



LOMIPEAU

Tongan rheumatic fever co-design initiative

**Phase 3 Report
Prototype Embedding Phase
September 2023**

Fakatapu (acknowledgements)

'Oku mau tōmu'a fakatapu heni ki he 'e tau Tamai Fakahevani' koe mātafi e Tonga 'o hono finangalo' kae 'a tautolu 'a e faingamalie 'o e moui ni.

Fakatapu ki ha'a taki lotu moe ngaahi kupu ngāue fekau'aki 'oku tau kaungā ngāue fakataha koe'uhi koe ngāue mahu'inga ni.

Fakatapu ki a Hou'eiki mo ha'a Matāpule, Fakatapu ki ha'a Tauhi fonua moe kāinga 'o e fonua ni (Tangata Whenua). Fakatapu foki ki he tākanga ngāue 'a e Kāinga Māori (Te Tima Maori), tākanga ngaue 'a e kāinga Ha'amoā (Samoan Co-Design Team). Fakatapu ki he Potungāue Mo'ui (Te Whatu Ora) pea moe kāinga Matala Mai (ThinkPlace).

'Oku oatu 'a e fakatapu moe faka'apa'apa lahi ki he ngaahi famili', 'a e kau tauhi fanau' moe fanau kotoape na'a nau loto tō, loto mamahi'i me'a, loto fakatō ki lalo moe loto mahuinga'ia ke tokangēkina 'a e me'a 'oku mo'onī, 'a e me'a 'oku totonu, 'a e me'a 'oku fakamatāpule mo taau koe'uhi koe ngaahi mo'ui kuo uēsia 'e he Mofi Lumetika pea koe 'uhinga ia 'a e ngāue mahu'ingani. Uisa 'oku tu'u e lā mo e poupou.

This report provides a backbone to the Tongan ethnic-specific stream under the Rheumatic Fever Co-design Initiative, commissioned by Te Whatu Ora and under the guidance of ThinkPlace and partners.

The guiding intent of the initiative is 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.

Lomipeau loosely translates as 'the wave cutter or suppressor;' and was the name of the double hulled canoe (kalia) of the Tu'i Tongan Uluaki Mata'o Tele'a who spearheaded a lot of social change in Tonga during his reign.

We consider Lomipeau to be a fitting name for our team, metaphorically referring to Rheumatic Fever and Rheumatic Heart Disease as the wave (peau) and our role as the Tongan Co-Design team to find solutions to cut through the peau.

For the Lomipeau team, it is our personal and professional mission to prioritise our Tongan indigenous knowledge to reflect the practice and values of the community that we serve. By acting and learning together with kāinga and systems partners, we can focus on systems changes as well as kāinga to track what really matters to our people.

This report provides an overview of Lomipeau's Prototype Co-design (Phase 3 of the overall Co-Design Initiative), following the 'Discovery Phase Report' released in April 2022 and the 'Prototypes Progress Report' released in September 2023. It provides a snapshot of how the prototyping areas have further developed and how systems changes are being embedded.

Our work is not in isolation and we would like to show our appreciation for our Māori and Samoan teams paddling the same vaka. Their support, thinking and love has been a key part of the Lomipeau journey and we are excited for our continued relationship to drive the necessary work moving forward.

We wish to thank the Tongan kāinga who provided their time, heart and lived experiences to the journey so far. We are blessed to hear, hold and elevate your stories.

We wish to acknowledge Te Whatu Ora for the courage to do things differently by demonstrating what compelling alternatives look like. True partnership with community means giving community the opportunity to lead and this project demonstrates that through the partnership between Te Whatu Ora, ThinkPlace and our Māori, Samoan and Tongan communities.

Contents

Introduction	PG4
<hr/>	
Context	PG5
Recap of Phase 1	PG 5
Recap of Phase 2	PG 7
Overview of Phase 3	PG 8
Economic modelling	PG 8
<hr/>	
Prototype #1: RF Champs Programme	PG10
<hr/>	
Prototype #2: Haohaoā Model	PG14
<hr/>	
Prototype #3: Faiva (Performance) and Posters	PG19
<hr/>	
Prototype #4: Tool for non-Tongan Clinicians	PG24
<hr/>	
Conclusions	PG26

Introduction

Lomipeau was one of three ethnic-specific streams operating within the Rheumatic Fever Co-Design Initiative, a three-year (2020–2023) initiative commissioned by Te Whatu Ora. The intention of the initiative was 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 Auckland.

During Phase 1 we formed the Lomipeau team. We are Tongan and have a range of skills including cultural knowledge, Tongan language knowledge, relationship capital, research and evaluation, co-design, youth work and graphic design. We also developed a Tongan approach to co-design – the Haohaoā model – that shaped how we engaged with Kāinga Tonga.

During Phase 2 we focused on ideas and solutions that would improve experiences for kāinga. We formed low-fidelity prototypes ready for further iteration and testing.

During Phase 3 we expanded these prototypes by working alongside kāinga to ensure we were focusing on those things that will have the biggest impact for kāinga. We developed, tested, refined and began the process of embedding the following four prototype areas:

1. **'RF Champs' programme:** a culturally-responsive and whole-of-kāinga peer-to-peer programme that creates safe places for young people and their families to heal from their trauma related to rheumatic fever.
2. **Haohaoā model:** a Tongan co-design model that draws on traditional Tongan values and knowledge that was used as the basis of Lomipeau's work, including the RF Champs programme, and that can be leveraged as part of future co-design initiatives that benefit Kāinga Tonga.
3. **Faiva (performance) and posters:** awareness raising and health communications collateral / tools that are based on peer-to-peer and traditional Tongan customs.

4. **Tool for non-Tongan Clinicians:** a tool that supports clinicians to provide haohaoā in practice, showing how this contributes to short-term and longer-term outcomes for kāinga.

Operating under the name of Lomipeau, we have taken inspiration from overcoming the challenges associated with navigating through uncertain seas to a distant island. This is similar to what kāinga experience as they navigate the complexities and impacts of rheumatic fever.

We sought to gain kāinga's trust while recognising the engagement fatigue they experience. We learned that some kāinga who had experienced rheumatic fever had also experienced significant unhealed trauma – from the disease as well as from the experiences of engaging with the health system. This prevented kāinga from exercising full agency of their own health and wellbeing journey and from supporting other kāinga on a similar journey. We also saw how language inhibited kāinga's understanding of rheumatic fever.

This was a logical place for our team to innovate as it is currently not in focus. We created the RF Youth Champs programme which provides safe ways for young people impacted by rheumatic fever to connect, share and learn. We learned that conventional methods used by the health system to engage Kāinga Tonga were not effective and that there was inspiration in traditional approaches used by Tongans. We created the the faiva (performance) that will continue to carry the stories of kāinga beyond this initiative.

As we conclude this Co-Design Initiative, we are grateful for the opportunity we have had to work alongside Kāinga Tonga. This initiative has demonstrated that the conventional approaches of engaging with Kāinga Tonga have limited effectiveness and that there is value in supporting Kāinga Tonga to identify solutions that will work for them. We look forward to seeing continued systems change that supports the wellbeing of Kāinga Tonga.

Context

Recap of Phase 1

Activities

During Phase 1, we undertook the following activities:

- We formed as a multidisciplinary team of Tongan practitioners and advisors (e.g. cultural / language expertise, research and evaluation expertise, co-design and visual design expertise, youth engagement expertise, etc.).
- We articulated the values and beliefs that would underpin our work with Tongan kāinga, which positioned our work within Tongan culture and taking a strengths-based view of our Tongan kāinga.
- We prioritised avoiding 'community fatigue' for kāinga. We asked ourselves what will make this rheumatic fever/rheumatic heart disease (RF/RHD) engagement different from the others, and what will we leave behind to sustain the conversation 'talanoa/talanga'.
- We developed the Haohaoā model (a uniquely Tongan approach to co-design) to guide our work.
- We formed relationships with Tongan kāinga to create safe and affirming conditions for Kāinga to participate.
- We undertook qualitative research activities to understand the realities and experiences of the Tongan kāinga. This included: (1) informal engagement with young people, kāinga, community members and Tongan clinicians, (2) Talanoa sessions with kāinga that included several members from each family to give a variety of views relative to role / position in the family, and (3) youth-specific sessions (talavou). Families were able to converse both in the Tongan or English language to allow a safe environment for them to share. Due to COVID-19, we undertook hybrid engagements (a mix of online and in person).

- We identified the common themes that were prioritised through the participants' lived experiences.
- We developed tools to communicate the experiences of Tongan kāinga, including personas and journey maps.

Co-design phases

We also identified the following four project stages to structure our co-design activities across the overall Phases 1–3 of the co-design initiative.

Tufunga Fonua

(Phase 1 of the Lomipeau approach, undertaken during Phase 1 of the Co-Design Initiative)

This phase refers to sustaining, building on and protecting Tongan values and was the building block for our approach and our understanding of rheumatic fever. The activities provided critical foundational understanding through evidence, relationship building and reframing rheumatic fever through our Tongan lens. It was also about tauhi va mafana: instilling trust in the system/process with respect to the potential for community engagement fatigue before evidence.

Tufunga Niu Vākai

(Phase 2 of the Lomipeau approach, undertaken during Phase 1 of the Co-Design Initiative)

This phase is inspired by the Tavakeoma bird flying high and far from land, seeking food in the ocean. Understanding Tongan people's lived experiences and integrating these with system insights and Tongan traditional knowledge identified the critical pain points that our Tongan community are facing with regards to rheumatic fever. Niu Vākai is how kāinga living in Aotearoa navigate the many systems that contribute to their migration dream. This phase relied on Lomipeau creating an environment where our participants, experts and Tongan community felt safe to share or retell their journey with the understanding it contributes to their freedom and protection from harm and towards

overall wellbeing for themselves and the wider community. It was important in this phase that we viewed people in both their 'atamai and loto (mind and hearts) to obtain the full truth of their lived realities. The activities were fluid and had direct involvement of our Tongan community.

Tufunga Tefua A Vaka Lautala

(Phase 3 of the Lomipeau approach, undertaken during Phase 2 of the Co-Design Initiative)

This title speaks of whether the vessel, or means for the journey, is fit for purpose. This phase was focused on how Lomipeau as a team (the vessel) would embed the learning and prototypes to enable tau'atāina (transformational change). It is important that, in our quest towards tau'atāina, the Lomipeau team not only built transformational responses and avenues but also ensured that ourselves, community and stakeholders are transformed within Tongan cultural practices and values. This ensured that solutions were created for our Tongan community and with their lens at the forefront.

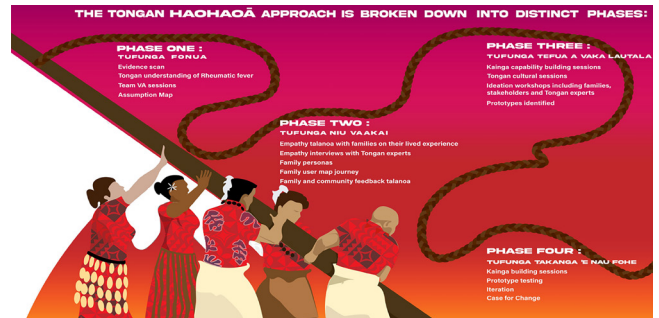
Tufunga Takanga 'E Nau Fohe

(Phase 4 of the Lomipeau approach, undertaken during Phase 3 of the Co-Design Initiative)

This title speaks of how collective efforts lead to effective and sustainable outcomes. This phase was focused on the implementation of the solutions across all facets of Tongan community. The solutions cannot be isolated but rather tested across all dimensions of the Tongan community and system for transformational change. Testing through prototypes, we iterated, refined, challenged and, most importantly, tauhi the vā between the different playing parts and people in our approach. During the testing phase the Taula sat with various individuals across the project team, Tongan participants and stakeholders to ensure the values were upheld throughout as testing unearthed biases, practices and views that do not reflect us as Tongan people. These activities help lead us to a place where we can start the transformational change process.

Insights

Below is a summary of the key insights that we identified during Phase 1. More detail can be found in our Phase 1 report.



Insight 1: Parents felt a sense of 'imposter syndrome' as they struggled to make sense of their realities based on the existing knowledge bases. The emotional labour levels due to a wide range of factors related to rheumatic fever are high for our kāinga.

Insight 2: Conversations and assumptions from medical practitioners highlighted the racism and discrimination evident from both a systemic and personal level. The healing process for our families is a crucial part of the journey and needs more attention from the health system in connection with our Tongan communities.

Insight 3: Mental health, pastoral care and spiritual guidance are key areas that need more attention. Holistic wellbeing is fundamental when dealing with Tongan families. You cannot focus on clinical care in isolation without the other dimensions to wellbeing.

Insight 4: A fundamental shift away from individualistic narratives and Eurocentric communication approaches and toward Anga Faka-Tonga (Tongan-specific and culturally responsive). Communication modes and approaches need to reach and capture the heart of our Tongan families.

Insight 5: Offloading of this stress resulted in elevated levels of anxiety, depression, confusion and misplaced anger. Knowledge gaps were evident across the rheumatic fever journey and elevated stress levels for our kāinga.

Recap of Phase 2

During Phase 2, we focused on ideas and solutions that would improve experiences for kāinga. We formed low-fidelity prototypes ready for further iteration and testing.

Through this phase the Lomipeau team was able to build a meaningful understanding of what is important to our Tongan families and identify key opportunities and leverage points for systems change through the prototypes.

It is important to note that these prototypes have a series of iterations and further refinements to be expected when connecting with key stakeholders and services to provide feedback and contribution.

Key feedback loop channels were established with our Tongan families allowing the Lomipeau team to provide continuous feedback on the progression of the prototype development and testing.

At the beginning of Phase 2, we reflected on what we heard and discovered during Phase 1 and identified the following three prototype areas (see the table below):

Through our engagement with Tongan kāinga and experts, we learned that the creation of spaces and experiences for Tongan kāinga to come together, to share with each other, to work through unresolved trauma, and to learn together is what forms the foundation for any other intervention.

Through the engagement and sharing of ideas with kāinga, we identified that what creates the ideal environment for this coming together of people is a facilitated peer-to-peer service that is designed for Tongans. We decided to build from the informal peer network that had developed within the co-design initiative and to run a small-scale pilot of what this peer-to-peer service can look like over a 9-month period.

Running alongside the peer-to-peer service pilot, we also co-designed with kāinga and sector stakeholders to identify:

- The key features required of any health communications that are targeted at Tongan families, and providing guidance to those who are developing health communications, including the national register project.

Prototype opportunity areas identified in phase 1.

Develop experiences that enable healing :	Proactive healthcare communication & promotion :	Model of care & healthcare journey :
<p>Autonomy over their journey/stories.</p> <p>Activating informal peer to peer support.</p> <p>Retreat for kāinga with leading Tongan mental health professionals.</p>	<p>Developing Tongan understanding of RF/RHD (Mofi lumetika).</p> <p>Identifying consistent messaging that aligns with cultural context.</p> <p>Retreat for kāinga with leading Tongan mental health professionals.</p>	<p>Reducing the emotional labour for kainga engaging with the health system.</p> <p>Developing and delivering a family centered model of care.</p> <p>Developing long term health care plans to support kāinga with a focus on transitions from child to adolescent through to Adulthood.</p>

These areas formed the basis of the 'how might we' questions which were the foundations of the co-design workshops with our Tongan families.

- The key features of the 'virtual hub' model of support around kāinga; in other words, identifying all the various ways that kāinga are currently supported.

During Phase 2, some of the key things we learned included:

- Self-agency and autonomy is created in and amongst kāinga when health advice comes from a culture of care followed by wrap around support.
- Kāinga Tonga do not have the bandwidth to make choices that affect their long-term realities. Kāinga are living in conditions where they can only focus on the day to day (social determinants of health).
- Use creative mediums to bring everyone together where the focus is not rheumatic fever (talking about it, without talking about it).
- Involve clinicians that can 'vibe' with young people and explain medical jargon in a non-condescending way (don't dumb it down, just be simple and clear).
- Elevate existing safe spaces like church faikava groups (for men), tou lalanga groups (for women), and coffee dates for younger parents.
- Some Kāinga Tonga would prefer health communication that includes faith-based references.
- A kāinga-centric /community-centric approach rather than an individualistic approach is required.
- Health professionals who genuinely understand Pacific ways of being are instrumental in effective healthcare by providing cultural safety both for service providers and users.

More detail can be found in our Phase 2 report.

Overview of Phase 3

During Phase 3, we expanded these prototypes by working alongside kāinga to ensure we are focusing on those things that will have the biggest impact for kāinga. The remainder of this report summarises what we did and learned in each of the following prototype areas:

1. 'RF Champs' programme (peer-to-peer)
2. Haohaoā model (Tongan co-design model)
3. Faiva (performance) and posters
4. Tool for non-Tongan Clinicians.

We also highlight that evaluation activities have been undertaken in parallel and the findings will be presented in a separate report.

Economic modelling

During Phase 3 we also explored the potential to do economic modelling to provide robust evidence of the cost effectiveness of the Lomipeau approach (ethnic-specific) relative to mainstream approaches.

To create an economic model a baseline was required from the health system to anchor and compare the subsequent economic analysis. We were unable to fund a suitable baseline model for rheumatic fever, for reasons such as: (1) there is no central database that pairs the incidence and prevalence rates of rheumatic fever with the associated costs, (2) patient cost information is commercially sensitive, (3) primary health organisations use multiple and different patient data management systems which makes it difficult to aggregate data at a national level, and (4) essentially the data sources are too fragmented and it was not possible to aggregate the data sources within the scope of this particular initiative. However, under the guidance of a health economist we were able to make a start on the work.

The revised objective of the work was to identify the typical pathways of a Tongan family when they engage with primary care or a clinic. On the following page are the typical pathways.

Typical pathways for a Tongan family when they engage with primary care or clinic

Scenario A: Positive case of strep A			
Pathway	Description	Economic Cost	Social & other costs
Access	Family visit a healthcare provider	Travel	Take time off work and school
Diagnosis	Practitioner examines child	Health physician	
Diagnostic tests	Healthcare provider performs a throat swab sample sent to a laboratory	Swab costs	
Treatment	Antibiotics	Medication (course)	Parent administers the course of medication (time)

Scenario B: Positive case of strep A and rheumatic fever develops			
Pathway	Description	Economic Cost	Social & other costs
Infection	Strep A infection	Travel	Take time off work and school
Onset of rheumatic fever	Joint pain, swelling, fatigue		Time of school, physical distress
Diagnosis	Examination, laboratory tests and Imaging studies	Swabbing, laboratory, medical imaging, health physician, travel, hospital stays	Take time off work and school, emotional distress
Treatment	Regular follow-ups and antibiotics and inflammatory medications	Medication, follow ups	Quality of life

Looking at the above scenarios, the key question is how the Lomipeau approach (an ethnic-specific approach) increased the likelihood of scenario A and decreased the occurrence of scenario B.

We recommend the commissioning of an economic modelling exercise to provide robust evidence for the cost-effectiveness of the Lomipeau (ethnic-specific) approach for Tongans; both in terms of health and socioeconomic impact.

Note: Social measures and values can be weighted using the Treasury social costing tool CBAX and estimations of the clinical costs retrieved from regional PHO and Te Whatu Ora databases.

Prototype #1 – RF Champs Programme

Phase 1 and 2 Recap

During the discovery work with kāinga in Phase 1, we heard that Tongan families who had experienced rheumatic fever had also experienced significant trauma. This was not only from the disease itself, but also from their interactions with the health system. Kāinga identified that they would benefit from experiences that enabled healing from that trauma.

During Phase 2, we explored potential solutions with kāinga. Kāinga identified the benefits of creating safe spaces for them and other kāinga to come together and share stories and experiences with each other. Together, we developed the concept of a peer-to-peer network that operated in a way that aligned with Tongan values, cultural practices, and family dynamics.

The benefits of this healing related to both management and prevention of rheumatic fever:

- Management: Kāinga who are experiencing the impacts of rheumatic fever are given the opportunity to heal from the negative experiences and have greater control over their own journey and healthcare, meaning they are better able to support other families experiencing rheumatic fever.
- Prevention: Kāinga who have healed from their trauma are better able to play an active role within their community and raise awareness of the risks of rheumatic fever and support family and friends with accurate and relevant information about how to stay safe from rheumatic fever.

Through our engagement with Kāinga Tonga, we identified that any peer-to-peer service pilot would need to include the following components:

- A small network that creates intimacy and trust.
- Regular connection and key events every couple of months.
- Separate subgroups for young people, men and women.

- Coordination of the service by suitably experienced people.
- Creating connections with Tongan clinicians and other experts to support the information needs of kāinga.

Phase 3 Activities

During Phase 3, we have put the ideas into practice and have piloted a place-based peer-to-peer programme for Tongan families that have participated in the co-design process over the past two years.

The prototype has developed into the 'RF Champs' programme. It is centred around young people, creating safe and inviting spaces for Tongan youth (including mixed ethnicities) who have experienced rheumatic fever. Aligned with our Tongan cultural practices, parallel peer groups have run for mums, dads and older generations. This has meant we are taking a whole-of-family approach, recognising the different roles that different people in the family play.

The young people's group have met together every two months or so. Many of the events have centred around an activity that acts as a draw card or attractor for the young people. Around this, we have wrapped pastoral support via a social worker, have brought in Tongan clinicians to talk with the young people, and have fostered connection and sharing among the young people.

We have also supported two of the young people to act as 'activators' or champions within the group. Supported by the social worker, they have stepped into a leadership space within the group and have taken responsibility for organising events and communicating with the young people between events.

The mums / dads / older generations have also participated in a group when they can. For example, the mums enjoy meeting together for coffee. They have been sharing their experiences and supporting each other on their own journeys.



Photos from the RF Champs Programme



What we learned

Below is a summary of the key learnings through Phase 3.

- The 'attractor' activities play an important role. What might look like a fun activity is an intentional and critical ingredient in making the experience special and different for young people.
- It is important to have an activator within each sub-group. The activator plays an important role in communicating with group members, encouraging participation, and creating safe places for people to continue engaging. Being one of the group members also means the activators are trusted and relevant.
- Clinicians have an important role to play but they need to be brought in at the right time and for the right things. Asking questions of a clinician is often a new thing for a young person, so they need to be supported to do so.

- Exploration of current life events and challenges is an important part of the programme. It can't be only focused on rheumatic fever.
- A lot of Tongan young people are of mixed ethnicities so require ethnic-specific approaches that work for them.

What we created

The following five features make the RF Champs programme what it is and distinguish it from previously implemented peer-to-peer groups that have failed to get the uptake.

The model on the next page shows how we have structured the various events. This model is relevant to all age groups, however the precise activity or topic will vary depending on which age-group is involved.

The defining features of the 'RF Champs Programme'

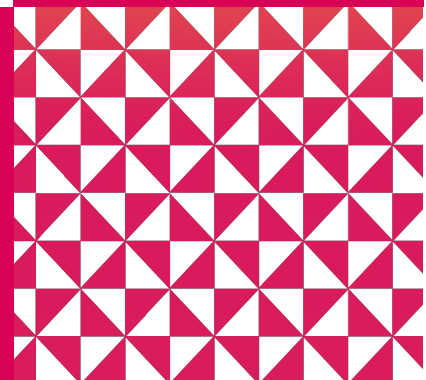
Creating a space for young people, and different spaces for mums, dads and the older generation. Paying attention to when gender-specific engagement is best.

Creating 'attractor' activities. For young people, this is something fun that they might not ordinarily do (e.g. escape room, nerf battle, or other play-based group activity). For mums and dads, it might be a coffee or faikava session.

Having people from within the group nurture the wider group. The group benefits from being supported by someone relevant and consistent. It also validates the 'champion' and creates pathways to greater opportunities.

Creating the opportunity to form connections with other people who have experience with RF. This provides an opportunity to overcome isolation and provide mutual support to each other on the journey.

Safely bringing clinicians into the space to remove the fear about clinicians, to grow confidence to ask questions of clinicians, and to support families with information they can use.



Haohaoā underpins the model and guides the design of everything within the programme. Short term interactions (hao) explicitly link to longer term outcomes (haoā).

- **Activities together:** these act as an attractor to bring people together, and create a conducive environment for forming connections, trust and safety.
- **Pastoral care:** this is an important part of the group time. It is built on the trust that has already been developed and helps maintain the vā. It creates the space for healing and mutual support. This also extends to family members if and when appropriate. For example, when picking up / dropping off young people we make time to connect with parents and grandparents using the notion of tauhi va māfana.
- **Hot topics:** because of the safety that has been created, it is possible to explore topics that are relevant. For example:
 - For young people living with RF/RHD – healthy relationships: how to keep up with your friends who don't have RF/RHD and avoid Fear Of Missing Out (FOMO).
 - For parents – talking to their child about body image (the scar) and monthly shots, and taking time off work for monthly shots (the health and employment systems collide, how can they work together?)
 - For grandparents – faito'o faka-Tonga (co-existence of traditional Tongan and western medicine).
 - Other carers/aunty/uncle – how to best support the young person and their parents without being condescending.
- **Clinicians:** with the other three building blocks in place, it is possible to overlay a specific rheumatic fever focus. Bringing in clinicians to share correct information and to shift perceptions of clinicians is important. Mental wellbeing and pastoral care elements are critical prevention and management tools. It also ensures relevant health communication that is not condescending.

- **Culture & identity:** the programme supports kāinga connecting with Tongan culture and growing their confidence. We learned that celebration of being 'Tongan' was very important for young people, especially those of mixed ethnicities. What does this look like in a New Zealand/Auckland context? Young people valued having a safe space to unpack cultural aspects that could be perceived as barriers, e.g. intersection of multiple cultural identities (mixed ethnicities, New Zealand-born Tongan contextualizing Haohaoā, gender diverse young people, etc.).

What might happen next

This pilot is ready to be expanded to cover more sites across Auckland. Each site would follow similar principles and be intergenerational (e.g. sub-groups for young people, mums, dads, and older generations).

Our aspiration is that each sub-group has an activator within the group, who is remunerated and receives pastoral support and professional development.

As previously highlighted, Tongan-centric peer-to-peer is the foundation for Kāinga Tonga to heal from past trauma associated with rheumatic fever, while also accounting for the fact that many Tongan young people are of mixed ethnicity. This enables Kāinga Tonga to have greater agency over their own rheumatic fever management journey, and then be better placed to support their kāinga and other kāinga to prevent rheumatic fever.

The building blocks of our time together

Haohaoā

This guides the design of the programme. Short term interactions (hao) explicitly link to longer term outcomes (haoā)

Activities Together

Age-appropriate, a reason to come together

Clinicians

Getting the right RF information, busting myths

Pastoral care

Creating community, healing, processing, talking, understanding where people are at right now

Hot topics

Safe exploration of topics that matter right now (e.g. healthy relationships)

Culture / Identity

Celebrating being Tongan, unpacking cultural aspects of identity (body)

Prototype #2 – Haohaoā Model

Phase 1 and 2 Recap

During Phase 1, we developed a Tongan approach to co-design through the Haohaoā model.

Haohaoā is inspired by traditional Tongan maritime navigation practices. 'Hao' refers to the act of navigating safely across dangerous seas while 'haoā' is the state of safety that is achieved by reaching the destination harbour. This was used as a metaphor for kāinga who experience rheumatic fever; the necessity to navigate the uncertainty and complexity of rheumatic fever (short term) in order for their kāinga to reach tau'ataina, a settled, safe and thriving future (long term).

The following is a more detailed description of the Haohaoā included in our Phase 1 report.

Tau'atāina

Our co-design approach was constructed using the concept of Tau'atāina.

"Tau'atāina loosely translates to 'freedom within reason' whereas fa'iteliha literally means you can do whatever you want, whenever you want. Within the Haohaoā model, tau'atāina means holistic wellbeing is achieved through tau'atāina not fa'iteliha."

We link Tau'atāina to a kalia or vaka (double hulled canoe/vessel) and the protection offered by the anchor (taula).

The taula provides safety for the kalia when it is stationary, however on voyage, the responsibility of the taula is shifted to the navigators at the helm, to protect the kalia to its destination. Tau'ataina, in the context of freedom, alludes to one's freedom, in particular from harm including sickness or preventable diseases.

The inferred taula for this journey is in the Faa'i Kavei Koula: the values that encompass Tongan way of life, through Faka'apa'apa (Respect), Tauhi vaha'a (Nurturing of relationships), Mamahi'i me'a (Loyalty/devotion) and Lototoo (Humility) in which self agency and autonomy can be achieved.

Life is similar to a kalia that is equipped to navigate and negotiate its path to high seas [lifetime]

Why the kalia is out there in the first place [essential ethic]

How to keep the kalia from sinking or drifting [personal ethic]

How to keep the kalia on course and from bumping to other ships / obstructions [social ethic]

Achieving wellbeing for Tongan people

Anchoring our approach in these values provides us with both the freedom of exploration and protection from damage or harm. It is intended that this approach signifies spirituality in the Tongan culture, with God at the centre of our Tau'ataina, haohaoā and wellbeing. Ultimately, it is aimed toward leading transformational change and achieving greater overall wellbeing and prosperity for our Tongan people.

"We can refer to 'hao' as short-term health outcomes whilst 'haoā' means long-term health outcomes."

Haohaoā asserts the notion of holistic wellbeing. However, it merely captures how Tongan people perceive it. Haohaoā in this Mofi Lumetika Fatu Taulanga (Rheumatic Fever Co-design) relates to navigation for health and wellbeing approaches meaning the journey of Lomipeau with families, its communities that currently 'Hao' from mofi lumetika that they previously suffered are now 'Destined', navigated toward that safe harbour, that land of Haoā from mofi lumetika, that place of 'Tau'ataina from mofi lumetika.

THE TONGAN HAOHAOĀ APPROACH IS BROKEN DOWN INTO DISTINCT PHASES:



Phase 3 Activities

The Haohaoā concept has continued to develop and has become a foundation for the RF Champs Programme (see previous section). Short term activities and interactions are seen within the context of the longer term and link explicitly to longer term outcomes. It is also seen as a key enabler of health communications with Tongan kāinga.

What we learned

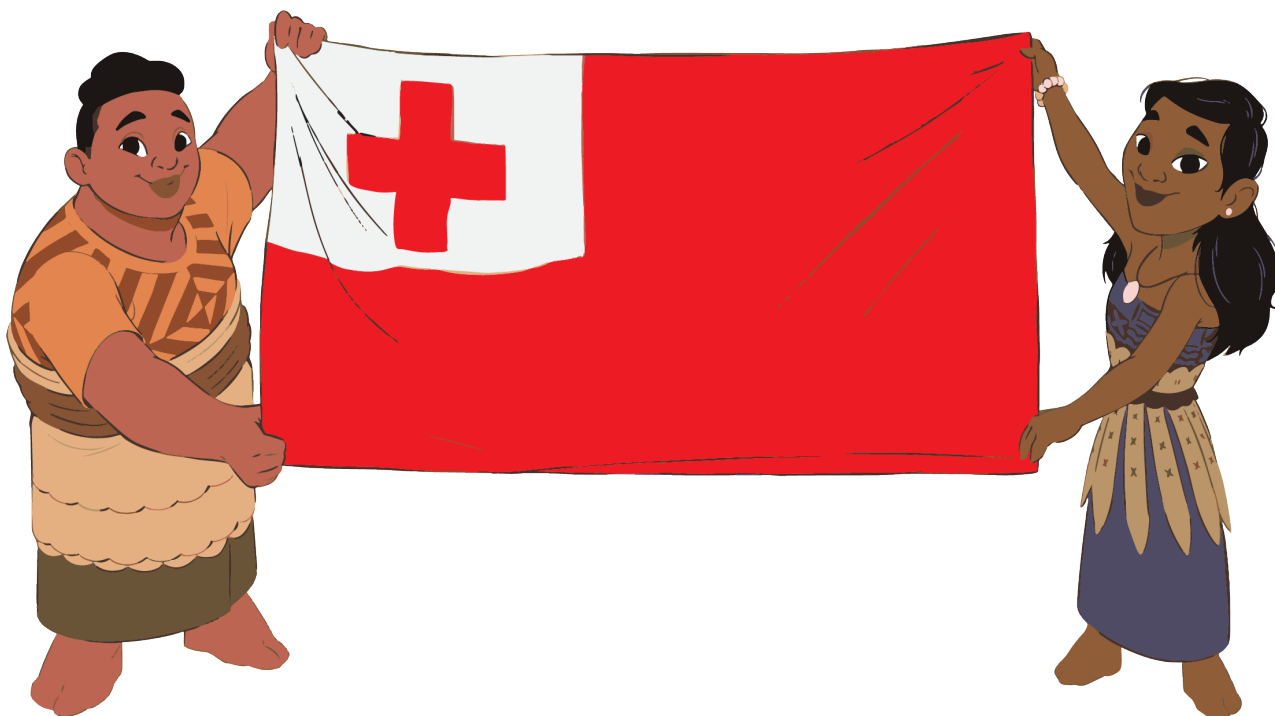
During Phase 3, we learned that:

- A starting point for creating Tongan-affirming models of care and health communications is to have a model or framework that is based on traditional Tongan knowledge that captures the hearts and minds of Tongan people both in New Zealand and back in Tonga.
- The framework makes it easier for non-Tongan clinicians to engage and create inclusive experiences for Tongan kāinga. The framework can also build capability for Tongan clinicians.
- Haohaoā enables self agency and autonomy for kāinga (hao) and how to achieve and sustain positive life outcomes (haoā) which may include:
 - Improving access to information and services (not just health).
 - Treatment options that accommodate the busy lives of kāinga and support medication adherence (e.g. antibiotics versus penicillin injection).
 - Having a wrap-around service in one place that addresses the social determinants of health like housing support and lifestyle advice like nutrition.
 - Understanding and navigating the health system(s).
 - Management advice in primary health care with a haoā approach. Affordable dental care options that youth champs can access at 18+ years old.
 - Clinicians being aware of transnational lives of kāinga, including how to manage rheumatic fever and rheumatic heart disease when travelling back home or abroad.

- We learned that Tongan adults often have dental work or care done back in Tonga as it is more affordable. Health / dental care in Tonga should be seen as a legitimate part of the kāinga's overall journey and included in the conversations in New Zealand about rheumatic fever treatment and prevention.

What we created

We created a Haohaoā guide written by Lomipeau team member, Reverend Ifalame Teisi. The guide explains the thinking behind Haohaoā and how it relates to Kāinga Tonga in terms of preventing and managing rheumatic fever (see next page).



Lomipeau –

A Tongan approach to reducing rheumatic fever

What is the goal?

To reduce the incidence and prevalence of rheumatic fever amongst Tongan families.

What is the problem?

There is a mismatch between the response of the health system and the Tongan communities' mindsets and attitudes (nonoa'ia) towards the symptoms of rheumatic fever.


The insights of the lived realities of Tongan families with the health system revealed that the primary cause of not seeking health services is that the symptoms are not considered serious enough to act upon immediately. The Tongan concept of "nonoa'ia" describes the mindsets and attitudes of Tongan peoples towards anything not considered urgent, serious, and not a priority (competing priorities makes rheumatic fever less urgent) – like the French concept of blasé. Nonoa'ia is a strongly held cultural mindset, attitude, perception and behaviour and the current tactics of translation of health messages; information raising awareness; reducing access barriers; having Pacific staff on hand in clinics; having multiple swabbing localities, collectively is still insufficient to overcome the collective inertia and cause community wide impact.

"You can lead a horse to water, but you can't make it drink."

To cause a coordinated community wide Tongan community response we must overturn nonoa'ia mindsets and attitudes – this is what the design challenges need to address.

How do we address the problem?

In order to overcome the nonoa'ia mindsets and attitudes we must leverage existing Tongan values and frameworks that have the ability to capture the hearts and minds of the Tongan peoples and make them move collectively and immediately. This capitalises on our Tongan sense of cultural collectivism.



The Haohaoā Tongan framework is one that has the sufficient cultural weight to transform the mindset and attitudes of nonoa'ia throughout the Tongan community. The Haohaoā concept can be described as the transmission of cultural knowledge across Tongan families to keep future generations safe by avoiding known dangers experienced by the previous generations. A Tongan maritime concept, it was originally used during the navigation and settling of the Pacific to pass vital information back to those who were still in transit or still to come. In the same way, the peer-to-peer and families prototype beyond its healing purpose, provides cultural knowledge and experiences that can be communicated to future generations of the dangers of not acting immediately and taking the symptoms seriously. The Haohaoā model complemented by the peer-to-peer prototype has the transformative cultural weighting to overcome long standing Tongan mindsets and attitudes – by capturing the hearts and minds.

In the Lomipeau work we have identified five stages where nonoa'ia needs to be designed for and addressed to account for all levels of the family journey and make responding to rheumatic fever urgent, critical and important right across the Tongan community.

1. Tongan mindsets and attitudes, e.g. Haohaoā framework
2. Screening/testing, e.g. affordable easy to use self-test kits
3. Clinical guidelines and attitudes, e.g. standardised and adhered to clinical guidelines
4. Treatments, e.g. antibiotic injections
5. Support across life course, e.g. peer-to-peer and families prototype.


Note that only the first and last items on this list (Tongan mindsets and attitudes and support across the life course) have been co-designed for and prototyped. Although work has commenced, there is still opportunity to co-design for the other critical stages to complete the whole family journey and experience.

While Lomipeau has been focused on reducing the incidence and prevalence of rheumatic fever, nonoa'ia is applicable across the spectrum of health conditions experienced by the Tongan community.

What might happen next

We hope that the Haohaoā model will be used by other Tongan groups working on co-design initiatives and that it will continue to be developed in order to benefit our Kāinga Tonga.

We have embedded elements of Haohaoā in the tool for clinicians so that it will be used in clinical settings to create better experiences for kāinga.



Prototype #3 – Faiva (Performance) and Posters

Phase 1 and 2 Recap

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

Phase 3 Activities

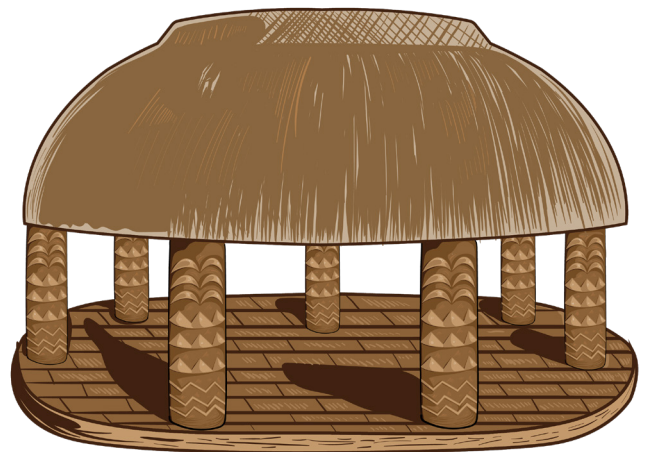
During Phase 3, we continued co-designing with kāinga to identify the best ways to raise and maintain awareness, exploring the types of messages that need to be shared. We also worked with Tongan clinicians to ensure that all messages are clinically accurate.

What we learned

During Phase 3, we learned that:

- Good rheumatic fever messaging needs to be on-going. When an awareness raising initiative finishes, this is often inferred as meaning that the issue has been resolved and prevention practices cease.
- Great rheumatic fever messaging is also a combination of creative and informative. The 'same old' generic messaging can fail to get cut through because it doesn't reflect the realities for Kāinga Tonga. For example, encouraging people to see a doctor for a sore throat, but not addressing the accessibility challenges (e.g. waiting times, time off work, added burden on primary care workforce, etc.).
- The best people to hear health messages from are your friends and family who have lived experience. This inspired us to think about how to leverage these trusted relationships.

- An effective way to deliver messages is by aligning them with traditional Tongan customs and practices that capture the minds and hearts of Kāinga Tonga. That is, use traditional mediums for raising awareness.



What we created – #1 Faiva/Performance

We were inspired by the learning that kāinga might think that rheumatic fever is gone when the awareness raising work or campaign finishes. We wanted to ensure this didn't happen with this co-design initiative so we created performance pieces (faiva). These were developed with kāinga and featuring the young people from the RF Champs Programme and their siblings. The performances use faiva faka-Tonga (performing arts) that is aligned with traditional Tongan ways of transferring knowledge intergenerationally.

"Faiva is an opportunity for everyone in the family to take part whether you are young or old. You learn the words, actions or music and talk about the meaning(s) and learnings behind it. It will live beyond the day of performing it."

The inaugural event took place on 6 July 2023. The song that was performed as part of this event has been titled: 'Nofo 'I Lelenga'. Nofo means to sit, to sit down, to stay, dwell, live, reside. 'I Lelenga' means in a place of lelenga or apprehension or trepidation. Families who have experienced rheumatic fever shared how they feel during their time of suffering: the state of constant apprehension, their state of fear, mental uncertainty, emotionally feeling afraid, physically feeling the constant pain and aching of the whole being, the living in Lelenga (apprehension).

The song is an original composition by Samiukatōa Uatahausi and written by Rev. Ifalame Teisi. The music begins with the Tongan nose flute (fangufangu) which is used to wake the King up and often associated with the opening of the national Tongan radio (primary source of communications back in Tonga). The intentional use of minor scales acknowledges the resilience of Kāinga Tonga living with rheumatic fever and rheumatic heart disease. Faiva is a medium that captures and communicates the contrasting perceptions of nōnō'ia (blasé attitude) and how

one might achieve haohaoā. This honours the mental and emotional challenges and triumphs of kāinga and those supporting them. It is a symbol of unification between young people who have suffered from Mofi Lumetika, their families and their communities. Nofo 'i Lelenga seeks to celebrate that this was not a journey of an individual but a community.

The lyrics speak of the trials rheumatic fever has set upon the lives of our young people and their families. The last verse seeks to depict the freedom in which they have experienced since overcoming Mofi Lumetika (rheumatic fever), however, forever bound by on-going treatments and the effects of Mofi Lumetika.

Below are the full lyrics of Nofo 'I Lelenga.



Nofo 'I Lelenga

Lea faka-Tonga

Teu hūfanga he tala 'oe fonua, kau talanoa
mofi lumetika, mahaki faingata'a.

TAU

Ko Te Whatu Ora, nofo 'i lelenga ē 'ae loto
mo'ui haohaoā.

Matal mai, Tangata Whenua, Soālaupule,
kainga 'o Tonga, Lomipeau 'ae vaka.

Tau'atāina tauhi haohaoā, mafu mama
mofi lumetika koe nofo 'i le le nga.

English

I will seek refuge in the words of our orators,
so that I may speak of Rheumatic Fever, an
illness that is difficult to bear.

CHORUS

Te Whatu Ora, I succumbed to a state of
apprehension, of what was once pure.

ThinkPlace, Tangata Whenua (reference to
peoples of the land of Aotearoa) and Te Tima
Māori, Soālaupule (Samoan Co-Design Team),
People of Tonga, Lomipeau is our ship.

Free but forever bounded, to keep on getting
through, mafu mama, mofi lumetika.



Photos from the inaugural performance



What we created – #2 Posters

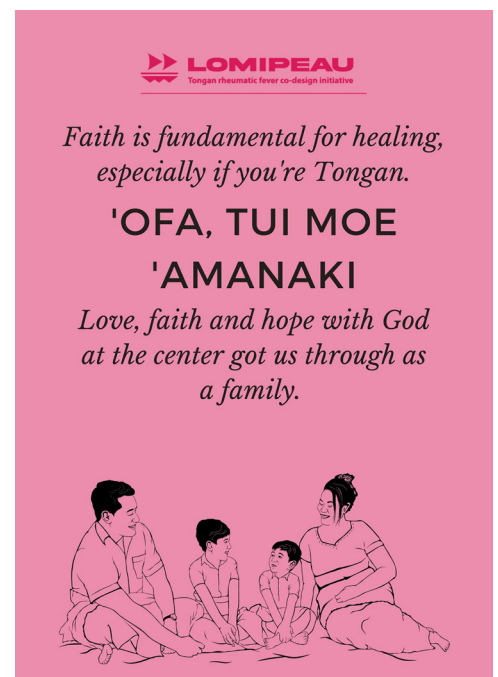
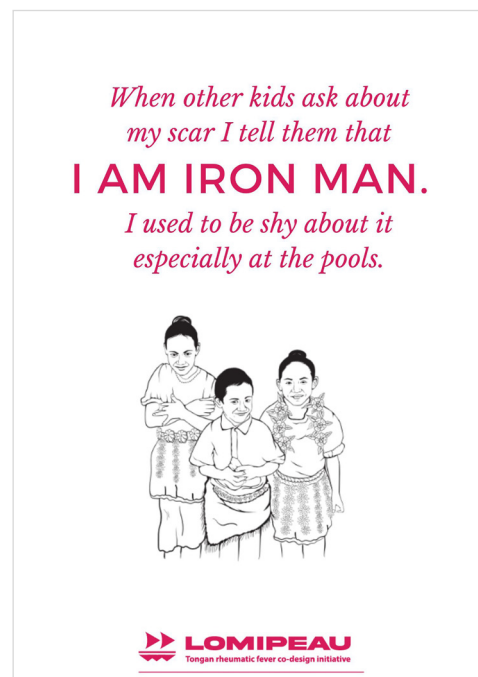
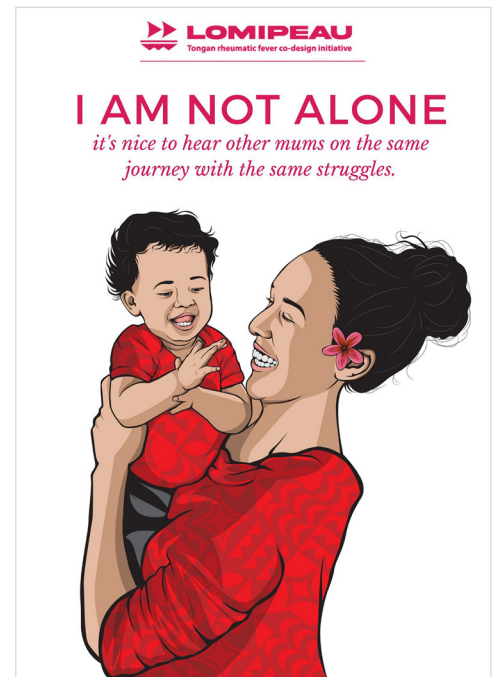
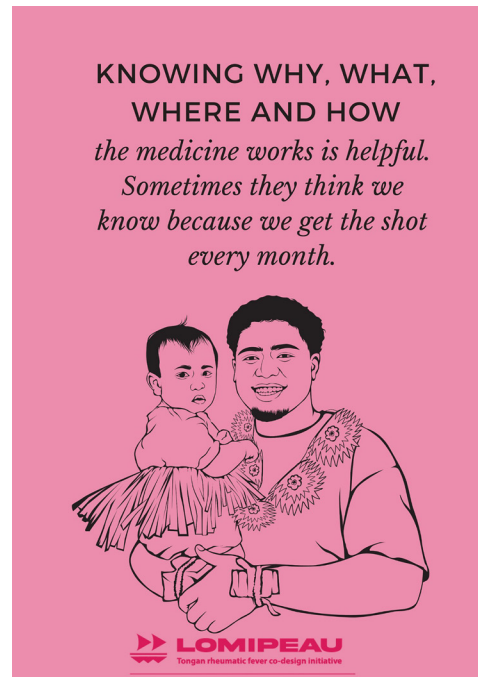
Another medium for sharing knowledge with kāinga is through the following posters that were displayed during the Faiva / Performance evening. This was a way to distill some of the key messages that kāinga wanted to or needed to hear from other kāinga who had also experienced rheumatic fever. Through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

What might happen next

The posters will be hosted on a public platform so that they can be shared by the young people, their families, and other stakeholders via social media.

Our hope is that the concept of using faiva for rheumatic fever awareness raising will be continued across the health system, including as an ongoing part of the RF Champs Programme.

Rheumatic fever posters displayed during the Faiva performance evening



Prototype #4 – Tool for non-Tongan Clinicians

Phase 1 and 2 Recap

Much of the trauma we heard about during Phase 1 related to the healthcare journey that kāinga experienced. We heard how clinicians have a critical role to play, but often don't understand Tongan culture and practices. And we heard how the healthcare journey is siloed, with different clinicians creating different experiences.

In Phase 2, we set out to reduce the emotional labour for kāinga engaging with the health system and to develop and deliver a family-centred model of care. Our prototyping work showed that non-Tongan clinicians would benefit from simple guidance that helped them to provide more kāinga-centred care.

Phase 3 Activities

During Phase 3, we worked with Tongan clinicians to develop and test an easy to use tool for non-Tongan clinicians to provide care that is affirming to kāinga. The tool has its foundations in the stories from kāinga, was developed with Tongan clinicians, and was tested with GPs, nurses and other health professionals.

What we learned

During Phase 3, we learned that:

- Most clinicians want to create better experiences for Tongan kāinga, but are lacking the resources to do so.
- Most clinicians aren't aware that the Tongan name frequently used for rheumatic fever (Mofi Hui) can be misleading.
- Kāinga want to have knowledge of different treatment options that are available to them.

What we created

On the next page is the tool that was created, giving clinicians inspiration about how to provide Haohaoā in practice, and how this contributes to short-term and longer-term outcomes for kāinga.

What might happen next

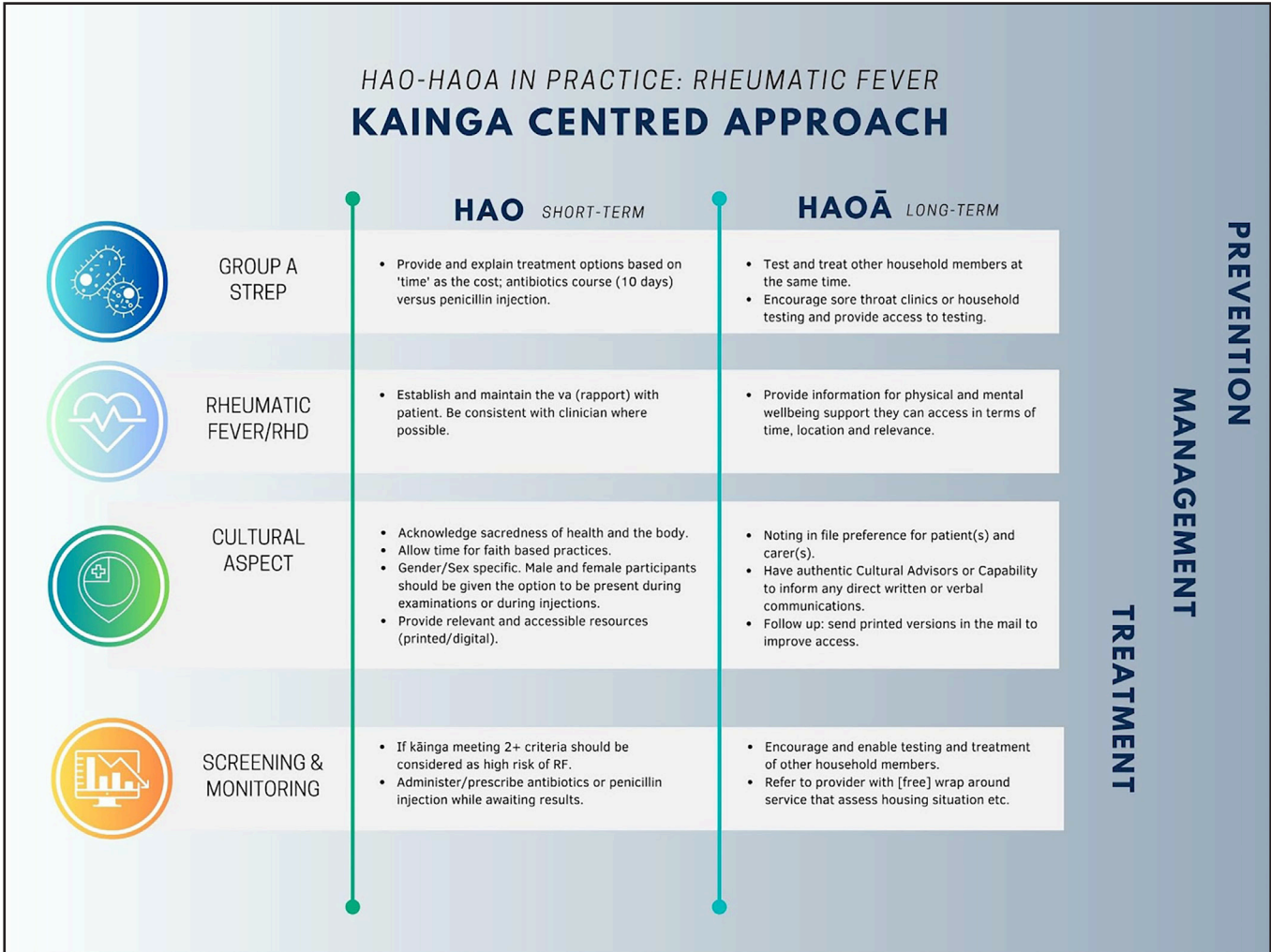
Digital and printed versions of the tool have been shared with clinicians who have been supporting the co-design process, and will be gifted to other clinicians.

There is also an opportunity for this tool and the Haohaoā tool to be incorporated into the training and professional development of clinicians and health professionals.





Tool for non-Tongan Clinicians about providing Haohaoā in practice



Conclusions

By allowing our Tongan values and customs to guide us, we were able to ensure we were not increasing engagement fatigue for kāinga and instead we sought to alleviate the fatigue. Because of this, the solutions that were identified, tested, refined and embedded are ones that are accepted and supported by kāinga and Tongan clinicians. This provides inspiration for the rheumatic fever prevention and management system: when communicating with or engaging with Kāinga Tonga, doing this in conventional ways will not get the impact that is hoped for.

Kāinga who have participated in this process have been supported to progress along their healing journey and to have agency in their wellbeing journey. There is potential for the design of the RF Youth Champs and the approach to the faiva and posters to influence all investment into health communications and service provision that impacts Kāinga Tonga

who experience rheumatic fever. The RF Youth Champs also provides a model for the health system to incorporate the voice of lived experience in a way that is deeper and more engaging than traditional consumer panels. We have demonstrated how, to have impact, health communications and awareness campaigns need to have longevity and use channels and language that is consistent with how kāinga engage.

Our final conclusion is that the 'rheumatic fever prevention and management system' is broader than those providing health services: it includes kāinga, church leaders, community leaders, sports clubs, and others who are engaging with young people and their families. By viewing the people in the system more widely we are able to see new opportunities to raise awareness and prevent rheumatic fever.

