Teresa Atkinson **JDC Nov/Dec 2021**

Living with Dementia in Extra Care Housing (DemECH)

[Author details]

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Project background

Funder: NIHR School for Social Care Research.

Partners: University of Worcester, Housing 21, Housing & Learning Improvement Network (HousingLIN), Housing and Dementia Research Consortium (HDRC) and Worcestershire County Council.

Advisers: Professor Richard Humphries and people affected by dementia on our advisory group.

[BOX ENDS]

[Main text]

Extra Care Housing (ECH) is an increasingly popular form of housing for older people, often as a preferred alternative to a care home. 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 grow as the prevalence of dementia increases and people are being diagnosed at a younger age. Supporting people affected by dementia is the biggest challenge faced by adult social care and it incurs substantial financial costs for society.

These costs 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 with dementia in ECH: some schemes have a separate area or unit for them, others take an integrated approach by supporting them alongside residents without dementia, and others still are only for people with dementia.

Everyone has a different experience of dementia, however, and little is known about what works well for whom. What are the challenges and opportunities afforded to this diverse population and their families? What helps people make the best decisions about moving in, or moving on? Is there an optimal time to move in? How can ECH support people over time as dementia and frailty progress? Can ECH be a “home for life” for people living with dementia?

Our project

Our new 18-month project (see box) will explore how ECH can help people to live well with dementia and will investigate the advantages and disadvantages of the three different models described above.

A comprehensive knowledge exchange strategy 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 with dementia can make decisions to receive support in the most appropriate and cost-effective setting.

Methodology

Phase one will involve a scoping review of the existing literature on supporting people living with dementia in ECH to identify the key advantages and challenges. Phase two will build on the information we have found from the literature review and involve undertaking three surveys with:

- people living with dementia to ascertain their awareness and knowledge of ECH and their experiences of living in this setting

- family carers of people with dementia in ECH, who will be invited to share their views on the benefits and challenges of this form of housing

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

Phase three will take place in nine case study sites (see diagram). These will be selected with three from each model of scheme; integrated; dementia unit; and specialist dementia. We will also address diversity in terms of ethnicity, gender, sexual orientation, rural/urban location, and size of scheme.

We know that some schemes have separate housing and care providers, which will also be represented within our sample.
We will build a profile of each scheme and model, encompassing information about the people who reside there and the amount of support and flexible care they require. It will tell us about who chooses to live in ECH and their levels of need.

Interviews will be carried out at each scheme, talking with people with and without dementia, staff members, the adult social care commissioner, and the social care link worker. We intend to offer face-to-face interviews (subject to agreement and comprehensive risk assessments) but, where this is not possible, virtual interviews will be arranged.

Appropriate support to undertake virtual interviews will be fixed up for people with dementia so as not to disadvantage them in any way or

cause unnecessary distress. Consent will be addressed as an ongoing process, while our interview questions will be informed by our review of the literature and survey results.

ECH residents' voices will be heard loud and clear. We are inviting some residents in each scheme to capture their own experiences via a video or audio diary, a source of experiential data that will heighten the impact of our project and the dissemination work that follows.

Finally, phase four will focus on dissemination of our findings. We will convene three online focus groups, one comprising dementia leads from ECH, a second with ECH care providers, and a third with commissioners of adult social care. These focus groups will help synthesise the data outcomes into meaningful guidance, both for professionals and for people living with dementia.

Our findings will be shared as widely as possible through a variety of networks and the dissemination process will be inclusive. For example, we will develop a suite of key insight booklets to guide future ECH development and awareness, such as booklets providing advice for commissioners, health and social care practitioners, older people, and those living with dementia and their families. Right at the heart of the new guidance and practice will be the voices of residents with dementia themselves since we will share their specially recorded diaries.

[Image]
Phase three: Case study data collection plan

None of this would be possible without the kind support of funders, our partners, and most importantly, the residents, workers and commissioners. We look forward to collaborating with our nine case study sites to discover how we can make these schemes even more beneficial for people with dementia and their families.

For more information or to register interest in being involved, please contact the author Teresa Atkinson at t.atkinson@worc.ac.uk.

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