

Supporting people living with dementia in Extra Care Housing

Submission date 10/01/2022	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input checked="" type="checkbox"/> Protocol
Registration date 13/01/2022	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 13/12/2022	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data <input type="checkbox"/> Record updated in last year

Plain English summary of protocol

Background and study aims

This study will explore how Extra Care Housing (ECH) can support people to live well with dementia. ECH allows people to live in self-contained accommodation, with access to 24-hour care that is flexible and adapts to changing needs. Schemes often also include access to communal amenities. The delivery of care is independent from the resident's lease or tenancy. Over a fifth of those living in ECH have dementia, yet little is known about what works well and for whom. This study will investigate the advantages and disadvantages of different models of ECH for people living with dementia.

Who can participate?

Nine case study sites will be identified that represent different models of Extra Care Housing (ECH) for people living with dementia. At the case study sites, residents with and without dementia, staff and adult social care professionals will be invited to take part in interviews in order to share their perspectives on living with dementia in ECH.

What does the study involve?

The study involves gathering data through interviews, as well as collecting data required to build up a picture of who lives in the ECH scheme and what level of care and support they receive. The study will last for 19 months. It will start with a scoping literature review, followed by three surveys (one with commissioners of adult social care, one with people living with dementia, one with family carers). The findings from these will inform later data collection.

The researchers will identify nine ECH case study sites. Data will be collected in order to build a descriptive profile of each site, in order to understand who lives in ECH and how are they supported to live well. At each site, the researchers will also talk to residents with and without dementia, family carers, staff, social care link workers, and adult social care commissioners. This will help understand the benefits and challenges of different models of ECH.

Dissemination of the findings will be supported by three online focus groups following data collection with ECH dementia leads, ECH care providers, and adult social care commissioners. These will ensure the creation of Key Insight booklets will provide meaningful guidance about ECH for practitioners and people living with dementia. The study will be informed throughout by the Advisory Group, which includes people living with dementia. This will ensure the study is rooted in the perspectives of all stakeholders.

What are the possible benefits and risk of participating?

By taking part in this study, participants will be providing valuable information that will inform good practice and development of ECH opportunities for people living with dementia. Participants will get to share their opinions on how people with dementia are best supported to live well in Extra Care Housing. The information will be helpful in enabling the researchers to produce guidance for professionals and the public living, working, or considering Extra Care Housing provision.

There is a risk that interviews might bring up topics that are sensitive, embarrassing or upsetting. Participants will always be offered the opportunity to pause or cease the interview if such an occasion occurs.

Where is the study run from?

University of Worcester (UK)

When is the study starting and how long will it run for?

June 2021 to December 2022

Who is funding the study?

The NIHR School for Social Care Research (UK)

Who is the main contact?

Teresa Atkinson

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Contact information

Type(s)

Principal Investigator

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Additional identifiers**EudraCT/CTIS number**

Nil known

IRAS number

303475

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

20/21 0010, IRAS 303475, NIHR 102645/ER/UWTA-P180, CPMS 51740

Study information**Scientific Title**

Supporting people living with dementia in Extra Care Housing (DemECH): a mixed-methods study exploring how Extra Care Housing can support people to live well with dementia

Acronym

DemECH

Study objectives

Limited awareness of what Extra Care Housing (ECH) is, and a lack of clear evidence regarding the advantages and challenges of ECH for people living with dementia causes problems for practitioners, older people, and their families when making decisions about housing and future care.

The need for this research was identified as a priority in the NIHR School for Social Care review of research priorities in adult social care research commissioned by the NETSCC. Specifically, this research will address the NETSCC research questions 10 and 11 concerning ECH/housing with care for people living with dementia:

'Examine different models of housing and levels of support, for different groups, peer support, and whether or not technology is cost-effective'

'What is the cost-effectiveness and the impact of different forms of housing and support on outcomes and care needs for different client groups?'

Research question: How do different models of ECH promote and sustain the wellbeing of people living with dementia?

Aim 1: To explore the ability of ECH to promote and sustain the wellbeing of people living with dementia

Aim 2: To identify and explore key factors that impact on the benefits and challenges of ECH for people living with dementia and their family members

Aim 3: To explore the relative advantage and disadvantages of different models of ECH for residents living with dementia

Aim 4: To develop a comprehensive knowledge exchange strategy that will maximise opportunities for the study findings to inform social care practice, working with commissioners, decision-makers, and providers.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 06/12/2021, West Midlands - Coventry & Warwickshire Research Ethics Committee (The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS, UK; +44 (0)207 1048009; coventryandwarwick.rec@hra.nhs.uk), REC ref: 21/WM/0232

Study design

Observational mixed methods multicentre case series

Primary study design

Observational

Secondary study design

Case series

Study setting(s)

Home

Study type(s)

Other

Participant information sheet

Health condition(s) or problem(s) studied

Dementia

Interventions

This 19-month project will use a mixed-methods design to explore how ECH can support people to live well with dementia. The mixed-methods framework will combine in-depth qualitative

data from nine case study sites, with quantitative data on ECH provision for people living with dementia in order to develop insight into who lives in ECH, and what are the relative advantages and disadvantages of different models of practice for different people living with dementia.

A profile of each scheme will be developed. This will include descriptive information with respect to the location, size, and design of schemes. It may also include researcher-generated photographs. Quantitative data will be collected and will include characteristics of residents living with dementia (e.g. age, gender, previous accommodation), care hours, and funding sources. It will also include demographic information about other people who reside there, and the amount of care that they require. Quantitative data will be analysed using descriptive and comparative statistics in order to establish any significant differences between different models of provision.

Qualitative in-depth interviews will also be carried out at each site with up to 5 residents with dementia, 1 interview with a resident not living with dementia, 4 members of staff, the adult social care commissioner and the scheme's social care link worker. This will provide a total of 12 interviews per site, with an overall project sample for qualitative interviews of 108 interviews; up to 45 people living with dementia, 9 people living without dementia, 36 ECH staff, up to 9 adult social care commissioners (dependant on geographical location of schemes) and up to 9 social care link workers.

Intervention Type

Other

Primary outcome measure

The benefits and challenges of ECH for people living with dementia and their family members, assessed using in-depth qualitative interviews with multiple participants at each case study site at a single point in time (between February to June 2022)

Secondary outcome measures

The relative advantages and disadvantages of different models of ECH for residents living with dementia, assessed using in-depth qualitative interviews with multiple participants at each case study site at a single point in time (between February to June 2022)

Overall study start date

01/06/2021

Completion date

31/12/2022

Eligibility

Key inclusion criteria

For participants taking part in interviews at case study sites:

1. Have first-hand knowledge and experience of the case study site at hand
2. Occupy one of the following roles:
 - 2.1. Resident living with diagnosed or suspected dementia
 - 2.2. Resident without diagnosed or suspected dementia
 - 2.3. Staff role at the particular scheme (housing or care)
 - 2.4. Adult social care commissioner relevant to the scheme
 - 2.5. Social care link worker relevant to the scheme

Participant type(s)

Mixed

Age group

Mixed

Sex

Both

Target number of participants

(Up to) 108 participants across 9 study sites (max 12 at each site)

Total final enrolment

100

Key exclusion criteria

Participants will be excluded if:

1. They are not connected to the selected ECH scheme sites included
2. They do not have the capacity to take part in interviews
3. They refuse consent or request to be withdrawn from the study after consent has been provided
4. A personal consultee advises against their participation on their behalf
5. They shows signs of negative attitude, discomfort or upset, or of not wishing to take part, when explaining the study and study processes, or before or during the interview

Date of first enrolment

13/12/2021

Date of final enrolment

15/07/2022

Locations**Countries of recruitment**

England

United Kingdom

Study participating centre

Not provided at time of registration

United Kingdom

-

Sponsor information

Organisation

University of Worcester

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Sponsor type

University/education

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Funder(s)**Funder type**

Government

Funder Name

School for Social Care Research

Alternative Name(s)

NIHR School for Social Care Research, SSCR

Funding Body Type

Government organisation

Funding Body Subtype

National government

Location

United Kingdom

Results and Publications

Publication and dissemination plan

As a minimum, and in accordance with the NIHR School for Social Care Research (UK) minimum required outputs, dissemination will include:

1. A project summary, including key findings and insights, to be featured on relevant professional web pages (e.g. Association for Dementia Studies website, NIHR SSCR website, HousingLIN website).
2. Articles published in peer-reviewed academic and professional journals
3. Conference or other online platform events (e.g. UK Dementia Congress, HousingLIN events)
4. Social media activities throughout the project and beyond in a way that captures the voices of people living with dementia in ECH

All of the dissemination activities will be channelled through a comprehensive Dissemination and Impact Plan developed soon after the project starts, so that impact can be planned for, and embedded into the research process. Dissemination channels will include key national networks, such as the HousingLIN, HDRC, and the Dementia and Housing Working Group. As the research progresses, the researchers will have 6-monthly reviews of the plan in order to maximise our dissemination efforts in line with concurrent opportunities. At the final review meeting of the Dissemination and Impact Plan, the researchers will plan additional activities to take place after the research ends.

The Research Team will work with members of the Advisory Group to consider an array of appropriate media to convey findings to different stakeholders. Emphasis will be on identifying mechanisms to provide prompt, informative and timely knowledge exchange to stakeholders. In particular, Jeremy Porteus and the HousingLIN network will work closely with the Research Team to develop a plan that ensures key audiences are influenced (e.g. the current all-party parliamentary group (APPG) on Housing and Care for Older People Inquiry and the Commission on Housing and Care in Social Care, chaired by the Social Care Institute for Excellence (SCIE)).

The researchers will make a suite of Key Insight booklets, which will be made available online, free of charge, to three key stakeholder groups involved with ECH: people affected by dementia, care providers and commissioners of adult social care. These booklets will draw together the main findings that are most relevant to each group to ensure future ECH can successfully support the needs and wellbeing of people living with dementia.

All contributing authors will be acknowledged in publications according to good practice authorship guidelines; the funders will be acknowledged in all study outputs in line with NIHR guidance. A publicly accessible report summary will be available on the University of Worcester Association for Dementia Studies website post-study and findings will be promoted widely through study partners. A full study report will be made available to the funder.

Intention to publish date

01/12/2023

Individual participant data (IPD) sharing plan

Data will be available to share upon request to the Association for Dementia Studies at the University of Worcester, after completion of the study (31/12/2022). It will include anonymised transcripts of interviews (for qualitative analysis). This data will be retained for 10 years. Personal data from participants will not be shared and will be securely destroyed 3 months after the end of the study. Participants will give consent for the use of their anonymised data, for the purposes of research, at the point of collection. For access to datasets following the completion of this study, contact Teresa Atkinson (t.atkinson@worc.ac.uk) in the first instance, or the Association for Dementia Studies generally at dementia@worc.ac.uk.

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	Consultee information sheet version 0.3	01/12/2021	10/01/2022	No	Yes
Participant information sheet	Professional information sheet version 0.3	01/12/2021	10/01/2022	No	Yes
Participant information sheet	Resident information sheet version 0.3	01/12/2021	10/01/2022	No	Yes
Participant information sheet	Resident information sheet (easy read version) version 0.3	01/12/2021	10/01/2022	No	Yes
Protocol file	version 0.3	16/11/2021	10/01/2022	No	No
HRA research summary			28/06/2023	No	No