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School for Social Care Research

People who fund their own social care

Kate Baxter and Caroline Glendinning

Scoping Review



Improving the
evidence base for
adult social care
practice

The School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

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ABSTRACT

Very little is known about the many adults in England who purchase social care services and support using their own, private resources. However, rising eligibility thresholds for local authority-funded care combined with population ageing means the numbers of self-funders are likely to increase. The importance to local authorities of self-funders is also increasing with the implementation of the Care Act 2014.

This review sought evidence on: the size of the evidence base; characteristics of the self-funding population; information and advice sought by and available to self-funders; and providers' experiences of self-funders. A self-funder was defined as someone who pays for all of their social care or support from their own private resources or 'tops up' their local authority residential or domiciliary care funding with additional private spending. Social care was defined as care homes (both with and without nursing), domiciliary care, day care and care received as part of extra-care housing.

185 potentially relevant pieces of work published since 2000 were identified. After applying inclusion and exclusion criteria, and removing duplicates, details were extracted from 71 publications. The majority focussed on residential care, domiciliary care or both. The studies used a wide range of research methods. Some were based on national or multi-regional samples; others were local studies.

The evidence suggests that the number and percentage of self-funders has increased in both residential and home care. There are differences between regions and across local authorities. There has been very little research about the socioeconomic or other characteristics of self-funders, but some evidence that dependency levels of self-funders in care homes appears to be lower than local authority-funded residents.

Self-funders often approached their local authorities as the first point of contact for advice but could feel disadvantaged by their perceived unwillingness to help. They are often signposted elsewhere and not followed up by local authorities. The main information issues for self-funders living in or considering residential care were fees and finances, particularly the long term financial implications of care.

There was very little evidence about the experiences of home care agencies or care homes in providing care to self-funders, although home care agencies were beginning to see the potential of the market for self-funders. There were some concerns by care home managers that self-funders and local authority-funded residents were not treated equitably in relation to assessments and reviews.

There are many gaps in the research evidence base, including: accurate figures on the number and characteristics of self-funders, and factors that influence the level of demand; the transparency of fees and contracts; dependency levels; how the tasks carried out for self-funders might differ from local authority-funded clients; experiences and outcomes for self-funders; and the experiences of providers. Almost no research was found on the self-funders experiences in housing with care schemes or day centres.

RECOMMENDATIONS FOR ADULT SOCIAL CARE PRACTICE RESEARCH

In the course of carrying out this review, a number of gaps were identified in the research evidence base. Key areas for potential future research relevant specifically to adult social care practice are summarised below. These are important in helping social care practitioners in planning and delivering care, and in providing information and advice, to the self-funding population.

■ **Robust estimates of the numbers of self-funders, both in care homes and receiving care at home.**

- methods of identifying and measuring current and future numbers of self-funders
- numbers and rates of transition from wholly self-funding to local authority-funded (with or without top ups)
- factors influencing numbers of self-funders
- variations across regions and local authority areas

■ **The characteristics of self-funders, and any relationships between these characteristics and people's use of services and support.**

Such characteristics might be:

- dependency levels
- socioeconomic status
- ethnicity
- working age people, including those in employment and those in receipt of compensation payments

■ **Experiences of self-funders in considering and meeting their care needs:**

- met and unmet need, for people who are wholly self-funding as well as for people topping up to meet needs not covered by local authority funding
- tasks undertaken for self-funders living at home, for example, whether they ask for a wider range of support (such as cleaning, domestic help, escorting, pet care) than people who are wholly local authority funded
- outcomes for people signposted elsewhere by local authorities
- use of prevention and re-ablement services
- self-funders' use of advocacy services
- awareness of rights, for example, to an assessment and care account, or to a re-assessment following a change in needs

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- **Experiences of domiciliary and residential care providers in delivering care to self-funders,**
including;
 - challenges and opportunities of providing care to self-funders
 - the impact of increasing dependency as eligibility thresholds for local authority funding rise
 - the relationship between funding status and hospital discharges/lengths of stay
 - self-funders' experiences of the care element of housing with care schemes and of day care services.

KEYWORDS

Self-funders, social care, adults, older people, home care, residential care

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INTRODUCTION

The NIHR School for Social Care Research commissioned this short scoping review of research evidence about people who fund their own social care in England. The purpose of a scoping review is to map current knowledge about a subject and identify gaps in that knowledge (Arksey and O'Malley 2005). This review, undertaken between January and March 2014, comprised three elements: a search of electronic databases; a search of the websites of selected organisations; and contacts with a small number of organisations known to have been active in research about self-funders. The remainder of this report describes why it is important to understand what evidence exists about self-funders; details the methods for searching for and analysing the evidence found; presents the findings by themes; and concludes with a discussion of the gaps in research evidence and areas for future research.

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BACKGROUND

Very little is known about the many adults in England who purchase social care services and support using their own, private resources. It is estimated that 43% of older and physically disabled adult residents of independent care homes fund the entire cost of their care. If those 'topping up' local authority funding with some additional private spending in order to meet their actual care home fees are included, then the total numbers contributing to the costs of their care rises to an estimated 57% of all care home residents (LaingBuisson 2013a, cited in Humphries 2013). The numbers of people paying for their own domiciliary and day care are much less reliable; Humphries (2013) quotes an estimate of 70,000 older people paying for care at home and an additional 200,000 older people purchasing help with domestic tasks such as shopping and cooking. Patterns of self-funding are geographically variable, with the highest proportions in South East England and the lowest in North East England. Older people are likely to be the largest group of social care self-funders, but some working-age people with adult-onset disabilities may also pay for their own care, especially if they have large accident-related compensation payments.

Both the numbers and importance of self-funders are likely to increase in future with major implications for social care research, policy and practice. First, as local authorities raise eligibility thresholds for adult social care, more people are rendered ineligible for publicly-funded support. Currently, almost all English councils restrict eligibility to people with needs deemed to be substantial or critical (an increase from 47% in 2005/06 to 87% in 2012/13) (ADASS 2011). In the light of continuing severe restrictions on local authority expenditure, this pattern is unlikely to be reversed within the near future; indeed, there may well be further increases in the proportion of councils restricting eligibility only to those with critical-level needs. Coupled with continuing increases in demand for social care associated with population ageing, this means growing numbers of people are likely to be ineligible for publicly funded care and reliant on their own private resources to fund the support they need.

Secondly, self-funding adults and older people will become of increasing importance to councils as they implement the modified proposals of the Dilnot review of care funding as part of the Care Act 2014. Councils already have some interest in those care home residents who pay for all their care but whose capital assets are dropping towards the current £23,250 threshold; once below this threshold, councils are obliged to meet a means-tested proportion of care costs*. However, from 2016, all those paying for their own social care, whether in residential or community/domiciliary settings, will be able to ask for an assessment to establish which of their care costs are eligible to be included in their 'care account' and count towards their care costs 'cap' of £72,000 (HM Treasury 2013).

* See Appendix 1 for list of resources giving fuller details of relevant charging policies.

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People who are ineligible for council-funded services and support are also a major target for information and advice services. Councils have been urged to develop these, as universal services for all local residents, for several years. The *Putting People First Concordat* required local authorities to develop 'a universal information, advice and advocacy service for people needing services ... irrespective of their eligibility for public funding' (HM Government 2008, p.3). Similarly, the current Government's *Vision for Adult Social Care* urged councils to ensure that 'everyone – whether using a personal budget or their own funds – can get the information and advice they need' (DH 2010, p.18). In future, the information needed by people not (currently) eligible for publicly funded social-care support will increase in both scale and complexity with the implementation of the care 'cap' funding reforms and the creation of individual 'care accounts'.

AIMS

This scoping review aimed to identify evidence from existing literature about people who fund their own social care in England. Specifically, evidence was sought to address the following questions:

1. What is the size of the self-funding population in England and what are its characteristics – for example age, region or type of care?
2. What information, advice and other forms of help are needed, sought by and available to those currently funding their own social care support or expecting to have to do so in the future?
3. What experiences do care providers have of people funding their own social care support; what challenges do self-funders present to providers; and how might these challenges be resolved?
4. What are the gaps in available evidence?

DEFINITIONS OF SELF-FUNDING AND SOCIAL CARE

Before the search could begin, it was essential to define what was meant by self-funders and social care.

The Wanless Social Care Review (2006) listed the ways in which people could contribute their own savings or income towards social care in the current system. These were:

- a care home place privately arranged with little or no contact with the local authority and then fully self-funded;
- a care home place arranged through a local authority and then fully or partly self-funded from savings and income after a means test;
- a care home place state-funded with relatives paying 'top up' fees;
- domiciliary care arranged by the local authority and which, after a means test, is partly or fully funded by a user's savings or income;
- private funds spent on domiciliary care privately arranged, either through an agency or directly with a care worker.

In their Care of Older People report, LaingBuisson (2014) label self-funders of care home places as 'pure' self-payers (who fund all their care from private resources), 'quasi' self-payers (who receive third party top-ups of their local authority funding) and 'full' payers (who pay the full fees for care arranged and contracted for by the local authority).

A third-party contribution, often referred to as a 'top-up', is an amount of money that can be paid to a residential home in addition to the fee paid by a local authority. The top-up fee is intended to buy the resident 'extras', such as a single room, an en-suite room or a room with a view, but is commonly used to pay the difference between the amount the local authority routinely pays and the standard care home fees. In England, any top-up to a local authority-funded care home place must be paid by a third party, not the resident themselves.

Top-ups do not exist in the same way for home care services, although in theory it is possible for someone in receipt of local authority funding for their home care support to buy additional care from their own resources.

A means test involves a financial assessment of a person's income and assets. It determines whether or not someone assessed by a local authority as being eligible for social care support has sufficient funds to be able to pay a contribution to (or perhaps the full cost of) that support. People who make a means-tested contribution to their support receive the same level of advice and help in arranging and reviewing that support as someone who is wholly local authority-funded; this means that they are distinct from self-funders who generally organise their support themselves.

People who receive local authority-funded support as a cash Direct Payment (DP) are in a position to arrange and buy services in a way that is similar to self-funders. However, as is

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the case with people paying a means-tested contribution, DP users have been through an assessment process and should have regular reviews by their social services department; thus, they are in a significantly different position to self-funders who may not have had any contact with social services or other information and advice organisations.

For the purposes of this review, a self-funder was defined as *someone who pays for all of their social care or support from their own private resources (including social security benefits such as state pension or attendance allowance), or 'tops up' their local authority residential or domiciliary care funding with additional private spending*. People who make a required means-tested contribution to their local authority funding or who receive cash direct payments were not included as self-funders.

The Dilnot report on Fairer Care Funding gives a very broad definition of social care and support as follows:

Social care supports people of all ages with certain physical, cognitive or age-related conditions in carrying out personal care or domestic routines. It helps people to sustain employment in paid or unpaid work, education, learning, leisure and other social support systems. It supports people in building social relationships and participating fully in society (Commission on Funding of Care and Support 2011, p.4).

This current review is limited to adult social care. In addition to care homes* and home care, day care and extra-care housing have been included in this review as settings where adult social care is delivered. Extra care housing schemes (also known as housing with care) provide groups of purpose built self-contained homes with 24-hour care to help people who are no longer able to manage in their own homes to live independently with support. We opted not to include equipment and home adaptations, as these are often complementary to home care. In addition, local practice in relation to eligibility for public funding varies, both over time and depending on the relative involvement of the NHS and the local authority social care and housing services.

Thus social care was defined as *care homes (both with and without nursing), domiciliary care, day care and care received as part of extra-care housing*.

* The use of the terms nursing home and residential care home changed in 2000. Since then, all homes have been called care homes, either with or without nursing care (see the Care Standards Act 2000, chapter 14, section 3 (www.legislation.gov.uk/ukpga/2000/14/contents)).

METHODS

This review was restricted to research evidence published since 2000. Relevant articles and reports were identified through searches of electronic databases and augmented by searches of the websites of selected organisations. The searches were restricted to England because of the salience of local funding and eligibility arrangements and the limited transferability of research from other welfare regimes.

The following databases were searched: ASSIA (Applied Social Science Index and Abstracts); Scopus; Social Services Abstracts; Social Policy and Practice; and Social Care Online.

The searches of electronic databases identified 164 potentially relevant references. The search of relevant websites identified 21 references. All 185 references were downloaded to a reference management software package. After duplicates were removed, the titles and abstracts of the remaining 136 references were read to assess their relevance. Any references that were not based on empirical research or secondary analysis were excluded, for example, debates, guidance or think pieces. Ninety-one references were identified as potentially relevant and read in full. After further de-duplication and exclusion, relevant details were extracted from 71 references on the following areas of interest:

- the size and characteristics of the population funding their own social care support;
- information and advice either available for or wanted by this population;
- providers' experiences of people funding their own social care support;
- other pertinent issues not already included; and
- reported gaps in evidence.

Data were not extracted from LaingBuisson's (2004, 2010) market reports on care of the elderly and older people (LaingBuisson 2013a), as these reports were not freely accessible, were too expensive to buy for a study of this size, and were not available through the inter-library loan system. However, upon request, LaingBuisson provided the chapter giving data on self-funders of care home places from their latest Care of Older People, UK Market Report 2013/14. These data were extracted.

Appendix 2 gives full details of the databases, search strategy and search terms; inclusion and exclusion criteria, and the number of references included and excluded at each stage.

A small number of research groups and organisations that had been active in research about self-funders were contacted and asked if they were currently undertaking any relevant research. Details are given in Appendix 3.

FINDINGS

The size of the evidence base identified

This scoping review was restricted to research evidence about self-funders of social care in England published since 2000. Details were extracted from 71 references. Some studies were reported in a number of references. This section gives an overview of the types of references and the topics covered.

Sixteen of the 71 references were articles published in peer-reviewed journals. Three references were articles published in magazine-style journals that are not peer reviewed. One reference was a press release of a report about the home care market. The remainder (51) were reports. Just under half the reports were undertaken by university-based research groups with well-established reputations. Around half were undertaken by (or on behalf of) government-related or regulatory organisations such as the Care Quality Commission, Commission for Social Care Inspection or the Office of Fair Trading, and the remainder by voluntary sector organisations, local councils and consultancy groups.

The majority of references focused on residential care (30), domiciliary care (12), or both (22). Only two references focused on housing with care and none were about day care. The remaining five were about adult social care more generally with occasional references to residential or domiciliary care.

The studies used a wide range of quantitative and qualitative research methods. They included common methods such as online, telephone and postal surveys, face-to-face questionnaires and semi-structured interviews, focus groups and in-depth case studies. Many references described using multiple methods. A small number of studies used existing data to model future projections. Other commonly used methods were mystery shopper exercises; analysis of the content of telephone calls to advice lines, formal complaints or Freedom of Information requests; analysis of consultations and written submissions; and routinely collected evidence from regulatory inspections.

Any formal assessment of the generalisability of the publications or research studies on which they were based was not undertaken. However, about a third of the studies reported were based on national or multi-regional research; large-scale quantitative surveys formed an important part of these studies, although many used mixed methods. About a quarter of studies were also based on national or multi-regional data but used predominantly qualitative methods. A further quarter of studies were small scale or locally-based, for example research in a single local authority. The remaining studies comprised national market reports and models or projections based on national data. Thus, the findings from the majority of studies might be considered generalisable in the sense that they report on data from a wide range of the relevant population and the social care services available to them. Findings based on smaller scale research in local populations may not be generalisable in the same way, but the findings will be relevant in areas or populations with similar characteristics.

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Five of the reports identified used models to project future costs and/or demand for social care (Forder 2007, Forder and Fernandez 2010, Hancock and Hviid 2010, King *et al.* 2010, Wittenberg *et al.* 2004). Baseline data for the models came from various sources, including some datasets. Those datasets mentioned specifically as sources of data on self-funders were: LaingBuisson's Domiciliary Care Market Surveys and Care of the Elderly Market Reports; the English Longitudinal Study of Ageing (ELSA) (which includes a question asking people whether they buy care privately as a result of having difficulties undertaking activities of daily living); and the 2000 Health Survey for England (HSE) (which asks older people about their use of private help and about the number of hours a week they use).

The Market Analysis Centre at the Institute of Public Care (2012) analysed data from ELSA to determine the age and gender of people funding their own home care. Netten *et al.* (2001) analysed data from two earlier surveys carried out by the research team, but no other reports were identified that had undertaken secondary analysis of existing datasets (either quantitative or qualitative).

The size and characteristics of the population funding their own social care support

Overall figures

The evidence gives no definitive figure for the number or percentage of people funding their own home care in England, but estimates suggest it is in the region of 20% to 25% of the home care market. In 2006, about 290,000 people were receiving around three hours a week of self-funded home care (Wanless 2006). Self-funders were thought to account for around 20% of the home care market (Poole 2006). Also in 2006, it was estimated that 150,000 older people paid for their own home and community services (compared with 600,000 funded by local authorities) (Commission for Social Care Inspection 2008, Henwood and Hudson 2008). About a quarter of people who were funded by local authorities also purchased additional support using their own money. By 2011 it was estimated that around 170,000 people funded their own home care (National Audit Office 2011, Putting People First Consortium, Institute of Public Care Oxford Brookes University and Melanie Henwood Associates 2011). Home care providers reported that self-funders accounted for between 6% and 25% of their clients (Putting People First Consortium, Institute of Public Care Oxford Brookes University and Melanie Henwood Associates 2011).

McClimont and Grove's (2004) survey of UK Home Care Association members found that the total number of privately-funded hours of home care reported was 8% lower in 2004 than in 2000, even though the number of survey respondents and the average volume of hours per provider were both higher. The authors suggested a number of reasons for this, including that people in need of services but no longer eligible for public funding may be going without because: they were unable to afford purchasing their own care (or unwilling to pay the price); that they may not have needed care in the first place; that they may be relying on informal care or care purchased outside agencies; and that

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agencies may have been concentrating on fulfilling local authority contracts, leaving little capacity for self-funders. The issue of people being ineligible for public funding but unable to afford to pay for their own home care was raised again in 2008 (Commission for Social Care Inspection 2008, Henwood and Hudson 2008). These people were described as 'lost to the system', that is, not known by local authorities.

The evidence suggests that both the number and percentage of people who pay for their own care home places have increased. Approximately 118,000 older people wholly funded their places in 2006 (Commission for Social Care Inspection 2008). In reports published in 2011, the figure was estimated as 170,000 (National Audit Office 2011, Putting People First Consortium, Institute of Public Care Oxford Brookes University and Melanie Henwood Associates 2011). LaingBuisson (2014) calculated that 177,000 people funded their own care home places (86,000 in nursing care homes and 91,000 in residential homes). From evidence collected between 2002 and 2004, it was estimated that around 30% of care home places were self-funded (Commission for Social Care Inspection 2006, Wanless 2006, Williams and Netten 2005). The Putting People First Consortium (2011) reported that 45% of people in care homes in England were self-funders in 2010; Carr-West and Thraves (2013) reported that the figure was 43% in 2012, according to LaingBuisson's Care of the Elderly Market Survey. On average, 24% of self-funders eventually fall back on state support at an estimated cost to local councils of £425 million in 2011/12 (Carr-West and Thraves 2013). GHK Consulting Ltd (2011) suggests the percentage of self-funders in care homes increased from 36% in 2005 to 43% in 2010. LaingBuisson (2014) give the figure as 44% in 2013/14, rising to 58% if top-ups are included. They also suggest that the percentage of people who wholly fund their places will fall to 35% when the capital assets threshold is increased from £23,250 to £118,000 in April 2016.

An examination of user choice and provider competition by the National Audit Office (2011) found that 60% of local authorities did not know how many people in their area funded their own care home places. Few local authorities offered self-funders formal support to help them avoid falling back on state funding. The 39% of authorities that knew how many spent down their assets and eventually qualified for state funding estimated it cost 3.5% of their residential care budget, representing around half a billion pounds annually.

Estimates of total private expenditure on social care also vary. One estimate was that a total of around £417 million per year was being spent on home care by self-funders (Wanless 2006). However, the total value of payments on all forms of social care by self-funders, including care home fees, top-up fees and means-tested users chargers, was estimated to be £5.9 billion – 50% of all personal social care expenditure (Commission for Social Care Inspection 2008, Forder 2007). The Care Quality Commission (2013a) stated in its annual report to parliament on the state of health and social care in England that 36% of the funding for registered providers of adult social care came from self-funders and 10% from local authority-funded care with top-ups.

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Care home fees and top-ups

Self-funders paid on average £44 per week more than publicly-funded residents in 2002, and over 40% of homes had at least one resident for whom a relative topped up the fees (Wright 2002). In 2005, a postal questionnaire of nurses working in nursing homes found that in almost three-quarters of homes a top-up fee was paid by an average of 42% of publicly-funded residents (Ball *et al.* 2005). The average weekly top-up fee was £58.

Self-funders in nursing homes were found to pay about 30% more than the fees paid for by local authority-funded residents (Garvican and Bickler 2002). A study by the Office of Fair Trading (2005a, 2005b), initiated by a super-complaint from the consumer body, *Which*, looked at the care home market for people aged over 65. They found that 30% of residents were self-funders, 45% wholly local authority-funded and 25% part local authority-funded. Thirty-five per cent of the latter made top-up contributions. Despite self-funders accounting for 30% of residents, they paid higher fees than local authority-funded residents and so contributed more than 30% of the market value. The study also reported that increasing numbers of people are paying top-up fees and that 40% of local authorities suspect that there are more top-up fees being paid than they know about.

In a report by the Care Quality Commission (2013b), the proportion of people in receipt of a local authority-funded care home place who indicated that they or their families topped up their care increased for all age groups between 2010/11 and 2012/13. Homes registered to provide dementia care had a lower percentage of wholly self-funded places (34%) and a higher percentage of places funded by local authorities without a top-up (46%) than care homes not registered to provide dementia care (41% and 40% respectively). Care homes registered to care for older people, compared to those not registered for older people, tended to have a higher proportion of self-funded places and fewer local authority-funded places without top-ups. For homes that provided nursing care, the proportion of self-funded places was lower than care homes without nursing. LaingBuisson (2014) suggested 27% of local authority-funded care home residents received a third party top-up in 2013.

There is little evidence about the numbers of people using financial products to help pay for their care. One study estimated that about 5,000 Immediate Needs Annuities (INAs) were in place in 2011, which meant that only 4% of self-funders in residential care had one (Lloyd 2011). Another study estimated that approximately 40,000 houses were sold per year to pay for care home places with between 120 and 640 possibly sold unnecessarily, as people may have been eligible for NHS continuing care (Henwood 2006). It has been estimated that only about 5% of single pensioners can afford to pay care home fees from income rather than capital (LaingBuisson 2014).

Differences in regions

Three studies reported specifically on differences between regions in the numbers of self-funders and use of top-ups. In the South East and South West of England, more care home places were wholly self-funded (47.6% and 43.2% respectively) than were funded by the

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local authority without top-ups (38.9% and 38.3% respectively). The greatest percentage of local authority-funded places without top-ups occurred in the North East at 64.1% (Care Quality Commission 2013a). Similarly, LaingBuisson (2014) reported the percentage of self-funders in care homes in the South East of England as 59% and the South West and the East of England as 53%. The North East was found to have the lowest percentage of self-funders at 19%. London had 38% self-funded care home places; the reason for this relatively low level was suggested to be due to older people moving out of London to live in cheaper care homes or to be closer to family.

The Think Local Act Personal Partnership (2012) explored local factors affecting self-funding of care and third party top ups in four different areas – Bradford, Hampshire, Hartlepool and London Borough of Kensington and Chelsea (LBKC). The percentage of self-funders in care homes ranged from 15% in Hartlepool to 57% in Hampshire. On average, top-ups were paid for 18 % of local authority-funded care home placements, ranging from up to 1% in Hartlepool to up to 31% in Bradford.

The same study showed that on average 30% of people receiving home care services were self-funding (ranging from 14% in LBKC to 64% in Hampshire). However, a further 6% were found to buy services using their own funds in addition to those funded by the local authority. The authors reported that the percentage of self-funders was linked to local FACS (Fair Access to Care Services) thresholds – the higher the FACS level, the more self-funders.

Four studies reported on self-funders in specific local authorities. Bolton (2012) studied Wiltshire's 'help to live at home' service for older people and showed that data about self-funders' use of services was poor; although the council did not know the exact number of self-funders, they estimated that self-funders and direct payment users combined purchased about half of all regulated home care services in the county.

Using evidence submitted to an inquiry about whether the needs and preferences of older Londoners were being met in 2004, Robinson and Banks (2005) reported that around half of older Londoners own their own homes and so have to pay the costs of their care home places. This results in many choosing a home outside London where places are cheaper. However, this means that many Londoners are denied the choice of a care home close to family, friends and familiar surroundings. In addition, where finances were tied up in housing, people found it hard to find the money to buy the support which would enable them to remain in their own homes.

A study by Thornber (2008) of services and service users in Hampshire reported that 60% of people in residential care in the county were self-funders. Results of a postal questionnaire sent to a random sample of older people in Hampshire showed that 1.3% of the total older population were self-funders of home care (Institute of Public Care 2010). In the latter study, the most common reason given for paying for their own care was having a level of money over the local authority financial threshold. The people most likely to be paying for care were reported as: the very old; women; people who lived alone; and, in equal numbers, less mobile older people, seaside communities of wealthy

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older people and people living on social estates with limited budgets*. Self-funders were more likely to use an agency care worker than a privately employed individual for help with bathing and washing, but less likely to use an agency for help with dressing and eating. The voluntary sector was reported to play an important role in supporting cleaning, gardening and shopping, although it is not clear whether this support was paid for or provided by volunteers.

Dependency levels

A number of papers discussed the dependency levels of self-funders. In 2011, providers reported in interviews that self-funders were typically people who had experienced a crisis that necessitated immediate action; often they did not know what they were looking for beyond a general idea of getting some help (Putting People First Consortium *et al.* 2011). One reported concern was that people might choose a level of support that was greater than they needed, for example choosing a care home when home care would have been sufficient. Previous evidence appears to support this. Challis *et al.*'s (2000) survey of older people admitted to residential or nursing homes found that low dependency residents in nursing homes were more likely to be self-funders than those with high dependency; 67% of those who had paid in full for their nursing home care were low dependency. The authors suggested a reason for this may be that those people able to pay viewed nursing homes as having medical associations and thus less stigma than residential care homes which were associated only with accommodation needs. Alternatively, they suggest it may be a form of forward planning, that is, to avoid the stress of relocation in the future should needs increase.

Netten *et al.* (2003, 2001) survey of care home managers appears to support Challis *et al.*'s finding. Netten *et al.* found that 43% of self-funders admitted to nursing homes were admitted directly from hospital; the corresponding percentage for publicly-funded admissions was higher (63%). The percentage of admissions to residential homes directly from hospital was similar for the two groups at 43% and 42% respectively. The authors compared physical dependency and cognitive impairment of self-funders and publicly-funded residents on admission; although they warn readers to treat the findings with caution due to some differences in the timing of the data collection, overall, physical dependency and cognitive impairment at admission were lower for self-funders. Self-funders admitted to residential homes were significantly more able than publicly-funded admissions. In addition, Netten *et al.* found that self-funders appeared to have less access to local authority-arranged home care prior to admission; those who did receive home care prior to admission received fewer hours per week than publicly-funded residents.

Another study by Netten and colleagues (2001), this time linking two large scale surveys, found that levels of cognitive impairment were lower among self-funded residents than those publicly-funded. They also found, however, that for similar levels of physical ability,

* Some of these categories were taken from a commercial demographic profiling and categorisation system (MOSAIC) for social marketing. Definitions of these categories were not given in the report.

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self-funders with severe cognitive impairment were more likely to be living in independently-run residential care homes than nursing homes, thus paying lower fees.

A third of self-funding residents in Wright's (2002, 2003) study of issues arising on admission to care homes reported that they did not need any help with activities of daily living before admission. Half needed some help with shopping, a quarter needed help with at least four activities of daily living, but half still did their own gardening. The main reasons for moving into a care home were illness, fear of living alone, feeling the need for more support and relieving children's anxieties.

Henwood and Hudson's (2008) study of people unable to gain local authority-funded support but who believed they had significant needs found that, in many cases, people who were self-funding were steered towards residential care before other options had been explored fully. The authors labelled this as a '*systematic* predisposition to move people precipitously into the private care home sector' (p.63), with care home owners wishing to maximise occupation, hospital staff wanting to release beds and GPs looking for a quick solution to complex cases all cited as playing a role.

None of the references found reported findings specifically about the dependency levels of people who funded their own home care.

Age, gender, ethnicity and client group

Little is reported specifically about the age, gender or ethnicity of self-funders, or the client group to which they belong. In a review of the older people's home care market, the Market Analysis Centre at the Institute of Public Care (2012) reported data from ELSA (English Longitudinal Study of Ageing) on the age and gender of self-funders of home care. Of men aged 65 to 70, 1.18% were self-funders; 3.33% of women in that age range were self-funders. Of men aged 75 and over, 4.23% were self-funders; 9.69% of women in that age range were self-funders.

Netten *et al.* (2001) survey of care home managers found that self-funding residents tended to be older on admission than publicly-funded residents (mean age 85 v. 83 years). In Ekosgen's (2013) study of self-funders as employers, three-quarters were age 65 or over with half over 80 years old. Three-quarters were female and 98% of the 108 people surveyed were white British.

The most detailed data on ethnicity was reported by Wood (2010), based on a survey of what 770 care users (138 were self-funders) across ten local authorities said they wanted to change about their lives and what support they needed to facilitate these changes. She presented a graph (but no exact numbers or percentages) of respondents' ethnic group broken down by funding source, which showed that just over 50% of people who reported themselves as 'White Other' were self-funders, as were just under half who reported themselves as 'Black Other'. There were fewer reported self-funders in the other white or black categories: around 35% of 'White Irish' and 15% of 'White British' were self-funders; about 30% of Black Caribbean and less than 10% of Black Africans were self-funders. About 20% of the Pakistani and 10% of the Indian populations that responded

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to the survey were self-funding. Without the number of people in each category it is hard to know the representativeness of these percentages.

Wood (2010) also reported on client group by funding source. Although actual numbers were not given, a graph shows that between 25% and 30% of older people completing the survey were self-funders, followed by around 18% of people with a physical impairment, about 20% each of people with a hearing or visual impairment, and less than 10% of people with mental health needs or a learning disability.

Other characteristics of self-funders

Other reported characteristics of care home residents related to their marital status, home ownership and assets. Netten *et al.* (2001) found that self-funded residents were less likely to be married on admission than publicly-funded residents (15% and 20% respectively), and that 81% of self-funders admitted to care homes were home owners, although half had sold their homes prior to admission. Six per cent were found to be eligible for public support, 35% had low incomes but high assets, and 25% had low incomes and low assets. While residents could be philosophical about selling their houses to fund their care, relatives tended to be angrier (Wright 2002). In an investigation into the information and advice needed by older people moving into a care home, the Commission for Social Care Inspection (2007) found that 50% of people who funded their own care did not have a care assessment. Some people continued to spend their own savings even though they had dropped below the threshold of eligibility for public funding (Commission for Social Care Inspection 2008).

In relation to home care, Wood (2010) found that 55% of self-funders reported spending less than £5,000 a year on care and support, but a third did not know how much they spent. Sixty-four per cent felt they received value for money; a disproportionate number of those who felt they did not receive value for money were from minority ethnic groups. Ekosgen's (2013) study of self-funders-as-employers showed that most participants purchased help for personal care and for help to live independently, although three (out of 108) purchased employment-related help such as being driven to work or help with taking notes at work. Twenty-five per cent purchased some care directly (not through an agency); these people were more likely to be under 50 years old, to have management experience or to be/have worked in adult social care.

One study examined duration of stay and outcomes for inpatients on an assessment ward for older people with cognitive impairment (Ball *et al.* 2004). This survey looked, among other things, at factors influencing discharge from hospital and found that self-funders were discharged significantly earlier than patients who would be local authority-funded on discharge (5.2 weeks versus 10.9 weeks respectively), regardless of clinical and social characteristics. The authors suggested that this was due to the wait for local authority funding to be arranged. No information was given about destination on discharge (that is, home or to a care home).

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Information and advice

There is an abundance of research evidence about the generic information and advice needs of people who use health and social care services. It is clear that all service users need access to good quality, relevant information to make informed choices (Baxter *et al.* 2008). Evidence also suggests that, among other things, the timeliness, coordination, quality and signposting of information could be improved (Baxter and Glendinning 2011, Bottery and Holloway 2013, Swain *et al.* 2007).

The aim of this section of the report is not to reiterate these common findings, but to present research evidence on issues that relate specifically to self-funders purchasing home care services, or funding their care home places (either in full or topping up local authority-funded places) in housing with care schemes or attendance at day centres.

Information needs of self-funders in general

A number of studies discussed general information needs of self-funders rather than needs relating to specific types of care. For example, the National Audit Office (2011) found that 69% of self-funders did not feel well informed about the financial implications of long term care. An analysis of phone calls to an advice line provided further evidence of the importance of financial information. It showed that a third of calls were about information, advice or advocacy and another third about funding and quality of care (Independent Age 2012). The most common topic of guides sent out by the same service was care home fees (27% of guides); 17% of guides sent out were on third party top-ups. However, Hudson and Henwood's (2009) research reported that key national organisations contacted for information or advice were not confident in giving advice about finances; the authors noted that providing factual information is easier than giving advice on what actions to take.

Robinson and Banks' (2005) London-based study also showed a serious lack of financial information and advice which they felt was especially important for self-funders. This lack of information included widespread confusion about entitlements to NHS Continuing Healthcare* (which is not means-tested) rather than means-tested social care. One of their recommendations was that central government should fund local authorities to provide information, advice, advocacy and service brokerage to all older people, including self-funders. Others have made similar recommendations – that there should be universal information, advocacy and advice services for all people needing services, and their carers, including self-funders (Putting People First Consortium *et al.* 2011, Thornber 2008).

CSCI's (2006) review of the state of health and social care showed that local authority commissioning strategies in 2005/06 were confined to people eligible for local authority-funded support, and that only 23% of local authorities had identified a need to provide more support and advice to self-funders. For self-funders, negotiating the system to find relevant information or advice at the right time was difficult; they were often left to their

* See Appendix 1 for a brief description of NHS Continuing Healthcare and further reading.

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own devices, not knowing where to turn (Care Quality Commission 2009) and left feeling that local authorities were not interested in providing information (Bright *et al.* 2013). Self-funders often did not think about approaching their local authority for advice (Wright 2000); others were deterred by the stigma they felt was attached to approaching social services (Putting People First Consortium *et al.* 2011). The authors of the latter study made the point that having sufficient resources to self-fund did not guarantee any greater control over the situation than for people with fewer funds. Self-funders have also been shown to be the most disadvantaged and isolated people in the system, ending up with their care arrangements by chance rather than through making active choices (Henwood and Hudson 2008). Bottery and Holloway (2013) made a similar point when they mapped the typical journeys taken by people needing social care support; they found that information provided by local authorities on assessments, quality and availability of care was poor, especially for people who appeared to be obvious self-funders.

Information and advice needs for self-funders of domiciliary care

Evidence specifically about the information and advice needs of self-funders of home care is sparse. It shows that self-funders lacked information or advice at an early stage in their process of finding home care, primarily through a lack of access to local authority assessments and advice, and online information that was hard to navigate.

The first point of contact for self-funders searching for information and advice was usually a local authority telephone advice service, staffed by people who often had a background in home care, but no professional social care qualifications; these advisors acted as gatekeepers to professional staff and assessments (Commission for Social Care Inspection 2008, Henwood and Hudson 2008). This suggests that some self-funders may have been signposted away from information and advice from qualified professionals. A study showed that self-funders and their relatives in Hampshire felt disadvantaged by the unwillingness of statutory services to help them, including help with issues such as exploring care options and options for paying for care (Thorner 2008).

Another survey of older people in Hampshire revealed that a significant proportion of those who were self-funders of home care had not had any contact with the local authority (Institute of Public Care 2010). Nineteen per cent of self-funders said they were self-funding because they preferred to manage their affairs independently, 11% did not wish to share their financial or personal situation with the local authority, and 17% did not believe they would be eligible for funding from the local authority. In a later study of both domiciliary and residential care, the Institute of Public Care, as part of the Putting People First Consortium (2011), found that 67% of local authorities offered assessments to self-funders, 91% offered information, 84% offered advice and 39% signposted self-funders to other advice or providers.

Henwood and Hudson's study of self-funders found that many were 'lost to the system' (Commission for Social Care Inspection 2008, Henwood and Hudson 2008, Hudson and Henwood 2008). They found that self-funders, including those funding home care, were disadvantaged by a lack of advice and information about care options; many were

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invisible to local authorities. Their study was based in six local authorities; only one had a strategy to support self-funders, but it was not yet in place. The onus appeared to be on people asking for advice rather than being offered it, with some people following information and care leads that took them up dead ends. Signposting to other information varied in quality and was seen by the authors as an exit strategy whereby no further responsibility towards the people asking for information was acknowledged and no attempts were made to follow them up. Hudson and Henwood (2008) suggested each area should have a system to track self-funders to make sure that their needs were met.

Ekosgen (2013), in their study of self-funders who employed care workers directly, found that there was a lot of information and advice online, but that it was often hard to navigate and tended to be aimed at direct payment users, which made it hard for self-funders to find even though it was clearly relevant to them. They found few websites specifically aimed at self-funders. Although the self-funders interviewed for the study found the information and advice they had received to be helpful, the authors suggested some self-funders had expensive and inflexible care and arrived at their care package in spite of, rather than because of, the support they had received. Baxter *et al.* (2008) also found that home care agencies did not target information specifically at self-funders. Agencies used the same written information to advertise to all potential clients, which meant they relied on word of mouth to attract self-funders.

Two other studies discussed the importance of word of mouth and/or peer brokerage in gathering information. In a survey of 770 home care users, Wood (2010) found that the 138 self-funders who responded were less concerned than the sample as a whole about the professional training and accreditation of their care workers as a guide to quality; the authors suggested they looked for more subjective signs, such as recommendations via word of mouth. A small study which aimed to gather information about developing peer support brokerage found that participants in two focus groups for self-funders supported the idea of peer brokerage and wanted it to be part of a clearly signposted information and advice service (Clark and Hornby 2011).

Finally, raising awareness of benefits such as Attendance Allowance or Disability Living Allowance was shown to be important to almost a quarter (7/31) of older people who funded their own home care in Hampshire (Institute of Public Care 2010).

Information and advice needs for self-funders of residential care

There is more evidence about the information and advice needs of self-funders of care home places than of home care services. Much of this evidence relates to information needs about fees and finances, but there is also evidence of lack of opportunities for self-funders to receive initial assessments and ongoing reviews of their care and needs.

Evidence from Dalley and Mandelstam (2008) suggests that self-funders considering a care home face three problems, with local authorities failing: to assess people they expect to be self-funders; to separate needs assessments from financial assessments; and to help self-funding residents when their funds run low. Hudson and Henwood (2009) also draw attention to the fact that needs and financial assessments are often conflated in practice.

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Initial assessments and ongoing reviews

The evidence shows that not all older people who self-fund their places in care homes receive an assessment of their needs before entering the home. Netten *et al.*'s (2001) survey of care home managers found that about half of self-funders received a local authority assessment before admission. Challis *et al.* (2000) in their study of dependency levels on admission to care homes did not record data on assessments before admission, but did conclude that the high number of low dependency self-funders suggested a need to provide better assessment and placement services to self-funders.

Two-thirds of older people in one study had never had any domiciliary care in their own homes before they entered residential care, but they would have paid for support if they had known how to get it; some felt that they may have remained at home for longer if they had done so (Wright 2002, 2003). Wright suggests that the more isolated people are both geographically and socially, the less likely they are to find the information they need. Local authority care managers reported discouraging people who they thought would not qualify for means-tested local authority-funded residential care from asking for a full assessment; this meant that people did not receive advice about alternatives to care homes, different types of home or associated financial issues (Wright 2000, 2003).

In their study of people's experiences when finding a care home, the Commission for Social Care Inspection (2007) found that the availability of assessments was not well publicised to people likely to fund their own care. Moreover, little more was offered than a list of care homes following any assessments given. While 42% of local authority care managers gave some limited advice or signposted people to other sources of information, only 21% supported self-funders through the whole process of choosing a care home. Similarly, Netten *et al.* (2001) found the local authority was involved in negotiating a care home place in only a fifth of cases in their study. A related article offered some limited qualitative evidence that relatives wanted more advice about their parents' needs or someone from the local authority to take an interest in their needs (Netten and Darton 2003).

In a study of care home closures, Williams and Netten (2005) found that advice for self-funders varied across local authorities; only about a third of closure protocols mentioned self-funders, with half of these saying that they treated all residents the same regardless of funding, and the other half stating that self-funders would only be given information and advice if they requested it or if they had no relatives. Case studies undertaken as part of the same study showed that self-funders were not monitored after they had moved homes following a closure, so there was no information on how they were settling in or whether the new care home was suitable (Williams *et al.* 2007). Henwood and Hudson also found that self-funders did not receive ongoing reviews from local authority care managers (Commission for Social Care Inspection 2008, Henwood and Hudson 2008).

The view from self-funding residents in Thornber's (2008) study was that the regulatory system was not effective – they wanted someone to take on a mediating and quality assurance role for self-funders in care homes.

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Information about fees and finances

The evidence shows that self-funders of care home places generally lack information about fees, top up fees or their financial implications. Older people in care homes were confused about finances, and their relatives were worried by their own very poor understanding of the financial implications if, for example, they had to sell a parent's house (Wright 2003).

Three publications discussed financial products. Lloyd (2011) estimated the potential future demand for Immediate Needs Annuities (INAs) and suggested that one reason why some households were deterred from purchasing them was the obligation to obtain independent financial advice first. Carr-West and Thraves (2011, 2013) found that 40% of people in care homes would benefit from an existing financial product, but only 3% of councils provided a list of independent financial advisors who could give advice about products for funding care. They reported that, after undertaking a needs or financial assessment, all local authorities provided basic financial information, usually in documents or on their websites, while 47% referred people to independent financial advisors. However, only 17% of local authorities referred self-funders to independent financial advisors before they received a needs or financial assessment, even though providing early access to financial information and advice could help self-funders to maximise their assets, reduce stress on families and save money for local authorities (Carr-West and Thraves 2013, Thraves 2013, Carr-West and Thraves 2011).

As well as poor information about financial products, evidence shows that there was a lack of information about who could pay top-up fees, the rules about home owners being covered by local authority contracts for the first 12 weeks of permanent residence in a care home (the 'disregard' period) (Wright 2003) and whether or not residents and their relatives who topped up their fees were told by their local authorities that they could choose an out of area home that might be cheaper (Ball *et al.* 2005).

Clarity of contracts and price transparency were highlighted as problematic areas. In their response to a super-complaint that the market for care homes was not working well, the Office of Fair Trading found that sufficient information about prices was more difficult to obtain than more general information and advice. This was seen as particularly important if an older person or their relative was under pressure to choose a home quickly or if they were making a one-off choice (i.e. for a permanent rather than temporary home) (Office of Fair Trading 2004).

The Office of Fair Trading conducted another study initiated by a further super-complaint about the care home market for people aged over 65 (Office of Fair Trading 2005a). They found that almost three-quarters of contracts between care homes and residents contained fee-related terms that were either unfair or unclear. In 47% of contracts they analysed, it was not clear who should pay what amount. Older people who had recently been admitted to care homes were asked whether or not they had a written contract or statement of their terms and conditions. Having a contract was considered important, as it

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protected people from unexpected fee changes in the future. Twenty-six per cent did not know, but a further 26% knew that they did not have one.

In relation to top-up fees, local authorities were not usually involved in these contracts and this raised concerns that top-ups might be unjustified (Office of Fair Trading 2005a). The Commission for Social Care Inspection (2007) also found that people lacked information about what fees would cover, how often they would increase and what financial help was available from the NHS towards nursing costs or NHS Continuing Healthcare. GHK Consulting Limited (2011) evaluated the impact of the OFT's 2005 study and found some improvements, for example, about 70% of local authority-funded residents felt that the amount of information available about top-ups was about right, although 30% of people who were wholly self-funded wanted more information about fees. In addition, the authors found that when choosing a care home, 30% of self-funders considered just one, and 38% just two or three possible homes.

According to Passingham *et al.* (2013), 75% of local authorities were not signposting relatives to independent advice (including financial advice) before they signed contracts for top-up fees. Only about a fifth of local authorities undertook annual reviews of the sustainability of top-ups.

Sources of information and advice when choosing a care home

In Wright's (2002) study of issues arising when older home owners entered residential care, most older people were found to rely on their relatives to find information about finances and care home fees. About a third of relatives sought information from social services and a third from care home managers. The remainder sought information from friends, banks or financial advisors, or did not obtain information or advice from anyone. Social services were not always considered helpful. Care home managers were felt to have vested interests, and the study showed that they did not draw people's attention to their eligibility for Attendance Allowance or income support. A report by the Commission for Social Care Inspection (2007) showed that social workers, friends and relatives, and visits to care homes were still the most influential sources of information in 2007. In a survey undertaken as part of the study, 63% of relatives and carers of residents said that the written information they received did not tell them what they wanted to know. People were seeking expert, face-to-face impartial advice.

In a study of the issues faced by self-funders when first contacting local authorities about residential care, Dalley and Mandelstam (2008) analysed calls to the Relatives and Residents Association advice line and found that a quarter of all calls were about self-funding and assessments. Families felt that they received mixed and muddled messages from local authorities. A search of local authority websites for the same study found some good examples of accessible information, but also some pages that were hard to navigate, some pages that were not available, and some sites that used many different terms to mean the same thing (for example, adult social care, services for older people or adults and community services).

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In the Office of Fair Trading's (2005a) study of the market for care homes for the over 65s, local authorities were found to vary in the amount and type of advice and support they offered to self-funders. Twenty-seven per cent of self-funding residents had received information on care homes from their local authority. Information was found to be particularly unclear about the availability of care homes that did not require a top-up – between 11% and 14% of local authorities provided this information with 11% letting people know the size of the top-up. The study also found a lack of clarity about the circumstances in which top-ups should be paid or increased, and a lack of information on local authorities' responsibility to pay the top-up if the third party defaulted.

Uncertainty and a home for life

Many older people funding their own care home places were concerned about what would happen to them when they ran out of money, particularly if they would have to move to a cheaper home (Wright 2002, 2003, Netten *et al.* 2001). In addition, many people were not aware that if their needs increased, they may have to move to a more suitable home (Wild *et al.* 2010, Commission for Social Care Inspection 2007). Henwood and Hudson also found that self-funding residents were not warned that they might have to move to a cheaper home once their funds ran out (Commission for Social Care Inspection 2008, Henwood and Hudson 2008).

Information needs and Housing with Care schemes

Only two studies discussed information or advice needs for people considering housing with care schemes. Most tenants and leaseholders interviewed for a study on affordability and choice of housing with care schemes reported that they felt well informed about the schemes before they moved in; residents were often helped to obtain information by family (Garwood 2013, Pannell *et al.* 2012). Most self-funders did not mention social workers as a source of information. The most frequent source of detailed cost information was reported to be from meetings with housing with care scheme staff. However, in some schemes there was a reported lack of information and advice about social security benefits, and residents reported their main fear was concern about whether their care needs would become too high to remain in the scheme in the future; unplanned changes in circumstances were a particular concern for couples.

Day centres

No studies covered the information and advice needs of self-funders using day centres.

Providers' experiences of people funding their own social care support

The evidence on providers' experiences of self-funders is limited for both home care and care homes, although there is a slightly stronger evidence base around home care.

Home care provider experiences of self-funders

Patmore (2003) found in his study of home care services for older people that in agencies which held large block contracts with local authorities, meeting the block contracts could take priority over delivering services to self-funders or providing privately paid-for extras

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for local authority-funded customers. He also found that some providers were not interested in supplying privately paid-for extras (such as house cleaning or dusting ornaments) to local authority-funded customers. The Putting People First Consortium (2011) also found examples of self-funders being turned down by home care agencies with big local authority contracts because of lack of capacity, but also of self-funders being taken on by such agencies because it was easy to fit one more person onto the local authority-dominated rota.

In their study of people who pay for care, the Putting People First Consortium (2011) found that providers varied in their understanding of the self-funder market – for some it was their core business but for others it was marginal. Some home care providers distinguished between self-funders and direct payment users, preferring self-funders because of their greater purchasing power. Some providers saw themselves, in the long term, providing services predominantly or exclusively for self-funders, as this would allow realistic prices to be charged without intervention from the local authority (IPC Market Analysis Centre 2012). Self-funders were usually charged a higher rate than local authorities (Baxter *et al.* 2008).

Managers of home care agencies have reported feeling that they lack good information about the potential local market of self-funders, but that it is a good market strategy to accept self-funders seeking a modest amount of help, as over time these clients are likely to need more intensive support (IPC Market Analysis Centre 2012, Putting People First Consortium *et al.* 2011). It has also been reported that home care providers expect the market for self-funders to continue to increase as FACS eligibility thresholds rise, meaning more people will have to fund their own care, and, if the level of personal budgets falls, more people will also have to top up their local authority-funded care (LaingBuisson 2013b).

There was some evidence that the overall approach of home care providers was affected by their experiences with self-funders (Baxter *et al.* 2008, Patmore 2003). For example, Patmore (2003) found that agencies that appeared most responsive to customers' requests had large numbers of self-funders and may have developed a 'can do' attitude that spilled over to local authority-funded customers. However, both Patmore and Baxter *et al.* found that restrictions imposed through local authority contracts spilled over to self-funders as well. For example, some agencies were concerned about loss of fees when self-funders were in hospital and were considering introducing a holding fee to keep a package open, as already existed for local authority-funded clients (Baxter *et al.* 2008).

Patmore (2003) also found that small, single branch agencies found it easier to make case-by-case decisions for self-funders than branches that worked under the constraints of a head office. Likewise, agency managers in Baxter *et al.*'s (2008) study reported they found it easier to deliver flexible support to self-funders because they could negotiate directly with them rather than go through a local authority care manager. Visit lengths may also be longer for self-funders; it has been shown that some agencies have a minimum length of visit for self-funders of 30 minutes (IPC Market Analysis Centre 2012).

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Agency managers also felt that self-funders (along with direct payment users) were more demanding, had higher expectations, believed they had more rights than local authority-funded customers and were more likely to flag up issues of concern (Bunnin *et al.* 2011, Baxter *et al.* 2008). However, care workers apparently treated all customers the same and were not aware which were self-funders (Baxter *et al.* 2008).

Care home provider experiences of self-funders

Two studies were concerned with self-funders and fees. In one, the majority of homes that responded to a survey about experiences with top-ups had at least one example of a relative struggling to pay the top-up (Passingham *et al.* 2013). In addition, some care home owners were confused and concerned about local authorities moving from minimal use of top-ups to routine use; they believed the reason for this was that the fees local authorities paid were too low. Care home managers interviewed for Wright's (2003) study about admissions to care homes reported a clear preference for self-funded rather than local authority-funded residents. The author suggested that this was because self-funders could be charged higher fees than local authorities were willing to pay. In an earlier paper, Wright (2000) reported that many care home managers had experienced self-funding residents' finances being depleted to below the threshold for eligibility for local authority support, but then facing long delays before receiving a financial assessment.

Three studies drew attention to inequities between self-funders and local authority-funded residents. Scourfield's (2010) study of reviews in residential care found that home care managers (as well as local authority care managers) felt that it was inequitable that local authority-funded residents received independent annual reviews but self-funders did not. Some care homes did their own annual reviews to try to compensate for this but were aware that they were not independent. Furthermore, the Commission for Social Care Inspection (2007) found that people funding their own care felt powerless throughout the process of moving into a care home with no one to turn to and no rights of redress beyond the care home. In a later study of the new role of the Local Government Ombudsman in managing complaints by self-funders (Bunnin *et al.* 2011), both care home and home care providers noted that the Ombudsman would provide much needed help to a group of service users who lacked protection or support; several providers planned to amend their written information to make it clear to self-funders that they had a right to approach the Ombudsman.

Experiences of housing with care scheme providers and day centres

No publications reported on the experiences of housing with care providers with self-funders. One mentioned day centres in its exploration of the limits of the market in English social care (Needham 2013). Needham looked, among other things, at the use of day centres by self-funders (and personal budget holders) and found that although some day centres did not allow self-funders, one had recently opened its door to them for the first time. No information was provided about their subsequent experiences with self-funders.

REPORTED GAPS IN THE RESEARCH EVIDENCE

This section presents details of the gaps in research evidence that were reported in the references identified. The Putting People First Consortium (2011) identified the lack of information local authorities had about the number of self-funders in their areas. Many publications agreed that the data on self-funders was generally very poor. Some stated specifically that better data were needed to enable rigorous analysis to inform policy (see, for example, Commission for Social Care Inspection 2008, Forder 2007).

In 2002, there were no government statistics on the number of people who were self-funders when first admitted to a care home (Wright 2002). Numbers of self-funding residents were calculated at the time (and still are) by subtracting the number of places filled through local authority contracts from the total number of residents. Wright felt this may be an underestimate, as some self-funders may be covered by a local authority contract initially (until their house was sold) or because they had no relatives to arrange care on their behalf. Others also suggested that knowledge about the number of self-funding residents and the total amount paid in top up fees was not clear (Passingham *et al.* 2013, Poole 2006, Wanless 2006). The lack of information about top-up fees, and the fact that many were negotiated and agreed without local authority knowledge, was seen as important because local authorities are liable for top-ups if relatives can no longer pay.

The Office of Fair Trading (2004) proposed a number of areas where research was needed following their investigation into the functioning of the market for care homes. One substantial issue concerned price transparency, particularly the ease with which self-funding residents that might later become publicly-funded can gain clear information on pricing policies. The OFT felt research looking at price transparency was especially important, as a lack of clear information on prices for self-funders and people topping up their fees could impact on price competition and ultimately lead to higher prices. A further area suggested for research was whether contracts were in place for self-funders and people who topped up fees, and whether contracts contained clear and fair clauses about charges. The OFT also suggested research into consumer behaviour and the impact on the market when making choices under pressure in an emergency.

LaingBuisson (2014) also suggested there were gaps in knowledge relating to financial products. Two key barriers to demand for financial products were shown to be their perceived value (because people do not understand the risks and potential costs of care) and their affordability. Specifically, LaingBuisson advocated the insurance industry undertake research to understand the size of the potential market for insurance products and the target customers.

McClimont and Grove (2004) suggested further research to identify the level of demand from self-funders for home care services and the factors that influenced that level of demand. In addition, little information is known about the different types of self-funders, for example, those with sufficient resources to be ineligible for public funding, or those

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with few resources but insufficient needs to qualify for local authority-funded home care (Henwood 2009, Dalley and Mandelstam 2008). Nor is there much information about the ages of self-funding service users, or about those who opt to employ care workers directly (ekosgen in association with Breakthrough UK 2013, Wanless 2006). Poole (2006), in her background paper for the Wanless Review, added that there was little information available about the tasks carried out for self-funders and whether these focussed less narrowly on personal care than for local authority-funded recipients of care.

Little is known about the outcomes for self-funders who approach local authorities for advice or information and are signposted elsewhere (Commission for Social Care Inspection 2008, Henwood and Hudson 2008). Local authorities rarely collect information about these people, what happens to them, or the effectiveness of signposting. As Henwood and Hudson suggest, this represents a significant gap in the information that might inform local authorities' planning and commissioning.

A further major gap in evidence suggested by Hudson and Henwood (2009) is information about the availability and use of advocacy for self-funders making a decision to enter a care home.

DISCUSSION

This scoping review was commissioned by the NIHR School for Social Care Research to determine the size and scope of the research evidence base about people who fund their own social care in England. It comes at a time when both the number and importance of self-funders is likely to increase, not least because of rising FACS eligibility thresholds and the introduction in 2016 of care accounts as part of the Care Act 2014. Increases in FACS eligibility thresholds will mean that people who have care needs that are moderate or perhaps substantial, and who previously would have been eligible for local authority support, may no longer be eligible: they will have to decide whether to purchase their own support, rely on informal care from friends or family, or manage without support. The introduction of the Care Act 2014 means that all self-funders will be able to ask for an assessment of their needs to establish which of their care costs are eligible to be included in their care account and so count towards their care-cost cap. Local authorities will need to be aware of how many of their residents are self-funders and be able to offer them assessments; self-funders will need sufficient information and advice to be able to make suitable choices about the level and type of care they need, and to know the financial implications.

The aim of this review was to identify what is known about self-funders, specifically their characteristics and information needs, and provider experiences of delivering support to them. The purpose was to identify a wide range of relevant literature. Therefore, the search strategy that was developed was deliberately broad. Data on the three main themes were extracted from the publications identified, and other relevant evidence was noted. However, there are a number of major gaps in the evidence base identified.

One major gap is in studies that focus specifically on the experiences of self-funders. Although some studies interviewed self-funders and attempted to capture something of their experiences, such as Henwood and Hudson's (2008) *Lost to the System*, these studies did not form a major part of the evidence base. Only one study mentioned people topping up local authority-funded home care. However, the evidence presented was from the perspective of providers (they were reluctant to provide additional privately funded care) rather than service users. In addition, there is a plethora of evidence suggesting that information for self-funders is hard to obtain and understand, yet we know very little about, for example, how it feels to be a self-funder navigating different information sources or what pathways self-funders follow when choosing care.

None of the publications reported findings about the dependency levels of people who funded their own home care, although there was some evidence that people who fund their own care home places may be less dependent than those who are publicly-funded. As FACS eligibility thresholds increase, fewer people who have moderate-to-substantial needs will be eligible for state funding for home care, even though they may have limited income or savings. It is not evident from the research identified for this review whether this group of people will purchase their own support, rely on informal carers or manage

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without help at home. This raises questions about the level of unmet need. In addition, with the current policy emphasis on prevention and re-ablement, research that explores how and whether people access the low level support they need might be pertinent.

There is plenty of evidence about different aspects of information for self-funders. One important distinction that is made in the evidence is between information and advice, information being the provision of factual material that people can use to make their own choices, and advice being guidance on the best course of action to take. The evidence suggests that there is relevant information for self-funders, but it is often not well signposted, not obviously aimed at self-funders, and not always easy to understand. This is the case particularly for financial information. There is an opportunity for research that explores changes in the supply and delivery of information prior to the implementation of the Care Act. In relation to advice, the research evidence shows that advice is more difficult to obtain than information, especially financial advice for people moving into a care home. Again, in the lead up to the implementation of the Care Act and the introduction of care accounts, there is an opportunity for research that explores people's awareness of their right to a care account and the implications of good financial advice.

There was evidence on the overall numbers and percentages of the self-funding population, although these were generally estimates, sometimes based on data collected for other purposes, rather than robust national statistics. However, there was very little evidence on the socio-economic characteristics of self-funders. Evidence about the following groups was especially limited: the numbers of self-funders from black and minority ethnic communities; of working age; in different income groups; who lack capacity; from rural compared to urban environments; and with different living arrangements (for example, alone or with others). Therefore, little is known about any differences in, for example, attitudes to, or experiences of, self-funding by people from different socio-economic groups or how these differences might affect access to social care support. In addition, the majority of research evidence relates to people aged 65 or over. We found no evidence specific to, for example, self-funders of working age with impairments, such as multiple sclerosis or following a stroke, or of people with acquired brain or other injuries who have received compensation payments.

Some national surveys (for example the Health Survey for England and the English Longitudinal Survey of Ageing) do now include questions to older people living in their own homes about their needs for, receipt of, and payment for care, including self-funded home care. Data are also available by Primary Care Group (and now Clinical Commissioning Group) on the number of people receiving NHS-funded nursing care in care homes, although these data cannot be separated into council versus self-funded recipients. In time, new evidence based on research using these data sources will add to current levels of knowledge about the number and characteristics of self-funders.

More evidence was available about home care than care home providers' experiences of self-funders, but the evidence base was not large in either case. Some of the evidence about the experiences of home care providers was undertaken at a time when the local

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authority systems for commissioning home care were different (with more emphasis on block contracts), and so the attitudes of providers to self-funders relative to local authority-funded clients may be different now. More recent research suggests that some home care providers are becoming more aware of the importance of the self-funding market. We do not know how an increase in the number of self-funders, and potentially an increase in their average needs as a result of rising FACS eligibility thresholds, will impact on home care agencies or their staff. In relation to care homes, there was some evidence that care home managers felt that there were inequities between self-funded and state-funded residents, specifically around opportunities for reviews, but no evidence about the impact of these inequities on self-funders. We found very little research evidence on what (if any) were the challenges and opportunities of providing care to self-funders compared to people receiving public funding in either home care or care homes.

Only one study reported evidence about the relationship between self-funding status and length of stay as a hospital inpatient. This is surprising given the potential impact on duration of stay of arranging suitable care on discharge, not least because of the financial implications for local authorities of delayed discharges*. In addition, there was a lack of evidence on the roles of NHS or social care practitioners in giving information to self-funders about options on discharge, or on what kind of help self-funders want when choosing and arranging social care ready for discharge. This is particularly important, as other evidence does suggest that many people have to make decisions about moving to residential care in haste, such as on discharge from hospital. It is also important in the light of care accounts. If, in the absence of a social care needs assessment prior to discharge, self-funders opt for a level of care that is more intensive (and so more expensive) than they need, they may find that only a proportion of what they are paying counts towards their care cap.

Evidence on social care within housing with care schemes and on day care centres was especially sparse. Only two studies were identified that reported on self-funders and housing with care schemes. None of the identified studies focussed on day care centres.

Thus, although self-funders account for a large and increasingly important proportion of the market for social care, there are many gaps in the research evidence identified in this scoping review.

*A recent study by Challis *et al.* (2014) examined factors that influenced delayed discharge and length of stay, but did not explore the impact of self-funding status specifically.

REFERENCES

ADASS (2011) *ADASS Budget Survey 2011*, available from www.adass.org.uk (accessed March 2014).

Arksey H, O'Malley L (2005) Scoping studies: towards a methodological framework, *International Journal of Social Research Methodology*, 8, 1, 19–32.

Ball J, Ford P, Smith V (2005) Working in care homes: a survey, *Nursing Standard*, 20, 6, 41–46.

Ball S, Simpson S, Beavis D, Dyer J (2004) Duration of stay and outcome for inpatients on an assessment ward for elderly patients with cognitive impairment, *Quality in Ageing and Older Adults*, 5, 2, 12–20.

Baxter K, Glendinning C (2011) Making choices about support services: disabled adults' and older people's use of information, *Health and Social Care in the Community*, 19, 3, 272–279.

Baxter K, Glendinning C, Clarke S (2008) Making informed choices in social care: the importance of accessible information, *Health and Social Care in the Community*, 16, 2, 197–207.

Baxter K, Glendinning C, Clarke S, Greener I (2008) *Domiciliary Care Agency Responses to Increased User Choice: Perceived Threats, Barriers and Opportunities from a Changing Market*, Social Policy Research Unit, University of York, York.

Bolton J (2012) *Wiltshire Council. Help to Live at Home Service – An Outcome-Based Approach to Social Care. Case Study Report*, Institute of Public Care, Oxford Brookes University, Oxford.

Bottery S, Holloway J (2013) *Advice and Information Needs in Adult Social Care. Report for the Think Local, Act Personal Partnership*, Independent Age, London.

Bright L, Clarke A, Dalley G (2013) Finding out about social care: what information seekers want, *Working with Older People*, 17, 2, 85–94.

Bunnin A, Johnston L, Vanson T (2011) *Complaints About Privately Funded and Privately Arranged Adult Social Care. Report to the Local Government Ombudsman*, Office for Public Management, London.

Care Quality Commission (2009) *Care Quality Commission Response to the Green Paper on Shaping the Future of Care and Support Together*, Care Quality Commission, London.

Care Quality Commission (2013a) *The State of Health Care and Adult Social Care in England in 2012/13. Technical Annex 2: Adult Social Care Funding Data Collection*, The Stationery Office, London.

Care Quality Commission (2013b) *The State of Health Care and Adult Social Care in England in 2012/13*, The Stationery Office, London.

People who fund their own social care

Carr-West J, Thraves L (2011) *Independent Ageing: Council Support for Care Self-funders*, Local Government Information Unit, London.

Carr-West J, Thraves L (2013) *Independent Ageing 2013. Council Support for Care Self-funders*, Local Government Information Unit, London.

Challis D, Hughes J, Xie C, Jolley D (2014) An examination of factors influencing delayed discharge of older people from hospital, *International Journal of Geriatric Psychiatry*, 29, 2, 160–168.

Challis D, Mozley CG, Sutcliffe C, Bagley H, Price L, Burns A, Huxley P, Cordingley L (2000) Dependency in older people recently admitted to care homes, *Age and Ageing*, 29, 3, 255–260.

Clark L, Hornby V (2011) *Peer Support and Peer Brokerage for Self-funders*, Barnsley Age Concern, Barnsley.

Commission for Social Care Inspection (2006) *The State of Social Care in England 2005–06*, Commission for Social Care Inspection, London.

Commission for Social Care Inspection (2007) *A Fair Contract with Older People? A Special Study of People's Experiences When Finding a Care Home*, Commission for Social Care Inspection, London.

Commission for Social Care Inspection (2008) *The State of Social Care in England 2006–07*, Commission for Social Care Inspection, London.

Commission on Funding of Care and Support (2011) *Fairer Care Funding – The Report of the Commission on Funding of Care and Support*. The Dilnot Report, The Stationery Office, London.

Dalley G, Mandelstam M (2008) *Assessment Denied? Council Responsibilities Towards Self-funders Moving into Care*, Relatives and Residents Association, London.

Department of Health (2010) *A Vision for Adult Social Care*, Department of Health, London.

ekosgen in association with Breakthrough UK (2013) *The Workforce Implications of Adults and Older People who Self-fund and Employ their Own Care and Support Workers*, Skills for Care, Leeds.

Forder J (2007) *Self-funded Social Care for Older People: An Analysis of Eligibility, Variations and Future Projections*, PSSRU Discussion Paper 2505, Personal Social Services Research Unit, University of Kent, Canterbury.

Forder J, Fernandez JL (2010) *The Impact of a Tightening Fiscal Situation on Social Care for Older People*, Personal Social Services Research Unit, University of Kent and London School of Economics, Canterbury and London.

People who fund their own social care

Garvican L, Bickler G (2002) The relationship between the NHS and residential and nursing care for older people: a survey of home owners and managers in East Sussex, Brighton and Hove, *Quality in Ageing and Older Adults*, 3, 4, 24–33.

Garwood S (2013) *Older People with High Support Needs in Housing with Care*, Joseph Rowntree Foundation, York.

GHK Consulting Ltd (2011) *Evaluating the Impact of the 2005 OFT Study into Care Homes for Older People*, Prepared for the Office of Fair Trading by GHK, Office of Fair Trading, London.

Hancock R, Hviid M (2010) *Buyer Power and Price Discrimination: The Case of the UK Care Homes Market*, Institute for Social & Economic Research, University of Essex, Colchester.

Henwood M (2006) *Self-funding of Long-term Care and Potential for Injustice: Background paper for BBC Panorama*, Melanie Henwood Associates, Towcester.

Henwood M, Hudson B (2008) *Lost to the System? The impact of Fair Access to Care. A Report Commissioned by the Commission for Social Care Inspection for the Production of The State of Social Care in England 2006–07*, Commission for Social Care Inspection, London.

Henwood M (2009) Improving support for self-funders, *Community Care*, 4 June, 28–29.

HM Government (2008) *Putting People First. A Shared Vision and Commitment to the Transformation of Adult Social Care*, HM Government, London.

HM Treasury (2013) *Budget 2013*, HC 1033, Stationery Office, London.

Hudson B, Henwood M (2008) *Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria*, Commission for Social Care Inspection, London.

Hudson B, Henwood M (2009) *People who Fund their Own Care and Support. A Review of the Literature and Research into the Existing Provision of Information and Advice*, Social Care Institute for Excellence, London.

Humphries R (2013) *Paying for Social Care: Beyond Dilnot*, Kings Fund, London.

Independent Age (2012) *The Real Cost of Care. Five Ways Our Care Home Funding System Penalises the Average Older Person and their Family*, Independent Age, London.

Institute of Public Care (2010) *People who Fund their Own Personal Care at Home in Hampshire*, Institute of Public Care, Oxford Brookes University, Oxford.

IPC Market Analysis Centre (2012) *Where The Heart Is ... A Review of the Older People's Home Care Market in England*, Institute of Public Care, Oxford Brookes University, Oxford.

King D, Malley J, Wittenberg R, Darton R, Comas-Herrera A (2010) *Projections of Demand for Residential Care for Older People in England – Report for BUPA*, Personal Social Services Research Unit, University of Kent and London School of Economics, Canterbury and London.

People who fund their own social care

- LaingBuisson (2004) *Care of Elderly People – Market Survey 2004*, 17th edition, LaingBuisson, London.
- LaingBuisson (2010) *Care of Elderly People: UK Market Survey 2010–11*, LaingBuisson, London.
- LaingBuisson (2013a) *Market Survey of Older People*, LaingBuisson, London.
- LaingBuisson (2013b) *Reversing the Rise in Local Authority Homecare [Press Release]*, LaingBuisson, London.
- LaingBuisson (2014) Chapter 7, Sources of Finance. *Care of Older People, UK Market Report 2013/14*, 26th edition, LaingBuisson, London.
- Lloyd J (2011) *Immediate Needs Annuities: Their role in funding care*, The Strategic Society Centre, London.
- McClimont B, Grove K (2004) *Who Cares Now? An updated profile of the independent sector home care workforce in England*, UK Home Care Association, London.
- Mickelborough P (2005) *Domiciliary Care Markets 2005*, LaingBuisson, London.
- National Audit Office (2011) *Oversight of User Choice and Provider Competition in Care Markets: Department of Health, and local authority social services: report by the Comptroller and Auditor General*, The Stationery Office, London.
- Needham C (2013) Personalized commissioning, public spaces: the limits of the market in English social care services, *BMC Health Services Research*, 13, Suppl.1, S5.
- Netten A, Darton R, Bebbington A, Forder J, Brown P, Mummery K (2001a) Residential and nursing home care of elderly people with cognitive impairment: prevalence, mortality and costs, *Aging and Mental Health*, 5, 1, 14–22.
- Netten A, Darton R, Curtis L (2001b) *Self-funded Admissions to Care Homes*, Research Report 159, Department for Work and Pensions, Leeds.
- Netten A, Darton R (2003) The effect of financial incentives and access to services on self-funded admissions to long-term care, *Social Policy and Administration*, 37, 5, 483–497.
- Office of Fair Trading (2004) *Response to the Super-complaint on Care Homes Made by the Consumers' Association on 5 December 2003*, Office of Fair Trading, London.
- Office of Fair Trading (2005a) *Care homes for Older People in the UK. A market study*, Office of Fair Trading, London.
- Office of Fair Trading (2005b) *Care Homes for Older People in the UK. A market study. Annexe L. Paying for care*, Office of Fair Trading, London.
- Pannell J, Blood I, Copeman I (2012) *Affordability, Choices and Quality of Life in Housing with Care: Report*, Joseph Rowntree Foundation, York.
- Passingham A, Holloway J, Bottery S (2013) *Care Home Top-up Fees: The Secret Subsidy*, Independent Age, London.

People who fund their own social care

Patmore C (2003) *Understanding Home Care Providers*, Social Policy Research Unit, University of York, York.

Poole T (2006) *Private Expenditure on Older People's Social Care. Wanless Social Care Review – Background Paper*, King's Fund, London.

Poole T (2009) *Funding Adult Social Care in England (Briefing)*, The King's Fund, London.

Putting People First Consortium, Institute of Public Care Oxford Brookes University and Melanie Henwood Associates (2011) *People Who Pay For Care: Quantitative and Qualitative Analysis of Self-funders in the Social Care Market*, Putting People First Consortium, London.

Richards M (2002) Self-funding residential care, *Elder Law and Finance*, 2, 2, 38.

Robinson J, Banks P (2005) *The Business of Caring: King's Fund Inquiry into Care Services for Older People in London*, King's Fund, London.

Scourfield P (2010) Self-funders in care homes: should they be offered an annual review of their placement from their local authority?, *Working with Older People*, 14, 2, 17–22.

Swain D, Ellins J, Coulter A, Heron P, Howell E, Magee H, Cairncross L, Chisholm A, Rasul F (2007) *Accessing Information About Health and Social Care Services*, Picker Institute Europe, Oxford.

Think Local Act Personal Partnership (2012) *Follow-on Study: Older People who Pay for Care*, Think Local Act Personal, London.

Thornber K (2008) *Getting Personal: A Fair Deal for Better Care and Support. The Report of Hampshire County Council's Commission of Inquiry into Personalisation and the Future of Adult Social Care*, Hampshire County Council, Winchester.

Thraves L (2013) The human factor (support for self-funders in care homes), *The MJ*, 6 August, www.themj.co.uk/article/?id=194394&typeid=3 (accessed March 2014).

Wanless D (2006) *Securing Good Care for Older People: Taking a Long-term View*, King's Fund, London.

Wild D, Nelson S, Szczepura A (2010) 'A 'home for life' in residential homes for older people in England: exploring the enhancers and inhibitors, *Housing, Care and Support*, 13, 2, 26–35.

Williams C (2009) A fair deal for self-funders, *Community Care (online)*, 29 April, www.communitycare.co.uk/2009/04/29/a-fair-deal-for-self-funders/ (accessed March 2014).

Williams J, Netten A (2005) English local authority powers, responsibilities and guidelines for managing the care home closure process, *British Journal of Social Work*, 35, 6, 921–936.

Williams J, Netten A, Ware P (2007) Managing the care home closure process: care managers' experiences and views, *British Journal of Social Work*, 37, 5, 909–924.

People who fund their own social care

Wittenberg R, Comas-Herrera A, Pickard L, Hancock R (2004) *Future Demand for Long-term Care in the UK: A Summary of Projections of Long-Term Care Finance for Older People to 2051*, Joseph Rowntree Foundation, York.

Wood C (2010) *Personal Best*, Demos, London.

Wright F (2000) *Capital Offences: Variations in Local Authority Treatment of Older Homeowners Entering Residential Care – A Summary of Some Key Research Findings*, Institute of Gerontology, King's College, London.

Wright F (2002) *Asset Stripping: Local Authorities and Older Homeowners Paying for a Care Home Place*, The Policy Press, Bristol.

Wright F (2003) Discrimination against self-funding residents in long-term residential care in England, *Ageing & Society*, 23, 5, 603–624.

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APPENDIX 1: LIST OF RESOURCES DETAILING CHARGING AND FUNDING POLICIES

Charging policies for residential care

People with capital assets of over £23,250 are required to pay the full costs of their residential care. All others pay a means-tested contribution based on their income and assets. Capital assets of less than £14,250 are disregarded for the purposes of means-tested contributions. Each £250 of capital assets between £14,250 and £23,250 count as £1 'tariff' income per week.

For a detailed description of charging rules for residential care see the 'Charging for Residential Accommodation Guide (CRAG)', available at www.gov.uk/government/uploads/system/uploads/attachment_data/file/301250/CRAG_34_April_2014.pdf.

For a summary of the charging rules, see the 'Paying for Permanent Residential Care' factsheet 10 from Age UK, available at www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS10_Paying_for_permanent_residential_care_fcs.pdf?dtrk=true.

Charging policies for domiciliary care

Councils in England charge for home care services according to a combination of level of service and the user's means to pay. The detail of charging policies varies across councils. Some policies are common across councils; for example, charges should not reduce service users' incomes to less than the 'basic' levels of Income Support or the Guarantee Credit element of Pension Credit, plus a buffer of not less than 25%. This is to prevent users' independent living from being undermined by charging policies. Councils may take users' savings and other assets into account when assessing charges but are not required to do so. Savings may be taken into account to provide a tariff income as set out in the CRAG rules (see above), but the value of the user's main residence should not be taken into account. Higher savings limits may be set, but lower ones should not be.

For a detailed description of charging rules for domiciliary care see 'Fairer Charging Policies for Home Care and Other Non-residential Social Services', available at www.gov.uk/government/uploads/system/uploads/attachment_data/file/208323/Fairer_Charging_Guidance_final_2013-06-20_rc.pdf.

For a summary of the charging rules, see the 'Paying for Care and Support at Home' Age UK factsheet 46, available at www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS46_Paying_for_care_and_support_at_home_fcs.pdf?dtrk=true.

NHS Continuing Healthcare and NHS-funded nursing care

In certain circumstances, the NHS funds all or some of a person's care.

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NHS Continuing Healthcare is a package of ongoing care arranged and funded solely by the NHS. Eligible people must have been assessed as having a 'primary health need'. NHS Continuing Healthcare eligibility is need-driven rather than condition-specific. Primary health need is determined according to the nature, intensity, complexity and unpredictability of care needs. It is provided to people living in any setting except a hospital, for example, a care home, their own home or a hospice. For people receiving NHS Continuing Healthcare funding whilst living in care homes, the NHS contracts with the care home and pays the full care home fees for accommodation, board and care.

NHS-funded nursing care refers to NHS funding of nursing care for people living in care homes with nursing. People should be considered for eligibility for NHS Continuing Healthcare prior to consideration for NHS-funded nursing care. For people eligible for NHS-funded nursing care, funding is paid by the NHS directly to the care home for care provided by registered nurses employed by the home.

For a detailed description of NHS Continuing Healthcare and NHS-funded nursing care, see the National Framework for NHS Continuing Healthcare and NHS-funded nursing care at www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf.

A summary is available from the Age UK factsheet 20 on NHS Continuing Healthcare and NHS-funded nursing care www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS20_NHS_continuing_healthcare_and_NHS-funded_nursing_care_fcs.pdf?dtrk=true.

Reforms to the care and support funding system

In February 2013, the government published their 'Policy Statement on Care and Support Funding Reform'. The document set out the detail of a new funding model for adult social care, based on the recommendations of the Commission on the Funding of Care and Support (The Dilnot Review). The document describes the government's case for change, details how the model would work for individuals, and discusses legislative changes that might have been required, including revisions to the then draft Care Bill. The document highlights, as given on the relevant government webpage, are that from April 2017:

- personal care costs will be capped at £75,000 over a person's life time for care they've been assessed as needing by their local council (with a lower cap for people who need care before retirement age, and free care for people who have care needs when they turn 18)
- people will get financial help if their property and savings are worth £123,000 or less
- less wealthy people and those with the highest level of need get the most financial help.

The new legislation will also mean that from 2015, no one will need to sell their home to

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pay for residential care costs during their lifetime. If someone needs residential care and can't pay for it without selling their home, they will be able to defer payments until they are ready to sell.'

The detail given above and the full document 'Policy statement on care and support funding reform and legislative requirements' can be accessed from www.gov.uk/government/publications/policy-statement-on-care-and-support-funding-reform.

In May 2014, the draft Care and Support Bill, into which the statement on funding reform fed, received royal assent, and thus became an Act of Parliament (that is, it became law). It is known as the Care Act 2014. The Act covers many areas of adult social care, including local authorities' responsibilities for the provision of information and shaping the care market, entitlements to care and support, charging for and funding of care, and continuity of care when moving across local authority boundaries.

The full Care Act 2014 is available at: <http://services.parliament.uk/bills/2013-14/care.html>.

For summary factsheets see: www.gov.uk/government/publications/the-care-bill-factsheets.

APPENDIX 2: SEARCH TERMS AND STRATEGY

This review was restricted to research evidence published since 2000. Relevant articles and reports were identified through searches of electronic databases, augmented by searches of the websites of selected organisations. The searches were restricted to England because of the salience of local funding and eligibility arrangements and the limited transferability of research from other welfare regimes.

The following databases were searched:

- **ASSIA (Applied Social Science Index and Abstracts)** indexes around 650 English language social science journals. Subject coverage includes social services, health, employment, ethnic studies, education, criminology, and related areas.
- **Scopus** is an abstracting, indexing and citation database covering peer-reviewed research literature and web sources in the natural sciences and medicine, social sciences, arts and humanities.
- **Social Services Abstracts** provides bibliographic coverage of current research in the areas of social work, human services, and related topics, including social welfare and social policy. It indexes and abstracts over 1,400 serial publications and includes abstracts of journal articles, dissertations, and citations to book reviews.
- **Social Policy and Practice** is a bibliographic database containing over 200,000 records. Subject coverage includes public and social policy, public health, social care, community development, mental and community health, homelessness, housing, crime, law and order, families, children and older people. Indexes journal articles, books, grey literature, and UK government publications.
- **Social Care Online** is a freely available resource which aims to be the UK's most extensive database of social care information. Social Care Online indexes journal articles, reports and government publications.

The aim was to identify a broad range of relevant literature.

Search terms and strategy

1. ab("social care") OR ti ("social care")
2. ab("social service*") OR ti ("social service*")
3. ab("social support") OR ti ("social support")
4. s1 OR s 2 OR s 3
5. ab("self fund*") OR ti ("self fund*")
6. ab("top* up") OR ti ("top* up")
7. ab("private* purchas*") OR ti ("private* purchas*")

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8. ab("private spend*") OR ti ("private spend*")
9. ab("personal fund*") OR ti ("personal fund*")
10. ab(private* NEAR/3 fund*) OR ti (private* NEAR/3 fund*)
11. ab(private* NEAR/3 pay*) OR ti (private* NEAR/3 pay*)
12. ab("private expenditure") OR ti ("private expenditure")
13. ab("pay for care") OR ti ("pay for care")
14. ab("self financ*") OR ti ("self financ*")
15. ab("paid for") OR ti ("paid for")
16. s 5 OR s6 OR s7 OR s8 OR s9 OR s10 OR s11 OR s12 OR s 13 OR s 14
17. ab("residential care") OR ti ("residential care")
18. ab(care NEAR/3 home*) OR ti (care NEAR/3 home*)
19. ab("domiciliary care") OR ti ("domiciliary care")
20. ab("non-residential care") OR ti ("non-residential care")
21. ab("day care") OR ti ("day care")
22. ab("extra care housing") OR ti ("extra care housing")
23. ab("housing with care") OR ti ("housing with care")
24. s 17 OR s18 OR s19 OR s20 OR s21 OR s22 OR s23
25. s4 OR s24
26. s16 AND s25

Limits applied to each search:

Date: After 01 January 2000

Type: Scholarly journals

Language: English

Inclusion and exclusion criteria

The searches of electronic databases identified 164 potentially relevant references. The search of relevant websites identified 21 references. All 185 references were downloaded to the reference management software package Endnote X7.

Table A1 shows the numbers of references identified, read, removed because they were duplicates, and excluded because they were not relevant.

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Table A1: Number of references identified and read

	Number
References identified through database searches	164
References identified through targeted webpage searches	21
References downloaded to reference management software	185
Duplicates removed	-49
Abstracts read	136
References excluded	-26
Duplicates removed	-19
Full references read	91
References excluded	-18
Duplicates removed	-7
New references added	+5
References from which data extracted	71

References were included if they were:

- empirical research (all methods)
- reviews of empirical research
- secondary analysis of existing data
- models/simulations using existing data.

References were excluded if they:

- were debates, viewpoints or think pieces
- were policy documents
- were guidance documents
- did not focus on England
- were not about social care
- were not about self-funders.

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Due to time limitations, we did not undertake a formal assessment of quality and treated all evidence equally.

The titles and abstracts of 136 references were read, 91 references were read in full.

We extracted relevant details from 71 references on the following areas of interest:

- the size and characteristics of the population funding their own social care support
- information and advice either available for or wanted by this population
- providers' experiences of people funding their own social care support; and
- gaps in available evidence.

Three reports were unavailable for this review in full text version. These were market reports on older people by LaingBuisson. Each report costs around £800 to purchase and were not available via inter-library loan. Limited data from these reports were available from citations in other references. However, LaingBuisson provided the relevant chapter from their latest market report on care of older people (LaingBuisson 2014) free of charge for this review.

APPENDIX 3: CURRENT RESEARCH

The Personal Social Services Research Unit at the University of Kent and the London School of Economics and Political Science, and LG Futures are reviewing and developing new adult social care Relative Needs Formulae. One element of the research will be to consider the availability of new data on self-funders as there is currently a lack of nationally available data on these service users. For further information see: www.lgfutures.co.uk/adultsocialcarernf.

In addition, four research groups or organisations known to have been active in research about self-funders were contacted and asked if they were currently undertaking any relevant research. We received responses from three.

The Institute of Public Care at Oxford Brookes University recently completed work funded by the Department of Health's Developing Care Markets Quality and Choice programme. The aim was to develop a 'Self-funders Toolkit' to help local authorities gain a better understanding of the likely number of self-funders in their area, how to find out more about them and how to meet their needs. This piece of work involved updating IPC's previous analysis of ELSA data and adding analysis of Life Opportunities data about people who pay for care in their own home. IPC has also recently undertaken work to estimate the number of self-funders in two sub-regions and one local authority to help them prepare for the Care Act.

Melanie Henwood Associates is currently working on issues around assessment and eligibility. This work is not related specifically to self-funders but will have implications for them.

The Social Care Institute for Excellence are developing two NICE (National Institute for Health and Care Excellence) guidelines as part of their NICE Collaborating Centre for Social Care. The principal role of the guidance is to provide recommendations on 'what works', in terms of both the effectiveness and cost-effectiveness of the intervention or service. The guidance may look at who should carry out the intervention and where it should be carried out. Although NICE social care guidance does not routinely describe how services are funded, the two guidance projects mentioned below do include self-funders. Both will use the best available evidence to provide recommendations for good practice, aimed at improving outcomes for users of social care services and their families or carers. Although primary research will not be conducted during the guidance development, published and other evidence will be collated; this may add to the existing level of knowledge about self-funders.

One guide is entitled 'Home care: delivering personal care and practical support to older people living in their own homes'. This guidance covers older people living at home and in receipt of home care. It includes people who organise or fund their own care. The final guidance is scheduled to be published in July 2015.

The other is on 'Social care of older people with complex care needs and multiple long-

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term conditions (including physical or mental health conditions)'. This guidance covers older people who organise and/or fund their own care, in addition to those for whom care is organised and/or funded by the local authority. The final guidance is scheduled to be published in September 2015.

School for Social Care Research

Phase I (2009–2014) of the NIHR School for Social Care Research (SSCR) was a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York. Phase II (2014–2019) of SSCR is a partnership between the London School of Economics and Political Science and the Universities of Bristol, Kent, Manchester and York, and is part of the National Institute for Health Research (NIHR) www.nihr.ac.uk/.

The logo for the London School of Economics (LSE), consisting of the letters 'LSE' in white on a red square background.The logo for King's College London, featuring the text 'KING'S College LONDON' in a serif font with a horizontal line underneath.The logo for the University of Kent, with 'University of' in a smaller font above the word 'Kent' in a large, bold, sans-serif font.The logo for The University of Manchester, featuring the word 'MANCHESTER' in a bold, sans-serif font with '1824' below it.

The University of Manchester

The logo for the University of Bristol, featuring a crest with four quadrants and the text 'University of BRISTOL'.The logo for The University of York, with 'THE UNIVERSITY of York' in a serif font.

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