

# 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

<b>Submission date</b> 10/07/2025	<b>Recruitment status</b> Recruiting	<input checked="" type="checkbox"/> Prospectively registered
<b>Registration date</b> 17/07/2025	<b>Overall study status</b> Ongoing	<input type="checkbox"/> Protocol
<b>Last Edited</b> 11/07/2025	<b>Condition category</b> Mental and Behavioural Disorders	<input type="checkbox"/> Statistical analysis plan
		<input type="checkbox"/> Results
		<input type="checkbox"/> Individual participant data
		<input checked="" type="checkbox"/> Record updated in last year

## 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](mailto:Shadreck.mwale@uwl.ac.uk)

## Contact information

### Type(s)

Public, Scientific, Principal investigator

### Contact name

Dr Shadreck Mwale

### ORCID ID

<https://orcid.org/0000-0002-5773-8458>

### Contact details

Geller Institute of Ageing and Memory, School of Biomedical Sciences

University of West London

W5 61-63 Uxbridge Road

London

United Kingdom

W5 5SA

+44 20 8209 4278

[shadreck.mwale@uwl.ac.uk](mailto:shadreck.mwale@uwl.ac.uk)

## 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**

Government

### Funder Name

National Institute for Health and Care Research

### Alternative Name(s)

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

### Funding Body Type

Government organisation

### Funding Body Subtype

National government

### Location

United Kingdom

## Results and Publications

### Individual participant data (IPD) sharing plan

The datasets generated 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?
<a href="#">Participant information sheet</a>	Participant information sheet	11/11/2025	11/11/2025	No	Yes
<a href="#">Study website</a>	Study website	11/11/2025	11/11/2025	No	Yes