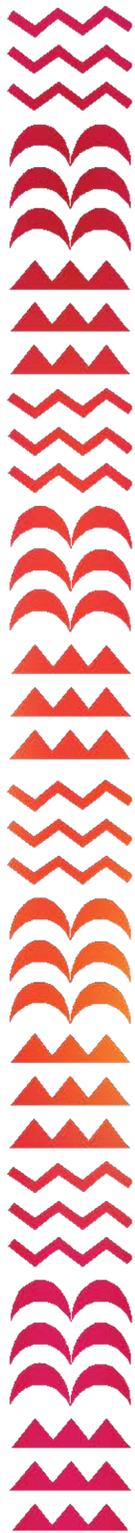


RHEUMATIC FEVER CO-DESIGN INITIATIVE DISCOVERY PHASE REPORT

APRIL 2022

Lomipeau
Tongan Co-Design Team





FAKATAPU | ACKNOWLEDGEMENTS

Fakatapu ki he Otua ko'ene pule 'oku fakaleveleva. Fakatapu ki a Hou'eiki mo ha'a Matapule, Fakatapu kia ha'a Tauhi fonua moe kainga 'o e fonua ni (Tangata Whenua). Fakatapu foki ki he tākanga ngaue '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 ngaue fekau'aki 'oku tau kaungaa ngaue fakataha koe'uhi koe ngaue mahu'inga ni. Kae 'ata kiate au ke fakakakato atu 'a e ngāue mahu'inga kuo tau ikuna makatu'unga 'i he 'e tau ngaue fakataha ' koe kakai pe 'e taha.

This report is part of 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.

We wish to thank the Tongan kāinga who provided their time, heart and lived experiences contributing to the development of this report.

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

We would like to thank ThinkPlace for their expertise and continued support of the Lomipeau team and the Tongan community. Their deep understanding of design thinking and values based approach has enabled a process where innovation and cultural safety work hand in hand to produce quality insights that truly reflects our community.

We also would like to thank the Ministry of Health for their leadership and guidance. 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.

This work is driven by our Tongan values and we hope the readers feel that through this report.



CONTENTS

Our approach	4
Insights	11
Family personas	19
Journey map	26
Opportunity areas	28
References	31

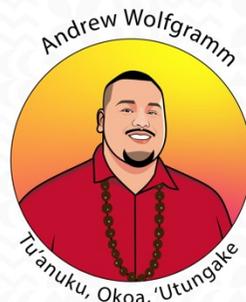
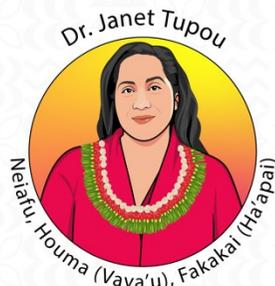


OUR APPROACH

This section describes how the Lomipeau team has approached the work.

This initiative has created an opportunity for our 'Tongan-ness' to be expressed and to guide the way we approach every aspect of the work. This meant that we started by developing our own co-design methodology that is inspired by Tongan values, concepts and stories.

LOMIPEAU



We value Anga faka-Tonga (our Tongan culture).
Faa'i kavei koula (faka'apa'apa, Tauhi vaha'a, mamahi'i me'a, loto tō).
'Ofa (Love)

We believe Our families need a holistic approach to prevent or overcome RF.
Our families are dealing with complex issues already.
All Tongans strive for good overall wellbeing.

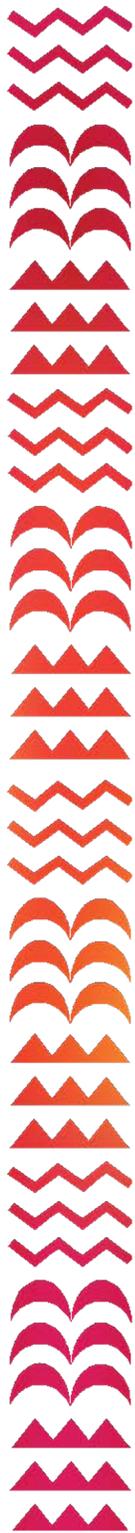
We assume Tongans are disengaged with the NZ health system.
Tongans have a relaxed attitude towards health that do not present physical symptoms.
We do not want to bother others, families or health system.

ABOUT US

Fakatapu ki he fanau moe fanga mokopuna 'a hou'eiki mo ha'a matāpule, kole keu hufanga he fakatapu kakato 'o e Fonua moe Lotu ka 'atā ke fakahoko atu 'a e fatongia ni.

Lomipeau loosely translates as 'the wave cutter or suppressor' and was the name of the kalia (double hulled canoe) of the Tu'i Tonga Uluaki Mata or Tele'a who spearheaded a lot of social change in Tonga during his reign (Mahina-Tuai, 2009).

We consider the Lomipeau to be a fitting name in the sense as a metaphor talks to Rheumatic Fever as the peau (wave) and our role as a Tongan Co-Design team finding solutions and ways to cut through the peau, taking our people to a destination of good health and wellbeing. Our role as a team is to lead the Lomipeau kalia/vaka with all our tools and ability to support our Tongan community.



HAOHAOĀ MODEL | A Tongan approach to co-design

Our co-design approach was constructed using the Tongan concept of Tau'atāina. In this context, we link Tau'atāina to traditional Tongan vaka (sea vessel) and the protection offered by the Taula (anchor).

**“Koe fotunga ‘o e Tonga ‘a e faa’i Kavei Koula:
‘Faka’apa’apa, Tauhi vaha’a, Mamahi’i me’a, Lototoo”**

In conceptualizing tau'atāina, the Taula (anchor) provides safety for the Vaka when it is stationary however, on voyage, the responsibility of the Taula is shifted to the navigators at the helm, to protect the vaka to its' destination. Tau'atāina, in the context of freedom, alludes to one's freedom and safety from harm.

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

*Life is similar to a kalia that is equipped to navigate
and negotiate its path to high seas [lifetime]
How to keep the kalia from sinking or drifting
[personal ethic]?
How to keep the kalia on course and from bumping
to other ship [social ethic]?
Why the kalia is out there in the first place [essential
ethic]?*

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 center of our tau'atāina, hao haoā and wellbeing. Ultimately, it is aimed toward leading transformational change and achieving greater overall wellbeing and prosperity for our Tongan people.

Hao-haoā asserts the notion of holistic well-being. However, it merely captures how Tongan people perceive it. Hao is to succeed in getting in, out or through, to escape, or be acquitted. It can also mean having enough room or space in the house or land. Haoā then refers to sustaining being hao. Hao-haoā 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 harbor, that land of haoā from mofi lumetika, that place of tau'atāina from mofi lumetika.

TONGAN

Rheumatic fever Haohaoā approach

This co design approach was constructed using the Tongan Concept of Tau'atina.

In this context, we link Tau'atina to traditional Tonga vaka (boat) and the protection offered by the Taula (anchor).

In conceptualizing Tau'atina. 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. Tau'atina in the context of freedom, alludes to one being free from harm.

The inferred Taula for this 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 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'atina, Haohaoā and well being.

Ultimately it is aimed toward leading the transformational change and achieving the overall wellbeing and prosperity for our Tongan people.

**Koe fotunga 'o e Tonga 'a e faa'I
kavei koula faka'apa'apa, tauhi
vaha'a, mamahi'I me'a'loto to'o.**



HAOHAOĀ MODEL | A Tongan approach to co-design

Phase 1: TUFUNGA FONUA

This phase refers to the importance of building/protecting all that is Tonga through our unique values to protect our relationship with all things Tonga. This phase is the building block for our approach, our understanding of rheumatic fever and its connections to the Tongan people. The activities will provide critical foundational understanding through evidence, relationship building and reframing rheumatic fever through our Tongan lens.



Phase 2: TUFUNGA NIU VĀKAI

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 systems insights and Tongan traditional knowledge will identify critical pain points our Tongan community are facing with regards to rheumatic fever. This phase relies on Lomipeau creating an environment where our participants, experts and Tongan community feel tau'atāina to share their stories with the understanding it contributes to their freedom and protection from harm and towards overall wellbeing for themselves and the wider community. It is important in this phase that we view peoples in both their 'atamai and loto (mind and hearts) to obtain the full truth of their lived realities. The activities are fluid and have direct involvement of our Tongan community.

HAOHAOĀ MODEL | A Tongan approach to co-design

Phase 3: TUFUNGA TEFUA A VAKA LAUTALA.

Is the vessel or means for the journey fit for purpose? This phase is focused on transforming our Tongan community experiences into the possibilities for our people to create solutions that not only focus on addressing the issues but drive transformational change for our people. It is important that in our quest towards tau'atāina the rheumatic fever team not only build transformational solutions but ensure that ourselves, community and stakeholders are transformed within Tongan cultural practices and values. This will ensure that the solutions being created are created for our Tongan community with their lens at the forefront of the prototypes created.

Phase 4: TUFUNGA TAKANAGA 'E NAU FOHE.

Collective efforts lead to effective and sustainable outcomes. This phase is focused on the implementation of the solutions across all facets of Tongan community. The solution cannot be isolated but rather tested across all dimensions of the Tongan community and system for transformational change. Testing through prototypes, we will iterate, refine, challenge and most importantly tauhi the vā between the different playing parts and people in our approach. During the testing phase the Taula will sit with various individuals across the project team, Tongan participants and stakeholders to ensure the values are upheld throughout as testing can unearth biases, practices and views that will not reflect us as Tongan people. These activities will help lead to a place where we can start the transformational change process.



KĀINGA ENGAGEMENT

The engagement with Tongan kāinga consisted of three styles:

- Informal engagement with young people, kāinga, community members and Tongan clinicians.
- Talanoa sessions with 4 families.
- Youth-specific sessions (talavou).

The Lomipeau team conducted a series of talanoa with Tongan families who have experienced rheumatic fever. The families were targeted specifically as they were Tongan and have experience going through rheumatic fever in a New Zealand context. The talanoa sessions were conducted online due to COVID restrictions and were later transcribed for analysis.

For the talanoa sessions, a total of 4 families participated. For each family, several family members participated which gave a variety of views relative to role / position in the family.

The Lomipeau team captured the voices of the family through recordings which were in the talanoa sessions with the Lomipeau team. It is important to note that families were able to converse both in the Tongan or English language to allow a safe environment for them to share.

A thematic analysis was conducted with the data to form key themes which is the basis of this report. Thematic analysis allows for an empathy lens to be placed over the voices of the participants where common themes were able to be built through prioritizing the participants lived experiences.

This insights that follow sit alongside the Lomipeau team's family personas and journey map to provide a fuller insight to the lived experiences of our Tongan kāinga with regards to rheumatic fever.



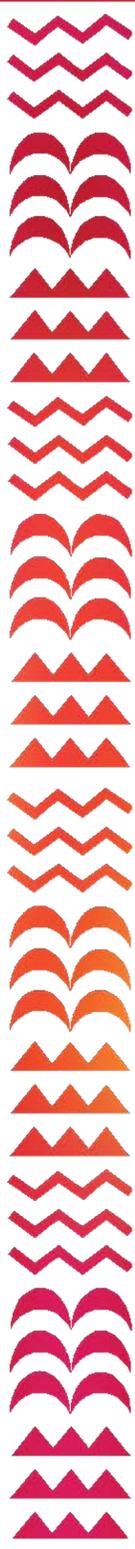


INSIGHTS

This section describes the five key insights that have been identified by Lomipeau.

These insights were arrived at following desktop research, informal engagement, talanoa with kāinga, and thematic analysis.

The insights illuminate the experiences of Tongan families within the rheumatic fever system and provide a basis for identifying change opportunities.



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

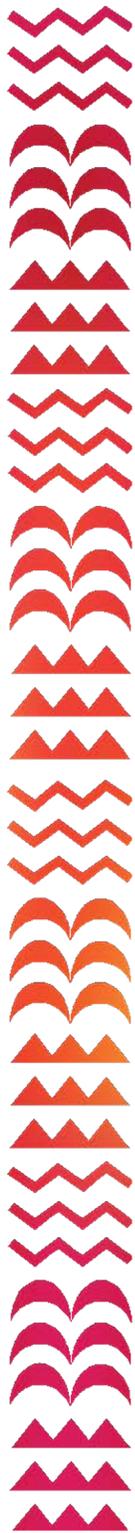
Preliminary themes and insights from the data highlight the heightened degree of emotional labour levels for kāinga Tonga that are impacted by rheumatic fever. It was noted that there was a tendency for kāinga to feel frustrated and confused as a result of miscommunication, 'feeling lost' with a lack of direction and clarity from the initial stages of diagnosis. More specifically, parents felt a sense of 'imposter syndrome' as they struggled to make sense of their realities based on the existing knowledge bases.

"That was freaking me out. That is where I lost myself in that moment."

"Every time I get to talk about it, the disappointment is still there because I feel like we weren't treated properly at the beginning and then it took me a while to get over myself and get over that."

"If you ask a lot of Island families, they don't understand it. Do we have enough translators out there?"

"One moment we are talking about one thing the next we are talking about something else, and it affects our feelings."



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.

In our talanoa with kāinga, they reflected on how traumatic the rheumatic fever experience was. Conversations and assumptions from medical practitioners highlighted the racism and discrimination evident from both a systemic and personal level, which made the rheumatic fever journey difficult and harrowing. The talanoa session itself acted as a 'place of healing' noting that healing needed to take place from a collective, whole household approach.

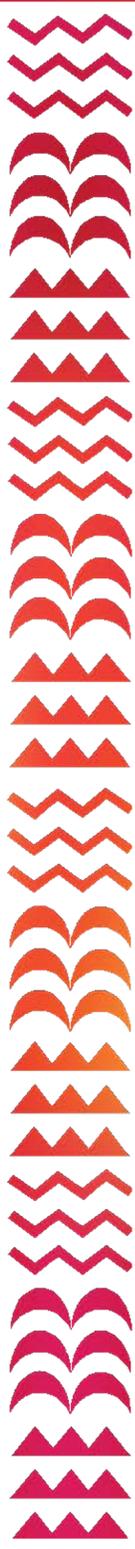
“It has been a great experience discussing this matter. I was talking to the Reverend. It has given us this opportunity to use this platform because our voices are important.”

“I still think to that day, and I cry because it affected our family so much.”

“A lot of it is loneliness. Like I said, if they provided a house, they would move but then it is about companionship for the boy being around other kids. It is about her being around her dad, but it is entirely up to them. I feel like it is about being lonely and them not wanting to be on their own.”

“We still think about it, I sometimes blame myself, could we have done something different? Is our house too small? it always plays on our minds.”

“They didn't get it right, from the treatment and also how they investigate it and identify the health issue. Also, racism. If I can be blunt about that.”



INSIGHT 3



Mental health, pastoral care and spiritual guidance are key areas that needed more attention.



Holistic wellbeing is fundamental with dealing with Tongan families. You cannot focus on clinical care in isolation without the other dimensions to wellbeing.

Areas of holistic wellbeing were neglected and needed more attention, according to preliminary findings. Mental health, pastoral care and spiritual guidance are key areas that needed more attention. Support tools looking at the whole person, and not one area, would enhance physical, emotional, social and spiritual wellbeing, rather than just their illness or condition.

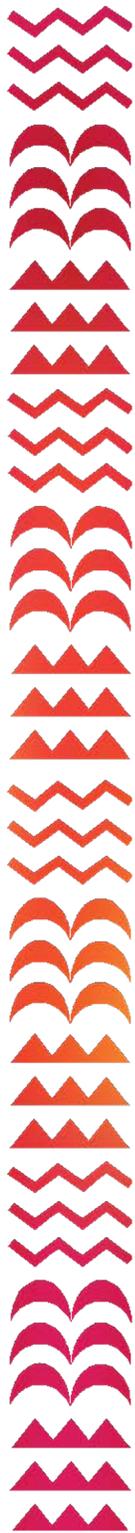
“I will be honest with you; I am happy where I am because I am next to my church. I feel safer, and I feel like this is where I need to be. It is part of my calling”

“He is the only child that is struggling and dying inside internally. He is bleeding inside and longing.

“We had to think what it’s going to be like for him not able to play rugby because he loves rugby”

“I think for me personally, for us as a family, first it has been affected a lot I guess, mentally, physically, spiritually and emotionally.”

“During lockdown we got quite worried and had to call our doctor. He was going through depression and I know that for sure. He locked himself in his room and didn’t want to go out anywhere at all.”



INSIGHT 4



A fundamental shift away from individualistic, Eurocentric communication approaches.



Culturally specific communication modes and approaches need to be collectively centered to reach the heart of our Tongan families.

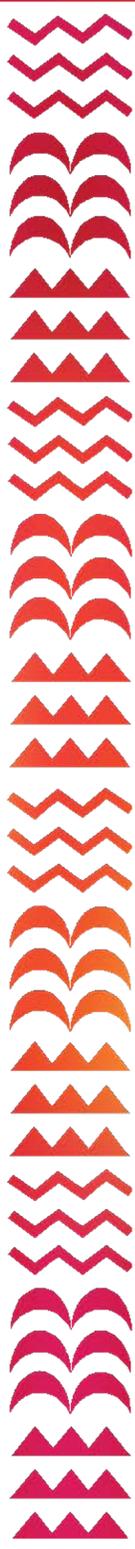
Anecdotal evidence from kāinga revealed the need for Pacific modes of communication to be adopted as well as adapted in order to improve communication and rapport with health practitioners.

A fundamental shift away from individualistic, Eurocentric communication approaches highlights the importance of decolonizing dominant ways of communication that is often taken for granted. Movement away from these 'one size fits all' modes enables improved understanding and communication with kāinga, empowering them further to share their knowledge and understanding.

"I did disagree for the surgery to go ahead. I had to ring my mum and she had to convince me to get the surgery done for the sake of his life."

"We always keep our wider family informed, they know how to support our son, they know what to do, it is important they're all part of it."

"They should know the best way to share information to our people."



INSIGHT 5



Offloading of this stress resulted in elevated levels of anxiety, depression, confusion and **misplaced anger**.



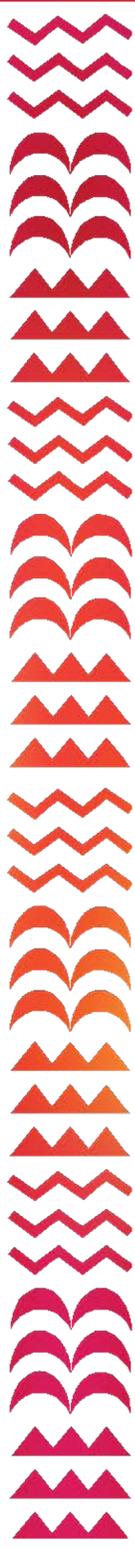
Knowledge gaps was evident across the rheumatic fever journey and elevated stress levels for our kāinga.

Based on what our kāinga told us, knowledge gaps in the rheumatic fever space was evident in areas such as medical appointments and understanding technical terms and medical jargon. Consequently, the flow on effect was that stress levels for kāinga then increased and it was noted that the offloading of this stress resulted in elevated levels of anxiety, depression, confusion and misplaced anger.

“It is because of the bad experience I faced from the very first time we were admitted. The doctor doesn’t know and now the doctor says go through heart surgery.”

“I had to take him into [medical centre], had to put him in a wheelchair because he couldn’t move. They said he doesn’t have rheumatic fever, but he has three of the symptoms.”

“They didn’t get it right, from the treatment and also how they investigate it and identify the health issue. Also, racism. If I can be blunt about that.”



INSIGHT 6



Where there were high trust models in action, the vā between health professionals and kainga flourished.



High trust models are critical to foster the vā between health professionals and our kainga.

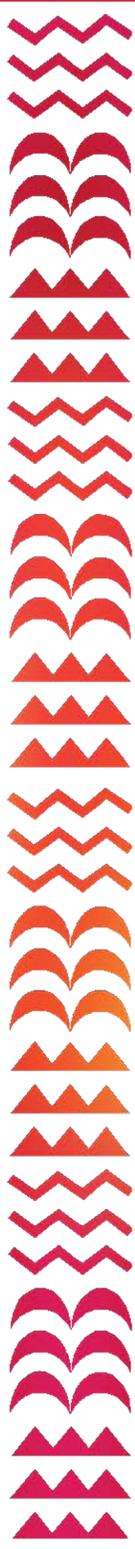
Where there were high trust models in action, the vā between health professionals and kainga flourished, creating a warm, reciprocal relationship that went beyond the rheumatic fever space. The exchange of service and communication was memorable and assisted in situations where stress and emotional labour was high. It was also noted that an absence of warm relational practices between the kainga and health professionals produced feelings of isolation, being and 'feeling left out' harboring further distrust in the system.

"I am not going to give you my passport, nor is my son or my husband because we are residence here. My husband has been brought up here in New Zealand."

"That was my first disappointment and it started off straight away like that. I was really put off with the whole process of going through the surgery, the treatment and all the medical evaluation."

"Our GP was really good, he knew our family and was making sure we were supported."

"It is easier if you have someone you can trust, because they want what's best for you and your child"



INSIGHT 7



Kainga want and need a safe space where they can share.



Regular opportunities paired with the right platform is key for kainga Tonga to share their experiences: a safe space.

The call to action here was very clear: kainga want and need a safe space where they can share and self disclose their experiences, restore their faith and strengthen relationships within their fāмили and with other kainga coping with rheumatic fever. To date, there are no established peer groups in the Tongan community.

“I just want to say I really appreciate what you are doing because it turned the light back on for me. I am glad there are voices and an organization out there.”

“Like myself I have just come into your space now but how long have I carried this until today and I am able to reopen up to speak to you. To be able to have a good conversation and release it.”

“I am really glad to come into your space because I think with this talanoa, how many mums out there are going through what I am going through and have to come in and they haven’t experienced the fact that they have to come in face to face and talk to somebody like yourself. I am very privileged to me in your space.”



FAMILY PERSONAS

This section includes three different family personas. Each family is different, with different needs and different experiences. These family scenarios have been inspired by the stories we heard from kāinga during the discovery phase.

These personas are useful for two reasons: (1) they help us understand what families experience, and (2) they help us think about how potential solutions will impact these families.

FAMILY PERSONA #1 (Lea faka-Tonga)

Konga e talanoa mo e fāmili

Ko e fale nofo'angaa 'oku 'ikai ke lahi fe'unga mo taau ki he tokolahi 'oe fāmili pea 'oku tokolahi moe fānau 'oku nau lolotonga ma'u 'ae mofi lumetika 'i he fāmili.

Neongo 'oku te'eki 'i ai ha 'ilo pau ki hono tupu'angā, ka kuo nau ohi pe si 'enau mo'ui ke kāinga 'ae anga 'enau nofō moe mofi lumetika.

🌀 Ko e mēmipa 'e 10 tupu'a e tokolahi 'oe fāmili

🌀 Koe ngaahi to'u tangata kehekehe 'oe fāmili 'oku nau nofo fakataha

🌀 'Oku lolotonga ma'u 'e he mofi lumetika 'ae fāmili 'ni

Tokanga ki ha ngaahi me'a 'e tupu mei ai

🌀 Fāmili

🌀 Kau fakataha mo e fānau

🌀 Tokonga'i e ngaahi palopalema faingata'a 'oe mo'ui lelei

Mahu'inga'ia, fie'ilo kiai, me'a 'oku fai, fakamu'omu'a

Mahu'inga 'aupito 'a e fāmili.

Mālohi e tui faka-Kilisitiane.

Fiefia 'a e fānau 'i he nofo fakataha moe fāmili 'o nau feohi mo kaungā fiefia mo honau kāinga.

Founga ngaau'e 'oku fakalata mo manakoa

Ko e founga ngāue 'oku fakalata mo manakoa ki he kāinga ko e tauhi vā māfana ka 'oku 'ikai ko ha tu'utu'uni pe ke muimui kiai.

Fehangahanga moia, manavasi'i pe tokanga kiai

'Oku 'ikai ke 'oatu 'a e fakamatala totonu mo taau ki he ngaahi fāmili.

'Ikai ke lelei 'a hono fakahoko 'a e ngāue ki he faka'ehi'ehi e tō'onga mo'ui ma'ae ngaahi fāmili 'o e kāinga Pasifiki.

Fakangatangata mo fakasi'isi'i 'a e fehokotaki moe vaaofi e nofo fakafamili koe'uhi ko e mofi lumetika.

Ko e ngaahi fiema'u, 'amanekina mo e taumu'a ne faka'ānau

Ko e faingamālie ke pōtalanoa tau'atāina mo fakatokanga'i 'a e ngaahi me'a koia 'e lava ke hoko ia ko e tokoni ki he fekumi 'oku fai.

Ko e ngaahi fakakaukau 'oku mahu'inga e lava ke fakahoko ia 'i he founga ko'e 'oku faingofua ange mo mahino lelei ki he kāinga Tonga.

Ko e founga 'e lava ke 'ilo ai kimu'a na'a hook mai 'a e mofi lumetika ki ha taha.



FAMILY PERSONA #1 (English)

Contextual story of the family

Large family living in a small to medium sized house.

Rheumatic fever is present within multiple children in their household. The family is still unclear as to the cause of it but they have adapted their lives to living and managing rheumatic fever.

- 🏠 10+ members in the household
- 🏠 Multiple generations living in the households
- 🏠 Rheumatic fever is active in the family

Motivational focus

- 🏠 Family
- 🏠 Child's participation
- 🏠 Managing complex health issues

Values, interests, activities and priorities

Family is really important.

Mum is the primary carer for the child as she wants to prioritise their health and advocate for them.

Active children and family engaged in local sport clubs.

Preferred mode of engagement

The family prefers relational over transactional.

Challenges, concerns or fears

The right information is not being communicated correctly to families.

Not enough is being done in the prevention space that caters to Pacific families' needs.

Limiting one's ability to connect with other family members because of rheumatic fever.

Needs, hopes and aspirational goals

The ability to share their stories and being part of the solutions.

That messages are delivered in a way that Tongan communities can understand.

Earlier detection solutions of rheumatic fever in place.



FAMILY PERSONA #2 (Lea faka-Tonga)

Konga e talanoa mo e fāmili

Mātu'a ngāue mālohi, nofo 'i he fale moe 'api pe ia 'o e fāmili.

Ko e fānau longomo'ui 'aupito mo manako 'i he sipotī, pea mo hono poupou'i kinautolu 'e he ongo mātu'ā.

'Oku nau fehokotaki lelei mo ho nau ngaahi fāmili. Pea 'oku taimi lahi 'enau feohi mo kaunga nofo mo honau kāinga.

🌊 Ko e mēmipa 'e 6 'i he ngaahi fāmili

🏠 Fāmili longomo'ui 'i he sipotī

🌊 Ko e fāmili ' ni 'oku nau mo'ua 'i he mofi lumetika

Tokanga ki ha ngaahi me'a 'e tupu mei ai

🌊 Fāmili

🌊 Fiefia 'a e fānau

🏠 Mo'ui lelei.

Mahu'inga'ia, fie'ilo kiai, me'a 'oku fai, fakamu'omu'a

Mahu'inga 'aupito 'a e fāmili kiate kinautolu.

Ko e tefito'i ngāue 'a e fine'eiki ko hono tokanga'i 'a e fānau. Ko hono loto ia ke ne poupou'i mo fakamu'omu'a 'e nau mo'ui ke lelei.

Ko e fānau longomo'ui pea 'oku nau fekau'aki moe ngaahi sipoti fakakolo.

Fehangahangai moia, manavasi'i pe tokanga kiai

Na'e fakaloloma 'a e founa hono faka'ilo 'e he toketā kiate kinautolu pea moe ngaahi fakamatala 'oku fekau'aki moe mofi lumetika ne 'ikai ke ongo lelei.

Ko hono uēsia e mo'ui lelei faka'esino mo faka'atamai 'a e fānau tangata tupu me ' i he ngaahi fakangatangata ki he'e nau kau koia ki he sipotī.

Ko e liliu lahi 'oku hoko 'i he fāmili ke nau tokoni'i e fānau ' hono uēsia 'e he mofi lumetika.

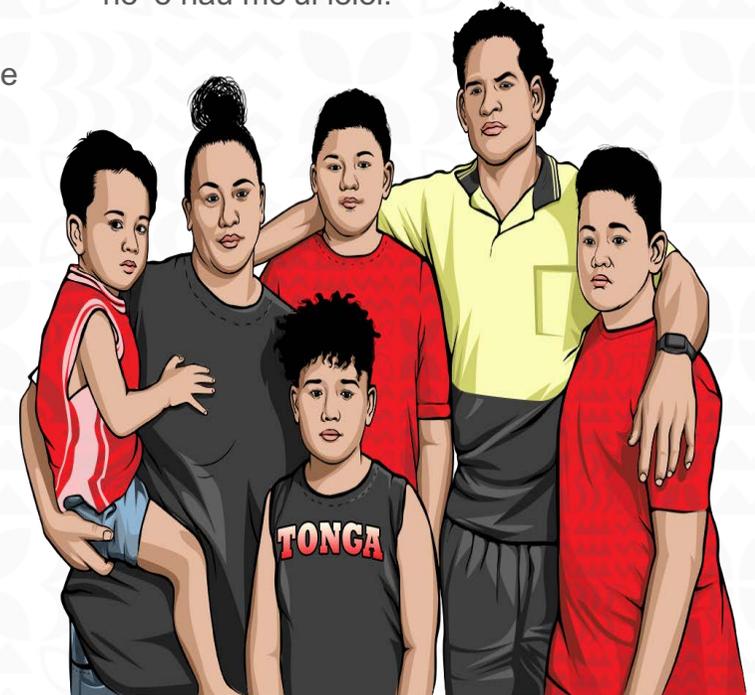
Na'e lahi moe ngaahi palopalema kehe kehe 'oku hoko 'o uēsia 'aupito 'a e mo'ui lelei tukukehe ange 'a e mofi lumetika.

Ko e ngaahi fiema'u, 'amanekina mo e taumu'a ne faka'ānau

Fekumi ki ha ngaahi founa 'e lava ke kau e fānau ' ki he ngaahi me'a 'oku fai neongo e ngaahi faingata'a 'oku uēsia ai 'e nau mo'ui lelei.

Na'a lavas ke fakahoko ha ngaahi tokoni faskafaito'o makehe telia 'e ngaahi uēsia 'oku fakatupu 'e he mofi lumetika.

Ke mahu'inga mālie pe 'a e mo'ui ki he fānau neongo 'a e faingata'a 'oku hook ki he 'e nau mo'ui lelei.



FAMILY PERSONA #2 (English)

Contextual story of the family

Working parents, residing in a family-owned house.

Really active kids involved in sports with parents supporting them.

The family are highly connected to their wider family and spend a lot of time interacting with them.

🏠 6 members in the household

🏆 Active family in sports

🏠 Rheumatic fever is active in the family

Motivational focus

🏠 Family

🏠 Child's participation

🏆 Managing complex health issues

Values, interests, activities and priorities

Family is really important.

Mum is the primary carer for the child as she wants to prioritise his health and advocate for him.

Active children and family engaged in local sport clubs.

Preferred mode of engagement

The family prefers relational over transactional.

Challenges, concerns or fears

Negative experience in being diagnosed with rheumatic fever and the information shared by doctors.

Limited participation in sport, which impacts on the boy's physical and mental wellbeing.

Massive change for the family to support the child affected by rheumatic fever.

Needs, hopes and aspirational goals

Finding ways to engage child in activities despite health issues.

Affording other health treatments on top of the impacts of rheumatic fever.

Child to live meaningful life despite health issues.



FAMILY PERSONA #3 (Lea faka-Tonga)

Konga e talanoa mo e fāmili

Na'e laka hake 'i he ta'u e 7 e nofo 'a e fāmili mo e mofi lumetika. Ko e ki'i fāmili ' ni 'oku toko taha pē 'a e fānau '.

Ko 'enau tefito'i pa'anga hu mai mei he ngaue e tamai pea ngaue taimi kakato 'a e fa'ē ki hono tokanga'i 'ena ki'i tamā.

Hokohoko lelei 'a e fengau'e'aki mo e toketā fakafāmili, falemahaki mo e kau mataotao 'oku nau ngāue ki hono tauhi e mo'ui lelei.

🌊 Ko e mēmipa 'e 3 'i he fāmili

🏠 Mo'ua he faingata'a 'o e mofi lumetika

🌊 Ko e 'ofa 'a e fa'ē

Tokanga ki ha ngaahi me'a 'e tupu mei ai

🌊 Mavahe'i mo'ui mei he faingata'a ki he mo'ui lelei

🌊 Ha kaha'u ma'ae fānau

🏠 Lava ke mahino lelei ange ki he ngaahi fāmili 'ae ngaahi me'a 'oku fekau'aki moe mofi lumetika

Founga ngāue 'oku fakalata mo manakoa

Ko e tauhi vā māfana ka 'oku 'ikai ko ha tu'utu'uni pe ke muimui kiai.

Mahu'inga'ia, fie'ilo kiai, me'a 'oku fai, fakamu'omu'a

Ko e taimi lahi 'oku uēsia ai e mo'ui e fānau 'i hono ma'u kinautolu 'e he mofi lumetika.

Mahu'inga'ia he vahevahe tatau, 'ikai ke filifili manako 'a e fakahoko fatongia.

Kumi ki ha ngaahi founga 'e ma'u ai 'e he fānau 'a e tu'unga lelei taha 'o e mo'ui.

Fehangahangai moia, manavasi'i pe tokanga kiai

Ko e founga ngāue 'a e potungāue mo'ui oku ne fakatupu 'a e ngaahi uēsia ki he loto moe fakakaukau.

Lahilahi 'ae 'ikai ke mahino lelei e founga fakangāue pea 'oku ne uēsia leva e mo'ui 'ae fānau ' 'i he lolotonga ni.

Ko e ngaahi uesia koia ki ho nau loto moe 'atamai na'e te'eki ai ke lava 'a hono fakalelei'i.

Ko e ngaahi ngāue fakapolofesinale na'a nau fa'a fakahoko na'e 'ikai ke hioa mo taau.

Ko e ngaahi fiema'u, 'amanekina mo e taumu'a ne faka'ānau

Ko ha founga fakangaue 'oku 'ikai ke filifilimānako ki ha ni'ihi 'i ha 'uhinga tokua ko 'enau tokosi'i.

Ke nofo'ia 'e he fānau ' 'ae mo'ui hoa mo taau 'o hange koia 'oku anga mo maheni kiai 'a e tokolahi 'oe fonua.

Ke fakahoko 'e he kau ngaue fakapolofesinale 'a ho nau ngaahi fatongia ke hoa mo taau ke ma'u ai 'a e mo'ui lelei.



FAMILY PERSONA #3 (English)

Contextual story of the family

Over 7 years living with rheumatic fever in the family.

Small family with an only child. Father is the main source of income whilst mother cares full time for the child.

Continuous interaction with GPs, hospitals and specialist care.

🌊 3 members in the household

🏠 Living with rheumatic fever

🌊 Mother's love

Motivational focus

🌊 Healing

🌊 Child's future

🏠 Improving people's experiences with rheumatic fever

Values, interests, activities and priorities

Long term impacts of rheumatic fever on the child's health.

Values, equity and being treated fairly.

Finding ways to give the child the best quality of life.

Preferred mode of engagement

The family prefers relational over transactional.

Challenges, concerns or fears

Trauma from health system.

Major complication impacting the child's current health.

Unhealed trauma.

Multiple unfair treatment experiences from health professionals.

Needs, hopes and aspirational goals

A health system that is equitable in its treatment of minorities.

For the child to live as close to a normal life as possible.

Healthcare professionals to take more responsibility.

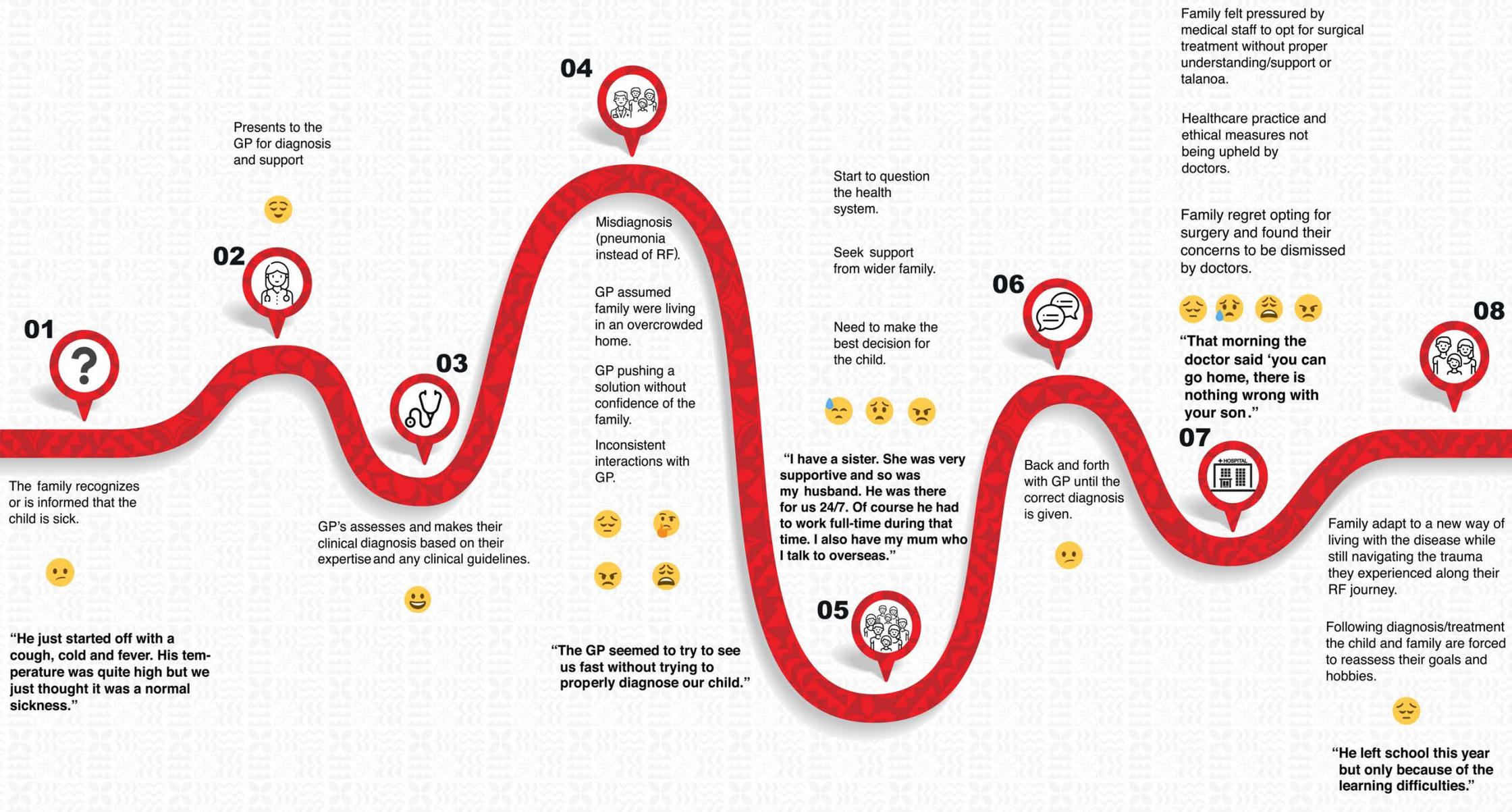




JOURNEY MAP

This section includes a journey map that illustrates some of the emotional highs and lows for kāinga as they progress through their rheumatic fever journey.

JOURNEY MAP





OPPORTUNITY AREAS

This section describes the three main opportunity areas that have been identified through the discovery phase and based on the experiences of kāinga.

As we head into the next phases of the initiative, these opportunity areas will guide us to develop and test new approaches in partnership with kāinga, who play an important part in transforming the system for the benefit of kāinga.

FAKAHAOHAOĀ = HAO HAOĀ | Opportunity areas



Prototype territory 1: Peer to Peer

Components

- Develop experiences that enable healing from RF/RHD related trauma with leading Tongan Mental Health professionals.
- Activating informal peer to peer across kāinga engaged with the co-design initiative

How we will prototype

- Create experiences / events for kainga engaged with the Co-Design initiative, supported appropriately by professionals.
- Foster community-led initiatives that aim to expand the reach of the informal peer-to-peer network



Prototype territory 2: Proactive Health Communication & Promotion

Components

- Developing Tongan understanding of RF/RHD (in progress via 'mofi lumetika')
- Identifying messaging tone/style/content that aligns with cultural context and that is consistent across all media.
- Explore delivery mechanisms and formats that enable messages to reach the right audience and be received/understood across a variety of media (including video).
 - Behaviour change triggers (what messages encourage timely recognition and seeking treatment)

How we will prototype

- Align with community settings where people gather and use established communication forums.
- Fostering community led initiatives so there is a 'pull' rather than 'push' of information
- Work with Tongan clinicians and experts to ensure health messages are correct and aligned with clinical guidelines



Prototype territory 3: Model of care and healthcare journey

Components

- Information delivery at time of diagnosis.
- Reducing the emotional labour for kainga engaging with the health system.
- Health/ support/ social worker understanding of RF/RHD and capability support.
- Developing and delivering a family-centred model of care.
- Development of long term healthcare plans that support kāinga autonomy with a focus on transitions from child to adolescent to adult hood.
- Implementation of culturally responsive guidelines and practice

How we will prototype

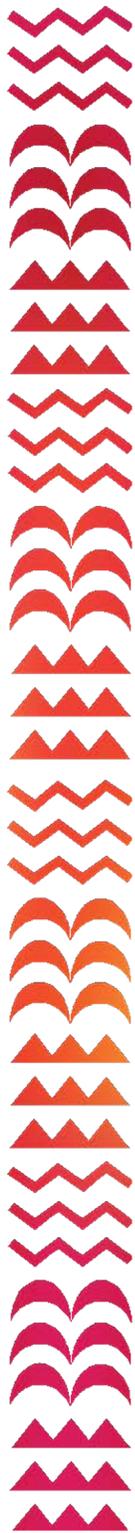
- Partner with healthcare providers to identify feasible changes to the current model of care and to test the new approaches.
- Fostering community led initiatives to identify precise pain points and to be active participants in identifying possible solutions.
- Identifying key people with an influence over different parts of the experience/journey and influence them to try different approaches.





REFERENCES

This section includes references to publications that formed part of the desktop research phase. This phase informed our understanding of rheumatic fever and helped guide our engagement with kāinga.



REFERENCES | Part 1

Anderson, A., Leversha, A., Ofanoa, M., Malungahu, M. G., Burgess, H., Wade, W. J., ... & Peat, B. (2018). Māori and Pacific whānau experiences of recurrent rheumatic fever and unexpected rheumatic heart disease in New Zealand. Auckland: The University of Auckland.

Baker, M., Gurney, J., Moreland, N. J., Bennett, J., Oliver, J., Williamson, D., ... & Lennon, D. Modifiable Risk Factors for Acute Rheumatic Fever: A Case-Control Study.

Bennett, J., Anderson, A., Malakai'Ofanoa, P. A., Baker, M. G., Brown, R., Devlin, G., ... & Wilson, N. (2021). Acute rheumatic fever—a preventable, inequitable disease: a call for action. *The New Zealand Medical Journal*, 134(1535), 93-95.

Bennett, J., Zhang, J., Leung, W., Jack, S., Oliver, J., Webb, R., ... & Baker, M. G. (2021). Rising ethnic inequalities in acute rheumatic fever and rheumatic heart disease, New Zealand, 2000–2018. *Emerging infectious diseases*, 27(1), 36.

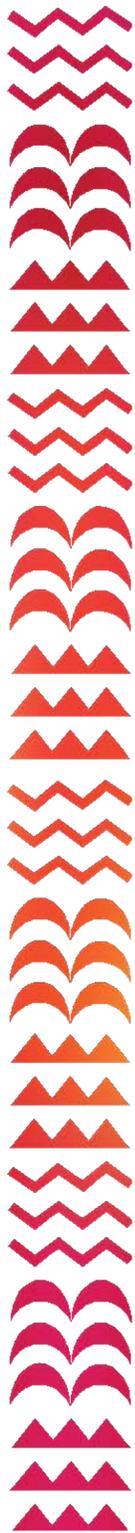
Colquhoun, S. M., Carapetis, J. R., Kado, J. H., & Steer, A. C. (2009). Rheumatic heart disease and its control in the Pacific. *Expert review of cardiovascular therapy*, 7(12), 1517-1524.

Duffy, E., Thomas, M., Hills, T., & Ritchie, S. (2021). The impacts of New Zealand's COVID-19 epidemic response on community antibiotic use and hospitalisation for pneumonia, peritonsillar abscess and rheumatic fever. *The Lancet Regional Health-Western Pacific*, 12, 100162.

Milne, R. J., Lennon, D. R., Stewart, J. M., Vander Hoorn, S., & Scuffham, P. A. (2012). Incidence of acute rheumatic fever in New Zealand children and youth. *Journal of paediatrics and child health*, 48(8), 685-691.

Morton, S. M., Napier, C., Morar, M., Waldie, K., Peterson, E., Atatoa Carr, P., ... & Cha, J. (2022). Mind the gap—unequal from the start: evidence from the early years of the Growing Up in New Zealand longitudinal study. *Journal of the Royal Society of New Zealand*, 1-21.

Naea, N., Dobson, A., Leversha, A., Williams, S., Knott, K., Clayton-Bray, L., & Dickinson, A. (2016). Awareness and understanding of rheumatic fever among Pacific people in Auckland. *Neonatal, Paediatric & Child Health Nursing*, 19(1), 7-12.



REFERENCES | Part 2

Oliver, J. R., Pierse, N., Stefanogiannis, N., Jackson, C., & Baker, M. G. (2017). Acute rheumatic fever and exposure to poor housing conditions in New Zealand: A descriptive study. *Journal of Paediatrics and Child Health*, 53(4), 358-364.

Oliver, J., Robertson, O., Zhang, J., Marsters, B. L., Sika-Paotonu, D., Jack, S., ... & Baker, M. G. (2021). Ethnically disparate disease progression and outcomes among acute rheumatic fever patients in New Zealand, 1989–2015. *Emerging infectious diseases*, 27(7), 1893.

Thornley, S., Marshall, R. J., Bach, K., Koopu, P., Reynolds, G., Sundborn, G., & Ei, W. L. S. S. (2017). Sugar, dental caries and the incidence of acute rheumatic fever: a cohort study of Māori and Pacific children. *J Epidemiol Community Health*, 71(4), 364-370.

Webb, R., & Wilson, N. (2013). Rheumatic fever in New Zealand. *Journal of paediatrics and child health*, 49(3), 179-184.

Wimalasena, N. N., Chang-Richards, A., Wang, K. I. K., & Dirks, K. N. (2022). What makes a healthy home? A study in Auckland, New Zealand. *Building Research & Information*, 1-17.