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Older people: Care and Self-funding Experiences

Research Report and Findings

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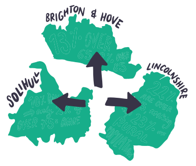
EXECUTIVE SUMMARY

Older People: Care and Self-Funding Experiences

Why is this research important

This research examines the **ethical and moral dimensions of self-funded care** by prioritising older people's experiences of self-funding for the first time.

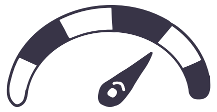
What we did



The research was undertaken in three geographical areas in a **three year participatory research study**.

We **explored ethical dimensions of care by listening to the experiences** of older people, unpaid carers and stakeholders.

Ethical & moral issues

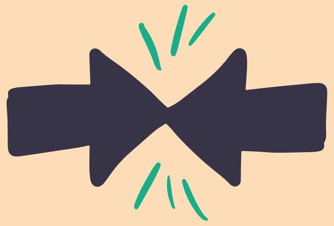


Risk & responsibility

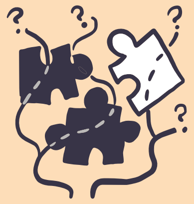
Views of carers & stakeholders

Findings

Self funders are **lynch pins** to the social care system yet their experience is **invisible**



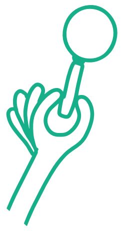
Social care **challenges** and tensions (like the myth of choice) are **systemic**



Navigating the **complex social care system** and managing care arrangements can be **overwhelming for self-funders**

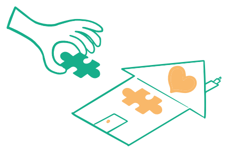
Recommendations

A **fundamental reform of social care is needed**, that acknowledges needs of self funders, examines care costs and improves care quality and access.



More accurate and holistic assessment of care and support needs for everyone with possible care and support needs in practice, as well as in law.

Better information for and about self-funders, and greater advice and support for self-funders.



Further research into experiences of self funders from marginalised communities is needed, and evaluation of information advice and guidance initiatives.

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Introduction

This report highlights our main findings from a three year-participatory research project which explored how older people experience the process of finding and paying for personal care from their own resources in three local authority areas in England. We were interested in examining the ethical and moral dimensions of self-funded care by bringing older peoples' experiences to the fore. We contextualised the experiences of older self-funders by obtaining the views of stakeholders and family carers, giving a rounded picture of the risks and responsibilities associated with self-funded care from different perspectives.

At the beginning of our research, we could not have imagined that a global pandemic would significantly impact on the final months of the project. The implications of COVID-19 included developing new approaches to co-production in response to our physical separation from our co-research teams. It also seemed important that we asked at least some of our research participants how their self-funded care had been impacted by the pandemic and the actions taken to control the spread of the virus. This report therefore, includes a 'post-script' reflecting the additional interviews which took place during the height of the first wave of the pandemic.

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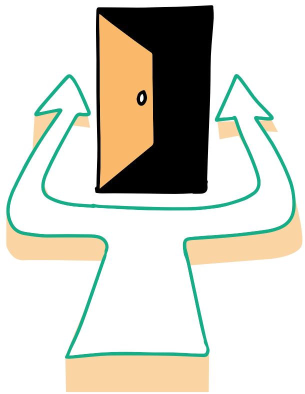
Context & Background

In the UK, social care is funded by Local Authorities and access to publicly-funded support for care is determined by national eligibility criteria and means testing. Social care services have experienced the impact of a decade of austerity and cuts to public expenditure with spending levels dwelling below the 2010/11 level (Bottery and Babalola, 2020). Financial pressures have been worsened by increased costs, rising demand for care and the ongoing challenges associated with sustaining a social care workforce. In this context, research has demonstrated high and growing levels of unmet need affecting people at all levels of wealth, including people who pay for their own care (Dunatchik et al., 2019).

Until relatively recently, self-funders, or, people who pay for all or part of their social care have been largely invisible in policy, practice and research (Henwood, 2019; Baxter and Glendinning, 2015). Self-funders cover a wide spectrum of people paying for care in different circumstances. We use the term ‘self-funders’ to include people who:

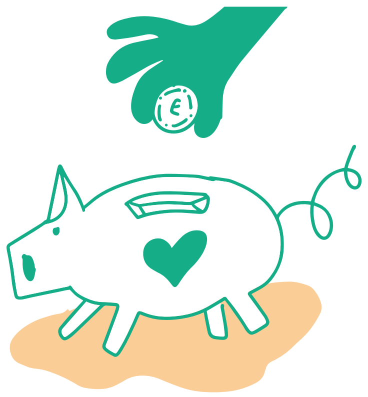
have financial assets which exceed defined capital limits

have care and support needs which do not meet national eligibility criteria



have bypassed assessment by statutory social care services, regardless of eligibility or financial status

are purchasing additional care services over and above their care and support needs that are met by the local authority



are having their care home fees topped up by a third-party payment to cover the fee element that is in excess of the rate that the local authority will pay.

Older people are the largest group of people who pay for all or a part of their social care and also the most likely to experience difficulties in accessing and managing their own care (Tanner et al., 2018). Very little is known about the experience of older self-funders and how they may navigate complex and fragmented care systems to secure and manage the care they need (Baxter et al., 2020). Despite their relative invisibility, older self-funders constitute a significant and continuous presence as consumers of social care services as well as playing a central, yet little discussed role as financial lynch pins to care services.

Given the complex and diverse ways in which older people are likely to fund their own care, there is an absence of national data about self-funders and local authorities possess only limited information (Baxter, et al 2020). Data on the number of people who pay for their own care are therefore based on estimates.

(Competition and Markets Authority, 2017)

Current estimates suggest that the number of self-funders in England is approximately 230,000 (Henwood et al., 2019). There are important regional differences which highlight both the polarisation and weaknesses of the care market. For example, affluent areas tend to attract care providers whose business models are based on self-funders; this potentially impacts on both the cost of care for self-funders and Local Authorities who commission care for people whose care is publicly funded. Conversely, less affluent areas have fewer self-funders which can impact on the financial stability of care providers who have to manage on the lower fee rates commonly negotiated by Local Authorities.

Policy and legislative context

Since the advent of the Care Act (2014) the duties and responsibilities placed on Local Authorities should mean that self-funders are more visible in strategic planning, policy and service delivery. The 'wellbeing principle' (Section one) places a duty on Local Authorities to promote the wellbeing of all individuals with care and support needs, regardless of how they are funded. This includes the duty to offer an assessment of need to anyone with an appearance of need and regardless of whether they are self-funders (Department of Health, 2017). A number of sections in the Care Act are designed to fulfil the duty for Local Authorities to prevent, reduce or delay deterioration in a person's circumstances (Section two). For example, each Local Authority must promote the effective operation of a care market (Section five) so that people wishing to access care can choose from a variety of sustainable services delivered by a range of providers. Moreover, market shaping includes developing intelligence on future as well as present demand for services. Local Authorities also have a duty to provide information (Section four) in order to support people to make informed decisions about how to meet their care needs. A significant element of the Care Act included a £72,000 limit on the amount of money that people aged 65 and over would pay for care. This, so called, 'care cap' was due to be implemented in 2020 but was formally suspended in 2017. Theoretically, the duties cited here should have significant implications for self-funders in terms of their rights to access information about services; choice of services; opportunities for assessment of need and support to make informed choices about care. However, evidence demonstrates that successive cuts to adult social care combined with additional demands have compromised the ability to fully realise the potential of the Care Act and diluted potential benefits to self-funders (ADASS, 2016; Hastings et al., 2015; Glasby et al., 2020).

Care Ethics

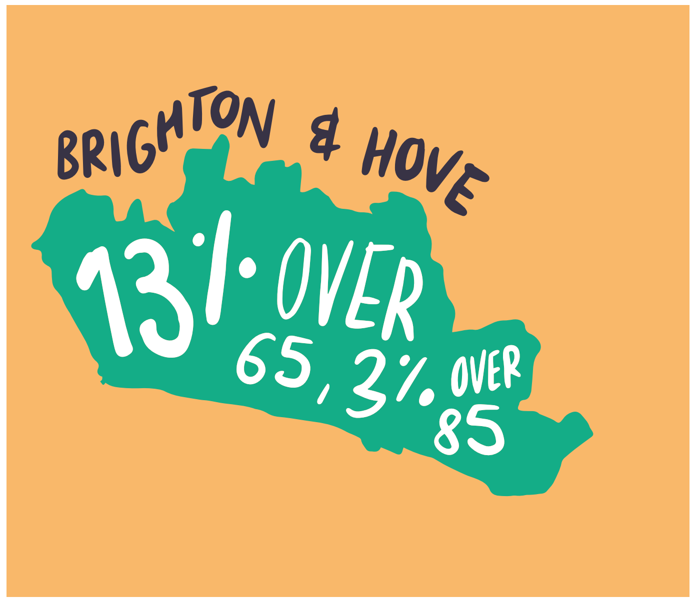
The project was underpinned by an ethics of care framework. Care ethics understands the need for care as part of being human and something we all experience at certain times in our lives. It also shifts from focusing on care as a 'product' to looking at care as an exchange in relationships between people; someone may be both a care giver and a care receiver and care is often reciprocal. Rather than viewing care as a personal responsibility that we owe to ourselves and close family members, care ethics sees being responsive to the care needs of others as a political and collective responsibility that we all owe to one another (Tronto, 2017).

A care ethics approach exposes some of the complex ethical issues that often remain hidden in policy and practice's concern with 'meeting care and support needs' (Lloyd, 2010). In this project, our care ethics lens meant that we adopted a critical stance towards the assumption that care needs can be met straightforwardly and efficiently through market models and principles. For example, we questioned how well some of the key tenets on which current policy rests, such as the exercise of choice, individual responsibility and management of risk, accord with the central concerns of older people who need care.

Underpinned by a care ethics approach, the overarching aim of this three-year study was to generate co-produced knowledge of self-funding through the real time, lived experiences of older people whose voices are largely absent from the literature on self-funding. To achieve a fuller perspective of the risks, challenges, benefits and opportunities of self-funding, we carried out fieldwork with unpaid carers (family members, friends, neighbours) and a range of stakeholders (for example, service commissioners, care providers, social workers and paid carers). Research was undertaken in three sites:

Brighton and Hove

Brighton and Hove has a comparatively small proportion (13%), of older people aged 65 years or more, yet a relatively high proportion of people aged 85 years or more (3%) and 2,400 people who are aged 90 or more. More than a third of all households comprise one person and 22% of residents over 60 experience income deprivation. 8% of people over 65 are Black minority ethnic (BME). Brighton and Hove has a high number of LGBTQ residents (11–15%). The study was carried out in collaboration with a community partner experienced in care services in the area as well as local older citizens who were an established co-research group (Ward et al., 2012).



Solihull

Solihull is a metropolitan borough council (MBC). It includes both large urban areas and rural areas with dispersed communities and very few public services. Although broadly affluent, there are areas of deep poverty within Solihull; three Wards in North Solihull include areas which fall within the 10% most deprived neighbourhoods in England. There is huge disparity in healthy life expectancy within Solihull, with people living in the most deprived areas having a life expectancy nine years below those living in the most affluent areas. Solihull has become more ethnically diverse in recent years as a result of net migration from neighbouring Birmingham. The 2011 Census showed that 10.9% of the population were from a Black or Minority Ethnic (BAME) background, though this is still lower than for England (14.6%) and the West Midlands (17.3%). The number of older people from a BAME background in Solihull is low; only 2% of its population are aged 75 and over compared with 17% of those aged 0-15 years. In Solihull, our community partner was a registered charity providing advice and support to older people. All of the co-researchers in this site were older volunteers for the community partner organisation.

Lincolnshire

Lincolnshire is a large and sparsely populated county and is the fourth largest county in England. 47% of the population in Lincolnshire live in rural areas compared to 18% in the rest of England. People aged 65 and over account for 23% of the rural population and 19% in urban areas. Lincolnshire's older population is higher than the national average representing 22% of the population. The population of non-white people in the county remains small (2.4%) and is predominantly made up of younger people. Within the most deprived 10% of the 32,844 lower-level super output areas used to measure overall deprivation in England (2015), 29 areas were in Lincolnshire. Distinct patterns of deprivation include, rural access to housing, transport and infrastructure services. Relatively high levels of deprivation are seen around the East coast and in more urbanized areas in the West of the county.
In Lincolnshire, the study was carried out with a community partner who is a registered charity providing a range of care and support services in rural Lincolnshire. A co-research team of older citizens worked on the project representing a number of districts in the county.

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Methodology

Research questions

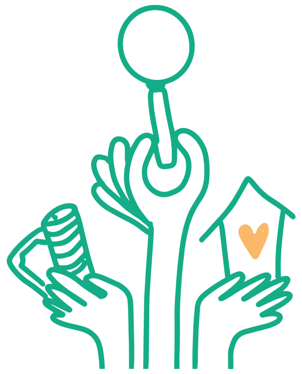
Our study aimed to answer the following questions:

1. How are relationships of care negotiated and managed by: older people who are self-funding; those who may be acting on their behalf (family, friends, neighbours); front-line care staff and provider organisations?

2. What risks does self-funded care generate for different stakeholders and how are these managed?

3. What insights can the ethics of care contribute both to understanding care relationships in a self-funding context and to informing commissioning and service provision?

4. What local information is available about older self-funders and how is this used to inform service commissioning?



5. How does older people's assessments of their care needs impact on identifying, purchasing and managing care services?

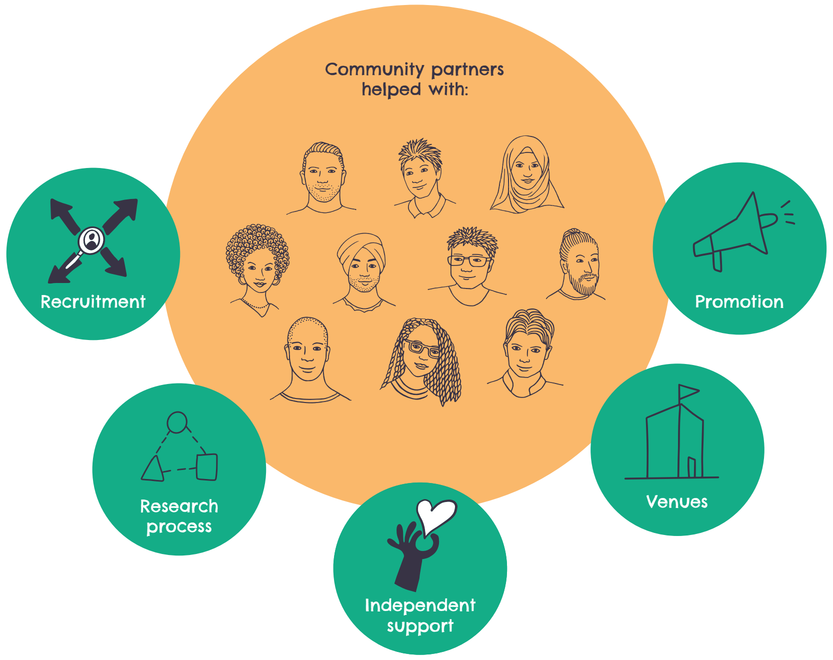
Co-production

Our research approach was based on co-production. This means, ‘an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge’ (Involve, 2018 p.4). Our key concern was to develop knowledge rooted in older people’s experiences but we also sought to embed ongoing dialogue with local stakeholders in our research processes.

This section outlines the different people involved in sharing power and responsibility in our project.

Community partner organisations

In each site we identified a voluntary sector community partner organisation which could provide local knowledge and support for the research. The role of the community partners varied across the three sites but included: helping with the recruitment of co-researchers and research participants; promoting the research amongst other third sector and statutory organisations; providing a venue and practical support for team meetings; and offering a source of independent support for co-researchers. A key representative from the community partner organisation was a regular member of team meetings, contributing to discussions and decisions about the process of the research in the locality.



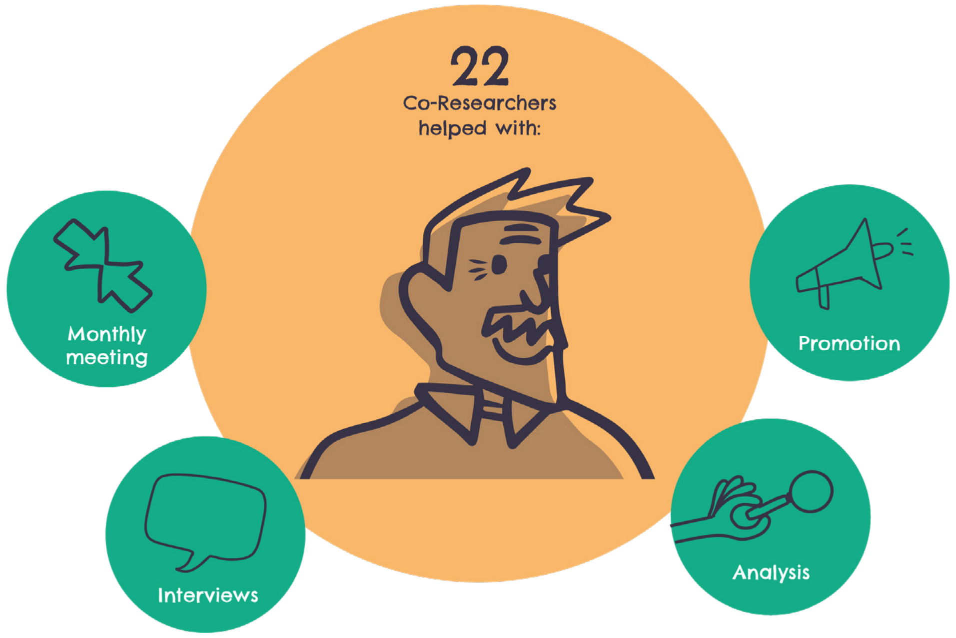
Co-researchers

Putting relationships to the fore means that we wanted to carry out the research in partnership with people who are most affected by the issues we are investigating. ‘Co-research’ refers to research that is ‘done with’ or ‘by’ people who are actively involved in the process, as distinct from research that is done ‘to’, ‘about’ or ‘for’ them (Fudge et al., 2007). Co-research means that research knowledge is generated with older people and therefore is rooted in their experiences. Benefits of co-research are that the research may be more relevant, of higher quality, more likely to generate change and be carried out in a way that reflects partnership, respect and equality (Gradinger et al., 2015). Members of the research team had previous experience of working with older people as co-researchers and we were able to build on this in the current project (Ward and Gahagan, 2010; Littlechild, Tanner and Hall 2014).

In each of our three sites, we recruited a team of older people who had different experiences of care to work with us as co-researchers. The community partners helped us to recruit the co-researchers, but we also used other methods of recruitment, including contacting other community organisations and older people’s groups. In Brighton, some of the co-researchers had been involved in previous research with the academic researchers and four new co-researchers were recruited to join the existing team of five. 10 co-researchers were recruited in Lincoln and 12 in Solihull. There were some changes during the three and a half years of the project but a stable core of 22 co-researchers remained throughout.

The minimum expectation of the co-researcher role was attendance at a monthly team meeting in the local site. The meetings were used for a range of activities, including planning the research, drafting the interview schedules, agreeing recruitment strategies, discussing interviews and processes for analysing the data, discussing findings, and planning various research events. The meetings continued throughout the duration of the project, becoming virtual meetings following the Covid-19 restrictions.

We hoped that, in addition to attending the meetings, some co-researchers would be interested in becoming more directly involved in some of the research processes. It was up to each co-researcher to decide which activities they would like to take part in. In each site, some or all of the co-researchers took part in the following activities, over and above attending the monthly meetings: visiting local organisations and venues to distribute recruitment information or give talks; carrying out interviews with older people, carers and stakeholders alongside the academic researchers; helping to code and analyse the data; taking part in presentations, conferences and training events; and designing dissemination materials. Some co-researchers kept reflective diaries recording their experiences of involvement.



Knowledge Exchange

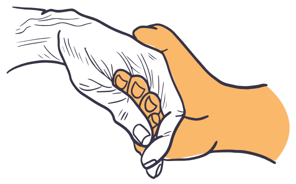
Another key strand of co-production in the project was working with key stakeholders in each site. The aim was to draw on local knowledge and experience in planning and carrying out the research and to bring together different perspectives on giving and providing care. This approach drew on previous work by some members of the research team (Ward & Barnes, 2016).

The Knowledge Exchange meetings were held every six months, meeting for a total of six times in each site across the life of the project. Knowledge exchange participants included local authority managers and commissioners, social workers, and managers and practitioners from private, voluntary and independent sector organisations. Meetings were led by an independent facilitator and membership was kept small (around 20-25 participants) to encourage open, honest and reflective discussions of opportunities, challenges and tensions in commissioning, managing and providing care. Older co-researchers took part in designing, developing and running knowledge exchange events which enhanced the sharing of experiences from different perspectives. Events focused on particular topics, such as information for self-funders. Later events focused more on emerging research findings and involved older co-researchers reading and discussing anonymised extracts from interview transcripts with older people and unpaid carers. As well as sharing views, experiences and understandings from different perspectives which generated research knowledge, the events also created new opportunities for participants to learn from each other about roles, responsibilities and resources related to care. A full report of each Knowledge Exchange meeting was sent to members after the event to encourage wider reflection on the issues raised.

Research methods

Participants

There were three separate groups of participants in our study:



Older people who were paying for all of some of their social care to meet personal care needs. Each site aimed to recruit around 25 older people and to interview each of them three times, approximately six months apart, over an 18-month period. We recruited older people through a range of means, including: flyers and notices distributed at community venues and groups; flyers distributed by the community partner organisations and other care providers; newspaper and radio notices; co-researchers using their own contacts and networks to distribute information.

Unpaid carers (family members or friends) who were supporting an older person who was self-funding all or part of their care. In each site we aimed to interview 15 carers, either individually or in focus groups. We used similar methods of recruitment to those used to recruit older people.

Local stakeholders who had different organisational roles and responsibilities in relation to self-funded care for older people. In each site we aimed to interview 15 stakeholders, either in person or by telephone. We identified stakeholders through our knowledge of local organisations, assisted by contacts in the community partner organisations and Knowledge Exchange membership.

We aimed to include a diversity of older people's experiences in our sample, particularly from older people whose voices are less heard in research from BAME and LGBTQ communities. Although we explored many different avenues to recruit participants from these communities our final sample has few people from BAME or LGBTQ communities. We reflected on the reasons for this with colleagues from, and active in, these communities who helped us generate interest in participation. Issues of trust about getting involved in research and past negative experiences of research were offered as possible reasons. In one site, a BAME elders group declined to participate as no one in the group recognised themselves as a potential participant, even though some were involved in unpaid caring roles. The challenges of building sufficient trust with an LGBTQ elders' group were familiar to another LGBTQ researcher activist who confirmed in her experience many older LGBTQ people were reluctant to take part in research because of lifelong experiences of stigma and discrimination.

The number of participants interviewed in each of these groups is shown in the Tables 1 to 3. Some of the older people interviews were with couples but these have been counted as one interview.

Table 1: Number of interviews with older people per site across the three interviews

OLDER PEOPLE				
	T1	T2	T3	Total
Solihull	27	24	18	69
Brighton & Hove	18	17	12	47
Lincolnshire	20	20	18	58
Total	**65**	**61**	**48**	**174**

Table 2 Number of interviews with unpaid carers per site

UNPAID CARERS	
Solihull	16
Brighton & Hove	15
Lincolnshire	15
Total	**46**

Table 3 Number of interviews with stakeholders per site

STAKEHOLDERS				
	Independent sector	Local authority professionals	Paid care workers	Total
Solihull	10	4	4	18
Brighton & Hove	3	8	5	16
Lincolnshire	7	5	3	15
Total	**20**	**17**	**12**	**49**

Interviews

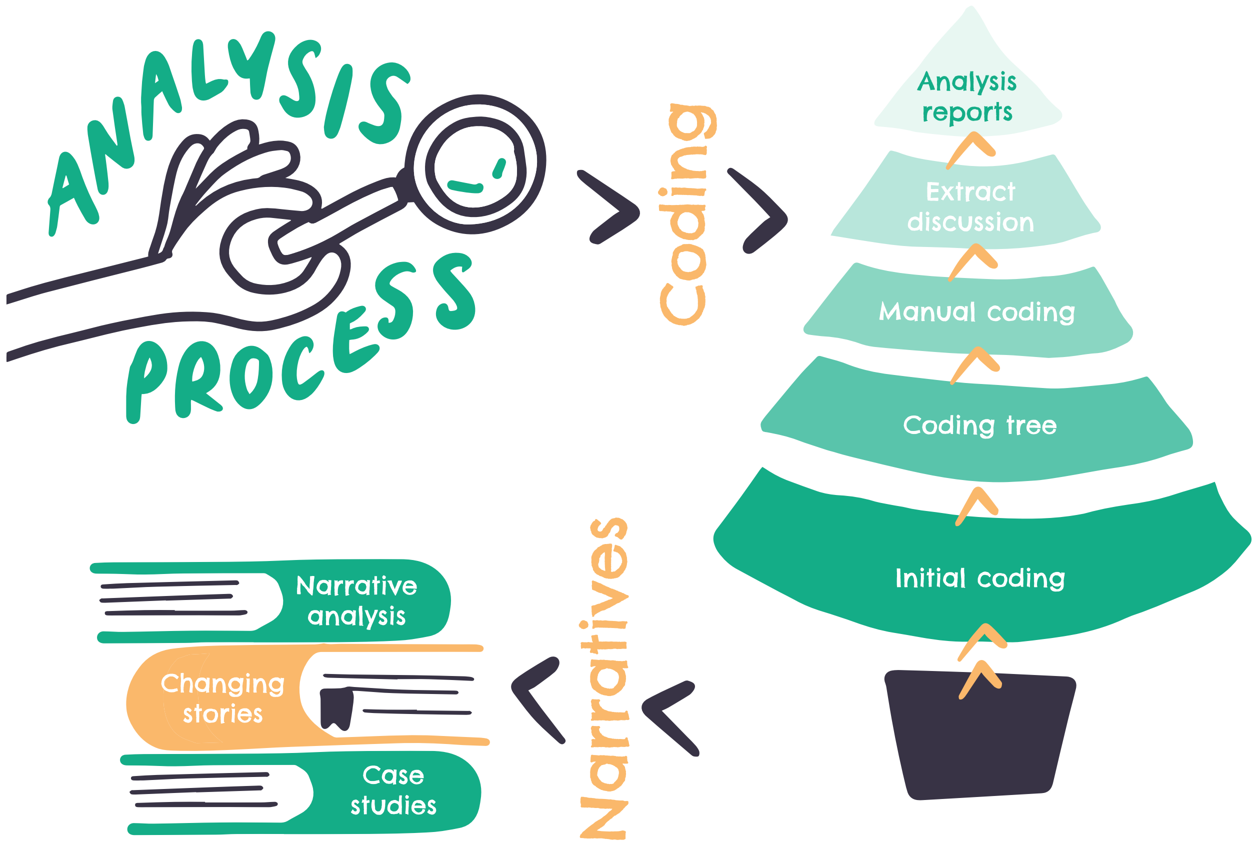
A separate topic guide was developed for each of the three sets of interviews – older people, unpaid carers and stakeholders – in consultation with the co-researchers in team meetings. Their ideas and suggestions were amalgamated to produce one topic guide to be used across the three sites, though there was scope to adapt this as needed in each interview. Interviewees could choose where the interview took place. Nearly all older people and unpaid carer interviews took place in the person's own home. Some older people were supported by a family member, supporter or personal consultee if they lacked the decision-making capacity to consent to take part. Co-researchers were directly involved in most interviews. This facilitated an open, conversational style to the interviews, allowing us to get as close as possible to the lived experience of participants. All interviews were audio recorded and fully transcribed.

Analysis

Co-researchers were closely involved in making sense of the data, both through helping to code the interview transcripts and deciding on a coding structure and then subsequently through discussing the meaning and significance of the data. This again reflected our efforts to keep older people's lived experience at the heart of the study.

Our processes for analysing the data followed Braun and Clarke's (2006) stages. We started with familiarising ourselves with data and identifying initial codes. A draft coding tree was developed in each site based on initial interviews and this continued to be extended and refined as subsequent interviews were coded. Co-researchers undertook manual coding, and this was recorded by the research fellows on NVivo or Word. When coding was completed, interview extracts that fell under broad themes were analysed and discussed by co-researchers, working on their own, in sub-groups and in team meetings. We discussed the meaning and significance they attached to the data and what they thought were the key themes. After this process had been completed in each site, the analysis was brought together and condensed in separate cross-site analysis reports for each of the three participant groups.

As a second process of analysis, we used narrative analysis of the older people interviews to complement and enrich the understanding gained from thematic analysis (Riessman, 2008). The narrative analysis looked at the stories that older people were telling about their experiences of paying for care across all three interview transcripts. This was useful in identifying persistent and changing stories that were not apparent in the decontextualization of the data through coding.
The narrative analysis was particularly helpful in the development of case studies that illustrate perceptions, attitudes and experiences over a period of time. These can then be compared to identify the different stories that older people tell about self-funded care and how these relate to their wider lives and identities.

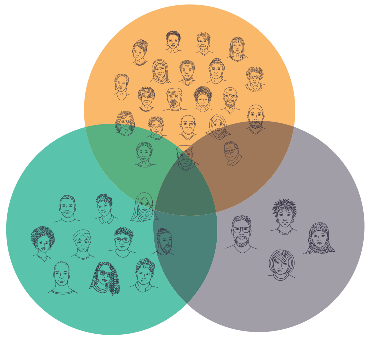


Co-production evaluation

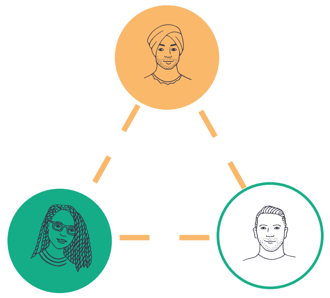
The project included an evaluation of the co-production process carried out by a researcher independent of the project (Cornish, 2020).

The aims of the evaluation were to explore:

how the approach to the project promoted the active involvement of older people as co-researchers



the impact of this approach on older co-researchers, academic researchers and stakeholders



how existing networks have been engaged in the co-construction of new learning between academic, 'lay', practitioner and professional communities.

Ethical approval

Ethical approval was given initially by University of Brighton Research Ethics committee and subsequently by Health Research Authority (HRA) Social Care Research Ethics Committee in December 2017. Each site also obtained local authority research governance approval. Separate ethics approval was given for the independent evaluation of co-production by the University of Brighton Research Ethics Committee in March 2020.

In carrying out the interviews our primary concern was the wellbeing of the older person or carer and this meant being attentive and responsive to signs of fatigue, discomfort or distress. We paid particular attention to ethical processes for involving older people who might lack the mental capacity to consent to participate as we thought that it was important that their experiences of self-funded care were included and understood. We did this by seeking advice from personal or nominated consultees, as set out in the provisions of Mental Capacity Act 2005. We were also mindful that we might become aware of possible safeguarding concerns so we had agreed processes for acting on these if such concerns arose.

In common with all participatory research approaches, we were also very aware of our responsibilities of ethical research practice in working with older co-researchers. We again drew on care ethics in developing a relational research practice that is attentive to the different needs and circumstances of our co-researchers. The risks of 'insider research' were a feature for some of our co-researchers who were facing similar issues to our research participants in their own lives. We understood that building supportive and trusting relationships in the team was an important ethical as well as practical element of our work.

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Findings

Our older people participants

65 older people took part in the study across the three sites. The ages of participants ranged from 60 – 95, although the majority were over 85 (see table 4 for age and gender and appendix 1 for further details). All participants apart from three people were of White British ethnicity, and these were: one person who was Asian, one who was White Irish and one was White European. We have changed the names of the participants in reporting the findings below. The number 1, 2, or 3 that appear in brackets after the name refers to first, second or third interview with that participant.

Table 4 Age and gender of participants

Age	Male	Female	Totals
60 - 64	0	1	1
65 -69	1	2	3
70-74	0	5	5
75-79	4	2	6
80-84	7	6	13
85-89	7	14	21
90-94	3	9	12
95-100	2	2	4
Total	**24**	**41**	**65**

Most participants took part in three interviews, but during the course of the study, 13 participants died and six were unable to participate in the third interview because of ill health. They all lived at home at the start of the study but six had moved into residential care by the third interview. Across the sites, participants lived in a range of circumstances, including co-residence with their spouse or partner and living alone. One site included a large proportion of never married women and people ageing without children. Most participants were wholly self-funding, although a few had some care and support needs met by the local authority which they were 'topping up' by buying additional care. The local authority assumed responsibility for meeting the care and support needs of two participants when their circumstances changed during the study. The majority of older people had organised care themselves, sometimes with the support of family, and the local authority managed the care package for two people who were fully self-funding. The care packages also varied. In two of the sites, care was mainly provided through care agencies, but in one site many participants directly employed private individual carers, with a number purchasing long-term live-in care. All participants across sites were living with long-term, co-existing conditions which impacted their daily lives. The care tasks included: washing, bathing, dressing, help with getting out of bed and going to the toilet, skin care, medication supervision and meal preparation. In addition to personal care, participants paid for and managed diverse combinations of additional sources of help, such as: gardening, shopping, cleaning, chiropody, physiotherapy, and what one or two participants referred to as companionship.

The need for care and becoming a self-funder

The main triggers of the need for care were the impact of long-term conditions, illness, and critical incidents, or a combination of these factors. Some participants' care needs developed gradually but for many the need for care followed a sudden deterioration in health, or critical incident, such as a fall or hospital admission. In this context, participants were often unaware of the implications of being a self-funder. They were unprepared for the complexities of finding, agreeing and purchasing care as well as for the reality that they would have to pay for care themselves.

Some participants had become aware of the financial threshold when they approached the local authority for support and were told following the assessment process that they were not eligible. For others, the question of eligibility for statutory care appeared less clear cut. They may have had a period of 'free' (intermediate or reablement) care following hospital discharge but when that came to an end, had been told they needed to source and pay for their own care. There were also participants who had never approached the local authority for support, either assuming that they would not be eligible for help or because they did not want to disclose personal information. It is not possible to deduce how many of these people might have qualified for support.

> *Everybody said, "Social Services will help you", and they were very good at first when [my husband] was in hospital. But once they discovered that we had more than £23,000 pounds in the bank …they really didn't want to know.*
>
> **ROBERT'S WIFE (1)**

Feelings about paying for care

Participants reflected a range of attitudes about paying for their own care, ranging from stoical acceptance, to resentment and irritation. Many had assumed that care would be arranged along similar lines to the NHS and be free at the point of delivery, covered by the tax and national insurance contributions they had made over their working lives. The expectation of 'cradle to grave' support for care and health through the welfare state meant that some people were unprepared for having to pay for care and felt that this was unjust.

> *I mean I'd rather not be paying for it… Worked all my life, paid taxes all my life, looked after a sick husband and a mother with dementia, and saved the country some money doing that and working full time and you think, when you need it, it's not there.*
>
> **BRENDA (1)**

Finding and securing care

Obtaining information about the availability of local care services was usually an ad hoc process. Participants generally had little guidance or advice about self-funded care, including the kinds of things they should consider. Information provided by or on behalf of local authorities seemed to be limited and difficult to find. As a result, many looked for other sources of information and often,

> *We all did it on our own, because you were asking is there any outside help, I think it was quite difficult actually. I honestly think it's difficult. Age UK, I know, does a great job but we were kind of working in the dark, most of the time. So, it's down to who you know.*
>
> **BEV AND WALTER'S DAUGHTER (2)**

Access to sources of information relied heavily on people being able to use the internet, being socially active or having family members to seek out information for them. Finding the most suitable type of care, and the best carers to meet their needs often came from conversations with others in their social networks.

> *Well, more by, well, by pure accident. One of my other stepdaughters lived across the road from someone who was managing an agency that provided, not 24-hour care, caring, so we arranged to try this person for nights.*
>
> **ISABEL (1)**

The widely held assumption that self-funders are people who can choose the care they pay for did not match the reality for many participants. Choice is only possible if there are a range of options to choose from, accessible information and knowledge about what the options are and a match between needs and aspirations with at least one of the options on offer. This did not apply to many of the participants in our study. In reality, choice was limited for participants by a number of factors. These included: a lack of knowledge about options and entitlements; the older person not meeting the criteria for services that were available; cost; distance and/or area covered by the service; or a lack of available care services to meet the older person's needs. Often participants purchased care based on what was available, rather than what was needed:

We've chosen the place because that's the only one we could get at the moment. There's only a few if you've dementia (and you're) relatively young and active that cuts you out of about three quarters if not more. ...And I find that there a very few in (area) that, I mean that was one...and there's a new one in (area), which I would have chosen but which is having problems starting up.

JIM'S CONSULTEE (1)

For many participants, therefore, 'choice' was not a meaningful concept or experience. The lack of care services was particularly acute in some rural areas where people often paid a care premium to reflect the cost of petrol and travel time. In addition, in order to secure a care service, some participants purchased more care than they really needed as carers had a minimum visit time to reflect travel time to rural locations:

See, it's living in the sticks which is a problem..... so we tweaked it a little bit, because initially it was just for an hour in the morning. So, we increased slightly the hourly rate and to take into consideration the mileage that the person might be doing and we extended it to two hours, and as soon as we'd done that we got an immediate response.

ADELE'S PRIMARY CARER (1)

Managing the care arrangements

Participants were also faced with the significant responsibility of managing the care that they purchased. Managing care involved activities such as: agreeing the care needed; negotiating with care agencies when changes were required or when things went wrong; arranging to end a contract with one agency and begin another; and negotiating and renegotiating the cost of care.
Without the benefit of an assessment of their care needs, participants had to work out for themselves how much care they needed and for what tasks, taking account of what they felt they could afford. Those managing self-funded care on a stringent budget had to be careful about the amount they spent on care, with potential implications for how effectively they were supported and their longer-term wellbeing:

I decided I wanted to have someone come once a week because that's all I can afford, so that's how it all happened really, you know I got turned down (by social services) but then I thought, well, you know, I'm going to pay for it myself...

PENELOPE (1)

The care agency might advise on the care that could be provided, but this did not necessarily tally with the older person's view of their needs or spending priorities:

...and a Thursday I used to have a cook here then, but it was quite unnecessary really, I mean and as the prices went up, so no I decided it was paying that much money out for somebody for an hour when all they do is put things in the microwave which I can do.

SYDNEY (1)

A commonly cited experience was the difficulty in securing care at the times that older people wanted it. Paying for care did not mean that they could choose their preferred times; more frequently, the timing was a matter of significant compromise.

I have an hour, but you have to give them 15 minutes leeway either side of nine o'clock because of traffic, you know, if they get delayed at the previous client or whatever. So, you don't grumble until quarter past nine has gone, if you see what I mean. So, you've got to be prepared to just give and take a little bit with the care company, you can't just say, 'I want you nine until ten and I want you there on the dot, and you'll do this, this and this...' You know? You can't do that.

HESTER (3)

Paying for care also did not guarantee consistency of care workers and this was a significant concern for many participants. Being cared for by a regular, or at least familiar, group of care workers gave older people a sense of security without which they could feel very vulnerable. This was a significant issue when unfamiliar carers were entering their home late at night.

> *Well when I get my regular carers, they're super because I know them all and they're great. But you see, that's the other thing as well, when you're up in bed, you go and do your best to get into bed and everything and then someone's coming up the stairs that you realise isn't your (usual) carer … I don't like a stranger coming up my stairs and I've had some really weird people in the past you know and it's a bit disconcerting, I don't like it.*

ELAINE (1)

Having opposite gender carers perform intimate tasks, especially without warning, could be upsetting:

> *Well I don't like having men, especially for the morning calls to wash me, and they have sent men on a few occasions. I think they have more problems at the weekends getting staff. I'm really not happy with that at all so I told them, I've said that on more than one occasion, but if they turn up in the morning, what do I do? Because I can't get myself dressed. I'm not going to say, "Well I'm not getting up, I'm not getting out of bed," you know, so I just try to pretend I'm not there you know, it's like this body's somewhere else. It feels very uncomfortable.*

KAMILLA (1)

A consequence of a high turnover of staff was that participants had to spend time instructing each new carer in how they needed or liked to receive care. This could be exhausting when repeated often, as well as eating into the time available for the performance of tasks.

> *And another thing, they start 10 o'clock at night and when a new person comes, I have to sit there for an hour and a half to explain everything on his (husband's) medical condition, where things are, where the emergency exit and the toilet and tea, coffee, you know, all that. And then I go upstairs to sleep … and then by half past 5 I am down again to see them off at 6 o'clock. ... So, I have to train them and that's the problem...*

DEEPAK'S CONSULTEE (2)

Whatever their dissatisfactions with care workers or care agencies, participants were often loathe to change care provider. Sometimes they felt bound by loyalty towards the care workers, even if critical of the agency itself. Several participants also expressed the view that other agencies were likely to be no better and, indeed, could be worse:

> *If you try somebody else, everybody's got the same problem. There's not enough carers so, so trying somebody else … it's probably the devil you know is better than the devil you don't.*

BRENDA (1)

However, some participants were very satisfied with the care they were receiving. Most participants were sympathetic to the circumstances of care workers including their conditions of employment, low pay and often unrealistic time pressures. Responsibility for failings in care tended to be attributed to the agency rather than to individual care workers.

> *The carers are great – management are rubbish. As soon as, in particular, middle management get involved then things start to change. We had a particularly difficult problem with the first care agency and parted company after about four or five months. I have respect for carers. We had two carers and one worked 14 days on the trot – it's not good, you know… because she's only paid the minimum rate. That's horrible, horrible…I have no respect whatsoever for management – particularly middle management – who get things wrong.*

JUDY'S CONSULTEE (1)

Dealing with the finances and anticipating future needs

The question of whether the care that participants were paying for was 'value for money' was complex and difficult for many to work out. Some participants found that it was impossible to judge quality by cost as these two measures were not necessarily aligned.

> *Paying a bit more doesn't assume that you're going to get any better service, because the way the care agencies are organised …and the way they operate, that doesn't necessarily mean putting more money into it, it means looking at how they do things really.*
>
> **KAMILLA (1)**

Assessing value for money and managing finances was made more difficult by the imposition of extra charges, for example, for care received on bank holidays or extended calls. Unexpected charges generated extra work in making sense of the invoices:

> *… with a minute over and they charged me extra for it… Quarter of an hour yeah you get charged as if it was 45 minutes not 30. So, I'm not getting what I'm paying for … that's the other thing, you have to check everything. Check the time all the time they're here, if they go 1 minute over you get charged more.*
>
> **BRENDA (1)**

There was evidence that some participants were frightened or worried by bills for care that they did not expect or charges that they could not understand. It was not uncommon for participants to pay for carers from more than one provider which could create complex invoicing and payment systems.

> *Either come to the house and see you, or ring you and talk about it, you know, not this "you owe this amount of money and we hope you will pay this as soon as possible". Of course, I rang my son, he said "oh don't worry about it mum" but of course I did worry about it. And when eventually I did get to talk to somebody, actually, you know, I said "I think this is a very bad way of doing things", I said, you know "we're elderly people" …*
>
> ***MARION (3)***

A number of participants experienced an increase in the cost of their care with little evidence of any kind of review or consultation explaining the reasons for the proposed increase. In these circumstances, participants often felt there was little they could do about it. This highlights the reality that participants were not in a position to decide to 'exit' an unsatisfactory service as it would leave them without essential care.

> *Probably I'm going to have to [pay more], they all put their prices up now, because that happens at that moment … I'd have to be very careful, because it would get out of hand if you're not very careful*
>
> ***SYDNEY (1)***

In common with all older people who need care, self-funders have to manage and adapt to changes in health which are often unpredictable. But, in addition, self-funders have to make sure they have the funds to pay for additional care. Many participants worried about the potential deterioration of their health, what this would mean for their future care needs and how they would pay for this. Even participants who were resigned to or accepting of the need to pay for care were worried about the prospect of all of their money being spent on care fees.

> *Well you see I know at the end of life that's what it's about, if you've got money you should pay…we can afford to pay for care and we'd hope to have enough money to pay for it, but I wouldn't want to use all the money I had, to give (it) away after working all our life…I don't mind sharing it but I don't want to be paying it until my money runs out, and you can't cover that one because you don't know how long you'll live.*
>
> ***JIM'S CONSULTEE (1)***

The experiences of informal carers and family members supporting self-funders

Our participants

It is often family members and unpaid carers who organise and manage self-funded care on behalf of their older relative. To gain a wider understanding of self-funding we interviewed unpaid carers and family members. 46 people took part in interviews and a further nine people took part in one of two focus group discussions about family care. Carer participants included those who were co-resident with the person receiving care and those managing care at a distance. Some participants were in full or part time paid work and many had additional care responsibilities. Table 5 provides details of the gender of participants and their relationship to the older person they supported.

Table 5 Unpaid carers relationship to person receiving care

Relationship to person receiving care	Male	Female	Total
Spouse / partner	4	7	11
Son/ daughter	10	21	31
Other relative		1	1
Friend		1	1
Colleague / neighbour	1	1	2
Total	**15**	**31**	**46**

In common with older participants in this study, carers' personal circumstances were characterised by diversity. Care relationships, the circumstances in which participants became carers, the nature of the care they gave and its impact on them, highlighted a range of experiences. Many participants reflected on the challenges and demands of their caring role rather than focusing solely on issues related to supporting someone who is self-funding their care. However, it is important to note this broader context, as supporting someone to manage self-funded care is invariably accompanied by other caring tasks and responsibilities. Here we focus on ways in which the additional responsibilities of arranging and managing paid care imposed a significant extra demand on unpaid carers.

Unpaid carers and self-funding

Many of the challenges that unpaid carers faced in finding and purchasing care were very similar to those experienced by the older people we interviewed. Difficulties in accessing information, finding appropriate care services, the lack of meaningful choice, managing the care arrangements and the nature of relationships with care providers were highlighted.

> *We don't even know how the system works, and when you're just given like right, go off and sort it, it's like well where do I even start, where do you start? So for me I just think there's just not enough support, there wasn't enough support for us to make the correct decisions in the first place, there wasn't enough understanding and help.*

ANDREA

It was evident that finding and arranging care, often when under pressure, resulted in some participants making rapid decisions without fully considering the cost of care or its potential future implications. Uppermost in participants' minds was a sense of relief that some kind of care had been found. For some, cost was not identified as a high priority as the primary concern was purchasing the best care for their relative/friend.

> *...well, you know, she's 96, goodness gracious, and we'll have to sell the house, but we'll cross that bridge when we come to it. So, you know, but did I think about the money, no, not massively...... ...and I guess we should have sat down and said, "Right, let's have a, let's look at this in black and white, who's paying what", etc, etc, but you don't do that.*

LIAM

Additional skills for managing self-funding care

Being an unpaid carer for someone who is self-funding is likely to involve taking on a number of new and unexpected roles including finding care, ongoing oversight and management of the arrangements, managing the finances, negotiating changes and resolving difficulties with care arrangements. Unpaid carers experienced similar challenges to the older people we interviewed related to navigating and negotiating complex and fragmented systems. The challenge of buying care was often overlaid with concerns intertwined with the relationship with the person who needed care, including: working out what might be best for the person needing care; supporting the person to make decisions; and negotiating with the older person what was acceptable to them in terms of the type and amount of care purchased and the costs involved.

In addition to the day-to-day oversight of finances associated with care, unpaid carers also needed to think ahead in terms of planning for potential future care costs. These skills often necessitated managing the finances of their relative and yet only a minority of participants indicated that they had received financial advice to support them in this task. At a practical level, the ability to check invoices and the match between the cost of care and the care provided was crucial. A number of participants reported significant problems in managing payment systems that were difficult to understand. Problematic issues that were highlighted included: inaccuracies in invoicing; mischarging; uncertainty about what was being charged for; and difficulties in dealing with different financial systems when more than one care provider was involved.

> *I spent hours with a spreadsheet trying to match up the invoices and the credit notes to make sure that the money that we've put in from our funding actually matches the invoices and … it's taken me hours to make sure. I've had to have phone calls with the company, I've had to sift through, well, I've got literally a folder of invoices and credit notes*
>
> ***JO***

Some participants had to budget for increased or changed care needs and plan ahead for when their relative's finances neared the threshold for state funded care. The possibility of continuing health care arose for a minority of participants which added another layer of complexity and uncertainty. Dealing with such issues is a hidden and unrecognised aspect of unpaid care. Participants expressed the need for support and advice on the longer-term implications of decisions about care, particularly for moving into a care home. Given the weekly outlay in care home fees, understanding what allowances might be available and applying for them, the extent of top ups and what the implications might be of reaching the funding threshold added layers of uncertainty to an often very stressful situation.

Responsibility for managing someone else's money

Participants were often motivated by a desire to get the best care they could for their relative/friend. This process often meant trying to ensure the older person was involved in the decision-making process, but many carers felt anxious about whether the decisions they had made were good enough:

> *...you want to get the best solution and you're never convinced that that's what you've got. Could we have done better, could we have managed it better, could we have done things differently, you know?*
>
> ***PHILLIP***

This highlights the profound sense of responsibility that can come with having to make decisions about another person's care, particularly if it means the person moves to a care home. Some of the unpaid carer participants had power of attorney for financial management but not necessarily for care and support. Decision-making was more challenging if the older person lacked decision making capacity about care choices and preferences. Family members also faced difficult and sometimes contentious decisions about whether and how much to 'top up' care home payments, necessitating long-term planning about their own circumstances.

> *Well I think we'd have been worried that long term, we wouldn't be able to continue with it. It's a bit of a difficult purchase really, because you don't know how long you're going to need it for, you know. There is an end point.*
>
> ***SADIE***

Decisions about spending on care reflected difficult feelings and responses for some participants. For example, participants expressed feelings about the unfairness and inequity of parents paying for care after they had contributed to the welfare state throughout their working lives and managed their money carefully:

> *It's essentially an unfair situation in that she and dad will have paid all their contributions over all those years and then when they require something, ah, they don't qualify, because they've been frugal and prudent they've got to pay for it out of those savings which really isn't what they made those savings for.*
>
> ***MATT***

These feelings about the 'unfairness' of having to pay for care were, as discussed previously, shared by some older people needing care. It can be very difficult to adjust to the idea that care needs to be paid for from lifetime savings if the person's intention is to pass on something to children and grandchildren:

> *Initially he was a bit resentful I think because he absolutely wanted his savings to go to … because I know dad and I know how important it was to him that the grandchildren, needed, you know, looking after and … he'd scrimped and saved in order for them to get some money when he died, because I knew that, that was also in the back of mind in terms of paying for his care.*
>
> ***AVA***

A number of participants had either gone through the process of selling their relative's home to pay for care or were in the process of so doing, or actively considering it. For some participants their relative's home was also their family home and selling it was a wrench from their past histories and highlighted feelings of guilt, grief and resentment.

Selling the family home often highlighted the issue of how long the finances would last before they reached the threshold to apply for Local Authority funding. This created a number of anxieties and ethical dilemmas.

> *… you're in this awful kind of roulette situation where you think, well, she might die, well she will die, we all die, but, you know, and you're thinking, well, will she die before the money runs out? That's an awful situation to be in. […] Well, I think we've got, if the house sells we've got about five years.*
>
> ***VICTORIA***

Additional impacts on unpaid carers

Many of the impacts on unpaid carers for older people who are self-funding are familiar to all unpaid carers. Looking after someone who needs care can involve a great deal of emotional and practical labour. The demands of caring on the carer's time, the personal impact on health and wellbeing, juggling other aspects of everyday life are well-documented and recognised within research and social care policy.

Less well recognised is the financial impact on unpaid carers who contribute to the cost of their older relative's care. Several participants referred to paying for their relative's care for reasons which included a lack of advice or assessment and assumptions that their relative would not be entitled to state support. As a result, these participants used their own resources to pay for care or top up to cover the cost of care.

> *When she first came out of hospital I was having them seven days a week, four calls a day, but I couldn't sustain that, it already takes more than, you know, most of my wages … for that first few months, if I'd have carried on at that level I don't think I would have had the money to keep doing it. It has gone into my savings, I'm not going to kid you, it's, you know, my savings are reducing.*
>
> ***TAMMY***

In sum, paying for care does not remove the need for care to be given by unpaid carers; indeed, as we have shown, it adds other responsibilities and demands such as, financial management and day to day oversight of care. Difficulties such as the unreliability of care workers or poor quality of care can leave unpaid carers feeling that self-funded care is causing more problems than it is solving.

> *I found it really, really intrusive…the guy that came said that he had half an hour (for each call) and there was no allowing for the time in between. And so they were either early or late or didn't show. I had appointments, I was getting stressed, and the stress was passing onto him (husband). It was just a nightmare. Now I might have been, I might have been unlucky because I do know of people who do have care for elderly parents and things like and that say that's okay you know. Albeit that they pay through their nose for it. Erm, but it didn't suit me. (It put me off) having care in the home.*
>
> ***AVA***

Stakeholders' perspectives on self-funding

To better understand the wider context of self-funded care, we interviewed stakeholders from the statutory, private and voluntary sectors who had some form of interest or role in working with people who self-fund their care.

Our participants

Table 6 Stakeholder participants

Stakeholders			Total
Local Authority			17
	Local Scrutiny Organisation	1	
	ASC Commissioners	3	
	Senior local authority managers	9	
	Practitioners (social workers)	4	
Private and Voluntary Sector			20
	Managers or practitioners in voluntary sector community organisations	7	
	Managers or owners of private domiciliary care provider organisations	7	
	Managers of charitable residential and day care organisation	1	
	Managers of community interest or not-for-profit companies	2	
	Manager of private care advice and support company	1	
	Manager of private care home	1	
	Independent social worker	1	
Care Workers			12
	Self-employed PA	1	
	Self-employed Cleaner	1	
	Independent care worker	2	
	Agency care worker	8	
	Total		49

The selection of stakeholders provided a range of different perspectives on self-funding and in the next section.

Knowledge and understanding of self funding

We explored the extent to which stakeholders recognised and understood issues related to self-funded care. Local authority participants in strategic and senior positions were aware of the responsibilities of Local Authorities under the Care Act to fulfil responsibilities which were relevant to self-funders:

> *So, the Care Act is very clear on the fact that the Council does not just have a responsibility for those people who come to the Council for assessment and to arrange their care but it has a much wider responsibility across the whole county in terms of those people who choose to fund their own care.*

SENIOR LA 4

Specific statutory responsibilities towards self-funders were interpreted slightly differently between the three local authorities. Even so, there was unanimous recognition amongst the statutory sector participants that local authorities should be engaging much more with self-funders:

> *I think that Local Authorities are very, very aware of the potential for self-funders in terms of there is a need for us to get involved much earlier regardless of the Care Act kind of requirement that we should be supporting more people. .... I think that Local Authorities are starting to realise actually the earlier they start to have conversations with people the better they can help them inform their decisions later so that the impact is less.*

SENIOR LA 5

However, knowledge about self-funders was limited and local authority participants reported, for example, a lack of reliable local data on the number of people who fund their own care. The key points of contact with self-funders were if they approached the local authority for an assessment of need, either when first needing care or later when they reached the threshold for publicly funded support, or in the event of a safeguarding alert being raised.

> *I suppose that's the difficulty, it's really, really hard to get that information... I don't see how we can get that information. We don't have the relationship with the self-funder, we would be reliant on the homes to tell us, I suppose, give us that information and they're not going to give us that sort of information. So, we only really start to hear that there is somebody running out of money at the point of which they're running out of money.*

ASC COMMISSIONER 1

There was often open acknowledgement that local authorities knew very little about the experiences of self-funders and how they made decisions about their care. In common with existing research, responses from statutory stakeholders suggested a narrow response to market shaping which was not informed by reliable data, including data on future projections:

> *the market shaping question is interesting …it depends on what we actually know, because the more we know the better we can help shape the market. We don't know how many of the home care agencies have got self-funders… I mean I would probably assume that all of them have. We don't know how many and we don't even know … what they charge. …. I mean this is part of the reason why it's very difficult with care homes to say, you should try and ensure your self-funders have got money in the bank, because we're not party to that contract…. So yeah, I mean if we knew how many people were out there, I mean a lot of it we just try and base it on, I think, the demographics of (location) and knowing how many people at each age group are around and how many of those we are in contact with, which is quite a finger in the wind.*

SENIOR LA 6

Care providers recognised the changing profile of people purchasing care services, with growing numbers of older people with complex needs now being supported to live in their own homes.

> *I think we've definitely seen a real, and I would say a major shift in terms of practical provision in peoples' homes which is what care in the community is all about, far more complex cases. I can remember when we first started it was a fairly, relatively simple process to provide domestic and laundry, shopping support in someone's home. Now you're dealing with far more complex cases so there's dementia out there, there's Parkinson's, there's other chronic conditions, whereas perhaps those people used to be in homes, they're now in the community in their own homes and we are very, very aware that you're dealing with much more complex issues.*

MANAGER OF VOLUNTARY SECTOR ORGANISATION 3

This point about the changing profile of self-funders is very pertinent to understanding why the self-funding of care poses so many challenges to very frail older people. Interviews with care providers highlighted challenges and tensions in the care market which would directly impact on self-funders. These included: difficulties in recruiting and retaining enough care staff able to deliver quality care; the importance of self-funders in sustaining the business models of care providers; and the challenges for some providers of delivering on a statutory contract while trying to meet the needs of a self-funded client base:

> *… one problem that we do have when we take on private care packages, they say, "You know I'm private so I should get my nine o'clock in the morning." It doesn't work like that, you would be put into a run so yes, some people think because they're paying for that out of their own pocket or direct payment, or however they were paying for the care, they feel that they should get precedence over even our previous service users … well from our point of view they would get the same times or anything that we would offer with social work (i.e. state-funded clients).*

MANAGER OF PRIVATE CARE AGENCY 2

In the absence of direct and reliable knowledge about the experiences and challenges of being a self-funder, some stakeholders made assumptions about, for example, greater flexibility and choice that paying for a service might bring:

> *There's more flexibility for self-funders I feel, because obviously they're purchasing a service in a sense that they can say when they want it to come, how long for, because it's more their own decision because they're arranging it more, whereas when we're involved then we go by our assessment, …. see if (agency) has got availability … but we can't always give the times that the person wants so we have to go with whatever's available. There isn't as much flexibility and choice I wouldn't say for those that aren't self-funders.*

LOCAL AUTHORITY PRACTITIONER SW2

The assumption that self-funders have more choice in the care they purchase contradicts participants' experiences of the care market in practice. For example, this social work practitioner reflected that in rural areas a self-funder would be potentially disadvantaged by minimum amounts of time that agencies would deliver care:

> *You can get some agencies that will do half an hour calls and then the same agency won't do anything less than an hour in the more rural areas, yeah. So, I suppose actually for someone that's coming through us, we could put a 10-minute call in, whereas if you're a self-funder you're going to struggle to get an agency to come out for 10 minutes, yeah, yeah. I hadn't thought of that actually, often people are told it's minimum of an hour.*

LOCAL AUTHORITY PRACTITIONER SW3

There was acknowledgement from some participants, that exercising 'choice' in the position of needing care may not be so straightforward:

> *…. because actually the biggest power is to vote with your feet but when you're 92 and frail and the thought of moving care home or trying to find a new provider when your family are busy or you're on your own, it's an overwhelming task and so you just sit there and think, ah it's not so bad, I'll get on with it even though it's costing me £25 an hour and actually if it was a cleaner or anyone else I'd have sacked them.*

SENIOR LA 4

Information and advice for self funders

Although local authority participants were aware of their statutory duty to provide information and advice (under the Care Act), they consistently acknowledged that it was an area that needed improvement. Local authority stakeholders felt that providing better and more accessible information could help self-funders make 'better' decisions and 'wise' choices which would delay them reaching the financial threshold for state funded care in the future.

> *It's like if you are self-funding then these are the kind of figures that you need to be looking at … how long your money will last … Because there are some who want … it's like almost spending their money on the wrong things. It's kind of like, you know, if there's a finite amount of money, the advantage of the assessment with, you know, a qualified social worker… should be to identify the particular needs where someone would get the most help if they've covered. Which might be live-in care, it might be different hours of home care, it might be something else, but the last thing you want is for people to waste their money on things, that they don't need to do, because money for care flows away like nothing else.*

SENIOR LA 6

While the importance of accessible information and advice about paying for care was recognised, there seemed less clarity about the best way to achieve that. Some stakeholders were considering ways in which existing community 'hubs' could help to improve information, but this appeared to be more focused on 'signposting'. Some of the participants from the voluntary sector reflected that much of their work with self-funders was helping them to navigate the system, often in the absence of statutory support mechanisms. They recognised that providing self-funders with long lists of care agencies, many of which might not be relevant to their specific needs, was not always helpful.

> *… charities like us, you know, the reason we're here is to help navigate the public sector sometimes, you know what I mean, a lot of our work is actually trying to help people navigate that and that's one of the biggest problems for self-funders is having that difficulty of being able to navigate systems and understand what's there.*

MANAGER OF VOLUNTARY SECTOR ORGANISATION 2

The growing complexity of need amongst self-funders has implications for the level and type of care that older people need to purchase but also their ability to access information about care and navigate the care system. Older people are having to rely on the market to meet their needs but without the resources or abilities that are needed to successfully engage with and navigate that market.

> *We get referred to us a lot of people who just don't have the support that they need, and in particular we've had some quite striking instances of people who did have money, or property, who … were left to their own devices, and if for example you're completely deaf and confined to your home, it's actually quite hard to source out the market in things, and in fact, yeah, so I'm very concerned about those issues, about access for individuals and their vulnerability.*

MANAGER OF VOLUNTARY SECTOR ORGANISATION 2

Some independent sector stakeholders identified a specific need for financial advice for self-funders but there was a lack of clarity about whose responsibility it was to provide this. An organisation that charged a fee for providing advice and support to self-funders liaised with a specialist financial advice organisation.

> *What I always try to do with my client, is to explore how long they can be self-funded and that's important and if they are self-funding, what are they doing about how they're going to pay for care. So, I normally use SOLLA which is the Society of Later Life Advisors, a financial advisor and I will signpost them to an advisor that deals with older, adult funding issues and they will then look at the pot of money that they have and how the best way is for them to fund their care, without their money running out.*

MANAGER OF PRIVATE CARE ADVICE AND SUPPORT COMPANY 1

The local authorities operated 'brokerage' schemes based on different approaches to arranging care and for which the self-funder could be charged an arrangement fee. It was unclear how many self-funders in each area had actually used the local authority brokerage schemes, but it was neither a widely used or, at this stage, well-publicised service:

> *It feels like people would only know about the brokerage if they approached Social Care, rather than that being clear on any website, when you're thinking do I call Social Services or not, that informed decision isn't there from the beginning I think.*
>
> *ASC COMMISSIONER 2*

One of the dilemmas that local authorities faced was how they could offer advice on market-based products and remain impartial. This adds a further layer of complexity to the ways in which Local Authorities might develop or improve their current approach to giving information and advice about self-funded care.

> *... It annoys me a little bit that I can't say to someone, "Actually, this home's a bit better, go to that one." You know? I think that would improve their experience but it would be unethical because it means that just because they're rich, they're getting extra support, extra recommendations from the council. Whereas someone who has less money doesn't have that privilege and that would be wrong. So, I can see why we can't do that. But it does feel a bit frustrating that we can't give more information,*
>
> *ASC COMMISSIONER 2*

Some local authority participants reflected the view that there is a straightforward relationship between having 'information' and exercising 'choice', in that if older people 'knew' about available services they would inevitably have more 'choice'.

> *Give people the right information about choosing the right care at the right time. …. And it's just about having that information at the outset I think it's about those people who perhaps might want to make their own choices but haven't got the full amount of information, they haven't got that independent advice that would see them make a wise choice at a time when they're able to do that, rather than later on when perhaps it's being enforced on them.*
>
> *SENIOR LA 4*

However, this pre-supposes the existence of a range of suitable services from which, when armed with appropriate information, the self-funder can choose.

Financial planning and future needs

Interviews with older people and unpaid carers highlighted anxieties about future care needs and having sufficient funds to cover additional care costs. Local authorities appear to be caught in a tension between on the one hand, wanting to engage with self-funders to ensure they use their own funds appropriately and on the other, not engaging with them at an early enough stage to influence their care decisions.

> *So, there's a challenge, I guess to capture them earlier and to meet their needs earlier, to understand, I guess the culture around why maybe the local authority isn't seen as being the place to go, for the minimum, it's seem to come for the maximum, if you know what I mean?*
>
> *SENIOR LA 3*

The realities of self-funders reaching the capital threshold are fraught with complex ethical and legal issues. Local authorities must grapple with the pressures of managing their limited resources to serve their communities, against meeting the needs of individual older people whose resources have depleted and whose care costs exceed local authority contracted rates. Social workers face significant ethical challenges when they are asked to assess the care and support needs of older people whose financial resources have depleted but who are happy and settled in care homes that charge above the local authority rate:

> *The fact that self-funders are able to choose where it is that they reside, within the city, because they've got money, and they can pay for it, but once they reach that financial threshold, where the money drops to a certain point, the council has a legal obligation to provide care for that individual, and … how you make the decisions based upon what happens next, is difficult, basically.*
>
> *ASC COMMISSIONER 3*

These are difficult decisions for care providers too, which have to be weighed against the realities of managing a business and remaining financially viable.

> *Because that's a big question I get asked, what happens when my money runs out? Where do I go from here? Will I be expected to leave the care home? And I would say some of the bigger care home groups, they're a business, they're not a charity, not your best friend*

MANAGER OF PRIVATE CARE ADVICE AND SUPPORT COMPANY 1

The significance of self-funders in the social care market

Although self-funders do not have much recognition as a distinct group, there was a tacit acknowledgement amongst stakeholder participants that self-funders were a necessary pillar of the social care market. The systemic problems associated with funding for social care, and the low rates at which local authorities commission care mean that some care providers rely on self-funders as a more viable source of income or a way of 'cross funding' services provided to service users who are state funded.

> *I think the bit that Councils perhaps aren't quite as open with is the acknowledgement that self-funders subsidise the state market… I've heard providers stand up and say it but I have never heard anybody in any Council stand up and say. They all know it's true but I've never heard anybody stand up and say, absolutely our self-funding market is basically subsidising whatever the Council is paying….If it wants to have this system whereby self-funding individuals prop up the rest of the system that's fine, everybody needs to be honest about it, everybody needs to own it, but they need to advise people and support them to be able to do that and make better choices.*

SENIOR LA 5

8

Discussion

Our aim in this project was to generate understanding of the ethical dimensions of self-funded care. In this section we explore the tensions and questions our analysis identified and reflect on these in relation to our overall framework of ethical issues in self-funded care.

Is self-funding care necessarily problematic for older people who need care?

Some older people and unpaid carers reported **positive experiences of care.** The factors which contributed to positive care included: valued relationships with care workers; appreciation for the work that care workers did and care arrangements that were reliable and worked well. Clearly many older people were happy with, and grateful for, the care they received from a variety of sources including, independent care agencies, voluntary care providers and independent/unregulated carers. However, even when participants were satisfied with care, they often identified a backdrop of worry or uncertainty about their care, for example, the impact of changes in care arrangements or managing future care costs.

Many participants related experiences of trying to **navigate a complex and fragmented system;** of worry and concern over invoicing and payments; and of not receiving the care they expected or that they had paid for. The fact that care was being paid for by older people did not generate the 'consumer power' that might be expected. Older people and unpaid carers often felt obliged to accept inadequate care because they feared exchanging it for even worse care or being left with no care at all. Our participants' experiences contradict the idea that the 'customer' has the power to define the terms of care arrangements and use 'voice' (complaint) or 'exit' (move to another provider) if dissatisfied.

Care is a process that involves relationships, intimacy and unequal power. Despite some financial power, the purchaser of self-funded care is usually low on other forms of power, dependent upon the care-giver for help with vital tasks of daily living that cannot be jeopardised or dispensed with. Care relationships require negotiation and trust to work well. Although some self-funded care relationships were giving older people the nature and amount of care they wanted, for other participants market considerations generated tensions and competing priorities for providers that acted in opposition to the pre-conditions for quality care identified by older people and unpaid carers such as, continuity in relationships, reliability, timeliness and good communication.

Is better information the solution?

As far as local authority stakeholders are concerned, the **absence of reliable information about self-funders made it difficult for them to fulfil their market-shaping responsibilities**. They acknowledged that they did not have accurate information to reliably predict future demand for care, the likely number of self-funders reaching the financial threshold for publicly funded care or the best ways to stimulate the growth and development of the care market in order to ensure a sufficient range of care services.

The challenge of finding reliable, accessible information about local care services faced by older people and unpaid carers was an area that was much discussed by different participants. Local Authority participants acknowledged the need to provide accessible information about care options for people who are self-funding. The hope was that access to good quality information would assist people in making choices about care. But local authority participants also recognised the tensions associated between, on the one hand, self-funders wanting information about care providers who are likely to be best at meeting their needs and, on the other, the local authority's need to remain impartial.

While having information is, without doubt, **important there are tensions in framing the provision of information as the key to 'good' care decisions.** It was evident from our study that participants, often responding to the need for care in a crisis, struggled to process and absorb information. Most of the time, older participants and family carers made care decisions based on ad hoc information such as personal recommendations or the care that was available at the time. More fundamentally, care is based in relationships and making decisions about care is multifaceted, involving complex personal and emotional dimensions that link with perceptions of independence and vulnerability, as well as financial considerations.

Are ‘wise choices’ possible?

Prior to the Care Act there was little mandatory basis for developing a coherent strategy for self-funders beyond responding to requests for funding support when self-funders reached the capital threshold. The wider contemporary challenges to social care funding combined with growing numbers of people paying for their own care who often have complex and high support needs has started to generate more awareness of self-funders. There was an acknowledgement from local authority participants of the need to develop an active engagement with self-funders as well as promoting the right for people to have an assessment of need. **A supportive, easily accessible and neutral infrastructure is needed to provide advice on future planning if older people are going to have the necessary tools to navigate the care market.**

It was evident that a major concern for local authorities is that large numbers of people who buy their own care will run out of money and become eligible for statutory funded care. This appeared to be the basis of initiatives and future work plans to improve information and advice on care services. They used the phrase **‘wise choices’ to refer to the need for older people to use their financial resources judiciously in order to extend their ability to pay for their own care.** ‘Wise choices’ implies not only ‘choice’ but also that decisions are informed by both an accurate assessment of current care needs and potential needs in the future. Given the acknowledged shortcomings around accessible information, the complex emotive dimensions of decision-making, the continued policy narrative highlighting choice, and the uncertainty and unknowability of future needs, it is questionable whether the notion of older people making wise choices is realistic. It is also apparent that individuals will have different value judgements, aspirations and evaluations of risk; even with carefully delivered financial advice, not all may choose to carefully apportion their finances for a future they may not live to see.

Responsibilities and risks in self-funding

Participants **understood and experienced the challenges and risks in social care in different ways, reflecting their perspectives and priorities.** From the perspective of older people and family carers, challenges and risks focused on issues which affected their need to buy care and their experience of the care they had purchased. Local authority participants, as already noted, prioritised the importance of improving information and advice and risks associated with not knowing how many self-funders were in the system and what their needs were and might be in the future. Care provider participants tended to highlight the challenges associated with their financial viability and of providing good quality care in a business environment built upon inadequate local authority contracted rates. As a result, care providers would, when possible, mitigate those risks by targeting all or some services at self-funders. All of the independent/unregulated carers we interviewed said that they had left ‘traditional’ care providers because they were disaffected with the quality of care they were able to provide. Their motivation for becoming independent included managing their own risks through ‘choosing’ their client base, managing their workload and undercutting what they saw as an inflated cost of care.

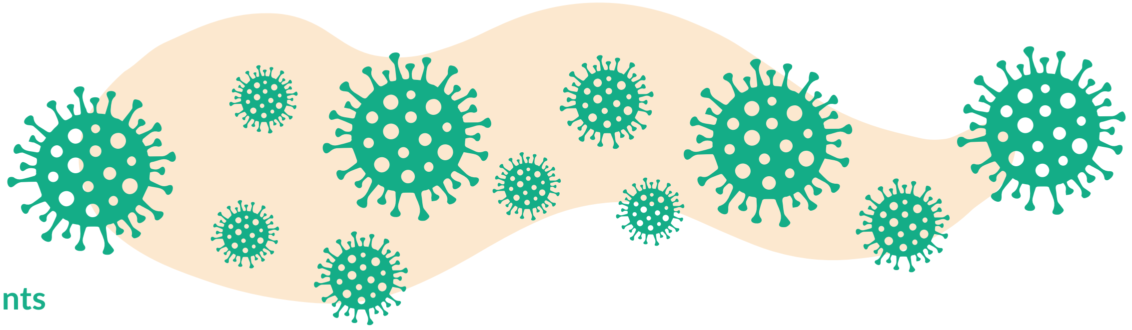
Many stakeholder participants who worked in local authorities **were acutely aware of the contradictions and tensions in the current social care system and the risks the system generates.** Practitioners, for example, described wrestling with difficult ethical questions including the risk of potential decline and increased mortality for an older person faced with the prospect of moving to an alternative, cheaper care home when top ups are not available. This risk becomes more significant as the gap between what the Local Authority will pay and what the care homes charge for private residents has widened.

It seems that the marketisation of social care and the lack of public funding for social care over the last decade mean that self-funders play an important role in supporting the market. The ‘crisis’ in social care is largely understood as connected to the low rates that local authorities pay care providers which are not enough to cover workforce costs or to make a profit. Self-funders were described by one participant as ‘pawns in a game’, that many care providers depend on, or target, as part of their business strategy. It appears that many people involved in care - from providers, to people using services, to local authorities - know this is happening but there is a pervasive ‘silence’ that obscures the fact that self-funders are the invisible lynch pin in the social care system.

9

Post-script

Our findings in the main study had highlighted the challenges of managing self-funded care and we were concerned about how the impact of the pandemic could be affecting people's access to care. Moreover, at the time, there seemed to be little information about how people who relied on home care were faring. After securing ethical consent for additional fieldwork, we carried out 'post script' interviews between April and August, 2020, with a small sub-sample of participants from our main study. The primary aim of this additional fieldwork was to capture some initial insights on the impact of the pandemic for self-funders, family carers and stakeholders involved in care provision.



Participants

We interviewed 36 participants: 18 older people; five unpaid informal carers or family members and 13 stakeholders, including care providers in the independent sector, local authority commissioners and independent care workers. Decisions on who to approach to participate was based on our prior knowledge of individual circumstances in order to ensure a range of perspectives. We followed our existing protocols throughout the process but interviews were carried out by telephone or online platforms. Interviews were recorded and transcribed and analysed thematically and in line with our previous analysis strategies.

Findings

Older people and informal carers

The older people we spoke to demonstrated considerable stoicism in managing difficult circumstances where usual forms of support were compromised. However, the anxiety for some was very evident:

> *…there were days, hard days when I really did feel, oh I've had enough of this, you know, this isn't me, I can't go out, I can't do anything, I can't speak to anyone, invite them, you know, and whereas normally I have, thank goodness for the telephone, because as I say I think the phone was ringing all day and every day… the worry was there, the worry all the time of, if something went wrong, oh I can't, how am I going to get that fixed, because there's no one will come to do it.*
>
> *KATH*

Some participants referred to additional, and unexpected offers of help either from their carers, family members, or neighbours. Some also mentioned being contacted by the local council to find out how they were managing.

> *We are grateful. People seem to be more understanding and patient and more mindful of everyone's needs including their own. If I ask somebody to do something, could you put your mask on, sit here because of, wash your hands because of, everyone says, 'yes yes' it's the amenability of people that has changed which is really nice.*
>
> ***ADELE***

A significant number of older participants ordinarily lived much of the time inside their homes. On the surface, lockdown did not change their day-to-day lives but did create the need to negotiate a number of interconnected concerns and risks. For example, understanding what was safe practice for carers in terms of PPE was difficult because of the media coverage, and confusion, about PPE, safe practice and who was responsible for providing it and paying for it.

> *… the misunderstanding about which mask to wear, when, came because of an email that was sent to all the carers, not the clients. And so they started coming to me, oh, two of them, three of them have come to me with the wrong masks on. …they really should have had a bit of training for that, I think. Because for three different carers to come, three different times with the wrong masks on, you know, through my door, they're supposed to put them on before they get in the door. And I've sent two of them away to go to the car and get another.*
>
> ***LESLEY***

Many of the participants who directly employed carers asked them not to come but continued to pay them at least some money each week. The implication of carers stepping down temporarily, as well as day centres and social clubs and groups closing, was that older people were more reliant on family care and managing without their usual supports.

> *And, of course, she's losing money, so I'm actually going to pay her 20 quid a week, but I did pay her for the first week and a half. And I sympathise that she's losing money, but I did say, well, she can apply for Universal Credit, and she hasn't bothered. I mean, I've known her ten years and I feel a bit mean in some ways, but I don't know what else I can do.*
>
> ***BRENDA***

Two unpaid carers experienced the (non COVID) deaths of their family members during lockdown. One participant's view was that the impact of the pandemic directly impacted on his mother's deterioration and death as familiar carers from overseas left suddenly to return home and replacement carers were inexperienced:

> *I tried to have to explain it to her what was needed to be done and then by that time I was not going in the house, I was doing all my, trying to keep in the garden and talk to my mum through the French windows so I didn't, it was six of one and half a dozen of the other. Do I go in and then put her at risk of this virus or do I just try and explain to the carer as best I can? And it was, but it was too much for her.*
>
> ***KIERON***

Stakeholders

A major challenge for care providers, was ensuring that, in the context of staff isolating, shielding or being away from work sick, sufficient staff were available to manage existing care commitments. Some stakeholders put staff (non-service delivery) on furlough, others who provided services using older people as volunteers also had to make adjustments. In one site the local authority used the emergency legislation (Care Act Easements) to reduce care as a means of managing demand and workforce shortages:

> *So, we were having real difficulties organising packages of care for people, particularly at the beginning…. So we made the decision to utilise the Care Act Easements and then reduce some people's packages of care where the families were able to help or they had alternatives, and that supported us to kind of direct the care at those people who needed it the most….Care at home, there was probably a period of about four weeks where we could not get a package very easily, providers were having difficulty accessing personal protective equipment, there were people waiting for care and therefore that's why as part of the Care Act Easements we did reduce some packages and used those hours elsewhere. Like I said about a third of the workforce were off sick.*
>
> ***ASC COMMISSIONER 1***

Different types of providers were more or less impacted by the challenges. For example, the independent care worker we interviewed negotiated individualised and negotiated decisions about the care she provided to individual people:

> *I had to cut down my work, not because I wanted to but a lot of, well several of my clients had family who were obviously at home furloughed and able to step in… so we agreed that I would go once a week to do her shopping … And so that was hard, I felt awful cutting down from my usual hours to only one day a week but she was insistent that she'd be ok and I didn't want to put her at any more risk than she was, so… from the point of view of keeping my client safe I was happy to hunker down.*

INDEPENDENT CARER 1

In the context of the emergency, a number of stakeholders across the sectors described positive examples of improved cooperation between agencies and closer partnership working.

> *I guess the most innovative things are just we have been working with our partners a lot closer, so our health colleagues, because we've had to make decisions quicker there's been reduced bureaucracy and governance and we've been more responsive than we normally would I guess to make decisions, introduce additional funding to providers, that kind of thing. … I mean we know a lot more about providers and kind of who they're providing care to than we ever have. I mean there's a lot of talk at the moment around recovery and reset, so we're keen to take the learning from COVID, although it was horrendous experience at the peak, you know, some things are working a lot better.*

ASC COMMISSIONER 1

Hospital discharge arrangements and the urgent need to free up hospital beds meant that people being discharged, including people who would be self-funding, had a longer period of 'free' care under health funding. These arrangements again highlighted examples of rapid response to the circumstance and improved cooperation between health and social care, hospital and community services. They also pointed to greater contact in some cases with self-funders.

> *Because obviously normally if someone who's self-funding contacts us, we would offer them an assessment if they want that but we would go through the option of, you know, organising themselves but a lot of people to be honest choose to organise things themselves. So it's a lot more social work time on completing assessments and doing care funds, and obviously because these people will probably then be used to the Council being involved, they will probably want us to stay involved I would imagine. So, I think there will be an ongoing impact in terms of our workload.*

ASC COMMISSIONER 1

For local authority participants there was a sense that statutory services needed to have good oversight of their local social care sector during the emergency. As well as their statutory duties for people whose care is publicly funded, they had additional duties to coordinate emergency funding across the care providers and meet public health requirements for guidance on practice and PPE. These requirements have potentially given local authorities better oversight of people who are self-funding and care providers who they do not contract with for statutory care

> *…that's been a big focus, because we have less visibility about what sort of care goes on, but we have responsibility for it, and that's been borne out in the (emergency) funding that they, has come to the Council and then gotten out. Um, so, so yes, I think we're probably in a better place and around knowledge and visibility of the market and what we need to do, than we perhaps were before the virus*

SENIOR LA 4

10

Conclusion

Our research has highlighted the significance of self-funders to the social care system and the enduring invisibility they experience as a group of care users, whose needs are not well understood. It is clear that many of the challenges in social care are systemic and, in different ways impact adversely on older self-funders, their families and, indeed, some of the stakeholders we interviewed. Every one of the participants was doing their best to negotiate the tensions and challenges inherent in the system.

The context of COVID-19 has exposed the fault lines of our current social care system, including its pivotal but under-recognised importance to NHS care and the lack of political attention it has received over a long period. At this point it is too early to tell but there are indications in our data that the new ways of working prompted by the crisis could encourage greater collaboration between different sectors and more visibility of people who use care services, including self-funders.

Our motivation in undertaking this project was prompted by our awareness of the lack of older people's voices in policy and practice debates about care and the funding of care. Our hope is that the findings from this project will contribute to the debate on the future of social care for older people.

11

Recommendations

The future of social care funding

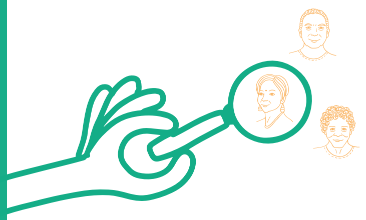
Self-funders are caught in the vortex of inequalities and shortfalls inherent in the current social care system, many of which have been illuminated by the Covid-19 pandemic. We add our voices to those of many others calling for an urgent fundamental and comprehensive reform of social care.

Debates about how to address ‘catastrophic’ care costs need to include care purchased in private homes, including live-in care.

The current reliance on self-funders as lynchpins of the care market needs to be an openly acknowledged and integral consideration in decisions about the future funding of social care.

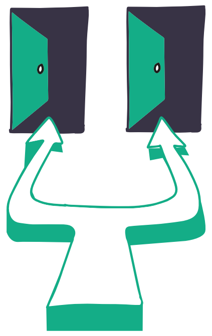
Information about self-funders

There needs to be a national data base of information about the amount, nature and financial value of privately funded care. The quality and outcomes of self-funded care should be routinely collected at a local level to inform market-shaping activities.

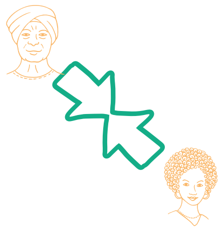


The experiences of self-funders and unpaid carers who support them must be a central component of the information used to plan and deliver care.

Information, advice and support for self-funders and unpaid carers



Clear and accessible information about social care and associated finances should be available to self-funders and unpaid carers. Information should be tailored to reflect different stages in people's care including: widely available public information to inform people about care costs, options and where to get advice about care; tailored information, advice and support for the decisions that self-funders have to negotiate once they need care, including the implications of depleting financial resources; signposting to independent financial advice.

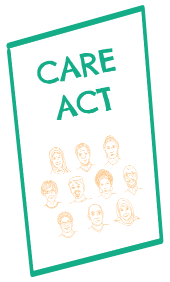


Access to independent person-to-person advice and support should be available to self-funders and unpaid carers when they are making decisions about buying care. Digital information and brochures do not satisfactorily convey complex information to people who are experiencing ill health, crisis and distress.

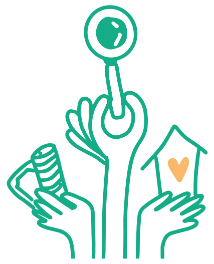
Self-funders and unpaid carers need to be involved in planning and producing advice and information resources and systems to ensure they are fit for purpose.

Assessment of care and support needs

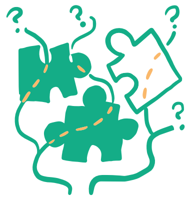
Eligibility criteria should be reviewed as they currently exclude people with significant care needs who do not meet the strict criteria. This can have adverse consequences for health and wellbeing as older people are forced to prioritise spending what they can afford on care or go without.



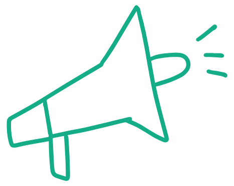
More effort should be made to inform the public, care providers and health care professionals of the right of everyone with an appearance of need to an assessment under the Care Act.



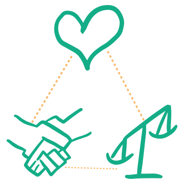
The assessment of care and support needs offered to self-funders should, as stated in the Care Act, be a service in its own right, giving an opportunity for advice and information about care options and other sources of support.



Assessments of need should take account of the additional burden associated with purchasing and managing care and the ability of the person to find and manage their own care.



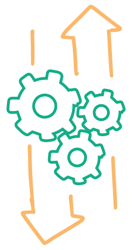
The option for self-funders to request local authorities, for a fee, to arrange their care should be better publicised. There should be an opportunity for older self-funders to understand the potential advantages and disadvantages of the service the local authority is offering.



Carer assessments should pay attention to the additional demands of supporting self-funders placed on unpaid carers. Advice and support to carers should take account of, and include, the impact of supporting a self-funder to manage their care.

Access to quality care

Closely linked with the issue of social care funding, urgent action is needed to improve the quality of care available to self-funders. Key issues are the consistency and continuity of care, regular timekeeping and competence of care staff.



The care market needs to be equipped to meet the complex and multiple needs of many older self-funders. This requires a suitably trained social care workforce who, in turn, receive appropriate recognition, remuneration and support for their role.

Self-funders need transparent and concise written information about care costs and additional charges. Invoices should be unambiguous and a named person to deal with queries should be identified on the invoice.

Local authority responsibilities for market shaping must address the lack of availability of care options, especially in rural areas, where choice can be a redundant concept.

Greater oversight and monitoring of self-funded care should be integral to the work of organisations with responsibilities for ensuring quality and safety of care.

The growing number of unregulated carers should be acknowledged in the development of a straightforward registration/screening system.

Further research

More extensive and longitudinal research is needed on the experiences of self-funders, including those from more marginalised communities.

There should be evaluation and dissemination of initiatives to inform, advise and support self-funders in order to develop good practice in local authorities and care providers.

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Appendix

Older people who were funding their care

Pseudonym	Age at first interview	Summary details	Self-defined financial status
Adele	91	Adele (widowed, no children) lives alone, but since T2 has had a carer living with her most of the time, and since COVID lock down this arrangement has become permanent. Lives with a number of long-term conditions and care provided by independent carers and live in carer who originally came from a voluntary care provider.	Getting by
Agnes	88	Agnes lives in sheltered housing, she is bedbound and has carers four times a day to support her via statutory funded care and ‘topping up’ through her own contribution.	Getting by
Alfred	82	Alfred has Alzheimer’s. He was receiving care daily care. He entered a care home at the time of the second interview and died before the third interview. His interview was given by his wife as consultee.	Well off
Alice	91	Alice lives alone (never married, no children) and receives care from a mix of independent and agency care staff. Care arrangements have changed significantly over the period of fieldwork due to changes in personnel.	Comfortable
Annie	80	Annie has advanced dementia and very limited movement. She lives in her own home, with 4 calls a day plus a night-sitter. She died shortly after 3rd interview. Her interview was given by her daughter as consultee.	Comfortable
Arthur	85	Arthur lives in sheltered housing, he had carers twice a day via statutory funded care and ‘topping up’ through his own contribution.	Getting by
Belinda	73	Belinda had partial paralysis and reduced vision following a stroke. She lived in sheltered accommodation which provided carers four times a day. She also purchased weekly help with shopping from an agency carer and attended a weekly day centre. Her care had been paid for by Social Services but she had become self-funding after receiving an inheritance. She died before 3rd interview.	Getting by

Bernard	79	Bernard had pulmonary fibrosis. He lived in sheltered accommodation. He died before the third interview.	Comfortable
Betty	95	Betty is unable to walk, and has poor eyesight. She had two carers four times a day for personal care and meals, plus help from a friend for cash management, shopping etc. Barbara died before third interview.	Getting by
Bev	95	Bev has mild dementia; her husband Walter has COPD. At the start of the study, they lived with their daughter and son-in-law but moved to a care home after the first interview. Bev was present in all three interviews and participated to a degree, though her husband, daughter and son-in-law contributed substantially.	Comfortable
Brenda	81	Brenda has long-term problems with her joints. She has had a knee replacement and is awating further surgery. She also had a heart condition. She pays for carers to make her sandwiches and flasks to last 24hrs because of her difficulty standing. She worries about her conditions getting worse and falling so she sleeps in an armchair to avoid going upstairs to bed.	Comfortable
Bronwyn	89	Bronwyn has a care visit each morning and pays for a cleaner. She relies on a friend to help with her financial management, and on family for other practical help.	Getting by
Charles	91	Charles was living alone after being widowed. Following a series of falls, his GP advised that he moved to a care home which he did on a self-funded basis. Three care home moves and great unhappiness led to a social worker being involved to get Charles back home to his bungalow with live in care. Charles is now living at home, relatively stable but frail and susceptible to falls, as well as being blind.	Getting by
Claire	73	Widowed and lives alone. Has one son. Mobility difficulties and needs care when showering and dressing after a shower. Also has help with shopping and domestic tasks.	Getting by

Colin	84	Colin was widowed three years ago and first employed carers after an operation. He retained the carers to help him as he prepared to downsize to a smaller property.	Comfortable
Cyril	92	Cyril lives alone after the death of his wife who lived with dementia. Cyril and his daughter cared for her at home until her needs became too complex to manage. Cyril has severe arthritis which has impacted on his mobility. Over the course of fieldwork he had a long awaited knee replacement but was very ill due to infections associated with surgery. Did not take part in T3.	Getting by
Dale	88	Dale has a spinal injury and receives help with personal care and preparing meals. Social Services pay for part of his care through his Direct Payments, which they substantially reduced before our 3rd interview. He also has weekly day care. He was interviewed with his daughter.	Comfortable
Deepak	78	Deepak had a major stroke plus colon cancer and is unable to move. He has 3 calls a day plus a night-sitter. He died shortly after our third interview. His interview was given by his wife as consultee.	Struggling over basics
Dennis	89	Dennis had early Alzheimer's disease. He has day care four days a week and a weekly carer to clean and supervise his shower. Otherwise his three sons provided all his care. His wife is in a care home. He was present during the interview, which was given mainly by his sons.	Getting by
Donald	89	Donald lives with his wife in their own home. He has a carer every morning, plus twice a week for shopping and sometimes to help with getting to hospital appointments.	Comfortable
Doris	65	In receipt of a Direct Payment for her and her husband. Doris has post-polio syndrome and husband, David, has post-polio syndrome and Parkinson's Disease.	Getting by
Dorothy	85	Dorothy was receiving some statutory funded care and 'topping up' through her own contribution. She had carers morning and evening to help her wash and dress, take medication and cook meals.	Getting by

Douglas	89	Douglas lives alone following the death of his wife. Douglas has had two strokes which affect his speech (mildly but Douglas' subjective experience is that it is marked); his mobility and his eyesight (severe sight disturbance). Douglas relied on care from a single carer procured by his daughter (free-lance) of whom he was very fond. She provided help with letter writing to all of Douglas' distant family. However, arrangements changed by T3 as she left and moved away from the area and Douglas was using services from a local agency.	Comfortable
Edith	98	Edith was contributing to her care and was very happy with the care she received. The participant died before interview 2.	Getting by
Edith	92	Although Edith might have been eligible for state support she refused to engage with the LA. Her son lived next door and she had a private carer who liaised with her son to ensure that Edith had everything she needed.	Comfortable
Elaine	94	Elaine cancelled her morning call because her preferred carer left the agency. She now has an evening call only five days a week.	Getting by
Eric	82	Eric inherited money late in life which meant that he was not eligible for state support. He had a private carer who lived in the flat below him as well as other carers who provided meals.	Between comfortable and getting by
Esme	95	Esme's daughter lived at home with her, in part as carer. She received a daily morning call and attended day care three times a week. Esme decided to move to residential care before the third interview and was very happy there. Her daughter was present for the interviews.	Comfortable
Evelyn	79	Evelyn lives alone (widowed, no children) and has mobility difficulties associated with arthritis and mental health problems associated with depression and anxiety.	Well off
Florence	92	Florence has carers three times a day for personal care and meals. She changed agency and by the third interview was sleeping downstairs. Her daughter contributed to her first interview.	Getting by
Fred	81	Fred had an accident with left him with a profound spinal injury and paralysis. He lives with his wife.	Comfortable
George	81	George lives in sheltered housing, he has arthritis and has carers three times a day via statutory funded care.	Well Off
Harriet	93	Harriet lives alone and is widowed (has a grown daughter). She has heart problems and has care a few times a week, but predominately for practical help which she finds too tiring in light of her heart condition. Harriet died between T2 and T3.	Comfortable
Hester	84	Hester has macular degeneration, arthritis and balance problems. She receives daily help with personal care.	Comfortable
Ian	80	Ian lives in an up-market supported housing complex. He receives daily help with household chores and social outings. The care is provided by the in-house care team.	Comfortable
Iris	91	Iris had lost her adult daughter 5 years prior to the first interview and her two sons both had young families. Iris had agency carers at the first interview, a live-in carer at the second interview and had been to stay in a care home at interview 3.	Comfortable/ Getting by
Isabel	94	Isaac and Isabel live alone but Isabel has a family from a previous relationship. Isabel lives with dementia and her needs are becoming more complex. Isaac has reduced mobility but this largely identified as 'age related' rather than ascribed to a particular condition. Following an unsuccessful trial in a care home, Isabel came home and Isaac purchased live in care which has been in place for the past 3 years.	Comfortable
Jim	95	Jim has dementia and has 4 morning calls a week for personal care and housework to support his wife. He also has day care once a week. Jim used to live in a care home but returned home as they both found it unsatisfactory. His interview was given by his wife as consultee.	Comfortable
Josephine	89	Josephine has three visits per week from a private carer for cleaning and help with showering. She also has some help to prepare food from in-house carers employed by the housing agency who manage her accommodation.	Comfortable

Judy	76	Judy has Parkinson’s disease and has been receiving care for 3 years. Her needs increased over time to twice daily calls. She died before 2nd interview. Her interview was given by a consultee.	Comfortable
Juliet	88	Juliet had multiple health problems and had carers three times a day as well as a cleaner who was very supportive. She was interviewed with her friend who was staying with her at interview 1 and 2 but Juliet died before interview 3.	Getting by
Kamila	71	Living with MND. Not contactable at second interview.	Getting by
Kath	93	Kath lives alone following the death of her husband. She has been very independent with support from a cleaner who provides additional support when needed, and a very helpful gardener. Kath had two strokes during the time of fielwork. She has not needed extra care but her supporters have provided extra care and she has had a range of equipment delivered to help her manage at home. Respite care, on a self-funded basis and in a local care home is booked to support her daughter to go on holiday. She also has an annexe in her daughter’s house waiting for her should she need it.	Comfortable
Kay	86	Kay has dementia and has carers each morning for dressing and personal care. She was present during the interview but did not speak at all.	Comfortable
Kitty	82	Kitty is severely disabled and unable to access the kitchen in the house she has lived in for many years. She receives care from a number of different sources and has some involvement with Social Services.	Struggling over basics
Lesley	74	Lesley has acute allergy to latex, and rheumatoid arthritis. She has carers twice daily for personal care. She changed care agency at the time of the third interview. Her daughter contributed to the third interview.	Comfortable
Mabel	84	Mabel lives alone and has long standing difficulties with arthritis and visual impairment (cataracts) which improved somewhat after surgery. Has had a long-term carer who, as much as anything, provides important social contact and ancillary services.	Comfortable
Marion	72	Marion had major abdominal surgery which resulted in her needing care (she paid for this). Once recovered, she kept the carers on although not then for personal care. She said she didn’t really need them but thought it best to keep them on ‘just in case’ and while she could afford it. It is evident that the relationship with the carers is vital to her and she feels she gives something back by listening to them and being helpful. By the end of the fieldwork, her health had deteriorated and the help was more necessary but had not been increased. She was very pleased with a new male carer who could do ‘manly things’ (basic handyperson stuff).	Comfortable
Millicent	92	Millicent and her husband Patrick lived in privately-owned sheltered accommodation. The care was originally for Patrick but he died before 2nd interview and Millicent continued having some care for herself. Millicent’s daughter contributed to two of the interviews.	Comfortable
Nia	73	Nia lives with her husband and has a diagnosis of Multiple Sclerosis. She has a deteriorating condition and complex needs which are largely managed with support and care from her husband. Their primary self-funding relates to purchasing a large range of equipment to support Nia at home.	Comfortable
Norma	89	No audio T1 – Norma has trouble walking and is deaf. She contributes to her care.	Getting by
Penelope	69	Living with ME. Penelope had been through an ASC assessment but her needs were not considered great enough. She pays for carers to visit once a week to help her wash and cannot afford more help, although she would like it.	Getting by
Piers	65	Couple married for seven years. Piers has two grown children. Piers had a major stroke and had self-funded care for personal care (showering, dressing) x 5 per week plus self-funded care for social activities x 1 per week.	Getting by

Rachel	80	Rachel lives with her husband and has two grown children. She lives with Parkinson's Disease and has had lymphoma. She has personal care every morning. Her husband looks after most of the practical tasks but Rachel has regular periods of respite to support her husband to go away. This includes respite, self-funded in a care home where she has had both very positive and very negative experiences.	Comfortable
Reg	76	Reg has Vascular Dementia and uses a sitter service. He died before second interview. He was present during the interview but did not speak at all.	Comfortable
Robert	84	Robert had dementia. He lived at home but died before 2nd interview. He had carers 7/7 pm only. He was present in the interview, which was given mainly by his wife.	Comfortable
Sally	73	Sally has rheumatoid arthritis. She cancelled all care provision after the 2nd interview as she found the timing unreliable and she felt much better as a consequence of non-prescribed medication.	Struggling over basics
Sarah	87	Sarah was widowed and had a daughter that lived a few doors away in the same road. At the first interview she had private carers as well as agency carers. At the second interview she only had her private carers. At interview 3 she was in an expensive care home and confirmed that she had sufficient funds to last her at least 10 years.	
Sidney	88	Sidney was diagnosed with MS in his 50's. He uses an electric wheelchair to move around his flat. He has a daughter who lives in the same building and sons who take turns to cook meals for him. Sidney employed three care companies. His wife had died 4 months before 1st interview.	Comfortable
Sylvia	90	Lives alone after being widowed. Describes self as getting more frail and has care a few times a week, largely for practical support with some personal care as and when needed.	Comfortable

Terry	76	Terry is a gay man who has neuropathy and other health issues. He lives in sheltered housing but refuses state support or agency carers as feels strongly about carers earning less than £12 an hour. He pays friends to provide his care.	Getting by
Tony	89	Tony had multiple health issues that meant he was unable to walk. He was widowed and had 5 children, only one of whom lived locally. Tony managed his own care but was frustrated by the amount of work it took to manage. Tony died before interview 3.	Comfortable
Trevor	87	Trevor married later in life when they were both widowed. Each partner has two children from first marriages. Trevor has long term health conditions following a serious stroke 10 years ago including very limited communication and mobility. His wife has severe arthritis which causes her significant pain and limitations to mobility. Care has changed over the course of fieldwork to include live in care (2 episodes) to cover acute incidents (falls) and, by T3 full time, publically funded care.	Getting by
Virginia	87	Virginia lives alone now as she was widowed just before T1 and had purchased self-funded care for her husband. Subsequent to his death, she relied on ancillary services including, cleaning and gardening and had some temporary care when she had a knee replacement.	Comfortable
Wilfred	76	Wilfred has vascular dementia leading to aggressive behaviours. He moved to a care home full-time, eventually funded via CHC. His interview was given by his wife as consultee.	Comfortable
Winifred	69	Winifred has no siblings, was divorced and had no children. She has severe problems with her back that make it difficult for her to walk very far or to sit in cars. She has had care for many years.	Getting by

Unpaid informal carers supporting older people who were self-funding

Pseudonym	Age	Details about the care receiver and / or their care	Self-defined financial status
Aaron	63	Lived with mother and self-funded care at home until she moved into a care home. Had several moves in several months before dying in hospital.	Comfortable
Andrea	Under 65 and working	Mother cared for by 'Companions' from an organization that is unregulated – not CQC.	-
Anna	63	Mother has dementia, and is very mobile. Was in sheltered accommodation, recently moved to care home. Found it hard to find homes that support people with dementia who are mobile.	Comfortable
Annette	55	Mother has dementia. Recently started agency care in her own home for personal care. Previously all help was by daughters.	Comfortable
Ava	Under 65 and working	Cared for Dad who had dementia and died recently. Her partner (66) has Parkinson's and Lewy Body and she is now supporting him. .	-
Becky	Retired	Caring for husband.	-
Bella	-	Father has dementia. Daughter hired a friend as an independent carer. Also provides care herself.	-
Cathie	70, working	Helped to arrange care for a friend at a distance. Cathie was part of a friendship group of older lesbians who arranged and shared care for their friend between them.	-
Daniel	63	Mother has dementia. Poor service from agency, so family contracted small team of independent carers.	Comfortable
Darren	Retired	Supported his wife at home for several years until her dementia advanced to the point where he was not able to cope. She is now in a local care home and he visits her daily.	-
Dawn	63	Supporting step-father at home with self-funded care. A lot of family conflict.	Well off
Delia	58	Supporting mother whose health collapsed after the death of her husband. Having self-funded care at home.	Comfortable
Emma	Under 65 and working	Mother fell ill while on holiday with Emma and she is now in a local care home but wants to return to her own home. Her father has dementia and is a care home in North.	-
Fay	Retired	No speech. Husband in a care home for 2 months but will be assessed in 1 month to see if qualifying for NHS continuing care or she has to pay.	-
Frances	69	Husband has Parkinson's dementia. Has used respite and day care but now considering f/t residential care	Getting by
Francesca	63	Supported mother and father in extra care housing and with self-funded care. Mother moved into a care home (self-funded) following the development of dementia and a serious fall. Mother had died before interview.	Comfortable
Frank	65	Mother has depression, dementia and mobility problems. Conflict over whether health or social care problem. Mother was receiving short-term health care at home at time of interview. Has used self-funded care in the past and was expecting to self-fund soon.	Struggling over basics
Greg	81	Wife has dementia, registered blind, arthritis. Care agency 7/7 mornings for personal care and exercises.	Comfortable
Gryff	60	Father has dementia. Son runs his own business and has his office in father's home. Carers 7/7 for personal care.	Struggling over basics
Joanna	-	Mother has advanced dementia. Lives in own home. 2 carers 4 times a day, plus night sitter.	-
Karolyn	59	Mother self-funded into a care home after developing very serious mobility impairment following falls / hip fracture.	Well off
Kerry	Under 65 and working	Supporting her mother at a distance. Four siblings shared the management of their mother's care. Some family conflict but mostly supportive.	-
Kieran	Retired	Mother is 96 and still independent. Participant has a history in health and social care and still struggled with the system.	-
Laura and Jo	75 / 40	Husband had a major accident resulting in severe injuries with long term complications. Laura providing co-resident care and daughter employed (self-funded) to provide some care in combination with self-funded care agencies and some continuing health care funding.	Well off/ (mother) Getting by (daughter)

Liam	56	Supported mother from a distance at home with care after his mother developed dementia. At the time of the interview his mother had moved into a care home (self-funded).	Comfortable
Liz	70	Husband has dementia and incontinence. Had day care and is now in care home.	Getting by
Louise	-	Husband has dementia and heart condition which limits medication. Uses day care 2/7, considering 3/7.	-
Margot	70	Husband has Parkinson’s and visual impairment. Wife is also carer for her mother. Care agency 7/7 mornings but thinking of having evening care as well.	Comfortable
Matt	Retired	Mother lived nearby and had state care after an operation but a surprise when they had to arrange for care after that. Mother has now moved into a care home – resents paying when others don’t.	-
Nancy	70	Aunt lives alone. Was in hospital after a fall. Carers 4 times a day.	Comfortable
Nigel	Retired	Caring for his second wife, who has advanced dementia.	-
Oliver	-	Mother has dementia, incontinence, mobility problems. Son lives with her, also cares for disabled brother and f/t employment.	-
Robin	69	Supported mother to remain at home with self-funded care until she died at home.	Well off
Roger	69	Supported a long-standing colleague who lived alone and developed dementia. Had organized care at home for a number of years. At the time of the interview had supported his friend to move into a care home with her agreement.	Well off
Rosalind	58	Supporting mother who has significant mental health problems following the death of her husband. Self-funded care at home.	Comfortable
Ruby	59	Supported neighbour with self-funded care following a stroke and also cared for father self-funding at home.	Getting by
Sadie	51	Organised care at home for mother with vascular dementia.	Comfortable
Selena	65	Invited father to live with her and her husband after his wife died. Father has cognitive impairment. Receives self-funded care via an agency, day Centre and regular respite in a care home.	Comfortable
Sophie	Under 65 and working	Mother in good care home but has run out of money.	-
Tammy	Under 65 and working	Supporting her mother who fell very ill while visiting. Tammy was told her Mother was not entitled to state support as she wasn’t a local resident. Three years on and the care arrangements haven’t changed.	-
Tamsin	57	Mother has dementia. Daughter is main carer, also to husband with cancer. Family conflicts. Carers help with housework. Mother very resistant to having care. Daughter considering moving home to live with mother.	Comfortable
Tina	59	Father has dementia, was living in a retirement complex. Recently moved to a nursing home.	Comfortable
Veronica	66	Supporting mother at home living with depression and physical disabilities from Parkinson’s Disease	Comfortable
Victoria	54	Supported mother at home and into a care home following discharge from hospital. Her mother had died shortly before the interview.	Comfortable
Wayne	Retired	Has working history in ASC. Disappointed in home care services and Father-in-law is now in a local care home.	-
William	Retired	Has care for his wife who has been ill since start of marriage. Two heart attacks when young. Recently moved to the area and very happy with the care received.	-

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Older People: Care and Self-funding Experiences
Research Report and Findings

Designed by Nifty Fox Creative, 2020