

# Barriers to older Pacific peoples' participation in the health-care system in Aotearoa New Zealand

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## ABSTRACT

**Introduction.** Participation in the health-care system is a key component of healthy ageing strategies. The number of Pacific people aged  $\geq 65$  years in Aotearoa New Zealand will increase significantly over the next decade. Addressing the considerable health inequities and unmet need for care Pacific Island people experience when compared to other ethnicities in Aotearoa New Zealand should be a priority. **Aim.** To identify barriers to older Pacific peoples' participation in the health-care system in Aotearoa New Zealand. **Methods.** A participatory action research design was utilised. In total, 104 Pacific co-researchers contributed to focus groups using *Talanoa*, a traditional method of conversational dialogue deeply rooted in Pacific Island culture. Data were collected in Pacific Island languages from storytelling and conversations shared within the focus groups. Data were translated into English and analysed using a collaborative approach. **Results.** Three main themes captured older Pacific peoples' barriers to participation in the health-care system: accessing health care; relationships with health-care providers; and understanding the health-care system. **Discussion.** Older Pacific people have the capacity to influence locally driven programmes to be more responsive to their needs and aspirations. Improving older Pacific peoples' participation in health care will require a commitment to partnership and inter-sectoral collaboration identified in recent ageing strategies. The findings will inform local communities, and policy and practice aimed at improving the health and wellbeing of Pacific peoples who are ageing in Aotearoa New Zealand.

**Keywords:** CALD (Culturally and linguistically diverse), co-researchers, Gerontology, health equity, health-care access, healthy ageing, older people, participatory action research.

## Introduction

Aotearoa New Zealand (NZ), like many countries, is experiencing population ageing. The number of Pacific people in NZ aged  $\geq 65$  years is expected to more than double from 21 300 in 2018 to 46 700 by 2034.<sup>1,2</sup> Three Pacific Island ethnic groups make up most of the Pacific peoples' population in NZ. Of the 381 642 Pacific peoples in NZ at the 2018 Census, the largest group was Samoan (49%), followed by Tongan (21.6%) and Cook Island Māori (21%).<sup>3</sup> Pacific peoples experience considerable inequities in health status and have shorter life expectancy. Pacific Island males live, on average, 5 years less and females 4.5 years less when compared to the overall population of NZ.<sup>4</sup> Further, they have higher recorded rates of chronic health conditions such as diabetes, cardiovascular disease, respiratory conditions, stroke and renal disease than any other ethnic group in NZ.<sup>4,5</sup> In addition, multi-morbidity has increased for Pacific peoples,<sup>4</sup> and they have high rates of unmet need for care.<sup>2</sup>

Recent documents, *Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025* and *Bula Sautu: A window on quality 2021: Pacific Health in the year of COVID-19*, highlight the complexity and multifaceted mechanisms underpinning health inequities experienced by Pacific peoples.<sup>4,6</sup> A wide range of circumstances related to education, housing, and employment, experienced over the life course, contribute to disparities in

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## WHAT GAP THIS FILLS

**What is already known:** The Pacific Island population in Aotearoa New Zealand is ageing rapidly. Pacific peoples experience considerable health inequities and unmet need for care.

**What this study adds:** Older Pacific people experience distinctive barriers to participation in health care. Their voices should be included in planning health-care services appropriate to their ageing population.

health status.<sup>2,4,6</sup> The recent call to action from the United Nations Decade of Healthy Ageing supports the global pledge by the World Health Organization that no one will be left behind.<sup>7</sup> Congruent with equity themes in global health strategies, health equity for all ethnicities, including Pacific peoples, has become a priority for central government in NZ.<sup>3,8</sup>

NZ's primary health-care system is heavily subsidised by central government. Consumers access primary care through medical centres located in the community. NZ citizens and people with residency status are encouraged to enrol in a Primary Health Organisation, which provide lower cost or sometimes free care. Primary health care is provided by general medical practitioners, practice nurses and other health-care professionals associated with medical centres. Integrated family health-care services geared towards Pacific people have become more available in communities where a high percentage of Pacific people live.

To ensure health equity goals are realised, it is imperative health-care services are appropriate and accessible for Pacific people. Older Pacific peoples' perceptions of well-being and ageing in their communities suggest the need for a more holistic model of health<sup>9</sup> and culturally appropriate support and services.<sup>10</sup> However, few studies in NZ have focused specifically on older Pacific peoples' perspectives on healthy ageing and their experiences of health-care services. Older Pacific people tend to be included in the general Pacific Island adult population; thus, their specific needs are often not reported. Although the *Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025* identifies priorities for action for the health and disability system over the next 5 years, it does not specifically focus on older Pacific peoples' needs.<sup>4</sup> Consequently, little is known about older Pacific peoples' experiences of participating in the health-care system. This study aimed to identify barriers to older Pacific peoples' participation in the health-care system in NZ.

## Methods

### Study design

A participatory action research design was utilised. Older Pacific people were included as co-researchers to provide expertise and share their authentic knowledge. The success

of the study relied on the inclusive approach in building relationships, facilitating communication, and breaking down barriers between academic researchers and the co-researchers.<sup>11</sup> Communities are empowered by authentic involvement in interpreting and translating research findings into actions leading to improvements in local policies and services.<sup>12</sup>

This paper reports on the first phase of the Pacific Islands Families : Healthy Pacific Grandparents (PIF:HPG) Study. The PIF:HPG Study was undertaken in three phases involving issue identification, solution building, implementation and evaluation. Co-researchers were guided through a cyclical action–reflection process where their leadership was integral to implementing the research recommendations and evaluating effectiveness.<sup>13</sup> The current paper utilises an exploratory qualitative approach, within the participatory action research design, to identify how the co-researchers perceived their participation in health-care services. Ethics approval was gained from Auckland University of Technology Ethics Committee (16/465 on 14th December 2016).

### The co-researchers

Older Pacific people ( $N = 104$ ) were recruited as co-researchers from groups accessed through a Pacific community social service provider in South Auckland. Co-researchers were included if they lived in the mainstream community and self-identified as older people. Three ethnic-specific participatory action research groups were formed comprising Samoan, Cook Island Māori, and Tongan older people, representing the three main Pacific groups in NZ. The age range was 52–90 years (median age 70 years). Academic researchers with an understanding of methodology and cultural and linguistic competence facilitated partnerships with the respective groups. Initial meetings dedicated time to discuss the research partnership with the groups to ensure they were comfortable with the co-researcher role. Written co-researcher information and consent forms were available in the respective Pacific languages and in English.

### Data collection

Our co-researchers comprised 23 Samoan, 42 Cook Island Māori and 39 Tongan older people who participated in a total of 24 focus group sessions across two rounds. Each ethnic-specific group was divided into four focus groups ranging in size from 4 to 11 co-researchers. Groups were a mix of female-only, male-only and mixed gender. The gender makeup of the groups was decided by co-researchers. The first round of focus groups explored experiences of the health-care system, whereas the second round concentrated on ideas discussed in the first round. Some co-researchers participated in two rounds; others participated in only one. Most of the focus groups were convened at community venues where co-researchers regularly met. The university's south campus was used for the final discussion of themes.

The timing and duration of focus groups (approximately 2 h) was arranged to suit the needs of co-researchers and attention was given to their safety and comfort. Refreshments and transport were provided for all sessions.

Data collection was guided by *Talanoa*<sup>14</sup> and focus group conversations were held in the co-researchers' own language. *Talanoa* is deeply rooted in Pacific Island culture and embraces a traditional approach, respectful of language, storytelling and conversations groups have together.<sup>14</sup> Ethnic-specific researchers skilled in *Talanoa* facilitated a flexible and open style of conversation, increasing authenticity of accounts of events and issues considered important to co-researchers. The topic questions were open-ended allowing the group to lead conversations in ways that were meaningful. Prompting and probing comments increased depth and clarity in the conversations. Congruent with *Talanoa*, the researchers encouraged respectful sharing of knowledge and ensured everyone in the groups had an opportunity to speak and be heard. *Talanoa* concluded when researchers considered data saturation had been achieved. The focus groups were audio-recorded and transcribed verbatim in their respective Pacific Island languages.

## Data analysis

Data were translated into English language from the transcripts and preliminary analysis was undertaken by three of the research team utilising Braun *et al.*'s thematic analytic process<sup>15</sup> to generate codes from the data. These initial findings were translated back into the respective languages and presented to co-researchers to affirm as reflecting their views. The willingness of co-researchers to be involved in authenticating and verifying the findings contributed to the rigour of the study. Furthermore, co-researchers were committed to translating the findings into policy and practice in their respective communities during the solution building and implementation phase of the study. Subsequently, the initial codes were translated back into English to enable three of the research team to undertake in-depth thematic analysis; first, independently, then, collaboratively. From the codes, themes and sub-themes were constructed from across the entire dataset.<sup>15</sup>

## Results

Three main themes captured barriers to participation in health-care services: accessing health care; relationships with health-care providers; and understanding the health-care system.

### Accessing health care

Getting to and from health-care services was a barrier. Many relied on family for getting to and from health-care services. Many preferred Pacific Island providers, but they were often

some distance from home; 'Samoan doctors are good too, but the problem is that they are too far away' (Samoan co-researcher). Further, Pacific Island general practitioners (GPs) were in demand, making it difficult to schedule appointments. Worry about voicing their own needs over family members' demands, such as work commitments, contributed to reluctance asking for transport assistance. Waiting times caused tension when family members had taken time off work; 'at the doctors you have to wait 2 h. First you wait for the nurse to call you in to take your readings, blood pressure, blood sugar and after that you wait again, up to 2 h at least before you are seen by the doctor' (Cook Island Māori co-researcher). Shame associated with social isolation, loneliness, and lack of family support contributed to reluctance to ask others for transport assistance. Some had little time or capacity to attend to their own health-care needs because they were caring for grandchildren and family.

Affordability presented another barrier. Associated costs had to be factored in; 'taxi there, then taxi back, plus paying the doctor's fees, plus the chemist fees' (Samoan co-researcher). Multiple demands on household income were balanced against health care. Financial strain caused feelings of shame:

There are times when I'm too embarrassed to go [medical appointment], I am struggling [financially], reason is because my income from my benefit, money goes out for my house and everything else, that has to go. When it comes to the misinale [annual church donation], I usually borrow money, but I don't tell anyone. (Tongan co-researcher)

Kinship ties and family obligations, such as the traditional practice of giving to family back in the Pacific Islands and to the church were often prioritised. Thus, health-care needs were sometimes concealed, resulting in deferred care; 'I believe a lot of us put a hold on seeing the doctor due to the costs' (Tongan co-researcher). Tension existed between seeking health care and meeting family obligations; 'our bodies get sick, but we say we don't have money, but we have money when we have family obligations' (Samoan co-researcher).

The prohibitive cost of podiatry and physiotherapy services was raised by co-researchers. Joint stiffness made reaching their feet to cut toenails a struggle. Inability to maintain foot care impacted on mobility. Attempts were made to access affordable podiatry services; 'I asked my doctor if they can refer me to this service [diabetic podiatry service] but the doctor said to me this service is only for diabetics' (Samoan co-researcher). Co-researchers understood podiatry students provided foot care to hospital patients free-of-charge, but were not available in primary care. Some GPs filled this service gap; 'the doctor trims it there monthly, he'll ring me to come in on a Thursday to clip my toenails' (Tongan co-researcher).

## Relationships with health-care providers

The quality of relationships with health-care providers became especially important when they were from a different ethnicity. Meaningful communication was key to building relationships:

There are other doctors you want to go to where you can see that they are happy to see you and you can tell that they want to help you. That's what we want, to go to the person who we know is most keen to know why you have come to the doctors. (Samoan co-researcher)

Loss of continuity from being assigned to different GPs or locums impacted on relationships; 'when going for our 3-month diabetic check-up I get very angry when I go for my appointment, and they tell me to go see another doctor because my usual doctor has too many patients' (Samoan co-researcher). Establishing relationships with new GPs was difficult during the typically short consultations.

Style of communication was important. Co-researchers felt excluded from the consultation when GPs spent most of the consultation looking at a computer; 'my treatment by the doctor, they just sit on their computer and type or click the mouse then look at the X-ray and say, 'nothing is wrong with you' (Samoan co-researcher). This style of engagement and lack of touch were interpreted as GPs having low interest in examining affected body parts.

Co-researchers felt assumptions were sometimes made regarding severity and significance of presenting symptoms. Lack of interest in skin, feet and eye problems was attributed to low priority given to minor health conditions; 'the doctor says okay, yes I will send a report but it's very low priority compared to other [cases]' (Tongan co-researcher). Lack of attention to these health problems had a significant impact on co-researchers' mobility, vision, and comfort. Cultural shyness prevented patients' asserting requests for treatment for perceived minor health-care issues and affected the relationship between some co-researchers and their GPs.

Sharing cultural values and traditions with GPs from the same ethnicity was important. Speaking the same language facilitated comprehension and increased trust; 'my doctor is Tongan, it makes it easier for me to explain the things that are wrong with me, and we understand each other' (Tongan co-researcher). Co-researchers preferred speaking to health-care professionals in their first language when unwell; they could more freely express how they were feeling.

## Understanding the health-care system

Having access to culturally appropriate and meaningful information was important in understanding health-care regimes. Medical jargon posed a barrier:

Language is very important, I've heard people say, "doctors are used to their own language, the language they use is different to the language we use" – speaking

the jargon doctors use is not understood by many older Samoan people. (Samoan co-researcher)

Reluctance to seek clarification and ask questions related to cultural shyness and feeling overwhelmed; 'he speaks English to me. Sometimes, I don't understand what he's talking about' (Cook Island Māori co-researcher). Some co-researchers developed strategies to enhance understanding; 'sometimes I get scared because I don't understand what he is saying so I often ask him to write things down so I can take it home for my daughter to explain' (Cook Island Māori co-researcher). Understanding specific treatment plans and medications increased compliance; 'It's not really what the doctors are giving our people but rather it's the people's understanding of how and when the tablets or meds should be taken' (Cook Island Māori co-researcher). Sometimes the difficulty was understanding English spoken with a range of different accents:

If it is a real palagi [European], then it would be better because I would understand a little when he explains. But if it was a Chinese. You know when a Chinese speaks English, you do not understand ... although I don't speak good English, I still understand. It's because it is the palagi's language, that's why. (Samoan co-researcher).

Co-researchers wanted a wider range of printed information on common medical conditions and remedies in Pacific Island languages:

... there are things they give us at the hospital but there's no one who can read it all so it just ends up in the rubbish. What about printing it in Tongan and distributing it in the community ... like for example gout, I want to know more about it because my heel is getting sore. (Tongan co-researcher)

Interpreting services were inconsistent; 'by the time the interpreter had arrived my clinic was already finished' (Samoan co-researcher). Cultural shyness and feeling disempowered prevented patients asserting the right to interpreter services, which were not always offered. Sometimes it was assumed an interpreter was required without consulting the patient first; 'I'm really good at communicating and I was surprised when the interpreters came because I didn't ask for one' (Tongan co-researcher). Others were uncomfortable having an interpreter present during private consultations; 'I don't want any interpreter' (Cook Island Māori co-researcher). At other times, families were relied on to interpret medical terminology.

Mistrust resulting from past medical mishaps, medication side-effects and fear of being diagnosed with serious diseases, such as cancer, were further barriers; 'we don't want to see the doctor because we don't want to hear what is wrong with us because then we start to worry' (Samoan co-researcher). Co-researchers spoke of traditional Pacific Island healing approaches such as massage and herbal remedies as part of their holistic approach to health.

'Will there ever be a time when research will be done on our traditional Tongan medicinal brews, to be legalised, to be recognised, for us to take ownership and to use our Tongan medicinal drinks, for it to be accessible?' (Tongan co-researcher). Further, the significance of their deep faith in God when it comes to their health and wellbeing was evident; 'I thank God for everything, for good health and strength' (Samoan co-researcher).

## Discussion

Three themes captured multiple barriers to co-researchers' participation in the health-care system: access to health care, relationships with health-care providers, and understanding the health-care system. Although some of these findings resonate with priorities identified in the recent New Zealand Pacific Health and Wellbeing Action Plan (2020–25)<sup>4</sup> and recommendations in the Bula Sautu report,<sup>6</sup> the current study privileges the voices of older Pacific people. Previous research has identified lack of transport and affordability of services as barriers to Pacific Island families accessing health-care services.<sup>2,9,16</sup> However, our findings provide nuanced understandings on how the intersection of age, family commitments and cultural obligations impact on older Pacific peoples' access to health care. Traditional practices of giving money to the church and family in the Pacific Islands was frequently prioritised over health-care needs. Other studies identified considerable financial strain Pacific Island families experience from balancing household expenditure with traditional gift-giving.<sup>17</sup> Upholding these traditional practices rested more heavily on older generations and were prioritised over health-care needs.

Building trust with health-care providers was important for participation in health care. However, limited Pacific Island providers, lack of continuity, and short appointment times prevented establishing effective relationships. Studies from GPs' perspectives suggests cultural and generational differences, and communicating through family members, interfered with building rapport.<sup>18</sup> Pacific Island nurse-led care for chronic conditions would improve continuity of care. Increased Pacific Island health-care workforce capacity will be crucial in planning for projected ageing of the Pacific Island population.

Culturally sensitive strategies to enhance the quality of relationships included establishing rapport during initial greetings, maximising face-to-face engagement, using touch, and conveying genuine interest in the presenting problem. Cultural shyness inhibited questions or seeking clarification; thus, GPs should take the lead in providing essential information and evaluating comprehension. Moreover, communication style should be appropriate to the cultural and linguistic needs of older Pacific Island people. This included asking if interpreter services were required and providing choice in how information was provided. Some of these strategies

reflect earlier findings and recommendations,<sup>16,19</sup> reiterating the importance of ongoing cultural competence education and refresher courses for all health-care providers.

A holistic approach to health care is supported by Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–25.<sup>4</sup> This should include recognition of traditional Pacific Island healing modalities such as massage therapy, herbal remedies and faith in God deeply rooted in older Pacific peoples' experiences of health and wellbeing. This will require an inter-sectoral and all-of-government approach.<sup>4</sup> The findings from this study should inform major health reforms being undertaken by Health New Zealand. An integrative approach to primary health care should improve access to podiatry and physiotherapy services with important implications for preventing falls, maintaining mobility and healthy ageing.<sup>20,21</sup> Access to funded podiatry services for a wider range of long-term health conditions and disabilities beyond type 2 diabetes has potential to improve mobility, prevent serious skin infections and enhance healthy ageing for older Pacific people.<sup>21</sup>

Empowering co-researchers to undertake leadership roles was a major strength of the study. Further, *Talanoa* contributed to authentic and meaningful conversations. The findings formed the basis for wider community engagement and highlighted the older Pacific peoples' capacity to influence locally driven programmes to be more responsive to their needs and aspirations resonating with the Decade of Ageing global pledge that no-one will be left behind.<sup>5</sup> The co-researchers were connected to social groups in their local community; thus, the views of more socially isolated older Pacific people may not be represented. Future research could compare differences between the cultural groups to assist in planning more finely tuned Pacific Island services.

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**Data availability.** The data that support this study cannot be publicly shared due to ethical or privacy reasons and may be shared upon reasonable request to the corresponding author if appropriate.

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