PARTICIPANT INFORMATION SHEET

Māori Health Providers

Project title: Taringa Whakarongo – Older Māori and whānau experiences and perspectives of hearing loss and hearing health care services.

Student Researcher:
Alehandrea Manuel (Ngāti Porou)

Principle investigators/PhD Supervisors:
Associate Professor Elana Curtis (Ngāti Rongomai, Ngāti Pikiao, Te Arawa)
Associate Professor Grant Searchfield

Kia ora, ko Alehandrea tōku ingoa. I am a Māori PhD student at the University of Auckland. You have been invited to take part in a study that will explore older Māori and whānau experiences and perspectives of hearing loss and hearing services in Auckland. It is also looking into the way hearing health care staff and Māori health providers engage with hard-of-hearing Māori patients and whānau and ask about hearing services.

This PhD research is funded through a Brain Research New Zealand Māori PhD Scholarship under the supervision of Associate Professor Elana Curtis and Associate Professor Grant Searchfield. The purpose of this information sheet is to inform you about this study so you can decide your ongoing participation. It is important that you understand this information. It includes important details you need to know about the study. Take as much time as you need to decide. Feel free to talk about your participation in this study with your whānau or health care providers.

The study will take place over the next 22 months, finishing in February 2021. You can ask any questions about the research at any time during the study course. If you are willing to take part in this research, I will contact you to arrange a meeting with you to answer any questions you may have and decide where, when and how you wish to talk about your experiences.
What is the purpose of the study?
Māori have higher self-reported rates of disabling hearing loss than non-Māori, yet suffer greater barriers to accessing hearing health care and hearing technology than non-Māori. From a Kaupapa Māori stance, the qualitative methods in this research will be used to bring older Māori and whānau realities of the hearing health care system to the forefront.

New Zealand could potentially have hearing services tailored towards Māori with ongoing participation and partnership with hard-of-hearing Māori, whānau, and corresponding communities and organisations. The study will also involve the analysis of the hearing health care workforce and Māori health care professionals’ perspectives in delivering and providing hearing services for Māori. Findings from this study will open spaces for creating more effective hearing services and research for Māori.

Why have you been invited?
If you self-identify as Māori and provide health/disability services for hard-of-hearing Māori (60 years and over) in Auckland you are eligible for this study.

Participation in this research is entirely voluntary, and you are under no obligation to do so.

What is involved in the study?
**Focus Groups**
Should you wish to participate, you will be involved in a focus group with 8-10 Māori Health Providers to discuss hearing loss, hearing health care services, and engagement with Māori patients. I will give you a call to have a talk about eligibility and provide further details of the study. The focus group will be 1 to 2 hours in Auckland.

Kai will be available at the focus groups. You will be provided with a koha ($50 voucher) as an appreciation of your time and travel for the study.

**Right to Withdraw**
You have the option to withdraw from the focus group at any time before the focus group begins. You do not have to answer all of the questions in the focus group and can leave the focus group at any time without having to give a reason.

The focus group will be audio recorded. If you withdraw from the focus group when it is in progress, it will not be possible to withdraw the information that you have provided up to that point as it will be part of a discussion with other participants. Your compensation will not be impacted upon once attending the interview for however long you participate in the interview for.

Transcripts will not be available for editing, and information cannot be withdrawn later, because of the possible impact of this on the contributions of others in the group discussions.

**Risks and benefits to the study**
This research is consistent with Kaupapa Māori research and aligns with the Treaty of Waitangi principles. The findings from this research will identify areas needed to be redeveloped or improved on in New Zealand’s hearing health care system. Such information will guide our workforce in how we can provide equitable hearing services for Māori and whānau.

Precautions have been put into place to make sure that no information will be provided to identify participants. The external transcriber involved in the project will sign a confidentiality agreement. Challenging and negative experiences may bring up thoughts and feelings of pain or discomfort for you. We have provided details of support organisations and people that participants may debrief with following the interviews.
Confidentiality and Privacy
Strict confidentiality of your information will be maintained. A third party who has signed a confidentiality agreement will transcribe the audio tapes. All transcripts will be de-identified. No individual will be identified in any report, presentation or publication carried out as a result of this study.

Information given in the focus group will be heard by all participants involved, therefore we will not be able to guarantee that your identity will remain hidden. We ask that you respect each other and keep one another’s identity and what was talked about in the focus groups confidential (by not telling people outside of the study including colleagues, family members, and close friends about who has been involved and what has been said in the interviews).

Data storage
Audio recordings of the focus groups will be deleted after transcription. All hardcopy transcripts will be stored in a secure locked cabinet in the Audiology Department of the University of Auckland. Stored data will be accessible only to the research team members. Electronic data and audio tape files used within this research will be password protected within the secure electronic filing systems of the University of Auckland Audiology Department.

All data will be kept securely in a locked cabinet on the University of Auckland premises for a period of six years, or until the study, theses, peer-reviewed publications and research outputs have been completed. After this, all information will be destroyed by a disposal company that provides security for confidential documents.

Results and dissemination
The study is expected to end in February 2021. Under a Kaupapa Māori framework the presentation of the data analysed will avoid any victim blaming and deficit framing. Reports will be available for all participants and you will be informed of where copies of the full research can be found. The reviewed findings will be written up for publication and submitted to appropriate journals.

Reports will also be available for stakeholder groups and agencies responsible for and with an interest in ageing, dementia, hearing loss, and disability services. You will also have the opportunity to attend meetings with other Māori health and disability providers, the hearing health care workforce, and hard-of-hearing Māori communities to discuss the findings and where to go from there.
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<th>Contact details</th>
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For concerns of an ethical nature, you can contact the Auckland Health Research Ethics Committee at 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.

For Maori cultural support: 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 phoning 09 486 8324 ext 2324.

For questions or complaints about the study: If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by phoning 09 4868920 ext 3204.

If you wish to talk to someone who isn’t involved with the study, you can contact an independent health and disability advocate on: Email: advocacy@hdc.org.nz Phone: 0800 555 050 Fax: 0800 2 SUPPORT (0800 2787 7678)

If you feel anxious, down, overwhelmed, depressed, or just need someone to talk to, you can call or text the following services: 1737 is run as part of the National Telehealth Service. Free call or text 1737 any time, 24 hours a day. You will get to talk to (or text with) a trained counsellor.

You can call the Depression Helpline on 0800 111 757 or free text 4202 (to talk to a trained counsellor about how you are feeling or to ask any questions).

For any medical or health concerns: Please contact your health provider, or contact Healthline, a 24/7 service where you can get advice from a registered nurse: 0800 611 116

Approved by the Auckland Health Research Ethics Committee on [19/06/2019] for three years. Reference number [000100].