



PHASE 3 FINAL REPORT

A Tale of Two Systems

A Tale of Two Systems. Phase 3 Report:

Samoa Team, Rheumatic Fever Co-Design Initiative.

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EXECUTIVE SUMMARY
THE FUTURE IS HERE

Measina

A **measina** is a treasure that represents something of cultural value and significance in various cultures. In the context of the Samoan culture, a measina can be in the form of a siapo (a fine cloth), an ietoga (fine mat) or gagana (language).

In Fa'asamoa (the Samoan way), a cultural measina is gifted by a host to guests in recognition and acknowledgement of the relationship, support and contribution to a special event or gathering that has culminated in a successful outcome.

In the context of this report, the measina is not a siapo or a fine mat, but rather the **insights and experiences** of our Samoan community and the various stakeholders who have contributed and donated their valuable wisdom and knowledge to inform this work.

As the project team, our touchstone throughout this work has been our Samoan alagaupu (proverb):

“E ui ina sui faiga, ae tumau pea fa’avae. Though the approaches may change, the foundations remain the same.”

This Samoan proverb encompasses the concept that our Fa'asamoa practices may change but our foundations of it endure throughout time.

E ui ina sui faiga, ae tumau pea fa’avae.

Though the approaches may change, the foundations remain the same.

We present this measina to you, the reader, on behalf of our Samoan families, community and all stakeholders who have been involved in this journey in the hope that you will treasure and value this measina as we have.

Soifua ma ia manuia.

Samoa Team

Introduction

Overview

The impact of rheumatic fever and rheumatic heart disease on Samoans is significant. And, yet, our experiences and knowledge are not valued within the rheumatic fever prevention and management system.

The Rheumatic Fever Co-Design Initiative has signalled hope for Samoans who are impacted by rheumatic fever, creating a belief that the system can change, and that Samoans can influence that change.

The Samoa team has been able to focus solely on the experiences and Fa'asamoa solutions of Samoan families and Samoan practitioners and professionals. In a system that often treats Pacific Peoples as a homogeneous group, this has been significant in enabling a different approach.

By leveraging Samoan relational and cultural capital, we have been able to convene a network of people with lived expertise, clinical knowledge, system knowledge and leadership expertise. This network is energised and have hope that the system can change.

By placing Samoan families and their aspirations at the centre of the work we

have been able to identify and test 'new to the system' innovations that we collectively believe will provide the best healthcare and aim to contribute to reducing rates of rheumatic fever among Samoan families.

This Samoa-led approach has been critical in getting to the depth of insight, opportunity and change that has been achieved through this initiative.

The co-design initiative has demonstrated the change that Samoans can inspire and lead when given the opportunity.

Everything has been co-designed. We have co-discovered, co-planned, co-decided, co-tested, and co-implemented together with families and other system partners. The prototypes have been developed collectively with endorsement from Samoan families. We are confident they represent the collective

voice and demand for change Samoan families and communities expect from the rheumatic fever prevention and management system.

Our invitation to you

As this phase of the journey comes to an end, we reflect on how the co-design initiative has demonstrated the change that Samoans can inspire and lead when given the opportunity. Collectively, we need to continue working in this way if we want our future generations to be freed from the impacts of rheumatic fever.

While an energy has been created among Samoans and non-Samoans who have engaged with this work, there is a risk of the system returning to the status quo. Samoans and allies have put their hands up to champion change and are moving together. Accountability now sits with the whole of the health system to intentionally support this groundswell through the embedding of these innovations. The seeds have been sown and the sprouts are growing. You have the power to grow these sprouts into a flourishing plantation.

This Phase 3 report titled **A Tale of Two Systems**¹ aims to provide a comprehensive summary of the prototype areas that Samoa Team have endeavoured to embed across the New Zealand health system as part of the co-design initiative.

The prototypes were created by Samoans to inspire change across the health system. Their purpose is to nudge the system away from the status quo and to give a sense of what can be possible.

We invite you to sit with the knowledge, stories and recommendations included within this report and to continue creating the space for Samoan perspectives to guide our actions in the rheumatic fever prevention and management space.

You have the ability to influence change within your role, within your organisation, and across the wider system. We offer you the tools, resources and learning to equip you to action the change.



1. A Tale of Two Systems refers to the key discovery that was identified during Phase 1 that the journeys of Samoans across the rheumatic fever ecosystem tell a compelling story that there two systems that Samoans are navigating – the Fa’asamoa holistic system of wellbeing and the formal New Zealand health system.
<https://www.tewhatuora.govt.nz/publications/rheumatic-fever-co-design-initiative/#samoa-team-discovery-report-phase-1>

THE FUTURE IS HERE

Our Key Reflections

In this section, eight reflections have been highlighted that define how the work has been undertaken and what we have learned about creating change within the rheumatic fever prevention and management system. We have titled this section 'The future is here'. This initiative has showcased what is possible when power is shared and provides a vision of what the new future looks like. We're not talking about it or imagining it, we are putting it into practice – the future is here.

Reflection 1: The work was centred on families, their experiences and their stories

We have intentionally put families at the centre of this work. We acknowledged that we needed to earn and grow trust with families and that the stories of families are theirs and are precious. Our accountability to families ensures that their voice remains strong and authentic throughout, and that what is included in this report is consistent with their expectations.

Critically, families have determined where we focused in terms of new solutions. Early assumptions about where the opportunities lay were put aside as families guided us

towards the interventions that would have the greatest impact on their experiences and wellbeing. Our families are the experts and we honour their expertise.

In practical terms, being family-centred has required us to curate safe spaces to share with each other. The Ōtara Scorpions Rugby League Club has been a safe home base for our engagement with families: we shared meals, listened as families shared their stories, and we supported families to design their Fa'asamoa solutions.

This video tells the story of partnership with families and the Ōtara Scorpions Rugby League Club:

▶▶ [Video case study 1 – Ōtara Scorpions](#)



Reflection 2: Relational capital is the critical ingredient for engaging Samoan families

Through this work we have given greater visibility to the all-important nature of relational capital and its ability to create safe, comfortable and beneficial engagement with Samoan families.

From our Samoan worldview, relational capital is Mana. Mana is all encompassing and extends to cultural, social, spiritual, political and clinical knowledge, perspective and practice.

In Fa'asamoa, we value, honour and recognise the Mana that each individual brings to bear when we build and initiate new relationships or enhance and sustain existing relationships.

It is in the practice of honouring Mana that deep trust, familiarity and understanding is formed and this provides the critical base to work together towards shared aspirations and outcomes.

Our work has shown that it is common for two to four layers of engagement to be necessary to create the conditions for two different parties to safely engage with each other. We also learned that this necessary and valuable relational capital that is held by

Samoans is rarely valued explicitly or implicitly by the system, and Samoans are often doing this vital work without acknowledgement or recognition, despite the resulting organisational and community benefits.

This co-design initiative has role modelled what it looks like to acknowledge the capital that Samoans contribute and the results are evident in the depth and uniqueness of the prototypes that were developed.

During Phase 2, we visualised the four-layer engagement process that our team have utilised when engaging with community and the sector (see **Diagram 1** on the following page).

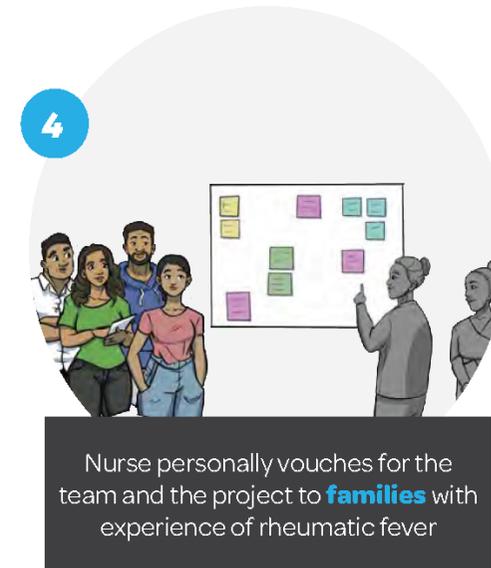
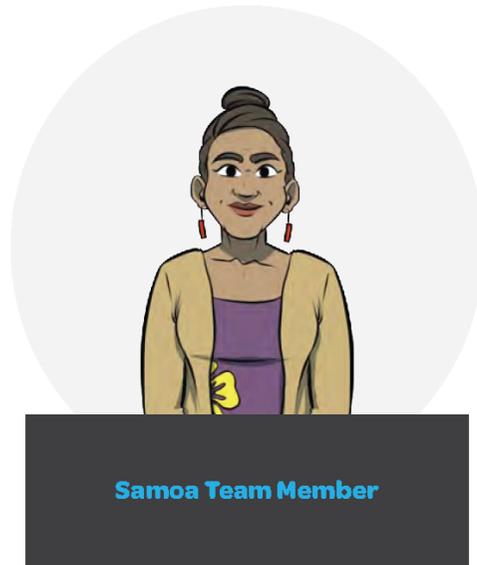
In addition, we challenged the ‘hard to reach’ narrative that is commonly believed across the system. We saw that Samoan families, and young Samoan men in particular, are not hard to reach; they just need to be engaged in ways that work for them. By expending our own social, relational and cultural capital and by working through the layers of engagement identified above, we were able to reach, create connections with, and safely engage with Samoan families in ways that worked for them and that created a positive experience for them.

This video tells the story of the prototype designed by young Samoans:

▶▶ [Video case study 2 – Youth Talanoa night](#)



Diagram 1: Four Layer Engagement



Reflection 3: Soālaupule is a Samoan response to addressing power imbalances

We have observed a rheumatic fever and prevention system that is characterised by deeply engrained power imbalances. These power imbalances reduce the agency of Samoan families and make it impossible for families to have a positive and empowered experience through their rheumatic fever management journey.

By way of example, we heard from families who have been heavily impacted by rheumatic fever and, despite countless hours of health-system engagement, didn't understand the basics of this serious but preventable autoimmune disease. One of the key issues amongst our people was that they could not connect a sore throat to a potentially damaged heart. We also heard from non-Samoan clinicians who are aware of the power imbalances but lack the confidence or knowledge to address it. Our response to this challenge was to look for inspiration within established Samoan knowledge.

We came back to the concept of Soālaupule: a uniquely Samoan approach that acknowledges the authority or mandate that

each individual or party holds. Soālaupule acts as a power-leveller by acknowledging the contribution and value of everyone involved, creating a space of equal standing. We worked with Samoan families and practitioners to conceptualise how Soālaupule could be applied practically in a rheumatic fever context and tested this. The results were clear: Soālaupule practices foster meaningful conversations, shared decision making, and provides the safety and comfort for non-Samoan practitioners to engage with Samoan families in ways that are consistent with Samoan practices.

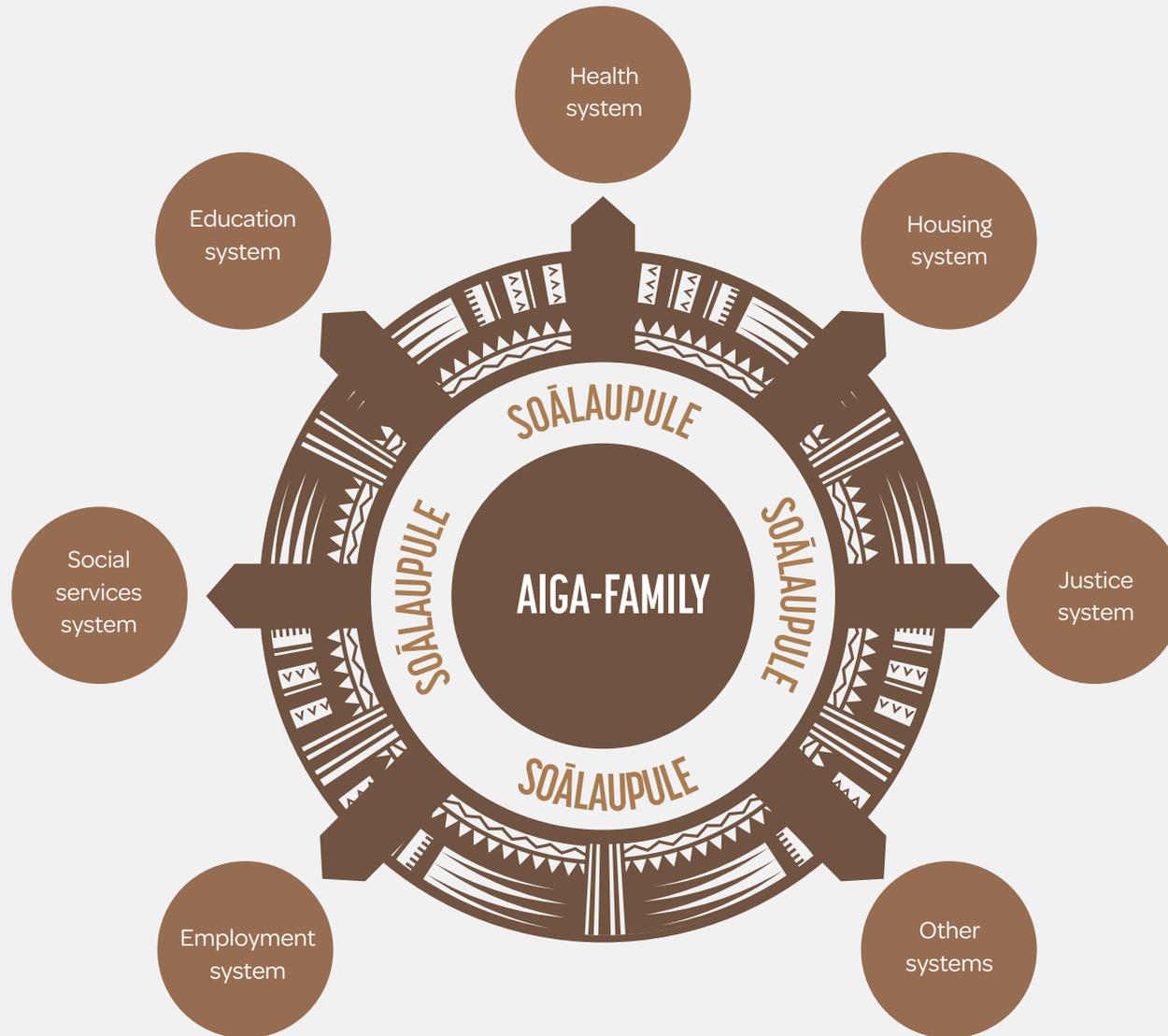
This video tells the story of Soālaupule and its application in health settings and practice:

▶▶ [Video case study 3 – Soālaupule capability build](#)



The potential for Soālaupule to transform the way Samoan families are engaged with across multiple systems / sectors is significant (See **Diagram 2** on the following page).

Diagram 2: Soālaupule has significant transformative potential across multiple systems and sectors.



Reflection 4: Demonstrating how established knowledge can be valued within rheumatic fever contexts

Soālaupule is one example of established Samoan knowledge that has been a foundation of our work throughout this initiative. The knowledge is not new; it has been passed down from generation to generation and is core to how we, as Samoans, operate.

What is new, however, is applying this established knowledge in an intentional and mindful way within the rheumatic fever prevention and management system. While there are individual practitioners who will engage with Samoan families in ways that are consistent with Soālaupule, this practice is not widely undertaken. We reflect on the continual drive for 'new innovations' when what might be needed most is something that is not new, but that hasn't been brought to a specific setting. For this reason, we focused our efforts on testing how Soālaupule could be understood and practiced by health professionals.

**Soālaupule.
The knowledge is not new; it has been passed down from generation to generation and is core to how we, as Samoans, operate.**

Reflection 5: Creating new ways for two systems to work together

We uncovered an important insight during Phase 1 and expressed this as the 'Tale of Two Systems' (see **Diagram 3** on page 17). The left side shows family perceptions of how the system sees and treats them: they are seen as a small and insignificant individual travelling along an all-important process. They are defined by numbers and diagnosis and procedures.

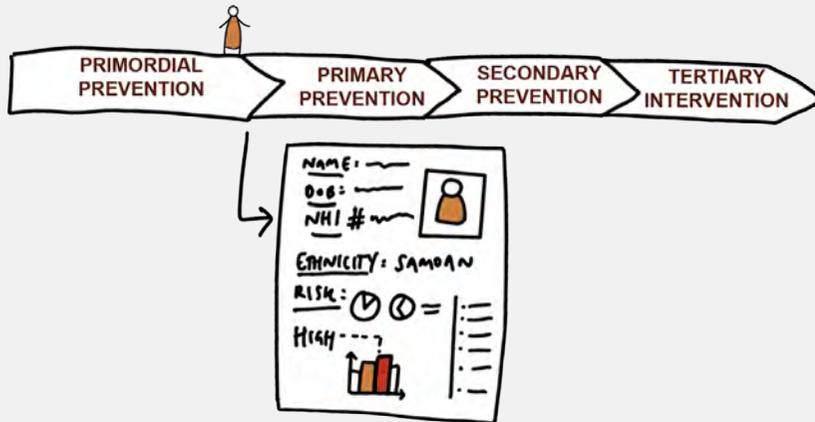
The right side shows how Samoans want the system to see them: not as individuals, but as families connected to culture and community, with many interconnected dimensions to themselves and their health journey (inspired by the Fonofale model).²

The coming together of these two mental models is abrupt and creates unsafe, uncomfortable and unhelpful health experiences for Samoan families.

² Pulotu-Endermann, F.K. (2001). Fonofale Model of Health.

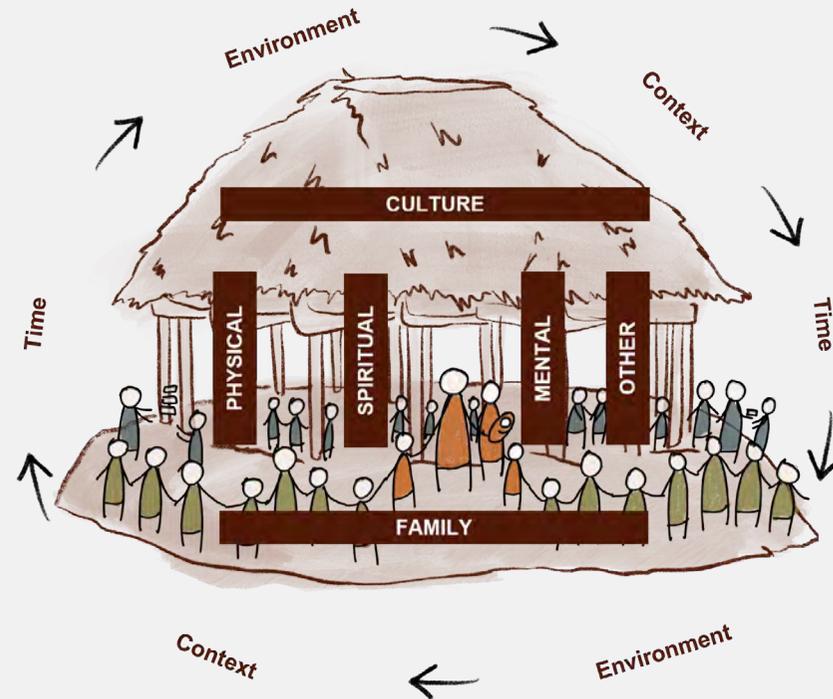
Diagram 3: A tale of two systems

HOW THE SYSTEM SEES ME



Adapted from Fonofale model developed by Fuimaono Karl Pulotu-Endemann

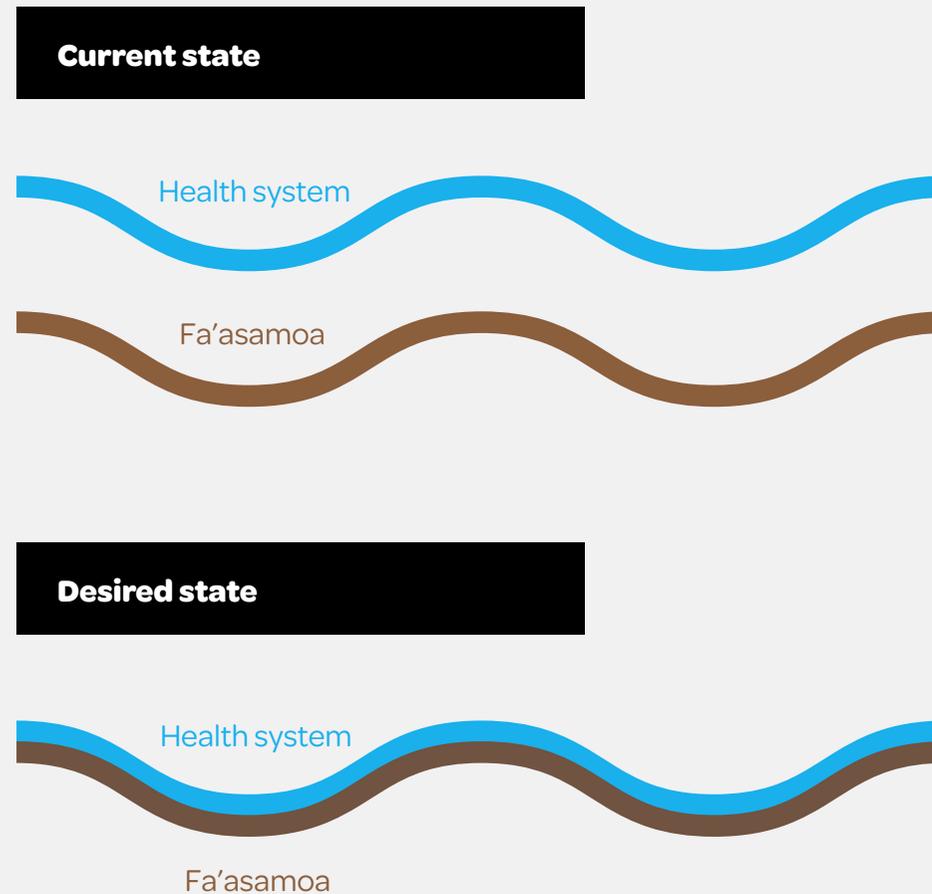
HOW I WANT THE SYSTEM TO SEE ME



A further important discovery was that Samoan practitioners and professionals experienced the same “Tale of Two Systems”. We learned that Samoans working within the system are relentlessly attempting to blend these two systems so that Samoan families get the benefits of both, but without the downsides.

The desired future state is one where the mainstream health system and Fa’asamoa (the Samoa way) run in parallel, mutually supporting each other. It sees Soālaupule as an embedded practice alongside existing practices in the health system, in a way that fosters shared ambition through nuanced approaches (see **Diagram 4**).

Diagram 4: Working towards a future in which Fa’asamoa (the Samoa way) and Soālaupule are embedded practice within the mainstream health system



Reflection 6: Family-centred care is enabled by a community-led and system-building approach.

This initiative has shown that community-led is necessary but not sufficient to create the change that is needed.

The system understands the need for family-centred care but finds it challenging to provide healthcare practice that delivers to that aspiration. In our experience, we have found that supporting community-led solutions in partnership with system stakeholders³ results in family-centred care (see **Diagram 5**). These actions are consistent with Te Mana Ola: The Pacific Health Strategy (in which Soālaupule is identified as a priority area) as they follow the same principles outlined in their Soālaupule Ecosystem Framework.

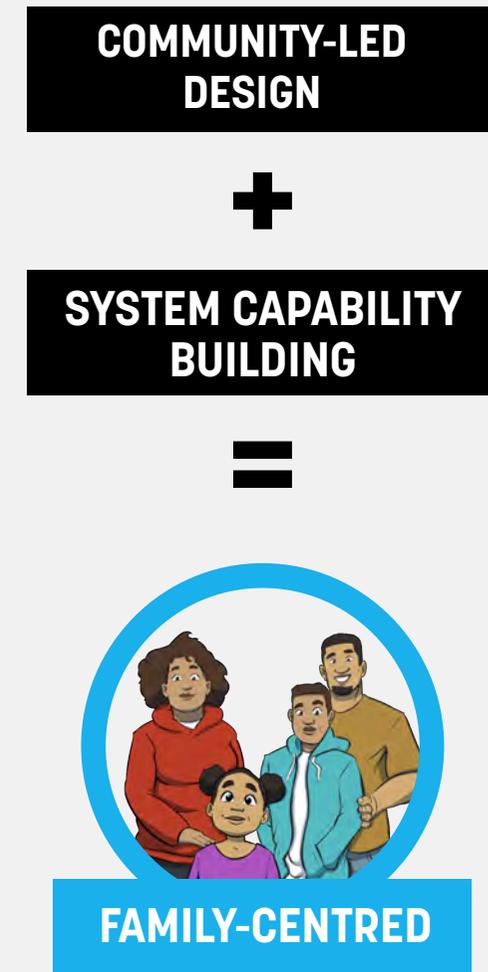
As an example, Samoan families and practitioners designed 'Soālaupule in healthcare practice' as a prototype. Because this prototype was designed by Samoans through their worldview, the prototype focuses on the wellbeing of the family in its entirety, not just the individual.

The prototype was then taken up and supported by the wider community who hold varying positions across the health system. It is these people, who are operating within the system, who have the relationships, knowledge and capability to strengthen the intersection points between the two systems. These individuals must be invested in and supported in order to deliver family-centred outcomes.

By supporting, unleashing and enabling this wider collective of influencers to negotiate the extension and embedding of these community-led solutions across the system, family-centred care becomes systemised in practice.

A community-led and system building approach leads to family-centred care.

Diagram 5: A framework for achieving family-centred care



³ Individuals and organisations that hold mandated power and resources across the health system.

Reflection 7: Build the power sharing foundations to enable community-led prevention innovations

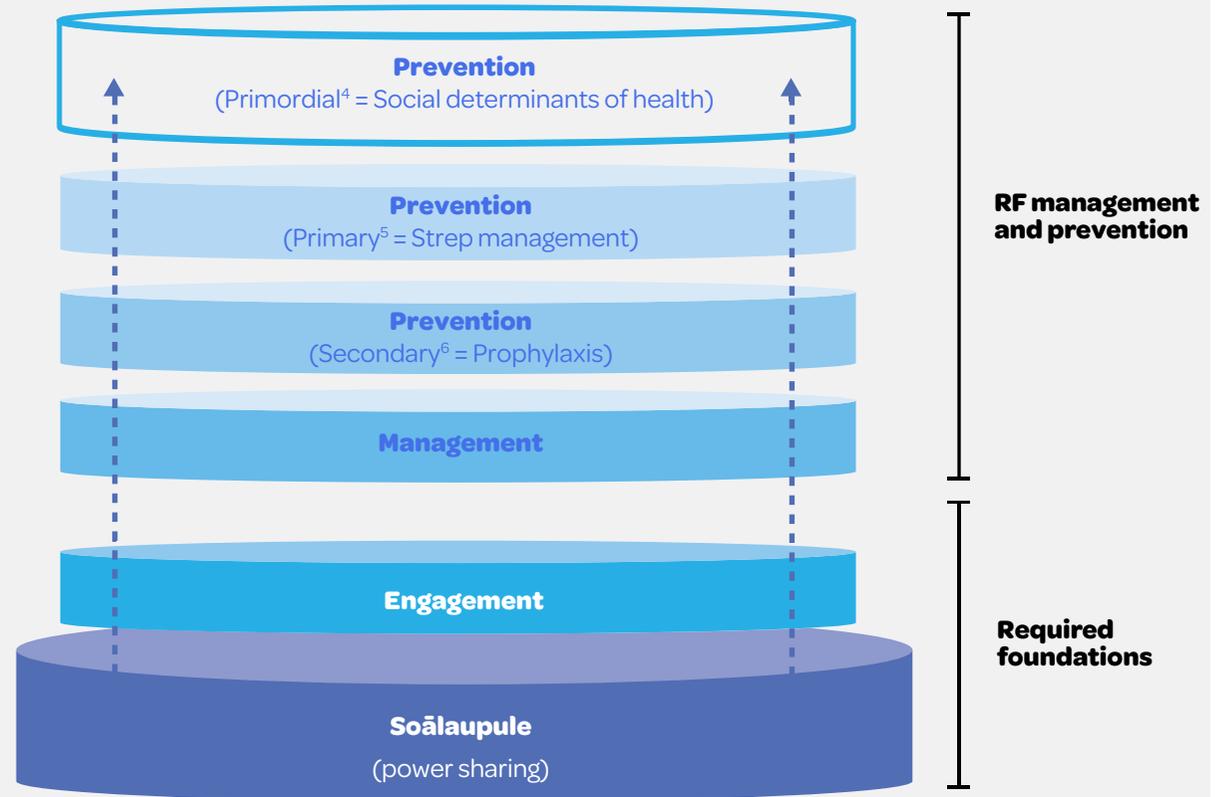
Early on we wondered if the most impactful way to reduce rheumatic fever rates was to disentangle the complexities around complex social determinants of health, such as housing conditions and occupancy. We learned however that base knowledge of rheumatic fever was low and that families wanted a rapid response to the healthcare that they were currently experiencing that was not meeting their immediate need.

As we were using Soālaupule in our engagement with families, it gave them the power to determine the direction of the work. As we progressed, we saw how this starting focus on management and secondary prevention creates the shared foundation to focus on primary prevention, and eventually on primordial prevention. This was due to the high level of buy-in of families and wider community members and system stakeholders as they coalesced around the actions for change.

Diagram 6 shows that by applying the sharing of power we have established the trusted

and firm foundation to, over time, move into solutions that address primary prevention and primordial prevention.

Diagram 6: Framework for managing and preventing rheumatic fever based on a foundation of power sharing



⁴ An example of primordial prevention is ensuring that houses are free of dampness.

⁵ An example of primary prevention is antibiotic treatment of Strep A infection.

⁶ An example of secondary prevention is regular antibiotic treatment to prevent progression to rheumatic heart disease after having experienced rheumatic fever, or as management for those with rheumatic heart disease.

Reflection 8: Samoan families have spoken; it's now time for the system to respond

Families have graciously and generously shared their stories and experiences with us and have inspired new possibilities for the rheumatic fever prevention and management system. Trust and goodwill has been created and strengthened. As a team, we have felt a weight of accountability to families.

As we conclude our role in this journey, we ask you to share in that accountability. If you are reading this report, it is likely that you have an ability to influence change within your role, within your organisation, and across the wider system. Together, we have an accountability to families to create the change they are asking for. Samoan families have spoken, and the system has an accountability to respond positively and decisively to honour those voices.

Table 1 shares some inspiration about how you could influence change.

Table 1: Some ways you can influence change

	<p>You have trust and relational capital with families and are in a position of influence.</p> <p>Incorporate rheumatic fever awareness into your engagements with Samoan families.</p>
Community organisations	<p>There are now suitable tools and a network of competent and caring health professionals to support you to do this.</p> <p>Be open to ways to partner differently with government; the system needs to acknowledge the work you are doing and to recognise it.</p>
Health practitioners	<p>If you are using Soālaupule practices already, keep doing it! And use the tools we've created to talk about why you use Soālaupule practices with colleagues who don't.</p> <p>If you don't use Soālaupule practices already, make the most of the tools we've created and find ways to build power sharing practices into how you engage with Samoan families. We don't expect you to be an expert, we simply ask that you acknowledge that power imbalances exist and be open to the potential ways you can shift that.</p>
Employers of Pacific health / social workforce	<p>Take a moment to reflect on the value that your Pacific workforce are bringing to your organisation, despite it not being recognised.</p> <p>Review job descriptions and organisational structures to ensure that this value is made explicit and situated appropriately within organisational structures to influence decisions, and is recognised through remuneration.</p>
Policy makers / commissioners / funders	<p>Recognise and listen to the Pacific leadership voices that are connected to the community, know what is required and have the energy to drive change. Invest in these people and create a platform for a wider leadership remit.</p> <p>Take learning from this initiative in terms of time, space, and resource for power to be shared and for community-led solutions to be embedded across the system. We won't get different outcomes if we keep operating as we always have.</p>



**METHODOLOGY AND LEARNING
OUR JOURNEY**

Overview of Phases 1 and 2

Phase 1

During Phase 1, we formed the multi-disciplinary Samoa Team, established the foundations for undertaking the work in ways that leveraged the strengths of our Samoan worldview (Fa'asamoa – the Samoan Way), and engaged with Samoan families, practitioners and professionals to understand their experiences with rheumatic fever and rheumatic heart disease.

Detail about the formation of the Samoa Team, and the diverse range of skills and experience of its team members is contained in Evaluative Case Study 2 in **Appendix C**.

We identified nine key insights regarding the experiences of Samoans that shaped the subsequent identification of prototypes.

1. E lē o le fale a o le anoāfale. It is not the house, but the people of the house that matter. A house represents much more than accommodation to Samoan families.
2. For many young Samoans, it is preferable to avoid the health system because of prior experiences.
3. Samoans prioritise collective wellbeing and sometimes this comes at the expense of individual wellbeing.
4. Samoans are missing out on vital opportunities for 'prevention'.
5. Young Samoans experience the rheumatic fever management journey as energy-sapping and disheartening.
6. The rheumatic fever system is missing out and lacking, because it cannot access or leverage the high value Samoan cultural and relational capital sitting in community.
7. Samoan practitioners and professionals feel undervalued. The rheumatic fever system takes advantage of their cultural and relational capital, and goodwill.
8. The rheumatic fever system is tokenistic in its respect for Samoan leadership, but Samoan leadership can inform and deliver what is really required to eliminate rheumatic fever.
9. Fragmentation and competition are hallmarks of the rheumatic fever system in Aotearoa.

▶▶ To find out more, please read the [Samoa Team Phase 1 Report](#).



During Phase 1 we identified four opportunities for change, represented by the following illustration (see **Diagram 7**).

1. Unleashing the cultural and relational capital of **Samoa families** to design and lead system responses to “overcrowding”.
2. Unleashing the cultural and relational capital of **young Samoans** to reimagine the rheumatic fever wellbeing and healthcare experience.
3. Unleashing the cultural and relational capital of **Samoa practitioners and professionals** to disrupt the system levers that reinforce inequity and inefficiency across the rheumatic fever ecosystem journey.
4. Unleashing at scale the cultural and relational capital across the full spectrum of **all-of community Samoan leadership** to establish a rheumatic fever system that supports Samoan ways of being sustainably into the future.



A Tale of Two Systems

A Tale of Two Systems

The key discovery from Phase 1 is that Samoans’ lived experiences of rheumatic fever in Aotearoa tell a Tale of Two Systems.

Phase 1 laid the vital foundation for the work by capturing the voices and experiences of Samoans from across the rheumatic fever ecosystem. The lived experience of Samoans – of young Samoans, of Samoan families (aiga) and of Samoan practitioners and professionals – was illustrated through the personas of Malia and Amosa and their respective journey maps. (See **Appendix B2: Soālaupule Capability Building Workshop.**)

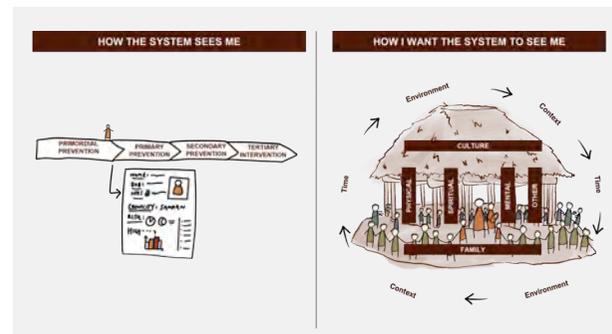
These provided clarity and focus on the people we are designing for, the “moments that matter” and the opportunities for change. ‘Malia’ is the persona that represents young people and the family/community experience. ‘Amosa’ is the persona that represents the Samoan practitioner/professional experience.

The base challenge for the current rheumatic fever system is that it is inherently driven by one system worldview. This first system is the formal New Zealand health system which is

complex and not people-centred. We heard experiences of Samoans whose wellbeing was diminished, rather than strengthened, by this system.

The second system is our Samoan holistic system of wellbeing which stems from our view of the world, Fa’asamoa (the Samoan way). This is described by the Fonofale model developed by Fuimaono Karl Pulotu-Endemann⁷. There is no space for Fa’asamoa in the current health system and this results in poor outcomes for Samoans and for the health system.

The opportunity for the greatest impact lies in our personal and collective response to this Tale of Two Systems. These insights from Samoan young people, aiga and health professionals gave us the mandate to explore the imbalance of power across the two systems, and create and test ways in which the strengths, wisdom and expertise of both systems can be leveraged to improve prevention and management of rheumatic fever for Samoan people in Aotearoa.



See **Diagram 3** on page 17 for a larger version of this image.

⁷ Pulotu-Endemann, F.K. (2001). Fonofale Model of Health.



Phase 2

Phase 2 was about engaging more deeply with Samoan families, health professionals and other system stakeholders to genuinely co-design solutions that would reflect a Samoan worldview. As we spent time with people, we learned more about the experiences of Samoans within the rheumatic fever system:

- Cultural and relational capital is key to the safe and enthusiastic engagement of participants.
- Engagement depends on multiple levels of trust and reciprocity.
- Whole-of-family engagement is critical.
- Language and representation is not negotiable.
- There's been a lot of research, it's time for action... systems action.
- Make it easy for leaders to be system actors: engagement and action should be fully facilitated and supported.

We were also brought back to the established Samoan practice of Soālaupule: a Samoan concept that has been established over many generations that balances power by acknowledging each person's mandate and strengths. Soālaupule is the inclusive decision-

making process that Samoans use in their aiga (family) both nuclear and extended, the nu'u (village and its different groups such as, village council, women's group, untitled men's group) as well as in the Ekalesia (church).

We observed that a critical benefit of using Soālaupule in the co-design process is that Samoans have confidence knowing that Soālaupule is not a stand-alone concept but rather one that embeds important Samoan values such as ava fatafata (mutual respect), fa'aaloalo (respect), fa'amaoni (faithfulness) and alofa (love) and rooted in the foundations of tofā (wisdom, knowledge). These values and beliefs give Samoans stability, unity, confidence and feelings of safety.

If you haven't already watched the Soālaupule video we introduced on page 14, we would encourage you to do so.

▶▶ [Video case study 3 – Soālaupule capability build](#)

Phase 2 helped us identify six potential prototype areas (see **Table 2** on the next page). These became the basis for further developing, testing, iterating and embedding throughout Phase 3.

Table 2: Six potential prototype areas developed during Phase 2

Prototype Area	Working Title	Description	Underpinning Insights	Impact We're Hoping To See
#1	Myth Busting	Myth busting initiative to support families to understand the basics of rheumatic fever.	Many families who have extensive experience of rheumatic fever don't know the basics. This is disempowering and prevents them from having autonomy over their health journey.	The language of rheumatic fever has been demystified for Samoan families.
#2	Let's Talk Rheumatic	Take a deep dive into the experience of young people to take an entirely different approach to designing communications with young people.	The ways of talking about rheumatic fever with young people do not resonate with their social norms and needs.	Creation of rheumatic fever communications that connect more deeply with young Samoans.
#3	The Fa'asamoa Way	Developing a capability framework for health professionals based on the Fa'asamoa way.	Samoan families have healthcare experiences that don't create space for Samoan ways of being.	Capability uplift of health professionals to understand and value Samoan ways of being.
#4	Delivering better quality primary care	Developing a capability framework and tools for health professionals that support them to provide better quality care to Samoan families.	Clinical guidelines don't always appear to be followed, implying that there are challenges for clinicians in accessing and understanding these.	Capability uplift of health professionals to provide better quality primary care.
#5	Mapping the rheumatic fever system for a locality	Extending the data review work within the Ōtara-Papatoetoe locality prototype from a Samoan data perspective.	A connected view of data, investment and activity is lacking, and greater connection has the potential to reveal new insight.	A higher level of data sharing and collaboration in the rheumatic fever prevention and management system results in more informed decision-making.
#6	Pharmacy-based rheumatic fever prevention	Testing a pharmacy-based sore throat management and rheumatic fever prevention model.	Pharmacies have played a key role during COVID-19 and create an additional layer of accessibility for families.	Pharmacies are supported to provide accessible rheumatic fever prevention services.

 To find out more, please read the [Samoa Team Phase 2 Report](#).

Our prototypes

Overview

During Phase 3, we continued engaging with Samoan families, health professionals and system stakeholders. As we continued to explore and co-design together, the shape of our prototypes changed. This reflected the deepening of our understanding of what families and health professionals experience and reflected the areas that stakeholders were most interested in supporting.

You can see how the six prototype areas from Phase 2 changed through Phase 3. 'Myth Busting', 'Let's Talk Rheumatic', 'The Fa'asamoa Way', and 'Delivering better quality primary care' from Phase 2 collectively became the following:

1. **Soālaupule Family Meeting Guide**
2. **Soālaupule Capability Building Workshop**
3. **Rheumatic Fever Infographic and Glossary**
4. **Youth "Let's Talk Rheumatic" Information Event**

The following two areas from Phase 2 retained the same name during Phase 3:

5. **Pharmacy Based Rheumatic Fever Prevention**
6. **Systems mapping for Le Afio'aga o Aotearoa (Ōtara-Papatoetoe Locality)**

A key part of our approach has been to intentionally leverage Samoan relational capital to enable and empower 'extension partners'. These are the people who are able to champion particular prototypes, and they played a critical role in designing, testing, iterating and embedding the prototypes. They are at the heart of driving the system change we are seeking to create. You will read more about our extension partners later in the report.

This section briefly summarises each prototype area. The full prototypes can be found in **Appendix B: Tools to support practice**.

A developmental evaluation has been undertaken in parallel with the prototype development. The findings of that evaluation are provided in a separate report written by the evaluators.

In addition to that separate report, five Evaluative Case Studies are included in **Appendix C** of this report to share perspectives from a range of people who contributed to this co-design initiative.



PROTOTYPE 1

Soālaupule Family Meeting Guide

Overview of the prototype

The Soālaupule Family Meeting Guide is a tool designed for health practitioners to support enhanced communication and equitable power sharing with Samoan patients and families.

The guide outlines an inclusive decision making process between patients and their families with health professionals. From beginning to end of the Soālaupule meeting process, the Fa'asamoa way of doing things is applied and power dynamics are shared. Applying values like *ava fatafata* (mutual respect), *fa'aaloalo* (respect), *fa'amaoni* (faithfulness) and *alofa* (love), combined alongside clinical best practice.

The initial problem or insight we responded to

Families told us they didn't know or understand what rheumatic fever is even after being diagnosed. Their healthcare experiences do not affirm Samoan values and ways of relating.

Healthcare workers told us that they need help to better communicate and engage with Samoan patients particularly regarding their diagnosis and its severity. They see the challenges that families experience but lack the confidence and know-how to respond.

What we created

We brought together families and practitioners to design a better healthcare experience. After a period of exploration, development and testing, we agreed on a meeting structure and style that shares power based on Soālaupule. From this, we developed the Soālaupule Family Meeting Guide as a way to support practitioners.

What we learned along the way

Some key learning included:

- Healthcare interactions create unequal power balance.
- If families don't feel acknowledged, it is hard for them to build a trusted relationship with health professionals.
- The guide gave health professionals the confidence to interact differently.
- Interactions felt different for families when Soālaupule elements were used
- You don't need to wait to deliver a

culturally competent service: you can start today.

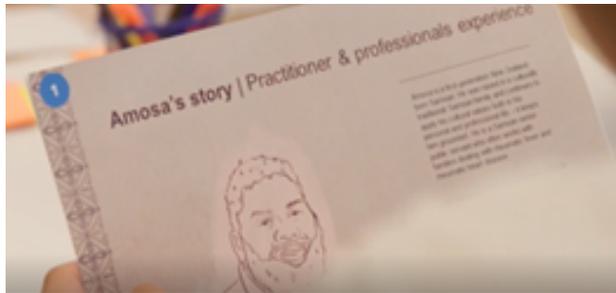
- When tested through role play scenarios, Samoan families agreed that using Soālaupule will promote cultural competence and improve health equity.

Embedding change within the system

In parallel with the development of the tool, we have been working alongside champions and stakeholders to co-design, test and embed the tool. While the tool was designed for clinical settings (e.g. for use by a GP or practice nurse), the principles of Soālaupule can be applied to any interaction between a health professional and a Samoan family.

Soālaupule provides a foundation for non-Samoan health professionals to improve their healthcare practice. The guide complements clinical best practice. The tools are being further developed and made available through the Goodfellow Unit. Health professionals and organisations are embedding Soālaupule in their practice. We invite you to do the same!

This prototype has practically demonstrated how clinicians can balance the power in clinical interactions; what is significant is the shift from talking about the problem to demonstrating a solution.

PROTOTYPE 2**Soālaupule Capability Building Workshop****Overview of the prototype**

The Soālaupule Capability Building Workshop is a learning and development module for health professionals that explains and demonstrates the value of applying Samoan principles of dialogue, consensus building, and power sharing, through the application of Soālaupule in health. It is particularly helpful in decision making, resource allocation, and engaging families in determining appropriate support and care for families with rheumatic fever.

The initial problem or insight we responded to

Families told us that their healthcare experiences do not affirm Samoan values and

ways of relating. We heard that non-Samoan health professionals find it challenging to traverse the complexities of Samoan families' social, spiritual, political, and cultural values. They also lack understanding of how these values influence family health decisions and frame their understanding of quality healthcare.

What we created

We again brought together families and practitioners to design a better healthcare experience. After a period of exploration, development and testing, we agreed on a capability building module for non-Samoan clinicians, based on Soālaupule.

We created and socialised a Soālaupule learning guide with organisations that have an interest in workforce capability.

What we learned along the way

We learned that there is strong demand among organisations to have practical advice for delivering culturally competent services. Knowledge of the problem is widely shared but there has been a lack of practical support for those who want to deliver their practice differently.

We learned that Soālaupule is a powerful unifying concept. It can be explained in ways that non-Samoans grasp the essence of it and how it can be applied without diminishing the meaning attached to Soālaupule for Samoans.

We learned that taking a systems approach is more effective than relying on individual clinicians to bring Soālaupule into their practice. We observed professional networks that have the desire and ability to leverage concepts like this across a wide range of practitioners, and they can play an important role in the systems change.

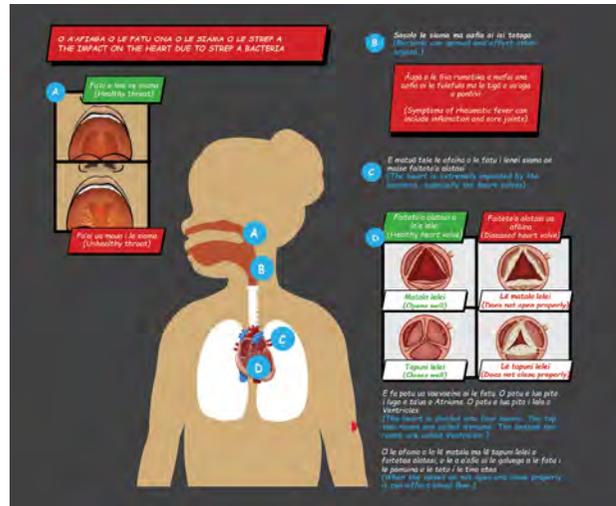
Embedding change within the system

The tools are available on the Te Whatu Ora website. We have worked with several organisations to roll tools out through their networks (e.g. the Goodfellow Unit, Pasifika GP Network, Pasifika Chapter of the Royal New Zealand College of GPs, etc.). Several other organisations have already aligned their practice with Soālaupule.

The development of the Soālaupule Capability Building module becomes a model for how ethnic-specific and culturally competent training of the health workforce can happen in ways that immediately increase the capability of the workforce.

PROTOTYPE 3

Rheumatic Fever Infographic and Glossary



GLOSSARY:

TERMS	TRANSLATED or EXPLANATION
Rheumatic Fever	Fiva Rumatika
Heart Valves	Faitoto'a (alattasi)
Strep throat	O le fa'afatiga e mafua'ia: siama o le Strap A
Atrium/Ventricles	Atrium – potu e 2 pito i luga o fatu Ventricles – potu 2 pito i lalo o le fatu
Medicines/Antibiotics	Fuaila'u tui (antibiotics) Vala'au ma fuaila'u tui
Penicillin injection	Tui Penisilini
Erythromycin	Fuaila'u tui e sui ai le fuaila'u penisilini (eritromisini)
Diagnosis	Ua fa'amaonia'ua maua i le Fiva Rumatika oia o sa'iliga ma su'esu'e'ega
Inflammation of joints and heart valves	Fuaila'ua so'oga o pona'i fa'apea ma faitoto'a/alattasi o le fatu
Sore joints	Toga so'oga o pona'i

Overview of the prototype

The glossary prototype was inspired by insights and discussions with Samoan families dealing with rheumatic fever. It is a bilingual visual tool for Samoan and non-Samoan clinicians to have conversations about rheumatic fever with families in a way that Samoan families can understand. The resource has been represented and translated in a way that helps to bridge a language barrier between a Samoan patient and a clinician with little grasp of the Samoan language.

The infographic and glossary was prepared for a specific context: a child is experiencing a sore throat, and the family visits a GP. You can imagine how the infographic and glossary can be used by the GP in that situation to explain what is happening in a way that supports understanding for the family. It visually explains the impacts of strep throat and rheumatic fever on the heart and also describes the journey of the strep throat bacteria.

In particular, the prototype demonstrates two things that are more widely applicable to rheumatic fever health communications with Samoan families:

1. How a clinical process can be explained visually.

2. How translations and consistent terminology can help explain medical terms.

The initial problem or insight we responded to

Even after experiencing rheumatic fever / rheumatic heart disease, many families don't know what rheumatic fever is or how it came to be in their family. Specifically, they did not understand the terms and words used to describe rheumatic fever symptoms and treatment by health professionals. One of the key issues amongst our people was that they could not connect a sore throat to a potentially damaged heart.

We also discovered that there were inconsistencies in the Samoan language when it came to rheumatic fever related medical terms, i.e. there were differing words / phrases when describing the same medical terms. This lack of shared language makes it challenging for families to understand what health professionals are saying and means opportunities for family-to-family knowledge sharing are limited.

What we created

We brought families and practitioners together to understand what creates confusion and misunderstanding, and explored ways that information can be communicated effectively to families.

We iterated our way from a detailed glossary (full list and description of all the terms that might be used in a clinical setting related to rheumatic fever) to a dual language infographic for GP settings. The visual glossary describes how Strep A bacteria impacts the throat, body and potentially the heart.

We engaged with clinical peer reviewers to ensure the concepts, definitions and explanations were clear and accurate.

What we learned along the way

Some of the key things we learned through the process include:

- There are health equity and safety risks due to inconsistent definitions and use of Samoan language.
- Dual language (Samoan and English) is important and it removes some of the barriers between health professionals who don't speak Samoan language and families who do.

- Visual / pictures are an essential way of communicating with families.
- More information was requested related to heart valves, throat swabbing, and the general impacts of rheumatic fever if not treated properly.

Embedding change within the system

The tool has already been used by various stakeholders within role play settings and within their practice.

The prototype tool will be made available on the Te Whatu Ora website and should be used to inform any future health communications / awareness raising within the Samoan community.

This prototype is a proof of concept that taking a different approach to health communications improves the ability of Samoan families to understand rheumatic fever. We recommend that adequate resource is allocated to developing additional standardised national bilingual (Samoan / English) engagement and communications resources with visual aids to provide consistency and clarity.



PROTOTYPE 4**Youth “Let’s Talk Rheumatic” Information Event****Overview of the prototype**

This prototype trialled ways to raise awareness of rheumatic fever among Samoan youth. Instead of being targeted by a ‘campaign’, young people preferred to have the opportunity to share stories and experiences together as a group of young

people, supported with pastoral care to create safety.

This prototype has implications for anyone who wants to work together with young people to engage and empower other youth to learn and take ownership of rheumatic fever prevention in the community.

The initial problem or insight we responded to

Messaging about rheumatic fever and rheumatic heart disease doesn’t resonate with Samoan young people; Samoan young people told us they weren’t receptive to the current information about rheumatic fever. As a result, young people have low awareness and understanding of rheumatic fever. This prototype aimed to specifically engage young people to attend information evenings that would be meaningful for them.

What we created

We brought young Samoans together to explore what information and mediums could be used to deliver health messages that resonate with young Samoans. A talanoa (discussion) evening was created by Samoan young people who have experienced rheumatic fever for their peers (16–25 year olds).

The prototype provided a space for young people to engage with a medical practitioner and young Samoans living with rheumatic fever to learn, understand and get information about the disease. It was also an opportunity for young people to access pastoral care throughout the planning of the event.

What we learned along the way

Samoan young people are often characterised as disinterested and ‘hard to reach’. But when supported with adequate resources and safety, they were inspired to share important messages with their peers in a relatable and engaging way.

The health system assumes that young people need another campaign, but young people want to feel safe and share connection with others. Pastoral care is powerful.

There are places that are well equipped to provide this safety and pastoral care (for example, the Ōtara Scorpions Rugby League Club, an extension partner) and should be supported as they are performing a vital service in engaging our youth.

Embedding change within the system

A systemic approach to equipping and supporting young people to prevent and manage rheumatic fever in local communities is needed.

This prototype is proof of concept that by engaging our youth in a supported manner, rather than running another campaign, puts them in control and enables community-led awareness raising of rheumatic fever.

As stated above, this prototype has implications for **how** youth communications are undertaken and **who** are seen as potential community partners for awareness raising initiatives. We recommend that resource is directed to community-based personal and pastoral care for young people as a key pillar of rheumatic fever prevention efforts.

Below is the link to the video case study, available on the Te Whatu Ora website.

▶▶ [Video case study 2 – Youth Talanoa night.](#)

PROTOTYPE 5

Pharmacy-Based Rheumatic Fever Prevention



Overview of the prototype

We supported the President of the Pacific Pharmacists' Association to explore how pharmacies might play a strengthened role in community-based prevention and care of rheumatic fever. While this is not a new idea, we were specifically looking at the application of the idea to a South Auckland context and how the approach could be community-led.

We developed a pilot concept for a pharmacy and community partnership to test pharmacy-based sore throat checks and prescription of antibiotics, as well as community-led communications and engagement.

The initial problem or insight we responded to

It is not always easy or practical for families to access a doctor or health practitioner to get a sore throat checked for strep. The time and cost to see a doctor for a sore throat is a problem for many families. When families do not get a sore throat checked, it is a missed opportunity for prevention of rheumatic fever.

Pharmacies played a critical role in their local communities during the COVID-19 pandemic and Pacific community-led engagement and events were successful during the COVID-19 pandemic. How might those successes be leveraged for rheumatic fever prevention?

What we created

The prototype proposed a pharmacy-based sore-throat management / rheumatic fever prevention model including sore throat checks and antibiotic prescription. In addition, this prototype would draw from the experiences and expertise of Samoan patients and families to inform the design and delivery of services, including communications and engagement with the local community.

The design question was: how might we advance pharmacy-based interventions to complement and increase the detection of

strep throat and prevention of rheumatic fever for Samoan people?

What we learned along the way

We learned that local communities are ready and keen to design and test this solution, but the health system is experiencing significant change and disruption and is not yet ready or able to support such a pilot.

We also learned that an effective response to rheumatic fever is to create a variety of options and choices that enable families to take prevention measures that suit their lifestyle and needs. It is not sufficient to say that families need to see their GP as this is not always practical.

Embedding change within the system

We are aware of similar pilots being run in regions outside of Auckland. We recommend that a South Auckland pharmacy pilot be run, and critical to its success is the involvement of community in the design and implementation of the pilot. Through the co-design initiative, community has been activated and is ready to engage further.

PROTOTYPE 6

System Mapping for Le Afio'aga o Aotearoa (the Ōtara-Papatoetoe area Locality)

Overview of the prototype

The Ōtara-Papatoetoe area is the location for the development of one of the first locality prototypes as part of the health system reforms. Ōtara-Papatoetoe is home to large Pacific and Māori populations. These are dynamic and connected communities with many strengths including multilingualism, high rates of volunteering, self-reported life satisfaction and high numbers of community providers and groups.

However, there are also significant challenges that include housing unaffordability, many damp and mouldy homes and historical lack of investment in community amenities and resources. Health system reports show that Māori and Pacific children and young people in the area are most at risk of acute rheumatic fever. Because of the high burden of disease, Le Afio'aga o Aotearoa has identified rheumatic fever prevention and management as one of their prototype locality priorities.

The Samoa Team commissioned research experts, Pacific Perspectives Ltd. (led by Dr Debbie Ryan and Dr Gerard Sonder) to undertake further research and analysis that built on prior work that they had done with Le Afio'aga o Aotearoa. Specifically, Dr Ryan and Dr Sonder focused on the implementation of rheumatic fever prevention and control in primary care at a locality level, that encompasses primordial, primary and secondary prevention.

The following content has been drawn from the Executive Summary, conclusions and recommendations of Pacific Perspectives Ltd's report provided directly to Le Afio'aga o Aotearoa.

The initial problem or insight we responded to

Over decades, there has been frequent media attention highlighting the inequity of this poverty related disease that is rare in high income countries, and mainly affects Māori and Pacific children, especially in South Auckland.

Since 2011, rheumatic fever has gained political attention with more than \$100 million invested in rheumatic fever prevention and management. Major investment in scientific

research has also been made; more than 272 international peer-reviewed articles have been published related to rheumatic fever in New Zealand. These investments have not resulted in any demonstrable effects on the incidence of acute rheumatic fever for Pacific children.

The Pae Ora 2022 legislation and the health system reforms offer the opportunity to improve rheumatic heart disease prevention and control with better national oversight, guidance, and control (uniform national guidelines, improved coherent surveillance and data collection). A major system change involves the reorganisation of primary and community care as 'Localities' serving geographically defined communities. Localities are tasked with coordinating services to enable more seamless care, tailored to the needs of the local population of a specific geographic area. The disestablishment of District Health Boards, and the yet to be established role of localities in population health, means there is a risk that rheumatic heart disease prevention and control will deteriorate.

What was created

Dr Ryan and Dr Sonder prepared a summary report of their findings, and this is included in **Appendix A3**.

What we learned along the way

Evaluations of rheumatic fever prevention and management programmes recognise that it is generally more feasible to address the challenges caused by fragmented and siloed health care systems initially in smaller geographic and administrative areas, before upscaling to national levels.

This offers the unique opportunity for Le Afio'aga o Aotearoa (and other locality-based initiatives) to take the lead in all rheumatic fever control programmes and data collection in their locality. This can be achieved by providing guidance and oversight for the implementation of rheumatic heart disease prevention and control, with uniform guidelines and protocols for all providers, and the prospective design of uniform and comprehensive data for the entire locality population.

Embedding change within the system

The full conclusions and recommendations from Pacific Perspectives' report are included in **Appendix A3**.

There are recommendations for action at both local and national levels including:

- Clarify and reorganise surveillance and 'other' data collections urgently. Maximise the opportunity to establish an integrated locality data-hub, that is fully aligned with national data collections (2-way system).
- Implement Public health programmes consistently:
 - top-down: uniform, consistent, always up-to-date, and accessible for all health care workers through their digital systems
 - bottom-up: connect with target groups, tailored, culturally appropriate engagement at locality level.

Top-down and bottom up always need to be aligned.

Scaling the prototypes

Embedding Samoan worldview and practices in the New Zealand health system

The Samoa Team prototypes are designed to interact across the system, reaching individuals, impacting policy and creating a narrative shift that speaks directly to our collective values and beliefs.

Accordingly, each prototype has the potential to be scaled to meet the demands of each level of the system, specifically:

- Scaling out, or impacting greater numbers. This involves replication and dissemination, increasing the number of people or communities impacted.
- Scaling up, which involves a focus on the institutional and systemic conditions (e.g. policies, rules and laws) that need to be in place for the prototype to succeed.
- Scaling deep means focusing on deepening change beyond the surface

structures and procedures to the beliefs, underlying assumptions, norms, cultures and “hearts and minds” of people, organisations, systems or communities (Coburn, 2003).⁸ As Cole and Hagan (2022, p. 3)⁹ note, scaling deep is “necessarily uncomfortable” due to the complexity and time required, therefore placing it at odds with the standard public sector construct of professionalism (COCO Centre for Community Organizations, 2019; DiAngelo, 2018; Saad,2020).

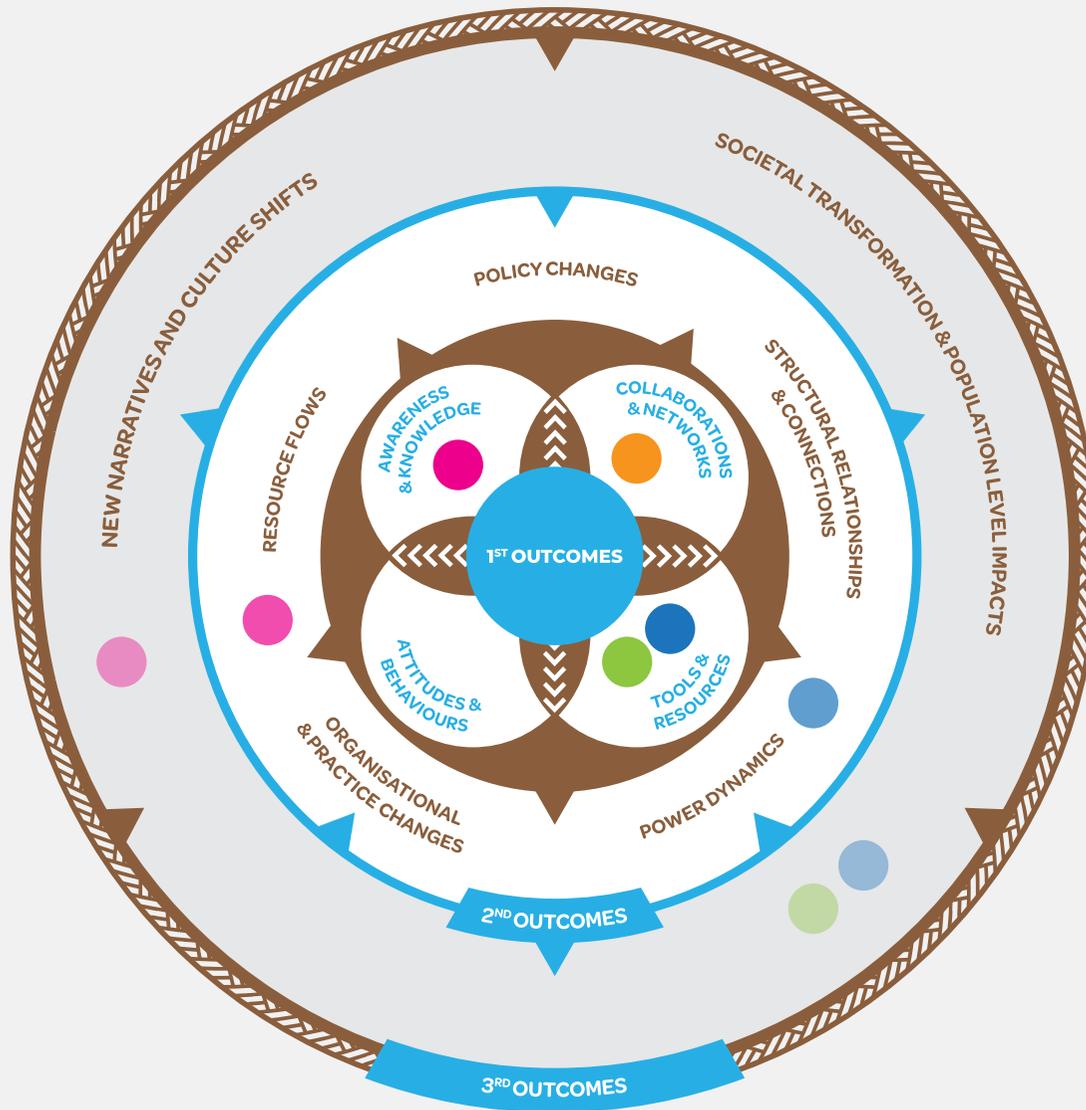
The following diagram and tables identify how the different prototypes are scaling out, up, and deep (See **Diagram 8** on page 42).



⁸ Coburn, C. (2003) Rethinking Scale: Moving Beyond Numbers to Deep Lasting Change, Educational Researcher; Aug/Sep 2003; 32, 6.

⁹ Cole, L. & Hagen, P. (2023) Scaling deep through transformative learning in public sector innovation labs – experiences from Vancouver and Auckland, Public Management Review; 3.

Diagram 8: How the prototypes have the potential to scale out, scale up and scale deep



Prototype	Scaling Out	Scaling Up	Scaling Deep
Soālaupule family meeting guide, Soālaupule capability building workshop	●	●	●
Rheumatic fever infographic and glossary	●		●
Youth-led information sharing	●		
Systems mapping Ōtara-Papatoetoe locality	●	●	●

The colour circles in the diagram correspond with the table to indicate which prototypes are scaling up, scaling out or scaling deep. Some prototypes are scaling in more than one dimension. More commentary is provided for each prototype in the tables on the subsequent pages.

Adapted from: Williams, S (2017) Evaluating Societal Effects of Transdisciplinary Co-production Processes: Final Report

Table 3: Explanation of how the prototypes have the potential to scale out, scale up and scale deep

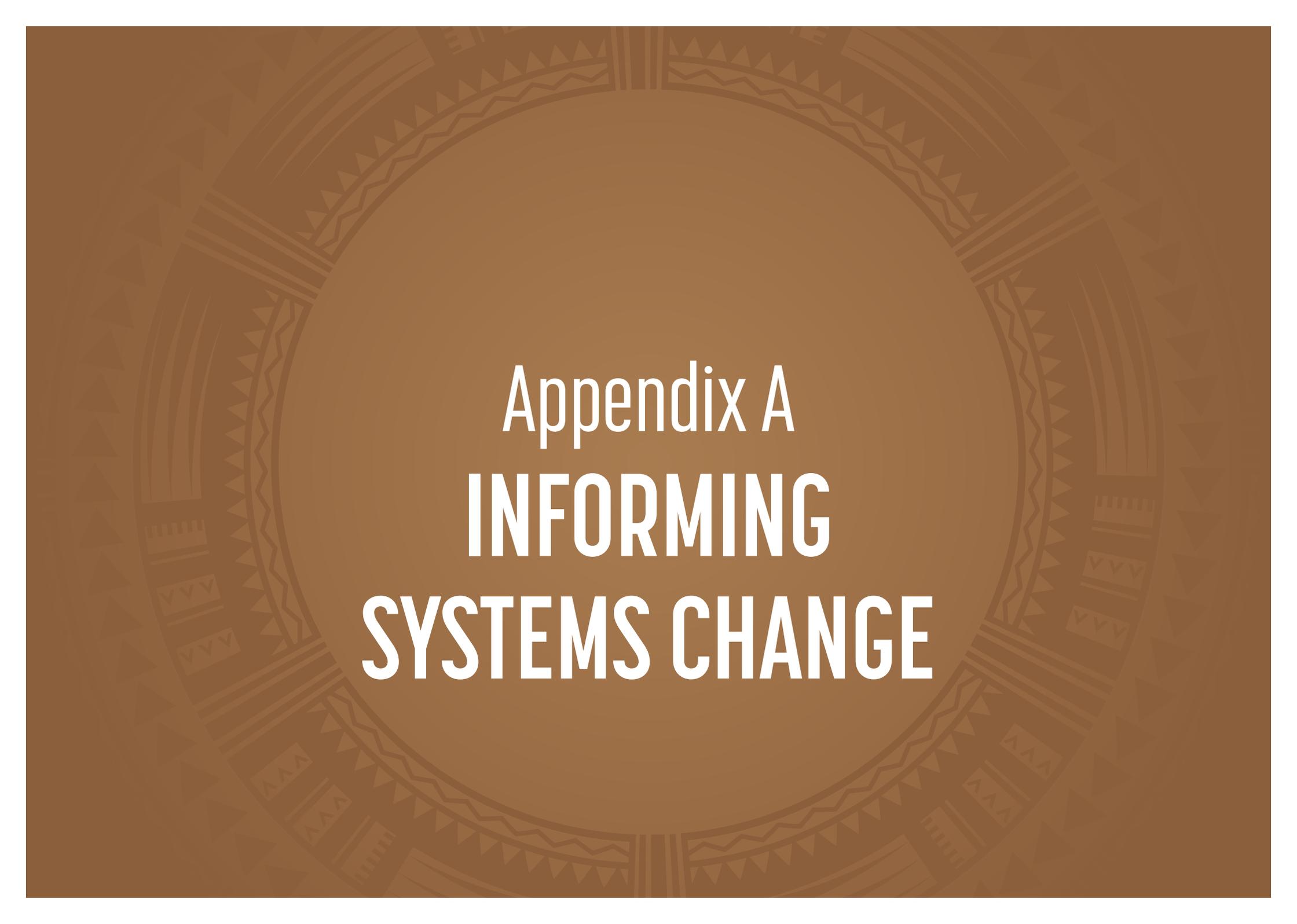
	Soālaupule family meeting guide Soālaupule capability building workshop
Scaling out	Champions in advocacy roles in the health system believe Soālaupule has the potential to reimagine the ways in which Samoan people interact with the ‘system’, and the system’s interaction with them. The framework is not just health related and can be used in education, housing, justice etc.
Scaling up	<p>Goodfellow Unit for Continuing Education (University of Auckland) are producing capability building opportunities for health professionals based on Soālaupule approach. Goodfellow eLearning provides high quality online resources for healthcare professionals working in primary care, using peer reviewed evidence-based content.</p> <p>Te Tāhū Hauora Health Quality & Safety Commission is exploring how Soālaupule may inform the development of a System Safety Strategy for Aotearoa.</p>
Scaling deep	Potential for deep shifts in the ways non-Samoans relate to and interact with Samoan people, particularly in service settings and the way in which Samoans interact with health professional.

Table 3 continued: Explanation of how the prototypes have the potential to scale out, scale up and scale deep

Rheumatic fever infographic and glossary	
Scaling out	Contributing to toolbox for capability building for health professionals through Goodfellow Unit for Continuing Education (University of Auckland) and Te Whatu Ora Counties Manukau.
Scaling deep	Glossary challenges the paradigm that a lack of understanding is the fault of the patient. It provides a tool to support a practitioner to engage in a two-way peer to peer conversation with a patient and their family. It also provides a tool for patients and families to ask questions and seek clarification as they wish.
Youth-led information sharing	
Scaling out	<p>Ōtara Scorpions Rugby League Club collaboration with South Seas Healthcare is delivering health prevention and management “in community, by community”.</p> <p>Ōtara Scorpions is also investigating how it can extend provision of pastoral care to young people with rheumatic fever.</p> <p>The Talanoa night demonstrated how building a broader connection among supporters (friends, aiga) aids better understanding of rheumatic fever management, and supporting loved ones and each other through navigating rheumatic fever.</p>

Table 3 continued: Explanation of how the prototypes have the potential to scale out, scale up and scale deep

Systems mapping Ōtara-Papatoetoe locality	
Scaling out	<p>Greater numbers will be impacted through the consistent implementation of public health programmes focused on rheumatic fever.</p> <ol style="list-style-type: none"> 1. Top-down: uniform, consistent, always up-to-date, and accessible for all healthcare workers through their digital systems. 2. Bottom-up: connect with target groups, tailored, culturally appropriate engagement at locality level. Top-down and bottom up always need to be aligned.
Scaling up	<p>Le Afio’aga o Aotearoa (the Ōtara Papatoetoe area locality) provides leadership to rheumatic fever prevention and management programmes and data collection in their locality by providing guidance and oversight for the implementation of initiatives with uniform guidelines and protocols for all providers, and the prospective design of uniform and comprehensive data for the entire locality population. A data hub is recommended that is specifically designed to closely monitor, evaluate, and adjust (real time) all activities aimed at rheumatic fever prevention and management in the locality area.</p>
Scaling deep	<p>Current system fragmentation prevents systematic and uniform data collection that is designed to answer specific surveillance questions. As a result, immediate information feedback loops to improve the interventions and information about which interventions are (cost) effective is not available. Systems mapping allows us to build a fuller picture of rheumatic fever, expanding the impact and reach of any initiatives. In particular, it can:</p> <ul style="list-style-type: none"> • Provide us with a holistic understanding of the RF system (interconnections, dynamics, stakeholders, relationships) • Identify feedback loops • Uncover unintended consequences • Create space for collaboration and co-creation • Inform strategic decision-making • Monitor interventions, along with challenges and opportunities



Appendix A
**INFORMING
SYSTEMS CHANGE**

Connecting an Ecosystem of Influencers

Appendix A1

Connecting an ecosystem of influencers

The Samoa Team (project team) has set out during Phase 3 of the co-design initiative to embed and extend the five prototypes into the rheumatic fever system in Tāmaki Makaurau, Aotearoa (Auckland, New Zealand). This has been primarily achieved by utilising the cultural, social, and relational capital of Samoan community members (patients, families, and health professionals) and project team.^{B1}

As highlighted in The Water of Systems Change, shifting power dynamics and building relationships (the semi-explicit) across sectors and political divides may feel especially threatening to foundations, but it is essential work in systems change.^{B2}

At the conclusion of Phase 3, this work has created a multi layered ecosystem of champions from across the community,

practitioners and stakeholders that is extending and embedding. These solutions stem from a Samoan worldview (Fa’asamoa – the Samoan Way) and understanding of wellbeing, and provide tools, resources, evidence, and information to support non-Samoans in their everyday practice.

Kania et al (2018) states that transforming a system is really about transforming the relationships between people who make up the system.^{B3} For example, the Goodfellow Unit (a unit set up to provide continuing medical education^{B4}) has recognised the value of the community-led prototypes developed by Samoa Team. The Unit is committed to work alongside Samoan practitioners to extend and embed the Soālaupule approach and prototypes (family meeting guide and capability building workshop) into its extensive online learning platforms. This will support medical practitioners to learn, understand and apply Soālaupule into their

practice.^{B5} This is a significant milestone for community-led prototypes produced as part of co-design initiatives as the Goodfellow Unit is supported by The Royal New Zealand College of General Practitioners and College of Nurses Aotearoa, New Zealand as a leading hub for learning for professionals in general practice and primary healthcare.

Further examples of system stakeholders that have committed to extending and embedding the Samoan-designed prototypes into their own systems, structures, and practices include:^{B6}

- Pasifika GP Network and Pasifika Chapter of the Royal New Zealand College of General Practitioners. Champions: Dr Apisalome Talemaitoga (Chair, Pasifika GP Network) and Dr Monica Liva (Chair, Pasifika Chapter of the Royal New Zealand College of General Practitioners).

^{B1} Read Evaluative Case Study 2 (Confluence of Influence) and Evaluative Case Study 5 (Navigating the System) in Appendix C.

^{B2} Kania, J., Kramer, M., & Senge, P. (2018). The Water of Systems Change.

^{B3} Kania, J., Kramer, M., & Senge, P. (2018). The Water of Systems Change

^{B4} The Goodfellow Unit was set up in 1978 to provide continuing medical education and is part of the School of Population Health, Faculty of Medical and Health Sciences at the University of Auckland. <https://goodfellowunit-history.blogs.auckland.ac.nz/>

^{B5} Read Evaluative Case Study 1 (Soālaupule - a process and a prototype) in Appendix C.

^{B6} The embedding of these prototypes was progressing at the time of publication, June 2023. It may be subject to change at the discretion of the stakeholder.

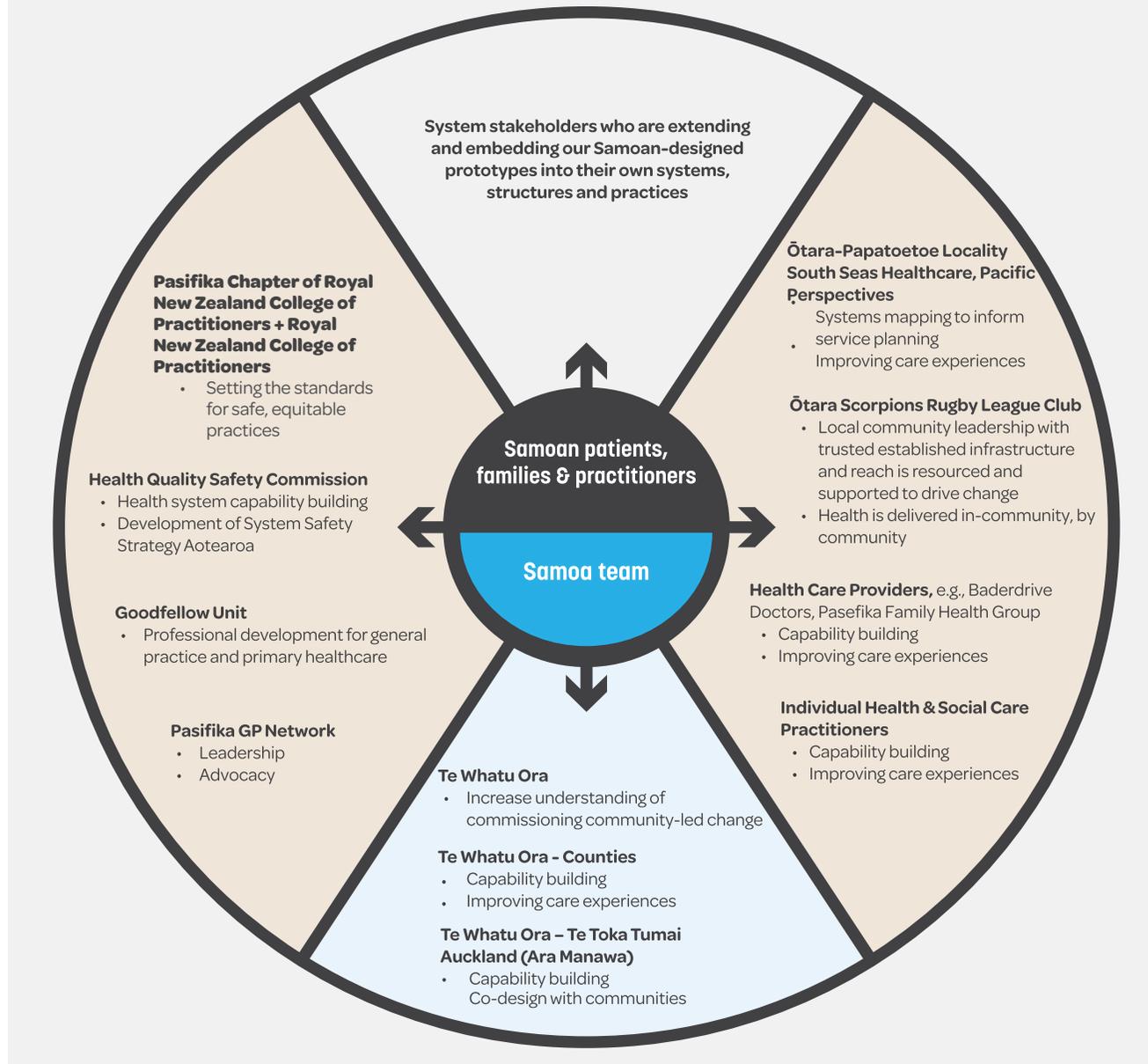
The leadership across these critical organisations for Pasifika health believe Soālaupule is a game changer for the health system. They see its potential to be scaled across all health conditions and settings and are working across multiple fronts to extend and embed the learnings and tools from our prototypes. This includes working with Goodfellow Unit and others to develop and disseminate capability building nationally.

Our pathway of partnership from community-led designed concepts to prototypes that can be embedded into and across many systems provides the blueprint for others to design and embed change.

The following diagram illustrates the ecosystem web of change that we have convened and supported to action systems change to address the inequities experienced by Samoans and improve the national health system.



Diagram 9: A more equitable, accessible, cohesive and people-centred system



Principles for Systems Change

Principles for systems change

As Samoan practitioners of systems change, the work has been driven from our Samoan worldview (Fa'asamoa) with a fusion of co-design and systems change.

We have used the Water of Systems Change (Krania et al, 2018) in practice to support individuals to identify the opportunities for change within their own system.

Through this work, we have tested and

“We are working from our Samoan worldview and using co-design mindsets, tools and practices and driving change at a systems level.”

confirmed that the following four conditions need to be in place to effectively challenge systemic inequity.

A foundation of trust and reciprocity

As we invite individuals and organisations to join the journey of change, we intentionally and openly discuss and model trust and reciprocity in the way we work together:

- We acknowledge, value, and give room for the wisdom, experience, and expertise that each individual brings.
- We prioritise genuine care and love for one another.
- We know that we are human and will make mistakes, but we will demonstrate maturity in finding our way forward together.

A safe space to be brave and courageous

We know there is an incredibly powerful pull to hold the status-quo in place. We provide a safe space where individuals can be brave and courageous and open to wondering and trying different things together:

- We share an understanding and agreement that the system struggles to deliver equity of outcome for everyone.
- We accept that we are working on a complex problem, and that there will not be one easy fix.
- We say to those we are working with that “This is one big prototype. The primary focus of our work is learning.”^{B7}
- We use the language and practice of co-design to make it comfortable for people to get to action quickly. For example, “What would a Minimum Viable Product to test that idea be?”

Intentional focus on power and accountability

We hold ourselves and others to account around our mandated roles in the system and how we can better respond to Samoan patient and community requirements:

- We support individuals in all spaces to raise their intentional consciousness of power and explore ways to share and distribute power and decision making.

^{B7} Cabaj, M., Tjebbes, A., and McNair, D. (2022) Evaluating Social Innovation Prototypes: A Guide, Social Innovation Canada.

Appendix A2

- We support leaders on their personal journey of change to shift and transform historical power bases that hold inequity in place.
- We coach those who hold power to be conscious of their accountability to those most impacted by decisions - rather than accountability to those who currently hold power.
- We support individual leaders to identify and action steps they can take in everyday practice that shifts power out from the status quo power bases.
- We develop and share tools and resources that support conversations and actions about power.

Giving every individual the agency and opportunity to take action

The concept of systems change must not feel so big and so removed for individuals that they cannot see what they can do right now to contribute to change. There are not enough opportunities for people from different parts of our systems to come together with people who are impacted by those systems, to learn and practice together differently. Prototyping incorporates a range of tangible activities

that many individuals can contribute to and participate in over time.

- We invite patients, young people, families, practitioners, and professionals to identify their immediate starting point for change (prototype concepts).
- We provide workshops where patients, families and practitioners are physically designing, testing, and learning about those opportunities for change (prototype development and testing).
- We put in place formal arrangements with community champions and stakeholders to recognise their valued contribution and give them agency and resource to participate in prototyping. Their contribution also includes extending and embedding the learnings and tools into their everyday practice and systems, and across their spheres of influence.



Systems Mapping Report for Le Afio'anga o Aotearoa (Ōtara-Papatōetoe Locality)

Systems Mapping Report for Le Afio'aga o Aotearoa (Ōtara-Papatoetoe Locality)

Rheumatic fever in Aotearoa New Zealand: System mapping

A report prepared to support Le Afio'aga o Aotearoa (Ōtara-Papatoetoe Locality) planning for rheumatic fever prevention and control. This report was commissioned by the Samoa Team of the Rheumatic Fever Co-Design Initiative.

This report was prepared by Dr Gerard Sonder, Public Health Physician and epidemiologist PhD and Dr Debbie Ryan, Principal, Pacific Perspectives Ltd. May 2023.

Part 1 of this report has been shared directly with Le Afio'aga o Aotearoa (Ōtara-Papatoetoe Locality).

Part 2 which consists of an Executive Summary, Conclusions and Recommendations appears below.

Part 2 Executive summary, conclusions and recommendations.

Figures and diagrams referred to are contained in Part 1 of 2 reports.

Executive summary

Acute rheumatic fever (ARF) is a delayed auto-immune response to an untreated throat infection caused by group A Streptococcal bacteria (GAS). Repeated GAS infections are thought to trigger an immune mediated process that leads to ARF. Frequent episodes of ARF in a child or young person can cause permanent damage to heart valves.

ARF and the resulting Rheumatic Heart Disease (RHD) are associated with the social determinants of health including low income, household crowding, the quality of housing, and access to healthcare. ARF and RHD prevention and control programmes span infectious diseases, child health, adolescent health, maternal health, and adult chronic disease and involve public health as well as aspects of individual healthcare, reflecting the overall need for health system strengthening and coordination.

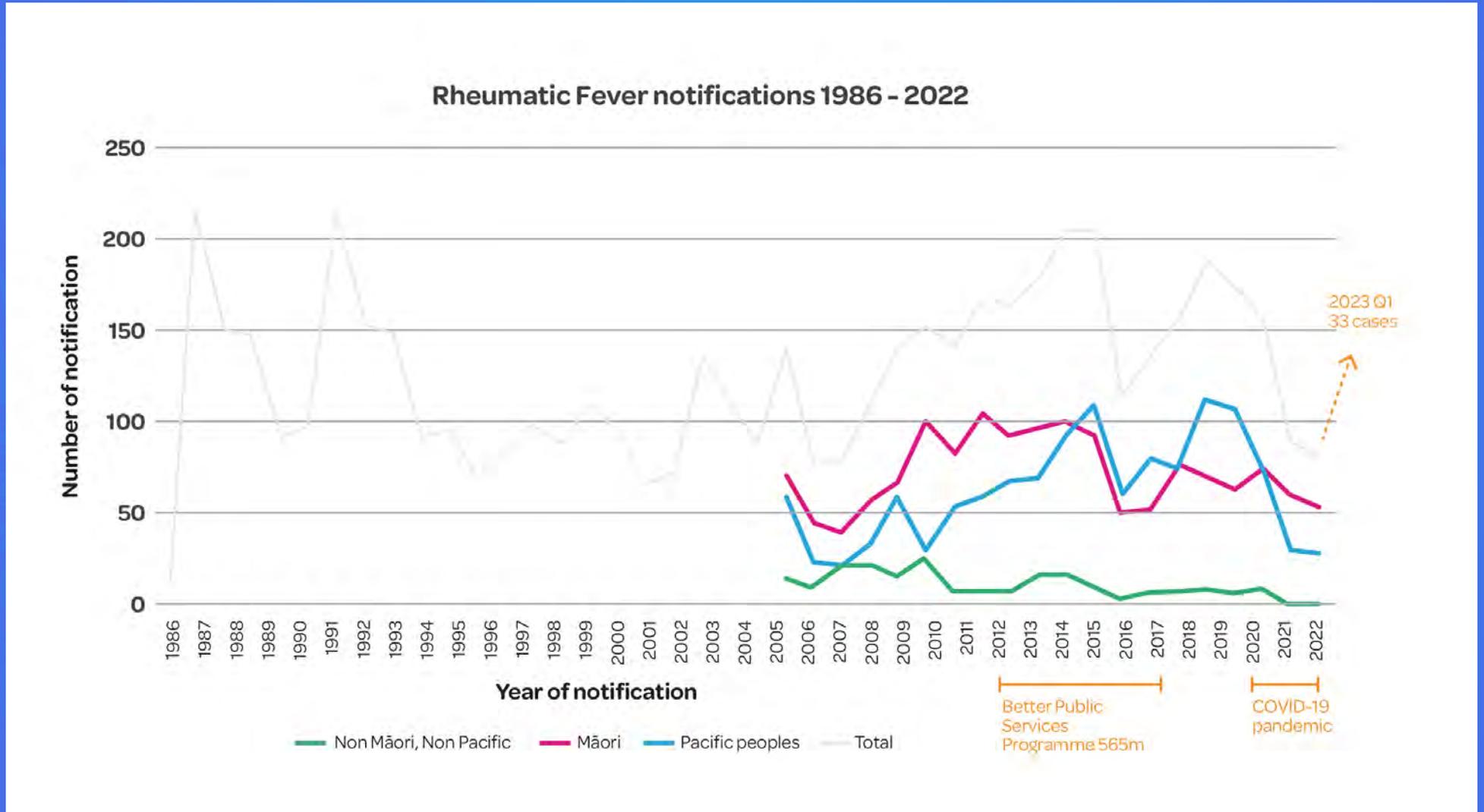
ARF and RHD have been largely eliminated in most high-income countries, however in settings where equity and economic development are not rapidly improving, active disease prevention and control measures are needed to reduce the burden of RHD. This remains the case in most of the developing world. New Zealand and Australia are outliers

amongst high income countries, with very high rates of disease affecting mainly Māori and Pacific in New Zealand and Aboriginal and Torres Strait Island populations in Australia.

In New Zealand, ARF is a notifiable disease under the Health Act 1956 and included in national surveillance since 1986. With the commitment to improving equity as part of the Public Health and Disability Act 2000, ARF cases were made notifiable by (prioritised) ethnicity (**Figure 1** refers).

National surveillance data confirm that ARF in Aotearoa occurs almost exclusively in Pacific and Māori children living in highly deprived areas. Although the annual number of ARF cases in New Zealand is low (fluctuating between 75 and 200 cases per year in the past decades), an estimated 60% of people with ARF develop RHD and thereby contribute to the increase in prevalence of chronic RHD. As a result, many (mainly Pacific and Māori) New Zealanders live with RHD, resulting in a mortality for RHD that is higher than, for example, the mortality for cervical cancer. People with rheumatic fever die, on average, fifteen years earlier than their peers, which contributes to longstanding and persistent differences in life expectancy between European/other, and Māori, and Pacific peoples.

Figure 1: Acute Rheumatic Fever cases notified under the Health Act 1956, 1986-2021, since 2003 by Māori prioritised ethnicity.



Appendix A3

The high burden of disease specifically for Pacific populations in South Auckland was confirmed by a cross-sectional study published in 2023, conducted between 2014 and 2016, among a random sample of the South Seas Healthcare enrolled patient population aged 16–40 years. The study found an RHD prevalence of 22 per 1,000 (95%CI 9 to 36 per 1,000) among Polynesian young adults, of whom more than half had not been previously diagnosed. This is comparable to the prevalence of RHD in low-income countries in Africa.

Over decades, there has been frequent media attention highlighting the inequity of this poverty related disease that is rare in high income countries, and mainly affects Māori and Pacific children in South Auckland. Since 2011, rheumatic fever has gained political attention with more than \$100 million invested in rheumatic fever prevention and control programmes. Major investment in scientific research has also been made; more than 272 international peer-reviewed articles have been published related to rheumatic fever in New Zealand. These investments have not resulted in any demonstrable effects on the incidence of ARF.

Hospitalisation and notification data suggest that between 2000 and 2016, ethnic inequalities have worsened. A simple linear regression of all notified cases of ARF 2003–2019 (the beginning of notification by ethnicity until the beginning of the COVID-19 pandemic) shows a similar trend: **a significant decline in Non-Māori-Non-Pacific cases, a significant increase in Pacific cases and an unchanged number of Māori cases, indicating increased inequity between ethnic groups.**

The recently reported fall in ARF incidence, in particular for Pacific children, was most likely a result of changes in population dynamics related to the COVID-19 pandemic. Notifications in the first quarter of 2023 suggest that the total numbers could again reach pre-COVID-19 levels this year.

Evaluations of international RHD prevention and control programmes, and a comprehensive evidence synthesis of RHD prevention and control programmes in New Zealand, found that an important reason for failures is the fragmented and devolved organisation of health care systems, that make it difficult to implement public health programmes uniformly and consistently. The system fragmentation prevents systematic

and uniform data collection that is designed to answer specific surveillance questions. As a result, immediate information feedback loops to improve the interventions and information about which interventions are (cost) effective is not available.

A 2018 peer reviewed evaluation of the New Zealand Rheumatic Fever Prevention Plan (RFPP) 2012–2017 found that that there was a lack of:

- a built-in evaluation plan,
- national Standard Operating Procedures (SOPs), and
- coordination of implementation.

This made it impossible to draw conclusions about why the incidence of ARF showed an initial slight decline. A cost-effectiveness assessment of the programme was also not possible. Although partial funding of the programme continued, the initial decline in ARF rates was not sustained and ARF rates were reported at pre-programme levels.

The Pae Ora 2022 legislation and the health system reforms offer the opportunity to improve RHD prevention and control with better national oversight, guidance, and prevention and control (uniform national guidelines, improved coherent surveillance

Appendix A3

and data collection). A major system change involves the reorganisation of primary and community care as 'Localities' serving geographically defined communities. Localities are tasked with coordinating services to enable more seamless care, tailored to the needs of the local population of a specific geographic area. The disestablishment of DHBs that had an important role in monitoring health and commissioning healthcare services in their districts, and the yet to be established role of localities in population health, means there is a risk that RHD prevention and control will deteriorate.

The Ōtara-Papatoetoe area is the location for the development of one of the first Locality prototypes as part of the health system reforms. Ōtara-Papatoetoe is home to large Pacific and Māori communities. These are dynamic and connected communities with many strengths including multilingualism, high rates of volunteering, self-reported life satisfaction and high numbers of community providers and groups. However, there are also significant challenges including housing unaffordability, many damp and mouldy homes and an historical lack of investment in community amenities and resources.

Health system reports show that Māori and Pacific children and young people in the area are most at risk of ARF. Because of the high burden of disease, Le Afio'aga O Aotearoa has identified rheumatic fever prevention and control as one of their prototype locality priorities.

Evaluations of rheumatic fever prevention and control programmes recognise that it is generally more feasible to address the challenges caused by fragmented and siloed health care systems initially in smaller geographic and administrative areas, before upscaling to national levels. This offers the unique opportunity for Le Afio'aga O Aotearoa to take the lead in all rheumatic fever prevention and control programmes and data collection in their locality. This can be achieved by providing guidance and oversight for the implementation of RHD prevention and control, with uniform guidelines and protocols for all providers, and the prospective design of uniform and comprehensive data for the entire locality population. A data hub is recommended that is specifically designed to closely monitor, evaluate, and adjust (real time) all activities aimed at rheumatic fever prevention and control in the locality area.

System Mapping

This system mapping focuses on the implementation of rheumatic fever prevention and control in primary care at a locality level, that encompasses primordial, primary and secondary prevention (Report 1 refers).

Conclusions

- Poverty related determinants of health are important causes of ARF. Discrimination, barriers to access to healthcare and inequity in the quality of care received, are also factors in the persisting disparities in disease rates for Māori and Pacific.
- The fragmentation of the health system and the problems with monitoring and surveillance require clinical leadership. Regulation to improve population health is an important tool for public health action.
- Data collection must be standardised and improved to enable the interpretation of effects and evaluation of cost-effectiveness of numerous prevention and control programmes that have to date, not resulted in reducing inequities in disease or improving longer-term outcomes.

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Recommendations: Local

- **Lead** coordinate and mandate; organisation, uniformity, implementation, leadership.
- **Implement** Public health programmes consistently:
 - top-down: uniform, consistent, always up-to-date, and accessible for all healthcare workers through their digital systems
 - bottom-up: connect with target groups, tailored, culturally appropriate engagement at locality level
 - Top-down and bottom up always need to be aligned.
- **Clarify and reorganise** surveillance and 'other' data collections urgently. Maximise the opportunity to establish an integrated locality data-hub, that is fully aligned with national data collections (2-way system).

Recommendations: National

- **Anticipate** worldwide workforce shortages of general practitioners and nurses. Reorganising, designing and implementing protocols for public health programmes can reduce the pressure

on clinicians by establishing uniform processes for purposeful delegation and supervision of non-clinical staff to ensure continuity and quality of care.

- **Communicate** locality needs to Te Whatu Ora: support national public health leadership. Recommend that National Public Health standards, and the 'CD manual' (chapter Rheumatic Fever) are urgently updated and maintained. This process needs to be ongoing and frequent so that new knowledge and insights are shared and implemented uniformly throughout the country.
- **Communicate** surveillance needs to Te Whatu Ora: there is currently suboptimal use of official national surveillance data that are collected under the Health Act 1956 (due to quality issues with the data). Recommend that Te Whatu Ora either enforce the Health Act and improve the notifications or develop official uniform surveillance alternatives.





Appendix B

TOOLS TO SUPPORT PRACTICE

Introduction

Further to the summaries of the prototypes included earlier in the report, this section contains more detailed content related to the following four prototypes:

Appendix B1: Soālaupule Family Meeting Guide

Appendix B2: Soālaupule Capability Building Workshop

Appendix B3: Rheumatic Fever Infographic and Glossary

The following section has been presented in a way so that each prototype is self-contained and can be printed as a quick reference guide to be used in daily activities. For this reason you will notice some of the introductory material repeats for each prototype.



PROTOTYPE

PHASE 3 FINAL REPORT:
A TALE OF TWO SYSTEMS

Soālaupule Family Meeting Guide

A Tale of Two Systems. Phase 3 Report:

Samoa Team, Rheumatic Fever Co-Design Initiative.

Prepared by: Annie Ualesi, Louisa Ryan, Sam Lafolua, Toleafoa Alfred Schuster, Tai'ivao Lemalu Siniva Ieru-Cruickshank, Caleb Va'a, Jodi Meadows, Nadine Metzger, Loncey Craig, Justis Kamu.

Commissioned by **Te Whatu Ora - Health New Zealand.**

Supported by **ThinkPlace.**

E ui ina sui faiga, ae tumau pea fa'avae.

Though the approaches may change, the foundations remain the same.

Our invitation to you:

As this phase of the journey comes to an end, we reflect on how the co-design initiative has demonstrated the change that Samoans can inspire and lead when given the opportunity. Collectively, we need to continue working in this way if we want our future generations to be freed from the impacts of rheumatic fever.

While an energy has been created among Samoans and non-Samoans who have engaged with this work, there is a risk of the system returning to the status quo. Samoans and allies have put their hands up to champion change and we should continue to acknowledge and recognise their efforts, wisdom and leadership.

We invite you to sit with the knowledge, stories and recommendations included within this report and to continue creating the space for Samoan perspectives to guide our actions in the rheumatic fever prevention and management space.

Appendix B1

Prototype: Soālaupule Family Meeting Guide

Introduction

The Soālaupule Family Meeting Guide outlines some principles of Fa’asamoa (The Samoan Way) and recommends ways to enable those values and beliefs to be more thoughtfully considered and applied to enable more effective conversations and engagement of Samoan families experiencing rheumatic fever.

Fa’asamoa (the Samoan Way) refers to cultural values and beliefs that guide and teach individuals how to lead their life. Samoan views on health and wellbeing can be described by the Fonofale model developed by well-known Samoan health practitioner Fuimaono Karl Pulotu-Endemann (Pulotu-Endemann, 2001).^{A1}

For Samoans, the Vā is the space and relationship with others, it defines how one interacts with another person e.g., adult–child, matai–non-matai, brother–sister etc. Tausiga o le Vā is the practice of nurturing, maintaining, and protecting any relationship. Therefore,

Samoans will interact respectfully with health professionals and staff, particularly where they believe they are receiving respect.

What is Soālaupule?

Soālaupule is made up of three different words – soa/lau/pule.

“Soa” which means ‘to partner or share’; “lau” which means ‘your or yours’; and the word “pule”, which means ‘authority’ or “mandate”. The combination of these three words, forming the word Soālaupule, can be translated and interpreted as ‘to share your authority, mandate’ in any given setting.

Soālaupule serves two purposes: to demonstrate the value of applying Samoan principles of dialogue and consensus building; and to create an open and equitable space where all perspectives are being shared, towards a shared outcome, action.

It should be acknowledged that the current clinical practice puts the patient and medical expert in an unequal power dynamic. Soālaupule is an inclusive decision-making process used by Samoans to achieve consensual decisions and outcomes. It is widely used in many settings including aiga

(families – nuclear and extended), the nu’u (village and its different groups such as village council, women’s group) as well as in the Ekalesia (church).

Importantly, the concept recognises the need to equalise the unequal power dynamic between parties. Soālaupule enables issues to be dealt with in a manner that is beneficial to both parties for the betterment of everyone involved. In this case, health staff and patients and their aiga should have shared authority in the discussion, decision-making and outcome(s) of a meeting. For example, patients with rheumatic fever are treated respectfully by health staff and are actively encouraged, supported for their opinions and advice, as well as consulted on all aspects of care and decision-making.

It’s critical to this guideline that Samoan patients and their families (aiga) are treated with respect of their values – ava fatafata (mutual respect), fa’aaloalo (respect), fa’amaoni (faithfulness), and alofa (love) – and beliefs such as their faith. In response, the same respect will be reciprocated for health staff and services.

^{A1} Adapted from Fonofale model developed by Fuimaono Karl Pulotu-Endemann

Appendix B1

Samoan families experiencing rheumatic fever have voiced their concerns about the health systems' poor understanding of their health worldview. Several reasons are mentioned including most notably:

- Ineffective communication and engagement with the health sector and staff;
- Poor access to relevant and appropriate health information;
- Lack of inclusion in the decision-making process;
- Poor understanding of the health system, practices and processes e.g. referral and treatment pathways.

These concerns have significantly contributed to the poor health outcomes and status of Samoans experiencing rheumatic fever in Tāmaki Makaurau and Aotearoa.

Understanding Samoan health worldview

Cultural values, beliefs, and worldviews on health have considerable influences on Samoans' health seeking behaviours and how they engage with the health sector.

Their past experiences from Samoa may include a mistrust of medical treatment and the need to seek medical assistance at hospital i.e. people tend to go as a last resort. This also derives from Samoans still practising traditional treatments such as herbal medicine (vai) and fofō (massage) which are used alongside western health remedies.

Community ecosystem – Samoans function in a collectivist culture which are typically interdependent and group centric. Co-operation and collective achievement are emphasised over self-fulfilment and personal gain where Samoans feel a strong sense of responsibility to those around them. Often, individuals can expect their relatives to look after them in exchange for unquestioning loyalty. Understanding this 'family/community' outlook and approach will support more meaningful and respectful communications and engagement.

Communication style – Samoans tend to be very polite and modest when communicating to others. They tend to be very shy and respectful, preferring to tell you what they think you want to hear rather than directly telling you the truth and causing offence.

How to apply Soālaupule when meeting Rheumatic Fever patients and their families

This guide explains and gives practical examples of how to apply Soālaupule to help improve communication, engagement, and establish more effective relationships between health staff and Samoan aiga with rheumatic fever.

With Soālaupule, the parties acknowledge that they are partners seeking the best outcome for the patient and their families.



SOĀLAUPULE FAMILY MEETING GUIDE

BEFORE THE Soālaupule

Values	Actions	Sharing power with your partner
Fa'aaloalo (respect)	Health staff to provide sufficient notice of consultation meeting with patient (date/time/location/participants /rationale). Reiterate that support people are welcome to attend.	Patients and aiga involved early, will feel acknowledged and respected and can develop a more trusting relationship with the health team.
Ava Fatafata (mutual respect)	Health staff to check/confirm patient and aiga are ready for consultation meeting.	Patient and aiga can collectively discuss and prepare in advance for consultation. For example, availability of family members to attend, adequate transportation, arrange time off from work, and bringing the right forms.
Tausiga o le va - nurturing, protecting and building the relationship	Health staff to be flexible around consultation meeting date/time.	Patient will appreciate flexibility and receptiveness for an alternative date/time.

INTRODUCING THE Soālaupule*Arrival at meeting venue*

Values	Actions	Sharing power with your partner
Fa'aaloalo (respect)	<ul style="list-style-type: none"> Greet patients at the door; provide comfortable seating and private space. If a Samoan health interpreter is present, allow them to facilitate the welcome, use appropriate traditional Samoan greetings (i.e.) proper pronunciation of names and acknowledgment/understanding of chiefly matai titles. 	<p>Being hospitable and acknowledged respectfully is very important to Samoans.</p> <p>Common Samoan greetings you can use; Talofa lava (hello) and Malo le soifua (hello and good health)</p>
Ava Fatafata (mutual respect)	<p>Welcome and salutations:</p> <ul style="list-style-type: none"> Offer the choice to the patient and aiga to say a prayer to open the meeting. Ask for correct pronunciation of their first name / surname/chiefly matai title(s). Acknowledge and welcome aiga/support person. Clearly introduce yourself, your role and service – Samoan greetings can be facilitated by an interpreter. 	<p>Make sure the patient and aiga understand what is happening, and language resources and visual aids are available to them including speakers of Gagana Samoa, patient advocates and chaplains.</p>

DURING Soālaupule
Soālaupule discussion

Values	Actions	Sharing power with your partner
Fa'aaloalo (respect)	<ul style="list-style-type: none"> • State purpose of meeting clearly. • Make available visual or other aids to support the discussion e.g. glossary, drawings, diagrams. 	Samoans tend to be very polite and modest when communicating with others. Encourage them to speak by asking for their opinions or advice based on their personal behaviours or experiences.
Ava Fatafata (mutual respect)	<ul style="list-style-type: none"> • Be flexible with time for mutual input / questions throughout the discussion. • Encourage and support the opinions and advice of the patient and aiga. • Explain the importance of the referral process - which is to seek a second opinion or more expert advice. 	<p>Samoans are visual people. They are more likely to understand the verbal discussion better if they can visualise the spoken words.</p> <p>Use visual aids, glossary, diagrams to explain.</p> <p>Frequently check their understanding of the information being shared.</p>

AFTER THE Soālaupule*At conclusion of meeting*

Values	Actions	Sharing power with your partner
Fa'aaloalo (respect)	<ul style="list-style-type: none"> • Thank all for attending the Soālaupule - Interpreter can lead the closing comments /process. 	Important to give patient and aiga the opportunity to acknowledge and thank the health staff for the meeting.
Ava Fatafata (mutual respect)	<ul style="list-style-type: none"> • Offer the patient and their aiga the choice of having a prayer to close the meeting. • Ask if their questions/concerns have been well addressed. • Ensure follow-up plans are clearly explained and understood. • Ask if there are any barriers to their ability to action the follow-up care plan (i.e. appointments, medication costs). • Review any 'take home' instruction or information documents to ensure their understanding. • If possible, provide a key health worker contact name and number they can call if they need more information. 	<ul style="list-style-type: none"> • If you communicate well, the patient and aiga will have a good understanding of the reasons and benefits of the follow-up plan increasing likelihood of adherence. • Offer translated material if available. • Confirm contact details are current and correct (name, address, phone number, email address).
Alofa (love)	<ul style="list-style-type: none"> • Thank you in Samoan – Fa'afetai (informal) or Fa'afetai tele lava (formal). • Goodbye in Samoan – Tofā soifua or Manuia le aso (have a good day). 	

PROTOTYPE

PHASE 3 FINAL REPORT:
A TALE OF TWO SYSTEMS

Soālaupule Capability Building Workshop

A Tale of Two Systems. Phase 3 Report:

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Prototype: Soālaupule Capability Building Workshop

Explainer: This prototype is aimed at providing health professionals with a learning and development module that explains and values Soālaupule.

This workshop is relevant for practitioners and professionals across the health system who wish to deepen and improve their understanding of, and engagement with Samoan patients and their families, particularly when it comes to decision making.

The prototype is set out in a format that encourages health professionals to learn alongside their colleagues about Soālaupule, understand its context, and how it can be applied in the workplace.

While the Soālaupule Capability Building Workshop can be read as a single item, we strongly advise that the Soālaupule Family Meeting Guide and Rheumatic Fever Infographic and Glossary are utilised as learning aides for this workshop to enhance one's learning and understanding of Soālaupule.

Overview of workshop

Soālaupule is an approach that creates equity by sharing power and decision making.

The exercise will cover three components:

- Session 1: What is Soālaupule?
- Session 2: Understanding the lived experiences of Samoans across the rheumatic fever system
- Session 3: The Tale of Two Systems

Session 1: What is Soālaupule?

Activity

1. Read the reading material for this session
2. Reflect on the following questions:
 - a. What do you wonder after reading this?
 - b. Where do you see the opportunities for change in your everyday work?
 - c. What is one action you can commit to take in response to this learning?
 - d. Who can support you and what is the formal process that will keep you to account around this change?

Reading Material

What is Soālaupule?

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Appendix B2

Importantly, the concept recognises the need to equalise the unequal power dynamic between parties. Soālaupule enables issues to be dealt with in a manner that is beneficial to both parties for the betterment of everyone involved. In this case, health staff and patients and their aiga should have shared authority in the discussion, decision-making and outcome(s) of a meeting. For example, patients with rheumatic fever are treated respectfully by health staff and are actively encouraged, supported for their opinions and advice, as well as consulted on all aspects of care and decision-making.

▶▶ [Watch the video: Case Study 3: Soālaupule Capability Build](#)

Refer to the **Soālaupule Family Meeting Guide** on page 65 for more information.

Session 2: Understanding the lived experiences of Samoans across the rheumatic fever system

Activity

1. Read the reading material for this session: Personas and Journey Maps.
2. Reflect on the following questions:
 - a. What do you notice about their journeys?
 - b. Where do you see the opportunities for change in your everyday work?
 - c. What is one action you can commit to in response to this learning?
 - d. Who can support you and what is the formal process that will keep you to account around this change

Reading Material

Personas and Journey Maps

- We use Personas and Journey Maps to help us in our learning.
- Personas help us understand the people who are impacted by the problem.
- Journey Maps help us understand their lived experience.

Personas

Personas are characters that are created to help us understand the different types of people in a system. They are not real people, but an amalgamation of the characteristics and experiences of Samoans we interviewed. The quotes are representative of the things that people said to us, as well as direct quotes attributed to individuals.

Malia represents a family/community perspective

Malia represents young people with rheumatic fever / rheumatic heart disease that were interviewed. Malia's journey map tells the story of Malia's experiences. It helps us see the relationship between Malia and the health and social care system, and the opportunities for change.

Amosa represents a practitioner/ professional perspective

Amosa represents Samoan practitioners and professionals that work across the rheumatic fever health and social care system. Amosa's journey map tells the story of Amosa's experiences. It helps us see the relationship between Amosa and the system, and the opportunities for change.

Appendix B2

Journey Maps

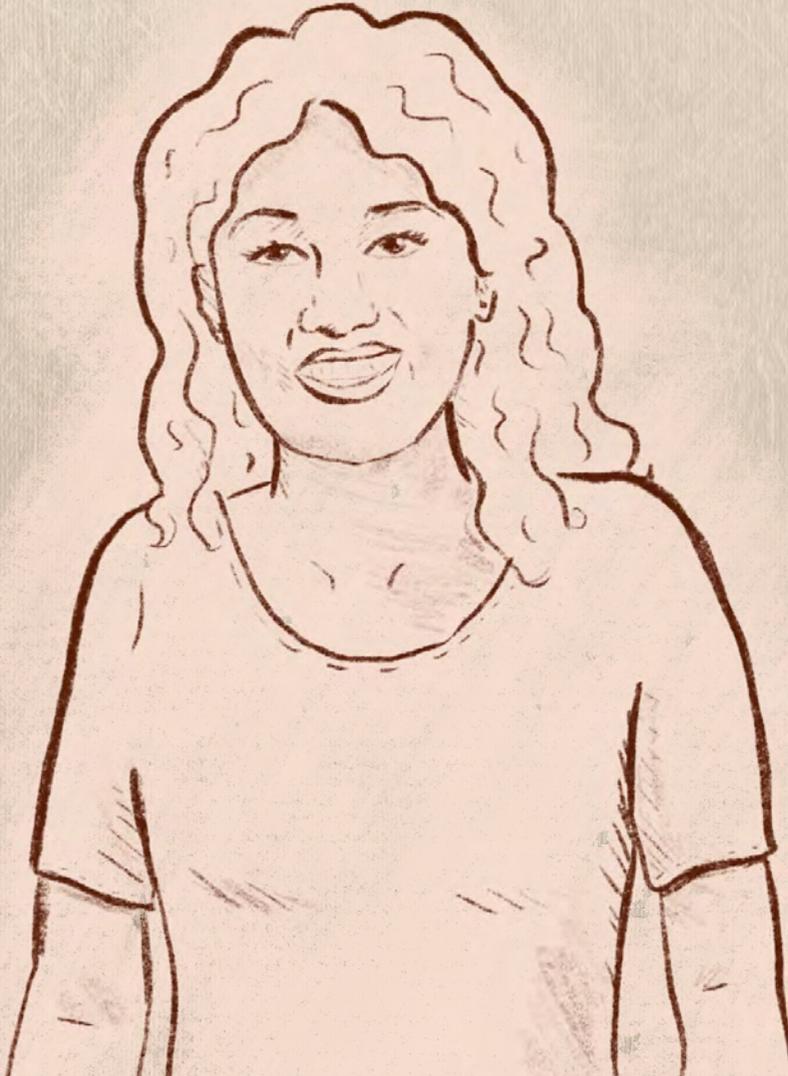
Journey Maps are a representation of the lived experiences of Samoans we interviewed. A special and unique feature of our Journey Maps is the identification of Malia and Amosa's wellbeing needs as Samoans, as pictured by the Fonofale model.^{A2} This highlights how their wellbeing is impacted by the multiple dimensions of wellbeing, including Tausiga o le Vā. Samoans place significance on Tausiga o le Vā – the nurturing, maintaining, caring and keeping of the relationship between all beings, entities and dimensions. Samoans believe that when all elements are working together in harmony, a person's wellbeing in its most holistic sense, thrives and flourishes.

Refer to **Malia and Amosa's User stories** from page 74.



^{A2} Pulotu-Endermann, F.K. (2001). Fonofale Model of Health.

Malia's story | Community lived experience



Malia's mother is a first-generation New Zealand-born Samoan. Malia is in her mid twenties and lives with her extended family in Tāmaki Makaurau. She's proud to have completed a tertiary qualification. She was given a lot of independence growing up and feels fortunate to have done things like travel and have a good start in the employment sector.

Like many of her generation, she is living the hopes and dreams of her migrant grandparents who have worked hard to give her parents a better life. Her family values are strong and their great aspirations for her can be daunting.

She struggled with a respiratory condition growing up and thought her first signs of rheumatic fever in her early twenties were just signs of her existing illness. She's determined to be more than her rheumatic fever condition and hopes to live abroad one day.

Malia's journey



"I love my family but sometimes feel obligated to do the 'family thing.'"

"I just worked a full day...and all of a sudden, my joints are so sore. I can't move..."

"It's gotten really bad. I have no choice but to go to A&E."

"I didn't know what my diagnosis meant despite being in hospital for five days. The cardiologist didn't take time to notice I had questions"

Situation

I visited my uncle's house for a family gathering. He's my fave uncle and he needed my help with visitors from Samoa. There were 20 relatives that stayed over for a few weeks. It was uncomfortable squashing in the four-bedroom house but it's for family.

I've got a new job. I'm coughing a lot and my chest feels a bit congested. I start getting some sore joints and feeling tired. But I think it's just my respiratory condition, so I'll just get it checked at my next regular appointment.

The doctors told me they were going to do an echocardiogram. They couldn't see anything. They didn't tell me what the echocardiogram was for or why I was getting it.

They picked up the heart murmur in the second echocardiogram. He just told me I have RF. It felt like he assumed I knew what it was because I'm a Pacific Islander and he didn't make time for my list of questions.

Wellbeing needs



I need to keep the Vā with family members in harmony.

I don't want to burden my family; I don't think I need to see my GP just yet. I'll suck it up.

Hearing the words, 'echocardiogram' caused anxiety for Malia which was compounded by the lack of explanation for why she needed it.

I expected the doctor to do the basics and explain what was happening to me. The palagi view of the Vā was only clinical and transactional but for me it's relational.

Implication

The negative implications of 'overcrowding' are not considered when the Samoan community (and collective societies) gather for cultural or family gatherings.

People may not be presenting to GPs because of costs and because it is daunting for Pacific people.

This is a critical moment for Malia; her anxiety levels are high and demonstrates a less than acceptable standard of care for a patient.

Clinicians may apply a 'one size fits all' lens on Pasifika in NZ irrespective of their level of education and socio-economic status.

Emotions



OBLIGATED



FEAR



SCARED



JUDGED



TENSION BETWEEN INDEPENDENCE & CULTURE



BEWILDERED



OVERLOOKED



LOST



UPSET & OVERWHELMED



Malia's journey



“They told me I have RF and I can go home. But I'm like, OK, am I well enough to go home, or am I gonna die?”



“I didn't realise my appointments will be ongoing for 10 years and I am angry that this was not made clear to me.”



“The nurses or the ladies that would do my injections are the ones that really informed me of what I needed to do and would check in to see if I was okay.”



“My chest hurts. I'm not sure what to do. I need a GP referral but what if something bad happens before I get there?”

Situation

I am being discharged from the hospital but I feel like they have not provided me with enough information to ensure I am safe when I go home. I have to Google everything.

I have to organise my first appointment for my Penicillin injection. I'm feeling nervous, in shock and angry that this is my life for the next ten years.

The best part is the nursing staff because they really listened to my concerns and answered all my questions. I learned a lot about RF and my case. I'm annoyed that this is my new routine but I'm at peace that I found a credible and reliable source of information.

I started to have chest pains and I panicked because I am not sure if it is RF or my other condition playing up. I can't go directly to the cardiologist without a GP referral. Waiting for a GP referral is making me anxious, what if I have a heart attack?

Wellbeing needs



The Vā was still disrupted for me and the opportunity to restore harmony by getting information from the doctor has gone.

Mistrust of those in this Vā I am forced to be part of causes mental stress.

There's harmony in Vā with the nurses. I feel safe with these professionals.

My mental health is being affected by the stress of not knowing what to do and not trusting the information given.

Implication

Marginalised people do not trust the system and a less than standard experience within the system amplifies their suspicion and mistrust.

Without access to trusted sources of information, people risk making poor decisions that may have long term effects on their health and aiga.

Marginalised people feel more open and at home when they are listened to and made to feel welcome.

Without access to trusted sources of information, people risk making poor decisions that may have long term effects on their health and aiga.

Emotions

 CONFUSED

 OVERWHELMED

 PLEASANTLY SURPRISED

 FEAR

 DISTRUSTFUL

 ISOLATED

 SUPPORTED

 PANIC



Malia's journey



"The nurse treated me like the doctor that diagnosed me at the hospital, a brown person who is poor and has this disease."

"If I want to live abroad I have to now think about my injections and what's that gonna look like in a different country? Who will support me over there?"

Situation

I am getting home visits due to COVID-19 restrictions. The nurse seemed to question my ability to live in a good neighbourhood and be in a family that owns their home.

It's been two years since I was diagnosed and although the treatment routine is taking me time to adjust to, thoughts about how to navigate this routine with aspirations of travel abroad adds stress to my planning.

Wellbeing needs



This one bad experience has impacted the harmony of Vā with the nurse; it overshadows the good experience I had with the clinic nurses.

The relational Vā with family and friends is the support I lean on outside of my treatment and it is this Vā that will bring back some normality.

Implication

Implicit biases heightens suspicion and creates barriers to understanding and good relations with those in authority.

People living with RF need a road map to help them live a normal life.

Emotions

JUDGED

FEARFUL

ANNOYED

UNCERTAIN

Amosa's story | Practitioner & professionals experience



Amosa is a first-generation New Zealand-born Samoan. He was raised in a culturally traditional Samoan family and continues to apply his cultural values both in his personal and professional life – it keeps him grounded. He is a Samoan senior public servant who often works with families dealing with rheumatic fever and rheumatic heart disease.

He brings a unique understanding of Pacific communities' living circumstances into his work, and applies that understanding where it can support positive outcomes for Pacific families. He is an active contributor in his community and has strong relationships with numerous people through his involvement in the church and the local sports club.

Amosa's journey

PERSONAS AND JOURNEY MAPS



"I can't just say, sorry that's a housing problem or social problem."



"I'm going through the backdoors, through family members and saying, 'Hey this person needs extra support', going to housing etc to try and influence that way."



"Because, you know, if we can strengthen everything, and I go back to that whole Fonofale model, let's get the base right. We got the pou you know, and then everything becomes stronger."



"E iai le mea foi lele kakou ke le mafai, e iai le faaaloaloga foi lea e faapea, ku'u ai pea ia, aua le koe fesili i ai" / "There is that respect, where we should just leave it as it is, don't ask them again."

Situation

I meet with a Samoan family on a social issue and find out two of their children are also struggling with RHD and other social issues. They need more support than my organisation is funded for. I can't help them as we are only funded for specific activities.

Even though my organisation doesn't support me, I'm going out to my networks to support this family and provide them the much-needed social support. I'm drawing on my networks (family and friends and contacts across the provider/institution network).

After a lot of work, the family got the support they needed, but I'm reflecting that I'm going beyond my job description and what I'm resourced to do. It is culturally important and professionally necessary – family needs to be at the centre.

I update my manager, who is Pālagi. While he understands the principles, he doesn't understand the experiences and struggles of Pacific families. He says RF interventions that worked in other parts of Auckland, will also work in our South Auckland region. I don't question his authority; despite the frustration I feel – he doesn't understand what it's really like to be Pacific.



Wellbeing needs

Ensuring family's RF circumstances and context are holistically addressed, is vital for their wellbeing.

He expends his social, political capital to ensure all aspects of the social concerns of this family are being addressed.

My culture is informing and driving the best approaches to effect change and to address the conditions that limit the required support.

This one-size-fits-all approach doesn't match the holistic nature of a Pacific approach to wellbeing. It doesn't consider family, culture.

Implication

A competitive and "one size fits all" funding model for RF resources confines funding outcomes to individual sectors and perpetuates the fragmented systems approach to addressing RF.

Samoan people are using "common sense" approaches, going above and beyond job description and their institutional mandate, to provide the totality of required support and assistance for families experiencing RF.

Cultural and social capital is necessary in delivering Pacific for Pacific services.

Raising the hard issues around systems inequities and racism are difficult and viewed as counter-productive to the practice of Samoan values of respect, not questioning authority; to always show gratitude.

Emotions



CONCERN



MOTIVATED



RELIEVED WITH RESULT



FRUSTRATION



EMPATHY FOR FAMILY



JUSTIFIED



FRUSTRATED WITH SYSTEM



DEFERENCE



Amosa's journey



"I don't think that government has all the answers to my problems...but I do believe in community led solutions, that community knows best...I'm interested in disrupting the status quo."

"I think that if it's led from the top, it's always top of mind, because with rheumatic fever, people probably think it's all fixed by now."



"That was a good discussion. We keep having these conversations though, raising things that aren't listened to... I wonder when something will finally change... Oh well, time to go home."

Situation

I'm at the gym with some of my friends who are also Pacific professionals. I talk about what my manager said. Everyone talks about the systemic changes they think is needed. A senior community leader says we need a re-think of the role of government, public sector and communities when addressing issues like RF. Another says we need Pacific leadership at the table for funding allocations and Pacific champions with mana and influence.

We had a good discussion. We all go home. Nothing changes.

Wellbeing needs



Amosa hopes for influential and stronger Pacific leadership at a higher level in the system

Without changes to the system, Amosa is left feeling undervalued and deflated

Implication

Transformational change calls for a disruption of the status quo, driven by multiple actors: those who lead collaboration, those who contribute, and leadership from across community. Keeping RF top of mind across sectors and within communities calls for champions with influence and mana.

Emotions



ENERGISED



HOPEFUL



DISAPPOINTED

Session 3:
The Tale of Two Systems

Activity

1. Read the reading material for this session
2. Reflect on the following questions:
 - a. What do you wonder after reading this?
 - b. Where do you see the opportunities for change in your everyday work?
 - c. What is one action you can commit to in response to this learning?
 - d. Who can support you and what is the formal process that will keep you to account around this change?

Reading Material

The Tale of Two Systems

Despite years of investment and effort to reduce rheumatic fever and rheumatic heart disease in Aotearoa, Samoans have continued to carry an unequal burden of these conditions. The unique opportunity of this work has been to capture and amplify the distinctive experiences and expertise of Samoans in Aotearoa to inform new ways of approaching this complex problem.

Malia and Amosa’s journey across the rheumatic fever ecosystem tell a clear and compelling story: “A Tale of Two Systems”.

One system is our Samoan holistic system of wellbeing which stems from our view of the world, Fa’asamoa (the Samoan way). It is a holistic understanding of the complex nature of a person’s health and wellbeing that is multidimensional. Samoans place significance on Tausiga o le Vā – the nurturing, maintaining, caring and keeping of the relationship between all beings, entities and dimensions. Samoans believe that when all elements are working together in harmony, a person’s wellbeing in its most holistic sense, thrives and flourishes.

The second system is the formal rheumatic fever health and social care system in New Zealand. This system is also complex and not people-centred. Over and over again, we heard experiences of Samoans whose wellbeing was diminished, rather than strengthened, by the rheumatic fever health and social care system. Our complex understanding of wellbeing was disregarded and met by a poorly communicated clinical diagnosis, followed by months and years of being judged, stereotyped, marginalised and disempowered. Any stories of a positive experience were few and far between.

It is important to note that these experiences were felt by Samoans and their families across the whole ecosystem. This includes Samoans living with acute rheumatic fever (RF) and rheumatic heart disease (RHD), and Samoan practitioners and professionals who work across the rheumatic fever health and social care system. Their inherent wisdom, knowledge and expertise is trivialised or ignored resulting in countless missed opportunities for prevention and persistently poor outcomes.

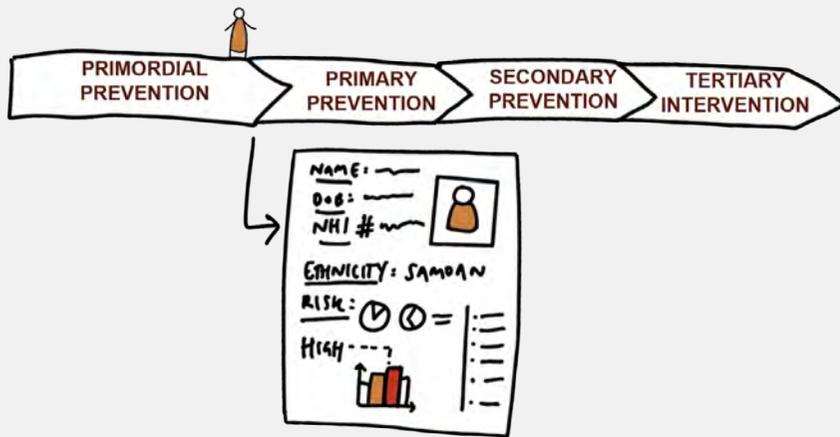
Samoans are utilising their own personal and relational capital to mitigate the trauma for themselves and those they are providing care for, and this deeply affects their wellbeing. The formal rheumatic fever system in New Zealand does not acknowledge, understand or value the existing and inherent strengths and know-how of Samoans. Critically, it cannot access or leverage the existing base of knowledge and power in Samoan individuals, families and communities to inform truly effective prevention and management of rheumatic fever.

The opportunity for the greatest impact lies in our personal and collective response to this Tale of Two Systems. These insights give us mandate to explore the imbalance of power

across the two systems, and create and test ways in which the strengths, wisdom and expertise of both systems can be leveraged to remove the blight of rheumatic fever from our nation.

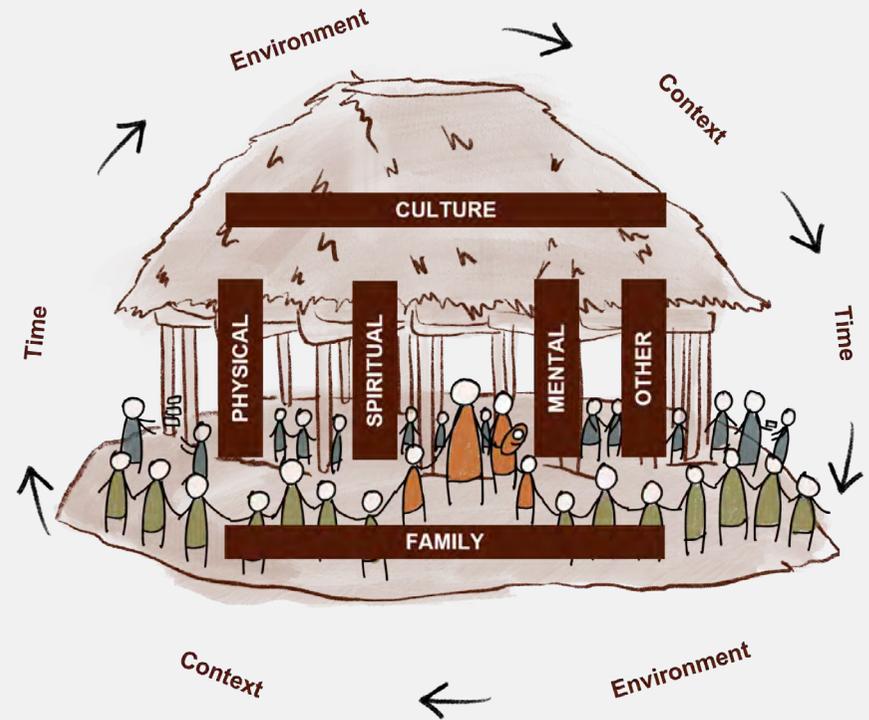
Diagram B2.1: A tale of two systems

HOW THE SYSTEM SEES ME



Adapted from Fonofale model developed by Fuimaono Karl Pulotu-Endemann

HOW I WANT THE SYSTEM TO SEE ME



PROTOTYPE

PHASE 3 FINAL REPORT:
A TALE OF TWO SYSTEMS

Rheumatic Fever Infographic and Glossary

A Tale of Two Systems. Phase 3 Report:

Samoa Team, Rheumatic Fever Co-Design Initiative.

Prepared by: Annie Ualesi, Louisa Ryan, Sam Lafolua, Toleafoa Alfred Schuster,
Tai'ivao Lemalu Siniva Ieru-Cruickshank, Caleb Va'a, Jodi Meadows, Nadine Metzger,
Loncey Craig, Justis Kamu.

Commissioned by **Te Whatu Ora - Health New Zealand.**

Supported by **ThinkPlace.**

E ui ina sui faiga, ae tumau pea fa'avae.

Though the approaches may change, the foundations remain the same.

Our invitation to you

This prototype was created by Samoans to inspire and spark change across the health system. Its purpose is to nudge the system away from inertia and to give a sense of what can be possible.

The prototype is a reference point for you to launch further change. It is not necessarily a finished product, and we invite you to use it as a base for further work.

We simply ask that you hold true to its intent – to honour and respond to what Samoans want and require to prevent and manage rheumatic fever. We encourage users to seek cultural guidance and reassurance from other Samoans who are well versed in their culture (Fa'asamoa) and Gagana Samoa (Samoan language) before making changes to this document.

The infographic and glossary was prepared for a specific context: a child is experiencing a sore throat, and the family visits a GP. You can imagine how the infographic and glossary can be used by the GP in that situation to explain what is happening in a way that makes sense to the family. It visually explains the impacts of Strep Throat and Rheumatic Fever on the heart and also describes the journey of the Strep Throat bacteria from the throat to the heart.

In particular, the prototype demonstrates two things:

1. How a clinical process can be explained visually.

2. How translations and consistent terminology can help explain medical terms.

People who engage with Samoan families identified the terms in the glossary as the ones that can cause the most confusion for families.

While the content is not universally applicable to all clinical processes related to rheumatic fever, the principles of how to communicate with families are universal and can be applied within other contexts. That is our invitation to you.

Lastly, the infographic and glossary can be utilised as a tool of engagement as part of the Soālaupule Family Meeting Guide and complementary to the Soālaupule Capability Building Workshop.



**FIVA RUMATIKA: O LE MEA E TATAU ONA
FAI, MA LONA A'AFIAGA I LE FATU**

(RHEUMATIC FEVER: What you should know
and the impact on the heart)

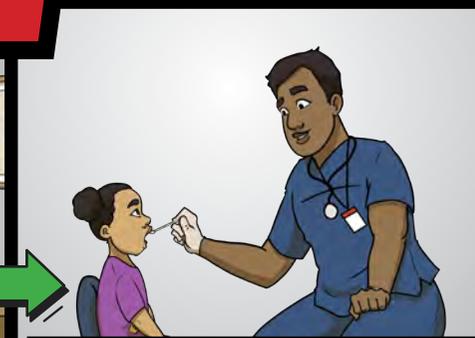
**FIVA RUMATIKA: O LE MEA E TATAU ONA FAI...
RHEUMATIC FEVER: WHAT YOU SHOULD DO...**



Tigā le fa'ai
(Sore throat)



Va'ai lau foma'i
(Visit the doctors)



Siaki lou fa'ai pe mafua i le siama o le Strep A
(Get throat tested for Strep throat)



E 3-7 aso e faatali ai mo le i'uga o lau siaki
(After test, it takes 3-7 days for results to return)



Manaia tele!
(Congratulations, you have not tested positive for Strep A)

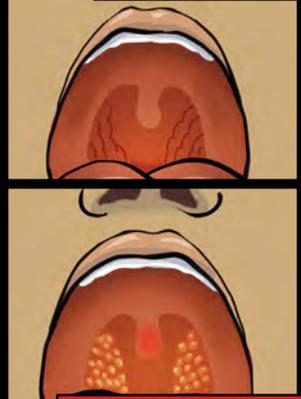


Amata togafitiga e pei o le tui po'o fuāla'au penisilini, faapea fuāla'au tui mo ē a'afia i tui ma fuāla'au penisilini
(Treatment begins with either penicillin injections or tablets. Sometimes it will be erythromycin if the patient is allergic to penicillin)

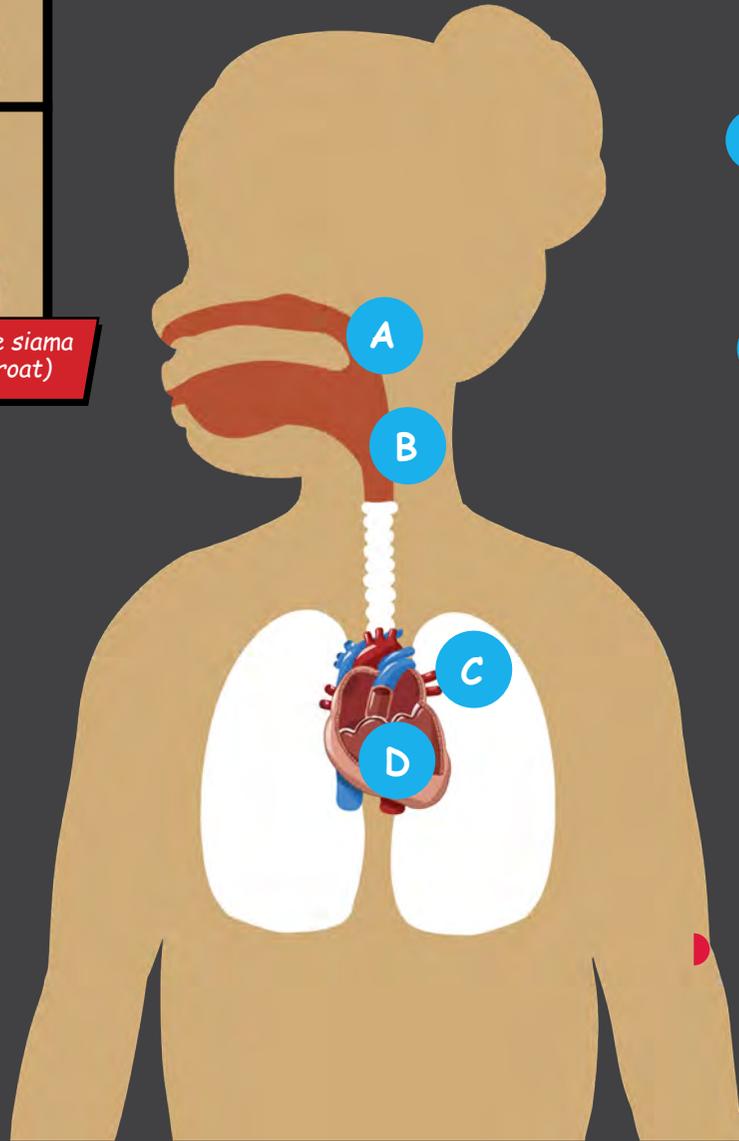
O A'AFIAGA O LE FATU ONA O LE SIAMA O LE STREP A THE IMPACT ON THE HEART DUE TO STREP A BACTERIA

A

Fa'a'i e leai se siama (Healthy throat)



Fa'a'i ua mau i le siama (Unhealthy throat)



B

Sosolo le siama ma a'afia ai isi totaga (Bacteria can spread and affect other organs.)

Åuga o le fiva rumatika e mafai ona aafia ai le fulafula ma le tigā o so'oga o ponāivi
(Symptoms of rheumatic fever can include inflammation and sore joints)

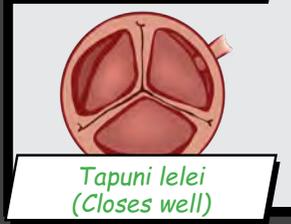
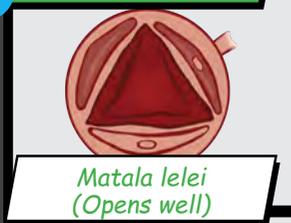
C

E matuā tele le afaina o le fatu i lenei siama ae maise faitoto'a alatasi (The heart is extremely impacted by the bacteria, especially the heart valves)

D

Faitoto'a alatasi o lo'o lelei (Healthy heart valve)

Faitoto'a alatasi ua afāina (Diseased heart valve)

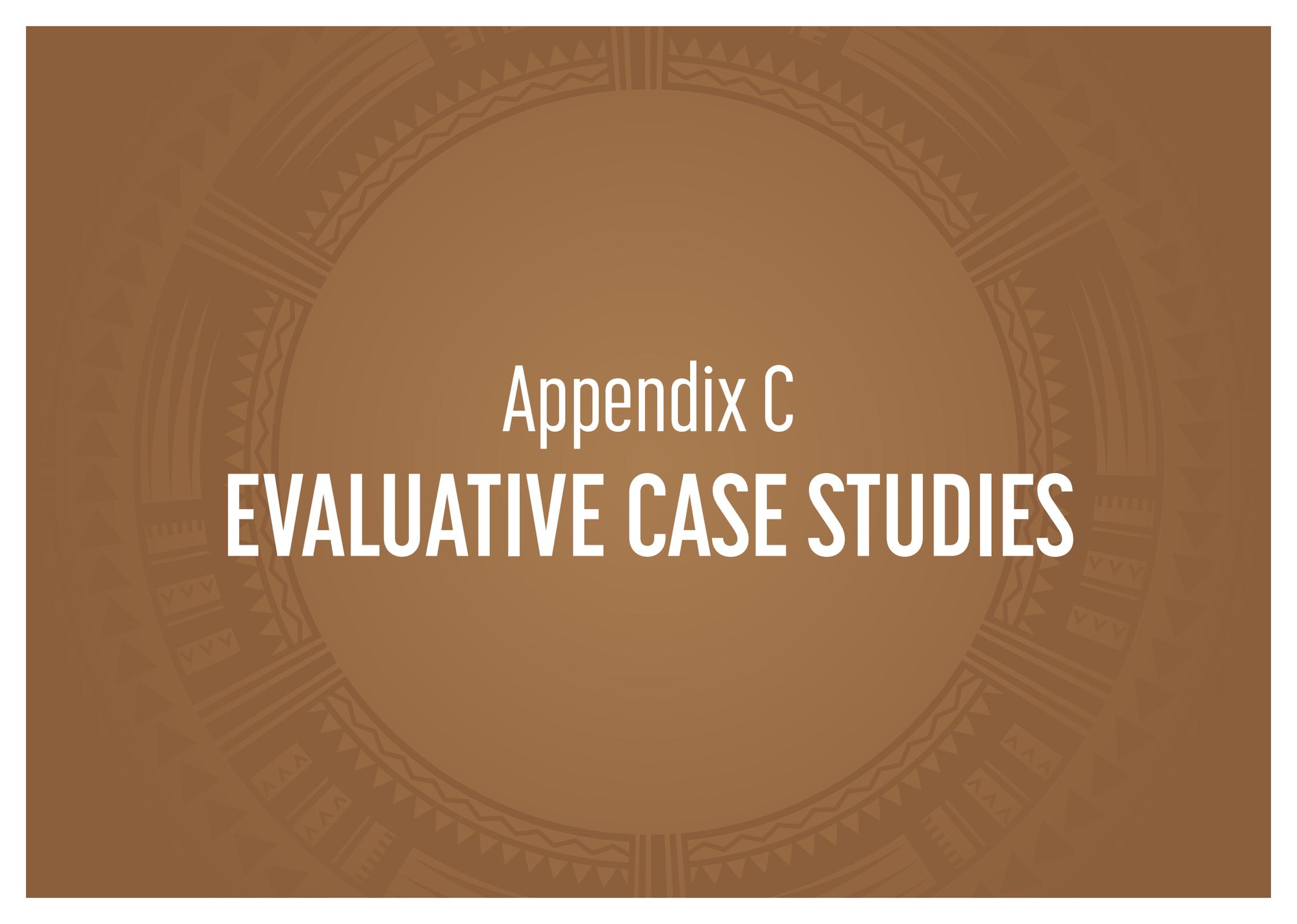


E fa potu ua vaevaeina ai le fatu. O potu e lua pito i luga e ta'ua o Atriums. O potu e lua pito i lalo o Ventricles
(The heart is divided into four rooms. The top two rooms are called Atriums. The bottom two rooms are called Ventricles.)

O le afaina o le lē matala ma lē tapuni lelei o faitotoa alatasi, o le a a'afia ai le galuega a le fatu i le pamuina o le toto i le tino atoa
(When the valves do not open and close properly it can affect blood flow.)

GLOSSARY:

TERMS	TRANSLATED or EXPLANATION
Rheumatic Fever	Fiva Rumatika
Heart Valves	Faitoto'a alatasi
Strep throat	O le fa'a'i tigi e mafua ile siama o le Strep A
Atriums/Ventricles	Atriums – potu e lua pito i luga o le fatu Ventricles – potu e lua pito i lalo o le fatu
Medicines/Antibiotics	Fuāla'au tui (antibiotics) Vaila'au ma fuāla'au tui
Penicillin injection	Tui Penisilini
Erythromycin	Fuāla'au tui e sui ai le fuāla'au penisilini(erotomaisini)
Diagnosis	Ua fa'amaonia ua maua i le Fiva Rumatika ona o sā'ililiga ma su'esu'ega
Inflammation of joints and heart valves	Fulafula so'oga o ponāivi fa'apea ma faitoto'a alatasi o le fatu
Sore joints	Tigā so'oga o ponāivi



Appendix C

EVALUATIVE CASE STUDIES

Introduction

The following evaluative case studies were created by the specialist evaluator who worked alongside the Samoa Team.

There are five evaluative case studies:

- **Evaluative Case Study 1:**
Soālaupule – a process and a prototype
- **Evaluative Case Study 2:**
Confluence of influence – assembling the Samoa Team
- **Evaluative Case Study 3:**
Developing young people and their capacity to affect change in the rheumatic fever system
- **Evaluative Case Study 4:**
Creating meaningful community partnerships – Ōtara Scorpions Rugby League Club
- **Evaluative Case Study 5:**
Navigating the system.

The evaluative case studies are also supported by video case studies (refer to links on pages 11 to 14) which provide perspectives on aspects of the evaluative case studies.

Evaluative Case Study 1: Soālaupule – a process and a prototype

Summary

Soālaupule, although an established and traditional practice in Samoa, is a relatively new approach in the health sector. It encompasses the idea of sharing authority or mandate in each setting, aiming to address the negative experiences Samoan families had during health conversations where they felt excluded and lacked power.

“Soālaupule comprises three action words. ‘Soa’ means to partner or to share. ‘Lau’ means yours and ‘pule’ means ‘authority’ or ‘mandate’, explains co-designer Toleafoa Alfred Schuster. “So, when you bring that together, Soālaupule means sharing authority or your mandate in a particular way, in any given setting.”

During the co-design insight sessions, the team heard from Samoan families that their general experience of health conversations with professionals was less than positive.

“They were not treated with respect in the sense that they weren’t brought into the conversation,” remembers fellow co-designer

Louisa Ryan. “We heard they didn’t have any power. They were not given the opportunity to talk about their story.”

“When you respect people’s worldviews, cultural norms, individual knowledge, and who they are, that’s when you have really good trusting relationships and meaningful relationships and conversations,” explains Louisa. “And that’s what Soālaupule will achieve.”

As a result, the team found that knowledge and understanding of rheumatic fever amongst individuals and families living with the disease was relatively low.

Recognising the need for a power rebalance, the team developed a design prototype that applies Soālaupule to clinical best practice and tested it with both families and professionals.

The testing served as an opportunity to introduce Soālaupule to non-Samoan health professionals and gather reactions on its value in improving engagement with Samoan families.

“Soālaupule creates an environment where there is a rebalancing of power,” explains Toleafoa.

“The rebalancing comes in the form of recognition and valuing the importance of the circumstances of Samoan families in their journey and their experience of rheumatic fever,” he says.

Toleafoa saw the testing as not only an opportunity to introduce Soālaupule to non-Samoan health professionals who may not be familiar with the concept. It was also a way to solicit reactions from Samoan and non-Samoan health professionals as to whether they saw value in Soālaupule to positively influence and adjust the engagement with Samoan families. The test sought to nudge in-depth reflection from those present.

The feedback received after the prototype test was overwhelmingly positive, with many practitioners acknowledging the significance of addressing power dynamics in health consultations and the importance of building consensus and shared solutions.

“The focus on the power dynamic was a revelation for many practitioners,” notes Toleafoa.

West Auckland General Practitioner Dr Maemaeroa David believes using a method such as Soālaupule has enormous potential for better health outcomes for Samoan communities.

“Soālaupule shows us that it’s the system failing our people, not the people failing in the system.”

“Soālaupule shows us that it’s the system failing our people, not the people failing in the system”, she says.

For Dr David, the power of Soālaupule lies in the fact that it sets up a health interaction in traditional and familiar ways. “This can shift the engagement of Samoan patients because we’re interacting with them in ways that they can recognise and feel comfortable with”, she says.

Similarly, Denzel Laumatia-Paki Principal Advisor, Equity (Pasifika) Royal NZ College of GPs believes the practice of Soālaupule in health settings has enormous potential.

“It empowers Samoan people to have the autonomy to self-navigate their spaces and provide advocacy on behalf of themselves, their aiga, and their families,” he says. Following the workshop, the team has successfully established partnerships with the Pasifika GP Network, the Pasifika Chapter for the Royal New Zealand College of General Practitioners and the Goodfellow Unit at Auckland University. These organisations aim to transform the Soālaupule Workshop into a continuous learning module specifically designed for non-Samoan practitioners with the aim of using Soālaupule to promote respectful and effective healthcare interactions.^{C1}



^{C1} See Appendix A1: Connecting an Ecosystem of Influencers

Evaluative Case Study 2: Confluence of influence – assembling the Samoa Team

An important part of this co-design process has been the leveraging of relational capital by the core project team to create safe and inclusive spaces for Samoans to participate. The following case study talks about how the team needed a diverse range of skills and experiences and how the openness of the team to emerging insights and opportunities resulted in the final prototypes.

Summary

The “confluence of influence” in the co-design process was the team of Samoan practitioners (Samoa Team) who came together to co-design responses to prevent and manage rheumatic fever in Samoan communities. According to team leader Annie Ualesi, a multi-disciplinary team who held relational and cultural capital in Samoan spaces was more important than co-design experience.

While co-design skills can be learned, the relationships each team member brought from the health and policy systems and the Samoan community alongside their deeply

held Samoan worldviews (Fa’asamoa – the Samoan Way) were invaluable to the co-design processes.

The team’s extensive background in funding, planning, commissioning, community work, negotiation, and coalition building allowed them to open doors to deeper conversation and creation.

The importance of this “confluence of influence” is that the team was able to apply Fa’asamoa values in the way they worked, which centred around community, *ava fatafata* (mutual respect), *fa’aaloalo* (respect), *fa’amaoni* (faithfulness), and *alofa* (love) reciprocity, trust, and respect (*fa’aaloalo*). It helped them to design several prototypes that unleash Samoan capital and support Samoan ways of being in the rheumatic fever system.

Case Study

When people with influence across the system converge on one point, it could be called a confluence of influence. In this case, it was a team of Samoan practitioners brought together to co-design responses to rheumatic fever in Samoan communities.

Despite only two members of the team having previous co-design experience, this was not an issue for team leader Annie Ualesi.

“I knew a multi-disciplinary team who held relational and cultural capital in Samoan spaces was more important than co-design experience” explains Annie. Whilst co-design skills can be learned, the relationships each team member brought from the health and policy systems and the Samoan community alongside their deeply held Samoan worldviews (Fa’asamoa) were invaluable to the co-design processes.

“This co-design initiative has been all about relationships” says Annie. “Our design team expended all their social, cultural and relational capital to open doors to deeper conversation and creation.”

Louisa Ryan, a senior Samoan health professional with experience in funding, planning, and commissioning agrees.

“This was a true co-design process,” she says. “Co-design is not just community voices. It was about listening and unpacking what is happening in rheumatic fever responses to a level where there is a deeper understanding. It wasn’t just a one-day chit chat with our people. We went round and round through several community sessions and kept building.”

“Our design team has expended all their social, cultural and relational capital to open doors to deeper conversation and creation.”

Annie comments, “We invited people to come close and held them on our journey for months and ensured there was reciprocity in that relationship so we could create together.”

In the process of gathering insights from Samoan communities and health professionals over many months, the team developed the co-design skills they needed, which they overlaid over a Fa’asamoa foundation.

“During the discovery and prototyping phases, we applied Fa’asamoa in the way we were working, which centred around community, reciprocity, trust, and respect,”

Toleaoa Alfred Schuster explains, who has an extensive background in international policy, negotiation, and coalition building.

He explains he saw the potential of Fa’asamoa to fulfil the needs of their community in the rheumatic fever space, especially when it came to spirituality and values.

Deep insight from Samoan communities and practitioners showed, however, that there are two systems; a Samoan holistic system of multidimensional wellbeing and the rheumatic fever health and social system in New Zealand, which is not people centred. The second system, according to Toleaoa, was letting Samoan communities down, as it was “specific to a set of outcomes that serviced institutional accountability, rather than the needs of people and communities.”

During their many discovery and prototyping sessions, the team heard that the rheumatic fever health and social care system diminished, rather than strengthened, the wellbeing of Samoan communities.

“Samoan health professionals told us the system often forced them to work outside of their job scope and description,” says Annie.

Toleaoa agrees. “They possess a strong power base, but this is used in an informal and ad hoc

manner to break down systems barriers to respond to family circumstances. The system acknowledges the gains of this approach but doesn’t move to formalise or normalise it. And that is the shift that needs to happen.”

For Samoan people with rheumatic heart disease, the impact of the two systems was even greater. Retired nurse Tai’ivao Siniva Cruikshank describes how, during the first community meetings, participants asked her what rheumatic fever was.

“These people had already had operations to repair their heart valves from rheumatic fever,” she says. “That is where I thought oh my goodness there is nothing out there.”

Gradually, during the co-design process, a prototype began to emerge. “Soālaupule is a Samoan practice that helps Samoans feel stable, united, confident and safe when actively participating in and contributing to decisions and processes,” explains co-designer and systems innovator Sam Lafolua, “and we used Soālaupule to help direct and guide the process of engaging families during our co-design sessions.”

As it unfolded, it became clear that Soālaupule itself was not only the basis for how the co-design occurred, but also what was being designed. “We didn’t consciously set out to

take this approach,” explains Toleafoa. “It was only later that we realised this way of working was in fact a prototype.”

Altogether, six prototypes emerged from the project, all of which are designed to support Samoan ways of being in the rheumatic fever system. They include a Soālaupule capability workshop and framework for health practitioners who work with Samoan families, a visual glossary to support communications and engagement, youth-led information sharing, a locality system mapping analysis to inform rheumatic fever care and services and a pharmacy-based approach to rheumatic fever prevention and treatment.

For designer Jodi Meadows, these would not have been possible if not for the relationships forged in the early stages. “The story of this work is about how people were brought together in constructive and respectful ways to design prototypes that can cut across so many different medical experiences and journeys,” she says.

Once the co-design process gathered traction, Annie brought in experts in evaluation, visual design and communications to support the prototyping process. Although the team grew, it stayed true to its Fa’asamoa foundations. “The work was done in such

respectful ways” explains,” Jodi. “We were constructive with our conversations, and everyone had space to find their own spot.”

Although Tai’ivao was new to co-design, she found the experience both enlightening and empowering. “I was tired of being involved in projects where things I said were not valued”, she says. “But this was for Samoa. It had Samoan team members and was focused on Samoan families.”

She wants people to remember that this project is grounded in the voices of the Samoan community. “I want them to be mindful of the fact that this is the voice of the community. We want to see this project translated into decision making, so the community doesn’t lose their trust in us.”

For Annie, the co-design initiative has not only unleashed Samoan capital into the system via the six prototypes, but it has also unleashed several Samoan co-designers.

“Everyone has been able to explore their own personal understanding and practice of systems change and co-design” she says. “They will take this to all the other work they do, whether it be in the community, in the system or services.”

“I was tired of being involved in projects where things I said were not valued...but this was for Samoa. It had Samoan team members and was focused on Samoan families.”

Annie is extremely proud of what the team has created. “Nobody I know has gone to the depths we have with Samoans and co-design before.” She recognises that there is a lot on the line. “The burden is heavy. It is constant but it has been alleviated by the level of validation from families, practitioners, and stakeholders. We know we are onto a winning thing,” she says.



Evaluative Case Study 3: Developing young people and their capacity to affect change in the rheumatic fever system

In March 2023, a Talanoa (discussion) night organised by Samoan young people took place at the Ōtara Scorpions Rugby League club in Ōtara, with the aim of supporting and educating other youth about rheumatic fever. In attendance were young people, their families, health professionals and a large support crew.

The idea for this community gathering originated from discussions held during separate co-design sessions, where young participants and their parents shared insights.

“It started as a discussion with young people who came with their parents to our insight sessions,” explains Caleb Va’a, from the Samoa team. “But it soon developed as an idea for a community night where young people can gather around and share the ups and downs of the health journey with rheumatic fever.”

For brothers Antonio and Daniel Afaese who both live with rheumatic fever, involvement in the talanoa night was not only a way to learn more about their condition, but also share

“Youth like me like to be active... and do stuff for a good purpose.”

what they’ve learned about rheumatic fever with others.

Antonio believes that personally hearing messages from those who live with rheumatic fever is an important prevention tool.

“Hopefully it created big awareness towards the issues and dangers of rheumatic fever,” he says. “If you get a sore throat, get to the doctors immediately,” emphasises Daniel.

The brothers were supported by several friends to organise the talanoa night, with Caleb providing ongoing pastoral support to the entire crew. For Caleb, the night was not only an opportunity for the young people to influence those present, but it also offers the opportunity to start influencing a system.

Antonio and Daniel actively participated in the Talanoa night to expand their own knowledge about the condition and to impart what they had learned to others.

Team leader Annie Ualesi challenged the notion within the formal health system that these young individuals are “hard to reach”, emphasising their significance as an integral part of the community.

Inspired by their involvement, some participants expressed a desire to engage in similar meaningful activities, driven by a shared purpose and a desire to make a positive impact.

“I never thought I’d be doing stuff like this” says crew member and MC for the Talanoa Night, Johvan Laga’aia. “But youth like me like to be active, to get out there and do stuff for a good purpose. That’s a good thing. And I reckon we should be doing more of it”.



Evaluative Case Study 4: Creating meaningful community partnerships – Ōtara Scorpions Rugby League Club

Summary

Early in the co-design initiative, the Samoa team and the Ōtara Scorpions Rugby League Club began a key partnership, brokered by several members of the Team who were involved with the Scorpions as players, work colleagues, or members of the Ōtara community.

As Ōtara Scorpions Sports and Rugby League Club president Tagaloa Willie Maea explains, the involvement of the club was motivated by the knowledge that several member families were also personally impacted by rheumatic fever.

“We’re one of those communities where this illness is prevalent,” explains Tagaloa. He saw the involvement of the club in the co-design process as an important part of rheumatic fever prevention.

“If we can help prevent just one child from having rheumatic fever, then we are doing our job in our community”, he says. Despite the

prevalence of rheumatic fever, many in the community including those with rheumatic fever, still didn’t fully understand what rheumatic fever was and how they could manage their own condition and prevent it happening to others.

Through co-design sessions at the Scorpions, individuals like Mr Tovea Tofa shared their experiences and aimed to raise awareness among parents and children about being cautious and seeking medical attention at the earliest signs of rheumatic fever.

“Sa lilo i manatu o lo’o a’afia ai le atali’i i le ma’i (I had no idea my son had the virus)”, explains Mr Tovea Tofa who attended the co-design sessions at the Clubrooms in Ngati Ōtara Park.

“O le aoga le na o le ma o mai i le polokalame, ma fa’asoa atu ai ma le atali’i e fesoasoani ai i matua ma nisi o fanau o tuputupu a’e, ina ia mata’itū vaega ia, ma o e va’ai le foma’i pe afai o maua i āuga o le Fiva Rumatika (That is why we are part of this programme, to share my experiences with my son so we can help parents and children who are going to be more cautious and get checked by doctors once any signs of the rheumatic fever are detected)”, he says.

The involvement of community members was fundamental to the design of the Soālaupule framework, youth talanoa evening and visual glossary. Community members like Mr Tofa and his family attended several co-design sessions where they worked on prototypes alongside Samoa Team. For Mr Tofa, contributing his insights and ideas was an opportunity to support his son, contribute to creating a healthier Samoan community and a way to give thanks to God for giving life and strength to his son.

“We got conversations happening with the experts in a place that is comfortable, that is a safe place, that it’s somewhere where families can come and they can trust”.

So, o le aogā le na o le matou o mai, e matou share atu i tagata, “fa’amolemole ia puipui mai lou aiga mai le fa’ama’i o le Fiva Rumatika. E le o se fa’ama’i faigofie. E faigata. Ma lo’u fa’aaloalo lava. (So that is the importance of our participation. We came to advise people ‘please protect your family from rheumatic fever’, it is not an easy sickness, very complex),” he stated.

Following the prototype design, the club became an extension partner (of the project) and arranged for South Seas Healthcare to attend their club gala day, to make throat swabbing available to the hundreds of club members who attended. The role of the Scorpions club as a trusted and familiar place was vital to the successful gala day.

“We got conversations happening with the experts in a place that’s comfortable, that is a safe place, that it’s somewhere where families can come and they can trust that the information we give them is good for them”, explains Tagaloa.

For Samoa Team leader Annie Ualesi, deep community involvement like that of the Scorpions and their members is where change in the health system starts. “The Scorpions have multi-generational, multi-family reach in Ōtara,” she says. “This is what community-led

health looks like. This is what happens when you unleash Samoan social, relational and cultural capital into the health system.”

For Mr Tofa, it’s a matter of teamwork. “All Samoa from everywhere around the world, especially here in New Zealand need to work together as a team to protect our family from rheumatic heart disease. So that’s my advice, thank you”, he says.

 [A video version of this case study can be accessed here.](#)



Evaluative Case Study 5: Navigating the system

Despite years of investment and effort to reduce rheumatic fever and rheumatic heart disease in Aotearoa, Samoans have continued to carry an unequal burden of these conditions.

Recently there is increased understanding that the high prevalence of rheumatic fever among Pacific people can be attributed to structural inequities and institutionalised racism within the New Zealand healthcare system.

In this system, low complexity, low-cost options which place the burden of rheumatic fever on the individual, such as sore throat checks and changing health-seeking behaviours, are preferred over acknowledging and addressing the structural conditions driving the highly uneven distribution of rheumatic fever.

During the discovery phase, the Samoan co-design team tasked with identifying improvements to the rheumatic fever system found that there were in fact two systems; a Samoan holistic system of multidimensional wellbeing and the mandated rheumatic fever health and social system in New Zealand.

The second system, according to designer Toleafoa Alfred Schuster, was letting Samoan communities down. “The rheumatic fever system is complex” he says. “It is also not people-centred, instead it is set up to monitor outcomes that service institutional accountability, rather than the needs of people and communities.”

Team leader Annie Ualesi agrees. “The existing rheumatic fever system in New Zealand doesn’t acknowledge, understand or value the existing and inherent strengths and know-how of Samoans,” she says.

Accordingly, the Soālaupule prototype that emerged from the co-design process leverages the strengths, wisdom and expertise of both systems to disrupt the imbalance of power across the two systems, and ultimately improve prevention and management of rheumatic fever for Samoan people in Aotearoa.

Navigating a co-design project which challenges power imbalances through the health system has been challenging at times for one Te Whatu Ora portfolio manager. “At the beginning, some people were confused about what we were doing, which made things a bit difficult,” she says. “While some of us had experience with co-design, this approach was

different, and we needed to emphasise that it was a more community-led, patient-centred, and in-depth process.”

The Te Whatu Ora portfolio manager worked hard to hold space for the different approach required by a relational co-design project. “It’s a delicate balance between releasing control and trusting that things will work out,” she says. “One of the things I learned is that we need to take the time and be patient. We can’t just come out with those very rigid, do-do-do plans. Instead, we need to provide that space and really good resources for people to do the work.”

Whilst several prototypes have emerged from the team Samoa Team co-design, it remains to be seen how they are accepted by, and fit within the health system, despite the best efforts of individual champions. “Understanding where different power brokers or influences lie within the system is a significant challenge when it comes to navigating systems change”, explains Toleafoa Alfred Schuster.

“Inequities, discrimination, and privilege are deeply embedded within systems, and we need to acknowledge and address them when implementing systems change.” He notes that this can make some conversations hard

to have. “Unfortunately, people tend to avoid discussing these uncomfortable topics, which makes it challenging to bring about meaningful change.”

Designer Jodi Meadows believes that part of the answer lies in funding innovation and systems change as ongoing conversation, rather than a transaction. “Co-design is not transactional”, explains Jodi. “It is about conversations and relationships over time. Rather than key deliverables, we should be having conversations around what is this going to take. We need to push the system to understand that if we are all aligned with a purpose and that is what we are working towards then that is a much better way of funding innovation.”

