

Participant Information Sheet

The University of Melbourne

Title	Exploring the challenges, considerations, support needs, and digital preferences of parents/caregivers of young children with cochlear implants.
Short Title	Challenges, considerations, support needs, and digital preferences for parents/caregivers of young cochlear implant recipients.
Protocol Number	2
Project Sponsor	The University of Melbourne
Coordinating Principal Investigator/ Principal Investigator	Dilshan Delgama
Associate Investigator(s)	A/Prof Karyn Galvin Prof Kathleen Gray Dr. Jaime Leigh Dr. Karolina Kluk-De Kort
Location	Online

Part 1 What does my participation involve?

1 Introduction

Thank you for your interest in participating in this research project.

This Participant Information Sheet tells you about the research project. It explains the processes involved in taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

The University of Melbourne

2 What is the purpose of this research?

This study aims to explore the experiences of parents/caregivers of children who have received a cochlear implant at a young age (less than 3 years old). We invite you to complete an anonymous survey about the challenges, considerations, support needs, and digital preferences both before and in the first 6 months after your child receives a cochlear implant. Based on this information, we hope to have a better understanding of your experiences, and work towards designing a digital tool to support parents/caregivers in the future.

3 What does participation in this research involve?

Should you agree to participate, you will be asked to complete an anonymous survey lasting about an hour. The survey will focus on challenges and considerations both before and in the first 6 months after your child receives a cochlear implant, your needs during this time, and your preferences for a digital solution, such as a mobile app or online support group. There will also be some questions about you and your child at the beginning of the survey related to the time when they received an implant i.e., your child's age at the time, the country you were living in, and what you knew about cochlear implants beforehand.

There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

The survey will be advertised to parents/caregivers whose child received a cochlear implant in Australia and New Zealand.

5 Do I have to take part in this research project?

Participation in this research project 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 withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your child's routine care or your relationship with professional staff.

6 What are the possible benefits of taking part?

There are no direct benefits to you for participating in this research. The outcomes of the research will help contribute to the development of a digital tool to support future parents/caregivers of children before and in the first 6 months after their child receives an implant.

The University of Melbourne

7 What are the possible risks and disadvantages of taking part?

It is possible that some questions in this survey may make you feel upset about your own experiences or those of your child. You have the option to stop the survey at any time, and you are under no obligation to participate further in this research. If you feel the need for assistance or support after or during the survey, the primary researcher can be contacted for debriefing. Alternatively, you can seek support from services, such as Beyond Blue (1300 22 4636) or Parentline (<https://kidshelpline.com.au/parents/issues/how-parentline-can-help-you>).

8 What if I withdraw from this research project?

You have the option to stop the survey and withdraw at any time. However, since the survey is anonymous, it will not be possible to exclude your data from the analysis once you have completed the survey.

9 Could this research project be stopped unexpectedly?

There are no foreseeable reasons for the research project to be stopped unexpectedly.

10 What happens when the research project ends?

If you would like to receive a written summary of the study outcomes, you have the option to voluntarily provide us with your email address. The written summary will be sent to those who provide their email address once the data analysis is completed.

The study outcomes will also be published in scientific journals and presented at scientific conferences to share with clinicians, researchers, educators, and service providers.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

The survey is anonymous unless you choose to provide your contact information. You may choose to provide your contact information so that the researchers can contact you to discuss your survey responses, and/or so that the researchers can provide you with a written summary of the study outcomes. The contact information that you choose to provide will remain confidential.

The survey will be conducted through a licensed University of Melbourne version of Qualtrics. Qualtrics is an online tool designed for survey creation and administration. All data collected on Qualtrics will be exported and stored electronically on password-protected University of Melbourne computers. The data will only be accessible to the researchers connected to the research project. Digital data will be retained for a period of five years from the date of any publication resulting from the research project. After this period, the data will be destroyed in line with The University of Melbourne data storage and destruction policies at the time.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. Since the survey is anonymous, you will not be identified in any publication and/or presentation. Even if you decide to provide your contact details to discuss the survey responses with researchers or because you are interested in receiving a written summary of the study outcomes, information in any publication and/or presentation will be presented in such a way that you cannot be identified.

Since the survey is anonymous, it will not be possible to exclude your data from the analysis once you have completed the survey

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will only be disclosed if required by law.

12 Complaints

This project has obtained ethics approval from The Royal Victorian Eye and Ear Hospital Human Research Ethics Committee [project ID number: 109653]. If you have any concerns or complaints about the conduct of this research project, which you prefer not to discuss with the research team, you may contact The Royal Victorian Eye and Ear Hospital Human Research Ethics Committee (Tel: (03) 9929 8525 or Email: ethics@eyeandear.org.au). All complaints will be treated confidentially. When corresponding, please provide the name of the primary researcher (Dilshan Delgama) and/or the name or ethics ID number of the research project.

13 Who is organising and funding the research?

This research project is part of the primary researcher's PhD thesis at The University of Melbourne.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

The University of Melbourne

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of The Royal Victorian Eye and Ear Hospital Human Research Ethics Committee.

15 Further information and who to contact

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the primary researcher:

Research contact person

Name	Dilshan Delgama
Position	Primary researcher
Telephone	+61 415 727 821
Email	ddelgama@student.unimelb.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	The Royal Victorian Eye and Ear Hospital Human Research Ethics Committee
HREC Executive Officer	Kerryn Baker
Telephone	(03) 9929 8525
Email	ethics@eyeandear.org.au

Participant consent declaration

By beginning this survey, I declare:

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my child's future care.