

Participant Information Sheet Health Service Participants

Project title: Keteparaha: A Community Framework to Support Māori Ageing and End-of-Life Study

Name of Principal Investigator (PI): Dr Melissa Carey

Name of Co-investigator(s): Professor Merryn Gott, Dr Tess Moeke-Maxwell

Researcher Introduction

The principal researcher on this project is Dr Melissa Carey. Melissa is a Health Research Council Māori Health Postdoctoral Research Fellow at the University of Auckland within the School of Nursing and is working on this project for three years (2020-2023). Melissa is a member of the Te Ārai Palliative and End-of-life Research Group. Melissa is Nurse and has worked within the clinical nursing setting for many years.

Project Description and Invitation

Tēnā Koutou Katoa,

You are invited to take part in a study being conducted by researchers based in the School of Nursing at the University of Auckland. You have been selected to take part because we are interested in learning about what will support Māori people to be able to age well and have the best end-of-life journey possible. We would like to invite you to be a part of this project to provide your perspective on the delivery of care to ageing Māori people and their families. We would also like to understand how care and community service is delivered to Māori communities at end-of-life within the local health district. This will support the development of a compassionate community toolkit which we are co-designing with the Māori kaumātua and their whānau.

Your participation is entirely voluntary (your choice). You do not have to take part in the study. You can withdraw at any time with no questions asked. To help you make your decision, please read this information sheet carefully. You may take as much time as you like to consider whether to take part in the study.

Interview

If you agree to participate you will be invited to attend an interview at a private location and time that suits you. The interview will take approximately 40 minutes and will be voice recorded even if you consent to be recorded you may ask to stop the recording at any time. You may request a copy of your transcript for editing prior to inclusion in the research findings, please indicate this on the consent form should you wish to receive a copy. You will have two weeks from the time of receiving the transcript to make any changes.

Data storage/retention/destruction/future use

Information we gather will be used in reports, publications, conference presentations but will not identify you in any way. Following the completion of the study, printed copies of transcripts, audio sound bites and copies of photos and other information will be stored in a locked cupboard. Digital information will be stored on in a University of Auckland managed digital storage space indefinitely.

Right to Withdraw from Participation

If you agree to participate you also have the right to withdraw from participation at any time without giving a reason. You can withdraw any data traceable to you up until the 1.04.2022.

Confidentiality

Your participation in this study will be confidential and all data will be de-identified. If the information you provide is reported/published, this will be done in such a way that its source cannot be identified

Contact Details

Please feel free to contact any of the persons listed below for further information or any concerns about the research.

The primary contact for more information about the study is Dr Melissa Carey. Please contact her at m.carey@auckland.ac.nz Phone (09) 923 3003.

Other members of the research team are:

Dr Tess Moeke-Maxwell: Email: t.moeke-maxwell@auckland.ac.nz

Professor Merryn Gott Email: m.gott@auckland.ac.nz

Head of School: Dr Julia Slark: 09 9238471 j.slark@auckland.ac.nz

School of Nursing
University of Auckland
Private Bag 92019
Auckland 1142

If you require Māori cultural support, talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324. If you have any questions or complaints about the study, you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 486 8920 ext 3204.

AHREC Chair contact details: For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Approved by the Auckland Health Research Ethics Committee on 1/07/20 for three years.
Reference number **AH1062**.