

# **The Involved Study**

Involving South Asian, Black African and African Caribbean People in  
Designing Better **Dementia** Support



Work Package 3 Participant information sheet, V3, 03.10.2024

## **Study Lead and Host**



## **Joint Lead**



## **Collaborating Organisation**



# THE INVOLVED STUDY:

## Involving South Asian, Black African and African Caribbean People in Designing Better Dementia Support

### Information Sheet for Participants

We would like to invite you to participate in an exciting opportunity to help shape the future of dementia care for people from South Asian, Black African and African Caribbean backgrounds. Your participation is entirely voluntary, and you will have the chance to ask any questions before agreeing to take part.

#### What is this study about?

Research shows that the numbers of people in ethnic minorities expected to develop dementia is set to increase. This means that more people from these communities will need skilled dementia support, however, services are not ready for this.

According to research studies, ethnic minority groups do not use dementia services; of those that do use them, many do not find them useful because of cultural and language barriers.

A lack of communication between ethnic minority groups and service commissioners and providers means understandings, expectations and provision do not align. To provide effective support to people from ethnic minority groups, it is important to understand their sense of belonging and what supports them to live well with dementia in their space and place.

Sandwell and Wolverhampton are localities vibrant with ethnic minority communities. This project will involve speaking with South Asian, Black African and African Caribbean people in these two places, connecting them with service providers and commissioners to develop more appropriate dementia support.

## What do we want to find out?

We are interested in finding out about what supports you to live a good quality life and what this means for supporting people affected by dementia. We want to understand what helps you feel a sense of belonging and how this is connected to the place in which you reside. This information will help better inform commissioners of services about what works well for people with dementia and their families from these communities.

## Who can take part?

We would like to speak with people who have been affected by dementia. This could mean that you are either:

- A person with a diagnosis of dementia from a South Asian, Black African or African Caribbean background, residing in Wolverhampton or Sandwell.
- A person who has personally or professionally provided care to a person with dementia from a South Asian, Black African or African Caribbean background who resides in (or resided in) Wolverhampton or Sandwell.
- A South Asian, Black African or African Caribbean person who knows about dementia through others and resides in Wolverhampton or Sandwell.

Please note that you must be aged over 18 years to take part.

## What do I have to do?

You will be invited to take part in a face-to-face group discussion where we will help you draw, map and make notes of your ideas for what helps you to live well. For example, this could relate to important places you visit, or your relationships with people. You don't need to know how to draw and you don't have to draw if you don't want to. We are there to help with that. You will be with us for approximately 4 hours. During this time, we will have regular breaks with refreshments and lunch provided. As a small token of appreciation of your time, you will receive a £40 gift voucher.

## What will be done with the information?

We will use your information to help develop a model for good dementia support. If you agree, we will invite you for a follow-up discussion so that we can share our findings with you to let us know if they are representative of your ideas. The final model that we produce will be written up as reports and publications and presented at conferences.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure on a password-protected file on the University of Wolverhampton One Drive.

Once we have finished the study, we will keep all the data for 10 years in line with the University regulations. We will write our reports in a way that no-one can work out that you took part in the study.

### **My English is not very good, can I still take part?**

Yes! The research team can speak and understand a number of South Asian languages and a member of our Experts by Experience team can speak and understand some African and African Caribbean languages and dialects. Please let us know if you need language support to be part of this project and we will ensure that this is provided.

### **What are the risks and benefits?**

It might be possible that you find talking about your dementia journey upsetting. If you become upset, you have the choice to pause or not to continue with the discussion. You can stop your involvement at any time. Our team is trained and will be able to support you and be sensitive to your needs. You will also receive a list of support services you may find useful.

The benefit of taking part is that you will help to shape better dementia support services for people from South Asian, Black African, African Caribbean communities who have been traditionally under represented and under served in dementia support services. You will also have the opportunity to meet with peers during the group discussions.

### **Will my taking part be kept private?**

Yes! All your information will be kept confidential, unless you disclose that you or others may be at risk of harm, we may have to notify the relevant authorities. All data will be stored in a secure password protected computer that only the research team can access. All data will be retained for 10 years post-study completion on the University of Wolverhampton One Drive in line with the University's regulations.

### **What are my choices about how my information is used in this project?**

You can withdraw from the study at any time, without reason. However if you decide to withdraw from the project, two weeks after a discussion group, we will keep your anonymous information. This is because at this stage we will have anonymised all the information and started analysis. It then becomes difficult to identify your information to remove.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. All data will be retained for 10 years post-study completion on the University of Wolverhampton One Drive in line with the University's regulations.

### Where can I find out more about how my information will be used?

You can find out more about how we use your information by:

1. Get in touch with the research lead. Their details are below. We would be very happy to answer your questions.
2. At [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)

### CONTACT



#### Dr Karan Jutla (Project Lead)

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## Ethics

All research is looked at by an independent group of people, called a research ethics committee to protect your interests. This research project was given a favourable opinion by the Health Professions Ethics Committee at the University of Wolverhampton on 22<sup>nd</sup> August 2024 and by the South Central - Oxford C Research Ethics Committee on 29<sup>th</sup> October 2024.

## Complaints

If you want to complain about how researchers have handled your information, you should contact the project lead (see details above). If you are not happy after that, you can contact:

The University of Wolverhampton's Pro-Vice Chancellor for Research & Knowledge Exchange - Professor Prashant Pillai, MBE. Email: [p.pillai@wlv.ac.uk](mailto:p.pillai@wlv.ac.uk)

Or

The University of Wolverhampton's Research Integrity Manager - Miss Jill Morgan. Email: [J.Morgan4@wlv.ac.uk](mailto:J.Morgan4@wlv.ac.uk)

For more information regarding research integrity at the University please visit <https://www.wlv.ac.uk/research/research-policies-procedures--guidelines/research-integrity/>