



# Co-designing Pacific interventions: A research journey

Associate Professor Malakai 'Ofanoa, Rose Lamont, Dr Maryann Heather, Dr Hinamaha Lutui, Dr Samuela 'Ofanoa, Dr Siobhan Tu'akoi, Professor Felicity Goodyear-Smith



Waipapa  
Taumata Rau  
**University  
of Auckland**



# Beginning of the partnership

Invitation in 2015 to bring a New Zealand clinician and patient dyad to PaCE and NAPCRG.





# Journey to NAPCRG 2016

Travel to NAPCRG 2016 with Dr Tana Fishman to attend the PaCE workshop and learn about patients/communities engaging in research.





# Establishing the Pacific Peoples Health Advisory Group (PPHAG)



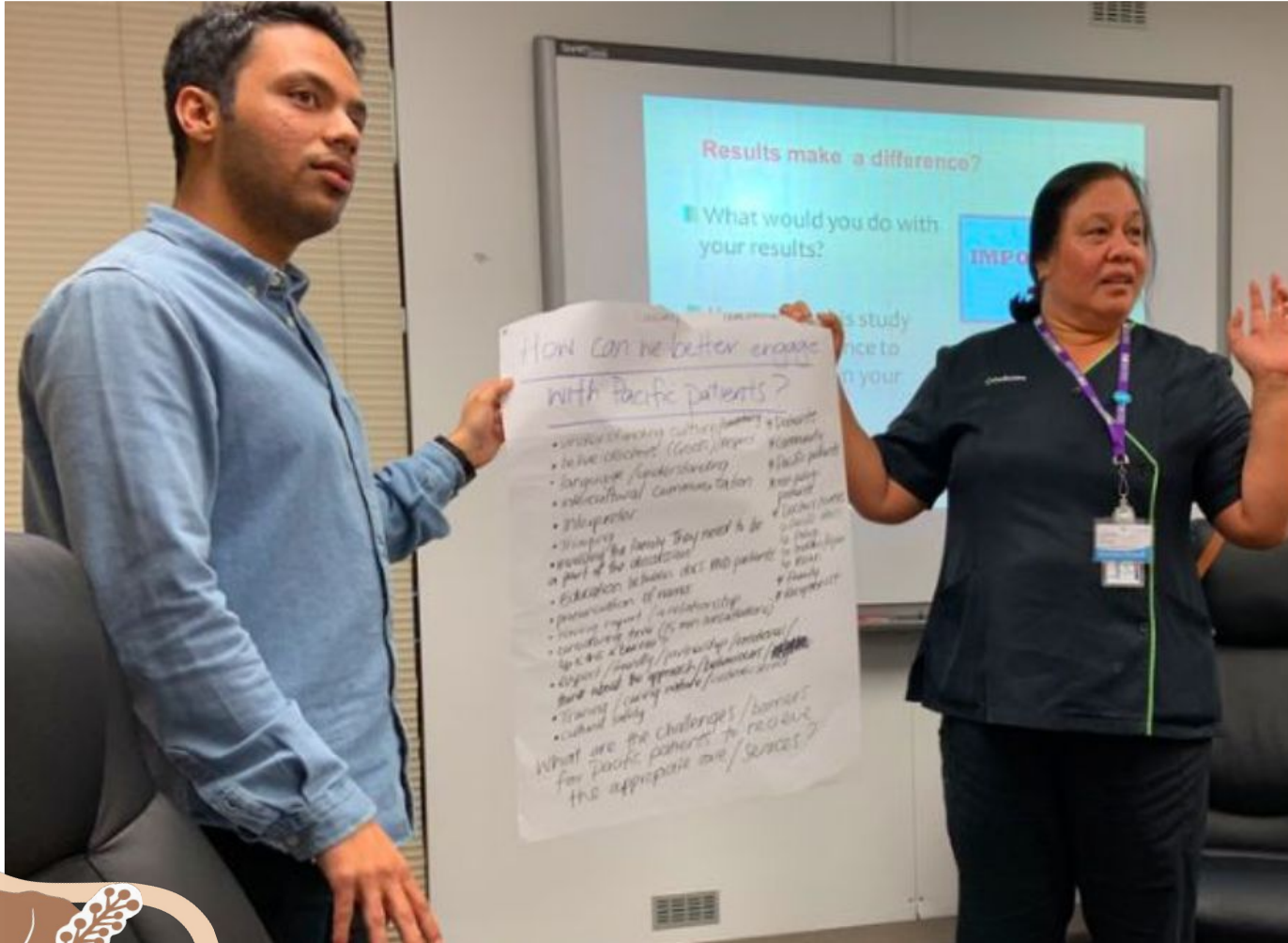


# Development of a Pacific Practice-Based Research Network (PPBRN)





# Clinical perspective of PPBRN





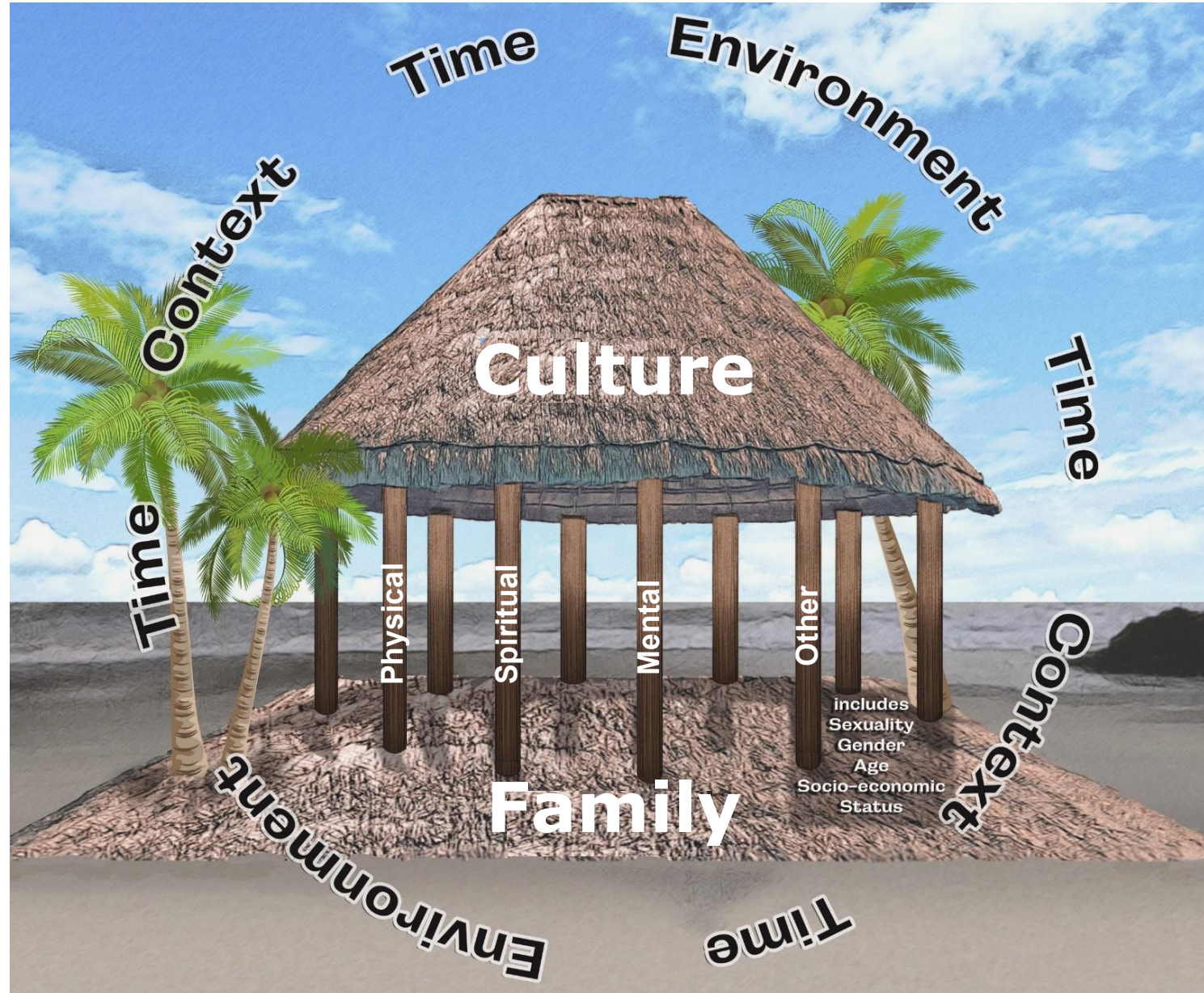
# Talanga workshops

Talanga means "interactive talk with a purpose"





# Fonofale model





# Kakala model

Making a flower garland



Māfana - warmth



Mālie - 'well done'



Teu - conceptualisation



Toli - collation



Tui - weaving

**MAFANA**  
Application  
Transferability  
and sustainability

**TEU** Conceptualisation

**TOLI**  
Data collection  
through Talanoa  
and Nofo

**TUI**  
Analysis

**MALIE**  
Relevancy and  
usefulness

**LUVA** Reporting and outcomes



Luva - gifting



# Fa'afaletui model

## Top of the mountain

See the whole landscape (big picture)

## Top of the tree

Middle-stance lens

## Person in the canoe fishing

Closest to 'school of fish'.  
Knows the small details





## Questions to workshop 19 Nov 2020

### Asking questions: PICO

**P** Who are the people – population, patients, participants?

**I** What is the intervention or area of interest? Eg prevention of rheumatic fever

**C** Is there a control or a comparison? Eg comparing with another option including what happens now?

**O** What is the outcome? Eg how effective is something? what are people's experiences? what is the best way to do something?

### Gout ✓

*How can we make it easier for Pacific People to access medication for gout?*

### Rheumatic fever ✓

- *How can we get the Pacific community in South Auckland to engage in sustained health promotion about the relationship between sore throats and rheumatic fever?*
- *What is an effective health promotion intervention for sustained rheumatic fever and rheumatic health disease prevention strategies in South Auckland Pacific communities?*
- *Do the way that Pacific families live influence development of rheumatic fever?*
- *What are the contributing factors for the high rheumatic fever rates in Pacific children in NZ and what might be done to modify these?*

### Skin infections

- *What are the factors that contribute to skin infections amongst Pasifika children?*
- *Does travel history from the islands have an impact on developing skin infections (impetigo), particularly for children?*
- *What is an effective health promotion intervention for preventing skin infections in South Auckland Pacific children?*

### Disability

- *How can we ensure that Pacific Peoples are getting access to the right equipment? (Limitations with modern technology, communication, disbelief of information)*
- *Are Pacific people aware of proper health care for disabled people?*
- *What is the relationship between Pacific cultural practices and the access or denial of disability services in NZ?*

### Elderly Pasifika people

- *How can primary care help improve care for elderly Pasifika?*
- *What are appropriate services for Pacific peoples to care for their elderly family members?*

### Teenage pregnancy

*How can we improve Pacific teenagers taking precautions?*

# 1. Gout

Improving uptake of urate-lowering therapy for Pacific gout patients in South Auckland, New Zealand.

# 2. Rheumatic fever

Reducing rates of rheumatic fever for Pacific people in South Auckland, New Zealand.





# Gout in New Zealand (NZ)

- Severe pain & swelling caused by urate crystals in joints.
- Pacific people are more likely to get gout, at earlier age, & less likely to be taking urate lowering therapy.
- Diet contributes 10% to variations in uric acid levels while genetics, weight, & kidney problems are the main contributing factors (90%).



SYMPTOMS



inflammation, redness

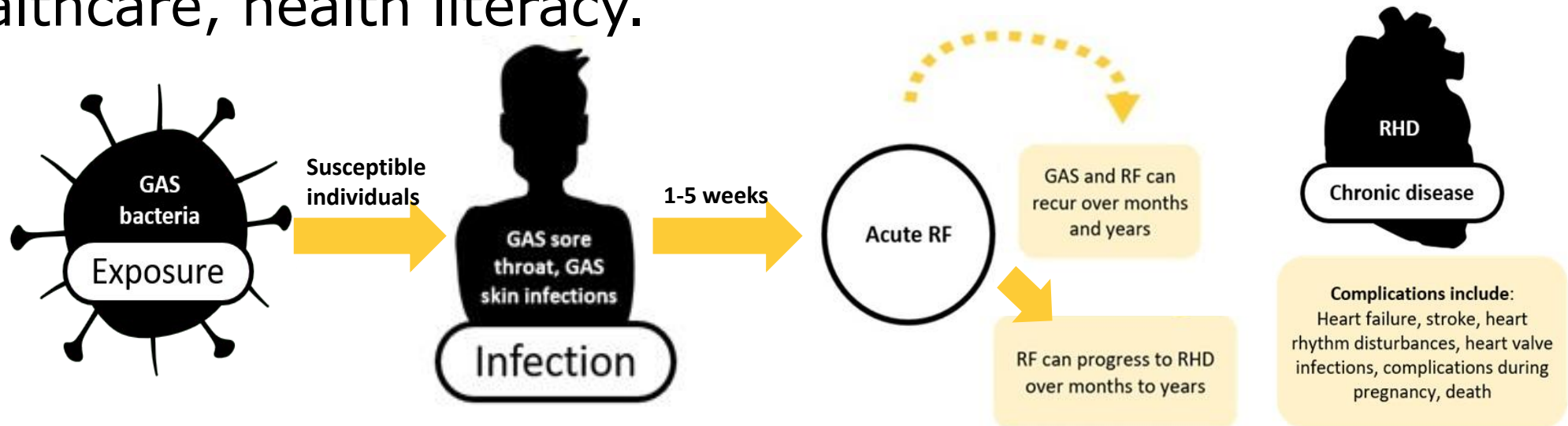


severe pain  
(especially at night)



# Rheumatic fever in NZ

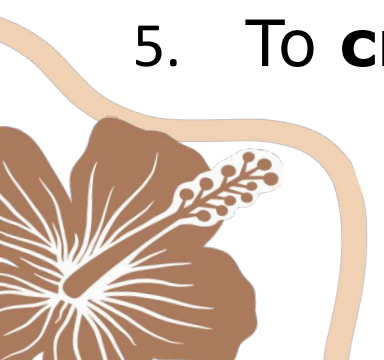
- Despite being eliminated from most high-income countries, disproportionately affects Pacific children in New Zealand.
- Initial hospitalisation for ARF is 24 times higher for Pacific people compared to non-Māori, non-Pacific people.
- Household crowding, socioeconomic disadvantage, access to healthcare, health literacy.



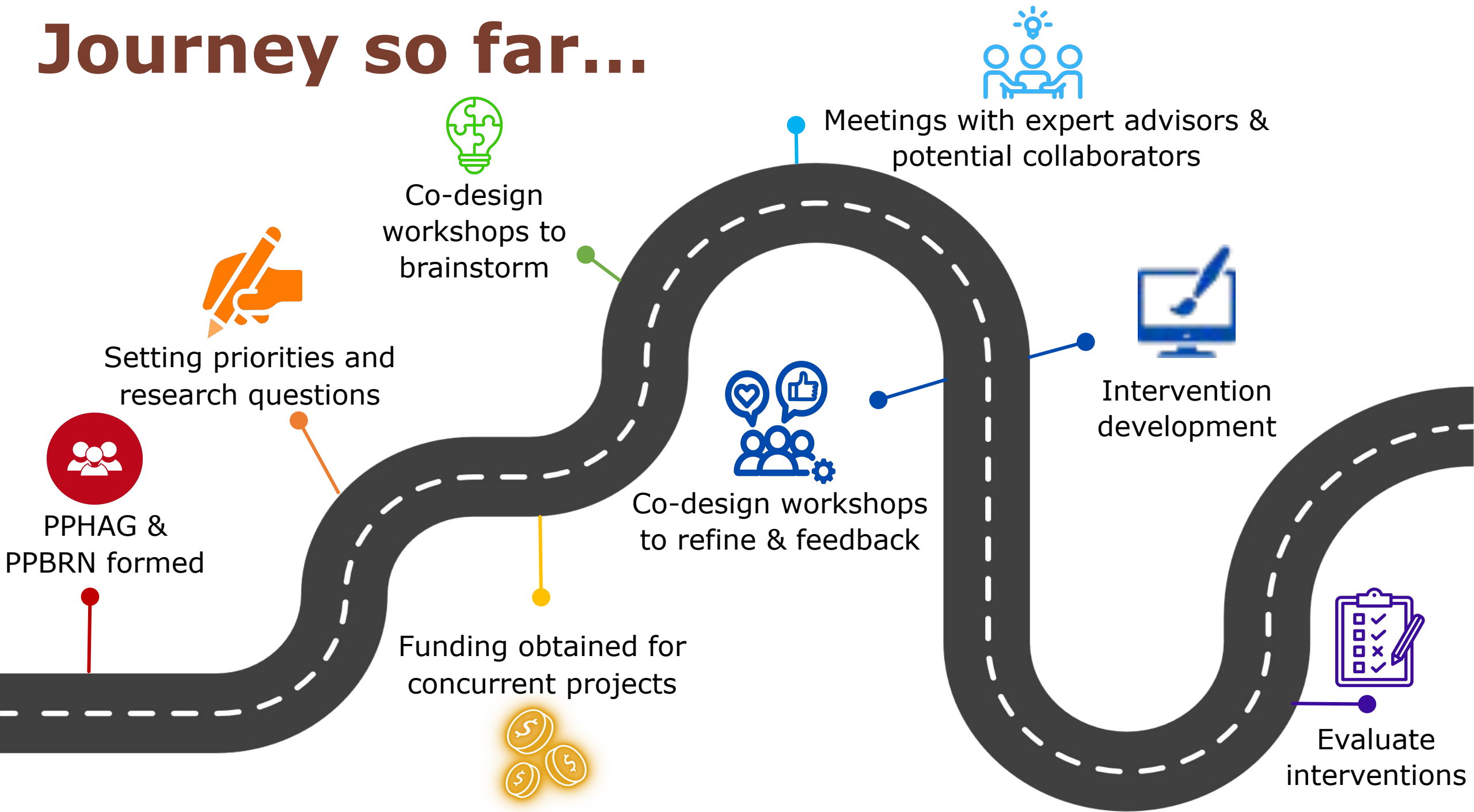


# Project objectives



1. To **determine the burden** of disease in Auckland general practices, comparing Pacific, Māori, and non-Pacific non-Māori.
  2. **Stocktake of interventions** to identify what has been done before.
  3. To **co-design approaches** with Pacific communities living in South Auckland, New Zealand.
  4. To **evaluate** the implementation and effectiveness of the co-designed intervention.
  5. To **create an implementation framework**.
- 

# Journey so far...



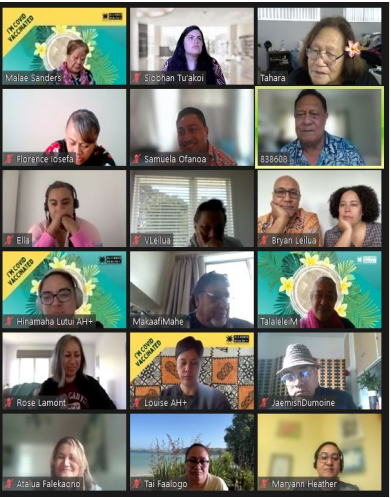



# Co-design workshops



**What has been done?**

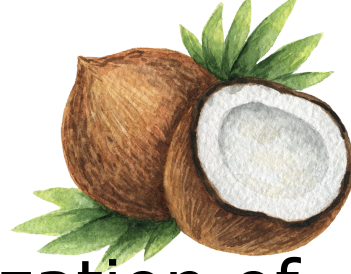
- Review of international studies to improve use of ULT for gout undertaken by Iqbal Gill, Masters student.
- Stock take of NZ gout programmes.





# Gout project

NIU: Nesians Improving Uptake of Urate-Lowering Therapy



the uric acid level in their blood. ... every day to prevent further gout attacks.

*Medical*

*SHOW THE TARGETS.*

Medicine and how it works	Stop the medicine and seek urgent medical attention if you experience any of these symptoms
Allopurinol Reduces the amount of uric acid your body makes.	rash, itching, exfoliation (skin flaking off), fever, aching joints, mouth ulcers, swollen lips, difficulty breathing, kidney stones (severe pain in your back or side), blood in the urine
Febuxostat Reduces the amount of uric acid your body makes.	diarrhoea, nausea, headache, rash, mouth ulcers, swollen lips, difficulty breathing
Probenecid Increases the amount of uric acid removed by your kidneys.	rash, itching, fever, mouth ulcers, swollen lips, difficulty breathing, kidney stones (severe pain in your back or side), blood in the urine

*\* I can't even pronounce these meds & I speak English*

General advice about gout medicines  
Gout medicines, like any medicine, can be harmful if not used correctly.

Where can I find out more?

- Pacific conceptualization of gout
- PPHAG and PPBRN identified a need for resources
- Simple and visual
- Pacific languages
- Cater to diverse age groups
- Can utilise during clinical appointments, community events and on social media.

*GP video for information (Vanisa)*

*Accessible on phones/device*

*Influencers - Pacific men*

*show comparison of gout/non gout*

*video series of giving correct info*

*show cooking/dancing*

*plamplet*

*Access to website with more info*

*Use humour*

*Gout*

*Spread video, report, metrics*

*actual/short show medication*

*VIDEO*

*captured and uploaded to play in waiting rooms in the clinics*

*to captions could be translated*

*Video can be affordable - interviewing people on the street and getting those messages approved by docs.*

*teaching to have good + correct understanding of gout to GP practice*

*to help what about symptoms and what to do if you have them*

*updated photos*

*head info*

*updates front page*

*better visuals*

*reduce info*

*medical (argon vs a simplified version)*

*\* even though it's from GPs, maybe the message is better to come from people who are trained in presenting*

*EXPLAINING*

*\* important video is good + patient + time*





# Pacific gout educational resources

## Short video



## Physical brochure



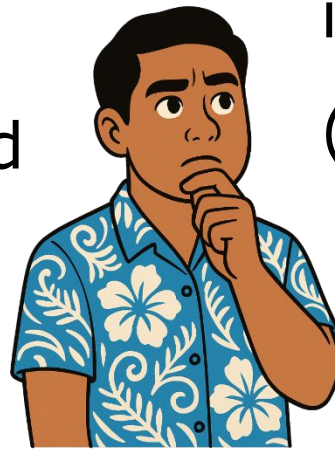
# Feasibility & effectiveness

## Views of health professionals

- 12 participants
- Challenges in delivering gout education in clinical appointments
- Lack of resources available to aid discussions with patients
- Benefits of the co-designed resources for practices

## Effectiveness on gout knowledge

- Pilot RCT using a pre-post survey
- 132 participants
- Preliminary findings show that exposure to the co-designed resources was associated with increased gout knowledge ( $p < 0.0001$ ).





# Rheumatic fever project



1. Content analysis of how rheumatic fever is portrayed on TikTok



2. Survey to explore Pacific people's understanding of rheumatic fever



3. Co-designing a by Pacific, for Pacific social media campaign



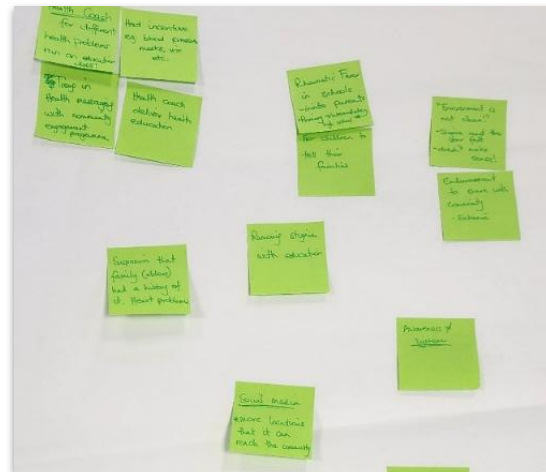
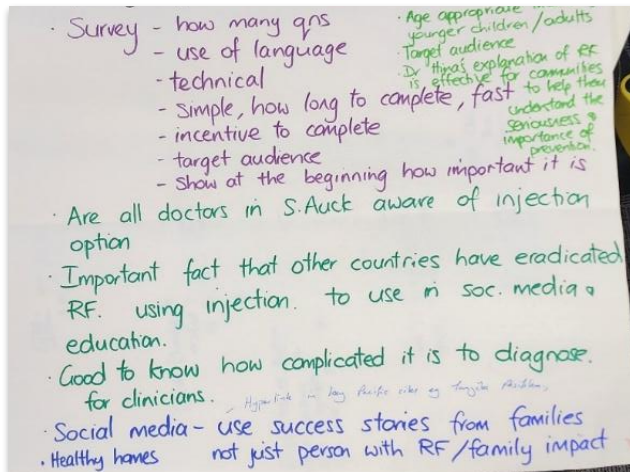
*Most people in our Māori and Pasifika (communities) use social media as their main source of obtaining health information, because social media is popular within younger as well as older generations (Samoan, 16-24 years)*

*Some Pacific people may be too shy to ask (doctors) information so they would go out of their way to search for it themselves (Cook Island Māori/Tongan/NZ European, 35-44 years)*



# Opportunities for rheumatic fever

- Improving general awareness of rheumatic fever, understanding of the varied symptoms and the importance of seeking timely healthcare
- Co-designing by Pacific, for Pacific resources and approaches
- Connecting our communities better with health and social services





# Progress & future directions

- Finalizing the evaluations which investigate feasibility and effectiveness
- Establishing and continuing partnerships with organizations and general practice clinics for implementation
- Celebration of the Pacific community's leadership and impact



# Other outcomes

- Publications – journal articles & book chapters
- Conference presentations – national & international
- Pacific primary care research capacity-building
- Have lots of fun



Dr Hinamaha Lutui



Dr Melenaito Tohi



Dr Alvina Pauuvale





# Learnings from PPBRN

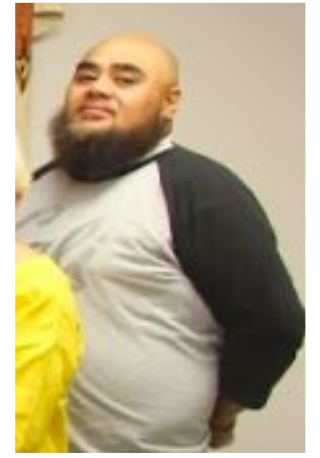
- Listen to our communities
- Innovation to change the future
- Empowered to challenge the system and find positive solutions forward together





# Reflections from PPHAG

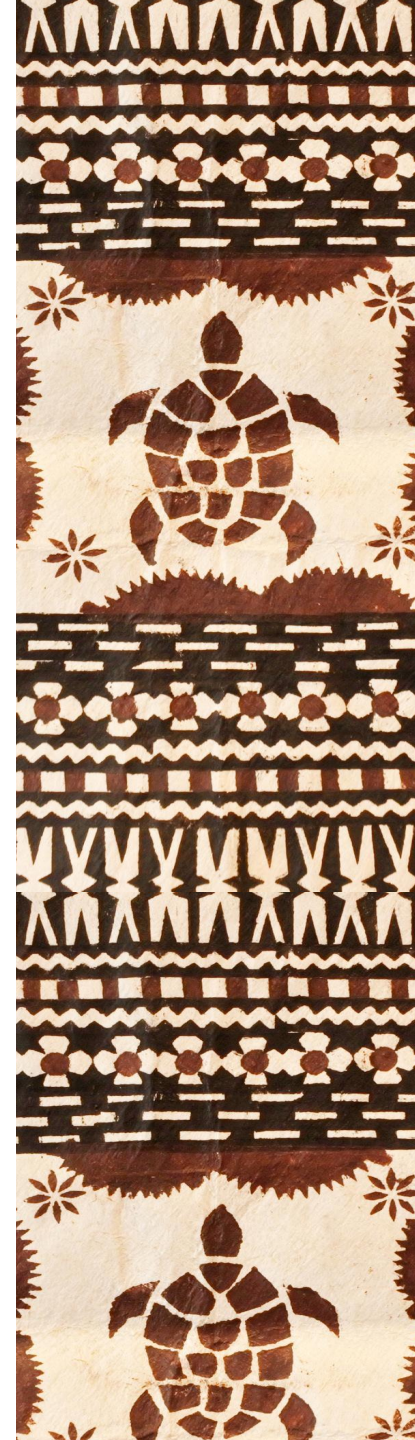
- Importance of community
- Strengths in collaboration and co-design
- Pacific values and talanoa





# Acknowledgements

- Pacific People's Health Advisory Group
- Pacific Practice-Based Research Network
- NAPCRG & the PACE program
- Clinical, Pacific & Māori expert advisors
- Funders: Health Research Council of New Zealand, Arthritis New Zealand, Royal Society Te Apārangi



PACIFIC RESEARCH  
COLLECTIVE

**hrc**nz



Arthritis NZ  
Mateponapona  
Aotearoa



EXPLORE | DISCOVER | SHARE



Waipapa  
Taumata Rau  
**University  
of Auckland**



