PARTICIPANT INFORMATION SHEET
Whānau

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 rates of hearing loss than non-Māori. The difficulties in accessing hearing services and technology however remain. We want to explore experiences and perspectives of hearing loss and hearing services in Auckland from hard-of-hearing Māori 60-and-above, and whānau. Your voices will help change the delivery of hearing services.

Why have you been invited?
You have been invited to participate in this study by a hard-of-hearing person in your whānau.

- Whānau of people aged 60-and-above who self-identify as Māori with a self-reported hearing loss and reside in Auckland are eligible for this study.
- Whānau included in this study can be whakapapa whānau (members genealogically connected by common ancestors) and/or kaupapa whānau (members with a common purpose or disabling experience who provide supporting and nurturing roles).
- Participation in this research is entirely voluntary, and you are under no obligation to do so.

What is involved in the study?
Should you wish to participate, you will be involved in a go-along interview and/or whānau interview. This will be chosen by the hard-of-hearing person in your whānau.

- A go-along interview (3-4 hours). The researcher will talk with you and follow you through your hearing service journey to learn about your lived experiences. We will have to get permission to do the research in your selected hearing service before the go-along interview.
- A whānau interview (1-2 hours) in a place chosen by you and your whānau.

Kai will be available at the interviews. Whānau will collectively be provided with a koha ($100 voucher).

Right to Withdraw
Your participation in this study is your choice. If you would like to take part in the study, you do not have to answer all of the questions and you can withdraw from the study at any time without having to give a reason. The interviews will be audio recorded. It will not be possible to turn off the audio recorder during the whānau interview, as it will be part of a discussion with members of your whānau.

If you do decide to leave the interview, we will not be able to withdraw or delete the information you have given us before you leave. Information cannot be withdrawn later, because of the possible impact of this on the contributions of others involved in the interviews. If you decide to withdraw from the study after information is collected, whānau will still receive the koha.

Risks and benefits to the study
This research is consistent with Kaupapa Māori research and aligns with the Treaty of Waitangi principles. As such the analysis and reporting of information will avoid any victim blaming and deficit framing. 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. No individual will be identified in any report, presentation or publication carried out as a result of this study. Because your whānau know each other, we will not be able to guarantee that your identity will remain hidden. We however ask that you each keep one another’s identity and what was talked about in the interviews confidential (by not telling people outside of the study who has been involved and what has been said in the interviews).

There will be an external transcriber involved in the project who will sign a confidentiality agreement. 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.

Data storage

Audio recordings of the interviews 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.

You will be included in decisions around ownership, confidentiality, and the use of whānau information. Later in the study you as a member of the whānau will also be asked if you would like to receive verbal feedback on the findings of the study. You will have the opportunity to receive and provide verbal feedback on the findings of the study, as well as be provided with a data section to identify whether their comments have been utilised faithfully.

Under a Kaupapa Māori framework the presentation of the data analysed will avoid any victim blaming and deficit framing. The reviewed findings will be written up for publication and submitted to appropriate journals. Reports will be available for all participants and you will be informed of where copies of the full research can be found. 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 Māori health and disability providers, and hard-of-hearing Māori communities to discuss the findings and where to go from there.
**Contact details**

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<th>Available Help Services</th>
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<td>Student Researcher:</td>
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<td>Alehandrea Manuel</td>
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<td>Principle investigators/PhD Supervisors:</td>
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<td>Head of Audiology Department:</td>
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<td>Phone: +64 9 923 8404</td>
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For questions regarding participants’ rights and ethical conduct of research, contact the Auckland Health Research Ethics Committee (AHREC): 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 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

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