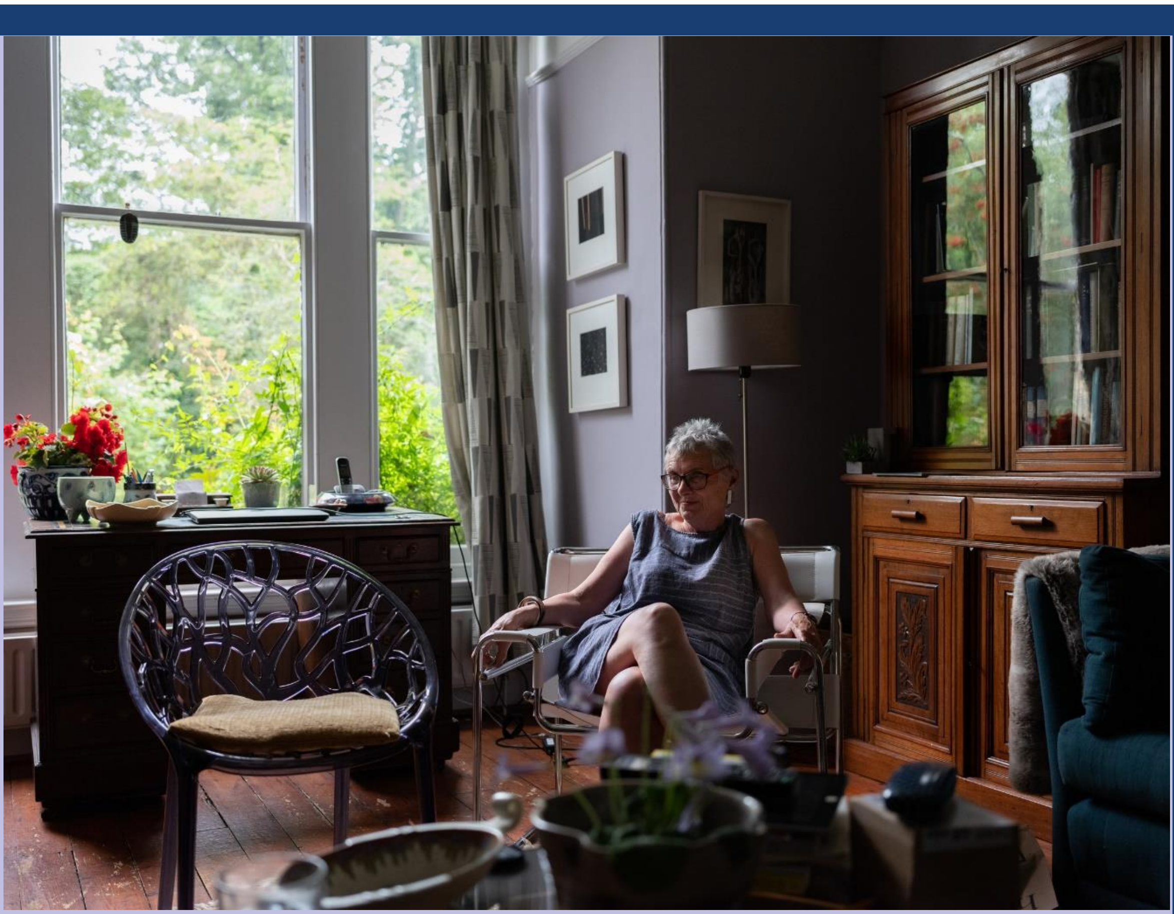
NIHR | Policy Research Unit Older People and Frailty



Full Report

Preferences for new models of care research study:

Phase One

Magdalena Walbaum, Martin Knapp,
Raphael Wittenberg, Jane McDermott

December 2022

Preferences for new models of care research study:

Phase One

Full Report

September 2022, revised December 2022

Magdalena Walbaum[a], Martin Knapp[a], Raphael Wittenberg[a], Jane McDermott[b]

NIHR Older People and Frailty Policy Research Unit
[a] Care Policy and Evaluation Centre, London School of Economics & Political Science, London, UK.
[b] School of Health Sciences, Faculty of Biology, Medicine and Health, The University of Manchester, Manchester, M13 9PL, UK

This report presents independent research funded by the National Institute for Health Research Policy Research Unit in Older People and Frailty. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Policy Research Unit Programme Reference Number PR-PRU-1217-21502

Context

The world population is ageing, presenting several challenges related to changes in physical and mental functioning (1). Projections of the English population estimate that the number of people aged 65 and over will increase by 41% between 2018 and 2038, from 10.1 to 14.3 million; and of those aged 85 and over by 72%, from 1.4 million in 2018 to 2.3 million in 2038 (2). Importantly, population diversity is increasing significantly, with a growing number of people from ethnic minority groups, with a mix of religions, languages and identities (3). The number of older people unable to perform at least one basic activity of daily living (ADL) is projected to rise by 48%, from 3.5 million in 2018 to 5.2 million in 2038 (2), and the number of older people with four or more long-term conditions is projected to more than double between 2015 and 2035 (4). This growth in the older population, and of older adults living with long-term conditions, and the increasing diversity, will consequently increase overall demand for social care and potentially also affect patterns of preferences (4).

Some projections estimate that there will be differences by gender, with a greater increase in the proportion of older women who are not independent in ADLs than in the proportion of older men (4). Some factors such as smoking, having low net financial wealth, and being sedentary, increase the risk of long-term conditions (5), which in turn is linked to adverse health outcomes, such as frailty and mortality (1). The projected increase in the absolute numbers of older people with dependency will inherently increase demand for more complex care to support their independent living (6). Looking at other subgroups, projections have shown that the number of older people living with dementia in England will increase by 81%, from around 748,000 in 2019 to 1,352,400 people in 2040 (7). Furthermore, the composition of the older populations living with dementia will change significantly. For example, the number of older people living with dementia as well as other long-term conditions will rise substantially by 2035 (4), further increasing the complexity and intensity of care demands.

These growing numbers of older people and especially of older people with high care needs have increased and altered patterns of demand for care and different housing options to accommodate their various needs. The housing market has shifted from what, for many people, was just a binary choice of staying in one’s own home or moving into a residential or nursing home toward a more diverse market with different and more flexible care arrangements that aim to respond to individual needs (8, 9). Policy makers acknowledge the need for a person-centred model of care, and not a “one-size-fits-all” approach, where care is provided in a holistic and integrated way. This is centred around valuing and involving older people, their carers and family members in decision-making to ensure people are able to express and hopefully achieve their preferences (10).

In this study, we aimed to understand current preferences for different aspects and models of social care and, on the basis of the best evidence, to explore how those preferences might change in the future.

Research questions:

1. What are the new models of social care for older people?
2. What are the current and projected future preferences of older people in relation to key dimensions of social care, including:

a. Receipt of unpaid care, identity of unpaid carer (spouse, child, other family, other person).
b. Care in one’s own home or in a ‘specialist’ care setting.
c. The physical, social and external (community) environments for individuals living in their own homes.
d. Type of specialist care setting (from housing with minimal support/supervision through to nursing home care and, indeed long-stay hospital).
e. Locality (e.g., moving to the seaside, or closer to family).
f. Choice of co-residents (family members, friends, strangers, nobody).
g. Preferences linked to ethnic, religious, cultural or other characteristics.

Methods

We conducted a scoping search of the new models of care implemented in the UK, specifically in England, to describe the different characteristics or components of these models experienced by people who use those services to be considered for discussion in a series of focus groups. The search terms and websites included for the scoping search are set out in the Appendix. The selection of components was agreed between the research team and the advisory group and then prioritised by policy colleagues within the Department of Health and Social Care (DHSC). Based on this prioritisation, we conducted five focus groups between March and June 2022, each lasting 1.5 hours, with people aged 50 years and older. Participants were contacted and selected using purposive sampling to capture the heterogeneity of the English population by age, gender, ethnicity, socioeconomic status, and place of residence. We first recruited three focus groups of adult participants from different age groups, gender and place of residence, without specific quotas for ethnicity or socioeconomic group. Subsequently, we recruited two further focus groups, one with members of the black Afro-Caribbean community and one with members of lower socioeconomic groups. The focus groups were semi-structured discussions of the preferences of the participants between the selected types and components of care. Two focus groups were face-to-face and three virtual using Zoom. Written or oral informed consent was obtained from participants in advance. All focus groups were audio-recorded with permission and recordings were transcribed verbatim.

The qualitative data were analysed using thematic analysis (11). We categorised the data into five different themes linked to the components of care prioritised for inclusion, with the unit of analysis being the individual. The first theme looked at housing settings with four sub-themes: preferred housing with care setting; people to share the home with; ages of co-residents; and geographical location. The second theme explored community assets; and the third theme looked at the use of technology for care through two sub-themes: assistive technology and tele-care. The fourth theme explored the provision of care, with two sub-themes: provider of care and use of direct payments. Finally, the fifth theme focused on control and dignity, with three sub-themes: decisions on daily routine and flexibility of care provision, management of money, and spiritual, cultural, religious, and sexual identity. Analyses were conducted in NVivo 16.1. Ethical approval was obtained through the London School of Economics and Political Science research ethics process.

Results

This section is organised as follows: first we summarise the findings related to the description of new models of care implemented in England; then we present the components of care prioritised for this study together with the results of the focus groups. The discussion is organised around the themes noted above.

We had a total of 39 participants in the focus groups: 10 males and 29 females. Mean age was 67 years, ranging from 50 to 85. Twenty-six were white British, 12 black African-Caribbean and one Indian. Participants came from different socioeconomic groups: C1, C2, D and E. Places of residence were the North West, Yorkshire, East Midlands, London, and South East England. The overall composition of the five focus groups reflects the general diversity of the English population. It is not statistically representative in terms of the proportions of the population by demographic characteristics (such as age, gender, ethnicity, socioeconomic status and region of residence), but such representativeness would not be expected or feasible in a qualitative study of this kind. The information provided by each participant reflects whether they were in the first or second set of focus groups. Thus, some provide age, gender, ethnicity and socioeconomic status, whereas others provide only information related to age, gender and ethnicity.

1. New models of care

The new models of care identified from our review emphasise the importance of providing services for individuals to tackle issues around loneliness and isolation, build strong relationships, support independent living in one's own community whenever possible to promote well-being (8, 12) and help older people maintain their dignity and autonomy (13). Regarding the provision of care, these different new models of care overlap in some of their characteristics and components that seek to ensure that care is consistent and reliable, with a reviewed care plan. Also, people value a caring and compassionate approach to providing care, including effective communication and trusting relationships between the person and his or her carer(s).

Community-focused models

The importance of being close to one's family and staying connected to the local community as part of the approach to care is well evidenced. Thus, there has been increasing advocacy for models with a wider approach in the provision of care, including services and support than would not usually be considered as formal social care (10), suggesting a leading role for communities in recognising links and connections for support and provision of care, both formal and informal. The COVID-19 pandemic has highlighted that care provision should be part of a much broader local offer in each community (9), including smaller micro-enterprises and a more active voluntary sector as part of the community assets available for the population. When thinking about needing care or support in old age, people put great emphasis on living in different places, such as general or specialised housing, that promote and improve wellbeing and maintain independence for as long as possible.

There are several examples of models of care led by various organisations to promote a more community-based approach in the funding and delivery of care as a way of providing support for older people, connecting people to their communities and local voluntary sector services. These community organisations, working in partnership with local authorities, are often able to provide more personalised care, giving individuals choice and control in decisions. An example of a community-based approach to care is The Keep it Local campaign (9), aiming to create collaborative public services by investing in the local economy and to act as social connectors in their neighbourhoods. Community organisations recognise the existing links and connect key parts of their community, with both formal and informal services, including those that do not require Care Quality Commission (CQC) registration.

The innovative Buurtzorg model, first implemented in the Netherlands by the Buurtzorg company (14), has been adopted with appropriate adaptations in a number of local areas, including Wiltshire County Council. This approach works on the principle of mutual responsibility regarding care between individuals, their families and the community, working with residents and families to collectively manage budgets and finding alternative models to support adults with care needs.

Housing LIN introduced the concept of Continuing Care Neighbourhoods (15), focusing on a more co-ordinated approach of support for older people from different health and care providers, voluntary organisations, and other community groups and public services. Other examples of models which focus on connecting individuals to the community are the Living Well programme in Cornwall (16) that aims to move towards a more proactive, long-term and planned approach to care. The focus is on meeting a person’s whole-life needs proactively, not reacting to an episode of ill-health and subsequent cycle of dependency. As reported by the King’s Fund, other examples of local models of care are the app called Careview developed and used in Leeds, which identifies households with signs of isolation to alert agencies that there may be cause for concern; and the Rotherham social prescribing service, where a team of voluntary and community sector advisers receive referrals from GPs, assess the individual’s needs and refer them to the voluntary and community sector for support (10).

Integrating care models

Integrating care models aim to address the existing fragmentation of care. Some of these models commission from a specialised organisation the integration of different providers to form a more comprehensive network of support and care (9). This enables these models to provide better access to information on available options of care and advice, enabling people to make more informed choices regarding their care in case of need. Some examples of these models of care in England are Devon Cares, where the Northern Devon Healthcare NHS Trust works alongside local home care providers to organise care for people; and the Outcomes-based commissioning project in Wiltshire, where the care plan is determined based on an assessment undertaken by customer care co-ordinators and linked to a payment based on a desired outcome as opposed to units of time inputs.

Other integrating care models work in multidisciplinary teams aiming to integrate the work done by different sectors such as health and social care, housing and other community organisations around the individual who needs care to maximise uptake of the resources offered by each sector and thus ensure more co-ordinated and personalised care. One example of an integrated care model is the Encompass Multispecialty Community Provider in Kent (10), where teams comprising GPs, community nurses, pharmacists, social prescribers, social care workers and health and social care co-ordinators assess individuals at higher risk of hospital admission and then co-design the care model with them. Another example is the Age UK co-ordinators programme (17) which involves Age UK, local GPs, community teams and social services to identify older people with multiple long-term conditions and provide them with holistic care packages.

Summary of the new models of care

These examples of different new models of care are some of the multiple and diverse initiatives implemented in the country in order to improve the provision of care towards more personalised, well-informed and connected models of care for the population. Commission reports by the Social Care Institute for Excellence (SCIE) have shown that, when well-implemented, these models of care improve user satisfaction, giving individuals more choice and control over their decisions and lives (18, 19). They have also had a positive impact on increasing workforce stability, providing a better opportunity to build strong and meaningful relationships between individuals and their carers (18).

In the next section, we will describe in greater depth the different components of these models of care, providing examples from the literature and also bringing in what we learnt from the focus groups.

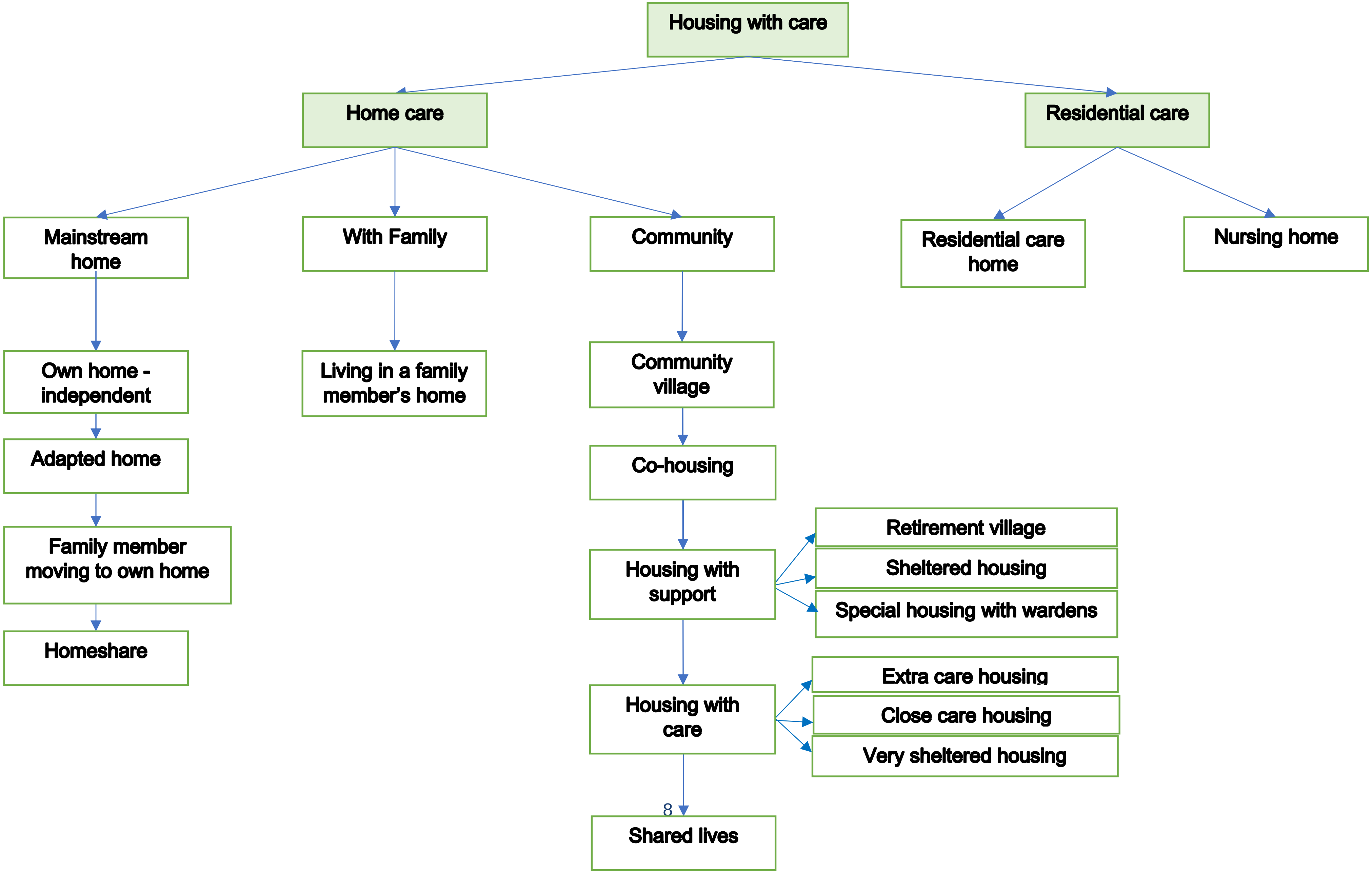
2. Components of the new models of care

Theme 1: Housing

Sub-theme: Housing with care settings

For the purposes of this study, we categorised the various housing with care settings into two big groups: home care and residential care (See Figure 1). Home care includes all settings where the person can live independently in an owner-occupied or rented home with their own front door. These settings overlap in practice, making it difficult to disentangle them entirely. However, for the purposes of organising the findings and the following discussion with participants of the focus groups, we furthered categorised this group into *Mainstream home, With family* and *Community* settings (See Figure 1). Residential care settings comprise those where the person does not live independently with their own front door; it includes nursing homes and residential care homes.

Figure 1: Housing with care settings



Home care

Mainstream home

There are different options of mainstream home independent living (20) which are suitable to meet general needs or to take specific needs into consideration through adaptations. This can include specific physical adaptations to the home such as installation of handrails or wider door frames for wheelchairs to increase accessibility. This facilitates visits by people with mobility problems, identified as a priority for many older people (12, 21).

Home-share is a form of shared living which brings together people with spare rooms who need help to live independently in their own homes with people who provide companionship and help in exchange for affordable accommodation. This scheme could prove mutually beneficial as it offers companionship, preventing loneliness, bringing financial benefits in the form of affordable housing for the home sharer and low-cost support for the homeowner, and enabling someone to live independently in their own home for longer (22).

With family

Living with family is considered as mainstream housing in some reports. An older person might move to the home of a family member who can provide care and support to maintain the person's independent living. People can also receive care and support from external staff or have appropriate physical adaptations to the home to meet any specific needs. For people living in their own home or in a family member's home, other resources, services, and amenities are usually available within the community.

Community housing settings

The community housing setting includes various forms of 'specialised' homes to buy, rent or access through private or social and affordable rent schemes built within a development usually designed for people older than 50 or 60 years. The aim is to support independent living with appropriate levels of care and support depending on preferences and needs (8). Personal care and support are generally arranged or provided within the development, with a focus on building a sense of community, through the inclusion of shared facilities, such as social spaces and other amenities that are open to the public, and social activities based on people's preferences. Although these housing settings have been shown to be good models of care in countries such as Australia (20), in England they are unevenly distributed across the country, with most of the developments concentrated in London and the South East (8, 20), and as many as 40-50% of owner occupiers aged 65 and over unable to afford to purchase retirement property, further limiting their implementation (8).

Community villages

Community villages is an umbrella term that includes large purpose-built or purpose-adapted developments of specialised housing, usually designed for people aged 50-60 or over to live independently but with on-site access to support and care depending on each person's preference and level of need (22). They provide self-contained accommodation alongside on-site facilities specifically designed to deliver personal care and support to older adults with communal spaces which might include a lounge, shared garden or outdoor spaces, laundry facilities, gym, restaurant, or cafés. A report by Stirling and Burgess in 2021 provides a more detailed description of various types of community villages (20). In general, they can be further grouped into ‘housing with support’ and ‘housing with care’ based on the level of care provided on-site. Housing with support settings have scheme managers and emergency call systems for people who can either live independently with support or share an ordinary or purpose-built home with a small number of other adults with disabilities of working age or older people. They may include a 24-hour alarm system, warden and a programme of activities. Some examples of housing with support settings are sheltered housing, retirement housing or villages, and special housing with wardens.

The housing with care settings, sometimes also known as integrated retirement, are built to provide more care to people as their needs increase over time, and where staff are usually based 24 hours a day on site, with different packages of care and domestic services available such as 24-hour alarm system, wardens on-site, communal lounge, programmes of activities and domestic help that can include assisted bathing and meals provision. Some examples of housing with care are assisted living or very sheltered housing and extra care housing, both of which provide managed care and support services. Retirement villages with close care are also considered as housing with care, where care is provided on-site and is usually linked to a care home for closer care.

Co-housing

Co-housing, also called community-led housing, is a form of housing for sale or rent that combines self-contained accommodation with some shared communal facilities that are created and run by residents. Residents come together to manage their community and share activities, possibly including sharing meals and eating together. Residents have their own self-contained homes and private spaces, and they decide when and how they want to interact. There are a few schemes that have been developed specifically with older people in mind, although there are co-housing communities that are inter-generational. They can also be designed specifically for groups with common interests (22).

Shared Lives

Shared Lives schemes support adults over the age of 16 with intellectual disabilities, mental health problems or other needs that make it harder for them to live on their own. These services are regulated by CQC. They are seen as an alternative to supported living or residential care, although the proportion of older people who use this scheme is still small (23). The schemes match someone who needs care with an approved carer to ensure a mutually beneficial relationship and compatibility in terms of skills, interests and the home environment. The person with care needs shares and becomes part of the carers’ life, including their family, social network and neighbourhood life. Shared Lives approaches vary to enable greater flexibility about care but can include full-time live-in arrangements, short breaks and respite or day care. This model facilitates continuity of care and provides relationship-based care, encouraging social interaction and better integration with the community (24). In a survey conducted by Callaghan et al. in 2017, older people living under this scheme rated their quality of life highly, with those using long-term placements reporting higher scores (24).

Residential care settings

Residential care settings include places where personal care and accommodation are provided and regulated together as one package: they are communal establishments rather than independent living (22). People may live in this form of housing with care for short or long periods. Whilst care homes can be used for respite care, for many people it is their sole place of residence and so it becomes their home, although they do not legally own or rent it, and as such they do not have the rights of tenancy enjoyed by residents of the other housing with care models described above, and sometimes have less control over the care and support they receive (18). These settings include nursing homes and residential care homes. Nursing homes provide 24-hour nursing and personal care, while residential care homes provide only personal care. There are specialised care homes which accommodate people with specific needs such as dementia (20).

Focus group discussions on housing with care settings

The discussions held with the participants of our focus groups about housing with care showed that, in general, individuals preferred to stay living independently in their own homes for as long as possible. This preference was especially stressed by participants from higher socio-economic groups, who usually described wanting to live independently in a well-suited home. All participants considered making physical adaptations to their homes, such as shower rails, if needed. Community settings were also positively accepted as a housing option if care needs increase.

> *"Yeah, I totally agree. I would live at home for as long as possible. I have a three-bedroom semi at the moment, but I have considered selling up and trying to find a two-bedroom ground floor apartment."* (Female 77, White British, SEG C1).

Participants considered moving to a community setting as an opportunity to receive good quality care while maintaining their independence if these settings provided an "own front door". This was especially highlighted by participants from lower socioeconomic groups (D and E), who mentioned that they would prefer to move to a community housing setting as the first option rather than stay living in their current homes. However, they mentioned that the costs associated with community settings usually limited their choice.

> *"I'd prefer a community where I'd have my own place, but yet would have like a communal front room where we could all go and meet if we needed. But you have still got my own like little flat really. That's what I would prefer"* (Female 58, White British, SEG D).
>
> *"…but I'd prefer the community. But I've been looking into it and they just price you out of it. For what I'm paying now for my own home, it's like that plus another half to rent a room. It is expensive."* (Male 62, White British, SEG E).

Residential and nursing care homes were the least preferred housing setting. These settings were seen as outdated, and participants frequently mentioned the poor quality of care people received when living in care homes.

> *"But there's no way in a million years she would ever go in a care home. I wouldn't want her to and I certainly wouldn't want to go in a care home. So, it's just a case of keeping her as independent as possible for as long as possible"* (Female 55, White British, SEG C1).
>
> *"Yes, I'm of the same opinion, really* [referring to another participant's remark that care homes are not the best setting]. *One of the things that I've experienced (…) visiting care homes, and that's why I said we need to abolish*

> *them. Because no… well, I don't think they have anything to offer today, but I do think care in the community is the way forward for us."* (Female 79, White British).

> *"Many times, I've visited people in care homes and the carers that I see there, I don't think they're competent for that ethnicity, and the things that they do… It's really awful."* (Female 69, Black Afro-Caribbean).

Participants from black Afro-Caribbean ethnic groups also preferred to stay living in their own homes for as long as possible. Their preference was driven not only by the value they placed on their independence, as with other participants, but also by their culture, where there is a more intimate relationship between families and their communities. They mentioned that, when people age, they assume that their children will take care of them, so parents usually move to their children's homes (or vice versa). Also, it was often mentioned that they usually support and provide unpaid care to people within their close communities.

> *"…coming from my culture back home is that we don't have people in* [care] *homes. The family looks after them. So, I have got five children and I'm hoping when I get old that they would look after me either in their homes or come to my home and look after me because I do believe that when a person gets old after looking after so many children that they should be put in homes. It the children's responsibility and the grandchildren to look after the elderly".* (Female 74, Black Afro-Caribbean).

> *"Yes. There is way to – it's very fundamental that people stick together. When you're old, the children, the grandchildren take care of you until you die. That's the way, from my background in Africa and then most of Caribbean that is the same way we go, I used to visit a lot of them in the Caribbean".* (Male 55, Black Afro-Caribbean).

Sub-theme: People to share their home with

This sub-theme focused on exploring the preferences of individuals regarding who to live with in case they cannot live independently because of their increasing needs for help with daily living and personal care tasks. In the focus groups, we discussed if they would prefer to share their home with a relative, if they would consider letting a room under a home-share arrangement, to receive care from a live-in carer in their own home or would consider moving to a carer's home as in a Shared Lives arrangement. Preferences were mixed regarding sharing their home if they were not able to live independently. Some participants would prefer to live with a family member, but there was a strong preference for maintaining their independence and privacy even if that meant living on their own and receiving care from a person who comes every day to support them with their daily activities.

> *"It's an awful thing to think that you've got to depend on somebody, I think, and if we do have to do it then, as I said, nobody knows what's around the corner, do they? I suppose I would prefer them to come here, to do their things and then go back home".* (Female 71, White British, SEG D).

Other participants would prefer to live with a formal carer in their own homes, as opposed to living with a family member, and mentioned that this arrangement would make them feel safer, especially during the night.

> *"I wouldn't mind sharing with somebody as long as I could keep my own privacy. I think it would be good to have a carer here, because sometimes of the night things happen and you feel pretty on your own."* (Male 75, White British)*"*

There was a negative perception towards a home-share arrangement, and participants highlighted that they would not feel comfortable living under this arrangement, again giving importance to feeling safe at home.

> *"Because I think you're better with friends and neighbours and family who you're used to, rather than strangers"* (Female 77, White British, SEG C1).

Sub-theme: Ages of co-residents

The next sub-theme focused on discussing the preferences of individuals about the age of their co-residents if living within a community housing setting. The evidence found by the National Care Forum's survey showed that 43% of respondents would consider living in a mixed-age community, compared to 36% that would prefer to live with people of their similar age group (25). In general, participants from the focus groups agreed that they would prefer to live with people of mixed ages with a minimum accepted age, as they considered that it was important to being able to talk about different topics and socialise with people of different ages. However, they would not like to live somewhere that is too noisy: they specifically mentioned loud music and parties.

> *"I don't think they should mix the young with the old. We're set in our ways, unfortunately, and it's like you just want a bit of peace like later on, don't you?"* (Female 61, White British, SEG D).

> "*Mixed ages for me too… I think you don't want to be with all old people, because a lot aren't young at heart, are they? … and I think if you're mixing with younger people, it keeps you feeling younger."* (Female 74, White British, SEG C2).

When we asked them for a specific age limit, participants agreed that around 50 years old would be an appropriate age limit for this type of community housing setting.

> *"I'd be happy – I mean, obviously, somewhere around about my age group. There's no point talking to someone in their 30s about rap music, because it'd be like, "Well, what are you talking about?" But anything sort of my age group that you can talk about stuff from the 70s, the 80s and all by that time, because we'd be all old fogies and anybody else that's younger than us wouldn't really understand. So yeah, something like that, something our age. I don't know – you could set an age limit to it. I don't know – 50+ or 55+ I don't know. Starting from there. Something like that."* (Male 55, White British, SEG C2).

Sub-theme: Geographical location

The report by Stirling and Burgess showed that there is already a substantial shortage of housing with care settings, which is expected to get worse given population ageing (20). Also, there is an unequal distribution of these settings around England, with the majority in London and the South East and a considerable undersupply in other parts of the country. Cases were even reported where older people had to move from North West England to Scotland due to the limited availability of appropriate housing with care settings, leaving their families and communities behind. This could have a significant impact on wellbeing, given the importance of social connections that *"are as important as money and health to a good later life*" and are strongly interrelated (26). Several studies have found that older people prefer to stay living in their own neighbourhoods: they value the strong attachment to their communities, an established trust, sense of belonging, and ability to rely on their neighbours (27).

Other reports showed that people considered it attractive to live in the outskirts of a town, suburban areas or more rural settings rather than in an urban or city centre location. Evidence from international studies also supports these findings, showing that, as people grow older, their preference grows to live in a small town or in the countryside on the outskirts of a major city (12). However, the focus groups showed that participants preferred to stay living in their current neighbourhood, this being the main driver for choosing where to live when they age or as their care needs increase. We discussed the high value of living in a familiar place, where they know all the resources available and the social connections they have with neighbours and families. When we discussed moving to a housing setting in the countryside or other geographical locations, participants all agreed that, although it would seem nice, they would not move away from their communities or families.

> *"Just my neighbourhood because you know people there, you're handy for your relatives. You can't move away and then expect your relatives to travel and visit you. So, I'd stay in the same area."* (Male 75, White British).
>
> *"I think I'd prefer to stay in my own home with my friends and my family. My family and grandkids live about 10 minutes' drive away. It's where all your memories are and where I think you'd be most comfortable."* (Male 76, White British).

Theme 2: Community assets

Community-focused models enable service users to have better access to community assets, which have been shown to be a high priority for people and have played an important role in people's lives when planning their care (10, 28). Relationships with neighbours, having access to local facilities and proximity to good transport links were key factors encouraging people to want to remain at home. This theme focused on exploring the preferences of older people about which resources provided by the community were considered most important for their wellbeing and their care. We discussed the importance of having access to informal services and support provided by the community, and to link to and maintain the social connections provided by and within the community.

All participants considered the links they had with their respective communities and neighbourhoods as important, especially during the Covid-19 pandemic. They also agreed that the new models of care should promote community-based care and value community life and social gathering as necessary for their wellbeing. They mentioned that key assets were the availability of good public transport, local shops, library, pubs and community centres so they can go and do different activities.

> *"Within the community, because these places are just going to – they're dying out, so to have something like that would be nice. A little pub, pop-up pub or something like that."* (Female 58, White British, SEG D).

Almost all participants mentioned the importance of having good public transport, mentioning some free services that allowed them to move easily around their community which they previously used but were no longer provided.

> *"And they'll pick you up and take you to wherever. So, I think that's good to keep in a community, because at least you've got the access. And the drivers are like, become their friends… And that's part of the community, and that's taking them to bingo or wherever they want to go. That's a good setting"* (Female 61, White British, SEG D).

The black Afro-Caribbean group mentioned the importance of having good access to Afro-Caribbean food shops and accessibility to participate in Sunday church services.

> *"I think the important thing that has been mentioned is access. Access to these areas so the transport is a very important element of that, being able to get there affordably. So, it doesn't necessarily just mean African Caribbean shops, but it means a range of shops, the accessibility is key"* (Male 63, Black African-Caribbean).

Theme 3: Use of technology

Technology devices include tools that may be used within new models of care to support carers and service users to maintain their independence, to help with prevention and to improve productivity and quality of care by enabling new ways of working and reducing psychosocial and emotional stress of carers (29, 30). Use of technology has surged rapidly in recent years, with the Covid-19 pandemic increasing its use further. However, the care sector has experienced some challenges in adopting technology, in part due to a limited understanding about the opportunities these technologies bring and the way they work, and partly due to the limited incentive for investment in technologies within the new models of care as a result of the way in which care is funded and commissioned in England (29).

There is evidence that, when used, technology has facilitated older people to stay safe while isolating, receive care and maintain their social connections (31, 32). It has also enabled older people to live more independently, have more control of their lives and connect with their family and friends. It has facilitated older people's care, improving their psychological wellbeing, reducing anxiety and helping them to feel optimistic about the future (33). Nevertheless, the uptake and benefits of technology have not been equally distributed across the population: for example, there are important digital inequalities between gender, age, and socioeconomic groups (29, 34). The pandemic highlighted the digital inequalities between different socioeconomic groups, which, by limiting receipt of care, had a negative impact on wellbeing (29).

Sub-theme: Assistive technology

Assistive technology in the context of care refers to '*any device or system that allows individuals to perform tasks they would otherwise be unable to do or increase the ease and safety with which tasks can be performed*' (35). There is a broad range of different assistive technology tools that have been implemented as part of the new models of care to support people to maintain or improve their personal control and independence and to continue living at home for as long as possible. Assistive technology can help reduce potential risks, as well as support the work of paid or unpaid carers and enable remote care through tools for remote alert and monitoring (33). The TAPPI report (29) provides an extensive and detailed list of examples of new models of care that have included the use and implementation of assistive technologies in England. Some of them, such as the ExtraCare Charitable Trust, are implementing innovative apartments in community villages to give residents the chance to use these technologies in a real-world environment. Other models, have focused on delivering a person-centred approach to digital learning among older people and people with low levels of confidence in using technology (36) to improve their digital skills so that they can live more independently and be ‘tech confident’ (37), thereby improving their quality of life (38).

There is some evidence reporting several barriers and issues with assistive technology, such as price barriers for the user, or lack of ongoing support for the use of the technology and inappropriate choice of equipment for personal capabilities and preferences. There are also issues with the lack of integration and interoperability of different technologies and the data they generate. A review of evidence on technology-based tools for people with dementia and their carers found that, while there were a range of tools available, there was limited evidence of widespread practical application and that individuals adapted everyday technologies to their needs (39). Similarly, the recent report by Knapp et al. (40) found that there is lack of evidence supporting the effectiveness of digital technologies in enabling people living with dementia and carers to live well or whether the use of technological devices have had a positive economic impact on their users.

For the purpose of this study, we categorised assistive technology into three main groups (41, 42) to facilitate discussion with participants in our focus groups about their preferences regarding its use and to explore whether there were differences in their preferences depending on the complexity of the existing technologies:

- Care technology devices used *by the person with care needs*: assistive technology that can be used independently by the person and are usually supportive and responsive products which help people in completing their everyday activities in some way, by making activities easier, by providing reminders or by raising alerts.
- Care technology devices used *with the person*: These are collaborative devices which foster interaction between the older person and his/her carer or between the person and the technology. In most cases these devices encourage, support or enable communication (e.g., reminiscence aids), or help a person engage with others through interactive forms of ‘play’ (e.g., puzzles and games, sensory play).
- Care technology devices used *on the person*: technology that can monitor the home environment, track the person’s location, monitor vital signs, physiological measures, and lifestyle behaviours, and record or transmit data (or both) to provide guided care. It includes wearable and non-wearable sensors such as pressure mats, smart devices (e.g., smart watches).

Focus group discussions on assistive technology

All participants of the focus groups acknowledged the use of technology as important and beneficial to maintain their independence for longer and to help them with their daily activities as their care needs increase.

> *"I think technology has a role to play, because I have seen where it has really helped"* (Female 81, Black Afro-Caribbean).

However, all participants recognised the existence of the 'technological divide' and that there is a knowledge barrier to fully engage with it. They highlighted the importance of receiving appropriate training so they could first understand the usefulness of the device and then be able to make a more informed decision whether or not they would use it.

> *"I would like to see certain aspects of what could be introduced to help me stay at home and learn about it, what would the benefits be, and as I move forward to increase it to other things. But you need to teach me."* (Female 74, White British).

Also, they mentioned the importance of receiving ongoing support because of the rapid and continuing changes in technology that sometimes made them feel overwhelmed or that they would not be able to keep up with the updates.

> *"And it's a shame for the older people, because they're not catching up as quick."* (Male 62, White British, SEG E).

In general, focus group participants would feel comfortable with assistive devices used 'on' them such as smartwatches, pressure mats or monitors that took their physiological measures, as they would help them to feel safer at home. However, there were differences in preferences about the use of cameras in their home. Some participants said they would consider having cameras to monitor their activities and help them feel safer, while others were against it.

> *"Yeah, I'd be quite happy with the camera, if someone is checking up on you every so often. I think that's quite a good idea, or even a tracker on you or something".* (Female 50, White British, SEG D).

> *"That's very invasive, isn't it, intruding on our lives. I mean, I can hardly understand the present IT system we have, never mind all these complicated devices that they're going to bring out. But also, I would prefer that Big Brother isn't watching me".* (Female 74, White British).

Sub-theme: Tele-care

There is mixed evidence regarding the preferences of people for tele-care. Some studies show that people do not want technology to replace face-to-face activities or communication with health and social care professionals. However, as described by the TAPPI report (29), the use of tele-care might provide an opportunity for better care, if it works alongside options that are person-centred, and focuses on what individuals need and on their preferences. The study by Vera et al. (43) conducted in England showed that the experiences and preferences of people with mental health problems for tele-consultation during the Covid-19 pandemic were dynamic and varied. They were shaped by factors such as the reason for contacting care services, their relationship with care providers, and their ability and individual preferences to use remote technology. Participants in that study identified the benefits of remote care provided through video or phone calls, such as making care more accessible for some people. However, they also mentioned that they would prefer to maintain face-to-face care at least for certain appointments (43).

Focus group discussions on tele-care

Most of the participants in our focus groups were not users of formal social care services, and so their experience with tele-care was mainly related to tele-consultation with GPs and nurses. However, their experiences were useful to illustrate their preferences regarding the provision of remote care if social care was needed. Participants in the focus groups generally agreed that there is a place for both face-to-face and remote care, acknowledging the benefits of the latter, but also indicating that, with remote care, they felt that the service was less engaged or personalised compared to face-to-face contacts.

> *"I agree with* [name of one participant]*, about technology is a tool… Tools cannot replace human beings. And it can help with the medical society, but face-to-face is most important."* (Female 81, Black Afro-Caribbean).
>
> *"I had to have physio and that was Zoom, and I found it OK, because of the fact that I didn't have to go out of my house and get sorted, go to the appointment… she zoomed me and did the physio like that. I didn't have a problem with that. Somebody older might not, but in my era I'd be fine with that. It was easier for me."* (Female 58, White British, SEG D).

As mentioned previously, most of the discussion centred on medical appointments, and some participants mentioned the difficulties they had with tele-consultations due to technological issues like the inability to send photos via WhatsApp or because of difficulty in having to show on camera the reason for contacting the GP.

> *"Definitely face-to-face, because I had a problem where I had to take a picture and I couldn't get the right angle – it was something in my mouth and I couldn't get the right angle. So that was difficult… plus, I can't get Zoom on my phone anyway. And I don't have a laptop, so it's a bit difficult."* (Female 52, White British, SEG E).

Two participants with physical disabilities and high care needs mentioned the usefulness of tele-consultation and how it enabled better communication with their doctors and better care of their needs.

> *"Like going to the doctors, it's hard for me to get up, I've to make appointment times, I'm relying on carers coming at the right time and getting me ready. If I can go and talk to my doctor and if I've got a sore foot, wave it at the camera so he can have a look at it without going down there … I wouldn't like to go back to the point where we didn't have the technology."* (Male 75, White British).

Theme 4: Provision of care

The new models of care are moving towards more person-centred and relationship-centred care, focusing on building relationships between staff and care users based on trust and maintaining an individual's identity. They are centred on strengths-based approaches, focusing on the person's strengths, skills and capabilities. They seek to co-produce the person's care plans, enabling them to have more control over their care and support, recognising the value of shared decision-making and respecting the person's dignity. They also seek to promote equality, where every person, regardless of age, ethnicity, gender, sexual orientation or disability, has the right to receive good quality, personalised care (18).

Sub-theme: Provider of care

The new organisational models have focused on organising care workers and the delivery of care on a more community-based model to improve care workers' experiences and achieve more personalised care, enabling continuity and the building of relationships (44). These models are moving away from the more isolated and fragmented 'time-and-task' oriented approach towards smaller self-managed teams, providing more autonomy for care workers and better communication between members of care teams. Working in limited geographical areas avoids time being spent travelling between service users. This in turn has led to more flexible, improved and more efficient working environments for care workers and higher quality care that meets the changing needs of service users. Some examples are the Wellbeing teams, the Love2Care in Devon, and the Place-based teams in Monmouthshire. These models also provide training, ongoing mentoring and development opportunities for care workers, aiming to improve the specialist knowledge of each team member and to ensure that staff have the skills they need to care for individuals in a person-centred way.

Among participants of the focus groups, the majority had experienced either providing or receiving unpaid care by a family member or a friend. They acknowledged the burden involved in caring, and so mentioned that their preference would be to receive care from a formal care worker as their main provider of care.

> *"I think it depends on the family's situation because if the family is working they can't give 24-hour care, so it could be a combination with help from outside to help them…I don't think it's fair to put the complete burden on the family because they have their lives also".* (Female 56, Black African Caribbean).

When we discussed if they would prefer receiving care from regular or varying care workers, all participants agreed that they would prefer to receive care from the same person and not different staff on different days, as they considered it essential to building a relationship and confidence.

> *"I would prefer to have carers [care workers] that come in and I know, rather than a bunch of people that just keep rotating all the time. Because obviously, they'll get to know you, you have a rapport with them…they know what your needs are, they know what your habits are, the routines..."* (Male 55, White British SEG C2).

> *"And he has care, but he gets a different carer [care worker] every other day. It's not often that the same carer comes and he's fed up to the back teeth of it. He has to explain what to do, and now he's got the point where he won't do anything. He'll just lie in bed…"* (Male 66, White British SEG C2).

Also, they mentioned that building a relationship was essential to receiving good quality care as it enables the care worker to know the preferences and needs of the person, making it possible to perceive more easily when something unusual or wrong is happening and needs attention.

> *"And you build up a relationship – I know that sounds like a strong word, but you build a relationship up, and then you would hopefully think that that carer would say, "Are you alright today? You seem out of sorts."* (Male 54, White British SEG D).

As part of the discussion, participants highlighted the importance of the experience of the carer and highlighted that receiving high quality care was one of the most important aspects when making decisions and choosing their care provider.

> *"Yeah, I think all of those things that she said, but personally, I couldn't care less who it was, providing they are well-trained"* (Female 73, White British).

Sub-theme: Use of direct payments

There is a move to a more personalised approach that promotes individual choice and a healthier market in which people can exercise more autonomy regarding the management and payment for their care. In England, the use of direct payments has increased. Direct payments provide greater choice by enabling users to employ their own personal assistant or manage their own care package (45), and ensuring users feel more in control and independent. Specialised subcategories of direct payment arrangements are individual service funds and integrated personal budgets that involve health and social care commissioners working together (18). Individual service funds are arrangements between a provider, the commissioning authority and the person, to provide flexible support under the terms of a contract between the provider and the commissioning authority. Providers make themselves accountable for how that funding is spent. Integrated budgets aim to organise better and integrate the funding sources for health services, social services and other benefits with a single point of access (46).

There was incomplete understanding among focus group participants of the funding system for social care in England, as shown in other studies (47, 48). In part, this can be explained by the complexity of the care system and because most people do not have direct experience of it themselves (45, 49). Given the purpose of our focus groups, we only provided a brief explanation of social care funding and then we focused on discussing their preferences regarding the use of direct payments. Only a few participants had experience with this approach. In general, the focus group of older people were better informed and understood the scheme. They agreed that, if using this scheme, they would prefer to manage it through an agency. This would make them feel safer and they would be able to hold the agency accountable for the spending.

> *"I think I would go maybe down the agency side, mainly because, just employing someone, if you could check them out and police checks and all that, I think probably – just personally – using an agency would be most likely safer."* (Female 77, White British, SEG C1).

Theme 5: Control and dignity

It is the duty of local authorities to promote the well-being of someone with social care needs, which includes being respected and treated with dignity, and having control over day-to-day life (50). There is vast evidence showing that people consider being treated with respect and dignity as one of the most important characteristics that they would look for when choosing their care provider or model of care (51), highlighting the need for independence, autonomy, choice, control and privacy as ways of supporting their dignity (52, 53). Furthermore, the review by Cleland et al. identified that older people have a strong preference to be treated with dignity and respect for their spiritual, cultural, religious and sexual identities by trained and skilled care workers (51). Evidence on preferences of people living with dementia (54, 55) showed the importance of considering their autonomy, sense of control, decision-making and feeling that they still have a purpose in life to engage in meaningful activities without being stigmatised in their care (56). Similarly, studies focusing on people receiving end-of-life care showed that this group of individuals mentioned the importance of maintaining independence and autonomy, feeling safe and being treated with respect and dignity (57, 58).

Sub-theme: Decisions on daily routine and flexibility of care provision

There are some examples of community advocates and organisations working alongside local authorities, supporting and encouraging local microenterprises to ensure that individuals can exercise choice regarding their care. These organisations, for example Community Catalysts, aim to offer more personalised care and have been found to be more flexible than larger providers in the way in which care is delivered (9). People consider it important to have daily routines (55), and they want to be involved in the decisions related to them such as the activities they do, the visits they receive, the time they get up and go to bed, and the timing of meals.

Discussions with focus group participants reached similar conclusions to those found in our literature review. Focus group participants mentioned the importance of being able to decide what to do in their daily lives as a way to maintain their independence, control and dignity as individuals. They mentioned that they considered it important to have routines, valuing models of care where they could have flexibility in decisions about their daily routines and their care.

> *"…sit down and discuss a package and say, "Right, well I want a meal in the morning, a meal at dinner," or, "I want somebody to come in first thing in the morning, last thing at night." To be able to choose."* (Female 50, White British SEG D).

> *"Yeah, I think you need to have a lot of control over what time you want to get up, what time you want to go to bed, what time you want to do everything. You don't want someone coming in and going, "Right, here we go. There's a routine. This is what you're doing for the next week. This is what time you're getting up, breakfast, whatever." You've got to have some kind of structure to your day, but whatever you want to do, not what someone else wants to tell you. And they'll fit it around because we can't do it until the carer has come in."* (Male 67, White British SEG C2).

An important issue mentioned during the focus groups was the importance of being able to choose their meals and the type of food they wanted to eat.

> *"To my mother, food is the most important thing. Absolutely the most important thing, and she loves choosing what we have. She plans the meals with my brother and she likes to know what we're going to have in the week."* (Female 59, White British SEG C1).

Sub-theme: Management of money

Another aspect of maintaining control and being treated with dignity is the ability of the person to be able to manage their own money. We discussed with participants if they would prefer to manage their money for as long as possible or if they would prefer someone else to do it. Since the ability to manage their finances may not be in the person's control, for example if they develop severe dementia, we framed it to reflect the value of maintaining control over their own life. They all agreed that it was an important aspect of their lives, and that they would prefer to manage their own finances for as long as possible. Some of them also mentioned that they would consider power of attorney for a family member.

> *“I think you manage your own as far as you can but again if you have a trusted family member it’s worth getting a power of attorney so that would be preferable…somebody who has power of attorney over your finances that you trust is probably the best way to go.”* (Male 62, Black Afro-Caribbean).

Sub-theme: Spiritual, cultural, religious and sexual identity

All the new models of care must comply with the Equality Act 2010 which provides an updated legislative framework to protect the rights of individuals and to promote equality of opportunity for all (59). Therefore, knowledge and respect of the person’s identity, culture and beliefs are key aspects when providing good-quality care (51). This includes receiving care from trained staff who understand and are able to provide care that responds to the different or specific needs of individuals from diverse cultural and ethnic backgrounds, or with diverse religious beliefs and sexual identities (60, 61). For example, in relation to LGBT groups, it is essential that care providers are well trained to manage the impact of discrimination, stigma and misgendering associated with gender and sexual identity, which can exacerbate mental and physical health problems (62). It can become more critical when people are diagnosed with dementia, as they may lose their inhibitions due to the condition or have episodes of regression where the person can go back to periods when they struggled with their identity or other people’s response to that identity, in turn exacerbating the anguish and confusion caused by dementia.

As mentioned previously, the more intimate interaction between family members that we discussed with participants in the black Afro-Caribbean ethnic group is another example of the importance of considering cultural backgrounds when planning and providing care. Previous evidence has noted this interaction, where there is more family-based decision-making around care arrangements that can sometimes go against the person-centred model of care that seeks to maintain the autonomy of the individual (63). Participants from this group mentioned the importance of having flexibility in their care and good accessibility to the life of their community, their religious ceremonies and celebrations as a way of respecting their cultural and religious beliefs.

> *“That’s what we’re missing here. That’s what friends all over the country are saying, that is what is missing. So, we’re looking at a model for older people, when it comes to social care, is to find a fit. And also, ensure that companies that are trying to fit an ethnic background that the government and local authorities help them to realise the standards that they need to meet.”* (Female 85, Black African-Caribbean).

There were also differences between groups in the importance they attached to food and hygiene, and they highlighted that those are usually unmet needs.

> *"The meal is not catered to Afro Caribbeans to ethnicities, it was at the beginning but whatever happened with their funding that's gone. So, now they have meals that she doesn't eat so that's a waste of money she has to pay for."* (Female 74, Black Afro-Caribbean).
>
> *"I don't say that the English don't cook properly but they too, the Black want their home and it has seasoning, and taste, and that will help them" (*Female 85, Black Afro-Caribbean).
>
> *"So, how you wash an elderly Black woman or elderly Black man, you would say everybody washes the same. Nowadays in care homes with these wipes, people use wipes to wash their face, do your arms, do your breaks. That is not a wash for a Black woman, is it? It's not a wash for a Black woman. Well, for a Black person. We wash with water and soap. And so, these may be small things, but they are crucial to our preference."* (Female 74, Black African-Caribbean).

Discussion

This first stage of the study reviewed new models of care being implemented in England, aiming to understand current preferences of people for different components of care and to explore how those preferences might change in the future. The evidence showed that the new models of care are shifting towards being more person-centred: valuing and involving older people, their carers and family members in decision making. The new models of care are emphasising the important roles played by the community and the need for coordination and integration between different service providers to create more flexible care arrangements, helping to ensure that people are better informed of the choices available to them and are supported to try to achieve their preferences.

People value their independence and control over their lives, which then translates into a preference for models of care that allow them to stay living in their own home or moving to a community housing setting with their own space for as long as possible. The available evidence and the views expressed by participants in our focus groups also emphasised the importance of community assets when people plan their care. An important priority for new models of care is therefore to promote or maintain social connections between older people and their neighbours, supporting participation in community life and ensuring access to local facilities. Building a relationship with a care provider that is based on trust and confidence was seen as essential to receiving good quality care: it enables the provider or carer to know the preferences and needs of the person and thus provide better tailored support.

Importantly, we found differences in preferences for some components of care between participants from different ethnic and socioeconomic groups, supporting what was found in the literature. This highlights the need to ensure that care arrangements align with individual preferences, beliefs and values. It is clearly important to understand and respond to variations in preferences for care across the population. In the proposed next phase of our research, we therefore aim to understand how care preferences are shaped by individual demographic, socioeconomic and needs-related factors.

Previous studies and our focus group discussions also touched on concerns regarding the costs of care. There are clearly affordability barriers that limit some people’s access to what might be their preferred model of care or their preferred quality of provision. We will need to factor that into the next phase of this study, and of course it is pertinent when considering future care policies.

Appendix

Exploratory search terms

Results: 351
Search: (preference) AND ("model of care" OR setting) AND (social care) AND (adult) AND (UK OR England OR "United Kingdom" OR Scotland OR Wales OR "Northern Ireland") Filters: from 2010/1/1 - 3000/12/12

(("prefer"[All Fields] OR "preferable"[All Fields] OR "preferably"[All Fields] OR "prefered"[All Fields] OR "preference"[All Fields] OR "preferences"[All Fields] OR "preferred"[All Fields] OR "preferring"[All Fields] OR "prefers"[All Fields]) AND ("model of care"[All Fields] OR ("setting"[All Fields] OR "setting s"[All Fields] OR "settings"[All Fields])) AND ("social support"[MeSH Terms] OR ("social"[All Fields] AND "support"[All Fields]) OR "social support"[All Fields] OR ("social"[All Fields] AND "care"[All Fields]) OR "social care"[All Fields]) AND ("adult"[MeSH Terms] OR "adult"[All Fields] OR "adults"[All Fields] OR "adult s"[All Fields]) AND ("UK"[All Fields] OR ("england"[MeSH Terms] OR "england"[All Fields] OR "england s"[All Fields] OR "englands"[All Fields]) OR "United Kingdom"[All Fields] OR ("scotland"[MeSH Terms] OR "scotland"[All Fields] OR "scotland s"[All Fields]) OR ("wales"[MeSH Terms] OR "wales"[All Fields] OR "wales s"[All Fields]) OR "Northern Ireland"[All Fields])) AND (2010/1/1:3000/12/12[pdat])

Translations

preference: "prefer"[All Fields] OR "preferable"[All Fields] OR "preferably"[All Fields] OR "prefered"[All Fields] OR "preference"[All Fields] OR "preferences"[All Fields] OR "preferred"[All Fields] OR "preferring"[All Fields] OR "prefers"[All Fields]

setting: "setting"[All Fields] OR "setting's"[All Fields] OR "settings"[All Fields]

social care: "social support"[MeSH Terms] OR ("social"[All Fields] AND "support"[All Fields]) OR "social support"[All Fields] OR ("social"[All Fields] AND "care"[All Fields]) OR "social care"[All Fields]

adult: "adult"[MeSH Terms] OR "adult"[All Fields] OR "adults"[All Fields] OR "adult's"[All Fields]

England: "england"[MeSH Terms] OR "england"[All Fields] OR "england's"[All Fields] OR "englands"[All Fields]

Scotland: "scotland"[MeSH Terms] OR "scotland"[All Fields] OR "scotland's"[All Fields]

Wales: "wales"[MeSH Terms] OR "wales"[All Fields] OR "wales's"[All Fields]

Websites searched

Age UK: https://www.ageuk.org.uk/

Alzheimer’s Society: https://www.alzheimers.org.uk/

Centre for Better Ageing: https://ageing-better.org.uk/

Health Foundation: https://www.health.org.uk/

HousingLIN: https://www.housinglin.org.uk/

Personal Social Services Research Unit (PSSRU) Kent: https://www.pssru.ac.uk/

Social Care Institute for Excellence (SCIE): https://www.scie.org.uk/

The King’s Fund: https://www.kingsfund.org.uk/

The National Care Forum: https://www.nationalcareforum.org.uk/

References

1. Nguyen H, Wu YT, Dregan A, Vitoratou S, Chua KC, Prina AM. Multimorbidity patterns, all-cause mortality and healthy aging in older English adults: Results from the English Longitudinal Study of Aging. Geriatrics & Gerontology International. 2020;20(12):1126-32.
2. Hu B, Hancock R, Wittenberg R. Projections of adult social care demand and expenditure 2018 to 2038. LSE, CPEC Working Paper 7, LSE Care Policy and Evaluation Centre, London; 2020.
3. Office for National Statistics. Census 2021 www.ons.gov.uk2022 [Available from: https://www.ons.gov.uk/census.
4. Kingston A, Comas-Herrera A, Jagger C. Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study. Lancet Public Health. 2018;3(9):e447-e55.
5. Nguyen H, Chua KC, Dregan A, Vitoratou S, Bayes-Marin I, Olaya B, et al. Factors associated with multimorbidity patterns in older adults in England: Findings from the English Longitudinal Study of Aging (ELSA). Journal of Aging and Health. 2020;32(9):1120-32.
6. Kingston A, Wohland P, Wittenberg R, Robinson L, Brayne C, Matthews FE, et al. Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies (CFAS). Lancet. 2017;390(10103):1676-84.
7. Wittenberg R, Hu B, Jagger C, Kingston A, Knapp M, Comas-Herrera A, et al. Projections of care for older people with dementia in England: 2015 to 2040. Age Ageing. 2020;49(2):264-9.
8. Robinson D, Green S, Wilson I. Housing options for older people in a reimagined housing system: a case study from England. International Journal of Housing Policy. 2020;20(3):344-66.
9. Locality. The community opportunity: lessons for adult social care from the Keep it Local campaign. Locality, UK; 2021.
10. Bennett L, Honeyman M, Bottery S. New models of home care. The King's Fund, England; 2018.
11. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nursing & health sciences. 2013;15(3):398-405.
12. Abramsson M, Andersson E. Changing Preferences with Ageing – Housing Choices and Housing Plans of Older People. Housing, Theory and Society. 2016;33(2):217-41.
13. Hill SR, Mason H, Poole M, Vale L, Robinson L. What is important at the end of life for people with dementia? The views of people with dementia and their carers. International Journal of Geriatric Psychiatry. 2017;32(9):1037-45.
14. Buurtzorg. The Buurtzorg Model 2006 [cited 2022 February]. Available from: https://www.buurtzorg.com/about-us/buurtzorgmodel/.
15. Battersby R. Continuing Care Neighbourhoods: neighbourhoods that continually care 2015 [cited 2022 February]. Available from: https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Viewpoints/HLIN_Viewpoint73_ContinuingCare.pdf.

16. The King's Fund. Living well in Cornwall 2012 [cited 2022 February]. Available from: https://www.kingsfund.org.uk/projects/integrated-care-collaborative-programme-four-communities/cornwall.
17. The King's Fund. Age UK care co-ordinator roles 2012 [cited 2022 February]. Available from: https://www.kingsfund.org.uk/publications/innovation-nhs/age-uk-care-co-ordinator-roles.
18. King EL, R. Sheikh, S. Templeton, F. A place we can call home: A vision and a roadmap for providing more options for housing with care and support for older people. Social care institute for excellence, UK; 2021.
19. King EL, R. Sheikh, S. Future options for housing and care: Improving housing that facilitates care and support for older people. Social care institute for excellence, UK; 2021.
20. Stirling P, Burgess G. Understanding supply, demand and investment in the market for retirement housing communities in England. Cambridge Centre for Housing & Planning Research, University of Cambridge, UK; 2021.
21. Aitken D, Gilroy R, Willis K. A Home for Life or a Home for Now? Understanding Indifference toward Accessibility and Adaptability Features among Some Older Homebuyers. Journal of Aging and Environment. 2020;34:1-18.
22. Social care institute for excellence. Models of housing with care and support 2021 [cited 2022 August]. Available from: https://www.scie.org.uk/housing/role-of-housing/promising-practice/models.
23. Shared lives plus. The state of Shared Lives care in England 2020-2021. https://sharedlivesplus.org.uk/; 2021.
24. Callaghan L, Brookes N, Palmer S. Older people receiving family-based support in the community: a survey of quality of life among users of 'Shared Lives' in England. Health & social care in the community. 2017;25(5):1655-66.
25. National Care Forum. The Customer of the Future: Results from a panel survey by Information by Design. NCF CEO’s Conference, Rethink the futureTime to act2021.
26. Centre for Ageing Better. Later life in 2015: An analysis of the views and experiences of people aged 50 and over. Centre for Ageing Better, England, UK; 2015.
27. Lloyd J, Parry W. Older Owners: Research on the lives, aspirations and housing outcomes of older homeowners in the UK. Strategic Society Centre, UK; 2015.
28. Associated Retirement Community Operators, Later Life Ambitions. Coming of age: Better housing options for older people. Housing LIN, UK; 2020.
29. Beech L, Porteus J. The TAPPI Inquiry Report, Technology for our ageing population: Panel for innovation - Phase one.: Housing LIN, UK; 2021.
30. Spann A, Vicente J, Abdi S, Hawley M, Spreeuwenberg M, de Witte L. Benefits and barriers of technologies supporting working carers-A scoping review. Health Soc Care Community. 2022;30(1):e1-e15.
31. Chang JE, Lai AY, Gupta A, Nguyen AM, Berry CA, Shelley DR. Rapid Transition to Telehealth and the Digital Divide: Implications for Primary Care Access and Equity in a Post-COVID Era. Milbank Q. 2021;99(2):340-68.
32. Jutai JW, Tuazon JR. The role of assistive technology in addressing social isolation, loneliness and health inequities among older adults during the COVID-19 pandemic. Disabil Rehabil Assist Technol. 2022;17(3):248-59.

33. Damant J, Knapp M, Freddolino P, Lombard D. Effects of digital engagement on the quality of life of older people. Health Soc Care Community. 2017;25(6):1679-703.
34. Office for National Statistics. Internet users www.ons.gov.uk2021 [cited 2022 March]. Available from: https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/datasets/internetusers.
35. Lariviere M, Poland F, Woolham J, Newman S, Fox C. Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: findings from an embedded ethnography of a national dementia trial. BMC geriatrics. 2021;21(1):121.
36. Age UK. One Digital www.ageuk.org.uk2021 [cited 2022 March]. Available from: https://www.ageuk.org.uk/our-impact/programmes/digital-skills/one-digital/.
37. Morris C, Carson I. Digital boomers: A theory of change for older people, technology & independent living. Rethink Partners, UK; 2018.
38. Joint Improvement Team. JIT Scotland Telecare in Scotland rwww.jitscotland.org.uk2015 [cited 2022 July]. Available from: https://www.jitscotland.org.uk/action-areas/telecare-in-scotland/.
39. Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M, Damant J. Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. Dementia (London). 2019;18(2):725-41.
40. Knapp M, Shehaj X, Wong G, Hall A, Hanratty B, Robinson L, et al. Digital technology to support people living with dementia and carers. NIHR OPF PRU Rapid Responses, NIHR Older People and Frailty Policy Research Unit, England; 2022.
41. Gibson G, Newton L, Pritchard G, Finch T, Brittain K, Robinson L. The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia (London). 2016;15(4):681-701.
42. Eost-Telling C, Hall A, Yang Y, Hanratty B, Knapp M, Robinson L, et al. Rapid review of digital technologies to prevent falls in people living with dementia. NIHR OPF PRU Rapid Responses, NIHR Older People and Frailty Policy Research Unit, England; 2022.
43. Vera San Juan N, Shah P, Schlief M, Appleton R, Nyikavaranda P, Birken M, et al. Service user experiences and views regarding telemental health during the COVID-19 pandemic: A co-produced framework analysis. PloS one. 2021;16(9):e0257270.
44. Kruger D. The care commitment: A new model of social care for England. UK: DEMOS; 2021.
45. Wittenberg R, Read S, Erens BOB, Knapp M, Wistow G, Dickinson F, et al. Who should pay for social care for older people in England? Results from surveys of public attitudes to the funding of adult social care. Journal of Social Policy. 2022:1-25.
46. Duffy S. Individual Service Funds (ISFs) and Contracting for Flexible Support: Practice guidance to support implementation of the Care Act 2014. Think local act personal, UK; 2015.
47. Dixon J, Exley J, Wistow G, Wittenberg R, Knapp M, Mays N. The sociocultural framing of public attitudes to sharing the costs of social care for older people in England. Health Soc Care Community. 2022.
48. Sussex J, Burge P, Lu H, Exley J, King S. Public acceptability of health and social care funding options: funding options for the NHS and social care in the UK. UK: The Health Foundation; 2019.

49. Wood C, Vibert S. A Good Retirement: public attitudes to the role of the state and the individual in achieving financial security in later life. London: DEMOS; 2017.
50. UK Public General Acts. Care Act 2014 www.legislation.gov.uk2014 [cited 2022 July]. Available from: https://www.legislation.gov.uk/ukpga/2014/23/contents.
51. Cleland J, Hutchinson C, Khadka J, Milte R, Ratcliffe J. What defines quality of care for older people in aged care? A comprehensive literature review. Geriatrics & gerontology international. 2021;21(9):765-78.
52. Hall S, Dodd RH, Higginson IJ. Maintaining dignity for residents of care homes: a qualitative study of the views of care home staff, community nurses, residents and their families. Geriatr Nurs. 2014;35(1):55-60.
53. Hall S, Longhurst S, Higginson I. Living and dying with dignity: a qualitative study of the views of older people in nursing homes. Age and ageing. 2009;38(4):411-6.
54. Wehrmann H, Michalowsky B, Lepper S, Mohr W, Raedke A, Hoffmann W. Priorities and Preferences of People Living with Dementia or Cognitive Impairment - A Systematic Review. Patient Prefer Adherence. 2021;15:2793-807.
55. de Boer ME, Hertogh CM, Dröes RM, Riphagen, II, Jonker C, Eefsting JA. Suffering from dementia - the patient's perspective: a review of the literature. International psychogeriatrics. 2007;19(6):1021-39.
56. Milte R, Shulver W, Killington M, Bradley C, Ratcliffe J, Crotty M. Quality in residential care from the perspective of people living with dementia: The importance of personhood. Archives of gerontology and geriatrics. 2016;63:9-17.
57. Dening KH, Jones L, Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. Palliative medicine. 2013;27(5):409-17.
58. Hill SR, Mason H, Poole M, Vale L, Robinson L. What is important at the end of life for people with dementia? The views of people with dementia and their carers. Int J Geriatr Psychiatry. 2017;32(9):1037-45.
59. UK Government. Equality Act 2010: guidance www.gov.uk2013 [cited 2022 July]. Available from: https://www.gov.uk/guidance/equality-act-2010-guidance.
60. Ward R, Pugh S, Price E. Don't look back? Improving health ando social care service delivery for older LGB users. Equalities and Human Rights Commission, UK; 2010.
61. Selman LE, Brighton LJ, Sinclair S, Karvinen I, Egan R, Speck P, et al. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. Palliative Medicine. 2018;32(1):216-30.
62. Age UK. Safe to be me: Meeting the needs of older lesbian, gay, bisexual and transgender people using health and social care services. Age UK, UK; 2021.
63. De Souza J, Gillett K, Froggatt K, Walshe C. Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography. Palliative medicine. 2020;34(2):195-208.

This document is available in large print.

Please contact the NIHR Older People and Frailty PRU for assistance.

Email: pru-manager@manchester.ac.uk

Telephone: 0161 306 7797

Front Cover Image
From Centre for Ageing Better image library
Licensed under CC0 1.0 Universal (CC0 1.0)