This protocol has regard for the HRA guidance

FULL/LONG TITLE OF THE STUDY

Supporting people living with dementia in Extra Care Housing (DemECH)

SHORT STUDY TITLE / ACRONYM

DemECH

PROTOCOL VERSION NUMBER AND DATE

0.3 (16.11.21)

RESEARCH REFERENCE NUMBERS

IRAS Number:	**303475**
SPONSORS Number:	**20/21 0010**
FUNDERS Number:	**102645/ER/UWTA-P180**

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature:

Date:

17/11/21

Name (please print):

Dr John-Paul Wilson

Position:

Deputy Pro Vice Chancellor Research

Chief Investigator:

Signature:

Date: 29/11/21

T Atkinson

....

Name: (please print):

....T.Atkinson...

LIST of CONTENTS

KEY STUDY CONTACTS

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Funder(s)	National Institute for Health Research School for Social Care Research The London School of Economics & Political Science Houghton Street London WC2A 2AE
Committees	DemECH Advisory Group

STUDY SUMMARY

Study Title	Supporting people living with dementia in Extra Care Housing (DemECH)
Internal ref. no. (or short title)	DemECH
Study Design	Mixed methods multiple case study
Study Participants	Residents living in Extra Care Housing (ECH) (including people living with and without dementia); family carers of people living with dementia in ECH; ECH staff and managers, adult social care commissioners, ECH social care link workers
Planned Size of Sample(if applicable)	**Survey:** 3 surveys with 100 responses per survey **Case study sites:** 9 ECH schemes

	Interviews: At each case study site: 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 workers. **Three online focus groups** will be convened: one comprising dementia leads from ECH, a second with providers of care within ECH, and a third with commissioners of adult social care.
Follow up duration (if applicable)	N/A
Planned Study Period	1st June 2021 to 31st December 2022
Brief Synopsis	This project 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 project will investigate the advantages and disadvantages of different models of ECH for people living with dementia. The project will last for 19 months. It will commence 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). Findings from these will inform later data collection. We 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, we 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 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 project will be informed throughout by the Advisory Group, which includes people living with dementia. This will ensure the project is rooted in the perspectives of all stakeholders.
Research Question/Aim(s)	**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 our findings to inform social care practice, working with commissioners, decision-makers, and providers.

FUNDING AND SUPPORT IN KIND

FUNDER(S)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
National Institute for Health Research (NIHR) School for Social Care Research (Grant number 102645/ER/UWTA-P180)	£99,600

ROLE OF STUDY SPONSOR AND FUNDER

The University of Worcester (UW) is the Sponsor for this study. UW takes responsibility for ensuring that the design of the study meets appropriate standards and that arrangements are in place to ensure appropriate conduct and reporting. UW will ensure that all necessary approvals from a HRA research ethics committee are obtained before engaging participants in the study. Signed ethically approved consent and acknowledgement forms from any participants who will be involved in the project will be obtained.

The study is funded by the National Institute for Health Research School for Social Care Research. The funder has not had any influence over the study design or analysis.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

The Research Team (Teresa Atkinson, Dr Simon Evans, Rebecca Oatley)

The Research Team are based at the Association for Dementia Studies at the University of Worcester. The Research Team will be undertaking all aspects of the research with guidance and advice from the Advisory Group.

DemECH Advisory Group (Professor Dawn Brooker MBE, Jeremy Porteus, Dr Vanessa Pritchard-Wilkes, Mr Stephen Medley, Professor Richard Humphries, Dr Julie Barrett, 2 User Representatives)

This group represents professionals with expertise across ECH and also includes two people living with dementia who live in ECH (experts by experience/User Representatives). The co-applicants to this proposal and User Representatives have detailed knowledge of the ECH sector enabling them to provide insight and guidance across the commissioning of adult social care and placements, the lived experiences of people living with dementia in ECH, understanding of the experiences of living with dementia in ECH from previous research, and a wealth of experience at policy level, both locally and nationally. Two of the co-applicants (Vanessa Pritchard-Wilkes and Stephen Medley) are providing their support in kind. The Advisory Group will play an important role in guiding the study and ensuring findings reflect the perspectives of people living with dementia and are beneficial to informing adult social care strategy and provision. There will be six Advisory Group meetings across the project.

User Representatives

The User Representatives will be supported by a familiar member of their ECH team and the PPI lead, Teresa Atkinson. Additional meetings will support their involvement. The initial meeting will explain the project in detail, discuss the nature of their role, and identify any individual support needs. A second meeting will address any particular training needs that may be identified. A third meeting will include a celebration party and lunch as recognition of their efforts, as well as an opportunity to evaluate their contribution, gain feedback and debrief of their involvement in the study.

KEY WORDS:	Dementia; Extra Care Housing; housing with care; adult social care; mixed methods case study

STUDY FLOW CHART

See **Appendix 1**: DemECH: Overview Diagram

And **Appendix 2**: DemECH: Gantt Chart

STUDY PROTOCOL

Supporting people living with dementia in Extra Care Housing (DemECH)

1 BACKGROUND

Extra Care Housing (ECH) is an increasingly popular form of housing for older people, often as a preferred alternative to a care home (Evans *et al.,* 2020). This project will explore ECH can help people to live well with dementia. ECH aims to support people to live in self-contained accommodation, with access to 24-hour care that is flexible and adapts to changing needs (Evans *et al.,* 2017). Schemes often also include access to communal amenities. The delivery of care is independent from the resident's lease or tenancy.

Many people appreciate the independence that having their own apartment within an ECH scheme can offer, while also being able to access help and support, enjoying opportunities for social interaction and feeling safe. Over a fifth of those living in ECH have dementia (Barrett, 2021), a number that is likely to increase as the number of people with dementia is increasing and people are being diagnosed at a younger age.

Supporting people living with dementia (and those that, in turn, care for, or otherwise support them) to live as well as possible in their communities, is a global public health goal (World Health Organisation, 2017). It is also the biggest challenge faced by adult social care, and incurs substantial financial costs for society. These have been calculated at £26.3 billion a year (Knapp *et al*., 2014), including £10.3 billion spent on social care. This represents 13.8% of the total cost of social care in the community and 69.7% of the total cost of social care in residential care settings.

ECH has potential to be an alternative to costly, and sometimes unpopular, residential care for those living with dementia (Holland *et al*., 2015). Previous studies have highlighted key features of ECH that can help people with dementia, including dementia-friendly design, flexible care, appropriate technology, and lots of opportunities for social activities (Twyford, 2018; Evans *et al.,* 2020).

Three different approaches have been taken to supporting people living with dementia in ECH: some schemes have a separate area or unit for people living with dementia, others take an integrated approach, supporting people living with dementia alongside residents without dementia, and a third type of scheme are only for people living with dementia. However, everyone has a different experience of dementia and little is known about what works well for whom.

2 RATIONALE

Limited awareness of what ECH is and a lack of clear evidence regarding the advantages and challenges of it for people living with dementia causes problems for practitioners who are responsible for adult social care commissioning and allocation (Smith *et al.,* 2017), as well as for older people and their families when making decision about future care (Verbeek *et al.,* 2019).

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 (Cyhlarova and Clark, 2019). 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 cost-effectiveness and the impact of different forms of housing and support on outcomes and care needs for different client groups'*

The topic of living with dementia in ECH also emerged as a key area for future research in previous NIHR-funded projects carried out by the Co-Principal Investigators (ECHO: CO88/CM/UBDA-P73 and ASSET: T976/T11-017/UWSE). These research projects also included interviews with a range of stakeholders, including people living with dementia, family carers, adults social care commissioners and ECH care staff. Additionally, the research was identified as a priority by people living with dementia in focus groups undertaken by the co-applicant, the Housing & Dementia Research Consortium (HDRC, 2016).

This project will include a comprehensive knowledge exchange strategy that will maximise opportunities for the findings to inform social care practice, future commissioning, and public awareness of ECH. These findings will help ensure that people living with dementia can make decisions about, and be supported, in the most appropriate and cost-effective setting. Findings will be of particular relevance to policy and practice as they will contribute new understanding with respect to which models of ECH work best for people living with dementia, family carers, and practitioners.

3 THEORETICAL FRAMEWORK

This study is a mixed methods design that combines in-depth qualitative data from multiple case study sites and quantitative data on ECH provision for people living with dementia. This approach is suitable as it will reveal insight into the experiences of people living with dementia, and the ways in which different models of ECH provision can be a part of adult social care's response to supporting people to live well with dementia. In effect, this will contribute to a growing evidence base with respect to practice in ECH housing that is rooted in the perspectives of people living with dementia.

The mixed methods approach is valuable in health and social care research as it draws upon both qualitative and quantitative methods in order to provide insight into the multiple influences that impact upon intersections between people and the services or interventions that are provided. With respect to this study, the mixed methods approach is suitable for exploring and answering a research question that lies at the intersection between living well with dementia and the provision of ECH.

In order to understand the perspective of people living with dementia in ECH, qualitative interview data will provide insight into individual perspectives, and the wider social and political systems that influence different stakeholders involved in ECH. Additional quantitative data at each case study site will ensure that detailed descriptive case studies can be developed. This data will contextualise the qualitative data, and contribute to a broader understanding of the population in ECH, and the cost-effective nature of such support. This will provide new knowledge that recognises the intersections and competing priorities of different stakeholders involved in the provision of ECH. In turn, the findings will be shaped into Key Insight booklets (and other dissemination work) designed to improve knowledge and awareness of the ability of different models of ECH to promote and sustain the wellbeing of people living with dementia.

The mixed methods approach aligns well with a biopsychosocial model of dementia (e.g. Kitwood, 1997; Spector and Orrell, 2010) and an ecological systems approach that is useful in understanding the interrelated nature of person and context (Bronfenbrenner, 1995). The biopsychosocial model of dementia recognises that the reality of living with dementia is impacted by social constructs, history, and interaction, as well as the physiological changes within the brain (Kitwood, 1997; Spector and Orrell, 2010). Stemming from this model is the concept of ecopsychosocial interventions, that are designed to enable people and their families to live well with dementia (Zeisel *et al.,* 2016). The prefix 'eco' recognises that the environment in which a person lives can have an important impact on the experience of dementia (ibid.). In the case of this study, the environment includes both the physical and social location(s) that ECH provides. With respect to older adults in general, Lawton's (1973) 'environmental press model' provides a basis for describing the optimal 'middle level' environment as one that is neither too stressful, nor too supportive. ECH can be framed as an ecopsychosocial intervention that has an inherent flexibility designed to adjust to Lawton's appropriate middle level, such that the environment remains appropriate (neither too stressful, nor too supportive) as the person ages and needs potentially change. Bronfenbrenner's (1995) 'ecological model' provides a similar conceptual theory focussed upon a symbiotic relationship between person and context. Combining the biopsychosocial model of dementia with a systems theory approach ensures that this project has an underpinning theoretical framework that considers the influence of wider political, economic, and societal level factors, as well as the individual experience of living in ECH. In turn, this will ensure that the insight generated is relevant to people living with dementia, the priorities of adult social care, and the wider stakeholders involved in ECH for people living with dementia (e.g. care providers, housing providers, commissioners).

The diagram in **Appendix 1** shows an overview of the study framework.

3.1 Note on terminology

For the purposes of this study, we will use the terms 'people living with dementia' and 'family carers'. The focus of this study is on ECH, and thus to denote people as 'patients' would be problematic as it reduces an individual's personhood and limits identity to the scope of their medical condition and interaction with health services. "Service user" can have similar connotations with respect to a relationship with social care services. Although the NIHR SSCR more usually refer to "users", we would concur that this has problematic issues with respect to power dynamics and dependence that are unhelpful to the perception of people living with dementia. DEEP (Dementia Engagement and Empowerment Project, 2015) guidance also suggests avoiding terms such as "patient", "service user" or "client", and suggests "person/people with dementia" may be more acceptable. Furthermore, some residents living in ECH may or may not "use" care provision, or "use" local authority provision and thus, the term "people living with dementia" is felt to be more inclusive and avoid a potential implication of a hierarchy between different persons.

During the case study and interview/diary stages of research, we will also refer to "residents living with dementia" or "residents living without dementia". These terms recognise the (potential) long-term and permanent nature of the person's tenancy or lease agreement in the particular ECH scheme. Whilst these are overarching terms, the in-depth nature of the qualitative design gives opportunity to further contextualise the individual differences, roles, and relationships that each of the people living with dementia exist within in. It is also likely participants themselves will express a range of different terms in their qualitative data, as participants will be drawn from a range of different backgrounds, roles, and sectors; we will endeavour to make it clear how the varied terminology relates, where it coheres or diverges.

The term “family carer” is used to designate all those who informally support someone who is living with dementia, despite the fact they may or may not be family, may or may not see themselves in the role of a carer (in fact may find that term restricting of their identity). Where the family carer lives in the ECH with the resident living with dementia, they will be described as a “family carer resident”.

As per NIHR SSCR guidance, the term “practitioner” is used to denote any person in a professional capacity in the ECH environment. That includes (but is not limited to) ECH volunteers, care staff, managers, social care link workers and adult social care commissioners.

We will use the term “stakeholders” as a broad term to denote all of the above, but also anyone else who has an interest or involvement in ECH at any level (for example adult social care commissioners, social care link workers, staff and volunteers, other health care professionals, other local authority leads, and community members and groups).

Finally, it is important to note that the term ECH is not used by all providers. Terms such as “assisted living” and “very sheltered accommodation” can be used by providers to denote a model of housing and care provision that is akin to the ECH model. Thus, in this study ECH is defined as a site of multiple occupation, that supports 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. These criteria are based on that used in previous research with respect to ECH (e.g. Evans *et al.,* 2020).

4 RESEARCH QUESTION/OBJECTIVES

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

4.1 Objectives

Objective 1: To identify and explore key factors that impact on the benefits and challenges of ECH for people living with dementia and their family members

Objective 2: To explore the relative advantage and disadvantages of different models of ECH for residents living with dementia

Objective 3: To develop a comprehensive knowledge exchange strategy that will maximise opportunities for our findings to inform social care practice, working with commissioners, decision-makers, and providers.

4.2 Outcomes

Outcome 1: Identification of the benefits and challenges of ECH for people living with dementia and their family members

Outcome 2: Identification of the relative advantages and disadvantages of different models of ECH for residents living with dementia.

Outcome 3: Development of a comprehensive knowledge exchange strategy that will include the production of Key Insight booklets for different stakeholder groups (people affected by dementia, care providers and commissioners of adult social care) based upon findings and co-produced relevant Advisory Group members.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

This 19-month project will use a mixed method 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 (e.g. profile of residents, care hours, funding sources) 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.

The project will comprise four phases:

Phase One: Scoping literature review

Phase Two: Survey of people living with dementia, family carers and adult social care commissioners re: existing provision, knowledge, and experiences

Phase Three: Mixed method case studies

Phase Four: Focus group data synthesis

5.1 Phase One: Scoping literature review

Phase One will involve a scoping review of the existing literature on supporting people living with dementia in ECH in order to identify existing knowledge with respect to the key advantages and challenges. This will inform the nature and scope of survey and interview questions in subsequent phases.

5.2 Phase Two: Survey of people living with dementia, family carers and adult social care commissioners re: existing provision, knowledge, and experiences

Phase Two will build on the findings of the scoping review and will involve undertaking three surveys. Ethical approval for the undertaking of these surveys will be sought from the University of Worcester College of Health, Life and Environmental Sciences Ethics Panel. Permission for this has been granted by the NIHR SSCR. The three surveys will be undertaken with:

- People living with dementia, to ascertain their awareness and knowledge of ECH and, where appropriate, their experiences of living in an ECH setting.

- Family carers of people living with dementia in ECH will be invited to share their views on the benefits and challenges of ECH.

- Adult social care (ASC) commissioners in England will be asked to identify key elements of current ECH strategies for people living with dementia including levels of provision, funding, profile of recipients (ethnicity, gender, etc.), benefits and challenges.

The surveys will elicit a combination of quantitative and qualitative information. We anticipate a minimum of 100 responses for each survey. Surveys will be hosted using the Survey Monkey online platform that is fully GDPR compliant. However, a paper-based version will also be available for people living with dementia if the online platform is inaccessible.

5.3 Phase Three: Mixed method case studies

Phase Three will involve in-depth study at nine case study ECH studies. These sites with be purposively selected with three from each model of scheme (integrated, separate dementia unit, specialist dementia). We will also seek to address diversity in our case study sites in terms of ethnicity, gender, sexual orientation, rural/urban location, and size of scheme. Furthermore, we know that some schemes have separate housing and care providers, which will also be represented across the sample.

Recruitment of the case study sites will be coordinated via the Housing and Dementia Research Consortium (HDRC). This is a national network (hosted by the University of Worcester) of housing and care providers, commissioners, researchers, and others with an interest in research into housing and dementia.

During Phase Three, we will build a profile of each scheme. 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.

Phase Three will also involve in-depth interviews 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. It should be noted that where a resident living with dementia lives in ECH with a spouse/partner (who may or may not be living with dementia), each partner will be offered the opportunity to participate in an interview together and/or apart. However, a family carer resident in ECH, will be excluded from being interviewed as the resident without dementia at the ECH case study site. That is, the resident not living with dementia will be selected from a population who are neither living with dementia, nor living with a partner who is living with dementia.

Interviews will be conducted by members of the Research Team (Teresa Atkinson, Rebecca Oatley). People living with dementia will be given the option to take part in the interview with the support of another person (e.g. care staff member, family carer). The team will follow established procedures developed specifically for people living with dementia to ensure all are fully supported in their participation. We anticipate that interviews will last up to an hour, but the nature of qualitative interviews can vary between people and thus, there will be flexibility planned for, but with mindfulness in respect of the wellbeing and fatigue of all parties involved. Where possible, interviews will be face-to-face, however, we recognise that due to the ongoing impact of COVID-19, it might be necessary to conduct interviews via telephone or video conferencing technology. If required, people living with dementia, will be provided with appropriate support to enable participation via alternate technology so as not to disadvantage or distress them.

A draft interview schedule will be developed following the findings in Phase One and Two, and in conjunction with the advice and expertise of the Advisory Group, including the User Representatives.

The interview schedule will be piloted prior to data collection. Table 1 demonstrates the different groups targeted for interview, the number of interviews planned and the focus of interview questions.

Participant Group	**Number of participants to be interviewed**	**Focus of interview questions (to be refined and developed following Phase One and Two)**
Residents living with dementia	Up to 5 per case study site	Advantages and disadvantages of the ECH environment (e.g. care flexibility, technology, shared facilities, connections with the community, relationships with others, activities)
Resident not living with dementia	1 per case study site These will not be conducted at dementia specific sites	Their perspective on the provision of ECH for people living with dementia (e.g. inclusive activities, relationships with others, impact of stigma)
ECH staff members	4 per case study site	Their perspective on the benefits and challenges of supporting people living with dementia to promote and sustain wellbeing in ECH environment.
Social care link worker	1 per case study site	Their perspective on the benefits and challenges of supporting people living with dementia to promote and sustain wellbeing in ECH environment.
Adult social care commissioner	1 per case study site	Their perspective on the benefits and challenges of commissioning ECH for people living with dementia.

Table 1 Interview participants and focus of interview questions

Interviews will be audio recorded, transcribed, and undergo thematic analysis (Braun and Clarke, 2006) using NVivo software. A sample of transcripts will be discussed by members of the Research Team (Teresa Atkinson, Dr Simon Evans, Rebecca Oatley) in order to develop a coding frame for full analysis. Qualitative data will be analysed for themes overall, and in relation to the different models of ECH.

All data collected during Phase Three will have identifying features removed and where appropriate, pseudonyms will be used. Data management, protection and confidentiality is further detailed in Section 8.

5.4 Phase Four: Focus group data synthesis

Three online focus groups will be convened: one comprising dementia leads from ECH, a second with ECH care providers, and a third with commissioners of adult social care. Participants will be recruited from members of the HousingLIN and the Housing and Dementia Research Consortium. Groups will have 5-8 participants and will provide an opportunity to synthesis the data outcomes from previous phases into meaningful guidance for practitioners and people living with dementia. Relevant members of the Advisory Group will be invited to lead the focus groups (e.g. Dr Vanessa Wilkes-Pritchard will be invited to lead the ECH care providers focus group). Focus groups will be audio recorded using in-built video conferencing software and comments will be used to inform the preparation of Key Insight booklets.

6 STUDY SETTING

This study will identify nine ECH case study sites at which in-depth mixed methods data will be collected in order to address the research question. As different providers use different terminology to depict the ECH model, a criterion has been established based on previous research (see Section 3.1). These ECH schemes with be purposively selected with three from each model of scheme (integrated, separate dementia unit, specialist dementia). We will also seek to address diversity in our case study sites in terms of ethnicity, gender, sexual orientation, rural/urban location, and size of scheme. Furthermore, we know that some schemes have separate housing and care providers, which will also be represented across the sample.

Recruitment of the case study sites will be coordinated via the Housing and Dementia Research Consortium (HDRC). This is a national network (hosted by the University of Worcester) of housing and care providers, commissioners, researchers, and others with an interest in research into housing and dementia.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

The sample population in this study is a purposively selected group that includes the multiple stakeholders involved in the provision of ECH for people living with dementia. Table 2 demonstrates the inclusion and exclusion criteria for each sample during each phase of this project. All participation is voluntary.

Sample sizes are based on previous experience of carrying out research in ECH, which suggests these estimates are pragmatic with respect to recruiting people living with dementia, and sufficient to generate sufficient in-depth data in order to answer the research question. The Co-Principal Investigators worked on two previous NIHR-funded projects that used a similar approach (ECHO: CO88/CM/UBDA-P73 and ASSET: T976/T11-017/UWSE).

7.2 Sampling technique

The sampling technique throughout this study is purposive as the focus is on seeking in-depth data that will provide rich detail from participants who have ‘privileged knowledge’ about the topic under study (Denscombe, 2017, p. 41). Case study site selection will also be purposive. These sites will be selected with three from each model of scheme (integrated, separate dementia unit, specialist dementia), so as to explore the advantages and disadvantages of the relative models. We will also seek to address diversity in our case study sites in terms of ethnicity, gender, sexual orientation, rural/urban location, and size of scheme. Furthermore, we know that some schemes have separate housing and care providers, which will also be represented across the sample.

hase of research	Sample population	Inclusion criteria	Exclusion criteria	Size of sample
Phase Two: Surveys	People living with dementia	Self-identifies as living with dementia	n/a	100
	Family carers of person living with dementia in ECH	Family carer of person living/or who lived with dementia in ECH	n/a	100
	Adult social care commissioners	Employed in adult social care commissioner role and involved in the commission of ECH	n/a	100
Phase Three: **Case studies**	Case study site	ECH is defined as: - Self-contained accommodation - 24 hour care available onsite that is flexible and adapts to changing needs - Some shared/communal amenities - The delivery of care is independent from the resident's lease or tenancy. Willing to participate Located in England, UK	Non-ECH model of housing Located in Wales, Scotland, Northern Ireland or outside of UK	9
	Interviews with resident living with dementia	60+ years of age Diagnosis of dementia Resident in ECH case study site *May include additional interview with spouse/partner of the resident living with dementia if living together in ECH.	No diagnosis of dementia Does not live in ECH study site	5
	Interviews with resident not living with dementia	60+ years of age No diagnosis of dementia Resident in ECH case study site	Family carer resident of people living with dementia Does not live in ECH study site	1

	Interview with ECH staff members	Member of staff employed at ECH case study site	Not employed at ECH case study site Volunteers	4
	Interview with social care link worker	A practitioner from the relevant local authority adult social care services	Outside of stated location Job role outside of adult social care	1
	Interview with adult social care commissioner	The relevant local authority adult social care commissioner at each case study site	Outside of stated location Other job role	1
Phase Four: Focus groups	ECH Dementia lead	Employed in a lead role with specialist dementia care knowledge	n/a	5-8
	ECH Care providers	Employed by an ECH care provider in a senior managerial capacity	n/a	5-8
	Commissioners of adult social care	Employed in adult social care commissioner role	n/a	5-8

Table 2 Sampling criteria and size for each method of data collection at each phase of research

7.3 Recruitment

7.3.1 Surveys

Surveys will be distributed across a range of existing networks. All participation will be voluntary and will involve self-identification of the appropriate eligibility criteria.

- People living with dementia will be recruited for the survey through members of the Housing and Dementia Research Consortium (HDRC; hosted by the University of Worcester) and through organisations, such as Age UK, Dementia UK, Admiral Nurses, the Alzheimer’s Society, Together in Dementia Everyday (TIDE) members, the Association for Dementia Studies’ newsletter, and social media. Some people living with dementia might be supported to participate by relevant practitioners or family carers.

- Family carers of people living with dementia in ECH will be recruited through the above organisations, we will also promote this opportunity through Dementia Carers Count and Carers UK.

- The adult social care commissioners will be identified through the Association of Directors of Adult Social Care (ADASS) in England.

7.3.2 Case study sites

The purposive sampling of case study sites will be coordinated by the Housing and Dementia Research Consortium (HDRC; Dr Julie Barrett). Sites will only be selected from those in England due to the devolution of health and social care legislation across the UK.

Interview data- Recruitment will be coordinated by the Research Team (Teresa Atkinson, Rebecca Oatley) and the Advisory Group (Dr Julie Barrett, and Dr Vanessa Pritchard-Wilkes) in conjunction with the ECH manager and/or dementia lead at each case study site. Where appropriate, researchers (Teresa Atkinson and Rebecca Oatley) will also attend resident group meetings/activities and display recruitment literature around the site. All participation will be voluntary. ECH residents will be approached via a member of ECH staff to invite them to participate in the study, help them to understand the purpose and requirements of participation, and assist them in deciding if they would like to participate.

Relevant practitioners connected to each study site will also be identified and asked by researchers (Teresa Atkinson and Rebecca Oatley) in conjunction with ECH managers to self-select to participate in the interview opportunity.

7.3.3 Focus groups

Participants for the three focus groups will be identified through the HDRC members networks. These extensive networks will facilitate reach to appropriate participants who will self-select into the study. Recruitment will cease once sufficient numbers have consented to participate in the online focus group exercises.

7.4 Consent

7.4.1 Surveys

Participant information explaining the nature and objectives of the survey, and consent questions, will be presented as part of the online questionnaire itself. This explains the purpose of the study, the requirements of taking part, and the possible risks associated with participation. All participants must answer three questions before being able to continue with the survey:

I am over 18 years old (Tick box)

I have read and understood the information about the project (Tick box)

I agree to take part in the survey (Tick box)

All data collected at this stage is anonymous and is focussed upon provision, knowledge, and experiences of ECH for people living with dementia. The survey responses and the results of a scoping literature review will be used to refine the focus of interviews in the subsequent phase.

The survey information and consent procedures will be designed and approval will be sought from the University of Worcester College of Life, Health and Environmental Sciences Research Ethics Panel.

7.4.2 Case study sites

Case study sites will be purposively selected to accord with the inclusion/exclusion criteria and models identified. Members of the Advisory Group (Dr Julie Barrett, Dr Vanessa Wilkes-Pritchard) will support with identification of potential sites. Case study site managers will be approached by the Research Team (Teresa Atkinson, Rebecca Oatley) who will explain the nature of the study and its aims and objectives.

This may be done via telephone call or via email. As part of this process and to aid understanding, case study site managers will be provided with a project information sheet setting out the details and expectations of the nature of their involvement.

Participation by the ECH site will be voluntary and those who wish to participate will provide an email confirming their involvement. Anonymity of the case study sites will be preserved throughout the study. All data collected will use pseudonyms and any images taken will not capture any identifiable features.

7.4.3 Interviews

All participants taking part in interviews will be presented with a participant information sheet explaining the nature and objectives of the study, the requirements of taking part, and the possible risks associated with their participation. They will be given the opportunity to ask questions before being also presented with a consent form. Participant information will be tailored to each participant group. Table 3 sets out the different participation information sheets that will be designed and provided. No interview (face-to-face or via video/telephone conferencing) will proceed without the written consent of the participant at hand.

1.	For residents living in ECH with, and without dementia
1a.	A simplified “easy-read” version of the above
2.	For practitioners working in, or with ECH
3.	For people acting as a personal consultee of someone unable to give informed consent (with a consultee declaration form rather than consent form)

Table 3 Versions of Participant Information Sheets and consent forms to be developed

Participant information and consent documents will be designed in line with HRA guidance (http://www.hra-decisiontools.org.uk/consent/) and approved by the appropriate HRA Research Ethics Committee (REC)

Residents living with dementia A key part of the research design is the inclusion of people living with dementia. Ethically, it ensures that the perspectives of people living with dementia in ECH are represented in line with a “nothing about us, without us” ethos. In addition, people living with dementia in ECH can provide first-hand perspectives with regards to the experience of living in ECH. However, involving people living with dementia in research means that attention must be drawn to the issue of capacity to provide informed consent to participate. Indeed, some people living with dementia will lack the capacity to make an informed decision with regards to participation, whilst others might experience fluctuations in their capacity as a result of their dementia.

For the written consent process to be ethical and valid in law, participants with capacity must be able to:

- Understand the purpose and nature of the research
- Understand the requirements of participation and potential risks/benefits of participation
- Understand that participation is voluntary
- Be able to retain the information long enough to decide whether they wish to participate
- Be capable of making this decision at the particular time it is needed to be made

The Research Team will be mindful of the potential vulnerabilities and implications of participation in the research for participants and will need to develop sensitive and relevant practices of informing and negotiating consent to participate. An initial consultation with ECH managers (with additional guidance from family/friends as appropriate), will identify residents who are likely to be willing to participate. The Research Team (Teresa Atkinson, Rebecca Oatley) will have an initial conversation with the resident to establish a judgment on that resident's understanding and capacity to provide informed consent. The Research Team member will make a written record of the conversation and the reactions of the resident. Where residents living with dementia do have capacity to make an informed decision with regards to participation, they will be offered the opportunity, and an information sheet and written consent form will be used prior to any data collection.

For those participants who are assessed to lack capacity to consent to participate in the research, the Research Team will seek the advice of a personal consultee in adherence with Policy & Compliance provided by the National Institute of Health Research using permission obtained from a consultee as provided for in the Mental Capacity Act (2005). The consultee will not be involved in the research in a way that would prejudice their advice. In such cases, the Research Team will:

a. Ask someone who knows the person well (e.g. a family member, friend or carer) whether they know if the person would object to taking part in the research

b. Consider what the person themselves appears to be telling us about being taking part, (even if they can't understand the whole idea of research project, a person might still be able to indicate positive or negative feelings)

Figure 1 Flowchart depicting consent process

c. Monitor the person before and during the interview for signs of distress. Cease the interview if observe or are alerted to signs of distress or upset

Figure 1 provides further detail of the process involved in assessing capacity and seeking informed consent for participation.

Staff and related practitioners All staff are also entitled to freedom from pressure to take part in research if they do not want to. It is recognised that participation in research about one's workplace or role could be sensitive and thus, the Research Team will be considerate to the pressures of balancing work commitments with involvement in the research. Informed consent about the requirements and risks of involvement will be essential.

All participants have the right to withdraw from the research at any time. They also have the right to withdraw their data after participation, which will be destroyed upon their request. It is considered unlikely that participants will experience any physical adverse effects as a result of their participation in the study. However, close attention will be paid to individual responses to the intervention by the staff in each care home and any adverse effects will be recorded, and the Research Team informed.

7.4.4 Focus groups

All participants will be presented with a participant information sheet prior to agreeing to take part. This will explain the nature and objectives of the study, the requirements of taking part, and the possible risks associated with their participation. All members of focus group activities are professionals and there should be no concerns with respect to their capacity to consent to participation.

8 ETHICAL AND REGULATORY CONSIDERATIONS

8.1 Assessment and management of risk

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 cost-effectiveness and the impact of different forms of housing and support on outcomes and care needs for different client groups’*

The topic of living with dementia in ECH also emerged as a key area for future research in previous NIHR-funded projects carried out by the Co-Principal Investigators (ECHO: CO88/CM/UBDA-P73 and ASSET: T976/T11-017/UWSE). These research projects also included interviews with a range of stakeholders, including people living with dementia, family carers, adults social care commissioners and ECH care staff.

8.2 Assessment and management of risk

The aim of this study is to explore the ability of ECH to promote and sustain wellbeing for people living with dementia. For the underpinning rationale and justification for this research, see Sections 1-3.

The co-applicants were involved in the design of this study. They represent a range of practitioners with an expertise in adults social care, housing, ECH, and living with dementia. The full Advisory Group, which includes two people living with dementia, will continue to advise and inform the study as it proceeds.

8.2.1 Potential risks/burdens/benefits

Survey - risks for people living with dementia/family carers

There is a risk that some people living with dementia/family carers will not be able to access to the online survey. In order to mitigate this risk, a paper version of the survey will also be developed and available. This is to maximise the response rate and ensure that no person is disadvantaged or distressed during the opportunity to participate. No personal or identifiable data will be recorded during the survey phase of data collection.

Risks for case study sites

Whilst a detailed descriptive profile of each case study site will be developed, all identifying information will be removed.

Researchers will be taking photographs/videos at case study sites; however, it will be imperative to have the correct photograph permissions to do so, and photographs will not contain any names, logos, residents, or members of staff.

Risks for practitioners (e.g. ECH staff)

At all stages, there is a risk that practitioners will find the research participation to be an extra burden in addition to their work responsibilities. However, the benefit is offset by getting their expert opinion and experiences, which is crucial to the aims and objectives of the study. Participation within the interview stage will be negotiated by the researchers alongside senior management team to ensure participation of staff members is both voluntary and does not impact their work responsibilities.

Participation in surveys will generate anonymous data and thus, there is no risk that staff can be identified in relation to their responses. During the interview stage, all interviews will be undertaken in a private space, and data will remain confidential within the study. The exception will be if a safeguarding disclosure is made. Appropriate safeguarding legislation and policy will always be adhered to (*Care Act 2014*).

It is not anticipated that participants will share personal information in the focus group, and participants will be reminded of this at the outset and during participation. All focus group participants will be asked to agree to act respectfully within the group environment.

Risks for resident participants

All interviews will be undertaken in a location of the resident’s choice. There is a risk that the preferred location may be a public space within the ECH location and therefore, we cannot guarantee that the interview will not be heard by others. However, we will discuss this risk with the resident before starting the interview and remind them that an alternate private location can be made available if required. Interview data will remain confidential within the study. The exception will be if a safeguarding disclosure is made.

All residents will be offered the choice to be accompanied by another person during the interviews if they so wish. Where a person living with dementia resides in ECH with their spouse/partner, both parties will be offered the opportunity to take part in an interview together and/or apart.

The focus of interviews will be the experience of living in ECH. This focus might include topics that could be personal, sensitive, embarrassing or upsetting. Researchers are experienced in dealing with sensitive topics and will always be mindful as to the resident's wellbeing. Residents will be reminded of the opportunity to cease the interview at any stage should they wish to.

Questions will be framed in terms of the benefits and challenges of living in ECH. Questions will be piloted to ensure there is no suggestion that our research means an ECH's future is under threat or that blame for any perceived failings in running it is being sought. This research is not an evaluation of specific ECH schemes, and we will take positive action to avoid this potentially upsetting impression.

There is a risk that semi-structured interviews can prompt conversation about personal or sensitive areas that participants may not be comfortable with. A list of question topics will be shown and talked through with participants (and their consultee if they have one) before interview. Residents will be told that they do not have to answer any question they are not comfortable with and may ask to move on, or stop the interview at any time. Researchers undertaking interviews will be alert to any signs of distress. If a resident shows signs of distress, or of reluctance to take part, at any time before or during interview, that interview will be paused, and the participant (and their consultee if they have one) asked if they are happy to continue, would prefer to re-arrange for another time, or withdraw altogether. With appropriate permission from the resident and/or consultee, the researchers will alert ECH staff to support a resident if they do become distressed or upset during the interview process.

A transcript of the interview will be offered to each participant (or their consultee if they have one) at a later date. Pseudonyms will be used in the transcript and any specific identifying details will be removed or altered to anonymise. Personal data will be kept secure and only accessible by the Research Team and will be destroyed after the study ends (for more detail, see Section 8).

8.2.2 Exposure to COVID-19

We will only undertake face to face data collection if local and national guidance allows visitors to ECH and the interviewees feel safe to do so. We will use appropriate PPE, physical distancing, and room ventilation also in line with local and national guidance. We will also take into account the specific organisational policies of the University of Worcester and the ECH housing providers involved. This situation will be continually monitored as it is likely to change, perhaps multiple times, throughout the duration of the project. We will also ask participants if they feel safe to conduct interviews face-to-face, or if they'd prefer to do so online or by phone. We recognise that should the situation with respect to COVID-19 change and we are unable to undertake any face-to-face interviews, we will be reliant on using video technology or telephone to undertake interviews. We accept that this could add a level of bias to our sampling, particularly of residents living with dementia that could disadvantage those who cannot access (with or without support) the relevant technology to participate.

8.3 Research Ethics Committee (REC) and other regulatory review and reports

HRA REC approval is required as per the contract with the funder (NIHR SSCR). As per the contractual agreement, no research activities will start until appropriate HRA ethical approvals are in place. This will be applied for via the Social Care Research Ethics Committee (SCREC) using the Integrated Research Application System (IRAS).

Under the terms of the *Mental Capacity Act 2005*, people who lack the capacity to consent cannot be included in research unless the research concerns their condition. This research is concerned with developing understanding of the provision of ECH in relation to people living with dementia, in order to develop the evidence base underpinning the option of ECH as a means through which to promote and sustain the wellbeing of people living with dementia. This will benefit both people living with dementia, and those who support them. Hence, the research is concerned with the condition and thus, involving people who lack capacity to consent can be justified under the terms of the *Mental Capacity Act 2005.*

Substantial amendments to procedures that require review by SCREC will not be implemented until that review is in place and other mechanisms are in place to implement at site. All correspondence with the SCREC will be retained. The Principal Investigator (Teresa Atkinson) will produce the annual reports (within 30 days of the anniversary date of the approval) as required, and notify SCREC at the end of the study. If the study is ended prematurely, the Principal Investigator (Teresa Atkinson) will notify the SCREC, including the reasons for the premature termination. Within one year after the end of the study, the Principal Investigator (Teresa Atkinson) will submit a final report with the results, including any publications/abstracts, to the SCREC.

8.4 Regulatory review and compliance

The Association for Dementia Studies is designated as a Research Centre within the University of Worcester. Its overall governance and quality assurance systems are rigorous and set in place by the University of Worcester. We work within the legislative framework of English Law. Of particular pertinence to our work are the *Mental Capacity Act 2005*; the *Equality Act 2010*; the *Data Protection Act 2018* and the *Freedom of Information Act 2000*. We work as professionals within the codes of conduct from the General Social Care Council, British Psychology Society and the Nursing and Midwifery Council.

Once permissions have been granted for access to each case study site, the researchers accessing those sites will familiarise themselves with local policies and procedures and abide by them (e.g. identity badges, DBS clearance, health, and safety, safeguarding). Before any individual recruitment can begin at each site, the Principal Investigator (Teresa Atkinson) will ensure that appropriate approvals from participating organisations are in place.

8.5 Amendments

Amendments will be decided amongst the project management team. For any amendment to the study, the Principal Investigator or designee, in agreement with the sponsor, will submit information to the appropriate body in order for them to issue approval for the amendment. The Principal Investigator or designee will work with sites so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

8.6 Peer review

This study has undergone high quality peer review as part of the bidding process for funding. It was submitted to the NIHR SSCR programme. The study proposal was internally peer reviewed by Professor Eleanor Bradley, Director of Research & Knowledge Exchange, within the University of Worcester, submitted for review by the NIHR Research Design Service, as well as independent reviewers on the SSCR committee panel, with amendments made in line with reviewer feedback

8.7 User, Carer and Practitioner Involvement

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. The topic of living with dementia in ECH also emerged as a key area for future research in previous NIHR-funded projects carried out by the Co-Principal Investigators (ECHO: CO88/CM/UBDA-P73 and ASSET: T976/T11-017/UWSE). These research projects also included interviews with a range of stakeholders, including people living with dementia, family carers, adults social care commissioners and ECH care staff.

Two people living with dementia in ECH are involved as User Representatives on the Advisory Group for this project. They will be involved at each of the six planned Advisory Group meetings in order to provide advice and guidance as the research progresses. They will also be directly consulted at each stage of the study (e.g. developing information sheets, survey questions, interview schedules, data synthesis). This will support the Research Team in ensuring that information is accessible and that the focus of the research is centred upon the perspectives of people living with dementia.

The User Representatives will be supported by a familiar member of their ECH team and the User Representation Lead (Teresa Atkinson). Additional meetings will support their involvement. The initial meeting will explain the project in detail, discuss the nature of their role, and identify any individual support needs. A second meeting will address any particular training needs that may be identified. A third meeting will include a celebration party and lunch as recognition and reward for their efforts, as well as an opportunity to evaluate their contribution, gain feedback and debrief of their involvement in the study. User Representatives will be offered payment at £30 per ninety-minute meeting and we estimate £20 per meeting for travel. No User Representative will be out of pocket and we will follow best practice guidelines about offering payments so that we prevent problems in relation to the benefits that they might receive. Lunch and refreshments for in-person meetings will be provided by the University of Worcester. User Representatives will also have the opportunity to contribute to dissemination activities and conference attendance.

Members of the public are also being actively sought to participate in the Phase One surveys. Alongside the scoping literature review, this input will help shape the selection of the nine case study sites and interview schedules for each sample population.

8.8 Protocol compliance

Protocol deviations will be adequately documented on the relevant forms and reported to the Principal Investigator and Sponsor immediately.

8.9 Data management, protection, and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 2018 with regards to the collection, storage, processing, and disclosure of personal information and will uphold the Act's core principles.

Participants will be provided with a data privacy notice, which outlines how we intend to use and store their data for the stated purposes of the study. This will be covered in the information sheet and consent forms completed prior to any data collection. Only members of the Research Team will have access to the data. Minimal personal data will be collected in line with the minimum requirements necessary to undertake the study (e.g. name and preferred contact details).

Any face-to-face meetings (interviews or other audio data) will be recorded digitally on an encrypted recording device, with recordings transferred to secure cloud-based storage on the University One Drive at the first opportunity in preparation for transcription using a trusted external transcription service. Interviews and focus groups sessions conducted online meetings using Microsoft Teams will be recorded using the facilities provided on Teams, which includes an automatic transcription option. These recordings are saved to Microsoft Stream (a secure cloud-based service).

Transcripts will be checked for accuracy and anonymised through the removal of people's names and other personal information. Where necessary, pseudonyms will be used, with unique participant identification codes used in data storage. All study participants will have a code identifier known only to the Research Team. A key to codes will be securely stored separately. However, it should be noted that information on a participants' place/role within ECH scheme will be important to retain for the sake of context; it is possible participants with a particular role may be identifiable by that role, if the ECH is identifiable. However, this is unlikely given that there are estimated to be over 1600 ECH schemes in the UK. Participants' preferences on anonymity and identification will be gathered as part of the data collection process and materials reporting on this research will be checked by participants for satisfaction regarding the level of anonymity. Following checking, interview and audio recordings will be deleted. The exception will be where there is specific written consent to reproduce a section of anonymised audio data/commentary for the purposes of dissemination. These will be stored via a participant code and any personal details will not be recorded outside of the record.

Transcripts will be stored electronically on computers and access will be controlled via passwords and permissions to dedicated study folders. Where it is necessary to create hard copies of transcripts, then these will be securely stored in locked filing cabinets that are accessible only to research staff. Participants' personal details (including their names and addresses) will only be used to maintain contact with participants. This will be stored separately from transcriptions and will be kept in a separate file on a password protected computer at the University of Worcester. Access to data will be limited to quality control, audit, and analyses. Data shared between sponsor and co-investigators will be anonymised to minimise breach of confidentiality.

8.8.1 Home working.

All electronic data will be stored using the University of Worcester OneDrive for Business. Should guidance around the pandemic prohibit office-based working, this means that researchers will still be able to access and store data in a secure way, following the relevant university guidelines for home working during the pandemic. Electronic data will not be stored using home computers. Hard (paper) copies of personal data will not be kept at home.

8.8.2 Sharing of data.

As part of the checking of transcripts, it may be necessary to share recordings between researchers or between the Research Team and translators. Recordings will be cloud based and can only be accessed using a secure, password-based process. Recordings will not be downloaded and will be deleted once the checking and transcribing process has been completed.

8.8.3 Reporting of data.

In reports of the work, where excerpts are quoted from interviews, any information that might lead to the identification of participants, other people or organisations will be disguised where possible. ECH schemes will not be identified specifically by name or town, but only by region and pertinent demographic factors.

8.8.4 Data disposal.

Recordings of meetings including focus groups, interviews and online interviews will be deleted once a transcription of the meeting has been checked and agreed. Records of personal details will be securely deleted at the end of the study. All written records data will be kept for 10 years in line with University of Worcester (2013) Guidelines and Procedures for Good Research Practice. Stored information will be subject to the usual controls under the Data Protection Act 2018 and University of Worcester (2016) Policy for the effective management of research data.

8.9 Indemnity

Indemnity/insurance arrangements will be covered by the University of Worcester's Employer's Liability, Public Liability and Professional Indemnity insurance. More information and letters with policy details can be found on the University’s finance pages at: https://www2.worc.ac.uk/finance/758.htm

8.10 Access to the final study dataset

The co-applicants of this project detailed at the outset of the protocol will be granted access to the full anonymised dataset on request. Any secondary analysis of the data will be permitted with consent from participants.

The co-applicants will work together to identify at what points study progress can be promoted (e.g. through social media and the ADS website). It is a contractual requirement for a Principal Investigator to send a draft copy of a proposed publication (including articles, presentations, and press releases) to the NIHR SSCR at the same time as submission for publication or at least 28 days before the date intended for publication, whichever is earlier.

9 DISSEMINATION POLICY

9.1 Dissemination policy

As a minimum, and in accordance with the NIHR SSCR minimum required outputs, dissemination will include:

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

All of our 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, we will have six-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, we will plan additional activity 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 APPG on Housing and Care for Older People Inquiry and the Commission on Housing and Care in Social Care, chaired by SCIE).

We will make a suite of Key Insight booklets, which will be made available online, free of charge, to three key stakeholder groups involve 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 (see section 9.2); 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.

9.2 Authorship eligibility guidelines and any intended use of professional writers

The final report will be written by the project team, in particular those at the Association for Dementia Studies, led by the Principal Investigator (Teresa Atkinson). Other members of the project team will contribute, revise, and approve as appropriate. All authors who make a substantial contribution to the final study report will be named individually. By substantial contribution we mean (in line with guidance from the International Committee of Medical Journal Editors, 2021) that they will have: Contributed to the conception or design of the work or the acquisition, analysis, or interpretation of data; helped draft or critically revise the report; had final approval of the version to be published; and agreed to be accountable for all aspects of the work.

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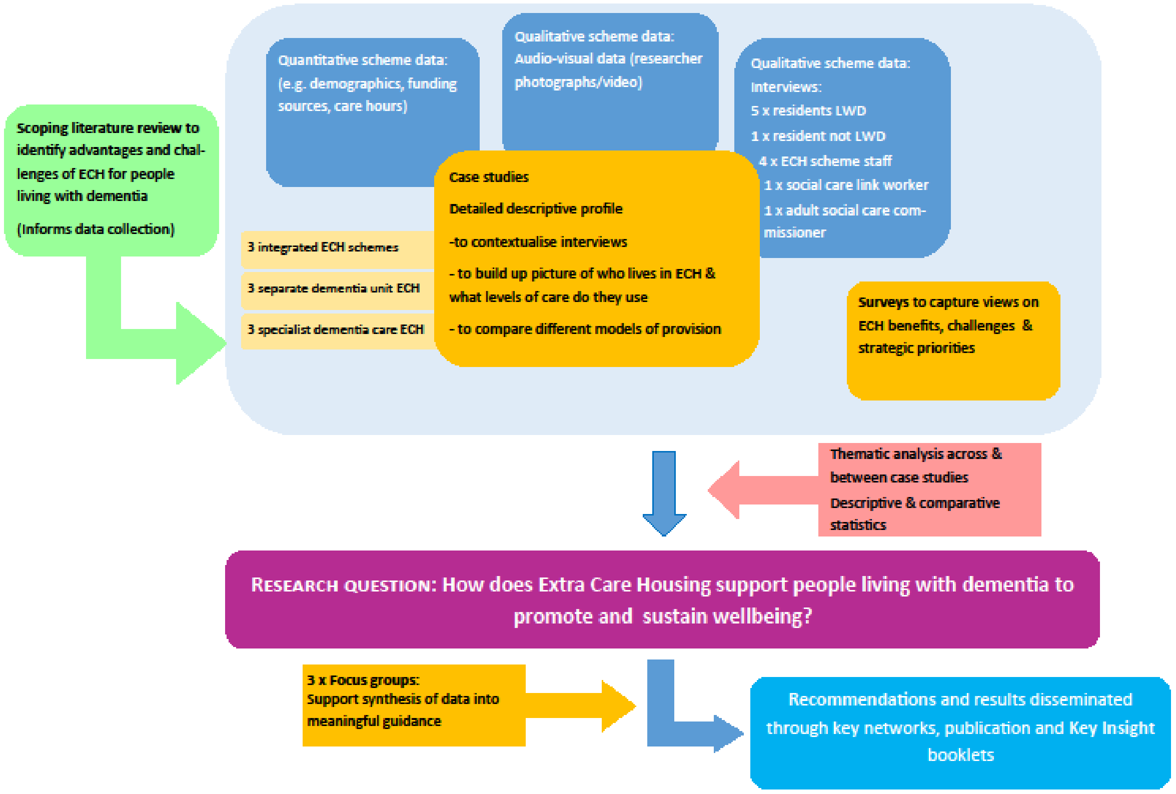
Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
1	0.3	17/11/21	RO	Replaced “nominated” with “personal” on p. 17
2	0.3	17/11/21	RO	Deleted all references to participant-generated photograph/video data throughout protocol (tracked deletions)
3	0.3	17/11/21	RO	Adjusted Gantt chart to reflect ethics delay (Appendix)
4	0.3	17/11/21	RO	Deleted reference to participant-generated photograph/video data on project diagram (Appendix)

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the REC.

Appendix 1: DemECH: Overview Diagram



Scoping literature review to identify advantages and challenges of ECH for people living with dementia

(Informs data collection)

Quantitative scheme data: (e.g. demographics, funding sources, care hours)

Qualitative scheme data: Audio-visual data (researcher photographs/video)

Qualitative scheme data:
Interviews:
5 x residents LWD
1 x resident not LWD
4 x ECH scheme staff
1 x social care link worker
1 x adult social care commissioner

3 integrated ECH schemes
3 separate dementia unit ECH
3 specialist dementia care ECH

Case studies
Detailed descriptive profile
-to contextualise interviews
- to build up picture of who lives in ECH & what levels of care do they use
- to compare different models of provision

Surveys to capture views on ECH benefits, challenges & strategic priorities

Thematic analysis across & between case studies
Descriptive & comparative statistics

RESEARCH QUESTION: How does Extra Care Housing support people living with dementia to promote and sustain wellbeing?

3 x Focus groups:
Support synthesis of data into meaningful guidance

Recommendations and results disseminated through key networks, publication and Key Insight booklets

DemECH V0.2 17 Nov 2021

Figure 1 DemECH Project Overview

Appendix 2 DemECH project Gantt chart

Stages & Tasks	**Jun**	**Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**
Stage One																			
Recruitment	🟧	🟧																	
Literature Review		🟧	🟧																
Ethical Review	🟧	🟧	🟧	🟧	🟧	🟧													
Advisory Group Meetings		🟩		🟩			🟩			🟩			🟩			🟩			
Stage Two: Surveys																			
Commissioners				🟧															
Carers					🟧														
People living with dementia					🟧														
Stage Three																			
Identification of case study sites						🟧	🟧												
Data collection at case study sites								🟧	🟧	🟧	🟧	🟧	🟧						
Data Analysis: survey data						🟧	🟧												
Data Analysis: case study site data										🟧	🟧	🟧	🟧	🟧	🟧				
Focus Groups x 3													🟧	🟧	🟧				
Stage Four																			
Reporting					🟥						🟥					🟧	🟧	🟧	🟧
Knowledge Exchange, Impact & Engagement reporting						🟦											🟦	🟦	🟦
Peer reviewed publications						🟩 Lit	🟩	🟩								🟩	🟩	🟩	🟩
Videos, webinars and guidelines																🟩	🟩	🟩	🟩
Advisory Group Meetings	🟪			🟪			🟪			🟪			🟪			🟪			🟪