



Making it easier for Urdu speakers to go to dementia memory clinics

Interviewing Carers

Centre for Primary Care and Health Services Research,
University of Manchester

1. You are invited to take part in a **research study**

You will have one or two interviews in person, on the phone, or the computer using Zoom or Microsoft Teams.

Before you decide it is **important** for you to **understand** why the research is being done and **what it will involve**.

Please take time to read the information. **Ask** if anything is **not clear** or if you would like **more information**.

You can hear this information sheet by scanning this code:

QR CODE
WILL GO
HERE

2. What is the purpose of the study?

We want to speak to you if you **look after an Urdu speaker** with dementia.

You must have been at the **NHS memory clinic** with them at least once. This could be when they were interviewed, tested or when you were told they have **dementia**.

You must be in the **North West**.



We want to hear about your **experience at the service**, what happened, what was good, and what was bad.



This can help us see what problems are in memory clinics and how we can improve them to make memory clinics better for the British South Asian community.

3. Why have I been chosen?

- > You are **South Asian**
- > Speak **English OR Urdu**
- > You are from the **North West**
- > You are over 18 years old
- > You were present with an Urdu speaker with dementia at an NHS memory clinic when they were diagnosed in the last 5 years

4. Do I have to take part?

No. It is **up to you** to decide whether or not to take part. The **standard of care** you receive or the person you care for receives will not be affected in any way.

5. What will be involved if I agree to take part?

You will take part in **one** or **two interviews** with Nadine Mirza, the researcher. You decide how many interviews.

Each interview will be up to **1 hour** long and can be:

- > In person at your home
- > In person at a community location
- > Over the telephone
- > Over the computer using Zoom
- > Over the computer using Teams

Only your voice will be recorded. You will pick the date and time. We can arrange the interview(s) over email or on the phone depending on what you prefer.

After the interview you will be asked to fill out a feedback form about your experience of participating in the study.

If you agree to participate we will ask you to give us some information:

- > Gender
- > Date of Birth
- > Religion
- > Marital Status
- > Country of Birth
- > Ethnicity
- > Employment Status
- > Estimated Household Annual Income
- > Languages spoken
- > Highest level of education
- > Subject of education
- > Years lived in the UK
- > Your role as a caregiver
- > Your household
- > Which memory clinic you have experience with

If you are not comfortable disclosing this information you can still participate in the interview.

We would also need an email or home address to send you forms to fill, to send you a gift card to show our appreciation for you participating, and to send you the results of the study if you want. If you would like to receive the findings from a phone call you will have to provide a phone number.

If you would prefer we tell your GP you took part we will need some more information:

- > Date of Birth
- > GPs name
- > GPs address



6. What are the benefits of taking part?

You will be helping us find out how we can improve dementia memory clinics for British South Asians like you. To thank you for taking part we would like to give you a gift card.

If you participate in one interview this will be worth £15. If you participate in two interviews this will be worth £30. Here is a list of gift cards we are offering for your participation.



You can choose which place you want the gift card for and you decide whether this will be emailed or posted to your house.

7. What are the risks of taking part?

The interview may ask sensitive questions which could be upsetting. It is important for you to know that if you do not want to answer a question you do not have to.

- > You can take a break or skip a question during the interview at any time.
- > You can reschedule the interview at any time.
- > You can stop the interview completely at any time.
- > You can ask to withdraw from the study at any time.



Before any interview you can have a call with the researcher to address any concerns.

This is optional. You can use this call to know more about them and why they are doing this study, and to ask any questions about the study.

8. What will happen if I want to stop taking part in the study?

You are free to stop taking part in the study at any time.

If you decide to stop taking part we will not use your information. We will get rid of it safely and securely so that it cannot be used.

9. Will me taking part in the study be confidential?

All your **personal information** will be kept confidential. This means it will not be shared with anyone who is not authorised eg. outside the research team.

The only time it will be shared outside the team is if the researcher feels you are being harmed, or may harm yourself or others.

Your information will be stored securely at the University of Manchester and your name will not be shown. We will use an ID code instead.

~~Ahmed Khan~~

PD01 ✓

10. Who is organising and funding the research?

The study is **organised** by the Centre for Primary Care and Health Services Research at the **University of Manchester**.



The study is **funded** by the **Medical Research Council**.



The study has been approved by the **University of Manchester Research Ethics Committee**.

11. What will happen to the results of the research study?

We will publish the results in a **PhD thesis** and in **academic books and journals**.

The results may also be **presented at conferences**.

You will not be identified in any of this. We will always use the ID code instead.

12. What if I need more information or there is a problem?

If you need **more** information or if you have any questions please contact the researcher:



Researcher: Nadine Mirza

PhD Student

Email: nadine.mirza@manchester.ac.uk

Phone: 0773 239 5882

If you have a **minor complaint** please contact the supervisor:

Supervisor: Prof. Peter Bower

Email: peter.bower@manchester.ac.uk

Phone: 0161 275 7683

If you have a **serious complaint** please contact:

Research Ethics Manager

Email: research.complaints@manchester.ac.uk

Phone: 0161 306 8089

If you decide to take part please read the consent form and sign it. If you cannot do this we will take a voice recording of your consent.

**Please take time to decide if you want to take part.
Thank you for reading about this study.**

Keep reading to find out information about your privacy.

YOUR PRIVACY

The law says that we must have a **legal reason** to collect your data.

We can collect your data for two legal reasons:

- 1) A task carried out in the public's interest
- 2) A process needed for scientific research

The University of Manchester is the **data controller** for this research.

This means the University of Manchester is **responsible** for making sure your data is:

- 1) Kept secure and confidential
- 2) Only used in the way the researchers tell you it will be used

Your data will be **anonymised** as soon as possible. This means we will remove any personal information that can be used to identify you.

The remaining data will be kept for **5 years**.

Your anonymised data may be shared with other researchers at the University of Manchester.

These researchers will be investigating dementia in ethnic minorities. They will not be told who you are.

Anyone who wants to use your anonymised data to research dementia in ethnic minorities will need to get ethical approval.

You can learn more about your data privacy by reading the University privacy notice attached.

Keep reading to find out about COVID-19 measures

COVID-19 POLICY

Due to the COVID-19 pandemic we have taken some steps in the way the research will be done to make sure we are following government advice and being safe.

You should read all of this information before you decide to participate in this study. If you decide not take part please inform the researcher. If you have any questions please ask the researcher.

If you are interviewed in person it would be at your home or a public venue of your choice. This has a risk of infection. You can instead choose to be interviewed on the telephone or on the computer with Zoom or Microsoft Teams.

If you prefer an in person interview:

- > You can wear a mask
- > The researcher will ask you if you want them to wear a mask
- > The researcher will take a test 24 hours before the interview
- > The researcher will bring spare N-95 masks and sanitiser
- > The researcher will sanitise their hands before the interview
- > The researcher will sanitise any recorder before the interview

If you are from a vulnerable group or have symptoms you should not interview in person.

If the government rules change your interview may be postponed or you may be asked to switch to the telephone or the computer.