PARTICIPANT INFORMATION SHEET
Hard-of-hearing Māori

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 and your whānau are invited to take part in a Kaupapa Māori research study that will explore older Māori and whānau experiences and perspectives of hearing loss and hearing services in Auckland.

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 voice will help change the delivery of hearing services.

Who is eligible for the study?
You have been invited to participate in this study through a hearing service, Māori health care provider, or Māori disability support service in Auckland.

- 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.
- You do not have to be attending a hearing service to be eligible for the study.
- Participation in this research is entirely voluntary, and you are under no obligation to do so.
- I work as an audiologist at Auckland District Health Board. Patients who have seen me for any hearing services will not be eligible for the study.

What is involved in the study?
A go-along interview AND/OR a whānau interview:

- 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. Whānau members that you would like to be involved should contact the research team. 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).

Kai will be available at the interviews. A $100 voucher will be provided for your time and travel.

Right to Withdraw
Your participation in this study is your choice. If you do not wish to participate, you do not have to provide a reason and it will not affect any care you receive. If you would like to take part in the study, you can withdraw from the study at any time without having to give a reason. 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.

The interviews will be audio recorded. You can request to turn off the audio recorder at any time during the go-along interview. 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.

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 you will still receive your koha.

Risks and benefits to the study
This research is consistent with Kaupapa Māori research and aligns with the Treaty of Waitangi principles. Findings from this research will show how older Māori and whānau experience hearing loss. The information will also guide how we can provide equitable hearing services for Māori and whānau.

Challenging and negative experiences may bring up thoughts and feelings of pain or discomfort for you and/or whānau. 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. At the interview you will have the opportunity to choose your pseudonym (a name that differs to your real name). If a statement within the interview is reported, only the pseudonym will be mentioned.

The information within whānau interviews is heard by all participants involved in the interview. Because your whānau know each other, we will not be able to guarantee that your identity will remain hidden. We ask that you 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 your information. You will have the opportunity to receive and provide verbal feedback on the findings of the study, as well as hard copies of the data section to identify whether your comments have been used 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. You will 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>
<th>Contact Details</th>
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| **If you have any questions about the study or would like to participate please contact:** | **Student Researcher:**  
Alehandrea Manuel  
Email: alehandrea.manuel@auckland.ac.nz  
Phone: 022 541 3282 |
| **Principle investigators/PhD Supervisors:**  
Associate Professor Elana Curtis  
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Dr. David Welch  
Phone: +64 9 923 8404  
Email: d.welch@auckland.ac.nz |
| **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].*