Plan Overview

A Data Management Plan created using DMPonline

Title: Understanding barriers and facilitators to hearing aid use in teenagers

Creator: Sumeya Abdi

Principal Investigator: Sumeya Abdi

Data Manager: Sumeya Abdi

Project Administrator: Sumeya Abdi

Affiliation: University of Manchester

Template: University of Manchester Generic Template

Project abstract:

We will be interviewing deaf and hard-of-hearing teenagers to understand barriers and facilitator of hearing usage. These will be coded using the theoretical domain framework.

ID: 151304

Start date: 08-05-2024

End date: 30-07-2025

Last modified: 11-05-2024

Understanding barriers and facilitators to hearing aid use in teenagers

Manchester Data Management Outline

1. Will this project be reviewed by any of the following bodies (please select all that apply)?

- Ethics

2. Is The University of Manchester collaborating with other institutions on this project?

- No - only institution involved

3. What data will you use in this project (please select all that apply)?

- Acquire new data

4. Where will the data be stored and backed-up during the project lifetime?

- University of Manchester Research Data Storage Service (Isilon)

5. If you will be using Research Data Storage, how much storage will you require?

- < 1 TB

6. Are you going to be receiving data from, or sharing data with an external third party?

- No

7. How long do you intend to keep your data for after the end of your project (in years)?

- 0-4 years

Guidance for questions 8 to 13

Highly restricted information defined in the Information security classification, ownership and secure information handling SOP is information that requires enhanced security as unauthorised disclosure could cause significant harm to individuals or to the University and its ambitions in respect of its purpose, vision and values. This could be: information that is subject to export controls; valuable intellectual property; security sensitive material or research in key industrial fields at particular risk of being targeted by foreign states. See more examples of highly restricted information.

If you are using 'Very Sensitive' information as defined by the Information Security Classification, Ownerships and Secure Information Handling SOP, please consult the Information Governance Office for guidance.

Personal information, also known as personal data, relates to identifiable living individuals. Personal data is classed as special category personal data if it includes any of the following types of information about an identifiable living individual: racial or ethnic origin; political opinions; religious or similar philosophical beliefs; trade union membership; genetic data; biometric data; health data; sexual life; sexual orientation.

Please note that in line with data protection law (the UK General Data Protection Regulation and Data Protection Act 2018), personal information should only be stored in an identifiable form for as long as is necessary for the project; it should be pseudonymised (partially de-identified) and/or anonymised (completely de—identified) as soon as practically possible. You must obtain the appropriate ethical approval in order to use identifiable personal data.

8. What type of information will you be processing (please select all that apply)?

- Audio and/or video recordings
- Anonymised personal data
- Personal information, including signed consent forms

For the study, there will be recording the audio from the interviews and I will be transcribing the audio myself as the chief investigator. I will remove any personally identifiable information during the transcription process. After transcription, the audio will be destroyed.

We will store all the consent forms on the University of Manchester Research Data Storage Service (Isilon).

9. How do you plan to store, protect and ensure confidentiality of any highly restricted data or personal data (please select all that apply)?

- Anonymise data
- Store data on University of Manchester approved and securely backed up servers or computers

10. If you are storing personal information (including contact details) will you need to keep it beyond the end of the project?

- No

11. Will the participants' information (personal and/or sensitive) be shared with or accessed by anyone outside of the University of Manchester?

- No

12. If you will be sharing personal information outside of the University of Manchester will the individual or organisation you are sharing with be outside the EEA?

- Not applicable

13. Are you planning to use the personal information for future purposes such as research?

- No

14. Will this project use innovative technologies to collect or process data?

- No

15. Who will act as the data custodian for this study, and so be responsible for the information involved?

Anisa Visram

16. Please provide the date on which this plan was last reviewed (dd/mm/yyyy).

2024-05-09

Project details

What is the purpose of your research project?

Hearing aids (HA) are the current gold standard management for most permanent hearing loss. There are over 50,000 children with a hearing loss (HL) and many of whom are hearing aid users. HA are assessed to ensure they provide benefits regarding speech intelligibility to the user and are programmed to optimally aid the user. However, there is often a drop in HA usage when paediatric patients reach their teenage years. Our study aims to understand the factors affecting teenager HA usage and from those responses develop a rehabilitative framework to improve audiology services.

Our study will be a long-form 1 hour interview with hearing-impaired teenagers who were issued HA, regardless of their usage. The parents of teenager HA users. As well as professionals who work with teenage HA users. The teenagers can share their lived experience on factors affecting their HA usage. Parents provide a third party perspective having observed their child's HA usage throughout different stages of their life. As for professionals, we will interview teacher's of the deaf and paediatric audiologists who have experience of working with many hearing-impaired children throughout different age groups and might see similar factors affect HA usage.

What policies and guidelines on data management, data sharing, and data security are relevant to your research project?

I will be using the University of Manchester data management, data sharing, and data security policies and guidelines.

Responsibilities and Resources

Who will be responsible for data management?

Sumeya Abdi
Sumeya.abdi@postgrad.manchester.ac.uk

What resources will you require to deliver your plan?

I will be using Microsoft Teams to host the interviews and record the audio. I will be using my training fund to pay for physical consent forms to be printed so that I have written consent from participants and their parents.

Data Collection

What data will you collect or create?

Our study will be a long-form 1-hour interview with hearing-impaired teenagers who were issued HA, regardless of their usage. The

parents of teenage HA users. As well as professionals who work with teenage HA users. The teenagers can share their lived experiences on factors affecting their HA usage. Parents provide a third-party perspective having observed their child's HA usage throughout different stages of their life. As for professionals, we will interview teacher's of the deaf and paediatric audiologists who have experience of working with many hearing-impaired children throughout different age groups and might see similar factors affect HA usage.

How will the data be collected or created?

I will record the audio only from the online meeting. The participants will be made aware of that the recording has begun. I will delete the audio recording after the transcription has been completed and anonymised.

Documentation and Metadata

What documentation and metadata will accompany the data?

I will document the methodology as part of my research. I will record the participant's age, ethnicity, degree of hearing loss, socioeconomic status, hearing aid adherence or professional background. This is so secondary users are aware of the demographic of those interviewed if they were to repeat the study and find similar or different results.

Ethics and Legal Compliance

How will you manage any ethical issues?

The biggest ethical issue is around the participation of children in the study. Ensuring that children are informed about the study and what their participation would require and how their data will be handled.

All participants who have expressed interest in the study will be given a telephone call or video call discussion where the chief investigator can explain the study and answer any questions. This is to prevent any misunderstanding and ensure that all consent given by participants is fully informed consent. Any discussion about the study or during the study with a child under 16 will be done with the parent/guardian's presence and consent. As per the policy in our department, people below the age of 16 cannot be seen alone without a parent/guardian/chaperone present.

We will have 2 different consent forms: the first is designed for a younger reading age as the youngest participants will be 13 to accommodate anyone with a delayed reading age. The second will be a standard consent form with layman terminology meant for older teenage and adult participants. Both will have areas for participants to sign that they have consented to the study but also for their parents/guardians to sign if the participant is under 16 years of age.

We will ensure our consent forms are suitable for younger readers by having them reviewed by local youth charities and asking for the younger teenager's feedback. The consent forms are also based on a template created by the University of Manchester to ensure it meets the university's ethical and academic guidelines.

Another issue is that we will be recording the interviews in order to accurately transcribe the information. The participants will be made aware of the recording both in the consent process and before the interview begins. It will be explained that the recording will be destroyed after it is transcribed and any identifiable information will be removed in the transcription process. They will be told that if they do not want to be recorded then they can withdraw from study. Until the transcription is anonymised, participants can withdraw from the study and the recording and transcript will be destroyed. The person interviewing and processing the transcription will be the chief investigator who has an enhanced DBS check. The chief investigator will be in a secure room and will conduct the study over a video conference program. We recommend participants to go to a private quiet room however we don't have control over this and leave responsibility to the participants.

We have decided to only take participants who have attended mainstream education. It is to rule our participants that socialisation differs too much from the norm. School is a big factor in a child's life and non-mainstream educational facilities can lead to different experiences that might impact responses. For example, understanding if peer stigma can impact hearing aid usage is difficult if participants attend a home school or one-on-one educational arrangements. The majority of children with hearing loss attend mainstream education therefore with a small sample we don't want to over-represent a niche experience. It also can reduce participants who may have additional needs that are severe enough to impact their ability to participate in the study.

We also plan on excluding participants who don’t speak English at a conversational level. Hearing loss can be a difficult barrier to overcome in terms of communication and if we include participants who don’t speak English then it adds to the complexity of the communication. With long-form interviews, keeping children engaged can be difficult so having to communicate through an interpreter whilst also considering hearing loss can add to difficulty. We also want to ensure that the consent is informed as when we are contacting potential participants to assess their interest as our researchers are only able to speak English. Our written information will all be written in English and will be sent out as such, therefore we already exclude non-English speakers.

General Medical Council (2014).Good medical practice: working with doctors working for patients. Rev edn. Manchester: General Medical Council, General Medical Council. Available at: https://www.gmc-uk.org/-/media/documents/Good_medical_practice___English_1215.pdf_51527435.pdf (Accessed: 15 November 2018).

Consortium for Research into Deaf Education (CRIDE) (2023) Education provision for deaf children in England in 2022/23

How will you manage copyright and Intellectual Property Rights (IPR) issues?

According to the University of Manchester policy, IP created as part of a thesis or dissertation will be the property of the student. Therefore this project will remain my property.

Storage and backup

How will the data be stored and backed up?

The data from the study will be backed up weekly on to the University of manchester research servers.

How will you manage access and security?

The entirety of the research will be undertaken by myself as the chief investigator. The academic supervisor will review the data and analysis of the data but that information will have all personal information removed. No confidential or identifiable patient information will be viewed at any point by a person outside of the chief investigator. All the data will be saved on the University of manchester servers in a locked folder only accessible by the chief investigator. After the interviews have been transcribed, they will be destroyed and the transcription will not contain identifiable information.
There will be a separate secure folder containing the participant consent forms.

Selection and Preservation

Which data should be retained, shared, and/or preserved?

As this is a qualitative study on lived experience, there will not be much use for data after my submission. My analysis will have more value than the raw data and that will be submitted for publication. Therefore none of my data will need to be retained or preserved beyond my submission. The analysis will be shared as part of my submission and hopeful publication.

What is the long-term preservation plan for the dataset?

I will not be storing my data beyond the submission.

Data Sharing

How will you share the data?

According to university policies my anonymised data will be available as part of my submission.

Are any restrictions on data sharing required?

None.