Plan Overview

A Data Management Plan created using DMPonline

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

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Principal Investigator: Sumeya Abdi

Data Manager: Sumeya Abdi

Project Administrator: Sumeya Abdi

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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 facilitators of hearing usage.

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End date: 30-07-2025

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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?

- P Drive (postgraduate researchers and students only)
- University of Manchester Research Data Storage Service (Isilon)

Initially, the data will be stored on the P drive whilst the data will be processed. However after the research is completed, the dissertation will be published and the analysis will be stored on the 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 of the audio from the consent process and the interviews. I will be transcribing the audio myself as the chief investigator and I will remove any personally identifiable information during the transcription process. After transcription, the interview audio will be destroyed.

We will store all the consent audios 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 costs of the study For example, paying participants £10 per hour for their efforts.

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, what their participation would require and how their data will be handled.

To ensure that our partpacntas are giving informed consent, We have designed our patient information sheets to be understandable for laymen. We have used simplified language as we have children participants. However in our verbal consent process, we will go over the information and explain the research and answer any questions participants may have. By verbally explaining the research, we can be more confident that participants have a good understanding of the study. The participants' information forms are also based on a template created by the University of Manchester to ensure it meets the university's ethical and academic guidelines.

As we have a verbal consent process. The participants will be given a written version of the consent form in advance so they know what they will be asked to consent to. Therefore if they have any questions or are unsure on any aspect, the verbal consent process will allow for discussion.

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 before the consent process and before the interview begins. It will be explained that the recording of the interview will be destroyed after it is transcribed and any identifiable information will be removed in the transcription process. However the consent process recording will be kept as part of the records of the study. It will be stored in a secure server from the University of Manchester and be destroyed at date according to the policies of the University of Manchester.

Participants will be told that if they do not want to be recorded then they can withdraw from study. That at any point they can withdraw from the study and the recording and transcript will be destroyed.

We have decided to only take teenage participants who have attended mainstream education. It is to rule out participants who's socialisation differs too much from the norm. As most deaf teenagers attend mainstream education, we hope for the study to be representative of the majority of deaf teenagers. 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 the impact of peer stigma on 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 fluent 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. Though by excluding non-fluent English speakers, we are excluding experiences that are valuable and add unconsidered elements to barriers faced by hearing aid users. I believe it is something that can be explored in more detail in future research.

When working with children, there is an issue with boredom. This can often stem from the study not being engaging enough and the children finding participating tedious which can impact the data. However, it is difficult to avoid and often the boredom impacts the later questions as the children lose enthusiasm. Therefore, I will try to reverse the questions' order so that I have full engagement with all the questions.

Another consideration is whether the children are being coerced into participating. We need children to want to participate and not feel pressured by adults. I will try and recruit through announcements and neutral professionals who are not direct care professionals for the child.

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 on 2 locked folder only accessible by the chief investigator. One folder with the audio of the interviews and other folder will have recordings of the verbal consent.

After the interviews have been transcribed, they will be destroyed and the transcription will not contain identifiable information. However the folder of the verbal consent audio readings will remain until submission date when it will be destroyed.

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.