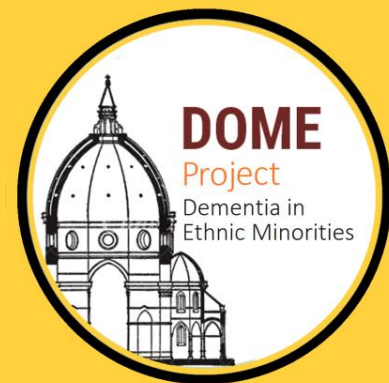


The Dome Project Advisory Group



Information Sheet

You are being invited to join **The Dome Project Advisory Group**, which involves advising a research student on how to design their dementia study so that it is easy to understand for Urdu speakers with dementia, and sensitive to people from a South Asian culture.

Before you decide to join, it is important for you to understand why are being asked and what will be involved in The DOME Project Advisory Group.

Please ask if there is anything that is not clear or if you would like more information.

Contact details are at the end of this sheet.

1. Who will run the Dome Project Advisory Group?



Nadine Mirza is a PhD student at the School of Health Sciences, at The University of Manchester. She will run the Dome Project Advisory Group.

2. What is the Dome Project Advisory Group?

The DOME (Dementia in Ethnic Minorities) Project is a research project being conducted by Nadine for her PhD.

In this research project Nadine is looking at Urdu speaking South Asians experiences of trying to get help in dementia services, what struggles they face, and how services can improve.

Her research project will involve a study in which she will interview Urdu speakers with dementia and their carers who have been to memory clinics and memory assessment services.

It is very important that this interview study is both **dementia friendly** and also **culturally sensitive for Urdu speakers**.

This means that the design of the study and the materials used in the study must be:

- Understandable for people with dementia

- Understandable in both English and Urdu
- Sensitive to South Asian culture

Patient and Public Involvement Advisory Groups are when patients and members of the public consult on research studies to make sure it is designed well for the participants.

They can advise on matters that the researcher may not have realised or may not have the knowledge for.

The DOME Project Advisory Group has been set up so that South Asian Urdu speakers with a knowledge of dementia can advise on how to make this interview study easy to understand and participate in for Urdu speakers with dementia and their carers.

3. Who can join the Dome Project Advisory Group?

You can help advise and consult in our interview study if you can read English **AND** Urdu and:

- Have a diagnosis of mild dementia
- Care for someone with a diagnosis of dementia
- Work in a dementia memory service with South Asian service users
- Are a dementia charity or dementia community organisation partner who works with South Asians

4. What will you have to do?

If you decide to take part you can keep this information sheet and you will have to sign a Consent Form.

You will receive an Appointment Form confirming your role.

You will then be asked to attend up to 5 meetings (each 1 hour long).

These may be a week apart or less, depending on your availability.

These can be online (anywhere) or in person (if you are from Greater Manchester) depending on your convenience.

If they are online they can be on Zoom, Microsoft Teams, Skype, Google Hangouts or Whatsapp.

If they are in person, Nadine can meet you at your home or at a community location of your choice.

In the meetings we will talk about the interview study and Nadine will ask you your opinions and advise. The meetings will cover:

- The best way to conduct dementia friendly interviews and ideas for questions
- Ways to recruit Urdu speaking participants with dementia and their carers
- Designing dementia friendly English and Urdu research materials such as

the advert, information sheet, and consent form

- Ideas for dementia friendly audio and video versions of the research materials

After each meeting you will be asked to take away some homework, which will take between 1-2 hours.

The homework will be reviewing research materials in English and Urdu to make sure the language and content is understandable and also culturally sensitive.

This homework will be email or mailed to your home depending on your choice.

This can be completed in your own time.

People with dementia can choose to have a family member or carer attend meetings with them and help them with homework if they wish.

5. Will you be paid for taking part?

For each meeting and its homework, you will receive £50 compensation.

If you are able to take part in all 5 meetings with homework you will receive £250.

You can also receive an additional £50 if you wish to review the entire set of study materials at the end of the group.

If meetings are in person and you have to travel to a community location you will also be compensated for your travel.

Payment can be provided via bank transfer or cash payments depending on your convenience and you will be asked to sign a receipt.

6. Will the outcomes be published?

The potential outcomes will be published in Nadine's PhD thesis.

You will also be asked if you want to receive updates on this work.

7. What happens if you change your mind?

It is up to you to decide whether or not to get involved.

If you change your mind and no longer want to be involved please contact Nadine via telephone or email.

You can leave the Dome Project Advisory Group at any time without giving a reason and without harm to yourself.

If you decide not to take part you do not need to do anything further.

8. What information about you will we need?

In order to volunteer we will need to collect information that will allow us to contact you and to send you homework.

This may include:

- Telephone Number

- Email Address
- Home Address

These will be stored on Nadine's university password protected computer storage. Only she will have access to this.

She will only ever collect information that is appropriate and necessary.

9. What are your legal rights?

Data protection law requires us to have a valid legal reason to process and use personal data about you, known as a 'legal basis'.

For PPIE activities, the specific reason is that it is "a public interest task" and "necessary for the pursuit of the legitimate interests of the University (i.e. PPIE)".

We may also use your personal information in the following situation, which is likely to be rare: "Where we need to protect your vital interests (or someone else's interests)"

If we require your consent for any additional uses of your personal information, including your image and more sensitive personal information (e.g. 'Special Category Data') we will obtain it.

By law you have rights in relation to the personal information we hold about you.

These include the right to:

- See the information/receive a copy;

- Correct inaccurate information;
- Have any information deleted;
- Limit or raise concerns to our processing of the information;
- Move your information ('portability');

The above would be granted unless it is legally prohibited and/or would put you or another person at serious risk of harm.

To find out more about your different rights or the way we use your personal information to ensure we follow the law, please visit our PPIE Privacy Notice: <http://documents.manchester.ac.uk/display.aspx?DocID=43063>.

Your personal information will be kept confidential at all times.

We would not share information with other people or organisations about you or pass on your contact details without your permission.

10. What if you have a complaint?

If you have a complaint that you wish to direct to members of the research team please contact:

Nadine Mirza

nadine.mirza@manchester.ac.uk

0773 239 5882

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

The Social Responsibility and Public Engagement Team, Faculty of Biology, Medicine and Health, Simon Building, The University of Manchester, Oxford Road, Manchester, M13 9PL

Email: srbmh@manchester.ac.uk

Telephone: 0161 306 6797

If you wish to contact us about your data protection right, 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

<https://ico.org.uk/make-a-complaint/>

Telephone: 0303 123 1113

11. Contact Details

If you have queries about the information provided or you are interested in joining the Dome Project Advisory Group then please contact:

Nadine Mirza

nadine.mirza@manchester.ac.uk

0773 239 5882