

# Polokalama Fekumi ki he Kanisā ‘o e Halanga-me’atokoní—Ko e vakai ‘a e Tongá: Tongan New Zealanders’ views on how to ensure the National Bowel Cancer Screening Programme works well for the Tongan community

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## ABSTRACT

**AIM:** The National Bowel Screening Programme (NBSP) fails to deliver screening equitably to Pacific New Zealanders. This research explored Tongan New Zealanders’ experiences of participating in the NBSP and their views on ensuring the programme works well for the Tongan community.

**METHOD:** In 2021, we conducted two talanoa focus groups with Tongan New Zealanders who had participated in the NBSP (n=26), recruited through a Pacific provider in Auckland. Participants were aged 60 or more and were Tongan born. Interviews with four Pacific experts working in the NBSP were also undertaken. Their views on the NBSP were explored and analysed using thematic analysis.

**RESULTS:** While the research participants valued the opportunity to participate in the NBSP, they had many valuable insights about strengthening it, as did the Pacific experts. Key was a by Tongan, for Tongan service run by Tongan providers, one based on Tongan models of health and health promotion, Tongan values and ways of working, and using the Tongan language, which empowers Tongans to take control of their health.

**CONCLUSIONS:** This research demonstrates critical elements of an effective, culturally appropriate and empowering NBSP for Tongans led by Tongan providers. If these findings are enacted, more effective delivery of bowel screening to Tongans will likely be enabled, reducing inequity in participation between Tongans and other New Zealanders. What is required is courage and political will to shift power and resources to ensure equitable outcomes in the NBSP, not only for Tongans but for all Pacific peoples.

In 2023, the National Bowel Screening Programme (NBSP) in Aotearoa New Zealand (Aotearoa) did not deliver services equitably to Pacific participants. Fifty-eight percent of New Zealanders overall were screened, but only 49% of Māori and 39% of Pacific people.<sup>1</sup> Pacific peoples are 60% more likely to die from bowel cancer compared to European people (HR 1.6 95% CI 1.4–1.7).<sup>2</sup> Screening rates also differ between Pacific communities in Aotearoa, with only 35% of Tongan New Zealanders currently screened, compared, for example, to 42% for Cook Islands Māori (In an email, the National Bowel Screening Programme, 2023). Further, the Pacific community is a significant, young and growing population in Aotearoa, which will have an increasing need for an effective NBSP.<sup>3</sup>

There is very little research on the views of

Pacific New Zealanders exploring how the NBSP can work better for Pacific peoples, including for Tongans. Recent research by Dunlop explores the perspectives of Tongan and Samoan New Zealanders towards stool testing. Dunlop found that Pacific people “were willing to do stool testing despite having reservations about hygiene concerns and feelings of shame or embarrassment.”<sup>4</sup> Sandiford et al., identified that telephone follow-up increased participation in stool testing returns for Pacific peoples, including Tongans, by 3.6%.<sup>5</sup> Further, giving NBSP participants the option to return stool samples to a community laboratory rather than through the mail resulted in a small but significant increase in screening participation by Pacific peoples.<sup>6</sup>

The peoples of the Pacific have many different cultures and histories, including different experiences

of colonisation. As such, it is essential to recognise the needs and aspirations of the various Pacific cultures in Aotearoa. In this research, we do so by focussing on Tongan New Zealanders.

However, Pacific communities also have much in common. This includes:

*“... shared understandings and experiences of being of Pacific Island origin with a relatively recent history of immigration to New Zealand; there are similarities in Pacific peoples’ social and cultural values and views of the world.”<sup>7</sup>*

Pacific peoples also share a history of an Aotearoa healthcare system that has been culturally inappropriate and disempowering for them<sup>8</sup> where they continue to encounter racism, which negatively impacts their health.<sup>9,10</sup> Yet there has been considerable progress in providing Pacific-led health and social services and Pacific health promotion leadership.<sup>7</sup>

Pacific models of health and health promotion have also emerged in Aotearoa. The Samoan Fonofale<sup>11</sup> and Tongan Fonua<sup>7</sup> and Fonua Ola<sup>12</sup> are commonly used models that speak to the holism of the Pacific approach. Fonua Ola includes six dimensions of Pacific health and wellbeing: spiritual, mental, physical, economic, cultural and ecological.

Tu’itahi and Lima propose the following Pacific definition of health promotion:

*“... the empowering of Pacific people and their communities to take control of their holistic health and wellbeing and their future. It is an Indigenous approach that is inter-disciplinary and multi-dimensional.”<sup>7</sup>*

Tongans view the world holistically and think and work collectively. Because of this, they are guided by the core values of Fefaka’apa’apa’aki (mutual respect), Feveitokai’aki (sharing, cooperating and fulfilment of mutual obligations), Lototoo (humility and generosity) and Tauhi vaha’a (loyalty and commitment). This collective approach is inconsistent with a focus on the individual, common in Western thinking and Western health systems, and a dominant value in Aotearoa.<sup>13,14</sup>

For Pacific peoples, healing a disease requires an internal process focussed on relationships.<sup>14</sup> Your response is to put things right with yourself, your relatives and your God. You are seeking the natural balance of things. At the same time, Western

medicine has a strong focus on the physical healing of the individual by seeking treatment to kill the organism and get rid of the disease.

This research aims to contribute to closing the gap in knowledge on how to ensure the NBSP meets the needs of Pacific New Zealanders and, therefore, decrease the inequity in bowel screening rates. The study explored Tongan New Zealanders’ experiences of participating in the NBSP and their views on ensuring the programme works well for the Tongan community. The views of key Pacific experts with knowledge of the NBSP were also sought.

## Methods

We conducted two talanoa focus groups with Tongan New Zealanders who had participated in the NBSP (a women’s group [n=12] and men’s group [n=14]).<sup>15</sup> Participants were recruited among patients who had experience in the NBSP and were members of The Fono, a Pacific health provider in West Auckland. Participants were all aged 60 or more, as this was the age eligibility for participation at the time, and were all Tongan born. (Since this research was undertaken, it has been announced that the eligible start age for bowel screening will be lowered from 60 to 50 years for Māori and Pacific people. The lower age range is already in place in Te Whatu Ora Waikato and Tairāwhiti and MidCentral as part of an evaluative implementation). We also undertook four interviews with Pacific experts working in the NBSP. The talanoa and interviews were conducted by VP and AP, well-known Tongan doctors from the community. They were supported by ML. Talanoa is a conversational research method. It was guided by a semi-structured interview schedule that aimed to have a “healthy conversation” that was strengths-based. Focus group questions included “What was your experience of the bowel screening programme, what worked well, and what did not work well for you and your family, and how can the bowel screening programme be improved to meet the needs of the Tongan community?” A nurse from The Fono was present to answer any questions or provide follow-up. The talanoa and interviews were conducted in Tongan and English, audio-recorded and transcribed in English by VP and AP. Data were analysed by VP and AP using thematic analysis<sup>16</sup> and discussed with the wider team. When this research was conducted in 2021, the NBSP was underway. The Fono was contracted to

promote the programme and support people to participate. The University of Otago Human Ethics Committee (Health) provided ethical approval (H20/076).

## Results

### Experience of NBSP

#### *Appreciation for the NBSP*

All the participants highly valued participating in the NBSP. As one person said, *“I join and echo what others said about how important this programme is for our people.”* One participant shared that while he was given a clean bill of health, friends of his had the test too late and had since died.

#### *Valuing prevention*

Many Tongans accept that “prevention is better than cure,” which was demonstrated by the appreciation the participants revealed for the programme. One participant noted that:

*“I was very happy when I received the letter to join the bowel screening programme because I have had other health problems back in the Island and here in New Zealand. I only found out when I was sick. This one is to find out before I am sick ... Therefore, I am very happy and have done it for number of years. I do the test as soon as I received the kit.”*

The participant reported that some members of the community died despite being tested because their cancer was too advanced. Others *“were lucky to find out early, and treatment helped them.”* However, participants agreed that if people do not understand the service, the need for it and if it is hard to access, then the “noble saying” that prevention is better than cure will just remain a nice statement.

#### *Fatalism*

For many Tongans, there is also a strong sense of fatalism about death, as with many Pacific cultures. As one participant notes, *“at this age [60+], we have reached a good age, and if we die, it's ok.”* Associated with this was that people would rather not know, as one participant stated, *“what will be, will be.”*

#### *Fear of cancer*

This attitude could be related to fear of cancer, as one participant said,

*“I did not want to participate in NBSP is because I am afraid of cancer. When the pack arrives, I just put it up on the shelf, hoping to have the strength to do it later, but when Christmas cleaning came, they got dumped in the bin.”*

#### *Confidence to do the test*

One participant explained the importance of people having the confidence to do the test.

*“As mentioned by others, it will be better to have Tongan information so you can understand and have confidence that you are doing it correctly. I was fearful that if I do it wrong, my result will be bad. I do not want to have cancer and the wrong result.”*

#### *Bowel screening is a process, not a one-off event*

Critical to the success of the programme is ensuring that people understand that bowel screening is a process and not a one-off event. As one expert explained, *“If the previous result was good, then when the second kit comes to them, they will start ignoring it, will have that kind of Pacific ... attitude, oh well, I'm okay, I'm healthy so I'm not going to do that.”*

During the talanoa, VP and AP shared a lot of information. At one point VP described the NBSP as like a *“warrant of fitness like the warrant we need for our vehicles.”* The idea is that *“New vehicles require less frequent tests, but older ones like us need more frequent testing.”* At the end of the talanoa, one participant commented, *“Thank you very much; this meeting helps me to understand the need to continue the screening, and I will actively participate from now onwards.”*

#### *The importance of the collective*

The collective nature of Tongan society was frequently referred to by participants, including the role of women in family decision-making. As one man noted, *“This [discussion] has highlighted the important role women have in promoting health in the family because they can motivate the men to participate.”*

### **Use of language and source of information**

If a letter is sent, the information must be in Tongan and well explained. One person noted that *“Many people do not have a good understanding of basic English, let alone technical terms commonly used in health and medicine. It is essential to use language that people understand.”* Another said, *“I am lucky I can understand English, but I know others never participate as they do not understand the communication.”* As one person explained, *“It is most important to have the information leaflet in Tongan, listed in steps and using a lot of diagrams ... But even in Tongan, it is not always easy to understand.”*

In Tongan culture, it is essential to know who is sending the message to trust the source of the information. As one participant notes, *“When I received my pack, it did not come from Fono Henderson Clinic, and I imagined it must have come from the office of NBSP. When I looked at it, I was not motivated to touch it and did not feel I need to do anything with it.”*

All the experts spoke of problems with the use of language and its meaning. As one expert explained, *“It is important for the information to be clear to our people; I know it’s very clinical some of the words on the leaflet or flyer.”* One participant summed up these concerns as follows:

*“Receiving a pack from people I do not know, about a programme I have not heard about, and resources not written in Tongan, is a sure road to failure of the programme and low uptake from the Tongans. As a Tongan, it is important that for me to engage in the programme, I need to understand the value and benefits that I am investing in the programme.”*

### **Ways to ensure the NBSP meets the needs of the Tongan community**

When asked, participants and experts discussed a range of ways to ensure the NBSP meets the needs of the Tongan community. Participants were clear that the appropriate method to promote the NBSP was talanoa, healthy conversation where people are empowered to speak their minds and share their ideas. Experts advise having more talanoa time, maybe four times a year, so that relationships are built. Participants and experts emphasised using Pacific radio to promote the programme. This is particularly important because people over 60 are listeners,

not readers. They are the generation who were born outside of Aotearoa.

Experts emphasised the importance of the church in the lives of Tongan New Zealanders to promote the programme. As one expert explained, *“The church is a place where people’s lives are influenced ... Church makes a difference in how people will listen [where they] are willing to make a change.”*

Promoting the programme can be done effectively, as it was in the talanoa session for this research. As one participant stated,

*“Pacific and Māori are commonly assumed and labelled as uninterested, and they do not value their health; therefore, they do not turn up to their appointment, DNA [do not attend appointments]. The attendance we had contradicts all that. There is something good and beautiful we are witnessing here [referring to the talanoa focus group for this research].”*

As one expert, The Fono Bowel Screening Coordinator, noted:

*“I just have to remind them [that] doing the test is very important ... And some of the people I think it’s good because they know me, so they asked me if I can come and pick it up, so I can drop the test to the mailbox because they cannot drive.”*

She also explained that home visiting is very valuable. She sometimes joined the community nurses on their home visits to promote the programme.

The experts agreed that it is possible to successfully run the NBSP for Tongans. People do understand the importance of prevention. However, the service must be run in a Tongan way. The experts were clear that a collective approach, working with key community leaders and the community as a whole, was critical. They also spoke of the need for relationship-building and frequent and long-term community engagement. They were clear that the idea of bowel screening needed to be socialised with the community to succeed. Further, the experts in this study clearly state that a holistic approach is required. The funding and services in the health sector are usually focussed on single health issues. What is required is a wrap-around service that addresses all their health needs.

## Discussion

This research indicates that the NBSP can be better used by Tongan New Zealanders, especially if promoted by a Pacific provider, as occurred for the participants in this research. While the participants greatly appreciated the NBSP, they shared many valuable insights about how the programme could be strengthened to maximise its value to the Tongan community, as did the Pacific experts. Barriers to overcome include ensuring Tongans understand the importance of the programme to them, address any fatalism or fear associated with bowel cancer, have the confidence to do the test and recognise that screening needs to be repeated every 2 years.

In stressing the collective nature of Tongan society, participants emphasised the importance of delivering the programme to the community, not to individuals. In the Pacific culture, critical decisions lie with the community, not the individual. In Tongan society, women are recognised as the custodians of the family's health and wellbeing, and their decisions are respected by men and children. Tongans brought up in Aotearoa often play a crucial role as translators for older family members if services are not delivered in Tongan. Further, if the community understands the programme, they can support others to participate and focus on their health. These participants clearly expressed the Fonua concept of katoa or the collective.<sup>7</sup>

Currently, the programme has much emphasis on the invitation letter as the first point of communication. In the Tongan context, you speak to somebody. Participants were clear that for Tongans, a letter is not appropriate, especially when written in English, that they may not be able to read. Writing to people in a language they cannot understand is disrespectful and runs the risk that they will develop a negative view of the programme and not participate. Since this research was conducted, there is some information available in Tongan. People must also trust the source of the information they receive. Ideally, the message and the messenger are one and the same.

Experts and participants agreed that translation is more than just the translation of the words into Tongan. Bowel screening is a difficult medical concept with scientific terms that are complicated even in English. Translating them into a Pacific language is more than just getting a specific word; it is grasping the meaning of that word, whether written or spoken. It is important to consider how

things are explained and avoid miscommunication. This is something more easily done face-to-face. Hence, the importance of talanoa and personal interactions. One concern is the concept of "testing". People may understand a test to be like a school or driving test where there is a pass/fail. Consideration could be given to renaming the "test". Perhaps the concept of "Tā e lango kei mama'o" would be better. It refers to preparation ahead of time. When stormy weather comes, you must prepare to remove the canoe from the water by putting out the log upon which to roll it. To survive, you must have the log ready ahead of time.

Promoting bowel screening is further complicated by the fact that Tongans regard the bowel as a taboo area that is not something to be spoken about in public.<sup>4</sup> It is a very private matter, only discussed among people of the same gender; hence, there are separate focus groups for women and men in this study. This finding supports that of Dunlop, who found that Tongan and Samoan New Zealanders "*were strongly opposed to mailing stool samples and had a preference for dropping samples at laboratories instead.*"<sup>4</sup>

Experts agreed that the programme should be run by Tongans, for Tongans to empower the Tongan community to take control of their health<sup>7</sup> about bowel screening. This was supported by participants who consistently called for Tongan-based approaches in their feedback. The findings emphasise the need for a programme based on Tongan models of health and health promotion, on Tongan values and ways of working, using the Tongan language. This is best done collectively, face-to-face using talanoa, supported by Pacific radio and community networks. Careful attention is needed to use language to explain medical concepts in ways people understand. It is best delivered as part of wrap-around services, not just a programme on a single issue, in line with the Tongan holistic understanding of health.<sup>7</sup> Participants in the NBSP need support at all stages of the process.

Fortunately, there are Tongan providers available to undertake this work, although full coverage would require further resourcing. Pacific providers continue to demonstrate their critical role in working with their communities, particularly apparent during the COVID-19 pandemic.<sup>17-19</sup>

Tongan churches are an ideal setting for health promotion, as the experts in this research advised. In Aotearoa, the church is the village, the Pacific

marae. The church is a place where people feel safe. People place much trust in the church and church leaders, who can be very influential.<sup>7,20</sup>

Since colonisation, disease management has been primarily considered the realm of doctors and other health experts among Tongan people. This power dynamic has often made people passive healthcare recipients rather than active participants in their health. People can see screening as technical and clinical. Tongans often see the Western health system as there for treatment, not prevention. Therefore, if you do not have a problem, there is no need to look for, or accept, help. This colonisation of healthcare has distracted people from self-care to dependence on experts.

It is essential to bring back the concept of self-care to enable people to “*increase control over, and improve, their health*,”<sup>21,7</sup> to enable people to feel that it is all right to do self-care and that they can do it correctly, as the focus group participants in this study were able to do. COVID-19 has meant that people have undertaken self-care, e.g., using masks, staying home and testing. This has reinforced for people that self-care is an acceptable thing to do. This may have empowered people to do self-care in other areas of health.

Racism and systemic bias are key factors in the chronic inequities and poor health outcomes Pacific peoples endure in Aotearoa, as “*Ethnic inequities in health are unjust, unfair and patently avoidable*.”<sup>10</sup> This research demonstrates the critical elements of an effective, culturally appropriate and empowering NBSP for Tongans. If these findings are enacted, it will likely ensure more effective delivery to Tongans and close the equity gap in participation between Tongans and other New Zealanders.

Effective health promotion for Tongan and other Pacific communities in Aotearoa requires Pacific leadership at national and local levels of the health system, concerted effort to build a Pacific health workforce, the grounding of programmes in Tongan models of health and health promotion and taking a strengths-based approach that builds on the enormous capacity of Pacific communities.<sup>7</sup>

### Strengths and limitations

A key strength of this research is that it was undertaken with one Pacific community, Tongan, by leading Tongan health researchers known to the participants, using Tongan methodology, language and cultural practices. This research

provides a model for high-quality research with Pacific communities, which is much needed given the scarcity of such research. As NBSP participants, the focus group members had first-hand experiences of the programme, allowing them to provide detailed insights into the programme and ways to improve it. They were also members of The Fono. It is possible that Tongans not connected to a Pacific provider, as well as those who have not participated before, may encounter further obstacles not identified by this group. While all participants were 60 plus, the views of these older Tongans may not be representative of younger generations, including those 50 plus who are now eligible for the programme and are more likely to have been New Zealand-born. Nevertheless, this research provides one of the first studies of Tongan New Zealanders’ views about the NBSP. Doing so provides valuable insights from a leading Pacific community in Aotearoa and avoids conflating the views of the multiple Pacific ethnicities. However, given the common threads between Pacific communities in Aotearoa and internationally, it may provide valuable insights for others.

### Implications

Many Tongans die unnecessarily from bowel cancer because the NBSP, while available, is not accessible to many Tongans. Taking a Tongan approach to the programme delivery is the solution recommended by the NBSP participants and experts in this study. Reimagining the delivery of the NBSP, starting with Tongan communities first, would create a programme much more suitable for the Tongan community. This research provides the critical elements of such a programme, as outlined above. We acknowledge that this may require resourcing. However, to develop an equitable service, this is a solution that is urgently needed. Further research is necessary to understand the views of younger Tongan NBSP participants, those who have yet to participate and the other Pacific communities of Aotearoa.

### Conclusion

While the NBSP is currently available in Aotearoa, many Tongans are not aware of the service or why it is needed and cannot access it in a culturally appropriate manner. While the recently announced age reduction to 50 for Pacific peoples is an essential step in increasing accessibility, it does not take away the need to reimagine the programme from a Tongan, a

Pacific, perspective. The Tongan participants and Pacific experts in this study provide invaluable advice about how to improve the service so that it equitably meets the needs of the Tongan community, and likely that of other Pacific

communities in Aotearoa and internationally. What is required is *“the courage and political will to make changes that enable power and resources to be distributed fairly and equitably for all.”*<sup>7</sup>

**COMPETING INTERESTS**

None to declare.

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