



RHEUMATIC FEVER  
CO-DESIGN INITIATIVE

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**Samoa Team  
Report – Phase 1**

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

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



## Rheumatic fever and rheumatic heart disease have stolen too many years of life from Samoan families for too long.

This initiative is taking a new approach to this problem by looking at how we, as Samoans, might take the lead in addressing this problem. Fa'asamoa (the Samoan way) is a foundation of our wellbeing and must take precedence. The mainstream system does not hold the answer for us, but can partner with us to create solutions that work.

We acknowledge the Creator of all things.

We acknowledge those who have gone before.

We thank and acknowledge the Samoan individuals and families who have trusted us with their precious gifts of knowledge, experience and wisdom.

We thank and acknowledge the non-Samoans who have travelled with us on this journey of discovery and change.

We acknowledge the teams at ThinkPlace and the Ministry of Health who are open to learning and doing differently together with us.

**Fa'afetai, fa'afetai, fa'afetai tele lava.**

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

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



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**Key discovery:**  
**A tale of two systems**

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**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.

The journeys of Samoans 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, but it is not people-centred and is creating harm.

**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)<sup>1</sup>, 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.

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



**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.

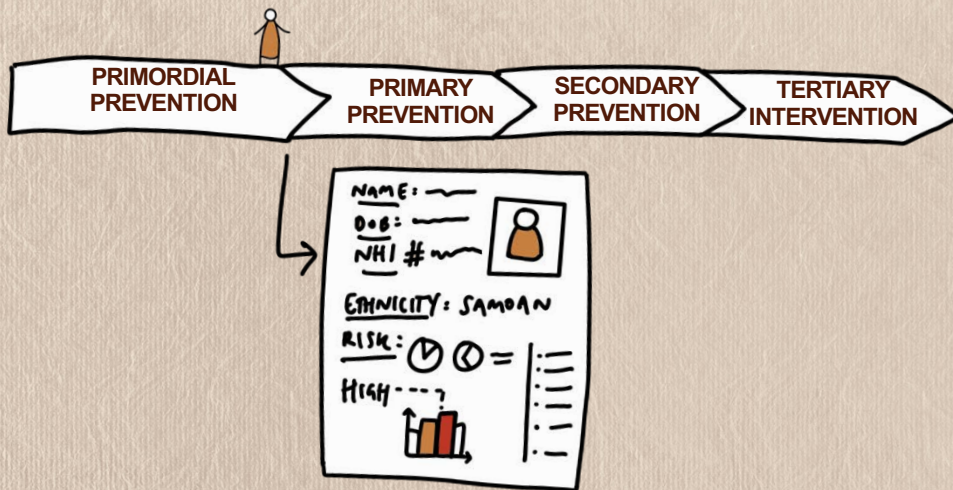
The formal rheumatic fever system in New Zealand does not acknowledge, understand or value the existing and inherent strengths and know-how of Samoans. Critically, it cannot access or leverage the existing base of power in Samoan individuals, families and communities to inform truly effective prevention 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.

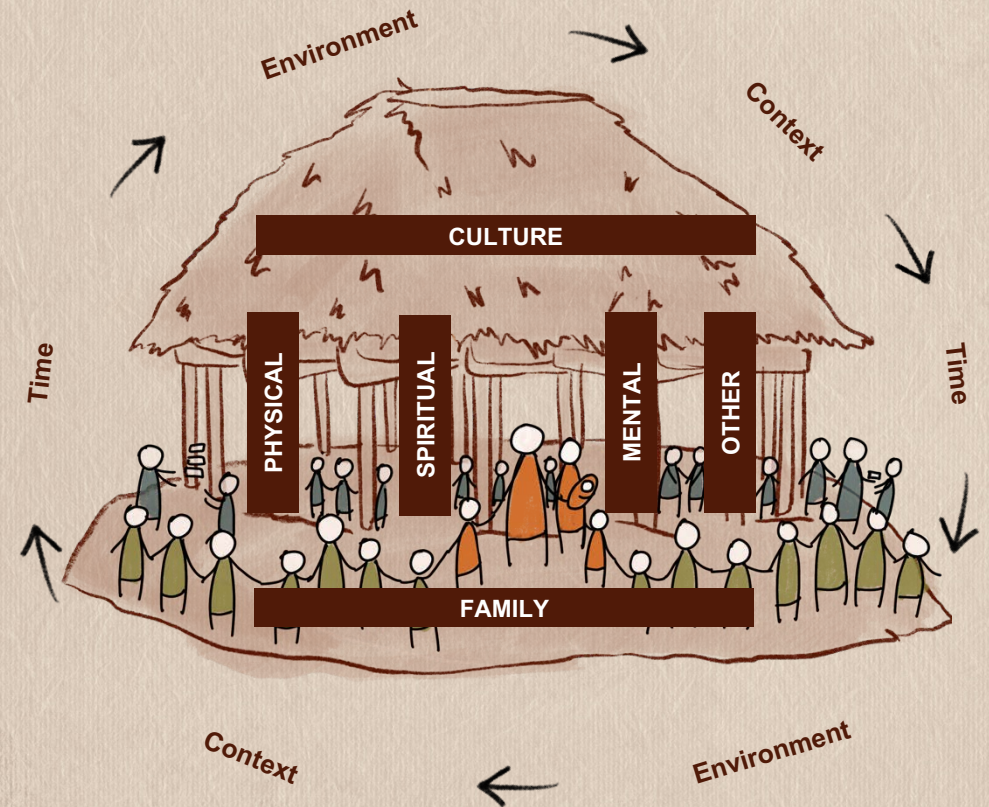
We warmly invite you to join us on this exciting journey of change.



## HOW THE SYSTEM SEES ME



## HOW I WANT THE SYSTEM TO SEE ME



Adapted from Fonofale model by Fuimaono Karl Pulotu-Endemann





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# **Our approach**

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The objective of the Rheumatic Fever Co-Design Initiative is:

## Co-design with communities and other system stakeholders

*doing with, not doing to*

*the community voice is vital,  
especially those with lived experience  
– children and young people and  
their whānau*

*it is not the community's problem to solve*

## to identify and embed innovative and sustainable system improvements

*understanding and taking action*

*new perspectives that continue beyond this initiative*

*the system is where change is needed*

## to prevent and manage rheumatic fever

*reducing the number of  
people who develop  
rheumatic fever*

*improving  
experience/  
outcomes for people  
who develop  
rheumatic fever*

*Group A streptococcus,  
rheumatic fever and rheumatic  
heart disease*

## for Māori, Samoan and Tongan people in Tāmaki Makaurau.

*identified priority groups*

*identified priority location  
(includes the three DHB regions)*



**This report captures the work that is focused on the experience of Samoans**

As Samoan practitioners of change, the work has been driven from our Samoan worldviews with a fusion of co-design and systems change.

**We are working from our Samoan worldview**

*and*

**Using co-design mindsets, tools and practices**

*and*

**Driving change at a systems level**

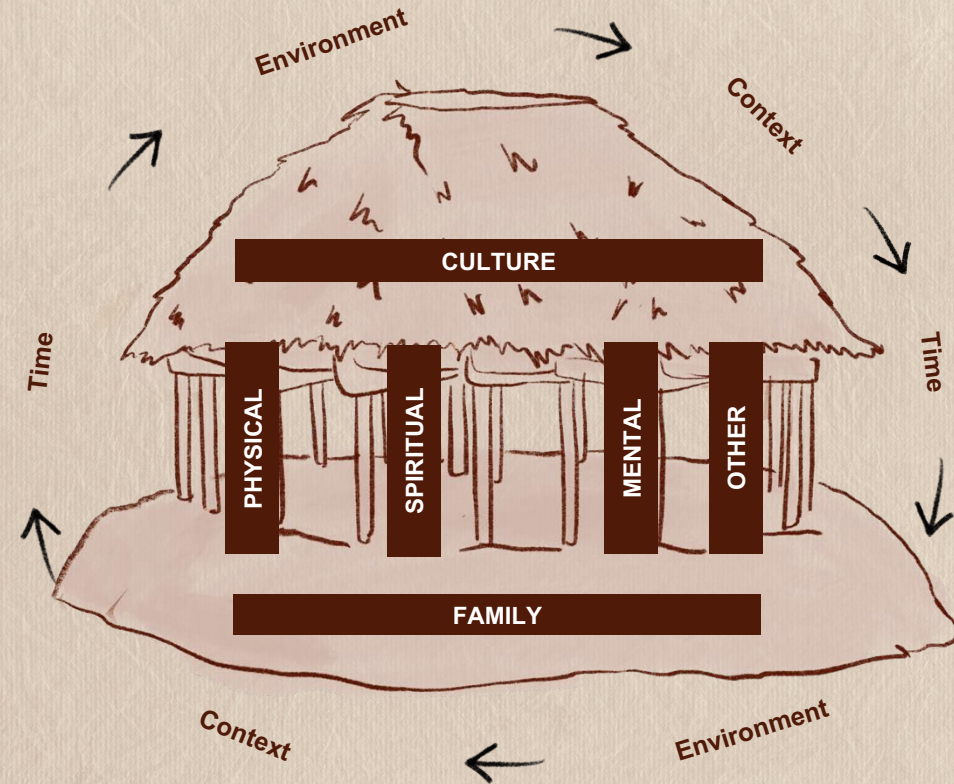


## From a Samoan worldview

**As Samoan practitioners of change, the work has been driven from our Samoan worldview.** We do so with the recognition of the dynamic and complex nature of the Samoan worldview, particularly in diasporic spaces<sup>2</sup>. While the mainstream methodology and language of co-design and systems change may be relatively new, Samoan's deep understanding and lived practice in the complexity of interconnected systems and innovation is long standing.

The Fonofale model developed by Samoan Fuimaono Karl Pulotu-Endemann (Pulotu-Endemann, 2001) seeks to capture our worldview to support the mainstream New Zealand audience in understanding our comprehensive view of health and wellbeing as an interconnected, multidimensional and holistic system. The model identifies multiple dimensions that together contribute to the holistic wellbeing of a Pacific individual.

This thinking holds similarities with the biblical/theological perspective that all parts of the body work together in harmony for the wellbeing of the body as a whole.



*Fonofale model by Fuimaono Karl Pulotu-Endemann*

<sup>2</sup> *Diasporic refers to the dispersion, spread or scattering of a community of people from their native or indigenous territory who have settled in another geographic location.*



**For Samoans, the Vā (literal: “space”) is significant and is understood and used in different contexts and processes. In this instance, it can be used to understand the relationship (i.e. what is it that connects us?) and the relatedness (i.e. why is the connection important?) between each entity of the Fonofale model.** Samoans place significance on the practice of Tausiga o le Vā – the nurturing, maintaining, caring and keeping of the relationship and relatedness between entities.

As explained by Samoan writer Albert Wendt, **the Vā is the space between, the betweenness, not empty space, not space that separates but space that relates, that holds separate entities and things together in the Unity-that-is-All, the space that is context, giving meaning to things.**

The meanings change as the relationships/the contexts change (Wendt, 1996).

For example, the Vā can have implications across the breadth of strategic, social, economic, spiritual and political spheres. Samoans believe that when all parts are working together in harmony, our wellbeing in its most holistic sense, thrives and flourishes.

Through our discovery, we have used the Fonofale model and understanding of Vā to capture and present how the rheumatic fever system in New Zealand has impacted Samoans’ wellbeing and to provide a framework for considering opportunities and solutions. This is a unique feature of our journey maps<sup>3</sup>.

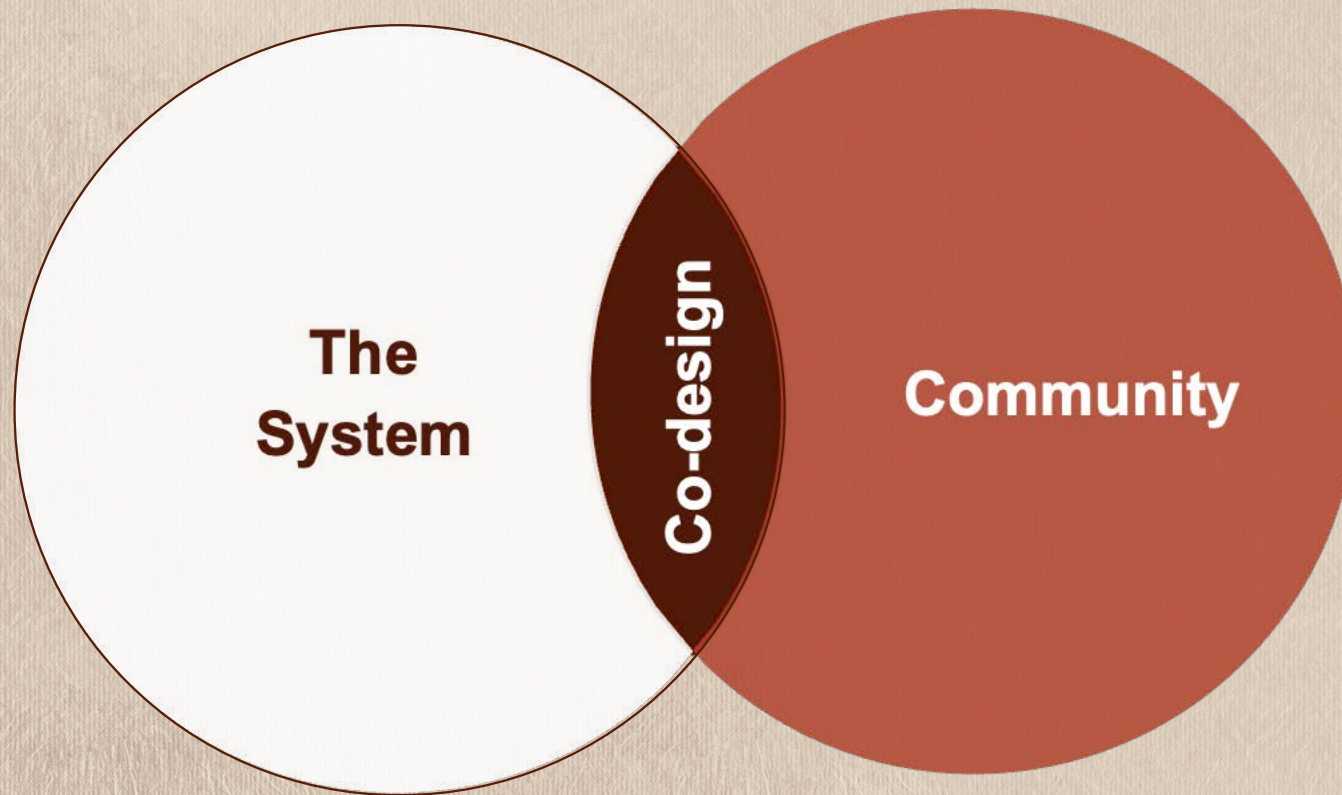
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<sup>3</sup> *A journey map helps us see the relationship between a person and the system or service, and where the opportunities for change may lie.*



## Using co-design mindsets, tools and practices

Co-design is working with the community as active participants in the design process to create shared value.





## Using co-design mindsets, tools and practices (continued)

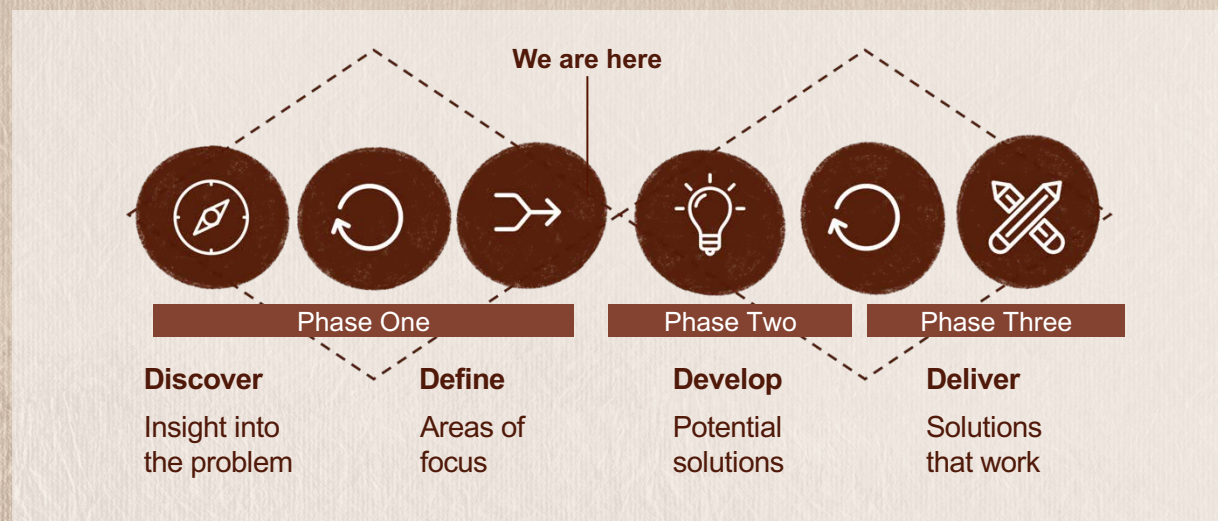
### We are using a four phase approach to co-design:

- Discover and seek insight into the problem
- Define areas of focus
- Develop potential solutions
- Deliver solutions that work

This report marks the end of Phase One and informs our work as we transition into Phase Two.

### Discovery has included:

- Desktop review of evidence and literature
- Interviews with Samoans with rheumatic fever/rheumatic heart disease
- Interviews with Samoan practitioners and professionals working across the health and social care system for rheumatic fever/rheumatic heart disease
- Engagement with stakeholders across the rheumatic fever system



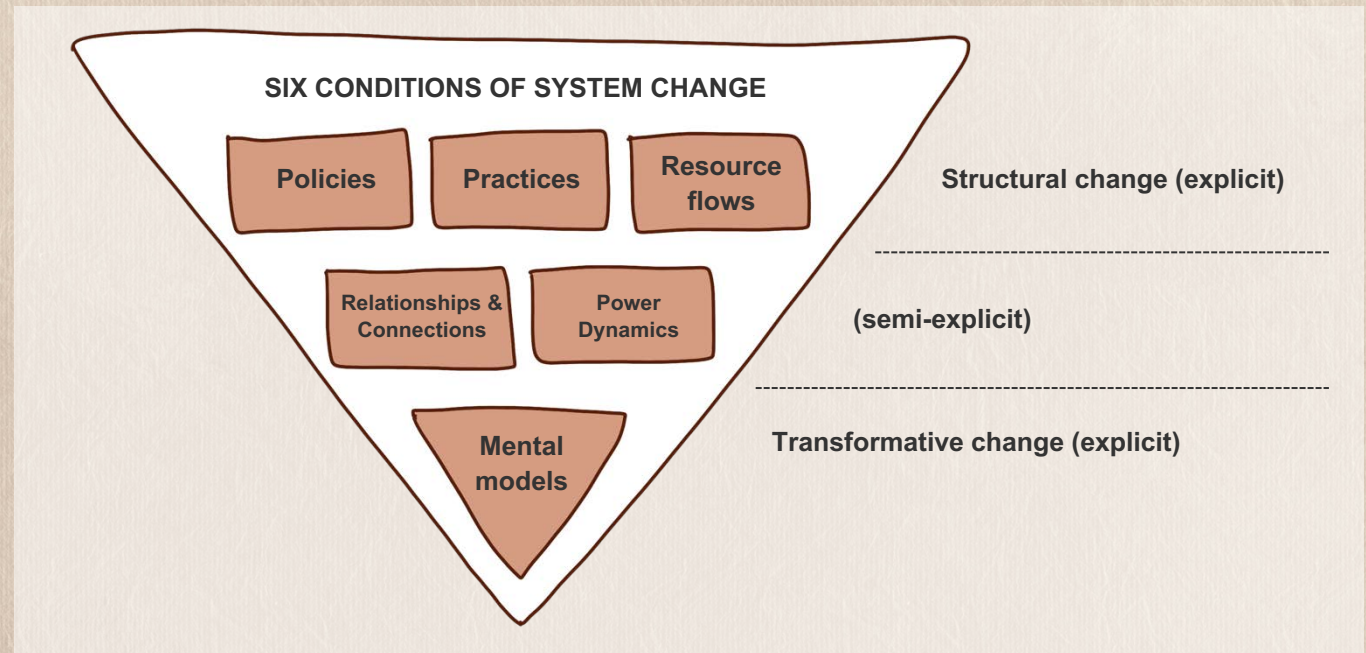


## Driving change at a systems level

**Systems change is about shifting the conditions that hold a complex problem in place** (Kania, Kramer, & Senge, 2018). We use the Six Conditions of Systems Change framework<sup>4</sup> to understand the existing rheumatic fever health and social system and its drivers.

It is insufficient for us to simply work at the explicit level of change that includes policies, practices and resource flows. It is essential that we understand and work to shift the relationships and connections, and power dynamics that sit at the semi-explicit level. In addition, to achieve transformational change that meets the expectations and aspirations of Samoans, we must work to understand and shift the mental models and mindsets that dominate the rheumatic fever system.

These mental models and mindsets drive the system that is currently in place and exacerbate inequity due to their inherent bias.



<sup>4</sup> **Policies:** Government, institutional and organisational rules and regulations that guide activities.

**Practices:** Activities, the things people do.

**Resource Flows:** How money, people, knowledge, information and other assets are allocated and distributed.

**Relationships & Connections:** Quality of relationships and connections between actors.

**Power Dynamics:** Who gets to decide, who holds power, how is power distributed, who has authority and influence?

**Mental Models:** habits of thought, deeply held beliefs and assumptions that influence how we think and what we do.

Credit: Kania, J., Kramer, M., & Senge, P. (2018). *The Water of Systems Change*. FSG.

[https://www.fsg.org/publications/water\\_of\\_systems\\_change](https://www.fsg.org/publications/water_of_systems_change)



## Our starting hypotheses

**From our early exploration, it was clear that despite significant investment and effort over many years, the prevalence of rheumatic fever for Pacific peoples in Aotearoa, particularly Samoans, has remained high (Health Quality & Safety Commission, 2021).**

Rheumatic fever is associated with an array of socioeconomic, systemic, cultural, and medical factors, and there is a notable lack of evidence about how effective rheumatic fever interventions have actually been for Pacific communities (Pacific Perspectives, 2015). We became interested in the notion of **polycultural capital** (Mila-Schaaf & Robinson, 2010) as a strength-based view of how Samoans mediate and operate the inequitable space of rheumatic fever in Aotearoa (Tuitama, 2020). In other words, despite the challenges and limitations of the rheumatic fever system, how is Samoan know-how being applied to navigate the rheumatic fever journey and system, and what can be learned from that and amplified for the greater good?

We wondered how Samoans were applying their polycultural capital to minimise and mitigate the incidence and harm of rheumatic fever and so our starting research question was:

*How might we access and understand polycultural capital in the Samoan ecosystem to find solutions that might reduce, prevent and best manage rheumatic fever in Tāmaki Makaurau?*

In addition to Samoans who had personal lived experience of rheumatic fever, we were also interested in how Samoan practitioners and professionals across the rheumatic fever health and social care system were applying their polycultural capital to minimise and mitigate the incidence and harm of rheumatic fever. So, our additional research question was:

*How might we expand/identify institutionalised polycultural capital, within working arrangements that support, reduce and manage rheumatic fever in Tāmaki Makaurau?*



## *Our starting hypotheses (continued)*

As we explored these hypotheses, Samoans had a level of appreciation for the concept of polycultural capital. Cultural capital and relational capital added to the depth of understanding and application.

Samoan know-how (polycultural capital, cultural capital, relational capital) are at the heart of the opportunities we have identified for deeper exploration in Phase 2.

Our objective is to capture the highly valuable combination of Samoan values, expertise, power and networks that sit untapped across Samoan individuals, families and communities which could, and should, be unleashed to resolve rheumatic fever in Aotearoa.





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# Emerging insights

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**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.**

Our homes are a place for the gathering of the collectives – such as family, aiga (extended family), villages, and church networks. Homes are an extension of our cultural practices of care and reciprocity of relationship.

New Zealand houses are structured in ways that don't accommodate Samoan ways of wellbeing and living, and Samoan families are expected to significantly adjust their wellbeing practices to adapt to the narrow understanding of housing in New Zealand.

Within this narrow view, conversations quickly move to 'overcrowding' being the problem and, as a result, families experience judgement and blame.

Families feel that they **have little control** over the housing system, and are looking for culturally-affirming and practical ways to be healthy within the constraints of the available housing stock.

**For many young Samoans, it is preferable to avoid the health system because of prior experiences.**

Young Samoans seeking health advice have low levels of trust in the formal health system, based on their prior experiences of it, as well as the negative experiences of their families and friends.

The reasons for this mistrust are varied. It includes things such as clinicians making racist or judgemental remarks, or clinicians making assumptions based on what people look like and perpetuating stereotypes.

The result of these experiences is that people view seeking medical/health treatment as a last resort and **will absorb the pain.**

**Samoans prioritise collective wellbeing and sometimes this comes at the expense of individual wellbeing.**

Thinking collectively and focusing on the wellbeing of others are essential aspects of being Samoan. People feel a deep sense of love, commitment and sometimes obligation to put the needs of the collective ahead of their own needs. As a result, people may sometimes not prioritise their own health and wellbeing needs.

Samoans experience the health system as focusing on the individual which places undue pressure on people to choose between prioritising their own wellbeing and that of the collective.

Samoans need a rheumatic fever system that **recognises and affirms the nature of Samoan families**, the roles within those families, and how the family works together around prevention and management of rheumatic fever.



## Samoans are missing out on vital opportunities for ‘prevention’.

Because of the low levels of trust in the health system, and because health information is not fit-for-purpose, Samoans are missing out on opportunities for relatively low-levels of intervention that may prevent more significant interventions at a later date.

We heard stories of people being in hospital for many days, and in treatment for many months and years, without ever feeling like they had a clear understanding of their diagnosis, condition and care pathway. Samoans experience health information and its communication as ineffective and not useful.

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

## Young Samoans experience the rheumatic fever management journey as energy-sapping and disheartening.

Many young Samoans who have experienced rheumatic fever feel their mental health has been affected by the stress and frustration associated with uncertainty about their future.

There is a lack of appropriate support and tools to enable them to take control of their own lives, resulting in feelings of hopelessness.

Young Samoans want to make plans for their future that involve travel, career progression and activities that bring them joy, but without a clear roadmap they are unable to make long-term decisions.

We heard a desire from young Samoans to be **given the opportunity to navigate** their own journey.

## 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.

In spite of the challenges that families experience, they are extremely resourceful and utilise their cultural and relational capital to navigate an inequitable system and maximise opportunities.

**Families learn from each other’s experiences** to better understand and make the most of the system and available resources. Hearing from other families rather than health practitioners represents a safe environment to share experiences and learn from each other.

Informal peer-to-peer support is providing real and relevant information for everyday life with rheumatic fever, but there are no formalised opportunities for this in the system.



**Samoan practitioners and professionals feel unvalued. The rheumatic fever system takes advantage of their cultural and relational capital, and goodwill.**

Samoan professionals across the rheumatic fever system apply their relational and cultural capital to mobilise the required support for families affected by rheumatic fever.

This capital is held personally by the Samoan professional. It is inherent to them and is not given to them by the system. However, Samoan professionals choose to expend this personal capital to meet the wellbeing needs of others.

This capital sits unrecognised by the system, despite it benefitting greatly from it. Samoan professionals are required to go outside their individual and institutional mandates to enable the system to deliver the positive outcomes it seeks.

This raises considerable questions about the true efficiency/inefficiency and efficacy of the existing mandated rheumatic fever system.

**Embedding the recognition and expert practice of Samoans' cultural and relational capital** would be a game changer for Aotearoa's rheumatic fever system.

**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.**

Samoan expertise and knowledge is confined to and characterised by “a response to” rather than “an influencer of” the systems' decision making around best approaches and resourcing to support Samoan families experiencing impacts of rheumatic fever.

Samoan and Pacific leadership have advocated for many years for Pacific leadership to be given true mandate to drive change in the rheumatic fever space, but this has not been actioned.

There has been tokenistic recognition of our leadership, while true power, decision making and resourcing of the system is held tightly by others. There has been little room for “by Pacific, for Pacific” leadership of solutions. This includes minimal influence and involvement in: the design of targeted strategies; the allocation and assignment of relevant human, technical and financial resources; and representation at the highest levels of sector and institutional leadership.

A recent Ministry of Health report provided a snapshot of Pacific health leadership in District Health Boards across Aotearoa New Zealand. It showed that all 20 DHBs lack Pacific representation in senior management positions where decisions impacting Pacific health are made (Ministry of Health, 2020).

We heard clearly that the “one size fits all, clinical focused” rheumatic fever system has not adequately met the needs of Samoans and their wellbeing. Real change calls for **Samoans being placed in influence-holding and decision-making roles at system leadership and governance levels.**



## Fragmentation and competition are hallmarks of the rheumatic fever system in Aotearoa.

It is a well-known and accepted fact that the rheumatic fever system in Aotearoa is highly fragmented and that the tools and processes of the system reinforce long-held competitive mindsets and behaviours.

The wellbeing of Samoans is impacted by the fragmentation and competition that thrives across the health and social care system, and within and across bureaucracies and government agencies.

We heard stories of system levers such as commissioning and funding holding these conditions in place and making it extremely difficult for individuals and organisations to work together to create and action a shared strategy for change.

The system's metrics and measures of success embed division and complacency rather than **incentivising holistic and positive cross-sector/agency outcomes** for individuals, families and communities.

The system does not encourage or reward cross-agency and cross-sector collaboration and innovation. For Samoan families, this results in service delivery that is one-dimensional and short-sighted, where health related support is provided without addressing the interrelated social and economic determinants of rheumatic fever.





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# Personas and journey maps

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## Introducing our personas

**Malia** and **Amosa** are two personas we have created to illustrate the experiences we heard.

Personas helps us understand the people we are designing for and with. They 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.

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. This highlights how their wellbeing is impacted by the multiple dimensions of wellbeing, including the Vā.



**MALIA**

### 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**

### 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.



## Malia's story | Community lived experience



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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.

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# 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

TENSION BETWEEN INDEPENDENCE & CULTURE

FEAR

SCARED

BEWILDERED

LOST

JUDGED

OVERLOOKED

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



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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.

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# Amosa's journey



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

**Situation**



**Wellbeing needs**

**Implication**

**Emotions**

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.

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

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.

CONCERN  
 EMPATHY FOR FAMILY



"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."

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).

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

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.

MOTIVATED  
 JUSTIFIED



"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."

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.

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

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

RELIEVED WITH RESULT  
 FRUSTRATED WITH SYSTEM



"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."

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.

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

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.

FRUSTRATION  
 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





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# Opportunities for change

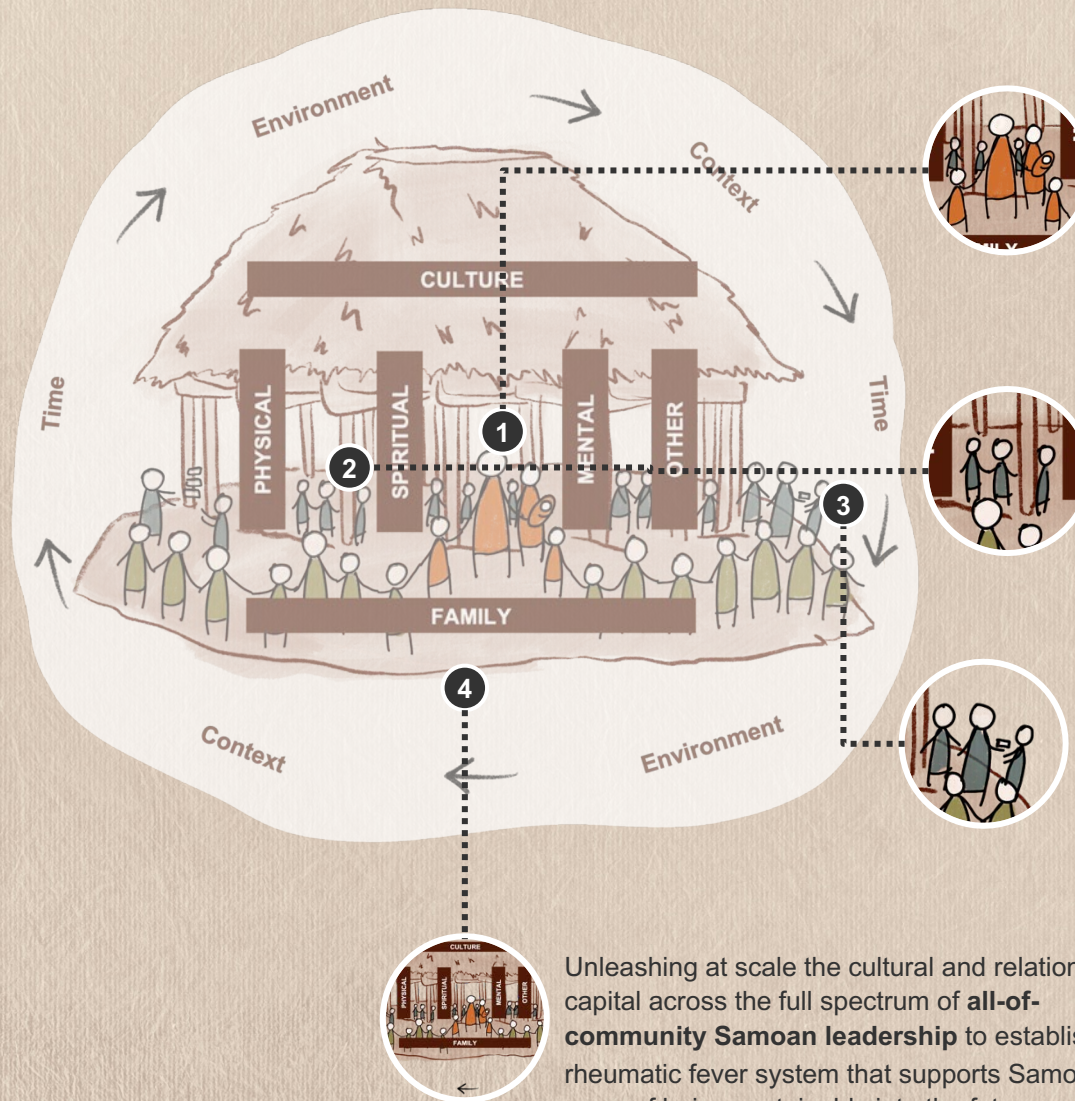
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# Summary of opportunities

Through the discovery phase, we have identified four main change opportunities.

As we progress the work, we will co-create and test specific concepts and solutions associated with these change opportunities. We will select concepts and solutions that have the potential to significantly change the rheumatic fever system and the experiences and outcomes for Samoans who interact with, and are part of, the rheumatic fever system.



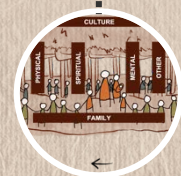
Unleashing the cultural and relational capital of **Samoan families** to design and lead system responses to 'overcrowding'



Unleashing the cultural and relational capital of **young Samoans** to reimagine the rheumatic fever wellbeing and healthcare journey



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



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



**OPPORTUNITY 1**



**Unleashing the cultural and relational capital of Samoan families to design and lead system responses to ‘overcrowding’**

This opportunity is informed by insights that:

- 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.
- Samoans prioritise collective wellbeing and sometimes this comes at the expense of individual wellbeing.

We know that NZ housing conditions aren’t conducive to Samoan multi-generational ways of life and living, and yet Samoan families are stigmatised and judged for ‘overcrowding’.

We know that conversations and decisions around having additional family members come and stay is a sensitive topic for our families, due to cultural expectations and contexts.

This opportunity takes a strengths-based, culturally-informed and community-led approach to design and test how families can have difficult but necessary conversations and find our ways of thriving within the constraints of the NZ housing system. It is about families claiming the power to make choices that keep their children and young people safe without compromising our cultural values and relationships.

**PARTNERSHIP & COLLABORATION OPPORTUNITIES FOR:**

- Samoan families
- Family and cultural leaders such as matai (chiefs)
- Housing and accommodation sector
- Migration and settlement sector
- Communications, marketing and media



**OPPORTUNITY 2**



**Unleashing the cultural and relational capital of young Samoans to reimagine the rheumatic fever wellbeing and healthcare journey**

This opportunity is informed by insights that:

- For many young Samoans, it is preferable to avoid the health system because of prior experiences.
- Young Samoans experience the rheumatic fever management journey as energy-sapping and disheartening.
- Samoans are missing out on vital opportunities for ‘prevention’.

Culture is dynamic and contextual, and young Samoans are creating their own understanding and practice of being Samoans in Aotearoa. This includes an increasing number of young Samoans who are of mixed ethnic heritage.

They have their own trusted sources, their own communication platforms and tools, and they have the right and know-how to manage their own journey with the right support and tools.

We will be exploring opportunities for young Samoans with rheumatic fever to come together to define, design and test what the ideal wellbeing and healthcare journey looks like for them.

We will leverage peer-to-peer connection and learning, disruptive technologies, and youth-led engagement and communications.

**PARTNERSHIP & COLLABORATION OPPORTUNITIES FOR:**

- Young Samoans
- Innovators in storytelling and movement building
- Leadership development sector
- Technology sector
- Youth development and education sectors
- Health and social care sectors



**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**

This opportunity is informed by insights that:

- Samoan practitioners and professionals feel undervalued. The rheumatic fever system takes advantage of their cultural and relational capital, and goodwill.
- 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.
- Fragmentation and competition are hallmarks of the rheumatic fever system in Aotearoa.

The Samoan and Pacific workforce is a critical element of a thriving rheumatic fever system. This opportunity leverages their expertise and know-how to tackle the levers, tools, rules and structures that reinforce inequity and inefficiency.

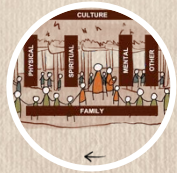
We will be exploring opportunities for Samoan practitioners and professionals to come together to define, design and test innovative models and tools for: strategic positioning of Pacific leadership in systems leadership and governance; policy development; funding and commissioning; and holistic impact measurement.

**PARTNERSHIP & COLLABORATION OPPORTUNITIES FOR:**

- Samoan and Pacific practitioners and professionals
- Leadership development sector
- Innovators and change makers in policy, funding and commissioning and holistic impact measurement



**OPPORTUNITY 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**

This opportunity is informed by insights that:

- 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.
- 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.

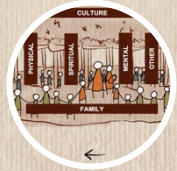
There are powerful forces for change that sit completely outside and untouched by the formal rheumatic fever system in Aotearoa.

Pacific leadership has advocated for these forces to be recognised, valued and leveraged to eliminate complex conditions like rheumatic fever from our nation for years. The changes forced upon us by COVID-19, global political unrest and climate change require action. There is no longer an appetite for inaction and complacency – locally, nationally or across the globe. This opportunity looks to take action now to establish a sustainable, equitable and Aotearoa-appropriate rheumatic fever system that intentionally enhances, rather than diminishes, Samoans’ wellbeing.

We will be bringing together Samoan leaders from across all spheres and strata of community to work collaboratively and strategically to widen the base of rheumatic fever leadership from health to all-of-community.

We will future-proof the rheumatic fever system by embedding Samoan leaders and Samoan ways of being within and across the mainstream systems architecture to ensure that what impacts Samoans in relation to rheumatic fever is Samoan-led, Samoan-informed and Samoan-centred.



**OPPORTUNITY 4** continued

**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**

We will work respectfully and in partnership with Māori, understanding that what is good for the indigenous peoples of Aotearoa is good for us, because they generously open the door for us to follow.

We're not waiting for change any more. We are stepping boldly into the future to take hold of the blessing, wellness and prosperity that our ancestors envisioned for us.

**PARTNERSHIP & COLLABORATION OPPORTUNITIES FOR:**

- Samoans who can collaborate and play to the strengths of the collective
- Innovators in governance and leadership
- Systems thinkers and doers
- Entrepreneurs and creatives





# Join us on the journey

**We have begun with the first step.**

**We are listening, learning and doing.**

**We are ready to go to the next level.**

**We want to work with others to create an Aotearoa where  
rheumatic fever no longer steals from us.**

**If you're up for it, contact us.**

Email: [annie@called.world](mailto:annie@called.world)

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

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



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