

Developing a toolkit through interviews with memory clinic staff on working with South Asian service users



Information Sheet

You are being invited to take part in a research study [as part of a student project – a PhD project on the development of a toolkit to improve access to and diagnosis of dementia in memory services for British South Asian Urdu speakers]. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

1. Who will conduct the research?

Nadine Mirza, MPhil
PhD Student, University of Manchester

Prof. Peter Bower, PhD
University of Manchester

Dr. Waquas Waheed, MRCPsych, MD
University of Manchester

2. What is the purpose of the research?

Our research aims to identify barriers British South Asians face accessing memory clinics and what can be done to address them. We will form a toolkit which will include a training programme for memory clinic staff with a focus on cultural understanding, sensitivity, and working with interpreters. To do this we need the perspective of memory clinic staff on their experiences working with British South Asian services users, what issues exist, how to address them, what solutions should be there, and what an ideal training programme could consist of.

3. Why have I been chosen?

You have been chosen as one of up to 25 as you are:

- Staff involved in dementia care for a memory service
- Over the age of 18 years
- Fluent in speaking and reading English
- Able to give informed consent

4. What would I be asked to do if I took part?

You will be asked to participate in one video interview, up to 1 hour. This video interview will be conducted via Zoom or Microsoft Teams and audio recorded.

If you decide to take part you will be emailed a consent form and asked to sign it and email it back. You will also be asked to fill in a demographics sheet and email this back as well. The date and time for the interview will be scheduled over email.

In the interview we will discuss:

1. Current training on working with ethnic minorities and British South Asians
2. Experiences interacting with British South Asian service users, particularly Urdu speakers, including issues faced.
3. Current protocol for addressing any mentioned issues.
4. Feedback on possible solutions to these issues.

The date and time for the second video interview will be scheduled at the end of the first interview or via email afterwards.

5. What information will you collect about me?

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will need to collect:

- Gender
- Age
- Ethnicity
- First language
- Second/Other language
- Highest level of education (including subject area)
- Duration overall working in dementia care
- Profession title
- Duration at current place of employment
- City and county where based
- Brief description of role

For audio recordings:

- Audio recordings will be obtained during the interview through Zoom.
- Recordings will be voice only recordings of you and the research student.
- Recordings will be used within this research project by transcribing them verbatim while deidentifying information and anonymising it by assigning all participants a numerical code which will be used in place of their name within the transcripts.
- Data from the transcripts will be analysed to identify information that will inform the development of a staff training programme.

Only the research team will have access to this information.

6. Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

7. What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

8. Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Only the study team at the University of Manchester will have access to your personal identifiable information, that is data which could identify you, but they will anonymise it as soon as practical, assigning each participant a numerical code.
- All documents you provide will be stored on the research student's University of Manchester P-Drive for up to 5 years. If it is ever shared with the other members of the research team mentioned above it will be through a university approved Dropbox for Business account.
- Appropriate access controls are in place to ensure that access to confidential research information is restricted to the research team.
- Your participation in the study will be kept confidential to the study team listed above.

For audio recordings:

As your participation in this research will be recorded in Zoom and your personal data will be processed by Zoom this may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the European Commission to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible

following the completion of data collection.

The audio recordings will be managed as follows:

- The audio recordings will be transcribed by Nadine Mirza, the researcher.
- Personal information will be anonymised in the transcripts.
- Audio recordings will be obtained through Zoom and stored as mp3 files on the research student's University of Manchester P-Drive.
- Audio recordings will be deleted and erased from the P-Drive immediately after being transcribed.
- Transcriptions will be stored on the research student's University of Manchester P-Drive for up to 5 years.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

9. What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

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If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

Audio recordings are essential for participation in this study, therefore, you should be comfortable with the recording process at all times and should alert the researcher to stop the recording at any time if you no longer wish to take part.

10. Will I be compensated for taking part?

There will be no monetary compensation for participating in this research.

11. Will the outcomes of the research be published?

The potential outcomes may be published in peer reviewed journals. It will also be published in a PhD thesis.

12. Who has reviewed the research project?

This project has been reviewed by the University of Manchester Proportionate Research Ethics Committee.

13. Who has funded the research project?

This project has been funded by the Medical Research Council.

14. What if I want to make a complaint?

During the interview inform the researcher if you have a complaint. Prior to or after the interview, procedures on making a minor complaint or formal complaint are as follows:

Minor complaints

If you have a minor complaint then you need to contact the researcher in the first instance.

Prof. Peter Bower
peter.bower@manchester.ac.uk
(0)161 275 7638

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing:

research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#)

Tel: 0303 123 1113

15. What Do I Do Now?

If you have any queries about the study or if you are interested in taking part then please contact the researcher:

Nadine Mirza
Tel: 0773 239 5882
nadine.mirza@postgrad.manchester.ac.uk