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Supporting people living with dementia in Extra Care Housing

Submission date
10/01/2022

Recruitment status
No longer recruiting

Registration date
13/01/2022

Overall study status
Completed

Last Edited
13/12/2022

Condition category
Mental and Behavioural Disorders

[ ] Prospectively registered
[X] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] 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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Integrated Research Application System (IRAS)
303475

Central Portfolio Management System (CPMS)
51740

National Institute for Health and Care Research (NIHR)
102645

Protocol serial number
20/21 0010, , /ER/UWTA-P180

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

Primary study design
Observational

Study design
Observational mixed methods multicentre case series

Study type(s)
Other

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(s)
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)

Key secondary outcome(s)
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)

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

Healthy volunteers allowed
No

Age group
Mixed

Sex

All

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
United Kingdom

England

Study participating centre
Not provided at time of registration
United Kingdom
-

Sponsor information

Organisation
University of Worcester

ROR
https://ror.org/00v6s9648

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

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?
HRA research summary			28/06/2023	No	No
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