



## Participant Information Sheet for Pacific people living with Parkinson's disease

<b>Study title:</b>	<b>Understanding the experiences and impact of Parkinson's symptoms for Pacific People and their whānau</b>
<b>Investigators:</b>	Leigh Hale, Katrina Bryant, Charleen Silcock, Megan Lupe School of Physiotherapy, University of Otago

### **Mālō e lelei, Talofa lava, Kia orana, Ni sa bula vinaka, Faka'alofa lahi atu and warm Pacific greetings**

#### **Introduction**

Thank you for showing an interest in this project. Please read this information sheet carefully. Then, take time to consider and, talk with relatives, friends or whānau before deciding whether or not to participate.

If you decide to participate, we thank you. We also welcome you to bring any relatives, friends or whānau to your appointment. If you choose not to participate, there will be no disadvantage to you, and we thank you for considering our request.

#### **What is the aim of this research project?**

The aim of this project is to investigate the experiences and impact of Parkinson's symptoms associated with mobility and fall risk in Pacific people living with Parkinson's disease. This information will help us inform delivery of services for Pacific people living with Parkinson's and their whānau.

#### **Who is funding this project?**

This project is funded by The Michael J. Fox Foundation for Parkinson's Research.

#### **Who are we seeking to participate in the project?**

We are seeking 30 men and women diagnosed with idiopathic Parkinson's disease who self-identify as Pacific people and are aged over 18 years.

Volunteers should:

- not exhibit severe physical and/ or cognitive impairments associated with another medical condition
- be able to walk for at least 30m (with or without walking aids)

#### **If you participate, what will you be asked to do?**

If you agree to participate in this study, we will ask you to do three things:

1. Have a talanoa. Here we will talk about your experiences and impact of living with Parkinson's and your experiences of the health care delivery you have received. This might include aspects such as being diagnosed, experiences of changes to your health, wellbeing and interactions with people. In this interview, we will ask open questions where the line of

questioning develops as the discussion progresses. With your permission we will audio-record this talanoa. Later we will type out word for word what was said in the talanoa to help us remember exactly what you said. This talanoa may take up to one hour to complete and we may wish to have a second talanoa with you to check with you some aspects of what we discussed.

2. Attend a testing session: At this session we will:
  - a. Ask you some questions about your general and physical health, and information about your condition.
  - b. Perform some tests These tests include:
    - i. *Cognition tests*: We will ask you five short questions that test main areas of brain function, including orientation, memory, language, and visuospatial function.
    - ii. *Motor function tests*: We will test your movement using a Parkinson's-specific test ("the Movement Disorders Society – Unified Parkinson's Disease Rating Scale").
    - iii. *Balance test*: We will assess how you can adjust your balance in standing in a controlled manner.
    - iv. *Walking test*: This test involves standing up, walking a short distance and turning around.

This testing session may take 1-2 hours to complete. However, the tests can be taken in the same or different sessions, and you can have as many breaks as you would like or need.

*We will repeat this test session 12 months later* and this will help us to understand if anything has changed regarding your health status.

3. Complete a "falls calendar". After your initial test session, we will give you a printed calendar (or e-mail it to you, if you prefer) in which you can write down whether you had any falls. We will contact you monthly via telephone, text message or e-mail to collect details about any falls you have had for approximately one year after your initial test session.

We will discuss with you where and when it would be best to be tested and have the talanoa. We will also discuss with you what language you would be most comfortable using during the testing sessions and talanoa and provide a translator if necessary.

We will provide you with three \$40 grocery vouchers ((i) after the first test session, (ii) after the one-year test session, and (iii) after the talanoa) as a token of thanks for participating in the study and to help reimburse any costs you may incurred in participating (e.g. travel and/or parking costs).

### **Is there any risk of discomfort or harm from participation?**

Any balance and walking tests should cause no discomfort. The main risk of taking part in this study is that during the balance and walking testing there is a slight risk of losing balance while completing the tests. We will minimise this risk by: (i) ensuring the researchers testing you are trained in the safety requirements of the tests; (ii) asking you not to repeat any test that may be uncomfortable or too difficult for you to perform. If you feel unsure about attempting any test, you can say you do not wish to complete that particular test.

If our balance, walking, or any other tests show that you are at risk of falling, we will advise you to see your General Practitioner and give you a report to take with you.

## **What information will be collected, and how will they be used?**

The information from the questionnaires, the talanoa, and the balance and walking tests will help us better understand the experiences and impact of Parkinson's in Pacific people living with Parkinson's. Using the falls calendar will allow us to see whether your balance and walking tests performance reflects your risk of falling. These results will inform the development of future practices and services appropriate for Pacific people living with Parkinson's disease. No commercial use will be made of the data.

## **What about anonymity and confidentiality?**

All information obtained from this study will be kept private and confidential, including the audio recording from the talanoa. To make sure of this, you will be given a unique identifier, separating you from your responses. Information used for any publications, reports or presentations will be kept anonymous. The research team will discuss with participants how best they think we should report the findings of this study and to who we should report to.

The researchers, students and staff working on this project may have access to the data, but the data collected will be securely stored so that only these people will gain access to it. At the end of the project, any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed.

Reasonable precautions will be taken to protect and destroy data collected by email. However, the security of electronically transmitted information cannot be guaranteed. Therefore, caution is advised in the electronic transmission of sensitive material, for example via email.

## **If you agree to participate, can you withdraw later?**

Participation in this study is entirely voluntary. You may leave the project at any time and without any disadvantage to yourself.

## **Any questions?**

If you have any questions now or in the future, please feel free to contact:

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*This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research, you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email [gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)). Any issues you raise will be treated in confidence and investigated, and you will be informed of the outcome.*