

# Choice and control in social care: experiences of older self-funders in England

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## ABSTRACT

This paper considers the experiences of older self-funders in England in the context of policies promoting choice and control. Self-funders are people who are not state-funded; they pay for social care from their own resources. Choice and control have been operationalised through personal budgets, based on the assumption that managing resources enhances ability to access appropriate care and support. This paper uses data from 40 qualitative interviews with self-funders and their relatives, and 19 with professionals. It explores the impact of the financial and social capital that self-funders are assumed to have; and asks how older self-funders experience choice and control. The study found that older self-funders drew on personal experiences, family and friends for information; were reluctant to spend their wealth on care due to competing priorities; and felt they had more control over the timing of decisions than people who were state-funded. Personal wealth appears to be perceived differently to funds 'gifted' to people through cash for care schemes.

**Keywords:** self-funders; choice and control; social care; older people

## 1. INTRODUCTION

This paper considers the experiences of self-funders in England in the context of policies promoting choice and control. Self-funders are people who are not state-funded, but who pay for social care from their own resources.

Personalization, choice and control are key elements of adult social care in many countries (Moberg, Blomqvist, & Winblad, 2016). Operationalized through personal budgets (PBs) and direct payments (DPs) in England and other forms of cash for care payments internationally (Glendinning & Kemp, 2006; Ungerson & Yeandle, 2007), a fundamental assumption is that enabling people to manage the resources available to them will enhance their ability to access appropriate care and support, and tailor it to their needs.

The introduction of PBs for those in receipt of state funded social care support in England was intended to mirror the opportunities assumed to be available to self-funders:

*Personal Budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders. (HM Government, 2007, page 2)*

The assumption appears to be that self-funders are, and act as, model consumers, that is, they have the funds and freedom to purchase the type and amount of care they wish from any provider they choose. However, to date there has been little research on the experiences of self-funders, and specifically on the levels of choice and control available to them (Baxter & Glendinning, 2015).

This paper uses data from a qualitative research project that explored the experiences of self-funders in seeking information about social care in England to answer the research question: How do self-funders experience choice and control, and to what extent do they act as model consumers?

## 2. BACKGROUND

### 2.1 Social care for older people in England

Social care for older people typically covers support with activities of daily living such as getting up and dressing, going to the toilet, and making and eating meals. People receive care in their own homes (called home or domiciliary care) or in a residential/care home.

Local councils do not fund social care for everyone. To be entitled to state funding, people are assessed on (a) their need for care and (b) their ability to pay for it. Assessment of care needs is relatively straightforward – people discuss their needs with a trained assessor and if those needs are above a defined threshold then the person qualifies for state funding, subject to a financial assessment. The financial assessment is based on a person's income and assets. If a person has assets (including in some circumstances the value of their house) of above £23,250 then they are not entitled to any financial support from their local council and so must fund their care themselves. This group are referred to as self-funders. With assets below this level there is a sliding scale of contributions based on income, until a lower limit of £14,250 of assets, under which the council pays all the costs of care.

New legislation in 2015 (Care Act, 2014) made it compulsory for councils to assign PBs to people of all ages eligible for support. A PB is an allocation of funding offered after an assessment of care needs. A PB can be taken as a direct payment (cash held in a personal account), or as a 'managed PB' in which case the budget is retained by the council or placed in a third party's account to be managed on behalf of the person needing care. PBs can also be taken as a combination of a DP and managed PB. Managed PBs were introduced to enable people to benefit from the choice and control that DPs aim to offer, but without the responsibility for managing a cash budget. In 2014, 82% of eligible older people were using PBs (ADASS, 2014). However, the use of direct payments by older

people remains low; 15% of eligible older people used DPs in 2014 compared with 37% of younger adults (ADASS, 2014).

There is no definitive evidence on the number of self-funders in England, but estimates suggest up to 25% of home care hours are provided to self-funders and over 40% of care home places are paid for by self-funders (Baxter & Glendinning, 2015). The ageing population and rising eligibility thresholds for council-funded care due to years of austerity mean that both the proportion and total number of self-funders are likely to rise. Evidence that self-funders are charged higher rates and so cross-subsidize council-funded care suggests they are also important for the sustainability of care providers (Competition and Markets Authority, 2017). The growing importance of self-funders has also been recognized in legislation (Care Act, 2014) which made it mandatory for local councils to establish information and advice services for all people in their locality, whether they are eligible for council support or self-funded.

On the supply side, following reforms in the early 1990s (Department of Health, 1989; Lewis & Glennerster, 1996) and the introduction of a quasi-market (Le Grand & Bartlett, 1993), the vast majority of social care is now provided by independent (for- and not-for-profit) organisations. The Institute of Public Care (2014) suggests 89% of home care was provided by the independent sector in 2011/12. Ninety one per cent of care home places were provided by the independent sector in 2010 (Forder & Allan, 2011).

## **2.2 Choice and consumerism in English social care**

The introduction of a quasi-market in social care aimed to drive up quality, efficiency and service responsiveness through competition and consumer choice (Clarke, Newman, & Westmarland, 2008; Glendinning, 2008; Lewis & Glennerster, 1996; Rodrigues & Glendinning, 2015). Such market-based systems place the service user in the central role of consumer, as a rational actor empowered to commission services from a range of suitable options available in a free market (Christensen & Pilling, 2014; Needham, 2013). The ideology of consumerism ran in parallel with economic arguments for markets and choice. This discourse defines choice as an intrinsic good in itself, key to citizenship, autonomy and independence (Burchardt, Evans, & Holder, 2015; Glendinning, 2008; Rabiee, 2013). As Clarke et al (2008) discuss, the diverse meanings of choice, such as choice as the freedom to choose, choice as the capacity for self-direction, and choice as a market mechanism, make it a powerful concept.

Important to both quasi-market and consumerist approaches is the availability and quality of information and the capacity to use that information (Dixon, Robertson, & Bal, 2010; Moberg et al., 2016). Glendinning (2008) summarizes some of the issues facing social care service users in making choices, including issues specific to people likely to be self-funders. These include an assumption that people who have more financial resources from which to draw find it easier to make choices by virtue of a wider field of affordable options (Clarke, Smith, & Vidler, 2006). Furthermore, non-financial resources, such as social capital, are taken to be important determinants of ability to exercise choice; examples of social capital include knowledge of services, skills in dealing with professionals, and friends or relatives with appropriate skills to act as advocates or 'choice editors' (Glendinning, 2008, p. 457). Thus people with higher levels of cognitive, material or human resources are assumed to be able to use those resources to find relevant information about care, make informed choices and further increase their inherent advantage (Corrigan, 2005; Lent & Arend, 2004; Rogers & Mead, 2004). Formal information and support services can help to reduce differences in the level of non-financial resources people possess (Lent & Arend, 2004). However, even for people with existing high levels of knowledge and/or material or social capital, the costs of an exhaustive search for information can be prohibitive (Baxter, Glendinning, & Clarke, 2008), potentially limiting the effectiveness of choice policies (Propper, Wilson, & Burgess, 2006; Thomson & Dixon, 2006). Thus increasing opportunities to make choices without improving access to relevant information and support services can be futile (Corrigan, 2005). It follows that self-funders, if they

are to act as model consumers in line with the above, need good information, ownership and control over financial resources, and the means of combining these to make efficient and effective care choices.

### **2.3 Older personal budget users and support to exercise choice**

The system has evolved to support PB users, but not self-funders, to operationalize choice. This support begins with an assessment of needs, a fundamental part of the process of determining eligibility for council-funded services. As the number of people using DPs or PBs has increased, additional roles in support planning, brokerage (i.e. liaising with providers and arranging care) and management of budgets have developed to assist budget holders in exercising choice and control. For people using managed PBs, these services are an integral part of the service from the local council; for people using cash direct payments, there is often an option to use the council's services or those of an independent organisation, with use of the services paid for from the DP budget. PBs (both managed PBs and DPs) are also audited, usually annually, to monitor their use, ensure people's outcomes are being achieved, and check on the quality of services and any safeguarding issues.

Empirical evidence suggests that older PB users (who usually use managed PBs) value being involved in planning how to use their budget (Hatton & Waters, 2013). For some groups, such involvement has been associated with better outcomes (Hatton & Waters, 2013) and more personalized care (Rodrigues & Glendinning, 2015); however the level of involvement some people want in making choices is limited. Rabiee and Glendinning (2014) suggest that older people often do not want choice over how much care they need or which organisation provides it. Choice and control for older people typically sits at the 'micro' level of the individual's daily routine; people want to make choices about what to eat for lunch or what to wear, which care worker visits and at what time (Duncan-Myers & Huebner, 2000; Rabiee & Glendinning, 2014; Steffansson, Pulliainen, Kettunen, Linnosmaa, & Halonen, 2016), but not about which care agency delivers the care. Rabiee et al (2016) also found, in a study of how support planning and brokerage assisted older people in using PBs to exercise choice and control, that the size of budgets and rules on their use appeared to limit choice.

### **2.4 Self-funders and the exercise of choice**

The limited empirical evidence about self-funders suggests that, unlike PB users, they are not assisted to operationalise choice. A recent scoping review illustrated that self-funders struggle to find and understand information about social care (Baxter, 2016; Baxter & Glendinning, 2015). Information and advice in the early stages of looking for care and navigating care systems are particular gaps. Self-funders often do not consider approaching their local council for advice (Wright, 2000) or can be deterred by a perception of stigma associated with asking the council for help (Putting People First, Oxford Brookes University, & Melanie Henwood Associates, 2011). They can be disadvantaged and isolated, ending up with care arrangements by chance rather than through any active choice (Henwood & Hudson, 2008). People moving into care homes have reported feeling powerless and unsupported throughout the process (Commission for Social Care Inspection, 2007), and having sufficient financial resources to self-fund has not been found to guarantee any greater control over care than for people with fewer resources (Putting People First et al., 2011).

Despite recommendations, prior to the Care Act in 2014, that information, advocacy and advice services should be made available to self-funders as well as council-funded service users, only 23% of local councils responding to a 2005/06 survey identified a need to provide more advice and support to self-funders (Commission for Social Care Inspection, 2006). Self-funders are often left to navigate the care system themselves (Care Quality Commission, 2009).

In addition to receiving limited help in choosing and arranging care, the post-purchase appropriateness and quality of care that self-funders receive is not monitored in the same way as for PB users. For example, care home managers are concerned about the inequity of undertaking annual reviews for residents funded by the council but not self-funders (Scourfield, 2010).

Thus the, albeit limited, evidence to date suggests that older self-funders are not supported in exercising choice to the same extent as older PB users. The work presented in this paper adds to this evidence by exploring new empirical data on older self-funders' experiences of exercising choice. The findings are relevant to care systems aiming to enhance and extend opportunities to exercise choice and consumer-related behaviours.

### **3. METHODS AND DATA**

#### **3.1 Study design and aims**

The overall aim of the study was to explore experiences of seeking information about self-funded social care (Baxter, Heavey, & Birks, 2017). The design comprised depth interviews with people who had looked for information for themselves or a relative. Complementary interviews with social and health care staff and third sector organisations examined their experiences of being asked for and providing information. Strategic level managers from five councils were interviewed about local priorities regarding self-funders; findings from strategic level managers are not included in the current paper.

Ethical approval was obtained from the Social Care Research Ethics Committee (reference: 15/IEC08/0026).

#### **3.2 Data collection**

Older self-funders and their relatives were purposively recruited to capture maximum variation in characteristics and experiences, including location, age, and level of support needs. All lived in England.

To be eligible to take part, people needed to have looked for information or advice about paying for care in the previous 18 months, either for themselves or for someone else. Definitions of 'care' were broad and could include getting help at home (for example, help with washing or getting out and about) through to moving to alternative accommodation such as a care home.

The research team worked with a wide variety of organisations to recruit participants between July 2015 and February 2016. These included local councils, local and national voluntary organisations, individual and groups of care homes and home care agencies.

Interviews were semi-structured and designed to last 60 to 90 minutes. Those with self-funders/relatives covered: circumstances and social care needs; experiences of seeking information; and suggestions for a resource to help with the process of seeking information. The section of the interview about seeking information was designed to be the most comprehensive, covering all aspects of the process including knowledge of social care, starting points in seeking information, organisations contacted, help in seeking information, information found and usefulness of information.

Interviews also took place with professionals from a range of health and social care-related organisations who, as part of their job, might be asked by self-funders for information about social care. Recruitment took place across England between September 2015 and March 2016. Although some were recruited from the same councils as self-funding participants, they were not matched in any way. Interviews lasted between 45 minutes and one hour and covered topics such as the types of contacts from self-funders, typical questions asked, information provided, the process of offering information, any training they had received, and impacts of the Care Act.

#### **3.3 Analysis**

The interviews were analysed thematically following the Framework approach (Ritchie, Lewis, Nicholls, & Ormston, 2013). The main analysis of self-funders' data focussed on their journeys from initial triggers for considering care, through information seeking, to arranging care. Coding and analysis of interview data from professionals covered areas such as the type, format, and perceived

quality of information and advice offered, facilitators and constraints to offering information and advice, and current/future challenges.

Data presented in this paper focus on older self-funders' and relatives' experiences of choice and control, including seeking and using information, and the effects of social and financial capital on choice-making. Data from interviews with those working in practice offers an alternative perspective to self-funders' views on how the information and support they are given facilitates choice making.

### 3.4 Participants

Tables 1 and 2 give the numbers of self-funder/relative and professional interviews respectively. Of the forty interviews conducted with self-funders or their relatives, three involved two participants (for example, a son and daughter-in-law searching for information for a parent), giving a total of 43 participants. Twenty seven interviews were conducted with women, 10 with men, two jointly with husband and wife dyads, and one with two sisters. Four self-funders were aged under 65: two (aged 62 and 64) were included in the analysis but a husband and wife team was excluded as they were both aged under 40 and so considered too different from the older population of interest. The relatives of self-funders were typically adult children (aged over 50) or spouses of self-funders (aged over 65).

[INSERT TABLES 1 AND 2 HERE]

## 4. STUDY FINDINGS

The diverse sample interviewed in this study described a wide range of experiences of seeking information about care homes and home care across England. Despite this diversity, common themes were evident across interviewee types, locations and forms of care. The following sections discuss these commonalities but also illustrate divergent experiences.

### 4.1 Does financial capital increase the field of affordable care options?

Clarke et al (2006) claims that money expands the field of options available and powers choice: 'if we have enough money, we can persuade someone to sell us what we want' (p330). The experiences of self-funders in this study suggests that this is not necessarily the case.

There were examples supporting the hypothesis that financial capital increases the field of affordable options. Some people were content to pay for care and felt this afforded them more choice and control than people who relied on council funding. Basic levels of home care funded by local councils are often limited to help with activities of daily living, whereas study participants felt paying for care themselves enabled them to purchase help from a wider choice of activities and thus avoid "*becoming institutionalized*" (Self-funder, SSD37) in their own homes. They also noted the relative value of care: "*At our age, money's worth nothing*" (Self-funder, SSH09).

More typically, however, participants felt financially comfortable but not rich. They talked of savings that were only marginally higher than the eligibility threshold and of modest pensions: "*I don't consider we're rich, we're talking about £20,000 in the bank [...] I wouldn't think that's a lot of money nowadays*" (Relative of self-funder, SCD02). Concern about the costs of care eroding savings people wanted their children to inherit were prevalent and consistent. Many participants felt it was unfair that they were expected to use their savings for care when others who they perceived had been less frugal were state-funded. This sense of unfairness was one reason that people looked for ways to avoid paying for care. Some spoke of signing their houses, or proportions of them, over to their adult children, or giving money away to grandchildren. Some approached solicitors for advice about protecting assets to leave as inheritance and clarification about the use of housing wealth to pay for care. Thus people's emotional responses to needing to pay for care meant some consciously reduced the level of assets they had available or were willing to spend, placing limits on their field of options.

In line with research by Ward et al (2012), people were also concerned about the financial sustainability of paying for care in the long term and its effects on future decisions. The cost of care home places average £31,200 a year (rising to £43,732 for a nursing home) (LaingBuisson, 2017) so even substantial savings can be eroded quickly. This was a particular concern when adult children lived with a parent or where a self-funder lived with a spouse; people worried that houses would be sold to pay for care and relatives would be left with nowhere to live: *“I think my brother’s wondering, cos he lives with my mother, you know, what, what would be expected of him if she went into care; would the house have to be sold?”* (Relative of self-funder, SCD21). This concern is unfounded and reflects people’s lack of understanding of the system; the value of a person’s home is usually disregarded if occupied by a dependent. Concerns over inheritance also affected judgements and caused family disputes. An older woman who felt lonely living alone in her own home considered moving to a care home for companionship, but her children were reluctant for her to do so because it would mean spending her housing wealth (their anticipated inheritance) on care. Therefore family pressure also resulted in limits being placed on spending and hence choices.

#### **4.2 Does social capital facilitate access to information?**

Social capital, such as knowledge of services or skills in dealing with professionals, is believed to be an important determinant in ability to exercise choice (Glendinning, 2008). Participants in this study felt they received very little help in making choices and so social capital was particularly important.

Not all self-funders and relatives in this study had what might be considered a high level of social capital on which to draw. Some had no or limited networks of family and friends with whom to discuss their choices and plans; they often reported feeling isolated and finding themselves feeling burdened with being in control of decisions about care for themselves or an elderly spouse or relative, with little or no external support. When new knowledge was gained during the search for care – through social networks or personal experience – it could come too late to be of use.

When approaching local councils for information, people reported that councils were *“not terribly interested”* (Relative of self-funder, SCD26) once it became apparent that a person would be self-funding. Sometimes the lack of interest was explicit but in other cases it was not: *“She was quite nice, but the implication was ‘Why are you wasting my time?’”* (Relative of self-funder, SCH03).

People in the main felt they received very little help from their councils with information-gathering or decision-making. Some felt, in retrospect, that they might have made different choices if they had had more personalized support; they might also have felt more comfortable with their decisions:

*I didn't make an informed choice when I put mum in the most expensive nursing home in the city, I just thought ooh it's local, we'll worry about the money later (laughs) and it was a worry. (Relative of self-funder, SCH29)*

*Very difficult to make a decision, very difficult and you're not sure you're making the decision on the right grounds at all really, and I'm still not sure. (Relative of self-funder, SCH03)*

Self-funders and their relatives reported that this lack of help from local councils meant they often had to rely on two interrelated forms of social capital to aid their decisions: their knowledge and their social networks.

Self-funders’ knowledge about social care came from their own or other people’s experiences, in particular work experience. Some worked in health or social care jobs or had friends or family who worked in such jobs; these roles were not usually related directly to finding information about care, but gave people insights into how the systems functioned and what they could (and could not) offer. This in turn gave people the confidence to know what to look for: *“I knew [care home] by reputation and I went to visit, looked round, spoke to the managers and made a decision”* (Relative of self-funder, SCH31).

Self-funders also drew on previous experiences of searching for information about care for other people in different contexts, or developed knowledge and competence as they progressed in their current searches for information. Knowledge gained in the latter way could come too late: *“Now I know a lot of the problems, I’m becoming quite good at it, but it’s a bit late in the day”* (Relative of self-funder, SCH14). As many decisions about care were one-off or infrequent, participants had few opportunities to apply their recent learning. However, they used these newfound competencies by offering advice and recommendations to people in their social networks, thus creating a cycle of knowledge exchange: *“It’s just general conversations I think with people that I know and the friends that I have nowadays are [...] mainly my age group and they have problems, usually with husbands, and things crop up in conversations”* (Relative of self-funder, SCD18).

Nevertheless, although people felt reassured about choosing a particular care provider if others within their networks made a recommendation, not all choices based on recommendations worked out well; some people found they had different experiences to their friends and revised choices quite quickly. This reflects the very personalized and experiential nature of care that makes it hard to judge appropriateness in advance, and the limited use of some forms of social capital.

As well as social networks, participants drew on internet searching skills; some initiated searches on the internet whereas others used the internet after being signposted to specific webpages by local councils and other organisations. Some undertook quite basic searches, for example, looking for contact details of care homes that they then rang or visited. Others accessed information that was more sophisticated including quality ratings and staff-to-resident ratios. However, to use the internet effectively, people needed a degree of knowledge and confidence. Self-funders are typically older people, many in their 70s and over. While familiarity with web-based searching is becoming increasingly common in ageing populations not all were comfortable with this medium. Older individuals sometimes received support from adult children with web based searching. However, some adult sons and daughters, although competent in using the internet, were confused or overwhelmed by the information on offer about long-term care.

### **4.3 How are self-funders empowered to make choices?**

Market-based systems depend on empowered consumers making rational decisions about purchases (Clarke et al., 2006; Glendinning, 2008). Empowerment is a complex concept (Newman & Vidler, 2006; Perkins & Zimmerman, 1995). For the purposes of this paper, it refers to people’s ability and means to have control over their care-related decisions. The previous sections have shown how self-funders, in this sample, do not necessarily feel empowered by having funds to spend on care, or always have sufficient and relevant social capital. As a result, they want assistance in making choices from professionals. This section reports on self-funders’ experiences of seeking help from people they perceived to be relevant professionals.

Self-funders expected help in finding and understanding relevant information. They wanted personalized guidance, tailored to their needs and communicated in an effective way. This was often articulated as being able to speak with a named individual, on more than one occasion if needed, to seek clarification without repeating their whole story, and to receive reassurance about their options and decisions. In reality, they were provided with generic information and rarely spoke to the same person twice, even within a single organisation.

Self-funders and their families felt particularly frustrated that those in professional roles often stated that they were not allowed to recommend specific providers. They could, for example, advise people on what *types* of provider would best suit their care needs, and were able to offer lists of such providers, but they could not help prioritize them. The lists they could provide were sometimes lengthy and/or out-of-date, presenting further difficulties for self-funders. The lack of direct advice on which providers to choose left people feeling uncertain about the choices they made: *“There’s a*

*lot of information out there but it's not necessarily information you need; it's almost like you need advice and reassurance that the decisions you're making are good ones" (Relative of self-funder, SCH03).*

Occasionally people reported that professionals had given them advice while making it clear this was something they should not be doing: *"One day this lady said 'Look, I shouldn't tell you this, but'" (Relative of self-funder, SCH39) and "they are not allowed to recommend, although unofficially one of the ladies did" (Relative of self-funder, SCD04). Although frustrating, there appeared to be a degree of understanding about why professionals would not make recommendations:*

*Very often one person will manage absolutely beautifully in a home where somebody else just doesn't manage at all [...] maybe that's another reason for not making recommendations, you can't actually say that because it's been all right for these people it's going to be all right for you. (Relative of self-funder, SCH06)*

This experience chimes with that expressed by people acting on recommendations from social networks and again illustrates the personalised and experiential nature of care.

The view from practice was that they wanted to facilitate self-funders' choices by providing relevant information, but were not there to, and indeed were not allowed to, offer recommendations about specific providers. Participants based in local councils explained that they did not make recommendations to people using PBs either – they were there to offer information on options and guidance on meeting care and support needs, but not to make choices for people. However, occasionally practitioners mentioned that, off the record, they might try to suggest to self-funders that they think twice before choosing some providers known to be of poor quality. One interviewee from a voluntary organisation commented that:

*It would certainly not be something I'd want to put in an email [but] if the conversation went that way, if someone asked me, quite often people do ask 'are they any good?' and all I can say is [that] we've had no negative feedback or we've had some bits of negative feedback; and that's not misrepresenting the fact, it's just, [...] that's about as opinionated as we can be. (Professional, PVO15)*

Self-funders felt much of the information provided to them was generic or insufficiently personalised. For example, information about assessment processes, how to get help or where to look on council websites was in the form of leaflets or factsheets aimed at PB users rather than self-funders. Some professionals did report offering personalized conversations intended to be as relevant to people's individual circumstances as possible. However, these conversations could be tailored in a very basic way, thereby limiting discussions to services on offer in specific localities or to broad care needs (for example, care homes or care at home). Thus, there is a mismatch between what self-funders and professionals understand as tailored information that is useful in empowering self-funders to act.

Professionals were also aware of the danger of overloading people with information and so made judgements about how much information people might find useful and how much help they needed in sifting through it. In essence, they judged the capacity of self-funders to take on board and act on information:

*So we have to play it by ear [...] whether they want something there and then, or whether they just want to be told; if someone's happy to just go and look, [...] do the research themselves, then we can just send them away with that, but if they want an actual list then we can make a bespoke list. [...] [If someone needs] more intensive support than someone else then we'll tailor the information differently. (Professional, PVO01)*

The Care Act legislation of 2014 made it mandatory for local councils to provide written information about care to anyone enquiring about it, including self-funders. One council-based practitioner felt

this helped her tailor information better. Previously the council in question had sent people large amounts of generic information, but since the Care Act they had introduced a requirement to send people a detailed list of the information they had been offered, and this acted as a catalyst for more concise and personalized information which should better facilitate self-funders' choices.

#### **4.4 Self-funders' experiences of control**

Previous research has failed to support the idea that those with sufficient financial resources to self-fund have greater control over care than people with fewer resources (Putting People First et al., 2011). This section considers the level of control experienced by self-funders in this study.

Despite the generally high level of dissatisfaction with having to pay for care, some participants felt it gave them a sense of control and freedom. An important element of this control was timing. People reported being able to arrange care quickly by bypassing intermediary organisations (e.g. local authorities or voluntary organisations): *"We just rang up and somebody came out, because I think they're quite happy to have people who are self-funding, I think [...] the private carers and homes like self-funders"* (Relative of self-funder, SCD28). Furthermore, self-funders were often able to take control and purchase relevant equipment immediately instead of waiting weeks for the same equipment through local councils. This promptness compared with frequent reports of long waiting times to receive council assessments of needs or finances and, in the case of people eligible for council funding, the prospect of additional waits for care to be arranged.

For some people, taking a long time to make a decision was desirable. This was particularly so in instances where needs were low but expected to increase. In these circumstances, people valued the time to explore options or make independent choices before reaching a crisis. For example, a woman who was managing at home but becoming increasingly frail chose to move to a care home before her needs increased so she could settle into the new environment. Being self-funding enabled such individuals to be in control of the pace of their decision-making.

In contrast, relatives of self-funders in need of care upon discharge from hospital reported feeling under enormous pressure to find out about and arrange care very quickly. Some reported choosing and moving into a care home within a day or two of being assessed as ready for discharge. For others, discharge from hospital to a temporary care home was followed by a move to a different care home within weeks or possibly months. Moving can be very disruptive and unsettling. Some professionals stressed the importance of enabling people to have the time to make informed choices about their place of residence on discharge but self-funders did not feel they had this time.

Time pressure was not the only factor that precipitated feelings of a lack of control. Often, difficulties in navigating the care system left people feeling overwhelmed:

*[I] quite often visualise myself as a beetle lying on its back with its legs flying everywhere in the air, flailing around. And sometimes somebody helpful picks me up and puts me the right way down and I can get on and do things, but at other times I have to work really hard to get in the right position so I can then address issues myself. (Self-funder, SSD23)*

For others the issue was about losing control to the local council. Although people wanted hands-on support from the council, or another third party, too much support could leave people feeling peripheral to decision making. This could be due to the timing of arrangements and slow-moving council processes, or to councils judging the amount (and thus cost) of care needed to be substantially more than people wanted or were willing to pay for: *"I made the decision to get a [council] care assessment done. And then after that it was just taken out of my hands"* (Relative of self-funder, SCD02).

## **5. DISCUSSION AND CONCLUSION**

Social care policy in many countries has been driven by a desire to increase choice, control and personalization for service users. In theory, people funding their own care have the freedom to select the type, amount and provider of their choice. Implicitly, in the English system, there seems to be an expectation that people with sufficient assets to be self-funders also have sufficient social and financial capital to navigate the social care system and make meaningful choices, without support. Since the roll out of PBs, systems to support choice and control have been developed specifically for PB users. Self-funders have received less policy, practice or research attention. This paper has presented findings that add to our understanding about self-funders' experiences of choice and control within the English social care system.

Specifically, the study suggests older self-funders and those looking for care on their behalf feel relatively unsupported in seeking information and making choices about care. Social capital, in the form of personal experience and discussions with family and friends were key in information seeking. While skills in searching the internet were also important, the value of this source was tempered by overwhelming amounts of information on care. The individuals in this sample did not consider themselves rich and reluctance to spend what they perceived as large amounts of money on social care potentially limited their fields of choice. Views about choice and control were mixed, with some people relishing the freedom to arrange their own care, whilst others struggled to make sense of systems and timescales. Professionals who self-funders approached for help reported trying to judge how much information people could digest in order to tailor it to their needs.

Although grounded in the English system, the findings have implications for systems in other countries where reforms have been driven by a desire to operationalise choice and control for care users through cash for care schemes.

One of the basic principles behind cash for care schemes is that ownership and control over resources incentivise people to manage those budgets effectively and efficiently to meet their needs. Self-funders might be seen as exemplars of such principles. However many self-funders in this study were reluctant to spend their personal finances on care despite recognised benefits such as a wider range of available choices and greater flexibility over timeframes. The reason for this reluctance appears to be that self-funders (and their families) felt a competing incentive to protect their assets, for inheritance or based on a sense of fairness, rather than to spend them on care. If the consequence is that self-funders are tempted to purchase sub-optimal levels of care and so live with unmet need then, over time, this might result in them becoming vulnerable to conditions or events that could lead to greater long-term use (and costs) of social and health care. It may be, therefore, that people in receipt of state funds through cash for care schemes are better placed to act as model consumers precisely because the funds have been 'gifted' to them or are ring-fenced with no competing pressures for their use. This may have important policy implications for countries considering options for future funding and delivery of care.

It is also apparent from the findings that self-funders and their families need support to seek and act on information about care. Social care, in the form of a care home or receipt of care at home, is an experience good - its quality cannot be judged *a priori* but only through experience (Nelson, 1970) - and so it is incredibly difficult for people with no experience or even knowledge of the social care system to make unsupported decisions. Indeed, Rabiee et al (2016) found in a study of older people using PBs that they did not *wish* to take responsibility for choosing providers as they were aware that they did not possess relevant information or experience to do so. It follows that self-funders or others using cash for care budgets would benefit from professional support not just to navigate information systems but to comprehend and manage that information such that they feel empowered and confident to make choices. This is particularly relevant when people first start to seek care and have little or no experience to fall back on.

Self-funders felt that they had control over the timing of their search for care (except in relation to hospital discharge). They were able to bypass local council processes and make decisions at their

own pace – for some this was quicker than would have been possible with council involvement and for some it was slower. For those who needed care or equipment quickly, this was an obvious advantage, but control over timing also enabled people to explore and compare options or take time to adapt to changing circumstances. Any system in which funds are provided at the point of need, which is often a stressful time, might benefit from considering ways in which people’s individual decision-making behaviours can be taken into account. Time constraints impact on people’s decision making behaviours (Godinho, Prada, & Garrido, 2016; Ordóñez, Benson III, & Pittarello, 2015) and so policy makers should be aware of the potential impacts of people making decisions about social care in timeframes that fit the system rather than their individual preferences.

Disempowerment is particularly salient in relation to hospital discharge. An important issue for health and social care in England over recent years has been delayed transfers of care to the patient’s usual or a new place of residence after an in-patient stay. This situation arises when a patient is clinically ready for discharge from hospital but is waiting for a package of care at home, or a care home place, to be arranged. Self-funders and their relatives felt under extreme time pressure to make decisions about these arrangements. Social workers assist in arranging care packages for people using PBs and may offer to help self-funders but, even where offers are made, they are not always accepted. Social workers therefore act as intermediaries for PB users, absorbing some of the pressure and potentially speeding up discharge arrangements. There is anecdotal evidence that self-funders take longer to arrange care than PB users and so have longer hospital stays with the subsequent increased risks of infection or morbidity (Rosman, Rachminov, Segal, & Segal, 2015). However, there is no evidence as yet about feelings of empowerment or levels of satisfaction with post-discharge care arrangements among people receiving help compared with those who do not.

Our evidence speaks to earlier research (Corrigan, 2005; Lent & Arend, 2004; Rogers & Mead, 2004) which suggests an underlying assumption that financial assets and capacity to arrange care are related. While local councils have a duty of care for all their local residents, not just those whose care they fund, limited resources mean they focus on those most in need, such as people who lack mental capacity. While we are not aware of any published evidence of a correlation between people unable to arrange their own care and those funded by the council, we question whether people with greater financial assets are any more able to arrange care than those with fewer assets. In fact, people with fewer assets or lower incomes could be more likely to have had contact with and so be familiar with welfare systems, putting them at an advantage.

Finally, our research did not explore the impacts of choice and competition on the quality of life of self-funders, or their use of formal or informal care. These are evidence gaps where future research might help understand differences in access to and use of care services, and so facilitate the design of better support for people self-funding long-term social care.

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**Table 1: Number of self-funders and relatives interviewed**

	<b>Age of interviewee</b>	<b>Self-funder</b>	<b>Relative</b>	<b>Total</b>
<b>Domiciliary care</b>	<65 years	4*	5	9
	65 and over	4	7	11
<b>Care home</b>	<65 years	0	10	10
	65 and over	8	5	13
<b>Total</b>		<b>16</b>	<b>27</b>	<b>43</b>

\*A husband and wife both aged in their twenties were excluded from this analysis. Two other self-funders were retired and aged over 60 but under 65. They are included in the analysis.

**Table 2: Number of professionals interviewed**

<b>Practitioner</b>	<b>Number</b>
Local council customer service/first contact (PFC)*	3
Community social worker (PSW)	4
Hospital social worker (PHS)	3
General practitioner (PGP)	3
Voluntary organisation (PVO)	3
Provider manager (PHM)	3
<b>Total</b>	<b>19</b>

\*Letters in brackets denote ID codes

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