

## PARTICIPANT INFORMATION SHEET

Project title: [What do Māori want for palliative pain management in Tairāwhiti?](#)

Tēnā koe,  
Ko Manawaru, ko Hikurangi ngā maunga.  
Ko Te Ārai, ko Waiapu ngā awa.  
Ko Ohako, ko Taharora ngā marae.  
Ko Rongowhakaata, ko Ngāti Porou ngā iwi.  
Ko Kathleen Mason tōku ingoa.

My name is Kat and I am a Master of Health Science student at the University of Auckland where I am completing the research portion of my Masters. For the research, I would like to understand what Māori in Tairāwhiti want for palliative pain management. This will include finding out about Māori experiences of palliative pain and preferences for how palliative pain is managed. This will build towards an understanding of what good community-based palliative pain management could look and feel like for Māori. Pain is a common symptom experienced by people at end of life but each person's experience is unique. Palliative pain can be felt across multiple dimensions and have physical, spiritual, mental and/or emotional components. By understanding how whānau tend to the pain of loved ones with palliative care needs we hope to help other whānau by sharing information from this study. We also think that the information gathered through this study will be useful for health services and health professionals who provide palliative care to whānau.

You are being approached because you and your whānau may have some valuable kōrero to share about your experiences, and that you may be interested in participating in this study. Your participation is entirely voluntary (your choice). You do not have to take part in the study if you do not wish to. To help you decide if you would like to participate or not, please read this information sheet carefully. You can take as much time as you like. Please feel free to discuss the study with your whānau.

### Research team:

- Mrs Kathleen Mason, Rongowhakaata, Ngāti Porou; Student, Master of Health Science, Te Kupenga Hauora Māori, Faculty of Medical and Health Science, The University of Auckland; Research Assistant, School of Nursing, The University of Auckland; Member of Te Ārai Palliative Care and End of Life Research Group.
- Dr Joanna Hikaka, Nga Ruahine; Supervisor, Te Kupenga Hauora Māori, Faculty of Medical and Health Science, The University of Auckland; The Centre for Co-Created Ageing, School of Nursing, Faculty of Medical and Health Science, The University of Auckland; The Māori Pharmacists' Association.
- Assoc. Prof. Donna Cormack, Ngāi Tahu/Kāi Tahu, Kāti Māmoe; Co-Supervisor, Te Kupenga Hauora Māori, Faculty of Medical and Health Science, The University of Auckland.

- Assoc. Prof. Melissa Carey, Ngati Huri, Raukawa; Co-Supervisor; Honorary Research Fellow, School of Nursing, The University of Auckland; Member of Te Ārai Palliative Care and End of Life Research Group; Associate Professor, School of Nursing and Midwifery, Edith Cowan University.

### What does the study involve?

We would like to hold whānau hui with Māori who have palliative care needs as well as whānau who are caring for them, or with whānau who have cared for whānau members with palliative care needs. Whānau hui will only include members of your whānau and any whānau or support networks you or other members of your whānau who are participating may wish to be present.

The whānau hui will take between one and two hours to complete at a time and place that is suitable for you and your whānau. Provision will also be made for whānau hui to be conducted by telephone or online using Zoom should the need arise.

Participation is entirely voluntary and you can choose not to participate without experiencing any disadvantage. If you agree to participate, you are free to change your mind before or during the whānau hui.

This information sheet is for you to keep.

If you decide to take part in the study, you will be asked to sign and return the consent form. Consent forms will be stored separately from the research data in a secure location for a period of six years and then securely destroyed according to the University of Auckland Data Management and Retention policies. We will provide you with a copy of your consent.

Because of the sensitive nature of the research topic, there may be some kōrero that you or members of your whānau find uncomfortable. You do not have to answer any questions you do not want to and you do not have to give a reason why.

We will give each participant a demographic form to fill in at the whānau hui. This information will help us with our analysis of the kōrero shared during whānau hui. You can choose what information you want to share with us. The researcher(s) will gather the forms in from participants at the end of the whānau hui. The demographic data form will be stored in a locked cupboard at the University of Auckland that will only be accessible to the research team.

Kaumātua or another researcher(s) may accompany the student researcher at whānau hui to support whānau engagement and the use of te reo and tikanga Māori. We welcome the use of te reo Māori during the hui and you can choose to use as much or as little as you would like. You can also ask to have the whole whānau hui conducted in te reo.

With permission, whānau hui will be audio recorded using a digital audio recorder.

You can ask for the recording to be stopped at any time without giving a reason. It may not always be possible for the recording to be stopped immediately on request during the hui, for

example, when another person is contributing to the kōrero. However, you can choose to not answer questions or leave the room without providing a reason.

Audio recordings will be stored in a secure folder on the University of Auckland network. It will only be accessible by the members of the research team named above.

Audio recordings will be transcribed by the researcher. However, if a third party is used to transcribe the audio recording, they will be required to sign a confidentiality agreement. Any audio recordings sent to a third party for transcribing will be sent using a secure file transfer service.

A researcher may also take notes during the whānau hui.

Unless all agree that the whānau can be identified as participating in the research, your participation in the research is confidential. This will mean that any identifying information such as your name and the names of people, organisations and places mentioned during the whānau hui will be removed from the hui transcript before it is analysed.

### Benefits and risks

Participating in the study will give you an opportunity to share your kōrero about how Māori whānau prefer to manage or look after pain experienced by whānau members with palliative care needs. The study has the potential to benefit Māori with palliative care needs as well as whānau who are caring for a whānau member with palliative care needs.

Health services may also benefit from the information gained by this study. It could help them to become more responsive to the needs of whānau who require palliative pain management and has the potential to expand care options.

Successful completion of the study will also help me to gain a Master of Health Science.

There are no high-level risks associated with participating in this study. However, the sensitive nature of the study may mean that some emotional discomfort can occur. If you feel uncomfortable during any part of the whānau hui you can ask for it to be stopped without needing to provide a reason. You may wish to take a break before carrying on or withdraw from participation and this will be respected. You can ask for time to be made available immediately after the interview or at another time by Zoom or telephone, for a post-hui debrief.

Should you require support after the whānau hui, please let one of the research team members know. If you would prefer to talk to someone outside of the research team, talk to a trusted whānau member or friend, or you can reach out to the following services:

Need to talk? Call or text 1737

Samaritans 0800 726 666

Lifeline Aotearoa 0800 543 354 or text message 4357

### Who pays for the study?

There is no cost to you to participate in the study.

A \$40 gift card or vouchers will be offered as a koha to recognise your contribution to the study.

A Māori Health Masters Research Scholarship has been applied for from the Health Research Council of New Zealand.

### What are my rights if I participate in this study?

#### *Participation is voluntary:*

Participation in the study is voluntary and participation will not result in any disadvantage.

#### *Withdrawal from participation and withdrawal of data:*

You have the right to withdraw from the study at any time without any disadvantage.

Because you are participating in a whānau hui, it will not be possible to withdraw your data from the study once it has been recorded. Your data will contribute to the context of the kōrero being shared by all whānau hui participants. However, if all participants of the whānau hui wish to withdraw their data, they will have a two-week period after the whānau hui to do so and they do not have to provide a reason.

#### *Confidentiality:*

Your participation in the study is confidential. Your name and any other identifiable factors mentioned during the interview (such as the names of health providers, any specific dates, names of staff, places etc.) will not be used when whānau hui are transcribed into written format. This ensures that information you provide will not be linked back to identify you. All transcribed whānau hui and recordings will be securely stored on a password protected research drive at the University of Auckland for six years after which it will be destroyed as per the university protocols

Any information that may personally identify you will not be included in any reports or publications generated by this study.

We ask that you keep whānau hui discussions confidential. We cannot guarantee that all whānau participants will comply with this request, however, we will discuss this request at the beginning of the whānau hui to provide an opportunity for all participants to kōrero about this.

#### *What will happen after the study?*

Your recorded whānau hui will be transcribed into written format. You will be offered the opportunity to check your transcript. You will be given three weeks after receiving the transcript to email the researcher any changes. If we don't hear from you in that time, it will be presumed correct.

De-identified whānau hui transcripts will be analysed to generate important understandings and meanings of your whānau experiences. This will be undertaken by researchers who are Māori with the support of the research team members who are also Māori. Early findings from the study will also be shared with whānau participants. This will ensure that the knowledge and findings produced from this study accurately reflect whānau voices.

Data collected over the course of the study will be stored in a secure folder on the University of Auckland network for a period of six years after which it will be destroyed in accordance with University of Auckland data retention and management policies. It will only be accessible to members of the research team.

Results of this study may be reported in academic and professional healthcare journals and presented at conferences in Aotearoa New Zealand and internationally. Findings will be shared with participants and the broader public through news, social and web media posts. Once the study is completed, a summary of the findings will be made available to you if you would like to receive it. We expect that the summary of findings will be available from August 2025.

## Contact Details

### *Research team:*

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*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](mailto:ahrec@auckland.ac.nz) or at 373 7599 x 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

*Additional Māori support:*

If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324, or contact the Auckland and Waitemata District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 4868920 ext 3204 to discuss any questions or complaints about the study.

Approved by the Auckland Health Research Ethics Committee on 01/11/2024 for three years.  
Reference number [AH28378].