

Participant Information Sheet

Research Title: *Hearing healthcare transition experiences for emerging adults with hearing loss.*

Lay Title: *R U Ready? How young people who are d/Deaf or hard of hearing experience hearing healthcare changeovers.*

Researcher(s): Jermy Pang¹, Nerina Scarinci¹, David Allen² & Naomi Clarry³

¹ *University of Queensland, St Lucia, Australia*

² *Macquarie University, Sydney, Australia*

³ *Consumer and Community Involvement member, Sydney, Australia.*

Thank you for your interest in participating in this research project. Please read the following information about the project to help you decide whether you would like to participate. Please feel free to ask any questions about the project.

If you decide to participate in this research, your participation is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to stop at any time, and you do not need to give any explanation for your decision. Any data collected up to the time of withdrawal from participation will form part of the research project results. If you do not want your de-identified data to be included, please let the researchers know at the time of withdrawal of consent.

You will be given the Participant Information and Consent Form to sign, and you will be given a copy to keep. Your decisions - whether to take part or not, or to take part and then withdraw - will not affect your relationship with the University of Queensland, your hearing services provider, or any other organisation.

What is this research about?

Young people who are d/Deaf or hard of hearing could experience changes to their eligibility for and/or access to the Australian Government Hearing Services Program once they reach 26 years of age. This study will explore the experience and perceptions of d/Deaf or hard of hearing young people about the hearing healthcare transition process.

What will I need to do?

If you agree to participate, you will be asked to do 3 tasks:

Part 1: Complete a brief (~5 minute) online survey about you and your hearing history.

Part 2: Create your own artwork using art supplies provided by the research team with some guiding questions set out in instructions provided. The artwork you produce can be as imperfect or as polished as you would like. You can choose to use whatever medium you prefer, including photo collages, memes, sketches, paintings, or clay. Your personal artwork will need to be completed before Part 3 as it will form the basis of our conversation.

Part 3: Take part in an interview to talk about your artwork in the context of hearing healthcare changeover experiences. You may choose to participate in the conversation via either:

- A. A one-on-one meeting with the interviewer (face-to-face or Zoom video call), which will be audio recorded. A support person may be present for this meeting. The interview duration will be between 45-60 minutes depending on how much you wish to share, or
- B. A small focus group (face-to-face or online via Zoom video call) with the interviewer and a maximum of 3 other young adults, which will be audio recorded. The focus group will likely last between 2 and 3 hours.

Face-to-face interviews and focus groups can only be offered to participants living on Gadigal Land (Sydney). You can choose between the Australian Hearing Hub at Macquarie University, or your local public library if meeting room facilities are available. If you are from rural or interstate locations, it is still possible to participate remotely via a video-call using Zoom or Teams with auto-captioning.

If you do not have access to stable internet connection or wish to participate 'offline', you are invited to return your artwork via post along with a written/emailed note explaining the artwork. In this scenario, the researcher may reach out to you to clarify your responses.

We can post out your art pack to your nominated address wherever you are located.

What are the possible benefits of taking part?

We cannot promise that you will receive any direct benefits from this research. Possible benefits may include:

- a better understanding of art-based research methods and how art-making processes can bring out reflections to help you talk about experiences and feelings;
- increased awareness about hearing healthcare transitions and other perspectives.

All participants will keep the art supplies used in Part 1 of the study.

The research results will be disseminated to the broader scientific community via peer-reviewed publications, and conference presentations. Non-peer reviewed sources will also be included such that the research outputs will be as accessible to deaf/hard of hearing communities, and public audiences.

Emerging adults and younger adolescents' voices are not frequently represented in hearing health research so the findings from this study will improve our understanding of - and build evidence about the hearing health needs of this population.

What are the possible risks and disadvantages of taking part?

Care will be taken to make sure that the interview questions are not uncomfortable, however, there reliving experiences can be upsetting for some people. To support you to feel safe, you do not need to share any information you don't feel comfortable sharing. You should never feel pressured to share anything you don't want to, and if you feel affected negatively by any part of the conversation, please let the researcher know at once, who will support you to:

- pause to talk to someone you trust, or
- reach out to services that are freely available, such as Kids Helpline Resources for young people, Youth Beyond Blue online chat (where anonymity is ensured), or a local healthcare /support service. A list of youth-friendly services will be made available to you.

What will happen to the information about me?

All information collected about you will remain confidential. Your interview transcripts and artwork will be coded so that no one can identify you. The information about you will be stored in a secure location (on the University of Queensland Research Data Manager system) and only research team members with permission can have access to them. Once the interview has been transcribed, the interview recording will be deleted. The coded data collected for this project may be used for future research.

It is anticipated that the data from- and the results of this research project will be published and/or presented in a variety of forms. In any publication and/or presentation, information will be provided in such a way that it cannot be traced back to you, except with your permission. The Participant Consent Form will explain how your creative works can be credited to you, should you wish. Your information will be kept for 5 years after which time, a written request will be submitted to remove stored data related to this project.

What will happen if I decide to withdraw?

Your participation in this research is voluntary and you are free to withdraw from the research anytime without needing to provide any explanation, and you will not receive any penalty or bias as a result of your withdrawal. Should you decide to withdraw, you may decide that all the information collected from/about you should be destroyed and not used in the research, without needing to provide any explanation for this decision. In this case, we will keep only information we need to ensure that you are not contacted again, which will be destroyed at the end of the research project.

Can I hear about the results of this research?

Once the study is completed, a summary of findings will be shared back with you. We will also use this information to publish the study's findings for other scientific research. You will not be identified in any externally shared reports or publications (such as scientific journals) about the study.

Who can I contact if I have any concerns about the project?

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with the researcher contactable on jermy.pang@uqconnect.edu.au if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on +617 3365 3924 / +617 3443 1656 or email humanethics@research.uq.edu.au

This research Ethics ID number: 2023/HE000860