Aston University

**Stakeholder Knowledge Elicitation/Engagement To Identify Current Practice and Problems with Decision Making for Hearing Intervention in Children**

**Participant Information Sheet**

## Invitation:

We would like to invite you to take part in a research study.

Before you decide if you would like to participate take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

## What is the purpose of this study?

The overall research project aims to develop a decision support tool to help parents/guardians of children with a deafness diagnosis in making informed, shared (with clinicians) decisions regarding the treatment and communication options for their young deaf child.

This first phase study as part of the overall research agenda aims to understand the process and problems parents/guardians face when making decisions on behalf of their young deaf child; this information will help inform the design of the proposed shared decision-support tool to hopefully enhance the decision-making process.

## Why have I been chosen?

To ensure that a range of perspectives are captured in this research, we hope to engage with three categories of stakeholders, noted below. You are being invited to participate because you represent one of these stakeholder groups:

- **Clinicians and professionals** who work directly with deaf children regarding cochlear implants and/or hearing aids and/or who make hearing healthcare decisions (including choosing sign language) regarding treatment of deaf/Deaf children.
- **Parents/guardians of deaf/Deaf children** who may or may not wear hearing devices, use British Sign Language and who may or may not have made a decision in the past to choose an intervention and/or a communication mode for their children or who are new parents/guardians currently considering different

intervention options and communication modes for their young deaf child.
- **Adults (18+ years old) who are deaf/Deaf** and whose parents made a decision regarding hearing devices or mode of communication on their behalf when they were young.

## What will happen to me if I take part?

If, after reading this information and having any questions you might have answered to your satisfaction, you decide to participate, you will be asked to:

1. Complete a short pre-interview screening questionnaire that is designed to allow us to ensure we include all representative stakeholders in this study.
2. Participate in a series of two online interviews which will focus on your experiences relevant to and insight into the proposed decision-support tool.

Interviews will be arranged at dates/times to suit you and using online collaboration tools (e.g., Zoom, MS Teams) of your choice. It is recommended that you arrange to participate in the interviews at time and in place where you will be free from interruption and from being overheard. You will be free to not answer any question you are uncomfortable with. You will also be free to stop your participation at any time up to 2 weeks from the date of your last engagement/interview. Each interview is expected to last approximately 60 minutes. You do not have to participate in the second interview if you do not wish to.

## Do I have to take part in this study?

**No**, it is up to you to decide whether or not to take part. You do not need to give a reason if you do not wish to participate.

If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. Both these documents will be emailed to you and after having had a good opportunity to fully read this information sheet, you must send a copy of the signed consent form back to the researcher so a date for your first interview can be arranged. If you decide to take part you are still free to withdraw at any time up to 2 weeks from the date of your last engagement/interview without giving a reason.

## Will my taking part in this study be kept confidential?

**Yes.** A code will be attached to all the data you provide to maintain confidentiality.

Your personal data (name and contact details) will only be used if the researchers need to contact you to arrange study visits or collect data by phone. Analysis of your data will be undertaken using coded data.

The data we collect will be stored in a secure document store (paper records) or electronically on a secure encrypted mobile device, password protected computer server or secure cloud storage device.

To ensure the quality of the research, Aston University may need to access your data to check that the data has been recorded accurately. If this is required, your personal data will be treated as confidential by the individuals accessing your data.

## How will the conversation during the interview be recorded and the information I provide managed?

With your permission we will audio record the interview and take notes.

For participants requiring sign language interpretation services, assistance of an expert British Sign Language (BSL) interpreter will be sought and the audio/verbal discourse between the researcher and the BSL interpreter will be audio recorded. This service will be arranged by the researcher and paid for by the research team.

Each individual recording will be typed into a document (transcribed) by a transcriber approved by Aston University. This process will involve removing any information which could be used to identify individuals e.g., names, locations etc.

Audio recordings will be destroyed as soon as the transcripts have been checked for accuracy.

We will ensure that anything you have told us that is included in the reporting of the study will be anonymous.

You of course are free not to answer any questions that are asked without giving a reason.

## What are the possible benefits of taking part?

While there are no direct benefits to you of taking part in this study, the data gained will inform the design of a novel shared decision-support tool which will hopefully improve the decision-making process faced by parents of children with deafness diagnoses.

## What are the possible risks and burdens of taking part?

A key aim of this study is understanding the process and problems parents/guardians face when making decisions on behalf of their young deaf child. As this is a sensitive issue, there is a risk that some participants may find discussions about such topics uncomfortable or distressing. If we believe that you are becoming unduly distressed as a consequence of the discussion in interview, we will call for a break in the interview and a decision as to whether to continue or not will be made in discussion with you. Support resources are provided at the end of this information sheet should you feel they are useful. In rare cases, there is a risk that a participant may disclose information that forces us to break confidentiality due to perceived risk to themselves or others; you are reminded, therefore, that you are free to not answer any question you may find uncomfortable.

In terms of burden, you will be required to take 10 minutes to complete the pre-interview screening questionnaire. Thereafter, you will be invited to a maximum of 2 interviews that are expected to last no more than 60 minutes each. As such, the maximum time commitment asked of you is expected to be 130 minutes. Interviews will be scheduled over a 6-month period.

## What will happen to the results of the study?

The results of this study may be published in scientific journals and/or presented at conferences. If the results of the study are published, your identity will remain confidential.

A lay summary of the results of the study will be available for participants when the study has been completed and the researchers will ask if you would like to receive a copy.

The anonymised results may be used for research by other research teams as described in Appendix A.

## Expenses and payments

No payments or expenses are being made for participation in this study.

## Who is funding the research?

This research is being funded by Aston University.

## Who is organising this study and acting as data controller for the study?

Aston University is organising this study and acting as data controller for the study. You can find out more about how we use your information in Appendix A.

## Who has reviewed the study?

This study was given a favourable ethical opinion by the Aston University Research Ethics Committee (UREC).

## What if I have a concern about my participation in the study?

If you have any concerns about your participation in this study, please speak to the research team and they will do their best to answer your questions. Contact details can be found at the end of this information sheet.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Research Integrity Office at research_governance@aston.ac.uk or telephone 0121 204 3000.

## Research Team

For further information you should contact:

Mr. Wahid Zaman (PhD Researcher), Telephone: 0121 2044093
Email: zamanw@aston.ac.uk
Dr. Joanna Lumsden (Principal supervisor), email: j.lumsden@aston.ac.uk
Dr. Amanda Hall (Associate supervisor), email: a.hall@aston.ac.uk

## Additional support resource links:

- NHS Self-help therapies:
  https://www.nhs.uk/conditions/stress-anxiety-depression/self-help-therapies/

- Mind for better mental health:
  https://www.mind.org.uk

- Young Minds:
  https://youngminds.org.uk/find-help/conditions/anxiety/

- Overcoming- help for mental health:
  https://overcoming.co.uk/14/Help-For-Mental-Health

- Royal National Institute for Deaf People (RNID), known as Action on Hearing Loss (2011 to 2020)- Local support services that are run by volunteers who are deaf or have a hearing loss themselves:
  https://rnid.org.uk/information-and-support/local-support-services/

- NHS wellbeing support:
  https://www.nhsemployers.org/covid19/health-safety-and-wellbeing/support-available-for-nhs-staff

Appendix A: Transparency statement

Aston University takes its obligations under data and privacy law seriously and complies with the General Data Protection Regulation ("GDPR") and the Data Protection Act 2018 ("DPA").

Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of research, and cannot be used to contact you.