



## **Participant Information Sheet for Pacific people living with Parkinson's disease and their whanau**

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

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

If you agree to take part in this project, we would like to have a talanoa with you 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 korero with you to check with you some aspects of what we discussed.

We will discuss with you where and when it would be best to have the talanoa. We will also discuss with you what language you would be most comfortable using in this talanoa.

We will provide you with a \$40 grocery voucher 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?**

There should be no discomfort or harm in taking part in this project.

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

The information from the talanoa will help us better understand the experiences and impact of Parkinson's in Pacific people living with Parkinson's. 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, the audio recordings and 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:

Megan Lupe School of Physiotherapy, University of Otago Charleen Silcock School of Physiotherapy, University of Otago	<b>Email:</b> <a href="mailto:megan.lupe@otago.ac.nz">megan.lupe@otago.ac.nz</a> 0212790843 <b>Email:</b> <a href="mailto:charleen.silcock@otago.ac.nz">charleen.silcock@otago.ac.nz</a>
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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). Any issues you raise will be treated in confidence and investigated, and you will be informed of the outcome.*