

Te Tīma Māori

Rheumatic Fever Co-Design Initiative



DISCOVERY REPORT
ĀPERIRA 2022

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 kawea 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 Manatū Hauora, 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 the Ministry of Health 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



CONTENTS

08 TE TĪMĀ MĀORI - KO WAI MĀTOU?

09 TE WHĀINGA ME NGĀ MĀTĀPONO
Aim and Design Principles

10 TIKANGA MATATIKA
Ethical Frameworks

11 TE HAERENGA
Our Process

13 NGĀ KITENGA
Insights

31 TUAKIRI
Personas

36 NGĀ TAUIRA
Ideas and Prototyping

Te Tīma Māori - Ko wai mātou?



**KATARAINA
DAVIS**
Team Lead



**PAORA
DAVIS**
Kaumātua



**GRAHAM
TIPENE**
Māori visual designer



**MATTHEW
MULLANY**
Researcher



**JONO
COLE**
Visual Designer



**TE AMOHANGA
RANGIHAU**
Te Reo Māori expert



**CARA
RYAN**
Kairaranga/Enabler
and Comms

Te Whāinga

Our Aim

**“Te Whakaorite - Tinana, hinengaro, wairua,
whānau kia māmā, kia ngāwari, te oranga”**

– Māmā with tamaiti living with Rheumatic Fever

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.

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.

Te Haerenga

Our Process

HŪRAE 2020 - HUNE 2021

Understanding our wero, who we know and what we know. Building connections and relationships.

ĀKUHATA 2021

We talked to our overall process, and understood our Māori ethical frameworks that exist.

OKETOPA 2021

We developed and tested our pātai and areas of focus for our whānau wānanga and uiui.

NOEMA 2021

Multiple uiui (questioning) and wānanga (deep discussion) with whānau, stakeholders, and kura.

TĪHEMA 2021

We brought together all of our kōrero with our whānau and started the analysis process to unveil the themes and kōrero presented in this report and continued feeding back to whānau.

HŪRAE 2021

Our team was curated and quickly started working to understand our collective strengths. We built our collective 'Whāinga' and what we stand for in this kaupapa.

HEPETEMA 2021

We worked to understand who we know, and through whanaungatanga reached out to our whānau.

- Whānau Māori who have tamariki living with Acute Rheumatic Fever.
- Whānau Māori who have not been impacted by Acute Rheumatic Fever.
- Kura Māori, Bilingual Units, Kura Auraki.
- Kahukura - Community Leaders.
- Iwi and hapū leaders.

HĀNUERE - MĀEHE 2022

Finalising insights, working on ideas, refining those down with our whānau.





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

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.

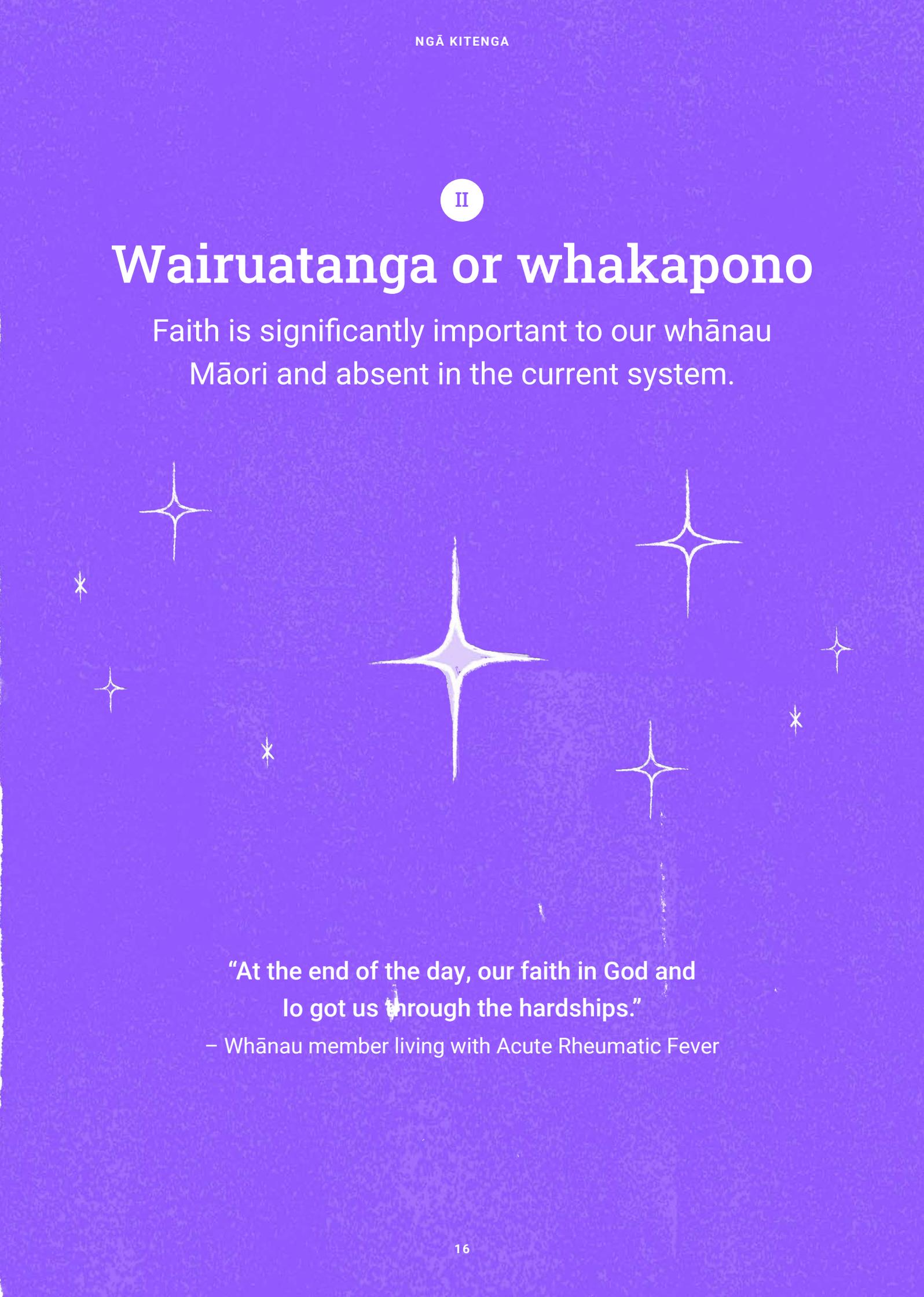
WHĀNAU-BASED DRIVERS TO ACHIEVE ASPIRATIONS

- 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.

II

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.

OPPORTUNITIES

- How might Te Ao Wairua be acknowledged and seen as a principal requirement within the current health system?
- How might karakia be understood and used within the system?



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.

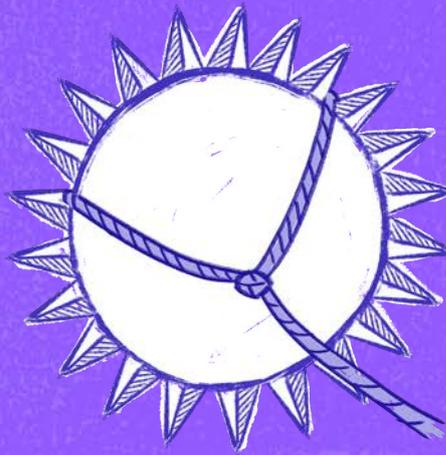
OPPORTUNITIES

- How might we build capability and understanding of Tikanga Māori and its importance in our current system?
- How might we grow and embed tikanga Māori into our Māori homes?

IV

Storytelling

Stories that create connection.



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

– Pāpā, Māngere

“I think about that advert and he’s had a heart operation - that
looks like quite an extreme case. I couldn’t understand how you
get from the sore throat to that. It’s not clear.”

– Pāpā Māori, 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.

OPPORTUNITIES

- How might we use stories to build awareness and connection points to Rheumatic Fever and Rheumatic Heart Disease for our whānau?
- How might we share stories that use language whānau are familiar with?



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

“I had the same community group GP that took care of me and my whānau. They knew us all.”

– Tangata mōhio

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.



**“Te kuaka mārangaranga, kotahi manu
i tau ki te tāhuna: tau atu, tau ra.”**

*The godwit flock has arisen; one bird has
come to rest on the beach: others will follow.*

– Community Leader/Kahukura, Manurewa

**“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.

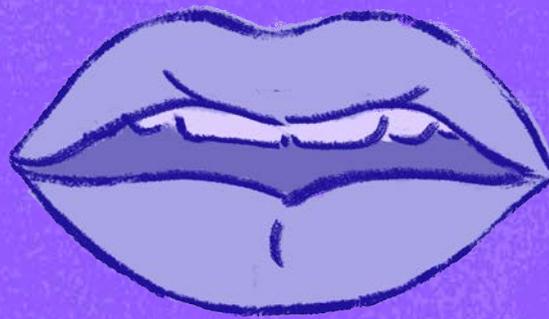
OPPORTUNITIES

- How might community kahukura be recognised more as a key part of any community?
- How might we increase resource to kahukura to enable them to continue and grow their mahi to be kahukura?

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 its place, it should not be whānau facing.

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

OPPORTUNITIES

- How might we move away from a deficit model perspective in the way we communicate information about Rheumatic Fever?
- How might we think about upholding people's mana in the way we build awareness around Rheumatic Fever?



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

‘Take the whakamā away from our tamariki.’

– Kaiako, Kura Auraki, Māngere

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.

OPPORTUNITIES

- How might manaakitanga underpin the way we communicate with whānau?



Tuakiri

Personas

WHAT PERSONAS ARE (AND AREN'T)

Personas are fictional people based on real research data. They provide a snapshot into a group of peoples' broader lives and what's important to them, as well as their lived experience of a particular issue. They are not intended to be representative of all Māori people, but provide a useful lens to apply when developing new solutions.

HOW PERSONAS ARE CREATED

Personas are created after qualitative research has been conducted, through a process of identifying patterns in the participants' contexts, perceptions, and behaviors.

HOW TO USE PERSONAS

Personas are useful for showing how a group of people think about and behave in relation to a particular issue or service. They can be used to evaluate and inform solutions and help internal staff understand the perspectives and motivations of people who they might not often get the chance to interact with. However, personas should not be used instead of directly engaging with the people who have lived experience of a service or issue.

Te Whānau Rongo



**“Sitting in the lounge and my Mum says
“Take your shoes off” to the nurse.”**

– Māmā with a tamaiti living with ARF, Manurewa

**“Kei hea koe e haere ana, me tōnā kī kei tiki
aku pūwero mō te Rheumatics.”**

– Māmā, Māngere

MOEMOEĀ

- Mana Ōrite.
- Te whakaōrite.

BEHAVIOUR

- Asserts Tino Rangatiratanga – expresses expectations to do with her whānau.
- Follows and practises tikanga.
- Speaks Te Reo Māori.
- Practices karakia.

ENABLERS

- Connected to Te Ao Wairua.
- Grounding and belonging in space and place.
- Collective – My Mum, sisters, are people I can go to.
- Appreciation and openness to learn, practitioners.

BARRIERS

- All racism – Mispronunciation of names.
- Lack of ability for whanaungatanga.
- When there is a lack of tikanga – Taking off shoes in the house.

Kahukura Paul



“Loyalty to your kaupapa, consistency in being there, has our tamariki come year in year out.”

– Coach, Māngere

“Do people actually believe that tamariki and rangatahi are our chiefs of tomorrow? It doesn’t look that way. How are our kids meant to be well, no one is excited about their future?”

– Youth Hub Leader, Henderson

MOEMOEĀ

- Mana Ōrite.
- Te whakaōrite.
- A system that listens to our whānau and values tamariki and rangatahi.
- All our kids love sports.
- All our kids find what they love doing in life.
- All of our kids feel supported, nurtured and have somewhere to go and be connected to.

ENABLERS

- Aroha
- Tika
- Pono
- Community
- Belonging
- Support

BEHAVIOUR

- Runs programmes, coaches teams, is a seen face in their community.
- Is looked to for advice.
- Whānau feel safe around them.
- Always looking out for their community.
- Holds mana, and has many followers.

BARRIERS

- Blatant racism – Mispronunciation of names.
- No belief in our tamariki.
- Things that make it hard for our kids to participate in anything.
- No connection to marae, hapū, iwi.
- Matemateāone.

Ngā Tauira

Prototypes

There is a need to find space for both a Te Ao Māori system view and 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.

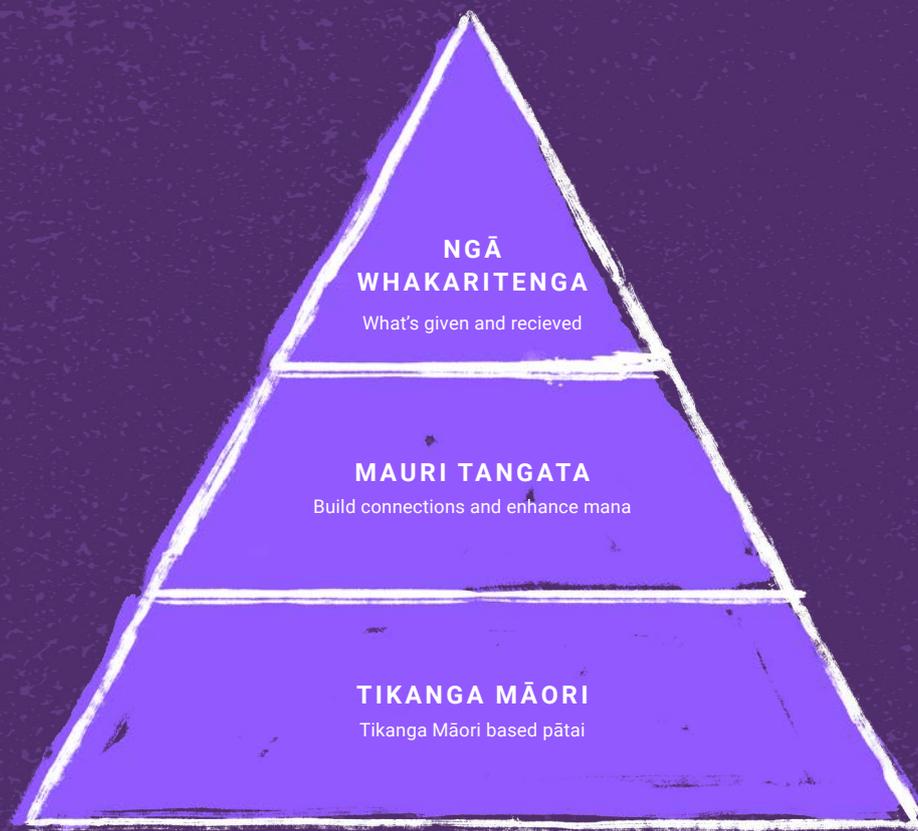
This model below has guided the process to ideate and refine ideas with our whānau who have participated in this co-design process. It puts tikanga Māori at the core of our process, it considers and values people and their mauri, and finally moves into preparation.

“If whānau are wanting to use traditional methods of healing, then they can. Rongoā Māori heals more than just physical ailments.”

– Māmā, rongoā specialist

“How do we come together? I feel like I’m at the party but no one is asking me to dance.”

– He tangata mōhio



- **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.

Ngā Tauira e Ono

Our six Prototypes

In our previous report we highlighted six potential ideas to be prototyped and tested in phase two. Through conversations with whānau, stakeholders, hapū and iwi we decided to place more focus on three.

These headlining ideas that have been prototyped, tested and are now into their embedding phase.

- 1 Te Kura ā Rongo**
- 2 Rheumatic Fever Communication to whānau with whānau**
- 3 Kaupapa Māori based Rheumatic Fever Visual Resources**

From prototypes 1-3 have fallen a subset of three more prototypes that have naturally found space to be weaved through each of the below prototypes.

4 SYSTEM CAPABILITY BUILD

There are opportunities to build system capability through the sharing of Te Kura ā Rongo. With the sharing of this taonga comes a requirement to learn and understand where it has come from. There is also a requirement to build our capability around Te Reo Māori when delivering this. Te Tīma Māori commit to holding this space for whānau and stakeholders.

5 CONNECTING THE SYSTEM

Through efforts to prototype our communication prototypes with whānau we highlighted a key place that all media has in the dissemination of information leading us to build connections around Rheumatic Fever with Aotearoa media, and Māori media into the health system to smooth out the process to deliver great and important content to whānau Māori.

6 HE POROPOROĀKI/ WHAKATAU WAIRUA

This idea will see all of these prototypes brought together and launched with and for whānau Māori at the forefront to close off this Rheumatic Fever Co-Design Initiative, to whakatau mauri and look forward to the future ahead.

Te Kura ā Rongo

Te Kura ā Rongo brought together by our whānau and their stories. Visually presented by Graham Tipene and Jono Cole. Our karakia composed by Te Amohanga Rangihau is our response to protecting stories and voice, leading through tikanga Māori, and intergenerational dissemination of knowledge to whānau.

Te Kura ā Rongo is a piece of mahi toi that is cyclic in nature. It is a koha to our whānau, and an opportunity to share kōrero about this kaupapa to eradicate Rheumatic Fever in Tāmaki Makaurau. Designed to be visible in the home and act as a point of conversation with whānau and friends who enter their home. An added opportunity to continue embedding tikanga into our households, our kura, the system.

WHĀINGA Objectives

- Continues to encourage tikanga Māori practices in the whare, at kura, the system
- Is a repository of knowledge through the visual print, and the karakia.
- Acknowledges importance of te ao Wairua for whānau Māori.

ANGA WHAKAMUA

Recommendations for embedding

Implemented by October

- Kōrero with at least 20 new whānau in Tāmaki living with ARF to gift Te Kura ā Rongo share the kaupapa, our learnings and aspirations. There is potential here to work with National Hauora Coalition and Starship Foundation Community Health Workers.
- Te Kura ā Rongo will open the Rheumatic Fever Action Plan.
- Korero with at least 20 kohanga reo, Māori medium kura, kura auraki schools to gift Te Kura ā Rongo share the kaupapa, learnings and aspirations.
- A social media campaign, and kaitahi event to bring all of these ideas together in 2023.



TIKANGA MĀORI

What did we ask?

- Does this idea encourage tikanga Māori?
- How does this connect to Wairuatanga?
- Will this achieve intergenerational dissemination of knowledge?



MAURI O TE TANGATA

Who did we ask and how?

- We continue to utilise Te Kura ā Rongo at all engagements connected to this kaupapa to increase awareness and normality of tikanga practise.
- We shared early ideas of the visual piece with all whānau and stakeholders to gain feedback.
- Gifted a beautiful piece to whānau participants lifting wairua and improving mauri.



NGĀ AKORANGA

Learnings

- We have received nothing but great feedback about this mahi toi, and the karakia. All whānau we have been engaging with are now familiar with this karakia, and ask for a copy to share far and wide.
- Having the ability to open source this karakia has been an important learning.
- Tikanga Māori continues to keep us safe, if you are Māori or not. Non-Māori see value in these practices.
- Just like pou whakairo (carved pillars) in a whare tupuna (meeting house) this mahi toi acts as a repository of knowledge that will carry knowledge through generations as this piece is kept within whānau and handed down.



NGĀ WHAKARITENGA

How did we test?

- 1 TE KURA Ā RONGO**
 Te Tima Māori sat in wānanga regarding our response to wairuatanga, maintaining tapu, and data protection. This led to our karakia Te Kura ā Rongo. We committed to our karakia anytime we engaged with each other, our whānau, their kōrero and this kaupapa.
- 2 KOHA FOR WHĀNAU**
 Secondly we had kōrero about the koha our whānau would receive outside of putea (funds) and kai (food). This koha recognises their contribution to this mahi, and the relationship between us and this important kaupapa.
- 3 DELIVERY**
 We then paired them together in a print presented by Graham Tipene and Jono Cole, framed packed and delivered the print to all whānau who have contributed to this kaupapa.
- 4 WIDER SYSTEM**
 We will share this karakia across the system in the Rheumatic Fever Action Plan, using this opportunity to build capability of whānau working in the system also.

II

Rheumatic Fever Language Guidelines

This idea acknowledges that 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.

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' is what our whānau hear. While there is a place for this kōrero, it should not be whānau facing.

We've identified that these guidelines need to exist not only through the health sector, but in all sectors that influence and impact Māori including Media.

If you'd like to kōrero or access a copy of the guidelines, get in contact with timamaorirf@gmail.com

WHĀINGA Objectives

- This idea will be effective across all parts of the system that are forward facing to whānau. Particularly the health sector, and media etc.
- This idea will lead with the mana of whānau at the forefront.
- Will encourage shared responsibility in the way we communicate with whānau.
- Will remove blame from whānau.

ANGA WHAKAMUA Recommendations for embedding

- Disseminate guidelines and opportunity for kōrero to spaces that are forward facing to Māori. (August-November)
- Work with Te Whatu Ora, Pūmanawa about our recommendations. (Ongoing)
- Work with Māori media to share kōrero, and embed into their criteria or process to storytell. (August-November)
- A social media campaign, and kaitahi event to bring all of these ideas together in 2023.(March 2023)



TIKANGA MĀORI

What did we ask?

- How does this idea demonstrate manaakitanga?
- How does this idea practise whanaungatanga and consider a collective?
- How will this enable whānau to assert tino rangatiratanga?



MAURI O TE TANGATA

Who did we ask and how?

- Kōrero/wānanga with whānau participants about their thoughts regarding language.
- Spent time to understand process - media communicating and storytelling to whānau.
- Tested flowchart with whānau Māori, and stakeholders.



NGĀ AKORANGA

Learnings

“These guidelines should be considered across the board, its not just about Rheumatic Fever.”

- It was highlighted that this idea displays manaakitanga by highlighting kōrero that doesn't serve our people.
- Clarity is paramount, words like 'systemic' don't hold much meaning for whānau, however 'the environment around you' does. Therefore we then created an accessible flowchart regarding the appropriate language when facing whānau Māori verses the system.
- Whānau turn off when they hear jargon from a system, it takes away their ability to feel included and belong. Therefore it takes away the opportunity for learning and sharing.



NGĀ WHAKARITENGA

How did we test?

- 1 Te Tīmā Māori had kōrero with whānau and stakeholders about the power in words and possible alternatives to words like poverty, 3rd world country etc. This also highlighted the appropriate time and place for this kōrero.
- 2 We held space with multiple Māori media experts in te ao Māori to discuss the process of storytelling, and what it takes to create collective movement.
- 3 This lead us to create alternatives to the highlighted negative wording like poverty and 3rd world country condition, it also helped us lean into shared responsibility when communicating with whānau.



Rheumatic Fever Video Resources

This idea acknowledges Māori storytelling, and encourages our skills as orators, singers, poets, lyricists.

Stories that create connection, and resonate with our whānau Māori are absolutely necessary to see the eradication of Rheumatic Fever in our communities in the years to come. There is a need to aid methods of intergenerational learning and transmission of knowledge to future generations.

These videos will be created for Māori by Māori and will be underpinned by our initial findings and feedback from whānau. They will be made for our babies and whānau in kohanga reo, Māori medium kura, and stakeholders including health promotion teams. They will be aspirational, mana-enhancing, and they will resonate with our tamariki Māori.

WHĀINGA Objectives

- These videos will work to carry knowledge through generations.
- They will resonate and be accessible to all whānau Māori.
- They will create connection and movement within Māori communities and collectives.
- They will draw attention to achieving hauora, rather than fighting a condition.

ANGA WHAKAMUA Recommendations for embedding

- Partner with kāhui Kohanga reo/ Māori mediums schools to share and gift videos and key points of communication. (August - November)
- Partner with Punarau Media to create new videos for whānau, Kohanga Reo and Māori Medium Kura. (August - November)
- Work with Te Whatu Ora, Pūmanawa about our recommendations.
- Social Media campaign and kaitahi utilising tested videos to gain more movement. (March 2023)



TIKANGA MĀORI

What did we ask?

- How does this idea demonstrate manaakitanga?
- How does this idea practise whanaungatanga and consider a collective?
- How will this enable whānau to assert tino rangatiratanga?
- What is currently working for whānau in terms of knowledge sharing?
- Are the current videos working for whānau?



MAURI O TE TANGATA

Who did we ask and how?

- Kōrero/wānanga with whānau participants about their thoughts regarding current and new Rheumatic Fever, and hauora resources.
- Kōrero and wānanga with Māori animators to understand process and what it would take to create successful videos.



NGĀ AKORANGA

Learnings

- According to whānau the current videos are aimed at those working in the space and do nothing to create connection for whānau. Patronising is a word to describe these videos.
- Findings showed videos that don't resonate with whānau
- Videos must show emotion, and help whānau to overcome possible barriers.
- Videos must show Māori who are happy and strong.
- Cartoon videos are great to share at Kohanga Reo, documentary like videos with actual whānau in them are good for adults and older generations.



NGĀ WHAKARITENGA

How did we test?

- 1 Interacted with current rheumatic fever resources available to whānau and kaimahi. Wānanga with Māori animation specialists Punarau Media, makers of Pipi Mā, to kōrero about what makes change for our whānau, and the learnings from creating Pipi Mā?
- 2 We held space with multiple Māori media experts in te ao Māori to discuss the process of storytelling and it's impacts on whānau Māori.
- 3 Plan to create new videos

References

- Anderson, A., Leversha, A., Ofanoa, M., Malungahu, M.G., Burgess, H., Wade, W.J., Naisali, R.S., Sims, M.A., & Peat, B., *Māori and Pacific whānau experiences of recurrent rheumatic fever and unexpected rheumatic heart disease in New Zealand*, Auckland, New Zealand: University of Auckland, 2018
- Anderson, P., King, J., Moss, M., Light, P., McKee, T., Farrell, E., Stewart, J., & Lennon, D., *Nurse-led school-based clinics for rheumatic fever prevention and skin infection management: Evaluation of Mana Kidz programme in Counties Manukau*. The New Zealand Medical Journal, 129(1428), 2016
- Auckland District Health Board, *Rheumatic Fever prevention programme*. Auckland, New Zealand: Auckland District Health Board, 2016
- Bryers, C., *Rheumatic Fever Review – An Examination and Recommendations for Designing a Rheumatic Fever Awareness Campaign*, Waitematā District Health Board, 2021
- Counties Manukau Health, *Rheumatic Fever prevention plan*. Auckland, New Zealand: Counties Manukau Health, 2013
- Graham R, Masters-Awatere B. *Experiences of Māori of Aotearoa New Zealand’s public health system: a systemic review of two decades of published qualitative research*. Indigenous Health. 2020;
- Grayson, S., Horsburgh, M., & Lennon, D. *An Auckland regional audit of the nurse-led rheumatic fever secondary prophylaxis programme*. The New Zealand Medical Journal, 2006
- Harré, N., Thomas, D., Brown, K., Raza, F., & Lennon, D., *Communicating information about sore throats and rheumatic fever to South Auckland high-school students*. The New Zealand Medical Journal, 113(1111), 2000
- Health Quality & Safety Commission., *A window on the quality of Aotearoa New Zealand’s health care 2019 – A view on Māori health equity*. Wellington, New Zealand: Health Quality & Safety Commission 2019
- King, J., Moss, M., & McKegg, K., *School based primary health care programme evaluation: Final report*. Auckland, New Zealand: Counties Manukau District Health Board. 2014
- Mills, C., Reid, P., & Vaithianathan, R., *The cost of child health inequalities in Aotearoa New Zealand: A preliminary scoping study*. BMC Public Health, 12(1), 2012
- Ministry of Health, *Healthy Homes Initiative*, 2021
- Ministry of Health, *Whakamaua: Māori Health Action Plan 2020-2025*, 2020

REFERENCES

- National Hauora Coalition. *Rheumatic fever prevention programme: Antibiotic adherence trial*. Auckland, New Zealand: National Hauora Coalition, 2019
- Oliver, J., Robertson, O., Zhang, J., Marsters, B., Sika-Paotonu, D., Williamson, D., Wilson, N., Pierse, N., & Baker, M., *Progression of acute rheumatic fever to recurrence, rheumatic heart disease, and death in New Zealand children and youth: A cohort study*. Heart, Lung and Circulation, 2019
- Office of the Prime Minister's Science Advisor, *Evidence Synthesis: Group A Streptococcus and acute rheumatic fever in Aotearoa New Zealand*, 2021
- Oliver, J., Robertson, O., Zhang, J., Marsters, B.L., Sika-Paotonu, D., Jack, S., Bennett, J., Williamson, D.A., Wilson, N., & Pierse, *Ethnically disparate disease progression and outcomes among acute rheumatic fever patients in New Zealand, 1989–2015*. Emerging Infectious Diseases, 27(7), 2021
- Pū Manawa, *Rheumatic fever*, 2021
- Rangihau, John, *Puao-Te-Ata-Tū: The Report of the Ministerial Advisory Committee on a Māori Perspective for the Department of Social Welfare*, 1988
- Salter K. *Beyond awareness: Rheumatic fever knowledge in the Tamaki Community. Initial findings and unintended consequences*. University of Auckland; 2021.
- The Heart Foundation., *Ngā Kokonga Ngākau: Perceptions and experiences of Māori Heart Health in Te Tai Tokerau*. The Heart Foundation, 2018
- Waitangi Tribunal, *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry: Wai 2575*, 2019
- Waitemata District Health Board., *Rheumatic Fever prevention programme*. Auckland, New Zealand: Waitemata District Health Board, 2016
- White H, Walsh W, Brown A, Riddell T, Tokin A, Jeremy Rea. *Rheumatic Heart Disease Indigenous Populations*. Heart Lung Circ. 2010

