

Participant Information Sheet

Kaumātua and Whānau 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 a nurse and has worked in clinical nursing settings for many years.

Project Description and Invitation

You are invited to take part in a study which is 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 the needs of 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 as we develop and design together a toolkit to support Māori people and their whānau within the Manurewa community. If you would like to be involved, you and a whānau member can participate in a focus group this group will meet 5 times during the research project, during 2021. We would also like to invite a few of the focus group participants to a digital story workshop which will be conducted in 2022.

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.

Project Procedures

Focus Group

The kaumātua and whānau focus group will meet five times during the second year of the research project, during 2021. Meetings will occur at a Marae or other private venue such as in the Manurewa Citizens Advice Bureau offices. During these sessions the focus group will discuss important aspects of the toolkit design, including the resources available. If you must travel a distance to the meetings, you may be eligible for some support to get there, such as a \$20 fuel voucher, some refreshments will be provided.

With your permission, the focus group will be audio-recorded you will be unable to have the recorder turned off, instead, you can choose to leave the group or not to answer any questions. Anything you contribute in a focus group discussion cannot be withdrawn even if you withdraw your participation. you may choose not to answer any questions that are asked. The audio recordings will be stored on a password protected computer at the University

of Auckland and only members of the research team will have access to them. They may be transcribed by a third party who has signed a confidentiality agreement.

Digital Story

You are also being asked if you/a family member would like to be involved in a digital story-telling workshop (Friday afternoon, Saturday and Sunday). You can choose to provide photos of your experience of healthy ageing in South Auckland and/or end-of-life experiences with your whānau. 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 or your support person, 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 own healthy ageing experience or the care whānau provide to a family member who has a life limiting illness. 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 don’t expect you to know how to make a video. However, it would be good if you or your supporter knew how to use a computer. You would not have to invite a supporter if you did not want to.

We have room for only 3 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. However, any data/ information that has been shared focus groups will not be able to be removed from the project as we will not be able to identify these contributions after they have been collected.

Confidentiality

If you do participate in the focus group, you may be identified by other participants in the group and you will be known to the researchers. We will ask you to agree to keep anything you hear in the focus group discussion confidential.

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**.