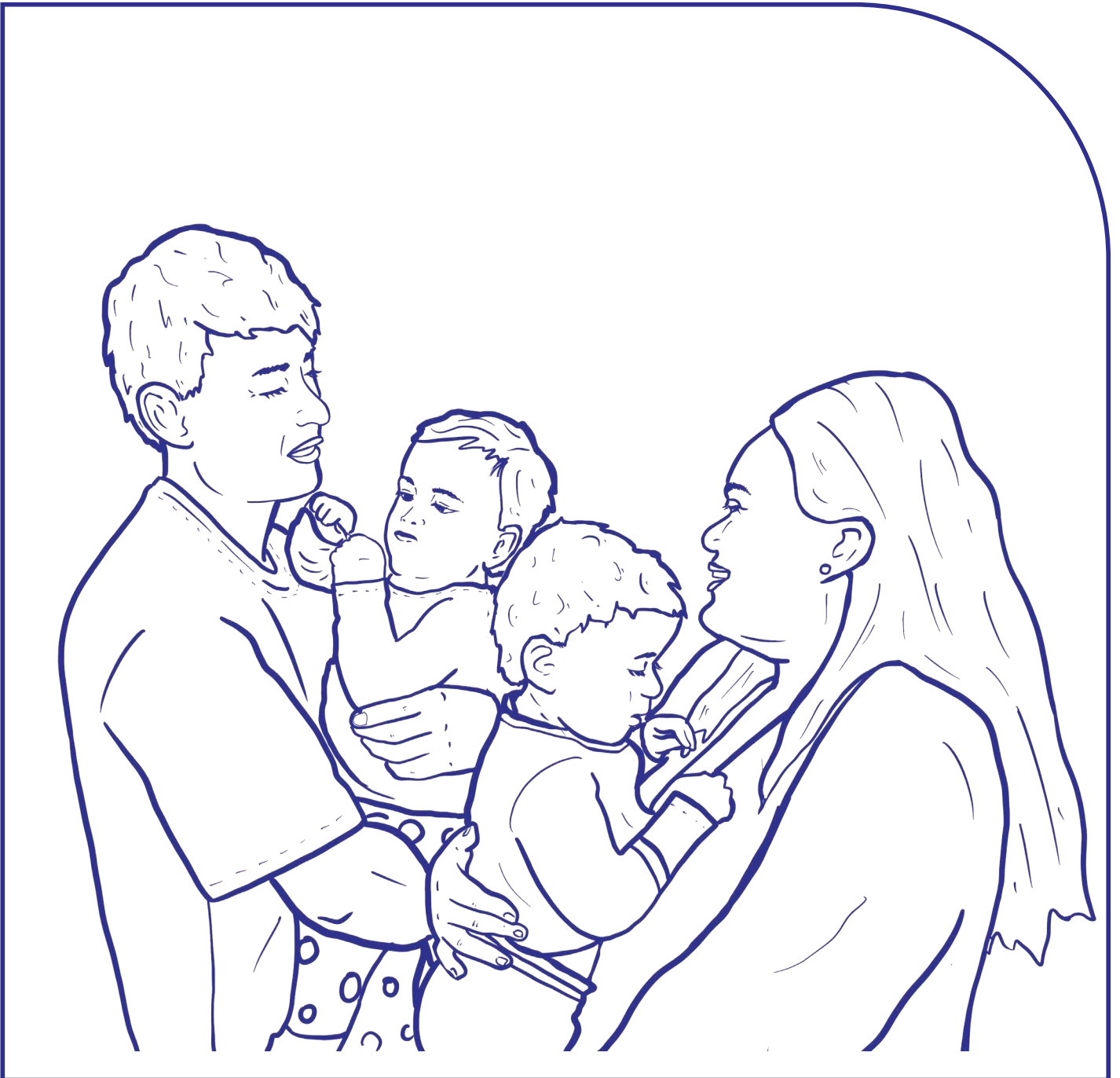


Reflection on Phase One of the Rheumatic Fever Co-design initiative

An interim process evaluation

31 March 2022



Acknowledgements

We would like to thank everyone who opened their hearts and minds to reflect on the co-design initiative to date. We acknowledge that there are families who, despite having suffered tremendously from rheumatic fever and other challenges due to health inequality, are still generously and bravely giving their time to participate in this initiative. I look forward to seeing what we can do to make a difference for them.

Many of the team members wanted to acknowledge Sue Zimmerman, who was instrumental in the beginning of the initiative. Her characteristics of leadership, determination and grace were cherished by the whole team.

– Mondy Jera, author of this interim process evaluation

How to read this report

This document provides a glimpse into what it's been like working on the rheumatic fever co-design initiative over the first phase of work. Whilst this interim evaluative piece was a requirement of the job, it was also a delight to hear the candid thoughts from the team about what has been working well, along with some of the challenges. This is a new way of working for many of us; although the cultural frameworks and tikanga are not new, bringing it all together in this way has made the journey unique.

In this report, there is a brief introduction to the challenges of rheumatic fever, and a description of the developmental evaluation method. The report then outlines the activities, highlights and challenges of four key milestones for Phase One. There are summarised quotes to support the findings in each section.

The report ends with a summary of the key points expressed by the team. We hope you enjoy learning from our work to date and that we can share and influence the future for best practice in co-design.

Introduction

The rheumatic fever co-design initiative was commissioned by the Ministry of Health (the Ministry) in late 2020. The aim of the initiative was to do something different and to empower and support communities to try some new solutions for themselves. There are three communities involved: Māori, Samoan and Tongan. The co-design initiative is based in Tāmaki Makaurau.

In part, the co-design initiative aims to balance out some of the inequities in the system. Rheumatic fever is considered a disease of inequity because it has virtually been eliminated in non-Māori and non-Pasifika peoples of Aotearoa. The persistence of rheumatic fever in Māori and Pasifika populations is a concern for health professionals, academics and communities. It is reflective of wider system inequities such as the continued lack of access to warm, dry and otherwise adequate housing along with difficulties accessing culturally safe and appropriate health care.

Over time, there has been a mix of responses to preventing and managing acute rheumatic fever (ARF), with the main ones being: sore throat management/skin check clinics in schools, public health campaigns to raise awareness, e-learning modules for health professionals and the Healthy Homes Initiative. Historically, there has been a struggle to track people at risk of ARF or who had ARF and are on a prophylaxis regime to prevent rheumatic heart disease (RHD). Also, diagnosing ARF is not always straightforward, and the classification of the disease at the time of hospital admission may not reflect the true prevalence or incidence of the disease (it gives a trend over time, but it isn't 100% accurate).

The public health message to communities has been to get sore throats checked and treated as early as possible. The focus has been on preventing ARF by catching group A strep infections early. While communities seem to be aware of that message, it places the burden of prevention onto parents and

children to: identify a sore throat (or skin infection), get a throat swab, get the antibiotics, take them all, and monitor for signs of getting better or worse. In the communities, we are learning about a mix of fear, shame and resignation. For example, we've learned that Māori communities commonly call rheumatic fever, *The Rheumatics*, which might signal the condition is somewhat expected.

This illness of inequity should be anything but normalised. This co-design initiative was set up to reveal some of the dynamics at play and try something new to combat this complex, unequally distributed disease. The purpose of the initiative is to increase the involvement of communities in co-designing new approaches.

Alongside the co-design initiative, the Ministry has commissioned short-term, high-impact initiatives with DHBs. These projects also employ some co-design methods, but those DHB initiatives are not the subject of this monitoring project. Rather, we are reflecting on our activities to date as a co-design team.

This report comprises a developmental evaluation of Phase One of the co-design initiative, which goes through the stages of: setting up the core design teams, connecting with the sector, creating a new way of working and setting up the discovery methods. The next phase is developing some new community prototypes for testing, and that will be evaluated separately, utilising a different method.

Method of reflection

To reflect on Phase One of the co-design initiative, we chose to use an adaption of a developmental evaluation (DE) because this method is well-matched to reflecting/monitoring/evaluating in complex environments. This style is also good for learning about emergent, innovative practices and was chosen because the co-design initiative relies on varied models and practices. This method is also good for teams working in uncharted techniques. It will guide us towards exploring the question, *what is emerging as the innovation takes shape?*

The reflective nature of DE means that our practitioners in the design teams can learn as they go with thoughts about what is working well and what needs to change. And chiefly, DEs are good for evaluating topics that have the hallmark of complex systems, such as this exploratory community co-design initiative¹.

This evaluation can also be seen as an interim check in, because the community prototypes will be evaluated more thoroughly starting later this year. This report could be useful for those evaluators to get a sense of this new approach and how the teams have felt about the process to date.

This approach has been influenced by the social Innovators at FSG, a global non-profit social advisory group. They ran a think tank about DE and then articulated why DE adds value and how it differs from other types of evaluative methods.²

- 1 DE focuses on understanding an innovation *in context*** and explores how both the innovation and its context evolve and interact over time.

Our innovation in context is the focus on working closely with three distinct ethnic groups living with the impacts of ARF in Tāmaki Makaurau. Our questions ask, *What is uniquely Samoan, Tongan and Māori in the landscape of rheumatic fever and how do we find new and better ways to prevent and manage with them?*

- 2 DE is specifically designed to improve innovation.** By engaging early and deeply in an exploration of what a new innovation is and how it responds to its context, DE enables stakeholders to document and learn from their experiments.

This process has been unique, so this moment of reflection and accountability are key to the project's longer-term success. We are keen to share our learnings on the project to date.

- 3 DE supports timely decision-making in a way that monitoring and later-stage evaluation cannot.** By providing real-time feedback to initiative participants, managers, and funders, DE supports rapid strategic adjustments and quick course corrections that are critical to success under conditions of complexity.

- 4 Well-executed DE uses an inclusive, participatory approach that helps build relationships and increase learning capacity while boosting performance.**

Whilst this interim reflection process hasn't included the voices of the community participants, the design teams pointed out that their processes going forward will include a reflective practice with the participants as they enter into the prototyping phase.

¹ https://ssir.org/articles/entry/reconsidering_evidence_what_it_means_and_how_we_use_it

² <https://www.fsg.org/blog/case-developmental-evaluation>

Method of engagement

There were two ways of collecting information for this feedback and reflection process: interviews and a videoask³ inquiry. The following team members were interviewed in a relaxed, semi-structured style. The interviewees were:

Peter Harrison	ThinkPlace lead
Cass Patel	ThinkPlace designer
Kataraina Davis	Māori design lead
Riki Nofu'akifolau	Tongan design lead
Annie Ualesi Samoan	Samoan design lead
Emma Solomon	Ministry of Health, Portfolio Manager
Kimberley Sanerivi	Ministry of Health, Portfolio Manager

The interview was reflective in nature. The aim was for the team members to reflect on how the initiative is progressing, describe some of the effective aspects of the initiative to date and consider some of the challenges.

The interviews were focused on the following four key milestones from Phase One:

1. Establishing the core design teams

This milestone involved not only contracting in the design leads, but then having the design leads assemble their teams to lead the community work.

2. Connecting with the sector

This process was about meeting others who have been working in the sector including renown experts, DHBs, health professionals, academics and other government agencies. Some of these meetings were formal in-person or online hui while many were informal, individual meetings with various team members.

3. Creating a new way of working

There was acknowledgment that this way of working deeply with three ethnic groups was different for us all. Some of these differences included the types of research questions we were asking, the way team members were being contracted and the development of new frameworks. The initiative was designed to bring a fresh approach via the communities, so “creating the new” has been a mantra of the project.

4. Setting up the discovery methods

This was the process of creating ways to engage with the families and communities via hui, talanoa and individual conversations. The discovery process was the way the teams were gaining new insights that will then be used to co-design community prototypes in Phase Two.

³Videoask is a research tool by Typeform. It's a way to collect information by having the researcher ask a question in video form. Participants can reply with a video, a voice recording or a text response. This was used in lieu of face to face interviews for each extended design team member. It was useful to keep the project expenses down and it meant the team could respond in their own time.

For each milestone area, the interviewees remarked on what worked well and what could have been better. The idea being that we could pivot on anything that needed improving going forward and pass on the learnings to the Ministry for future co-design initiatives. It was also a time to ponder, deepen our practices and strengthen our ideas as we reflected together.

In addition to the seven interviews, Mondy recorded a videoask and distributed the link to the wider co-design teams. The teams were able to respond with short video clips, audio tracks or written messages. These three broad questions were asked of the teams:

1. What is the most important thing you've learned so far about the rheumatic fever co-design initiative?
2. If you could do something different with this co-design initiative, what would that be?
3. At this point, what would you like the Ministry of Health to understand about this co-design initiative?

In total, there were ten responders to the videoask questions.

A note about the writing of the report. Under the headings of "What worked well" and "What was challenging" there are bullet point lists that are summarised from the participants. Also, the quotes are from the interviews, but they have been edited for readability in context, and occasionally amalgamated to reflect two or three similar statements. The quotes are anonymised.

Establishing the core design teams

In the beginning, three ethnic-specific core design teams were established. Each team has a lead, along with community, design and research experts from a range of speciality disciplines.

Māori design team

Kataraina Davis (lead)
Te Amohanga Rangihau
Matthew Mullany
Paora Davis
Graham Tipene
Cara Ryan
Jono Cole

Samoaan design team

Annie Ualesi (lead)
Dr Marion Muliaumaseali'i
Louisa Ryan
Toleaoa Alfred Schuster
Sam Lafolua

Tongan design team

Riki Nofu'akifolau (lead)
Dr Janet Tupou
Tapuvakai Vea
Reverend Ifalame Teisi
Andrew Wolfgramm

Although ThinkPlace is the agency contracted to lead the overall work, the design leads had mandate to hire their supporting teams. Maurea Consulting is the official partner of ThinkPlace, and they lead the Māori design work.

The way the teams have been contracted represents an innovative approach. The Māori team have been contracted via Maurea Consulting. In contrast, the Pasifika teams are independent practitioners, so ThinkPlace takes responsibility for the contract administration of the Samoaan and Tongan design teams. Every person in the Māori, Samoaan and Tongan design teams is engaged via a monthly retainer that allows the team members to carry time between weeks and months.

Whakawhanaungatanga has been of core importance to establishing the teams. Guided primarily by Maurea's tikanga, given their status as tangata whenua, the emphasis has been on building trust and learning about each other's unique culture and gifts. There has been significant time spent getting to know each team member and building trust; we explored where everyone comes from, what they believe, what they want to achieve for their communities, and what they want and need to learn. This has been unique, as many projects purport to work in this way but don't take the time to do it in practice.

KEY ACTIVITIES IN ESTABLISHING THE DESIGN TEAMS

- The core project team initially consisted of nine people: the three design leads, four ThinkPlace team members, and two Ministry of Health team members. For the first few months, there were fortnightly core design team meetings and fortnightly meetings with the leadership group (design leads plus ThinkPlace leads). These meetings allowed time to build trust with each other, speak freely about fears and challenges, and deepen the team's general knowledge of rheumatic fever and the key things that keep the disease in place in Tāmaki Makaurau.
- Through the early months of 2021, the ethnic-specific design teams were established. Each design lead identified and invited 3-4 additional team members to join their ethnic-specific teams. The onboarding process took place between May and August 2021.
- In July 2021, once most of the wider team was in place, everyone gathered at Manukau Institute of Technology in Ōtara to invest time in whanaungatanga, align on the initiative aims and structure, and base our work on an understanding of Te Tiriti Waitangi and te ao Māori.

"Forming the relationships was a really big part for me because we were going to work with each other for such a long time."

"We are learning and doing from our own cultural values space."

WHAT WORKED WELL

- The level of trust that was built from the very beginning started us off in a good place
- Finding people to work on the teams who have shared values and shared cultural values
- Having the time and space for relationship and trust-building by having all team meetings begin with karakia and plenty of time for whanaungatanga
- We got to learn who we are as people – sparking, connecting, aligning our values
- Having time to develop our personal networks and connections
- Ministry support and buy-in and trust for the methods
- Supporting each other and building our skills and confidence
- The autonomy and trust from ThinkPlace to do things in the way the design teams needed to work in their cultural methods
- Putting relationships at the forefront
- The diversity of skills in the design teams; having a mix from varied backgrounds and specialities that aren't necessarily in design training
- The design teams found their own confidence by listening to each other and learning from one another
- Approaching the work with humility
- Setting up strong tikanga for our ways of working

WHAT WAS CHALLENGING

- Not backing our capabilities, being worried about not having the right capabilities, perceived lack of capability or fear of not doing it “right,” and/or devaluing each other’s skills at times
- Trying to find the right mix of skills/capabilities for each team
- Having differences in and across the teams caused some disharmony
- When skills and capability were held rather than shared with others
- The contracting process was slow, both between the Ministry and ThinkPlace and with the design teams because the contracting required flexibility in outlining the ways of working – we had to be emergent in our style, which can be challenging for contract terms
- There was a steep learning curve for understanding the complex nature of rheumatic fever
- It was slow to get the initiative moving in the beginning, and there was pressure to move things within the Ministry at pace – it was in tension with taking time to build strong relationships that are essential for success
- As the extended design teams came on board, the relationships became more distant than the initial core team of fewer people
- Finding people within the cultural groups with the specific design skills required
- Finding the people with the right mix of skills **and** a robust understanding of their own culture
- Having the title of “team leader” can cause challenges for the teams and the communities due to hierarchical cultural structures
- Part-time workforce on the teams meant it was hard to get together sometimes, and this also meant that some team members went over and above their contracted hours
- Needing more design capability in communities for co-design initiatives
- There were some initial questions externally about why there were only three ethnic groups chosen for the co-design initiative (and why those specific ones)

“I was worried that if we can’t find [the culturally appropriate] person to fill the role, what is the plan B?”

“We need to value different types of capability in these co-design projects.”

“This project is different to others I’ve worked on before, so we’re learning as we go.”

Connecting with the sector

The design teams had dozens of meetings and informal/impromptu conversations with stakeholders from across the communities, the health system and social support system to build connections and enhance understanding. This included conversations with academics, physicians, public health researchers, families/whānau with rheumatic fever, nurses, PHOs, DHBs and researchers from the Office of the Prime Minister's Chief Science Advisor (OPMCSA). Learning was shared at the fortnightly check ins.

KEY ACTIVITIES INVOLVED IN CONNECTING WITH THE SECTOR⁴

- Key stakeholder mapping workshop with the short-term high-impact DHB groups
- Face to face meetings with preeminent academics at Otago and Auckland Universities
- Meeting various researchers with a special interest in health equity or rheumatic fever specific to Māori and Pacific communities
- Meeting with other physicians with a long-standing stake in rheumatic fever activities
- A meet and greet hui with the Pū Manawa group, sharing our approach with Pū Manawa and hearing about their work
- Being looped into discussions with the OPMCSA research group who are conducting a review of evidence about rheumatic fever

“After about seven weeks on the RF project, I realised how much I appreciated the people who have been there a long time and they’re used to the same faces, and they already knew who was who. But I realised I can bring a new energy, and I can ask them questions and refresh their thinking. I can also bring a part of myself and my community into the RF project and the sector.”

“Coming into the Ministry of Health, having coffee ready and welcoming us in – that’s manaakitanga, and it makes me feel like I belong in there.”

⁴We have been asked not to “name drop” those clinicians and researchers we have connected with, as many of the connections are also personal relationships. We have respected that request in this report.

WHAT WORKED WELL

- Many of the people working in this area were already known to the teams so that made it easy, and personal networks in general were already strong across the sector and in Tāmaki Makaurau
- Having great networks and using strong tikanga meant it got us “into rooms” we might not normally have had access to
- There were already good relationships with many sector players such as with DHBs and Healthy Homes
- Sharing what we’re doing freely with other groups
- Coming into the sector and being humble toward other experts and professionals
- Adopting a stance of relentless optimism and positivity
- Giving time to tikanga and connecting in a very Māori way
- Connecting with Pū Manawa and having a session with them
- Ministry of Health showing manaaki for the teams, like having coffee and food ready
- The walkthroughs to share our work, being open with our approach
- The sector has been really open and excited about the co-design initiative

“It was a bit of a curveball when the Pū Manawa group came along as they were quite an established group already. But quickly the relationships were built, and we got to know each other and understand what we’re all trying to achieve.”

WHAT WAS CHALLENGING

- Meeting with people who were challenging to us personally or about the co-design initiative in general, such as with people who don’t believe in the co-design methods
- It was hard when it was so new and starting out cold for some people
- People were scrutinising Budget 19 and wondering why funding was given to a co-design process, so that had to be managed
- It took a while to build some of the relationships and it felt “forced” sometimes
- Tackling the cynicism
- There is a lot of hurt and trauma in the community around RF to be worked through
- Team members who don’t feel like they are natural networkers

“We had to put our own personal capital on the line to say that ‘this time it’s going to be different.’”

“It’s important for key parts of the sector that they feel and see the tikanga-led approach.”

Creating a new way of working

From the beginning, there has been an emphasis on devolving the leadership from ThinkPlace and the Ministry to the ethnic-specific group leads. It was pointed out early on by the design teams that there are in fact four ethnic ways of working: Māori, Samoan, Tongan and Pākehā/Palagi. Although ThinkPlace has some design frameworks, it was the intention that that the groups would utilise their own culture and design models to carry out the work in their communities.

This way of working has not been without its tensions and growing pains along the way. There are different styles of leadership being employed by each team. There are various gender and age dynamics within and across the teams that each group has had to navigate. For example, the Tongan team pointed out that Tonga is a kingdom, which means there is a system of hierarchy at play. Cultural nuances of who is a leader and how that plays out in establishing the teams has been expertly navigated.

It was pointed out that this way of working is perhaps not “new” as this section suggests. Rather this initiative has allowed for people to work in the ways they are already accustomed to, and the ways of their cultures.

EXAMPLE OF KEY ACTIVITIES FOR NEW WAYS OF WORKING

- Paying associates competitive rates on a retainer type model
- Providing verbal internal report sessions to the Ministry, rather than written reports alone
- Karakia or prayer to open and close team meetings
- Collective leadership and decision making through fortnightly meetings with initiative lead and design leads
- Utilising the mix of methods of system change, co-design, and ethnic-specific groups working deeply in their cultural practices while also working across the groups
- Learning about the concept of polycultural capital and other ethnic-specific frameworks that support indigenous design

"There are so many levels of letting go from everyone who is involved."

"The concepts and philosophy were not new, but we wanted to draw up our cultural frameworks and leave them for others to use."

"Having more Māori leadership throughout is key to successful projects like this. It's a protective factor."

WHAT WORKED WELL

- Exploring polycultural capital as a way of skill-building, explaining things, expressing cultural frameworks in a structured way
- Building up everyone's tikanga together as guided by the Māori team
- Trust-based commissioning is at play here; the Ministry is trusting ThinkPlace and ThinkPlace is in turn trusting the design leads to run their activities in the way they know best – the communities are also trusted as experts in their own health
- The partnership, the collegiality, the way of connecting and taking the time to build trust
- Having the Ministry be more hands-on (versus being above)
- Allowing the space for the cultural ways of working to be more widely embraced
- Having the initiative's tikanga set up in the beginning and adhered to
- Having the mandate and autonomy to do something new and different, working in the way we need to
- Having the trust to work in our own cultural ways
- Being able to authentically work in indigenous practice
- Having the opportunity to deepen practice for Tongan and Samoan cultures rather than lumping Pasifika together (which is a more common practice across government)
- Working with those with mana whenua status
- Paying associates on a retainer model and remunerated at a rate they are worth
- The closeness of the teams makes it feel like a family
- The initiative has created a safe way of working and to be yourself

"It was new for us working online because of Covid, and it built trust in a way we didn't expect – it made people feel more comfortable somehow."

"This is indigeneity in practice."

"We're all figuring this out together."

"I know it's hard for the Ministry to let go of the reins and I'm thankful for that, but that means we have to come through with the goods."

WHAT WAS CHALLENGING

- Because this approach is trust-based, when trust gets eroded, we need to stop and build it up again
- Disappointing that we couldn't do as many face-to-face meetings because of Covid
- Nervousness about stepping on toes or unknowingly offend people
- Hearing second hand if someone is having challenges with the way of working rather than hearing directly (e.g., via ThinkPlace as a funnel)
- Hard to initially find co-design frameworks with a Pasifika flavour – there were more Māori examples to draw on, but fewer Pasifika ones
- Adjusting to contracting/consulting for some of the team members, especially part-time
- Cynicism by some people about co-design in general or thinking we're going to do it badly, or worry from people who have seen it done badly and tarring us with that same brush
- Feeling like we're being measured against traditional frameworks
- When it felt like the Ministry/ThinkPlace had too much power over the initiative
- Having to defend the initiative to external people
- People working out of their contracted hours and the perception that they can't bill for extra hours
- 'Norming and forming' on the go means you need a lot of time for trust-building and testing things out

"E raka te matau, e raka te mauī; the ability to work in both worlds and looking right and left to understand both sides and how they work."

"It's not new in that we're drawing on cultural practice, but what's new is the way we're piecing it all together."

"The project works well when we have synergies and power levelling and help each other see what we're all good at."

"I absolutely love this way of working. I've never worked on a true co-design project before. This is the first time I've experienced true transfer of power."

"You can think of this project as a collection of individuals, not as a project via one agency (ThinkPlace)."

Setting up the discovery methods

Each workstream developed an approach to how they would engage with their communities to explore their experiences of rheumatic fever. The Covid pandemic lockdowns and restrictions disrupted the ability to carry out face-to-face activities, so the teams had a significant pivot to online engagements.

EXAMPLE OF KEY ACTIVITIES LEADING INTO DISCOVERY

- MoH sharing of data, literature, information and ongoing monitoring reports with the wider teams
- Background literature prepared by ThinkPlace and distributed to teams
- Literature scan by OPMCSA, summarised by ThinkPlace
- Establishing ethical best practice for each team
- Development of data collection processes for each team

"If you're not feeling a bit uncomfortable doing this kind of work, you're probably not in the right space."

"I have a lot of faith in the people who are running the project and we have the right people and we're on the right track."

"We need to have community buy-in – the community needs to be singing our song, actually building the song to sing."

WHAT WORKED WELL

- Distributed leadership and collective decision making
- The extra time due to Covid delays meant the teams had more time to build community/whānau relationships which ultimately helped with rapport
- The ability to meet people online meant that it strengthened the rapport once people were able to meet face-to-face – the initial Zoom meetings took the heat out of an initial face-to-face encounter with the design teams. In essence, it created a healthy distance that seemed to help build rapport in the long run
- Covid restrictions meant we could think more widely about ways to get hold of people – it improved efficiency with our time and it meant connecting with people was easier and quicker
- Continuing to share our learning and reflections, both internally and externally
- Having strong, existing relationships with ethnic communities
- ThinkPlace paying the koha on time was really important for the discovery process
- The amount of koha that was given and the food parcels really warmed hearts and made people want to be part of the process
- The three-year timeframe is critical to do this well because it takes time to build the right relationships
- Everyone pivoted as much as they needed to
- Working during Covid meant people could open up about their experiences of RF over Zoom more than they might have in person

“Some people compare this project to other co-designs, but some of those projects weren’t actual co-design projects.”

“It was easy and seamless for us within our communities, except for some external white noise that caused some dramas.”

“We need to not avoid conflict but learn how to deal with it on this project.”

WHAT WAS CHALLENGING

- Not everything was done in the spirit of collegiality, and this was hard for the process when knowledge wasn't shared
- It took a long time to get to this phase and this was hard to manage with external scrutiny of the initiative
- Time delays due to Covid caused extra stress for initiative timelines and reporting
- Not all team members enjoyed meeting people online or felt it was culturally appropriate
- Communicating to the communities who the design teams were, because the teams were essentially consultant teams hired by ThinkPlace, but this was confusing to communities as the design teams didn't have their own brand, per se
- Explaining the Western notion of "consultants" to the community, especially in relation to health topics
- It's hard within a Western model to demonstrate the value of the relationship building phase required to do well in the discovery phase
- Being compared to other projects that weren't true co-design
- Challenges with some inter-team relationship dynamics at times caused tension and impacted negatively on certain team members
- The regular team meetings fizzled out somewhat during this period which impacted on the relationships
- Communities have had no say in their wellbeing historically, which makes it hard to engage them sometimes
- Ensuring methods of discovery are aligned and there is flexibility for ways of doing research and discovery, such as using rongoā for Māori methods
- A clash of perspectives between a Western project management approach versus a culturally led approach which has its own timelines and things get stalled for legitimate reasons

"Covid actually increased the accessibility to families."

"Everyone pivoted and got on with it because everyone felt the weight of this work."

"Discovery isn't just a process of talking to 10 or so people. It's about networking and building relationships and it takes time. It's about doing discovery in a relationship-based way (as opposed to traditional design research processes)."

Summary of findings

The key things we're learning as the initiative takes shape are summarised here.

Time

Nearly everyone in this initiative has commented that the amount of time it takes to build trust and relationships to do true co-design cannot be underestimated. Time is needed to build trust within the teams and with the sector professionals as well as with the families who have experienced rheumatic fever. There is no substitute for this relationship building time. The team understands that this presents challenges for contracts and initiative deadlines, but time is most certainly one of the most critical success factors for this initiative. It has taken many years for rheumatic fever to take hold in the communities and it will take time to reach the families in the ways that will have the biggest impact. New ways of working are being developed as we go – time is needed to adjust, build, reflect and unlock what is working for the communities.

Trust

Trust is slowly being built over time. Part of this process is acknowledging that communities have been very hurt; not only by rheumatic fever but by co-design or other community initiatives that haven't gone so well. Because the design teams have personal capital on the line with their communities, the initiative relies on taking the time to strengthen relationships and forge new ones.

Trust has also been a crucial factor in working together as a big design team; we each bring our own skills, knowledge, experience and cultural expertise.

Being vulnerable and open has been a key tenet of the approach to date. Many of the team members talked about the number of tears that have been shed together as we laid the foundations of trust – it's been an emotional and personal journey for each of us. If for any reason the sense of trust was broken, the timelines were disrupted, as it was fundamental to rebuild again.

People

One interviewee said, *"Even when you've got the right conditions you still need the right people."* There has been acknowledgement that having the right people on board is key to success. Who the "right" people are for this co-design initiative has been described as those who have a passion for their communities and are culturally connected and grounded in their practices/tikanga.

The initiative has relied on a wide skillset, recognising the unique gifts of each team member, and strategically chosen by the design leads. Capability has been built along the way, with ThinkPlace taking care not to be the agency holding the design methods too tightly. New frameworks have been built, new ways of doing things are emerging, and everyone is learning as we go. This spirit of openness to trying something different infuses the initiative and having people with this attitude of bravery has been at the core. That essential bravery has been demonstrated by the Ministry team, ThinkPlace, the design teams and the whānau/communities.

Apprehension

The significance of the initiative has weighed heavily on most team members at one point or another, for various reasons. For the design teams, they are deeply invested in their own communities and are close to the whānau who have suffered from rheumatic fever or other health inequities. For the design leads, there are professional as well as personal reputations at stake. For ThinkPlace, there is a keen sense of gravity and responsibility to do co-design well, and QA the process whilst respecting the mana of the teams. In addition, there is the responsibility to spend the budget wisely, pay equitably, support the government's goals and report back on the initiative's efficacy. The Ministry team also has a lot to be accountable for, both to government and the wider sector.

Power levelling and devolving leadership

True co-design involves redistribution of power and leadership. It's hard to achieve – timelines and limited budgets are often major hurdles to co-designing well. For this initiative, it was noted that, *"The duration and budget illuminate the funder's intent."* For this co-design initiative, the Ministry has provided a budget and timeframe that support a true co-design process. The design teams have taken notice of that and hence feel the heightened need to do this well and to be accountable.

Some interviewees noted the shift in power with remarks like, *"I don't feel like I'm waiting for the palagi/pākehā to tell me what to do."* The fact that it's been easy to access what is required, such as on-time and sufficient koha for participants, has made a world of difference to working in true, equitable partnership. The teams have been given the support and mandate to lead their emerging ways of working in their culturally led practices; this feels like a true first for many team members.

Final thoughts and an overall team reflection

A draft of this report was shared with the teams, and during an all-team hui, people shared their final thoughts on the process to date. **Here are their words to leave us with...**

"I'd love more sharing amongst the teams but that can be done less formally, normalise working between the teams more."

"We need to be constantly checking in with the families to ensure we are capturing and checking our biases as well."

"We've had such as massive barrier with Covid and still managed to get this done."

"The contracting of the three groups having the power to own the process and it's been really freeing."

"There is power in the collective."

"It's been nice that we were gentle with each other when we got sick and needed to rest."

"Sometimes the word 'evaluation' means that our kaupapa gets shut down."

"The Samoan specific nature of it is quite a new way of thinking, which means having to learn more about Samoan concepts and ways to analyse in these frameworks."

"For me, I whakapapa for all Tonga, Samoan and Māori and I love to hear all that's being shared by everyone."

"We've been able to identify expertise that sits in other teams that we are able to reach out to, and where opportunities crossover to the work of the other teams which may provide opportunities to come together – there's power in the collective."

"This process of reflection is critical and so is the way we've been grouped in our special ethnic groups."

"Traditional Samoan practices and the dynamic practices of the younger Samoan generation are cropping up – how do we navigate that?"

"We need to meet all together with the three groups to unlock the synergies and explore the similarities – it's encouraging to hear we're on the right track."

"Having a fresh set of eyes really helps."

"Getting together helps us refine our thinking."

"I'd like to spend more time together as a whole group."

"The outcome we have now speaks to the process."



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