Plan Overview

A Data Management Plan created using DMPonline

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

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Affiliation: University of Manchester

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Project abstract:

We will be interviewing deaf and hard-of-hearing teenagers to understand barriers and facilitators of hearing usage.

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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?

- Other storage system (please list below)

The data will be stored on the chief investigator's University-approved onedrive until submission and on university-approved servers accessible by the supervisor (i.e. Research Data Storage or OneDrive) for 5 years after submission.

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

- Not applicable

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)?

- 5 - 10 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 recordings of the audio from 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.

Consent forms and emails confirming consent will have personal formation so will be stored on a secure university-approved servers. Initially on P drive and then Research Data Storage or OneDrive after submission

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?

- Yes – Other

Consent forms will be kept and stored electronically and emails confirming consent for 5 years following study completion. And contact details if the participant consents to specific purposes.

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?

- Yes

The participants will be given an option to have their contact details kept to be contacted about participating for future research.

“The participants will be given an option to have their contact details kept to be contacted about participating for future research.” But you have made no such update to the consent form (i.e. another row in the optional section of the consent form which says something like “I agree that the researchers may retain my contact details in order to contact me about future research opportunities”

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).

2024-09-27

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

Anisa Visram
anisa.visram@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 as amazon vouchers.

Data Collection

What data will you collect or create?

Interview recordings will be saved as .mp3 but will be destroyed as soon as it is transcribed. It will be approximately 5GB.
Interview transcripts will be stored as docx. It will be approximately 2GB
Coded Transcript File will be stored as docx. It will be approximately 2GB

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?

Participant information sheet: documents that explain the research project what their participation entails and how the data will be processed.
Assent Forms: Signed forms from the participants themselves. These will be encrypted and securely stored.
Interview Guide: A copy of the interview questions or guide, including any prompts or follow-up questions used during the interview.
Coding Scheme: Documentation of thematic or qualitative coding used in data analysis, including definitions for each code or theme.
Software Used: Details on any software or tools used for data analysis, which can help with reproducibility.
Ethical Review Board Approval: The approval document, reference number, and date.

Ethics and Legal Compliance

How will you manage any ethical issues?

One ethical issue is that we will be recording the interviews in order to accurately transcribe the information. The participants will be made aware of the audio recording before the interview begins. The video of the meeting will not be recorded but participants can switch off their camera if that helps them. It will be explained that the recording of the interview will be destroyed after it is transcribed and any identifiable information such as names or age will be removed in the transcription process. Some participants may feel uncomfortable with being recorded so even though it is clearly stated in the consent form, it is important to make it clear when the recording has begun and to give participants an opportunity to withdraw consent if they change their mind. Participants will be told that if at a later date, they withdraw from the study, the recording and transcript will be destroyed. This is until the data has been anonymised then it won't be possible to do so.

We have decided to only take teenage participants who have attended mainstream education. 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 teenagers with hearing loss attend mainstream education therefore with a small sample we don't want to over-represent a niche experience. By recruiting only from teenagers who attended mainstream, we 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 participants 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 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. As we do not have resources to translate information or interpret during the session therefore we will exclude non-English speakers. 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.

There is a potential for participants to become distressed recalling the impact of hearing aids on their lives. We have a plan in place to support participants if they become distressed with a step-by-step guide on how to support the participants.

The participants will be given written consent forms that go through in detail what they are consenting to by agreeing. It explains how the data will be processed and used. Prior to the consent form, they will have been given a participant information sheet which goes into further depth on the research purpose and how the data will be used.

The audio from the interviews will be transcripted and during the transcription process, any identifiable information will be removed from. The audio data will then be destroyed. This will be undertaken by the chief investigator who will also be undertaking the interview.

Any documents containing identifiable information e.g. consent forms and the pseudonymisation key will be encrypted and stored in a locked folder within the chief investigators university approved onedrive.

We have applied for ethical review by the committee of the Division of Psychology, Communication and Human Neuroscience within the School of Health Sciences and the faculty of the Faculty of Biology, Medicine and Health. To ensure we meet the University of Manchester’s ethical standards.

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 will be stored on the student's University-approved onedrive during the project, and in the longer term on university approved servers accessible by the supervisor (i.e. OneDrive or Research data storage). Any personal or confidential data will be encrypted.

How will you manage access and security?

The p drive or onedrive is only accessible to the student. In the longer term the data will be stored on OneDrive (or Research data storage) in folders accessible only to the supervisor.

Selection and Preservation

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

Anonymised data, excluding interview transcripts, will be retained for data quality purposes and for potential further analysis.
Audio recordings will be destroyed after transcription. Personal data in the form of the recruitment log and ID key will be deleted at the end of the study except in the case where explicit consent has been give to retain this data.
Consent forms will be kept and stored electronically (along with emails confirming consent) for 5 years following study completion.
All data stored beyond the lifetime of the project will be stored on secure servers approved by the University, that is Research Data Storage or OneDrive.

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

The fully anonymised and non-identifiable data and analysis (excluding interview transcripts) will be stored beyond my submission in an online research repository.

Data Sharing

How will you share the data?

The anonymised data and analysis will be made available on an online research repository.

Are any restrictions on data sharing required?

No.