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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
10/07/2025

Recruitment status
Recruiting

Registration date
17/07/2025

Overall study status
Ongoing

Last Edited
11/07/2025

Condition category
Mental and Behavioural Disorders

[X] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] 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

Contact information

Type(s)
Public, Scientific, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
342835

Central Portfolio Management System (CPMS)
69718

Protocol serial number
160824

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

Primary study design
Observational

Study design
Multi-centre mixed method ethnographic study

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?
Study website	Study website	11/11/2025	11/11/2025	No	Yes