Full Title:

Understanding how and why live-in care packages are arranged and sustained when dementia is the primary support need: A mixed method study.

Short Title:

LIVE-DEM

Principal Investigator

Professor Ruth Bartlett, BA, MA, PhD, RN (Mental Health) Professor of Applied Dementia Research, University of Southampton.

Co-Investigators

Dr Stefan Brown, Royal Holloway, University of London
Dr Laura Cole, University of West London
Mr Terry Clarke, Director of Integrated Care & Commissioning, London Borough of Merton.
Ms Aimee Day, Freelance Dementia Advocate
Dr Karen Harrison-Dening, Dementia UK
Dr Catherine Henderson, London School of Economics and Political Science.
Mrs Morwenna Rogers, University of Exeter Medical School.
Mr George Rook, living with dementia and activist campaigner
Professor Joanna Thompson-Coon, University of Exeter Medical School

Researchers

Ms Elisa Aguzzoli, London School of Economics and Political Science.
Ms Anita Chonzi, University of Southampton

Community Partners

St John’s Dementia Support, Winchester.
The Good Care Group, London

Funder:

NIHR Health Services and Delivery Research Programme (HS&DR, Ref:163287)

Sponsor:

University of Southampton

Protocol Version number and date:

Version 2.0, April 2025

Study summary

Full title	Understanding how and why live-in care packages are arranged and sustained when dementia is the primary support need: A mixed method study.
Main research area	Dementia
Study type	Mixed methods comprising of a synthesized review, a two-pronged survey, evaluative case studies and workshops.
Participants	Survey: First prong: ICB commissioners/leads in England (n42) + local authorities (n=153) Second prong: directors of homecare providers in England specialising in live-in care (n142+) Evaluative case studies: Ten households in the south of England employing a live-in care worker when dementia is the primary support need; to include at least two non-white British households. Workshops: 1# directors of commissioning and procurement, strategic leads within the NHS and local authorities, and senior health and social care professionals to discuss current understanding and knowledge of live-in care. 2# representatives from central and local government, NIHR dementia Policy Research Units, Alzheimer's Society, Dementia UK, and other charitable organisations. 3# persons living with dementia, including family carers.
Study duration/length	30 months
Start date	January 1st2025
Scheduled End date	June 30th 2027
Key study milestones	*Study set up*: months 1-3 /January to March '25 *Synthesised review*: months 3-6 / March to June '25 *Ethics approvals*: months 3-6/ March to June '25 *Survey work*: months 1-18 / January to June '26 *Evaluative case studies*: 1-18 / January to June '26 *Data analysis and integration*: months 16-24 / April '26 to Dec '26 *Workshops*: months 6-24 / June '25 to Dec '26 *Community Conference* held month 27/April '27 Final report: month 30/June '27.
Funder	NIHR Health Services and Delivery Research Programme (HS&DR, Ref:163287)
Study Registration	researchregistry10840 registered on 16 Nov 2024
Principal Investigator	Professor Ruth Bartlett Professor of Applied Dementia Researcher School of Health Sciences, Building 67 University Road University of Southampton Southampton, SO17 1BJ R.L.Bartlett@soton.ac.uk

Key words

Dementia
Live-in Care
Ageing in Place
Mixed methods
Survey
Evaluative case studies

List of abbreviations

AiP	Ageing in Place
ICB	Integrated Care Board
LAG	Lay Advisory Group
PI	Principal Investigator
RQ	Research Question
SOG	Study Oversight Group

Table of Contents

1. Introduction

1.1. Brief Overview

The study aims to understand how and why live-in care packages are arranged and sustained, when dementia is the primary support need, and to characterise the nature of this market in England (e.g., number, size, and scope of providers).

The objectives are to:

a) synthesise and examine current evidence on live-in care, paying particular attention to data on how and whether this care model supports AiP for persons with dementia.
b) scope health and social care commissioning of live-in care; to evaluate and characterise different types of live-in care packages, when dementia is the primary support need, paying particular attention to criterion used, fees, and resources required, such as space within the home.
c) examine the process of arranging a live-in care package when dementia is the primary support need, from multiple perspectives – paying particular attention to the involvement of persons with dementia in the process, identifying principles of good practice, and areas for improvement.
d) analyse experiences of receiving live-in care using the concept of AiP and compare experiences across diverse contexts, households, and communities.
e) share learning through an ongoing process of knowledge exchange with an engaged community of stakeholders, including the co-design of an evidence-based resource with Admiral Nurses, social workers, and people living with dementia.

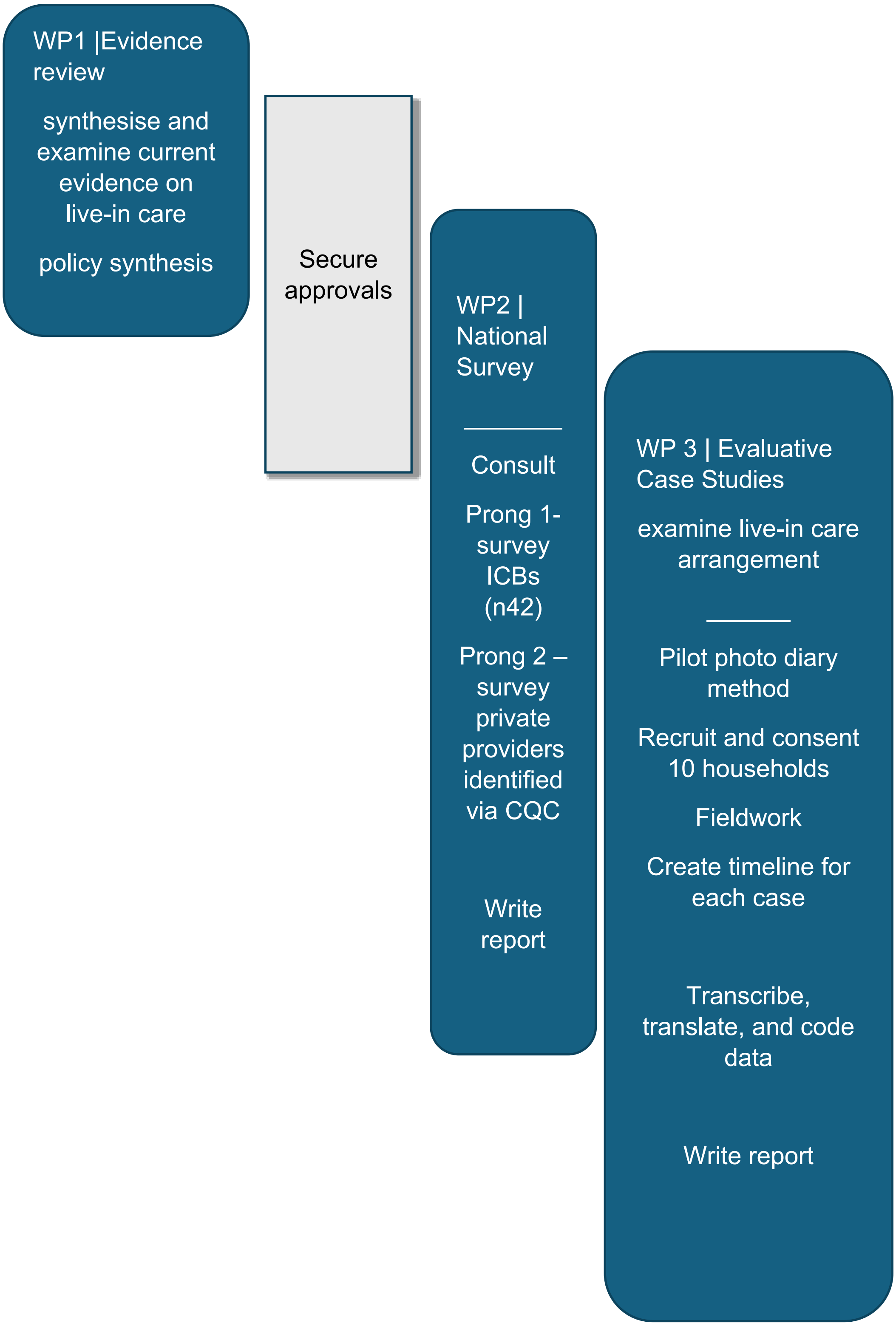
1.2. Summary of methods

For objective (a) will map the research and policy evidence on live-in care, with a focus on people living with dementia. For objective (b) we will conduct a two-pronged survey using the software Qualtrics. The first prong will be aimed at commissioners of integrated care boards; the second prong, care providers listed as offering live-in care. For objectives (c) and (d) we will conduct evaluative case studies with ten households employing a live-in carer when dementia is the primary support need. For objective (e) we will engage with relevant parties, including commissioners, government ministers, service providers, and families living with dementia, in a series of workshops.

1.3. Main benefits of the research

The proposed work will clarify how many live-in care packages are arranged and enhance understanding of what it is like to have a live-in carer when dementia is the primary support need. We will provide evidence that decision-makers, including commissioners and people living with dementia, can use when planning and monitoring long-term care. Finally, we will test out and refine the concept of AiP for a dementia context.

1.4 Study flow chart



2.0 Background and Rationale

2.1 What is the problem being addressed?

Dementia is a complex neurological condition and recognized form of disability, affecting approximately 52.2. million people worldwide and 750,000 people in England (1). It progressively affects a person's capacity to remember, think and communicate, making it challenging for those affected to live independently at home (2). Social barriers, including negative stereotyping and a lack of information and support, create additional problems for persons living with dementia, including family carers (2). People with dementia require more hours of care to support activities of daily living than people without dementia, and as the condition progress, many will require 24-hour care.

It is estimated that the number of people aged 85+ years with high dependency and in need of 24-hour care (with people with dementia being the largest diagnostic group) will double by 2035 (3). At the same time, the number of people with dementia under the age of 65 years is growing, many of whom will require age appropriate, 24-hour care (4). Research into supporting people in their own homes is a strategic priority for Government, with integrated care aiming to provide care closer to peoples' home, giving individuals more choice and control (5).

The vision for adult social care is for care services in England to intervene early to support individuals to live well at home (6). Currently, however, relocation to a care home is often regarded as the only solution to supporting a person with dementia when their needs increase; in fact, the chance of moving to a care home is increased fivefold for people with dementia compared to people without dementia (7). One reason for this is because care home placement is perceived as the only affordable option by local authorities, another is because families can reach a 'tipping point' and decide they can no longer support a person at home (8). As the demand for round-the-clock care grows, people need to know about all the long-term care options available, not only care homes.

One alternative to moving to a care home, and an unexamined model of service delivery, is live-in care. Live-in care is when a paid care worker moves into (rather than visits) a client's home to provide support. An internet search brings up several companies in England that offer live-in care to people with dementia. Many local authorities in England list live-in care providers in their service directories, and the Care Quality Commission (CQC) ranks such services highly, as they provide highly personalised care (9). Yet, live-in care is a relatively 'hidden market' - it was not included in the government's recent Market Sustainability and Fair Cost of Care exercise (local authorities were only asked to report on the cost of home care visits and care home places) (10). Neither is live-in care mentioned on NHS websites, including the NHS social care internet pages or NICE guidance for older people with social care needs. Consequently, we do not know how many people living with dementia are using this service, nor how, why, or for whom live-in care packages are arranged. It is a major knowledge gap that LIVE-DEM will address.

2.2. Why is this research important?

LIVE-DEM is the first study of live-in care in England, when dementia is the primary support need. Understanding more about live-in care in this context has the potential to improve the long-term care options for thousands of people living with dementia, at risk of moving to a care home, when they do not want to. People with dementia are entitled to have choices equal to others and are not obliged to live in a particular living arrangement (11). By focusing on this relatively unrecognised service model, the research has the potential to improve the decisions that people make about long-term care. It will achieve this by co-producing accessible information with and for families living with dementia and providing much needed evidence for future updates on homecare quality standards and social care reforms.

Research into live-in care in England is timely because it will improve public knowledge of this option, and the different types of arrangement that are available, potentially giving individuals more choice and control over their lives. Dementia is a strategic priority within the government's Major Conditions Strategy (12), as well as adult social care reforms, which centre on putting people at the heart of care (6). More broadly, the research will provide decision-makers, including commissioners and families with much needed evidence on the characteristics and experience of live-in care, when dementia is the primary support need.

Live-in care represents a promising approach to enabling a person with dementia to stay well at home. It also offers respite for family carers. By enhancing understanding of live-in care, among Admiral nurses (specialist dementia nurses), social workers, commissioners and other stakeholders, the proposed research could lead to an increasing number of local authorities funding and/or arranging this form of in-home care. It has the potential to improve the quality of information provision by care professionals and help commissioners to achieve their strategic goals around enabling independent living and avoiding crises and unplanned hospital admissions. The evidence could be translated to other service areas and client groups, such as adults with learning disabilities.

2.3. How does the existing literature support this study?

A brief scoping exercise was conducted for the proposal, guidelines and related reviews were sought via NICE Evidence, the Cochrane Library, TRIP database, MEDLINE and CINAHL. Related grey literature was sought via the Social Policy and Practice database and HMIC (Health Management Information Consortium). We found one scoping review of 13 studies involving live-in care published in 2017 (13). Most studies were conducted in Israel (n8) and focused on older people or frail populations (not dementia) (n7). (Only one study about au-pairs was conducted in the UK). The review revealed positive health outcomes for older people associated with live-in care due to less disturbed routine, but also a risk of mistreatment towards clients by the live-in care worker. Authors call for more longitudinal research in different countries to build the evidence base (13). We found other studies on live-in care, but these have been conducted in countries where the arrangement is more common due to national policies, e.g., Canada, where authorities promote working as a live-in care worker to gain Canadian citizenship (14) and Israel where live-in care is partially subsidized by the state (15). These studies focus on the employment rights of live-in care workers (16). Except for one PhD study conducted in Israel, we found no studies of live-in care focused on persons with dementia (17). The Live-in Care Hub-a UK-wide network of live-in care providers-commissioned research in 2019 (18). It identified two models of live-in care–an introduction service with limited involvement and a full management service providing training and oversight of the carer workers. Charges range from £799 to £1080 per week. The proposed study would be the first national study of live-in care in England, when dementia is the primary support need, and will provide much needed robust evidence about how and why live-in care is arranged in diverse contexts, the benefits and drawbacks of this care arrangement, and the likely scale of expenditure for people employing live-in carers.

While live-in care seems a viable option, it does have the potential to exacerbate existing inequities in the care system due to the resources required to procure a live-in care worker, notably space, and reliance on migrant care workers. Most research in this area has focused on the precarious situation of live-in care for the care worker. For example, recent research by the Rights Lab at Nottingham University has found that paid migrant live-in carers are vulnerable to modern slavery and labour exploitation (19). In Germany, where the market is less regulated and there are different employment models, the idea of live-in care is viewed with scepticism because of its potential for abuse to the care worker (20). In this country, long-term care is not a market in which it is easy for people to make informed choices, especially when these choices are often made at times of crisis, and the social care funding system is so complicated (21). Hence, our plan is to research live-in care from multiple perspectives to improve clarity and provide evidence that will help families navigate the system, and providers develop and improve this form of homecare.

3. Aim and Objectives

3.1 Aims

The study aims to understand how and why live-in care packages are arranged and sustained, when dementia is the primary support need, and to characterise the nature of this market in England (e.g., number, size, and scope of providers).

3.2. Objectives

a) To synthesise and examine current evidence on live-in care, paying particular attention to data on how and whether this care model supports Ageing in Place (see below) for persons with dementia.
b) To scope health and social care commissioning of live-in care; to evaluate and characterise different types of live-in care packages, when dementia is the primary support need, paying particular attention to criterion used, fees, and resources required, such as space within the home.
c) To examine the process of arranging a live-in care package when dementia is the primary support need, from multiple perspectives – paying particular attention to the involvement of persons with dementia in the process, identifying principles of good practice, and areas for improvement.
d) To analyse experiences of receiving live-in care using the concept of AiP and compare experiences across diverse contexts, households, and communities.
e) To share learning through an ongoing process of knowledge exchange with an engaged community of stakeholders, including the co-design of an evidence-based resource with Admiral Nurses, social workers, and people living with dementia.

4. Study design

4.1 Overall design and conceptual framework.

The study is a concurrent transformative mixed-methods design (24). We will collect data at the same time using a mix of methods, including a synthesised review, a two-pronged survey, and evaluative case studies. Triangulation will be the guiding principle for the study – that is, 'the combining of multiple methodologies to investigate the same phenomena' (in this case, live-in care) (25). We will apply different forms of triangulation including investigator triangulation (different interviewers), theoretical triangulation (co-investigators with different disciplinary backgrounds) data triangulation (collecting survey and qualitative information), methodological triangulation (combining approaches) and through the systematic triangulation of perspectives (i.e., clients, providers, commissioners). We will use a partnership approach throughout the research process, working collaboratively with people living with dementia and other relevant parties to co-produce the research. Specifically, we will co-design an evidence-based resource with Admiral Nurses, social workers, and people living with dementia.

The concept of Ageing in Place (AiP) is a key concept informing the study, hence the transformative (theory-driven) element in the design (9). AiP is the ability to live in one's own home and community, safely, independently, and comfortably, regardless of age, income, or ability level (26). In the context of dementia, there are practical problems to facilitating AiP such as decreasing self-reliance and high load of carer responsibility (27). The study will test out and refine the concept of AiP for a dementia context. The concept of intersectionality will provide an additional theoretical layer for the study. We will examine how one social identity (e.g., age, socio-economic status, ethnicity, disability) intersects with another to influence the arrangement and sustainment of a live-in care package.

The study comprises four Work Packages (WPs) as described below; the implementation of which, and links between them are visually represented in the flowchart.

WP1: Mapping evidence (objective a).

We will identify and map the evidence on live-in care, with a focus on people living with dementia. The WP will include a synthesised review of research evidence that reports on live-in care for adults including those with dementia and consider the perspectives of those providing, receiving, and commissioning live-in care. In parallel, the University of Southampton's dedicated public policy engagement unit, Public Policy Southampton (PPS) will conduct a policy synthesis of the existing policy landscape to support the research team in their wider understanding of what has come before and current policy windows. Findings from this WP will be used to develop survey questions for WP 2, and data-collection protocols for WP 3.

WP2: National survey (objective b).

We will run a two-pronged survey to evaluate and characterise different types of live-in care packages, when dementia is the primary support need, paying particular attention to criterion used, fees, and resources required, such as space. The sampling frame for the survey are commissioners in the ICBs and local authorities in England (first prong) (n=42+n=153) and directors of care providers in England listed on the CQC website as specialising in live-in care (n=400+) (second prong). Before survey work, to improve recruitment, we will organise an online consultation event with live-in care providers, to gauge providers' appetite for participating in a survey and to ascertain what might support them to participate. We will explore with those joining the consultation whether they think providers will be willing to report their fees and other sensitive market information.

WP3: Evaluative case studies *(objectives c and d)*

We will conduct evaluative case studies with ten households in the south of England who employ a live-in carer, to examine the process of arranging and sustaining a live-in care package when dementia is the primary support need. At least two households will be non-

White British. Within each household, our standard approach to data collection will be to conduct interviews of between 45 to 60 mins with the person with dementia and family carer; live-in care worker; and care co-ordinator (e.g., a social worker or nurse) (n18). These could be single, dyad, or triad interviews depending on the capacities and preferences of participants. We will conduct repeat interviews if necessary. We will construct annotated timelines from these interviews to show when, how, and why the package was arranged. We will use photo-diary method to enable participation and to provide (visual) information about any changes in the arrangement. We will analyse experiences of receiving live-in care using the concept of AiP and compare experiences across diverse contexts, households, and communities – paying particular attention to the involvement of persons with dementia in the process, identifying principles of good practice, and areas for improvement.

WP 4: Knowledge mobilization and impact (objective e).

We will share learning and mobilise knowledge through a series of workshops with relevant parties, including commissioners, service providers, and families living with dementia. We hope that the findings from stakeholder events will help to stimulate the updating of quality standards for homecare to incorporate live-in care when dementia is the primary support need

In summary, the key features of the proposed study design are:

- Co-production; working collaboratively with relevant stakeholders, including people living dementia throughout the research process.
- Mixing methods to investigate live-in care from multiple perspectives
- Concurrency; collecting data at the same time.

4.2 Setting/context

The study is concerned with how and why live-in care is arranged and sustained in England, when dementia is the primary support need. We are interested in live-in care arrangements that are privately funded, and those funded or arranged by local authorities. The survey will cover ICBs and private live-in care providers throughout England. The evaluative case studies will include households from three of the seven NHS regions – London, South East and South West.

Given the broad setting and novelty of the research, there are several relevant parties who will be involved in the research, including:

- People living with dementia, including family members.
- Patient organisations, charities and other third sector organisations.
- Practitioners working in health and social care
- NHS commissioners in England.
- Policymakers (e.g., adult social care, long-term care).

4.3 Mapping evidence

4.3.1 Objective

The objective of this WP is to identify and collate the current evidence on live-in care, paying particular attention to data on how and whether this care model supports AiP for persons with dementia.

4.3.2 Research Questions

We will address the following research questions:

- What is the volume, range and nature of evidence on live-in care?
- What is the volume, range and nature of evidence on whether live in care supports AiP for persons with dementia?

4.3.2. Identification of studies

4.3.2.1 Bibliographic databases

We will search the databases Medline, APA PsycINFO, EMBASE, Social Policy and Practice, Health Management Information Consortium (all via Ovid), CINAHL and Ageline (via EBSCOhost), British Nursing Index, ASSIA, Sociology Database and Sociological Abstracts (via ProQuest), the Cochrane Database of Systematic Reviews, the CENTRAL database, and the Social Science Citation Index (via Web of Science). We will use a combination of free text terms and subject headings to cover the concepts of live-in carers and the home setting. An example search strategy for Medline is shown in Box 1 below.

Box 1:

Ovid MEDLINE(R) ALL <1946 to March 19, 2025>

1	Dementia/	67059
2	Alzheimer Disease/	132035
3	Mild Cognitive Impairment/	45978
4	(dementia or demented).ti,ab.	157296
5	alzheimer*.ti,ab.	208272
6	(cognitive* adj impair*).ti,ab.	108008
7	(cognitive* adj decline*).ti,ab.	40074
8	cognitive deterioration.ti,ab.	2544
9	cognitive function.ti,ab.	58487
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9	439677
11	Nursing, Private Duty/	459
12	Home Health Nursing/	396
13	"home care".kw.	1940
14	"Live in care".ti,ab.	57
15	home care.ti.	10135
16	(formal care adj5 home).ti,ab.	51
17	(carers and "live in").ti,ab.	135
18	domiciliary care.ti,ab.	340
19	personal care assistant*.ti,ab.	53

20	live-in caregiver*.ti,ab.	43
21	resident caregiver*.ti,ab.	30
22	resident carer*.ti,ab.	21
23	13 or 14 or 15 or 16 or 17 or 18	11922
24	10 and 23	791

We will carry out forward and backward citation searching of included papers using Scopus and examine the included studies in any related systematic reviews. We will carry out hand-searching of any key journals identified during the search process. We will contact prominent authors in the field to seek further publications

4.3.1.2 Grey literature

Some of the listed databases e.g. Social Policy and Practice include grey literature. We will also search conference abstract databases (via Web of Science) and ProQuest dissertations and theses database. We will search grey literature repositories (the WHO Institutional Repository, WorldCat and CORE (collection of open access research) and search engines (Google Scholar and the Bielefeld Academic Search Engine). For search engine results, we will stop reviewing results after 100 hits or once saturation is reached (i.e. no more relevant hits are returned).

4.3.1.3 Website searching

We will seek additional studies and reports via the websites of the following organisations:

Alzheimer's Association (US)
Alzheimer's Society (UK)
Alzheimer's Disease International
Homecare Association (UK)

Finally, we will search the websites of the 29 county councils in England for local evaluations of live-in care.

4.3.2 Eligibility criteria

The inclusion and exclusion criteria to be applied to the studies identified through the search strategy are detailed below. We have organised the criteria according to the PCC format (Population, Concept, Context), in addition to providing criteria for geographic, study design, date and language limits.

Population

Include

Older adults receiving a live-in care package.

Older adults with dementia receiving a live-in care package.

Exclude

Concept

Include

Live-in care arrangements that are privately funded, and those funded or arranged by local authorities.

Live-in care as a type of domiciliary care that involves a dedicated, professional caregiver moving into the home to provide personal care and help with domestic tasks.

Exclude

Domiciliary care where the caregiver does not live in the person's home.

Personal care provided by family members or untrained caregivers.

Context

Include Live-in care provided in any private home with no geographical restrictions.

Exclude

Communal care provided in retirement villages

Study design

Include

Any study providing empirical evidence.

Exclude

Letters, editorials, discussion pieces

Date limit

None.

Geographical limit

None.

Language restriction

None

4.3.4 Process of applying eligibility criteria

As an initial calibration exercise of inclusion judgments and the clarity of our inclusion criteria, all reviewers will apply eligibility criteria to the same sample (n=100) of search results. Decisions will be discussed in a group meeting to ensure consistent application of criteria. Where necessary, inclusion and exclusion criteria will be revised to enable more consistent reviewer interpretation and judgement. The revised inclusion and exclusion criteria will then be applied to the title and abstract of each identified citation independently by two reviewers, with disagreements resolved through discussion or referral to a third reviewer as required. The full texts of all potentially relevant citations will be retrieved and assessed against the revised inclusion and exclusion criteria used to complete title and abstract screening by two reviewers independently, with disagreements resolved through discussion or referral to a third reviewer. Endnote 21 software will be used to support record management and screening. A PRISMA-style flowchart will be produced to detail the study selection process and reason for exclusion of each record retrieved at full text will be reported.

4.3.5 Data extraction

Data extraction of key information will be performed on all studies included in the review. For each included record, one reviewer will complete data extraction, and a second reviewer will check the extracted data for accuracy.

Data will be extracted in relation to the following:

- Author details (author names, title, country, date of publication, doi, publication type, etc)
- Study details (study design, country)
- Focus/aim of the study
- Observed sample characteristics of live-in caregivers (including sample size, inclusion/exclusion criteria, age of sample, gender, ethnicity, training)
- Observed sample characteristics of live-in care recipients (including, sample size, inclusion/exclusion criteria, age of sample, gender, ethnicity, comorbidities)
- Intervention details (e.g. type of live-in care, model of delivery, funding method).
- Comparator details (where appropriate)
- Outcome measures – all outcome measures related to the inclusion criteria
- Relevant inequalities addressed (any PROGRESS plus (11) criteria), including subgroup or moderation analyses undertaken
- Data collection method (e.g. trials, surveys, interviews, focus groups etc.)
- Type of analysis performed
- Themes or ideas relevant to the research questions.

4.3.6 Collating, summarising and reporting the results

Key characteristics of all included studies will be tabulated and described narratively. Studies conducted with similar population groups and/or examining similar interventions or models of care will be grouped together. The main findings will be presented alongside a visual representation of the studies included in the review.

4.4. Survey

4.4.1. Objectives

The objectives of the survey are to scope health and social care commissioning of live-in care, and to evaluate and characterise different types of live-in care packages, when dementia is the primary support need, paying particular attention to criterion used, fees, and resources required, such as space within the home. We have identified several ways for mitigating against poor response rates such as reaching out to local/regional care associations, local authority care and dementia-specific networks' forums, and other national networks (e.g., UK Home Care Association) and inform them of the study and survey work. We will ask local authorities to include a section concerning our study and the survey in their monthly newsletter.

4.4.2. Online consultation event

Before the survey, to increase response rate, we will organise an online consultation event with live-in care providers, to gauge providers' appetite for participating in a survey and to ascertain what might support them to participate. We will explore with those joining the consultation whether they think providers will be willing to report their fees and other sensitive market information, such as training. The consultation event will be advertised on our website, through LinkedIn and the Live-in Care Hub (with whom we have established links). It will be a 30 to 45-minute-long online consultation in which we will introduce our research and invite providers to tell us what information they would find useful for their businesses. We will consider the feedback from the engagement exercise in constructing the survey and considering any support that might help boost the response rate.

The questionnaire will be developed based on the outcomes and feedback from live-in care providers at the consultation event. The survey questions will be formulated accordingly and will be potentially based on past questionnaires intended for providers and agency directors of other types of home care (such as live-in nannies and/or live-in domestic workers). All questions will be revised by the study's researchers and collaborators, and tailored to the types of providers (i.e., regulated by CQC and non-regulated by CQC). Once agreed upon the survey questions, the questionnaire will be made available on Qualtrics, it will be distributed to the relevant audience and will be amply advertised.

4.4.3 First prong

We will send a questionnaire to commissioners of ICBs in England (n=42). While our original plan was to target only ICBs, given recent government announcements on reorganisations affecting ICB staff we have decided to mitigate this risk by also surveying local authorities in England (n=153). This short survey will feature a mix of closed and open questions, covering reasons for considering or commissioning live-in care, when dementia is the primary support need, as well as funding and contractual arrangements with providers. To reach the commissioners, we will use the NHS England Regional Network as a footprint. We will contact the Director of Commissioning in each of the seven NHS regions regarding the survey and seek research endorsement from the Association of Director of Adult Social Services (ADASS). We will obtain a formal letter of endorsement from ADASS, which will hopefully encourage local authorities to respond more favourably to the survey.

4.4.4. Second prong

We will send a questionnaire to live-in care service providers. For providers regulated by CQC, these are listed in the regulator's publicly available data. In addition, there are agencies providing introduction services who may not be regulated by CQC. We will use the CQC as the basis for our sampling frame (see 4.4.5. Survey sampling) and any strategies suggested by SOG and in our consultation event to locate introduction agencies and include them in the survey. This survey will include questions about service models, organisational model (company structure, for or non-profit, standalone or chain), number of clients (with dementia) in the previous financial year, fees/charges, staff recruitment (including recruitment from abroad and visa applications), training for staff, remuneration and benefits (pension, sickness and vacation pay), local market factors (e.g., demand from NHS and local authority commissioners and care managers, labour supply), source of referrals and duration of service provision. The survey will also cover care activities offered (e.g., personal care, indoor and outdoor household tasks, pet care, health care, therapeutic/enabling activities, outings, and transport). We will provide a certificate to survey respondents to show evidence of engaging in research. Moreover, we will share findings and mobilise knowledge about live-in care, specifically for people living with dementia via the planned workshops and monthly newsletter. These activities and incentives have the potential to significantly increase survey responses.

4.4.5. Survey sampling

Survey participants will comprise two groups: NHS commissioners and private live-in care providers.   We are not aware of studies of ICB or local authorities that are similar to the proposed study, making it difficult to know what response we can expect. Regarding the target number of ICB needed to obtain a minimum response for meaningful analysis, as we know the population size (N=42 for ICBs and n=153 for local authorities), we can set a recruitment target of 129 commissioners (assuming only one commissioner per organisation), at a confidence level of 95% and a 5% margin of error, assuming a proportion of 50% and 194 commissioners from ICB and local authorities. We aim to achieve 60% of this target in the first 3 months after launching the survey (n=78). Should we be unable to meet this target we will consult our advisory groups, sponsor and research manager on extending the survey for another month, taking advice on finding more potential commissioners to complete the survey, or closing it.

As to the number of live-in care providers, because this a very under-researched area, we do not have much evidence on the size of the market, and what response rate we can expect. We have consulted the CQC website looking for providers that have listed live-in care as a specialty. It is not straightforward to estimate the number of providers as there appears to be variability in how information on this characteristic appears in the CQC public data. According to their current care directory data (accessed 21/3/2025), there are 14,081 homecare providers, 10,953 of which are listed as providing dementia services and 12,743 of which provide services to older people. Live-in care is not listed in the CQC dataset as a service category. Online directories of home care services do allow filtering for live-in providers (e.g. homecare.co.uk, carechoices.co.uk), suggesting that there may be between 2000-3000 providers operating in England. However, many of these belong to provider groups or chains. Filtering CQC's list to 'brands' of homecare providers of services to older people gives 438 unique brand names of which 70 are also classified as home care providers. Our consultation event will be used to provide more direction on whether to target only head offices/directors or also subsidiaries/franchisees. We will then set a target for recruitment and update the protocol. If, having set our target, the survey gets less than 60% by 3 months after the launch, we will again consult our advisory groups, sponsor and research manager on extending the survey for another month, taking advice on finding more potential commissioners to complete the survey, or closing it.

4.4.6. Data collection

To ensure enough answers, we will contact local and regional care associations and tell them about the study; retrieve any useful contact information of live-in care providers and directors of home care providers that offer live-in care; and design an e-certificate for respondents to show evidence of their engagement. We will seek information on how to effectively reach directors and providers by contacting a chief executive officer of a large home care company.

4.4.5. Data analysis and integration

In terms of survey structure and content, we will first seek information on companies' business models and fee structures. Then, we will take the feedback from the consultation event into account in asking more or less detailed questions about fees and charges, depending on what is acceptable. For example, we might be asking for bands of fees and charges rather than asking for exact figures. We will conduct a descriptive analysis of the survey data. We will analyse key information on the size of live-in care providers, the type of recruitment, their match-making processes, and their awareness on CQC ratings. Adequate comparisons will be made between providers with similar characteristics. Our descriptive analysis will be useful as it will be mapping the live-in care services offered in England and compare the quality of live-in care provided cross-regionally. This survey will be integrated with the findings from the qualitative data analysis (WP3) which will aim at uncovering how and why live-in care services are arranged and sustained, especially for people with dementia, through a case study method.

In terms of the survey data presentation, descriptive statistics will include continuous data as means, standard deviations and categorical/ordinal data in terms of percentages and counts, applying appropriate disclosure controls. Wherever possible we will provide bar charts and other visualisations, and our outputs will include infographics. We may conduct further analyses to identify clusters of providers based on elements of their business models, their mission, and target market, by using clustering analysis techniques or extracting classes using latent class analyses.

4.5. Evaluative Case Studies

4.5.1. Objective

The objective of this WP is to examine the process of arranging and sustaining a live-in care package when dementia is the primary support need, and to analyse experiences of receiving live-in care (study objectives c and d). It will build on findings from the synthesised review and run concurrently with the survey.

4.5.2. Sampling

We aim to recruit ten households to the study from three of the seven NHS regions – London, South East and South West. This sample size will provide sufficient data for information power (28) and is a realistic number of households to recruit and support. We will identify potential participants via study partners and by advertising the study through our own and partner websites, newsletters, and other social media.

Each household will include the person living with dementia and live-in care worker, and where possible a family/friend carer or supporter, and a care coordinator (health / social care practitioner). See section 6 for further details on eligibility criteria.

We will sample for the following characteristics: variations in funding, geographical spread/location, educational and socioeconomic background, longevity and type of live-in care arrangement, severity of cognitive impairment, co-morbidities/disabilities, marital status, housing type, age, gender, ethnicity, and family carer kin-relationship (e.g., spouse, adult-child). To enhance diversity, we will sample at least two non-white British families. This will allow us to analyse and compare experiences of receiving live-in care across diverse contexts, households, and communities.

4.5.3. Data collection

Qualitative data will be collected over time using semi-structured interviews, photo diaries, field notes and researcher reflections within 10 households where a person living with dementia has a live-in care worker.

Within each household, our standard approach to data collection will be to conduct semi-structured interviews of between 45 to 60 mins with the person with dementia and family carer; live-in care worker; and care co-ordinator or health / social care practitioner (e.g., a social worker or nurse) (n18). These could be single, dyad, or triad interviews depending on the capacities and preferences of participants. We will conduct repeat interviews if necessary. Flexibility will be important to enable participation and achieve information power (28). Semi-structured interviews will be conducted using a topic guide and will be audio-recorded and later transcribed.

We will use photo-diary method to examine how the arrangement is sustained. Photo-diary method involves participants taking photographs, which capture their experiences and activities, and talking to the researcher about them afterwards. We will invite the person with dementia and live-in care worker to maintain a photo-diary for two 7-day blocks (3-4 months apart) using an easy-to-use compact digital camera we provide. Each block of 7 days will be preceded and followed by 45 mins of interview with the person with dementia and live-in care worker and/or family carer. Asking people to keep a photo diary at two separate intervals will revealing any changes in the arrangement and provide visual data about any sensitive or otherwise ‘unseen’ behaviours, such as assistance with eating and drinking and facial expressions, giving us another layer of meaning (36). Also, being able to photograph something enables individuals to express themselves in a freer way that is less reliant on language skills (33), and (c) the body and creative practices; information about how someone expresses themselves and moves around can all be gained through photo diaries. We expect to gain rich insights into what it is like to have a live-in care worker through this method.

We will modify our approach for each case to accommodate a person’s capacities, preferences, and situation, thereby making the research accessible (35,37). Care will be taken to be unobstructive in daily activities and preserve participants’ privacy and dignity in the home setting (38). Field notes will be made throughout the time in the field. Researchers will also complete reflective notes directly after each visit. The approach to recording field notes will be systematic using a standardised template (35).

Photo-diary method is an innovative approach to data collection. Therefore, we will pilot test the method first with two or three households where a live-in care worker is employed – our collaborator St Johns Dementia Support have already said they will help us to recruit some willing volunteers locally to do this. The aim of the pilot test will be to give us advance warning about how the method could be unsuccessful, where guidance might not be followed or understood appropriately, or whether the process or equipment is too complicated or burdensome. We will be steered by the lay advisory group during the piloting process and will modify our approach and the guidance if necessary, following the pilot test.

4.5.4. Data analysis and integration

Interviews will be audio-recorded, fully transcribed and translated where necessary to facilitate data analysis. A rigorous process to data analysis will be achieved by (i) using the abductive analysis approach i.e., creating inferences from both data and Ageing in Place theory (ii) coding and sorting data in a transparent way, and (iii) using NVivo - a qualitative analysis software programme designed to facilitate analysis via a code-based system. (i) The abductive analysis approach involves ‘taking relatively small data excerpts’ and working through them in detail considering relevant theories, ‘trying to find as many possible ways to understand the data as can be found’ (39: 176). Our relevant theory is ageing in place and because we want to compare and evaluate experiences across diverse contexts, households, and communities, ‘where’, ‘who’, ‘how’ and ‘what’ questions will guide data analysis-including, for example, where does live-in care take place? Who initiates what, and with whom? How does the person with dementia feel about the arrangement, and what activities does the arrangement enable the person with dementia and their family carer to do? What are the points of tension? Are they any conflicting priorities between family members, the person with dementia and live-in carer? Intersectionality is relevant too. We will analyse for how one social identity (e.g., socioeconomic status, age, ethnicity, disability) intersects with another to shape how each person perceives, organizes, and experiences the live-in care arrangement. ii) the coding and sorting process will be conducted jointly within the team with the aim of creating a robust coding tree using the words and sentiments of participants (as well as theory). The tree will be applied to a sample of interview transcripts from each fieldwork site. At which point, we will run an inter-rater reliability test, which will be repeated towards the end of coding to enhance rigor.

Annotated timelines will be constructed from these interviews to show when, how, and why the package was arranged. Visual data (photographs gathered from the use of the photo diary) will be analysed with participants - we will ask participants to select and talk about their favourite photos during post-diary interviews. The aim will be to identify principles of good practice, and areas for improvement.

We will use a triangulation protocol mixed methods integration technique, where findings from the survey and evaluative case studies will be combined and explored for agreements (convergence), complementary information on the same issue (complementarity), or appear to contradict each other (discrepancy or dissonance). We will create a joint display in the form of a table or matrix style to merge results and generate meta-inferences from both data sources, conveying alignment with our underpinning concept – namely AiP (40).

4.6 Knowledge mobilisation and impact

4.6.1 Objective

The objective for this WP is to share learning through an ongoing process of knowledge exchange with an engaged community of stakeholders, including the co-design of an evidence-based resource with Admiral Nurses, social workers, and people living with dementia.

4.6.2 Workshops

We will organise three workshops with relevant parties during or after each WP when mobilising knowledge is most likely to be useful to everyone.

The 1st (online) workshop in month 6 (June ’25) will involve Directors of Commissioning and Procurement, strategic leads within the NHS and local authorities, and senior health and social care professionals to discuss current understanding and knowledge of live-in care. This workshop will be run by Brown with input from Thompson-Coon and Rook and aims to open discussions about live-in care as a long-term care option. This workshop is likely to generate categories and questions for data collection and ideas for future research.

The 2nd (in person) workshop in month 16 (April ’26) will bring together those identified in the stakeholder exercise conducted by the Public Policy Unit during WP1. It is likely to involve representatives from central and local government, NIHR dementia Policy Research Units, Alzheimer’s Society, Dementia UK, and other charitable organisations. The aim of this workshop will be to review initial key findings, discuss potential policy recommendations and better understand scenarios based on the expertise of the relevant stakeholders. This workshop will be run at the University of Southampton by Bartlett with Brown in partnership with the Public Policy Team at University of Southampton (UoS). It may be followed by a follow up (online) session towards the end of the study.

The 3rd (in person) workshop in month 26 (February ’27) will involve persons living with dementia, including family carers to discuss findings from the evaluative case studies. This workshop will be run at an accessible community venue in London by Rook and Day with input from Brown, Cole, and Harrison-Dening. It will follow an established co-design process developed by Dementia UK and generate content for an information resource. An artist will be invited to this workshop to create drawings of the process for the illustrated summary.

4.6.3 Newsletter

We will publish a short eye-catching monthly e-newsletter to publicise the research study and share findings in a timely and professional way to a wide audience, including people living with dementia, family carers, health and social care professionals, service providers, and senior leaders working in long-term care.

4.6.4. Podcast series

We will create a short podcast series to be hosted on Spotify. Studies about live-in care from around the world will be introduced and discussed with a variety of guests.

5. Eligibility Criteria

5.1. Inclusion criteria

The characteristics of research participants for WP 2 are described in Box 2 below.

Survey prong	Inclusion criteria	Exclusion criteria
Commissioners	Working in English ICB or Local Authorities responsible for Adult Social Services Responsible for adult social care commissioning (short and long-term services)	Outside of England Responsible for children’s social care
Providers	CQC-regulated private providers offering live-in care (1 or more carers available to a client 24 hours/day on a continuous basis) as their main service or as a part of mix of home care services Private providers, unregulated by CQC, offering introduction or matching services to people seeking a live-in carer.	Shared Lives services Voluntary sector organisations brokering personal assistants for people receiving personal budgets from a Local Authority NHS services

Households involved in the evaluative case studies will comprise of private residences in the south of England that employ a live-in carer when dementia is the primary support need.

Where possible we will sample with the following characteristics:

- variations in funding the live-in care worker.
- geographical spread/location,
- educational and socioeconomic background,
- longevity and type of live-in care arrangement (e.g. short, long term),

- severity of cognitive impairment,
- co-morbidities/disabilities,
- family carer kin-relationship (e.g., spouse, adult-child).
- protected characteristics, e.g., age, gender, ethnicity, and sexuality.

All members of the household /care triad must be willing to take part in the case study and be over the age of 18 years.

5.2. Exclusion criteria

Persons with dementia who are unwell or receiving hospital treatment will not be included in the study. Households where one or more member of the care triad (i.e., person with dementia, family carer, live-in carer) are not willing to take part in the case study will be excluded.

Family carers may cohabit with the person living with dementia and the live-in care worker. However, people living with dementia without a cohabiting family member will not be excluded from the study; in these instances, a family member/friend or supporter outside of the household will be included in the study instead.

6. Recruitment and consent

For the survey, the recruitment and consent process will be as follows.

The final approved version of the questionnaire will include a cover letter and participant information sheet (PIS) embedded at the start of the questionnaire informing potential participants about the study, what participating will entail, how data will be managed and stored, and who they can contact if they have questions or encounter any issues.

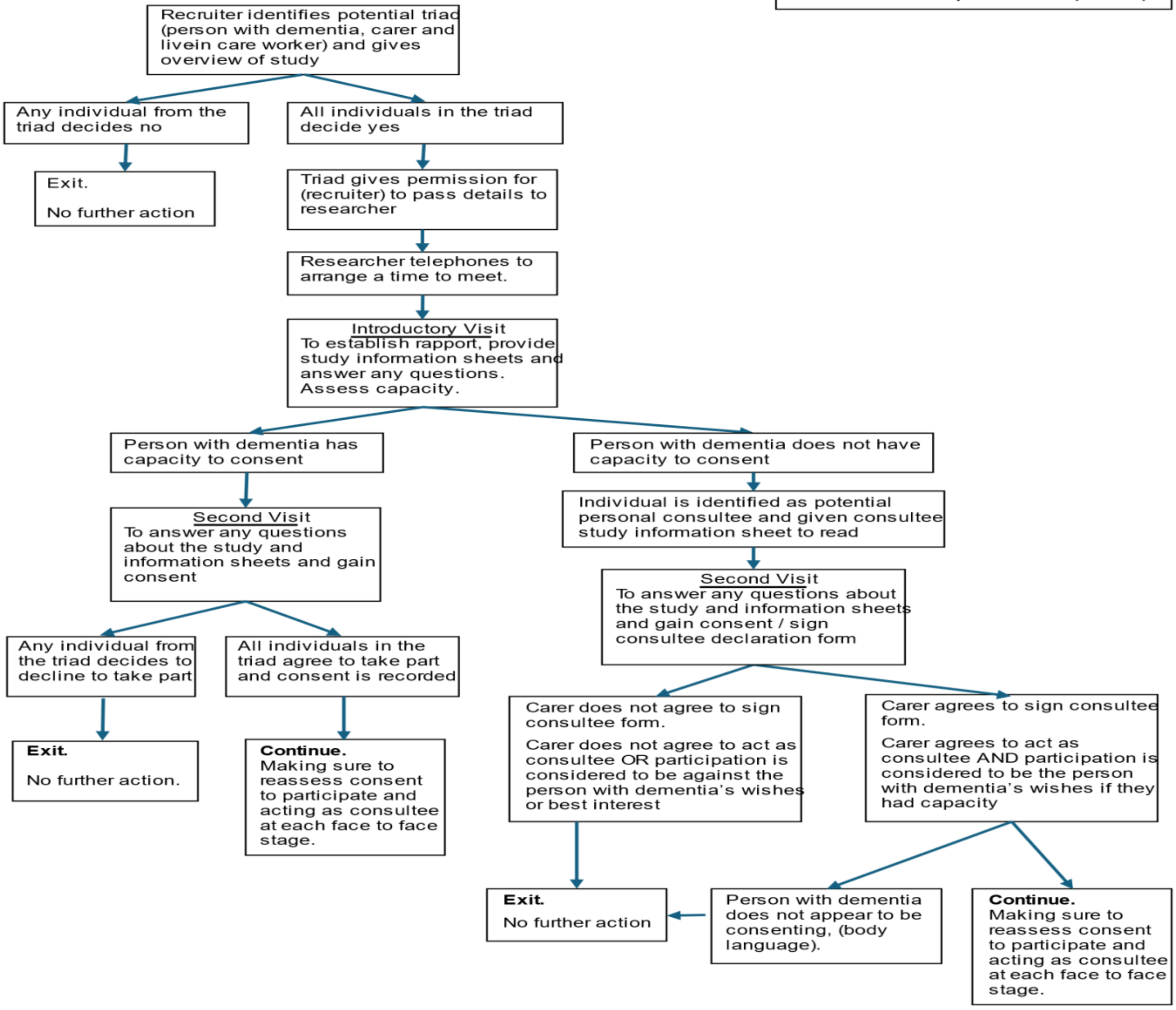
Consent to participate in the survey will be implied if the participant completes and returns the survey; this will be made clear in the participant information sheet.

For evaluative case studies, the recruitment and consent process will be as follows. First, the study will be advertised via our community partners and networks, including St Johns Dementia Support, The Good Care Group, ARC Wessex, and PenARC with clearly defined eligibility criteria. Interested individuals will be invited to approach the study researcher by email or phone and asked to provide information about themselves in respect of the eligibility criteria. If these criteria are met the study researcher will contact the potential participant and explain the purpose of the study verbally by phone or video call and provide a participant information sheet via email and post. At this point, the researcher will arrange an initial visit.

On the introductory visit, the researcher will meet with all members of the care triad (e.g., person with dementia, family carer, live-in carer) to introduce and explain the study and seek to establish a rapport. They will explain what it means to be involved, that their participation is voluntary, and they can withdraw at any time. All participants (including people with dementia) will be assumed to have capacity to consent to take part in the study in accordance with the Mental Capacity Act [MCA] (2005). If the participant is still interested and agreeable, the researcher allows at least two working days to elapse, then contacts the potential participant again to ask for their agreement to continue to a second visit when a consent will be obtained.

Written consent will be obtained from all participants who are able to sign a consent form prior to taking part in the study. Verbal consent will be obtained from any participants unable to sign, or who prefer not to sign (as might be the case with a live-in care worker). Verbal consent will be audio-recorded and documented in the Study Research file. Consent is an on-going process (29) and we will seek oral consent on each occasion if the participant is seen on multiple occasions.

Diagram 1
Flowchart of protocol (WP3)



7. Ethical considerations

People living with dementia will be assessed for their capacity to understand, retain, weigh up information, and ask questions about the research. If a person with dementia does not have the capacity to make an informed decision, then a personal consultee will be sought (in most cases this will be their next of kin/family carer; MCA, 2005). For participants living with dementia who do not have family carers we will take steps to identify a supporter or an advocate willing to act as their nominated consultee.

The consultee will be provided with a consultee study information sheet and asked to sign a consultee declaration form, confirming that when able to make an informed decision the person would have likely wanted to take part in the study and that taking part would be in their ‘best interest’. We will use the process consent method, which recognises that decisions are context specific, and that capacity is situational (41). This will involve a process of ongoing consent monitoring, paying special attention to any signs (e.g., body language) that the participant might not be happy to be involved in the study, especially when verbal and expressive abilities may be impaired. Should the person with dementia show signs of distress or wishing to not continue with the study, then they (along with the carer and live-in care worker - WP3) will be withdrawn from the study (see diagram 1).

Confidentiality and safeguarding (anonymity) Participant details will be confidential, and participants will remain anonymous, not being able to be recognized from the information that they provide. Any photographs (WP3) that includes a person's face or geographical identifiers (such as street names) will be screened and participants will be able to select which (if any) of the photos they wish to be made public, during a final sit-down interview, a form of 'consent by editing' (30). Participants will be informed that should they tell us in an interview, or we observe that they or someone else is at risk of harm, then we will need to pass this on to the relevant authorities for safeguarding; should this happen, we will discuss this with them first. A helpful contacts sheet will be provided for any participants who researchers believe would benefit from details of local support services.

Extra steps will be taken to protect the welfare of participants with dementia. For example, researchers will endeavour to create a 'safe context' for fieldwork and build rapport with participants, by spending time getting to know people. In line with the MCA Code of Practice guidelines (2006), we will conduct an informal 'risk-benefit assessment' with each participant with dementia and their identified supporter and agree an appropriate and personalized strategy for minimizing risk (31). Care will be taken so as not to embarrass or distress the person with dementia when observing or in conversation.

To ensure inclusivity of people with dementia (considered under-served group in research; NIHR, 2020), we will additionally provide easy read versions of the information sheets and consent forms. Easy read documents will be designed following DEEP guidance documents written by people living with dementia and in collaboration with Rook. This includes using simple formatting (large print, black ink on yellow paper) and photographs of the research team. We will read the information sheet (original or easy read versions) aloud to the person if preferred. We will also provide people living with dementia with a copy of DEEP’s guidance document regarding “things to think about before you become involved in a study” available on their website.

Contact will be made with local services with a track record in offering support to people living with dementia. In line with the Dementia Research Ethics Resource. the study will offer all participants an opportunity to discuss their contribution at the end of the data collection. As part of the research process participants will be offered an opportunity to discuss findings and output from the study. all participants will receive a thank you card and an illustrated summary of research findings.

7.1. Assessment and Management of Risk

7.1.1 Risk of harm (all participants)

The researcher will not disclose any personal information regarding the interview without the specific consent by the participant. It will be made clear that if the researcher is given information about any person being abused or neglected (or at risk of harm) then confidentiality will be broken (if a disclosure is made of a situation of extreme and immediate harm or and adults being harmed and unable to act to protect themselves) and the relevant safeguarding persons/agency/service will be contacted. If the researcher is concerned, then they will inform the participant before breaking confidentiality (if safe to do so). Participants are made aware of this final point in their participant information sheets and are required to initial a related bullet point statement in the consent form (see below).

Should issues of risk or harm be raised, the researcher will follow a specific protocol agreed by the research team. The researcher should immediately contact their line manager / study PI or senior member of the research team (e.g. work package lead) to gain support and guidance. Action will be taken according to the severity of the potential risk or harm. Actions of safeguarding include contacting the emergency services, notifying support/care teams (e.g. care coordinator), the employer (live-in care provider), or Care Quality Commission.

7.1.1.1 Inclusion in consent form

I understand that if I say something that indicates that I or someone else is at risk of harm, the interviewer is obliged to take appropriate action and would discuss this with me before telling anyone else.

7.1.1.2 Inclusion on the participant information sheet

Everything you say will be confidential unless you tell us, or we see, something that suggests that your situation is life-threatening, abusive or may place others at risk of harm. If this happens, we will be obliged to break confidentiality. We would discuss this with you before telling anyone else.

7.1.2. Risk of non-participation

There is a risk that people living with dementia (or their consultee), family carers, and live-in care workers may be reluctant to be involved, due to a perception that complaining or making any negative comments may jeopardise future care (person living with dementia, consultee, family members) or employability (live-in care worker, care coordinator). Potential participants may not trust that their views will be kept confidential and may decline to participate. We shall address this risk by reiterating that we are not inspectors or making judgements, that details and information from individual interviews will be kept confidential (not shared with others in the triad/ household), and that we will endeavour to mask identifying details as much as possible in outputs (such as quotes in publications).

7.1.3. Risk of harm (specific to live-in care worker)

Live-in care workers are considered to be an at-risk group due to their vulnerability to exploitation. This is due to the personal care that they provide in someone’s home, which potentially leaves them isolated/hidden, having blurred boundaries between care and domestic work, having insecure immigration status, and relying on employers for work and accommodation. Consequently, there are concerns of labour exploitation or modern slavery.

7.1.4. Risk of harm (Researcher)

The researcher will follow and be guided by the lone working procedures of the University of Southampton. This includes terminating an interview visit should they feel uneasy or at risk by the environment, circumstances, participants, or any other persons visiting the participant's home. When visiting participants in their own home, researchers will work within a "buddy-system", this requires the researcher to work with a named colleague who is aware of their location and has contact details and approximate start and end times for the visit. The researcher will call their 'buddy' before entering the participant's home, and once they have left the home. The researcher and the 'Buddy' will agree on a coded message that the researcher will say when calling the buddy to indicate that they are feeling unsafe and in need of immediate assistance (calling the emergency services). The buddy system supports the researcher whilst in the field and ensures their safety. We will complete a (departmental) risk assessment form prior to commencing the study.

7.2. Ethical approvals

University of Southampton Ethics Committee approval will be obtained for LIVE-DEM. University (LSE) Ethics Committee approval will be obtained for the pre-survey consultation. Social Care Research Ethics Committee approvals will be obtained for the survey and evaluative case studies. This is appropriate as the survey and the case evaluations will be involving staff members from the NHS (ICBs, care-coordinators e.g. nurses) and people living with dementia who may lack capacity to consent.

8. Public Involvement

People with lived experience of dementia, including family carers, as well as people from organisations that provide services or represent people who use services, have been or will be actively involved in all aspects of the research study, including:

- designing the study
- management of the study (e.g. lay advisory group)
- developing participant information sheets and interview schedules
- data analysis and interpretation
- co-designing outputs
- participating in the Community Conference and other impact events.

Public contributors have played a vital role in the design of this study and will continue to participate throughout the study. The research team includes a person with lived experience of dementia (George Rook) and an independent dementia advocate (Aimee Day), both of whom were involved in the planning and development of this study. George Rook is a man living with dementia and Chair of LEAP, the Lived Experience Advisory Panel, Dementia UK, and Chair of the Shropshire and Telford Health Economy Steering Group. George will be supported in his PPI role by Aimee Day. The team also includes a representative from Dementia UK, a national charity providing over 400 Admiral nurses (nurses specialing in dementia care) to families living with dementia. We are also working with community partners, including St Johns Dementia Support, Winchester and The Good Care Group, one of the leading providers of live-in care in England. All public contributors were involved in the planning stages of the research and contributed to the development of research objectives and impact plans.

Public contributors are part of the research team. They will take part in research team meetings in-person (once a year) and team meetings online (monthly), as well as bi-annual lay advisory group meetings (which will also have additional PPI representation), and impact activities, including workshops and the community conference. Public contributors will ensure the patients' and families' priorities and needs remain the focus of the study and will contribute to the design and management of the study, recruiting households to the study, data collection, interpretation of findings, and ensuring impact. George Rook and Aimee Day will run the study's lay advisory group, which will involve managing and working with a group of four to eight patients and carers, for the duration of the study. The Lay Advisory Group will support the development of resources and participant information sheets, recruitment, and sharing research findings.

NIHR guidance on PPI, paying public contributors, and co-producing a research study will be followed (NIHR, 2021).

9. Funding

The research costs for this study have been provided by the NIHR Health Services and Delivery Research Programme (HS&DR, Ref:163287), funding amount: £515,574.52, approved on 15th October 2024.

10. Data handling and management

10.1 Overall strategy

In this study, quantitative data (from the surveys) and qualitative data (from the evaluative case studies) will be collected from participants in accordance with the University of Southampton's Research Data Management Policy.

All data collection protocols and data management tools will be stored on MS Teams; Files will be imported in a logical folder structure accessible only to authorized professional research staff using a password. Interview sound files and transcripts will be assigned a logical and uniform anonymized label that contains coded information about the source (type, date, researcher etc.) and a unique identifier to facilitate their filing and accessibility throughout the research process by the team. The processes for handling, processing and storing the different datasets are described below.

10.1.2 Quantative dataset (questionnaires)

Surveys will be run using Qualtrics cloud-based online survey software, for which LSE holds a license. A link to the surveys will be sent to potential participants by email. Concise participant information will be provided to the participant to read and give consent before they can proceed with the survey. We will monitor response rates weekly and report monthly updates to the team. When the survey is closed, the raw data will be downloaded in csv and SPSS formats and the survey data deleted from the platform within one month. Data from the survey will be stored on the university's secure shared, password-protected OneDrive and SharePoint sites. All data will be managed in full compliance with the UK data protection laws, national guidance from the Health Research Authority, and LSE Research Data Management, Information Security, and Data Protection Policies.

All data will be held in Henderson's LSE OneDrive folder created for the study and shared with the named researcher Aguzzoli. LSE OneDrive is regularly backed up in an automated process and is provided and managed by LSE IMT. The folder will include separate sub-folders for: research materials such as questionnaire development, ethics applications and approvals, sampling frames, data files, reports, communications materials, communications with the PI and research team, and protocols and plans.

Data from survey participants will be analysed using Stata statistical software. Only aggregate and summary data will be shared with the PI and research team (so that individual participants cannot be identified). Data will be fully anonymised in research reports and other outputs to remove any characteristics that could identify research participants.

10.1.3 Qualitative dataset (case studies)

Qualitative data from the case studies (WP3) will be collected via audio-recorded interviews, digital camera, and paper documents (e.g. field notes, researcher reflections, demographic information sheets). Interviews will be audio-recorded using an encrypted audio-recorder that only the researcher will have access to. Digital audio files and photographs will be downloaded by the researcher onto the University of Southampton's secure computer network as soon as possible after leaving the household. Paper documents will only have the participant's identifying code and no names will be used. Documents will stay in the researcher's possession until they arrive back onto university premises where they will be transferred into an appropriate document folder which will be stored in a locked cabinet in a security card protected office.

Audio files will be transcribed and documented on MS Word by a professional transcription company. Prior to working with the company, we will ensure that a confidentiality agreement is in place and that files are able to be shared securely. To prepare for the analysis, all documents (transcripts, field notes, reflections) and photographs will be uploaded onto NVivo to help organise and manage the data.

11. Peer Review

This protocol has been peer reviewed by the funder.

12. Monitoring and governance

We will produce an annual progress report by 01/01/2026 and final progress report by 30/12/26. The DFR – Final Contractual Output - is due 14/7/2027.

13. Training

The Principal Investigator will review and provide assurances of the training and experience of all staff working on the study. They will manage the contracted researcher working on the study employed at the University of Southampton (Anita Chonzi), providing opportunities, structured support, encouragement and support, to engage in a minimum of 10 days professional development per year (pro rata), in line with the Researcher Development Concordant.

14. Intellectual Property

Background Intellectual Property used in connection with the study shall remain the property of the participating organisation introducing it. The University of Southampton will own the Foreground Intellectual Property generated by the study. Each participating organisation can use all Foreground Intellectual Property generated during the study for academic and research purposes (including publication purposes) and for clinical care including research involving studies funded by third parties.

15. Indemnity Arrangements

Insurance cover for LIVE-DEM will be available from the University of Southampton. This cover is Professional Indemnity and Public Liability.

16. Archiving

The lead researcher and each participating organisation recognises that there is an obligation to store and archive research data securely at the end of the study. The Principal Investigator confirms that they will archive research data for a minimum of 10 years from the study end date in line with the University of Southampton's Research Data Management Policy.

17. Dissemination Policy

17.1 Overview

The data arising from the study will be owned by the University of Southampton. On completion of each work package, data will be analysed and tabulated and included in the final report. The final report will be submitted to the funder and once approved deposited in the University of Southampton's institutional open access research repository. A DOI will be requested and assigned to the final report. This means the report will be locatable and permanently available to read (redistributed and reuse) by anyone with internet access at no cost to the reader.

The Principal Investigator will lead the first main publication of results and the final report. Thereafter, any participating researcher who wishes to publish independently, may do so, informing the Principal Investigator and other members of the team in writing not less than forty-five in advance of the submission for publication, in line with the collaboration agreement.

We will provide study participants with information on how and when research findings will be made available through the study newsletter, website, and/or via email or telephone call.

Dissemination strategies will be integrated throughout the study from the start to engage clients, providers, and the wider population about our work on live-in care when dementia is the primary support need. We will engage respectively with all participants, partners, and stakeholders and co-design outputs wherever possible.

Our main mechanisms for engagement include:

- a dedicated LIVE-DEM webpage hosted by PPS, which will offer information about the research study's aims, milestones, research team and funder and be augmented by insights and outputs as the study develops.
- a study 'kick-off' event at the University of Southampton, to which all the research team and study partners will be invited, including people living with dementia and family carers. We will take photos and share these on our webpage and social media to spark interest in the study.
- A short eye-catching monthly newsletter to communicate new and share findings in a timely and professional way. The newsletter will link readers to our webpage and help to keep people engaged in LIVE-DEM.
- the series of workshops outlined in WP4 is designed to inform and engage with different stakeholders during the lifetime of the study.
- A short podcast series about live-in care, recorded, produced, and disseminated with support from PPS. We will co-design the series with study partners and aim to

include the voices of a diverse range of people with real-life experience of live-in care.

- During the final third of the study a member of the research team will write an accessible blog which will be hosted on the website and will be offered to range of relevant organisations such as The Conversation for wider dissemination. Under pinning this web presence will be a sustained social media campaign utilising PPS' existing channels (X, LinkedIn, Meta) to promote each output and offer a space for interaction with relevant interested parties.
- Community Conference: the study will end with a Community Conference for up to 70 invited guests at an accessible venue in Winchester. The aim of the conference will be to harness peoples' knowledge and experience of live-in care as a long-term care option when dementia is the primary support need, while marking the end of LIVE-DEM and discussing possible next steps to enhance impact. Relevant parties will be invited including research participants, local authority partners, third sector providers, members of the Study Oversight Group and Lay Advisory Group. The event will be inclusive and promoted using a variety of formats, email, social media, print and telephone.
- Providing a translation and interpretation service when necessary. We will organise a translator for non-White British study participants if necessary, and BSL interpreter for any deaf attendees at the Community Conference.

This will be the first scientific study conducted in England about live-in care when dementia is the primary support need. As such, LIVE-DEM has the potential to achieve understanding and awareness impacts – people will gain understanding of how and why live-in care packages are arranged and sustained, when dementia is the primary support need, and commissioners will know much more about the nature of this market in England than they did before the research. As such, LIVE-DEM has the potential to change commissioning practices and stimulate the updating of quality standards for homecare to incorporate live-in care. We expect the research to have health, and well-being impacts by providing the information people (within care systems, communities, and families) need to plan long-term care. Finally, LIVE-DEM will provide new insights about Ageing in Place in a dementia context.

These anticipated impacts will be achieved by co-creating a wide range of outputs with and for different audiences. As well as preparing a final report for the funder, we plan to co-design an evidence-based resource about the system for funding and arranging live-in care with Admiral Nurses, social workers, and people living with dementia, including family carers.

We will work with the University of Southampton's dedicated public policy engagement unit, Public Policy Southampton (PPS) to design and deliver a policy engagement strategy. This strategy will include policy related activities, outcomes and communications which will lead to policy impact as outlined below. We will adopt the practice of 'triple writing' research outputs: virtually every output will lead to two other outputs [see table 1 below for details of planned outputs and anticipated impact].

17.2 Planned outputs

Planned outputs from this study and target audiences are shown below in Table 2.

	Planned outputs	**Target audience**	**Potential outlets**	**Expected impact/outcome**

Public-orientated	1.Illustrated summary of study and its findings 2a. Co-designed resource about the the system for funding and arranging live-in care. 1b. Easy read briefing note based on evidence synthesis	Case study participants Individuals and families living with dementia	LIVE-DEM Study website Community Conference Dementia UK website Global Dementia Observatory Knowledge Exchange Platform; Guardian Society; Daily Echo	**Understanding and awareness impact –** Increased clarity and openness about how live-in care is funded and arranged, and how well it works. **Capacity and/or preparedness impacts** influencing the development of live-in care services; cultivating networks to further research.
	2b. Feature article about the system for funding and arranging live-in care. 5b. Conference presentation reporting research	nurses, social workers and other primary care staff.	Journal of Dementia Care UK Dementia Congress LinkedIn	
Policy-orientated	3a. Policy synthesis substantive report, slide deck and verbal presentation 3b. Policy-briefing	Policy makers; parliamentarians; senior decisions makers	Parliamentarians, relevant All Party Parliamentary Groups (e.g., Ageing and Older people, Dementia) and Select Committees.	**Conceptual impact** raising the agenda with MPs and parliamentary; reframing debates about long-term care Enabling researchers to stay up to date, help to prevent unnecessary duplication of work. Advancing scientific methods of data collection and triangulation. Refinement of the concept of Ageing in Place for a dementia context.

Academic-orientated	4a. LIVE-DEM Study Protocol 4b. A scientific article reporting the evidence synthesis 4c. A conference presentation reporting findings from evidence synthesis. 5d. A scientific article reporting research as a whole 5e. Seminar presentation	Health and care researchers; gerontologists; mixed methods researchers	BMJ Health Services Research Int. J. of Care and Caring. Transforming Care Conference and Network Ageing & Society or The British Journal of Social Work KCL Home Care Research Forum & our research departments. Ageing Europe Network Global Observatory of Long-Term Care	

17.3 Authorship eligibility guidelines

All those who have made a significant contribution to the conception, design, execution, or interpretation of the reported study, and made a substantial contribution to an article should be listed as co-authors.

Any others who have participated in certain substantive aspects of the paper (e.g. recruitment or language editing), will be recognised in the acknowledgements section.

The corresponding author will ensure that all appropriate co-authors and no inappropriate co-authors are included on the paper, and that all co-authors have seen and approved the final version of the paper and have agreed to its submission for publication.

17.4 Funder requirements

We will follow the guidance stipulated by the NIHR when publicising and communicating our research:

- Notification of press releases and copies of press releases at 3 least working days before contacting the press/journalist.

- Notification of outputs and copies of articles and presentations should be sent to the funder 28 days before they are due to be published or presented.
- The NIHR’s contribution should be acknowledged in full using the statement below.
- Research articles should be published in journals as open access that make the output available using the Creative Commons Attribution (CC BY) licence and allow immediate deposit of the final published version in other repositories without restriction on re-use.
- The independent nature of the research and its intellectual property provenance will be emphasised by a disclaimer (see below).

18. Acknowledgement and Disclaimer

This study is funded by the NIHR: 163287. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

19. References

1. World Health Organisation. A blueprint for dementia research. Geneva; 2022.
2. Alzheimer's Europe Dementia as a disability? Implications for ethics, policy and practice A discussion paper. 2017.
3. Kingston A, Comas-Herrera A, Jagger C. Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study. Lancet Public Health [Internet]. 2018;3(9):e447–55. Available from: http://dx.doi.org/10.1016/S2468-2667(18)30118-X
4. Carter JE, Oyebode JR, Koopmans RTCM. Young-onset dementia and the need for specialist care: a national and international perspective. Aging Ment Health [Internet]. 2018;22(4):468–73. Available from: https://doi.org/10.1080/13607863.2016.1257563
5. Department of Health and Social Care. Guidance on the preparation of integrated care strategies. 2022 Jul.
6. Department of Health and Social Care. People at the Heart of Care: adult social care reform [Internet]. 2022. Available from: https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper/people-at-the-heart-of-care-adult-social-care-reform
7. Luppa M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia: A systematic review. Dement Geriatr Cogn Disord. 2008;26(1):65–78.
8. Samsi K, Cole L, Manthorpe J. 'The time has come': reflections on the 'tipping point' in deciding on a care home move. Aging Ment Health. 2021;
9. Care Quality Commission. Good Care Group Inspection Report. 2019.
10. Department of Health and Social Care. Market Sustainability and Fair Cost of Care Fund 2022 to 2023: guidance [Internet]. 2023. Available from: https://www.gov.uk/government/publications/market-sustainability-and-fair-cost-of-care-fund-2022-to-2023-guidance/market-sustainability-and-fair-cost-of-care-fund-2022-to-2023-guidance
11. United Nations Organization. (2006). UN Convention on the rights of people with disabilities and optional protocol. [Internet]. 2006. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
12. Department of Health and Social Care. Major conditions strategy: case for change and our strategic framework [Internet]. 2023. Available from: https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2
13. Salami B, Duggleby W, Rajani F. The perspective of employers/families and care recipients of migrant live-in caregivers: a scoping review. Health Soc Care Community. 2017;25(6):1667–78.

14. Atanackovic J, Bourgeault IL. The Employment and Recruitment of Immigrant Care Workers in Canada. Vol. 39. 2013.

15. Cohen-Mansfield J, Golander H, Iecovich E, Jensen B. Social Engagement Care for Frail Older Persons: Desire for It and Provision by Live-In Migrant Caregivers. Journals of Gerontology - Series B Psychological Sciences and Social Sciences. 2019 Aug 21;74(6):1062–71.

16. Green O, Ayalon L. Violations of workers' rights and exposure to work-related abuse of live-in migrant and live-out local home care workers - a preliminary study: Implications for health policy and practice. Isr J Health Policy Res. 2018;7(1):1–11.

17. Herz MK. Incorporating a Live-in Caregiver into the Home of a Couple Where One of the Spouses has Dementia: And Then There Were Three. 2018.

18. The Live in Carer Hub. 2019. [cited 2020 Mar 30]. Better at Home 2019. Available from: https://www.liveincarehub.co.uk/better-at-home-2019/

19. Ahlberg M, Emberson C, Granada L, Hussein S, Turnpenny A. The vulnerability of paid migrant live-in care workers in London to modern slavery. 2022;(August). Available from: www.nottingham.ac.uk/Research/ Beacons-of-Excellence/Rights-Lab/resources/reports-and-briefings/2022/July/Thevulnerability-of-paid-migrant-live-in-care-workers-in-London-to-modern-slavery.pdf.

20. Rossow V. Verena Rossow Der Preis der Autonomie: Wie sorgende Angehörige Live-in-Arbeitsverhältnisse ausgestalten.

21. Bottery S (The KF. What's your problem, social care? The eight key areas for reform. 2019;(November 2019):1–13. Available from: https://www.kingsfund.org.uk/publications/whats-your-problem-social-care

22. Pham MT, Rajić A, Greig JD, Sargeant JM, Papadopoulos A, Mcewen SA. A scoping review of scoping reviews: Advancing the approach and enhancing the consistency. Res Synth Methods. 2014 Dec 1;5(4):371–85.

23. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier L, et al. Scoping reviews: Time for clarity in definition, methods, and reporting. Vol. 67, Journal of Clinical Epidemiology. Elsevier USA; 2014. p. 1291–4.

24. Tashakkori A. and Teddlie C. Mixed methods designs. Creswell et al. (2003) in (eds.) Handbook of Mixed Methods in Social and Behavioral Research, p. 224. Thousand Oaks, California: Sage Publications. In: Handbook of Mixed Methods in Social and Behavioral Research,. Sage Publications; 2003.

25. Flick U. Doing Triangulation and Mixed Methods. London: Sage Publications; 2018.

26. Wiles JL, Leibing A, Guberman N, Reeve J, Allen RES. The meaning of "aging in place" to older people. Gerontologist. 2012 Jun;52(3):357–66.

27. Thoma-Lürken T, Bleijlevens MHC, Lexis MAS, de Witte LP, Hamers JPH. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. Geriatr Nurs (Minneap). 2018 Jan 1;39(1):29–38.

28. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. Qual Health Res. 2016;26(13):1753–60.

29. Dewing J. From Ritual to Relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. Dementia [Internet]. 2002 Jun 1 [cited 2014 Aug 15];1(2):157–71. Available from: http://dem.sagepub.com/cgi/doi/10.1177/147130120200100204

30. Capstick A. Travels with a Flipcam: bringing the community to people with dementia in a day care setting through visual technology. Vis Stud [Internet]. 2011 Jun [cited 2014 Aug 15];26(2):142–7. Available from: http://www.tandfonline.com/doi/abs/10.1080/1472586X.2011.571890

31. Brannelly T, Bartlett R. Using Walking Interviews to Enhance Research Relations with People with Dementia: Methodological Insights From an Empirical Study Conducted in England. Ethics Soc Welf [Internet]. 2020;14(4):432–42. Available from: https://doi.org/10.1080/17496535.2020.1839115

32. London NRDS. Patient and public involvement in health and social care research: A handbook for researchers. 2018.

33. DEEP. Involving people with dementia as members of steering or advisory groups. Available at: http://www.innovationsindementia.org.uk/wp-content/uploads/2018/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups-3.pdf. 2016.

34. Prosser J, SchwartzD. Photographs within the sociological research process. In: Prosser J, editor. Image based research: A qualitative sourcebook for researchers. Psychology Press; 1998.

35. Bartlett R. Modifying the diary interview method to research the lives of people with dementia. Qual Health Res [Internet]. 2012 Dec [cited 2014 May 13];22(12):1717–26. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23034779

36. Bartlett, R and Milligan C. What is diary method? London: Bloomsbury Press; 2015.

37. Conway E, MacEachen E, Middleton L, McAiney C. Use of adapted or modified methods with people with dementia in research: A scoping review. Dementia. 2023;

38. Given L. Sage Encyclopaedia of Qualitative Methods. Given L, editor. London: Sage Publications; 2008.

39. Timmermans S, Tavory I. Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis. Sociol Theory [Internet]. 2012;30(3):167–86. Available from: http://stx.sagepub.com/lookup/doi/10.1177/0735275112457914

40. Firestone AR, Cruz RA, Massey D. Theorizing With Joint Displays: Salient Contributors to Improving Preservice Teachers' Practice. J Mix Methods Res. 2024;18(2):115–36.

41. Dewing, J Process Consent and research with older persons living with dementia. Research Ethics Review 2018, 4, 2, pp59-64.