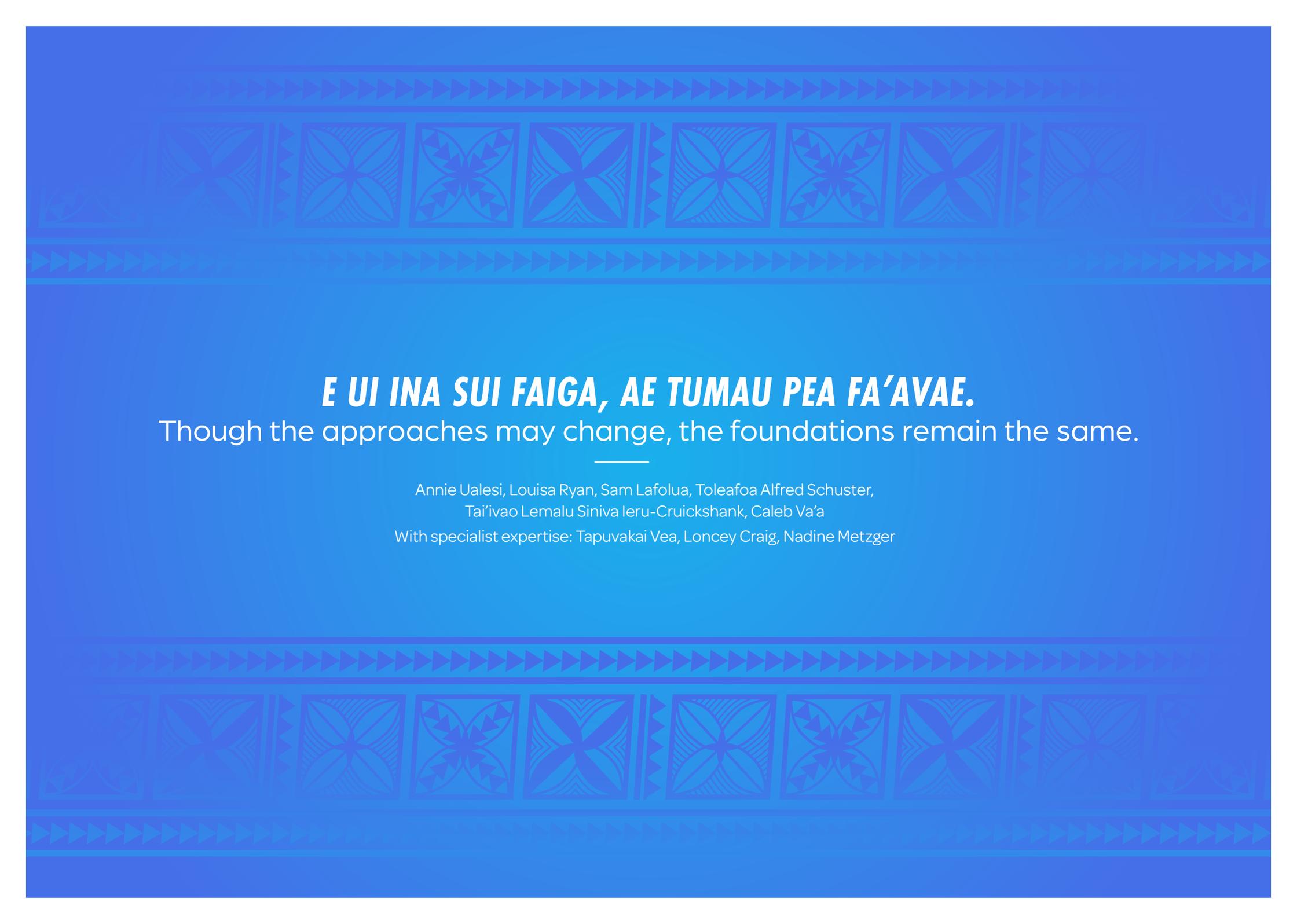




RHEUMATIC FEVER CO-DESIGN INITIATIVE

SAMOA TEAM PHASE 2 REPORT / 30 SEPTEMBER 2022



E UI INA SUI FAIGA, AE TUMAU PEA FA'AVAE.

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

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1. PURPOSE OF THIS REPORT

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This report covers phase two of a three-phase co-design initiative to address rheumatic fever¹ for Samoan people in Tāmaki Makaurau.

The three phases are:

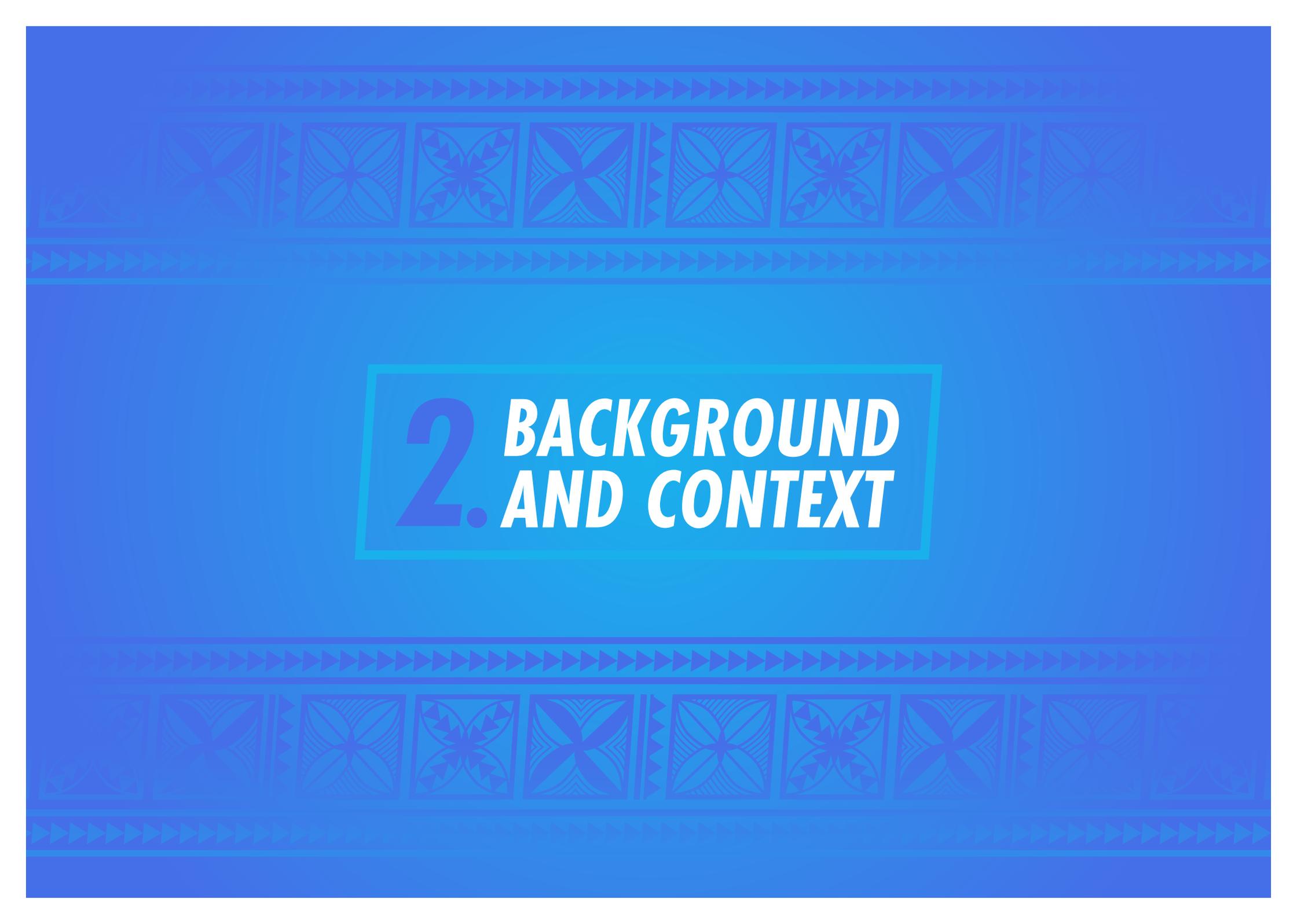
Phase 1: Discover and seek insight into the problem. Define areas of focus.

Phase 2: Develop potential solutions.

Phase 3: Deliver solutions that work.



¹In the interests of readability, we use “rheumatic fever” in this document to refer to both rheumatic fever and rheumatic heart disease.



2. BACKGROUND AND CONTEXT

2. BACKGROUND AND CONTEXT

At the end of **Phase 1 (Discover and Define)**, we identified **four** change opportunities².



1 Unleashing the cultural and relational capital of **Samoan 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 journey



3 Unleashing the cultural and relational capital of **Samoan practitioners and professionals** to disrupt the system levers that reinforce inequity and inefficiency across the rheumatic fever ecosystem



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.

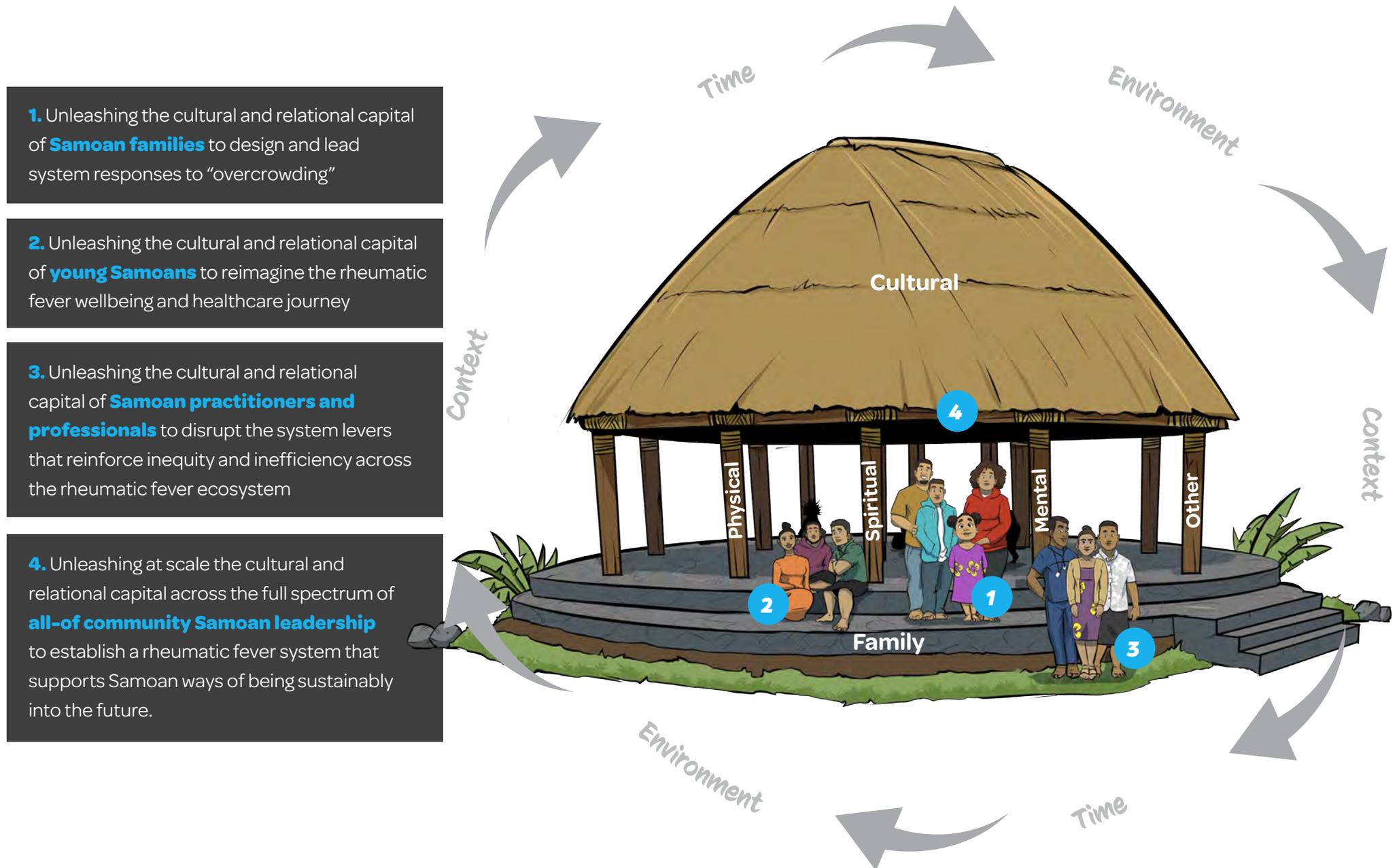
Together, these opportunities have the potential to collectively disrupt the incidence and experience of rheumatic fever for Samoan people.

The approach for this work is driven by Samoan worldviews, using co-design mindsets, tools, and practices to drive systemic changes. The initiative is led by a team who hold Samoan cultural and social capital as well as professional skills and expertise in the areas of co-design, systems change, community engagement, commissioning, policy development, clinical practice, public health, research and evaluation, international development and visual design.

²The report from Phase 1 of this initiative can be accessed here: <https://drive.google.com/file/d/154EASKlBi7prBGXWR7STlbrZLdfYft4U/view?usp=sharing>

Diagram 1 – Our 4 Change Opportunities

Adapted from Fonofale model by **Fuimaono Karl Pulotu-Endemann**



As we undertake this work, we reference the Equitable Evaluation Framework (EEF) and its intention to shift the evaluation paradigm to one with equity as core. The EEF helps practitioners challenge cultural norms that continue to promote preferences for a singular type of truth, knowing and evidence, which often reinforces an existing narrative.

We are constantly acknowledging and considering:

- **History³:** the uniqueness of Fa’asamoa (the Samoan way), our cultural heritage and traditions, and their evolving nature over time and across contexts.
- **Location:** the multiple cultural intersections of experience with rheumatic fever for Samoan people at individual, organisational, and systems levels. Time adds another layer in terms of generational and experiential differences, both in terms of age and the length of experience with the New Zealand health system. Our work within communities accounts for and responds to these intersections.
- **Power:** There is a deep understanding within this initiative of how some worldviews and systems have privileged the experience of some populations, whilst keeping others from

obtaining what they need to prevent or treat rheumatic fever. As a result, we deliberately avoid terms such as ‘household overcrowding’. We hold unapologetically tight to Samoan worldviews and values and will drive systems change from a Samoan perspective. We acknowledge that whilst past work may have defaulted to pan-Pacific solutions, this work will have limited value unless the system can adjust to accommodate Samoan solutions for Samoan people.

- **Voice:** We are deliberate in our amplification of Samoan voices, perspectives and experiences. The information, knowledge and wisdom of our Samoan leaders, families, young people, professionals, and the community at large is fundamentally and inherently valuable and important.
- **Relationship:** This work is being enabled by the team’s robust ecosystem of individual and collective networks. These have formed over many years through each individual’s demonstrated and lived practice as Samoans working from our Fa’asamoa (the Samoan way) values base of alofa (love), fa’aaloalo (respect), and tautua (service). These trusted relationships have allowed us to work closely with Samoan families, young people, professionals, leaders and the wider system

WE ACKNOWLEDGE OUR SAMOAN CULTURAL HERITAGE AND TRADITIONS

through a co-design process. As a result, we maintain our final accountability and responsibility is to our Samoan community. We will continue to approach this work from a position of honouring our families and serving their needs and aspirations first.

³History, Location, Power, Voice and Relationship are terms from The Equitable Evaluation Framework. GEO Grantmakers for Effective Organizations. (2021)



**3. WHAT WE HAVE
LEARNED SO FAR**

3. WHAT WE HAVE LEARNED SO FAR

Our work on this project is deeply reflective and developmental. We are aware that an initiative such as this one, which is driven by Samoan worldviews with a fusion of co-design and systems change, is world-leading and has not been undertaken before.

3.1 Unleashing the capital of families and young Samoans

Cultural and relational capital is key to the safe and enthusiastic engagement of participants.

Each team member has leveraged personal and professional relationships across community organisations, faith communities, professional bodies, the health system, across sectors to win the support and engagement of many individuals to participate in the work. This strong relational foundation allows the team to move into ideation and prototyping successfully and safely.

Engagement depends on multiple levels of trust and reciprocity.

A deep cultural understanding of the complex, nuanced and multifaceted nature of Samoan relationships, where there is a constant and ever-changing interplay of roles and relationships depending on the context, is vitally important to this work. Often, these complex relationships mean

that up to four levels of individual capital need to be expended to reach and engage Samoan families and young people effectively.

For example, an engagement that requires two layers of cultural capital might look like this:

Two Layers:

1. Team member engages with the leadership of a local sports club that has a very large Samoan player base and community following
2. Leader of sports club expends his personal capital to engage with club members and invite them to a co-design workshop

(see Diagram 2 on page 13 - Two Layer Engagement)

We acknowledge Tagaloa Willie Maea, Chairman of Otara Scorpions Rugby League club for partnering with us in this way.

An engagement that requires four layers of cultural capital might look like this.

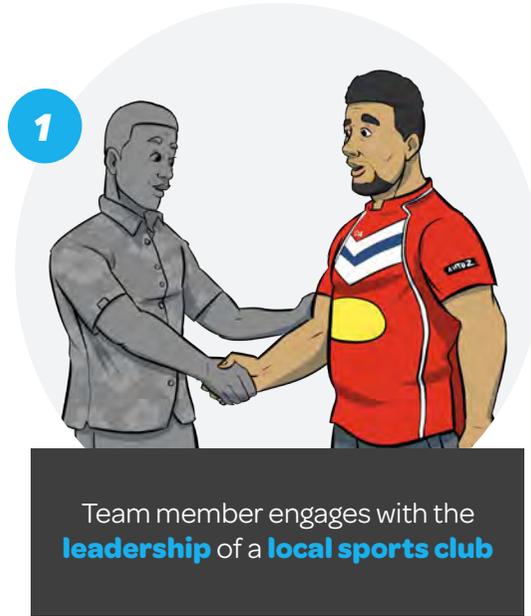
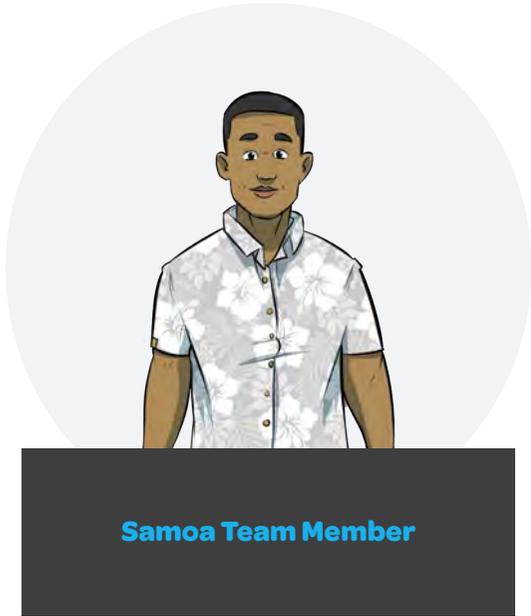
Four Layers:

1. Team members engage with leaders of Pacific health provider
2. Leaders of Pacific Health provider 'handshake' Samoa Team to their clinical leadership
3. Clinical leadership introduce Team Samoa to Practitioner (Nurse) who works with Samoan families
4. Nurse personally vouches for the team and the project to families with experience of rheumatic fever. The nurse supports the family to come to the event and attends with them.

(see Diagram 3 on page 14 - Four Layer Engagement)

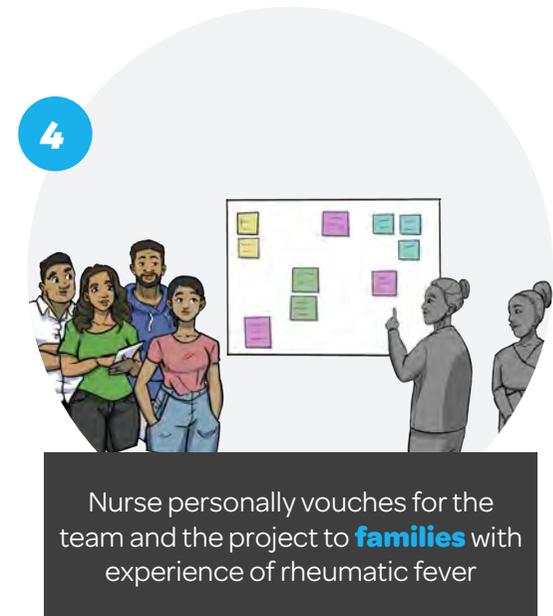
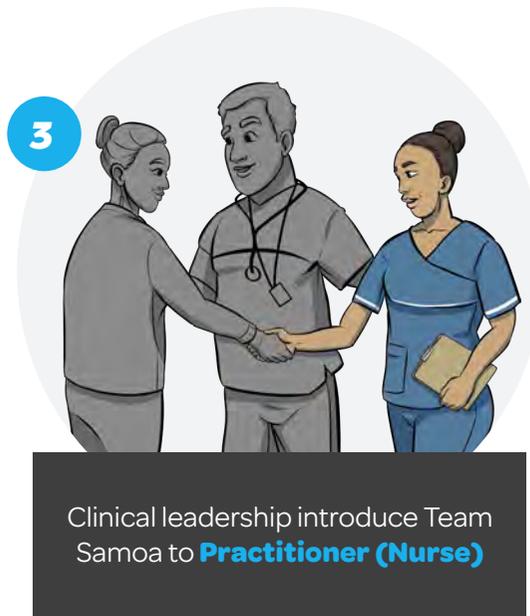
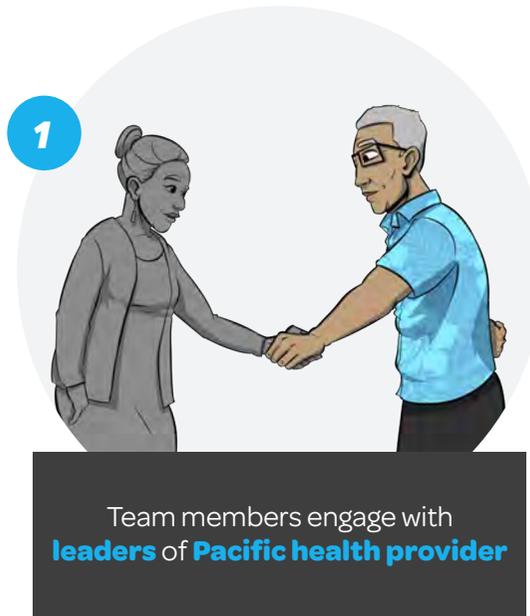
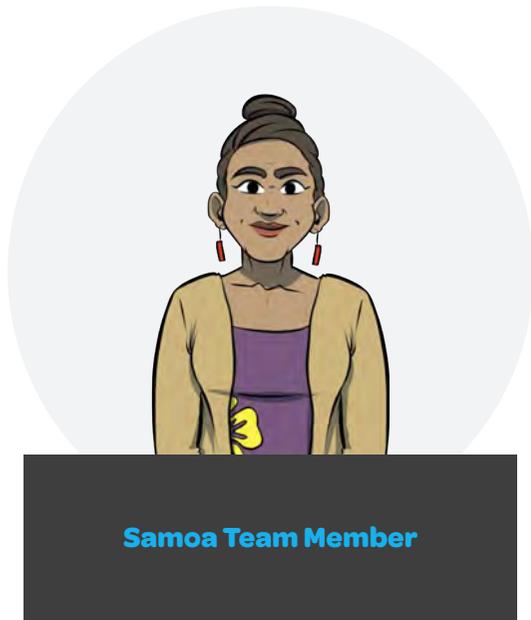


Diagram 2 - Two Layer Engagement



Two Layer Engagement

Diagram 3 - Four Layer Engagement



Whole-of-family engagement is critical

The ability to welcome and engage successfully across the multiple generations and compositions of Samoan families is critical to families being able to “come as you are” and engage easily and comfortably.

Language and representation is not negotiable

One of the essential conditions that enable the unleashing of Samoans’ individual and collective capital is creating a culturally safe space where Samoan ways of being and the use of Gagana Samoa (the Samoan language) are honoured and welcomed. Samoan ways of doing must be visible and encouraged as “the way we do things around here”.

Working in this way increases the level of comfort of Samoan participants, who know that accepted cultural practices will be honoured and understood. At the same time, it is important to note that there must also be consideration and space given to non-Samoan-speaking Samoans, particularly young people.

3.2 Working with Samoan practitioners and professionals

There’s been alot of research, it’s time for action... systems action.

Samoan practitioners and professionals have a deep desire to connect and make a difference. They have been engaged in conversations around rheumatic fever for many years and are tired of seeing little progress. One of the appeals of this project for the professionals involved in the prototypes is that it finally offers an opportunity to get on with actioning a response and changing the system.

Make it easy for leaders to be system actors: engagement and action should be fully facilitated and supported

This project has secured the commitment of several practitioners and professionals around our common agenda to reduce rheumatic fever and rheumatic heart disease in Aotearoa. These include partnership with the Ōtara-Papatoetoe locality prototype, health system leaders, and primary care professionals including pharmacists.

Their participation is facilitated by backbone support from Samoa Team, who have the resources and skills to convene and coordinate their participation, enabling them to focus on the prototypes without having to worry about

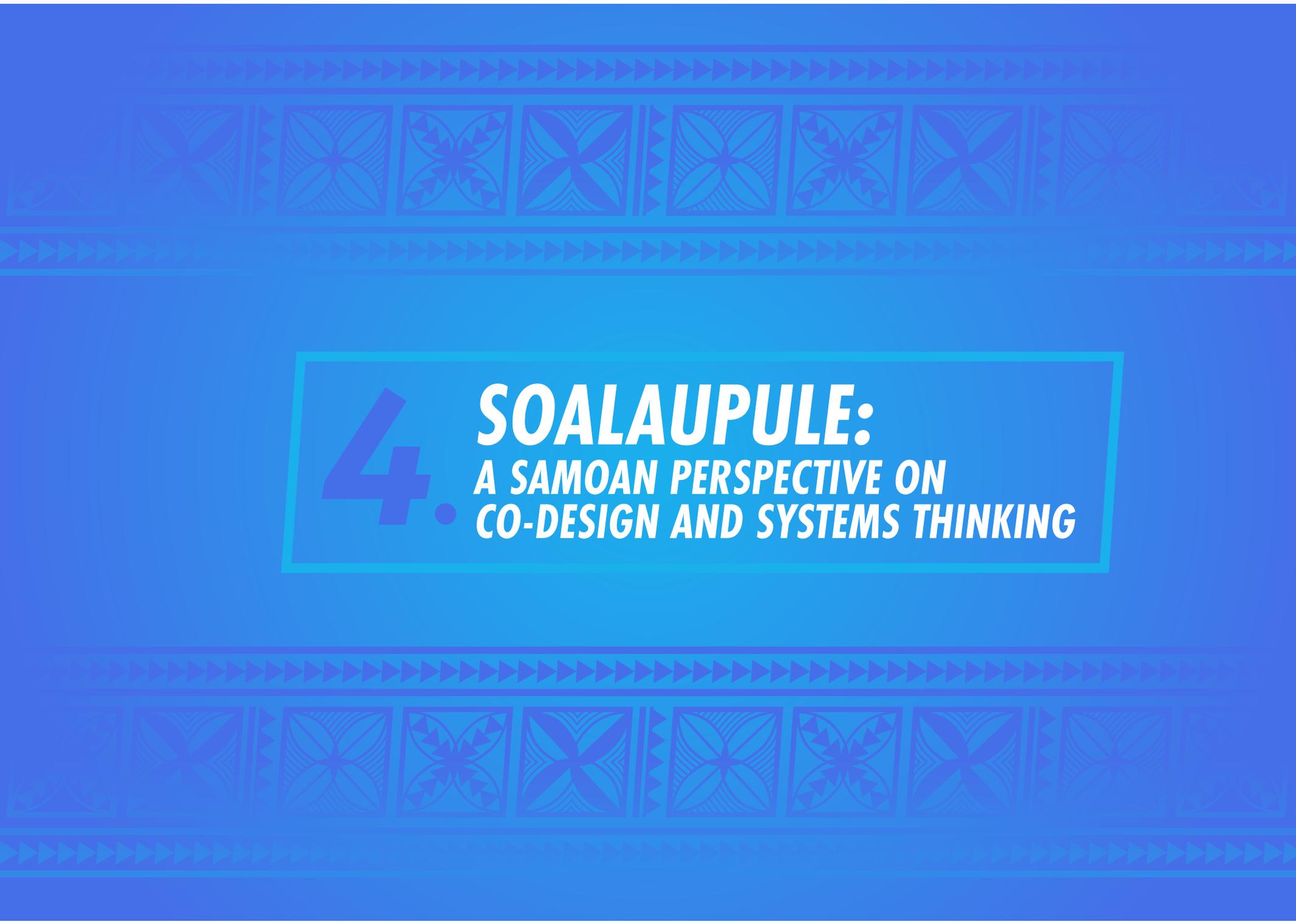
administration, resourcing, convening and coordinating.

3.3 Informing wider systems change

As outlined earlier, we are focused on shifting existing system paradigms to one with equity as core. We recommend that systems that commission, contract and manage work, particularly with a focus on under-served populations, have their own set of foundational principles that acknowledge and address individual, institutional, and structural barriers. Furthermore, there must be understandings and considerations made for cultural safety, cultural capital and cultural labour⁴.

We are discovering the extent that siloed approaches across the system have diminished the opportunity for families to experience the quality of care needed to address the multi-dimensional impacts of rheumatic fever and rheumatic heart disease. Collaboration must be mandatory.

⁴An example of cultural labour is when the only Pacific person in the room is asked and/or expected by others to provide the Pacific view on matters, or provide the role of cultural spokesperson or cultural practices on behalf of the group.



4.

SOALAUPULE:
A SAMOAN PERSPECTIVE ON
CO-DESIGN AND SYSTEMS THINKING

4. SOALAUPULE - A SAMOAN PERSPECTIVE ON CO-DESIGN AND SYSTEMS THINKING

The notions, mindsets and practices of co-design and systems thinking are not new to Samoan culture. There are long-standing practices that families, villages and faith-based communities use in their collective decision-making to achieve the objective of harmony and wellbeing for all. Soalaupule is a Samoan concept that relates to what is referred to in the modern world as co-design and systems thinking.

We write this perspective to highlight an existing Samoan concept that has existed over many generations that has given, and continues to give, Samoans a sense of confidence in actively participating and contributing to processes of change.

Soalaupule 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).

Soalaupule is not a simple or easy process. It is difficult as different ideas, wisdom and sacred knowledge are critically analysed, assessed and woven together by participants or a collective in the effort to gain a consensus.

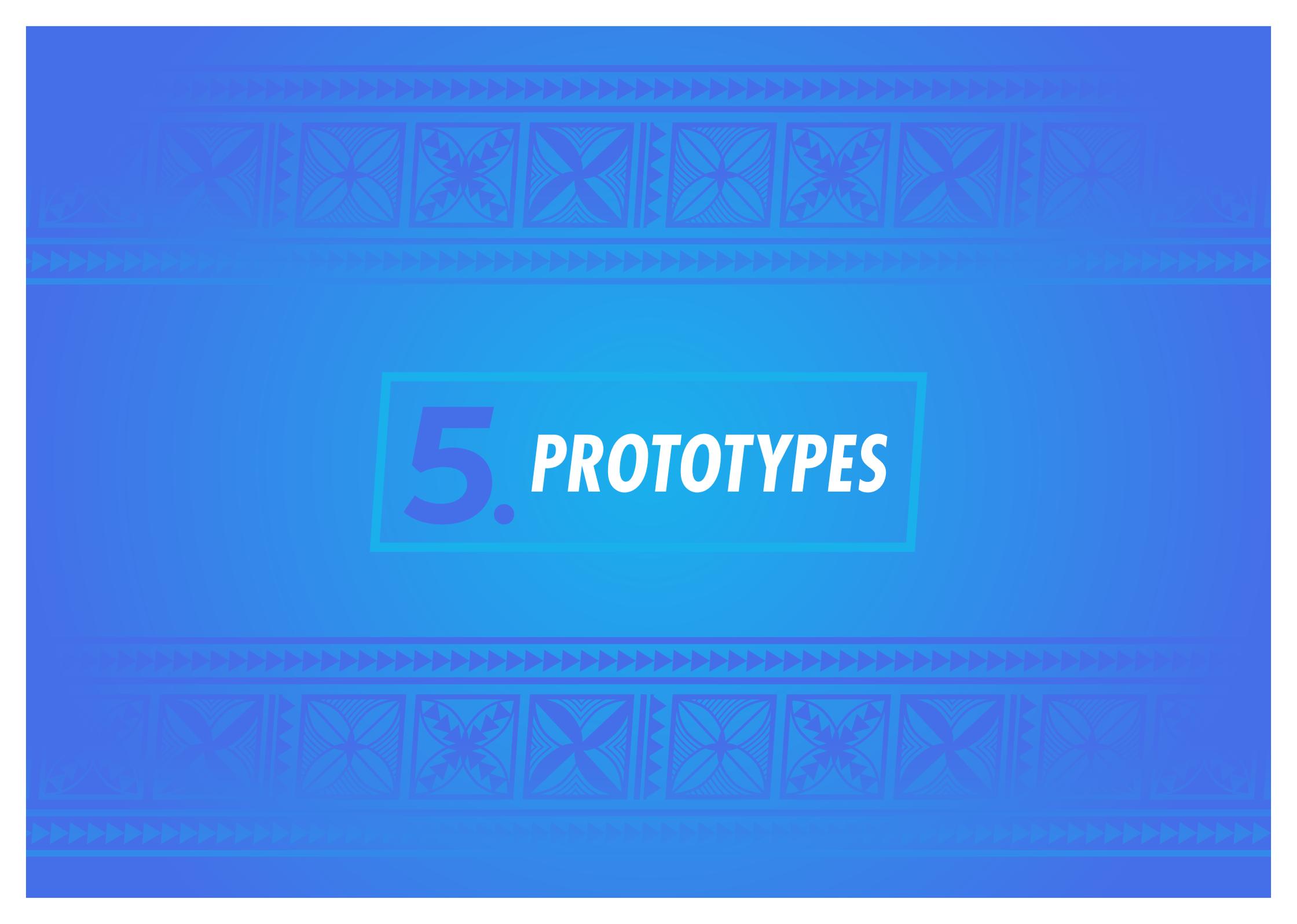
A critical benefit of using soalaupule in the co-design process is that Samoans have confidence knowing that soalaupule is not a stand-alone concept but rather one that embeds important Samoan values such as ava fatafata (mutual respect), fa'aaloalo (respect), fa'amaoni (faithfulness) and alofa (love)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

In soalaupule, we are not limited by the scope, order, and items or questions prepared for the project. Instead, space is given for deep exploration, clarification and elaboration through the process of talanoa or fetufa'aiga (sharing).

We will share more on soalaupule, co-design and systems change in future publications.

Writing about this unique Samoan worldview and practice is **not** an open invitation to non-Samoan practitioners to adopt this practice. We are mindful of other Pasefika practices such as talanoa which have become mainstream and used by non-Pasefika practitioners, and it is **not** our intention or desire that this occur with soalaupule.

SOALAUPULE IS A SAMOAN CONCEPT THAT RELATES TO WHAT IS REFERRED TO IN THE MODERN WORLD AS CO-DESIGN AND SYSTEMS THINKING.

The background is a solid blue gradient. It features decorative horizontal bands: a top band with a repeating pattern of small triangles, a middle band with a repeating pattern of larger geometric shapes (squares with internal floral or star patterns), and a bottom band with a repeating pattern of small triangles. A central light blue rectangular box contains the text.

5. *PROTOTYPES*

5. PROTOTYPES

The team is now working on six prototypes.

5.1 Myth Busting (working title)

From Discovery to Prototype

This prototype emerged from Phase

One - Opportunity 1: Unleashing the cultural and relational capital of Samoan families to design and lead systems responses to 'overcrowding'.

Design question

How might we as Samoans design information and ways to share information that help us understand how best to prevent rheumatic fever and/or how can we live with it better?

E fa'aapefea ona tatou fausia ni fa'amatalaga ma fa'asoa atu i ni auala talafeagai, e fesoasoani i le malamalama a o tatou tagata i le Fiva Rumatika, o ala e puipuia ai fa'aapea ma auala e mafai ona tatou ola fa'atasi ai ma leni gasegase? (translated for engagement with families)

Insights at the heart of the prototype

The Myth Busting prototype is designed to get the right information to the heart of Samoan families and communities. During our engagements, we heard from Samoan families that there is a persistent lack of clear and simple communication of the very basics of rheumatic fever to those most

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Samoa Team Phase 2 Report**

impacted. Despite many families spending years in the rheumatic fever health care system including multiple surgeries, many sought information as basic as:

- What is rheumatic fever?
- How do you get it?
- How can I stop people I love from getting it?

Importantly, our Samoan families identified that much of the work already done in this area had limited cut-through because of a strong clinical focus of the messages. During our initial prototyping sessions, the team noticed that families were readily and easily 'translating' clinical jargon into simple everyday concepts and messages for each other, were sharing stories and pathways around access and non-access, and learning from each other about key decision points on the journey.

The prototype

Our prototype consists of two elements:

- innovative framing and translation of key rheumatic fever prevention messages into ways and languaging that resonates with Samoan people's values, beliefs and lived realities
- partnering with key community and system stakeholders to deliver mass propagation of messages so they become standard practice

Prototype features

- Good information about what rheumatic fever is
- Information that supports navigating the system
- Use trusted people in the Samoan community
- Messages through Samoan lens
- Using Samoan lived experiences

What's next

The team is currently refining the features with the community and negotiating opportunities for testing by connecting with other work that is already underway. Strong synergy is noted between this prototype and the Let's Talk Rheumatic prototype.



5.2 Let's Talk Rheumatic (working title)

From Discovery to Prototype

This prototype emerged from Phase One - Opportunity 2: Unleashing the cultural and relational capital of young Samoans to reimagine the rheumatic fever wellbeing and healthcare journey.

Design question

How might we communicate basic information to young Samoans with rheumatic fever which enables them to understand what is happening and become active participants in their own healthcare journeys?

E fa'apefea ona fa'afaigofie i tupulaga ma fanau a Samoa o lo'o a'afia i le Fiva Rumatika ina ia malamalama i le mea ua tupu ma avea ma ala e fa'atupu manatu ina ia auai malosi ma malamalama i lana lava savaliga fa'a-le-soifua maloloina? (translated for engagement with families)



Insights at the heart of the prototype

We heard that young Samoan people and their families do not ask questions or complain, even when the system is not delivering a basic standard of care. Part of this is that the right information and messages haven't been delivered in the right ways.

Young people identified that the fact-based, health-focussed information around rheumatic fever that is currently out there is not relevant to the everyday realities of young people living with rheumatic fever. They say "We want young Samoans to see it, hear it, learn it, practice it, but don't get it".

The prototype

This prototype is testing the proof of concept that an entirely different approach to communications is required for young people.

This prototype has strong connection to the Mythbusting prototype but takes a deep dive into the experience of the young person.

There are three stages to this prototype:

- the requirements brief
- creation of content - minimum viable product (MVP)
- evaluation - understanding experience and impact of communications

Prototype features

- Young Samoans are part of designing the messages
- Use most accessible and relevant social media platforms (e.g. tiktok, instagram)
- Storytelling instead of facts
- Cartoon illustrations

What's next

Building on the high level requirements surfaced by young people during Phase 2, we will deep-dive with young people into the specificity. Because we do not want to duplicate anything that is already underway, the team is currently focussed on stocktaking and understanding the types of rheumatic fever communications and messaging that has gone out to communities, looking at what current social media and communications platforms are being utilised (and which aren't), and investigating the opportunities to partner and work alongside others already working in this space. We will also work with existing content creators wherever it makes sense.

5.3 The Fa'asamoa Way (working title)

From Discovery to Prototype

This prototype emerged from Phase One - Opportunity 1: Unleashing the cultural and relational capital of Samoan families to design and lead systems responses to 'overcrowding'.

Design question

How might fa'asamoa be valued to lead the change in the system, so that it is fair for Samoans?

Pe fa'aapefea ona fa'atāuaina la tatou Fa'asamoa (tu ma aga) ina ia taulamua auā ni suiga o le au'aunaga lautele (system), ina ia tonu (fair) mo tagata Samoa? (translated for engagement with families)

Insights at the heart of the prototype

The Fa'asamoa Way is about reducing alienation in the rheumatic fever system by valuing and actioning the fa'asamoa belief system within interactions between services/wider system and Samoan families.

We heard that inequities for Samoans within the wider health system also play out within the rheumatic fever system. Families say they feel alienated from decision-making, that consultations don't address their concerns or answer their questions, messages are too clinical and jargon-heavy, there is limited language support for Gagana

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Samoa, and most service/care providers have little, if any, knowledge of what matters for Samoans. The collection of these barriers can alienate individuals and families from the rheumatic fever system.

The prototype

The Fa'asamoa Way is imagined as a capability framework that can be used by stakeholders – particularly those with limited experience of fa'asamoa (the Samoan way), when working with Samoan people.

Our prototype consists of two elements:

- development of the capability framework - minimum viable product (MVP)
- partnering with key community and system stakeholders to propagate the framework to become common practice

Prototype features

Key features include:

- Young people included in decision making
- Family included in the consultation
- Communicating messages simply and in ways that are meaningful to the individuals and their families and make sense to their everyday lives
- Making Samoan families comfortable enough so they can communicate what they need and what they are looking for
- Language support

This prototype acknowledges the complex nature of Samoan communities in Aotearoa, from traditional through to contemporary, by ensuring a spectrum of practice that can respond accordingly.

Strong synergy is noted between this prototype and the 'Delivering better quality primary care' prototype.

What's next

The team is working with a South Auckland health and social services provider to refine and test this prototype. Stakeholders have raised that they see wider application for this prototype, beyond rheumatic fever and the health system.



5.4 Delivering better quality primary care

From Discovery to Prototype

This prototype emerged from Phase

One - Opportunity 3: Unleashing the cultural and relational capital of Samoan practitioners and professionals to disrupt the system levers that reinforce inequity and inefficiency across the rheumatic fever ecosystem.

Design question

How might we embed and sustain Samoan wellbeing practice to advance and strengthen primary care practice to deliver better quality of care for Samoans with rheumatic fever and their families?

Insights at the heart of the prototype

We heard from professionals that there is a limited understanding of, and inability to apply, the Samoan holistic system of wellbeing. When this understanding of wellbeing is disregarded by the rheumatic fever health and social care system, the wellbeing of Samoans is diminished, rather than strengthened.

We also heard that primary care best practice guidelines are not always accessed or adhered to, and that decision making tools to support best practice are not always easily available to practitioners when they need them. There is opportunity to use existing quality improvement

processes across primary care to embed better quality care.

The prototype

This prototype uses the existing quality improvement and capability building systems in primary care to embed better quality care for Samoans. This includes intentionally raising the priority of rheumatic fever for primary care in geographic areas where it is most relevant.

There are three elements to this prototype:

- supporting primary care to have quick and easy access to decision making tools that enable them to provide best quality care
- capability building module for practitioners to strengthen cultural competency
- use of quality improvement mechanisms to embed best practice

Prototype features

- Intentional focus on systemic change
- Using quality improvement processes to embed quality care for Samoans
- Capability building for primary care practitioners
- Winning hearts and minds – why this is important

We note the strong synergy and common components between the content of this prototype and 'The Fa'asamoa Way' prototype.

What's next

This prototype is being championed by Dr Apisalome (Api) Talemaitoga, Distinguished Fellow of The Royal New Zealand College of General Practitioners and Chair of the Pasifika GP Network. The team is working with Dr Talemaitoga and others to develop and test the minimum viable product of the capability building module and identify partners for delivery over the long term. We are undertaking mapping of the decision making process and tools, and the current pain points for practitioners. We are also mapping the quality improvement mechanisms that can be utilised to assist in embedding best practice.



5.5 Mapping the rheumatic fever system for a locality

From Discovery to Prototype

This prototype emerged from Phase One - Opportunity 3: Unleashing the cultural and relational capital of Samoan practitioners and professionals to disrupt the system levers that reinforce inequity and inefficiency across the rheumatic fever ecosystem.

Design question

How might we better understand the rheumatic fever system to identify the most impactful points for change?

Insights at the heart of the prototype

We heard from professionals that the rheumatic fever health and social care system is fragmented and disjointed and that it was unclear what impact previous investment into rheumatic fever prevention and management has had.

Preventing and managing rheumatic fever is a complex pathway with a number of points for prevention and intervention in place. We heard that it is unclear if the pathway is delivering optimal outcomes.

With data being held in different places by different agencies for different purposes, there is an incomplete picture of what the system is actually delivering, its impact and return on investment. This includes gaps such as a lack of clear visibility of who is getting care, at what points along the pathway families are accessing services or not, and who is being followed up or not.

The prototype

The prototype is testing that a more intentional focus on data will provide insight into where system intervention is necessary and impactful.

The prototype undertakes systems mapping to identify where the most impact may be able to be made for a local community.

Prototype features

- Accessing data and information from multiple sources
- Creating a more complete picture that informs decision making
- Informing how care and services are planned for a locality
- Considerations for investment

What's next

This prototype is a partnership with South Seas Healthcare Trust and is being championed by Dr Debbie Ryan of Pacific Perspectives.

Our prototype will sit within the locality prototype for Ōtara-Papatoetoe area which is co-led by South Seas Healthcare Trust and mana whenua, Ngāti Tamaoho and Ngāi Tai. The locality approach is focused on planning care and services for community health and wellbeing at a local level.

We are leveraging the systems mapping that the Ōtara-Papatoetoe locality prototype already has underway. Our partnership will support systems mapping for rheumatic fever to be undertaken to inform the locality's long term plans for how services will be delivered to their communities of interest.



5.6 Pharmacy-based rheumatic fever prevention

From Discovery to Prototype

This prototype emerged from Phase One - Opportunity 3: Unleashing the cultural and relational capital of Samoan practitioners and professionals to disrupt the system levers that reinforce inequity and inefficiency across the rheumatic fever ecosystem.

The design question

How might we advance pharmacy-based interventions to complement and increase the detection of strep throat and prevention of rheumatic fever for Samoan people?

Insights at the heart of the prototype

We heard that following the COVID-19 vaccination programme, communities are increasingly using pharmacies as 'go-to' places for basic diagnosis and preventative actions.

We heard that going to see a doctor is not always easily arranged or accessible and that it may be a barrier to getting strep throat diagnosed.

We engaged with a Pasefika pharmacist who believed that pharmacy could fill a gap in rheumatic fever prevention for communities and had been wanting to innovate in this area.

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The prototype

This prototype proposes a pharmacy-based sore-throat management/rheumatic fever prevention model including sore throat checks and antibiotic prescription. In addition, this prototype will draw from the experiences and expertise of Samoan young people and families to inform the design and delivery of services, including communication.

Prototype features

- Pharmacy-based model
- Sore throat checks
- Standing orders for antibiotics
- Rheumatic fever communications and messaging
- Embedding Pasefika wellbeing practice into pharmacy-based model

What's next

This prototype is being championed by Diana Phone, President of the Pacific Pharmacists' Association. Diana was awarded New Zealand Pharmacist of the Year in 2017.

We are learning from the pharmacy-based model in Te Tai Tokerau, Northern Region to refine our prototype for testing. We already have interest from pharmacies in Tāmaki Makaurau who are keen to test a pharmacy-based model.



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6. LET'S CONNECT

6. LET'S CONNECT

We know that duplication and fragmentation do not serve families, communities or systems well, so let's connect.

If you are working on related work, we'd love to hear from you.

If you'd like to know more about what we are doing, we'd love to hear from you.

If you're interested in partnering with us, we'd love to hear from you.

Email annie@called.world and let's get connected.

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

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

