

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	<input checked="" type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 17/07/2025	Overall study status Ongoing	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 11/07/2025	Condition category Mental and Behavioural Disorders	<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

Study website

<https://www.uwl.ac.uk/research/research-centres-and-groups/geller-institute-ageing-and-memory/research/ace-study>

Contact information

Type(s)

Public, Scientific, Principal Investigator

Contact name

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Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

342835

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

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

Secondary study design

Qualitative research

Study setting(s)

Built environment/local authority, Community, Workplace

Study type(s)

Other

Participant information sheet

Not available in web format please use contact details to request a participant information sheet

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 measure

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.

Secondary outcome measures

There are no secondary outcome measures

Overall study start date

01/01/2025

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

Age group

Adult

Lower age limit

18 Years

Upper age limit

100 Years

Sex

Both

Target number of participants

60

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

England

United Kingdom

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
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SW1E 6QP

Study participating centre
London Borough of Hounslow, Hounslow House, 7 Bath Road, Hounslow, TW3 3EB
The Thelma Golding Centre
92 Bath Road
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United Kingdom
TW3 3EL

Study participating centre
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Gun Wharf
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Study participating centre
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Dale Street
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Study participating centre
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Sponsor information

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Sponsor type

University/education

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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

Publication and dissemination plan

Working with African and African Caribbean PLWD, care partners, and families we will use the findings to improve how services recognise need and support this population. We will develop free and accessible training for health and social care practitioners and for anyone caring for African and African Caribbean PLWD.

We will also develop publications in public and Social Care facing journals.

Our goal is to ensure this vulnerable population has better experiences of health and social care services, are supported in living well with their dementia, and live at home longer.

Intention to publish date

01/01/2028

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