



PROTOTYPE

PHASE 3 FINAL REPORT:
A TALE OF TWO SYSTEMS

Soālaupule Capability Building Workshop

A Tale of Two Systems. Phase 3 Report:

Samoa Team, Rheumatic Fever Co-Design Initiative.

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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.

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?

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.

 Watch the video: Case Study 3: Soālaupule Capability Build

Refer to the **Soālaupule Family Meeting Guide** 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.

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** on the following pages.



^{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

PERSONAS AND JOURNEY MAPS



"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

PERSONAS AND JOURNEY MAPS



"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.



Wellbeing needs

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

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.

Emotions

CONCERN

EMPATHY FOR FAMILY

MOTIVATED

JUSTIFIED

RELIEVED WITH RESULT

FRUSTRATED WITH SYSTEM

FRUSTRATION

DEFERENCE

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.

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.

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.



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?
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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.

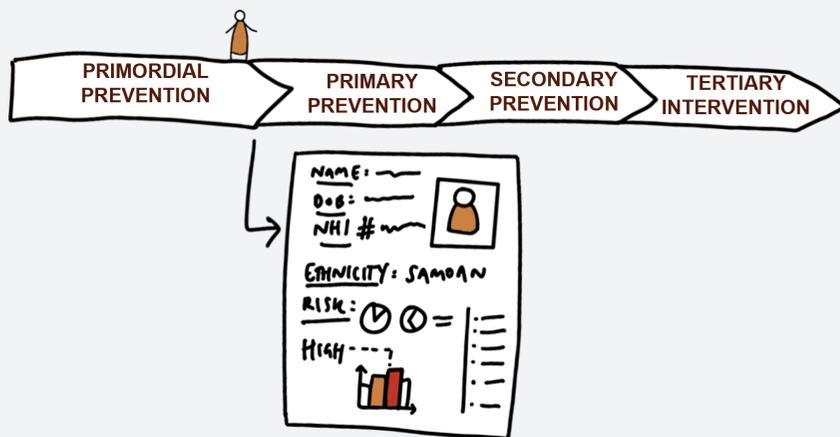
It is important to note that these experiences were felt by Samoans and their families across the whole ecosystem. This includes Samoans living with acute rheumatic fever (RF) and rheumatic heart disease (RHD), and Samoan practitioners and professionals who work across the rheumatic fever health and 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.

HOW THE SYSTEM SEES ME



Adapted from Fonofale model developed by Fuimaono Karl Pulotu-Endemann

HOW I WANT THE SYSTEM TO SEE ME

