

Participant Information Sheet

Māori Community Service Participants

Project title: Keteparaha: A Community Framework to Support Maori 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

Tēnā Koutou Katoa,

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 interview 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.

Digital Story

You are also being asked if you would like to be involved in a digital story-telling workshop which will be conducted in 2022 and will be held over a weekend (Friday afternoon, Saturday and Sunday). You can bring photographs, or a researcher can take photos if you agree. You do not have to agree to have any photos taken. You will be asked whether you agree to this on your consent form. If you choose to participate in a digital story-telling workshop you

can use your own photographs to enhance your story. If these images contain people other than yourself, you will need to obtain the appropriate permission prior to including these in your story.

We are interested in making ‘digital stories’ with some of our participants. A ‘digital story’ is a three-minute video that tells a story about your experience of providing community care for healthy ageing or life limiting illness for Māori in South Auckland. You will be given support to write a 200-word story about your experiences. This story is supported with photographs and images. Melissa Carey and Tess Moeke-Maxwell will visit you before the workshop to help you prepare your story and to answer any questions you have.

Making a digital story would not cost you anything but would require some of your time. You would join other participants at a digital storytelling workshop and would be able to bring someone to support you in making your digital video. The workshop will take place over 1 introductory session and then one weekend (Friday afternoon, Saturday and Sunday) in a special digital story-telling workshop.

We have room for 2 participants plus their supporters in the workshop in your area; therefore, it may not be possible for everyone who is interested in making a digital story to do so.

All participants in the introductory session and weekend workshop will be given a \$20 petrol vouchers to help with travel expenses to attend the workshop.

The digital stories will form an important component in our free online educational tool kit for whānau, iwi and their communities as well as the ageing and end-of-life care health care sectors. We will also use them as part of hui, conference presentations, on our website or social media and as teaching tools for nursing students and healthcare professionals.

All workshop participants and their supporters will receive a copy of the video to share with friends, family or anyone else they would like to show it to. You will retain copyright of the video.

Data storage/retention/destruction/future use

Only material from your digital story that you personally consent to (photos, audio and quotes) will be used. All other information we gather will be used in reports and publications but will not identify you in any way. Following the completion of the study, 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 a University of Auckland managed system and stored 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 01.04.2022.

Confidentiality

Your interview 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.

If you participate in the digital story workshop and make a digital story, your identity as part of this study will not remain confidential as people you know may see the video and recognise you or your story. Therefore, we cannot

guarantee confidentiality of your involvement in the study. Similarly, if you consent to researchers using your photographs, we cannot guarantee confidentiality, as someone may recognise you, members of your whānau, your home or property. Please note that there is no obligation to use personal photos to enhance your story. However, it is likely that you will want to include photographs in the digital story as it will help you tell your story better.

If you think you might be interested in being part of the digital storytelling workshop, please indicate this on the consent form. You will not be obligated to make a digital story if you are unable to attend or if you change your mind later.

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

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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**.