



Individuals with dementia living in extra care housing: an initial exploration of the practicalities and possibilities



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Abstract

This research paper draws together the responses from a national questionnaire which set out to document the variety and types of extra care housing schemes in use, and how well they support individuals with dementia. It sets the context of extra care housing in the UK. It provides a brief overview of the methodology used and limitations experienced. The findings identified that many of the schemes were developed with grant funding (this may be a limitation of the study), and local authorities also had considerable nominations rights in the schemes.

Schemes comprised varying numbers of individual properties or apartments. Most of the schemes were purpose built with flexible living space achieved through the use of one and two-bedroomed apartments. All schemes reported that provision for people living with dementia was integrated throughout the whole extra care scheme, suggesting more research may be needed on the prevalence or potential demise of other extra care models.

Models of care and support varied; some schemes had the same provider for both care and housing support whilst others had different housing and care providers. The majority of managers reported that individuals with dementia were not explicitly excluded from taking up residence in a scheme, but there was little conclusive evidence about what may cause someone with dementia to move out of extra care. Further research could helpfully contribute to the identification of barriers to entry and the extent to which inappropriate triggers for leaving might be avoided through policy, practice and individual person-centred assessment and planning processes.

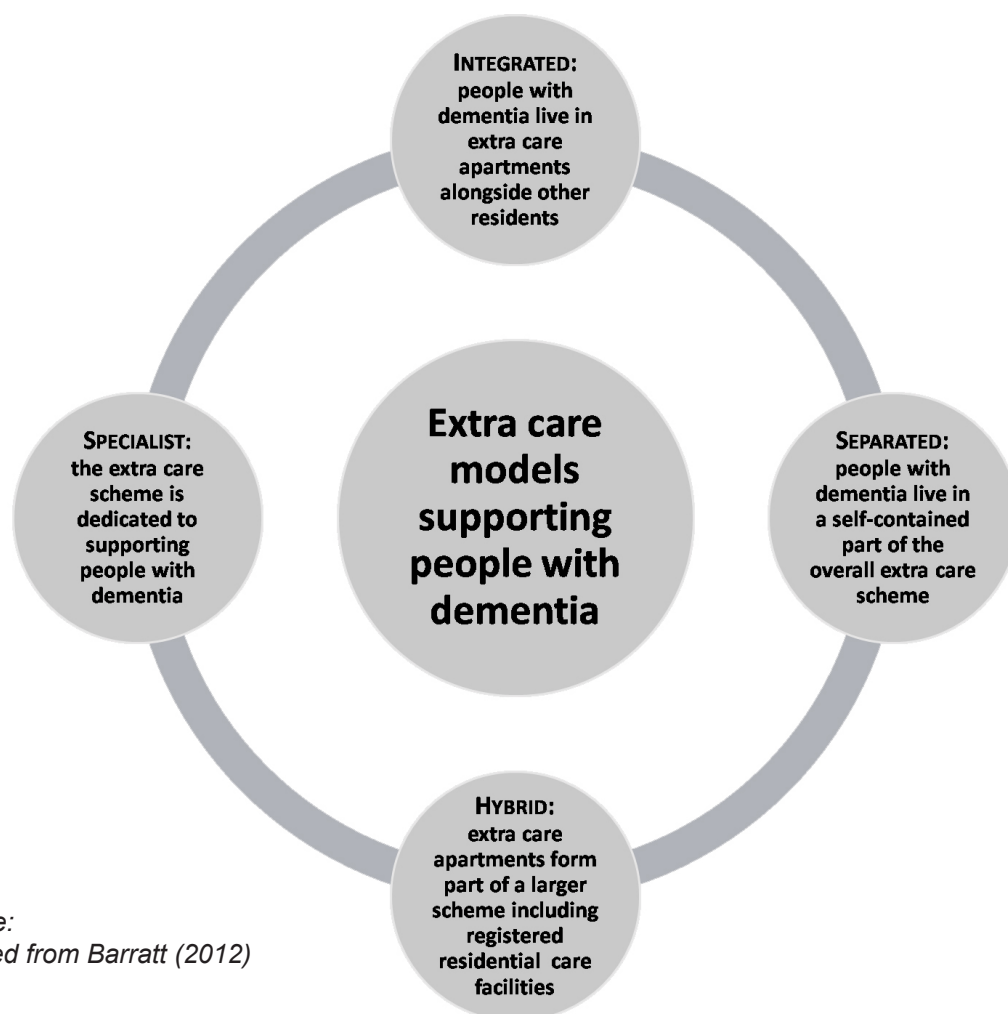
A perceived tension of designing space that is accessible and attractive to both people with and without dementia emerged as a theme throughout the study. The findings revealed a variable knowledge base about dementia design, but a strong commitment from individual managers and schemes to do their best for people with dementia.

Introduction

Extra care housing and other specialist supported housing models are relatively modern concepts in the UK, emerging from the early 1990s (McCafferty, 1995). There are around 60,000 extra care housing properties in the UK (EAC, 2015). However, there has been little early consensus on what extra care housing is and its development has been opportunistic and piecemeal (Tinker, et al., 2007). National government has been instrumental in supporting the growth of extra care and specialist housing by providing policy direction and guidelines (Department for Communities and Local Government, 2008; Barac & Park, 2009; Porteus, 2012; H M Treasury, 2015; Best & Porteus, 2016) and by supporting funding of extra care housing schemes through Government capital grants such as the Extra Care Housing Capital Fund (2004-2010), Social Care Capital Grant, Affordable Housing Programme, and the Care and Support Specialised Housing Support Fund. Such funds and associated commissioning guidelines were intended to encourage Local Authorities and housing associations to provide greater housing choice to older people and other people with disabilities or long-term conditions.

Extra care housing in the not-for-profit, or public sector, is usually delivered through partnerships involving, but not limited to, local authorities, housing organisations, investors and commercial developers, domiciliary care providers, health services, voluntary services and other commercial businesses.

Although there is no one defined model of extra care housing, broad approaches to extra care housing supporting people with dementia have emerged, described as integrated, separated, and hybrid (Barrett, 2012). Four resulting models are illustrated below.



Source:
adapted from Barratt (2012)

Occupants of an extra care housing scheme are known variously as residents, tenants, occupiers or owners. They are people who live in extra care housing, have their own self-contained homes, their own front doors and a legal right to occupy the property. Some residents will be tenants of rented apartments, some will own their apartment outright, and some will share the ownership of the apartment with the Registered Social Landlord (housing association) of the extra care housing scheme. For the purposes of this paper, the term 'residents' will be used.

Reasons for the research – what we know so far

Previous research sought to gain an evidence base for the further development and use of extra care by exploring the relative costs and outcomes for people in extra care (Baumker, Netten, & Darton, 2010; Brooker, Argyle, Scally, & Clancy, 2011; Weis & Tuck, 2013; Moriarty, 2015). Until recently, practice suggested that a vibrant and viable extra care housing scheme could be sustained if the population of extra care housing residents had well balanced levels of need. Current financial pressures within the adult social care sector due to an overwhelming demand for personal care are challenging that premise, with anecdotal reports that local authorities are increasingly wanting to place a greater proportion of people with higher levels of needs in extra care housing, with extra care housing being seen by many as an alternative to residential care.

There is a growing population of people living with or likely to develop dementia who might previously have moved into residential care (Alzheimer's Society, 2012). There appears to be increasing evidence and general agreement that moving to an extra care housing scheme is not the best option for people who already have advanced dementia (Dutton, 2009; Barrett, 2012). There is less conclusive evidence about how to best support individuals who develop dementia once they have moved into extra care housing, or how to avoid current triggers which seem to cause an individual with dementia to move out of extra care housing. In recognition of this, several housing associations have been striving to become 'dementia-friendly' organisations (Bligh & Dench, 2015). At the time of writing, the Alzheimer's Society is working closely with the specialist housing sector to develop a dementia-friendly housing charter (forthcoming).

Debate is also taking place about the importance of ageing in place and the role of the environment in supporting individuals to be as independent as possible. The environmental impact is two-fold. The design of the building can help or hinder an individual's daily activities within the environment, and the social environment and culture within a scheme can prevent or provide opportunities for interaction with others. Design research so far has focused either on generic models of extra care housing or on specialist buildings specifically for people with dementia, such as residential care. There has been little evaluation of the impact of integrating dementia design features into generic extra care housing models.

Extra care housing is becoming increasingly available, and is offered through private providers, local authorities and housing associations. Those provided by local authorities and housing associations have tended to be more 'affordable'. 'Affordable Rent' and 'Social Rent' are terms defined by the Homes and Communities Agency (HCA) to ensure rents are affordable to the local market, although there can be exemptions for specialist supported housing such as extra care housing (HCA, 2015).

There is limited published research on extra care housing for people with dementia (Malley & Croucher, 2005; Dutton R., 2009; Barrett, 2012). Much of the research that has been published is captured on the Housing Learning and Improvement Network's (LIN) dedicated webpages.

Its 'In Focus: Innovations in Housing and Dementia' pages are a leading repository which describe the range of extra care housing schemes currently operating nationally, how they are commissioned and designed, type of facilities they provide and the support they offer to enable people with dementia to live there.

This research set out to establish a national picture of the variety and types of extra care housing schemes and how they support individuals with dementia. It is an initial phase of a broader research study which aims to explore whether the combination of policy frameworks, the immediate interactional environment, and the broader culture within extra care housing constrains or enhances the experience of an individual living with dementia.

Methods - how the research was undertaken

The research is a pilot to the research study 'Individuals with dementia living in extra care: an exploration of the practicalities and possibilities'. The pilot set out to establish a national picture of the variety and types of extra care schemes and how they support individuals with dementia. Using the Housing LIN's communication channels, a newsletter was sent to Housing LIN members in the UK (including England, Scotland, Wales and Ireland) providing extra care housing, asking them to contribute to the study. The survey invited responses from all extra care schemes, as there is no current classification for just those who specifically support people with dementia.

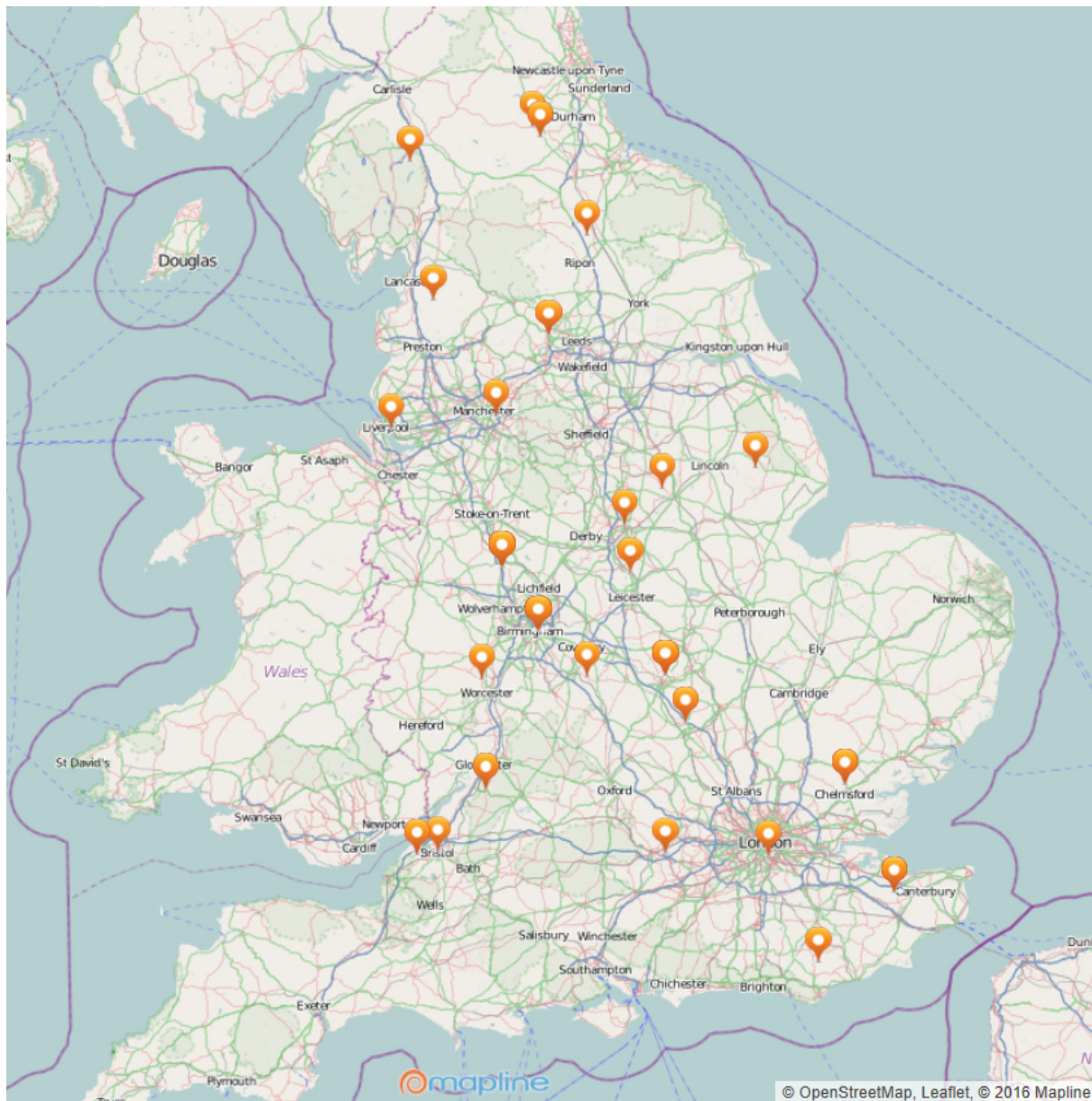
The qualitative questionnaire was developed with input from a critical friend in the Housing LIN. It was developed using Sheffield University Google Forms, hosted on an external website to provide access to people outside the university. The research study and the questionnaire were promoted via one of the Housing LIN Newsletters, with an 8-week period for completion. The Housing and Dementia Research Centre (HDRC) also copied the link to their members to encourage completion of the questionnaire. Six further responses were received after the close date which have been incorporated into the analysis.

In total, 35 questionnaire responses were received. Two (duplicate) responses were received for one scheme, and were merged before analysis. One response was made on behalf of 30 schemes operated by one provider. As far as possible the responses were split between the 30 schemes. The map below shows the geographic spread of responses made. It should be noted that some of the points represent an area where there was more than one response, for example there were 6 responses from Birmingham, 10 responses from the West Midlands area, 4 in East Sussex, 4 in Kent, 5 in Northamptonshire, 6 in Staffordshire, and a number of areas that had two respondents. A limitation of the research is that there are many parts of the UK that were not represented in responses.

For the purpose of analysis, 64 schemes were represented in part or whole. The responses have been analysed to reflect the three sections of the questionnaire; background information about the extra care housing scheme; information about the model of extra care housing provided by the scheme; and a self-reported rating of design features of the scheme that could support an individual living with dementia.

The findings of the pilot were used to confirm the appropriate choice of two case studies in the main research project. The findings provide a novel picture of the current state of practice in the field of extra care and give a backdrop from which to explore issues important to those living in, working in, or commissioning and developing extra care housing schemes.

Diagram 1: Map of respondents



Findings – what the research has shown

How the extra care housing schemes were developed

The majority of schemes were purpose built (90%) with only a small proportion being remodelled or partially remodelled alongside new-build. The responses indicated that of those schemes built in the last 5 years, two (20%) were for 40-50 bedded apartments, and the remaining eight (80%) were for more than 50 apartments, reflecting anecdotal information from developers and providers that changes in the extra care housing market are making schemes under 50 – 60 apartments no longer viable without grant funding.

Anecdotally developers and providers are suggesting that, with other complementary services on site and or with grant funding, schemes of between 40 and 50 apartments could still be viable. The schemes with over 150 apartments were all run by the same provider, using a village model.

The majority of respondents noted that grant funding had supported the development of the schemes. There were six respondents who did not answer this question. Seven schemes reported that they had developed the extra care housing without grant funding. Historically, there does not appear to be a correlation between grant funding and the age or size of the scheme.

A majority of schemes provided a mix of one and two-bedroomed apartments, with the ratio between the two varying. It is of note that 14 schemes provided only one-bedded apartments, which is in contrast to emerging evidence that older people prefer two bedrooms to offer flexibility in living arrangements. None of the schemes providing 100% one bedded apartments were built in the last five years. A number of schemes providing only one bedroom indicated that there were two living spaces, one of which could be used as bed space if required.

Arrangements with local partners and eligibility criteria for extra care housing

Nomination arrangements are usually seen as a key element in creating a successful extra care housing scheme, and can include eligibility criteria and arrangements to control the nomination of service users to extra care housing schemes. Such arrangements often include local authority rights to nominate individuals to be allocated an apartment and processes for partners to agree how apartments will be allocated, and subsequently which individuals should be allocated apartments.

Questionnaire respondents reported a number of nomination arrangements with local authority partners. One scheme specifically reported that potential applicants must meet the local authority eligibility criteria, and one scheme reported that there were constraints on setting affordable rents and service charges. There was no mention in responder comments of whether there were any constraints on how the local authorities exercised their nomination rights in the event of unfilled voids, or whether any financial recompense was made by the local authority to the housing provider.

Eligibility criteria were in place in all schemes, with none directly excluding individuals with dementia. A proportion of the reported eligibility criteria made explicit that the schemes were suitable for people with dementia. The remainder were silent on the issue, or had potential barriers to entry for people with dementia; for example, individuals must be able to live independently, could have mild dementia, or needed to be able to sign a tenancy agreement or have a valid power of attorney or court of protection.

Within the schemes with eligibility criteria which specified that individuals with dementia would be considered there were some limitations; for example, one scheme said that it was appropriate for individuals with low to medium dementia, whilst another required individuals to be able to orientate themselves in a new environment. A third manager said “an ability profile is completed with all residents prior to move in - this includes consideration of their safety for example if the person’s dementia is quite advanced and they are unable to orientate to their new environment then this would be an issue”.

Housing support and care provision

Extra care housing is a blend of housing and care, typically with a range of housing and care providers fulfilling different roles in responding to the pressures of care and housing needs (Riseborough, Fletcher, & Gillie, 2015). Given the current diversity in operation, clarity is needed on the different roles undertaken by the housing and care providers in each individual scheme, both for individual residents and for staff working at the scheme.

Respondents to the questionnaire represented a number of small housing providers, one regional provider, and three large national housing providers. It was possible to determine from the responses that 25 different care organisations were working in partnership with the range of housing providers in meeting the care and support needs at the schemes. Twenty of the care providers were only involved in one scheme each. Three care providers worked at two schemes each. One care provider supported eight schemes, and another care provider supported 30 schemes.

All but one extra care housing scheme provided on-site 24/7 care, which is seen as a fundamental part of the extra care housing service. The one scheme which did not provide overnight support offered a remote alarm system, but recognised the impact that the reduced staffing levels had on the level of need that could be supported. This resulted in a concern that individuals with dementia might not be able to be accommodated within the extra care housing scheme. All schemes had alarm call systems and there was variable use of tailored packages of telecare or assistive technology to support individuals through support or care plans. There did not appear to be any correlation between the provision of assistive technology and the age of the scheme. There was evidence at a number of schemes that individuals could choose their own care provider from an external agency rather than the on-site care team if they wished.

Care and support for individuals living with dementia

Respondents were asked what model of extra care housing scheme they operated and how they supported individuals with dementia. All but one respondent reported that the schemes integrated people with dementia throughout the scheme rather than having separate wings. One scheme reported that they had moved away from a separate wing for people with dementia towards an integrated scheme where individuals with dementia were not segregated. This approach away from separate wings has been confirmed anecdotally by other extra care housing managers with regional or national positions. Although such schemes do exist, within the responses to the questionnaire, there were no reports of specialist extra care housing schemes only supporting people with dementia, nor were there any extra care housing schemes reporting that they shared a facility with a registered residential care home for people with dementia.

It was clear from many of the comments made in the questionnaires that there was an aspiration to provide a home until death, but that that was not always possible. The main barriers cited included difficulty providing the necessary level and flexibility of support and or inappropriate behaviours. It was of interest that some comments reflected health and safety concerns, which in some instances was linked directly to the use of assistive technology to support people.

Seven respondents observed that limitations in supporting wider health conditions triggered a number of people to leave extra care housing because they needed nursing care. For example, one manager said:

“Most tenancies that are ended (except death) are ended due to developing dementia or the wider health conditions of our residents. These may be the need for nursing care which we do not provide in many cases. Customers with dementia have had to exit this service when their behaviours begin to provide health and safety issues and/or harm to themselves or other residents/staff.”

In contrast, only two schemes reported the lack of community health support as a reason for a move out of the scheme. The lack of sufficient night-time cover, defined as a minimum of two night-time staff, was cited by one respondent as a reason for being unable to meet residents' needs. The link between on-site support with appropriate peripatetic support from community health and social care teams and the ability of schemes to support increasing health care needs would merit further research.

Further research could usefully explore the exit criteria that do exist, the basis for making individual decisions to leave and whether any formal or informal guidelines are available to support making transition plans to help someone to move with the least possible impact on their physical and emotional wellbeing. There is a possible tension in extra care housing aspiring to offer a home for life for the majority of people and individuals having to move on if their needs cannot be met within the extra care housing scheme. Further research could also explore how effectively such arrangements are shared with prospective residents when they are considering moving into extra care housing.

A dementia friendly environment through design

The last part of the questionnaire considered the design features of the extra care housing schemes. A perceived tension of designing space that is accessible and attractive to both people with and without dementia emerged as a theme throughout the responses. For example, one manager commented:

“All rooms are sign-posted but that doesn't really help those with dementia. However, we are a general needs facility so would not want to move to pictures etc. unless we moved to a specific dementia floor or building.”

This is a tension that is likely to be experienced by all integrated models where people with dementia are not segregated, and where some design features that enable people with dementia to live as independently as possible are not universally welcomed or accepted.

Layout had been a prime consideration in many schemes, with careful thought given to the positioning of public and communal areas close to the entrance, the use of secure doors and lifts to separate public from private space, and the use of glazed doors to support recognition of activities within different areas. One scheme commented on the use of colour to emphasise key activities, suggesting that improvements could be made to use colour to highlight where toilets are located.

Concerns were raised about the length of corridors and the use of circular routes featured in the comments. There was no mention of resting spaces or other features that could have enhanced the corridors or circular routes. Some comments clearly demonstrated an understanding of the specific needs of people with dementia and design features including the use of windows to orientate people, the difficulties of dead ends, and the use of pictures to prompt discussion. For example, one manager said:

“The scheme is fairly small in size and so is easy to navigate. Residents rarely become lost partly as a result and there are plenty of design features to identify the location in the building. We do have small meaningful spaces and seating areas but there are also a few dead end corridors.”

Another respondent mentioned the use of memory shelves as being helpful for individuals with dementia in finding their own personal apartment.

The avoidance of clutter was one of the top three most highly scored questions within the design section of the questionnaire. The possible tension between residents being able to personalise areas of the extra care housing scheme and keeping areas free from clutter emerged as a theme from a number of respondents. Comments were made about the provision of signage to meet health and safety requirements, but there was no mention of the height of the signage and whether it could be seen by individuals with dementia with limited vision.

Some comments were made about improvements needed to include pictorial signage as well as written signs. The balance between public and resident needs was highlighted again, with a comment that:

“Areas are open to the public so we are careful as to what is on display but at the same time aware of making the area welcoming”.

There was recognition that lighting had an impact on individuals with dementia, with many schemes optimising natural light and trying to reduce the negative impact of long dark corridors. Two schemes used movement sensitive lighting. Some schemes had upgraded the lighting to dementia standards, one scheme used blackouts at night, and one scheme mentioned how light was used to counteract ‘sun-downing’ and to help reduce confusion about time of day or place.

There was a focus on use of colour to ‘theme’ areas to aid recognition. There was insufficient evidence from the responses to establish whether colours were used to optimise the navigational and comprehension skills of individuals with dementia, or were used to enhance the aesthetic appearance and support navigation of people without dementia. For example, one manager observed:

“Corridors are only painted in contrasting tones, different on all levels, and only certain areas have been emphasised with wall paper.”

The schemes that scored themselves more highly in this area tended to be recently redecorated. Some of the comments made suggested an understanding of the needs of individuals with dementia. For example, mention was made of contrasting colours to help sight and visual difficulties, and the reduction of shiny surfaces which can reflect unrecognisable images.

There was a mixed response to the question about the use of meaningful artwork within schemes. A number of schemes had used an interior designer, with other schemes consulting with residents and local people. Irrespective of whether artwork was selected by a designer or a group of tenants, the reflection of local interest was important in the works chosen. One respondent recognised the importance of the artwork in prompting discussion between residents and visitors.

Whilst the findings provide a novel picture of the current state of practice in the field of extra care housing they should be seen in the context of a limited research study. Some of the issues important to those living in, working in, or commissioning and developing extra care housing schemes are discussed below followed by review of the limitations of the research study.

Discussion

The initial questionnaire research findings are discussed here both in relation to current knowledge about extra care housing provision and support for people with dementia, and in relation to potential lines of enquiry for the broader research to be undertaken as part of this study.

Learning from experience

The responses showed variable levels of understanding of the needs of individuals with dementia, but all showed a desire to provide the best support possible and a willingness to critically reflect on the current service model being offered. Caution should be taken not to extrapolate this willingness to all extra care providers as responders to the questionnaire were self-selective, and may not be representative of those who did not respond.

Whilst some respondents commented on the desirability of providing an integrated scheme where individuals with dementia were not segregated, others recognised the tensions this sometimes created in developing dementia friendly environments that are acceptable to the general public and to residents without dementia.

Key principles

The results revealed a range of operating models and approaches but with some key areas emerging as consistently important to all. These are:

- providing an integrated scheme
- recognising limitations to eligibility for the scheme
- supporting individuals with a tailored package of care often until death
- having open discussions about whether the extra care housing scheme is best placed to support increasing complex needs
- balancing the needs of people with and without dementia, and
- making the most of the built environment.

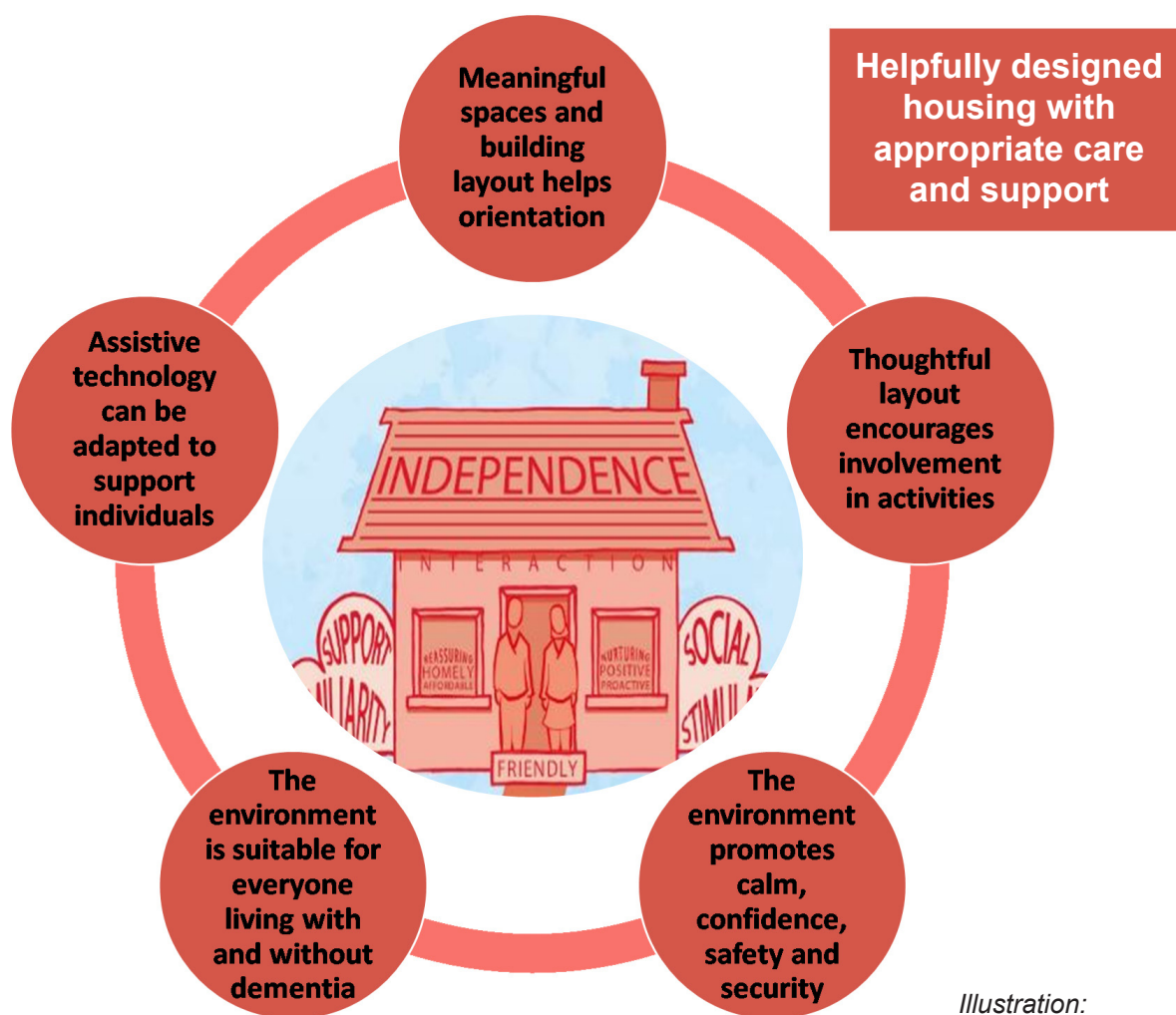
The importance of a well-designed environment

Many managers understood that design could help people live well with dementia, and ongoing maintenance and decoration programmes were described as opportunities to make improvements.

There are research and design guidelines to support managers who may be involved in making decisions about changes to the extra care environment, but not all are in an easily accessible format for front line managers. For example, research on design for dementia includes work on architecture and interior design (Brawley, 2001; Fleming & Purandare, 2010); Van Hoof, Blom, Post, & Bastein, 2013) as well as specialist research on matters such as designing environments to optimise visuo-perceptual considerations for people with Alzheimer's (Jones & Van der Eerden, 2008; Croucher & et al, 2015). Design guidelines cover interior design (Sandford, 2012; Fuggle, 2013), as well as specialist areas such as lighting (McNair, Cunningham, Pollock, & McGuire, 2010) and the outdoor environment (Mitchell &

Burton, 2006; Pollock, 2007; Mitchell, 2012; Delhanty, 2013) amongst others. The Kings Fund has developed a tool designed to assess the dementia friendliness of extra care housing (The Kings Fund, 2014) which is being adopted by some housing associations.

Drawing on the research and design guidelines, and taking into account the findings of this initial phase of extra care housing research, the model set out below has been developed to promote discussion in the next phase of the research about how a helpfully designed environment with appropriate care and support can constrain or enhance the experience of an individual living with dementia.



*Illustration:
Katey Twyford, 2016*

Operating in a changing legal and regulatory framework

Implementation of the Care Act 2014 had the potential to impact on the developing model of extra care housing. The Care Act and accompanying regulations and guidance (Department of Health, 2014) outlined how housing could support a more integrated approach to providing 'suitable accommodation' to meet care and support needs of older and vulnerable people at home.

Local authorities in their market shaping role should be proactive in promoting extra care housing as a housing option in meeting their general duty to promote wellbeing and offer information and advice on housing options. The requirement for housing to be considered as part of an assessment process to prevent, reduce or delay an adult social care need should give clarity and impetus to local authorities taking a more proactive role within the

agreed nomination processes with partner agencies. Given the limited insights provided by this research, further research into the impact of the Act on the nomination arrangements at schemes would be useful.

Central to the Care Act is the principle of wellbeing and the associated belief that individuals should have control over day-to-day life, including over care and support and the way it is provided (Section 1 (2) (d) promoting individual wellbeing). The Care Act 2014 sets out that care and support should be delivered in an integrated way with cooperation with partner bodies, including housing.

At the same time, the Act stipulates that individuals should be able to exercise greater choice and take control over how their care and support needs are met through personal budgets in conjunction with care and support plans. Models of extra care housing aspiring to meet the principle of individual wellbeing through choice and control are having to review the viability of operating models for provision of housing and care support. Only a few questionnaire respondents reported that residents were able to engage external providers to meet their care needs. Further research could usefully consider the cost effectiveness of extra care operating models if residents are able to opt out of using the onsite care and housing support providers, and the impact that could have on emerging models of extra care where residents take a core offer of on-site cover from the housing and care provider as a part of their tenancy arrangement.

Balancing policy, best practice and reality

Dementia and dementia care have historically not been seen as a high priority within the political agenda (Cantley, 2001 and 2002). More recently dementia has undoubtedly become more centre stage with policy documents such as 'Living Well with Dementia – A National Dementia Strategy (Department of Health, 2009) and the Prime Minister's dementia challenges of 2015 and 2020 (Department of Health, 2012; Department of Health, 2015). The growing knowledge and understanding of dementia and how individuals can be supported to live well with dementia is adding a new dimension to the discourse on housing for older people.

Factors that can help distinguish how well an extra care housing scheme can support people to live with dementia were established in Dutton's review of extra care housing and people with dementia literature (Dutton R. , 2010), Barrett's case studies from Housing and Dementia Research Centre's steering group report (Barrett, 2012) and a selection of case studies for the Housing LIN (Utton, 2013; Morrison, 2014; Stuart et al 2014; Yates 2014).

At the time of both the Dutton and Barrett reports there was inconclusive evidence about whether individuals with advancing dementia could be supported for life even with those distinguishing features. Where individuals could not be supported for life great importance was attached to having a supportive transition period and clear exit strategy.

This research has provided a contemporary view from a range of respondents that whilst extra care housing schemes aspire to provide a home for life, the reality is often influenced by practical issues presenting on a case by case basis. Issues include the practical restrictions cited on eligibility for apartments such as being able to orientate oneself, and the reported triggers for individuals leaving extra care housing such as increasing and complex health conditions.

If extra care housing is to be an option to support people with dementia to live as well as possible, further research is required on best advice for people with dementia considering extra care as a housing option, and best practice to support individuals with dementia living in extra care housing by minimising barriers through enabling building and interior design, and through policy, practice and individual person-centred assessment and planning processes.

Limitations of the research

This research supported the notion that individuals with dementia are being supported in extra care schemes, and that careful consideration and design can create a helpful environment to support individuals to live as well as possible. Much of the research is limited by the non-direct targeting of housing providers and the voluntary nature of the responses.

Whilst a rich source of information has been provided by those who did respond, caution should be exercised in interpreting the findings which cannot be considered as statistically significant. Nonetheless the findings did provide a deeper and more current narrative on previous research findings (Dutton R. , 2010), and did provide confirmation or contradictory views on anecdotal information gained from the extra care housing market (Dence, 2015).

The qualitative nature of the questionnaire led to subjective variations and interpretations in scoring (especially in the design section where similar comments were used for justification of scores ranging from 1 – 6). This was evidenced by two different sets of managers who responded on behalf of the same scheme. It was also evidenced by the use of similar examples and comments provided to justify different scores according to who made the response.

One respondent made a central reply on behalf of 30 schemes which inevitably resulted in non-tailored responses which could distort the results. For that reason, the design part of the questionnaire, which is likely to have the most variation by scheme, only counted the response once to avoid skewing the results.

Having acknowledged the subjective nature of the responses, the summary profile of scores did show a close 'grouping' of scores from providers across the different design areas, giving a broad view across the board.

Use of terminology within the questionnaire did not always support clear answers, for example, the reasons for leaving a scheme included 'inappropriate behaviour' which could have reinforced the view of dementia behaviour. It may have been better to use 'disinhibited' behaviour and seek comments. Another example is the word 'confused' which may have been better described as 'disorientation'. Terminology can develop in a way that makes sense to those with specialist knowledge, but makes it less accessible to those with less knowledge which can affect the translation from guidance and best practice into action. The use of terminology is evolving to support best practice in dementia support, and future research materials could usefully be shared with a dementia research group such as the South Yorkshire Dementia Research Advisory Group to ensure that latest best practice is included.

Whilst this initial research supported the notion that individuals with dementia are being supported in extra care housing schemes, the responses revealed some instances where more careful consideration and better design could potentially provide a more helpful environment to support individuals to live as well as possible. Further research could add to the current body of knowledge on whether the benefits of extra care housing outweigh its disadvantages if it does not meet best practice dementia standards.

Conclusion

Extra care housing and other specialist housing in the UK has developed since the early to mid-1990s across the public sector, not for profit and commercial sectors. Whilst there has been little early consensus on what extra care is (Tinker, et al., 2007), four main models of extra care housing for people with dementia have emerged including specialist, integrated, separate and hybrid (Barrett, 2012).

Opportunistic and piecemeal national government guidance has been instrumental in supporting the growth of extra care housing by providing policy direction and by supporting funding of extra care housing schemes through Government capital funds. The research identified that many of the current schemes were developed with grant funding, with local authorities party to nominations arrangements within schemes partnerships, usually alongside considerable nomination rights. Given the potential limitations of this research and the still recent implementation of the Care Act 2014, the role of local authorities in commissioning, developing and being partners in extra care housing schemes warrants further research.

The size of schemes varies considerably which does not appear to correlate with the availability of grant funding. Most of the schemes were purpose built with flexible living space achieved through the use of one and two bedroomed apartments.

All of the organisations taking part in the research reported that provision for people living with dementia was integrated throughout the whole extra care housing scheme, suggesting more research may be needed on the prevalence or potential demise of other extra care housing models. A perceived tension in designing space that is accessible and attractive to both people with and without dementia emerged as a theme throughout the study.

Models of care and support in the schemes involved in the research varied, with both different and the same housing and care providers supporting a scheme. The majority of managers reported that individuals with dementia were not explicitly excluded from taking up residence in a scheme, but there was little conclusive evidence about what may cause someone with dementia to move out of extra care housing. Further research could helpfully explore barriers to entry or how current inappropriate triggers for leaving could be avoided through policy, practice, and individual person-centred assessment and planning processes, taking into account recent changes as a result of implementation of the Care Act 2014.

The findings suggest a variable knowledge base about dementia design, but a strong commitment from individual managers and schemes to do their best for people with dementia. Future research resulting in best practice guidelines could be helpful for supporting all those involved in commissioning, designing, developing, and operating extra care housing schemes to appropriately support individuals with dementia to live as well as possible.

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Note

The views expressed in this paper are those of the author, and not necessarily those of the Housing Learning and Improvement Network.

About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading ‘knowledge hub’ on specialist housing, our online and regional networked activities:

- connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- provide intelligence on latest funding, research, policy and practice developments, and
- raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population

For information about the Housing LIN’s comprehensive list of online resources on housing and dementia, visit:

www.housinglin.org.uk/Topics/browse/HousingandDementia/

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Appendix: The original questionnaire, as sent to respondents

November 2016

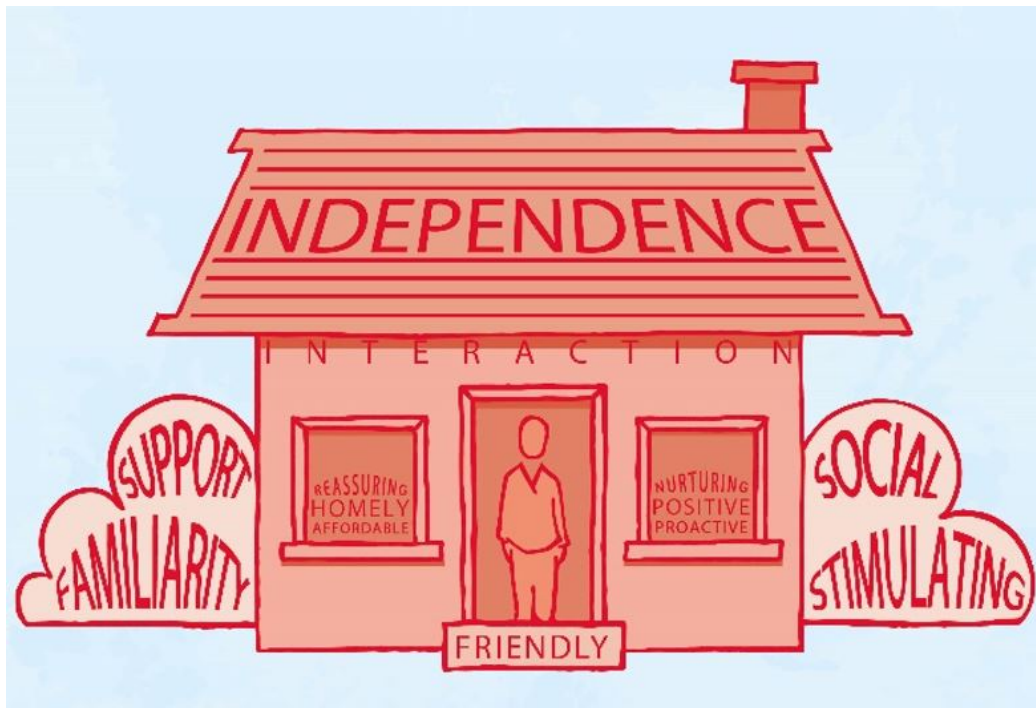
Extra Care Housing and its appropriateness for people with dementia

You have been sent this questionnaire as a HOUSING LIN member who is registered as providing extra care.

The questionnaire is the first part of a research programme on extra care for people with dementia. Its aim is to gather a national picture of how organisations support people with dementia to move into or to stay within an extra care scheme.

Please give some time to complete the questionnaire: it should take no more than 20 minutes and will help to build a full and up-to-date picture of UK extra care for people with dementia.

All information will be anonymised as part of the data analysis. The findings will be used to inform the next stage of the research programme which will explore a limited number of extra care schemes in detail.



Section 1 of 3

Background information

This first section is intended to find out the range of housing providers and partners currently providing extra care housing schemes

1. **What is the name of your scheme?**

.....

2.

Where is it located?

Please provide the postcode

.....

3.

Which county is it located in?

.....

4.

How old is the scheme?

Mark only one oval.

- Less than a year old
- 1 - 3 years old
- 4- 5 years old
- 6 - 10 years old
- 10 - 15 years old
- More than 15 years old

5.

Please say who the housing provider is

.....

6.

Who is the onsite 24/7 care provider?

.....

7.

Please detail below if there are different arrangements in place to an on site 24/7 care provider

For example, if there is an off-site 24/7 care provider or if all tenants have individual arrangements to purchase their own care

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8. **Please list below any local authorities who are partners in the scheme**

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9. **Was the scheme purpose built or remodelled from an existing building?**
Mark only one oval.

- Completely purpose built
- Completely remodelled from an existing building
- Partly remodelled and part purpose built

10. **Please make any comments as appropriate:**

.....
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.....

11. **How many apartments are there are in your scheme?**
Mark only one oval.

- Less than 40
- 40 - 50
- 51 - 100
- 101 - 150
- 150 - 300
- More than 300

12. **How many rented apartments do you have in your scheme?**

If you are unsure please give a rough approximate eg more than a third, half, two thirds etc

.....

13.

How many shared ownership apartments do you have in your scheme?

If you are unsure please give a rough approximate

.....

14.

How many outright purchase apartments do you have in your scheme?

If you are unsure please give a rough approximate

.....

15.

Please add any comments if appropriate

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16.

Please indicate the approximate ratio of one to two bedded apartments

This question intends to find out how many couples could be accommodated. A rough indication only is required. If you have 'one and a half' or 'one-plus' bedrooms please class them as one-bedroom.

Mark only one oval.

- 100% one bedded
- 90% one bedded 10% two bedded
- 80% one bedded 20% two bedded
- 70% one bedded 30% two bedded
- 60% one bedded 40% two bedded
- 50% of both one bedded and two bedded
- 40% of one bedded 60% of two bedded
- 30% of one bedded 70% of two bedded
- 20% of one bedded 80% of two bedded
- 10% of one bedded 90% of two bedded
- 100% two bedded

17.

If your scheme contains 'one and a half' or 'one plus' bedded apartments, how many do you have?

.....

18. **Do you have any apartments with more than two bedrooms?**

Mark only one oval.

- No - all apartments have either one or two bedrooms
- Yes - we have apartments with three or more bedrooms

19. **If you have apartments with more than 2 bedrooms please provide further detail below.**

(for example, how many do you have, do they have more than two people living in the apartments?)

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20. **Please indicate whether the scheme was developed with grant funding or a subsidy**

This may be central grant funding from the extra care capital funding rounds, or a local subsidy for example in the form of land contribution etc

Mark only one oval.

- Yes - capital grant funding or local authority subsidy was used
- No - the scheme was developed without capital grant funding or local authority subsidy

21. **Please indicate if there are any local authority controls or rights in place with the scheme**

For example fixed eligibility criteria, nomination rights, allocation rights, use of affordable rents and service charges etc.

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Section 2 of 3

Models of extra care

This section describes common models of extra care which support people with dementia. It aims to find out the extent to which common models of extra care are being used, or if there are any new models emerging.

22.

Please indicate which model best describes your scheme

Mark only one oval.

- Mainstream extra care which does not have people with dementia
- Extra care which integrates people with dementia throughout the scheme
- Extra care with a separate wing for people with dementia
- Specialist extra care scheme only for people with dementia
- Extra care combined with a registered residential home
- Other, please describe below:

23.

If your scheme does not fit one of the models listed, please describe below

.....
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24.

Please add any other comments that you would like to make about your particular model

.....
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.....

25.

Does your scheme have eligibility criteria which specify whether the scheme is suitable for individuals with dementia

Mark only one oval.

- No - there are no specific eligibility criteria for people with dementia
- Yes - there are criteria which specify it IS appropriate for people with dementia
- Yes - there are criteria which specify it is NOT appropriate for people with dementia

26.

If there are specific criteria, please describe any limits to entry and how they are defined

If there are no limits please indicate n/a

.....

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27.

Do you have formalised exit criteria?

Mark only one oval.

Yes - there is a formal exit policy with criteria to help guide individual decisions

No - we judge each case as it arises

28.

What are the main reasons (other than death) for tenancies coming to an end?

Please tick the main reasons that apply

Tick all that apply.

Move to be nearer family or friends

Difficulty providing the necessary level and flexibility of care in response to increasing needs

Targets for balance of dependency levels across the scheme

Inappropriate behaviours

Lack of community health support

Availability of resources / changes to benefits

Lack of ethnic diversity or ability of the scheme to meet different cultural needs

Other:

29.

Please provide any additional comments relating to the circumstances in which tenancies have ended

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Section 3 or 3

Design features of your scheme

There is a growing body of guidance on design features for extra care housing, including specific guidance to help support people with dementia.

This section explores how widely some of the most common design features have been included in schemes. It is expected there will be a large variation, especially with some of the older schemes.

This section asks you to rank how far you think each of the following design features have been taken into account in the communal and public areas of your scheme.

There is space to add any additional comments if you feel it is appropriate.

30.

Meaningful spaces and building layout help people with dementia to recognise where they are and why

Spaces are used for small activity corners, there are no dead end corridors, rooms contain objects that illustrate what the room is to be used for, glazed windows show what is inside to help orientation eg glazed walls, glazed cupboards

Mark only one oval.

	1	2	3	4	5	6	
There are no meaningful spaces or indicators and people sometimes get lost or don't know why they are there	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	The scheme has lots of meaningful spaces and indicators which help people recognise where they are and gives them something positive to do

31.

Please explain the reason for your ranking

.....

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32.

Thoughtful layout of rooms within the building guide people to where they are and what the rooms are used for

Rooms for use by different groups such as the public or tenants are positioned so that they are easily accessible with appropriate links between them e.g. the cafe is available in a public space, there is a secure door to the tenant areas including communal lounge and apartments, circulation corridors are not too long and reduce unnecessary doors etc

Mark only one oval.

	1	2	3	4	5	6	
Not at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Fully taken in to account

33.

Please explain the reason for your ranking

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34.

Simple spaces are created by decluttering the environment

For example: surfaces are plain and worktops only have meaningful objects on them; there is sufficient storage and no surplus equipment lying around; signs, notices and notice boards are meaningful and kept to a minimum

Mark only one oval.

	1	2	3	4	5	6	
Most spaces appear cluttered and confusing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Spaces are clear and all items are meaningfully placed

35.

Please explain the reason for your ranking

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36.

Lighting is sufficient and appropriate to the activity in the room

For example: natural daylight is optimised through glazing, roof lights etc; curtains can be drawn back as far as possible to let daylight in; darkness is encouraged during night-time hours to reduce nocturnal restlessness; lighting is used to highlight interesting features

Mark only one oval.

	1	2	3	4	5	6	
Lighting is poor, may not help someone know what time of day it is, and can cause confusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Lighting and darkness are optimised and appropriately used to help people with activities

37.

Please explain the reason for your ranking

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38.

Colour and patterns are used appropriately

For example: use of contrasting tones differentiate between foreground and background objects; contrasting feature walls emphasise space and activity areas; minimal use of patterns avoids distorting what a persons sees; if not essential, reflective materials such as mirrors and shiny stainless steel doors are not used or can be covered

Mark only one oval.

	1	2	3	4	5	6	
Colours, patterns and reflections cause sensory overload and confusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Appropriate use of colours, patterns and materials provide an understandable and calm environment

39.

Please explain the reason for your ranking

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40.

Artwork is meaningful

For example: tenants and families are involved in choosing artwork; artwork is used to break up monotonous spaces or provide a talking point; artwork that disturbs or disorients people is not displayed

Mark only one oval.

1 2 3 4 5 6

Artwork choice is adhoc or chosen by a designer who is not familiar with dementia care

Artwork is chosen and positioned carefully taking into consideration its impact on tenants and the public

41.

Please explain the reason for your ranking

.....
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.....

42.

Environmental features help individuals find their way effortlessly around the building

For example: routes through the building are as short as possible; the way to and back from parts of the building are signposted and landmarked; signs are repeated if necessary and appropriate; signs are easily understood (eg they employ symbols as well as words) and are at a height where they can be seen; doors are coloured to attract people into them or camouflaged to discourage people from using them
Mark only one oval.

	1	2	3	4	5	6	
The building is a maze to find your way around, people get lost and frequently have to ask directions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	The building is very easy to navigate without having to ask directions

43.

Please explain the reason for your ranking

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44.

Assistive technology (telecare) is available and widely used to complement support from carers and families as part of a care plan

For example, core technology such as call alarms are supplemented by other peripheral devices such as automated prompts and reminders, communication aids, locator devices etc
Mark only one oval.

	1	2	3	4	5	6	
Only call system in place	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Fully interactive system in place with individual devices installed as part of care plans

45.

Please explain the reason for your ranking

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That's it! Thank you!

Thank you for your time and support in completing this questionnaire which will provide an invaluable insight into the range of extra care models across the country and the different approaches to supporting people with dementia.

The information you have provided will be anonymised when it is analysed. Any findings will be generic and comments will not be attributed to individual schemes.

For further queries about this research please contact:

Katey Twyford

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Website: <http://www.sheffield.ac.uk/socstudies/postgraduate-research-students/katey-twyford>.

46.

If you are happy to be contacted again for more information please leave your contact details below

Please provide your name, position, and email address.

.....

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