

Te Tīma Māori

Rheumatic Fever Co-Design Initiative



A KAUPAPA MĀORI RESPONSE
OCTOBER 2023

KŌRERO MATUA

**Manawa nei e, te huaki rangi
Manawa nei e, te huaki papa
Hohou nuku te kokonga whare kia kitea
Hohou rangi te kokonga ngākau kia rongohia
Kauae rungatia, kauae rarotia
Kia pūkawatia te mānehurangi
Mō Hine-ngākau, mō Tama-ngākau
Hei oranga tinana, hei oranga wairua
Tau te Mauri!
Tau hā, tau ana!**

Me huataki ake ēnei kura kāinga kōrero i ngā whakaaro nui ki te wāhi ngaro, ki te mea ngaro. Huritao atu, huritao mai, e kore ngā Atua o te pō e tawhiti atu, e tawhiti mai i ō mātou whakaaro, i ō mātou kōrero me ā mātou mahi.

Toitū rere pō ngā matangaro nui e hinga atu nei, e hinga mai nei i roto i ngā tini pāheketanga o te wā. Mau ana he pareraututu hei tohu i te kōingo noa, i te aroha noa, kia maumahara noa. E whai mana ai ngā kupu kōrero, “he kura kāinga te hokia, he kura tangata tē hokia.” Nō reira rā e ngā mate, haere, okioki atu rā koutou ki rangi whakamoe Ariki.

Toitū rere ao ki a tātou ngā matahara nui e takatū tonu nei, ka mihi. Ka mihi ki a koutou ngāi ngākau manawareka ki Te Tīma Māori e whakamātau ana i ngā huarahi ārai i te mate weriweri nei, te mate Rūmātiki.

He tūhuratanga ake tēnei kaupapa i ngā kokoru o te whare whakaaro nui o te ira tangata kia kitea, kia pūrangiaho ai ngā tukutuku kōrero o te kokonga ngākau hāngai pū ki ngā whānau, ki ngā hapū, ki ngā iwi me ngā hapori. Hui katoa, ko te tōmina nui o ēnei kawenga mahi he kawē ake i te manemanerau whai oranga ki te iwi Māori - mai i ngā tamariki, ā, tae noa atu ki te reanga kaumātua. Tuia atu ki tēnei, ko te pupuru, ko te whakapūkawa i tētahi mānehurangi hou e toitū ai te toiora ki ngā reanga ka whai mai hei ngā rā ki tua.

Me mihi ka tika ki te hunga whai wāhi mai ki tēnei kaupapa. Ki a koutou o ThinkPlace, ki Te Whatu Ora, ki Te Tīma o Hāmoa, o Tonga hoki e whakapau kaha nei ki te whai māramatanga ora mō tēnei mate. Engari, mātua rā me mihi atu ki ngā huhua tāngata me ngā whānau i manawanui mai ki te tuku i ō rātou whakaaro me ō rātou kōrero. Me kore ake tēnei kaupapa i a koutou, mōkōri anō ngā mihi whakamānawa ki a koutou katoa.

Nā reira, tukua mai rā koutou kia piri, ka tomo mai ki te whata kohinga kōrero o Te Tīma Māori e karanga atu nei.

Tau hā, tau ana!

KŌRERO MATUA

**Heartfulness in the subconscious
Heartfulness in the conscious
To stimulate further what we understand
To foster further what is yet to be understood
Internalize it, externalize it
So that it may imbue a new reality
For her soul, for his soul
For physical and spiritual wellbeing
Contentment in life anew
Bring forth vitality!**

To preface, we offer our thoughts of reflection to the world unknown and the realm incomprehensible. As we continue to reflect, our divine deities will never be too close or too far removed from our thoughts, our discussions, and our work.

Secondly, we pay homage to the pantheon of loved ones that continue to bid us adieu within the vicissitudes of the times. As we attire the sacred tutu wreath, symbolic of our deep yearning, our deep love, and evocations for them that gives deeper meaning to the axiom, "humanistic knowledge is universal, humanistic experience is finite." To our dearly departed, leave us and return to the apotheosis of the distinguished.

Thirdly, we acknowledge the living, the embodiment and manifestation of legacies we all belong to. We express our gratitude for your commitment and belief in Te Tīma Māori in its quest to seek better outcomes as we combat Rheumatic Fever.

This project is an in-depth exploration into the narratives of litany surrounding the human heart that seeks to understand them in their current state, with the overall purpose of providing clarity to better articulate and measure the true context of health and wellbeing for our whānau, hapū, iwi and communities. Overall, this body of work is a concerted effort to address the inadequacies and inequities of healthcare for Māori – from the children to the old generation – to imbue a new reality for Māori health and wellbeing that is sustainable for generations to come.

We wish to acknowledge those who have made a tremendous contribution to this project. To ThinkPlace, to Te Whatu Ora and to both the Samoan and Tongan teams who have worked tirelessly to seek enlightenment around this disease. Finally, it would be remiss to ignore the illustrious assembly of all passionate individuals and whānau who committed to sharing their experiences and narratives that give substance and rigor to the work Te Tīma Māori have conducted. This project would not have been possible without you, so we express our sincerest gratitude to you all.

So, we welcome you all to join us and enter this store house holding the narratives of the heart so that you may marvel at the collected insights Te Tīma Māori have to share.

Bring forth vitality!

TE KURA Ā RONGO



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Whakarāpopototanga

Summary

The Rheumatic Fever Co-Design initiative provided an opportunity to take a kaupapa Māori response to rheumatic fever. By creating a standalone stream within the overall initiative that was led by Māori and for Māori, we have been able to place Māori aspirations, values and experiences at the heart of the work.

We know that rheumatic fever is a disease correlated with social inequities, meaning that whānau Māori are disproportionately impacted by rheumatic fever and rheumatic heart disease. But we learned that historical responses to rheumatic fever haven't resonated with whānau Māori. There has been a lack of hope and agency associated with the response, and that has impacted how whānau Māori engage with the topic of rheumatic fever.

We set out to change that. To acknowledge the wisdom, strength and courage that whānau Māori hold and how, with the right approaches and tools, whānau Māori can be equipped to prevent and manage rheumatic fever, despite the inequities that exist. We went back to what it means to be Māori, how we communicate important concepts and how we collectively keep ourselves safe spiritually, emotionally and physically. We reached deep into whanaungatanga and moemoeā – a vision of a different future.

Together, with whānau Māori and a range of other stakeholders, we have created solutions that are new to the rheumatic fever prevention and management system. We know the solutions work because they are based on intergenerational wisdom and we have tested them in today's context.

While it will take time for us to see a corresponding impact on rheumatic fever rates for Māori, we are laying the platform for future generations by growing awareness, hope and belief among our tamariki and their whānau. There is more to do, but the foundations are strong.

This report is a reflection on how we have gone about the work, from the beginning of the initiative to the end. It talks about what we did and, more importantly, why we did it and how we did it. We hope that our approach will inspire others who are tasked with serving the needs of Māori.

Te Haerenga

Our Process

PHASE 1

1 November 2020 - 31 December 2021

Curating our team, understanding our collective strengths. Building our shared whāinga and what we stand for in this kaupapa. Building connections and relationships and deepening discussions with whānau, kura and stakeholders through wānanga. Unveiled themes and shared these back with whānau for feedback.



PHASE 2

1 January 2022 - 30 June 2022

Finalising insights, working on ideas and possible solutions, refining those with our whānau. Identifying potential prototypes with whānau and stakeholders. Early development of those ideas.

PHASE 3

31 July 2022 - 31 October 2023

Further developing the prototypes and looping whānau back into this process to test our ideas. Creating awareness about the prototypes with kahukura and stakeholders within the community and across the system and beginning the process of embedding of the prototypes.

Forming a team with the necessary experience, knowledge and relationships

Our aspiration was to bring to a team that could connect all the different parts of Te Ao Māori, particularly tikanga, community (hapori), and Te Ao Māori within government. These are the necessary parts: you can't work within hapori without tikanga, and you can't work within government without hapori.

The relationship within our team was going to be critical. We embraced whanaungatanga by curating a team where the whanaungatanga was already established and strong. While Te Tīma Māori was a new team, our team dynamics built on the whanaungatanga that already existed among us.

The starting point was the relationship between the team lead and our kaumātua: we needed the wisdom, guidance and protection that only kaumātua can bring to enable the rest of us to contribute our skills and knowledge with confidence. We built the team around this with researchers, Māori language experts, visual designers, communications experts, etc. Everyone in the team are leaders in their own right.



Te Tīma Māori - Ko wai mātou?



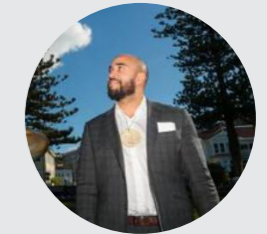
KATARAINA DAVIS
Team Lead



PAORA DAVIS
Kaumātua



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Māori Visual Designer



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JONO COLE
Visual Designer



TE AMOHANGA RANGIHAU
Te Reo Māori Expert



CARA RYAN
Kairaranga/Enabler and Comms

Early on, we focused on the foundations of establishing our team. We met, we talked, we listened to each other. But most importantly, we dreamt about how this kaupapa could be undertaken in ways that showcased the beauty of Te Ao Māori: a proof of concept of the richness that is enabled when Māori are placed in a position of influence. Through this process, we built trust in each other. It was more than trust – it was aroha. Aro-ki-te-hā: focusing on the breath, viewing each other's wellbeing with the utmost importance.

How we related as team was essential. We needed to model Te Ao Māori ways of working within our team so that when we engaged with whānau they would also feel it. We wanted whānau to have an experience of us being whānau, caring for other whānau. We wanted to ooze our whānau team to the whānau we engaged with. To guide us on this journey, we established our mātāpono (our design principles).

Ngā Mātāpono

Our Design Principles

MĀ TE ORA O TE KOTAHI, KA ORA TE KATOĀ.

By the vitality of one, comes the vitality of all.

MANA ŌRITE.

That our process will enable mana ōrite, and shared responsibility will be understood and applied resulting in shared access.

WE COMMIT TO A PROCESS THAT LEAVES OUR WHĀNAU BETTER OFF.

PATUA TE KAIKIRITANGA.

We will no longer let a condition born out of colonisation be upheld by racism.

WE REMEMBER - KEI ROTO I Ō TĀTOU RINGA TE RONGOĀ.

For us all to remember that we have healing properties in our fingertips, and it is all of our responsibility to eradicate Rheumatic Fever.

Creating spaces that were uplifting for whānau

Having our team in place meant we were well-placed to engage with whānau in ways that are mana-enhancing and value-adding. We again relied on whanaungatanga to engage with whānau. We didn't cold call or 'recruit', we carefully worked through our own personal connections and leveraged our relationship capital with trusted connectors to, in turn, be connected to whānau who had lived experience of rheumatic fever.

Through the process, we learned that one trusted connection was all that was needed. If there was trust in one of our team members, that created the ability for other team members to be involved and be trusted.

We know how challenging 'research' experiences can be for our whānau, so we wanted to signal that this one was different. We put a call out via a simple but effective information sheet – it showed us, our faces, a bit about us as people, and why we were committed to the kaupapa. This helped to open the door. Once we started with one whānau, it kept snowballing and we were introduced to others.

We thought hard as a team about how to make the experience for whānau as uplifting as possible and without placing additional burden on them. We know that 'research debt' exists within communities: the impacts of research projects that are extractive, mana-diminishing, or that don't lead to tangible change. We knew that the small gestures matter. We wanted to provide kai and acknowledge the contribution of whānau with putea via a gift card.

Because our initial hui with whānau were being conducted online due to COVID restrictions, we decided to surprise whānau ahead of time with a

beautiful selection of food. We wanted to signal from the outset that we were upholding the concept of reciprocity; whānau had offered to share time and their stories with us, and we wanted them to know how much we valued their contribution. We noticed that whānau were surprised and appreciative when they received their koha, and many commented that this had never happened to them before in the context of research. These gestures, while small, were important in signalling to whānau that they were valued, that their mana was acknowledged, and that we had put thought into creating that experience rather than it being an afterthought. The response was universal: people wanted to be part of this kaupapa.

When we met with whānau, we wanted to signal that this is a kaupapa Māori space that we were meeting in, while also acknowledging that every whānau has a different relationship to Te Ao Māori. We asked whānau if it was ok to open with karakia and mihi. Some responded, and others were more comfortable not responding. Whānau appreciated being asked and that we didn't assume it would be a certain way; their preferences were acknowledged and respected, and they were in charge, not us. The result was comfort being created for whānau.

We only ever had two members of our team as part of the initial conversations so we didn't want to overwhelm whānau. We acknowledged people from the outset and thanked them for their gift of time and stories. We put whānau at ease by letting them know it was fine to leave whenever they wanted to; to sort things out with the kids, or deal with anything else that was happening concurrently. We wanted the message to be that nothing is a problem, there is no way that we could be let down.

Protecting the wairua of whānau and their stories

We created an ethical framework, our tikanga matatika, that guided our research and discovery activities with whānau (see below for a summary of the framework). We took inspiration from the practice of rongoā; in the same ways that our ancestors gathered plants with intention and care, we wanted to

gather stories with intention and care. We looked at rongoā gathering practices (e.g. only gathering from the eastern side of the plant) and translated these to a research context (e.g. only gather stories in a positive light, take a strengths-based approach).

Tikanga Matatika

Our Ethical Frameworks

WHANAUNGATANGA

Whanaungatanga is about relationship, kinship and a sense of whānau connection. Achieving whanaungatanga during this kaupapa is of utmost importance; within our team, towards our whānau who participate, everyone. There needs to be a healthy level of trust, confidence and tension throughout the duration of this kaupapa to achieve anything. Just like whānau.

In this document we use the word 'whānau' rather than participants to talk about anyone who has participated in our process alongside us.

GATHERING RONGOĀ

- Karakia – be intentional, be deliberate
- Optimal time to gather is in the early morning
- Only gather from the eastern side of the rākau, you will always gather your research in a positive light
- You do not exhaust one rākau, responsibility to heal is a shared responsibility by many rākau
- Only take what you need

Early in our engagement with whānau, it was clear that the stories whānau were sharing with us were sacred. We started thinking about data protection, not from a physical standpoint but from a spiritual one. There was a strong element of wairua to the stories: a whānau member might have passed away, ancestors might have been spoken about, and whakapapa and whānau might have been talked to. Talking about whānau is about whakapapa, the most sacred of topics. We knew that mainstream approaches to data protection were not adequate; we needed to acknowledge tikanga and design a data protection framework that was fit for purpose for this kaupapa.

This led to the idea of creating a karakia specifically for this kaupapa. Because we had started hearing the stories and because our team included an expert in Te Ao Māori in Te Amohanga Rangihau, we had the opportunity, capability, and credibility within Te Ao Maori to create a karakia that spoke precisely to what was needed.

At that point in the project, the sole purpose of the karakia was to provide protection over whānau and their stories. By extension, the karakia also provided protection to our team as we listened to the stories and reflected on what we had heard.

A taonga that disseminates intergenerational knowledge

The karakia quickly became part of everything that our team did. It supported engagement with whānau, it supported our engagement with research data, and it supported our team hui – it was relevant in every setting. This led to the opportunity for the karakia to be another form of koha to whānau and other key leaders who had contributed strongly to this kaupapa.

We wanted the karakia to be something that was beautiful, that would make whānau proud to display it on their wall, and that could be a conversation point when other people came into their home. Again, because we had a Māori artist in our team in Graham Tipene, we had the opportunity, capability and credibility to design a beautiful mahi toi (artwork) that visually supports the words of the karakia.

The taonga and karakia, which was named Te Kura ā Rongo, was brought together by the stories of whānau and visually represented. The karakia was our response to protecting the stories and voice, leading through tikanga Māori, and intergenerational dissemination of knowledge. These were framed and gifted to whānau.

This led to another realisation: collectively, we had created a uniquely Māori tool for disseminating knowledge about the kaupapa and about rheumatic fever more generally. What had started as a koha



had become a strategic health communication and awareness raising tool that was richer, more relevant, and more inviting to whānau than the usual health communication and awareness raising tools.

We were using the karakia right across every touch point for Te Tima Māori and so it was being more used more widely across the system. As the stories travelled, so too did the karakia; the stories and the people were protected.

Moving from stories, to insights, to opportunities for change

We wanted a way to tell a story of what we had heard from whānau without necessarily telling each story. The stories belonged to whānau, they weren't ours. We wanted to go back to whānau with the important areas to focus on and validate with whānau. And we wanted other whānau to see themselves in this work, even if their own story was different. A team of live illustrators helped us tell the stories in a visual way and this highlighted the areas that were important to focus on.

A key insight was related to moemoeā; we wanted our whānau to be able to dream. We heard how they were put in a box, they couldn't dream big, they couldn't acknowledge what their hauora meant to them. We had intentionally designed the research to take a strengths-based and aspirational view and it was natural to elevate moemoeā as a central concept.

It was critical that whānau felt heard, could see themselves in it, and were happy with how their stories had created the building blocks for this kaupapa. We showed whānau the respect they deserve by going back to them before anyone else

outside of our team had seen the insights. We shared with whānau some slides of key headings and pictures and asked if we had understood their stories correctly. The response was overwhelmingly supportive.

We were delighted. It felt like we had achieved what we had hoped for – to do right by whānau and help them to feel comfortable with the process we were following. We now had the backing, support and mandate to move forward into exploring possible solutions. It felt like whānau were right alongside us. It also felt like we were making the right decisions when we were leading with the values we had set. We constantly checked in with whānau throughout the subsequent phases, taking whānau with us along the way. Whānau trusted us to keep pushing ahead. They gave us the permission to keep moving and we ensured we were keeping whānau with us on the journey.

The following pages include a summary of the key insights that came through the discovery work.

Ngā Kitenga

Insights

1 MOEMOEĀ – TE ORA O TE WHĀNAU

Te ora o te whānau, whānau overall wellbeing is a clear aspiration for whānau Māori. Laying foundations for our mokopuna to come was of utmost importance to our whānau who were constantly thinking about the future.

2 WAIRUATANGA OR WHAKAPONO

Is significantly important, but not acknowledged or valued.

3 TIKANGA MĀORI PROTECTS US

We have our own frameworks that can keep us safe. Tikanga binds us to the responsible thing to do for the betterment of a collective.

4 STORYTELLING THROUGH MANY PLATFORMS IS ABSOLUTELY NECESSARY

Māori are orators, storytellers, singers, poets, and lyricists. This way, information becomes knowledge and is passed on intergenerationally.

5 WHANAUNGATANGA

Quality connections and relationships between kaimahi and whānau is critical.

6 KAHUKURA ARE ENABLERS

7 HE MANA TŌ TE KUPU, TE MANA Ā KĪ

There is power in words. Kōrero to whānau Māori must be mana-enhancing.

8 MANAAKITANGA

9 AN AND AND APPROACH IS NEEDED (IN NGĀ TAUIRA)

Māori systems need to be acknowledged and there should be room for both.



Moemoeā – Te Ora o te whānau

Aspirations and wellbeing of whānau

“Tuatahi mai - ko tō rātou hauora, oranga, te hauora o te hinengaro, koina ngā mea tino hirahira.”

– Māmā, kaiako.

We built our pātai according to our ethical frameworks that asked us to ask questions and seek answers in a positive light. Therefore, prior to asking specifically about Rheumatic Fever, we asked about moemoeā (aspirations), and te ora o te whānau.

Te ora o te whānau, whānau overall wellbeing is a clear aspiration for whānau Māori. Laying foundations for our mokopuna to come was of utmost importance to our whānau who were constantly thinking about the future.

WHĀNAU-BASED DRIVERS TO ACHIEVE ASPIRATIONS

1 TUAKIRITANGA

Whānau spoke of the importance of ‘tuakiritanga’ finding strength in identity, and knowing who we are spiritually, mentally,

physically, and relationally. Finding grounding and belonging in tāngata and whenua (people and place).

2 WAIRUATANGA

3 ŪKAIPŌ

Belonging in place.

4 WHANAUNGATANGA

Strength in connections and relationships.

5 TE REO ME ONA TIKANGA

Connection to language and voice.

6 BLOOD MEMORIES

Thinking back to the healing properties at our fingertips.

7 MANAAKITANGA

Upholding mana of the collective, and service.

8 PŪRĀKAU

Connection to narrative.

9 THINKING MĀORI

10 OUR WHAKAPAPA

Give us something to look forward to.



Wairuatanga or whakapono

Faith is significantly important to our whānau Māori and absent in the current system.

“At the end of the day, our faith in God and lo got us through the hardships.”

– Whānau member living with Acute Rheumatic Fever

Wairuatanga is a principal requirement to strengthen identity and Māori wellbeing, as modelled in Tā Mason Durie’s Whare Tapawhā (the four-sided house) model. These walls represent taha wairua (spiritual wellbeing), taha hinengaro (mental and emotional wellbeing), taha tinana (physical wellbeing), and taha whānau (family and social wellbeing). Our connection with the whenua (land forms the foundation).

When all these taha are in balance, we thrive.

When all of these are out of balance our wellbeing is impacted. In this instance, te taha wairua is absent in our health system.

Many whānau addressed the connection to Te Ao Wairua (spiritual space). While its application may have looked similar or different from whānau to whānau, its importance was very clear.

III

Tikanga Māori

Tikanga Māori protects the lives of whānau Māori.

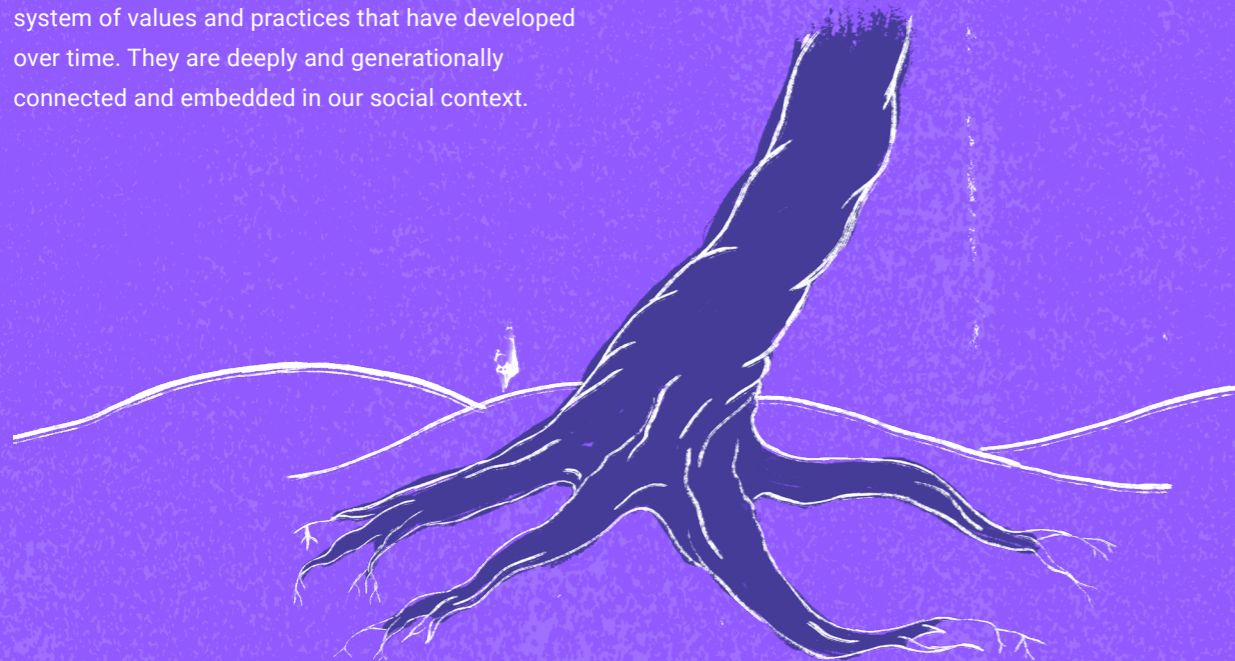
“Trends are trends, they don’t last long, it needs to be tikanga from an early age.”

– Kaiako, Finlayson Park

We have our own framework that keep us safe – Tikanga Māori. Tikanga Māori binds us to the responsible thing to do for the betterment of a collective – our collective. They are our customary system of values and practices that have developed over time. They are deeply and generationally connected and embedded in our social context.

Most of the whānau we spoke with spoke to the importance of tikanga. Whānau saw creating and maintaining tikanga around hauora Māori from an early age as important.

It is important that anyone working in this space understands what tikanga Māori is and why it is important. As this is the open door to supporting Māori.



IV

Ngā Kōrero

Stories that create connection.

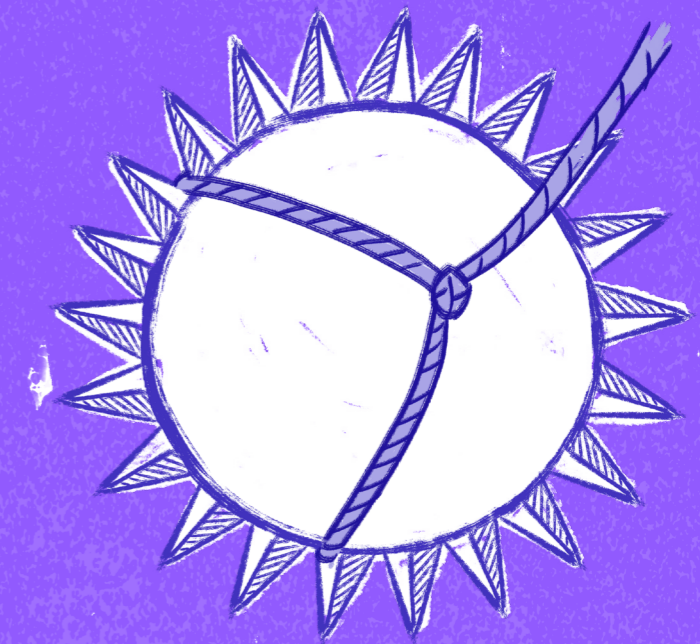
“I don’t actually know what it is, that’s where my complacency comes from.”

– Pāpā, Māngere

Māori are storytellers, orators, singers, poets, and lyricists. For generations this mode of information transfer and dissemination has taken place. We see it in kohanga reo, right through to wharekura level. There is more to be done in the area of communicating the solutions to tackling Rheumatic Fever in our communities.

Stories that create connection, and resonate with our whānau Māori are absolutely necessary to see the eradication of Rheumatic Fever in our communities.

At the moment there is confusion regarding what Rheumatic Fever is and how it can lead to Rheumatic Heart Disease, and open heart surgery. For many of our whānau it is clear that Strep Throat is common practice, and is important, but there is no understanding of what happens should they not test.



V

Whanaungatanga

Relationships and connections

“I don’t want to change my nurse when I move to college, I don’t know why I have to.”

– Rangatahi living with Acute Rheumatic Fever

Relationships and connections are central to Māori and Māori wellbeing. Therefore, it is imperative that the value of whanaungatanga be understood and embedded into the current system.

Whanaungatanga is the act of building, maintaining and gaining strength and trust through connection. It enables space for vulnerability and change, but more importantly communication; for example, important communication between nurses and tamaiti/rangatahi and whānau.

Some whānau spoke of positive experiences with their community nurses. These positive experiences related to time spent with the whānau during their Rheumatic Fever journey. They spoke of nurses taking time to know their whānau, not just the tamaiti living

with Rheumatic Fever. This enabled space and voice to assert tino rangatiratanga and communicate things necessary to that tamaiti and their overall wellbeing. For some the constant change of nurse from month to month or during the transition into college left whānau feeling uncertain, and sometimes fearful.



VI

Kahukura

Kahukura are enablers.

“Community Leaders are the ones that share information that is trusted, just because of the way they are, we listen and act.”

– Māmā whose son lives with Acute Rheumatic Fever

Kahukura are community leaders, respected and followed by the community, whānau, hapū and or iwi. They are known as people who support, encourage and strengthen whānau by modelling values, behaviours and actions that earn the trust of the people, often in their own time and with their own resources. They also allow space for flourishing leaders to come forward.

During the discovery phase of this kaupapa we spoke with many kahukura passionate about change in regards to Rheumatic Fever and Māori. Kahukura commonly provided space for those that didn’t have the connections they needed. They opened doors to increase access, and encouraged belonging and grounding for whānau in their community.

Equally, many of our whānau were kahukura in their own right and are motivated to share their story to help Māori. Some also take it upon themselves to have groups to do exactly this. Share stories, discuss solutions, and move forward together creating community amongst adversity.



VII

He mana tō te kupu, te mana ā kī.

For Māori there is mana and there is power in words. Kōrero to whānau Māori with reference to conditions that impact Māori must be mana-enhancing.

“All I hear is, poverty, Māori condition, third-world condition. What does that tell me about myself and my people? We are not that and that is not us.”

– Whānau member whose child is living with Acute Rheumatic Fever

Whānau described the usual words they hear in regards to Rheumatic Fever. Words like poverty, third-world condition, and sometimes ‘it’s a Māori condition’. While talking about issues of poverty has it’s place, it should not be whānau facing.

Again, our whānau have been made to feel whakamā and worthlessness by professionals operating in this space.



VIII

Manaakitanga is paramount

Manaakitanga is the practice of upholding someone else’s mana and keeping it at the forefront of our mind and heart.

“We wanna see our whānau who are happy, healthy and beautiful.”

– Ngā tangata mōhio, Tāmaki Makaurau

Tangata mōhio and whānau talked about wanting to see more happy, healthy, beautiful and successful Māori in any communications about hauora and wellbeing.

As talked about earlier, communications relating to Rheumatic Fever are far from mana-enhancing. We know that if there is transparency and information is shared in a mana-enhancing and understandable way there is less confusion and anxiety.

Also, many whānau, tamariki and rangatahi spoke of multiple situations leaving them feeling whakamā, mamae, and fearful. Many also described the diagnosis process as disempowering. Lacking space to probe and ask questions without being made to feel wrong for doing so. Most, if not all, could speak of times being collected from class during school time and being labeled as the ‘Rheumatic fever kid’ or constantly being questioned about why they are always having to leave class.



Kupu Arataki

Introduction

The approach outlined above led us to three core prototypes that we co-created, developed, tested and launched. Each of these prototypes addressed a specific challenge or opportunity related to the experience of whānau. The prototypes look different to what has come before in the rheumatic fever space, and that is a positive indication that we are on the right track. The uptake of the prototypes has been strong because the solutions have been designed by Māori for Māori.

This sections summarises our approach or philosophy for developing the prototypes and introduces the three prototypes in greater depth.



Ngā Tauira

Prototypes

There is a need to find space for both a Te Ao Māori system view and the current health system view to come together. As it stands, a Te Ao Māori perspective is not understood and valued enough at all levels of the system and therefore a key part of this puzzle is missing.

This model below has guided the process to ideate and refine ideas with our whānau who have participated in this co-design process. It puts tikanga Māori at the core of our process, it considers and values people and their mauri, and finally moves into preparation.



TIKANGA MĀORI

The base asks us to lean into tikanga Māori first, to ask questions like how might this idea enable tino rangatiratanga? Or how does this idea acknowledge tikanga Māori?

MAURI TANGATA

The middle asks us to always consider te mauri o te tangata: individual and collective mauri. How will this

make them feel? Will their mana be upheld by this idea? It also asks us to think about who we know that can help the development of this idea.

NGĀ WHAKARITENGA

Once all of the above has taken place, it is then we can start looking into the preparations to move forward.



Te Kura ā Rongo

Prototype 1

This karakia was created to protect the stories of whānau and those who are interacting with those stories as they travel across the country and through the system. It has been gifted to whānau and stakeholders to protect the stories and the people, and to inspire systems change for the benefit of Māori.

**KARAKIA COMPOSITION BY
TE AMOHANGA RANGIHĀU**

**MAHI TOI (ARTWORK) BY
GRAHAM TIPENE & JONO COLE**

WHAKAPAPA Origin

As explained in earlier sections, the karakia has been an emergent prototype. Initially, we acknowledged the sacredness of the stories that were being shared with us by whānau. We needed protection for those stories; for whānau who were sharing the stories, and for our team who were hearing the stories. This was a uniquely Māori response to data sovereignty.

The karakia was written specifically for this kaupapa, and we relied on it through everything we did. As we continued with the work, we saw the potential of the karakia as a form of koha to whānau and professionals we engaged with, and then saw the potential for the karakia to offer protection to the stories and the people more widely across the rheumatic fever prevention and management system.

NGĀ TURE AUHAHA Design Criteria

We adopted the following design criteria for this prototype:

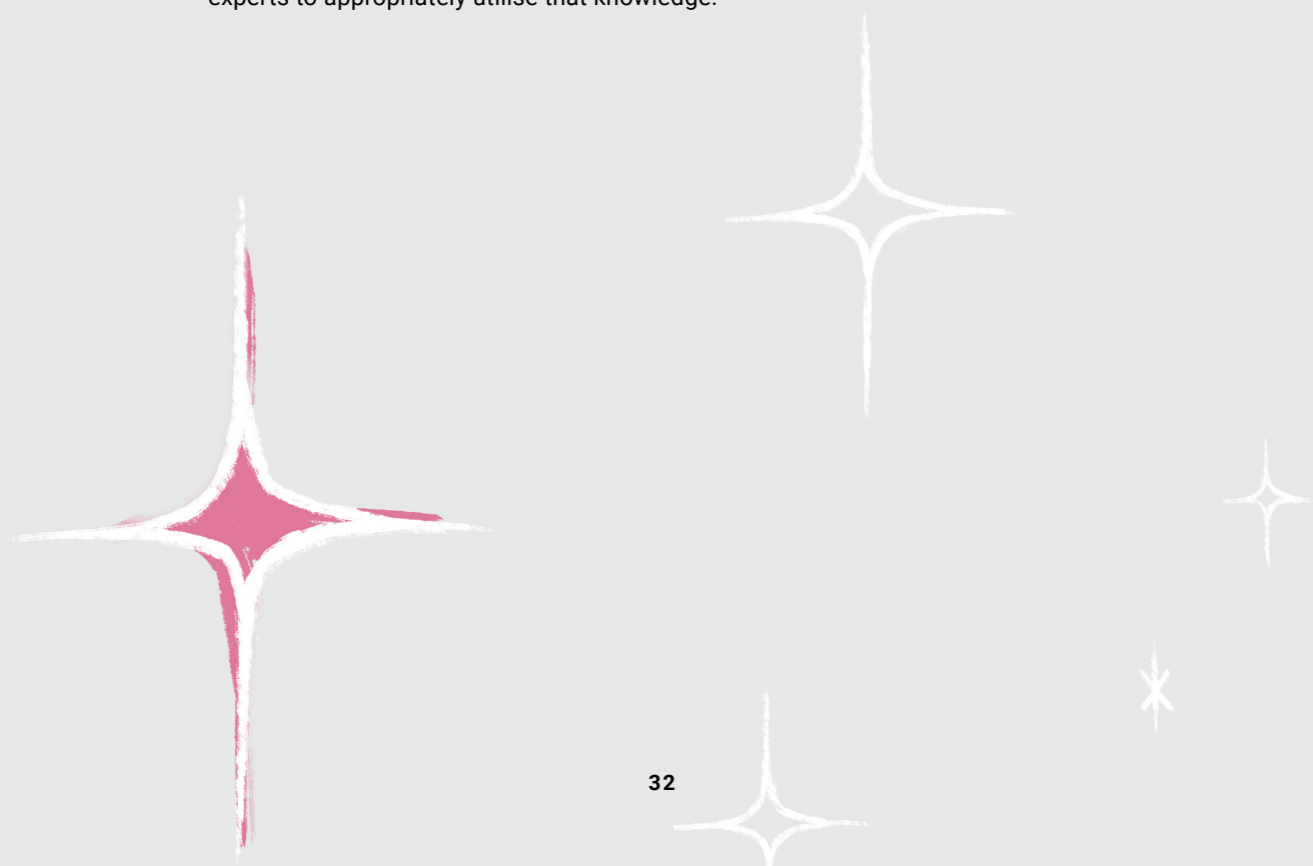
- Work with experts who have the credibility and capability within Te Ao Māori to imbue the karakia with the necessary tikanga.
- Make tikanga around rheumatic fever prevention and management to be known, acted on and talked about – without stigma.
- Ensure people are kept safe when we are discussing rheumatic fever and matters that are sacred to people.
- Be visually compelling through mahi toi to create opportunity for conversation and so the framed version of the karakia can proudly be displayed in our kainga and kura.
- Be a kōha to our whānau to acknowledge their contribution.

What might happen next

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

As this karakia has been specifically created in response rheumatic fever, we encourage its use by whānau, clinicians, and other stakeholders. Learn it and use it for its intended purpose of providing protection to people and their stories, and to place tikanga at the heart of how we engage with each other.

This prototype has highlighted the benefits and importance of valuing tikanga to ensure people are supported and protected through design processes and health service provision. Solutions to challenges experienced by Māori exist within Te Ao Māori and we need to create the space and resource for Māori practitioners and experts to appropriately utilise that knowledge.



Ko tō Manawa, ko tōku Manawa

Prototype 2

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

In video one, our guides Hinehui and Māreikura help us make sense of what rheumatic fever is. Video two explains why sore throats are an issue and what to do if you get one, and video three has a focus on our collective responsibility and the need to look out for one another.

WHAKAPAPA

Origin

We wanted to harness the power of storytelling as we know this is what feels natural to our people and is the way we share knowledge between generations. We know our people learn best when knowledge is linked to traditional cultural narratives such as the stories of Ranginui and Papatūānuku – these are stories that whānau are familiar with, find interesting, and hold true over many generations.

While it is rare for our tamariki (under 5 years old) to experience rheumatic fever, this is the age when the brains of our tamariki are like sponges. If we can get these stories and this knowledge into the minds, hearts and mouths of our babies, we will begin the process of generational change.

So we designed the kiriata for a young Māori audience, ideally played at Kōhanga Reo and Kura Kaupapa Māori, with animations, waiata, karakia and stories that would resonate with tamariki. The goal is that by the time tamariki Māori reach primary school, they know everything they need to know about rheumatic fever to keep them and their whānau safe.

The title of the kiriata (Ko tō manawa, ko tōku manawa | Your heart, my heart) creates a sense of togetherness and gives tamariki a memorable catch phrase that they can recite. The focus on the heart has resonated with whānau and has elevated the importance of talking about rheumatic fever.

NGĀ TURE AUHAHA

Design Criteria

We adopted the following design criteria for this prototype:

- Centre around powerful pūrākau that are familiar to tamariki and their whānau.
- Be mana enhancing, aspirational and resonate with tamariki.
- Have versions in both Te Reo Māori and mixed Te Reo Māori / Te Reo Pākehā to reach all whānau.
- Have a memorable story that is cherished and shared down through the generations.
- Lead with cultural knowledge and connection, while ensuring clinical knowledge is accurate.
- Be suitable for under 5's to set our tamariki up to prevent rheumatic fever.
- Be developed with a kaupapa Māori creative agency who are able to strengthen the narrative and bring the vision to life in ways that are tika and authentic.
- Be shared in a way with community stakeholders that enables them to utilise and share these resources as intended.

What might happen next

The videos have been created and are available for use. They have been co-created with a wide range of stakeholders and have been tested to ensure they resonate with tamariki Māori and whānau Māori.

We are grateful to have the support of Toi Tangata and the Kohanga Reo National Trust who are using the kiriata as a resource for their tamariki. As tamariki have experienced the videos, they have latched onto the catch phrase 'Ko tō manawa, ko tōku manawa'. They clearly find the videos engaging and relatable.

We encourage others in the system to use this resource in similar ways. The more these videos are watched by tamariki and their whānau, the greater the protection that whānau will experience. Looking into the future, we picture a world where today's tamariki are sharing the stories of the kiriata with their whānau, where the saying "Ko tō manawa, ko tōku manawa" is commonly used. Eventually, this can help to release the hold that rheumatic fever has had over our people and bring light to whānau.

We also encourage those in the health and social sectors who are communicating with whānau Māori to look closely at these kiriata and the ingredients that contributed to their creation, so that you can apply these principles in your own work in other contexts. If we empower tamariki with information that makes sense to them and is memorable, and if Māori develop these resources from start to finish, we can be confident that they will resonate with our people and have the long-lasting impact we hope for.





Kōrero Whakamana

Prototype 3

The language guidelines are a resource for media and health professionals to support them to talk to whānau Māori about rheumatic fever in a mana-

enhancing way. It provides practical alternatives to the negative words and phrases currently used to remove the stigma around this condition.

WHAKAPAPA

Origin

When talking with whānau and Māori health professionals, we heard that language typically used by media and health professionals had a strong bearing on how whānau felt about themselves. Examples of commonly-used language in relation to rheumatic fever includes:

- Third world condition.
- Families living in low socioeconomic areas are at greater risk.
- A condition of poverty.
- A Māori condition.

The consequence of this language is it implies that rheumatic fever is an immovable part of life for whānau, that there is nothing they can do to prevent it, that there is no hope, and that they can't escape it. It also implies that whānau are at fault for living in that area or socioeconomic status. It is language that keeps whānau down in the dumps and feeling like they can't change things.

Our insight related to moemoeā was that there was an opportunity for whānau to dream of a future without rheumatic fever. To support this dream, different language is needed. The idea was validated early; people knew that this was a problem, but weren't clear on what the solution was. So we created a simple flow chart (the language guidelines) that shows people what the alternative language choices are that are uplifting to whānau.

We also identified that a critical stakeholder was media. Media hold mana and are often seen as trustworthy or experts. Their voices travel to whānau and how they talk about rheumatic fever has an impact. We had the vision of media using better language so that language falls into the hearts of our whānau rather than the negative language. So we prioritised the places speaking directly to whānau, therefore Māori media.

NGĀ TURE AUHAHA

Design Criteria

We adopted the following design criteria for this prototype:

- Be suitable for use by a broad range of people including health professionals and clinicians, health promotion agencies, academics and people working in the media.
- Provide factual information in a mana-enhancing way.
- Focus dissemination firstly on sources that whānau engage with regularly such as Māori media outlets to quickly gain traction.
- Describe Rheumatic Fever in a relatable way for whānau, and remove the scary language and pictures.



He Kōrero Whakamana

Rheumatic Fever Language Guidelines

He Kōrero Whakamana aims to encourage all media and health services to utilise language that maintains the mana of tamariki Māori and their whānau when describing rheumatic fever.

When talking with whānau, Māori health professionals and Māori media, we heard that the language that is often used when talking about rheumatic fever has a strong and lasting impact on the way tamariki Māori and whānau Māori see themselves. The language can leave whānau feeling a sense of whakamā, therefore discouraging whānau from talking about rheumatic fever and the way it affects whānau.

We want whānau Māori to dream of a future without rheumatic fever, to believe this is possible, to believe that it isn't an immovable part of their future, and to feel comfortable talking about it.

Kia kaha tō tātou whakaaronui ki ngā whānau e noho nei, me te Rūmātiki.

If in doubt, ask yourself these three questions to ensure your language is mana-maintaining:

- Is the language fatalistic or does it imply there is hope?
- Does the language suggest it is the fault of the whānau or the result of the way our systems are designed?
- Does the language acknowledge the strengths of Māori who experience rheumatic fever?

AVOID THIS UNHELPFUL LANGUAGE

EMBRACE THIS LANGUAGE THAT MAINTAINS MANA OF TAMARIKI MĀORI AND THEIR WHĀNAU

Rheumatic fever is a third world condition.

Rheumatic fever is a complex condition that unfortunately discriminates against some people.

Rheumatic fever is a condition of poverty.

Inequities in society create the conditions for poverty, which increase the risks of rheumatic fever.

Rheumatic fever is a Māori condition.

It's a big challenge for us as Māori, especially for our tamariki and rangatahi.

Families living in low socio-economic areas are likely to get rheumatic fever.

Despite experiencing inequities, we Māori can draw on a range of approaches to protect ourselves against rheumatic fever.

Where you live determines whether or not you will get rheumatic fever.

Māori have effective ways of sharing knowledge across generations and can do so with rheumatic fever.

Preventing rheumatic takes a collective team effort – it is not the fault of an individual.

Rheumatic fever is preventable if parents take their children to the doctor.

We can redesign our health, social and housing systems to overcome the causes of rheumatic fever.

Māori are genetically predisposed to getting rheumatic fever.

There are things we can all do to keep our hearts strong and healthy.

The good news is there are ways we can prevent it.

Rheumatic fever is caused by whānau ignoring sore throats.

Early checking of sore throats is a great way to reduce the risks of rheumatic fever.

By looking out for each other, we can make a real difference.

What might happen next

The language guidelines have been created and tested and are available on the Te Whatu Ora website.

We encourage you to reflect on how you can bring life to the language guidelines in your own work. We hope to see whānau Māori experiencing less shame about the way rheumatic fever is spoken about to them in the health clinic and in the media. We hope to see people sharing these guidelines widely with their staff, colleagues, stakeholders and providers to ensure there is widespread change. We also hope to see other issues that impact Māori at a disproportionate rate due to systemic inequities responded to in a similar way to ensure our people are receiving information in a way that isn't harmful to them and their wairua.

Kōrero Whakakapi

Conclusion

Thank you for reading our report. We have mixed feelings as we conclude the Co-Design Initiative. We feel honoured to have been trusted by whānau to lead this kaupapa, and are genuinely excited by the potential these prototypes hold to create genuine change for whānau Māori. But we also feel a sense of accountability to whānau; while we have collectively made good progress, ultimately more is needed. We ask that you accept the insights, learning and inspiration in this report and hold them close to your heart.

We are grateful for the support of partners such as Long White Cloud Productions, Toi Tangata, the Kohanga Reo National Trust, and Television New Zealand. These partners have contributed immensely to this kaupapa and are playing a key role in extending the reach and depth of our prototypes.

And, finally, we wanted to close with four reflections about what are the most critical ingredients to include in any future initiatives focusing on outcomes for Maori.

REFLECTION #1

Provide space for whānau Māori to feel safe, to share safely, and to know that good things will come from their kōrero for the generations to come. Focus on moemoeā – creating a space to dream, breaking out of the negative conversations, creating the opportunity for people to be part of the solution, and give them the confidence that their stories are going to be protected and cared for.

REFLECTION #2

To achieve what is described in the first reflection requires a core team that cares about achieving this and that has the capability to create the time and space to continually take whānau on the journey. The team needs to hold those relationships and care for them – if done well, they will be connected to whānau forever.

REFLECTION #3

Create new narratives for contemporary challenges by being guided by traditional narratives. Stand on the shoulders of giants, utilising karakia and waiata to connect and share. After many years, these new narratives become known, understood and part of everyday life.

REFLECTION #4

Māori are highly connected, and anyone can be reached through whanaungatanga. Identify the necessary people to the kaupapa thrive and work through existing relationship capital to be connected. When people heard the story of this kaupapa, we wanted them to see the mana in it so they would want to be part of it. Acknowledge what work has been done previously – complement it. And look for new stakeholders for the future; key allies for the future may not have been involved in previous initiatives.

**Ko tō manawa, ko tōku manawa.
Your heart, my heart.**