Extra care housing in the UK

Scoping review protocol

Final Version

26 June 2024

Produced by	Exeter HS&DR Evidence Synthesis Centre Department of Health & Community Sciences South Cloisters St Luke's Campus Heavitree Road Exeter EX1 2LU UK
Authors	**Sian de Bell** Systematic Reviewer [1] s.c.de-bell@exeter.ac.uk **Zhivko Zhelev** Systematic Reviewer [1] z.zhelev@exeter.ac.uk **Alison Bethel** Information Specialist[1] a.bethel@exeter.ac.uk **Rob Anderson** Senior/Academic Lead[1] r.anderson@exeter.ac.uk **Jo Thompson Coon** Senior/Academic Lead[1] j.thompson-coon@exeter.ac.uk [1] University of Exeter
Correspondence to	s.c.de-bell@exeter.ac.uk
Date completed	26 June 2024
Source of funding	This work was commissioned by the NIHR HSDR programme as a project (project code NIHRXXXX) within grant number NIHR130538. JTC and AB are also supported by the NIHR Applied Research Collaboration South West Peninsula (PenARC).
Role of funder/institution in protocol creation	The aims and scope of this protocol and the planned work were informed by information provided by and discussions with members of the NIHR HSDR Strategic Commissioning team.

Declared competing interests of the authors	None
Rider on responsibility for document	The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HSDR programme, the NIHR Applied Research Collaboration South West Peninsula (PenARC) or the Department of Health & Social Care. Any errors are the responsibility of the authors.
DOI (Zenodo)	10.5281/zenodo.12698241

Table of Contents

1 Background

Both globally and in the UK, the population is aging. By 2050, the proportion of the people over the age of 60 will have doubled worldwide,(1) whilst in the UK, the number of people aged 80 and over is predicted to more than double in the next 40 years, from 3 to 6 million.(2) As people get older, their health and social care needs tend to increase; higher rates of non-communicable diseases are seen in older age groups,(3) and older people are more likely to have multiple long-term health conditions.(1, 4)

A long-standing policy objective, in the UK and internationally, has been to enable 'ageing in place', allowing people to live independently for as long as possible without having to move home or to a different area.(5) There are two main ways of enabling independence: taking preventative measures to reduce disease, and adaptation, to make environments and infrastructure suitable for people with additional needs or disabilities.(4) The Chief Medical Officer's Annual Report 2023 identifies the supply of suitable housing as a key factor in facilitating ageing in place in the UK.(4) However, only 9% of homes in the UK had four key accessibility features (e.g. step-free access) in 2018,(5) and half of homes that fail to meet basic decency criteria, as defined by the government, have a head of household who is aged over 55.(2)

Even with adaptations, mainstream housing may not meet people's needs as they age. Supported housing, which covers a range of different housing types such as supported living complexes, extra care housing and sheltered housing,(6) helps people maintain their independence in private accommodation but with the provision of additional care and support.(7)

Extra care housing is one form of supported housing. Whilst there is no single definition of extra care housing, it is generally considered to be a "*model of housing that combines independent housing with flexible levels of care"*,(8) with key features including:

- Self-contained accommodation (e.g. a flat in a larger complex).
- Communal activities (e.g. social events) and facilities (e.g. restaurant, hairdresser).
- Flexible and individualised 24-hour care provided on-site (including emergency assistance).(9)

These features underpin three key principles: the *promotion of independence*, to enable the individual can live independently in the community; *empowerment*, as services come to the individual when needed; and *accessibility*, as the environment and services are adapted for the individual.(10) By supporting aging in place, extra care housing is also meant to reduce the need to make potentially stressful and costly relocations.(11)

There are a range of providers of extra care housing, with the majority provided by housing associations, local authorities, and the private sector.(12) Unlike residential care homes, where people are usually licensees, residents of extra care housing will own, part-own, or rent their accommodation.(12) Accommodation and care are provided (contracted and paid for) separately. Residents may receive personal care, which generally refers to direct help (e.g. with getting up, getting dressed, and minor medical tasks that do not need a qualified nurse), and/or support, which is typically practical help (e.g. with shopping and washing).(12) Whilst residents may need healthcare, the provision of this is not generally organised by the scheme itself. The distinction between healthcare, other personal care, and support is complex and funding may be dependent on the category. Residents may receive funding for their social care and support, or self-fund, depending on their resources.

There has been research into the benefits of extra care housing. Most recently, Atkinson et al.(11) conducted a scoping review of extra care housing for people with dementia which found various advantages such as the promotion of independence and social inclusion, and integrated service provision, but also disadvantages relating to the management of advanced dementia and resourcing flexible care. These findings correspond with those of a previous scoping review of extra care housing for dementia.(8) A scoping review focusing on general populations in extra care housing published in 2006 found that extra care housing in the UK can promote independence and provide social support but that this is not the case for all residents, and that it does not necessarily offer a home for life.(13) There has also been recent primary research (e.g. the ECHO and ASSET studies) on extra care housing which has found that the benefits include increased quality of life for residents and reduced NHS costs.(5)

1.1 Development of the scoping review

This scoping review of research and other evidence has been commissioned by the NIHR HSDR Strategic Commissioning Group.

Demand for extra care and other forms of supported housing is greater than supply.(10) With a rapidly aging population, and a significant proportion of older adults indicating that some form of supported housing would be their preferred option for the future, knowledge is needed to inform future research priorities and policy related to extra care housing.(10) As identified above, recent reviews of extra care housing have focused on specific populations (older people with dementia),(11) whilst there has been both the publication of further primary research, and a changing policy landscape regarding extra care housing,(5) since the publication of older reviews.(8, 13)

Key questions remain regarding extra care housing, such as how different models of extra care housing can support people to live well.(8, 11) This review is intended to inform future research into extra care housing to answer these questions by identifying the existing evidence base on extra care housing in the UK.

1.2 Aim of the review

The aim of the review is to identify, appraise and describe the available empirical evidence relating to extra care housing in the UK.

To meet this aim, we will produce a scoping review following best practice guidelines(14, 15) and reporting the results according to the PRISMA Extension for Scoping Reviews (PRISMA-ScR).(16)

1.3 Review question

What is the volume, focus / research questions, study design, quality and main findings of empirical research and evaluations relating to extra care housing in the UK?

2 Methods

2.1 Identification of studies

2.1.1 Searches

Database searches will be conducted using search strategies developed by an information specialist (AB) in consultation with the review team and the commissioning group. The database search strategies will use both controlled vocabulary when available and relevant (e.g. MeSH in MEDLINE) and free-text searching (see Appendix A for an example search strategy). Search terms will be partly derived from the literature and from stakeholders and experts' input. Searches will be limited to English-language texts published after 2010 (this pre-specified date has been agreed with stakeholders and experts as explained below in section 2.1.2). The reference lists of all relevant documents will be searched for additional titles and forward citation searching completed.

Relevant websites will be searched for grey literature, such as:

- Housing LIN (www.housinglin.org.uk)
- Elderly Accommodation Counsel Housing Care (https://housingcare.org/)

2.1.2 Inclusion and exclusion criteria

Definition of extra care housing

Although there is no single definition of extra care housing, for the purpose of this review we define it as a type of 'housing-with-care' that meets the following criteria:

- Residents live in fully self-contained properties with their own front doors (e.g. with private kitchen and bathroom facilities).
- The property is rented or owned by the resident, or can be a shared ownership (part rent/part buy) arrangement.
- The provision of individualised and flexible care, with care and support staff available on-site 24/7, contracted to a care agency or provided by the local social services department.
- Housing and care are contracted, funded and managed separately.
- There are communal facilities and services (e.g. a manager's or care team office, a lounge, catering facilities/dining area, guest suites, and a garden).

Publications may not offer a clear description of the schemes on which they focus. We consider the first two criteria - self-contained accommodation and the provision of care – to be key to a scheme being extra care housing. All studies which clearly meet these criteria will be included. Studies where it is unclear, but likely, that this definition is met will also be included (with key features described as detailed in sections 2.2 and 2.4).

Resident population

The review will focus on extra care housing for any older people or schemes which are specifically for older people with dementia or other conditions or specific needs commonly related to older age. Residents must be ≥55 years of age which is a common eligibility criterion for extra care housing schemes for older people.(17) Studies including younger populations will be considered if they also include residents ≥55 years old.

Study design/Type of evidence

Publications reporting systematic reviews (as defined below) and primary research or evaluation evidence generated using established research methods will be included. All study methodologies - quantitative, qualitative and mixed-methods – will be eligible for inclusion. Examples include case studies, qualitative interviews and observations, surveys, quantitative analysis of routine data, randomised and non-randomised experimental designs etc.

We aim to include evaluations as well as research. Strictly, research aims to produce generalisable knowledge and typically seeks to answer a pre-specified question. In contrast, evaluations usually have more local and practical aims, for example to inform the decision-making of a particular organisation. Nevertheless, regardless of their original purpose and scope, good quality evaluations can produce potentially generalisable knowledge and insights that are as valuable as those from data collection and analyses framed as research.

Systematic reviews will be included if they focus on extra care housing in the UK or have a broader scope but report the results of studies from the UK separately. They also need to meet the following criteria(18) for a systematic review:

- Have a clear review question.
- Use a reproducible search strategy.
- Pre-specify their inclusion/exclusion criteria and screening methods.

- Assess the methodological quality of the included studies.
- Report their method(s) of data analysis.

Country

Only UK-based studies will be included.

Publication language

Only studies with the full text published in English will be included.

Year of publication

To capture the most relevant evidence, the searches will cover the period from 2010 to present and older studies (publication date 2009 or earlier) will be excluded.

This cut-off date has been agreed with key stakeholders based on changes to the funding, demographic, housing design and policy landscape for extra care housing over time. It will, for example, capture policy change following the formation of the coalition government in 2010, and the resulting shift in Department of Health funding from the Extra Care Housing Fund to the Care and Support Specialised Housing Fund, which had a greater private sector focus.(19)

Publication status

Both peer-reviewed papers and grey literature will be included. Relevant conference abstracts published in 2022 or later will be included if no full text publication is identified.

2.1.3 Process for applying the inclusion criteria

The results from the database searches will be screened following the standard process. A random sample (n=100) of hits will be screened by at least two reviewers. Decisions will be compared and discussed in a group meeting to ensure consistent application of inclusion and exclusion criteria. If necessary, definitions will be updated and explanatory notes added to aid the process.

Two reviewers will independently apply the inclusion and exclusion criteria to the title and abstract of each identified citation. We will obtain the full text of papers where either reviewer judges it to be a potential inclusion. Two reviewers will assess the full text of each record independently for inclusion, with disagreements settled through discussion or by a third reviewer.

The study selection process will be detailed using a PRISMA-style flowchart,(20) with a reason reported for exclusion of each record assessed at full text.

2.2 Data extraction

A data extraction form will be developed and piloted independently by two reviewers on a small sample of included documents. Data will be extracted by one reviewer and checked by a second reviewer. Disagreements will be resolved through discussion.
The following data will be extracted:

- Type of publication (e.g. peer-reviewed paper, conference abstract, report)
- Study design (e.g. case study, survey)
- Models of extra care housing and types of residents (e.g. age, diagnosis of dementia)
- Geographical location
- Study aims
- Study characteristics (e.g. participants, including PROGRESS-Plus characteristics;(21) methods)
- Findings, limitations and conclusions

2.3 Study quality assessment strategy

The mixed methods appraisal tool (MMAT) will be used to appraise the methodological quality of the included studies. The tool is designed for use in systematic reviews in which two or more of the following study designs are included: qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies. Since its initial publication in 2009, MMAT has been used in multiple systematic reviews and validated in a number of studies, with the most recent version published in 2018.(22)

Systematic reviews will be assessed using an adapted version of AMSTAR 2. This tool was originally developed to appraise systematic reviews of quantitative studies of healthcare interventions with randomised or non-randomised designs. Since eligible reviews are likely to include a broader range of study designs, we will adapt the tool as suggested by Lam et al. (33)

Both tools will be piloted by two reviewers in a small number of relevant studies. Disagreements will be discussed and operational definitions updated to improve reliability. Then, the methodological quality of each included study will be assessed independently by

two reviewers and disagreements will be resolved through discussion and, if necessary, arbitration by a third member of the team.

2.4 Data analysis and presentation

Descriptive analysis will be carried out to provide information on the volume, type and quality of the available evidence. This will include information on:

- The models of extra care housing reported in the included papers. Variation across extra care housing schemes included in the research will be captured using a framework of characteristics. We will start with a set of high-level categories (e.g. size of scheme, tenure mix, communal facilities) based on previous research (10, 13) and input from stakeholders, and inductively amend / develop the framework to reflect variation in the included studies.

- Focus of research – the type of questions the studies are aiming to answer.

- Volume, type, quality and results from research relevant to different models of extra care housing and different research topics. For instance, evidence of the residents' experience with extra care housing may come from different study designs (e.g. qualitative studies, surveys) and the studies may vary in terms of specific characteristics (e.g. focus on residents with dementia) and methodological quality.

Findings of the review will be summarised narratively and in tables and figures, as appropriate. Evidence gaps will be highlighted and recommendations for primary and secondary research will be made. Areas for primary research may include topics where no empirical research exists and topics where some primary research is available but due to its volume, focus or methodological quality, further primary studies might be beneficial. Where significant numbers of primary studies are available but there is no recent, good quality systematic review, we will identify topics/questions for secondary research.

The NIHR-INCLUDE guidelines(23) were used to reflect on Equality, Diversity and Inclusion (EDI) whilst designing the protocol, identifying groups, such as LGBT+ older people, and people from ethnic minorities, who might have different needs or preferences in ECH schemes. We will consider these groups, along with the PROGRESS-Plus characteristics, during the process of data extraction and analysis,(21, 24) and, where possible, use information relating to them to inform the findings and recommendations of the review.

3 Stakeholder and patient/public involvement and engagement

The following stakeholders will be involved:

- NIHR Health Service Delivery Research (HSDR) Strategic Commissioning team
- Housing Learning and Improvement Network (LIN)
- Association of Directors of Adult Social Services (ADASS)
- Extra care housing employees e.g. scheme managers

We will consult stakeholders throughout the review process, to discuss topics such as the focus of the review, analysis, and findings. Meetings will be held online (e.g. on Teams) and will be arranged to suit the project progress and stakeholder availability. We will also ask for stakeholder input on dissemination plans and materials as described below.

We will recruit and consult a Patient & Public Involvement and Engagement (PPIE) group to gain feedback from extra care housing residents and their families. This will ensure that the review process and the interpretation of findings are informed as much as possible by the lived experience of the target population. We will also ask the PPIE group for input on specific documents, such as the plain language summary and relevant dissemination materials. The meetings will be held online (e.g. on Teams) and will be arranged to suit the project progress and the PPIE members' availability.

4 Dissemination plans

We will produce a report on extra care housing, available as an open access article in the NIHR Journals Library.

Further materials for dissemination will be finalised after discussion with the project's advisory group. These are likely to include:

- an evidence briefing, giving a plain language summary of the report and its findings (primarily aimed at policy makers and commissioners);
- an article in an academic journal identified as being relevant to stakeholders for this review; and
- presentations at key national and regional meetings.

Outputs will be disseminated via the Exeter HSDR Evidence Synthesis Centre webpage and social media. Additional material may be produced to promote them, such as a blog post based on the evidence briefing and report.

5 References

1. World Health Organisation. Ageing and health Geneva: World Health Organisation; 2021 [Available from: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health.

2. Centre for Ageing Better. Summary report: The State of Ageing 2023. London: Centre for Ageing Better; 2023.

3. Vos T, Lim SS, Abbafati C, Abbas KM, Abbasi M, Abbasifard M, et al. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. The Lancet. 2020;396(10258):1204-22.

4. Whitty C. Chief medical officer's annual report 2023 - health in an ageing society. 2023.

5. Darton RA. Extra care housing: The current state of research and prospects for the future. Social Policy and Society. 2022;21(2):292-303.

6. Ward M PP. Supported Housing: Funding, standards and quality in UK supported housing [Available from: https://uksupportedhousing.com/knowledgebank/supported-housing/.

7. Department for Work and Pensions, Department for Communities and Local Government. Supported accommodation review - The scale, scope and cost of the supported housing sector. 2016.

8. Dutton R. 'Extra care' housing and people with dementia what do we know about what works regarding the built and social environment, and the provision of care and support? ; 2009.

9. Riseborough M, Fletcher P, Gillie D. Extra care housing – what is it in 2015? : Housing Learning and Improvement Network; 2015.

10. Care Services Improvement Partnership, Housing Learning and Improvement Network. The extra care housing toolkit. 2012.

11. Atkinson TJ, Oatley R, Evans S. Advantages and challenges of extra care housing in the UK for people living with dementia: a scoping review. Housing, Care and Support. 2023;26(3/4):84-102.

12. Pannell J, Aldridge H, Kenway P. Market assessment of housing options for older people. New Policy Institute; 2012.

13. Croucher K, Hicks L, Jackson K. Housing with care for later life: a literature review 2006 [Available from: https://www.jrf.org.uk/housing/housing-with-care-for-later-life-a-literature-review.

14. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implementation Science. 2010;5(1):69.

15. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005;8(1):19-32.

16. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. Annals of Internal Medicine. 2018;169(7):467-73.

17. Age I. Extra Care Housing: Factsheet2017. Available from: https://www.independentage.org/sites/default/files/2017-04/Factsheet-Extra-care-housing.pdf.

18. Krnic Martinic M, Pieper D, Glatt A, Puljak L. Definition of a systematic review used in overviews of systematic reviews, meta-epidemiological studies and textbooks. BMC Med Res Methodol. 2019;19(1):203.

19. Housing Learning and Improvement Network. Department of Health and Social Care Capital Funding Programme no date [Available from: https://www.housinglin.org.uk/Topics/browse/HousingExtraCare/FundingExtraCareHousing/DHCapitalFundingProgramme/.

20. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71.

21. Cochrane Methods Equity. PROGRESS-Plus no date [Available from: https://methods.cochrane.org/equity/projects/evidence-equity/progress-plus.

22. Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, et al. Improving the content validity of the mixed methods appraisal tool: a modified e-Delphi study. Journal of Clinical Epidemiology. 2019;111:49-59.e1.

23. National Institute for Health Research. Improving inclusion of under-served groups in clinical research: Guidance from the NIHR-INCLUDE project. UK: National Institute for Health Research; 2020.

24. O'Neill J, Tabish H, Welch V, Petticrew M, Pottie K, Clarke M, et al. Applying an equity lens to interventions: using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. 2014(1878-5921 (Electronic)).

Appendix 1 Example search strategy

HMIC Health Management Information Consortium <1979 to March 2024>

Social Policy and Practice <202405>

1	(Housing adj2 care).ti.	974
2	(extra adj2 care).ti.	530
3	(housing adj2 sheltered).ti.	653
4	(housing adj2 specialist).ti.	47
5	(housing adj2 integrated).ti.	30
6	(Living adj2 support*).ti.	215
7	(Living adj2 assist*).ti.	292
8	(Living adj2 independent*).ti.	703
9	(Retirement adj2 village*).ti.	84
10	(Retirement adj2 home*).ti.	27
11	(Continuing adj2 care).ti.	715
12	(retirement adj2 communit*).ti.	147
13	(Integrated adj2 living).ti.	17
14	(elder* or old* or adult* or people*).tw.	255387
15	disabil*.tw.	33843
16	dementia.tw.	17589
17	1 or 3 or 8 or 11	3002
18	14 and 17	1984
19	2 or 4 or 5 or 6 or 7 or 9 or 10 or 12	1354
20	18 or 19	2965
21	15 or 16	50376
22	20 not 21	2440
23	model*.tw.	59594
24	22 and 23	297

25	22 not 24	2143
26	remove duplicates from 22	2383
27	remove duplicates from 24	291
28	remove duplicates from 25	2102