# Understanding the support needs of African and African-Caribbean people living with dementia, their care partners and families and the impacts of delayed support: identifying inclusive strategies to facilitate timely and culturally appropriate social care support

Submission date	Recruitment status Recruiting	[X] Prospectively registered		
10/07/2025		∐ Protocol		
Registration date	Overall study status Ongoing Condition category Mental and Behavioural Disorders	Statistical analysis plan		
17/07/2025		☐ Results		
Last Edited		<ul><li>Individual participant data</li><li>Record updated in last year</li></ul>		
11/07/2025				

# Plain English summary of protocol

Background and study aims

This study is about understanding how African and African Caribbean people living with dementia, along with their families and care partners, seek support and how services respond to their needs. Research shows that this group often faces discrimination and delays in getting help, which can lead to worse health outcomes and a higher chance of being placed in care homes. The study aims to learn directly from people's experiences so that health and social care services can improve how they support this community.

#### Who can participate?

African and African Caribbean people living with dementia, their care partners, and family members are invited to take part in the study.

#### What does the study involve?

Participants will be asked to talk about their experiences of trying to get support from services. These conversations will take place over six months. The research team will also observe how social care and community teams make decisions about care, to better understand how services work.

What are the possible benefits and risks of participating?

There are no direct benefits, but some people may find it helpful to share their experiences to help improve services. There are no known risks to taking part.

Where is the study run from?

The study will take place in four areas: two in Greater London, one in Kent, and one in Northwest England. These areas have established African and African Caribbean communities.

When is the study starting and how long is it expected to run for? January 2025 to December 2027

Who is funding the study?

The study is funded by the National Institute for Health and Care Research (NIHR), through its Health Services and Delivery Research (HSDR) programme (UK)

Who is the main contact?

Dr Shadreck Mwale, Shadreck.mwale@uwl.ac.uk

# Contact information

#### Type(s)

Public, Scientific, Principal investigator

#### Contact name

Dr Shadreck Mwale

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#### Contact details

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# Additional identifiers

Clinical Trials Information System (CTIS)

Nil known

Integrated Research Application System (IRAS)

342835

ClinicalTrials.gov (NCT)

Nil known

Protocol serial number

160824, CPMS 69718

# Study information

#### Scientific Title

The African and Caribbean Elders (ACE) study

#### Acronym

**ACE** 

#### Study objectives

This study will examine the experiences of support seeking from the perspectives of AAC PLWD, care partners, and families, and the ways in which their support needs are understood, become recognised, and responded to, by social care (Adult Social Care Teams). Our objectives:

- 1. Develop a detailed conceptual model of help-seeking to explain what is known of pathways and access, and experiences of services that supports the provision of culturally appropriate care for AAC PLWD.
- 2. Examine and understand the experiences of AAC PLWD, care partners and families, of living with dementia, support seeking and encounters with services.
- 3. Provide detailed understandings and directly observed examples of recognition, assessment, and support of ACC PLWD, care partners, and families, by Adult Social Care teams.
- 4. Translate our findings into co-produced culturally appropriate and inclusive strategies that are actionable.

The goal is to (a) support services in delivering their statutory duty to promote equality and to make reasonable adjustments (b) deliver the detailed foundational knowledge to inform a longer-term programme to develop and evaluate interventions providing new or enhanced approaches to meet the needs of AAC PLWD, care partners, and families.

#### Ethics approval required

Ethics approval required

# Ethics approval(s)

approved 30/06/2025, West Midlands - Coventry & Warwickshire Research Ethics Committee (2 Redman Place, Stratford, London, E20 1JQ, United Kingdom; +44 2071048211; coventryandwarwick.rec@hra.nhs.uk), ref: 25/WM/0094

# Study design

Multi-centre mixed method ethnographic study

# Primary study design

Observational

# Study type(s)

Other

### Health condition(s) or problem(s) studied

Examining experiences of and accessing social care support by African and African Caribbean people living with dementia

#### **Interventions**

1. We will review existing research to identify what is already known about how this population access and are recognised by services. We will co-produce detailed qualitative research alongside African and African Caribbean PLWD, care partners and families, ensuring it focusses

on priorities relevant to them. This will take place within 4 Local Authorities (2 in Greater London, Kent and Northwest England) with established populations of African and African Caribbean older people and PLWD.

- 2. We will talk to African and African Caribbean PLWD (N=40), their care partners and families over a period of 6 months to understand experiences of support seeking and services.
- 3. We will observe team and case meetings of social care professionals (15 per LA) and community teams (3 per LA) serving these communities (N=90 days). This will help us to understand how services recognise and assess the needs of African and African Caribbean PLWD, care partners, and families, and how they make decisions about care.

#### Intervention Type

Other

#### Primary outcome(s)

Experiences of African and African Caribbean People living with dementia accessing social care support measured qualitative interviews and detailed ethnographic observations of social care staff's everyday work.

Data analysis will be informed by the analytic tradition of grounded theory. This uses the constant comparative method; as data is collected in one site, preliminary analysis of this will proceed in parallel, with this preliminary analysis informing the focus of later stages of data collection and analysis. Field notes of observation, experience, and near verbatim text will be written up into word files and all audio recordings of interviews (short and in-depth) will be transcribed verbatim by a professional transcription service. Analysis will involve the development and testing of analytic concepts and categories, and our strategies for their development include careful reading of the data, looking for patterns and relationships, noting anything that seems surprising and for any inconsistencies and contradictions across the range of perspectives gathered.

#### Key secondary outcome(s))

There are no secondary outcome measures

## Completion date

30/12/2027

# **Eligibility**

# Key inclusion criteria

- 1. Any staff working in adult social care teams
- 2. African and African Caribbean older people living with dementia
- 3. Families and care partners of African and African Caribbean older people living with dementia

# Participant type(s)

Carer, Employee, Service user

# Healthy volunteers allowed

No

#### Age group

Adult

#### Lower age limit

18 years

#### Upper age limit

100 years

#### Sex

All

#### Key exclusion criteria

- 1. Participants with dementia who are not of African heritage
- 2. Staff not working with adult social care teams

#### Date of first enrolment

01/08/2025

#### Date of final enrolment

31/07/2027

# Locations

#### Countries of recruitment

**United Kingdom** 

England

# Study participating centre

#### **Percival House**

Ealing Council 14-16 Uxbridge Road London United Kingdom W5 2HL

# Study participating centre

Westminster Council Public Health Team

Westminster City Hall 64 Victoria Street London United Kingdom SW1E 6QP

#### Study participating centre

London Borough of Hounslow, Hounslow House, 7 Bath Road, Hounslow, TW3 3EB

The Thelma Golding Centre

92 Bath Road Hounslow United Kingdom TW3 3EL

# Study participating centre Medway Council

Gun Wharf Dock Road Chatham United Kingdom ME4 4TR

# Study participating centre Liverpool City Council

Municipal Buildings Dale Street Liverpool United Kingdom L2 2TF

## Study participating centre Kensington and Chelsea Social Services Directorate

Town Hall Hornton Street London United Kingdom W8 7NX

# Sponsor information

# Organisation

University of West London

#### **ROR**

https://ror.org/03e5mzp60

# Funder(s)

Funder type

#### **Funder Name**

National Institute for Health and Care Research

#### Alternative Name(s)

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

#### Funding Body Type

Government organisation

#### **Funding Body Subtype**

National government

#### Location

United Kingdom

# **Results and Publications**

#### Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are not expected to be made available due to the study teams commitment to ensure confidentiality of study participants.

#### IPD sharing plan summary

Not expected to be made available

#### **Study outputs**

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes