

Fiji Heart Health Community Consultation WELLINGTON

Contents

Introduction (the WHY and the WHO).....	2
Purpose of community consultations	2
Anticipated outcomes from focus groups.....	2
What we did.....	2
Research Steering Committee.....	4
Summary of roles and responsibilities of the research steering committee:	4
Committee composition and expertise.....	5
Proposed Terms of Reference (ToR) for the Research Steering committee	6
Categories for Health Research Advisory Committee Terms of Reference:.....	6
Cultural frameworks.....	8
How Peoples of Fiji make decisions affecting our communities?	8
Important Points:	8
Feedback about the proposed framework.....	8
Suggested improvements involve:	8

Figures

Figure 1. Gender, age and ethnicity of attendees for the 2 consultations in Wellington.	3
--	---

Tables

Table 1. Summary of suggested committee size, frequency of meetings, and length of term.....	5
Table 2. Summary of suggested improvements on proposed cultural framework.....	9

Introduction (the WHY and the WHO)

As Peoples of Fiji, we propose conducting the first ever genetics study focused on premature coronary artery disease which runs in families at disproportionately high rates within our community. Peoples of Fiji (including i-Taukei, Rotuman and Indo-Fijian ethnic groups) form approximately 2% of Aotearoa's population and potentially experience 20% of heart attacks under 40-years of age in NZ. Due to inadequate ethnicity capture the data for Peoples of Fiji are excluded from health reporting, risk assessment calculations and academic reporting. In partnership with Ganna Research Network, the University of Otago, Fiji Gimit Foundation of New Zealand and Wellington Voso Vakaviti language class, we are undertaking consultations with Peoples of Fiji to provide an avenue for the community to speak into the foundational aspects of the proposed research, including the development of a cultural framework that is inclusive and representative of all Peoples of Fiji and in defining the roles and responsibilities of the community-led Research Steering committee.

Purpose of community consultations

There are 2 main purposes for these focus groups:

- To consult on a proposed cultural framework (see page 3) that will inform decision-making during the proposed genetic study with regards to patient data management, ethics, guardianship, confidentiality, data sharing and consent)
- To establish key attributes and roles for the research steering committee.

Anticipated outcomes from focus groups

- Establish meaningful connections and relationship.
- Receive and collate feedback on the cultural frameworks.
- Raise awareness about heart health initiatives and promote the intentions of the genetic study.
- Define roles and attributes for members of the research steering committee.

What we did

We completed two community consultations in Wellington on 9 and 10 of June 2023. These events were co-facilitated by i-Taukei and Indo-Fijian community representatives and began with a warm welcome, followed by masu/binti to set the tone. Two PowerPoint presentations were shared with the attendees (delivered by Pritika Narayan), and each presentation was followed by question-and-answer time, and then smaller facilitated group discussions, where groups were provided with a set of questions to discuss and answer.

The first presentation introduced the concept of heart health for Peoples of Fiji and emphasized the importance of understanding the "why" behind the research. This first presentation also explained the concept of data in the proposed study and the significance and potential roles and attributes of a steering committee in safeguarding and managing that data. After a break for food and refreshments, the second presentation introduced the proposed cultural framework, providing a framework for guiding principles in the study. The audience was encouraged to ask questions and engage in group discussions to share their thoughts and perspectives on the framework. Attendees were provided with the opportunity to provide Feedback and evaluate the event and participants had the opportunity to enter a prize draw. The event concluded with closing remarks, ensuring that everyone felt heard and valued for their contributions.

Basic Demographics

Women accounted for 64% of attendees. People in the 40-59 years age brackets formed more than 73% of the participants and people of Indo-Fijian ethnicity formed 69% of the groups compared to 31% of people with i-Taukei ethnicity. Unfortunately, no people from the Rotuman community attended.

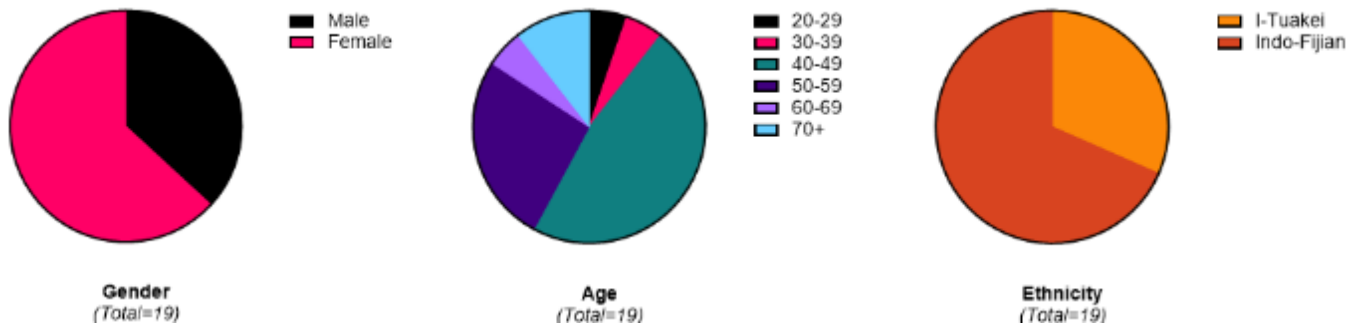


Figure 1. Gender, age and ethnicity of attendees for the 2 consultations in Wellington.

Research Steering Committee

Summary of roles and responsibilities of the research steering committee:

Clarity and Purpose:

- Ensure the purpose of the research is clear and increase education and awareness among the people of Fiji.
- Clarify the committee's type (advisory, governance, or steering) to establish its role and function.

Expertise and Representation:

- Include expert advisors and clinicians as subject matter experts within the committee.
- Foster diversity (in terms of gender, age, and background) to capture the perspectives of the diverse Fijian population.

Ethical and Transparent Practices:

- Uphold honesty, ethics, neutrality, and unbiased decision-making within the committee.
- Act as custodians of data, ensuring its protection and privacy while serving as gatekeepers for its use.

Effective Communication and Engagement:

- Foster open-mindedness, good communication skills, and relatability, especially in Hindi and Fijian languages.
- Develop a communications plan with simple language and engage stakeholders effectively.

Implementation and Monitoring:

- Collaborate with the research team to plan the implementation of research outcomes and monitor their progress.
- Have a clear pathway for how the research findings will be put into practice.

Governance and Authority:

- Establish a governance structure with defined roles and power balance between the committee and the sponsoring institution.
- Serve as effective policy makers, having the authority to make changes that positively impact the research and its outcomes.

Summary of roles

The research steering committee's roles and responsibilities encompass ensuring clarity of purpose, leveraging expertise and diverse representation, upholding ethical practices, facilitating effective communication and stakeholder engagement, overseeing implementation and monitoring progress, and establishing a robust governance framework. By fulfilling these responsibilities, the committee aims to drive impactful and ethically sound research that addresses the needs of the Fijian community and contributes to positive change, especially for heart health among current and future generations.

Committee size, frequency of meetings, and length of term

The responses indicate a preference for smaller teams to ensure focus and effectiveness. The frequency of meetings would be more frequent at the beginning and then transition to less frequent as the work progresses. The suggested term duration is around 2 years, although it may vary depending on the length of the research project.

Table 1. Summary of suggested committee size, frequency of meetings, and length of term

Category	Summary of Responses
Team Size	<ul style="list-style-type: none"> The suggested team sizes range from 5-8 members, with some favouring smaller groups for better focus and effectiveness. The consensus is that a smaller team is preferred. The exact number of members is not specified in detail.
Frequency of Meetings	<ul style="list-style-type: none"> Meetings initially would be more frequent (fortnightly or monthly) and then transition to less frequent (2 monthly, quarterly) as the work becomes established. A structured meeting schedule and timeline are suggested for efficient planning. The specific frequency of meetings is not discussed in depth.
Length of Term	<ul style="list-style-type: none"> The suggested term duration is around 2 years, aligned with the duration of the study. No specific discussion or consensus is reached regarding the length of the term. The term may vary based on the length of the research project.

Committee composition and expertise

In summary, committee should consist of individuals with the necessary expertise and qualifications to be considered as subject matter experts (Tier 1). They bring specific skills, knowledge and experience related to heart health, including individuals with lived experience and professionals from various backgrounds including health care, policy-making, and community involvement. Additionally, their affinity with the group and commitment to research/community (Tier 2) ensure their ability to represent the community's interests effectively and contribute to meaningful outcomes. Cultural, ethnic, and gender representation is crucial (Tier 3), ensuring diverse perspectives and inclusivity. The committee should reflect the broader community and be trustworthy individuals with proven track records.

Tier 1: Subject Matter Experts

- Consumer perspective is key, research participants, health consumers of heart health care, Individuals with lived experience
- Health Professionals who understand privacy
- Links to community health groups and ethnic health groups and/or health policy makers
- Legal/lawyers (although one participant was not keen)

Tier 2: Affinity with the Group and Commitment to Research/Community

- People with strong value systems and passion for the specific cause
- Individuals who are trusted and respected by the community
- Individuals with connections and commitment to the research/community
- Links to community health groups

Tier 3: Cultural, Ethnic, and Gender Representation:

- Diversity in ethnicity, gender, religion, and age
- Representative across generations, not limited to those born in Fiji

Proposed Terms of Reference (ToR) for the Research Steering committee

The below categories encompass the key themes and considerations for the terms of reference for a health research advisory committee, ensuring data protection, promoting health literacy, addressing ethics and governance, selecting a diverse and knowledgeable committee, facilitating implementation and monitoring, engaging stakeholders, and ensuring smooth committee operations.

Categories for Health Research Advisory Committee Terms of Reference:

1. Data Management and Protection:

- Protect research participant data and rights.
- Make decisions regarding data use, sharing, and publication while ensuring privacy and de-identification.
- Serve as custodians and gatekeepers of data.

2. Promotion of Health Literacy and Knowledge:

- Develop resources, events, and dialogue to promote health literacy among the People of Fiji.
- Increase awareness and education among the community for better engagement and ownership.

3. Ethics and Governance:

- Work with the research team to develop ethics applications and patient consent forms.
- Clarify the interface between the research committee and the sponsoring institution.
- Establish governance structures and power balance between the committee and the institution.
- Ensure the committee has the authority to make change and serve as policy advisors.

4. Composition and Expertise:

- Seek a diverse committee representing different genders, age groups, and cultural backgrounds.
- Include clinicians as subject matter experts, community leaders with understanding of the study, and good communicators of information.
- Consider language proficiency in Hindi and Fijian to ensure relatability.

5. Implementation and Monitoring:

- Include the role of implementing research outcomes with a clear pathway for implementation.
- Monitor the progress of the study and define responsibilities for monitoring.

6. Stakeholder Engagement and Communication:

- Develop a communications plan with simple language to engage stakeholders.
- Identify stakeholders, including participants, and consider funding sources and potential fundraising needs.
- Address the interface between the committee and the community, building trust through local/national team collaboration.
- Promote the study through various channels, such as churches, social media, word of mouth, and emails.

7. Committee Operations:

- Establish a vetting process for replacing committee members who leave.
- Lock in non-negotiable meeting times and commitment from committee members.
- Address criteria and requirements for committee membership.

8. Specific Focus:

- Focus on specific diagnoses like premature heart attacks or coronary artery disease.

Cultural frameworks

How Peoples of Fiji make decisions affecting our communities?

In Fiji, decision-making processes involve various cultural and traditional factors. The majority operate through a patriarchal system where males make decisions, often consulting elders, people in chiefly positions, and religious leaders. Individually, people seek advice from family members before making decisions. Decision-making occurs at different levels, including traditional methods, communal acknowledgment, and individual choices. However, the cultural framework in New Zealand may be a hybridized version, as decision-making processes have changed with time and displacement, compared to traditional practices. The importance of community leaders and individuals with lived experiences is emphasized for a collaborative approach. In healthcare, there is a contrast between Fiji and New Zealand regarding primary care and trust in the health system.

Important Points:

- Majority of decision-making in Fiji is through a patriarchal system, involving males, elders, and religious leaders.
- Individual decision-making and seeking advice from family members are common practices.
- Decision-making occurs at various levels, including traditional methods, communal acknowledgment, and individual choices.
- Decision-making processes have changed in the cultural framework of New Zealand.
- Collaboration and inclusion of community leaders and individuals with lived experiences are desired.
- Contrasts exist between Fiji and New Zealand in terms of healthcare decision-making and trust in the system.
- Personalized decision-making and the influence of handed-down traditions play significant roles.

Feedback about the proposed framework

Affirming comments include liking the simplicity and cultural appropriateness of the framework, agreement on the importance of strong roots, and the relevance/appropriateness of the mango tree as a symbol that is easy to relate to and identify with for all people from Fiji. Non-affirming comments mention the missing spiritual element and depiction of leaves and branches of Mango tree, lack of clarity on the research's end point and context, and the assumption of diaspora community sameness. Remaining questions revolve around addressing changes in the diaspora community as well as risks associated with the proposed research, mitigating those risks and data confidentiality and spelling this out within the framework.

Suggested improvements involve:

- incorporating the spiritual aspect
- clarifying the intended outcome
- creating a simple drawing of a single mango tree with the different parts highlighted and brief headings of key principles in Voso vakaviti, Fiji baat and Rotuma languages.

Table 2. Summary of suggested improvements on proposed cultural framework

Category	Summary of guiding principle	Suggested improvements/questions raised
1. Roots	Strong foundation, deep relationships, and trust	<ul style="list-style-type: none"> • Provide a context to understand the purpose of the framework. • What right do we have to make these decisions?
2. Trunk	Provides strength, stability, and protection	<ul style="list-style-type: none"> • Clearly define the intended outcome of the research • Confidentiality of data is key - individual should be anonymized
3. Seed	Represents new life and empowerment	<ul style="list-style-type: none"> • Biya is more appropriate word for seed in Fiji baat. • Address changes in the diaspora community,
4. Harvest/fruit	Benefits to participants and wider community	<ul style="list-style-type: none"> • Harvest - recognize risks and ways to mitigate risks, disbenefits and benefits • Framework assumes diaspora community is the same
5. Leaves	Diversity, spirit, representation of all, Connection through different languages, cultures, faiths coming together	<ul style="list-style-type: none"> • Explore and incorporate the spiritual aspect, family/sense of belonging and diverse identities that make up Peoples of Fiji

A CULTURAL FRAMEWORK FOR PEOPLES OF FIJI

Harvest: Tatamusuki/Fal

Benefits to community health and wellbeing
Provides sustenance for ongoing work

Leaves:

Draunikau /Patti

Incorporate all elements
(e.g. spiritual, cultural,
social) that influence
health and wellbeing



Seed:

Sorenikau/Biya

Creating opportunity
for future generations
to thrive

Trunk:

Taqomaki/Raksha

Protecting current &
future generations

Roots: Veimaliwai/Rishta

A strong foundation of relationship and trust