Plan Overview

A Data Management Plan created using DMPonline

Title: Interviews with memory clinic staff on working with British South Asian service users

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Project abstract:

BACKGROUND: British South Asians (BSAs) are highly susceptible for being diagnosed with dementia due to an increasing ageing ethnic minority population and South Asians having a higher prevalence of diseases associated with dementia. Despite this, BSAs referral to memory clinic services is low and they face barriers accessing memory clinics and the diagnostic process. AIMS: Qualitatively inevestigate the experiences of memory clinic staff working with BSA service users and the barriers BSA service users face accessing a dementia diagnosis. METHODS: One video interview with 30 staff members of memory clinics to investigate experiences working with BSA service users. The interview will discuss issues, gaps in staff training and working with interpreters. It will also discuss addressing issues and ideas for improving BSA access.

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Interviews with memory clinic staff on working with British South Asian service users

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

New data: We will be using audio recorded captured data from interviews and written data from demographics sheets.

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

- P Drive (postgraduate researchers and students only)
- Other storage system (please list below)
- University of Manchester Research Data Storage Service (Isilon)

Digital copies of the data will be stored on the research student’s University of Manchester student P-Drive. They will also be shared with the supervisor via the University approved Dropbox for Business.

In the long term, data will be stored on the academic sueprvisor's Manchester RDS.

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

- < 1 TB

6. Are you going to be working with a 3rd party data provider?

- No

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

- 5 - 10 years

Data will be kept up to 5 years after publication according to University of Manchester policy.
The only exception to this is the audio recordings, which will be deleted on 29th May, 2023.

Questions about personal information

Personal information, also known as personal data, relates to identifiable living individuals. Special category personal data is more sensitive information such as medical records, ethnic background, religious beliefs, political opinions, sexual orientation and criminal convictions or offences information. If you are not using personal data then you can skip the rest of this section.

Please note that in line with data protection law (the 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 personal information will you be processing (please select all that apply)?

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

We will be processing audio recordings of participants from interviews.
We will also be processing personal information provided via demographics sheets which will include:

- Gender
- Age
- First language
- Second/Other languages
- Highest level of education
- Subject of education
- Overall duration of working in dementia care
- Profession title
- Duration at current place of employment
- Current city where based
- Brief description of role

9. Please briefly outline how you plan to store, protect and ensure confidentiality of the participants' information.

Only the research team will have access to personal data. They will remove the participant’s name and give every participant a study code on all their documentation, except for the consent form, and any reference to them in documentation.

All documents, including transcriptions of audio recordings, will be stored on the research student's P-Drive and shared with the supervisor only via Dropbox for Business. Later they will be stored on the supervisor's RDS.

The audio recordings of the interviews will be saved to the student's P-Drive, transcribed, and deleted on 29th May, 2023.

Recordings will only be transcribed by the research student. Identifying information will be erased or changed within the transcripts and will only be identifiable by the participant’s study code.

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

Prof. Peter Bower

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

2022-08-25

0. Proposal name

0. Enter the proposal name

Interviews with memory clinics staff on working with British South Asian service users

1. Description of Data.

1.1 Type of Study

A qualitative study utilising video interviews

1.2 Types of Data

Qualitative data of interviews in the form of mp3 audio recordings and transcripts as a soft copy Word document.
Demographic data captured through the demographics sheet as a PDF. The data will also be recorded in a spreadsheet.

1.3 Format and scale of the data

Up to 30 audio recordings of interviews, saved as mp3 file formats.
Up to 30 completed demographics sheets and 30 signed consent forms saved as PDFs.
Up to 30 transcripts of interviews as Word documents.
We estimate the need for approximately 2 GB of total storage volume.

2. Data collection / generation

2.1 Methodologies for data collection / generation

Qualitative data will be captured through video interviews, which will be audio recorded using a University of Manchester approved online video platform with the participant's consent.
Each recording will be given a code name that numbers each participant. They will immediately be saved to the research student's P-Drive.

These recordings will be transcribed verbatim by the research student and identifying information will be anonymised as this is typed. The transcripts will be given the same code name as its respective recording. The transcripts will be shared with the supervisor via Dropbox for Business.

2.2 Data quality and standards

All data is being collected through the use of a semi-structured interview schedule and demographics sheets. All participants will fill out this information in the same manner.

Participants and study codes have been developed to organise the data digitally.

All data will be collected solely by the research student. All data will be inputted into spreadsheets by the research student. The academic supervisor will continue to observe and supervise data collection to ensure bias is not introduced.

Transcripts will be read over whilst listening to the audio recording to ensure they were transcribed correctly and corrected where needed.

3. Data management, documentation and curation

3.1 Managing, storing and curating data

Only the research team will have access to personal data. They will remove the participant’s name and give every participant a study code on all their documentation and any reference to them in documentation.

All documents and audio recordings will be saved to the research student’s P-Drive and only shared with the supervisor via Dropbox for Business. Later they will be saved to the supervisor's Manchester RDS.

Recordings will immediately be transferred to the student's P-Drive and deleted from the online video platform they were made through.

Recordings will only be transcribed by the research student and within 2 weeks of the interview. Identifying information will be erased or changed within the transcripts and will only be identifiable by the participant’s study code.

Audio recordings will be retained until 29th May, 2023 so they can be used to provide context to the transcripts for the research student if needed. On 29th May, 2023, they will be deleted permanently.

3.2 Metadata standards and data documentation

Research data (methods, anoynmised data, and findings) may be documented and made available through:

- The research student's PhD thesis
- Academic peer reviewed publications in journals
- Conference proceedings
- Publication on websites and through blogs
- Public engagement and information events

- A toolkit for memory clinics

This data will never reveal information about participants that makes them identifiable/ compromises their confidentiality and anonymity.

This data will include results derived from the data and the demographics data. This data may also include descriptions of the methods, interview schedules and topic guides utilised, information sheets given to participants, and glossaries and lists of abbreviations developed.

3.3 Data preservation strategy and standards

Only the research team will have access to personal data. They will remove the participant's name and give every participant a study code on all their documentation and any reference to them in documentation.

All documents and audio recordings will be saved to the research student's P-Drive and only shared with the supervisor via Dropbox for Business. Later they will be saved to the supervisor's Manchester RDS.

Recordings will only be transcribed by the research student and within two weeks of the interview. Identifying information will be erased or changed within the transcripts and will only be identifiable by the participant's study code.

All research data will be destroyed up to 5 years after publication by being deleted from the Manchester RDS.

4. Data security and confidentiality of potentially disclosive personal information

4.1 Formal information/data security standards

All digital data will be stored on the research student's University of Manchester P-Drive and shared via Dropbox for Business. Later it will be stored on the supervisor's Manchester RDS.

University of Manchester Information Security Policy
- http://documents.manchester.ac.uk/display.aspx?DocID=6525

4.2 Main risks to data security

The main risk is of personal data being accessed by another party outside of the research team.

All digital data will only be available via the research student's password protected P-Drive, Dropbox for Business, and the supervisor's RDS. Files will be encrypted when shared via Dropbox.

Data will be anonymised within two weeks of being collected (eg. all names removed from transcripts).

5. Data sharing and access

5.1 Suitability for sharing

Anonymised data will be suitable for sharing as well as any research materials that were developed.

5.2 Discovery by potential users of the research data

The anonymised data generated will be shared through Mendeley Data repository.

Mendeley Data repository will be assigned a Digital Object Identifier (DOI). The DOI can be cited in project reports and journal publications through a Data Access Statement or citation list. Descriptive metadata on each data collection held in Mendeley Data will also be accessible via the University of Manchester’s institutional data catalogue (Research Explorer).

Decisions on whether to supply research data to a potential new user will be made by the project supervisor, Prof. Peter Bower.

5.3 Governance of access

Decisions on whether to supply research data to a potential new user will be made by the project supervisor Prof. Peter Bower. Only data that has been anonymised will be shared.

5.4 The study team's exclusive use of the data

Data will be restricted solely to the research team up until the publication of the research student’s PhD thesis.

5.5 Restrictions or delays to sharing, with planned actions to limit such restrictions

Data will be anonymised.

Participant’s consent will be taken for data sharing via the information sheet and consent form.

5.6 Regulation of responsibilities of users

Prof. Peter Bower would determine a Data Transfer Agreement.

6. Responsibilities

6. Responsibilities

Prof. Peter Bower, PI will supervise data management and make executive decisions regarding it. He will also determine if the data is to be shared elsewhere.

Nadine Mirza, PhD Student will manage the data (processing it and sharing it with the supervisor) and will be monitored by the PI regarding this.

7. Relevant policies

7. Relevant institutional, departmental or study policies on data sharing and data security

The University of Manchester Research Data Management Policy
The University of Manchester Records Management Policy
The University of Manchester Data Protection Policy
The University of Manchester Intellectual Property Policy
The University of Manchester IT policies and guidelines

8. Author and contact details

8. Author of this Data Management Plan (Name) and, if different to that of the Principal Investigator, their telephone & email contact details

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