

Developing a Culturally Adapted Intervention to Improve Cognitive Functioning in British South Asians with Mild Dementia



Information Sheet

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done 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?

Sarah McMullen, MSc
PhD Student, University of Manchester

Prof. Peter Bower, PhD
University of Manchester.

Dr. Kelly Howells, PhD
University of Manchester.

Dr. Waquas Waheed, MRCPsych, MD
University of Manchester

2. What is the purpose of the research?

The purpose of this research is to select a therapy appropriate for British South Asians with mild dementia.

What is Dementia?

Dementia is a disease of the brain that causes a decline in the functioning of the brain. Dementia can cause problems with memory loss, understanding, judgement, movement, thinking speed, difficulties carrying out daily activities and many more.

Treatments for Dementia

There is no cure for dementia but medications and therapies are offered to help with dementia symptoms.

Therapies for dementia are important as they help people to live well with dementia. The two therapies offered by the NHS for mild to moderate dementia are **Cognitive Simulation Therapy** and **Reminiscence Therapy**.

Cognitive Stimulation Therapy involves taking part in group activities and exercises to improve memory, problem solving skills and language.

Reminiscence Therapy involves talking about things and events from the past. It also involves props such as photos,

music and other possessions with attached memories to help improve mood and wellbeing.

Our Research

We aim to select a therapy for Urdu speaking British South Asians with mild dementia.

Why have I been chosen?

You have been chosen as you:

- Are a **carer** of an Urdu speaking British South Asian with dementia.
- Speak Urdu and/or English
- British South Asian
- Are over the age of 18 years

3. Will the results of the research be published?

The results of this research will be published in students thesis, academic books, reports, blogs, social media, conference presentations or journals.

4. Who has reviewed this research project?

This research has been approved by University of Manchester Research Ethics Committee Reference: 2021-8716-19319.

What would my involvement be?

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

You will be asked to participate in the first focus group and you maybe be

invited to take part in a second focus group 8-12 weeks after the first focus group. This research will be conducted online via Zoom or Microsoft Teams. From providing consent to taking part in the first focus group you will be involved for around 3-4 weeks, if you are asked to take part in the second focus group you will be involved for an additional 8-12 weeks. The focus group itself will be approximately 2 hours long.

Prior to taking part in the focus group you will be acquainted with the focus group procedure by phone call or email. If you choose to participate you will have to sign a consent form or give audio-recorded verbal consent by telephone, fill out a demographics sheet and you will be given this information sheet to keep.

We will also ask you to fill out a contact sheet as you might be invited to take part in an additional focus group. You will also have the option to receive a summary of the study findings.

What is a Focus Group?

A focus group is a small discussion group of 6-8 individuals on a designated topic. It is guided by a leader. It is used to learn more about the opinions and suggestions on the designated topic.

This Research

Focus Group 1: You will help us select which therapy for dementia is more appropriate for the Urdu speaking British South Asian population.

You will be given a brief presentation on Cognitive Stimulation Therapy and Reminiscence therapy, including their strengths and weaknesses.

The types of questions for the discussion will include:

- Which therapy is more appropriate Cognitive stimulation therapy or Reminiscence therapy?
- Should the therapy have a certain type of structure?
- What aspect of the therapy makes it more appropriate?
- Which aspect of the therapy should be adapted and why?
- Should personal pictures and images be included as a part of the therapy?

This is not an exhaustive list of questions.

6. Will I be compensated for participating in the research?

There will be no compensation for participating in this research.

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

It is your decision whether or not to take part in this research. If you do decide to take part you will be given this information sheet to keep and will be asked to give written or verbal consent. You will also be asked to fill out a demographics sheet and a contact sheet.

If you decide to take part you are still free to withdraw from the research 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/pseudonymised 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 recording is essential for participation in the research study. If at any point in time you feel uncomfortable during the audio recording process you are free to stop the recording at any time.

Data Protection & Confidentiality

8. 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:

Demographics Sheet Data

- Gender
- Age
- Country of Birth
- Marital Status
- Employment
- First language

- Second/Other language
- Highest level of education
- Subject of education
- Years lived in the UK
- As you are a carer of a person with dementia, what level of dementia do they have mild, moderate or severe dementia?

We will also ask you to provide us with a contact number or email address by filling out the contact sheet so you can be contacted and sent the Zoom or Microsoft Teams invitation. It is essential that you are able read and gain access to this information sheet prior to giving consent. If you are unable to gain access to this information sheet by email or text message we will post out a copy of this sheet to your home address, if necessary. This will be the only time we will ask you to provide your home address.

The research will only be audio recorded via Zoom or Microsoft Teams.

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

We are collecting and storing this personal identifiable information in accordance with UK 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”.

10. 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.

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](#).

11. 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:

Your participation in the study will be kept confidential and only the researchers listed above will know

about it. The research will be audio recorded

For audio recordings:

- Research will be audio recorded via Zoom or Microsoft Teams.
- Verbal consent will be audio recorded on an encrypted password protected audio device.
- All audio recordings will be transferred immediately to a University of Manchester password protected secure drive and will be deleted from the original source.
- The audio recording for the research will be written/typed by the researcher Sarah McMullen.
- All personal information from the research transcript will be anonymised/pseudonymised by giving the participants a random ID number.
- Audio recording of the research study will be deleted once transcribed and anonymised/pseudonymised.

Your participation in this research will be recorded in Zoom or Microsoft teams and your personal data will be processed by Zoom or Microsoft Teams. 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 United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on the University of Manchester password protected secure drive following the completion of data collection.

Demographics sheets, Contact Sheets and audio recorded verbal consent will be stored on the University of Manchester password protected secure drive in a password protected folder. Only the research team will have this information.

All anonymised/ pseudonymised transcripts will be stored on the University of Manchester password protected secure drive. Only the research team will have this information.

Data from the transcripts will be analysed to identify information that will help select a therapy specifically British South Asians living with mild dementia.

Transcripts of the research study, will be stored for a minimum of 5 years by Sarah McMullen on the University of

Manchester password protected secure drive.

Demographics sheets, contact sheets (for future research), written consent forms and audio recorded verbal consent will be stored for a minimum of 5 years in a password protected folder by Sarah McMullen on the University of Manchester password protected secure drive.

Any hard copies of documents will be retained for 5 years, stored in a locked cabinet on the University of Manchester premises by Sarah McMullen. Appropriate access controls are in place to ensure that access to confidential research information is restricted to the research team. All computers in use will be password protected.

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.

Potential Disclosures

If at any point during the study you become distressed or upset we will provide you with a debrief sheet and

will contact your GP on your behalf if you so wish.

12. Will my information be used for future research?

If you make a decision to participate in this research, the information about your health and care may be given to other researchers who are doing other research in this organisation. This future research will be about dementia and ethnic minorities like this research. These organisations may be universities, NHS or companies doing health and care research. They may be in this country or in another country. Your information will only be used by organisations and researchers for research according to the UK Policy Framework for Health and Social Care Research.

This information will only be used for health and care research. This information cannot be used to contact and cannot affect your care. It cannot be used to make decisions about future services available to you.

13. If I want to make a complaint what do I do?

During the research if you have a complaint tell the researcher. Before or after the research, if there is a minor or formal complaint contact:

Minor complaints

If you have a minor complaint then you need to contact the researcher first:

Prof Peter Bower
Peter.bower@manchester.ac.uk

Formal Complaints

If you have a formal complaint or you are not happy with the response got 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 306 8089.

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

14. What Do I Do Now?

If you have any questions about this research or if you want to participate then please contact this researcher:-

Sarah McMullen
Sarah.mcmullen@postgrad.manchester.ac.uk
0161 275 1821

This Project Has Been Approved by the University of Manchester Research Ethics Committee Reference: 2021-8716-19319. UREC ID: 8716.