Exploring satisfaction with social care services amongst Pakistani, Bangladeshi and white British populations

Findings from cognitive interviews

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Summary

The overall aim of the wider research study was two fold. First the study set out to explore the extent of, and reasons for, differing levels of satisfaction with adult social care services among different ethnic groups. The ethnic groups chosen for this study were people from Pakistani and Bangladeshi origin, compared with the white British population. The qualitative stage sought to address this aim. A separate report (Gill et al, 2014) outlines the methodology and findings from this part of the research. The second aim of the study was to explore the extent to which existing social care satisfaction surveys (primarily focussing on questions from the Adult Social Care Survey) effectively capture satisfaction in a consistent way across ethnic groups. Through cognitive interviews, this second aim was addressed and this report details findings from this phase of work.

34 respondents were recruited and interviewed in total between December 2012 and February 2013:
- twelve white British respondents,
- fourteen Pakistani respondents, and
- eight Bangladeshi respondents.

Cognitive interviews took place in three areas of the UK (Leeds, Birmingham and London). Interviews were offered in Urdu, Punjabi, Bengali and Sylheti. Where interviews were conducted in languages other than English, we used the standard translations of the questions used in the Adult Social Care Survey and also conducted the whole cognitive probing part of the interview in the non-English language.

This summary presents only an outline of some of the key topics: the full report sets these out in more detail.

Little evidence of ethnic differences in responding to survey questions

The key research question for this phase of the project was whether the way in which questions about satisfaction are asked in surveys lead to systematic differences in how different ethnic groups respond, thus affecting their satisfaction ratings. This project found almost no evidence of ethnic differences in how Bangladeshi and Pakistani service users understand and respond to the survey questions compared with white British service users. Understanding and interpretation of satisfaction, quality of life and dimensions such as food and drink and safety were consistent even when interpreted in a way which made them relevant to the service user. This suggests that differences in satisfaction between groups reflect real differences in satisfaction (as explored in the in-depth part of this project, see Gill et al, 2014) rather than inconsistencies in data collection.

Whose perspective and satisfaction with services is being captured?

Some individuals who are in receipt of social care services have very complex needs and their health and/or disability can significantly limit what they can and can not do independently in every day life. We know that the Adult Social Care Survey (ASCS) questionnaire is not always completed solely by the service user. Instead someone else might assist the service user, or may even complete the questionnaire entirely alone on the service user’s behalf. It is likely that people caring for the service user, both relatives and friends and also care and support workers, will provide this questionnaire assistance, in varying forms. In the cognitive interviews, we attempted
to mimic these ‘real’ survey conditions by conducting paired cognitive interviews, during which family members or care and support workers often helped the service user with completing the test questionnaire or did it on their behalf.

When the person completing the questionnaire was not the service user, but where the questions asked directly about the service user’s experience, particular issues emerged. Carers (in this context either family members or care and support workers) reported difficulty answering some questions on behalf of the service user because they felt they did not know, or were unsure about, how the service user would answer or feel (for example Q10 about how help received to do things makes you think and feel about yourself, and Q7 about feeling safe; see Appendix B for questions). Where this difficulty occurred, carers either guessed or answered from their own perspective. Although there were interviews where the carer was confident that their response would mirror the service user’s (for example at Q1 about overall satisfaction with the care and support received), this was not always the case. The reference to ‘you’ in the question stems and response options might go some way to explaining this, as it could be easy for carers to forget that they were responding on someone’s behalf.

In addition, during the cognitive interviews we carried out, carers - when present in a paired interview - could answer differently to how the service user did (we collected the responses of both). On occasion, the carer would remind the service user of particular events or occasions that the service user had not initially considered (for example at Q2 about quality of life) and carers could influence the service user’s answer or even respond using their own perspective (for example at Q6 about the cleanliness and comfort of the home).

Ultimately the fact that satisfaction is not always reported in the eyes of the person receiving the care (the service user) is clearly an issue that should be borne in the minds of those analysing and interpreting the data. We know, for example, that ‘Asian’ service users are the group most likely to have help completing the questionnaire from someone living in their household (39% in 2011-12 compared with 19% for White)\(^1\) and the group least likely to complete the questionnaire by themselves (22% in 2011-12 compared with 31% for White). The survey data (from 2011-12) suggests that there is very little difference in satisfaction between those who filled in the questionnaire themselves (62% extremely or very satisfied) and those who had help from someone in the household (61% extremely or very satisfied) meaning that the higher levels of assistance with the questionnaire, amongst Asian respondents, from within the household are unlikely to explain the overall differences in satisfaction.

Interestingly, too, we know that there is a relationship between satisfaction reported and having help from a care and support worker (76% of respondents who had help from a care worker being extremely or very satisfied in 2011-12). White British respondents are more likely, when compared to Asian respondents, to have help from a care and support worker in questionnaire completion. This could go some way to explaining why white British respondents appear more satisfied overall with social care, but cannot explain all the differences.

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**Style and quality of the translation resulting in difficulty responding**

When a questionnaire is translated into other (non-source) languages, it is possible that errors can occur which result in a loss of functional equivalence. These errors have been classified in one of two ways. First, translation (or human) error, whereby errors stem from the translation process (mistakes, poorly chosen terms) rather than from features of the source question that make translation difficult. Second, the source question itself and features of this, such as use of vague quantifiers to describe the answer scale points, which are difficult or even impossible to translate in a way that preserves functional equivalence (Fitzgerald et al, 2011).

In the cognitive interviews, we did find evidence to suggest that unsuitable translations, in particular in the Urdu script, had been used (for example at Q1 about overall satisfaction and Q4 about personal care) and this made it difficult for respondents to answer some questions. This resulted from difficulties in reading the script as well as difficulty understanding particular translated words. This raises the question of whether poor or inconsistent translation of the questions is the reason certain BME groups report lower satisfaction with care and support services received.

We looked at the numbers from within these groups that complete the questionnaire in the Adult Social Care Survey. The percentage of respondents who take the questionnaire in translation is very low. In an analysis of the 2011-12 Adult Social Care Survey data, only three people of South Asian origin used a translated questionnaire. Since most of the issues aired in cognitive interviews related to the poor Urdu translation, we concluded that it is very unlikely that translation problems are the underlying cause of ethnic differences in satisfaction in the survey data. However it is possible that with an improved translation the uptake of the translated versions would be higher, improving access to the survey and reducing the high level of informal translations.

**Disentangling and isolating satisfaction with ‘social care’ services**

We know from prior experience of cognitive interviews with social care service users that respondents do not always confine their thinking to that of solely social care (Balarajan et al, 2010). Owing to the complicated way care services are organised, delivered and paid for, it can be difficult for individuals to know whether an aspect of their care came through Adult Social Services, the National Health Service (NHS) or from somewhere else.

In this project we found some evidence of respondents thinking about other public services, besides Social Services. This finding was irrespective of ethnic group as evidence was found during interviews with both white British and Pakistani respondents. At Q1, for example – the overall satisfaction question – there were white British respondents who included their psychiatrists and doctors and a Pakistani respondent who thought about physiotherapy. Additionally, there was some evidence to suggest that the inclusion of such health professionals could alter overall satisfaction, for example if poor service had been received in relation to them (a white British respondent answered ‘quite satisfied’ because of being unable to get an appointment with a psychiatrist). At Q3, too, both Pakistani and white British respondents were including doctors, psychiatrists and (medication received during a spell in) hospital. At Q12 (about ease or difficulty finding information and advice about support, services or benefits), there were respondents who thought about a broader range of services such as health/medical services and even housing. Similarly at Q7b (about whether care and support services help in feeling safe) the police and local council were mentioned.
This finding raises questions over which services are being evaluated, if respondents can think about services outside of ‘Social Services’ when answering social care satisfaction survey questions. The worry is that experiences (whether good or bad) of other public services could dilute the responses people give and alter the picture being painted of experience with social care services.

**Characteristics of the questions**

Certain respondents from all ethnic groups experienced some difficulty in understanding and responding to the questions as a result of words within the questions which were not well understood, long phrases within some questions and the inclusion of two or more concepts within the same question. We did not find clear evidence to suggest that respondents from non-white British ethnic groups had more issues with questions than the white British group, except for the questions on dignity. The wording on the easy read version was understood more readily, however there was evidence that the use of smiley and sad faces next to the answer categories did not assist respondents in selecting an appropriate response. This report details the findings in relation to problems with question wording. However, since the questions tested are widely used standardised questions the scope for making amendments may be limited, therefore we have not made specific recommendations in relation to question wording,
1 Introduction

1.1 Why the research has been carried out

Local Authorities routinely collect data about user experiences of and satisfaction with adult social care services using the Adult Social Care Survey. The questions are provided and the data analysed by the Health and Social Care Information Centre (NHS Information Centre, 2012; HSCIC, 2013). The data are collected by each of the 152 Councils with responsibility for Adult Social Care Services (CASSRs). Data from recent Adult Social Care surveys have shown that black and minority ethnic (BME) groups report lower levels of satisfaction with social care services than the White group. For example in 2011-12, while 64% of white respondents reported being extremely or very satisfied with the services received, 51% of Asian and Asian British and 53% of Black and Black British reported this. This is consistent with findings from previous years as well as 2012-13. When looking at combined extremely, very and quite satisfied there is still a disparity (91% of white and 84% of Asian, Asian British, Black and Black British reported this). The National Institute for Health Research School of Social Care Research invited applications for funding to carry out projects to explore the reasons for these disparities in satisfaction.

1.2 Outline of the research project

NatCen Social Research, the University of Stirling and the University of Leeds have been working together on a project to explore this issue specifically for Pakistani and Bangladeshi service users compared with white British service users. We chose to look at these particular groups for a number of reasons. There were clear differences between satisfaction levels for Asian as compared with white people and these communities also face inequalities in health indicators and satisfaction with health services. Both these communities have non-English languages which may impact on access to and satisfaction with services. Both communities are predominantly Muslim but differ culturally so allowing us to explore how cultural and faith issues interact. For reasons of practicality we decided to restrict the focus to two particular groups plus white British because extending it to other groups would have made the fieldwork and resulting analysis extremely challenging.

This project took two main approaches to looking at why satisfaction with social care services might be lower among these groups as compared with white British. Firstly we aimed to explore whether satisfaction was lower among these groups and what the reasons for this might be. Possible reasons for lower satisfaction include poorer levels of service being received by these groups, these groups being concentrated in areas or types of disability or need where service levels are worse, consistent services which are inappropriate for cultural or faith reasons, differing expectations of services, and language or communication barriers impeding access to services. The first element of the project involved in-depth interviews with social service users and relatives and key informant interviews and focus groups with local authority managers.
and providers and care workers. These phases of the research explored how satisfied people are and what contributes to satisfaction and how this relates to their situation. The interviews with those responsible for delivering services allows us to look at the extent to which services are adjusted to meet the needs of different groups and whether there are challenges in delivering quality services to these groups. The findings of this part of the project are reported separately (Gill et al, 2014).

The second approach to the research question is to explore whether the surveys which collect satisfaction data (primarily the Adult Social Care Survey) ask the questions in such a way which collects consistent and unbiased information from different ethnic groups. If certain groups understand the questions or respond to the answer scales in ways which are inconsistent this can lead to spurious differences in data. The second element of the project involved conducting cognitive interviews with service users and their relatives to explore how they go about understanding and responding to the adult social care survey questions.

The intention was that, if inconsistencies were identified in how different groups interpret the questions, suggestions could be made to improve consistency by adjusting the main question or providing additional clarification or adjustments to the questions. A second round of testing could then be conducted using these adjusted questions. Although issues were found with the questions, most of these did not cause ethnic differences in understanding or reporting. Therefore we have not made specific recommendations in relation to the ethnic differences in reporting and a second round of testing has not been conducted. The intention of this project was not to make general recommendations for change to the questions in the Adult Social Care Survey since they are drawn from the widely used ASCOF measure. Instead we describe the issues and problems found. These may lead to conclusions about potential improvements to the questions or adjustments to the way in which the data are analysed, but recommendations are not made here.

1.3 Report terminology

Throughout this report we refer to the individuals who assisted service users in answering the questionnaire and taking part in the cognitive interview as carers. Within the cognitive sample there was just one case where the carer assisting with the interview was a care and support worker. The rest were relatives or friends. In referring to types of care received we use ‘carer’ to describe a family member or friend who cares and ‘care worker’ or ‘care and support worker’ to describe someone who helps in a professional capacity.

1.4 Structure of this report

Chapter 2 provides details about the methodology, including an overview of the sample composition as well as details about how respondents were recruited and interviewed. Chapter 3 provides a summary of some general findings in relation to survey mode, assistance in completing the questionnaires and translation. Finally chapter 4 provides a detailed account of the findings for each individual question.
2 Methodology

2.1 Cognitive interviewing
Cognitive interviewing is a technique rooted in cognitive psychology which can be used to explore the process by which respondents understand and respond to survey questions. The method involves using two main techniques: think-aloud and probing. Using think-aloud respondents are asked to ‘think-aloud’ as they answer the survey question. In the probing technique the interviewer asks specific and general probes after the respondent has answered the questions. Both techniques are used to uncover four main stages of the question and answer process. These are understanding, recall, judgement and response. The aim is to understand:

- whether the question is being understood in a way which is consistent with the intentions of the researcher and consistently between respondents,
- whether respondents are able and willing to recall the information needed to answer the question,
- whether judgements about what to include or exclude or the level of accuracy required to answer the question are consistent, and
- whether the format of the answer allows the respondent to give the answer they wish to give (e.g. does the list of answer options include their answer, is the range on a numerical answer large enough).

Cognitive interviewing is usually used to test questions before they are included in a survey. However it can also be used to test existing questions, particularly where data analysis suggests questions may not be working in the way the researchers intended.

2.2 Sampling and recruitment
Cognitive interviewing is a qualitative technique and therefore uses small purposive samples. Quotas are set to reflect the range and diversity of the population of interest. The aim is to include people with the characteristics which could impact on the way in which they may approach the survey questions. Thus in this project it was important to include people from the three ethnic groups of interest, people of different ages, men and women and those who wished to respond in English and in different languages. The sample was also designed with a geographical spread and included Leeds, Birmingham and London which were the fieldwork areas for the in-depth element of the project which the cognitive interviewing followed (see Gill, 2014). Interviews were offered in languages other than English where requested so those who did not speak English could be included in the sample.
2.2.1 Sample composition

Overall we achieved 34 interviews as follows;

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Area</strong></td>
<td></td>
</tr>
<tr>
<td>Leeds</td>
<td>8</td>
</tr>
<tr>
<td>London</td>
<td>18</td>
</tr>
<tr>
<td>Birmingham</td>
<td>8</td>
</tr>
<tr>
<td><strong>Interview type</strong></td>
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</tr>
<tr>
<td>Paired</td>
<td>8</td>
</tr>
<tr>
<td>Carer</td>
<td>8</td>
</tr>
<tr>
<td>Easy Read</td>
<td>3</td>
</tr>
<tr>
<td><strong>Interview language</strong></td>
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</tr>
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<td>English</td>
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</tr>
<tr>
<td>Urdu</td>
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</tr>
<tr>
<td>Bengali</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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</tr>
<tr>
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<tr>
<td>Pakistani</td>
<td>14</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>8</td>
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<tr>
<td><strong>Gender</strong></td>
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</tr>
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</tr>
<tr>
<td>Receiving direct payments</td>
<td>7*</td>
</tr>
</tbody>
</table>

*Since we did not specifically collect this information during recruitment, or in the interview, this number is based on a reference to being in receipt of direct payments. It could be that there were others in the sample in receipt of direct payments but that this was not discussed.

Appendix A contains more detail about the individuals included in the sample.

The original plan was for interviews to be conducted with 48 respondents, most of whom had taken part in the qualitative stage of the study. During the qualitative element of the project we had faced difficulties in achieving the planned number of interviews. The reason for this was challenges in recruiting respondents. This reflected the isolated situation of social service users from these minority groups, the vulnerability of these users which affected their ability to take part and the resource constraints faced by the types of organisations we were relying on to help with recruitment. This meant that the sample for both phases of the research was smaller than intended.

As the table above shows, although the numbers in each group of interest were not equal we did include people with all the characteristics of interest. We conducted interviews with social service users individually, with carers or relatives individually, as
well as paired interviews in which the service user and relative or care and support worker both participated. This was intentional as we wished to replicate the situation in which the Adult Social Care Survey questions are answered. Many service users have the input of someone else in answering the questions (only 22% of Asian and Asian British service users in the Adult Social Care Survey completed the questionnaire by themselves with no input from anyone else). The only type of interview where we would have benefited from more interviews was the easy read interview but only two of the selected sample needed this type of interview.

2.2.2 Recruitment

There were two main recruitment methods for the cognitive interview sample. Firstly, people who had participated in an in-depth interview about satisfaction with social care services and who had agreed to a further interview were invited to take part in a cognitive interview. Although new sample was provided throughout the fieldwork period, because the cognitive phase overlapped with the end of the qualitative phase, the number of qualitative interviews with people who were suitable to re-contact was not enough to provide the whole sample. Therefore a second approach was used. The eight interviewers working on the project went to local community groups and day centres to recruit adults receiving formal social care. Interviewers liaised with local groups so that they would advertise the project using posters and leaflets prepared by the research team. In some cases interviewers attended group meetings and spoke to service users to tell them about the project. This is a similar approach to that used during the qualitative phase of the project.

The recruitment of the respondents and fieldwork took place from December 2012 to February 2013. The fieldwork was extended by a month owing to challenges with recruitment.

2.2.3 Recruitment challenges and approaches

There were a number of challenges faced by the interviewers throughout the recruitment period. As mentioned previously, there were a smaller number of respondents who had taken part in the qualitative stage of the study who were recruited by December than anticipated, which meant interviewers needed to supplement their samples by doing their own recruitment.

We experienced a recurring issue of the six white British core team interviewers struggling to engage with and recruit Bangladeshi and Pakistani respondents. To overcome this problem we had two core team interviewers working in each of the three areas, and the two bilingual interviewers travelling wherever they were needed. This worked well in practice, as did interviewers going to the community groups and day centres and having face-to-face contact with managers and service users. We also offered an incentive to managers for recruiting respondents and providing a venue for the interviews; £50 for two recruits or £75 for three (which was the same as was being offered for the qualitative interviews).
We aimed to offer gender matching for interviews when requested. Both bilingual interviewers were male as there were no suitable female candidates. This presented challenges during fieldwork because if female Asian respondents wanted a female interviewer, we were only able to offer a white British core team interviewer, or a female Asian NatCen researcher to accompany the male interviewer. This proved difficult logistically but was only requested by a couple of respondents.

2.3 Fieldwork approaches and interview format

2.3.1 Interview language

Interviews were offered in Bengali/Sylheti, Urdu and Punjabi, as well as in English. This was to ensure that people were not excluded from the research for reasons of language and also so we could test the translated versions of the questionnaires. We used six English speaking interviewers from our core team and hired one Bengali/Sylheti speaking interviewer and one Urdu and Punjabi speaking interviewer specifically for the project. This project was the first time NatCen had offered cognitive interviews in a language other than English. This required a special training session and enhancement of their criminal records bureau (CRB) clearance to work with a potentially ‘vulnerable’ group. Since this was the first cognitive interviewing project the bilingual interviewers had worked on they initially conducted interviews in English, observed by experienced interviewers so that they and the researchers could receive feedback on their performance. Their interviews in minority languages were transcribed and assessed by the research team.

2.3.2 Interview types

The questions tested were mainly drawn from the Adult Social Care Survey (ASCS). We tested the following versions of the questionnaire:

- the standard version,
- the Easy Read version, and
- the Bengali and Urdu translated versions of the standard questionnaire (not available in Punjabi).

Our experience from the qualitative phase of the project where we conducted interviews with social service users, showed that some service users are not in a position to take part in an in-depth interview. The same issue applies to cognitive interviews which are cognitively demanding and relatively long. Furthermore, the evidence from the Adult Social Care Survey findings shows that most service users rely on the help of others to complete the questionnaire. This could be a relative or carer who lives in their household or another household, or a care and support worker. Therefore we designed the cognitive interviewing phase in such a way that users who could not take part in a cognitive interview by themselves were not excluded from the research. We offered interviews with the service user, with their relative or carer, or a paired interview with the service user and their carer. We also offered an Easy Read
version of the questionnaire with simplified questions and pictures to illustrate what was being asked, which could be used in either an interview with the service user or in a paired interview. However, as mentioned above, this was rarely used because it is challenging for someone who requires an easy read questionnaire to take part in a cognitive interview.

We used these versions of the questionnaire and types of interview to create a number of protocols for the cognitive interviews:

- Standard version for individual interview with service users (also available in translation)
- Standard version for paired interview with service users and carer (also available in translation)
- Standard version supplemented with additional questions from a Carer’s Survey for individual interviews with carers
- Easy Read versions for paired interviews with service users and carer (not available in translation)

The standard and easy read questionnaires are included in Appendix B.

The Easy Read versions used different language, included pictures and also had faces (happy to sad) against the answer scales. The translated versions of the questionnaires used were the standard translations provided on the Health and Social Care Information Centre website.

2.3.3 Format of the interviews

The interviews lasted for around one to one-and-a-half hours, depending on the respondent’s ability to answer the questions and probes, and how much detail they went into. Respondents were given £20 for an individual interview or £15 each for a paired interview as a thank you for their participation.

Interviewers conducted the cognitive interviews, testing one of the different types of ASCS instrument. A mixture of think-aloud and verbal probing was used. Respondents were asked the questions and then interviewers explored, by direct probing in addition to think-aloud, the process by which the respondent had arrived at their answer. Towards the end of the test instrument, after many questions had been asked and explored, it was common for respondents to tire and consequently the data are sparser for some of the later questions.

Interviewers audio recorded the interviews with the participants’ consent.
2.4 Data management procedure

Interviewers who had conducted their interviews in English wrote notes after listening to the audio-recording which is our standard practice. For the interviews in other languages we initially had the bilingual interviewer’s recordings professionally translated into English and transcribed. We also asked the language interviewers write up their first interviews by listening and translating into the English notes template. At the same time, in order to quality control the interviewer’s notes and translation we asked a translation agency to translate the interviews. We ask the agency to translate verbatim, as the specific language and words used are important in cognitive interviewing, however this was not always possible as some English words don’t exist in Bengali/Sylheti, Urdu or Punjabi and vice versa. This resulted in very literal translations which didn’t make sense. It showed that the quality of the translated notes provided by interviewers was better. As a result we decided the interviewers would translate the interviews and write up their own notes in English.

A group of researchers then entered summaries of the data collected in the interviews into a Framework set up in NVivo from the interviewer notes. Framework allows a matrix approach to analysis in which data can be read horizontally as a complete case record for an individual, or vertically by question, looking across all cases. In reviewing the matrix the full range issues with each question could be systematically explored. It also allows sub groups of cases to be examined, allowing exploration of differences in the question and answer process between groups (for example between ethnic groups in this study).

The project was carried out in accordance with ISO 20252.
3 Findings relating to mode, translation and survey response

The cognitive interviews presented an opportunity to explore with respondents (service users and carers) issues which relate to how these survey questions are administered. Issues we report on first relate to the mode of data collection, the translation of the questionnaire and the general task of completing the survey.

3.1 Survey mode

There were mixed feelings in relation to which mode the questionnaire should be conducted in. Some respondents had a preference for paper self completion (allowing an opportunity to read the questions), whilst others would have liked a face to face interview because having an interviewer present could overcome some of the ambiguities with certain questions. Telephone would be problematic for people with hearing problems though there were respondents who favoured it. Finally the web was liked by some (for its privacy factor and ability to complete the survey in one’s own time) whilst others had concerns about people with literacy and/or computer problems.

3.2 Assistance with the questionnaire

It was common for social service users to say that they would attempt to complete the questionnaire alone first, and then seek help if they found they needed it or didn’t understand certain questions. Help could be from someone within the household, who might also be the carer, their care and support worker or someone from outside the household.

Often carers were involved in opening of the service user’s post and would therefore inform the service user that a questionnaire had come for them. Sometimes the carer would skim read it first, deciding how long it was and would take to complete, before choosing whether or not to pass it onto the service user.

There were some service users who commented that the tick box format of the questionnaire meant that they could complete the whole thing alone. Had it been a questionnaire which required written answers, they would have needed help.

3.3 Questionnaire introduction and instructions

The introduction text in the questionnaire was generally regarded as unproblematic, clear and was not off-putting in any way. Those who read it often commented that the confidentiality statement was encouraging and may persuade people to take part.

Two issues were highlighted in relation to the introductory text:
1. The word ‘advocate’ was not always understood.

2. The reference to ‘you’ could be confusing for carers who were completing the questionnaire on behalf of the service user.

3.4 Translation

There was a general finding in some of the cognitive interviews with Pakistani respondents (both those who completed it in translation and those who didn't) in relation to the translation of the questionnaire. For the cognitive interviewing we used the standard translated versions of the questionnaires available from the Adult Social Care Survey. The Urdu script that has been chosen was not always seen as appropriate. There were comments throughout certain interviews which suggested that the font was difficult to read. One Pakistani respondent (Male, 60+), for example, said that it would be better and easier to understand if it was written in “proper Urdu”.

There was also a general lack of understanding in the Bengali interviews, which may have been down to the questions asked or down to the relative inexperience of the cognitive interviewer. A carer of a service user (female, Bangladeshi, 18-59) answered the whole questionnaire from her own perspective, as it was not clear to her that the questions were meant to be answered on behalf of the service user.

Later in this report we discuss question specific issues which relate to the translation of certain words.

Data from the Adult Social Care Survey shows the type of help people receive help with in completing the questionnaire: 15% overall and 36% of Asian respondents (2011-12 data) receive help with translation. This suggests that at present informal translation may be taking the place of the official written translations. This could be a result of lack of awareness of the translated versions, difficulties with the style of the translated versions or literacy issues among those requiring translations. In several cognitive interviews in translation the interviewer read out the questionnaire rather than the respondent reading it themselves.

We recommend that further information is collected about the uptake and use of translations in the Adult Social Care Survey and that the existing translations are reviewed and checked.
4 Question specific findings

This chapter details findings from testing each question, using cognitive interviewing methods. A copy of the complete questionnaire, in both the standard and the Easy Read format, can be found in Appendix B. We report on findings from interviews with individual social service users, paired social service user interviews, and those who completed the Easy Read (ER) version of the questionnaire. We also incorporate findings from interviews with carers who completed their own separate questionnaire containing mostly equivalent questions.

Each subheading refers to one particular question or set of questions. In brackets, we refer to the question numbering since we do not show the full questions within this report (these can be found in the separate appendix). The shorthand used in the referencing to question numbering is as follows: Standard Questionnaire (SQ); Carer Questionnaire (ICQ) and Easy Read Questionnaire (ERQ).

4.1 Overall satisfaction with care and support services received (Q1)

The first question in the questionnaire asks for an overall rating of satisfaction with the care and support services received. A definition of what is meant by ‘care and support services’ is provided beneath the question and lists equipment or care provided by staff paid to help. Reference is also made to different types of arrangements for those staff/help: including from Social Services, an agency and care purchased by money from Social Services through a Direct Payment.

4.1.1 General findings

Regardless of ethnicity, respondents in the sample tended to answer this question thinking about their experience of the care and support they had received and no evidence was found to suggest lower levels of satisfaction were associated with ethnic differences. There was evidence that carers sometimes use their own opinions when answering on behalf of the service user. However this was usually coupled with an expressed confidence that the service user’s response would have been the same:

- A white British carer (whose spouse was the service user) answered ‘I am quite satisfied’ when thinking of the person who comes to shower and help to dress him. The carer said that she thought the service user would have answered the same as he is happy with the lady that comes.

- A Bangladeshi carer (whose father was the service user) answered ‘I am very satisfied’, and considered what the care and support workers do when they come to see her father. Here the carer said that the service user is satisfied as he is not forced to do things he doesn’t want to. The carer also mentioned that care and
support workers come into the home and chat away in English, even though her father does not understand, but he seems to enjoy it.

In the few paired interviews, the carer and the social care user provided the same response. In general respondents based their answer on:

- the people providing the care (care workers, staff in the care home);
- the frequency and duration of care received;
- the actual tasks they received help with (personal care, provision of meals); and/or,
- the equipment and home modifications provided and/or their experience of the day care centre.

Respondents rated their experience, again regardless of ethnicity, in relation to:

- the standard of care received (how nice the care workers were, how good the modifications were to their home),
- whether their needs were being met (sufficient visits from the care workers, provision of all the necessary equipment) or,
- what they thought social services were able to offer them (they do what they can).

Overall this shows a consistency in understanding of satisfaction and how respondents rated their satisfaction.

During the data analysis we explored whether there was a link between general health (since this was collected as part of the cognitive test questionnaire) and overall satisfaction with care and support services. There were no clear patterns observed.

4.1.2 A broad question with many answer categories

The question about satisfaction was described as too broad on occasion. There were respondents (or their carers) who commented that there were many different aspects to care (selection of care workers, direct payments, level of help given, provision of equipment) which made selecting one overall answer difficult. ‘Social services’ was broadly understood, encompassing anything from the whole system or the people who provide care in the community, to individual care workers and even other health professionals and services such as doctors, psychiatrists and hospitals.

Respondents from the Pakistani and Bangladeshi ethnic groups only, occasionally made reference to the fact that there are too many response options and that people from minority ethnic groups who are not fluent in English may struggle. In particular the first two (extremely and very satisfied) and the last two options (very and extremely dissatisfied) (in the standard questionnaire version) were seen as too similar.
4.1.3 Translation issues

An issue which applied throughout the entire questionnaire relates to the choice of the Arabic script which is used in the Urdu version of the standard questionnaire. There were Pakistani respondents who reported finding the question difficult to understand as a result of this. Additionally the word ‘satisfied’ was not understood by one Pakistani respondent, because of the font, however on this occasion the question was still understood and this did not impede the respondent’s ability to answer.

One Bangladeshi respondent (female, 18-59) really struggled with the Bengali questionnaire. The interview had to be carried out and explained in a combination of English and Sylheti. The respondent struggled to understand the questions in both languages, and the Easy Read version of the questionnaire had to be used.

4.1.4 The Easy Read questionnaire

Whilst only three respondents in the sample answered this question using the Easy Read version (two who were doing an easy read interview and one who was shown this question on the easy read questionnaire), the question was understood in similar ways and the answer strategies tended to mirror those described above. However, there was a noted desire to tick more than one box and to pick the happiest smiley face.

4.1.5 Implications for further cognitive interviewing

In the Adult Social Care Survey, conducted in 2011-2012, 51% of Asian respondents, compared with 64% of white British, reported feeling either extremely or very satisfied (NHS Information Centre, 2012). One of the research questions for this project was whether cognitive interviews with Pakistani and Bangladeshi respondents, and with a white British control group, would show differences in how the questions were understood, so explaining some of the difference in levels of satisfaction reported. In fact the problems experienced with the question were not related to ethnic group, but instead were more general. There is therefore no evidence that ethnic differences in satisfaction reflect inconsistencies in how the question about satisfaction is understood or answered by people of different ethnicities. A further round of cognitive interviews could look at other ethnic groups from within the ‘Asian’ survey category, such as Indians, who may respond differently, but this was not within the remit of this study which focuses on Bangladeshi and Pakistani service users.

4.2 Quality of life (Q2a & b)

Two questions are asked in relation to quality of life: Q2a, which is the general quality of life assessment, and Q2b which asks whether care and support services help towards a better quality of life. Respondents were asked to think about the good and bad things which make up their quality of life and choose an answer on a seven point item labelled scale with the best answer being ‘so good, it could not be better’ and the worst being ‘so bad, it could not be worse’. 
4.2.1 General findings for Q2a

Respondents tended to answer this question using consistent answer strategies and thinking patterns. No ethnic group differences were observed. Respondents (both service users and their carers) tended to use three strategies with slightly differing points of comparison:

- make an assessment of the quality of their life at the moment,
- compare themselves to the lives of others (“there are people who are worse off than me”), or
- compare their life now to how it had been in the past, for example before they became sick or disabled.

There was evidence of carers answering both on the behalf of the service user and about their own quality of life. On occasion it was unclear who the carer had answered about. Carers could influence the service user’s response if they were present, for example in a paired interview, by reminding them of aspects of their lives or events which the service user had not previously considered.

As with the satisfaction question, there were occasional comments which suggested that there are too many answer options and that they should be made simpler but no specific suggestions for reducing them were made.
4.2.2 Interpretation of ‘quality of life’

Figure 1 below is a diagram summarising how respondents thought about quality of life when they answered this question. Some respondents focused on just one aspect of their life (for example their health) whilst others thought generally, about all aspects of their life. Although this does not show complete consistency in the domains mentioned, they are all reasonable interpretations of quality of life and demonstrate a consistent understanding of the general concept.

![Diagram of quality of life domains](image)

Figure 1: Domains which made up respondents’ definitions of quality of life.

4.2.3 Findings for Q2b

The findings for Q2b, which was about whether the care and support services received helped the respondent have a better quality of life, were fairly consistent. Respondents talked about whether their needs were being met (in terms of care and support received), and the financial help received. The answer frame was, in some cases, seen as inflexible with respondents wanting to report further differentiation, replacing a simple ‘yes/no’ response choice. This was often because “to some extent” the care and support services had helped but not entirely, or that the care received was not good enough.
The ‘Social Care Related Quality of Life’ (SCRQOL).

A number of questions, which appear in the Adult Social Care Survey, are used to devise a composite outcome measure called the ‘Social Care Related Quality of Life’ (SCRQOL) (Netten et al, 2011). This measure combines service user’s answers to the questions about different domains into an overall score out of 24. A score is given based on the responses to eight questions which feed into the SCRQOL (Q3, Q4, Q5, Q6, Q7, Q8, Q9, and Q11). At each question a score of 3 is given if the respondent chooses the first response option, the ‘ideal’ answer (classified as ‘no need’), a 2 is given if the respondent gives the next most ideal answer response option 2, a 1 is given if the respondent chooses the third response option (‘some need’) and 0 is given if the respondent chooses the forth response option (‘high needs’). A score of 0 would mean a respondent has high need on all questions, and a score of 24 indicates no needs.

4.3 Control (Q3a & b)

4.3.1 General findings

The question about how much control the service user has over their daily life was generally understood consistently across the cognitive sample. Occasionally respondents (both service users and carers and from all ethnic groups) were confused by what the question was initially asking but after re-reading it, or having it re-read to them, tended to work it out. Often respondents framed their answers in relation to their health and their specific needs. For example there were respondents who did not choose the first response category because to ‘have as much control over my daily life as I want’ would mean being in perfect health and not needing care services or medication.

The kinds of things respondents talked about in relation to having control, included:

- doing what you want when you want to do it
- being independent
- having the ability to get up and go out
- having financial control and being able to spend how you want to
- being able to get yourself washed and dressed and use the toilet alone
- making your own choices without people telling you what to do
- having control over your own mind
- control in the sense of God and fate controlling your destiny.
4.3.2 The ambiguity of ‘adequate control’

There was some ambiguity around the term ‘adequate’ in the second response category (‘I have adequate control over my daily life’). Whilst there were respondents who understood what this meant (some control but not all of it; you can do some things for yourself but not everything; enough, ample), there were also respondents who questioned the meaning. When interviewers, or carers who were present, clarified this word, they often used the words ‘sufficient’ or ‘enough’. This ambiguity was not related to ethnic group.

4.3.3 Whether care and support services helped in having control

Question 3b which follows the control question was answered quite straightforwardly however there was evidence to suggest that respondents think not only about social services when they answer this question, but also include other services such as health services. This occurred for white British and Pakistani respondents only though nothing suggests that it was ethnicity or culturally related. One Pakistani respondent, for example, who answered ‘Yes’ to Q3b, had thought about the doctor, hospital and direct payments. A white British respondent, too, had considered a psychiatrist and also mentioned a doctor. This respondent’s answer to Q3b was two fold: ‘Yes’ for the key worker and ‘No’ for the doctor.

4.3.4 Easy Read

The question was misread and answered in relation to the (care) staff controlling the service user’s life. The respondent selected No because the staff are nice and friendly and don’t control her (Pakistani, 18-59). Although this is only one case it does demonstrate the potential for misunderstanding of this question.

4.4 Personal care (Q4a & b)

4.4.1 General findings

The question about ‘keeping clean and presentable in appearance’ (Q4a) had minor problems, however almost universally respondents were able to answer and mentioned very similar aspects of personal care during probing. There were cases where the respondent didn’t understand the term ‘presentable in appearance’, and this was not related to ethnic group, however they were still able to grasp the aims of the question (possibly because of the reference to keeping clean). Being clean and presentable meant being washed, well dressed and with clean clothes on each day, being cleanly shaven, smelling and looking good.

Again, as with previous questions, the word ‘adequate’ was not always understood however this did not appear to impede the respondent’s ability to answer or choose the appropriate response category. One (Pakistani) respondent would have preferred the word ‘happy’ instead of adequate.
4.4.2 Translation issues

A Pakistani respondent did not understand the Urdu translation of ‘appearance’, although the use of the word clean in the question allowed her to understand the question to some extent. In another case the respondent did not understand the context and meaning of the question. The respondent was thinking about whether the house was clean and presentable and was not thinking about personal appearance.

4.5 Food and drink (Q5a & b)

The next question (Q5a) that feeds into the quality of life outcome measure is around food and drink. The question aims to capture adequacy and timing of food and drink in the respondent’s life. Q5b asks whether care and support services help the individual get food and drink.

4.5.1 Findings for Q5a

It had been expected that this was a domain of life where there might be ethnic differences. The qualitative findings have shown that there are differences in satisfaction between different ethnic groups related to cultural expectations about food and its preparation (Gill et al, 2014). The cognitive testing showed that there were no ethnic differences in how this survey question about food and drink was understood, or answered. Respondents thought about the types of food they eat, which was traditional food in some cases but the meaning of the question itself was understood consistently. This suggests that the question is effective in capturing ethnic differences in satisfaction in relation to this domain. Respondents tended to answer this question in relation to whether (or not) their needs were being met. There were respondents who talked about there being enough food in the fridge when they needed it or about how their consumption of food was linked to their care needs, for example having to be fed meals at the times the care and support workers visited or not being able to cook so relying on someone else to do so. Occasionally respondents mentioned the financial aspect (affordability) of being able to have the food you want when you want it.

Getting ‘adequate’ food (a term used in response options 2, 3 and 4) was thought about in various ways:

- the amount of food consumed (enough or ample);
- the variety, or type, of food consumed (having a mixture of healthy and indulgent food);
- the nutritional value of the food consumed;
- the quality of the food consumed (lean meat, fresh fruit and vegetables); and,
- the cost of food (and how finances can control what somebody can eat).

‘Timely’ food and drink (a term used in response options 3 and 4) was understood consistently with respondents reporting the regularity of eating times, having food at
the right times, food over the 24 hour day and having the right spacing between meals.

Evidence was found in interviews testing both the standard and the Easy Read questionnaire, of service users being less satisfied with food and drink in their lives when they are discouraged from eating certain foods because they are told that they are not good for their health.

4.5.2 Findings for Q5b

This question asked about whether care and support services helped the service user to get food and drink. Again, no ethnic group specific differences were found in relation to how this question was understood and answered. Support was thought about both in terms of financial support (being given the money to have adequate food and drink) and practical support (being offered food choices by the care worker or having help with food preparation, shopping and reading instructions).

There were some respondents who showed a preference for a response frame which allowed for greater discrimination. In other words yes/no was too restrictive and did not allow all to answer in a way that they wanted to. ‘To some extent’ and ‘yes and no’ were spontaneous responses given.

4.6 Accommodation (Q6a & b)

This question asks respondents to state how clean and comfortable their home is (6a) and whether care and support services help in keeping it clean and comfortable (6b). The answer options are; 1 ‘My home is as clean and comfortable as I want’, 2 ‘My home is adequately clean and comfortable’, 3 ‘My home is not quite clean and comfortable’, or 4 ‘My home is not at all clean and comfortable’.

4.6.1 Findings for Q6a

This question was generally easy to answer, as respondents believed ‘clean and comfortable’ was a clear concept to think about. They thought about their flats or houses (the interior, not the exterior and garden), and their daily/weekly routine.

It was clear that there were a number of different interpretations; what is clean and comfortable to one person may be dirty and untidy to another. The first answer category ‘My home is as clean and comfortable as I want’ indicates that the respondent should answer with their own opinions (‘…as I want’) rather than their family’s or carer’s opinions, which may be different. However this is not indicated in the question wording or the other answer categories. It was slightly harder for carers to answer on behalf of the respondent as they may have different preferences, especially if they do the cleaning themselves. It was also pointed out that there is a difference between clean and comfortable. A home could be clean but not comfortable, or the other way round; a little untidiness can make a home feel comfortable to some.
It was also suggested that it isn’t care and support services’ job to help you keep your home clean and comfortable; it’s up to the individual. There were questions over whether food and cleaning is considered to be, or should be, part of the care package.

In cases where there was a struggle to choose between option 1 and 2, respondents chose option 1. For example, if living in a shared house, most of the house might be option 2, but their personal space, for example their bedroom, is option 1.

There may have been difficulties with understanding the word ‘adequately’ (used in the second answer option). As with previous questions, interviewers used words such as ‘sufficient’ or ‘enough’ to help explain the term. For example a respondent described ‘adequately’ as “a puzzling word”, and thought ‘moderately’ might be a better word (male, white British, 18-59).

4.6.2 Findings for Q6b

Respondents thought about help from family members and paid cleaners, which could make it difficult to answer a straight Yes or No to whether care and support services help them in keeping their home clean and comfortable. In a paired interview, this question was left unanswered because the respondent (female, white British, 60+) and the carer (her daughter) disagreed; the allowance they receive is used to pay a cleaner to come for one hour a week, and the rest of the cleaning is the family’s responsibility – each household member has tasks, including the respondent. Therefore, they decided the question was too difficult to answer and wrote a comment instead.

Where people had paid for cleaning help, it was often from private services rather than local authority provided. There was an issue with those who paid for private cleaners with Direct Payments answering inconsistently. One group answered ‘No’, as they saw it as their money to do with what they please, while the other group were aware the money was from Direct Payments and saw this is part of care and support services and answered ‘Yes’.

4.6.3 Findings for Q6b Easy Read

In the Easy Read version of the questionnaire, the term ‘staff’ is used instead of ‘care and support services’. This appeared to be confusing and the two respondents (both females, Pakistani, 18-59) were not sure who was covered by this and whether to include people like day centre staff. This led to confusion over why day centre staff would help you with keeping your home clean and comfortable. For example one respondent asked “Why would staff want to?” as she was thinking about the staff at the community centre she goes to and couldn’t understand why they would want to keep her home clean and comfortable.

4.6.4 Ethnicity related differences

Options 1 (my home is as clean and comfortable as I want) and 2 (my home is adequately clean and comfortable) were selected by people from all three ethnic groups and from people who received help from care and support services in keeping it clean and tidy, and those who did not.
Only Pakistani and Bangladeshi respondents chose options 3 (my home is not quite clean or comfortable enough) or 4 (my home is not at all clean or comfortable). Reasons given for this were; not having enough space to move around in (for example care and support services do help with this by tidying and moving things around, but can’t change the size or layout of the house), not getting enough help with this from care and support services, and no longer being able to clean and tidy due to their health condition. These are issues unrelated to ethnicity, although there was evidence in one Bengali interview of the respondent understanding clean but not comfortable.

4.7 Personal Safety (Q7a & b)

This question asks respondents how safe they feel, and instructs them to think about how safe they feel inside and outside of the home (7a). It then asks if care and support services help them to feel safe (7b). Q7’s answer options are; 1 ‘I feel as safe as I want’, 2 ‘Generally I feel adequately safe, but not as safe as I would like’, 3 ‘I feel less than adequately safe’, or 4 ‘I don’t feel at all safe’.

4.7.1 Findings for Q7a

Respondents were aware the question was asking about safety inside and outside the home and gave appropriate answers. If their answers for inside and outside were different, respondents either ticked multiple answer options; for example a carer said she would pick both option 1 for her father (service user) inside the home as there is always someone there for him, and option 2 outside of the home where there is risk of him falling (male, Bangladeshi, 60+). Or they would pick the answer that best reflected both circumstances; for example if thinking about outside only, one carer would have picked option 4, but as they were thinking about outside and in the home they picked option 2 (female, Pakistani, 18-59). Respondents generally feel safer in their homes than when they are outside. This feeling of safety increases when a support worker is present.

Respondents thought about different safety issues according to their health conditions. These varied from falling over in their house or on the street, to fear of being mugged or getting abused outside of the home, to fear of oneself and suicidal thoughts. Others had no perception of fear (as part of their illness or disability) and so although they may have felt as safe as they want, their family or carers worried about their safety. There was an issue with carers answering on behalf of respondents; the question asks how safe you feel, and so they felt unable to answer on the respondents’ behalf if it is not something they have discussed.

As there is no time frame given in the question, respondents thought about varying time frames. For example, they thought about the past year, since they moved into their home, the present, or the future and how things could change. The question asks about safety in terms of fear and in terms of physical safety, therefore respondents sometimes wanted to choose different options for each.
If respondents had experienced a serious incident such as a bad fall or a burglary their answers tended to focus on this particular incident.

4.7.2 Findings for Q7a Easy Read

It was difficult for one Easy Read respondent to think about safety both inside and outside the home at the same time (female, Pakistani, 18-59). She will not go out alone as she fears getting run over by cars, and so only feels safe if her father or a member of staff from the day centre she attends is with her. She feels very safe at home and at the day centre, but not outside. She decided on option 1 as throughout the questionnaire she wanted to pick the happiest smiley face. However it was clear for this question that this did not reflect situation she described.

4.7.3 Findings for Q7b

Although respondents generally found this question easy to answer, there was evidence that it was not clear to respondents who ‘care and support services’ is referring to in relation to personal safety. For this question respondents thought about services which are not care and support services, such as the Police and the Local Council, if they had received help or a service from them that made them feel safer. For example, one respondent (male, Bangladeshi, 18-59) said the question made him think about the police who he sees as a ‘care service’, so found the question confusing and thought about the police, his support service and the housing association he lives in when answering, as they all help him to feel safe. It is clear that personal experiences are very important, and that perhaps respondents need to be reminded of what ‘care and support services’ covers.

Respondents who answered option 1 to 7a (I feel as safe as I want) tended to answer ‘Yes’ to 7b (care and support services do help them in feeling safe), and respondents who answered option 2 to 7a (I feel adequately safe) tended to answer ‘No’ to 7b. All respondents who picked option 3 or 4 (feeling less than adequately safe or not at all safe) answered ‘No’ to 7b.

Reasons given for answering with option 3 or 4 (not feeling safe enough) were; being refused bathroom modifications by the local authority after a number of falls in their home (male, Bangladeshi, 60+), anti-social behaviour around their home and police/council noise team failing to resolve the matter (female, white British, 18-59), feeling unsafe at home after a home safety system had been taken away (reason not given) (female, Pakistani, 60+), and feeling unsafe when home alone due to suicidal thoughts (female, white British, 60+). These answers show there is a recurring theme of feeling unsafe at home due to lack of action by the local authority or police, when answering ‘No’ to 7b.

4.8 Social Life (Q8a & b)

This question asks about contact with ‘people you like’, with the aim of understanding the respondent’s social situation (8a). It also asks whether care and support services help in having social contact with people (8b). The answer options are; 1 ‘I have as much social contact as I want with people I like’, 2 ‘I have adequate social contact
with people’, 3 ‘I have some social contact with people, but not enough’, or 4 ‘I have little social contact with people and feel socially isolated’.

4.8.1 Findings for Q8a
The question asks about contact with ‘people you like’, however while option 1 mentions contact with ‘people you like’, option 2, 3 and 4 only mention contact with ‘people’. In the Easy Read questionnaire, all answer options talk about contact with ‘friends and family’.

Respondents chose answers in line with the wording in the question itself (‘people you like’) as they felt although they had contact with people, this contact was not necessarily with friends or people they like. For example, having contact with neighbours that you don’t get along with (female, white British, 60+).

Reasons for lack of contact with friends and family included: a partner passing away, health conditions stopping them from being mobile (not being able to get out of the house often), friends having health conditions themselves (limiting their activities or meaning they were no longer around, having died), and not being able to work.

The question wording doesn’t make it clear whether ‘social contact’ includes contact with professional people such as day centre or support staff. Respondents did include care and support staff when thinking about their answer. For example, one respondent (female, white British, 60+) answered ‘I have adequate social contact with people’. She has lost many friends since her husband died as they are of a similar age to her and have their own medical problems, but she has regular contact with her care and support workers. However, as care workers are professionals it is not clear whether the question intends that this type of contact should be included since the answer categories refer to social contact but the question stem does not. Evidence from the qualitative phase of this project showed that for social service users care contact with care and support workers is extremely important and can even be the highlight of their day.

4.8.2 Definitions of ‘social contact’
‘Social contact’ had a variety of meanings to respondents. Interpretations included:

- contact with family members and friends,
- contact with people outside the home,
- contact with people who aren’t family members,
- contact with people from your own culture, religion or ethnicity,
- meeting new people.

There was also a range of types of social contact discussed; getting out of the house and seeing or meeting people, having a relationship, talking to people on the
telephone, sending Christmas cards, connecting with people over the Internet and social networking sites.

Respondents differed in terms of whether they considered contact by phone or the internet to be social contact. A respondent who was a carer for her father (service user was (male, Bangladeshi, 60+)) chose option 3 as his contact with people is restricted to them visiting him at home, but she believed her father would pick option 1 (I have as much social contact as I want) as he has a lot of visitors and phone conversations with people. She didn’t view it as ‘social contact’ as he doesn’t leave the house, so kept her answer as option 3 (I have some social contact but not enough). Only white British respondents mentioned the use of electronic social networks as part of ‘social contact’. For example, one respondent (male, white British, 18-59) answered option 1 as he has contact with people at school, and through using E-mail and Facebook Chat.

Pakistani respondents sometimes referred to social contact as cultural; one respondent thought it meant contact with people in your own culture and religion (male, Pakistani, 60+), and another stated the main reason she goes to a day centre is to see people of her own ethnicity as they get together to share things and discuss current affairs in their homeland (female, Pakistani, 60+). Although this may indicate some inconsistency in understanding, the question does ask about ‘contact with people you like’ and so for an individual who likes to mix with people from a similar cultural background this is within the meaning of the question.

4.8.3 Definitions of ‘socially isolated’

The final answer option refers to feeling ‘socially isolated’. Although respondents had varying definitions of what ‘socially isolated’ meant, in general they understood this. Definitions included; not being able to meet the people you want, staying indoors doing nothing, having little or no contact, having nobody to talk to, having no friends or family to look out for you, or being bullied at school. Similar and overlapping definitions were given by people from all three ethnic groups suggesting consistent understanding between the groups:

“Like no one actually bothers with you, you feel isolated, you feel like you’re by yourself, you’re on your own”
(male, Bangladeshi, 60+)

Of those who didn’t understand the term, one respondent claimed it is a hard concept to grasp (female, Pakistani, 18-59), another didn’t understand the term but understood feeling lonely and not being able to get out to meet people (female, white British, 60+). Another said she found question easy to answer but didn’t understand ‘feeling socially isolated’ (female, Pakistani, 60+).
Findings from the qualitative element of this project showed that social isolation and lack of companionship are important issues (Gill et al, 2014). It is therefore important that they are included this type of outcome framework.

4.8.4 Translation issues

In an Urdu interview with a Pakistani respondent, the interviewer had to read the question (Q8a) aloud twice and both the respondent and carer didn’t understand what was being asked. The interviewer thinks this was due to the respondent being read the questions and not reading them himself, and also due to the narrative nature of the question. In another Urdu interview, the respondent was unable to understand the term ‘social’, so the interviewer had to repeat the question twice. The respondent managed to understand the context of the overall question.

An issue that arose for Q8b in Bengali interviews with Bangladeshi respondents was that they were unsure how social services could help with social contact. However, as discussed above there were other respondents who considered contact with care and support workers to be a type of social contact.

4.9 How time is spent (Q9a & b)

This question asks respondents how they spend their time, and gives examples to think about such as leisure activities, formal employment, unpaid or voluntary employment, and caring for others (9a). It then asks if care and support services help them in the way they spend their time (9b). The answer options are; 1 ‘I’m able to spend my time as I want, doing things I value or enjoy’, 2 ‘I’m able to do enough of the things I value or enjoy with my time’, 3 ‘I do some of the things I value or enjoy with my time but not enough’, or 4 ‘I don’t do anything I value or enjoy with my time’.

4.9.1 General findings for 9a

In general, respondents thought about leisure activities when answering this question and understood the intended meaning. A range of issues were identified which relate to the fact that the way people wish to spend their time is diverse, but there were no clear consistent problems. Respondents thought about a wide range of activities;

- going to town or the park, day trips, shopping, going out to cinema,
- using a gym, swimming, keeping fit, playing sports,
- buying the right type of food and cooking,
- gardening, doing DIY jobs, electronics,
- reading, knitting, painting, pottery, using the computer, playing chess, playing card games, watching films or television, listening to music,
- writing letters, socialising, social networking, spending time with family or friends.
Only two respondents thought about work or voluntary work in their answers, which is likely to be due to the fact that this group of people are often unable to work. One (female, white British, 18-59) was thinking about voluntary work and employment when picking option 3 (I do some of the things I value or enjoy but not enough), in relation to the anti-social behaviour near her home and the noise impacts on her daily life and ability to work. A carer was thinking about work in terms of her husband, the service user (male, white British, 60+), no longer being able to work which he used to enjoy (no answer option picked).

Only one respondent (female, Bangladeshi, 18-59) thought about her answer in terms of caring for others. She picked option 3 and spoke about being able to do the things she enjoys but not having enough time to do them because she has children to look after.

Being self-reliant, living on your own, and not worrying about coming home late as you would if you were living with parents were other factors that were discussed.

A white British respondent (female, 60+) struggled to see the difference between answer options 1 (I'm able to spend my time as I want…) and 2 (I'm able to do enough of the things I value or enjoy). She wanted to pick both options but the interviewer said she could only pick one, so she chose option 2 but felt the answers were similar and said she could have picked either of them.

A Pakistani respondent (female, 18-59) had to hear the question three times before she understood what it was asking. She picked option 1 and was thinking about leisure activities. Another Pakistani respondent (female, 60+, Urdu interview) answered the question thinking about no longer being able to tie her shoes as she can’t tell her left from right now that she is blind. One respondent (male, Pakistani, 60+, Urdu interview) struggled to understand the answer options due to the complexity of the words and lengthy description of the options.

A carer struggled to answer this question on behalf of her father, the service user (male, Bangladeshi, 60+). She chose option 4 as she thinks her father doesn’t do anything or any activities as he doesn’t like going out, although he does interact with family who visit him: “It’s not that he don’t do it, he doesn’t want to do it, that’s what it is”. She felt the question wording should be changed as it sounds like it’s the family who stop the service user from doing things, but actually he doesn’t want to do anything.
4.9.2 General findings for 9b

Reasons given for answering ‘Yes’ to whether care and support services help them in the way they spend their time were:

- practical and other help from care and support workers at a day centre,
- a choice of activities at day centres,
- care and support workers going with them to guitar lessons and a youth club,
- care co-ordinator suggesting art classes to attend to socialise and make friends,
- personal assistance care helping them to do the things they want to do,
- support from people at a community centre, and
- guidance to avoid obstacles, rather than physical help.

Reasons given for answering ‘No’ to whether care and support services help them in the way they spend their time were:

- support workers meet personal needs but not social needs,
- practical support received, such as transport (and this respondent has rejected everything that has been offered),
- voluntary help received from family, and not from the local authority (male, Bangladeshi, 60+ who said he was “obviously” thinking in this way),
- not having much interaction with social services and not knowing what services they offer,
- not knowing about the benefits system and where to get a disabled badge from, and not knowing where to get advice from,
- having a mentor in the past who helped them with activities and no longer needing this support, or having a carer to do activities with and no longer needing a mentor,
- being encouraged to join art groups in the past (whilst living in assisted accommodation) and no longer needing to do this, and
- saying not for themselves, but acknowledging it might apply to others.

An carer in a paired interview (male, Pakistani, 18-59) wanted an answer option in between ‘Yes’ and ‘No’, as although the service user answered ‘Yes’, she said that he waits all day for the family to come home to help him. She was thinking only of family when answering the question.
4.10 Dignity (How help makes you think and feel about yourself) (Q10 and Q11)

There were two questions asked to understand dignity. The first asked about ‘how having help to do things makes you think and feel about yourself’ (Q10). The second asks about ‘how the way you are helped and treated makes you think and feel about yourself’ (Q11). The first (Q10) is not part of the SCRQOL. The reason for including these two similar questions is to capture how the way the service is provided impacts on how people feel as distinct from the fact that for some people needing help in itself affects how they feel, regardless of how the help is provided. The idea is that when respondents answer Q11, which is part of the SCRQOL, they have already expressed how they feel about needing help and so can instead focus on the nature and quality of the care received. The answer options are shown in the table below.

<table>
<thead>
<tr>
<th>Question 10</th>
<th>Question 11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Question</strong></td>
<td><strong>Which of these statements best describes how having help to do things makes you think and feel about yourself?</strong></td>
</tr>
<tr>
<td>1</td>
<td>Having help makes me think and feel better about myself.</td>
</tr>
<tr>
<td>2</td>
<td>Having help does not affect the way I think or feel about myself.</td>
</tr>
<tr>
<td>3</td>
<td>Having help sometimes undermines the way I think and feel about myself.</td>
</tr>
<tr>
<td>4</td>
<td>Having help completely undermines the way I think and feel about myself.</td>
</tr>
</tbody>
</table>

The Easy Read questions ask respondents how they feel when they need help and how they feel about the way other people treat them.

4.10.1 General findings for Q10 (impact of having help)

Respondents considered the following when thinking about having ‘having help’:

- having support, from family or care and support workers
- practical help from the local authority and family
- physical help to achieve something
- assistance to carry out the necessities of life
help to do things, to get more independence, encouragement rather than doing it for you
- making you feel more comfortable
- feeling vulnerable when people help you, or being dependent on people for help
- having help with everyday tasks such as going into town, filling in forms, sorting out benefits, managing money
- having someone do things for you if you can’t do them
- having someone do your washing and ironing, cleaning, grocery shopping, cooking, make you cups of tea, prepare your meals, even cutting up your food for you if you can’t feed yourself, personal care (washing, bathing etc.)
- help with childcare

4.10.2 General findings for Q11 (impact of the way you are helped and treated)

Respondents thought the question was asking a range of things in relation to ‘the way you are helped’:
- whether you are treated with dignity and respect, by your family or by your care and support workers,
- whether people are nice, friendly, kind and generous to you,
- the way you are treated by others and the way they approach giving you help; positively or negatively,
- about believing you are worthless after people have been nasty, about self worth,
- the help you get when you need it,
- having the chance to do as much as you can for yourself, and
- how you feel when you are helped with things.

4.10.3 Perceived overlap between the questions

A common issue was respondents thinking Q10 and Q11 were asking the same or similar things, and some respondents struggled to see or explain the difference. When probed, they often gave similar or the same answers to both questions.

One respondent thought Q10 was asking about feeling vulnerable when people help you or being dependent on people for help. She felt her answer (option 2) didn’t match the question, and chose this answer because having help;

“…helps me understand information sometimes and I can have a good conversation in relation to what we are doing. Which is helpful, but that is not what it asked”

(female, white British, 18-59)

The respondent initially found Q10 difficult to answer, finding it wordy, and as a mental health patient she felt she needs to be careful about whether someone is trying to trick
her. However she understood what the question meant after answering Q11 and coming back to Q10.

In a paired English interview, the service user (male, Pakistani, 18-59) says he found Q10 “quite simple” because he based it on his experience with his care workers. The carer (his mother) tells him not to think just about care workers, but also about family, and everyone else that helps him. He only included care workers in his answer, while his carer included everyone who helps him. However, they both picked option 1 (having help makes me think and feel better about myself). In these two examples, it appears that the respondents are thinking about the concept intended by Q11 when answering Q10.

One respondent (female, white British, 60+) in a paired interview with her daughter (the carer) understood the distinction between Q10 and Q11. She and her carer commented that although now having help does not affect how she thinks or feels about herself (option 2), this was different when she had first had her stroke. However the service user struggled to choose between option 1 and 2. The interviewer commented that she wanted to pick option 2 but didn't want to do a disservice to her daughter. The daughter chose this moment to leave the room as it was obviously a sensitive issue. The service user could not think of any examples of a time when she was made to feel good about herself.

Another respondent thought that this was a personal and sensitive question, and although thought it still needed to be asked in the survey, she admitted that she may have answered differently if she was answering it in a web survey. She chose answer option 1 but said;

“If I am honest I am thinking the third one because I have pride. I know I need the help. Generally it is the first one because it means that I can do things and things are sorted. But there are times when I wish I could do that, or I wish I could go shopping myself”.

(female, Pakistani, 18-59)

4.10.4 Understanding the questions as a whole

Respondents sometimes struggled with the question wording, and had to read it more than once to understand what it was getting at. This was found particularly among the Bangladeshi and Pakistani respondents. Bangladeshi respondents struggled to understand the wording of these questions and had to re-read them or failed to give an answer. One thought this question was asking him to praise himself and couldn’t understand why it was being asked. A number of Pakistani respondents couldn’t answer this question and couldn’t explain exactly what was wrong with it or why they couldn’t answer it.

A Pakistani respondent (female, 18-59) who answered the Easy Read questionnaire wasn’t able to understand the question. She answered with option 1 because she liked the smiley face, and wasn’t able to link the answer categories to the question.
There was a suggestion that the way the question was worded made it hard to understand. A suggestion was made to reword the question stem and answer options to make it less repetitive.

A carer and service user (female, Pakistani, 60+) in a paired Urdu interview didn’t understand the question, which the interviewer thinks is due to the complexity of the translation. In another paired Urdu interview the carer stated that the service user (female, Pakistani, 60+) found the concept of ‘having help to do things’ confusing. The carer says she also struggled because the question was very subjective, about the individual.

4.10.5 Understanding of the answer options

An issue mentioned for both Q10 and Q11 was respondents thinking options 1 and 2 were too similar. One respondent (female, white British, 60+) said ‘yes’ to the first 2 options, and when made to choose one picked option 2, but felt they were similar and could have answered with both options.

Carers had issues with answering this question, for example; one found it very difficult to choose between the first two options, but chose option 2 as she wasn’t sure if the help the service user (male, Bangladeshi, 60+) receives actually makes him feel better about himself. She thought it would depend on how independent a person is. Another didn’t know how the service user (female, Pakistani, 18-59) felt when she helps her, and finds this difficult to answer. She decided on option 2 as she has been helping the service user since childhood so maybe she is used to it.

Respondents’ ability to choose an answer option was also impaired by a lack of understanding of the term ‘undermines’.

Definitions of ‘undermines’

The word ‘undermines’ in options 3 and 4 was not always understood in both questions 10 and 11. This word was used in option 3 ‘Having help sometimes undermines the way I think and feel about myself’ and option 4 ‘Having help completely undermines the way I think and feel about myself’ for question 10.

Definitions of ‘sometimes undermines’ for Q10 and Q11 included:

- not feeling good about yourself or the way you are treated,
- to underestimate someone, and
- being in a situation where you don’t matter or you feel bad.

Definitions of ‘completely undermines’ for Q10 and Q11 included:

- not getting any help at all, people being rude to you, people underestimating you, and
- people bossing you around when they are giving you help.
Where respondents said they didn’t understand what the word ‘undermines’ meant, they tended to pick options 1 or 2. However a respondent (female, white British, 60+) who didn’t understand the word picked option 4 for Q11 and 10 as they were the lowest options on the list and so she assumed they would be the ‘worst’ option. In a paired interview, the service user (female, Pakistani, 18-59) picked option 4 for Q10 and option 3 for Q11, but the carer disagreed as she believes ‘undermines’ is difficult for the service user to understand, but she may have picked up on ‘the way I think and feel about myself’. There is therefore evidence that not understanding the term may prevent people choosing from the full range of answer options.

Respondents could not (or weren’t probed fully enough to) give an explanation as to why they didn’t understand the word ‘undermines’, just that they didn’t understand the meaning of it.

### 4.11 Ease or difficulty finding information and advice about support, services or benefits (Q12)

Service users and carers were asked a question about how easy or difficult they have found it to find information and advice about support, services or benefits. The reference period in the question is ‘in the past year’.

#### 4.11.1 General findings

Cognitive interviews revealed that respondents (both service users and their carers) thought about a broader range of services, and not just social care services, when answering. For example service users talked about health/medical services they had sought information for. Others included information about housing. Service users and carers were not always thinking about the past year when answering this question, and could think more generally or back over the past few years. Their situations, however, remained unchanged so this was not seen to be problematic.

#### 4.11.2 Who’s perspective and who sought the advice and support

Regardless of ethnicity, the response category: ‘I’ve never tried to find information or advice’ was used by both:

- Service users (and carers) who had not sought advice themselves but their carer (or someone else) had on their behalf; and,
- Service users who had not tried to seek information or advice and no one had tried for them.

The findings from the cognitive interviews showed that this question is at risk of being answered from the perspective of the carer, especially in circumstances where the service user would not have the capacity to try to get information themselves. One carer suggested that there should be an extra answer category for this, such as ‘I don’t have the capacity’. This could be merged with a response category for ‘someone else finds information for me’.
4.12 General health (Q13 in SQ and ERQ only)

The questionnaire included a section of general and demographic questions. The first question asked in the background section of the questionnaire is a general health question that asks ‘How is your health in general?’ The five point response scale ranges from Very good to Very bad. The equivalent question for the Easy Read version asks ‘How is your health today?’ with a five point response scale ranging from ‘I am very healthy really’ to ‘My health is really very bad’.

4.12.1 General findings

Respondents didn’t always consider all aspects of their health when answering. Whilst there were respondents who included mental health and physical health, there were also those who only considered their physical health (this was the case with the Easy Read questionnaire too). For example service users who only thought about physical health included one who ticked good because she is physically in good health and another who ticked ‘bad’ because of all the junk food she eats and how she pants and gets out of breath when she runs. There were no ethnic group differences observed at this question.

On the whole both service user and carer’s responses matched in terms of rating health in general. However there were cases in a paired social care interview, where the service user’s response was more positive (i.e. Fair) than the carer’s (i.e. Bad).

There was a possible translation issue at this question, in that a Pakistani respondent in a paired interview pointed out that she found it difficult to understand, though still was able to give a response, because of the chosen Urdu translation.

4.13 Ease and ability to perform tasks (Q14 & Q15 in SQ; Q15 & Q16 in ERQ)

The next questions in the background section of the questionnaire were two four part questions which ask the respondent about their ability to perform a number of tasks independently. Q14 asks about a) getting around indoors, b) getting in and out of a bed (or chair) by themselves, c) feeding themselves, d) dealing with finances and paperwork by themselves. (Q15) asks about a) washing all over, b) getting dressed, c) using the toilet and d) washing face and hands. The three point response scale ranges from ‘I can do this easily by myself’ to ‘I can’t do this by myself’. The Easy Read version of these questions is very similar questions though with smiley faces against the response scale.

4.13.1 General findings

These questions were described as easy to answer and factual rather than opinion and there were no apparent differences in the way Bangladeshi and Pakistani and white British respondents understood or approached them. There was one issue with
part a) of Q14 in that there were respondents who were confused by the clarification ‘(except steps)’ – these were from all three ethnic groups.

This question could be difficult to answer for respondents who had varying levels of difficulty with the task(s) being asked about (i.e. sometimes they manage but sometimes they have difficulty) or where they were able to perform some of the tasks but not others (can pay bills but has difficulty writing letters for example). Notably, part d) of Q14 caused the most issues in relation to the latter. For example one service user chose ‘I have difficulty doing this myself’ for managing finances though she did not think this was a reflection of her ability since she can manage her finances but needs help reading her mail. One respondent who completed the Easy Read version of these questions ticked two boxes as she can sometimes perform tasks but sometimes needs help. There was a suggestion from a service user to include an answer option ‘I sometimes have difficulty’.

4.14 Mobility outside of the home (Q16 in SQ; Q18 in ERQ)

This question asks respondents to best describe their ability to get around outside of their home, with the answer options; 1 ‘I can get to all the places in my local area that I want’, 2 ‘At times I find it difficult to get to all the places in my local area that I want’, and 3 ‘I am unable to get to all the places in my local area that I want’. The question was only asked of service users, not of carers. A similar question was asked of Easy Read respondents with an extra answer option of ‘I do not leave my home’.

4.14.1 General findings

Respondents answered with a spread of options 1, 2 and 3. The question was generally easily understood.

One issue that arose was respondents wanting to answer with more than one option, particularly in paired interviews, or not being able to decide on an option as their mobility depended on various circumstances. For example, one respondent (male, Pakistani, 18-59) answered with option 3 as he is unable to walk and would need help if he were to go out in his wheelchair, but his carer chose option 2 as the question asks respondents to include ‘getting around by yourself or with help from someone else’. They did not agree on which option to choose.

Another issue that arose was respondents wanting an additional answer option to say that they don’t want to go out at all, for example one respondent (female, Pakistani, 18-59) commented that she chose option 2 because she can manage on her own if she wants to go out, but her mother often persuades or makes her to go out when she would prefer to stay in. The answer options end in ‘…that I want’, which made one respondent (female, white British, 60) unsure what to answer, as although she has help from a friend to take her to the health centre once a week, she goes there because she *has* to not because she *wants* to, and doesn’t go anywhere else. She picked option 2 but thinks she possibly should have picked option 3. A suggestion
was made (female, Pakistani, 18-59) for the answer categories to be reworded in a way that would read more easily;

1 ‘I can get to all the places that I want to, in my local area’,
2 ‘At times I find it difficult to get to all the places that I want to, in my local area’,
3 ‘I am unable to get to all the places that I want to, in my local area’.

### 4.14.2 Translation problems

There were issues with both the Bengali and Urdu translations. A Bangladeshi respondent (female, 60+) commented that the question is incorrect as it appears to be intended for the carer and doesn’t apply directly to the user. A Pakistani carer of a service user (female, 60+) commented that these questions (referring to the whole questionnaire) were very difficult to answer because of the way they had been translated, and that they should be translated in more easy and understandable Urdu.

### 4.14.3 Easy Read

One of the two Easy Read respondents (both females, Pakistani, 18-59) understood her ‘local area’ to be outside of her house, and answered option 1 as she goes to all of the places she wants and discussed the various activities she does. The other picked three answer options; 1, 3 and 4, as she can get to all the local areas that she wants (1) and found options 3 and 4 easy to understand. She also explains that when it is bad weather she doesn’t leave her home, but can easily get to the local high street if she wants to.

### 4.15 Support or services (Q17 in SQ)

This question asks whether respondents have used a number of support or services in the last 12 months, provided by any organisation such as a voluntary or private organisation as well as Social Services. The services listed are; personal assistant, home care/ home help, day centre or day activities, lunch club, meals services, equipment or adaptation to the home, and lifeline alarm. The question is asked only of service users using the standard questionnaire, not carers or Easy Read respondents.

This set of questions (13-17) were generally found to be easier to understand and answer by respondents than the previous questions, as they are straightforward and require ‘Yes’ or ‘No’ answers, without any “confusing terminology” (male, white British, 18-59).

### 4.15.1 Difficulties and issues with the question

Although respondents generally found this question easy to answer, there were often services listed that they were unsure about (these are covered in more detail in the following sections). Issues with answering the question itself included the grid format, for example difficulties with placing ticks in the right boxes as they couldn’t relate the headings at the top to their answers, particularly towards the end of the list. One
respondent (female, white British, 60+) said that by the time she reached the last two on the list she had forgotten what the question was asking. Other issues raised were the small font making it difficult to read, and the need for a line under each question to ensure they were ticking the right boxes. There were a number of respondents aged 60+ who had an issue with this question for these reasons.

An interviewer noted that ‘Key worker’ could have been included on the list as it applied to one of the respondents’ situations (female, white British, 60+), and there is also nowhere to indicate that the respondent lives in a care home (female, Pakistani, 18-59).

4.15.2 Timescales
The question asks about support or services used in the last 12 months, however respondents thought about various time periods when answering the question depending on their circumstances. One way was to think about what support or services they had used since a change in their condition, for example one respondent (male, Pakistani, 60+) was thinking about the last two years since his problems became more serious, and another (male, white British, 18-59) was thinking about the last two to three years as the question made him think about the progress he had made with his condition in that time. Another way of answering the question was to think about what support or services they had received since a change in their life, such as a move of house, for example one respondent (female, white British, 60+) thought about since she moved into her bungalow eight months ago.

4.15.3 ‘Personal assistant’
The term ‘personal assistant’ was a source of confusion. Various definitions included; a secretary, someone who deals with paperwork, a Doctor’s PA, and ‘someone who works directly with you, personally’ (male, Bangladeshi, 18-59). Those who have these incorrect (in this context) definitions answered either ‘No’ or ‘Don’t know’ to this question, and were aware that they were unsure of the meaning. Other definitions given where respondents answered ‘Yes’ to this question included support workers paid for with Direct Payments, who help with shopping, washing and ironing, and supermarket personal shopping assistants. These various definitions show that respondents understood this question in a number of ways, and perhaps a definition of the term ‘personal assistant’ needs to be given so they know what to include and what not to include in their answer.

4.15.4 ‘Home care/home help’
Respondents answered this question thinking about their care and support workers, though some were unsure whether to include care and support workers as it asks about ‘home’ care and help, and they have care and support workers who help them with things outside of the home such as shopping. In relation to the previous ‘personal assistant’ term; one respondent (female, Pakistani, 18-59) defined ‘home care/home help’ as dealing with more personal things such as bathing and feeding, provided by an organisation.
4.15.5 ‘Day centre/day activities’

This wasn’t probed on as much as the term ‘personal assistant’ and so only two respondents commented on what they included in ‘day centre or day activities’. One (female, Pakistani, 18-59) answered ‘No’ as she was thinking about going to the Gym or Art classes, which she used to attend but no longer does. The other (male, Bangladeshi, 18-59) works at a project which he refers to as a ‘day centre’, but previously attended a day-care centre, so wasn’t sure how to answer. He originally answered ‘Don’t know’ but changed it to ‘No’. The interviewer commented that she wasn’t sure he had understood he word ‘used’ in the question.

4.15.6 ‘Lunch club/meals services’

One carer of a service user (male, Pakistani, 60+) commented that a ‘lunch club’ and ‘meals services’ were similar, and thought about Meals on Wheels or meals in a care home. Another respondent (female, Pakistani, 18-59) thought it was asking about people who need help with meals, and answered ‘No’, although she lived in a care home and so perhaps might be provided with meals. It is not clear what the difference between the two is so perhaps they should be combined into one answer option.

4.15.7 ‘Equipment’

Again, this term wasn’t probed very often, but one issue that emerged was a respondent (female, white British, 60+) being unsure whether to include equipment she has in her home as it was organised by her GP, but funded by the local authority. It was not explored fully by the interviewer, but although this question asks about support or services provided by ‘different organisations, such as a voluntary organisation, a private agency or Social Services’ as well as the local authority, the previous questions were only interested in social care provided by local authority funding.

4.15.8 ‘Lifeline Alarm’

Respondents who didn’t know what a ‘Lifeline Alarm’ is answered ‘No’ as they assumed they would know what it was if they have one. One respondent (female, white British, 18-59) originally discussed a recent scenario where she contacted the block manager of her flat and her voluntary work colleagues to make them aware that she was reaching a “danger zone”. However, she realised that the question was asking about a physical object which people press that calls for help. If she hadn’t realised this, she would have incorrectly answered ‘Yes’ to the question.

4.15.9 Translation problems

In an Urdu interview the respondent (female, Pakistani, 60+) did not understand the question due to the complexity of the way it has been translated, and asked the interviewer to explain the question in layman’s terms. Both the Urdu and Bengali translations had a list of 11 options (A-K), whereas the English question only had 8
options (A-G), so there were four more options in the translated versions. It is therefore unclear which options weren’t understood. One Bangladeshi respondent (female, 60+) didn’t understand option D. Another Bangladeshi respondent (female, 18-59) didn’t understand all of the options (she didn’t specify which) and felt the question was intended for a carer, not the social service user.

4.16 Practical help from family and friends (Q18 in SQ; Q19 in ERQ; Q13 in ICQ)

This question asks respondents if they receive any practical help on a regular basis from family, partners, friends or neighbours. The answer options are ‘Yes, from someone living in my household’, ‘Yes, from someone living in another household’, or ‘No’. It was asked of service users and carers, and a similar question was asked in the Easy Read version.

It is important to note that by this point in the interview (even earlier for some), respondents had grown tired of the questioning and probing and so there was less detail obtained for this question.

4.16.1 General

Respondents generally found this question easy to answer quickly, reporting having help from someone living in their household, someone living in another household, and often from both. Very few reported having no help from anyone.

Comments were raised around this set of questions that highlighted sensitivity issues. For example, one respondent (female, white British, 60+) said that although she didn’t find any of the questions intrusive, offensive or upsetting, some of them made her realise that she has a problem as she cannot do what she wants to do, which makes her feel low and helpless. A carer of a service user (female, Pakistani, 18-59) did not find these questions sensitive herself, but felt they may be to those with a mental health problem, a learning difficulty, a terminal illness, or a drug or alcohol dependency.

4.16.2 Section introduction

As issue brought up by a carer of a service user (female, Pakistani, 18-59) was that the introduction for this next set of questions was confusing. It states; ‘This last section is about yourself, the service user’, which made her question what the previous questions were about. As a result of this confusion she answered from her own perspective as the carer, relating to the help that she receives not that the service user receives. Another carer of a service user (male, Bangladeshi, 60+) had the same issue. After reading the question she asked; ‘Is this for my dad, yeah?’ (her dad is the service user) but, when the interviewer asked her what she thought the introduction meant, she went on to answer in terms of the help she receives, not the service user.
4.16.3 Question wording/ instructions

Family
There were a number of issues that arose from the way the question and instructions were worded. There was a pattern of respondents answering the question before they read or heard the answer categories. The question asks ‘Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?’, and respondents tended to answer “Yes, my wife helps me”, or “Yes, my children help me”. They then saw or were read the answer categories and had to answer ‘Yes’ in terms of whether the help comes from someone living in their household or in another household, or both.

4.16.4 Household
An issue that arose with a respondent living in a care home (female, Pakistani, 18-59) was that she answered ‘Yes, from someone living in my household’ and was thinking about help from her mother, who she sees as part of her household despite the respondent living in a care home and not at home with her mother.

4.16.5 Interviewer’s help
Although the question asks about ‘practical help on a regular basis’, a few respondents included help from the interviewer to answer these questions. One (female, white British, 18-59) brought up the interviewer helping her during the interview but the interviewer told the respondent to ignore her, so the respondent correctly answered ‘No’. Another respondent (female, Bangladeshi, 18-59) who was interviewed in Bengali answered ‘Yes, from someone living in another household’ and was thinking about the interviewer’s help with the questions.

4.16.6 Issue with the language used
A Pakistani paired interview respondent (male, 18-59) who was interviewed in English took some time trying to understand this question, and had to return to it after answering the other questions. He did not understand the word ‘practical’ and his carer had to do a rough translation into Urdu for him to be able to pick an answer.

4.16.7 Easy Read
Both Easy Read respondents (both females, Pakistani, 18-59) had to be prompted by either a day centre manager or the interviewer to answer this question correctly. One initially thought about help from her dad so answered ‘Yes, from someone living in my household’, but the day centre manager reminded her about help from her sister when her parents are busy or away, so she also answered ‘Yes, from someone living in another household’. The other answered with all three options (including no), and said she was thinking about help from her mum and the neighbours. She realised her mistake when talking through her answer with the interviewer and so put a cross through the tick next to ‘No’.
4.17 Whether completed the questionnaire alone or with help (Q19 in SQ; Q21 in ERQ; Q14 in ICQ) and type of help received (Q20 in SQ; Q22 in ERQ; Q15 in ICQ)

A question is asked towards the end of the questionnaire which establishes whether the respondent completed the questionnaire by themselves or whether they had help from someone else. The intention of this question is to establish whether the service user completed the questionnaire themselves or whether someone else assisted or filled it in on their behalf. It is clear from the follow up question about the type of help received that the intention of the question is for ‘I had help from someone...’ to be used where someone fills in the questionnaire on the service user’s behalf. In the cognitive testing both service users and carers were asked these questions.

4.17.1 Findings for both questions

Confusion at these questions was more likely where a carer was completing the questionnaire on behalf of the service user.

Whilst there were carers who answered the question correctly (i.e. on behalf of the service user, so ticking one of the ‘I had help’ options at Q19 and then the type of help at Q20), there were also carers who made the mistake of answering from their own perspective: so ticking ‘I filled it in myself’. This mistake happened across all ethnic groups.

A missing answer option was brought to our attention, at Q19. One carer of a service user (white British) suggested that there should be an option for carers to use: i.e. ‘my parent/daughter or son answered on my behalf’. However this overlaps with the existing category ‘I had help from someone living in my household’. However the finding chimes with the finding on the previous question that people think in terms of their relationship with the person who helps them rather than whether or not they live in the same household so this may well be something worth considering.

In our small cognitive sample, there were no real differences between Pakistani, Bangladeshi and white British respondents. In all groups, there were service users who self completed the questionnaire (I filled it in myself) and those who had help from someone living outside of their household. In the Pakistani and Bangladeshi group there were respondents who had help from someone living in the household, though there were no white British respondents who reported this.

We recommend that the question establishing whether there was any help in completion is reworded to make it clearer that carers who complete it on behalf of service user should not select the ‘I filled it in myself’ option. Linked to this we recommend that, although emphasis should continue to be put on service users completing the questionnaire themselves, the introduction to the survey and introduction to individual questions should be adapted so that in cases where the
carer is completing the questionnaire, it is made very clear that they should be recording the perspective of the care service user, not their own views.

There was little data for the question about type of help (Q20 in the SQ version). Those carers who had mistakenly answered the previous question (i.e. from their own perspective, therefore choosing ‘I filled it in myself’) approached this question in the same way: choosing ‘I didn’t have any help’.

In interviews with service users (and paired interviews too), the help and type of help question seemed to work without difficulty though occasionally the type of help question (Q20 in the SQ) was left blank. Presumably respondents had thought that they had indicated that they completed the questionnaire by themselves at the first question, meaning they did not need to provide any detail at the next (type of help) question, however this is our suspicion as interviewers did not probe where this occurred.

4.18 Disability, gender, age and ethnicity questions (Q21-24 in SQ; Q16-19 in ICQ)

Four questions were included at the end of the service user and Easy Read questionnaires which ask about disabilities and health problems, gender, age (grouped) and ethnicity. There were no specific findings relating to how these questions worked though findings from cognitive interviews suggest that they were straightforward enough to answer.
5 Conclusions and Recommendations

5.1 Conclusions

The cognitive interviewing described in this report formed one part of a larger project to explore the underlying reasons for lower satisfaction with social care found in Adult Social Care Surveys. This element of the research has found no evidence that inconsistencies in data collection or understanding of the survey questions leads to inconsistent measurement of satisfaction or social care outcomes. Even for topics such as food and drink where preferences and requirements may be different, the survey questions are acting as consistent measurement tools. This means that to look for explanations for differences in satisfaction we need to understand in detail what drives satisfaction for the different groups and why satisfaction is lower for Bangladeshi and Pakistani groups in particular. This is explored in detail in the companion report (Gill et al, 2014).

However the cognitive interviewing and subsequent discussion of the findings with those involved in designing and running adult social care surveys mean there are some recommendations which have emerged in the relation to the way data are collected. At the end of the project, when we had findings from the cognitive interviews as well as the in-depth qualitative element of the project we held three deliberative workshops to discuss the findings and to develop practical recommendations. These workshops were attended by service users, provider organisations, local authority adult social care workers and managers, as well as members of the teams responsible for running the surveys in local authorities. See the companion report for more detail on this phase of the research (Gill et al, 2014). This was supplemented with separate discussions with the Health and Social Care Information Centre and those involved in designing the survey questions.

In this section we highlight some of the key findings of the cognitive interviewing phase of this project with some associated recommendations.

5.2 Making the survey more accessible

There was evidence that the existing translations are not working well because of the style of language used, literacy issues and differences in dialects. The uptake of the written translations in the adult social care survey is low. Translation is provided informally by family members and some local authorities provide help over the phone in the languages they are able to. Overall response could be increased and the representation of Bangladeshi and Pakistani people in the sample could be improved if attention was given to how people who do not speak fluent English can participate. A number of recommendations were made which need further exploration before they are implemented:

- Use well-trained interpreters in preference to translated questionnaires for people with limited literacy (although there are cost implications).
• Involve service user groups and community groups in advance to prepare them to support people to complete the questionnaire but recognise the limitations and complications of this during analysis, particularly because where these community organizations are also providers, this may affect the responses given.

• Encourage the use of volunteer interviewers with standard training based in independent third sector organisations to support effective translation of the survey.

• Video materials in various languages could be developed to introduce and take people through the translated survey questionnaire. This could be useful even for the English version for those with limited literacy.

• Use plain language for the standard questionnaire as well as the Easy Read version.

• If written translations are to be retained, they need further testing and evaluation among the relevant groups and steps should be taken to raise awareness of them during the survey (information leaflets and staff in local authority contact centres being informed).

• Consider whether more qualitative approaches are needed to gather the views of some service users, or to understand satisfaction and outcomes in more detail.

5.3 The Easy Read version

There was some limited evidence, because of the small number tested, that the images on the easy read questionnaire could be a hindrance rather than a help. Respondents did not necessarily link the smiley faces correctly to the answer options and could be swayed by the faces rather than the options. During the workshops, there was evidence that the other images used in the questionnaire were a source of concern as they could be interpreted as patronising. At the same time, the findings on the use of language and wording used in the standard questionnaire, suggest that some elements of the easy read questionnaire in terms of the simpler language could be of use to a wider group than those currently offered it (those with learning disabilities). Consideration should be given to extending the use of the easy read version, without images, or incorporating some of the language from the easy read version in the standard version. This of course depends on the feasibility of making changes to the widely used standard questions intended to provide comparison over time.
5.4 Specific wording changes

This report is not designed to make recommendations for question by question changes to the wording or design of the questionnaire. The existing questions have been extensively tested and there is already a developing time series. Nonetheless, the report does highlight the use of a few particular terms which impeded understanding of the questions, e.g. ‘adequate’ and ‘undermine’, which could be considered for modification. There were also findings related to respondents not understanding the distinction between questions (e.g. between how being helped makes you and how the way you are helped makes you feel). The inclusion of an introduction which helps respondents understand this may help generate better data without altering existing questions.

5.5 Focussing on the correct services

The cognitive interviewing showed that respondents had difficulty confining their consideration to social care services provided by the local authority when considering satisfaction and social care outcomes. This finding was echoed by those from local authorities involved in running the surveys, who found people were not sure what the questionnaire was about and whether it was relevant to them. Sometimes irrelevant services were considered (e.g. health or police services) and in other cases services which should have been considered such as direct payments or equipment were not considered.

- A personally addressed letter with clear guidance should be used, this should describe the focus of the survey, whose experience should be captured and what services are being monitored (though there is potential concern about and whether respondents would feel less sure about the confidentiality of the survey)
- Use time references to prevent a past bad experience clouding feedback about current satisfaction with care.
- Local authorities should consider personalising the survey questionnaire and adding questions that would be useful in the local context (checking acceptability with the Health and Social Care Information Centre). This could be additional questions useful to that local authority, or including local terms used for specific services in existing questions or introductory letters.
- An alternative approach is to accept that service users think of all services, not just social specifically and include question which allow them to give their views on health and other services in the questionnaire (perhaps in new questions) to help them focus on social care in the existing questions.

5.6 Whose views are being captured?
There was evidence from the cognitive interviewing that the role of carers and care and support workers in completing the questionnaire could affect the answers given. Receiving help was common, however the questionnaire was addressed to ‘you’ and it was easy for those helping the service user to become confused, particularly later in the questionnaire about whose views and experience was being sought. This led to carers responding from their own perspective, either because they assumed the service user’s would be the same or because or because they thought it was their views which were being sought. Questions designed to provide information on who had answered the questions were not well understood meaning it would not always be possible to know who had been involved (carers responding ‘I answered it myself’).

- Letters accompanying the questionnaire should make it clear who the questionnaire is about (this already happens, though local authorities vary in the extent to which they personalise the letter because of respondent concerns about confidentiality)
- Additional guidance should be provided to help carers who are completing the questionnaire on some else’s behalf (guidance has already been developed by the HSCIC since the version which was tested in this project but this could perhaps be developed further)
- Consider whether an adapted questionnaire with slightly different wording could be used when being completed by a carer (less use of ‘you’)
- Consider including some questions aimed at carers so that they can give their own views if they wish and to help them understand that in the other questions the views of the service user are being sought.

### 5.7 Running the surveys

It was clear from the workshops that staff in local authorities are working hard to improve how the surveys work in their area and how they can use the data obtained. During the workshops these staff shared ideas and experience. One recommendation is that the 152 local authorities running the surveys should be supported in sharing good practice and experience, perhaps using online forums or occasional workshops or meetings.
References


