ISRCTN16639504 https://doi.org/10.1186/ISRCTN16639504

InvolveD: Involving South Asian, Black African and African Caribbean people in designing better dementia support

Submission date 12/12/2024	**Recruitment status** No longer recruiting	☐ Prospectively registered ☒ Protocol
Registration date 24/02/2025	**Overall study status** Ongoing	☐ Statistical analysis plan ☐ Results
Last Edited 18/02/2026	**Condition category** Mental and Behavioural Disorders	☐ Individual participant data ☒ Record updated in last year

Plain English summary of protocol

Background and study aims

25,000 people from ethnic minority communities in the UK have dementia and this number is expected to double by 2026. Hence, more people from these communities will need skilled dementia support; however, services are not ready for this. Research shows that many people from ethnic minority groups do not use dementia services; of those who 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 provisions do not align. To provide effective support to people from ethnic minority groups, it is important to understand their sense of the place (experience of their environments), and what is important to them both individually and collectively. Finding effective ways of enabling conversations between communities and commissioners/service providers is vital to building trust and improving care. Funded by the National Institute for Health and Care Research (NIHR), the InvolveD study aims to explore and evaluate an approach to working collaboratively with people from ethnic minority communities to understand what supports them to live well with dementia in the places they reside.

Who can participate?

A person aged over 18 years with a diagnosis of dementia, a person aged over 18 years who has personally or professionally cared for/supported a person with dementia both from a South Asian, Black African or African Caribbean background, residing in Wolverhampton or Sandwell, and a South Asian, Black African or African Caribbean person aged over 18 years who is familiar with dementia and resides in Wolverhampton or Sandwell.

What does the study involve?

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 a model for improved dementia through a series of community-based participatory workshops. Participants from the workshops will be invited to a follow-up session to make sure that this representation is true to their needs and sense of place. The research team will also be conducting interviews with people who took part in the advisory group and workshops to review the participatory approach of this project and how to evaluate the impact of the methods that were used in further studies.

Patient and public involvement: In developing the proposal, the research team have been speaking with local dementia organisations and groups representing the communities that they will work with to help shape the project. An Experts by Experience Group regularly meets with the research team at various points of this project to ensure that all methods and processes are supportive and inclusive of people living with dementia and their carers.

Dissemination: Findings will be published in academic and practice journals, presented at a conference and made accessible to the public via social media. The research team will also produce a short video co-created with our Experts by Experience to share the project findings with community members.

What are the possible benefits and risks of participating?
Benefits and risks not provided at registration

Where is the study run from?
University of Wolverhampton (UK)

When is the study starting and how long is it expected to run for?
May 2024 to May 2026

Who is funding the study?
National Institute for Health and Care Research (NIHR) (UK)

Who is the main contact?
Dr Karan Jutlla, K.Jutlla@wlv.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

Contact name
Dr Karan Jutlla

ORCID ID
https://orcid.org/0000-0002-9055-2233

Contact details
Office: WA202
Jerome K Jerome Building, Gorway Road
Walsall
United Kingdom
WS1 3BC
+44 (0)7725111574
K.Jutlla@wlv.ac.uk

Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
340269

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
SRfN18

National Institute for Health and Care Research (NIHR)
NIHR205153

Study information

Scientific Title
Developing a place-based model of support for people with dementia from ethnic minorities: a participatory research approach.

Acronym
InvolveD

Study objectives
This project aims to explore and evaluate a participatory approach to coproducing an inclusive place-based model to improve dementia support for people from ethnic minority communities, particularly South Asian, black African and African Caribbean communities.

Objectives:
I. To engage in and strengthen collaborative dialogue between stakeholders through participatory research to co-produce a shared understanding of place, assets, and support needs
II. To coproduce local place-based dementia models reflecting the perspectives, knowledge and other resources of all stakeholders, including people from the target communities
III. To evaluate the approach to participatory research and coproduction and establish means of evaluating the longer-term impact of the approach (the place-based models of support)

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 29/10/2024, South Central - Oxford C Research Ethics Committee (2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; +44 (0)207 1048144; oxfordc.rec@hra.nhs.uk), ref: 24/SC/0348

Study design
Qualitative ecological study

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied
Involving South Asian, Black African and African Caribbean People in designing better dementia support

Interventions
This project is a qualitative study adopting a participatory research approach. Sandwell and Wolverhampton are localities vibrant with ethnic minority communities. These localities are excellent case sites, having high levels of ethnic diversity, and interacting with significant socio-economic disadvantages, but with vibrant community assets.

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 a model for improved dementia by:
1. Formulating an advisory group to guide the research team, comprising people from community organisations, health/social care services, local charities and representatives from the target communities;
2. Conducting community-based participatory workshops with people from different backgrounds (people living with dementia, carers, community members, health and social care services, local charities) to understand people's sense of place and how this could improve dementia support needs.
3. Combining this information (analysis) to produce a model that is inclusive of everyone's views. Participants from the workshops will be invited to a follow-up session to make sure that this representation is true to their needs and sense of place.
4. Conduct interviews with people who took part in the advisory group and workshops to review the participatory approach of this project and how to evaluate the impact of the methods we used in further studies.

The outputs and anticipated impact from this study are organized into the following overlapping levels:

i) **Local place-based models of support and implementation plans for South Asian, Black Caribbean, and African Caribbean communities**: Through a participatory approach in two local authority areas, the study will coproduce local place-based models of better dementia support with partners representing communities, statutory and third sector organizations, and people with lived experience and carers. These models will be framed by the needs expressed by people with lived experience and carers to help them feel part of their community and live well.

The participatory approach and commitment to ongoing knowledge exchange throughout the project include working with the Advisory Group and Experts by Experience to co-develop detailed dissemination and implementation plans. This will ensure that local decision-makers collaborate with local communities to operationalize the place-based models of support. The participatory nature of the project and the commitment from partners in the Advisory Group will help secure local ownership across stakeholders for the models of support and their implementation.

ii) **A detailed approach to participatory research and coproduction of plans to improve support**: This will be informed by existing realist analyses of participatory methods. The study will use existing CMO (Context-Mechanism-Outcome) configurations as a starting point to analyze locally what participatory configurations work to coproduce the local plans. The place-based models of support will form some of the outcomes in the CMO configurations.

The study will work with local partners to plan future participatory work to continue developing local place-based support for communities. Additionally, the lessons from the participatory approach will be disseminated to other communities, with caution, as further empirical evaluation is needed to understand CMO configurations in different contexts and determine the approach's long-term value. The research team will use their extensive connections to begin discussions with national stakeholders about making the findings available to wider communities beyond the study sites. This will include discussions about the best formats for materials, such as short reports, testimonies, narratives from the sites, and training materials. Early engagement with networks will ensure awareness of the project and its plans for impact. A stakeholder map will be developed and shared with the Advisory Group to identify where they can support national engagement.

As the project progresses and a more detailed analysis of the participatory approach and CMOs emerges, the study will engage networks more fully to consider national impact. This will also be a time to engage national stakeholders and other sites in planning further studies to help generalize the participatory approach. The project and its intertwined outputs related to the place-based models of support and the participatory approach are seen as laying the foundations for future studies and a collaborative research program with the partners involved. This will include a longitudinal evaluation of the impact of the place-based model of support and further research to generalize the participatory approach to other contexts of improving dementia support within communities.

Intervention Type
Other

Primary outcome(s)
1. Local place-based models of support and implementation plans: Local place-based models of dementia support will be measured using a participatory approach with partners, including communities, statutory and third-sector organizations, and people with lived experience and carers throughout the project, with ongoing knowledge exchange and co-development of dissemination and implementation plans.
2. Detailed approach to participatory research and coproduction of plans: Participatory research methods and coproduced plans for improved support will be measured using an analysis of participatory configurations using existing CMO (Context-Mechanism-Outcome) configurations, and dissemination of lessons learned throughout the project, with dissemination to other communities and engagement with national stakeholders as the project progresses.

Key secondary outcome(s))
There are no secondary outcome measures

Completion date
31/05/2026

Eligibility

Key inclusion criteria

1. A person with a diagnosis of dementia from a South Asian, Black African or African Caribbean background, residing in Wolverhampton or Sandwell
2. A person who has personally or professionally cared for/supported a person with dementia from a South Asian, Black African or African Caribbean background who resides in (or resided in) Wolverhampton or Sandwell
3. A South Asian, Black African or African Caribbean person who is familiar with dementia and resides in Wolverhampton or Sandwell
4. They must be aged over 18 years old

Participant type(s)

Carer, Population, Resident, Service user

Healthy volunteers allowed

No

Age group

Mixed

Lower age limit

18 years

Upper age limit

100 years

Sex

All

Total final enrolment

153

Key exclusion criteria

1. Under 18 years old
2. Does not have the capacity to consent to participate

Date of first enrolment

30/01/2025

Date of final enrolment

30/11/2025

Locations

Countries of recruitment

United Kingdom

England

Study participating centre

University of Wolverhampton
Wulfruna Street
Wolverhampton
England
WV1 1LY

Sponsor information

Organisation
University of Wolverhampton

ROR
https://ror.org/01k2y1055

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated and/or analysed during the current study will be published as a supplement to the results publication.

IPD sharing plan summary

Published as a supplement to the results publication

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version 3	03/10/2024	17/02/2025	No	Yes
Participant information sheet	version 3	03/10/2024	17/02/2025	No	Yes
Protocol file	version 0.2	04/10/2024	17/02/2025	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes