Developing social care questions
Findings from qualitative research with service providers and service users

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1 Background

Social surveys have gathered minimal information on the receipt and payment of care. The questions vary between surveys and this inconsistency makes question comparison difficult. Existing questions that cover receipt and payment of care may be difficult to answer accurately due to the complexity of social care provision. Service users may find it difficult to distinguish between those providing social care (i.e. private care agencies) and those funding social care (i.e. Local Authorities). Additionally the charging arrangements for funding services are complicated and developments such as Direct Payments (cash) and Personal Budgets (accounts) are not reflected in existing survey questions. There is a desire across several fields for up-to-date information about the receipt and payment for care, especially in relation to people aged 65+.

Researchers in the Questionnaire Design and Testing (QDT) Hub at the National Centre for Social Research (NatCen) are working collaboratively with subject experts in the Personal Social Services Research Unit (PSSRU), London School of Economics (LSE) University of Kent and the University of East Anglia (UEA). The overarching aim of the research is to develop clear, robust questions for social surveys and economic evaluations on the 1) receipt of care and support services by older people; 2) payment for social care for older people; 3) receipt of informal care by older people; and 4) provision of informal care. More specifically, it is hoped that the modules of questions will cover:

- Community-based social care services
- Respite care
- Direct Payments and Personal Budgets for care
- Privately-purchased personal care and domestic help
- Community equipment
- Community health services
- Supported housing, such as supporting people funds
- Disability benefits
- Informal care by relatives and friends (receipt and provision)

Where relevant, questions aim to cover frequency and intensity of care service receipt and user contributions/charges.

Information relating to both individuals living in the community and those in care homes is of interest but for practical reasons the focus of this study is only on those living in the community (as only this group is included in the sample frames for general population surveys) aged 65 and over.

The purpose of this report

A large programme of work is currently underway with six objectives overall, including a review of current care questions (objective 1), consultation with key stakeholders (objective 2) and data owners (objective 3). A review of data linkage procedures has been included
(objective 4) as one idea is to link survey data with Local Authority administrative data about the characteristics of their clients and the social care services they receive. A key objective of the project is to develop a module of survey questions on social care receipt and provision (objective 5). The final stage is to pilot a question module (objective 6) which would be funded separately.

This report addresses the first stage of objective 5 (shown below):

1. NatCen and academic teams will work together, consulting external experts as necessary to develop a shared understanding of the different types of formal services, the terms used to describe them, methods of service delivery and receipt, and how user charges are determined and collected. It will be important to understand these from user and professional perspectives. We envisage in depth interviews with service providers and Local Authorities as well as depth interviews or focus groups with service users.

2. On the basis of this work a draft questionnaire will be prepared.

3. Conduct the first cognitive pilot (possibly more than one strand if the content of the questionnaire is too great to be tested in one strand). The focus is on testing new questions, although testing previous survey questions that have not previously been cognitively tested will also be included to look at the impact of question order effects and appropriateness in this question module. Cognitive testing would also cover questions aimed at gaining consent for data linkage.

4. Review questionnaire, make recommendations.

5. Share revised questionnaire and cognitive findings with funders and data users.

1.2 Methodology

The research outlined in this report consisted of 13 in-depth interviews with service providers (including an informal carer) and two focus groups with service users, aged 65 and over. The in-depth interviews were in London and the South East throughout August and September 2009 and the focus groups took place in two different London Boroughs during September 2009.

For the in-depth interviews a number of care providers were contacted by telephone in geographical areas accessible to the research team. Aiming to identify the Person Most Knowledgeable (PMK), a detailed recruitment protocol was used to assist the recruiters. Upon contacting the PMK, the researcher explained the study, and if informed consent was gained the researcher arranged a time for the in-depth interview. A letter explaining more about the study included the research focus, the organisations involved and how the project is funded. This was posted to the respondents in advance of the interview.

Focus group participants were recruited through contacting two day care centres. Staff put up posters in the centres and the managers of each centre took the lead in finding people who could take part. Following standard practice for focus groups, the participants were given £30 cash as a token of our appreciation for their help in this study.
1.3 Sample for in-depth interviews and focus groups

The in-depth interview with service providers was designed to cover respondents from the different sectors of the care provision:

- Local authority social services
- NHS
- Private providers of care
- Voluntary organisations
- (Informal) carers

The sample was also designed to include providers of services for areas of impact on the recipient: 1) Personal Care; 2) Food/nutrition; 3) Social participation and involvement; 4) Accommodation including cleanliness, comfort; 5) Nursing and therapy; 6) Employment and occupation. A list of the types of organisation which could provide the information on these impact areas was then formulated (such as a Day care centre, an Occupational Therapist or a Manager of a Local Authority Social care department). See Table 1 below for a breakdown of the individuals (from organisations providing care), who took part in the in-depth interviews. In addition the sample was designed to include respondents who would be able to give an overview of social care provision and provide information on assessment of needs and payments for social care (which do not come under areas of impact). The sample provided a good mix of respondents with an overview of provision.

The list below shows the 13 respondents for the in-depth interviews grouped by sector. Within each sector the respondents are listed roughly in order of the extent to which they provided an overview (at the top) or had regular contact with service users (at the bottom).

**Local Authority providers**
- Manager of Adult Social Services, London Borough
- Manager of direct payments team
- Team Manager of Benefits and Charging Consultancy in a Local Authority
- Head of assessments for Adult Services within a Local Authority
- Manager of a Social Services Intermediate Care Team
- Broker in a self-directed support (SDS) team within Social Services
- Social worker in Physical Disability Team

**NHS provider**
- Service manager for Adult multi-disciplinary team based in hospital

**Private sector providers**
- Manager of a (Local Authority contracted) private care organisation

**Voluntary sector providers**
- Specialist in funding for major charity for the elderly
- Manager of a day care centre
(Informal) carers

- Director of an unpaid carers organisation
- Informal carer (to a parent)

For the focus groups with service users, the samples were designed to include men and women from a range of age groups (over the age of 65). Table 2 below shows the characteristics of those who took part in the two focus groups.

Table 1.1: Summary of characteristics of focus group participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number with characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Focus group 1</td>
</tr>
<tr>
<td>Gender of participant</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>1</td>
</tr>
<tr>
<td>75-84</td>
<td>3</td>
</tr>
<tr>
<td>85+</td>
<td>2</td>
</tr>
<tr>
<td>Health status</td>
<td></td>
</tr>
<tr>
<td>Uses walking aid such as a walker/wheelchair/walking stick/needs the support of person</td>
<td>2</td>
</tr>
<tr>
<td>Has condition which causes memory problems such as dementia</td>
<td>1</td>
</tr>
<tr>
<td>Other (cardiovascular)</td>
<td>0</td>
</tr>
<tr>
<td>No condition reported</td>
<td>3</td>
</tr>
</tbody>
</table>

1.4 Conduct of the in-depth interviews and focus groups

Three researchers carried out the interviews and focus groups: two from the QDT Hub and one very experienced qualitative researcher. Two similar topic guides were used for interviews and focus groups.

In-depth interviews took place at service providers’ workplaces and were conducted face-to-face on a one-to-one basis, ensuring respondent confidentiality. Each interview lasted approximately an hour and was recorded with the respondent’s consent. Two researchers were present at each focus group. Each group consisted of around 6 people and were recorded with participants’ consent.

Following the in-depth interviews and focus groups, members of the research team listened back to the recordings and entered the qualitative data in an Excel analytical framework, or ‘chart’. This chart was based on Framework, the analytical tool developed by the former Qualitative Research Unit at NatCen. This chart allowed for the data to be organised in a
coherent and structured way. The Excel chart listed the areas explored in the interviews as column headings along the page and individual cases down the page. The chart summarised characteristics of respondents, such as job role and area of provision. Under each column a summary was made of each respondent’s thoughts and the issues they had raised. Thus, data could be read horizontally as a complete case record for an individual, or vertically by area across all cases. Once the chart was completed the data was reviewed, unravelling the matrix the full range of issues were unravelled.

1.5 Terminology in this report
Notably the term ‘carer’ was used in a number of ways to describe different roles within care provision. Those consulted during this qualitative research, which included both service providers and service users, used ‘carer’ when referring to:

1. A spouse, family member, friend or neighbour providing unpaid help to someone over the age of 65\(^1\);

2. A professional carer employed by Social Services/the NHS providing help to someone over the age of 65; and,

3. A professional carer employed by a private care agency or another organisation, which could be contracted by Social Services to provide help to someone over the age of 65.

It should also be noted that service users do not necessarily refer to their spouse, family member, friend or neighbour as ‘their carer’ (see section 6.2), and the use of terms may vary depending on the responsibilities of the person caring: for instance moving from shopping every other week for the person, to coming into the home every day to helping the older person with their daily living activities.

To add further complication to the use of the term ‘carer’, service users may not necessarily be paying for the services provided by the professional carer themselves. In certain cases social services may pay for the care on the person’s behalf. However an older person may pay for the professional carer, either using their own money or money from their direct payments or individual/personal budget. Notably some may not organise their own finances as someone else could be paying the carer for them.

Throughout the rest of this report, the term carer shall be placed in inverted commas (‘carer’) to highlight that this was how it was referred to by respondents. In chapter 6, we use the term ‘informal carer’ to describe a family member or friend who provides social care. However, we also explain why in this chapter why this term should be avoided in survey questions to describe such providers of care. In the final chapter we deal with how this term should be used in a questionnaire module as it is vital and equally important that:

- questions do not confuse respondents; and

\(^1\) Direct payments can be used to pay a ‘personal assistant’, who can be a friend, neighbour or family member who does not normally live with the person. Direct payments cannot be used to employ close relatives who normally live with the person, except in exceptional circumstances. This is taken from an information leaflet provided by one London Borough.
those collecting the data can be sure about **who** is being referred to when they look at the data.
2 Social Care

2.1 Conceptions of Social Care

Findings

The qualitative research with service providers and services users revealed the complexity in provision and understanding of social care. Amongst service users, the term ‘social care’ was understood in one of three ways.

1. Had no idea what it meant;
2. Understood it as any broad forms of help for someone who could not look after themselves irrespective of age; or,
3. Understood it as specific forms of help they had personally needed or currently require because of old age.

Service users, who understood social care as (2) above, mentioned ‘blanket care’, ‘help to get you back into society’ and ‘help with your health and home’. Service users who viewed social care in the third way, described social care as help needed when they could no longer do something or manage in an area for example, help to wash ones self or shower, or having a cleaner to help with domestic tasks.

Among service users who had an understanding of social care, needing help with washing or dressing was considered in important form of social care. A discussion in one focus group concluded that social care does not cover practical tasks such as changing a light bulb or fixing jammed doors or drawers. Although these are tasks that people aged 65+ find difficult, they are small tasks that could be aided by a neighbour or family.

Not surprisingly, service providers had a good understanding of the social care provision they were involved in. For example the manager of a private organisation who provides care for older people easily explained the tasks that ‘carers’ provide and how the LA subcontracts care, the informal carer clearly knew the care roles she provided and interviews with social services and NHS revealed their specialist role. In the in-depth interviews we did not explore how service providers defined social care.

The in-depth interviews revealed that social care provision is variable between areas at the local authority, health authority, borough or council level, and generally across the country. In addition to area differences, there are variations in time with changes being implemented and new policies being introduced. To ensure that the question module will be appropriate over time, the questions need to be carefully worded and avoid policy language. This will also help respondents as a consistent finding was that respondents cannot be expected to understand technical terms.
Implications for questionnaire design

- The term 'social care' is not consistently understood and is open to interpretation. It therefore should be used carefully and explanations provided, if used in a questionnaire.
- Variations in social care provision between areas and across time, means it is important that questions are designed in such a way that they are applicable across a range of circumstances. This implies a need to tie them to the needs of service users, rather than particular services (which may change).

2.2 Service provision amongst people aged 65+

Types of care

The qualitative interviews with service providers showed that social care services given in the receiver's home can broadly be considered as either Home services or Transition care. Home services include providing personal care, companionship, housework duties, laundry duties, preparing nutritious meals, sleep in duties and specific time duties, like getting a person up in the morning, putting them to bed or visiting to give them their medication. The aim of transition care is to maximise opportunities for people to be cared for in their own home. Services provided under the umbrella of Transition care include intermediate care, reablement services and residential care homes (see box 1 for how one service provider explained the different aspects of Transition care). All Home services are relevant for the question module and aspects of Transition care are also relevant, namely, intermediate care, reablement services and respite care. There are important differences in the way in which Home care and Transition care are provided (whether by Local Authorities or the NHS) and the various ways to pay for these services.

Box 2.1: Key Definitions of Transition care from the in-depth interviews

**Intermediate care**

Where a person has an assessment as to what their long-term destination should be, e.g. Residential or nursing home or at home. Intermediate care is now specifically used in reference to the provision of care at home and no longer covers a period in nursing home. This allows for rehabilitation at home and prevents people going into the hospital (in-depth interview with service manager of an adult multi-disciplinary team based in hospital).

**Reablement Service**

Team works intensely to optimise a person’s independence over a 6 week period. For example someone may not be able to walk on their own to the toilet but can manage if they hold onto furniture (in-depth interview with service manager of an adult multi-disciplinary team based in hospital).

**Care Home**

Can go to a care home for rehabilitation while reablement service sorts out
appropriate package of measures to enable person to return to own home (in-depth interview with service manager of an adult multi-disciplinary team based in hospital).

**Implications for questionnaire design**

- It is important to distinguish between care received at home as Home care and care received as Transition care where possible, since this impacts on who provides the service and whether there are user charges.
- Given the short time periods for which Transition care tends to be provided, among users of care, Home care is likely to be more prevalent and so the focus should be on collecting data on Home care.

2.3 **Who provides care and what care they provide**

Both service providers in the in-depth interviews and service users in the Focus Groups were asked which organisations or bodies provide social care. Figure 1 below illustrates all the different providers of social care for older people identified by service providers and service users. Service users identified the voluntary organisations who could receive social care. For ex-service men and women (served in WWII) they identified the RAF as providers of respite care and the British Legion provides care homes and will take them to their care homes. On a rare occasion a focus group participant identified that Friends of the Elderly ran the day centre (where the focus group took place) and provided the person with a cleaner. Age Concern/Help the Aged was recognised by service users and service providers as providing a handy man service. Although service providers recognised that the LA offered social care services, generally service users did not refer to LA social care, alternatively acknowledging the NHS and social care services as the main providers.
What is important in this research is to:
1) identify which services are provided and
2) look at how these services are understood by service users.

In this section we compare the range of services which service users identified as ‘social care’ services with the range of services mentioned by service providers in their interviews. It should be noted that service users' understandings of services were based on their experience. A smaller range of services were identified by service users in comparison with service providers. As the service users in the two focus groups only used a few services, this could explain the awareness of a lower number of services. However, it is also likely that service users understanding of the remit of ‘social care’ differ from the providers' definition. This is discussed in more detail below.

Table 2.1 below focuses on broad types of service provision. It includes types of provision recognised by service users (i.e. those consulted in focus groups), and those mentioned as being provided by service providers. Provision by or through the local authority is shown separately from provision through the NHS. The table shows whether the area of service provision was identified by service users and service providers, or only by service providers (if shown in the second or third column but not in the first column).

It is notable that there were no services identified by social care service users which were not mentioned by service providers (either local authority or NHS). However there were a wide range of services reported by service providers, which were not identified by service
users. This does not necessarily mean that data cannot be collected on these types of service in a questionnaire, but it does mean that care needs to be taken with the term ‘social care’ which respondents did not interpret as widely as service providers. For example, specialist services such as occupational therapists or speech therapists did not seem to be considered as ‘social care’ by service users.

Table 2.1. Care services identified by service users and identified by service providers as providing this service, whether it is paying, organising or actually providing the hands on service.

<table>
<thead>
<tr>
<th>Services identified by service users</th>
<th>Social care services provided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Local Authority or Social Services</td>
</tr>
<tr>
<td>Care in the home (e.g. washing, toileting, cooking)</td>
<td>Home Care</td>
</tr>
<tr>
<td>Thing around your neck to call for help</td>
<td>Telecare</td>
</tr>
<tr>
<td>Day Centre</td>
<td>Day Centre</td>
</tr>
<tr>
<td>Intermediate care</td>
<td></td>
</tr>
<tr>
<td>Getting specialised equipment &amp; adaptations e.g. a bath seat, stair lift, wheel chair, railings etc</td>
<td>Specialist adaptations to the home and or equipment e.g. raised toilet seat, bed raisers, chair raisers, bath seat</td>
</tr>
<tr>
<td>Laundry services (in exceptional circumstances e.g. when a service user suffers from incontinence)</td>
<td>Occupational therapist</td>
</tr>
<tr>
<td></td>
<td>Social Workers</td>
</tr>
<tr>
<td></td>
<td>Physiotherapists</td>
</tr>
<tr>
<td></td>
<td>Speech therapists</td>
</tr>
<tr>
<td></td>
<td>Language therapists</td>
</tr>
<tr>
<td></td>
<td>Community Rehab services</td>
</tr>
<tr>
<td></td>
<td>Medication Pumps</td>
</tr>
<tr>
<td></td>
<td>Provide respite care</td>
</tr>
<tr>
<td></td>
<td>Direct payments and Personal Budgets</td>
</tr>
</tbody>
</table>

Table 2.2 shows the more specific social care services provided, mainly related to the need for help with specific tasks (e.g. need for help with washing and bathing). This table shows provision by three types of provider (informal carer, private care provider, day care centre). The table shows that there is a great degree of overlap between understanding for services which are provided in the home on a day to day basis and involve personal care (e.g. washing, bathing, help getting up, help getting dressed). As mentioned in the previous section, participants in the focus groups felt that needing help with these types of task demonstrated that someone needed/received social care. Table 2.2 also presents the terms used by service users to describe the type of care in *italics*. With a few exceptions this shows a good overlap with how service providers described care tasks. ‘Help getting up’ was referred to by the private provider as ‘specific time duties’ and it is clear that terms like this should be avoided in a questionnaire for service users. Elsewhere in this report we
present findings related to the sensitivity of certain terms and alternative terminology that are more appropriate.

The table also shows a range of services which service providers offer and recognise as social care that the services users did not consider (shown as non-italics in table 2.2). Possible reasons for these not being recognised by service users may be that:

- they are not provided on a day to day basis so may be less salient in service users’ minds (e.g. help collecting prescriptions, help with repairs);
- service users may not know that the help is being given or may not realise the extent of the help (e.g. sorting out social care services);
- service users may consider help they would receive regardless of their social care needs and may even have been help which they provided to their ‘carer’ in the past (home repairs and maintenance);
- service user may consider the help to be a normal social activity which anyone might do (e.g. computer classes).

These findings again emphasise the importance of asking about specific services or needs, and not asking about ‘social care’ in general, as the interpretation for each term may vary. It is also important to note that if proxies are allowed to assist respondents in a survey they may have a wider interpretation of care provision than service users which would affect data measurement. In this qualitative research we did not interview the recipient of care mentioned by the ‘informal carer’ to understand if they had the same understanding of social care.

**Implications for questionnaire design**

- Asking service users about care received in specific areas of personal need should be possible and will generally be in line with definitions used by service providers.
- In other areas such as arranging care services, service users may not know the extent of help received, so consider whether data is required and falls in the remit of social care.
- In areas such as help with repairs, informal carers (family members) living in, and attendance at classes, respondents may not recognise these tasks or be resistant to think about these tasks as social care. It should be possible to collect data since respondents should know whether they receive it, but the questions need to be carefully worded to elicit this information.
Table 2.2. Care services identified by service users and care services provided by service providers (laid out to illustrate the areas of overlap). This table identifies specific areas of need.

<table>
<thead>
<tr>
<th>Services identified by service users</th>
<th>Services provided by Carers (adult child caring for a parent)</th>
<th>Services provided by Carers from private organisations</th>
<th>Services available in Day Clubs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing and washing</td>
<td>Help with showering</td>
<td>Bathing and washing</td>
<td>Bathing</td>
</tr>
<tr>
<td>Getting someone up in the morning</td>
<td>Steps in if carer doesn't turn up (statutory or private)</td>
<td>‘Specific times duties’ – getting a person up</td>
<td>Nail cutting</td>
</tr>
<tr>
<td>Helping someone to get ready for bed</td>
<td>Helping someone to get ready for bed</td>
<td>Helping someone to get ready for bed</td>
<td></td>
</tr>
<tr>
<td>Empty the commode</td>
<td>Helps with toileting</td>
<td>Help to go to the toilet</td>
<td></td>
</tr>
<tr>
<td>Preparing meals</td>
<td>Does all the cooking</td>
<td>Making meals &amp; cleans up</td>
<td>Provides Lunches</td>
</tr>
<tr>
<td>Help with home cleaning</td>
<td>Housework (dusting, polishing, vacuuming, general tidying, gardening, and takes out the rubbish)</td>
<td>Housework (dusting, polishing, vacuuming, general tidying, waters plants)</td>
<td></td>
</tr>
<tr>
<td>Help with laundry</td>
<td>All the laundry and ironing</td>
<td>Laundry (washing clothes, changing bed sheets, ironing)</td>
<td></td>
</tr>
<tr>
<td>Help you to go out</td>
<td>Supports the person to various places e.g. doctors, hospital</td>
<td>Befriending Accompanying person on a walk/ Taking a person on an outing</td>
<td>Befriending scheme Accompanying person on a walk</td>
</tr>
<tr>
<td>Does the shopping</td>
<td>Does the shopping</td>
<td>Does the shopping</td>
<td></td>
</tr>
<tr>
<td>Companionship</td>
<td>Companionship</td>
<td>Companionship Reads and writes, plays cards, crosswords &amp; quizzes</td>
<td>Companionship</td>
</tr>
<tr>
<td>Gives medicines</td>
<td>Reminds person of things e.g. to take their medication</td>
<td>Specific personal care e.g. skin or feet care, remind them of their medicines or gives medicines</td>
<td></td>
</tr>
<tr>
<td>Collects prescriptions</td>
<td>Collects prescriptions</td>
<td>Collects prescriptions</td>
<td></td>
</tr>
<tr>
<td>Sorts out care services</td>
<td>Helps get care services</td>
<td>Information and advice e.g. benefits Fuel efficiency talks</td>
<td></td>
</tr>
<tr>
<td>Live in care</td>
<td>Live in care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps person with their exercises</td>
<td></td>
<td>Exercise Classes</td>
<td></td>
</tr>
<tr>
<td>Supports another unpaid carer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Handiwork/Repairs</td>
<td>Respite care</td>
<td></td>
<td>Handy man service</td>
</tr>
<tr>
<td>Opitions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Examples include: replacing light bulbs, renewing bath sealant and tiling small areas, unblocking sinks, replacing toilet seats, fitting door chains and locks, smoke alarms, key safes.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2.4 The people involved in delivering social care services

The in-depth interviews with Service providers revealed the types of individuals involved in providing care services. The following people were mentioned across the interviews that were carried out:

- Trained nurses (offering the nail cutting service at a day care centre or changing dressings at home)
- Volunteers (person providing the handy man service)
- Care workers trained in health and safety, manual handling food preparation and qualified at NVQ level 2 or above
- Social workers
- Home based care team within a Local Authority
- Home care managers/ Home care workers
- Care co-ordinators (who facilitates the care package)
- Occupational therapist.

Although, gender was not explored in detail, female family members seemed to provide most of the care whilst male family members helped with organising the person’s care and shopping. Therefore it is important that the questions are worded to ensure male carers and their roles are captured in the questions.

2.5 Service users lack of awareness about whether services are provided by NHS or Social Care Services

The focus groups and the in-depth interview with the informal carer highlighted the difficulty of asking questions about the organisation that provides the care the person receives. This was shown by focus group participants saying:

- they didn’t know;
- their sibling or adult child “manages all of that”;
- the hospital did that; or,
- they only know the first name of the person who provides care and they did not know the name of the organisation that employs the worker (as their family member had quite possibly arranged this for them).

Participants discussed in the focus group that if they needed further assistance in arranging some care service they would either ask their family, the warden at their sheltered housing, someone working at their day centre or their GP to organise the care for them.

Although the informal carer interviewed for this study was well informed, this respondent did not know whether the social worker, occupation therapist or physiotherapist for her mother came from the hospital or social services. This was because she had spoken to many people to organise care for her mother, when her mother was in hospital. As a service provider indicated, service users tend to come into the system at a time of crises so it is not appropriate to expect them to remember precise details about who provided services. This was supported by our qualitative analysis or service users. This is an area
that needs to be carefully thought out in the question module as to whether to ask questions that look at services such as reablement which could be provided by both the health care services and the social services.

In both focus groups, participants were asked to sort a set of cards, which each had an example of a task (such as ‘help with washing or bathing’). Participants were asked to sort the ‘task cards’ into 4 groups in relation to whether they thought the task (or service) would be provided by:

1. The NHS;
2. Social care services;
3. Either the NHS or Social care services; or,
4. Other.
Additionally, participants were told that they could create a ‘don’t know’ group.

The exercise revealed that people on the whole had a clear understanding of the specific tasks described on the cards and knew if they received that service. When a person did not know about a service on the whole it was because they did not receive that service, although it was not always appropriate to explore this in a focus group setting.

What was clearly revealed by this exercise is that service users are not confident if the task or service is provided by the NHS or Social Services. In one focus group, participants created a new category in this exercise and called it ‘Carer’. This was because participants knew they received help with this task (or service) from the professional carer but they were unable to categorise their carers’ into provided by social care services or provided by NHS. The ‘other’ option wasn’t viewed as a satisfactory fit because they knew the carer fulfilled this role.

The qualitative research suggests that for the question module, care roles can be categorised into three groups of understanding of whom service users believe provides help with that task (or provides the service). Specific questions will need to be developed to look at who provides help with the task (or provides the service) in each group. The three groups are:

Group 1) service users can distinguish between a professional carer or family member who provides this service but who do not know which organisation provided the professional carer;
Group 2) service users do not know who provides the service and it is not clear how we could find this out in the question module;
Group 3) service users know which organisation provides the service.

The findings are presented in **table 2.4**.

**Services viewed as health care only**

In one of the focus groups, ‘help with eating’ was viewed to be the only serviced provided by the NHS. In the second focus group there were no services viewed as exclusively
provided by the health care sector. According to the knowledge that was harnessed through the in-depth interviews with service providers, this task is something that would be provided by social care services so does fall within the remit of the question module.

2.6 Care tasks or services that may be sensitive to ask about

In table 2.3 we provide evidence from the focus group and in-depth interviews about the sensitivity of asking about specific care role and understanding of care roles. We also present any evidence for how it should be asked and finally highlight any problematic issues for the question module in relation to the particular social care service. This research suggests that all of the tasks/services that were explored via the card sort exercise can be asked about in the question module. However, some tasks/services require sensitive phrasing. This research indicates that this is the case for:

- Help using the toilet or managing incontinence; and
- Help with eating.

It was also found that reablement and telecare are understood when described but the terms are not well known, so any questions which ask about these services will need an explanation.
<table>
<thead>
<tr>
<th>Understanding and Sensitivity</th>
<th>Tasks</th>
<th>Details for Question Development</th>
</tr>
</thead>
</table>
| **Understood the task/service but sensitive to ask** | Help with bathing or washing  
Sitting with people during the night  
Help with eating  
Lifting and moving people, e.g. from and to the commode  
Help using the toilet or managing incontinence | - Service providers viewed this as sensitive to ask. Advised asking if people need any help with going to the toilet. Can’t use lifting, a service provider suggested moving or handling |
| **Understood the task/service and NOT sensitive to ask** | Help with changing dressings  
Help with brushing teeth  
Help with getting dressed or undressed  
Help with Hair care  
Help with Skin care  
Help with preparing meals or serving meals  
Help with taking out the rubbish  
Help with housework or cleaning  
Help with handiwork and repairs  
Help with laundry or ironing  
Adaptations and equipment  
Transport to the day centre  
Day centre  
Lifting and moving people, e.g. from their bed to their chair | - Moving or handling more appropriate terms |
| **Understood the task/service when explained by other service users and NOT sensitive** | Help setting up Telecare (community alarm systems)  
Reablement | - Better to describe the service than ask directly such as help alarm worn around the neck |
| **Not understood** | | |
Table 2.4: Whether service users know who provides the service and whether they can distinguish between NHS/Local Authority provided social care

<table>
<thead>
<tr>
<th>GROUP</th>
<th>Tasks</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>GROUP 1</td>
<td>Help using the toilet or managing incontinence  &lt;br&gt; Help with brushing teeth  &lt;br&gt; Help with changing dressings  &lt;br&gt; Help with bathing or washing  &lt;br&gt; Help with getting dressed or undressed  &lt;br&gt; Help with preparing or serving meals  &lt;br&gt; Help with housework and cleaning  &lt;br&gt; Help with laundry or ironing</td>
<td>- Useable terms and could ask who provides the service by the type of individual i.e. professional carer or family carer but can’t ask about social care services etc.</td>
</tr>
</tbody>
</table>
| (Service users can distinguish which individual provides this service i.e. professional carer but not clear which organisation the professional carer come from or if service is provided by a family member) | Lifting and moving people, e.g. from their bed to their chair  <br> Sitting with people during the night  <br> Adaptations and equipment  <br> Reablement  <br> Day Centre  <br> Help setting up Telecare | - The tasks in this group are listed here because:  
  i) Further evidence is needed to know if who provides this care can be asked; or,  
  ii) Interviews with service providers showed there are variations in whether the LA or the NHS provides this service, and as service users don’t know who provides this service at the individual or organisational level it isn’t clear how we can explore these services in the question module |
| GROUP 2 | Hair care (Hair dresser)  <br> Help with eating (NHS)  <br> Help taking out the rubbish (Help the Aged)  <br> Help with handiwork and repairs (Help the Aged/Day centre’s handyman)  <br> Transport to the Day Centre (Social Services) | - Useable terms and could ask who provides the service at the organisational level |
| (Service users cannot distinguish who provides this service and not clear how we could find out) | | |
| GROUP 3 | | |
| (Service users know the organisation that provides this service) | | |
Implications for questionnaire design

We introduced 29 tasks/services to focus group participants in the card exercise. Due to time we were unable to extensively discuss how service users understood all 29 tasks but it was apparent when a task or service was poorly. In addition not all the cards were sorted understood (we have discussed above our findings related to 21 tasks). The exercise allowed us to explore service users' knowledge of who provides each particular service. The research also showed the multitude of services provided by carers, whether they were family members providing social care or professional carers provided by social services, private organisations or day clubs.

In addition, the card sort exercise showed that it will be difficult for respondents to provide detail on which body or organisation provides the service. The evidence suggests that it will be possible to ask what a 'professional' carer does for that person, as well as what family members do but it may be difficult to gather data on the distinction between different types of professional carer. However the latter will have to be phrased so that the respondent thinks about the types of help the child, or other family members provide.

We feel that it will be very difficult to design questions that captures where the (professional or paid) 'carer' comes from. Are they employed by Social Services' in-house homecare team or do they work for a private care agency? One man in one of the focus groups knew that his carer was “from 21” but could not reveal anything else about his/her employer. An internet search of providers with this name, in this person's area, revealed that he was quite possibly receiving care from a registered housing association, an organisation registered as a charity. The distinction between types of carer is probably vital, however it will not always be possible for the service user to be able to provide this level of detail.
3 Nature of service delivery

3.1 The location of service delivery
Service delivery was explored using the in-depth interviews with service providers and focus groups with service users. This enhanced our understanding of how care services are delivered, in terms of frequency, duration and the determining factors. Home care services are unsurprisingly always provided in people’s homes via a face-to-face visit from a carer whilst the care services offered by a day care centre can be provided at the day care centre building, in the community (exercise classes in church halls for example), or in people’s homes – the handy man service provided by Age Concern day care centres for example.

Any questions which are designed to tap into receipt of services delivered via a day care centre, therefore, need to be phrased in a way which includes services which are not received at the day care centre’s building: exercise classes delivered in the community for example.

3.2 The frequency of service use
In relation to home care services, the frequency of delivery tends to relate to the complexity of the service users’ needs. For example, users under the remit of Intermediate care would either be visited at home during ‘critical times’ (7.30am to 9am), if they have incontinence problems, or later in the morning if they are more able by themselves. A recent discharge from hospital may require more intense care, with several people involved in the delivery – regular visits from a carer to help with personal tasks and an Occupational Therapist to assist with exercises - and a service user with a very complex care plan may require four visits a day with two carers at a time so that they can be hoisted. According to those we consulted, home care visits generally tends to occur in the morning and again in the evening if necessary, as these are the times of the day people are most likely to require assistance: for example getting out of bed in the morning and into bed in the evening.

Day care services might operate four days during the week and on those days transport would be provided to bring people to the centre and take them home at the end of the day however people may not use these types of services every day. For instance all of the participants in one of the focus groups attended that particular day care centre once a week, on a Thursday. Questions can be designed with frequency in mind (i.e. once a week, 2-3 times a week etc).

3.3 The duration of service use
Depending on what needs to be done for the person, a service user may not necessarily receive a home care visit everyday and could instead, for example, have a carer visit them to clean their home for 30 minutes once a week. Regardless of the number of days care is delivered in a week, the duration (in hours) of care delivery could be 15 minutes, 30
minutes, 45 minutes or 1 hour depending on the complexity of the person’s needs. According to the manager of a Local Authority contracted private care organisation however, 30 minutes is the most common duration for a home care visit. For services other than homecare however, the duration may differ. So, a service user may attend a Day Care Centre for the whole day (i.e. 10am – 4pm) and therefore time bands need to be designed with other services in mind.

**Implications for questionnaire design**

- The complexity of a person’s needs, which will be translated in a complex care plan, will determine the frequency, and duration for receiving home care services. A decision needs to be made around whether questions should be designed to ask about the frequency of each service received separately or for each care/health provider.

- We suggest that a reference (or recall) period of a week is sensible. It is important in the question module to be able to identify the number of times in a day as well as the number of times in a week.

- For duration, we need to consider whether we ask about duration of care received over a week or on each day that it is received. We could use the existing time bands for hours per week (0, 1-19, 20-49, 50+) however this may not necessarily be translatable into per day amounts. It may be more appropriate to ask about smaller time frames in order to get a clearer indication of low receipt of care. There is also the distinction of whether the questions should ask about care provision in *total* or per *visit*.

Time bands could be used for most services, e.g. Home Care service delivery, as well as attendance of a day care centre. An alternative approach may be necessary to measure frequency for services are unlikely to be used/provided as regularly such as the Handy Man service.
4 Assessments and decision making around provision

4.1 Accessing services
It appears, through consulting both service providers and service users, that there are multiple ways in which people aged 65+ find out about the services that are available. Before we list the ways people find out about services, it is important to recognise a reoccurring view, held by both those involved in service provision and by service users which emerged during the qualitative work. This was the recognition that there are people aged 65+ living in the community who do not know about social care services that are available to them. These people may only find out about services when they really need them.

Service users, who become aware of the social care services available to them, tend to find out about these via the following channels:

- On reading a Local Authority, or London borough, manual which lists phone numbers of who to contact
- On picking up an Age Concern leaflet at the doctor’s surgery or in hospital
- Via the internet
- Through word of mouth – talking to friends or family members

Service users tend to first come into contact with social services via a number of access routes, the main ones are shown in figure 1 below.

**Figure 4.1: Routes through which older service users come into contact with social care services**

![Diagram showing routes through which older service users come into contact with social care services]
A very common route through which people aged 65+ come into contact with social care services is through the hospital. A participant in one of the focus groups spoke about PALS located in the hospital, and how you can ask them to get in touch with social services for you. Hospital discharge teams are responsible for ensuring that service user’s needs are met when they return home – i.e. they have a carer and the equipment that they need. The discharge team might refer the older person to the Intermediate care team, who would then be involved in helping the person to return to home living (usually free of charge for up to 6 weeks\(^3\)). According to a respondent from a large charity who was consulted as part of the qualitative work, the NHS has a duty to refer people to social services where they see the person may need help at home and social services have a duty of responding, and carrying out an assessment within three days otherwise they face a fine. These procedures are in place to ensure safe discharges.

A person’s GP may well contact social services on the person’s behalf, or sometimes on behalf of the carer, but more often than not the GP will advise the person to contact social services directly. GPs generally refer people to Intermediate care teams who provide rehabilitation care to people and help prevent them from going into hospital.

4.2 Service users lack of awareness of access routes

The level of awareness held by people aged 65+ in the focus groups was relatively low but may well be sufficient for data needs: for example, they knew that the hospital had contacted social services when they left hospital but did not know the details or they knew that a family member had contacted social services on their behalf but again they did not know any further information about the process. Supporting evidence about this lack of awareness was gathered from service providers, some of whom held the view that we should not ask service users about how they came to receive social care services as they will not always know.

Implications for questionnaire design

- Unless it is of specific interest to explore the detail about the process by which they accessed the service, which we feel that respondents would not always know, it is probably feasible to ask a basic question about the route of contact for different services. However there will always be a group of older people who will not remember the route nor simply not be able to recall so a ‘don’t know’ response category would be necessary.

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\(^3\) Intermediate care is not necessarily always 6 weeks. It can vary from between 4 – 6 weeks and in some cases exceed this amount of time.
4.3 Assessments

During the in-depth interviews, those we consulted were asked how the needs are determined for an individual aged 65+. There seemed to be agreement around the requirement for a ‘double assessment’, as a manager of a Day Care centre referred to it. As a result of the fair access to care criteria, people now face a 1) needs assessment, and a 2) financial assessment (means testing). The two assessments are described in detail below. Everyone is entitled to a free assessment from social services (regardless of their financial situation) although, according to a manager of Adult Services from one Local Authority, those with income and assets equating to more than the capital limit for that council do not usually have their needs assessed.

Of importance for the questionnaire design, especially if assessments are to be asked about, is that not only do Hospital Discharge teams (and Multidisciplinary teams) refer people to Social Services for assessments, but assessments can also be carried out in hospital. So, a person aged 65+ can be assessed in hospital prior to discharge. The manager of the Multidisciplinary team would explore what the person needs and find out about their destination on discharge. After discharge the social worker will talk to the person about post discharge care. Occupational Therapists and Physiotherapists may also be brought in to explore equipment and other needs once the individual is back in their own home. This means that assessments can happen in several sessions over a period of time.

People aged 65+ can undergo complex assessments. For example, there are several different kinds of assessments often carried out by multidisciplinary teams that sometimes merge to form the outcome assessment (i.e. a health assessment and a social services assessment). In particular, the qualitative analysis suggests that the intricacies in the assessment process should be avoided in a set of questions for older people. Primarily due to the complexity of these procedures as well as the lack of knowledge and memory problems that people within this population may face.

4.4 Needs assessments

During the needs assessment, the person is assessed in terms of whether they meet the Local Authority’s eligibility criteria for level of need. Local authorities assess older people’s needs for care services into four categories:

1. Substantial need;
2. Critical need;
3. Moderate need; and,
4. Low need.

By law, all Local Authority’s are required to provide care services for those categorised as ‘substantial’ or ‘critical.’ However some councils extend their remit and provide services to people with moderate and sometimes even low (level) need.

As well as the assessment, there is a self assessment questionnaire that takes the user around an hour to complete. The questionnaire contains a range of questions (15 in total
in one LA we consulted), to assess the level of need and each question carries points which are then converted into money. Social Services assessment and the self assessment questionnaire go through the Resource Allocation Tool (RAS) which decides on the financial allocation for each service user. We were not able to harness a comprehensive understanding of the RAS but it was mentioned by various providers.

Needs assessments should, according to a respondent who works for a large charity helping elderly people, always come before means testing assessments to ensure that a person-centred care plan is formulated. The user should be involved, however in reality the user’s needs often have to fit around the availability of care provision.

In considering the feasibility of asking service users about assessments, the researchers concluded that these assessments were interesting to a question module and the qualitative analysis surfaced the following issues:

- Service users are not necessarily going to know that the lady who came round for that chat was an ‘assessment’. Likewise they would not necessarily know that the results from the conversation (‘the assessment’) would have shaped what they ended up receiving as part of their care plan (Manager of London borough Day care centre)
- Assessments are complicated and differ by area (manager of Adult Services at a Local Authority).

Service users discussed assessments; usually relating to their own experience and it was evident that they were unable to give prolific detail. For example, some of the comments service users raised included:
- Social service come and make an assessment and assess what you need;
- 'Adult Services', which is social services still but is higher up and for the over 80s, do all of that;
- They come to you and ask how you are getting on and they have a look, they say you could do with a rail in the bathroom. They do not ask you whether you can afford to buy it though; and,
- You might have been financially assessed once upon a time and they send you forms to fill in.

### 4.5 Financial assessments

The second assessment (financial assessment) takes place to assess whether the person has the funds to pay for their own care (see section 5 on funding). During this assessment the individual provides information on their benefits, savings and assets information as well as their expenditure. There was agreement amongst service providers regarding the reality that financial means testing is complicated and largely dictated by the fairer charging guidance and the fair access to care criteria.
4.6 The co-ordination and interface of multiple services

The qualitative work shed light on a number of issues relating to how multiple services are co-ordinated. In summary these were:

- **Lack of understanding**: There is not a good understanding of how the National Health Service (NHS) and the Social Care Services work together. Service users tend to think of care in hospital and social services, and do not necessarily think about where there is cross over between the two, i.e. NHS community care.

- **Grey areas within provision**: There is often a ‘grey area’ around provision of certain services, such as medication and equipment.

- **Co-ordination for complex cases**: Service users with complex health conditions (such as dementia) can require heavy NHS input to their social care package. In these circumstances, the care responsibility will remain with Social Services however the NHS may fully fund or partly fund the care.

As we recognise throughout this report, the interface between health services and social care services is extremely complex and even service providers we interviewed found it difficult to explain how it is decided that a service is a ‘health’ service or that it is a ‘social care’ service. The table below shows some of the ways in which people saw the differences. According to one of the service providers (Manager of Adult Services at one London Borough) interviewed, service users think about health and social care in terms of the person’s job title: for example they had been seen by a Social Worker or the Occupational Therapist had been round to their home.

<table>
<thead>
<tr>
<th>HEALTH SERVICE (NHS)</th>
<th>SOCIAL CARE SERVICE (SOCIAL SERVICES)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Anything that impacts on a person’s ongoing physical or mental health” (Manager of Adult Services at one London Borough).</td>
<td>“Anything that impacts on someone’s social and wellbeing in life” (Manager of Adult Services at one London Borough).</td>
</tr>
<tr>
<td>Occupational therapists* and physiotherapists.</td>
<td>Social care may not always be provided by social services.</td>
</tr>
<tr>
<td>Continuing care fund should supply both health and social care free of charge if the primary health need is a health related one**.</td>
<td>It is illegal for a Local Authority to provide care to someone who has a health need as the individual will need input from trained health professionals (according to head of assessments at one London Borough).</td>
</tr>
</tbody>
</table>

*Occupational therapists can however be employed by social services, in community care for example.

** There are area variations in terms of what the NHS will allow under the continuing care fund, especially when the service user is in their own home.
Implications for questionnaire design

- Unless it is of specific interest to explore how users are assessed and the outcome of their assessments, we would suggest that questions about assessments are avoided in a question module. There may be some service users who will be fully aware of their assessment, particularly if they do not have memory or cognition problems and/or if the assessment was recent. However, there will be a substantially larger group of people aged 65+ who will either not know how they were assessed or will not remember and therefore collecting such information would be meaningless.
- Instead, we would suggest that questions about payment for services be included.
5  Funding and charging

5.1  How services are funded and service user awareness

Some understanding of how the services are funded was elicited by the services providers in the in-depth interviews. More importantly, for the benefit of a questionnaire for service users, respondents were able to highlight what people know about funding arrangements.

Funding for homecare services, provided by Social Services, seemed to be fairly straightforward. Some LA’s use money from central government to fund their own in-house homecare teams, whilst others subcontract the care and pay private care agencies. One respondent from a London Borough suspected that most people aged 65+ know that the council provides home care and day care. However a manager of a Local Authority who contracted private care agency told us that there is a lot of confusion regarding service users who are on their books as ‘social service clients’. These service users are invoiced by social services for their homecare but often assume the invoice has come from the private care agency, as the carer who visits works for the agency. Unfortunately we do not have the service user’s perspective regarding their reactions to receiving an invoice from social services and care delivered through a carer from a private care agency. Evidence suggests that service users may be unaware that their care was being organised by social services even if they are paying the social services. However, this highlights the confusing nature of such an arrangement which must be considered in the questionnaire design.

Telecare is a service which is funded by the Supporting People Fund which each LA receives from central government. Sometimes the money is directly transferred into social services or into housing support. Most intermediate care is funded by the NHS and is free to the service user (usually for up to 6 weeks) however people aged 65+ are unlikely to know who funds their intermediate care as it is a joint social and health care service. Funding for equipment is often complicated: some equipment can be provided by the NHS, others provided by the Local Authority.

The funding of day care centres is often more complicated. For example, a day care centre we consulted in one London Borough has major contracts with the Local Authority (LA) and the Primary Care Trust (PCT) and receives small grants from other sources, such as local charities. The money they receive from the LA covers the building(s), the staff and goes towards other costs too. People aged 65+ who attend this day care centre are unlikely to know about the complexity service funding, regardless of the fact that for the majority, the day charge comes from their own income sources.

5.2  State funded Vs privately purchased care

There was a general feeling among those we interviewed that there is a small percentage of people aged 65+ who privately purchase care services but do not come through social services at all. Some of this privately purchased care is easy to capture. For example...
according to the manager of one day care centre we interviewed, generally the charge for
attending a day care centre on a particular day comes from user’s own income sources.
Capturing the number of people using other care services such as privately purchased
home care or meals, is more difficult according to a manager of a benefits and charging
team at one LA. Although it may be difficult for Local Authorities to capture, it would seem
feasible to ask those responding to a questionnaire module whether they pay for services
privately and we think that people will be well informed and able to answer.

It would seem sensible to develop a questionnaire module which asks about services
received/help with tasks and then hone in on who provides each of the care.

5.3 Services which are FREE at point of delivery
There was a general consensus in terms of services that are free at the point of delivery
amongst respondents who we interviewed. All respondents who mentioned Intermediate
care/Reablement services stated that this type of short-term care is free (for the first 6
weeks); regardless of how much income or savings the older person has (incidentally
these were either representatives from Local Authorities/London Boroughs or people who
worked in Intermediate care). Likewise any care provided up until the point of an
assessment is usually free. Aside from these services, there are a few other services that
seem to be free at the point of delivery, i.e. the council funds the service:

- Care services for someone whose care package comes under section 117\(^4\) (after
care services) – this is a legal requirement for Local Authorities;
- Day care centre services, such as exercise classes, computer lessons and healthy
living promotion programmes and a befriending service (although in some Local
Authorities there may be a charge to cover lunch and refreshments, £5 per day for
example);
- Adaptations to the home, equipment and aids (although some Local Authorities will
set a limit on the cost of adaptations to the home, for example free: if under
£1000);
- A bathing service run by Age Concern (NB: this was only mentioned by one Local
Authority Representative); and,
- The (council’s) Handy man service.

Although the majority of the funding for the free services listed above will originate from
the Local Authority, and have money channelled down from Central Government, the
payment for the services is sometimes supplemented by other funding sources which
ultimately allow for the services to be free for the service user (the older person). Those
responding to a question module will probably say that they do not pay for this service that
they receive, however will not be able to answer questions about how the care is funded
in these circumstances. For example a respondent we consulted at a London Borough
Age Concern Day care centre explained how the fitness classes that are run by the centre
are part funded by the Local Authority and part funded by Sports England. Whereas the

\(^4\) Section 117, in community care legislation, obliges councils and the NHS to provide aftercare services,
including a care home place if that is needed, for people who have been discharged from hospital having
been detained for treatment under the Mental Health Act 1983
befriending service is part Local Authority funded and part grant funded from a local charity. Another free service that this particular day care centre provides is the 'Aging Well' programme that is primarily funded by the Primary Care Trust (PCT).

5.4 What determines how much an individual pays?

In-depth interviews with service providers, and particularly with representatives from a number of different Local Authorities/London Boroughs, highlight the reality that charging arrangements differ from one Local Authority to the next. Local Authorities can decide and set the charging policy. Some Local Authorities appear to offer the very basics to their service users, illustrated by the following quote from the manger of a Benefits and charging team in one Local Authority:

“We will charge currently where we can, so adaptations under a £1000 are free, equipment and aids are free but if we can charge for it, we will. That is the council's policy”

However other Local Authorities seem to operate on a much more generous policy and there are apparently a few which do not charge their users for services at all, as income levels are so low within the LA and it would cost too much to carry out assessments (Newham in London, for example).

Knowledge of charging policies within Local Authorities and other care providers was relatively minimal. Notably respondents were aware of the capital cut off limit – which does not include the value of the person’s home as capital. Broadly speaking, if a person exceeds this limit they pay the full costs, whilst if they fall under this limit they are financially assessed and depending on the outcome of the assessment social services will contribute towards or wholly fund the care services required. Among service providers (namely those in Local Authorities/London Boroughs), this capital limit ranged from £12,000 to £25,000 and no two Local Authorities consulted had exactly the same limit. A manager of Adult Services at one London Borough explained that the borough had not yet implemented the new charging policy but that in the future if someone has over £25,000 in assets they will have to pay full costs of all services including home care and day care centre services.

Participants in one of the focus groups had some knowledge of the capital cut off limit in the borough where they lived. One 73 year old lady referred to this as the “ceiling level” and talked about how you would have to pay, even if you had seven pounds above this. Two men in the same group both knew about the £22,000 capital limit in their borough:

“The level is twenty-two thousand. If you’ve got twenty-two thousand in the bank, you’ve gotta pay” (Male, aged 89)

One of the service providers who took part in the in-depth interview provided a better overview of the charging policy at the Local Authority who employed him/her, describing
three groups of people, in relation to charging for social care services. These are summarised in Table 1 below.

There was a general feeling that the Local Authorities are upfront about their capital limit and therefore individuals should be aware, when they come into contact with social services, that if their savings exceed the council’s capital limit, they are going to have to pay for any services that they require and end up receiving.

Table 5.1: Three groups of people within one Local Authority in relation to charging policy

<table>
<thead>
<tr>
<th></th>
<th>GROUP 1</th>
<th>GROUP 2</th>
<th>GROUP 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income/Assets/Savings</td>
<td>Have savings over the capital cut off limit (e.g. £24,500)</td>
<td>Have less than the capital cut off in savings and have some income from private pensions and savings</td>
<td>Receive basic state benefits (basic retirement pension and possibly attendance allowance) but have little else</td>
</tr>
<tr>
<td></td>
<td><strong>Income/Assets/Savings (including income from benefits and pensions)</strong></td>
<td><strong>Income/Assets/Savings (including income from benefits and pensions)</strong></td>
<td><strong>Income/Assets/Savings (including income from benefits and pensions)</strong></td>
</tr>
<tr>
<td></td>
<td><strong>GROUP 1</strong></td>
<td><strong>GROUP 2</strong></td>
<td><strong>GROUP 3</strong></td>
</tr>
<tr>
<td>Financial assessment</td>
<td>Will not be financially assessed</td>
<td>Will be financially assessed</td>
<td>Will be financially assessed</td>
</tr>
<tr>
<td>Contribution, if any,</td>
<td>Will be charged at full cost for their care services</td>
<td>LA will contribute towards their care services / person will pay the rest</td>
<td>Will not pay anything for their care services</td>
</tr>
<tr>
<td>from Local Authority</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.5 How payments are organised

In-depth interviews with service providers revealed a move towards ‘personalisation of care’ which involves Self Directed Support (SDS): direct payments and personal/individual payments. Before we describe what these systems are and how they operate, it is worth noting that not all councils have implemented these systems yet and in some Local Authorities, depending on the outcome of the financial assessment, social services may still invoice service users for the care that they receive. A manager of a Local authority contracted private care agency, for example, described how the agency invoice Social Services at the end of each month for the total calls that were made, at an agreed rate of £9.99 per hour. The private care agency does not invoice social services clients directly as social services will invoice their clients for the money that is owed to them.

Direct payments were an area that most in-depth interview respondents could talk about and knowledge and understanding was fairly consistent. Direct payments have been around for about 13 years however the take up by Local Authority varies tremendously. There are some LA’s where most social care users, including their older population, are using direct payments. Some have only recently got the system up and running whilst others are yet to do so. Direct payments came about as a result of disability groups lobbying for the rights of disabled users to have choice and control around how they managed and organised the money given to them from the state.
Calculated in terms of number of hours of care, instead of the LA (via social services) organising and delivering X hours of home care per week to the service user, the service user is given the equivalent in cash so that they can purchase their own care (in the form of a direct payment). Subsequently the service user can choose between paying an agency £15 per hour, for example, or a private individual £10 per hour. Interestingly, as a manager of an Age Concern day care in a London Borough explained, direct payments can be either “virtual” (i.e. Social services organises the services as they always have done) or “real”, where the LA would transfer the money for the care into the service users bank account. The qualitative work highlighted some of the advantages of direct payments are empowering older people by giving them the choice over which provider they use and the times of day they receive care visits.

Although some councils fund support services for direct payments to work with and help people receiving direct payments (and personal budgets, described in more detail below), universally service providers (in particular representatives from LA’s) spoke of the resistance, particularly amongst people aged 65+ to take up direct payments (and individual budgets). Some of the reasons for this resistance proposed by people aged 65+ included:

- At present this generation are not used to this kind of arrangement;
- Can be mentally and physically incapable of dealing with money;
- May be happy with their care and do not wish to manage their own money; and
- Do not want to have the responsibility of becoming an employer (therefore not having to manage employer associated tasks such as national insurance, annual leave, minimum wage etc).

**Personal/individual budgets** were described by service providers to be the same kind of arrangement as direct payments but with a different assessment process. Personal or individual budgets are calculated in weekly amounts under the Resource Allocation System (RAS), a tool used to calculate the budget needed to cover a person’s whole package of care over a number of areas including social care, health care and supporting people services. The overall package of funding is translated into a pot of money, based on the RAS scoring. There was a feeling among those we interviewed that the service user can choose how to spend the allocated money and personal budgets are encouraged to be spent creatively. For example, as long as their needs were being met, a service user could use some of their personal budget for a haircut if it was seen as helping increase their morale. Another example of creative expenditure given by a social worker we interviewed, was purchasing a laptop from a personal budget to help with shopping, instead of paying a care worker to do the shopping for him/her.

### 5.6 Personal budgets and direct payments from the user’s perspective

Participants in both focus groups were asked about their experiences, of using direct payments. Interestingly one group had not heard of them and the other group began discussing direct debits that they used to pay for their gas, electricity and other bills. Even when this group was re-prompted and asked about direct payments and
personal/individual budgets, which was also described to them, no-one had any knowledge or awareness of them. A manager of a benefits and charging team at a LA we interviewed explained that many older service users usually let the person’s family, or the carer, who organise the direct payments on the service user’s behalf. This could explain the minimal service understanding on what is direct payments and how they work by social care receivers.

Additionally, the way that direct payments are structured adds further confusion and service users struggle with the concept of direct payments, particularly because the council pays gross. For example, if a service user has to contribute £5 towards their care package which costs £50, social services gives that person £50 and then asks for £5 back, instead of giving them £45. In an in-depth interview, an LA manager of benefits and charging explained that this payment structure "confuses people no end". Direct payments were set up to follow the same structure as traditional services (where social services will invoice service users’ for their services), so that service users’ were given the same choice as to whether they choose to pay for the service. Similarly, a manager of a local authority private care agency explained that people aged 65+ receiving cash in the form of a direct payment do not necessarily understand that they are receiving a social service.

5.7 Informal carers and direct payments/personal budgets

If a relative is providing care for an older person, they can be paid out of the older person’s direct payments or personal budgets. This payment can be administered by the older person themselves, or if they do not want to manage this payment, Social Services will do this for them. Alternatively employees at charities like Age Concern or even other relatives can organise the payment of informal carers and act as the older person’s support broker. If a spouse is providing care to their partner, and they receive money for providing this care (even though direct payments/personal budgets are not supposed to be used to pay close relatives who normally live with the person), they will lose any income support they receive in their own name, as they are viewed by the State as employed.
**Implications for questionnaire design**

- Although not all of those responding to a question module will be able to answer questions on funding it may be practically possible to ask respondents to provide some personal documents such as direct payment and individual budget documentation and invoices from private care agencies or social services for care received. The Family Resources Survey (FRS) currently follows this procedure. The feasibility of this request could be explored in the two rounds of cognitive testing.

- There are several issues relating to asking respondents a questionnaire module about using direct payments and individual budgets:
  1) Some LAs have not yet implemented these payment systems and therefore answer categories may confuse such respondents.
  2) Even respondents who receive them may not necessarily be familiar with terms such as ‘Personal Budgets’ or ‘Direct Payments’ and therefore an explanation would need to be given for their inclusion in survey questions or answer categories.
  3) There will be respondents who have someone else, either a member of their family or a paid carer, organise their financial arrangements for them and therefore the service user may not be able to answer questions about this in detail.

- We feel that people who pay for their care in full will know this. We also feel that people who pay absolutely nothing towards their care will also know this. The problems arise for the group in-between: those who contribute towards the payment of their care. This group may well know that they contribute, especially if they receive direct payments or have a personal budget, but they might not know the exact amount that they contribute, i.e. the specific money details. Additionally, if someone else manages their finance for them, the service users’ knowledge about payment for care could be minimal.

- If family or carer organises direct payment or individual budget on service user’s behalf, it will be very difficult to ask the older person specific detailed questions about these forms of payments.
6 People who receive social care and provide care, help or support to others

6.1 Why are informal carers relevant to this research?
Informal carers were included in this qualitative research because we wanted to cover a range of different service providers. Informal carers could be receiving social care services for people aged 65+ as well as providing care to their spouse or partner or to others such as a neighbour. In addition, informal carers could help those receiving social care to answer the question module. For these reasons it was important to include informal carers in this qualitative research.

6.2 How should informal carers be referred to in the questionnaire module
Family or friends who provide care for a person aged 65+ should be referred to as ‘a carer’ and not an ‘informal carer’ according to support group for carers (see box 2 below for definitions that were given in the in-depth interviews). This was explored in the in-depth interview with the full time family member who provides care for mother. This respondent joked that her mother thinks it is funny that she is now called ‘the carer’ because it highlights the shift in roles. In the focus groups, service users never described their adult children as ‘carers’: they instead referred to their son or daughter does this or that. This suggests that the person receiving care may not necessarily think of their child as ‘a carer’. Although the carer we interviewed suggested that her mother was amused by this label, it could be a sensitive term to others because it reveals the change in generational care practices with the child now caring for the parent. In order to differentiate between a ‘professional’ carer and a family member/friend who provides care in the question module, consideration needs to be given to how both types of carers are distinguished in the question module to ensure the questions are measuring the intended carers role – whether it is the professional carer, the family/friend who provides care or both. The cognitive testing will provide an opportunity to test the questions to see that they achieve their measurement objectives sensitively. Although an informal carer should not be used in the question module, for the sake of consistency and clarity to distinguish between family member or friend who provides care and professional carers, we will continue to use informal carers in the rest of the report but place it in inverted commas (‘informal carers’) to identify that it is a problematic term.
Box 2: Definitions of Carer

“A carer is a person who provides unpaid support and practical assistance to a relative or friend to enable them to live independently”. (Director of a support group for carers)

“A carer is someone who is looking after a person who is ill, frail, or disabled, and not getting paid for doing so, or volunteering through an organisation…. This means you could be caring for a friend, neighbour or relative, for example it could be your child, husband, mother or cousin that you are caring for” (Definition of carer from the carer’s pack given to Carer’s from their local Social Services)

6.3 Which tasks and services are within the remit of family or friends who provide care and how can survey questions tap into these?

Family or friends carry out an important role in providing care for people aged 65+, revealed by service users as well as in the in-depth interviews with service providers. In the focus groups respondents described the role of family or a friend who provided support as “doing the tasks that others don’t do.” In table 5.1 below we present the tasks that service users revealed in the focus groups only get done if the family carer does them, usually carried out by the family carer, or could be done by the family carer but there are other service providers who do these tasks too. In table 2.2 (section 2.2) shows all the tasks that family carers do irrespective of whether they live or do not live with the person they are providing care for, and this was informed by the interview with the ‘informal carer’ as well as the focus groups with service users.

The in-depth interview with the ‘informal carer’ showed that other family members can step in and provide the same range of care. Also these family members can support the main carer by sharing the care roles or taking over all of them for a period of time, allowing the main carer to have a holiday or a break. In addition this interview showed that the services provided by the carer can change over time to meet the changing needs of the person receiving care, for example if the circumstances of the person receiving care improves or they need more care as they get older. These are two dynamic aspects of the family’s care role which could be examined through appropriate questions in the question module.
Table 6.1: Services/tasks that get done by the family carer by whether they are the only person who provides the service, usually provides the services or can provide the service but are not the main source

<table>
<thead>
<tr>
<th>Provided only by a family carer</th>
<th>Usually provided by a family carer</th>
<th>Could be provided by a family carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family do things others do not do and you can not do e.g. shopping</td>
<td>Taking the person out for day trips</td>
<td>See table 1a above e.g. Bathing and washing</td>
</tr>
<tr>
<td>The important cleaning jobs that are needed every month, or every 6 months or once a year</td>
<td>Housework</td>
<td>Preparing meals</td>
</tr>
<tr>
<td>Turning out the cupboards</td>
<td>Doing the laundry</td>
<td></td>
</tr>
<tr>
<td>Cleaning the oven</td>
<td>Support services provided by the carer like help with showering on days when the carer doesn’t do it</td>
<td></td>
</tr>
<tr>
<td>Washing the curtains</td>
<td>Emotional support</td>
<td></td>
</tr>
<tr>
<td>Finding about care services</td>
<td>Organising care services</td>
<td></td>
</tr>
<tr>
<td>Stepping in when care roles need doing when the professional carer fails to turn up e.g. bathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family level of emotional support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6.4 Why do family members provide social care?

This research revealed that family members may want to ‘look after’ the older person, such as their mum or dad, and can be reluctant to ask for help from private care organisations: The in-depth interview with the ‘informal carer’ explained that “it is always strange to have a stranger at home”. According to this respondent, her mother is comfortable to go into a respite care home to allow her to have a holiday. She has never done this and although she is thinking of having a holiday, after being a full time carer for a number of years, her sibling and his family have offered to look after her mother if she does take a holiday. This research shows that the type of care received by an older person is also influenced by the family and this needs to borne in mind in reference to proxy respondents who could influence how a question is answered.

The qualitative research also found that although the family may want to provide care, it can be difficult to know how to provide care. For example issues around how to move a person and how to help them to go to the toilet. Additionally, the in-depth interview with the carer highlighted that it is difficult to find this help or support. The in-depth interviews with service providers showed that providing physical care for a parent or spouse (such as help with bathing) can be a sensitive issue to ask about in the question module because it could be a delicate issue for both the recipient and the provider. If this form of care is asked about in the question module, it would need to be asked sensitively.
6.5 Other findings specific to those who receive and provide care

Carer’s needs are examined in the carer’s assessment. The carer’s assessment is an assessment carried out by the social services to look at an individual’s caring role and the effect that this role has on them to determine whether they are entitled to any support. The support could be in the form of:

- A break from caring; or,
- Help with housework; or,
- Equipment or adaptations to the home; or,
- Emotional support. (www.direct.gov.uk).

Where a person receives care from an ‘informal carer’, the Local Authority sees its role as providing additional support so looks at the ‘informal carer’s’ roles and responsibilities and fills the gaps. The ‘informal carer’ who was interviewed for this study, had a carer’s assessment which was carried out at home by a social worker who asked her if she needed a break from her caring roles and what she thought her mother needed. In addition she was asked about her financial situation. The director of a support group for carers in a London borough highlighted that carers assessments can be very poorly carried out to the extent that the person does not even realise that it was carried out. In her opinion, this assessment can be misused in some councils because they do not have the resources to support ‘informal carers’. The support available for ‘informal carers’ to help them with their care responsibilities vary greatly between areas. The ‘informal carer’ who was interviewed revealed that although she was told about services for her mother in name, she was not told how to access them and it had been very difficult. Even when care support was identified, it took a long time to arrange and receive the care service. The strategies she used to find out about services her mum needed and was entitled to were to look through the yellow pages, pick up leaflets in the library and telephone social services.

It can be financially difficult to provide care. When a spouse or partner receives money for caring, the person is no longer entitled to income support and other benefits because they are seen as employed. In some circumstances the carer could even have given up their job to take on the care responsibility full time. Carer’s assessment can provide money for shopping or cooking. Carers can receive carers allowance if they provide ‘live in’ care and qualify for respite care but can only receive money from personal budgets if they live outside of the home of the person for whom they are caring. The in-depth interview with the director of a support group for carers and the ‘informal carer’ revealed that it can be difficult for ‘informal carers’ to find out about their financial entitlements and how to receive them.

6.6 Support available for carers

The interview with the director of a support group for carers pointed out that ‘informal carers’ generally only seek out their help once established in the care role. This was supported in our research which found that the ‘informal carer’ only sought help after
providing care full time for more than a year. She was steered on by her relative who pointed out that there must be support available for ‘informal carers’. This support was needed because providing care can be a lonely pursuit as you do not get the chance to meet people, and this can be missed when you have changed your circumstances to provide care like giving up your job. The ‘informal carer’ who took part in this research, found out about her local support through a leaflet she picked up in her local library. The director of the support group for carers pointed out that they used to advertise help available to ‘informal carers’ for people aged 65+ by approaching people who looked tired and harassed in the supermarket and this was a successful method. The support organisation for ‘informal carers’ we interviewed runs:

- An informal social gathering once a month with ‘informal carers’ where they just meet and generally do not talk about their care responsibilities – a space where people just chat; and,
- Tai-chi classes.

**Implications for questionnaire design**

Family members, irrespective of whether they carry out a carer’s role, may help or fill in the questionnaire as a proxy respondent in situations when respondents are unable to or need help with filling in the questionnaire, so this needs to be borne in mind when the questionnaire is designed.

Questions can ask what care roles different family members do. They should explore a range of services, as the first reaction could be to think of the carer who provides personal care for example but forget other household tasks, such as shopping or driving a person somewhere which could result in undercounting of male carers contributions. However, sensitivity is needed when approaching questions regarding intimate care such as bathing and help using the toilet because this could be sensitive for both the respondent and the proxy respondent.

To capture fully the services received by ‘informal carers’ the introduction to the questionnaire and questions need to remind respondents to think about the person who cares for them because of their personal relationship (e.g. child, sibling, spouse, friend of the person being cared for) and also to think about professionals who provide social care. As service users know about services they receive, the questions could be ordered to identify services received and then ask who provides them.
7 Advice and guidance for the design of survey questions

This final chapter brings together 1) thoughts from both service providers and service users, having discussed social care in relation to developing a question module and 2) key themes which have been highlighted throughout this report.

7.1 Missing sub-groups

When asked whether the remit of the study seemed sensible, some providers did question why we were excluding people living in residential care homes as they are an important population to miss. Another subgroup within this population that service providers raised issues around were those with Dementia and other cognitive disorders. Considering that a large percentage of people aged 65+ have dementia, according to a Manager of Adult Social Services at one Local Authority that we spoke to, this will be an important group to miss in terms of their experiences, unless there is scope for carers of these people, or their family members, to be surveyed on their behalf (i.e. proxy respondents). Sheltered housing is in the community so should be included in a survey, as a Head of assessments at London borough told us.

The age of the survey population (65+) seemed very sensible and no-one had any objections to this. We tried to get some sense of thoughts on linking survey data to Local Authority although unfortunately there was little knowledge about this. A manager of Adult Social Services in one Local Authority suspected that many LA’s would display resistance to the idea because of data confidentiality issues and a manager of a major charity for the elderly suspected that admin records will be “all over the place”.

7.2 Terminology for questions about type of services

Service providers who were interviewed emphasised the importance of using ‘everyday language’, and avoiding technical or ‘policy’ language. So, referring to ‘brushing your teeth’ and not ‘Oral Hygiene’ and ‘Council’ should be used instead of ‘Local Authority’. Of equal importance is to avoid terms which are either:

1. Out of date or uncommon these days (e.g. ‘Domiciliary care’, should instead use ‘Home care’);
2. Inappropriate or could be offensive (e.g. ‘Informal carer’; or ‘Incontinence’, should use ‘going to the toilet’ – however a Social Worker thought that ‘incontinence’ would be ok to use);
3. Incorrect, or not in the remit of the provider’s job (e.g. ‘Lifting’, should use ‘Help moving people around’, ‘Assisting people to move’ or ‘transferring’)

It is also important for a question module which will be asked continuously over time, to refrain from using terms which may change in the future, for example ‘Direct Payments’ and ‘Personal Budgets’. Also in relation to ‘charging terminology’, a manager of a benefits and charging team at one Local Authority, who suggested avoiding terms such as ‘SDS’,
‘individual/personal budgets’ and ‘direct payments’ explained that they all mean different things to different people.

7.3 Use of the term ‘carer’
Throughout this report, the term carer has been used interchangeably. This has often been because those we consulted used it inconsistently and we wanted to retain the link to the raw data (i.e. what people said). It has become clear that there is no clear definition of a ‘carer’ and it is important to consider the survey population and how, as pointed out in chapter 2 and elsewhere in this report, service users may well refer to ‘their carer’ but may not know where the carer comes from (i.e. who they are employed by and how they were organised). We have learnt a number of lessons, which we feel can be applied to the questionnaire design:

- ‘Informal carer’ must be avoided.
- ‘Carer’ alone is ambiguous and will not lend itself to distinguish between paid and unpaid carers nor will it be possible to expect all service users to know who their carer is employed by.
- ‘Paid carer’ could be confusing as some older people may use their direct payments to pay their friend or family for the care they provide.
- ‘Care staff’, a term suggested at a recent meeting with members of the collaboration, seems to be fairly straightforward and could be used to refer to anyone other than spouses/friends/family/neighbours.
- Care provided by a person’s spouse, other family member, friend or neighbour should be captured by designing questions which refer to the person’s relationship to the person caring for them. For example, the answer categories to the question ‘Who helps you with this?’ could be 1) my daughter/my son; 2) another family member; 3) my neighbour, and so on.

7.4 What can be asked about in a survey
There was a strong feeling amongst service providers who were interviewed which was supported by the ability of service users to openly and easily discuss this, that it will be possible to ask service users about which services they receive. There was an equally strong feeling, however, that people might not know who provides them. Service users may just know someone (i.e. their carer or the Social worker) by name and more confusingly, they may have input and involvement from many different people from different organisations.

There was evidence to suggest that it should be feasible to ask about payment for services. For example, those receiving a personal budget should know that there is a pot of money available for them to spend and service users receiving direct payments would know the weekly amount that they receive. This was not a consistent view however and others felt that detailed questions about payments should be avoided.
7.5 What can not be asked about in a survey

There was evidence to suggest that the following should be avoided in a question module:

- **Details about, and the nature of, the application process**: service users may not know how they were assessed and how this shaped the amount of financial help that they ended up receiving.
- **Funding arrangements of the care that they receive**: for example whether the NHS or Social Services (LA) funds a certain service. Similarly, a service user may attend a day care centre and be completely unaware that the free services offered there (i.e. anything that is not covered by the day charge) are paid for by the LA.

7.6 Issues for consideration for a national survey

A reoccurring theme which emerged throughout the in-depth interviews with service providers was the recognition of great variation between Local Authorities (and Primary Care Trusts) in terms of care provision (i.e. services available to people aged 65+), assessments, funding and charging. Even neighbouring Local Authorities can have completely different rules. For example, one LA could be providing support to those in ‘substantial’ and ‘critical’ needs, whilst the LA next door to could be providing support to those with ‘moderate’ needs too. It appears from talking to a manager of adult services in one London Borough that this LA variation is often political but sometimes the model the LA adopts is framed by the socio-economic make up of the (older) population. Some LA’s for example, in very deprived areas, have to help everyone. This raises a question to us, although this was not explored, around whether the demographic make up of an LA might also have an impact: whether the older people are very old for example.

7.7 Other issues relevant to questionnaire design

- Instead of focusing on the negatives when talking about help and support that people need, such as help with continence, the questions should be positively phrased
- In a question module about receipt of care, it would be necessary to look at equipment and adaptations such as alarms (or telecare) and transport.
- In order to know whether people are LA funded or ‘self funders’, we would need to explore the extent of their income and savings.
- Some services may have their own brand or label and therefore people may not necessarily think about what the service is, but rather the name of the service. An example: In one London Borough, exercise classes provided by an Age Concern day care centre are called ‘Say Go’ and people who attend these may not necessarily think about the fact that they attend ‘an exercise class run by Age Concern’.
- Talk about personal care and practical help (social worker)
- Awareness of the detail of things like funding will depend on the users’ cognitive functioning. If questions are to be designed to be detailed, we may need to survey the person’s family or their ‘carer’ (i.e. proxy respondents).
- Older people do not like talking about money (Local Authority contracted Private Care Agency) as they think that they are paying too much for their care
7.8 Survey administration

Finally, but there are a number of important survey administration related issues, such as:

- The length of a question module;
- Proxy respondents; and,
- Survey mode.

It is unlikely that survey sponsors, or survey organisations, wanting to include a module of social care questions, such as the Health Survey for England (HSE) and the English Longitudinal Study of Aging (ELSA), would welcome a lengthy module, in terms of the time that it takes for an interviewer to administer the questions. With this in mind, and considering some of the difficulties certain members of a population aged 65+ may have, such as memory and concentration problems, we would recommend that a module should be designed that takes no longer than 10 minutes to administer. A shorter questionnaire module will have greater chance of inclusion on surveys.

Next, there is the issue of proxy respondents and whether a question module should be designed with proxies in mind. We feel that proxy questions would be beneficial, although there will be practical issues that will need consideration – such as how to identify when a proxy would be beneficial/necessary to collect the information the questions require, and how to ensure that the proxy is present at the respondents’ home for the interview.

There is also the issue of survey mode, which has not yet been discussed but should be considered. For now, it is assumed that the questions will be designed for use in Computer Assisted Personal Interviewing (CAPI) face-to-face surveys. The questions will be designed therefore to maximise the benefits of a face-to-face CAPI interview. There can be complex routing and there will probably be showcards, interviewer introductions, clarifications and other instructions.