



LOMIPEAU

Tongan rheumatic fever co-design initiative

Prototypes Progress Report

July 2022

FAKATAPU

(Acknowledgements)

Kole ke mau hufanga atu he talamalu 'o e fonua moe lotu' kae atā ke fakahoko atu 'a ho mau fatongia ni. '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 a Hou'eiki mo ha'a Matāpule, Fakatapu ki a ha'a Tauhi fonua moe kainga 'o e fonua ni (Tangata Whenua). Fakatapu foki ki he tākanga ngāue 'a e Kainga Māori, tākanga ngaue 'a e kāinga Ha'amoā. Fakatapu ki he ThinkPlace pea moe kau ngāue me 'i he potungāue mo'ui.

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

'Oku oatu ai 'a e fakatapu moe faka'apa'apa lahi ki he ngaahi famili', 'a e kau tauhi fanau' mo 'e nau 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 moui kuo uesia 'e he Mofi Lumetika pea koe 'uhinga ia 'a e ngāue mahuinga ni.

This report provides a backbone to the Tongan ethnic-specific stream under the Rheumatic Fever Co-design Initiative, commissioned by the Ministry of Health 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.

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.

As a starting point of our wayfinding, this report provides an overview of Lomipeau's Prototype Co-design (Phase 2 of the overall Co-Design Initiative, Stage 3 of the Lomipeau co-design process) following the 'Discovery Phase Report' released in April 2022. It provides a snapshot of how the prototyping areas have further developed.

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 the Ministry of Health 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 the Ministry of Health, ThinkPlace and our Māori, Samoan and Tongan communities.

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Faka hao haoā



Tufunga fonua

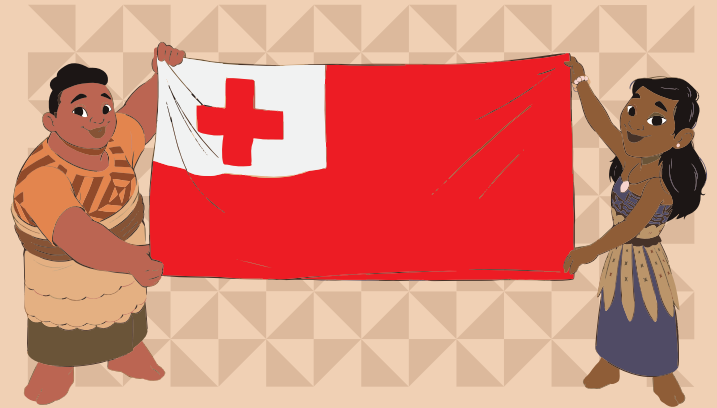
(Learning across the whole team/initiative)

A Tongan approach to co-design.

Tau'atāina + faa'i kavei koula = Hao haoā model
(A Tongan approach to co-design)

Critical foundational understanding of Rheumatic Fever (RF) through evidence and relationship building

Building on past and existing work both in NZ and in Tonga.



Tufunga niu vaakai

(Learning across each stage/prototype)

Ability to look beyond the immediate and seek new opportunities through ideation.

Seeking new ways of viewing ideas through genuine and meaningful collaboration.

Utilize design tools to support development of prototypes.



Tufunga tefua a vaka lautala

(Learning through each stage/prototypes)

An initial idea of a retreat for kāinga was explored however, sensemaking in phase 2 revealed that a different approach was needed.

Some kāinga preferred not to share their experiences “we just want to get on with life”. How might we engage this audience?

Tested Tongan infographic consent forms and feedback loop using infographic summaries sent to kāinga after each workshop.



Faka hao hao

This phase is focused on ideas and solutions and forming low-fidelity prototypes ready for further iteration and testing.

Through stage 3 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.

Prototype opportunity areas identified in phase 1.

Develop experiences that enable healing :

- Autonomy over their journey/stories.
- Activating informal peer to peer support.
- Retreat for kāinga with leading Tongan mental health professionals.

Proactive healthcare communication & promotion :

- Developing Tongan understanding of RF/RHD (Mofi lumetika).
- Identifying consistent messaging that aligns with cultural context.
- Retreat for kāinga with leading Tongan mental health professionals.

Model of care & healthcare journey :

- Reducing the emotional labour for kāinga engaging with the health system.
- Developing and delivering a family centered model of care.
- Developing long term health care plans to support kāinga with a focus on transitions from child to adolescent through to Adulthood.

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

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.

An additional workshop allowed current and new families to build on the prototype ideas. This workshop allowed the Lomipeau team to interpret ideas as low-fidelity prototypes by using illustrations. Prototypes are not models of the correct answer; they're ways of sense making if you're heading in the right direction. We started with the main concept, got their feedback, and then showed them the journey.

The Lomipeau team are currently analyzing the feedback and identifying key opportunities and leverage points to support the testing of the prototypes. We are leveraging our insights about what creates the ideal environment for this coming together of people; in other words a facilitated peer-to-peer service that is designed for Tongans. We are building from the informal peer network that has existed within the Co-Design Initiative and are running a pilot of what this peer-to-peer service can look like over a 6-9 month period.

Key components of the peer-to-peer service pilot include:

- 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.

Running alongside the peer-to-peer service pilot, we will be co-designing 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.
- 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.

Folau tau'atāina (enablers) :

- Allow families the space and time to reground themselves in the insights. Sense making in between workshops, did we get it right? Has the thinking or feeling changed?
- Important for spiritual activities to be part of the workshops.
- We can all bring a learning orientation to our ngāue, it's not just an innovation remit.
- Using language and examples that are relevant to our families to describe prototyping.
- The importance of a key individual to continue the relationship and communications with families.
- Giving space for families to reflect is just as important as getting through the activities.
- Responses to and treatment(s) are isolated from Tongan notions of well-being and holistic health.
- Prioritizing addressing the Social Determinants of Health is key to effective and sustainable solutions.

Stage 3 : Tefunga Tefua a vaka lautala

(Ideating with kāinga)

The Lomipeau team held workshops with kāinga and Tongan health professionals and other experts to build on the critical insights developed from Phase 1.

The workshops gave kāinga an opportunity to respond to ‘how might we?’ questions.

How might we develop experiences that enable healing from RF/RHD-related trauma?

How might we develop Tongan understanding of RF/RHD (in progress via ‘mofi lumetika’)?

How might we develop a model of care and healthcare journey that resonates with Tongan communities?

These questions allowed our families to develop solutions expressed in a variety of ways and captured through concept sheets.

The families were split into three groups, one group was made up of our young people, one group was made up of women and the other was made up of men.

The organising of these groups is aligned with Tongan cultural values to keep our participants safe, enabling an environment for families to express themselves freely.

Each group had access to resources and tools to build their ideas, where some built their ideas, others acted and drew their ideas.

Allowing different forms of creativity enables participants to express their ideas in unique ways.

A concept sheet was provided to each group to capture their ideas and was an important tool that allowed the Lomipeau team to analyze and make sense of the direction the groups were wanting to take their ideas.

It is important to note that the prototypes developed by our families are not the finished products nor are they exactly what families are after.



Prototype area 1:

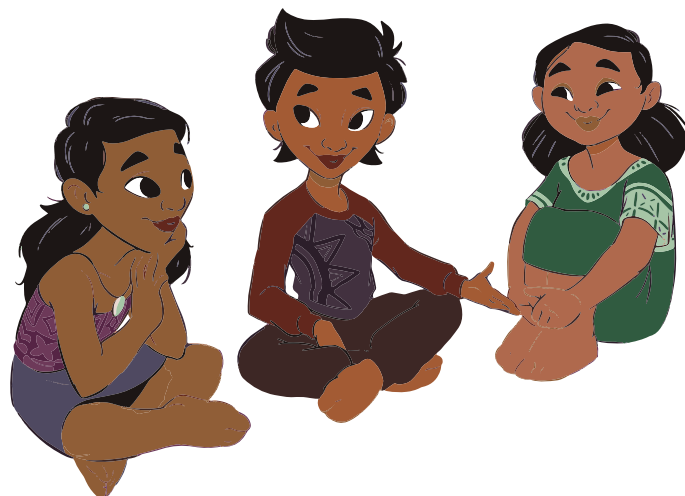
How might we develop experiences that enable healing from RF/RHD-related trauma?

Young people living with rheumatic fever build an eco-system of support through psychosocial activities that maintain good mental and physical health.

Tongan young people with Rheumatic fever experience major life changes in adjusting to their new norms.

It is important for our young people to feel supported and peer to peer is a key mechanism to achieving this.

Stigma attached to rheumatic fever contributes to the loneliness, not being able to participate in activities they used to be able to further isolate them, not only from their family but from their peers as well.



What have we learned?

Tauhi vā māfana (Transformative not transactional relationships.)

- 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).

Folau tau'atāina

Enablers

- Using creative mediums to bring everyone together where the focus is not rheumatic fever (talking about it, without talking about it).
- 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).
- Amplifying youth voices in a way that reflects their realities without taking it out of context (don't blame my family, help us build self-agency).
- Inclusive as many of us are of mixed ethnicities.
- Informal peer to peer support is a core component of giving our Tongan young people living with rheumatic fever space to heal, and it can play a strong role in allowing autonomy for them to lead a healthy life.

Next steps :

- How feasible are these ideas (online and offline).
- Youth voice is not only heard, but listened to. Equipping youth with the tools and resources they need to design, lead and deliver activities they want.
- Removing system barriers (including funding) that limits commitment and consistency in service delivery.
- Articulating the socio-economic conditions that our families live in through a sustainability lens.
- Looking into wrap-around support for our kāinga and how the communication barriers can be alleviated.
- Aligning with health providers that are running peer groups for young people to leverage the learning and better cater for Tongan youth.
- Exploring the role health providers can play in supporting peer groups for young people in ways that contribute to self-agency.

Prototype area 2:

How might we develop a Tongan understanding of RF/RHD (in progress via 'mofi lumetika')?

Kāinga can connect with the services they need in order to prevent or manage rheumatic fever.

The siloed nature of health and social services impact kāinga's navigation of the health system.

The concept of an app as an enabler for Tongan families to feel empowered in leading their journey and accessing the best quality care was identified.

This activity identified the types of information and the type of delivery that would be most useful to kāinga, irrespective of whether it is delivered by an app or other method.

Fetu'u taki has two meanings, 'the guiding star' or 'to communicate'.

Both meanings resonate with the prototype idea however, 'the leading star' narrative was prominent when the group demonstrated their idea with a skit.

What have we learned?

Tauhi vā māfana (Transformative not transactional relationships.)

- Medical practitioners need to be relatable and health information needs to be easy to understand.
- There is a preference to have reminders conducted in person, in order to tauhi or nurture the vā between kāinga and health practitioners.
- Consistent messaging across a range of platforms that cater to intergenerational households.
- Peer to peer support groups that meet in person and also talk online.
- What does a safe space look like for parents?
- Elevating existing safe spaces like church faikava groups (for men), tou lalanga groups (for women), and coffee dates for younger parents.
- Events that compliment their day to day lives.

Folau tau'atāina

Enablers

- Apps can be short term solutions but there needs to be more efforts made in terms of offline experiences for our kāinga that can achieve the same impact.
- There are key digital equity issues that our kāinga struggle with and this can potentially affect the full wrap around support available.

Language needs of our Tongan (and wider Pacific) community.

- Mofi Lumetika versus Mofi Hui - naming the symptoms can easily be mistaken for something else. Is this why misdiagnosis happens?
- Interactive, short quizzes similar to questions we would get asked at the hospital with timely follow up from a health professional.
- Consistent health communication that includes faith based references.
- **Cater to transient families**
- Ability to connect with the right services at the right time.
- Transferring care between different District Health Board regions (now part of Te Whatu Ora) or GP.

Next steps :

Addressing the siloed nature of health and social services through tauhi vā māfana that enables folau tau'atāina.

Surfacing and embedding insights about information flow (online and offline).

Feeding online aspects into relevant and existing work streams such as Fight the Fever app or Te Whatu Ora patient management system.

Consideration of inclusivity/diversity of Pacific audiences' interaction and engagement is worth looking into.

Prototype area 3:

How might we develop a model of care and healthcare journey that reflects our Tongan communities?

Kāinga have a 'hub community' that meets their well-being needs and enables services to work collaboratively.

Kāinga expressed dissatisfaction that their experiences are not recognised and highlighted opportunities to heal by coming together to share and learn from each other.

It is important to have a space that can facilitate sharing of their frustrations and for services to respond.

A hub community that is designed to enable services to work collaboratively together rather than working in isolation and ticking boxes.

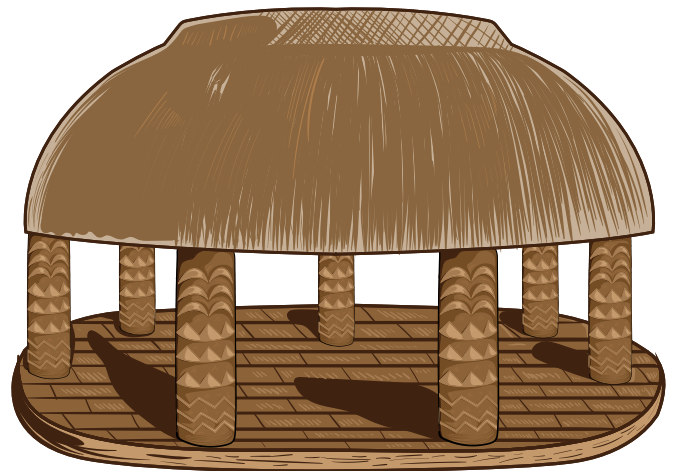
This is a foundational element of providing a model of care and healthcare journey that resonates not only with Tongan but other Pacific communities as well.

When we think about a model of care for Tongan families, it is highlighted through the features of the Tiare Ora that give key elements needed within a model of care framework.

What have we learned?

Tauhi vā māfana

- Interpersonal approach care leads to positive experiences with RF treatment and management
- **Social isolation from services and or family.**
- A family-centric approach rather than an individualistic approach.
- Wider network of support from health to social services under one roof.
- Enhanced experiences with services as families are connected to a hub community that represents them.
- Age appropriate care that reflects transitioning from child to adolescent to adulthood and beyond.
- Services rarely acknowledge that kāinga are juggling complex health and life issues.
- Health professionals who genuinely understand Pacific ways of being are instrumental in effective healthcare by providing cultural safety both for service providers and users.
- An integrated approach to service and funding is needed to address siloed approaches and funding barriers.

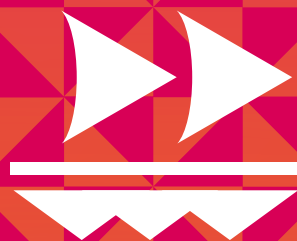


Next steps :

- Explore the idea of creating a small network that creates intimacy and trust. Scoping out what already exists in our rheumatic fever ecosystem.
- Improved referral paths and RF management processes that meet the complex needs of kāinga.
- Assess what areas might be missing for the needs of our kāinga – are they in a position where they feel comfortable to ask for help? Why/Why not?
- Creating connections with Tongan clinicians and other experts to support the information needs of kāinga.
- Coordination of the service by suitably experienced people and by looking into trusted health clinicians and experts that our kāinga feel safe with.

Running alongside the peer-to-peer service pilot, we will be co-designing 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.
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