

Hampshire County Council

**People who fund their own
personal care at home in
Hampshire**

Report

September 2010

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Executive Summary

A combination of demographic and social care policy changes has led to the need for a better understanding of older people who fund their own personal care at home in Hampshire. However, there is a lack of data about this group both nationally and locally. This study sought to: obtain a fuller understanding of what kind of care older people pay for and who they get it from; gather information on unpaid carers in these households; and test the conclusions of the first stage of this study about the likely number of people who fund their own personal care at home in Hampshire (excluding Southampton and Portsmouth).

The results indicate the wide variety of needs (and arrangements to meet those needs) which self-funders have, and the difficulties of generalising about who pays for personal care, how it is sourced, what kind of care and how much care is provided. This has implications for commissioners and providers in meeting the needs of such a diverse market.

The survey indicates that at least 3,190 or 1.3% of the older population pays for personal care (as defined by the Personal Care at Home Act), about half the number (6,377) indicated in the Stage 1 study. The true figure is expected to lie somewhere between the two estimates.

The very old, women, people who live alone, and less mobile older people requiring a degree of care/communities of wealthy older people living in large seaside housing/and older people living on social estates with limited budgets are the people most likely to be paying for care.

Most self-funders of personal care (defined as help with bathing and washing) and help taking medicines and help moving around the home are likely to use a care agency. Self funders are more likely to pay an individual for most other types of care, while lower level help and support (such as cleaners and transport) is frequently arranged on a more ad hoc and informal basis.

Given levels of owner occupation among older people in Hampshire (over 80% among the 65-74 year old age group) and relatively high house prices

in the county, extra care housing for sale or lease could play a useful role in meeting the needs of older people who pay for their own care.

Many self-funders appear to have had contact with HCC and many of those interviewed had been assessed and were either paying a contribution to HCC organised care, or paying in full for care arranged or recommended by HCC. However, the survey findings indicate that there are significant proportions of people who pay for care who have not contacted the council. There is scope to raise awareness of older people's entitlement to an assessment and to improve the provision of information to older people, their carers and 'tomorrow's older people' about the services and support which the council and other organisations can offer.

It is clear that there are also considerable numbers of people paying for lower level help and support who may not be in contact with HCC. The voluntary sector appears to play an important role in meeting the needs of this group, thereby potentially contributing to reducing demand for more intensive service later on. Help with shopping, cleaning and gardening are all areas where there is a need among the older population.

Attendance Allowance and Disabled Living Allowance also emerge from the study as having a valuable role in enabling older people to pay for care, lower level support, transport and other kinds of help. The study indicates that raising awareness of available benefits and of sources of advice and support could be useful for self-funders (and others). Evidence from another local authority indicates that some older people may require more than information to help them navigate access to the care and support they require.

The survey and interviews found that unpaid carers frequently provide care alongside other professional carers – the two categories of carer are not mutually exclusive. While the study has demonstrated that people who pay for their own care are a significant element in the home care market, the main source of personal care at home is unpaid, informal care. Supporting carers is therefore an important activity to enable older people to live independently at home.

1 Introduction

1.1 Background

This report presents the results of the second stage of a two-part study of people who fund their own personal care at home in Hampshire. The report was prepared by the Institute of Public Care (IPC) at Oxford Brookes University for Hampshire County Council (HCC).

The number and characteristics of people who fund their own care are of growing significance. This is due to three key factors: as a result of demographic changes and their implications for public services; due to an increase in real terms in the financial resources of older people and their potential impact on the wider social care market; and thirdly, the changing nature of social care as a consequence of the policy focus on personalisation, prevention and choice (noted in HCC's Commission of Inquiry into Personalisation and the Future of Adult Social Care in November 2008).

Local authority Directors of Adult Social Services are now expected to commission services for the whole population and there is a duty on local authorities to carry out a Joint Strategic Needs Assessment. However, there is increasing recognition that little is known about the current and potential future activities of self-funders and the impact they may have on social care service provision¹. Self-funding operates at a wide variety of levels from people who use friends, neighbours and local contacts to deliver low level community support such as assistance with household tasks, '*that bit of help*', through to those who purchase residential care with nursing.

At the time of commissioning this study, there was a need for all local authorities to prepare for the implementation of the Personal Care at Home Act 2010 by identifying the likely number of people who currently pay for their own personal care and their eligibility for future state-funded care. Based on earlier estimates in HCC's response to the government's consultation on the Personal Care at Home Bill, Hampshire is thought to have a relatively high number of self-funders. HCC had estimated that the cost of the Act (before grant) would be between £25.5m and £43.3m in a full year if all eligible self-funders approached the County for free care².

The new government has made it clear that it does not now expect the Act to be implemented. This second stage of the study has proceeded, because there is still a need to obtain information about the self-funding

¹ Hudson B and Henwood M (2009) A Parallel Universe? People who fund their own care and support: a review of the literature, ADASS/SCIE/JRF

² Hampshire County Council response to the Government's Personal Care At Home Bill consultation

population to inform HCC's future commissioning and facilitation of the market to meet the care needs of the whole population.

1.2 Objectives

The main objective of this stage of the study was to research the current care arrangements of self-funders in Hampshire: to find out what kind of care they pay for and who they get it from. There were two additional aims: to use the data to test the conclusions of the first stage of the study about the likely number of people who fund their own personal care at home in Hampshire (excluding Southampton and Portsmouth); and to take the opportunity to gather information on unpaid carers in these households.

The first stage report estimated that there is a range of between 3,000 and 4,500 older people who pay for their own personal care who would have been eligible for free personal care under the Personal Care at Home Act; and an additional 1,877 older people receiving domiciliary care from HCC which they pay for. This would indicate a maximum number of 6,377 older people in Hampshire paying for all or part of their personal care.

1.3 Methodology

To map the current arrangements for care that self-funders have made, a postal questionnaire was sent to a random sample of 1,000 older people from each district across the county (a total of 11,000 older people). The sample was drawn from the range of categories on the MOSAIC database relating to older households (MOSAIC is a commercial demographic profiling and classification system developed for social marketing purposes which categorises households into a number of different types – see Appendix 1 for further information). Bus pass data were considered as an alternative option to obtain a reliable sample of older households. However, this approach was rejected on the grounds that bus pass take-up is likely to be limited by a number of factors such as car ownership, frailty, disability and lack of bus services in some areas and consequently, the sample could be biased against the very groups we wished to include. All participants received a stamped and addressed envelope to increase the response rate.

A total of 1,260 valid responses to the questionnaire were obtained representing an 11.5% response rate (see Table 1). This rate is lower than we would have liked ideally, but not atypical for postal questionnaires and in our judgement sufficient to draw conclusions about people who pay for their own care in the county. The results are within a +/- 3% sampling error at the 95% confidence level. However, a number of factors will have affected the profile of respondents, and consequently the sampling error will be wider.

Firstly, the covering letter clearly stated that: '*If you do not need any help with everyday activities or if all of your care is paid for by the County Council, there is no need to fill [the questionnaire] in*'. Thus, those needing

or receiving care were much more likely to respond to the survey than those with no need for care or help. In addition, the response rate may have been low amongst the population paying for care in that the limitations of MOSAIC have meant some non-older people's households were targeted. There may also have been active non-response from two groups of older people: those who were wary of providing information perceived as sensitive, and those too frail or disabled to respond. We have taken this into account in our final conclusions.

It should also be noted that we cannot draw safe and reliable conclusions from individual districts due to the small number of respondents per district.

Table 1: Valid responses received by district

Local authority	Number of valid responses	Response rate
Basingstoke and Deane	116	11.6%
East Hampshire	114	11.4%
Eastleigh	95	9.5%
Fareham	126	12.6%
Gosport	121	12.1%
Hart	114	11.4%
Havant	97	9.7%
New Forest	113	11.3%
Rushmoor	102	10.2%
Test Valley	119	11.9%
Winchester	143	14.3%
Total	1260	11.5%

All respondents were asked if they would be willing to be contacted for follow-up telephone interviews. From those respondents who agreed and indicated that they paid for some level of care or support or provided care, a purposive sample of 31 older people was drawn from across the county, including one or more person from each district. The sample was drawn to obtain a more detailed qualitative picture of the nature of self-funders care needs, the range and quantity of services purchased, whether they have been in contact with the County, and the outcome of that contact.

Overall frequency data and district level frequencies are provided in two accompanying technical appendices.

2 Profile of respondents

2.1 Gender and age

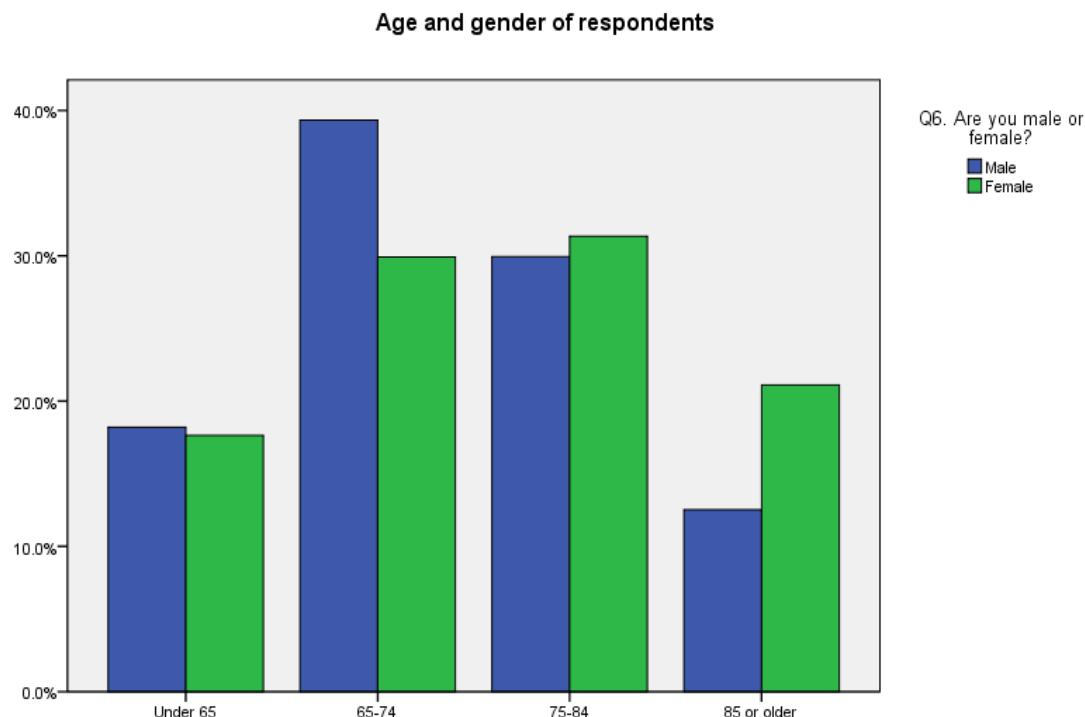
Slightly more than half of respondents were female (55.5%) reflecting the profile of the older population in Hampshire as a whole (see Table 2). The majority of respondents were aged between 65 and 84 years old. However people aged 85 and over were over-represented compared with the older population of Hampshire as a whole. This age group is the one most likely to need personal care.

The 18% of responses from those under 65 years old may be due to a number of factors: including women over retirement age but under 65 years old, younger carers responding on behalf of older residents, and weaknesses in the MOSAIC profiling system itself.

Table 2: Percentage of respondents by age group and gender

Age group	Male	Female
Under 65	18%	18%
65-74	39%	30%
75-84	30%	31%
85 and above	13%	21%
Total (column percentage)	100%	100%
Total (row percentage)	44.5%	55.5%
Predicted Hampshire total population aged 65+ (row percentage) ³	44.3%	55.7%

³ Projecting Older People's Population Information system (POSSI)
<http://www.poppi.org.uk/>



2.2 Ethnic origin

The great majority of survey respondents (99.6%) described their ethnic origin as White reflecting the very low proportion of people from Black or minority ethnic groups in the older population in Hampshire. One of the interviewees was of Asian origin.

2.3 Living arrangements

Overall 45% of respondents lived alone. However, when analysed by age group, more than three-quarters (76%) aged 85 and above live alone (see Table 3). Projections⁴ indicate that 50% of the Hampshire population aged 75 and over live alone, compared with 62% of the survey respondents aged 75 and over. This group are therefore over-represented in the survey responses.

Table 3: Percentage of respondents living alone by age group

Age group	Live alone %
Under 65	31%
65-74	31%
75-84	55%
85 and above	76%

⁴ Projecting Older People's Population Information system (POPPI)

Just over 60% of female respondents lived alone, compared with 30% of male respondents.

2.4 MOSAIC categories

In terms of the profile of respondents to the postal survey, the largest category was: 'Better off empty nesters in low density estates on town fringes', followed by: 'Older people living in large houses in mature suburbs', 'Higher income older champions of village communities', 'Empty nester owner occupiers making little use of public services', and 'Less mobile older people requiring a degree of care'.

Response rates were highest for: 'Older people living in large houses in mature suburbs' (16%) and 'Communities of wealthy older people living in large seaside housing' (15%); and lowest for: 'Older families in low value housing in traditional industrial areas' (3%) and 'Low income older couples long established in former council estates' (4%) (See Appendix 1).

2.5 Interviewees

The telephone interviews were focused on people who indicated that they paid for some level of care and the sample was drawn from across the 11 districts. Their profile reflects the higher proportions of survey respondents among the very old, and people who live alone, who pay for care.

Table 4: Profile of telephone interviewees

Gender	Number	Living arrangement	Number
Male	13	Live with spouse/family	13
Female	18	Live alone	18

Age group	Number
Under 65	2
65-74	8
75-84	8
85 and above	13

3 Care needs

3.1 Help with everyday activities

The postal survey covered the kind of care needed and the care received by older people in their own homes. Respondents were asked about whether or not they needed help with a range of everyday activities and also whether they got help with these activities, either from an unpaid carer

or by paying it for it themselves (see Table 5). The survey preamble asked respondents not to include information about help that was paid for by the County Council either directly or through a Direct Payment in order to obtain a picture of the care which people paid for from their own resources. The main type of help needed **and** received was personal care (defined in the survey as help with washing and bathing); help with moving around the home was least frequently mentioned.

The telephone interviews reveal a wide range of needs and conditions requiring care among those contacted, for example, people who had had a stroke affecting their mobility, speech and other capacities, people with Parkinson's, amputees and visual impairments were mentioned. Again, the need for personal care was the main area of care which people mentioned in the interviews – particularly help with getting showered and dressed in the mornings, and getting ready for bed in the evenings.

Table 5: Percentage needing and getting help with everyday activities

Type of help	Respondent category	Need help	Receive help
Personal care, eg, help with washing or bathing	All	15%	14%
	Aged 85+	25%	28%
Getting dressed	All	13%	11%
	Aged 85+	19%	19%
Taking medicine	All	11%	11%
	Aged 85+	20%	19%
Eating or drinking	All	9%	9%
	Aged 85+	15%	18%
Moving around your home	All	10%	7%
	Aged 85+	12%	10%

Note: It is not clear why some percentages for receiving help exceed percentages needing help, although some may have interpreted 'needing help' as needing additional help above what they already received.

Respondents who lived alone were less likely than others to say they need help with daily activities. This could reflect the possibility that people who live alone are more likely than others to move into a care home when they are unable to carry out these activities, as they are less likely to have access to unpaid care.

3.2 Volume of care

Respondents were asked how many hours a week of care they received. The range of hours was considerable, from a few hours to up to 24 hours a day. Therefore, it is most useful to report the mean amounts of care provided. These were:

- Personal care, eg, help with washing or bathing – 4 hours a week
- Getting dressed – 3.5 hours a week
- Taking medicine – 2 hours a week
- Eating or drinking – 9.25 hours a week
- Moving around your home – 14 hours a week.

It should be noted that these reflect the responses of people who needed and received that specific type of care.

3.3 Sources of help

3.3.1 Survey results

Survey respondents who received help with everyday activities were asked about where they got help from. The most common source of help was unpaid care from a spouse, family member or a friend; and the main type of help obtained was for personal care (see Table 6). **As a proportion of the total responses to the survey, 12.0% of respondents were paying for all or some of their personal care** (defined in terms of the Personal Care at Home Act to include personal care, help with getting dressed, eating and drinking).

Table 6: Type of help people have and how funded

Type of help	Pay an agency	Pay an individual	Unpaid carer	Total number
Personal care, eg, help with washing or bathing	32%	11%	67%	213
Getting dressed	23%	29%	61%	213
Eating or drinking	11%	16%	80%	188
Taking medicine	23%	12%	74%	158
Moving around your home	20%	14%	75%	130

Note: Row percentages do not sum to 100% as some respondents obtained care from more than one source and some receiving care did not complete this question

The much greater role of unpaid care, compared with self-funded care in Hampshire, corresponds with other research evidence which has

emphasised the critical role of unpaid carers in supporting people to live in their own homes: in the 2001 Census, 11% of the UK population reported providing unpaid care, and a quarter of these people provided personal care.

In terms of self-funded care, respondents were much more likely to be paying an agency than an individual, for personal care defined as help with washing and bathing, (32% compared with 11%) but more likely to pay an individual than an agency for help with getting dressed (29% compared with 23%) and help with eating (16% compared with 11%). All three types of care would be included in the Personal Care at Home Act definition of personal care. Care agencies range from national organisations such as Care UK to smaller businesses employing a few staff. Paying individuals could include paying neighbours and friends or others recruited through adverts, recommendations, or other means.

When the source of help with personal care (as defined by the Act) was analysed by age, it is clear that from age 65 onwards, the older the respondent receiving personal care, the more likely they are to be paying for it, and particularly paying an agency (see Table 7). For example, the percentage of respondents paying an agency increases from 15% in the 65-74 age group to 40% in the 85 and over age group, reflecting the greater need for personal care as people get older, and the lower level of unpaid care available in late old age.

Table 7: Source of personal care (including washing, bathing, help with dressing and eating) by age

Age group	Pay an agency	Pay an individual	Unpaid carer	Total number
Under 65	11%	36%	68%	44
65-74	15%	24%	75%	84
75-84	21%	25%	76%	122
85 and above	40%	29%	69%	77
Total	23%	28%	75%	327

Note: Row percentages do not sum to 100% as some respondents obtained care from more than one source and some receiving care did not complete this question

The high levels of unpaid care provided demonstrate its critical importance to older people with personal care needs (246 unpaid carers providing personal care). The proportion of people receiving unpaid personal care rises slowly up to age 75-84 where it peaks at 76% and then appears to fall, probably reflecting the declining numbers of people in the highest age category able to provide personal care, due to higher levels of ill-health and mortality.

The great majority of respondents living with their spouse or partner, or family or friend who received personal care (as defined by the Act) received unpaid care; a smaller proportion of people who lived alone received unpaid care, although this was still more than half (see Table 8). Correspondingly, respondents who lived alone were much more likely to pay for care than those who lived with their spouse or partner, or other family or friend. These results indicate the much greater likelihood that people who live alone pay for care.

Table 8: Source of personal care (including washing, bathing, help with dressing and eating) by household status

Household status	Pay an agency	Pay an individual	Unpaid carer	Total number
Live alone	35%	36%	54%	131
Live with spouse/partner	13%	20%	86%	172
Live with other family or friend	24%	19%	86%	14

Note: Row percentages do not sum to 100% as some respondents obtained care from more than one source and some receiving care did not complete this question

As a percentage of **all** responses to the survey, it was found that:

- 21.8% of people aged 85 and over paid for personal care (as defined by Personal Care at Home Act), compared with 7.9% of people aged 65-74;
- 14.5% of all female respondents paid for personal care (as defined by Personal Care at Home Act) compared with 9.1% of males; and
- 14.4% of people who lived alone paid for personal care (as defined by Personal Care at Home Act) compared with 10.0% of those who did not.

In other words, the people most likely to pay for personal care are likely to be female, living alone and aged 85 or above.

In terms of the MOSAIC categories, those people who were most likely to pay for the provision of personal care (as defined by the Act) were: M58 Less mobile older people requiring a degree of care (18%); M56 Older people living on social estates with limited budgets (15%); and L52 Communities of wealthy older people living in large seaside housing (13%). All bar one of those in the 'Older people living on social estates with limited budgets' category paid for an agency to provide personal care. It seems likely that people in this category were not paying for the full cost of their personal care, but rather paying part of the costs of local authority provided care.

3.3.2 Interview results

The telephone interviews were targeted on people who indicated in the postal survey that they were paying for care, and sought further information about how people sourced their care. Personal care was taken to include help with bathing, washing, getting dressed, eating and drinking, ie, as defined by the Personal Care at Home Act.

The interviews reveal a variety of arrangements:

- People who fully fund personal care and arrange it themselves

Seven of the 31 people who were interviewed fully funded their personal care and arranged it themselves. Some people had sourced their care themselves: for example, a woman aged 65-74 who needed a hoist for getting in and out of bed and going to the toilet was paying £460 a week for live-in care from someone she knew, with secondary care from someone she had met at a centre.

Some people had obtained a list of care agencies provided by HCC and used it to arrange care themselves, for example: a hospital social worker had recommended an agency which was now providing 30 minute visits every morning and evening to help with the care of a bedridden woman aged over 85.

- People who fully fund personal care arranged by HCC
- People who partially fund personal care arranged by HCC

It was not always possible to distinguish between these two groups. The amounts mentioned by some who said they were paying for personal care arranged by HCC indicate that they were not paying the full amount, and were probably unaware that they were paying only part of the full cost of the care provided. For example, one interviewee reported paying around £60 a month for three visits a day by carers to provide personal and other care. The care was arranged by HCC. Another interviewee paid £28 a week to Care UK for 6 morning visits a week to help with washing, dressing and making the bed. This had been arranged by HCC.

Most of those interviewed who were paying for personal care used a care agency rather than an individual – reflecting the role of HCC in both providing information about providers of personal care, and in organising personal care (but not delivering it). People paying for personal care arranged by HCC mentioned a range of care agencies rather than paying individual carers, including: Carewatch, Helping Hands, Grove Care, All Care, and Who Cares Home Help Agency.

- People who received fully funded personal care from HCC, but paid for other help and support

It emerged that a number of those interviewed were receiving free personal care from HCC, however they were self-funding additional help and care. Most frequently mentioned forms of additional help were: cleaners and gardeners, but help with shopping (doing it or accompanying the interviewee) and transport, particularly to attend medical appointments were also mentioned a number of times. Other support that people paid for included: an Age Concern lunch club, meals services, physiotherapy, and hair care. This echoes the conclusions of the Joseph Rowntree Foundation's Older People's Programme which found that older people highly value support which enables them to live in their own homes such as help with cleaning, gardening, transport and DIY⁵.

In addition, seven interviewees were in retirement or sheltered housing schemes with a warden service. Several mentioned the role of the warden in checking up on them and as a first port of call when they needed information or advice.

Attendance Allowance was mentioned by four interviewees as playing an important role in enabling them to pay for care and support, and three mentioned DLA as helping with their transport costs in particular. Raising awareness of, and helping people to claim these and other benefits may enable people to pay for the additional care and support which they may need.

3.4 Other types of help and support

People were asked in the postal questionnaire if they needed or received help with a number of other services: cleaning their home, shopping for groceries, and looking after their garden. Table 9 indicates that between a quarter (25%) and a third (33%) of all respondents needed help with these different activities, rising to around half of those aged 85 and over. For the very old, the need for help with cleaning was most frequently mentioned. Women were also much more likely to need help with these activities than male respondents: for example, 37% of female respondents said that they needed help with cleaning their home compared with 20% of male respondents, partly reflecting the high proportion of women in the older age groups.

Respondents appeared to be able to get help with cleaning, shopping and gardening: for every activity, a higher proportion of respondents said that they received help, than needed help, with these three activities.

⁵ JRF Older People's Inquiry (2005) That little bit of help, York: JRF.

Table 9: Other help needed and received

Type of help	Respondent category	Need help	Receive help
Cleaning your home	All	29%	35%
	Aged 85+	56%	60%
Shopping for groceries	All	25%	26%
	Aged 85+	54%	57%
Looking after your garden	All	33%	34%
	Aged 85+	49%	50%

Note: It is not clear why some percentages for receiving help exceed percentages needing help, although some may have interpreted 'needing help' as needing additional help above what they already received.

Interviewees also mentioned a range of practical help which they paid for, often following an OT assessment and advice, such as grab rails, chair raisers and showers.

3.5 Why people pay for care or other help

People were asked in the postal survey why they paid for help. The most commonly cited reason by people paying for their own care was that they had contacted HCC and been told that although their needs were high, they were above the income threshold (see Table 10). This was also common among those who were interviewed who were paying for personal care – at least 8 out of 22 had been told they were over the assets threshold.

However, nearly one in five (19%) of survey respondents who were paying for care said were doing so because they preferred to manage their affairs independently; 17% said that were doing so because they did not think they would qualify for help from the Council; and 11% did not want to share information about their financial or personal situation with the council. This indicates that there may be a significant percentage of self-funders who could be eligible for care and support from the council, but who have neither applied nor been assessed for care and support.

Table 10: Reasons why people pay for help

	All respondents N = 1260	Respondents who said they paid an agency or individual for care N = 181
I contacted Hampshire County Council but they explained that although my needs were high enough, I was above the income threshold so would have to pay myself	5%	23%
I prefer to manage my affairs independently	8%	19%
I thought I would not qualify for help from the County Council	6%	17%
I do not want to share information about my financial or personal situation with Social Services	5%	11%
I did not know the County Council provides this kind of help to some	5%	8%
I contacted Hampshire County Council but they explained I did not meet their eligibility criteria (i.e. my needs were not high enough)	1%	3%
Other	3%	12%

Among the 31 people who were interviewed, there were eight people who said they had not approached HCC for help. Their reasons included:

- Does not think she needs it - gets a decent pension and her husband's pension. Lots of people who need it more than her.
- Doesn't have any needs and income above threshold. When wife died contacted HCC and got council tax discount.
- Doesn't want to pay more and not sure what HCC can give her. Day care is brilliant. Husband on waiting list for nursing home.
- Hadn't thought to approach HCC for help.

- Mainly because haven't needed anything. Not aware of any services. Above assets threshold. Some equipment eg hospital bed, hoist, walked and incontinence pads from Integrated Community Equipment.
- Prefers to arrange things individually and pay, and did not think would qualify.

The other common reason among interviewees for paying for care was as a part contribution to HCC organised and part funded care.

3.6 Providing informal/unpaid care

3.6.1 Unpaid care

The survey's main focus was people who pay for personal care at home. However, it was anticipated that some respondents would be care-givers rather than receivers. Survey respondents were therefore asked if they provided "*a significant amount of unpaid care on a regular basis for a member of your family or a friend*". Nearly one in five (18%) said that they did provide significant amounts of unpaid care, compared with 15% of the over 65 population nationally⁶. It is assumed that most of this unpaid care was provided to resident spouses or parents: national data indicate that 48% of carers are providing care for someone living with them⁷. Twenty-one percent of women and 14% of male respondents said that they provided significant amounts of unpaid care on a regular basis. After 65, the proportion of people providing significant amounts of unpaid care increases with age from 14% for respondents aged 65-74 to 19% among those aged 85 and over (in contrast to the national trend reported in the Census where care giving falls with age).

3.6.2 Self-funding and unpaid care

The sample for the interviews was focused on people who said they paid for their own care. Of the 22 people interviewed who were paying for all or part of their personal care, 16 received significant amounts of unpaid care as well, mostly from a resident spouse or other family member. Clearly, self-funded personal care is not an alternative to unpaid care, but appears to play an important complementary role. Equally, three of the four interviewed who were receiving free personal care were also receiving significant amounts of unpaid care.

3.7 Help for carers

Twelve of the interviewees discussed help for unpaid carers. Eight of these people said they knew about carers' assessments, although only a couple had definitely had a carers assessment. In a couple of cases, the

⁶ NHS Information Centre (2010) Survey of Carers in Households in England 2009/10 Provisional results

⁷ NHS Information Centre (2010) Survey of Carers in Households in England 2009/10 Provisional results

interviewee/carer did not want to be assessed – partly because they did not think they did enough to merit an assessment. Nine of those interviewed said they knew of support services available to carers and mentioned a number of voluntary organisations, such as the Princess Royal Trust for Carers' monthly carers lunches, Alzheimer's Society lunches for carers and the One Community.

3.8 Freetext comments

To provide some additional depth to the study, some comments from the questionnaire responses are set out in Appendix 4.

4 Knowledge of social care and access to information

4.1 Assessment and means-testing

The interviewees were asked whether they knew they were entitled to an assessment, regardless of their means. Fifteen out of 31 said that they knew they were entitled to an assessment, although one interviewee said he only found out from the warden of his housing scheme. Eleven said that they did not know that social care was means-tested before they needed to look at options for care and support. This represents more than one-third of those interviewed and indicates that there is a need to raise awareness among the population, both young and old about the availability and costs of social care.

4.2 Additional help

Interviewees were asked: *Is there any help or care which you believe the County Council could provide you with?* They were not asked about their willingness or ability to pay for these services. A few points were made by more than one interviewee:

- Better advice and information at hospital discharge on services available and contact numbers.
- More respite care and sitting services.
- Help to take people shopping.

Other points mentioned included: help with decorating, help to collect rubbish bins, and befriending.

4.3 Information and advice

Most interviewees (24 out of 31) felt they could access good information and advice when making decisions about the future, frequently mentioning family members and wardens as sources of reliable and good information. The internet was mentioned by one interviewee only. The local council, GP and voluntary organisations, such as CAB, Age Concern or Centre for

Independent Living were mentioned as current or potential sources of information.

There was little specific information that interviewees said that they needed. Individual interviewees mentioned that information on respite services, power of attorney, rehabilitation and sitting services, and advice on finances and thresholds would be useful.

5 Comparison with Stage 1 findings

The Stage 1 report estimated that there is a range of between 3,000 and 4,500 older people who pay for their own personal care who would be eligible for free personal care under the Personal Care at Home Act; and an additional 1,877 older people receiving domiciliary care from HCC which they pay for. This would indicate a maximum number of 6,377 older people in Hampshire paying for all or part of their personal care.

As mentioned earlier in the report, the survey covering letter sought to exclude those with no need for help with everyday activities and those fully funded by HCC for their personal care, which means there is likely to have been a response bias in the postal survey towards people with a need for personal care, and that people who pay for personal care are also likely to be over-represented in survey responses.

Table 11 – Application of age-specific proportions paying for personal care to Hampshire older people population

Age group	Predicted Hampshire population in 2010 (POPPI) Column A	Survey based percentage paying for personal care (including help with washing, bathing, dressing, eating or drinking) Column B	Response rate Column C	Estimated numbers paying for all or part personal care AxBxC
65-74	123,800	7.9%	11.5%	1,125
75-84	81,500	12.8%	11.5%	1,200
85 and above	34,500	21.8%	11.5%	865
Total	239,800			3,190

Applying the proportions of people in each age category paying for personal care (as defined by the Personal Care at Home Act) to the predicted population in Hampshire (using the latest figures from the POPPI database) and multiplying each number by the survey response rate as a means of

weighting the results, it appears that there are 3,190 people paying for all or part of their personal care, equivalent to 1.3% of the total predicted older population in Hampshire in 2010 (see Table 11). It can be assumed that due to the factors discussed in the methodology section concerning under-responses from the most frail members of the population, this is likely to be a conservative estimate. The true figure is likely to be somewhere between the Stage 1 estimate of 6,377 (which was a maximum) and the Stage 2 estimate of 3,190.

6 Conclusion

The results of the survey and interviews indicate the wide variety of needs and arrangements to meet those needs which self-funders have, and the difficulties of generalising about who pays for personal care, how it is sourced, what kind of care and how much care is provided. This has implications for commissioners and providers in meeting the needs of such a diverse market.

The survey indicates that at least 1.3% of the older population pays for personal care (as defined by the Personal Care at Home Act). The very old, women, people who live alone, and less mobile older people requiring a degree of care/communities of wealthy older people living in large seaside housing/and older people living on social estates with limited budgets are the people most likely to be paying for care.

Most self-funders of personal care (defined as help with bathing and washing) and help taking medicines and help moving around the home are likely to use a care agency. Self funders are more likely to pay an individual for most other types of care, while lower level help and support (such as cleaners and transport) is frequently arranged on a more ad hoc and informal basis.

Given levels of owner occupation among older people in Hampshire (over 80% among the 65-74 year old age group) and relatively high house prices in the county, extra care housing for sale or lease could play a useful role in meeting the needs of older people who pay for their own care. It has the potential to provide the flexibility required to meet the needs of this diverse population.

Many self-funders appear to have had contact with HCC and many of those interviewed had been assessed and were either paying a contribution to HCC organised care, or paying in full for care arranged or recommended by HCC. However, the survey findings indicate that there are significant proportions of people who pay for care who have not contacted the council. There is scope to raise awareness of older people's entitlement to an assessment and to improve the provision of information to older people, their carers and 'tomorrow's older people' about the services and support which the council and other organisations can offer.

It is clear that there are also considerable numbers of people paying for lower level help and support who may not be in contact with HCC. The voluntary sector appears to play an important role in meeting the needs of this group, thereby potentially contributing to reducing demand for more intensive service later on. Help with shopping, cleaning and gardening are all areas where there is a need among the older population.

Attendance Allowance and Disabled Living Allowance also emerge from the study as having a valuable role in enabling older people to pay for care, lower level support, transport and other kinds of help. The study indicates that raising awareness of available benefits, and of sources of advice and support could be useful for self-funders (and others).

Evidence from another local authority indicates that some older people may require more than information to help them navigate access to the care and support they require. Advocacy and advice services or 'hot handholding' may be a better description of the kind of help required.

The survey and interviews found that unpaid carers frequently provide care alongside other professional carers – the two categories of carer are not mutually exclusive. While the study has demonstrated that people who pay for their own care are an important element in the home care market, it should in conclusion be emphasised that the main source of personal care at home is unpaid, informal care. Supporting carers is therefore an important activity to enable older people to live independently at home.

Appendix 1 – MOSAIC categories and response

MOSAIC category	Number of valid responses	Response rate
B05 Better off empty nesters in low density estates on town fringes	202	12.8%
D14 Older people living in large houses in mature suburbs	142	16.0%
D13 Higher income older champions of village communities	128	8.4%
B07 Empty nester owner occupiers making little use of public services	123	10.2%
M58 Less mobile older people requiring a degree of care	116	13.9%
L54 Retired people of modest means commonly living in seaside bungalows	103	13.0%
C09 Successful older business leaders living in sought-after suburbs	96	13.4%
M56 Older people living on social estates with limited budgets	76	10.2%
L52 Communities of wealthy older people living in large seaside housing	71	15.0%
A02 Retirees electing to settle in environmentally attractive localities	68	13.1%
L55 Capable older people leasing owning flats in purpose built blocks	53	7.2%
M59 People living in social accommodation designed for older people	38	13.0%
M57 Old people in flats subsisting on welfare payments	21	7.4%
K49 Low income older couples long established in former council estates	9	4.3%
L53 Residents in retirement second home and tourist communities	7	6.3%
O67 Older tenants on low rise social housing estates where jobs are scarce	5	12.2%
K50 Older families in low value housing in traditional industrial areas	2	2.8%
Total	1260	100.0%

Appendix 2 – Postal survey

Survey Care needs in Hampshire

How to complete the questionnaire

We are asking about help you pay for yourself or any care that is given to you by an unpaid carer (e.g. relative or friend).

We are not asking about any help paid for by Hampshire County Council directly or via a Direct Payment made to you by Hampshire County Council.

Please read each line and tick any appropriate answers. There are no right or wrong answers. We are interested in your experiences. All information is completely confidential. You can ask a friend, family member or worker to help you fill it in if you wish.

1. We would like to know **if you need or have any help** with some everyday activities, and if you do have any help, we would like to know the amount of help you receive.

	Do you need help with any of the following? Please tick any appropriate boxes	Do you have help with any of the following (unpaid help, or help that you pay for)? Please tick any appropriate boxes	If yes, how many hours of this help do you tend to receive each week? Please write number of hours per week
Moving around your home			
Getting dressed			
Eating or drinking			
Personal care, e.g., help with washing and bathing			
Taking medicine			

2. If you receive help, who do you get that help from?

Please tick all appropriate boxes	I pay an agency	I pay an individual	Unpaid carer (e.g. spouse, partner, family friend)
Moving around your home			
Getting dressed			
Eating or drinking			
Personal care, e.g., help with washing and bathing			
Taking medicine			

3. If you do pay for any of the help listed above, we would like to know the reasons why you pay.
Please tick any that apply to you.

I prefer to manage my affairs independently	
I do not want to share information about my financial or personal situation with Social Services	
I did not know the County Council provides this kind of help to some	
I thought I would not qualify for help from the County Council	
I contacted Hampshire County Council but they explained I did not meet their eligibility criteria (i.e., my needs were not high enough)	
I contacted Hampshire County Council but they explained that although my needs were high enough, I was above the income threshold so would have to pay myself	
Other (please give details)	

4. Do you need help with any of these other everyday activities?
Please tick any that apply to you.

The County Council can encourage private and voluntary organisations to develop such services.

	Do you <u>need</u> help with any of the following? Please tick any appropriate boxes	Do you <u>have</u> help with any of the following? Please tick any appropriate boxes
Cleaning your home		
Shopping for groceries		
Looking after your garden		

5. Which District Council area do you live in? Please tick appropriate box

Basingstoke and Deane		Havant	
East Hampshire		New Forest	
Eastleigh		Rushmoor	
Fareham		Test Valley	
Gosport		Winchester	
Hart			

To help us analyse the results of this research, it is useful to have a little background information.

6. Are you: **Male** **Female**

7. How old are you?

Under 65 **65-74** **75-84** **85 or older**

8. Do you provide a significant amount of unpaid care on a regular basis for a member of your family or a friend?

Please tick appropriate box

Yes **No**

9. Do you live? Please tick appropriate box

Alone	<input type="checkbox"/>
With partner/spouse	<input type="checkbox"/>
With friend or family	<input type="checkbox"/>
Other	<input type="checkbox"/>

10. Which of the following best describes your ethnic origin?

Please tick appropriate box

White	<input type="checkbox"/>
Asian or Asian British	<input type="checkbox"/>
Black or Black British	<input type="checkbox"/>
Mixed Ethnicity	<input type="checkbox"/>
Chinese or Other Ethnic Group	<input type="checkbox"/>

Please return in the FREEPOST envelope provided as soon as possible.

Many thanks for your help.

We would like to **carry out some telephone interviews** to find out more about the reasons why some people pay for help or for their own care. These would last around 15 to 20 minutes. Your **participation is entirely voluntary**.

Please could you provide us with your **name and day time telephone number** if you would be **willing to take part in an interview**.

Your answers will be treated in confidence and you will not be identified in any report of the findings.

If you have any questions, please contact Liz Cairncross at the Institute of Public Care, Oxford Brookes University on 01865 790312.

This slip will be detached from the survey to ensure that there is no way of identifying how an individual responded to the postal survey.

Name.....

Daytime phone number.....

Please return in the FREEPOST envelope provided as soon as possible.

Many thanks for your help.

Appendix 3 - Telephone questionnaire

Introduction

Hello, my name is: XXX from the Institute of Public Care at Oxford Brookes University.

When you recently completed a postal survey for us, you kindly agreed to take part in a telephone interview to help us find out more about the reasons why some people pay for help or for their own care. The interviews will help to improve and develop services in Hampshire.

Taking part in an interview is voluntary, so can I check that you are still willing to be interviewed?

Consent: Yes / No

Is now a good time?

If there is any question that you do not wish to answer, just let me know.

- 1) We want to get a picture of the kind of care and help that older people in Hampshire currently need, so can I start by asking you: if you have any need for care or other help to live at home?

Yes/No

- 1a) If yes, what are your current care needs? (Probe: May be several)

- 2) Do you get any kind of help with these needs?

Yes / No

- 2a) If yes, is this paid or unpaid help?
(Probe for all and check frequency/number of hours per week, paid or unpaid) (Clarify if they pay, whether this is for a council organised service)

2b) If pay for help and not council organised, can you tell me about how you found a care provider? (Probe individual or agency, ease of finding etc)

3) Do you have help with any other activities (for example: DIY/household maintenance, help with transport, eg lifts to appointments, gardening etc)?

Yes/No

3a) If yes, is this paid or unpaid help? (Probe: type of activity for which help received, frequency and paid/unpaid)

4) Do you provide any care or other help to enable someone to live at home?

(For example: To move around their home, Getting dressed, Eating or drinking help with washing and bathing, Taking medicine)

Yes/No

4a) If yes, what kind of care or help do you provide and to whom (check if resident or non-resident carer)?

4b) Roughly, for how many hours a week do you provide care or help?

If the person is a carer or receives unpaid care ...

5) Did you know that you / your carer is entitled to a carer's assessment in their own right (regardless of whether the cared for person is a self-funder or not)

Yes/No

- 6) Did you know that there are services available to support carers in the county?

Yes/No

Contact with County Council

- 7) Have you ever contacted the County Council/Social Services⁸ for help with care or support?

Yes / No (If no, go to Q.9)

- 7b) If yes, what happened? (Probe – who did they speak to, did they get a formal assessment, how recently, etc)

- 7c) If you contacted Social Services, were you offered an assessment of your needs?

Yes/No

- 8) If the County Council refused care/support:

- i) What was the reason for this? (Probe – eligibility, threshold, other)

- ii) Were you offered any other kind of help? Eg, advice, list of care providers (Probe for details)

- 9) If no (have not approached County Council), why not? (Probe – have informal carer, don't think would qualify, would have to reveal personal info, perceived quality of service etc)

⁸ Respondents are likely to be more familiar with 'Social services' than Adult Social Care.

10) Did you know that you are entitled to an assessment, regardless of your means?

Yes/No

11) Before you had a need to investigate options for care and support, did you realise that social care was means-tested, unlike health care?

Yes/No

12) Is there any help or care which *you believe* the County Council could provide you with?

Yes / No

12a) If yes, what would that be?

13) Do you feel you can access good information and advice when you have to make decisions about the future - eg care, finances, housing etc?

Yes/No

14) If you don't feel well informed, what information would be useful?

15) And how/where would you want to go to access it?

To help us analyse the results of this research, it is useful to have a little background information.

16) Could you tell me which of the following age groups you are in?

Under 65	75-84
65-74	85+

17) Are you: married / civil partnership/ cohabiting/ single / widowed / divorced / or separated?

18) Do you live on your own? Yes / No

19) Which of the following best describes your ethnic origin?

White (this includes British, Irish and Other White)

Asian or Asian British (this includes Indian; Pakistani; Bangladeshi; and Other Asian or Asian British)

Black or Black British (this includes Black Caribbean; Black African; and Other Black or Black British)

Mixed Ethnicity (this includes White and Black Caribbean; White and Black African; White and Asian; and Other Mixed)

Chinese or Other Ethnic Group

That was the final question. Thank you very much for taking part.

Note: If any answers indicate a need for further advice/they want an assessment etc, it is really important to us that the interviewer should recommend either Care Choice (Hampshire County Council Adult Services website) <http://www3.hants.gov.uk/carechoice.htm> or contacting Hantsdirect (Hampshire County Council telephone contact centre) tel: **0845 603 5630** to receive further info/access an assessment.

Appendix 4 – Freetext comments

Having fractured a bone in my ankle, I have had much difficulty living at home. A friend who is 75 years old has been looking after me – getting up through the night to assist me in going to the toilet – plus helping me up and down stairs. The GP or district nurse have not visited me – surely at 72 years – I could have had some help?

Social services not interested and I had to arrange my own wheelchair and two high rise toilets from the Red Cross. Having worked for the NHS for 22 years – for one so old – a visit by a GP or nurse would have helped particularly with a shower.

Survey respondent 07539

Being forced to pay is like a second class citizen in accessing support or information. Originally contacted when needs were lower and income higher. Now needs are higher and savings lower.

Even with live in paid agency, there is still a lot of care required by the family. Emergencies when agency let us down. House management, daily pop-ins, paperwork, financial management, garden, decorating etc, etc.

Survey respondent 01686 – paying for 24 hour live in care

Not so much personal care required since shower installed.

Survey respondent 01115

Most of the older people here are having problems getting hospital transport. Botley to Southampton by taxi costs £20 each way.

Survey respondent 02780

I am staying with my daughter at present as I am unable to looks after myself and can't afford the care and help I need at present. My daughter is a widow and needs an income, thus her visits to me are very difficult to arrange and involve a 170 mile journey.

Survey respondent 03634

Pay for half an hour a day. I don't want to share my financial situation because my spouse takes care of it.

Survey respondent 05260

24 hours a day supervision – Alzheimers. Full time care paid for by myself because council won't pay costs.

Survey respondent 05418

I found it would cost me too much (to pay for help). I think I also find it hard to have strangers in my home/only on pension.

Survey respondent 06881

HCC did a 6 week assessment and then passed me onto an agency I have to pay. I am in receipt of guaranteed pension credit and attendance allowance.

Survey respondent 06833

I have applied for financial help but have been told I cannot have as I can wash myself. The fact I can only go out in a wheelchair and use a stick indoors is apparently irrelevant.

Survey respondent 06589

Am bedridden so need constant help with every need. Have paid help 7 to 10 hours a week. Daughter lives in to look after mother.

Survey respondent 08026

I am a 97 year old widower living alone; have lost use of my legs but move about freely on ground floor of large Edwardian house in an electronically powered wheelchair; am just able to dress, undress, wash and get to the toilet, but with increasing difficulty; am thus enabled to stay in *my own home solely because* I have a lady companion, 21 years younger than me, who shares her life with me, does all our shopping and leg work to banks etc, prepares and shares all our meals and when necessary drives me in her car to outside venues. She remains independent, however, and sleeps and maintains her own house and garden nearby. I employ a char and gardener partially paid for by £48 per week attendance allowance.

Survey respondent 08257

Everything I pay for comes out of my disability living allowance.

Survey respondent 08570

Because I am not eligible for care to be provided, I have to find an agency myself. I have found this very difficult to find a reliable agency, which does not send a new person each time. Actually my daughter tries to find help, as it is far too difficult for me because I get confused.

Survey respondent 09451