### Appendix A. Sample composition

Achieved sample

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Appendix B. Interview protocols

Standard (individual/paired) protocol

P3143: Cognitive Testing of Social Care Satisfaction Questions

QUESTIONNAIRE GUIDE AND PROBE SHEET
(INDIVIDUAL SOCIAL CARE USERS VERSION)

Introduction

- Introduce yourself, NatCen, and the study
- NatCen Social Research and the Universities of Stirling and Leeds are carrying out a research project funded by the National Institute of Health Research (NIHR) School of Social Care Research (SSCR) to explore people’s experiences of receiving social care
- **What is the research about?** People receiving social care are asked in surveys how satisfied they are with their care. Some groups, including black and minority ethnic groups, are less satisfied than others. This research project aims to find out why.
- How will you do this? We will talk to Pakistani, Bangladeshi and White British people who are receiving formal social care and family members/friends who provide social care to explore with them how these survey questions work. We will review the questions to make sure that they collect accurate information. As part of this we want to get a range of people’s opinions on the questions in order to see whether the questions work as intended and are understood consistently by different groups

Interview Protocol

- Explain that we would like the R to think aloud while they complete a self completion questionnaire and at various points you be asking them to tell you what they thought of certain questions.
- Explain we are not interested in their answers as such, more about how they understand the questions and how comfortable they feel answering them.
- Stress there are no right or wrong answers and this isn’t a test.
- Explain how confidentiality and anonymity will be observed throughout the research.
- Remind them:
  - that participation is voluntary;
  - the interview could last about one hour;
- Stress the confidentiality of the process; all the findings will be reported anonymously. Please make sure they understand this.
• Explain that you will be recording the interview so that you don't have to make lots of notes during the interview. Check this is OK with the respondent. If they ask who will have access to the recording, tell them that only the small research team at NatCen.

• **EXPLAIN -THINK ALOUD** talking the R through an example e.g. the windows example

• Ask whether they have any questions before you start.

**Stage 1: Explore initial views on mode including the self completion mode**

**Probes**

- If you were asked to complete a self completion questionnaire measuring social care satisfaction what are the steps you would go through before deciding to fill it in?

- Would you fill it in alone or would you will it in with someone else? Why? If you filled it in with someone else how would you involve the other person? What would their role be?

- What is the best way for a survey to ask peoples’ views of their satisfaction with their social care? (If asked explain that Rs could be asked Qs f2f or over the phone by an interviewer or asked to fill in a paper or web based - Do you think questions measuring your satisfaction with social care should be asked in a self completion paper questionnaire or should it be asked by an interviewer face to face or over the phone or does it not matter?)

**Interviewer: Hand over self completion. Explain this is a test version.**

- What are your initial thoughts on seeing this questionnaire?

- If you received this questionnaire in the post what would you do with it?

- Would you think about filling it in or would you leave it? Why?

- Please talk me through how the form would be filled in? (Explore if R would seek permission/help from someone to fill it in or would this ‘helper’ fill it in for them).
Stage 2: Testing the Introduction in the self completion

Interviewer:

- Explain that you would like to hear their views on the introduction. Explain that you would like to hear their views on the introduction. Explain, where there are references to [your local social services department] in the document in the ‘real survey’ this would be replaced by the name of their local social services e.g. Swindon Borough Council Adult Social Care.
- Check if they are able to read the introduction (large print version available) or if they would like you to read it out to them.
- Ask the R to read the introduction and to let you know what they think of it as they are going through it. If you are reading it out ask them to feel free to stop you at any point to share their thoughts with you as you are reading it out.
- Explain that this is the standard introduction for the questionnaire. We are interested in what they would think of it if they received it in the post. The number to ring is not applicable for this testing project.

Your Social Care and Support Services

Introduction

We are contacting you because you receive, or have received, care and support services that are paid for (at least in part) by [your local Social Services Department]. By care and support services we mean you may be living in a care home, receiving a Personal Budget, home care, equipment, meals services, Direct Payments, or attending a day centre. We want to improve and develop our services so we want to get your views on the services you receive. In particular, we want to hear about your quality of life and how services have affected the quality of your life.

What to do if you need help to give your views

You can ask a friend, relative or an advocate to help you complete the questionnaire, but please remember that it is your views and your experiences that are important to us, rather than the views of anyone that helps you. If you prefer, you can also get in touch with [the telephone assistance line] to ask for someone independent from social services and your care provider to help you to complete the questionnaire. Staff from [Social Services] involved in the provision of your care, or anyone that you pay to care for you should not help you to fill it in.

What to do if you have queries

If you, or your friend or relative, have questions you would like to ask about the survey, or if you would like the questionnaire in another language or different format such as large print or easy read then please ring xxxxxxxxxx on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm.

What will be done with the results of the survey

The results of the survey will be used by the Care Quality Commission, the Department of Health and your [Social services department] to see how happy people are with their care and support services and assess their experiences of local care services. The results will also be used for further research or analysis.
Confidentiality
Your answers will be treated as confidential: they will not be passed on to your social worker, care manager, care and support worker or anyone providing you with services. You will not be personally identified and your answers will not affect the services you receive.

Reminder Letters
If you do not return this questionnaire then you may be sent a reminder letter. If you do not wish to receive a reminder then please send back an uncompleted questionnaire in the envelope provided.

Sending back the completed questionnaire
Once you have completed the questionnaire please return it in the envelope provided by [DATE]. You don’t need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Introduction Probes
- How easy or difficult is it to understand the introduction?
- Who is supposed to fill in the questionnaire? Who can help the form filler?
- What should be included in the introduction to encourage people to participate in the survey?
- Was there anything that you read/heard that would put you off completing this questionnaire? If yes, what were these and why were they off putting?
- After reading this introduction, who if anyone, would you involve in filling in the questionnaire?
Stage 3: Testing individual questions in the Self completion

INT ASK R TO ANSWER Q1
Section 1: The first question is concerned with your overall satisfaction with your social care and support

1. Overall, how satisfied or dissatisfied are you with the care and support services you receive?

   By ‘care and support services’ we mean any equipment or care provided by staff who are paid to help you. The staff could be from [Social Services], an agency, a care home or bought by you using money from [Social Services] through a Direct Payment.

   Please tick (✔) one box

   | 1 | I am extremely satisfied          |
   | 2 | I am very satisfied              |
   | 3 | I am quite satisfied            |
   | 4 | I am neither satisfied nor dissatisfied |
   | 5 | I am quite dissatisfied         |
   | 6 | I am very dissatisfied          |
   | 7 | I am extremely dissatisfied     |

(Measure 3A ASCOF)

Probes Q1 – THIS IS THE KEY QUESTION FOR US TO TEST.

- What Care and Support services did you think about when you answered this question?
- What did ‘Social Services’ mean to you in this question?
- How easy or difficult was it to decide on which answer option to use?
- Was there anything you weren’t sure whether to include or exclude and if yes, what were these? And how did you decide what to do about this?
- What would your experience have to be like to select ‘extremely satisfied’ or ‘very satisfied’? What about ‘extremely dissatisfied’? (Don’t probe on all categories but on extremes and any they considered by did not choose).
- Have you had a consistent experience of social care? If satisfaction has varied how did you choose your answer?
Section 2: The next section is about your quality of life

When answering the following questions please think about the quality of your life as a whole, including the help you get from others as well as [Social Services].

ASK R TO ANS Q2a-Q2b

2a. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

*Please tick (✔) one box*

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<td>So bad, it could not be worse</td>
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2b. Do care and support services help you to have a better quality of life?

*Please tick (✔) one box*

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(Optional question for councils in Adult Social Care Survey)

Probe Section 2 Introduction

- What do you think of the introduction?
- Explore: If R read it before answering the Qs and if it was clear.

Probes Q2a:

- How did you decide on your answer?
- How easy or difficult was it to rate the quality of your life as a whole? Why?
  If not covered in the above probe:
  - When you answered this question were you thinking of a specific occasion or thinking more generally? Why?
  - What did ‘quality of life’ mean to you in this question?
  - What were the good and bad things you thought about?

Probes Q2b:

- What did ‘care and support services’ mean to you at this question? (Probe if it meant social services only or included other services and if so what?)
- What did ‘better quality of life’ mean to you at this question?
- How easy or difficult was it to think about whether the services helped you to have a ‘better quality of life’?
3a. Which of the following statements best describes how much control you have over your daily life? By ‘control over daily life’ we mean having the choice to do things or have things done for you as you like and when you want. 

Please tick (✓) one box

- I have as much control over my daily life as I want  
- I have adequate control over my daily life  
- I have some control over my daily life but not enough  
- I have no control over my daily life

(Measure 1A and 1B ASCOF and ASCOT Q1)

3b. Do care and support services help you in having control over your daily life? By ‘care and support services’ we mean any equipment or care provided by staff who are paid to help you. The staff could be from [Social Services], an agency or bought by you using money you receive from [Social Services], using a Direct Payment. 

Please tick (✓) one box

- Yes  
- No

Q3a Probes

- What did ‘control over daily life’ mean to you at this question? Probe fully for examples the R thought about while answering this Q.
- How easy or difficult was it to decide on your answer?
- When you answered this question were you thinking generally or of a specific occasion? Why?
- What would it mean to have ‘adequate control over your daily life’? What would that be like?

Q3b Probes

- Did care and support services mean the same in this question as it did in Q2b or did it mean something different? If different probe fully for examples and why?
- Was there anything you were unsure about including? How did you decide whether to include or exclude these things?
4a. Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation?

Please tick (✔) one box

- I feel clean and am able to present myself the way I like
- I feel adequately clean and presentable
- I feel less than adequately clean or presentable
- I don’t feel at all clean or presentable

(Measure 1A ASCOF and ASCOT Q2)

4b. Do care and support services help you in keeping clean and presentable in appearance?

Please tick (✔) one box

- Yes
- No

(Optional question for councils in Adult Social Care Survey)

5a. Thinking about the food and drink you get, which of the following statements best describes your situation?

Please tick (✔) one box

- I get all the food and drink I like when I want
- I get adequate food and drink at OK times
- I don’t always get adequate or timely food and drink
- I don’t always get adequate or timely food and drink, and I think there is a risk to my health

(Measure 1A ASCOF and ASCOT Q3)

5b. Do care and support services help you to get food and drink?

Please tick (✔) one box

- Yes
- No

(Optional question for councils in Adult Social Care Survey)

6a. Which of the following statements best describes how clean and comfortable your home is?

Please tick (✔) one box

- My home is as clean and comfortable as I want
- My home is adequately clean and comfortable
- My home is not quite clean or comfortable enough

(NatCen Social Research: Appendices to cognitive interview report: satisfaction with adult social care among Bangladeshi, Pakistani and white British populations)
My home is not at all clean or comfortable
(Measure 1A ASCOF and ASCOT Q7)

6b. Do care and support services help you in keeping your home clean and comfortable?
Please tick (√) one box

☐ Yes 1
☐ No 2

(Optional question for councils in Adult Social Care Survey)

Q4a - Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation?

Probes Q4a
- What did ‘clean and presentable in appearance’ mean to you in this question?
- When were you thinking about when you answered this question? (Explore if R was thinking generally or specific occasion e.g. days personal assistant visits)
- How easy or difficult was it to select an answer? Why?
  Explore
- Whether having clean and presentable in the answer options made the question difficult to answer
- Whether R is thinking generally or of a specific occasion.

Probes Q5a
- How easy or difficult was it for you to answer this question? (Explore why? E.g. thinking generally)
- What kinds of food and drink did you think of?
- How would you describe ‘adequate food and drink’/ ‘timely’ food and drink’?
- How did you decide on your answer? (Explore use of answer options E.g. Under what circumstances do you think code 2 would be used and code 3 would be used?)

Probes Q6a - Which of the following statements best describes how clean and comfortable your home is?
- What did ‘clean and comfortable’ mean to you at this question? (Do they mean different things or the same thing?)
- How easy or difficult was it for you think of clean and comfortable when you answered this question?
- What area did you think about when you answered this question? (Explore, if R lives with other family members explore if R thought about their space only or the family space generally; did they think of their main residence, include garden or not etc)
- How did you decide on your answer? (Explore if R was thinking generally or a specific occasion and explore reasons for this)

Probes 4b 5b 6b
- When you answered Q4b, 5b and 6b were you thinking of the same care and support services? And was this the same as the earlier Qs?
- If no, what were you thinking about? And Why?
7a. Which of the following statements best describes how safe you feel?
By ‘feeling safe’ we mean how safe you feel both inside and outside the home. This includes fear of abuse, falling or other physical harm.

Please tick (✓) one box

- I feel as safe as I want 1
- Generally I feel adequately safe, but not as safe as I would like 2
- I feel less than adequately safe 3
- I don’t feel at all safe 4

(Measure 1A and 4A ASCOF and ASCOT Q4)

7b. Do care and support services help you in feeling safe?

Please tick (✓) one box

- Yes 1
- No 2

(Measure 4B ASCOF)

Probes Q7a
- How did you go about answering this question and deciding on your answer? If not covered above
- What did ‘feeling safe’ mean to you? What kind of things did you think about when you were answering this question?
- Please describe to me the area you were thinking about when you answered the question?
- Why did you think of this/these area(s)?
- What sort of time period were you thinking of? Were you thinking of a specific occasion or were you thinking more generally when you answered this question?

Probes 7b
- How easy or difficult was this question? Why was this?
- Were you thinking about the same area as you thought about in the previous question or a different area? If different: Where were you thinking about? And why?
- May I check did care and support services mean the same thing as in earlier questions? If no explore how R thought about it.
8a. Thinking about how much contact you’ve had with people you like, which of the following statements best describes your social situation?

Please tick (√) one box

- I have as much social contact as I want with people I like 1
- I have adequate social contact with people 2
- I have some social contact with people, but not enough 3
- I have little social contact with people and feel socially isolated 4

(Measure 1A ASCOF and ASCOT Q5)

8b. Do care and support services help you in having social contact with people?

Please tick (√) one box

- Yes 1
- No 2

9a. Which of the following statements best describes how you spend your time?

When you are thinking about how you spend your time, please include anything you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others.

Please tick (√) one box

- I’m able to spend my time as I want, doing things I value or enjoy 1
- I’m able to do enough of the things I value or enjoy with my time 2
- I do some of the things I value or enjoy with my time but not enough 3
- I don’t do anything I value or enjoy with my time 4

(Measure 1A ASCOF and ASCOT Q6)

9b. Do care and support services help you in the way you spend your time?

Please tick (√) one box

- Yes 1
- No 2

(Optional question for councils in Adult Social Care Survey)
General probes
- Were you thinking about the same time period as you did in the previous question or did you think about a different time period when you answered these questions? If different, when were you thinking about? Why did you think about this time?

Probes Q8a
- How easy or difficult was it to decide on your answer? Why? (Explore if it was difficult to generalise)
- What did ‘contact you’ve had with people you like’ in the question wording mean to you?
- Was your understanding of ‘social contact’ which is referred to in the answer options the same as ‘contact’ or was it different? IF DIFFERENT, explore meanings of both terms.
- The last answer option, refers to ‘feeling socially isolated’ what does this mean to you in the context of this question?

Probes Q8b
- What types of ‘help’ did you think about when you were answering this question? Was there any type of help that you weren’t sure whether to include? How did you decide whether to include or exclude the help?

Probes 9a
- What types of activities did you think about when you answered this question?
- How easy or difficult was it to answer this question?

Probes Q9b
- What types of ‘help’ did you think about when you were answering this question? Was there any type of help that you weren’t sure whether to include? How did you decide whether to include or exclude the help?
INT ASK R TO ANS Q10-Q12

10. Which of these statements best describes how having help to do things makes you think and feel about yourself?

*Please tick (✓) one box*

- Having help makes me think and feel better about myself  

- Having help does not affect the way I think or feel about myself  

- Having help sometimes undermines the way I think and feel about myself  

- Having help completely undermines the way I think and feel about myself

(ASCOT Q8)

11. Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?

*Please tick (✓) one box*

- The way I’m helped and treated makes me think and feel better about myself  

- The way I’m helped and treated does not affect the way I think or feel about myself  

- The way I’m helped and treated sometimes undermines the way I think and feel about myself  

- The way I’m helped and treated completely undermines the way I think and feel about myself

(Measure 1A ASCOF and ASCOT Q9)
Section 3: The next question covers knowledge and information

12. In the past year, have you generally found it easy or difficult to find information and advice about support, services or benefits? Please include information from different sources, such as voluntary organisations, and private agencies as well as [Social Services].

Please tick (✔) one box

- Very easy to find
- Fairly easy to find
- Fairly difficult to find
- Very difficult to find
- I’ve never tried to find information or advice

(Measure 3D ASCOF and the information Q that Juliette refers)

Probes Q10
- What did ‘having help to do things’ mean to you at this question?
- How did you feel about being asked this question?
- How easy or difficult was it to decide on your answer? Why was this?
- What did you understand by ‘undermines the way I think and feel about myself’?

Probes Q11
- What did ‘how the way you are helped and treated makes you think and feel about yourself’ mean to you in this question?
- Do you think this question is getting at the same thing as Q10?
- How easy or difficult was it for you to decide on your answer? Why?
- When you answered this question were you thinking of a specific occasion or thinking generally? How did you decide when to think about?

Probes Q12
- From when to when did you think about when you answered this question?
- What sources of information did you think about (when you answered this question)?
- Were there any types of information or advice that weren’t sure whether to include? If so what weren’t you sure about?
- How easy or difficult was it to answer this question?
- What would your experience have been like in order to select ‘very easy to find’?
Stage 3: Collecting Background Information primarily - less testing

INT ASK R TO ANS Q13-Q17

Section 4: This section is about your health broadly

13. How is your health in general?

*Please tick (✓) one box*

<table>
<thead>
<tr>
<th>Rating</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>1</td>
</tr>
<tr>
<td>Good</td>
<td>2</td>
</tr>
<tr>
<td>Fair</td>
<td>3</td>
</tr>
<tr>
<td>Bad</td>
<td>4</td>
</tr>
<tr>
<td>Very bad</td>
<td>5</td>
</tr>
</tbody>
</table>

14. Which of these statements best describes your abilities for each of the following questions.

<table>
<thead>
<tr>
<th>Question</th>
<th>I can do this easily by myself</th>
<th>I have difficulty doing this myself</th>
<th>I can’t do this by myself</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Do you usually manage to get around indoors (except steps) by yourself?</td>
<td>□1</td>
<td>□2</td>
<td>□3</td>
</tr>
<tr>
<td>b. Do you usually manage to get in and out of a bed (or chair) by yourself?</td>
<td>□1</td>
<td>□2</td>
<td>□3</td>
</tr>
<tr>
<td>c. Do you usually manage to feed yourself?</td>
<td>□1</td>
<td>□2</td>
<td>□3</td>
</tr>
<tr>
<td>d. Do you usually deal with finances and paperwork - for example, paying bills, writing letters – by yourself?</td>
<td>□1</td>
<td>□2</td>
<td>□3</td>
</tr>
</tbody>
</table>
15. Which of these statements best describes your abilities for each of the following questions?

<table>
<thead>
<tr>
<th></th>
<th>I can do this easily by myself</th>
<th>I have difficulty doing this myself</th>
<th>I can’t do this by myself</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Do you usually manage to wash all over by yourself, using either a bath or shower?</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>b. Do you usually manage to get dressed and undressed by yourself?</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>c. Do you usually manage to use the WC/toilet by yourself?</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>d. Do you usually manage to wash your face and hands by yourself?</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
</tbody>
</table>

16. Thinking about getting around outside of your home, which of the following statements best describes your present situation?

*You can include getting around by yourself or with help from someone else*

**Please tick (✔) one box**

- ☐ I can get to all the places in my local area that I want 1
- ☐ At times I find it difficult to get to all the places in my local area that I want 2
- ☐ I am unable to get to all the places in my local area that I want 3
17. Have you used any of the support or services listed below in the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Please tick (✔) one box per row

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>d. Personal assistant</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>e. Home care/home help</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>f. Day centre or day activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>g. Lunch club</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>h. Meals Services</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>i. Equipment or adaptation to their home (such as a wheelchair or handrails)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>j. Lifeline Alarm</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

General Probes
- How easy or difficult did you find these questions to answer?
- Was there anything that was unclear to you in any of these questions? If so, what?
- Thinking of the last set of Qs (Q13-17) you answered were there any that you weren’t sure how to answer?

Probes Q17:
- From when to when did you think about when you answered this question?
- Was there anything on the list that you weren’t sure you had used?
- Or was there anything on the list that you didn’t recognise? What were these?
Section 6: This last section is about yourself, the service user
The answers to the next group of questions will be used to get a picture of who took part in this survey. For example, we will use these questions to help us make sure that services are delivered equally to people with different backgrounds.

18. Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?

   Please tick (✓) as many boxes as apply
   Yes, from someone living in my household  A (1)
   Yes, from someone living in another household b (1)
   No c (1)

19. Did you fill in this questionnaire by yourself or did you have help from someone else? Please tick (✓) one box

   I filled it in myself 1
   I had help from a care worker 2
   I had help from someone living in my household  3
   I had help from someone living outside my household  4

20. What type of help did you have?

   Please tick (✓) as many boxes as apply
   I didn’t have any help a(1)
   Someone else read the questions to me b(1)
   Someone else translated the questions for me  c(1)
   Someone else wrote down the answers for me d(1)
   I talked through the questions with someone else  e(1)
   Someone answered for me, without asking me the questions  f(1)

General Probes
- How easy or difficult did you find these questions to answers?
- Was there anything that was unclear to you in any of these questions? If so what?
- Thinking of the last set of Qs (Q18-20) you answered were there any that you weren’t sure how to answer?
Probes for Q19 and Q20

- In Q 19 – what did you understand by ‘help’ in filling in the questionnaire?
- If you had discussed the answers with someone how would you have answered Q19?
- Were you thinking of any type of help which is not described in question 20?

INT TELL R TO JUST FILL THE REST OF THE QUESTIONNAIRE

21. Do you have any of the following....?
Please tick [✓] all that apply

- Dementia
- A physical disability
- Sight or hearing loss
- A mental health problem
- Problems connected to ageing
- A learning disability or difficulty
- Long-standing illness
- Terminal illness
- Alcohol or drug dependency

22. Are you male or female?

Please tick (✓) one box

- Male 1
- Female 2

23. Which age group do you belong to?

Please tick (✓) one box

- 18-24 1
- 25-34 2
- 35-44 3
- 45-54 4
- 55-64 5
- 65-74 6
- 75-84 7
- 85 or over 8
24. To which of these groups do you consider you belong?
Please tick (✓) one box

- White (British, Irish, any other White background) 1
- Mixed (White and Black Caribbean, White and Black African, White and Asian, any other Mixed background) 21
- Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background) 41
- Black or Black British (Caribbean, African, or any other Black background) 61
- Chinese 81
- Any other ethnic group 89

Stage 4: Overall feedback and close

- General Probes on the overall questionnaire (if not already covered)
- What is your general impression of questions you have answered in this questionnaire?
- Did the questions seem relevant to your situation? **If not, why not?**
- When answering the questions what were you thinking about? Were you thinking about recent experiences of care received, the overall experience of receiving care, the overall experience of obtaining and receiving care or something else?
- How did you choose your answer when your experience varied?
- If you were asked to complete this paper questionnaire would you fill it in? Would you do this alone or with someone else? Why is this? If fill it in with someone else – who would this be (relative/ formal social care provider)? What input would they provide?
- Now that you have seen the questions, what is the best way for a survey to ask them of social care receivers? Would it be face to face, over the phone, in a self completion like this one on paper or on the web or does it not matter? Explore reasons.
- What do you think the questionnaire designers could do to encourage people to fill in the questionnaire?
- What do you think of the layout of the questionnaire? - Location of the answer boxes?

**END INTERVIEW AND THANK RESPONDENT FOR THEIR TIME STRESSING THE VALUE OF THEIR PARTICIPATION IN THE RESEARCH. GIVE THEM (1) THE THANK YOU INCENTIVE AND (2) THE LEAFLET**
Informal carer protocol

**QUESTIONNAIRE GUIDE AND PROBE SHEET**
*(INFORMAL CARERS VERSION – testing Social care receiver and carer questions)*

**Introduction**
- Introduce yourself, NatCen, and the study
- NatCen Social Research and the Universities of Stirling and Leeds are carrying out a research project funded by the National Institute of Health Research (NIHR) School of Social Care Research (SSCR) to explore people’s experiences of receiving social care
- **What is the research about?** People receiving social care are asked in surveys how satisfied they are with their care. Some groups, including black and minority ethnic groups, are less satisfied than others. This research project aims to find out why.
- **How will you do this?** We will talk to Pakistani, Bangladeshi and White British people who are receiving **formal** social care and family members/friends who provide social care to explore with them how these survey questions work. We will review the questions to make sure that they collect accurate information. As part of this we want to get a range of people’s opinions on the questions in order for them to work as intended with social care users.

**Interview Protocol**
- Explain that we would like the R’s views on 2 questionnaires as someone who provides social care and so could be involved in filling in the questionnaire. Ask the R to think aloud while they complete the self completion questionnaire and at various points you will be asking them to tell you what they thought of certain questions.
- Explain we are not interested in their answers as such, more about how they understand the questions and how comfortable they feel answering them.
- Stress there are no right or wrong answers and this isn’t a test.
- Explain how confidentiality and anonymity will be observed throughout the research.
- Remind them:
  - that participation is voluntary;
  - the interview could last about one hour;
- Stress the confidentiality of the process; all the findings will be reported **anonymously**. Please make sure they understand this.
- Explain that you will be recording the interview so that you don't have to make lots of notes during the interview. Check this is OK with the respondent. If they ask who will have access to the recording, tell them that only the small research team at NatCen.
- **EXPLAIN -THINK ALOUD** talking the R through an example e.g. the windows example
• Explain that you will be asking their views on two questionnaires. Firstly, you will be asking them to fill in a questionnaire specifically for social care users. You will be asking them to fill in this questionnaire for social care users because often family members/friends help the social care user to fill in the questionnaire or may even fill it on their behalf. Secondly you will give them a carers’ questionnaire which explores people’s experiences of providing social care to family members/friends. For both questionnaires you would like to know how they understand the questions and go about answering them.

• Ask whether they have any questions before you start.
QUESTIONNAIRE 1: SOCIAL CARE RECEIVER QUESTIONNAIRE (Main priority)

Stage 1: Explore initial views on mode and self completion

Aim: To establish what they would do if the person they provide care for received a self completion questionnaire

Probes
- In what circumstances, if any, would you be involved in completing a self completion questionnaire asking social care receivers about their satisfaction of care received?
- Would you fill it in alone or would you fill it in with the social care receiver? Would there be anyone else involved? What would your involvement be?
- What is the best way for a survey to ask peoples’ views of their satisfaction with their social care? (If asked explain that Rs could be asked Qs f2f or over the phone by an interviewer or asked to fill in a paper or web based - Do you think questions measuring satisfaction with social care should be asked in a self completion paper questionnaire or should it be asked by an interviewer face to face or over the phone or does it not matter?)

Stage 2: Testing the Introduction in the self completion

INTERVIEWER HAND OVER THE SOCIAL CARE RECEIVER Q’aire

Interviewer: Hand over self completion. Explain this is a test version.
- What are your initial thoughts on seeing this questionnaire?
- Please talk me through how the form would be filled in? (Explore if R would seek permission/help from someone to fill it in or would they fill it in for the care user without their involvement).
- Would you think about filling it in or would you leave it? Why?
Questionnaire 1 Social Care users’ Questionnaire getting informal carers’ views on these questions.

Ask them to fill in the questionnaire as they would fill it in on behalf of someone they care for. The questionnaire is about the formal social care services they receive.

Interviewer:
- Explain that you would like to hear their views on the introduction. Explain, where there are references to [your local social services department] in the document and in the ‘real survey’ this would be replaced by the name of their local social services e.g. Swindon Borough Council Adult Social Care.
- Check if they are able to read the introduction (large print version available) or if they would like you to read it out to them.
- Ask the R to read the introduction and to let you know what they think of it as they are going through it. If you are reading it out ask them to feel free to stop you at any point to share their thoughts with you as you are reading it out.
- Explain that this is the standard introduction for the questionnaire. We are interested in what they would think of it if they received it in the post. The number to ring is not applicable for this testing project.

INTRODUCTION

Your Social Care and Support Services

Introduction
We are contacting you because you receive, or have received, care and support services that are paid for (at least in part) by [your local Social Services Department]. By care and support services we mean you may be living in a care home, receiving a Personal Budget, home care, equipment, meals services, Direct Payments, or attending a day centre. We want to improve and develop our services so we want to get your views on the services you receive. In particular, we want to hear about your quality of life and how services have affected the quality of your life.

What to do if you need help to give your views
You can ask a friend, relative or an advocate to help you complete the questionnaire, but please remember that it is your views and your experiences that are important to us, rather than the views of anyone that helps you. If you prefer, you can also get in touch with [the telephone assistance line] to ask for someone independent from social services and your care provider to help you to complete the questionnaire. Staff from [Social Services] involved in the provision of your care, or anyone that you pay to care for you should not help you to fill it in.

What to do if you have queries
If you, or your friend or relative, have questions you would like to ask about the survey, or if you would like the questionnaire in another language or different format such as large print or easy read then please ring xxxxxxxxxx on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm.

What will be done with the results of the survey
The results of the survey will be used by the Care Quality Commission, the Department of Health and your [Social services department] to see how happy people are with their care and support services and assess their experiences of local care services. The results will also be used for further research or analysis.

Confidentiality
Your answers will be treated as confidential: they will not be passed on to your social worker, care manager, care and support worker or anyone providing you with services. You will not be personally identified and your answers will not affect the services you receive.

Reminder Letters
If you do not return this questionnaire then you may be sent one reminder letter. If you do not wish to receive a reminder then please send back an uncompleted questionnaire in the envelope provided.

Sending back the completed questionnaire
Once you have completed the questionnaire please return it in the envelope provided by [DATE]. You don’t need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Introduction Probes
- How easy or difficult was it to understand the introduction?
- Who is supposed to fill in the questionnaire? Who can help the form filler?
- If you were to fill in this form on behalf of someone else, who would you do this for? INTERVIEWER GET THE NAME OF THE MAIN CARE RECEIVER.
- In what circumstance would you do this? How would you feel about filling this form in on behalf [NAME OF MAIN CARE RECEIVER]? How, if at all, would you involve them in completing this form?
- What should be included in the introduction to encourage people to participate in the survey?
- Was there anything that you read/heard that would put you off completing this questionnaire? If yes, what were these and why were they off putting?
Stage 3: Testing individual questions in the social care receiver’s self completion – how the questions work with carers

ASK R TO ANS Q1-Q3b

The first question is concerned with your overall satisfaction with your social care and support

1. Overall, how satisfied or dissatisfied are you with the care and support services you receive?
   By ‘care and support services’ we mean any equipment or care provided by staff who are paid to help you. The staff could be from [Social Services], an agency, a care home or bought by you using money from [Social Services] through a Direct Payment.

   Please tick (√) one box

   I am extremely satisfied  1
   I am very satisfied  2
   I am quite satisfied  3
   I am neither satisfied nor dissatisfied  4
   I am quite dissatisfied  5
   I am very dissatisfied  6
   I am extremely dissatisfied  7

(Measure 3A ASCOF)
The next section is about your quality of life
When answering the following questions please think about the quality of your life as a whole, including the help you get from others as well as [Social Services].

2a. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

*Please tick (✔) one box*

- So good, it could not be better 1
- Very good 2
- Good 3
- Alright 4
- Bad 5
- Very bad 6
- So bad, it could not be worse 7

2b. Do care and support services help you to have a better quality of life?

*Please tick (✔) one box*

- Yes 1
- No 2

(Optional question for councils in Adult Social Care Survey)

3a. Which of the following statements best describes how much control you have over your daily life? By ‘control over daily life’ we mean having the choice to do things or have things done for you as you like and when you want

*Please tick (✔) one box*

- I have as much control over my daily life as I want 1
- I have adequate control over my daily life 2
- I have some control over my daily life but not enough 3
- I have no control over my daily life 4

(Measure 1A and 1B ASCOF and ASCOT Q1)
3b. Do care and support services help you in having control over your daily life?

By ‘care and support services’ we mean any equipment or care provided by staff who are paid to help you. The staff could be from [Social Services], an agency or bought by you using money you receive from [Social Services], using a Direct Payment.

Please tick (☑) one box

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

**General Probes**

- How easy or difficult did you find these questions? Why?

**Q1 Probes (may be covered above) THIS IS THE KEY QUESTION TO TEST.**

- What Care and Support services did you think about when you answered this question? Do you think [NAME/INITIAL OF PERSON BEING CARE FOR] would have thought about the same services or different ones? Explore how R knows this and why different, if different.
- How easy or difficult was it to decide on which answer option to use? Was there anything you weren’t sure whether to include or exclude and if yes, how did you decide what to do about this? How did you select your answer?
- What would your experience have to be like to select ‘extremely satisfied’ or ‘very satisfied’? What about ‘extremely dissatisfied’? (don’t probe on all categories but on extremes and any they considered by did not choose).
- Has the person you care for had a consistent experience of social care? If satisfaction has varied how did you choose your answer?
- If your view is different from that of the person you care for, whose view would you have used to answer this question?
- What did ‘direct payment’ mean to you in this question?

**Q2a Probes:**

- What did ‘quality of life’ mean to you in this question?
- What did ‘life as a whole’ mean in this question?
- What were the good and bad things that you thought about when you are thinking about the answer to this question?
- How easy or difficult was it to rate the quality of [NAME/INITIAL OF PERSON BEING CARE FOR] life as a whole?
- Was there anything that you weren’t sure whether to include? If so what were these and how did you decide whether to include them or not?
- If your view is different from that of the person you care for, whose view would you have used to answer this question?

**Q2b Probes**

- What did ‘care and support services’ mean to you at this question? (Probe if it meant social services only or included other services and if so what?)
- How easy or difficult was it to think about whether the services helped [NAME/INITIAL OF PERSON BEING CARE FOR] to have a better quality of life?
Q3a Probes
- What did ‘control over daily life’ mean to you at this question? Probe fully for examples the R thought about while answering this Q.
- How easy or difficult was it to decide on your answer? How did you select your answer?
- When you answered this question were you thinking generally or of a specific occasion? Why?

Q3b Probes
- What care and support services did you think about when you answered this question? Probe fully for examples the R thought about while answering this Q.

INT ASK R TO ANSWER 4a to 6b

4a. Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation? Please tick (✓) one box

<table>
<thead>
<tr>
<th>Description</th>
<th>Box Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel clean and am able to present myself the way I like</td>
<td>1</td>
</tr>
<tr>
<td>I feel adequately clean and presentable</td>
<td>2</td>
</tr>
<tr>
<td>I feel less than adequately clean or presentable</td>
<td>3</td>
</tr>
<tr>
<td>I don’t feel at all clean or presentable</td>
<td>4</td>
</tr>
</tbody>
</table>

(Measure 1A ASCOF and ASCOT Q2)

4b. Do care and support services help you in keeping clean and presentable in appearance?

Please tick (✓) one box

<table>
<thead>
<tr>
<th>Description</th>
<th>Box Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

(Optional question for councils in Adult Social Care Survey)

5a. Thinking about the food and drink you get, which of the following statements best describes your situation? Please tick (✓) one box

<table>
<thead>
<tr>
<th>Description</th>
<th>Box Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>I get all the food and drink I like when I want</td>
<td>1</td>
</tr>
<tr>
<td>I get adequate food and drink at OK times</td>
<td>2</td>
</tr>
<tr>
<td>I don’t always get adequate or timely food and drink</td>
<td>3</td>
</tr>
<tr>
<td>I don’t always get adequate or timely food and drink, and I think there is a risk to my health</td>
<td>4</td>
</tr>
</tbody>
</table>

(Measure 1A ASCOF and ASCOT Q3)
5b. Do care and support services help you to get food and drink?

*Please tick (✔) one box*

- Yes  
- No

1. Yes
2. No

(Optional question for councils in Adult Social Care Survey)

6a. Which of the following statements best describes how clean and comfortable your home is?

*Please tick (✔) one box*

- My home is as clean and comfortable as I want  
- My home is adequately clean and comfortable  
- My home is not quite clean or comfortable enough  
- My home is not at all clean or comfortable

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 or comfortable enough
4. My home is not at all clean or comfortable

(Measure 1A ASCOF and ASCOT Q7)

6b. Do care and support services help you in keeping your home clean and comfortable?

*Please tick (✔) one box*

- Yes  
- No

1. Yes
2. No

(Optional question for councils in Adult Social Care Survey)

---

**General Probes 4a- 6b**

- When did you think about when you answered these questions? (Explore if R was thinking generally or specific occasion)
- Did you think of different time periods for different questions? If yes, what were these time periods?
- Were there any questions that you found difficult to answer? If so which ones, why? Topic hard/sensitive/didn’t know the answer due to a lack of knowledge.

**Probes Q4a**

- What did ‘clean and presentable in appearance’ mean to you in this question?
- Do you think your understanding would be different from [NAME/INITIAL OF PERSON BEING CARE FOR] or the same? If yes, how would it be different?
- How easy or difficult was it to select an answer? Why? (Explore if having clean and presentable in the answer options made the question difficult to answer).

**Probes Q5a**

- How easy or difficult was it for you think of food and drink when you answered this question?
- What kinds of food and drink did you think of?
- How would you describe ‘adequate food and drink’/‘timely’ food and drink?’
Probes Q6a
- What did ‘clean’ mean to you at this question
- And how about ‘comfortable’ what did this mean?
- How easy or difficult was it for you to answer this question?
- Explore: If R was thinking about the Q from the perspective of [NAME/INITIAL OF PERSON BEING CARE FOR] or theirs.

INT ASK R TO ANSWER Q7a -9b

7a. Which of the following statements best describes how safe you feel?
   By ‘feeling safe’ we mean how safe you feel both inside and outside the home. This includes fear of abuse, falling or other physical harm.

   Please tick (✓) one box
   - I feel as safe as I want 1
   - Generally I feel adequately safe, but not as safe as I would like 2
   - I feel less than adequately safe 3
   - I don’t feel at all safe 4

   (Measure 1A and 4A ASCOF and ASCOT Q4)

7b. Do care and support services help you in feeling safe?

   Please tick (✓) one box
   - Yes 1
   - No 2

   (Measure 4B ASCOF)

8a. Thinking about how much contact you’ve had with people you like, which of the following statements best describes your social situation?

   Please tick (✓) one box
   - I have as much social contact as I want with people I like 1
   - I have adequate social contact with people 2
   - I have some social contact with people, but not enough 3
   - I have little social contact with people and feel socially isolated 4

   (Measure 1A ASCOF and ASCOT Q5)
8b. Do care and support services help you in having social contact with people?

*Please tick (✓) one box*

- Yes [ ] 1
- No [ ] 2

9a. Which of the following statements best describes how you spend your time?

*When you are thinking about how you spend your time, please include anything you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others.*

*Please tick (✓) one box*

- I’m able to spend my time as I want, doing things I value or enjoy [ ] 1
- I’m able to do enough of the things I value or enjoy with my time [ ] 2
- I do some of the things I value or enjoy with my time but not enough [ ] 3
- I don’t do anything I value or enjoy with my time [ ] 4

(Measure 1A ASCOF and ASCOT Q6)

9b. Do care and support services help you in the way you spend your time?

*Please tick (✓) one box*

- Yes [ ] 1
- No [ ] 2

(Optional question for councils in Adult Social Care Survey)

**General Probes**

- Were there any questions in this section that you felt you couldn’t answer on behalf of [NAME/INITIAL OF PERSON BEING CARED FOR]? If yes – which ones and what was the problem?
- Would you answer on their behalf or speak to [NAME OF the care receiver]?
- What time period did you think about for these Qs?

**Probes Q7a**

- How did you go about answering this question and deciding on your answer? If not covered above
  - What did ‘feeling safe’ mean to you in this question?
  - What area were you thinking about when you answered the question? Why did you think of this/these area(s)?

**Probes Q8a**

- How easy or difficult was it to decide on your answer? Why? (Explore if R has knowledge of this)
  - What did ‘contact’ in the question wording mean to you?
  - The last answer option, refers to ‘feeling socially isolated’ what does this mean to you in the context of this question?
Probes 9a
- What types of activities did you think about when you answered this question? Why? – Were there any that you weren’t sure whether to include? Which were these?
- How easy or difficult was it to answer this question?

Probes Q8b and 9b
- What types of ‘help’ did you think about when you were answering this question? Was there any type of help that you weren’t sure whether to include? Why? **ASK R TO COMPLETE Q10-11**

10. **Which of these statements best describes how having help to do things makes you think and feel about yourself?**

   *Please tick (✓) one box*

   - Having help makes me think and feel better about myself
   - Having help does not affect the way I think or feel about myself
   - Having help sometimes undermines the way I think and feel about myself
   - Having help completely undermines the way I think and feel about myself

   (ASCOT Q8)

11. **Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself?**

   *Please tick (✓) one box*

   - The way I’m helped and treated makes me think and feel better about myself
   - The way I’m helped and treated does not affect the way I think or feel about myself
   - The way I’m helped and treated sometimes undermines the way I think and feel about myself
   - The way I’m helped and treated completely undermines the way I think and feel about myself

   (Measure 1A ASCOF and ASCOT Q9)

Probes Q10
- What did ‘having help to do things’ mean to you at this question?
- How easy or difficult was it to decide on your answer? Why was this? (Knowledge/sensitivity)
- Do you feel you could answer this question on behalf of the person you care for?
Probes Q11

- What did ‘how the way you are helped and treated makes you think and feel about yourself’ mean to you in this question? (Explore if R answered thinking about themselves or thought about the person they provide care for).
- How easy or difficult was it for you to decide on your answer? Why?
- When you answered this question were you thinking of a specific occasion or thinking generally? How did you decide when to think about?
The next question covers knowledge and information

12. In the past year, have you generally found it easy or difficult to find information and advice about support, services or benefits? Please include information from different sources, such as voluntary organisations, and private agencies as well as [Social Services].

Please tick (✓) one box

- Very easy to find
- Fairly easy to find
- Fairly difficult to find
- Very difficult to find
- I’ve never tried to find information or advice

(Measure 3D ASCOF and the information Q that Juliette refers)

Probes Q12

- From when to when did you think about when you answered this question?
- How sources of information did you think about (when you answered this question)?
- Were there any information or advice that weren’t sure whether to include? If so what weren’t you sure about and how did you decide whether to include this or not?
- How easy or difficult was it to answer this question?
- Were you thinking about information you had found or about information the person you care for had found?

ASK R TO ANS THE REST OF THIS QUESTIONNAIRE
This last section is about yourself, the service user
The answers to the next group of questions will be used to get a picture of who took part in this survey. For example, we will use these questions to help us make sure that services are delivered equally to people with different backgrounds.

13. Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?

Please tick (✓) as many boxes as apply

- Yes, from someone living in my household
- Yes, from someone living in another household
- No

A (1)  b (1)  c (1)

14. Did you fill in this questionnaire by yourself or did you have help from someone else?

Please tick (✓) one box

- I filled it in myself
- I had help from a care worker
- I had help from someone living in my household
- I had help from someone living outside my household

1 (2)  3  4

15. What type of help did you have?

Please tick (✓) as many boxes as apply

- I didn’t have any help
- Someone else read the questions to me
- Someone else translated the questions for me
- Someone else wrote down the answers for me
- I talked through the questions with someone else
- Someone answered for me, without asking me the questions

a(1)  b(1)  c(1)  d(1)  e(1)  f(1)
16. Do you have any of the following....?

Please tick [✔] all that apply

- Dementia a (1)
- A physical disability b (1)
- Sight or hearing loss c (1)
- A mental health problem d (1)
- Problems connected to ageing e (1)
- A learning disability or difficulty f (1)
- Long-standing illness g (1)
-Terminal illness h (1)
-Alcohol or drug dependency i (1)

17. Are you male or female?

Please tick (✔) one box

- Male 1
- Female 2

18. Which age group do you belong to?

Please tick (✔) one box

- 18-24 1
- 25-34 2
- 35-44 3
- 45-54 4
- 55-64 5
- 65-74 6
- 75-84 7
- 85 or over 8
19. To which of these groups do you consider you belong?

Please tick (✓) one box

- White (British, Irish, any other White background) 1
- Mixed (White and Black Caribbean, White and Black African, White and Asian, any other Mixed background) 21
- Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background) 41
- Black or Black British (Caribbean, African, or any other Black background) 61
- Chinese 81
- Any other ethnic group 89

General Probes on Q13-Q19

- How did you find these last set of questions?
- Are there any questions that people may find sensitive to answer on behalf of or while helping the person they provide help to, to fill in the Q’aire?
- If yes which ones and why?
- Were you clear about whom you were describing when answering the questions?

Probes Q14

- How did you go about answering this question?
- Did you fill it in from your point of view or the point of view of the person you care for? If you filled the questionnaire for the person you care for what would you have answered?

Probes Q15

- How easy or difficult was it to answer this question?
- How would you answer this if you filled in the questionnaire for someone else?

General Probes on the overall questionnaire

- What is your general impression of this questionnaire which is for people who are in receipt of some type of paid help?
- Are there any questions which should be skipped by carers if answering on behalf of the care receiver because it is inappropriate to ask a carer to answer? If yes, which ones.
- What do you think the questionnaire designers could do to encourage people to fill in the questionnaire?
- Did the questions seem relevant to your situation and the situation of the person you care for? If not, why not?
- When answering the questions what were you thinking about? Were you thinking about recent experiences of care received, the overall experience of receiving care, the overall experience of obtaining and receiving care or something else?
- How did you choose your answer when your experience varied?
**Stage 4: Testing the introduction in the carers questionnaire**

**INTERVIEWER: HAND OVER THE 2nd Q’AIRE**

**Interviewer:**
- Explain that you would like to hear their views on this introduction.
- Repeat procedure used for the previous Q’aire e.g. give large print version/read out
- Ask the R to read the introduction and to let you know what they think of it as they are going through it. If you are reading it out ask them to feel free to stop you at any point to share their thoughts with you as you are reading it out.
- Make it clear to the respondent that this is a standard introduction for the questionnaire which would usually be mailed out, for example now they cannot ring a number for more information.

---

**Introduction**

**Caring for Others**

**Why was I selected?**
You have been selected from our records at random, along with many other carers who have been assessed in the last 12 months, and everyone is being asked the same questions.

**What if the person I care for is in hospital or in a care home or hospice?**
We would still like you to fill in this form even if the person you care for is in hospital or has moved into a care home.

**Will my answers be confidential?**
Your answers will be treated in strict confidence and any help you may get will not be affected. You will not be personally identified in the results which are shared with the Department of Health and the Health and Social Care Information Centre. No-one directly involved in providing services to you will see your answers.

**What will be done with the results of the survey?**
The results will be used by us, the Care Quality Commission, the Department of Health and the Health and Social Care Information Centre to look at what people think about any help provided to them. The results may also be used for further research or analysis. You will not be personally identified in any report or summary.

**How can I find out more about the survey or get it in another format?**
If you have any questions about the survey, or need it in another format, e.g. another language or in large print. Please ring [insert telephone number at between [open time] and [end time] on [days]] to make a request.
If you look after a family member, partner or friend in need of support or services because of their age, physical or learning disability or illness, including mental illness, we would like you to complete this questionnaire.

Thank you for helping us by completing this questionnaire

<table>
<thead>
<tr>
<th>Introduction Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Who do you think should fill in the questionnaire reading this introduction?</td>
</tr>
<tr>
<td>▪ What should be included in the introduction to encourage people to participate in the survey?</td>
</tr>
<tr>
<td>▪ Was there anything that you read/heard that would put you off completing this questionnaire? If yes, what were these and why were they off putting?</td>
</tr>
</tbody>
</table>
**Stage 5: Testing individual questions in the Self completion**  
**ASK R TO ANSWER Q1-Q4**

**Section 1: About the person you care for**  
The questions in this section ask about the person you care for, by which we mean the person you look after or help, and your experience of support and services.

If you care for more than one person, please answer **only** in relation to the person you spend the most time helping. If you spend an equal amount of time caring for two or more people, please answer in relation to the person who lives with you. If you live with two or more people that you spend an equal amount of time caring for, please choose **one** person to answer about.

1. **Where does the person you care for usually live?**

   **Please tick [✓] one box**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>With me</td>
</tr>
<tr>
<td>2</td>
<td>Somewhere else</td>
</tr>
</tbody>
</table>

2. **What is your relationship to the person you care for?**

   **Please tick [✓] one box**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a (1)</td>
<td>Son (including step)</td>
</tr>
<tr>
<td>b (1)</td>
<td>Daughter (including step)</td>
</tr>
<tr>
<td>c (1)</td>
<td>Mother</td>
</tr>
<tr>
<td>d (1)</td>
<td>Father</td>
</tr>
<tr>
<td>e (1)</td>
<td>Brother</td>
</tr>
<tr>
<td>f (1)</td>
<td>Sister</td>
</tr>
<tr>
<td></td>
<td>Friend</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>
3. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

_Please tick (✓) one box_

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>We haven’t received any support or services from Social Services in the last 12 months</td>
<td>1</td>
</tr>
<tr>
<td>I am extremely satisfied</td>
<td>2</td>
</tr>
<tr>
<td>I am very satisfied</td>
<td>3</td>
</tr>
<tr>
<td>I am quite satisfied</td>
<td>4</td>
</tr>
<tr>
<td>I am neither satisfied nor dissatisfied</td>
<td>5</td>
</tr>
<tr>
<td>I am quite dissatisfied</td>
<td>6</td>
</tr>
<tr>
<td>I am very dissatisfied</td>
<td>7</td>
</tr>
<tr>
<td>I am extremely dissatisfied</td>
<td>8</td>
</tr>
</tbody>
</table>

(Measure 3B ASCOF)
4. Has the person you care for used any of the support or services listed below in the last 12 months? They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Please tick (✔) one box per row

- Support or services allowing you to take a break from caring at short notice or in an emergency.
- Support or services allowing you to take a break from caring for more than 24 hours.
- Support or services to allow you to have a rest from caring for between 1 and 24 hours (e.g. a sitting service).
- Personal assistant.
- Home care/home help.
- Day centre or day activities.
- Lunch club.
- Meals Services.
- Equipment or adaptation to their home (such as a wheelchair or handrails).
- Lifeline Alarm.
- They are permanently resident in a care home.

General Probes:
- Were there any questions that you found difficult to answer? Why
- Were there any questions that you found too intrusive to answer? Why? (Check for sensitivity)
- What time period or periods did you think about when you answered these Qs? Why did you think of this time period or periods?

Probes Q1:
- How easy or difficult was this question to answer?
- Did more than one answer apply or just one?

Probes Q3:
- How easy or difficult was this question to answer? Why?
- When you answered this question were you thinking of a specific occasion or thinking generally? Why?
- What support and or services did you think about when you answered this question? Were there any that you weren’t sure whether to include? If yes, how did you decide whether to include or exclude them from your answer?
- From when to when did you think about?
- How would you describe ‘extremely satisfied’/ ‘very satisfied’/ ‘extremely dissatisfied’? What would your experience have to be like to choose that option? (don’t probe on all but probe on extremes/ any they considered but did not choose)
- Whose satisfaction were you thinking about?

Probes Q4:
- How easy or difficult was it to remember the services that [MAIN SOCIAL CARERS NAME/INITIALS] had received?
- Was there anything on the list that you weren’t sure [MAIN SOCIAL CARERS NAME/INITIALS] had been used? If yes, how did you decide to include or exclude this/these services/support in your answer?
- Was there anything on the list that you didn’t recognise/understand?
- From when to when were you thinking about when you answered this question?

INTERVIEWER ASK R TO COMPLETE THE Q’aire

Section 2: The impact of caring and your quality of life
Some of the questions in this section look at the impact of caring on particular aspects of your life, while others ask about the quality of different parts of your life more generally. We are interested in your quality of life, rather than that of the person you care for.

5. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

Please tick [✔] one box

- I feel I have encouragement and support 1
- I feel I have some encouragement and support but not enough 2
- I feel I have no encouragement and support 3

(Measure 1D ASCOF)
Section 3: Information and advice quality
The next questions ask for your views about the quality of information and advice.

6. In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services.

*Please tick (✓) one box*

- [ ] I have not tried to find information or advice in the last 12 months 1
- [ ] Very easy to find 2
- [ ] Fairly easy to find 3
- [ ] Fairly difficult to find 4
- [ ] Very difficult to find 5

(Measure 1D ASCOF)

Section 4: Arrangement of support and services in the last 12 months
The next question is about organising the support and services for you and the person you care for.

7. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

*Please tick (✓) one box*

- [ ] There have been no discussions that I am aware of, in the last 12 months 1
- [ ] I always felt involved or consulted 2
- [ ] I usually felt involved or consulted 3
- [ ] I sometimes felt involved or consulted 4
- [ ] I never felt involved or consulted 5

(Measure 3C ASCOF)
Probes Q5
- What did ‘encouragement’ in your caring role mean to you in this question?
- What did ‘support’ in your caring role mean to you?
- How easy was to select an answer? (explore sensitivity)
- In what circumstances would a respondent select ‘I feel I have encouragement and support’ compared to ‘I feel I have some encouragement and support but not enough’?
- When did you think about? Why?

Q6 Probes
- How easy or difficult was it to select your answer? Why?

If not covered already
- What types of information did you think about when you answered this question?
- What ways of finding information and advice did you think about (when you answered this question)?
- Were there any forms of information and advice that you weren’t sure whether to include? If yes, what were these?
- From when to when were you thinking about when you answered this question?

Q7 Probes
- What did ‘involved or consulted’ mean to you in this question?
- If not covered already
- How easy or difficult was it for you to decide on your answer?

Closing Probes for this questionnaire
- How did you find these questions overall?
- Continuing to think about these questions, would you answer these questions if you were asked to? Would you do this alone or with someone else? Why is this? If fill it in with someone else – who would this be (care receiver/ another relative)?
- Any other feedback?
- What do you think of the layout of the questionnaire?
- location of the answer boxes?

END INTERVIEW AND THANK RESPONDENT FOR THEIR TIME STRESSING THE VALUE OF THEIR PARTICIPATION IN THE RESEARCH.
GIVE THEM (1) THE THANK YOU INCENTIVE AND (2) THE LEAFLET
Easy Read protocol

P3143: Cognitive Testing of Social Care Satisfaction Questions

QUESTIONNAIRE GUIDE AND PROBE SHEET PAIRED INTERVIEW (ER SOCIAL CARE USERS VERSION)

Introduction
- Introduce yourself, NatCen, and the study
- NatCen Social Research and the Universities of Stirling and Leeds are carrying out a research project funded by the National Institute of Health Research (NIHR) School of Social Care Research (SSCR) to explore people’s experiences of receiving social care
- What is the research about? People receiving social care are asked in surveys how satisfied they are with their care. Some groups, including black and minority ethnic groups, are less satisfied than others. This research project aims to find out why.
- How will you do this? We will talk to Pakistani, Bangladeshi and White British people who are receiving formal social care and family members/friends who provide social care to explore with them how these survey questions work. We will review the questions to make sure that they collect accurate information. As part of this we want to get a range of people’s opinions on the questions in order for them to work as intended with social care users.

Interview Protocol
- Explain that we would like the R to think aloud while they complete a self completion questionnaire and at various points you be asking them to tell you what they thought of certain questions and how they could be improved.
- Explain we are not interested in their answers as such, more about how they understand the questions and how comfortable they feel answering them.
- Stress there are no right or wrong answers and this isn’t a test.
- Explain how confidentiality and anonymity will be observed throughout the research.
- Remind them:
  o that participation is voluntary – can take breaks;
  o the interview could last about one hour;
- Stress the confidentiality of the process; all the findings will be reported anonymously. Please make sure they understand this.
- Explain that you will be recording the interview so that you don’t have to make lots of notes during the interview. Check this is OK with the respondent. If they ask who will have access to the recording, tell them that only the small research team at NatCen.
- **EXPLAIN -THINK ALOUD** talking the R through an example e.g. the windows example
- Ask whether they have any questions before you start.
- CHECK Rs UNDERSTANDS AND IS COMFORTABLE TO DO THE INTERVIEW.
Interviewer use your discretion to use think aloud and probing to reflect R’s comfort and ability.

**Stage 1: Explore initial views on mode including the self completion mode**

**Aim:** To establish what social care reviewer would do if they received a SC

**Probes**
- If you were asked to complete a self completion questionnaire what are the steps you would go through before deciding to fill it in?
- Would you fill it in alone or would you fill it in with someone else? Why? Who would you fill it in with?
- Surveys can ask questions in different ways, like on paper or an interviewer can ask the Qs in person or over the phone. What way would you like? Why

**Interviewer:** Hand over self completion to Social care receiver and ‘informal carer’.
- What are your initial thoughts on seeing this questionnaire?
- If you received this questionnaire in the post or were given it what would you do with it?
- Would you think about filling it in or would you leave it? Why?
- Please talk me through how the form would be filled in? (Explore if R would seek permission/help from someone to fill it in or would this ‘helper’ fill it in for them).

**INTERVIEWER:** Ask Rs to fill in the Q’aire in their usual way and that at certain points you will stop them at certain points to explore how the questions are working

**INTERVIEWER:** Direct probes to main form filler but ensure you have the views of the social care receiver if not the main filler. Ensure that interview notes clearly indicate who was answering each probe.
Your social care and support services

This letter is to ask you if you could help us.

The Questions
There is a form with this letter which has questions on it. The questions are all about the help you get and whether that help makes your life better.

There are no right or wrong answers. We are just interested in what you think. We are asking these questions to lots and lots of people.

Why are we asking these questions?
If you answer these questions, we can learn more about what people think about the help they get.

Your decision
You do not have to answer the questions if you do not want to. It is up to you. It will make no difference to the help you already get.

If you need help
If you need help with reading the questions and filling in the form, then you can ask a friend or someone in your family to help you. But please remember, we want to know what you think about things, not what your friends or family think.
If you do not have friends or family who can help, you can phone ………………….and someone there will help you.

Keeping your information private
The answers you give us will be kept private. The only time we would tell anyone what you have said is if you tell us that you are being hurt by someone or you are in danger.

If you want to find out more
If you want to find out more about why we are asking these questions, you can phone…………………..

Sending the form back
When you have answered the questions, please put it in the envelope we have given you. This envelope does not need a stamp. Please post it back to us by………………..

Thank you for your help.
Introduction Probes

- How did you find the first two pages?
- What did you learn from these two pages?
- Were the pictures helpful or unhelpful in understanding the information on these pages?
- Why are these questions being asked?
- From what you read do you think you have to answer the questions?
- What types of support are available to fill in the form?
These questions are all about your life.

Section 1

1. How happy are you with the way staff help you?

By ‘staff’ we mean people who are paid to help you. They may be:
- your care worker
- people who work at your care home or day centre
- people you pay with the money <Social Services> give you.

Please tick (✓) 1 box

I am very happy with the way staff help me, it’s really good

I am quite happy with the way staff help me

The way staff help me is OK

I do not think the way staff help me is that good

I think the way staff help me is really bad

CARE USER ASK FORM FILLER: How would you decide on the answer to this question if your view differs from the social care user?
IF MAIN FORM FILLER IS NOT SOCIAL CARE USER ASK CARE USER: Is the answer your carer gave the answer you would have given?
2. Thinking about all the different things in your life, good and bad, how would you say you feel about your life in general:

Please tick (✓) 1 box

- My life is really great
- My life is mostly good
- My life is OK, some good things, some bad things
- My life is mostly bad
- My life is really terrible
2b. Do staff help you to have a better quality of life?

By ‘staff’ we mean people who are paid to help you. They may be:
- your care worker
- people who work at your care home or day centre
- people you pay with the money <Social Services> give you.

Please tick (✓) 1 box

Yes

No

Q2 Probes
- What things did you think about when you answered this question?
- Interviewer go through list identified above
- and ask R - would you say that is a good thing or a bad thing?
- To help me to understand how the answer options work please tell me why you selected [R’s answer]?
- IF MAIN FORM FILLER IS NOT SOCIAL CARE USER ASK FORM FILLER: How would you decide on your answer this question if your view differs from the social care user?
- IF MAIN FORM FILLER IS NOT SOCIAL CARE USER ASK CARE USER: Is the answer your carer gave the answer you would have given?

Q2b Probes
- Who did you think about when you answered this question? Why?
- The question asks about quality of life. Do you know what this means? If yes, what did it mean to you in this question?
3a. How much control do you have in your life?

By ‘control’ we mean having a say about what happens in your life.

Please tick (✓) 1 box

I make all the choices I want

I make some choices, not all, but that is OK

I make some choices but not enough

I do not get to make any choices
3b. **Do staff help you to have control in your life?**

By ‘staff’ we mean people who are paid to help you. They may be:
- your care worker
- people who work at your care home or day centre
- people you pay with the money <Social Services> give you.

By ‘control’ we mean having a say about what happens in your life.

Please tick (✓) 1 box

[ ] Yes

[ ] No

Q3a and Q3b Probes
- These two questions talk about control. What did control mean to you in these 2 questions? Probe if possible for examples.
- Explore whether form filler and social care user have the same view.
4a. When it comes to keeping clean, and how you look (for example your clothes or your hair) how do you feel?

Please tick (✓) 1 box

I feel clean and I like the way I look

I quite like the way I feel and look, it’s OK

I feel a bit clean and tidy, but not enough

I do not feel at all clean or tidy
4b. Do staff help you to keep clean and how you look (for example your clothes or your hair)?

Please tick (✓) 1 box

Yes

No

Q4a Probes
- Can you talk me through how you decided on your answer? (checking for understanding and time thought about)
- Was there anything that you didn’t understand? What was this?
- Explore whether form filler and social care user have the same view about what is ‘clean and tidy’.
5a. What do you get to eat and drink?

Please tick (✓) 1 box

I get all the food and drink I like when I want it

I get enough food and drink

I do not get all the food and drink I want, but I do not think I will get ill because of it

I do not get all the food and drink I need, and I think this might make me ill
5b. Do staff help you to get food and drink?

Please tick (√) 1 box

Yes

No

Q5a Probes
- Can you talk me through how you decided on your answer? (checking for understanding and time thought about and answer option selected)
- Is this a good question or a bad question? (To establish if it is easy or difficult to understand and answer)
- What type of food and drink were you thinking of?
- Explore whether informal carer and R had a differing view, and if yes, how the answer was selected.

Q5b Probes
- Who did you think about when you answered this question? (Explore if informal carer and R had a differing view, and if yes, how the decision was made of who to think about)
6a. What do you think about your home?

Please tick (✓) 1 box

My home is as clean and nice as I want

My home is quite clean and nice, it’s OK

My home is not clean or nice enough

My home is not at all clean or nice

6b. Do staff help you to keep your home clean and nice?

you to keep your home clean and nice?
Please tick (✓) 1 box

Yes

No

(Optional Q)

Q6a Probes
- What is your home? (Explore indoor and outdoor spaces R thought about). Did you think about all these areas when you answered this question? Why/Why not?
- Why did you select [R’s answer] here?
- Explore whether informal carer and R had a differing view, and if yes, how the answer was selected.

Q6b Probes
- Did you think of the same staff here as in the previous question? No why different.
7a. How safe do you feel?

By feeling safe we mean feeling safe both at home and outside. This could be things like:

a. fear of abuse or being hurt,
b. fear of having an accident.

**Please tick (✓) 1 box**

I feel very safe

I feel quite safe, but not as safe as I would like

I do not feel safe enough

I do not feel safe at all
7b. **Do staff help you to feel safe?**

By feeling safe we mean feeling safe both at home and outside. This could be things like:

- a. fear of abuse or being hurt,
- b. fear of having an accident.

**Please tick (✓) 1 box**

<table>
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<th>Yes</th>
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**Q7a Probes**

- What do you think of the pictures? (Are they appropriate?)
- This question asks about feeling safe. What kind of things around feeling safe did you think about when you answered this question? How did you find this? Was this OK/difficult?
- Please describe to me all the areas you thought about when you answered this question? Why did you think of these areas?
- Why did you select [R’s answer] here?
- Explore whether informal carer and R had a differing view, and if yes, how the answer was selected.

**Q7b Probes**

- Did you think of the same staff here as in the previous question? No why different.
- Was this question OK or was it difficult to answer? Why
8a. How do you feel about your social life?

By social life we mean the time you spend with friends and family.

Please tick (✓) 1 box

I see my friends and family as much I want

I see my friends and family sometimes, it’s OK

I do see friends and family, but not enough

I feel lonely because I do not see my friends and family very much or at all
8b. Do staff help you to spend time with your friends and family?

Please tick (✓) 1 box

Yes

No

Q8a Probes

- When you answered this question what did you think about? (Explore if R was thinking about particular types of occasions e.g. just hanging out with friends or family or just thinking about parties)
- Who do you think about?
- Why did you select [R’s answer] here? (Explore whether informal carer and R had a differing view, and if yes, how the answer was decided on)

Q8b Probes

- Why did you select [R’s answer] here?
9a. How do you spend your time?

When you are thinking about how you spend your time, please include:
   a. anything you like doing
   b. work, whether you get paid for it or not
   c. looking after others.

Please tick (✓) 1 box

I spend my time as I want, doing the things I like

I can do quite a lot of the things I like, it’s OK

I can do some of the things I like but not enough

I do not do any things I like
9b. Do staff help you to spend your time as you want?

When you are thinking about how you spend your time, please include:
   a. anything you like doing
   b. work, whether you get paid for it or not
   c. looking after others.

Please tick (✓) 1 box

Yes

No

(Optional Q)

Q9a Probes
- How did you spend your time?
- Do you like doing these things?
- Are there things that you would like to do which you don’t do?
- Why did you select [R’s answer] here? (Explore if R found it easy to match their answer in their head with the answer options available)
- Explore whether informal carer and R had a differing view, and if yes, how the answer was selected.
10. How do you feel when you need help with things?

Please tick (✓) 1 box

Having help makes me feel better about myself

Having help does not change the way I feel about myself

Having help sometimes makes me feel a bit bad about myself

Having help makes me feel really bad about myself
11. How do you feel about the way other people treat you?

Please tick (✓) 1 box

- The way I am helped and treated makes me feel better about myself
- The way I am helped and treated does not change the way I feel about myself
- The way I am helped and treated sometimes makes me feel a bit bad about myself
- The way I am helped and treated makes me feel very bad about myself
12. Do you find it difficult or easy to find out about things like the support you could get, and your money, things like that?

Please tick (✓) 1 box

- It is very easy to find this out
  - [ ]

- It is quite easy to find this out
  - [ ]

- It is quite hard to find this out
  - [ ]

- It is very hard to find this out
  - [ ]

- I’ve never tried to find this out
  - [ ]
Q10 Probes
- How did you decide on your answer?
- What things that you get help with did you think about? Are there things that you get help with that you didn’t think about?

Q11 Probes
- What did ‘treat you’ mean to you in this question?
- How did you decide on your answer?
- The answer options refer to helped and treated did this affect which answer you selected?
- How did this question make you feel?
- Explore whether informal carer and R had a differing view, and if yes, how the answer was selected.

Q12 Probes
- How did you decide on your answer?
13. How is your health today?

Please tick (✓) 1 box

I am very healthy really

I am quite healthy

My health is OK

My health is not very good

My health is really very bad
14a. Do you have any pains in your body?

Please tick (✓) 1 box

I do not have any pain

I have some pain but not a lot

I have a lot of bad pain

It's good

It's OK

It's Bad
14b. How do you feel in your mind or your feelings generally?

Please tick (✓) 1 box

- I am not worried or sad at all
- I am sometimes a bit worried or sad
- I am a very worried or sad person

NatCen Social Research: Appendices to cognitive interview report: satisfaction with adult social care among Bangladeshi, Pakistani and white British populations
15. What kinds of things can you do by yourself?
Please tick (✓) 1 box for each question

I can do this easily by myself
I can do it by myself, but it is hard
No, I cannot do it by myself (I need help)

1.1.1 a. Can you usually get around the house (except steps) by yourself?

1.1.2 b. Can you usually get in and out of bed (or a chair) by yourself?

1.1.3 c. Can you usually feed yourself?
Please tick (✓) 1 box

1.1.4
d. Can you usually pay bills, write letters, that kind of thing, by yourself?

- [ ] I can do this easily by myself
- [ ] I can do it by myself, but it’s hard
- [ ] No, I can’t do it by myself (I need help)
16. Can you do these things yourself?
Please tick (✓) 1 box for each question

1.1.5
a. Do you usually manage to wash all over by yourself using a bath or shower?

1.1.6
b. Can you usually get dressed and undressed by yourself?

1.1.7
c. Can you usually use the toilet by yourself?
Please tick (✓) 1 box

1.1.8

Yes, I do this myself

No, I need help with this

No, somebody else does this for me

1.1.9

1.1.10

1.1.11

1.1.12

1.1.13

1.1.14  d. Can you usually wash your face and hands by yourself?

Q13-Q16 Probes
- How easy or difficult did you find these questions to answers?
- Was there anything that was unclear to you in any of these questions? If so what?
- Thinking of the last set of Qs (Q13-16) that you answered were there any that you weren’t sure how to answer? If so which ones and why? How did you decide your answer then?
- Did the carer and care user have the same view? If not, how did they decide on an answer?
Getting about
Section 5

18. Can you go out in your local area?

Please tick (✓) 1 box

I can get to all the places that I want

Sometimes it is difficult to get to all the places that I want

I can not get to all the places that I want

I do not leave my home
19. Do any of your family, friends or neighbours often help you to do things?

Please tick (✓) as many boxes as you need to

- Yes, and it is someone who lives in the same house as me
- Yes, and it is someone who lives in a different house to me
- No, they do not help me
21. Did you fill in this questionnaire by yourself?

Please tick (✔) 1 box

Yes, I filled it in myself

No, I had help from a member of staff

No, I had help from someone who lives with me

No, I had help from someone who does not live with me
22. What type of help did you have?

Please tick (✓) as many boxes as you need to

- I did not have any help
- Someone else read the questions out to me
- Someone else explained the questions to me
- Someone else wrote down the answers for me
- I talked about the questions with someone else
- Someone else answered for me, without asking me the questions
Q18-Q22 Probes
- How easy or difficult did you find these questions to answers?
- Were there any questions that you didn’t like answering? Which ones? Why? (understanding/sensitivity)

Q21-Q22 Probes
- Who decided on the answers to these questions?
- In Q 19 – what did you understand by ‘help’ in filling in the questionnaire?
- Was it easy or difficult to decide what type of help had been given?
- Were you thinking of any type of help which is not described in question 22?
- Do care user and helper agree on type of help given?

General feedback
If not already covered
- What do you think of the layout of the questionnaire?
  - location of the answer boxes?
  - Right justification of answer options

What did you think of the pictures on top of the questions? – Were they helpful or unhelpful – why? (patronising?)
- Did these pictures help you to understand the questions?
- Did you notice that next to some of the tick boxes there were pictures? (INTERVIEWER POINT out the pictures e.g. Q18).
- What do you think of these pictures? Were they helpful or unhelpful in answering the questions? (Why -Explore if Rs thought they were patronizing)
- Did views of helper and care user on design of questions and pictures differ?
- Did the questions seem relevant to your situation?

END INTERVIEW AND THANK RESPONDENT FOR THEIR TIME STRESSING THE VALUE OF THEIR PARTICIPATION IN THE RESEARCH.
GIVE THEM (1) THE THANK YOU INCENTIVE AND (2) THE LEAFLET

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