Qualitative Protocol Development Tool

The research protocol forms an essential part of a research project. It is a full description of the research study and will act as a 'manual' for members of the research team to ensure adherence to the methods outlined. As the study gets underway, it can then be used to monitor the study's progress and evaluate its outcomes.

The protocol should go into as much detail about the research project as possible, to enable the review bodies to fully understand your study.

The use of this collated consensus guidance and template is not mandatory. The guidance and template are published as standards to encourage and enable responsible research.

The document will:

- Support researchers developing protocols where the sponsor does not already use a template
- Support sponsors wishing to develop template protocols in line with national guidance
- Support sponsors to review their existing protocol template to ensure that it is in line with national guidance.

A protocol which contains all the elements that review bodies consider is less likely to be delayed during the review process because there will be less likelihood that the review body will require clarification from the applicant.

We would appreciate self-declaration of how you've used this template so we are able to measure its uptake.

Please indicate the compatibility of this template with any existing templates you already use by stating one of the following on the front of each submitted protocol:

- **This protocol has regard for the HRA guidance and order of content; OR**
- **This protocol has regard for the HRA guidance; OR**
- **This protocol does not have regard to the HRA guidance and order of content**

FULL/LONG TITLE OF THE STUDY

Original title submitted to funders: Developing a place-based model of support for people with dementia from ethnic minorities: a participatory research approach.

New Title: InvolveD: Involving South Asian, Black African and African Caribbean people in designing better Dementia support.

SHORT STUDY TITLE / ACRONYM

New Title: InvolveD: Involving South Asian, Black African and African Caribbean people in designing better Dementia support.

PROTOCOL VERSION NUMBER AND DATE

Version 0.2 04.10.2024

RESEARCH REFERENCE NUMBERS

IRAS Number:	340269
SPONSORS Number:	Generated by the Sponsor. Enter if applicable
FUNDERS Number:	NIHR205153

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature:
....

Date:
....../....../......

Name (please print):
....

Position:
....

Chief Investigator:

Signature:
....

Date:
04.10.2024

Name: (please print): Dr Karan Jutlla
....

LIST of CONTENTS

GENERAL INFORMATION	**Page No.**
HRA PROTOCOL COMPLIANCE DECLARATION	i
TITLE PAGE	ii
RESEARCH REFERENCE NUMBERS	ii
SIGNATURE PAGE	iii
LIST OF CONTENTS	iv
KEY STUDY CONTACTS	v
STUDY SUMMARY	v
FUNDING	vi
ROLE OF SPONSOR AND FUNDER	vi
ROLES & RESPONSIBILITIES OF STUDY STEERING GROUPS AND INDIVIDUALS	vi
STUDY FLOW CHART	vii
SECTION	
1. BACKGROUND	1
2. RATIONALE	2
3. THEORETICAL FRAMEWORK	2
4. RESEARCH QUESTION/AIM(S)	3
5. STUDY DESIGN/METHODS	4
6. STUDY SETTING	7
7. SAMPLE AND RECRUITMENT	7
8. ETHICAL AND REGULATORY COMPLIANCE	10
9. DISSEMINATION POLICY	17
10. REFERENCES	18
11. APPENDICES	20
Appendix 1 – Project Gantt Chart	
Appendix 2 – Project Workflow	
Appendix 3 – Information Flyer	
Appendix 4 – Outline for CBPR Workshops in work package 3	
Appendix 5 – Interview Guide for work package 5	
Appendix 6 – Participant Information Sheet for work package 3	
Appendix 7 – Participant Information Sheet for work package 5	
Appendix 8 – Consent Form for work package 3	
Appendix 9 – Consent Form for work package 5	
Appendix 10 – Distress protocol	
Appendix 11 - Amendment History	

KEY STUDY CONTACTS

Insert full details of the key study contacts including the following

Chief Investigator	Dr Karan Jutlla, University of Wolverhampton. Tel: 07725111574 Email: K.Jutlla@wlv.ac.uk
Study Co-ordinator	N/A
Sponsor	
Joint-sponsor(s)/co-sponsor(s)	N/A
Funder(s)	National Institute for Health and Care Research, Research for Social Care Programme.
Key Protocol Contributors	Dr Michael Clark, London School of Economics and Political Science, Email: m.c.clark@lse.ac.uk Tel: o20 7955 6528 Dr Opinderjit Takhar, University of Wolverhampton. Email: O.Takhar@wlv.ac.uk Dr Manjula Patel, Murray Hall Community Trust. Email: manjulapatel@nhs.net Tel: 01902826513 Mrs Emaan Syed, University of Wolverhampton. Email: e.syed2@wlv.ac.uk Dr Gurpinder Lalli, University of Wolverhampton. Email: Glalli@wlv.ac.uk Dr Joshua Blamire, University of Wolverhampton. Email: j.blamire@wlv.ac.uk
Committees	N/A

STUDY SUMMARY

It may be useful to include a brief synopsis of the study for quick reference. Complete information and, if required, add additional rows.

Study Title	InvolveD: Involving South Asian, Black African and African Caribbean people in designing better Dementia support.
Internal ref. no. (or short title)	InvolveD

Study Design	This qualitative study is framed on a Community-Based Participatory Research (CBPR) approach which entails sharing power and resources and building trust with participating communities to examine questions of concern to them.
Study Participants	Study participants will include: • 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 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. • A South Asian, Black African or African Caribbean person who is familiar with dementia and resides in Wolverhampton or Sandwell. • They must be aged over 18 years to take part.
Planned Size of Sample (if applicable)	Minimum: 80, Maximum: 210
Follow up duration (if applicable)	There are three data collection phases throughout the project: Work Package 3 will involve 8-10 community-based participatory workshops across Sandwell and Wolverhampton (4-5 in each location) containing between 10-20 participants in each workshop (minimum total number of participants = 80. Maximum total number = 200). Work package 4 will involve four follow-up feedback events with participants who took part in work package 3 (2 in Sandwell and 2 in Wolverhampton) These will be participants who took part in the workshops in Work Package 3 and so there will be no new participants. Work Package 5 will involve one-to-one online interviews with 10 stakeholders to understand their experience of the participatory processes adopted in this project.
Planned Study Period	The project started on 1 May 2024 and will complete by 28 February 2025 (22 months). Data collection will not begin until the required ethical approvals have been received.

Research Question/Aim(s)	The aim of this project is to explore and evaluate a participatory approach to coproducing an inclusive place-based model to improve dementia support for people from South Asian, Black African and African Caribbean communities.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
National Institute for Health and Care Research (NIHR), Research for Social Care Programme	£266,138.00 For UK Higher Education Institutions (HEI), NIHR fund 80% of the HEI's Full Economic Costing.
University of Wolverhampton	The University of Wolverhampton will provide the additional 20% remaining in kind.

ROLE OF STUDY SPONSOR AND FUNDER

In providing the funding, the funder has approved the study and is not involved in any decision-making regarding the running of the project. The funder will be involved in dissemination of findings as described below, and approvals must be sought from the funder for all publicity and publications/dissemination of findings. In sponsoring this study, the University of Wolverhampton assumes overall responsibility for the initiation and management of this study.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

The project has a formulated Advisory Group and Patient and Public Involvement and Engagement (PPIE) Group who have asked to be called “Experts by Experience”. Regular meetings have been planned with both groups throughout the lifespan of the project (please see appendix one: Project Gantt Chart). The project team do not see themselves as the core group taking guidance by these groups but rather working in equal partnership with them.

Our Advisory Group members are:

Barbara Stephens, CEO, Dementia Pathfinders.

Maxine Groves, Dementia Commissioner, Sandwell Integrated Care Pathway.

Dr Nadia Wahid, Clinical Dementia Lead, Sandwell Integrated Care Pathway.

Deska Howe, Health and Well-being Manager, African Caribbean Resource Centre, West Bromwich.

Suffia Parveen, EDI Lead, Ethnic Minorities Council, Wolverhampton City Council.

Jo Turnbull, Re-enablement service, Wolverhampton City Council.

Dr Qusai Bharmal, Consultant Psychiatrist, Black Country Healthcare NHS Foundation Trust.

Our Experts by Experience are:

Mrs Bhagwant Sachdeva, South Asian person living with dementia.

Mrs Jagdish Kaur Brar-Orgill, South Asian former carer to mother living with dementia.

Ms Harjinder Kaur, South Asian retired community psychiatric nurse and community lead for ‘Satrang’ (South Asian community support group in Wolverhampton).

Mr Carl Case, African-Caribbean carer and Director of Culturally Appropriate Resources for people living with dementia.

We have a designated PPIE Lead (Emaan Syed) who will be responsible for meeting with this group and ensuring that their views are represented in project and Advisory Group meetings.

To date, both groups have been involved in the design of the study through a series of consultation meetings ahead of submitting the funding application. Both groups provided feedback on the distress protocol (appendix ten) and the Experts by Experience have reviewed all participant facing materials including the information flyer (appendix one), participant information sheets (appendix six and seven and consent forms (appendix eight and nine). The Experts by Experience also discussed the project title and the difficulties of translating “place-based support.” The new title was suggested by the group with their input regarding the project logo.

Further meetings have been planned with both groups to discuss recruitment strategies amongst their networks, the co-facilitation of the workshops and training needs for the Expert by Experience with planned meetings for them to discuss the interim analysis and dissemination plans.

PROTOCOL CONTRIBUTORS

Name and role	Job title and affiliation	Responsibilities within the project
Dr Karan Jutlla, Principal Investigator	Reader in Dementia Care and Inclusion, Director for the Centre of Applied and Inclusive Health Research, University of Wolverhampton	Dr Jutlla will co-lead the research with Dr Michael Clark, ensuring that all researchers are compliant with relevant university, ethical and governance procedures and with the NIHR award conditions. She will ensure that the different parts of this study work to schedule and that the project overall completes its objectives. Along with other members of the research team, she will co-lead work packages 1, 4 and 5 and provide support to the part time post-doctoral research fellow employed for this project. She will work closely with the Emaan Syed (Patient and Public Involvement and Engagement Lead) to deliver identified research training for

		the Experts by Experience (PPIE Group).
Dr Michael Clark, Join-lead	Associate Professorial Research Fellow, London School of Economics and Political Science	In addition to supporting Dr Jutlla, Dr Clark will co-lead work packages 1 and 5.
Dr Opinderjit Takhar	Associate Director of Research and Knowledge Exchange, Director for the Centre of Sikh and Panjabi Studies, University of Wolverhampton	Dr Takhar's research and public engagement is heavily community-focussed on the South Asian population of the midland's region, where she has extensive contacts to be utilised in this project. She will co-lead work package 2 and provide support to Emaan Syed.
Dr Manjula Patel	CEO, Murray Hall Community Trust, Sandwell.	Dr Patel has over 30 years' experience of engaging community members and working alongside them to design and develop community support. As the partnership lead for the community dementia service, she will make a valuable contribution to the research team. She will co-lead work packages 2 and 3.
Dr Gurpinder Lalli	Reader in Education for Social Justice and Inclusion, University of Wolverhampton	Dr Lalli's experience as a qualitative researcher in constructivist methodologies with ethnic minority communities makes him a valuable member of the research team. He will therefore co-lead work packages 5 and 6.
Emaan Syed	Lecturer for Social Care, University of Wolverhampton.	PPIE Lead and co-lead for work package 3.
Dr Joshua Blamire	Research Fellow and Human Geographer, University of Wolverhampton	Dr Blamire will contribute to work packages 2-5, ensuring that the concept of place is embedded and developed in the methods and helping to define the details of the participatory research approach and its evaluation.
Post-doctoral Research Fellow	To be appointed	Main duties include supporting the research team to carry out activities to ensure that the project meets key milestones.

KEY WORDS:

Dementia in ethnic minorities

Dementia inequalities

Participatory research methods

Place-based dementia support

Dementia in South Asian communities

STUDY FLOW CHART

Please refer to appendix one for the Project Gantt Chart.and apendix two for the Project Workflow.

STUDY PROTOCOL

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

1 BACKGROUND

Estimates suggest that there are 25,000 people living with dementia from ethnic minority communities in the UK, and this is expected to double by 2026 [1]. Such change means an increased need for appropriate dementia support and yet people from these communities are under-represented in dementia services [5,23], and present later to them [2,3,5,16, 23,24]. There is strong evidence of a lack of culturally and linguistically appropriate dementia support services for people from ethnic minority backgrounds [2,5,17,18,19,28]. Reasons for this include poor awareness from services about faith, cultural norms and dietary requirements, and community perceptions of services being remote and/or institutionally racist [17]. Barriers including stigma and lower dementia awareness suggest a need for tailored information and services for people from ethnic minority groups, but services are not equipped for this change [2]. Evidence suggests that ethnicity and experiences of services interact with socio-economic disadvantages to exacerbate inequalities in dementia care [35]. Consequently, many from ethnic minority groups seek to make use of a religion-based sense of community for support, avoiding statutory services [3,28]. Community and religious venues are more important to their sense of place, identity and belonging and may be preferred in a place-based conception of dementia support.

These communities and service providers are socially and temporally separated in understanding the issues. This lies, in part, with how dementia services are situated within complex, top-down organisations. The importance of ‘place' is increasingly recognized in local governance and policymaking, drawing attention to the social fabric of people’s communities and their collective experience of their environments [22]. Developing ‘place-based’ support involves partnership working to align the commissioning of statutory services with communities, local assets and shared understanding [26].

This research will explore an approach to coproducing a place-based model to improve dementia care for people from ethnic minority communities by engaging with South Asian, Black African and African Caribbean communities within Wolverhampton and Sandwell. These localities are excellent case sites, having high levels of ethnic diversity, interacting with significant socio-economic disadvantages, but with vibrant community assets. Given the lack of research on evaluating methods for coproducing dementia support, this project will examine the methodological approach adopted in this study to establish means of evaluating the longer-term impact of the approach. Doing so will inform more generalisable applications of the participatory approach adopted.

In working with the communities, the concept of ‘place’ will be used as an anchor for helping stakeholders to work together, encouraging them to conceptualise and plan more appropriate modes of support to help people living with dementia and their carers by sharing experiences and sense of place and belonging with their communities. This is central to the participatory approach adopted in this project – helping people to explore together a sense of place and to articulate what helps with their sense of belonging and living a good quality life with dementia.

Currently missing from the evidence base is a robust understanding of place, place shaping, support and interactions with dementia, such as in operationalising ‘dementia-friendly’ places. This includes crucial gaps in our understanding of and evidence for what people from different backgrounds who are living with dementia want from these concepts. A focus on place on its own, though, could lead to a top-down approach, or could result in placing responsibility on citizens to deal with issues on their own [7,30,34]. Hence, the methods in this project being framed by a participatory approach with different stakeholders. There is substantial evidence that working in a participatory way with communities to increase their control over decisions that affect them can improve wellbeing [20,25,29]. Stakeholders will be supported to develop a shared sense of what place means in this context and of the model of support to help people belong in that place and live well.

2 RATIONALE

Interventions to improve dementia care are required at several social levels, including individual, community and organisational, and their interfaces [21,32,35]. Evidence shows that interactions between individual and place-based factors are complex and affect wellbeing. Those relationships need considering when developing improvement interventions [22]. Promising approaches to improve synergies between individual and community wellbeing, and service/support and neighbourhood design exist [4,35]. This study will draw on learning from this developing evidence base to explore improvements for dementia support for people from ethnic minority communities. Connecting more holistically with individuals and groups, and their sense of place and support, is key to improvement.

Local government is central to place-shaping [21], bringing leadership, coordination, expertise, and funding [26]. In addition to the Care Act 2014 responsibilities, a wide range of local authority responsibilities are vital to place-shaping for improved dementia support, but all need to be enacted with others in the community based on shared intelligence and learning about communities and dementia. Place is important to dementia care in the concepts of ageing in place [27] and dementia-friendly communities [13], but it is not clear how to develop a holistic and inclusive place-based approach to coproducing dementia support to address inequalities.

The aim of this project is therefore 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.

3 THEORETICAL FRAMEWORK

The Community-Based Participatory Research (CBPR) approach [8] frames the methods in this study; it entails sharing power and resources and building trust with participating communities to examine questions of concern to them.

A realist-informed model of CBPR will be adopted to evaluate the participatory approach of the project [14]. Central to realist methodology is understanding that for social programs, participants responses are affected by underlying mechanisms of the system and the resources offered to them (cause and effect). Realist methodology understands that programs work differently in different contexts, considering the importance of ‘place’ as what might work well in one context may not succeed in another context. A realist evaluation of the CBPR approach would therefore explicate how the approach adopted in this study can be adapted for use in further studies involving different contexts – helping us understand the mechanisms required for the creation of inclusive dementia services. In the realist-informed evaluation of the CBPR approach we will be examining issues of power with participants to identify how well they were managed and the extent to which, for example, trust and reciprocity were developed throughout the project.

There is little empirical evidence about the impact of participatory approaches to improving dementia care, especially in the context of working with minority communities. This project would address that gap in our knowledge by adopting an existing realist understanding of how participatory methods work and applying it to this context to evaluate the impact of the participatory approach adopted to develop the place-based model of support. Realist approaches identify CMOs behind how an intervention operates. In this proposal, sets of Outcomes would relate to both the participatory approach, and defining and operationalising the place-based care model. In respect to the latter, we would begin to examine the impact of the place-based models of support coproduced by partners but would not be evaluating fully their impact on improving care in this project. It is intended that this will inform a subsequent study for a longer-term evaluation of the place-based model of support. This perspective is informed by the ongoing evolution of the Framework for evaluating complex interventions [31], i.e. understanding the dimensions of complexity and their interactions, how they would be operationalized in an evaluative project, what theoretical perspectives would be helpful to evaluation, and what methods and data would be most appropriate for answering the evaluative question.

4 RESEARCH QUESTION/AIM(S)

The aim of this project is to explore and evaluate a participatory approach to coproducing an inclusive place-based model to improve dementia support for people from South Asian, Black African and African Caribbean communities.

4.1 Objectives

i. to engage in and strengthen collaborative dialogue between stakeholders through participatory research to coproduce 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 and (place-based models of support).

4.2 Outcome

The outputs and anticipated impact from this study sit in the following overlapping levels:

i) Local place-based models of support and implementation plans for South Asian, Black Caribbean and African Caribbean communities – through our participatory approach in the two local authority areas we will coproduce with partners representing communities, statutory and third sector organisations, and people with lived experience and carers, local place-based models of better dementia support. As noted, these will be framed by what people with lived experience and carers are saying about what they need to help them feel part of their place and live well.

Our participatory approach and commitment to ongoing knowledge exchange throughout the project includes working with Advisory Group and our Experts by Experience to co-develop detailed dissemination and implementation plans to help ensure local decisionmakers work with local communities to operationalise the place-based models of support. The participatory nature of the project and the commitment already secured by the partners agreeing to join the Advisory Group will help to 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, as noted will be informed by existing realist analyses of participatory methods. We will use the existing CMO configurations as a starting point to analyse locally what participatory configurations work to coproduce the local coproduced plans. The place-based models of support will form some of the outcomes (Os) in the CMO configurations.

We will work with local partners to help them plan future participatory work together to continue to develop local place-based support for communities. However, we will also begin to disseminate the lessons from the participatory approach to other communities. We will do this cautiously, as the approach will require further empirical evaluation to understand CMO configurations in different contexts and to determine the longer-term value of the approach. We have extensive connections as a research team and will use these to begin discussions with national stakeholders about making the findings of the participatory approach to developing place-based models of dementia support available to wider communities beyond the study sites. This will include discussions about the best formats for materials to assist in this e.g., short reports, testimonies and narratives from the sites, training materials etc. We will informally engage with our networks early in the project to make sure they are aware of this and our plans for impact. As a team we will develop a stakeholder map to help us in this and share it with the Advisory Group to help identify where they can support this national engagement.

As the project nears an appropriate stage where we have emerging evidence and a more detailed analysis of the participatory approach and the CMOs, we will engage our networks more fully in beginning to think about national impact. We envisage this also being a time to engage national stakeholders and other sites in planning for further studies to help generalise the participatory approach.

Significantly, we see the project and the intertwined outputs related to i) the place-based models of support and ii) the participatory approach as laying foundations for future studies and a collaborative programme of research with the partners involved in this study. This will include longitudinal evaluation of the impact of the place-based model of support and further research to help generalise the participatory approach to other contexts of improving dementia support with communities.

We will also disseminate the research through academic routes, including at least one conference paper and two peer-reviewed journal papers. We will produce an accessible plain English summary of the findings of this project hosted on a project website by the lead applicant (Centre for Applied and Inclusive Health Research) which has a designated Living Well with Dementia research cluster and ensure that participants are aware of where they can access this information. An event will be held with key stakeholders and community members to share the findings of this project - highlighting what good place-based dementia support looks like and our evaluation of the participatory approach. This is an opportunity for us to highlight next steps and further gain stakeholder 'buy-in.' We will co-produce a short video with our Experts by Experience highlighting the main findings of this project and discuss with them, the most appropriate methods for dissemination. In particular, we would like to capture their involvement in this project and key learnings – highlighting the relevance and importance of patient and public involvement to both community members and researchers and statutory services.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

To achieve the aim and objectives of this project, 5 work packages (WP1-5) have been established across 22 months (duration of project). WP1 is concerned with establishing research governance and ethical approval, whilst WP2 concerns undertaking a scoping review to develop a conceptual map of community-engaged and place-based support for improving dementia care, including any evidence of processes underpinning models.

Data collection begins in WP3, which will involve community-based participatory research (CBPR) [8], i.e. an approach that is about more equitably distributing power in decision making process and developing shared ownership of decisions and related plans. We will use CBPR to organise workshops with stakeholders (local citizens and local health and social care practitioners and decision makers) to allow them to articulate their sense of place and dementia support needs. We will undertake 6-10 workshops across Sandwell and Wolverhampton consisting of 10-20 participants in each workshop. Participants include people affected by dementia from the target communities and people with personal and professional experiences of caring for a person with dementia from the target communities. Participants will be supported through a series of visual or pictorially based approaches to draw, map and articulate what belonging and good place-based dementia support means to them. This may mean, for example, exploration stage methods e.g. drawing maps of their community with key places and people for them; visioning stage tools such as drawing timelines of the future from now of the best possible future in which they feel they belong, and worse scenarios; and decision stage tools such as ranking priorities with stickers. Such methods are more engaging than those principally based on discussion or writing [12]. Using such creative methods was identified as important in a previous study [11] and is endorsed by the Advisory Group and Experts by Experience for this study as a suitable way of engaging with people, including those who may lack literacy skills.

Evidence from WP2 and guidance from the Advisory Group and Experts by Experience will inform the discussions and methods in these CBPR sessions. Community-appropriate venues in Sandwell and Wolverhampton will be used. Following the guidance for UK Standards of Public Involvement and the toolkit guidance for engaging people from ethnic minority groups in health and social care research [11], we will ensure that the venue is accessible to the communities and individuals we are engaging with. We will use purposive sampling to recruit participants via our networks, the Advisory Group and the Experts by Experience. The research team on this project have sound networks with the target communities and will be guided by the Advisory Group and Experts by Experience who also work closely with the target communities. Potential participants will be sent information about the project via an informal flyer which will be shared via social media channels, WhatsApp networks and community organisation networks (see appendix three: Information Flyer). We will aim for equal representation of people living with dementia, family carers, individuals from the target communities, and voluntary and statutory sector organisations. Each workshop will consist of 4 members of the research team and 2 co-facilitators from the Experts by Experience group should they wish to participate (training will be provided). Workshops will be organised into smaller group tables, facilitated by members of the team, providing small group and one-to-one support for participants to allow sufficient opportunity for everybody to contribute fully. Flexibility remains crucial for the workshops so that we can deliver them in a bespoke fashion to the group from a framework of the goals of the workshop and possible CBPR approaches. For example, some groups may prefer to articulate their thoughts via post-it notes whilst others may prefer to visually map what gives them a sense of belonging to live well with dementia. Appendix four provides a generic outline for the CBPR workshops.

WP4 will involve the analysis of the WP3 workshops using a constructivist grounded theory (CGT) approach [9]. From this initial place-based models of desired support for people living with dementia from the target communities in Sandwell and Wolverhampton will be produced. Four follow-up events for roundtable discussion of the initial models will be organised with participants from WP3. Roundtable discussions will allow a larger number of participants to give feedback in a structured and interactive way. During the workshops in WP3, we will ask participants whether they would like to attend the follow-up event. Details of this will be sent to those participants who expressed an interest. Whilst we anticipate between 20-40 participants in each follow-up event, we can be flexible to a degree with organising these events and the number involved in each one. We do not anticipate having to turn people down for the follow-up events as ‘drop out’ rates from earlier stages tend to be high. If we cannot accommodate anyone interested in participating, we will let them know why we can’t and thank them for their interest. Facilitated by the research team, discussions in the follow-up events will include comparing community perspectives with responsibilities for statutory stakeholders. We will also compare these with existing and potential community assets for dementia support for the target communities as identified from WPs 2 and 3. In line with CGT, this will be reviewed with the Advisory Group and our Experts by Experience, engaging them in the analysis of data from WP3. This will be in the form of two discussions with them about interim analyses as we form the findings and materials to present to the follow-up events. As with the participatory workshops, both these groups will also give input for the follow-up events. The Experts by Experience will also be given the opportunity to facilitate the participatory workshops with training provided by Dr Karan Jutlla, the Principal Investigator, and others in the team.

The final work package, WP5, will involve a review of the participatory approach adopted in this study to establish a framework for the longer-term evaluation of the impact of the approach. To do this, we will interview 10 stakeholders from the previous WPs, 1-2-1 online, to examine their sense of CBPR and coproduction processes used in this project, and how to evaluate their longer-term impact (see appendix five: Interview Guide). This would inform further studies by developing a more generalized approach to coproducing place-based dementia support. Participants will include 2 people from the Advisory group, 2 people from the Experts by Experience group and 6 people who participated in the workshops (WP3) and follow-up events (WP4). These will be a convenience sample, but we aim to cover both localities (Sandwell and Wolverhampton) and each minority ethnic group. We will manage consent as in previous stages of the research.

Community-Based Participatory Research [8] frames the methods in this study; it entails sharing power and resources and building trust with participating communities to examine questions of concern to them. Developed by Kathy Charmaz, Constructivist Grounded Theory (CGT) [9] sees both data and analysis as created from shared experiences and relationships with participants. It considers the perspectives and philosophical standpoints of participants and researchers to create a shared understanding of the study phenomena. It moves away from traditional grounded theories, positioning the researcher as a coproducer of the analysis. CGT offers flexible guidelines involving open-coding, diagramming, memo writing, and the use of ontological and ecological analysis tools to construct a theoretical rendering of the data. For the participatory workshops in work package 3, this will involve:

- Open coding (initial thoughts) the notes taken from the facilitators.
- Open-coding the visuals produced from the workshops – what ideas come to mind when looking at the images? What have people decided is important to their sense of wellbeing and where and how has this been positioned?
- Focussing codes: open codes will be grouped into focussed codes.

- Diagramming to understand the relationships between the focused codes.
- Memo writing to explicate those relationships and the key themes and concepts they are pointing towards.
- Ecological analysis to situate key concepts within an ecological framework [e.g. 10].
- Theoretical rendering of the data: visually demonstrating the patterned relationships between key concepts and themes to produce a conceptual map of place-based dementia support for people from South Asian, Black African and African Caribbean communities.

Crucial to CGT is consulting with participants to validate the analysis, i.e. the place-based models. Work package 4 will involve four follow up feedback events to present our ideas allowing for further amendments via roundtable discussions.

The Advisory Group and Experts by Experience will also be consulted about interim analysis for their input.

For the interviews in work package 5, we will use a thematic analysis adopted by Braun and Clark [6] which involves six steps:

1. Familiarization of data: interviews will be transcribed and read in full.
2. Generation of codes: similar to the process involved in CGT, the transcripts will be open coded with initial thoughts and ideas.
3. Codes will then be defined into themes.
4. Themes will be reviewed by re-visiting the transcripts and ensuring they are representative.
5. The significance of the themes will be determined against the project aims and objectives.
6. Reporting of findings as part of the dissemination activities.

6 STUDY SETTING

The study will engage with South Asian, Black African and African Caribbean communities within Wolverhampton and Sandwell of the West Midlands in the United Kingdom. These localities are excellent case sites, having high levels of ethnic diversity, interacting with significant socio-economic disadvantages, but with vibrant community assets.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1.1 Inclusion criteria

- 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 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.
- A South Asian, Black African or African Caribbean person who is familiar with dementia and resides in Wolverhampton or Sandwell.
- They must be aged over 18 years to take part.

7.1.2 Exclusion criteria

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

7.2 Sampling

7.2.1 Size of sample

The minimum number participants will be 80. The maximum number of participants will be 210.

There are three data collection phases throughout the project:
Work Package 3 will involve 8-10 community-based participatory workshops across Sandwell and Wolverhampton (4-5 in each location) containing between 10-20 participants in each workshop (minimum total number of participants = 80. Maximum total number = 200).

Work package 4 will involve four follow-up feedback events with participants who took part in work package 3 (2 in Sandwell and 2 in Wolverhampton) These will be participants who took part in the workshops in Work Package 3 and so there will be no new participants.

Work Package 5 will involve one-to-one online interviews with 10 stakeholders to understand their experience of the participatory processes adopted in this project.

7.2.2 Sampling technique

The sample size is indicative of a maximum number of participants that can be recruited. In work package 3 the research team will consult as widely as possible, drawing on participants from different South Asian communities, Black African and African Caribbean communities with a range of personal experiences and professional roles and experience in social, health and voluntary sectors. The calculations about sample size are therefore based on a pragmatic assumption about the team’s ability to recruit participants and to collect and analyse data.

7.3 Recruitment

The informational flyer stipulating details about the project, who is legible and who to contact (appendix three) is the only document to be used to advertise for participants. The research team on this project have sound networks with the target communities and will be guided by the Advisory Group and Experts by Experience who also work closely with the target communities. Our Experts by Experience work with a large network of the target communities within Sandwell and Wolverhampton through their community groups and have agreed to circulate the flyer amongst their networks. Our Advisory Group, who consist of health and social care professionals and commissioners within Wolverhampton and Sandwell have also agreed to do the same. The information flyer will be shared via a number of mediums including social media channels, WhatsApp networks, community organisation networks and in-person at community gatherings. The Chief Investigator, Dr Karan Jutlla, has developed dedicated social media pages (Facebook and Instagram) to support people to live well with dementia from ethnic minorities (@drkaranjutlla). The flyer will also be posted via these mediums.

7.3.1 Sample identification

Potential participants will be first approached by any one of the following members of the research team:
- The Chief Investigator, Dr Karan Jutlla - whose contact details are given on all participant-facing materials.
- The Joint Principal Investigator, Dr Michael Clark.
- Dr Opinderjit Takhar.
- Dr Manjula Patel.

The research team member will arrange for a conversation with the potential participant via a medium that suits them (i.e. over the telephone or an online meeting) to discuss what the project involves, detailing the information in the Participant information sheet (see appendix five and appendix seven). In our conversations about the project with a person we will consider that they can i) understand the information about the project, ii) retain it long enough to make a decision, iii) weigh up the information to make a decision, and iv) communicate their decision about participating. This process will apply for all stages of data collection and will be ongoing throughout the research process. If researchers feel the person loses capacity in the process, we will consider how to tactfully proceed so as not to upset the person and their data from that point will not be included in the analysis. In line with the toolkit for engaging people from ethnic minority communities on health and social care research [11] participants will be provided a one-off £40 shopping voucher for taking part in the research.

7.3.2 Consent

Participants (including those who have a diagnosis of dementia) are only eligible for the study if they have the capacity to provide consent. It is to be assumed that all potential participants (including those with dementia) will have the capacity to consent to participate in the research study. Following the Code of Practice (2007) for Mental Capacity, the two-stage test for capacity to provide consent should be adopted. Members of the research team have experience of undertaking research with people who have dementia (Dr Karan Jutlla, Dr Michael Clark, Dr Opinderjit Takhar and Dr Manjula Patel). During the initial meeting, they will:

1. Ask the potential participant if they have a diagnosis of dementia or an impairment of the mind or brain, or any other disturbance that might potentially affect the way their mind or brain works.
2. Assess whether any impairment or disturbance such as dementia means that the person is unable to consent to take part in the study. This includes addressing four issues:
    - Does the person have a general understanding of the research process, the decision they need to make and why they need to make it?
    - Does the person have a general understanding of the likely consequences of making, or not making, this decision?
    - Is the person able to understand, retain, use and weigh up the information relevant to this decision?
    - Can the person communicate their decision either verbally or non-verbally?

All participants will be provided copies of the participant information sheet (appendix six and appendix seven) prior to giving consent and are to be given the opportunity to ask any questions. Consent will be re-confirmed at the start of the data collection workshops, where participants will be asked to sign or initial the consent form before the workshop begins (see appendix eight and appendix nine).

The research team members responsible for gaining consent will also:

- Be flexible with the time when information is being given, including the potential to talk online or by telephone more than once to discuss the research.
- Assess the individual communication skills/abilities of the person and ensure information is given in a manner that is accessible to them. Where necessary a member of the research team should translate the information on the participant information sheet and consent form or ensure that an interpreter has been made available to do so.

Possible visual impairments have also been accommodated for all patient facing materials have been designed on different coloured paper (pale yellow paper and black bold ink in some cases), 14-point font sizes with 1.15 line spacing.

It will be clearly explained to participants that they are free to withdraw from the study without giving any reason for a two-week period after data has been collected. If a participant does withdraw, their agreement will be sought to keep any data that has already collected from them up to their withdrawal. However, if they prefer, they are free to ask the team to delete this data. All data is to be anonymised. The notion of 'process consent' is to be adopted, where it is understood that at any point during the workshop, follow-up feedback event or interview, or for a two-week period after this, then consent can be suddenly and without warning, withdrawn.

8 ETHICAL AND REGULATORY CONSIDERATIONS

This study has been designed with several ethical considerations in mind:

Confidentiality:

As the workshops are in person and participatory, it will not be possible to maintain the confidentiality of participants from each other. However, participants identity will not be revealed in the write-up of the findings or subsequent publications. Furthermore, data and files will be kept in line with the Data Protection Act, General Data Protection Regulation (2018) guidance and the University of Wolverhampton's Research Data Management Policy. Once transcribed, the interview video recordings will be erased. Digital and electronic data (notes, pictures, transcripts of interviews, and annotations of recordings) will be scanned and kept in a password-protected University of Wolverhampton computer and all paper copies destroyed. It is only if a participant discloses that they or others may be at risk of harm, that the relevant authorities will be notified.

Consent:

This study will involve speaking with people with personal experiences of dementia (either because they have a diagnosis of dementia, or they have provided care for someone who is living with dementia). The research team responisble for gaining consent will ensure that all participants have capacity to take part in the research and will apply the principles of the 2005 Mental Capacity Act, to support and assess capacity where concerns are raised. This will be done informally as part of the process of gaining written consent. Whilst discussing the research its rationale and implications with potential participants, the designated research team members will ensure that the person has the capacity to decide for themselves whether or not to take part in the research, including that they: understand the purpose and nature of the research; understand what the research involves, its benefits (or lack of benefits), risks and burdens; understand the alternatives to taking part; are able to retain the information long enough to make an effective decision; and are able to make a free, informed choice. Participants will be required to provide written consent at the outset of the workshop by signing a consent form (appendix eight). As cognitive abilities can fluctuate, we will monitor capacity over the course of the research appointment and see informed consent as an ongoing process ensuring that people with a diagnosis of dementia understand the purpose of the research and their participation through regular check-ins. Members of the research team are experienced in conducting research with people living with dementia and assessing cognitive capacity.

Power balance:

Power is one of the crucial ethical and practical considerations in participatory research. Articulating different perspectives and exploring synergies and tensions is a goal of participatory approaches. For it to work it requires mutual respect, rapport and a sense of shared connection amongst participants to enable necessary and critical dialogue. The research team will continue to reflexively develop the partnerships and participatory orientation of this project to ensure that they carefully manage issues of power. They will consider evidence, of the ongoing trust pathways and the ripple effects of power-trust building-synergy interactions throughout the project to develop a healthy participatory environment. This project was developed in collaboration with statutory and community groups in Sandwell and Wolverhampton. We believe we have established a good foundation for us to be able to openly discuss and manage these issues. Sense check points are planned throughout the project to allow participants in the process to review, and if necessary, challenge, the sense of place and emerging model of support. Early meetings whilst writing the grant proposal and as the project commenced have helped build rapport and trust with the Advisory and Experts by Experience Groups, helping ensure they feel able to speak freely about plans for the project as we operationalise workstreams. This includes the overall governance of the project but also within and at the end of the workshops and feedback events detailed in work package 3 and 4. Our planning for the workshops in work package 3 will be undertaken fully aware of the need to address issues of power. The team will, for example, choose with the Advisory group and Experts by Experience community-based venues within which public participants will feel comfortable and to which members of the research team and colleagues from statutory organisations will be invited. In line with the principles for Equality, Diversity and Inclusion (EDI) and the toolkit guidelines [10], we will ensure that the venue for the workshops is accessible in terms of local links to public transport, car parking facilities and for is accessible for wheelchair users. We will consider any other reasonable adjustments any individual may need. Whilst the project is concerned with the experiences of those living with dementia from South Asian, Black Caribbean and African Caribbean backgrounds, this project will not exclude participants from other ethnicities who bring with them knowledge and insight about the target communities. For example, informal carers who have provided/are providing support to a person living with dementia for the target communities. In running the workshops and feedback events, the team will draw on the extensive experience of the research team in developing partnerships and collaborative working with the communities we are engaged with. This experience dates back many years – e.g. the ‘Twice A Child’ projects [15] conducted over the last 20 years, and members of the team [Dr Karan Jutlla, Dr Michael Clark, Dr Opinderjit Takhar, Dr Manjula Patel and Emaan Syed] are already working with many of these communities, including on the issue of dementia.

It is important to ensure community members are given voice during the workshops and feedback events and that enough time is dedicated to supporting them to feel confident to do this. Working alongside members who are heavily involved in community work (including members of the Advisory group and our Experts by Experience) the team will ensure that participants feel well informed and empowered to engage and participate. The team will also engage the Advisory group and Experts by Experience in discussions about the analysis of the materials from the workshops. A follow-up event in work package 4 provides a further opportunity for people to participate in defining the place-based model of support. Throughout the project the team, including community partners, would be reflexive specifically concerning these issues and how well they are being addressed and what might be done to improve issues of power through all stages of the project. This includes being reflexive concerning their own privileged positions as the research team.

Distress:

It is possible that discussing dementia support needs may be distressing for people who had had negative experiences of living with and/or caring for a person with dementia, and/or for the research team. In such scenarios, the protocol for responding to distress must be followed (see appendix ten: Distress Protocol).

Talking to people who do not have English as their first language:

Participants will include people from South Asian, Black African and African Caribbean communities meaning that some may not be able to speak and understand English. To help build rapport, members of the research team on this project are experienced qualitative bi-lingual researchers and will facilitate the workshops. The team are fluent in Punjabi (Dr Karan Jutlla and Dr Opinderjit Takhar), Hindi (Dr Opinderjit Takhar and Emaan Syed), Gujarati (Dr Manjula Patel), Urdu (Dr Opinderjit Takhar and Emaan Syed) and Mirpuri (Emaan Syed). They will ensure that they have a Bengali interpreter should any participants speak only this language. Furthermore, our Experts by Experience, Harjinder Kaur and Carl Case have also agreed to support in facilitating the workshops. Carl Case is fluent in Jamaican Patois and some African languages. Where required, the team will source an interpreter for any languages not spoken by the team. Both Harjinder Kaur and Carl Case have extensive experience in supporting the target communities. It is important to offer an opportunity for any invited participant to the workshops to meet with a suitable person or persons either from the research team or a community organisation to discuss the workshops and prepare for them - for example, what they can expect and what they would need to feel able to contribute openly and fully. As per the toolkit guidance for engaging people from ethnic minority backgrounds in health and social care research [11], we will provide an incentive for people living with dementia, carers, and members of the public to attend (£40 shopping voucher) and refreshments/lunch. We will also be using visually/pictorially based methods to allow participants to articulate what good dementia support looks like in the place that they reside. The consent form (appendix eight) and the participant information sheet (appendix six) will be translated into participants' language by a member of the research team or an interpreter if required.

Risks and Benefits:

It might be possible that a participant finds talking about their or a loved one's dementia journey upsetting. If they become upset, they have the choice to pause or not to continue with the discussion. They may stop their involvement at any time. They will receive a list of support services they may find useful, and the distress protocol must be followed (appendix ten).

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

The risks and benefits of participating in this research are detailed for participants in the participant information sheets (appendix six and seven).

8.1 Assessment and management of risk

A distress protocol has been developed for the research team to deal with issues where a participant or a member of the research team may become distressed (appendix ten). However, as stipulated in the participant information sheets (appendix six and seven), should a participant disclose that they or others may be at risk of harm, the relevant authorities will be notified. Prior to doing so, the team member concerned will arrange an urgent de-brief with the Chief Investigators of the project who will notify the relevant authorities.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

Before the study engages in any recruitment or data collection, a favourable opinion will be sought via the relevant REC via an IRAS application, including approval of the study protocol, distress protocol, consent forms, participant information sheets, and informational flyer to advertise for participants.

For NHS REC reviewed research

- Substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.
- All correspondence with the REC will be retained.
- It is the Chief Investigator's responsibility to produce the annual reports as required.
- The Chief Investigator will notify the REC of the end of the study.
- An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.
- If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.
- Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

Regulatory Review & Compliance

Before participants are recruited into the study, the Principal Investigator, Dr Karan Jutlla will ensure that all ethical approvals required are in place. For any amendment to the study, the Principal Investigator, in agreement with the sponsor will submit information to the appropriate body in order for them to issue approval for the amendment.

Amendments

The procedure for amending this protocol will be as follows:

- The Principal Investigator (PI), Dr Karan Jutlla, will approach the sponsor for support with the amendment and will discuss with the sponsor and research team whether the amendment is substantial or non-substantial. Where required the PI will submit the required documentation regarding amendments for the review of the Sponsorship Sub Committee.

- If approval is granted, the sponsor will submit a valid notice of amendment to the REC for consideration. The team will carefully review organisational information for both trusts and secure approval from local R&D officers for the proposed change if this is required. Version numbers will be used to track the latest version of the protocol, and this will be documented.
- The PI will ensure the necessary arrangements are in place to implement amendments.

8.3 Peer review

The research team are confident that suitable peer review has been undertaken in that it has been independent, expert and proportionate. The funding body has reviewed this proposal favourably. The protocol has also been reviewed within the School/Research Centre of the University of Wolverhampton, by the ethics subject panel for health, and by the Sponsorship Sub-Committee of the University of Wolverhampton.

8.4 Patient & Public Involvement

The “Experts by Experience” group have been formulated to guide all stages of the research project, ensuring that our methods are inclusive of those affected by dementia from South Asian, Black African and African Caribbean communities. This group have been involved in developing materials for the ethics application, including the change of project title and the logo to be used. Regular meetings have been scheduled with the group to help so that they can contribute towards decision making and have the option to facilitate the community-based participatory workshops. They will receive training and other support from the Principal Investigator, Dr Karan Jutlla to help them with this. Interim analysis will also be shared with them for their peer review. Furthermore, the participants who attended the workshops will have an opportunity to feedback on the development of the analysis as stipulated in the methods of the study. The Experts by Experience will be involved in the development of a short video towards the end of the project to share their involvement with the project and will guide on appropriate dissemination channels to reach the target communities. The project has a designated Patient and Public Involvement and Engagement Lead, Emaan Syed who will:

- Act as a single point of contact for the group.
- Organise meetings and provide feedback to the research team and Advisory Group.
- Ensure that their involvement is aligned to UK Standards for Public Involvement.
- Communicate to them the project status, providing feedback on their activities and their impact.
- Synthesise results and conclusions of their activities and feedback to the research team.
- Identify research training needs for their involvement in the CBPR workshops - which will be delivered by Dr Jutlla.
- Ensure that their time is appropriately allocated and recorded.

8.5 Protocol compliance

Accidental protocol deviations can happen at any time. They will be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

8.6 Data protection and patient confidentiality

All investigators must comply with the requirements of the Data Protection Act 2018 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles.

Only members of the research team and authorised transcribing services should have access to the data.

Data minimisation will be achieved by collecting minimal personal data. Personal data collected should include only the person's name and a contact number and/or email address.

The workshops will involve notetaking and images of the conceptual maps/information generated. The interviews will be recorded via the utilised platform (e.g. Microsoft Teams or Zoom).

Data and files will be kept in line with the Data Protection Act, General Data Protection Regulation (2018) guidance and the University of Wolverhampton's Research Data Management Policy. Once transcribed, the interview video recordings should be erased. Digital and electronic data (notes, pictures, transcripts of interviews, and annotations of recordings) should be scanned and kept in a password protected University of Wolverhampton computer and all paper copies destroyed. Any information that reveals the identity of the participants must not be included in the write up or dissemination of the research.

Participants' personal details (including their names and addresses) will only be used to maintain contact with participants. This will be stored separately from transcriptions and kept in a separate file on a password-protected University of Wolverhampton computer.

Access to data will be limited to quality control, audit, and analyses. Data shared between sponsor and coinvestigators will be de-identified to minimise breach of confidentiality.

All data will be securely held in a password-protected, encrypted format on the University of Wolverhampton OneDrive and will be retained for 10 years post-study completion in line with the university's regulations. Post study completion, the password will be known only to the Principal Investigator, Dr Karan Jutlla. This is in line with the University of Wolverhampton's regulations.

8.7 Indemnity

The University of Wolverhampton, as sponsor, shall provide indemnity and insurance to meet the potential legal liability of the sponsor for harm to participants arising from the design, management, or conduct of the research

8.8 Access to the final study dataset

Only the contributors detailed in this protocol will have access to the final dataset or professional transcribing services authorised by the University of Wolverhampton.

9 DISSEMINIATION POLICY

9.1 Dissemination policy

- The University of Wolverhampton owns the data arising from the study.
- On completion of the study, the data will be analysed and tabulated and a Final Study Report that will be submitted to the Funders and the relevant ethical bodies.
- A publications plan will be developed and agreed amongst the research team, detailing authorship and writing responsibilities.
- NIHR is to be acknowledged within all publications and presentation materials.
- Participants will be asked if they would like to be notified of the outcome of the study, either by provision of the publication, or via a specifically designed newsletter, presentation etc.
- Dissemination activities and channels are to be discussed and agreed with the Advisory Group and the Experts by Experience.

9.2 Authorship eligibility guidelines and any intended use of professional writers

Authorship on the final study report will include members of the research team. Authorship on any subsequent publications can include members of the Advisory Group and Experts by Experience.

As per the contract between the Sponsor and the Funders:

The Contractor (Sponsor) must notify the Authority's (Funder) Representative of any intention to issue a press release (whether it will be issued by the Contractor or any other party) at least three (3) business days prior to any press release issued by it or on its behalf, directly related to the Research or Foreground IP, Arising Know How or Research Data or of matters arising from such Research. The Contractor shall send one draft copy of the proposed press release to the Authority's Representative at least three (3) business days before the date intended for release. For the avoidance of doubt this obligation shall continue in full force and effect following expiry of the Research Period.

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11. APPENDICIES

Appendix 1 – Project Gantt Chart

Appendix 2 – Project Workflow

Appendix 3 – Information Flyer

Appendix 4 – Outline for CBPR Workshops in work package 3

Appendix 5 – Interview Guide for work package 5

Appendix 6 – Participant Information Sheet for work package 3

Appendix 7 – Participant Information Sheet for work package 5

Appendix 8 – Consent Form for work package 3

Appendix 9 – Consent Form for work package 5

Appendix 10 – Distress protocol

Appendix 11 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

Appendix 1 Project Gantt Chart

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

	2024								2025												2026	
	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb
Project Team Planning Meetings		🟩		🟩	🟩	🟩			🟩		🟩		🟩		🟩		🟩		🟩			🟩
Work Package 1: Establishing & mobilisation (KJ, MC)	▨	▨	▨	▨	▨																	
Establish research governance and ethical approval	🟦	🟦	🟦	🟦	🟦																	
Formally convene the Advisory Group (AG) and establish Terms of Reference (ToR) (commencing ongoing knowledge exchange)			🟧																			
Formally convene the Patient & Public Involvement and Engagement Group (PPIEG) and establish ToR (commencing participation and ongoing knowledge exchange)			🟪																			
Work Package 2: scoping models of community-engaged dementia support (MP, OT)			▨	▨	▨																	
Rapid scoping review			🟦	🟦	🟦																	
Share review findings with AG &PPIEG – discuss methods of data collection & recruitment for community based participatory (CBPR) workshops					🟧 🟪																	
Work Package 3: CBPR Workshops (MP, ES)						▨	▨	▨	▨	▨	▨											
CBPR Workshops: finalise methods for data collection, recruitment and appropriate venues						🟦																
CBPR Workshops: recruitment (invitations to participate and offers of personal support for them)							🟦	🟦														
CBPR Workshops: research training for PPIEG to participate								🟪														
CBPR Workshops: data collection									🟦	🟦	🟦											
Work Package 4: CBPR Analysis & feedback (GL, KJ)												▨	▨	▨	▨	▨	▨					
Follow-up feedback events: organise venues and send invitations												🟦										

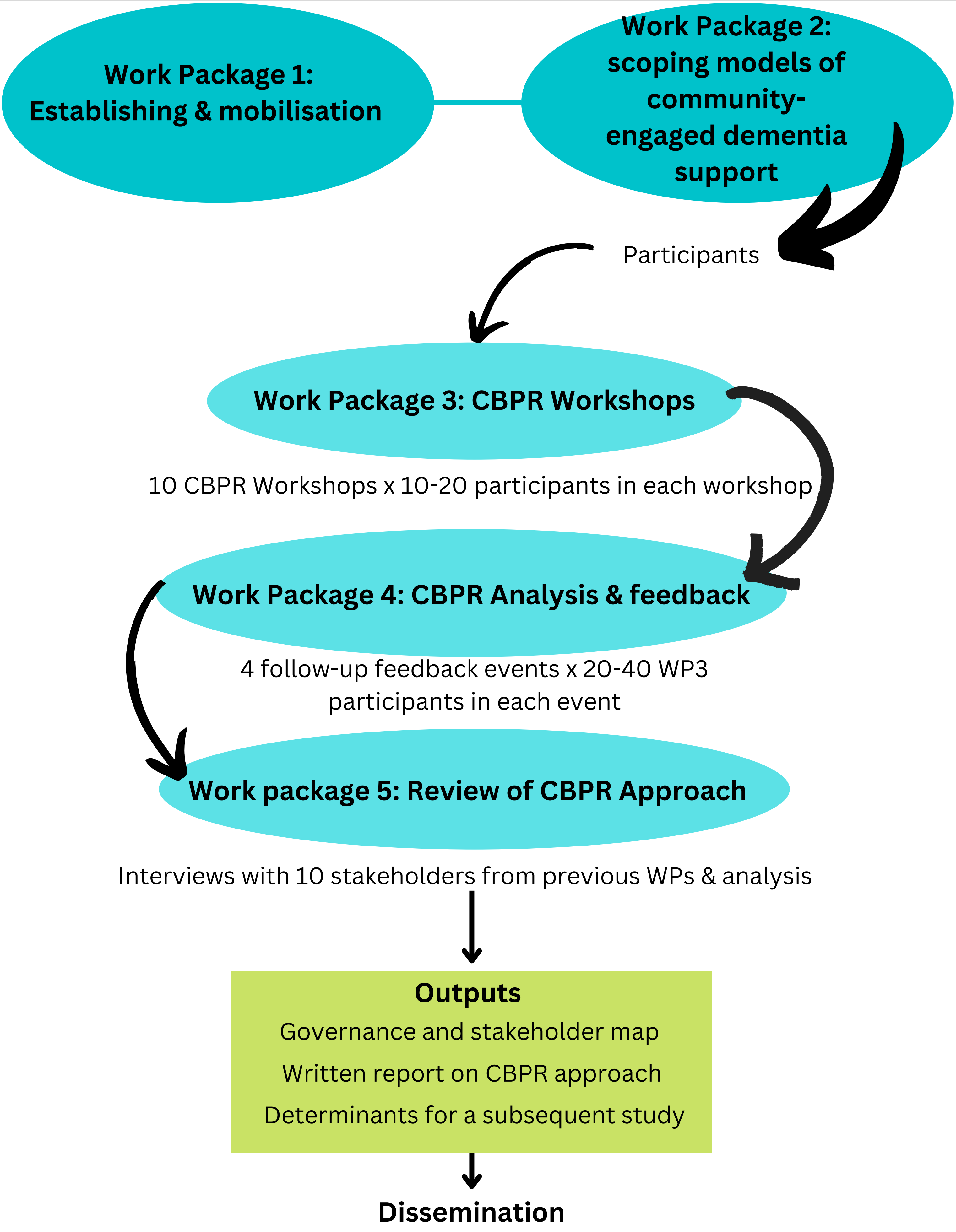
Appendix 1 Project Gantt Chart

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

CBPR Workshop analysis												🟦	🟦	🟦								
Ongoing knowledge exchange with AG and PPIEG to review interim findings, refine initial place-based models of support and plan the follow-up feedback events													🟧	🟪								
Follow-up feedback events: dissemination and further feedback from WP3 participants															🟦	🟦	🟦					
Analysis from feedback events: including ongoing knowledge exchange with AG and PPIEG to analyse feedback and refine the place-based models of support, local plans for implementation and ongoing local engagement and knowledge exchange to support implementation															🟦	🟦	🟦					
Work package 5: Review of CBPR Approach (GL, MC)																		▨	▨	▨	▨	▨
Interviews with stakeholders from previous WPs – informed by the realist understanding of participatory research and CMOs																		🟦				
Analysis of interviews/realist evaluation																			🟦	🟦		
Feedback to AG and PPIEG																			🟪	🟧		
PPIEG: Video production (pre-production: content & filming)																				🟪		
Video post-production (editing)																					🟦	
Write-up/produce stakeholder map and governance map																					🟦	🟦
Produce report on CBPR approach																					🟦	🟦
Final meeting with AG and PPIEG group to establish determinants for a subsequent study																						🟧 🟪
Dissemination																						🟦

Appendix Two: Project Workflow

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



Work Package 1: Establishing & mobilisation

Work Package 2: scoping models of community-engaged dementia support

Participants

Work Package 3: CBPR Workshops

10 CBPR Workshops x 10-20 participants in each workshop

Work Package 4: CBPR Analysis & feedback

4 follow-up feedback events x 20-40 WP3 participants in each event

Work package 5: Review of CBPR Approach

Interviews with 10 stakeholders from previous WPs & analysis

Outputs

Governance and stakeholder map

Written report on CBPR approach

Determinants for a subsequent study

Dissemination

InvolveD

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

Would you like to be part of an exciting project to help shape the future of dementia support for South Asian, Black African and African Caribbean communities?

Are you?
- 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 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?
- A South Asian, Black African or African Caribbean person who is familiar with dementia and resides in Wolverhampton or Sandwell?

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

If you answered yes to any of the above, and are interested in knowing more, please contact Dr Karan Jutlla on: XXXXX

Funded by the 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.

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.

UNIVERSITY OF WOLVERHAMPTON

THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

MURRAY HALL COMMUNITY TRUST

FUNDED BY NIHR | National Institute for Health and Care Research

REF: NIHR205153 Invitation Flyer v2 22.08.2024

InvolveD

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

Work Package 3 Participatory Workshop Outline, v1 (11/07/2024)

Indicative time: 10:00-14:00

10:00-10:30 30 minutes	Registrations, Refreshments, Welcome and Introductions Outline of the session	Ensure everyone has signed the consent form
10:30-10:50 20 minutes	Ice breaker	
10:50-11:00 40 minutes	Breakout session 1 (2-4 groups of 5 participants) *Current state - mapping the community to identify important places and people for belonging; identifying preferences and challenges for belonging in place.*	Each group will be led by a facilitator to capture the groups ideas and thoughts
11:00-11:20 20 minutes	Comfort break	
11:20-12:00 40 minutes	Breakout session 2 (2-4 groups of 5 participants) *Visioning - identifying the ideal state and required support for belonging in place in the future*	
12:00-12:45 45 minutes	Lunch (provided)	
12:45 – 13:30	Breakout session 3 (2-4 groups of 5 participants) *Prioritising - identifying priorities for development in community support*	
13:30-14:00 30 minutes	De-brief and close	
Equipment: Flip charts, markers, flip chart stand, post it notes, drawing-art materials (crayons, felt-tips, pencils, erasers)		

InvolveD

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

Work Package 5 Interview guide, v1 (11/07/2024)

Introduction

Thank you for agreeing to take part in this interview. It has been great to have your involvement in this project. As you are aware, one of the main aims of this project is to understand our community based participatory research approach and coproduction processes used in this project.

Could you please briefly outline your role and connection with this project.

Could you please tell me your initial thoughts about the participatory nature of this project?

Can you tell me what you think has worked well?

- Probe: Think about the benefits of the methods used

Can you tell me what you think could have been done better?

- Probe: Think about certain aspects that you felt weren't working

The InvolveD Study

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

Work Package 3 Participant information sheet, V3, 03.10.2024

Study Lead and Host

UNIVERSITY OF WOLVERHAMPTON

Joint Lead

THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

Collaborating Organisation

MURRAY HALL
COMMUNITY TRUST

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 authroities. 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/

CONTACT

Dr Karan Jutlla (Project Lead)

Telephone: To be added
Email: K.Jutlla@wlv.ac.uk
Address: Office: WA206
Faculty of Education, Health & Wellbeing
University of Wolverhampton, Gorway Road, Walsall. WS1 3BC

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 XXX committee on XXXXXX.

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

Or

The University of Wolverhampton’s Research Integrity Manager - Miss Jill Morgan. Email: 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/

The InvolveD Study

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

Work Package 5 Participant information sheet, V3, 03.10.2024

Study Lead and Host

UNIVERSITY OF WOLVERHAMPTON

Joint Lead

LSE
THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

Collaborating Organisation

MURRAY HALL
COMMUNITY TRUST

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 share your experiences of being part of this study so that we can understand the collaborative nature of this project and what worked well/hasn’t worked so well.

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 would like to understand your sense of Community Based Participatory Research and coproduction processes used in this project, and how to evaluate their longer-term impact. This would help inform further studies by developing a more generalized approach to coproducing place-based dementia support.

Who can take part?

We would like to speak with key stakeholders who have been part of our previous work packages, including members of the Advisory Group.

What do I have to do?

You will be invited to take part in an online 1-2-1 interview via Microsoft Teams or Zoom. With your permission, the interview will be recorded and will last between 30-45 minutes.

What will be done with the information?

Your interview will be transcribed and analysed alongside other interviews to help us identify key themes. This will form part of the project report, publications and presentations 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 interview. 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 Carribbean communities who have been tradtionally under represented and under served in dementia support services.

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 authroities. 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 the interview, 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/

CONTACT

Dr Karan Jutlla (Project Lead)
Telephone: To be added
Email: K.Jutlla@wlv.ac.uk
Address: Office: WA206
Faculty of Education, Health & Wellbeing
University of Wolverhampton, Gorway Road, Walsall. WS1 3BC

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 XXX committee on XXXXXX.

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:

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Or

The University of Wolverhampton's Research Integrity Manager - Miss Jill Morgan. Email: 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/

The InvolveD Study

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

InvolveD

Work Package 3 Consent Form V3, 03.10.2024

Study Lead and Host

UNIVERSITY OF
WOLVERHAMPTON

Joint Lead

LSE
THE LONDON SCHOOL
OF ECONOMICS AND
POLITICAL SCIENCE

Collaborating Organisation

MURRAY HALL
COMMUNITY TRUST

The InvolveD Study

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

PARTICIPANT CONSENT FORM Work Package 3

This consent form will have been given to you with the Work Package 3 Participant information sheet, V3, 03.10.2024. Please ensure that you have read and understood the information contained in the Information Sheet and asked any questions before you provide your consent to take part in this study. **If you have any questions please contact a member of the research team, whose details are set out on the Information Sheet**

To take part in the group discussion, please initial the following boxes where you agree:

I have read and understood the information in the Participant Information Sheet which I have been given to read or has been explained to me.	☐
I have been given the opportunity to ask questions about the study.	☐
I have had my questions answered satisfactorily by the research team.	☐
I agree that anonymised quotes, notes and drawings from the group discussion may be used in the final report, publications and presentations of this study.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason.	☐
I understand that my anonymised data will be retained for 10 years post-study completion on a password-protected University of Wolverhampton One Drive.	☐
I agree that my contact details may be passed to other members of the research team so that they can contact me to discuss taking part in other aspects of this project.	☐
I agree to take part in the research.	☐

Participant	**Researcher**
PRINT NAME:	PRINT NAME:
Signature:	Signature:
Date:	Date:

The InvolveD Study

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

Work Package 5 Consent Form 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

PARTICIPANT CONSENT FORM Work Package 5

This consent form will have been given to you with the Work Package 5 Participant information sheet, V3, 03.10.2024. Please ensure that you have read and understood the information contained in the Information Sheet and asked any questions before you provide your consent to take part in this study. **If you have any questions please contact a member of the research team, whose details are set out on the Information Sheet.**

To take part in the interview, please initial the following boxes where you agree:

I have read and understood the information in the Participant Information Sheet which I have been given to read or has been explained to me.	☐
I have been given the opportunity to ask questions about the study.	☐
I have had my questions answered satisfactorily by the research team.	☐
I agree that anonymised quotes from the interview may be used in the final report, publications and presentations of this study.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason.	☐
I agree to the online interview being recorded.	☐
I understand that my anonymised data will be retained for 10 years post-study completion on a password-protected University of Wolverhampton One Drive.	☐
I agree that my contact details may be passed to other members of the research team so that they can contact me to discuss taking part in other aspects of this project.	☐
I agree to take part in the research.	☐

Participant	**Researcher**
PRINT NAME:	PRINT NAME:
Signature:	Signature:
Date:	Date:

PROTOCOL FOR WORKING WITH PARTICIPANTS WHO ARE DISTRESSED

This project involves a data collection process that addresses what may be sensitive issues for some participants. Asking participants to consider what good dementia support includes may touch upon negative experiences of accessing support including experiences of racism in health and social care services. Data collection will occur in face-to-face workshops involving group discussions led by facilitators. It is possible that some participants may become distressed during this process. It is important, therefore, that we respond to any concerns or signs of distress sensitively and appropriately.

1. Data collection will be conducted by the research team, all of whom are experienced dementia researchers. Where data collection involves less experienced researchers (e.g. a research fellow or members of the Patient Involvement and Engagement Group as co-facilitators), then more experienced members of the research team will provide additional support, supervision and training.

2. During workshops one member of the research team will have a specific responsibility to monitor the discussions to watch for potential signs of distress. If a participant appears to become distressed during a workshop, then this researcher will offer to speak with the participant in a quiet space. They will offer the participant the option of ending their involvement in this part of the data collection process and ensure that they are supported afterwards, offering debrief information.

3. If a participant appears to become distressed during a one-to-one interview, then the researcher will interrupt the research process, pausing the recording and provide appropriate emotional support to the participant. They will offer the participant the option of ending or suspending the data collection and ensure that they are supported afterwards, offering debrief information.

4. In the event of the participant becoming distressed after data collection has finished, the researcher will offer appropriate emotional support and debrief information.

5. A member of the research team will also assess any additional needs they may require and signpost them to appropriate support within their local area. We will have a directory of dementia services at hand for Sandwell and Wolverhampton and will encourage them to inform their GP if the concern warrants medical or psychological attention. They will ask permission to follow-up the participant again within 48 hours to

continue to ensure their well-being. Dr Manjula Patel is CEO of Murray Hall Community Trust in Sandwell and is a co-applicant. She will follow up with anyone who may benefit from the charity's services. Harjinder Kaur is lead for DOSTI (Dementia and Older people's Support, Training and Information) in Wolverhampton. She will follow up with anyone who may benefit from this community initiative in Wolverhampton.

6. All participants will be provided with a debrief sheet at the end of data collection. This will have contact details for the research team as well as information about appropriate local services (e.g., the Wolverhampton Information Network - http://win.wolverhampton.gov.uk/kb5/wolverhampton/directory/home.page) and relevant phone numbers of dementia specific organisations and helplines.
7. *Reporting and review*. After the immediate distress has been resolved, a member of the research team will initiate an Adverse Event report. This will be reviewed by one of the study Chief Investigators within 24 hours following the standard operating procedures for adverse events.
8. *Supporting the research team:* The Chief Investigators on this project will ensure that the research team are supported and if they, or the team, feel distressed at point, they will ensure regular de-briefs and be encouraged to contact their employers counselling support.