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Understanding distance dementia care in England

Submission date
13/02/2026

Registration date
17/02/2026

Last Edited
13/02/2026

Recruitment status
Recruiting

Overall study status
Ongoing

Condition category
Mental and Behavioural Disorders

☐ Prospectively registered
☐ Protocol
☐ Statistical analysis plan
☐ Results
☐ Individual participant data
☒ Record updated in last year

Plain English summary of protocol

Work package 1:

Background and study aims
Distance care means giving or receiving unpaid care from a distance, usually 1 or more hours' travel time apart. Distance family carers often face unique challenges such as higher travel costs, difficulty attending appointments, and barriers to accessing support services. This research explores how health, social care, and third sector organisations currently support distance caring arrangements across England. The study aims to understand current policies and procedures around distance care, how health and social care staff and volunteers can best support distance carers and people who receive care from families from distance, and how distance care arrangements and support services can be improved.

Who can participate?
People who work or volunteer in health, social care, or third sector organisations in England can participate. This includes GPs, district nurses, social workers, care service staff, local authority representatives, voluntary sector workers, or other stakeholders supporting distance carers.

What does the study involve?
Participants will take part in an interview with a researcher, which will be like a conversation. The researcher will ask about your knowledge and experience around distance care relationships, including existing support for such relationships, what works well, and what could be improved. Interviews will take place on Microsoft Teams or by telephone, depending on your preference, and are expected to take around 45 minutes. The conversation will be audio recorded and automatically transcribed.

What are the possible benefits and risks of participating?
By taking part, you will help us understand the current state of distance care in England. Your insights will contribute to identifying examples of good practice and highlighting areas that need improvement in policy or procedures. This evidence will inform recommendations for local authorities and health and social care organisations to improve accessibility and support for distance carers, ultimately enhancing well-being for both carers and the people they care for. We do not expect you to face any risks by taking part in this research. However, if discussing

aspects of your work becomes uncomfortable, you can pause or stop the interview at any time. If you experience work-related stress or concerns during or after the interview, you may wish to access support through your organisation's employee assistance programme or occupational health services.

Where is the study run from?
The study is led by the University of Greenwich in London. The research team also includes people from:
1. King's College London
2. London School of Economics
3. University of Hull
4. Dementia UK (a charity that supports people affected by dementia)

When is the study starting and how long is it expected to run for?
February 2026 to March 2027

Who is funding the study?
The National Institute for Health and Care Research (NIHR) Research Programme for Social Care (UK)

Who is the main contact?
1. Dr Tiffeny James, tiffeny.james@greenwich.ac.uk
2. Dr Aysegul Kafadar, a.h.kafadar@greenwich.ac.uk

Work package 2:

Background and study aims
Many people with dementia want to stay living in their own homes. They often need support from family members and homecare workers to do this. However, nowadays more family members live far away from their relatives with dementia. We call these people "distance carers" if it takes them 1 hour or more to travel to their relative.
Distance carers provide important support, but they often face extra challenges, such as needing more time off work, higher travel costs, and difficulty communicating with homecare workers. They sometimes are not given the support they need or are not listened to by services.
This study aims to understand what it's like when someone with dementia is cared for by family who live far away, and how homecare workers support these situations. We want to identify what works well and what needs to improve, and create helpful guidance for both distance carers and homecare workers.

Who can participate?
We are looking for people in three groups:
1. People living with dementia who receive support from homecare staff and support from family or friends who live 1 or more hours away
2. Family or friend carers supporting a person living with dementia who receives support from homecare staff and who lives 1 or more hours away
3. Homecare staff and managers who support people living with dementia whose family members live at a distance (1 or more hours away)
We aim to speak with people from different backgrounds, living in different areas of England (cities and countryside), and with different distances between them and their relatives.

What does the study involve?
Participants will be asked to have an interview (conversation) with a researcher lasting 20-45

minutes about their experiences. Family members and people with dementia can choose to be interviewed in person or online, together or separately. Homecare workers will be interviewed by telephone, or video call, whichever works best for them. We will record the interviews and transcribe them so we have a written version of it. We will also invite people to take or find up to 5 photographs that represent their experiences of distance care which we will use to facilitate discussions during the interviews.

What are the possible benefits and risks of participating?
By taking part in this research, participants will help us understand how to improve distance care arrangements for people living with dementia in the future. To thank participants for their time, we will offer each person a £25 shopping voucher. We do not expect participants to face any risks by taking part in this research. It is possible that some discussions in the interview may be upsetting if, for example, participants feel they are not getting the care and support they need. If this happens, we can pause the interview or stop completely. We will also signpost people to support services.

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Who is the main contact?
1. Dr Tiffeny James (Principal Investigator), tiffeny.james@greenwich.ac.uk
2. Dr Aysegul Kafadar (Research Fellow), A.H.Kafadar@greenwich.ac.uk

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Study information

Scientific Title
ReCOgNising and SupportIng Distance dEmentia caRe (CONSIDER) in England: a qualitative study

Acronym
CONSIDER

Study objectives
Work package 1:
This research investigates how adult social care services in England recognise and support distance carers (e.g., unpaid family members, friends) and people who receive care from a distance, i.e., those living 1 or more hours from each other. Our preliminary website analysis of 152 UK local authorities revealed that only 7.2% explicitly provide information for distance carers online, despite the Care Act 2014 guaranteeing all carers the right to assessment regardless of location. Follow-up contact with 141 councils confirmed most support distance carers when the cared-for person resides in their area, yet significant gaps exist in written guidance, online visibility, and practical implementation.

Principal research questions:
1. How do staff or volunteers in health, social care, third sector, or other relevant organisations in England understand and provide support around distance care under the Care Act 2014?
2. What barriers and facilitators do professionals or volunteers encounter when assessing and supporting distance care arrangements for carers and those who receive care from distance?
3. What constitutes good practice in supporting distance care arrangements?

Work package 2
This research aims to understand distance dementia care in England, and provide strategies and

recommendations to develop policy and practices around distance care. We will achieve this through the following objectives:
1. Exploring experiences of distance care among people living with dementia, family carers, and homecare professionals
2. Identifying stakeholders' priorities for research and policy around distance dementia care
3. Co-producing tips for distance dementia carers
4. Co-producing good practice guidance for homecare professionals supporting people living with dementia with distance carers

Ethics approval required
Ethics approval required

Ethics approval(s)
1. Approved 06/02/2026, University Research Ethics Board (30 Park Row, London, SE10 9LS, United Kingdom; +44 (0)20 8331 8000; researchethics@gre.ac.uk), ref: UREB2026_10

2. Approved 24/11/2025, University Research Ethics Board (30 Park Row, London, SE10 9LS, United Kingdom; +44 (0)20 8331 8000; researchethics@gre.ac.uk), ref: UREB2025_29

Primary study design
Observational

Secondary study design
Descriptive qualitative study

Study type(s)

Health condition(s) or problem(s) studied
Distance care relationships and dementia care

Interventions
Work package 1:

Data collection:
We will conduct semi-structured interviews with a minimum of 12 staff or volunteers who work in health, social care, third sector, or other organisations who have knowledge and experience around distance care relationships in a professional/ voluntary capacity. Participants may include GPs, district nurses, social workers, care service staff, local authority representatives, voluntary sector workers, or other stakeholders relevant to distance care. We will offer to interview participants online or by telephone. Interviews will last up to 45 minutes. Online interviews will take place on Microsoft Teams. These will be recorded and automatically transcribed using Microsoft Teams and stored in the Microsoft Teams folder. Telephone interviews will be recoded using a password protected, encrypted recorder. Audio files will be transferred to the Microsoft Teams folder as soon as possible and then deleted from the recorder. We will check the transcript for accuracy against the recording and then permanently delete the recording. Transcripts will be pseudonymised. We will remove all identifiable information such as names of participants and services they work for and label them with the PIN. Before interviews, we will obtain consent via email.

Recruitment:
We will use purposive sampling, and contact eligible people identified in previous research who

consented to being re-contacted. We will also use snowball sampling, asking participants and PPI advisory group members to share study information with colleagues and within their networks.

Data analysis:
Interviews will be transcribed and pseudonymised. We will use an iterative approach, beginning analysis after the first interview to inform subsequent interviews. We will use Framework Analysis following guidance by Braun and Clarke (2022) to explore patterns of meaning across, within, and between participant groups. This method is well suited to applied qualitative research. Findings of this study will contribute towards our situational analysis of distance care.

Work package 2:
We will conduct semi-structured interviews using photovoice with up to 24 people with experience of facilitating, providing, or receiving distance dementia care currently or in the previous 12 months.

Sampling:
We will recruit a minimum of 24 participants to achieve conceptual depth within the data. Conceptual depth implies a sufficient depth of understanding to allow conclusions to be made. Based on experience from previous research, conceptual depth has been reached within 12 participants therefore we will aim for a minimum of 24 participants (12 home care professionals and 12 people living with dementia and their family carers). However, we will continue to recruit until we reach conceptual depth. We chose this method as this research aims to generate a wide understanding of distance dementia care, rather than a “complete picture”. To enable this, we will use purposive sampling to explore the topic from various angles. Purposive sampling enables selection of information-rich cases and is therefore helpful in achieving conceptual depth.
Reflecting our EDI strategy, we will use purposive sampling to achieve maximum variation in the sample by gathering as many different perspectives as possible and including people with a range of characteristics that intersect and impact experiences of distance care including:
1. Distances/travel times
2. Urban/rural areas
3. Ethnicity
4. Socioeconomic background
5. Private and local authority funded care
6. Homecare services with a range of CQC ratings

Recruitment:
We will advertise the study within our well-established homecare networks and across platforms such as Linked-In and X, for which co-applicant CW has an established account for distance care research (@dist_care). Our industry co-applicant, Dementia UK, will share study details via their website and newsletters, and through discussion with eligible families connected to their service. Co-applicants live in various locations around England and will share study information with their local carer services and groups. We will contact eligible people identified in previous research who consented to being re-contacted. We will also use snowball sampling, asking participants and PPI advisory group members to share study information with colleagues and within their networks. We have successfully recruited using these methods in multiple social care studies.

Data collection
In our experience, people living with dementia often prefer to be interviewed in person rather than online. As part of our PPI strategy and to enable participation, we will offer to interview people living with dementia and family carers in person or online. People living with dementia

and carers can be interviewed together or separately if both elect to participate. Interviews with homecare professionals will be conducted online. We will work flexibly, conducting interviews outside of the research team's normal working hours if necessary, to accommodate homecare professionals' schedules. Homecare workers may lack access to computers or the internet so can use devices of their choice (e.g. smartphone) or be interviewed by telephone, with call costs being met by the project. Interviews will last up to 45 minutes and be audio-recorded. Participants will receive a £25 shopping voucher.

Before interviews, we will record consent and collect demographic information to:
1. Support implementation of our EDI strategy
2. Ensure inclusion of people with diverse characteristics
3. Compare and contrast across participant experiences
4. Describe the characteristics of our sample. For family carers and people living with dementia we ask about age, gender; ethnicity; occupation (to indicate socioeconomic status); regional location in England; distance between
person living with dementia/family carer; relationship between the care dyad; and source of care funding. For homecare professionals, we will collect information about age, gender; ethnicity; role (homecare worker, manager, trainer); time in role; regional location; and agency CQC rating. If the latter is not known by participants, the researcher will collect this from the CQC website.

As part of our PPI strategy, we will use Photovoice, where possible, to help engage and empower participants during interviews. Photovoice is an innovative visual method involving asking people to take or find images representing their experience of a phenomenon, in this case, distance care. Photos will be shared with the researcher and used to facilitate discussion. This will be optional as some may find this burdensome/lack access to a camera. ML and AC have expertise in innovative visual methods. With consent, we will share images at the end-of-study knowledge exchange event.

Data analysis:
Interviews will be transcribed and pseudonymised. We will use an iterative approach, beginning analysis after the first interview to inform subsequent interviews. We will use Framework Analysis following guidance by Braun and Clarke (2022) to explore patterns of meaning across, within, and between participant groups. This method is well suited to applied qualitative research.

Intervention Type
Other

Primary outcome(s)
1. Knowledge and experiences of distance care measured using qualitative interviews at a single timepoint

Key secondary outcome(s)

Completion date
31/03/2027

Eligibility

Key inclusion criteria

Work package 1:
Staff and volunteers working in health, social care, third sector, or other relevant organisations in England who have knowledge or experience related to: the needs of people with distance care relationships; any support available to them; and gaps in policy or practice around distance care. We are interested in learning about distance care broadly, including for people affected by dementia, but they don't need to work with people affected by dementia to take part.

Work package 2:
People with experience of providing, receiving, or facilitating distance dementia care currently or in the previous 12 months within England

People with dementia:
1. With capacity to consent to taking part
2. Who receive home care
3. Who have a family carer that supports them from a distance

Family carers:
1. Aged 18 years or over
2. Who provides or has provided in the last 12 months, support to a person living with dementia who receives home care

Home care workers:
1. Aged 18 years or over
2. Who provides or has provided in the last 12 months, support to a person living with dementia who receives home care

Healthy volunteers allowed
Yes

Age group
Mixed

Lower age limit
18 Years

Upper age limit
100 Years

Sex
All

Total final enrolment
0

Key exclusion criteria
1. Do not have experience with distance care
2. Do not have mental capacity to consent to taking part
3. Under 18 years old

Date of first enrolment
13/02/2026

Date of final enrolment
31/12/2026

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University of Greenwich
30 Park Row
London
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SE10 9LS

Sponsor information

Organisation
University of Greenwich

ROR
https://ror.org/00bmj0a71

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

IPD sharing plan summary
Not expected to be made available