te Ao Māori within government”

Wairua and wairuatanga as Māori it's really the foundation of who we are! So, what has really enabled us coming together is a few elements. The first is that the kaupapa has been grounded in Ngāti Whātua, that has been really important. And the context of place, you know, where we are, who we are, the whānau that we are serving, the relationship that whānau have with the whenua, with the moana, I think that has been incredibly important.

Our focus wasn't on Ngāti Whātua at all, it was spread across Tamaki. And while we definitely have a bias towards Ngāti Whātua, I can't say that any of our whānau that we interviewed were Whātua. [We connected through kura, to whānau that were living with rheumatic fever in the community.]

Also, in relation to this team, what you have around the table is some really diverse experiences, [team member]

Their Ngā Mātāpono (design principles) and Tikanga Matatika (ethical framework) were premised on intergenerational and strengths-based Māori wisdom. The safety and wellbeing of the whānau was at the centre of their entire process and the resulting prototypes.

They can be safe knowing that their whakaaro and their kōrero can be honoured, by placing that within a context where the wider whānau and their tupuna are honoured, their mokopuna, that sort of more holistic way of looking at things. [team member]

At the time of writing, Te Tīma Māori had only recently completed their prototypes and are in the early stages of promotion and circulation. This section therefore draws on interviews with Te Tīma Māori leads and documentation to reflect on the development journey, the learning from the co-design and perceptions of the significance of the co-design, and the prototypes potential to bring about change in different ways.

Deep whānau engagement, supported by relationships

Te Tīma Māori co-design team deeply engaged with whānau throughout the co-design and prototyping processes in mana-enhancing ways. The relationships and trust developed between Te Tīma Māori and whānau

throughout the process meant that whānau were open and honest about their experiences with rheumatic fever, providing new insights from which to develop truly community-led prototypes.

They could feel Māori in the way that we were rolling as a team, in the way that the interviews rolled, so that we could be like yes we are here we are Māori and we are running a Māori process. And we want you to feel comfortable in that process and safe so that you can share with us and know that we will deal with your stories the best that we can and develop some prototypes that will help people. That was our main kaupapa. [team member]

At every stage, Te Tīma Māori checked and rechecked with whānau what was being developed and shared and this enabled trust and authenticity of the insights of the co-design process. Te Tīma Māori reported that whānau were happy with the prototypes and that whānau believed the prototypes were reflective of their experiences of living with rheumatic fever.

Our kōrero with whānau were safe and open, and there was a whanaungatanga that was laid down and it was just them in a tika way! Even though the majority of our interviews were done over zoom, because unfortunately it was in the time of covid. But it still provided that opening and that safety and it allowed them to be tau, and open in the process, that's what I felt and saw. [team member]

Innovation through Kaupapa Māori co-design processes

Framing the co-design process with Kaupapa Māori design principles and ethical frameworks introduced innovative aspects into what are usually western processes. While the processes used were not innovative from a Kaupapa Māori perspective, they drew on traditional Māori knowledge and practice, and having them as part of a government-driven initiative introduced innovation. For example, developing a Tikanga Matatika (ethical framework) that was based on traditional rongoā to ensure whānau stories were gathered with “intention and care”.

The Tikanga Matatika framework led Te Tīma Māori to create a karakia as part of the co-design process to support data sovereignty and create “safety and protection around the stories that we were hearing”. As the co-design progressed, the karakia evolved into becoming the foundation for the entire co-design process that followed. In addition, the karakia became in itself a prototype to disseminate knowledge about rheumatic fever. The karakia became a touch point for Te Tīma Māori across all elements of engagement and development, and accompanied the stories that were shared.

A further example of innovation in the co-design process was the use of live illustration of whānau stories, which highlights the value of creative media to support engagement.

They want to be heard, they wanted us to know what the classroom, what the community and what the whānau are going through. And because they see it all, you know, they see it all. One of the big things that really hit me is that not only were people talking about rheumatic fever, but they were talking about the impacts on their whānau and their community. That was really, really, that was a theme that came up time and time again. [team member]

Innovative new approaches grounded in Te Ao Māori

Three prototypes were developed from the co-design process.

- Creating a karakia (Te Kura ā Rongo) as a taonga that disseminates intergenerational knowledge and captures the cultural integrity of Te Tīma Māori and whānau
- Developing a series of kiriata (videos) titled ‘Ko tō Manawa, ko tōku Manawa’ for tamariki Māori about rheumatic fever prevention and management for kōhanga reo and kura kaupapa
- Developing language guidelines for media (Kōrero Whakamana) as a resource for media and health professionals to support them to talk to whānau Māori about rheumatic fever in a safe mana-enhancing way.

These prototypes are innovative and community-led for two reasons. Firstly, they take rheumatic fever prevention and management outside of the health sector and into other arenas that whānau living with rheumatic fever identified as being barriers and challenges they had experienced. The solutions were grounded in what whānau expressed they wanted and needed, rather than reflecting how the current system is oriented.

These kaupapa here, rongoā, were all things that we were bringing to the party, these were the things that were really important to us in terms of the karakia. We heard from the interviews is that tuakiritanga is the most important, their identity within themselves, but also their identity living with rheumatic fever as well. The different insights helped us uncover the depth of whānau living with rheumatic fever. Such as wairuatanga and how within te ao hauora wairuatanga isn't necessarily something that is talked about, more so a feeling and presence. [team member]

The co-design process gathered insights about the experiences of whānau with rheumatic fever and the resulting prototypes privileged their moemoeā (aspirations) for their whānau and community. As a result, one prototype was designed to be used within the education sector, rather than the health sector. The kiriata for kōhanga reo and kura is a preventative tool designed to disseminate knowledge about rheumatic fever before they reach the at-risk age.

Secondly, the prototypes reflect Te Ao Māori approaches by using traditional Māori knowledge, encouraging intergenerational change, being strengths-based and holistic. For example, the karakia is a uniquely Māori way of disseminating information and supporting whānau safety that feedback indicated was absent from the current health system.

We chose to be different with this kaupapa, but different in a positive way. So just like I said, we are used to the deficit way of sharing, used to the deficit whakaaro. So actually, getting the moemoeā brief was being rebellious in this kaupapa, going against the grain. No, we are not going to focus on the deficit around rheumatic fever, we are not going to focus on the negative, we are going to focus on the dreams of our people. And that stuff fell out of there, so while they are talking about, I don't want to feel whakamaa at school, I don't want to be shy in school, I don't want to do...Or I want to feel empowered, I want to feel safe. I want to feel empowered. I want to feel strong. I want to play sports. [team member]

Early signals of system impacts

Contribution to the Rheumatic Fever Roadmap

Te Tīma Māori believe the inclusion of Te Kura ā Rongo in the Rheumatic Fever Roadmap is itself a significant signal of system impact. Further, they felt the karakia was treated as the taonga it is, through the acknowledged recognition by Te Whatu Ora in the roadmap.

They saw the importance of it in the rheumatic fever roadmap that they were developing at the time, and at that point it was going bigger than our kaupapa here in Tāmaki. And showed a dedication to the eradication of rheumatic fever. But also showed a dedication to a Māori way of being, which we really appreciated. [team member]

Enabling community leaders and whānau to take action

Te Tīma Māori reported that an early system impact of the co-design process was that the Kaupapa Māori co-design process created the conditions and permission for people to take action in a system that has not always celebrated and empowered Māori.

Just advocating, advocating for their whānau, for their tamariki, for their whare, for all their people. Empowering them too, like the whānau that coordinated their son's shots to be a specific day so that it didn't take him out of softball, or sport. Really remembering that, ka taea — you can advocate for your whānau in the system. With aroha of course. [team member]

The kiriata provide an important statement and articulation that leadership in health can also emerge from within whānau and communities, and not simply from sector leadership. Those leading and supporting the design and delivery of te kiriata provide a voice to the community and the sector that their actions in their own lives and those of others have agency and can address the health challenges we face.

Positive early engagement with resources

It is too early to identify how effective the prototypes are because they are only just at the early stages of circulation. However, whānau involved in the co-design process reportedly were positive about the prototypes and felt genuinely engaged. For example, Te Tīma Māori identified that the pre-testing at kōhanga reo was positive with tamariki engaging with the kiriata and the messages they contained. Te Tīma Māori also reported whānau appreciation of Te Kura ā Rongo as a taonga that supports their rheumatic fever journey.

All resources are intended to be widely available for use. The karakia is already being used in reports and documentation, the language guidelines will be available on Te Whatu Ora website and the kiriata have been produced in te reo and as a bilingual resource to support wider reach and distribution.

The karakia has been gifted to a wide range of people who have contributed to this kaupapa. It opens the national Rheumatic Fever Roadmap that sets the government priorities for tackling rheumatic fever. It opens and closes the kiriata we have created (refer to Prototype 2) so it is getting into the hearts and minds of our tamariki. (Te Tīma Māori 2023 report)

Showcasing effective engagement with whānau

Te Tīma Māori and ThinkPlace identified that the prototypes demonstrate excellence when “communicating with Māori, in Māori aligned ways”. This is likely to increase the chance of system impact. They are based on what whānau with rheumatic fever identified would support them and reduce the barriers they experienced. This in turn gives the prototypes credibility and validity. The prototypes take a strengths-based approach, focusing on what will support whānau and what people can do rather than the problems or deficits encountered. The language guidelines in particular provide expertise and information for clinicians and media that they would not otherwise have access to.

It's not a lack of awareness around the cultural competency and cultural responsive services, it's actually a lack of knowledge around how to practically do that in really accessible ways. [programme lead]

Scaling and sustainability from Te Tīma Māori prototyping

Given the early stage of implementing the prototypes, we can only point to the potential for scaling the prototypes sustainably. However, the following points were highlighted by Te Tīma Māori about what would support successful scaling and sustainability.

- Distribution of the developed prototypes uses existing infrastructure e.g. kōhanga reo, kura and community leaders. This supports a more holistic approach to rheumatic fever prevention and maintenance because it is not just the health system actors who are involved, but the wider community. The use of existing infrastructure also is likely to speed up how the prototypes travel.
- Similarly, successful scaling is supported by leveraging existing connections and relationships. For Māori, the experience of historical trauma can mean that they have less trust in the health sector. So having the prototypes travel through existing connections will support greater uptake because trust already exists. In addition, sharing culturally grounded prototypes through culturally grounded connections reinforces and supports fidelity to the kaupapa.
- Prototypes will be easily accessible and widely available. Sharing the kiriata to the education sector has the potential to reach many tamariki and whānau nationwide. Similarly, having the language guidelines available on Te Whatu Ora website makes them easily accessible once potential users are aware of them.

Scaling potential of Te Tīma Māori prototypes

In their final report Te Tīma Māori identified future possibilities for each of their prototypes. **Table 2**, on the next page, details the scaling potential for Te Tīma Māori prototypes.

TABLE 2: Scaling potential for Te Tīma Māori prototypes

Scaling type	Te Kura ā Rongo (Karakia)	Ko tō Manawa, ko tōku Manawa (Kiriata)	Kōrero Whakamana (Language guidelines)
Scaling out	A cultural underpinning that speaks of aspirations for whānau in rheumatic fever and can be adopted in wider sector activities by whānau, clinicians, and other stakeholders (encouraged by Te Tīma Māori).	Distribution and use across kōhanga, kura and other hapori Māori (community) settings.	Distribution and promotion to sector networks to support engagement.
Scaling up	Potentially a touchpoint for wider sector service design and engagement relating to rheumatic fever.	Applying the principles of the resource within wider health sector settings so that meaningful engagement with whānau is supported and the wider challenge of systemic inequities in health are acknowledged and responded to.	Support and adoption of guidelines by sector leadership to enable greater engagement by clinicians and service planners.
Scaling deep	A cultural underpinning across co-design activity, used across many settings and embedded within the roadmap. Potential to be further embedded within rheumatic fever-related sector activities.	Effective distribution and promotion of the resource so that its messages and meaning are embedded with whānau and hapori. Looking into the future, we picture a world where today's tamariki are sharing the stories of the kiriata with their whānau, where the saying "Ko tō manawa, ko tōku manawa" is commonly used. Eventually, this can help to release the hold that rheumatic fever has had over our people and bring light to whānau. (Te Tīma Māori report)	Sharing guidelines widely with sector staff, colleagues, stakeholders and providers to ensure there is widespread understanding of engaging with whānau and enabling change and reducing stigma and alienation with health services.
Te Koha	The karakia was initially seen as a koha to participating whānau, and was a key foundation to the whole process.	Te kiriata as a koha to communities and the sector that reflects qualities of aroha (love, affection); humārie (humility); rangatiratanga and mana (leadership); whakapapa (kinship, connections and history); tauutu (reciprocal obligations); whanaungatanga (relationships and context) (Wehipeihana et al. 2022).	Provision of guidelines to the sector as a koha that enriches practice and ensures people are not receiving information in a way that is harmful and disengaging.

Learning from Te Tīma Māori co-design

Space for Te Ao Māori-grounded solutions

Te Tīma Māori and ThinkPlace highlighted the value of the Kaupapa Māori co-design process as a key learning. In a predominantly western system, creating co-design spaces that are grounded in Te Ao Māori enables people to be unapologetically Māori and understood and celebrated as such. This ensures greater credibility of the prototypes and also enables Te Ao Māori-grounded solutions.

We have never had to defend Kaupapa Māori here, because everyone is Māori. Sometimes you have to justify and reason your way through thinking that Kaupapa Māori is the way forward. But because we are Māori, we never had that resistance. [team member]

Solutions to challenges experienced by Māori exist within Te Ao Māori and we need to create the space and resource for Māori practitioners and experts to appropriately utilise that knowledge. (Te Tīma Māori 2023 report)

Reinforcing the holistic and intergenerational approach of Māori

Basing the co-design process on the moemoeā of whānau-enabled strengths-based prototypes that reflect and reinforce the holistic and intergenerational approach of Māori.

That was one of the key insights that we had, framing that in the positive and utilising the strengths of the whānau and building on that. [team member]

The prototypes were not just about the individual and their management of rheumatic fever, they were also about making things better for all now and into the future. Connecting with other sectors (e.g., education, media) to share messages about rheumatic fever management and prevention is a holistic approach that reflects the value of joined up initiatives that can complement and reinforce each other.

This is intergenerational, this is not just today and then hope for the best for this generation. But we do it today and hope for the best for all generations to come. Hence the video, and that is a way of us intergenerationally passing down. [team member]

Strong and trusted relationships enabling successful co-design

Relationships and trust were a foundational aspect of the co-design as well as an integral part of the prototyping. Te Tīma Māori had strong and trusting relationships with each other as well as with Te Whatu Ora and ThinkPlace. Their starting place with whānau participating in the co-design was to build trust and relationships that were grounded in tikanga. These strong and trusting relationships created buy-in and engagement by everyone involved and created the conditions for developing the innovative, culturally grounded prototypes.

We had high trust from the beginning, not only from ThinkPlace but also from Te Whatu Ora. They enabled us to really push the boundaries as it were in a range of ways, I think that they were quite up front with us that actually this is a new opportunity, an opportunity that our whānau hasn't had before. And a key part of that is actually believing that whānau themselves can contribute to having the answers, that solutions can come from whānau. [team member]

Learning for the wider health system

Engaging with people living with long-term conditions

A key insight from Te Tīma Māori prototypes is the value of engaging with people who are living with long-term conditions when exploring solutions to prevention and management.

Whānau living with rheumatic fever, through sharing their experiences identified the key challenges they live with and what would support them to realise their aspirations. The prototypes developed to respond to whānau needs are not health responses. They are responses that support prevention for future generations, that create a culturally grounded strategic health communication and awareness raising tool and enhanced their mana by seeking to change the language that was applied to their situation. These responses identify the worth of looking beyond the health system for those living with long-term conditions.

It's about serving whānau, and it's about...well really, what the most important thing about this whole kaupapa is that it is about listening to whānau. It is about understanding their aspirations, their insights, their wisdom, their expertise. And you know, really privileging that to help create a pathway through, a pathway forward. [team member]

Disseminating knowledge in creative and culturally grounded ways

Te Tīma Māori co-design process highlighted the benefits of sharing information through culturally grounded and creative means. Whānau engaged in the process deeply, in ways that is not always achieved in co-design processes.

The karakia and kiriata prototypes are examples of sharing knowledge in creative and culturally grounded ways. Early indications are that these prototypes are appealing to tamariki and whānau, likely because of their cultural grounding and creative approach.

Our whānau don't feel connected to the health system, at all, or feel safe in our health system. So how do we find a way for them to connect, through pūrākau. You know, tell the story that they are familiar with, to create a social cohesion to the health system. If our whānau are connecting through stories it becomes a bit more familiar, a bit closer to home. Otherwise it is just a lot of unknown jargon, unknown language. [team member]

They grasped it [the karakia] straight away, no worries. With the reo they had, it was beautiful to watch their reactions of how they listened to the karakia and it went right in, you could see its going in, it's not just surface, that's the power of karakia. [team member]

Taha wairua as a critical part of the identity of many Māori

A key area of learning from the co-design process was the absence of taha wairua from the health system in general. Te Tīma Māori created Te Kura ā Rongo as a direct response to this gap. The karakia was well received by whānau and also guided the entire Te Tīma Māori process.

Within te ao hauora, wairuatanga isn't necessarily something that is talked about. And so that is what we wanted to bring in, that was one of our first rau on the vine, and that's where the karakia came in. [team member]

Exploring ways with Māori to authentically integrate wairuatanga into the wider health system is potentially an area of discussion for future initiatives.

PART 3:

Findings from Lomipeau

Background to Lomipeau

Lomipeau — the wave-cutter

Lomipeau is the wave-cutter, a double-hulled canoe that sails around the Pacific. The Lomipeau team used the wave cutter analogy to communicate suppressing the wave of rheumatic fever and creating lasting change.

The Lomipeau concept draws on the idea of the challenges of sailing from one island to another, and the Lomipeau helps navigate these stormy seas. Rheumatic fever is similarly full of uncertainties, and navigating through rough seas is a metaphor that resonated with the participating Lomipeau kainga.

There are a lot of uncertainties sailing from one island to another or sailing from one to your destiny and it seems to us that rheumatic fever is also the same.
[team member]

Underlying Lomipeau is the Hao-haoā model; centring on wellbeing in the short term (hao) and long-term (haoā) — the short-term in the sense of the immediate needs of families, and the long-term in the sense of sustained approaches to preventing and managing rheumatic fever. Extending the wave-cutter approach further, if we are to reach the island safely it's important to invest in the long-term, rather than simply short-term initiatives.

The Tongan concept of freedom — tau'ataina — comes from the idea of lifting the anchor and putting it on the board and to sail safely from one port to the next. The anchor provides a boundary to enable people to sail safely within that freedom.

The naming of rheumatic fever is important — it was known as mofi hui or mofi ama (fever of the bones, fever of the heart), which are naming the symptoms. Lomipeau are looking to establish use of 'mofi lumitika' to name the disease itself and how to understand it.

Co-design process

The co-design approach is intended to bridge the clinical and Tongan thinking systems. This concept acknowledges the power distance that exists between experts and everyday people, and who may feel they lack the authority to question. The co-design is founded on bringing the lived experience and insight of Tongan kainga to shape new responses to rheumatic fever.

Co-design was seen as an important way of bringing a community voice and community-led solutions to challenges facing our communities, in a way that

can be sustained rather than as a one-off programme. The episodic nature of rheumatic fever management was identified by a clinical advisor as a key limitation of current clinical approaches:

when I look at it from a clinical side and looking at rheumatic fever and stuff, I'm like we've always had these interactions which are pulsated I'm going to call it. We come in then we went off. We come in then we went off. That doesn't work for our people because it's in front of sight and mind when we hear about it so when it's gone out of sight out of mind it means it doesn't exist anymore. Rheumatic fever has disappeared. So we know that has to be consistent, longitudinal and repeated over and over again. [clinical advisor]

The co-design provided the opportunity to tap into Tongan indigenous knowledge, by canvassing different concepts and approaches, and challenging existing narratives, such as the dominance of discourse on poverty and overcrowding.

Central to the approach was direct engagement with Tongan kainga, including virtually through lockdowns. For many Tongan families dealing with rheumatic fever, this is one of many pressing issues they face. However, those participating in the co-design recognised a common call that held the participating families together to develop approaches that can sustain families in the future.

The team were conscious of not over-reaching in what was being asked of Tongan kainga in their participation in Lomipeau. They therefore also looked to build on work that was done before, particularly in the Pacific health space.

It was noted that many families didn't want to talk about rheumatic fever; there is shame and fear of rheumatic fever because it is categorised as a disease of the poor and overcrowded families. But those who participated shared freely, even though this was often a raw space for these families. In their talanoa, the Lomipeau team took an empathetic approach, building a safe space for families and trusting relationships.

Early signals of system impacts

Establishment of youth peer-to-peer networks

Youth Champs is a peer-to-peer network that has leveraged learnings and insights from earlier phases of Lomipeau. Youth Champs looks to create a supportive and trusting network for service users and their whānau and provide regular opportunities for network members to connect, share experiences and access information. This network provides the opportunity for young people of different ages, all of whom have had rheumatic fever, to come together in a place that enables connection, confidence and learning.

Youth Champs started as a psychosocial support prototype for young people, and which has extended its role and value. An early finding of the co-design was that the trauma of rheumatic fever is something that requires more than just treatment, and instead needs something that brings a sense of healing; this is a central theme of Youth Champs activity. Healing was seen as an area that was lacking in current rheumatic fever service framing, and which a treatment paradigm didn't enable.

One of the reflections about it is that the approach to managing and preventing rheumatic fever has always been just about health, not the wellbeing..., and the wellbeing is a lifelong condition. [team member]

The confidence that has gradually emerged among young people was described by programme leads as inspiring. Those with rheumatic fever are often depressed and isolated, but have been drawn out through peer-to-peer activities. An example was given of one participant who became a youth activator, and is showing a huge turnaround with the growth in self-belief and confidence. The healing paradigm was seen as more than connection and confidence building; whilst rheumatic fever can bring families around a common need, it can also create stress and more trauma. The healing paradigm was therefore seen to be supporting rebuilding in familial relationships.

Key features of Youth Champs, from the perspectives of project leads, are:

- Enabling confidence and social connection to each other, building friendships through shared experiences, and in the process helping overcome fear and shame
- Building an understanding of their capabilities in living with rheumatic fever; enabling activation of their "God-given" talents – building resilience and navigating through life
- Potentially acting as a channel through which other forms of support can be activated for both young people and families
- Undertaking Faiva activities, encouraging song and theatre, to tell stories and tapping into health as a sacred thing.

Youth Champs enabled a range of activities, and also an opportunity to "just chill" in a setting that looks beyond the challenge of rheumatic fever and instead offers new hope.

We all know this about youth development but a lot of them just want to chill. A lot of their spaces, like in the last two ones, it's just chill out, like there's no planned activities, they just come and chill out and do whatever and it's in those moments that they can access, I mean connect with each other. [team member]

Looking ahead, it will be important to preserve and strengthen what works about Youth Champs for young people, so that it doesn't get supplanted by multiple new aspects from outside and lose its essence.

A safe space to connect and share

An important aspect of Youth Champs is creating a safe environment where network members can connect and share their experiences. Conversations with network members indicate that the programme has achieved this by:

- Providing fun and engaging opportunities for members to connect
- Bringing together individuals with shared experiences
- Creating connection through culture.

Providing fun and engaging opportunities for members to connect

Network members described Youth Champs as a 'safe' and 'fun' space to connect with others and enjoy respite from the day-to-day pressures and challenges that can accompany living with rheumatic fever. One kainga member explained that interventions and interactions relating to her sister's condition were often "sad" and heavily focused on technical aspects of rheumatic fever like symptoms. For this participant, Youth Champs was seen as a positive environment where network members could relax and enjoy themselves.

These kids have been through a great deal and the last thing they want to do is come to another serious, sad [thing]. Every time we talk about it it's always about the symptoms, it's always about her experience and it's nice to just be in this space where you don't have to explain. [kainga member]

Network members reported that their family members living with rheumatic fever had "come out of their shell" as a result of the Youth Champs programme. Both participants reported friendships emerging from the programme despite both young people being very shy generally.

He's still shy like because he's just a shy boy naturally but there are moments where I can just leave him, and he'll just go hang out with the friends that he's made through here. I've been really happy to see him make friends with people that have the same thing that he does. [kainga member]

Youth Champs has created a safe space for young people to connect and share, but it has also created a safe and positive environment for mothers and family members too. One mother described Youth Champs as an opportunity for her to spend time with other mothers and relax, knowing that her son is taken care of and having a good time:

Like selfishly, in my mind I'm just like yes, I can go and meet up with the other mums because I have other children at home too and so this kind of gives me my balance. It's good to get to exchange stories and sometimes we gossip about our husbands and it's just that time that we get to vent. Our kids are together having fun, we don't have to worry and then we just get to sit there and have our own little sessions. It's a nice, I love this space. [kainga member]

It could be all the emotions underneath the sun, but we all walk out with a smile on our face and like I do, I feel relieved, I just feel like, okay I can go another month. [kainga member]

Team members acknowledged that creating a similar space for fathers is a natural extension of this work:

What had naturally happened was that the mothers that would bring their young people did their kind of informal own peer to peer support group on their own, ..., so how can we support that and then what does it look like for the males in these people's lives, because it's the mums have their space so how do we explore that part. [team member]

Bringing together individuals with shared experiences

The opportunity to connect with others who have similar experiences was seen to be an important factor in making Youth Champs a safe and inclusive space for network members. One parent said that being around other young people with rheumatic fever has meant that her son "doesn't have to be someone he's not". A shared experience with rheumatic fever allowed her son to connect quickly with other youth in the group:

It was really easy I think with him and one of the other children in there. My son is really shy at times, just knowing that this other child got rheumatic fever, he's like 'Oh, we're the same mum'. [kainga member]

Another participant spoke about her sister feeling more comfortable connecting with others who live with rheumatic fever and valuing being connected with a community that she wasn't aware existed before she joined Youth Champs:

I think the biggest thing for her is that everyone here knows what she's been through. I get people are curious when she tells them that she's had rheumatic fever and I think she's gotten to a point where she's sort of sick of having to explain it. I think that's what she's most excited about, it's one layer less to deal with when she comes into the group. And also, connecting with other young people that are just like her. We didn't know anyone else before Lomipeau and I didn't realise there was a Tongan community that was out there. [kainga member]

The importance of this ability to connect on common ground was also highlighted by a clinical advisor to the programme, who noted the value this offers youth who often feel quite isolated because of their experience of rheumatic fever, and the support it provides to ongoing engagement with managing rheumatic fever.

I mean it's hard for the youth in general isn't it without having to have the complication of actually having a disease that's going to be with you for another 10 years minimum or more, depending on the complications and I guess that's also the navigation of support, making sure that you do have your injection or if there are complications who else they can talk to [clinical advisor]

Creating connection through culture

The third element that participants identified as important in creating a safe space for network members to share and connect was the cultural focus of Youth Champs. Participants spoke about Youth Champs as a way for them to connect with other Tongan people and to engage with aspects of their culture such as learning and speaking the Tongan language. The ability to connect with their culture also created a bond between participants that one network member described as "family outside of my family".

My son is half Tongan, and he hardly goes to his Tongan family. My husband's amazing but he's not really close with his Tongan side. Being with other Tongans, it gets him to learn his culture, if that makes sense. My kids are more Tokelauan than they are Tongan but being in this group, he goes home, and he speaks a little bit of Tongan to his siblings. [kainga member]

Overall, it was clear through discussions with network members that Youth Champs has successfully created an environment and a network that leverages opportunities for respite, shared experiences, and cultural connection to give people with rheumatic fever and their families an opportunity to connect and engage in a meaningful way. Participants expressed their gratitude for the ability to connect and engage in this way.

In Tongan society, ancient knowledge is transmitted through faiva, through stories, song and dance. As part of the prototyping, Lomipeau composed a song, working with a Pacific New Zealand Symphony Orchestra musician, that speaks to the feeling and emotions of rheumatic fever. Using music creates something that can be left behind for future generations to use and connect with. Rheumatic fever is intergenerational, it is not just those living with rheumatic fever, but their families as well and the music can connect the generations. This song was performed at the celebration evening by the Youth Champs, with families and supporters attending. The performance clearly was an emotional one that deeply connected with those attending the event, and the words and symbols behind the composition resonated with those attending.

We tapped into that, the ancient knowledge of using music and then that's something that we leave behind after this funding round and hopefully develop, because where we want it to go is that okay when people hear it, like the grandparents and the older rheumatic fever survivors, both here and in Tonga, they go "Oh, this is about rheumatic fever." It's top of mind for them. Instead of thinking of it as a published report in a way, this is something that it has longer term resonance to the families here about rheumatic fever. [team member]

The importance of faiva in providing a means of transmitting knowledge was acknowledged by a clinical advisor:

So what do we do in our culture? How do we repeat history from the present day into the future or from the past and future? We do it from words. We do it from our songs. ... So when the Youth Champs group decided that that was something they were going to do, it's having something that's long lasting, that's not just for today, that this could continue on even if this project disappears. That's not going to disappear. That song is going to be shared amongst the community and known as that song that was produced for that reason and if we continue on that community of trying to maintain keeping rheumatic fever in mind, that will stay with it. [clinical advisor]

Accessing and understanding information

Another core component of the Youth Champs programme was providing a way for network members to engage with information and resources relating to rheumatic fever and to connect them with experts that can provide advice and support. Conversations with network members indicated that Youth Champs provides more accessible ways to access information and advice, and is a motivating factor in seeking out information and advice.

A more accessible way to access information and advice

One participant spoke to the challenges that can accompany receiving and understanding information and advice following a rheumatic fever diagnosis.

This participant found it difficult to receive information in written form and much preferred being able to speak about what was going on for her and her child. Youth Champs provided an important avenue for her to speak with other parents and with experts about what was going on for her and her son.

It's actually helped me — we compare stories, it makes me think of ways that I can come up with my own coping mechanisms, and know it's okay to ask for help. To be honest, I'm not a reader. I would rather we do every session, comparing stories, [talking to experts], who talk more in-depth about certain things. [kainga member]

When asked if she felt she was getting the information she needed prior to Youth Champs, this participant said that she was not.

Youth Champs as a motivating factor in seeking out information and advice

One participant described herself as “not very studious” but spoke about Youth Champs as a motivating factor for learning more about rheumatic fever and seeking out information so that she could better support her sister and explain her condition to others.

When my sister was diagnosed and we were going to have to look after her, I didn't really learn much about it, all we knew is that there was something wrong with her heart. But being here and seeing other young people, it just reminds me of how much love I have for my sister and that's what pushed me to get to know more about her condition. I found myself the other day sitting there writing notes and I was like oh my God, I'm studying! [kainga member]

Challenging cultural norms about sharing health related information

Participants shared stories about the Youth Champs programme changing attitudes and behaviours around speaking openly about medical issues in the Tongan community. They spoke about a tendency for Tongan people to avoid speaking about, or to downplay the seriousness of medical issues. One participant reflected that this made Youth Champs feel “kind of weird”, because it was a space where Tongan people felt so comfortable and open to speak about their own experiences with rheumatic fever. Despite these cultural norms, network members spoke about sharing their own experiences and supporting others in their communities outside of Youth Champs as well as seeing the value of talking medical issues seriously.

We also have a cousin; she was also diagnosed with rheumatic heart fever. When she was diagnosed, she came and asked my mum for support and so that's how they did it. I was still young, but I know it really took a toll on them because they were both, had moved over from the Islands and everything was just new. No one talked about health issues. It's like a cultural thing. We don't talk enough about our health. It's sort of like “I've got a headache.” Oh well. But I was happy that my Auntie was able to have my mum for their support. [kainga member]

Scaling and sustainability from Lomipeau prototyping

Scaling potential of Lomipeau

Youth Champs is potentially seen as something that could be taken to other settings like Langimalie and Tongan Youth Society. Opportunities include the following:

- connecting to health services and rheumatic fever management through the network; but at the same time it is important not to lose the essence of what it is as a place of connection and healing
- sustaining the prototype – scaling out and potentially deeper over time as well, so that it has the potential to grow more widely in its delivery (scaling out) but also more deeply with existing participants (scaling deep).

Succession planning will be needed as the participants grow older and move to other things; one of the Youth Champs participants moved to a support worker role with the guidance of a youth worker, and this was seen as a starting point for building resilience in the initiative.

A notable offshoot of Youth Champs, that has alignment with scaling deep, is the extension of peer connection between families, with the formation of an informal mothers group that enables them to connect on their experiences of rheumatic fever.

Youth Champs network members reported high levels of satisfaction with the core components of the programme. When asked about potential areas for continued, future investment the following areas were seen to be important:

- Participants appreciated the vouchers to support transport costs and would like these to continue in future.
- Sharing food was seen as important for building connections and was another aspect of the programme that network members felt should continue.

“Definitely the breaking of bread. There’s a Tongan saying ...and that means that the food tastes better when it’s shared or when there’s more people. Obviously, food is yum but what the saying says is the food tastes better with company and we always take that value, when we meet we always have food there, we always break bread, that’s how we show our love. [kainga member]

Network members also identified a number of minor improvements that could be made for future iterations of the network:

- Extending support to babysitting services or financing to make it easier for parents to engage in face-to-face sessions with the network.
- Increasing face-to-face opportunities and exploring ways to support the consistency of attendance at these engagements.
- Exploring ways to create natural, casual interaction opportunities such as loosening requirements around registration forms.

“Maybe a little bit more outings and maybe a night where the mothers can just enjoy themselves, I don’t know, and then they can get free babysitters.”

“There are definitely things that could work better but it’s honestly out of everyone’s control. One would probably be just inconsistent numbers, just because a lot of our young people are getting sick and they’re just more vulnerable. I don’t think I would change much.”

Table 3, on the next page, details the scaling potential for Lomipeau prototypes.

TABLE 3: Scaling potential for Lomipeau prototypes

Scaling type	Peer to peer network (Youth Champs)	Faiva and youth videos	Celebration evening
Scaling out	Establishing similar peer to peer networks in other Tongan communities or organisations; testing potential for similar peer to peer networks in other Pacific communities.	<p>Composition of song on the experience of rheumatic fever which was performed at the celebration event.</p> <p>A further offshoot from Youth Champs was a series of engaging videos of Youth Champs youth filmed in TikTok style to communicate rheumatic fever management to families.</p> <p>Scaling out would involve developing more videos over time and distributing through Tongan youth and health channels, across different areas of rheumatic fever management and prevention.</p>	Replicating performance events across other Tongan youth settings through expanded Youth Champs programme.
Scaling up	Incorporation of youth peer networks in potential future activity signalled in the Rheumatic Fever Roadmap.	Promotion of song and videos aligns strongly with Tongan Faiva tradition where generational wisdom is transferred through song and dance. This has potential to reach into leadership in Tongan communities, such as churches.	Has the same scaling-up potential as the Faiva and youth videos.
Scaling deep	<p>Strengthening the depth of engagement of young people in the initiative so they can navigate rheumatic fever and their life course with confidence.</p> <p>Building a broader connection among the families of participating young people to better understand rheumatic fever management, and to support their loved ones and each other through navigating rheumatic fever.</p> <p>Connecting health providers to Youth Champs young people to better understand the experience of rheumatic fever and how care can be managed with respect, dignity and hope.</p>	Using song and dance as a way of transmitting knowledge on managing and preventing rheumatic fever.	Using Faiva as a way of directly communicating hope and potential of living a full life with rheumatic fever to families, and to further build confidence and connection of young people in the programme.

Learning and pivoting from the co-design

A wellbeing hub was an early prototype that was envisaged through the co-design. An emergent learning however was that it didn't need to be a physical space, and the relational space provided by Youth Champs was an approach that activated the wellbeing focus.

In early stages, an app was envisaged within Lomipeau, but this proved not feasible to implement and its purpose wasn't clear, not the difference it would make compared to other technological offerings. Youth Champs has emerged as a stronger focal point for activity.

Prevention of rheumatic was a starting point for the overall initiative; however this became seen as more of a system response, and in the Tongan families they were working with, the need for a healing space became evident.

The co-design practice and capability has shifted over time, but the hao haoā model remains the anchor. Some capability shifts through the co-design include:

- Co-design itself made participating families “happy” — build confidence in themselves and their youth
- Building relationships and trust takes time; burying the waves will not happen quickly
- Health messages are shared within churches more now, and there is a receptiveness to this; the sacredness of the body can at times make people reluctant to talk about it
- The co-design introduced mana-enhancing practice for the families; for example a cash koha that they could choose what to do with – engendered a response that “our stories have been honoured”
- Reaching out and involving kaingā was essential to the Tongan practice.

Learning from the Lomipeau co-design process to support future innovation

Youth Champs has sought to create a supportive and trusting network for service users and their whānau and provide regular opportunities for network members to connect, share experiences and access information.

Feedback demonstrates that the programme has succeeded in making network members feel safe and supported by Youth Champs. Network members believe that this was down to the fun and engaging environment, the opportunities to connect with others who have similar experiences and the connection that was created through shared cultural values and ways of doing things.

There is some evidence to demonstrate that Youth Champs has been an effective way to provide network members with trustworthy and relevant information and advice about rheumatic fever. Participants valued being able to learn and access information through stories and verbal communication. One participant also reported feeling motivated to learn more about her sister's condition as a result of being a part of Youth Champs.

Network members had minor suggestions to improve the programme such as providing more opportunities to meet face to face and support with babysitting arrangements, however, the feedback on the Youth Champs programme was overwhelmingly positive. Members felt safe, included and grateful for the opportunity to be a part of the Youth Champs network.

More broadly, the innovation that is the Youth Champs initiative emerged from both a comprehensive consultation with kainga, and also a focus on the strengths that the co-design leads themselves brought to the initiative. In the early stages of Lomipeau, there was some interest in developing clinical guidance for health professionals working with kainga, but this was not followed further as the real innovation lay in the community-based work of the initiative.

So I was able to give them that feedback like there is actually clear guidelines but maybe there was an opportunity at some point where it's an education thing for clinicians... that's the problem in health to be honest, is we go out to the community and then we go, as clinicians and as people who make policies and systems and programmes or pilots, we go ask them and then we go make it for our world instead of going what did they say. [clinical advisor]

This permission-giving by a clinical advisor was key to Lomipeau focusing its efforts on Youth Champs, and in culturally resonant ways of transmitting knowledge of rheumatic fever.

Learning for the wider health system from Lomipeau

Lomipeau offered a culturally resonant approach to rheumatic fever that responded to the lived experience of rheumatic fever by Tongan families. By working outside of established health system processes, meeting people in a safe and inclusive space, and acknowledging their time and input with kai and koha, Lomipeau were able to develop a tailored response that directly reflected the needs and feedback of communities. Lomipeau were then able to deliver on the trust and rapport to implement youth peer networks.

These highlight the importance of engagement and design by Tongan community leaders, working within Tongan frameworks, and translating these into approaches that work for the communities they serve. By reaching people with direct experience, innovative approaches are able to be built that responds to the challenges they face.

Lomipeau highlighted that treating rheumatic fever is not the same as being healed by the disease, and that in managing long-term conditions, health systems need to be mindful of how they can provide a place that gives a sense of psychological healing from the trauma of the condition, and which in turn can support long-term management of the condition.

A clinical advisor to the initiative also shared the importance of Youth Champs in providing a clinical safe space to share information about rheumatic fever, in the context of misleading and false information that is pervasive on social media. These have wider ramifications beyond just rheumatic fever.

If we can instil resiliency in them and that's what you're doing when you're connecting youth together who have got the same issue, you are creating some resiliency in that particular health aspect but also possibly in other areas too that go along with it, staying healthy in general, so not smoke, don't do the drugs and alcohol. There's lots of benefits of bringing the youth together but also enhancing their health knowledge and becoming experts in their own health area as well. [clinical advisor]

Finally, we note that Lomipeau has built both trust and expectation with their communities; the challenge for health funders with any co-design is ensuring that the hopes and benefits of prototypes such as these for communities are continued, and not suffer the same fate of so many pilots, trials or prototypes that are discontinued following their initial promise.

PART 4:

Findings from Samoa Team

Samoa Team approach

The work of the Samoa Team was carried out in three phases. In Phase 1, the multi-disciplinary Samoa Team, which grounded the work in Samoan worldviews (Fa'asamoa), engaged with Samoan families, practitioners, and professionals to gain insight into their experiences with rheumatic fever and rheumatic heart disease. This phase yielded nine key insights, including the recognition of “E lē o le fale a o le anoāfale” (it is not the house, but the people of the house that matter), the hesitancy of young Samoans to interact with the health system, the prioritisation of collective wellbeing, the identification of missed prevention opportunities, and an understanding how discouraging and difficult the rheumatic fever management journey can be for young Samoans. Furthermore, the team uncovered the untapped value of Samoan cultural and relational capital within the community, how Samoan practitioners and professionals feel undervalued, and the tokenistic approach to Samoan leadership and challenges of fragmentation and competition in the rheumatic fever system within Aotearoa.

Crucially, the team discovered that these insights described a “Tale of Two Systems”, revealing how the health system perceives and treats Samoans as individuals in a process dictated by numbers, diagnoses, and procedures, in contrast to how they wish to be seen — as interconnected families with deep ties to culture and community, influenced by the Fonofale model. The coming together of these two mental models is abrupt and creates unsafe, uncomfortable and unhelpful health experiences for Samoan families.

In Phase 2, the Samoa Team used these insights to inform deep engagement with Samoan families, health professionals and other system stakeholders to co-design solutions that reflect Samoan worldviews. This engagement resulted in the design of six community-led prototypes to contribute to addressing rheumatic fever in Samoan communities, as described below:

- 1. Soālaupule Family Meeting Guide:** The Samoan design team learnt while engaging with their community that some Samoan families have limited knowledge of the rheumatic fever disease and its severity, even after their diagnosis and surgery. The Soālaupule Family Meeting Guide was collaboratively developed through a process rooted in Soālaupule and serves as a vital tool for healthcare practitioners seeking improved communication and engagement with Samoan patients to enhance overall healthcare experiences.
- 2. Soālaupule Capability Building Workshop:** The non-Samoan healthcare workforce often fail to understand the complexities of Samoan social, spiritual, political and cultural values, and the ways in which these values influence decision making and perceptions of quality healthcare among

Samoan families. They see the challenges that families experience but lack the confidence and know-how to respond. A learning and development module for healthcare professionals was established to address this, applying Soālaupule and Samoan principles in dialogue, consensus building and power sharing. The guide aims to enhance Samoan healthcare experiences by fostering a better understanding of Samoan values and ways of relating among healthcare professionals.

3. **Rheumatic Fever Infographic and Glossary:** Discussion insights with Samoan families impacted by a rheumatic fever diagnosis revealed they are often unable to understand the terms of reference used by healthcare professionals when discussing rheumatic fever, and there are further inconsistencies across Samoan language adaptations of such terms. One of the key issues was that they could not understand the connection from a sore throat to a potentially damaged heart. The initiative developed a visual glossary to describe the journey of strep throat bacteria to the heart and its subsequent impact on the body, bridging the language barrier for healthcare professionals with little grasp of the Samoan language when consulting with Samoan families.
4. **Youth “Let’s Talk Rheumatic” Information Event:** The Samoan design team learnt that Samoan young people often weren't receptive to information currently available about rheumatic fever and further engagement was needed. A talanoa evening was organised by young people to engage their peers with healthcare professionals and Samoan youth impacted by rheumatic fever; empowering Samoan young people with the knowledge to reduce and prevent the disease in their local community. Pastoral care was also made available to Samoan youth impacted by rheumatic fever.
5. **Pharmacy Based Rheumatic Fever Prevention:** Samoa Team heard from families that it is not always easy or practical for them to access a doctor or health practitioner to get a sore throat checked for strep. When families do not get a sore throat checked, it is a missed opportunity for prevention of rheumatic fever. In response, the team 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.
6. **Systems Mapping for Le Afio’aga o Aotearoa (the Ōtara-Papatoetoe area Locality):** Evaluations of rheumatic fever prevention and management programmes recognise that it is generally more feasible to address the challenges caused by fragmented and siloed healthcare systems initially in smaller geographic and administrative areas, before upscaling to national levels. This prototype posed how Le Afio’aga o Aotearoa (and other locality-based initiatives) might take the lead in all rheumatic fever control programmes and data collection in their locality. This could be achieved by providing guidance and oversight for the implementation of rheumatic heart disease control, with uniform guidelines and protocols for all providers, and the prospective design of uniform and comprehensive data for the entire locality population. A data hub is proposed that is, specifically designed to closely monitor, evaluate, and adjust (real time) all activities aimed at rheumatic fever control in the Ōtara-Papatoetoe locality area, in order for communities to have the information on where best to focus to continuously monitor and evaluate the effectiveness of rheumatic fever programmes.

Early signals of system impacts

In phase 3 of the co-design initiative, the Samoa Team set out to embed and extend five of the six prototypes into the rheumatic fever system in Tāmaki Makaurau, Auckland.³ This was primarily achieved by utilising the cultural, social, and relational capital of Samoan community members (patients, families and health professionals) and the project team.

Some early signals of impact from Samoa Team prototypes are emerging. They show a receptivity to the prototypes among initial audiences and interest by key organisations in disseminating resources, and building into guidance. Champions of the prototypes span community members, practitioners and stakeholders across the ecosystem, embedding Fa’asamoa and initiatives designed by Samoans within best practice.

An outline of each prototype, early indicators of success and potential scaling opportunities are featured below.

Soālaupule Family Meeting guide

The Soālaupule framework was shared within a workshop of 60 participants and survey feedback from over half of attendees, most of which were patient-facing, expressed a clear understanding of the difference between two role play scenarios, one of which adopted Soālaupule. A majority of workshop attendees agreed they were highly likely to adopt Soālaupule in their day-to-day practice.

Testing of the guide with Samoan families via role play revealed using Soālaupule was useful and has the capability to promote cultural competence and improve health outcomes for Samoan people when engaging with the rheumatic fever healthcare system. Families highlighted that the guide meant they were welcomed properly, they were given good information, they were reassured, and they were involved in decision making.

Soālaupule Capability Building workshop

The adoption of a systemic approach, rather than expecting individual clinicians to integrate Soālaupule within their everyday clinical practice has the potential to achieve widespread system change. 18 key stakeholders and participants in the initiative have agreed to be an ‘extension partner’, and champion the capability workshop within their capability building activities. This includes:

- Integration of the framework into capability education offerings and modules by RNZCGP and the Goodfellow Unit at University of Auckland.
- Te Tāhū Hauora Health Quality & Safety Commission is exploring how Soālaupule may inform the development of a System Safety Strategy for Aotearoa.

I see the Soālaupule as a framework [and] a platform to provide a Pacific voice, in particular, empowering Samoan people to have the autonomy to self-navigate their spaces and provide advocacy on behalf of themselves, their aiga, their families. (external Pacific health stakeholder)

3. Prototype 5: Pharmacy Based Rheumatic Fever Prevention did not progress beyond design stage.

Rheumatic fever infographic and glossary

Clinical peer reviews of the glossary indicated that Samoan terms and phrases used to describe rheumatic fever language were clear and accurate. Some requests were made for further information on heart valves, throat swabbing and the overall impacts of rheumatic fever if not treated or managed correctly.

Youth “Let’s Talk Rheumatic” information event

A talanoa evening, organised by young people, was held at the Ōtara Scorpions Rugby League Club to provide an opportunity to build knowledge and awareness of rheumatic fever in the local community. The event challenges the notion that young people are ‘hard to reach’ or disinterested.

Although this was a one-off event, attendees of the event saw its application as an important prevention tool. In response, Ōtara Scorpions Rugby League Club is investigating how it can extend provision of pastoral care to young people with rheumatic fever. It provides a useful example of an “in community, by community” health prevention and management model.

Scaling and sustainability from the Samoa Team prototypes

The Samoa Team rheumatic fever management prototypes that have been developed for and by local Samoan communities have sought scaling potential beyond simply scaling out, that is, the replication and utility of such prototypes to benefit other Samoan communities in Aotearoa. Samoa Team have also explored the ways in which prototypes can achieve systemic change by scaling up; amending the institutional and systemic conditions that are currently inhibiting Samoan rheumatic fever management from succeeding. More importantly, some prototypes are seen to have scaling deep capability; upending the deeply belief systems, norms and cultures of the ways in which rheumatic fever among Samoan families are perceived and managed. As noted earlier, given the early stage of prototype implementation, **Table 4**, over the page, details the scaling potential for Samoa Team prototypes based on learning and feedback to date.

TABLE 4: Scaling potential for Samoa Team prototypes

Scaling type	Soālaupule Capability Building Framework	Visual rheumatic fever glossary	Youth “let’s talk rheumatic” information event	Systems mapping for Ōtara-Papatoetoe locality
Scaling out	Champions in advocacy roles in the health system believe Soālaupule has the potential to reimagine the ways in which Samoan people interact with the ‘system’ and the system’s interaction with them. The framework is not just health related, it can be used in education, justice, housing etc.	Contributing to a toolbox for capability building for health professionals through Goodfellow Unit for Continuing Education (University of Auckland) and Te Whatu Ora Counties Manukau.	Ōtara Scorpions Rugby League Club collaboration with South Seas Healthcare is delivering health prevention and management “in community, by community”. Ōtara Scorpions is also investigating how it can extend provision of pastoral care to young people with rheumatic fever. The talanoa night demonstrated how building a broader connection among supporters (friends, aiga) aids better understanding of rheumatic fever management and supporting loved ones and each other through navigating rheumatic fever.	Greater numbers will be impacted through the consistent implementation of rheumatic fever-focused public health programmes: 1. Top-down: uniform, consistent, always up-to-date, and accessible for all healthcare workers through their digital systems. 2. Bottom-up: connect with target groups, tailored, culturally appropriate engagement at locality level. Top-down and bottom-up always need to be aligned.
Scaling up	Goodfellow Unit for Continuing Education (University of Auckland) are producing capability building opportunities for health professionals based on Soālaupule approach. Goodfellow eLearning provides high quality online resources for healthcare professionals working in primary care, using peer reviewed evidence-based content. Te Tāhū Hauora Health Quality & Safety Commission is exploring how Soālaupule may inform the development of a System Safety Strategy for Aotearoa.			Le Afio’aga o Aotearoa (the Ōtara-Papatoetoe area locality) provides leadership to rheumatic fever prevention and management programmes and data collection in their locality by providing guidance and oversight for the implementation of initiatives with uniform guidelines and protocols for all providers, and the prospective design of uniform and comprehensive data for the entire locality population. A data hub will be established that will be specifically designed to closely monitor, evaluate, and adjust (real time) all activities aimed at rheumatic fever prevention and management in the locality area.
Scaling deep	Potential for deep shifts in the ways non-Samoans relate to and interact with Samoan people, particularly in service settings and the way in which Samoans interact with health professionals.	Glossary challenges the paradigm that a lack of understanding is the fault of the patient. It provides a tool to support a practitioner to engage in a two-way peer to peer conversation with a patient and their family. It also provides a tool for patients and families to ask questions and seek clarification as they wish.		Current system fragmentation prevents systemic and uniform data collection that is designed to answer specific surveillance questions. As a result, immediate information feedback loops to improve the interventions and information about which interventions are (cost) effective is not available. Systems mapping will enable a fuller picture of rheumatic fever expanding the impact and reach of any initiatives. In particular it can: <ul style="list-style-type: none"> • Provide us with a holistic understanding of the rheumatic fever system (interconnections, dynamics, stakeholders, relationships) • Identify feedback loops • Uncover unintended consequences • Create space for collaboration and cooperation. • Inform strategic decision-making. • Monitor interventions along with challenges and opportunities.

Reflections from Samoa Team co-design process for future innovation and health systems

Samoa Team reflections highlight how the work has been undertaken and what the team learned about creating change within the rheumatic fever prevention and management system are. Their key reflections are:

- **The work was centred on families, their experiences, and their stories:** The team intentionally centred this initiative around families, recognising the need to build and cultivate trust while acknowledging the precious nature of families' stories. This commitment to accountability ensured that the voices of families remained central and authentic throughout. Notably, families themselves played a pivotal role in determining the areas of focus for new solutions, redirecting initial assumptions to address interventions that had the most significant impact on their experiences and wellbeing.
- **Relational capital is the critical ingredient for engaging Samoan families:** Through their work, the team increased the visibility of the crucial role of relational capital in establishing safe, comfortable, and beneficial engagement with Samoan families. The initiative revealed that two to four layers of engagement were often necessary to create conditions for safe interaction between different parties. Additionally, the team challenged the commonly held 'hard to reach' narrative, demonstrating that Samoan families, particularly young Samoan men, are not challenging to engage; rather, they require approaches tailored to their needs.
- **Soālaupule is a Samoan response to addressing power imbalances:** Samoa Team observed a rheumatic fever and prevention system that is characterised by deeply engrained power imbalances. The team looked for inspiration within established Samoan knowledge and came back to Soālaupule: a uniquely Samoan approach that acknowledges the authority or mandate that each individual or party holds. Soālaupule acts as a power-leveller by acknowledging the contribution and value of everyone involved, creating a space of equal standing. When testing with Samoan families and practitioners to conceptualise how Soālaupule could be applied practically in a rheumatic fever context the results were clear: Soālaupule practices foster meaningful conversations, shared decision making, and provides the safety and comfort for non-Samoan practitioners to engage with Samoan families in ways that are consistent with Samoan practices.
- **Established knowledge can be valued within rheumatic fever contexts:** Soālaupule stands out as an illustration of established Samoan knowledge that served as a fundamental underpinning throughout the initiative, rooted in generational wisdom integral to Samoan cultural practices. This challenges the persistent pursuit of 'new innovations' by exploring the potential impact of something not entirely new but rather an established practice brought to a specific context. E ui ina sui faiga, ae tumau pea fa'avae. (though the approaches may change, the foundations remain the same).

- **Creating new ways for two systems to work together:** As mentioned previously in this report, one of the crucial insights was the emergence of the idea of "a tale of two systems." This project created new ways in which these two systems might work together, running in parallel, and mutually supporting each other.
- **A community-led and system building approach leads to the family-centred goal the system is chasing:** This design process demonstrated that while community-led efforts are necessary, they alone are not sufficient for the needed change. Rather, supporting community-led solutions in partnership with individuals and organisations that hold mandated power and resources across the health system results in family-centred care.
- **Build the power sharing foundations to enable community-led prevention innovations:** In Phase 1, the Samoa Team wondered if the most impactful way to reduce rheumatic fever rates was to disentangle the complexities around complex social determinants of health, such as housing conditions and occupancy. The use of Soālaupule in the design process, however, gave families the power to determine the direction of the work and the team soon learned families wanted to increase their knowledge around rheumatic fever, alongside a rapid response to the healthcare that they were currently experiencing that was not meeting their immediate needs. The team believes that the high level of buy-in from families, alongside the starting focus on management and secondary prevention has now created the shared foundation to focus on primary prevention, and eventually on primordial prevention.
- **Samoan families have spoken; it is now time for the system to respond:** Through their own co-design, as well as in participating in the evaluation, Samoa Team asks that, at the conclusion of their journey, that others who have the ability to influence change share the accountability to families to create the change they are asking for.

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