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Cognitive testing of integrated care questions

Report prepared by Ipsos MORI for HSCIC

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Introduction

1 Introduction

Background

Ipsos MORI was commissioned by the Health and Social Care Information Centre (HSCIC) and the Department of Health to test new questions on integrated care. Those questions that performed well in testing could be considered for inclusion in the Personal Social Services Adult Social Care Survey and Personal Social Services Survey of Adult Carers conducted by local authorities in England.

Approach

Ipsos MORI conducted 20 face-to-face cognitive interviews with carers and service users to test these new questions, check that they were easy to understand, and explore whether they were understood as intended. Ten interviews were conducted with each of the two audiences.

The questions consisted of nine questions to be tested with service users, and eight to be tested with carers, from a set of integrated care questions designed by Picker Institute and the University of Oxford¹. These questions were selected by reference groups that included representation from Department of Health, HSCIC and local authorities. The intention was to use the findings of cognitive testing to assist in the identification of a subset of questions from these nine and eight, to be considered for possible inclusion in future surveys.

HSCIC identified two local authorities that were able to help with the recruitment of participants; one in the East Midlands and another in London. These local authorities contacted a sample of service users and carers asking them if they would potentially be interested in taking part in the research, supplying them with an information sheet about the project. Service users and carers who expressed an interest were asked for their permission for their contact details to be passed to Ipsos MORI for the purpose of this project. Ipsos MORI then contacted participants by phone, provided more information about the project and recruited participants for the interviews.

The fieldwork took place between Friday 8th August and Wednesday 20th August, with a number of fieldwork days across the two local authorities. The interviews lasted roughly 45 minutes each and were conducted face-to-face by the research team, in the location chosen by participant.

After seeking informed consent, the participant was invited to complete the whole survey questionnaire, to which the new questions had been added.

¹ Developing measures of people' self-reported measures of integrated care, 2013
http://www.pickereurope.org/assets/content/pdf/News%20releases/Developing%20measures%20of%20IC%20report_final_07012014.pdf

The purpose of this was to recreate the typical survey experience as closely as possible, and ensure participants considered the new questions in the context in which they would be asked. Where the participant had difficulties with reading or writing, either the interviewer or someone else that was present went through the questionnaire with them.

Once the questionnaire was completed, the interviewer told the participants which questions would be cognitively tested, and went through each of them one-by-one, exploring how the question was understood, discussing each answer given by the participant, exploring the reasons for doing so and probing about how they felt about the way that the question was worded. This report includes the comments made by the participants, as well as our analysis of how they responded to the questionnaire and possible changes that could be made to the questions, where relevant. Much of the analysis also focuses on how the questions were understood by participants – at times, their responses do not match what might have been expected or intended when the questions were drafted – something that is worth considering if and when a subset of the questions is chosen to be added to the two surveys.

Analysis

An interim debrief was held on Friday 15th August after 13 of the interviews had taken place, which was attended by three of the interviewing team and a representative from HSCIC. At this meeting, the findings to date were discussed and a number of possible changes were suggested. Some of them were made to the two questionnaires, and tested in the remaining interviews. The questions affected are noted in the report, along with analysis of how the new wording worked.

After each day of fieldwork, interviewers wrote detailed notes about each of their interviews. These notes were used for the analysis, along with the debrief meetings and the audio recordings.

Prior to the project, HSCIC and the Department of Health sought ethical approval from the Social Care Research Ethics Committee, and obtained a favourable opinion.

2 Summary

2.1 Key findings

While participants found most of the questions easy to understand, the cognitive testing exercise showed that they did not always understand the questions as intended. Across the two audiences, three issues came up repeatedly.

First, most participants did not think of health staff or health services when answering questions on integrated care, even when the question wording made reference to these. This issue was much more common among service users than among carers. Two main reasons may account for this:

- The rest of the questionnaire specifically focuses on care and support, with health only coming into play in the section on integrated care. When participants reached that section of the questionnaire, care and support was at the forefront of their mind, rather than health.
- While most service users had health needs and interacted with health services on a regular basis, their interactions with care and support services and staff were much more frequent (e.g. daily) than their interactions with health services and staff.

Second, even when participants did take into account health services/staff when answering the questions, some viewed health and care services/staff as separate entities, reflecting the way these services are accessed and delivered. The implications of this were twofold:

- A few found it hard to give an overall answer to questions that asked about both health and social care jointly. For instance, they wanted to give a positive rating about one but a lower one about the other.
- They sometimes did not quite understand why questions were asked in the way they were. This issue was particularly salient for the last question (on whether people treating and caring for them/the person cared for worked well together).

Finally, while the section heading of the new questions to be tested specifically referred to the last 12 months, this timeframe was not always reiterated throughout the questions. As a result, some participants referred to events or situations that took place before the 12-month timeframe when discussing their answers.

2.2 Recommendations

The following steps may address the issue of people not considering health services/staff when answering the questions:

- expanding the survey introduction on the front page of the questionnaire for service users to explain what health services/staff are. This was discussed during the interim debrief meeting, added to the questionnaire for service users, and tested during the remaining interviews;
- reiterating this under the section headings focusing on integrated care, both for service users (section 4) and carers (section 5). We have suggested possible wording for this in the report.
- extending the wording of some questions to clarify who/what they are referring to. Again, we have suggested some possible wording for this throughout this report.

This should help ensure participants understand the questions as intended.

Regarding the second issue (participants considering health and social care services as separate entities), participants overcame their desire to give different ratings for health and social care services or staff by 'averaging' their answers and giving a combined answer. Other cognitive testing exercises we have conducted indicate that this is a frequent issue when people answer questions that have to combine two or more entities. For example, someone might give an overall rating for their health services, and are going through a similar thought process by balancing a perceived good experience of a physiotherapist and a perceived bad experience of a day centre.

As health and social care services become more integrated in the future, and people increasingly recognise the integration between them, service users and carers will be able to answer such questions in a more holistic way.

With the increased emphasis on delivering integrated care locally, the fact that some participants did not quite understand why some questions were asked in the way they were should become less problematic over time, as more service users and carers should start experiencing integrated care in their day-to-day lives over the coming years.

Finally, the issue about timeframe can easily be resolved by adding 'over the last 12 months' to the question wording. Throughout this report, we have suggested this addition for questions where we felt this was important.

2.3 Next steps

Going forward, the findings in this report may be used to inform a subset of questions to be considered for possible inclusion in future surveys. Below we have listed the questions that we feel tested sufficiently well, for consideration. Please note that the wording is sometimes different from the wording originally proposed, as it incorporates our suggested amendments based on the findings from the cognitive testing exercise. These amendments are highlighted in yellow below; all of them reflect slight additions to the original question wording.

Questions for Service Users

Q13. In the last 12 months, have you been involved as much as you wanted to be in decisions about your care and support?

- Yes, definitely
- Yes, to some extent
- No

Q14. Overall, do you feel that your family carer/member has had as much support from health and social services as they needed?

By support for carers we mean

- Yes, they have had as much support as they needed
- They have had some support but not as much as they needed
- No, they have had little or no support
- They did not want / need support
- There are no family carers/members to support

Q16. Do health and social care services help you live the life you want as far as possible?

- No
- Yes, to some extent
- Yes, definitely

Q17a. To what extent do you agree or disagree with the following statement... 'Health and social care staff always tell me what will happen next'.

By health and social care staff, we mean staff who are involved in your care and treatment. This might include doctors, nurses, physio, occupational therapists, social workers, personal assistants, paid carers, etc. When staff do not know what will happen next, please consider whether they try to find out and keep you informed.

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Questions for Carers

Q16a. To what extent do you agree or disagree with the following statement... 'Health and social care staff always tell me what will happen next'.

By health and social care staff, we mean staff who are involved in the care and treatment of the person you look after. This might include doctors, nurses, physio, occupational therapists, social workers, personal assistants, paid carers, etc. When staff do not know what will happen next, please consider whether they try to find out and keep you informed.

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

Q17. To what extent do you agree or disagree with the following statement... 'In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations.

Strongly agree

Tend to agree

Neither agree nor disagree

Tend to disagree

Strongly disagree

I haven't needed information in the last 12 months

Q18. In the last 12 months, have you been involved as much as you wanted to be in decisions about the care and support of the person you care for?

Yes, definitely

Yes, to some extent

No

I didn't want to be involved in decisions about care

Q21. Would you know who to contact if you need to ask questions about the condition or treatment of the person you care for?

Yes, definitely

Yes, to some extent

No

Don't know / can't remember

Personal Social Services Adult Social Care Survey

3 Personal Social Services

Adult Social Care Survey

In total, nine new questions on integrated care were tested for the *Personal Social Services Adult Social Care Survey* questionnaire with ten service users of local authority adult social care services.

The responses and reactions to each of these questions are detailed below, along with Ipsos MORI's analysis of the findings and suggested re-wording of the questions, where appropriate.

Q13. Were you involved as much as you wanted to be in decisions about your care and support?

Yes, definitely

Yes, to some extent

No

Main issues/ comments from interviews

The majority of participants across all 10 interviews found this question fairly easy to answer and thought it worked well. When probed, nine of the 10 participants were able to identify specific situations or moments in time that they had been thinking of when answering the question. The decisions about their care and support they thought of included:

- Decisions made when they first developed care and support needs, sometimes many years ago
- Their social services review, which usually took place annually
- All interactions with staff involved with their care and support
- Meetings held with a psychiatrist
- Development of their care plan with social workers

One participant, when probed, displayed a lack of understanding of what the question was exploring. They answered 'yes, definitely', but on further discussion, it appeared that this was more a reflection of their satisfaction with their social workers, rather than involvement in decision making.

When the decisions participants were referring to were explored, it became clear that some participants were not answering specifically about the last 12 months, but thought of decisions made about their care regardless of the time from when these decisions were made. This is despite the fact that 12

months is referenced in the section heading, which immediately precedes the question. Hence it may be worth reiterating this in the question wording.

However, it should be noted that the nature of the care and support received by some participants may mean that even specifying “in the last 12 months” in the question wording would not be particularly effective. While some participants have an annual assessment, or more regular contact, that makes a judgement based on the last 12 months possible, other participants do not. For example, one participant thought about the decisions made after experiencing a stroke six years ago when all key decisions about living independently were made. When pressed on this, he said that his needs haven’t changed since then, so no decisions were made in the past 12 months.

One participant did highlight the fact that there are “don’t know/ can’t remember” options at some questions and not at others. They didn’t feel that this was a problem for them, but felt that it might be for some service users who have conditions that might impact on their memory.

Ipsos MORI recommendations

Generally, the question works well and is easily understood by the majority of participants. The answer options provided were satisfactory to meet the full range of participants’ situations. Two possible alterations for this question might be:

- The addition of a “don’t know/ can’t remember” option. Ipsos MORI would generally advise including options like this on most questions, to avoid participants feeling forced to give an incorrect answer, if they are unsure, and minimise the number of respondents not answering the question. However, this was not a specific issue for any of the participants interviewed and we note that this option is not always offered in other parts of the questionnaire.
- Inclusion of “...in the last 12 months” in the question wording, to remind people that that the focus of the question is intended to be the past 12 months.

Q14. Overall, do you feel that your carer/ family has had as much support from health and social services as they needed?

Yes, they have had as much support as they needed
They have had some support but not as much as they needed
No, they have had little or no support
They did not want / need support
There are no family members or carers to support

Main issues/ comments from interviews

Participants generally found the question easy to understand and answer. However, when probed, it was clear that one participant had misunderstood the question, answering about support from health and social services provided to *them* rather than their *carer/ family*. Also, a handful of participants answered the question thinking of their paid carer; they did not have a family carer, but still did not make use of the code “There are no family members or carers to support”. Overall however, the large majority were clear about the subject of the question.

In the one instance where a participant gave the answer “There are no family members or carers to support”, this was because they were estranged from their family and didn’t have a professional carer. This participant felt comfortable answering the question and didn’t feel that it was too intrusive. Equally, they did not feel that anyone else in this situation may find the question awkward to answer as they perceived it to be a very matter-of-fact arrangement.

Participants considered different types of support when answering the questions: practical support, financial support and support with administrative tasks such as dealing with direct payments. It should be noted that the support they thought of was generally support provided by social services rather than health (except in one example where a physiotherapist was cited).

One participant answered “no, they have had little or no support” as they did not feel that the support received was the appropriate type of support. This suggested that they were interpreting the question more about the quality of support received rather than the quantity of support received. Generally however, discussions suggested that the majority of participants were considering the quantity of support provided (although this often overlapped with quality – e.g. not enough of the “right” support).

Ipsos MORI recommendations

Participants found it easy to recall the support that has been made available and that which hasn’t been made available. They were happy with the answer options provided and didn’t feel that any others were needed.

The Picker report states that the purpose of this question is to establish views around the key statement “My carer/ family have their needs recognised and are given support to care for me”; the implication is that the intention of the question is to focus solely on family carers or family members as opposed to paid/professional carers². As such, the wording could be modified as follows:

² Page 80, Developing measures of people’ self-reported measures of integrated care, 2013 http://www.pickereurope.org/assets/content/pdf/News%20releases/Developing%20measures%20of%20IC%20report_final_07012014.pdf

“Overall, do you feel that your family carer/member has had as much support from health and social services as they needed?” and the last code altered slightly to be “There are no family carers/members to support”.

For clarity, the types of support available for carers could be outlined, in particular the support available from health services. This could be done by adding “By support for carers we mean” at the end of the question.

Q15. Have all your needs been assessed?

All of my needs have been assessed
Some of my needs have been assessed
None of my needs have been assessed
Don't know / can't remember

Main issues/ comments from interviews

Generally participants didn't have any problems with this question, and felt able to answer it within the options provided.

A number of participants made specific references to the social care needs assessment that they had undergone, presuming that the question was referring specifically to this. Meanwhile, other participants made references to other meetings/ interactions that they had had in which their needs and/or care and support had been assessed or discussed in some way. For example, one participant talked about a meeting they had had with their father and a psychiatrist. Another participant stated that they felt that the question should specifically refer to “social care needs” as “needs” on its own may refer to many other strands of life that weren't relevant, but other participants found the survey provided enough context for them to understand what sort of needs the question referred to.

Among those participants who answered thinking of their social care needs assessment, a couple of participants were thinking back to an occasion that long predates the 12 month period stipulated in the section heading. For example, one participant answered regarding a needs assessment they had had following a heart attack six years ago, while another made reference to an assessment that took place three years ago after experiencing a stroke.

Meanwhile, another participant answered “some of my needs have been assessed” because they had undergone a mobility assessment but hadn't subsequently received mobility support. In other words, while all their needs had technically been assessed, they answered the question based on their satisfaction with the outcome of the assessment rather than how comprehensive it had been.

Generally participants were happy with the answer options provided and didn't feel that any others were needed. One participant gave an answer between two boxes however, as they felt all their needs had been

technically being assessed, but that as some people got things above and beyond their needs, they didn't want to give the most positive option possible, to take account of this – indicating that the respondent's satisfaction with their support entitlement affected their answer.

Ipsos MORI recommendations

While participants were fine with the question and felt able to answer it easily using the list of codes provided, there are a couple of possible alterations that could be considered:

- It might be helpful to add a question asking people if all their needs are being met before that one, to avoid the issue of unmet needs 'contaminating' the response they give at this question.
- As with Q13, it is clear that participants did not necessarily think about the past 12 months when answering the question. If this is what is required, it may be worth making this more explicit in the question wording. It is worth noting however that if the question wording includes "in the last 12 months" then an extra code needs to be added along the lines of "My needs have not been assessed in the last 12 months".

Q16. Do health and social care services help you live the life you want as far as possible?

Yes, definitely

Yes, to some extent

No

Main issues/ comments from interviews

Unlike some other questions, participants felt more readily able to answer about health and social care services together for this question.

Additionally, participants didn't have any problems with the answer scale and the options listed covered all eventualities.

Generally, participants were able to distinguish between services helping them to live the life they wanted as far as possible and whether or not their life was as they wanted. For example, a participant gave a positive answer because they had been provided with a wheelchair. They understood that this was health and social care services facilitating living life as far as possible, without being able to do everything they had been able to do prior to their accident. Equally, another participant noted that, while there were certain things that they would love to be able to do independently, such as personal care, this would never be possible and so health and social care services helped as much as they could.

However, one participant gave a negative answer on the basis that it wasn't possible for them to live the life that they wanted as a result of their stroke, while noting that this wasn't health and social care services' fault.

A couple of participants talked explicitly about whether or not health and social care services allowed them to make choices about what they wanted to do (e.g. about holiday destinations or choosing what would be cooked). It suggests that they answered the question thinking of independent living, which was probably the intention.

Ipsos MORI recommendations

This question works well and can be kept as it is.

Q17a. To what extent do you agree or disagree with the following statement... 'Health and social care staff always tell me what will happen next'

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Main issues/ comments from interviews

Although participants found this question easy to answer, upon further probing, they did not answer it thinking of "health and social care staff". For example, one answered thinking solely about their paid carer, and two answered thinking about social care staff only, despite all of them having health/medical needs and having regular contact with health staff. One participant, conversely, answered about their psychiatrist and did not think of their social worker. Finally, one participant distinguished between health staff and social care staff, and wanted to give a different answer for each.

When this finding was discussed at the interim debrief, it was agreed that a new sentence would be added to the introduction at the beginning of the questionnaire, to make the reference to health services more explicit; 'This questionnaire also asks about health services. These refer to services provided by staff like GPs, hospital consultants, nurses, and physiotherapists'. The addition of these sentences was made before the last four interviews with service users were conducted. While in the subsequent interviews participants appeared to have a better idea of what was meant by health and social care and seemed more likely to consider health services when answering the questions on integrated care, it is hard to gauge from just four interviews to what extent this resulted from the two sentences added to the introduction. However, there were no negative reactions from the remaining interviews to this addition.

One participant queried the purpose of having both a “strongly agree” and an “agree” option. However, other participants distinguished between these two when talking through their answers. Generally, participants were happy with the answer options provided and didn’t feel that any others were needed.

Ipsos MORI recommendations

The fact that most participants did not consider “health and social care staff” when answering the question needs to be addressed, as this issue is also affecting other questions. As such, we recommend keeping the two sentences added to the introduction after the interim debrief, and re-iterating this point later in the questionnaire as necessary. Possible ways forward could include:

- Under the heading for section 4, adding instructions such as “When answering this section, please think of all the health and social care services you may access. Health services include those provided by staff such as GPs, nurses, hospital consultants, physiotherapists, etc. Social care services include things like receiving a Personal Budget, support from a paid carer, equipment, meals services, Direct Payments, or attending a day centre.”
- Expanding the wording of Q17a, for instance by adding the following: “By health and social care staff, we mean staff who are involved in your care and treatment. This may include doctors, nurses, physiotherapists, occupational therapists, social workers, personal assistants, and paid carers.”

To differentiate more clearly between the “disagree” and “strongly disagree” options and between the “agree” and “strongly agree” options, it is recommended that the scale be amended to include a “tend to” option (strongly agree, tend to agree, neither agree nor disagree, tend to disagree, or strongly disagree). While only one participant in the research highlighted the scale and suggested that it should be changed, this change is in line with what Ipsos MORI would typically advise.

From previous cognitive testing and questionnaire development work, the rationale for this is that there is no crossover between any of the five codes (strongly agree, tend to agree, neither agree nor disagree, tend to disagree, strongly disagree). These codes are more linear, with respondents being more able to clearly differentiate between the codes on the scale. This approach is widely used, both by Ipsos MORI and other leading research agencies.

Q17b. To what extent do you agree or disagree with the following statement... 'Health and social care staff always ensure I know what will happen next'

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

Main issues/ comments from interviews

A lot of the participants' reactions to this question focused on its similarity to Q17a; all participants noted that the two questions were about how good staff were at communicating with them, and few participants could see any differences between the two wordings. This is unsurprising, given that the purpose of testing Q17a and Q17b was to see which of these two questions worked best. It is also reassuring that almost all participants gave the same answer option when answering both questions.

A couple of participants noted that sometimes staff do not know what will happen next, and answered "neither agree nor disagree" as a result. They felt that this was particularly true of social workers, who sometimes didn't have all the relevant information or had to involve colleagues in decisions about e.g. entitlement to support services. This finding mirrors similar responses to the equivalent questions in the cognitive interviews with carers.

One participant (separate to the one who commented on the scale at Q17a) stated that they didn't feel that having both "agree" and "strongly agree" answer options was necessary, as "you either agree or you don't".

Ipsos MORI recommendations

Participants were equally comfortable with the wording of Q17a and Q17b.

Regardless of which one is chosen, it may be worth adding the following clarification sentence at the end of the question: 'When staff do not know what will happen next, please consider whether they try to find out and keep you informed'.

In line with the reasons given in the recommendations for Q17a, we would advise changing to a 'tend to' agree/ disagree scale for this question.

Q18. Do you have a named health or social care professional who coordinates your care and support?

Yes

No, I coordinate my own care and support

Don't know / not sure

Main issues/ comments from interviews

The majority of participants generally felt that this question was easy to answer. They felt able to identify whether or not they had a named health and social professional who coordinated their care and support and generally the answer options provided were sufficient. However, there were a couple of exceptions to this which indicate that the question may not always be understood as intended, or may need altering slightly.

Some participants, though not all, interpreted “coordinating your care and support” as “liaising between different organisations, such as social services and hospitals”, or “making sure their day-to-day life runs smoothly”. However, even when participants thought they understood the concept of care coordination, and answered “yes”, when the exact circumstances were discussed further, a few issues were raised. For example, one participant thought they had a named professional but in reality coordinated their own care and got the practitioner to sign it off, while others couldn't remember the name of their professional or didn't get to see them enough, or wondered if a care coordinator was the same as a liaison officer.

For a couple of participants, the concept of care coordination was less clear; they thought it referred to things like checking care workers provide the care and support they are commissioned to do, or signing off their care plan. One participant answered “don't know/ unsure” as they were not sure if this was referring to the coordination of their whole care package, to their private care provider coordinating the different care workers involved in their care, or to something else.

One participant had a third-party coordinating their care and support, who they did not think was a “health or social care professional”. As a result, they did not feel they could answer “Yes”, but it was equally inappropriate to answer “No, I coordinate my own care and support”.

Ipsos MORI recommendations

We do not recommend using this question as we do not feel the concept of care coordination will be easy to clarify.

If it is important to include this question, then we would suggest making the following changes:

- To alter the second answer option from “No, I coordinate my own care and support” to “No”. This would give respondents who do not have a named professional, but do not coordinate their own care, a way to answer the question appropriately, while the additional information would be collected at Q18b anyway.
- To extend the wording to clarify what “coordinating your care and support” means.

Q18b. If the answer to Q18 above is ‘No’ then please give more detail below

No – I need and/or would like someone to coordinate my care and support

No – I coordinate my own care and support

No – I don’t have multiple needs so my care and support does not need coordinating

No – For other reasons

Main issues/ comments from interviews

Due to routing, only two out of ten participants actually answered this question and one of these should not have actually answered it anyway, but got confused with the routing. The other eight participants followed the routing instructions correctly and didn’t answer the question. The one participant who did answer the question did not feel any of the codes provided were relevant; they actually ticked the box for “No – I coordinate my own care and support” but they wanted to add a code along the lines of “No, I have a person who coordinates care and support but not a professional”. This is despite the fact that “No – For other reasons” would probably have been a more appropriate code.

Ipsos MORI recommendations

This question was only tested with one service user so it is not possible to draw robust conclusions.

Q19. Do all the different people treating and caring for you work well together to give you the best possible care and support?

Yes, all of them work well together

Most of them work well together

Some of them work well together

No, they do not work well together

Don’t know / not sure

There is no need for them to work together

Main issues/ comments from interviews

Participants experienced greater difficulties with this question than with any of the other questions tested. Indeed, as well as having to think about “all the different people” they have to make a judgement about what “treating and caring” means, whether the staff treating and caring for them work together, whether they work well together, and whether they get the “best possible care and support”.

Participants’ understanding of “all the different people treating and caring for you” varied greatly. Some thought of the full range of health and social care staff, others just thought of their support team, or of their paid carer(s). A few also considered their family carer when answering. When prompted, a number of participants acknowledged that there were other people involved in their care and treatment who they hadn’t considered when answering the question.

Indeed, participants’ emphasis when discussing their responses was generally on the people caring for them, rather than on those treating them. This could be because participants all received care and support on a day-to-day basis. It may also reflect the fact that the majority of this section emphasises “*care*”, “*social care*” and “*caring*”, whilst “*treatment*” and “*treating*” feature less prominently, are less frequently experienced by participants, and are perhaps more medical terms. As explained elsewhere in this chapter, health staff and health services were not at the forefront of participants’ considerations when answering the integrated care questions.

Generally, the answer options provided were deemed easy to understand, but not necessarily appropriate. Indeed, a few participants noted that because of the specific services being provided to them, the staff treating and caring for them did not need to work together, sometimes because they saw health and social care staff as two distinct entities. For example, one participant with mobility issues explained that they didn’t think there was any need for their GP, who they would see if they had a fall or their condition worsened, to liaise with their housing warden. At the interim briefing held following the first six interviews, the code “They do not need to work together” was therefore added to the questionnaire, to reflect feedback from participants who didn’t feel that integration is or should be a part of their day-to-day care and support. Subsequently, two of the four remaining participants selected this new option. When probed, they explained that they now only had one person at a time involved in their care, so there was no need for them to work well with anyone else.

Finally, two participants explained the answer they gave by their (dis)satisfaction with the care and treatment they received. Their answers were therefore driven by issues such as service satisfaction and entitlement to support, rather than by how effectively staff worked together.

Ipsos MORI conclusion and recommendations

The subject of the question is clearly very important. More than any of the other questions tested, it cuts to the core of integration of health and social care services. However, in its current form, it is not clearly understood.

Some participants noted that because of the specific services being provided to them, the staff treating and caring for them did not need to work together. Therefore, adding the code "They do not need to work together" goes some way to address these issues.

For those who do have a number of different health and social care workers involved in their care and support, a way to encourage them to think about who these individuals are might be by adding an explanation with examples of the different people who might be involved in treating and caring for respondents, e.g. "By people treating and caring for you we mean people like doctors, nurses, care workers etc."

We would anticipate that the addition of such an introduction, coupled with the increased awareness that service users will develop around the ideas of integrated care over time will encourage service users to think of health and social care services more holistically, rather than as separate entities that do not need to interact.

Personal Social Services Survey of Adult Carers

4 Personal Social Services Survey of Adult Carers

In total, eight new questions were tested for the Personal Social Services Survey of Adult Carers questionnaire, with 10 carers of users of local authority adult social care services.

The responses and reactions to each of these questions are documented in this chapter, along with Ipsos MORI's analysis of the findings and recommendations.

Q16a. To what extent do you agree or disagree with the following statement... 'Health and social care staff always tell me what will happen next'

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Main issues/ comments from interviews

Findings for this question are similar to those for service users, who were asked the same question (Q17a in the service user questionnaire).

Generally, participants felt able to answer this question and didn't have any problems with the "statement" format. The main issue with the question was participants' different understanding of "health and social care staff".

Some just thought of health staff when answering this question, such as GPs and hospital staff, whilst others only thought of social care staff, including social workers, and day centre staff. One participant also commented that they were thinking of the person they have the most contact with in response to this question. Encouragingly, about half of carers thought of both health and social care staff, mentioning NHS staff, GPs, hospital staff, social workers and care workers.

One participant struggled to understand the question, and asked who health and social care staff were as she was completing the questionnaire. Once she was given some examples, she felt able to answer the question.

Another participant was confused by how broad the definition of "health and social care staff" was, and whether the question referred to commissioned (e.g. care workers) or non-commissioned services (e.g. local authority social services and NHS). After consideration, they interpreted the question as including both commissioned and non-commissioned services.

Participants were generally happy with the answer options provided, though two issues were raised:

- A few carers pointed out that sometimes, health and social care staff didn't know what would happen next, but could not be held responsible for not knowing (e.g. because of potential service cuts, final decisions being made by more senior staff members, or the unpredictability of the condition of the person cared for). In these cases, participants did not feel that any of the codes provided enabled them to say that.
- One participant mentioned that she would have answered differently if health and social care staff were asked about separately, as in her case the social care staff weren't as good at keeping her informed as health staff. Therefore she would have liked different options for health staff and social care staff, or them to be asked about separately. Still, she was able to provide a combined "average" answer.

Ipsos MORI recommendations

There are a couple of possible alterations that could be considered to ensure that carers understand 'health and social care staff' as intended when answering the question. These mirror the recommendations made for question Q17a/b in the service user questionnaire.

- Expanding the heading for section 5 of the questionnaire as follows: "Section 5: Arrangement of support and services in the last 12 months. The next questions are about organising the support and services for you and the person you care for. When answering this section, please think of all the health and social care services the person you care for may access. Health services include those provided by staff such as GPs, nurses, hospital consultants, physiotherapists, etc. Social care services include things like receiving a Personal Budget, support from a paid carer, equipment, meals services, Direct Payments, or attending a day centre."
- Expanding the wording of Q16a, for instance by adding the following: "By health and social care staff, we mean staff who are involved in the care of the person you look after. This may include doctors, nurses, social workers, and paid carers."
- In line with the recommendations for Q17a and Q17b the Personal Social Services Adult Social Care Survey, and for the reasons outlined at Q17a in that section, we would advise that the scale be amended to include a 'tend to' option (strongly agree, tend to agree, neither agree nor disagree, tend to disagree, or strongly disagree).

In addition, it may be worth adding the following clarification sentence at the end of the question: *“When staff do not know what will happen next, please consider whether they try to find out and keep you informed”*.

16b. To what extent do you agree or disagree with the following statement... ‘Health and social care staff always ensure I know what will happen next’

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Main issues/ comments from interviews

The majority of the analysis of this question focused on its similarity to Q16a. Generally, participants answered both questions in the same way, and most struggled to differentiate between the two.

Despite acknowledging the similarities between Q16a and Q16b, four participants picked up on subtle differences between the use of “ensure” and “telling me” in the questions. In these cases, all four thought the term “ensure” described a more thorough process; they felt that it suggested making sure that carers fully understand what will happen next, and that there would be a follow-up conversation, so are more involved in the whole process. As one participant stated, the key difference to him when comparing both questions was the inclusion of “ensure I know” in Q16b, which he interpreted as being whether the communication from health and social care staff had not only been received, but understood. Another participant similarly said that to her, this meant that staff were going a step further rather than just telling her about the next steps; they were also checking she understood what exactly those next steps would be. It was also stated that “tell me” implies that the carers do not have much choice or say in the matter, and are being dictated to, whether they like it or not.

One participant commented that Q16a wording would be simpler for others to understand, as it was shorter and clearer for people with limited English to understand.

Other findings for this question are the same as those raised for Q16a (participants’ understandings of “health and social care staff” varied, and a few did not feel that staff knew what would happen next).

Ipsos MORI recommendations

Our recommendations for the wording of this question are the same as those made for Q16a.

When it comes to choosing which wording between Q16a and Q16b is preferable, Q16a is shorter and simpler to understand than Q16b. Q16b is

likely to generate slightly more negative responses than Q16a, as it puts more responsibility on staff to not only tell carers what will happen next, but also to check they understand and remember it.

In line with the reasons given in the recommendations for Q17a of the Personal Social Services Adult Social Care Survey, we would advise changing to a 'tend to' agree/ disagree scale for this question.

Q17. To what extent do you agree or disagree with the following statement... 'In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations'

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

I haven't needed information in the last 12 months

Main issues/ comments from interviews

Overall this question worked well, but a couple of participants had a problem with the time specification in the question. They felt that the provision of information about other services available is a one-off activity required at the beginning of the carer journey, and as a result the information they needed had been provided before the last 12 months. These participants answered "neither agree nor disagree" and they didn't think there was an appropriate response option.

A few participants mentioned that they had found out the information they needed via support groups or voluntary organisations themselves, rather than through health and social care staff. As a result, they gave a "disagree" or "strongly disagree" rating. This rating did not mean that they lacked information, but simply that the information they had accessed was not provided by health and social care staff.

Ipsos MORI recommendations

During the interim debrief, it was agreed that for the remaining interviews with carers, the code "I haven't needed information in the last 12 months" would be added, as some participants had mentioned the lack of suitable response options. Nobody in the remaining five interviews chose this option, but they did acknowledge that it could be an appropriate response option in certain cases.

In line with the reasons given in the recommendations for Q17a of the Personal Social Services Adult Social Care Survey, we would advise changing to a 'tend to' agree/ disagree scale for this question.

Q18. Were you involved as much as you wanted to be in decisions about the care and support of the person you cared for?

Yes, definitely

Yes, to some extent

No

I didn't want to be involved in decisions about care

Main issues/ comments from interviews

Generally, this question worked well. Participants understood it consistently; they found it easy to answer and were happy with the answer options provided.

The only issue with this question relates to the timings of the decisions made. Although the section heading indicates that a specific period is intended for this section (i.e. past 12 months), several participants spoke about decisions made at the point of entry or diagnosis, which in many cases would have been years before the specified timeframe. One participant mentioned that they were thinking about their last encounter with social services when answering this question, and said that this was how they answered all the questions, regardless of whether they said "12 months" in them or not.

Participants thought of various decisions when answering this question, including decisions made following the social care assessment of the person cared for, the choice of a day centre, how to contact GPs, decisions made regarding the medical treatment of the person they care for, and financial issues. Some also referred to decisions made during meetings with social workers, managers and independent advocates for the person cared for, to which they had been invited.

Ipsos MORI recommendations

During the interim debrief meeting, "in the last 12 months" was added at the start of the question, and the tense of question modified slightly. The following question wording was tested during the five remaining interviews with carers:

In the last 12 months, have you been involved as much as you wanted to be in decisions about the care and support of the person you care for?

Participants for the remaining interviews noticed the timeframe of the question and explicitly referred to it when answering the question by giving examples which fitted within the timeframe.

Q19. Thinking about the person you care for, when health or social care staff plan care or treatment for them does it happen?

Yes, it happens all of the time

It happens most of the time

It happens some of the time

No

Main issues/ comments from interviews

Participants raised a few issues about this question:

- Several participants had problems with the phrase “care or treatment” as they felt it was vague or they were unsure of what it meant and had to be prompted or given examples. A couple of participants thought the question referred to any instance where there is a plan to change the care/treatment which is currently provided, with one of them referring to annual and quarterly review meetings during which care is discussed.
- Many participants said that while care and treatment did happen, this was as a result of the family driving things forward and following things up, rather health and social care staff involvement. Their perception was that if they left it to health and social care services to make things happen, then they would not happen, or not in a timely manner. Similarly, one participant commented that the planned care and treatment sometimes took many months or even a year to happen, and that by the time it finally happened, sometimes this was too late as the needs of the person cared for had changed. Consequently the care and treatment planned, or the equipment or adaptations provided, were no longer appropriate. These issues, which mattered a lot to carers, were not quite captured by the question.
- Other questions in this section ask about the last 12 months, but there is no reference period in this question. A couple of participants were confused by this, and wondered if they should answer thinking of care and treatment planned in the last 12 months. In other cases, participants sometimes referred to care and treatment that had been planned more than 12 months ago, as nothing had been planned since then.

Ipsos MORI recommendations

As the question does not quite allow carers to say what they want to say (i.e. that they have to drive things forward for care and treatment to happen), we do not recommend including it in the survey.

However, if it is important to include it, a few changes could be made to make it easier for respondents to understand and answer it:

- Providing examples of “care and treatment”, so respondents feel clearer about what the question intends to capture;
- Adding a “don’t know” option, for those who still struggle to answer the question; and
- If the intention is to focus on the last 12 month, rewording the question accordingly (“*Thinking about the person you care for, when health or social care staff have planned care or treatment for them over the last 12 months, has it happened?*”), and adding a response code along the lines of “No care and treatment have been planned over the last 12 months”.

Q20. Thinking about the person you care for, to what extent do you agree or disagree with the following statement... ‘Their care and support is reviewed as often as it should be’

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Main issues/ comments from interviews

This question triggered a lot of feedback from participants, not because they did not understand it but because they did not like it; it did not allow them to say what they wanted to.

The main concern was that while reviews took place, nothing happened as a result, or their reviews always resulted in the amount of support they were entitled to being cut. Concerns were also raised that reviews focused on finances rather than on the wellbeing and needs of the person cared for. Another participant commented that from their perspective, reviews were fundamentally a negative thing, in that they felt they were only organised if services were going to be cut. Hence respondents were frustrated that the question did not focus on what they felt was a major issue for them and the person they cared for.

This impacted on the answers provided. For example, a carer answered the question negatively, despite the person cared for having had a review recently, because she was unhappy with the way the review had been conducted and the amount of support they were entitled to more generally. Another answered “Neither agree nor disagree” because while his son does

not get a review regularly, they don't want regular reviews either, for fear that they might generate unwanted outcomes.

One participant felt that "tend to dis/agree" options might be more appropriate than "dis/agree" ones as they would be less rigid. Another said that they answered "agree" and didn't feel that there was much difference between "agree" and "strongly agree", as you either agree or you don't. Typically, in Ipsos MORI surveys, we use "tend to dis/agree" and "strongly dis/agree" answer options rather than "dis/agree" and "strongly dis/agree" as there is clearer space between options. While this comment was made with regards to this question, it is equally relevant for all of the other questions that use this scale.

Ipsos MORI recommendations

As participants were generally negative about the focus of this question, it may be worth deleting it.

If the question is kept, we would advise changing to a 'tend to' agree/disagree scale for this question, in line with the reasons given in the recommendations for Q17a of the Personal Social Services Adult Social Care Survey.

Q21. Do you know who to contact if you need to ask questions about the condition or treatment of the person you care for?

Yes, definitely

Yes, to some extent

No

Don't know/can't remember

Main issues/ comments from interviews

No major problems were found with this question. Participants found it simple and very easy to answer, and were happy with the answer options provided.

One participant commented that the question was testing carers or challenging their abilities. They felt that they were being challenged about whether they knew who the correct person in health and social care was to contact. When explored, this was because the word "do" at the beginning of the question was found to be quite direct.

Perhaps unsurprisingly, participants who had been carers for many years were more confident in knowing who to contact if they had any questions, possibly because they had a wider network of helpful contacts.

Ipsos MORI recommendations

During the interim debrief meeting, it was agreed that for the remaining interviews with carers, the question wording should be amended to “Would you know...” rather than “Do you know...” due to concerns raised by one participant that the word “do” could be interpreted as testing the ability of respondents. Participants found the question very easy to answer with the revised wording, although not notably easier than the previous version.

This wording was intended to make the question less confrontational, as it focused on whether respondents could find out this knowledge rather than if they have the knowledge already. Further testing suggested that the remaining participants did not pick up on this distinction. Alternate wordings should be considered in any future testing of questions.

In the Picker report, the majority of the participants felt that the question and language was clear; the use of “don’t know” and “can’t remember” as one answer option was queried with participants in the Picker report, and combining the two response options was seen as appropriate by participants.

Q22. Thinking about the person you care for, do all the different people treating and caring for them work well together to give the best possible care and support?

- Yes, all of them work well together
- Most of them work well together
- Some of them work well together
- No, they do not work well together
- Don’t know/not sure
- There is no need for them to work well together

Main issues/ comments from interviews

Findings for this question are similar to those from service users, who were asked a very similar question (Q19 in the service user questionnaire).

First, there was some uncertainty about who exactly the question was referring to, with some participants thinking only of social care staff, excluding health staff, while others thought about all staff involved in supporting, treating and caring for the person they cared for, and mentioned staff such as nurses, GPs, physiotherapists, disability employment advisor, housing association staff, learning disability team, social workers, day centre staff, personal assistants, etc. If employment and housing are out of the scope of this survey, then this needs to be clarified in the question as carers of people with learning disabilities tended to refer to them.

Second, a few participants really felt that health and social care staff were two very separate entities and were not sure that they should or could work

together at all. They did not feel that there was any need for health staff and social care staff to work together, but could see the point of different health (respectively social care) staff working together. Reflecting this, one participant chose the response “most of them work well together”, but mentioned this was within their own separate fields of health and social care respectively.

Participants appreciated the “don’t know” option; a few of them commented that sometimes it is hard to know from the outside if staff worked well together or not.

Only four carers out of ten appeared to understand the question as intended, and found it easy to answer.

Ipsos MORI recommendations

During the interim debrief meeting, it was agreed that for the remaining five interviews with carers, the code “There is no need for them to work together” would be added, as some participants had mentioned the lack of suitable response options. Nobody in the remaining interviews chose this option, but they did acknowledge how it could be an appropriate response option in certain cases.

Our recommendations for this question are similar to those we made for Q19 in the questionnaire for service users; in its current form, the question is not consistently understood by respondents. Adding the code “They do not need to work together” goes some way in addressing the issues raised by participants, but it is not enough.

If this question is essential to keep, a way forward would be to expand its wording by adding an explanation with examples of the different people who might be involved in treating and caring for the person cared for e.g. “By people treating and caring for them we mean people like doctors, nurses, physiotherapists, occupational therapists, personal assistants, care workers, etc.”

Appendix 1: Personal Social Services Adult Social Care Survey questions tested

The questions tested are all of those in section 4 (Arrangement of Support and Services in the last 12 months) i.e. questions 13-19.

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.

ID number	
Local authority name	
Minutes taken to complete questionnaire	

Section 1: 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

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I am extremely satisfied | 1 |
| <input type="checkbox"/> | I am very satisfied | 2 |
| <input type="checkbox"/> | I am quite satisfied | 3 |
| <input type="checkbox"/> | I am neither satisfied nor dissatisfied | 4 |
| <input type="checkbox"/> | I am quite dissatisfied | 5 |
| <input type="checkbox"/> | I am very dissatisfied | 6 |
| <input type="checkbox"/> | I am extremely dissatisfied | 7 |

Section 2: 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.

2. 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

- | | | |
|--------------------------|---------------------------------|---|
| <input type="checkbox"/> | So good, it could not be better | 1 |
| <input type="checkbox"/> | Very good | 2 |
| <input type="checkbox"/> | Good | 3 |
| <input type="checkbox"/> | Alright | 4 |
| <input type="checkbox"/> | Bad | 5 |
| <input type="checkbox"/> | Very bad | 6 |
| <input type="checkbox"/> | So bad, it could not be worse | 7 |

2b. Do care and support services help you to have a better quality of life?³

Please tick (✓) one box

- | | | |
|--------------------------|-----|---|
| <input type="checkbox"/> | Yes | 1 |
| <input type="checkbox"/> | No | 2 |

³ Councils can choose whether or not to include this question in the live 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

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I have as much control over my daily life as I want | 1 |
| <input type="checkbox"/> | I have adequate control over my daily life | 2 |
| <input type="checkbox"/> | I have some control over my daily life but not enough | 3 |
| <input type="checkbox"/> | I have no control over my daily life | 4 |

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

- | | | |
|--------------------------|-----|---|
| <input type="checkbox"/> | Yes | 1 |
| <input type="checkbox"/> | No | 2 |

4a. Thinking about keeping clean and presentable in appearance, which of the following statements best describes your situation?

Please tick (✓) one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I feel clean and am able to present myself the way I like | 1 |
| <input type="checkbox"/> | I feel adequately clean and presentable | 2 |
| <input type="checkbox"/> | I feel less than adequately clean or presentable | 3 |
| <input type="checkbox"/> | I don't feel at all clean or presentable | 4 |

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

Please tick (✓) one box

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | I get all the food and drink I like when I want | 1 |
| <input type="checkbox"/> | I get adequate food and drink at OK times | 2 |
| <input type="checkbox"/> | I don't always get adequate or timely food and drink | 3 |
| <input type="checkbox"/> | I don't always get adequate or timely food and drink, and I think there is a risk to my health | 4 |

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

Please tick (✓) one box

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | My home is as clean and comfortable as I want | 1 |
| <input type="checkbox"/> | My home is adequately clean and comfortable | 2 |
| <input type="checkbox"/> | My home is not quite clean or comfortable enough | 3 |
| <input type="checkbox"/> | My home is not at all clean or comfortable | 4 |

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

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I feel as safe as I want | 1 |
| <input type="checkbox"/> | Generally I feel adequately safe, but not as safe as I would like | 2 |
| <input type="checkbox"/> | I feel less than adequately safe | 3 |
| <input type="checkbox"/> | I don't feel at all safe | 4 |

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

Please tick (✓) one box

- | | | |
|--------------------------|-----|---|
| <input type="checkbox"/> | Yes | 1 |
| <input type="checkbox"/> | No | 2 |

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

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I have as much social contact as I want with people I like | 1 |
| <input type="checkbox"/> | I have adequate social contact with people | 2 |
| <input type="checkbox"/> | I have some social contact with people, but not enough | 3 |
| <input type="checkbox"/> | I have little social contact with people and feel socially isolated | 4 |

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

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | I'm able to spend my time as I want, doing things I value or enjoy | 1 |
| <input type="checkbox"/> | I'm able to do enough of the things I value or enjoy with my time | 2 |
| <input type="checkbox"/> | I do some of the things I value or enjoy with my time but not enough | 3 |
| <input type="checkbox"/> | I don't do anything I value or enjoy with my time | 4 |

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

Please tick (✓) one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | Having help makes me think and feel better about myself | 1 |
| <input type="checkbox"/> | Having help does not affect the way I think or feel about myself | 2 |
| <input type="checkbox"/> | Having help sometimes undermines the way I think and feel about myself | 3 |
| <input type="checkbox"/> | Having help completely undermines the way I think and feel about myself | 4 |

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

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | The way I'm helped and treated makes me think and feel better about myself | 1 |
| <input type="checkbox"/> | The way I'm helped and treated does not affect the way I think or feel about myself | 2 |
| <input type="checkbox"/> | The way I'm helped and treated sometimes undermines the way I think and feel about myself | 3 |
| <input type="checkbox"/> | The way I'm helped and treated completely undermines the way I think and feel about myself | 4 |

Section 3: 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

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | Very easy to find | 1 |
| <input type="checkbox"/> | Fairly easy to find | 2 |
| <input type="checkbox"/> | Fairly difficult to find | 3 |
| <input type="checkbox"/> | Very difficult to find | 4 |
| <hr/> | | |
| <input type="checkbox"/> | I've never tried to find information or advice | 5 |

Section 4 Arrangement of Support and Services in the last 12 months

13. Were you involved as much as you wanted to be in decisions about your care and support?

Please tick (✓) one box

- Yes, definitely
- Yes, to some extent
- No

14. Overall, do you feel that your carer/family has had as much support from health and social services as they needed?

Please tick (✓) one box

- Yes, they have had as much support as they needed
- They have had some support but not as much as they needed
- No, they have had little or no support
- They did not want / need support
- There are no family members or carers to support

15. Have all your needs been assessed?

Please tick (✓) one box

- All of my needs have been assessed
- Some of my needs have been assessed
- None of my needs have been assessed
- Don't know / can't remember

16. Do health and social care services help you live the life you want as far as possible?

Please tick (✓) one box

- Yes, definitely
- Yes, to some extent
- No

17a. To what extent do you agree or disagree with the following statement... 'Health and social care staff always tell me what will happen next'

Please tick (✓) one box

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

17b. To what extent do you agree or disagree with the following statement... 'Health and social care staff always ensure I know what will happen next'

Please tick (✓) one box

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

18. Do you have a named health or social care professional who coordinates your care and support?

Please tick (✓) one box

- Yes
- No, I coordinate my own care and support
- Don't know / not sure

18b. If the answer to Q18 above is 'No' then please give more detail below:

Please tick (✓) as many boxes as apply

- No – I need and/or would like someone to coordinate my care and support
- No – I coordinate my own care and support
- No – I don't have multiple needs so my care and support does not need coordinating
- No – For other reasons

19. Do all the different people treating and caring for you work well together to give you the best possible care and support?

Please tick (✓) one box

- Yes, all of them work well together
- Most of them work well together
- Some of them work well together
- No, they do not work well together
- Don't know / not sure

Section 5: Your health

20. How is your health in general?

Please tick (✓) one box

- | | | |
|--------------------------|-----------|---|
| <input type="checkbox"/> | Very good | 1 |
| <input type="checkbox"/> | Good | 2 |
| <input type="checkbox"/> | Fair | 3 |
| <input type="checkbox"/> | Bad | 4 |
| <input type="checkbox"/> | Very bad | 5 |

21. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

a. Pain or discomfort

Please tick (✓) one box

- | | | |
|--------------------------|------------------------------------|---|
| <input type="checkbox"/> | I have no pain or discomfort | 1 |
| <input type="checkbox"/> | I have moderate pain or discomfort | 2 |
| <input type="checkbox"/> | I have extreme pain or discomfort | 3 |

b. Anxiety or depression

Please tick (✓) one box

- | | | |
|--------------------------|--------------------------------------|---|
| <input type="checkbox"/> | I am not anxious or depressed | 1 |
| <input type="checkbox"/> | I am moderately anxious or depressed | 2 |
| <input type="checkbox"/> | I am extremely anxious or depressed | 3 |

22. Please place a tick (✓) in the box that best describes your abilities for each of the following questions.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to get around indoors (except steps) by yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃
b. Do you usually manage to get in and out of a bed (or chair) by yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃
c. Do you usually manage to feed yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃
d. Do you usually deal with finances and paperwork - for example, paying bills, writing letters – by yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃

23. Please place a tick (✓) in the box that best describes your abilities for each of the following questions.

	I can do this easily by myself	I have difficulty doing this myself	I can't do this by myself
a. Do you usually manage to wash all over by yourself, using either a bath or shower?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃
b. Do you usually manage to get dressed and undressed by yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃
c. Do you usually manage to use the WC/toilet by yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃
d. Do you usually manage to wash your face and hands by yourself?	<input checked="" type="checkbox"/> ₁	<input checked="" type="checkbox"/> ₂	<input checked="" type="checkbox"/> ₃

Section 6: About your surroundings

24. How well do you think your home is designed to meet your needs?

Please tick (✓) one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | My home meets my needs very well | 1 |
| <input type="checkbox"/> | My home meets most of my needs | 2 |
| <input type="checkbox"/> | My home meets some of my needs | 3 |
| <input type="checkbox"/> | My home is totally inappropriate for my needs | 4 |

25. 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

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | I can get to all the places in my local area that I want | 1 |
| <input type="checkbox"/> | At times I find it difficult to get to all the places in my local area that I want | 2 |
| <input type="checkbox"/> | I am unable to get to all the places in my local area that I want | 3 |
| <input type="checkbox"/> | I do not leave my home | 4 |

Section 7: 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.

26. 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

- | | | |
|--------------------------|---|-------|
| <input type="checkbox"/> | Yes, from someone living in my household | a (1) |
| <input type="checkbox"/> | Yes, from someone living in another household | b (1) |
| <input type="checkbox"/> | No | c (1) |

27. Do you buy any additional care or support privately or pay more to 'top up' your care and support?

Please tick (✓) as many boxes as apply

- | | | |
|--------------------------|---|-------|
| <input type="checkbox"/> | Yes, I buy some more care and support with my own money | a (1) |
| <input type="checkbox"/> | Yes, my family pays for some more care and support for me | b (1) |
| <input type="checkbox"/> | No | c (1) |

28. Did you have any help from someone else to complete this questionnaire?

Please tick (✓) one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | No, I did not have help | 1 |
| <input type="checkbox"/> | I had help from a care worker | 2 |
| <input type="checkbox"/> | I had help from someone living in my household | 3 |
| <input type="checkbox"/> | I had help from someone living outside my household | 4 |

29. What type of help did you have?

Please tick (✓) as many boxes as apply

- | | | |
|--------------------------|--|------|
| <input type="checkbox"/> | I didn't have any help | a(1) |
| ----- | | |
| <input type="checkbox"/> | Someone else read the questions to me | b(1) |
| <input type="checkbox"/> | Someone else translated the questions for me | c(1) |
| <input type="checkbox"/> | Someone else wrote down the answers for me | d(1) |
| <input type="checkbox"/> | I talked through the questions with someone else | e(1) |
| <input type="checkbox"/> | Someone answered for me, without asking me the questions | f(1) |

30. We may be asking some people to take part in follow-up research for this study in the next year or so.

Would you be happy to be invited to take part in more research?

Note that even if you say “yes” there will be no obligation to take part in the future.

Please tick (✓) one box

Yes, I have written my name, address and phone number in the space below

No

Guidance for People Helping Somebody to Complete the Questionnaire

Thank you for helping your family member or friend to fill out this form. It is important for us to get their views. Please try not to influence their responses. Please read below how best you can help them.

First, would the person prefer to have a **Large Print** version of the form or an Easy Read version or perhaps one that's written in their preferred language? If any of those would be better, contact the person named on the covering letter using the phone number provided.

If you are helping the person by reading out the questions aloud...

- 1) Please read them out exactly as they are written. If they don't understand the question read the words out aloud again. If they still don't understand it may be that they would be better off with the easy-read version. If so, contact the person named on the covering letter using the phone number provided.
- 2) Please ask the person to listen to all of the response choices before deciding which one is their answer.
- 3) Some questions require more than one option to be chosen. For these, please pause after reading each option and prompt the person for a response.
- 4) You should read the text illustrated **in grey** out aloud. It signals that the questions refer to a different area.
- 5) Similarly you should read the text *in italics* out aloud because it explains what things mean.

If you are helping the person by translating the questions...

- 1) Please contact the person named in the covering letter. It may be possible for a translated version to be sent to your family member or friend. They could then complete it without any help.

- 2) If you are helping by translating out aloud, then please read out the questions exactly as they are written.
- 3) You should also translate the text in grey which describes that the following set of questions cover a different area.
- 4) You should also translate the *italicised* definitions which appear in some questions.

Thank you for helping to complete our survey

Appendix 2: Personal Social Services Survey of Adult Carers questions tested

The questions tested are questions 16-22 within Section 5 (Arrangement of support and services in the last 12 months)

Caring for Others

ID number	
Local authority name	
Minutes taken to complete questionnaire	

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.

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. How old is this person? _____ years

(If you don't know the exact age please give an approximate one)

2. Does the person you care for have....?

Please tick [✓] all that apply

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

3. Where does the person you care for usually live?

Please tick [✓] one box

- | | | |
|--------------------------|----------------|---|
| <input type="checkbox"/> | With me | 1 |
| <input type="checkbox"/> | Somewhere else | 2 |

4. 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

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | We haven't received any support or services from Social Services in the last 12 months | 1 |
| ----- | | |
| <input type="checkbox"/> | I am extremely satisfied | 2 |
| <input type="checkbox"/> | I am very satisfied | 3 |
| <input type="checkbox"/> | I am quite satisfied | 4 |
| <input type="checkbox"/> | I am neither satisfied nor dissatisfied | 5 |
| <input type="checkbox"/> | I am quite dissatisfied | 6 |
| <input type="checkbox"/> | I am very dissatisfied | 7 |
| <input type="checkbox"/> | I am extremely dissatisfied | 8 |

5. 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

	Yes	No	Don't know
a. Support or services allowing you to take a break from caring at short notice or in an emergency.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b. Support or services allowing you to take a break from caring for more than 24 hours	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c. Support or services to allow you to have a rest from caring for between 1 and 24 hours (eg. a sitting service)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
d. Personal assistant	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
e. Home care/home help	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
f. Day centre or day activities	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
g. Lunch club	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
h. Meals Services	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
i. Equipment or adaptation to their home (such as a wheelchair or handrails)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
j. Lifeline Alarm	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
k. They are permanently resident in a care home	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Section 2: About your needs and experiences of support

The questions in this section ask about the support and services that **you** use as a carer. They may be arranged by you or by Social Services. They may be provided by a voluntary organisation, a private agency or Social Services.

6. Have you used any of the support or services listed below, to help you as a carer over the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. Please do not include any unpaid help from family and friends.

Please tick (✓) one box per row

	Yes	No	Don't know
a. Information and advice	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
b. Support from carers groups or someone to talk to in confidence	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
c. Training for carers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
d. Support to keep you in employment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Section 3: 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.

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

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

Please tick [✓] one box

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | I'm able to spend my time as I want, doing things I value or enjoy | 1 |
| <input type="checkbox"/> | I do some of the things I value or enjoy with my time but not enough | 2 |
| <input type="checkbox"/> | I don't do anything I value or enjoy with my time | 3 |

8. Which of the following statements best describes how much control you have over your daily life?

Please tick [✓] one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I have as much control over my daily life as I want | 1 |
| <input type="checkbox"/> | I have some control over my daily life but not enough | 2 |
| <input type="checkbox"/> | I have no control over my daily life | 3 |

9. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?

Please tick [✓] one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I look after myself | 1 |
| <input type="checkbox"/> | Sometimes I can't look after myself well enough | 2 |
| <input type="checkbox"/> | I feel I am neglecting myself | 3 |

10. Thinking about your personal safety, which of the statements best describes your present situation?

By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.

Please tick [✓] one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I have no worries about my personal safety | 1 |
| <input type="checkbox"/> | I have some worries about my personal safety | 2 |
| <input type="checkbox"/> | I am extremely worried about my personal safety | 3 |

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

Please tick [✓] one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I have as much social contact as I want with people I like | 1 |
| <input type="checkbox"/> | I have some social contact with people but not enough | 2 |
| <input type="checkbox"/> | I have little social contact with people and feel socially isolated | 3 |

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

Please tick [✓] one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I feel I have encouragement and support | 1 |
| <input type="checkbox"/> | I feel I have some encouragement and support but not enough | 2 |
| <input type="checkbox"/> | I feel I have no encouragement and support | 3 |

Section 4: Information and advice quality

The next questions ask for your views about the quality of information and advice.

- 13. 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

<input type="checkbox"/>	I have not tried to find information or advice in the last 12 months	1
<hr/>		
<input type="checkbox"/>	Very easy to find	2
<input type="checkbox"/>	Fairly easy to find	3
<input type="checkbox"/>	Fairly difficult to find	4
<input type="checkbox"/>	Very difficult to find	5

- 14. In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.**

Please tick (✓) one box

<input type="checkbox"/>	I have not received any information or advice in the last 12 months	1

<input type="checkbox"/>	Very helpful	2
<input type="checkbox"/>	Quite helpful	3
<input type="checkbox"/>	Quite unhelpful	4
<input type="checkbox"/>	Very unhelpful	5

Section 5: 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.

15. 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

- | | | |
|--------------------------|--|---|
| <input type="checkbox"/> | There have been no discussions that I am aware of, in the last 12 months | 1 |
| ----- | | |
| <input type="checkbox"/> | I always felt involved or consulted | 2 |
| <input type="checkbox"/> | I usually felt involved or consulted | 3 |
| <input type="checkbox"/> | I sometimes felt involved or consulted | 4 |
| <input type="checkbox"/> | I never felt involved or consulted | 5 |

16a. To what extent do you agree or disagree with the following statement... 'Health and social care staff always tell me what will happen next'

Please tick (✓) one box

- | | |
|--------------------------|----------------------------|
| <input type="checkbox"/> | Strongly agree |
| <input type="checkbox"/> | Agree |
| <input type="checkbox"/> | Neither agree nor disagree |
| <input type="checkbox"/> | Disagree |
| <input type="checkbox"/> | Strongly disagree |

16b. To what extent do you agree or disagree with the following statement... 'Health and social care staff always ensure I know what will happen next'

Please tick (✓) one box

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

17. To what extent do you agree or disagree with the following statement... 'In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations'

Please tick (✓) one box

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

18. Were you involved as much as you wanted to be in decisions about the care and support of the person you care for?

Please tick (✓) one box

- Yes, definitely
- Yes, to some extent
- No
- I didn't want to be involved in decisions about care

19. Thinking about the person you care for, when health or social care staff plan care or treatment for them does it happen?

Please tick (✓) one box

- Yes, it happens all of the time
- It happens most of the time
- It happens some of the time
- No

20. Thinking about the person you care for, to what extent do you agree or disagree with the following statement... 'Their care and support is reviewed as often as it should be'

Please tick (✓) one box

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

21. Do you know who to contact if you need to ask questions about the condition or treatment of the person you care for?

Please tick (✓) one box

- Yes, definitely
- Yes, to some extent
- No
- Don't know / can't remember

22. Thinking about the person you care for, do all the different people treating and caring for them work well together to give the best possible care and support?

Please tick (✓) one box

- Yes, all of them work well together
- Most of them work well together
- Some of them work well together
- No, they do not work well together
- Don't know / not sure

Section 6: About yourself

The next group of questions helps us to get a better picture of the types of carers who took part in this survey.

23. In addition to your caring role, please tell us which of the following also applies to you?

Please tick [✓] all that apply

- | | | |
|--------------------------|---|-------|
| <input type="checkbox"/> | Retired | a (1) |
| <input type="checkbox"/> | Employed full-time | b (1) |
| <input type="checkbox"/> | Employed part-time (working 30 hours or less) | c (1) |
| <input type="checkbox"/> | Self-employed full-time | d (1) |
| <input type="checkbox"/> | Self-employed part-time | e (1) |
| <input type="checkbox"/> | Not in paid work | f (1) |
| <input type="checkbox"/> | Doing voluntary work | g (1) |
| <input type="checkbox"/> | Other | h (1) |

24. Thinking about combining paid work and caring, which of the following statements best describes your current situation?

Please tick [✓] one box

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | I am in paid employment and I feel supported by my employer | 1 |
| <input type="checkbox"/> | I am in paid employment but I don't feel supported by my employer | 2 |
| <input type="checkbox"/> | I do not need any support from my employer to combine work and caring | 3 |
| <input type="checkbox"/> | I am not in paid employment because of my caring responsibilities | 4 |
| <input type="checkbox"/> | I am not in paid employment for other reasons | 5 |
| <input type="checkbox"/> | I am self-employed or retired | 6 |

25. About how long have you been looking after or helping the person you care for?

Please tick [✓] one box

- | | | |
|--------------------------|--------------------------------------|---|
| <input type="checkbox"/> | Less than 6 months | 1 |
| <input type="checkbox"/> | Over 6 months but less than a year | 2 |
| <input type="checkbox"/> | Over 1 year but less than 3 years | 3 |
| <input type="checkbox"/> | Over 3 years but less than 5 years | 4 |
| <input type="checkbox"/> | Over 5 years but less than 10 years | 5 |
| <input type="checkbox"/> | Over 10 years but less than 15 years | 6 |
| <input type="checkbox"/> | Over 15 years but less than 20 years | 7 |
| <input type="checkbox"/> | 20 years or more | 8 |

26. About how long do you spend each week looking after or helping the person you care for?

Please tick [✓] one box

- | | | |
|--------------------------|------------------------------------|----|
| <input type="checkbox"/> | 0-9 hours per week | 1 |
| <input type="checkbox"/> | 10-19 hours per week | 2 |
| <input type="checkbox"/> | 20-34 hours per week | 3 |
| <input type="checkbox"/> | 35-49 hours per week | 4 |
| <input type="checkbox"/> | 50-74 hours per week | 5 |
| <input type="checkbox"/> | 75-99 hours per week | 6 |
| <input type="checkbox"/> | 100 or more hours per week | 7 |
| <input type="checkbox"/> | Varies – Under 20 hours per week | 8 |
| <input type="checkbox"/> | Varies – 20 hours or more per week | 9 |
| <input type="checkbox"/> | Other | 10 |

If other please specify:

27. Over the last 12 months, what kinds of things did you usually do for the person you care for?

Please tick [✓] all that apply

- | | | |
|--------------------------|--|-------|
| <input type="checkbox"/> | Personal care?
(Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet) | a (1) |
| <input type="checkbox"/> | Physical help?
(Such as helping with walking, getting up and down stairs, getting into and out of bed) | b (1) |
| <input type="checkbox"/> | Helping with dealing with care services and benefits?
(Things like making appointments and phone calls, filling in forms) | c (1) |
| <input type="checkbox"/> | Helping with paperwork or financial matters?
(Such as writing letters, sending cards, filling in forms, dealing with bills, banking) | d (1) |
| <input type="checkbox"/> | Other practical help?
(Things like preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital) | e (1) |
| <input type="checkbox"/> | Keeping him/her company?
(Things like visiting, sitting with, reading to, talking to, playing cards or games) | f (1) |
| <input type="checkbox"/> | Taking him/her out?
(Such as taking out for a walk or drive, taking to see friends or relatives) | g (1) |
| <input type="checkbox"/> | Giving medicines?
(Things like making sure he/she takes pills, giving injections, changing dressings) | h (1) |
| <input type="checkbox"/> | Keeping an eye on him/her to see he/she is all right? | i (1) |
| <input type="checkbox"/> | Giving emotional support? | j (1) |
| <input type="checkbox"/> | Other help? | k (1) |

28. Do you have any of the following?

Please tick [✓] all that apply

- | | | |
|--------------------------|-------------------------------------|-------|
| <input type="checkbox"/> | A physical impairment or disability | a (1) |
| <input type="checkbox"/> | Sight or hearing loss | b (1) |
| <input type="checkbox"/> | A mental health problem or illness | c (1) |
| <input type="checkbox"/> | A learning disability or difficulty | d (1) |
| <input type="checkbox"/> | A long-standing illness | e (1) |
| <input type="checkbox"/> | Other | f (1) |
| <input type="checkbox"/> | None of the above | g (1) |

32. Did someone help you to complete this questionnaire?

Please tick [✓] one box

- | | | |
|--------------------------|-----|---|
| <input type="checkbox"/> | Yes | 1 |
| <input type="checkbox"/> | No | 2 |

34. We may be asking some people to take part in follow-up research for this study in the next year or so.

Would you be happy to be invited to take part in more research?

Note that even if you say “yes” there will be no obligation to take part in the future.

Please tick (✓) one box

Yes, I have written my name, address and phone number in the space below

No

Appendix 3: Demographics of respondents

Participant Type and Gender Breakdown

ID	Participant Type	Gender
IM002	Carer	F
IM010	Carer	F
IM001	Carer	F
IM017	Carer	F
IM018	Carer	F
IM008	Carer	F
IM027	Carer	F
IM020	Carer	F
IM021	Carer	M
IM019	Carer	F
IM004	Service User	M
IM003	Service User	F
IM011	Service User	M
IM005	Service User	F
IM006	Service User	M
IM016	Service User	F
IM014	Service User	M
IM015	Service User	M
IM013	Service User	M
IM012	Service User	M

Participant Type and Age Group Breakdown

The table below shows the age group for each participant type for the 27 candidate participants nominated by local authorities. Twenty of these 27 participated in cognitive testing. The breakdown for only the 20 test participants is not available.

Participant Type	Age Group		
	Under 65	65 and over	Total
Service User	6	5	11
Carer	9	7	16
Total	15	12	27

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