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## **Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT)**

Agnes Turnpenny, James Caiels, Tanya  
Crowther, Lisa Richardson, Beckie Whelton,  
Julie Beadle-Brown, Julien Forder, Joanna  
Apps, Stacey Rand

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The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health.

Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

## **CONTACT**

QORU  
Personal Social Services Research Unit  
University of Kent  
Canterbury  
CT2 7NF

Email: [c.i.heath@kent.ac.uk](mailto:c.i.heath@kent.ac.uk)

[www.qoru.ac.uk](http://www.qoru.ac.uk)

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## EXECUTIVE SUMMARY

### INTRODUCTION

A recent review of the engagement of seldom-heard groups in health and social care research found that most research underpinning the evidence-base of policy and practice in health and social care in the UK tends to favour easily accessible groups. Those often excluded from social care research include a large group of people who, although having capacity to consent to taking part in research, are not able to respond to standard questionnaires and surveys. This group also consists of a large number of users of health and social care services. The inclusion of their experiences in research requires, among other things, robust but adapted data collection techniques (such as Easy Read questionnaires).

### THE ADULT SOCIAL CARE OUTCOMES TOOLKIT (ASCOT)

The Adult Social Care Outcomes Toolkit (ASCOT) is a measure of social care-related quality of life (SCRQoL) and is used as part of the Personal Social Services Adult Social Care Survey (ASCS) in England: an annual postal survey of all social care service users aged 18 and over receiving services funded (wholly or partly) by Social Services. The survey informs the Adult Social Care Outcomes Framework (ASCOF). ASCOT is also used by a number of Local Authorities in their internal evaluations and research, as well as assessments and reviews.

ASCOT measures social care-related quality of life across eight areas or 'domains' identified as central to SCRQoL by service users: accommodation; control over daily life; dignity; food and nutrition; occupation; personal cleanliness and comfort; safety; and social participation and involvement.

### AIMS AND METHODS

This study aims to develop and test<sup>1</sup> a robust Easy Read version of ASCOT, building on the previous work of a preliminary (un-tested) version that was developed in 2012. In particular, this research aims to ensure that an ER version is consistent with the standard version of ASCOT and that the ER version is adapted to the needs of respondents with learning disabilities: the wording and pictures provide all the necessary information in an easy-to-understand format, such that respondents are able to answer the questions.

We employed a combination of conventional survey (pre-)testing methods with approaches to create accessible information for people with learning disabilities.

The project received a favourable ethical opinion from the Social Care Research Ethics Committee (SCREC) in April 2013. Following this, research governance approval was obtained from three Local Authorities in the South East of England where participants were recruited.

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<sup>1</sup> We use the term *pre-testing* in this Report to signify that we are not reporting full validity and robustness testing, which will be covered in subsequent work (see Collins 2003).

A working group consisting of people with learning disabilities and/or autism was set up to assist the research team. The purpose of the working group was to guide development and revision of the questionnaire at every main stage and to provide feedback on draft versions. Initially the working group allowed us to evaluate the preliminary version of ASCOT-ER and identify issues related to the depiction, wording and structure of the domains. The research team worked with CHANGE, an organisation led by people with disabilities, to develop images for the revised questionnaire.

Eight focus groups with 32 participants with a learning disability and/or autism were conducted between November 2013 and January 2014. The aim of the focus groups was to gain feedback on the first revision of ASCOT-ER, which led to further revisions of the questionnaire. This second revision of the questionnaire was then tested with 22 people with learning disabilities and/or autism using cognitive interviews. These took place between March and May 2014.

The process of developing and re-designing the ASCOT-ER was guided by the analysis of three main questions:

- 1) Do the pictures help respondents to answer the questions, specifically:
  - a. How well do the pictures reflect the content of the questions?
  - b. Do the smiley faces help respondents to choose an answer? Is the difference between them clear?
- 2) Are the questions and response options easy to understand and are they interpreted consistently and in accordance with the domain descriptions by respondents?
- 3) Are respondents able to answer the questions? Are their answers based on their experiences? Is there any evidence of systematic bias in responding?

## FINDINGS

The starting point for developing the ASCOT-ER was a draft instrument based on the version initially developed in 2012. Subsequent analysis and development was an iterative process, with the revised instrument (phrasing of questions and pictures) being re-tested with participants following each tranche of fieldwork. In almost all domains illustrations were amended to improve the understanding and meaning of questions following the fieldwork. Findings from fieldwork also resulted in all questions – to a greater or lesser extent – being re-worded and in some cases structurally re-organised where the original structure led to confusion among participants.

The smiley/sad faces attached to each response option were re-designed and re-tested, while other accompanying aids (ticks/crosses and thumbs up/down) were discarded as participants reported these as confusing. In contrast, participants reported that smiley/sad faces were more 'standard' and more commonly used.

The quantitative analysis of the revised instrument's validity was limited by the small sample size; therefore any findings presented must be interpreted with caution. Nonetheless, domain scores were broadly similar in ASCS (2010/11 and 2011/12) and cognitive interviews, with some notable exceptions: control, safety and personal care.

The revised ASCOT-ER questionnaire appeared to work for the majority of cognitive interview respondents, but – as expected – not for everyone. It is clear that there is a sizeable group of people with learning disabilities who are not able to self-report subjective quality of life using a structured questionnaire. Some people found it difficult to use a four-point scale. Some of these people might have been able to respond using a three-point scale; for others, semi-structured interviews would have worked better. Other methods for collecting ASCOT data, particularly for individuals with higher levels of cognitive impairment (including the use of a semi-structured interview and an observational approach), are being developed as part of the wider QORU programme.

## CONCLUSION

The aim of this project was to develop and (cognitively) test an Easy Read version of ASCOT. This work started with the preliminary version of ASCOT-ER. Our findings suggest that the ASCOT-ER has made it easier for people with learning disabilities to interpret and answer the questions. In this way, the research contributes to the aim of improving the engagement of groups of people that are under-represented in the evidence and in the Adult Social Care Survey.

Findings also indicate that the revised Easy Read version adequately represents the ASCOT domains and the standard questionnaire. However, ASCOT-ER might benefit from further systematic testing, particularly around validity and reliability. Future work could include exploring the construct validity of ASCOT-ER by looking at the relationship between responses to the individual items and other indicators that we would expect to be theoretically related to these concepts (e.g. other quality of life and wellbeing measures). This could be done through systematic use of the tool, linking with the development of ASCS to ensure the results drew on and informed the survey as well as the ASCOF.

## 1 INTRODUCTION

A recent review of the engagement of seldom-heard groups in health and social care research found that most research underpinning the evidence-base of policy and practice in health and social care in the UK tends to favour easily accessible groups (Beadle-Brown et al., 2012). Those that are (at the very least) able to understand standardised interviews and communicate their thoughts are therefore more likely to have their views heard compared to others with communicative impairments. In order to be able to identify the outcomes of health and social care, and for whom different forms of health and social care based practice are most suitable, there must be a shift from the institutional exclusion of seldom-heard groups to their early inclusion in any research process.

There is a recognised need for more sophisticated and flexible responses to improve access and quality of services for people who are socially excluded. An integral part of this improvement is the inclusion of their views in both consultation and research about health and social care (Cabinet Office, 2010). Those often excluded from social care research include a large group of people who, although having capacity to consent to take part in research, are not able to respond to standard questionnaires and surveys. This group also consists of a large number of users of health and social care services. The inclusion of their experiences in research requires, among other things, robust but adapted data collection techniques (such as easy read questionnaires).

A variety of standardised tools is currently being used to collect data on health and social care outcomes in the UK; included in these are: Patient Reported Outcome Measures (PROMS) of specific conditions or procedures, the EQ-5D global measure of health related quality of life; and the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al., 2012; Makai et al., 2014).

The ASCOT measures social care-related quality of life and is used as part of the Personal Social Services Adult Social Care Survey (ASCS) in England: an annual postal survey of all social care service users aged 18 and over receiving services funded (wholly or partly) by Social Services (Forder et al., 2014). The survey is provided with written guidance, but respondents in need of additional support often rely on either paid or unpaid support if needed. The aim of the survey is to learn about the impact of social services on people's quality of life, and explore their views and experiences. It also informs the Adult Social Care Outcomes Framework (ASCOF). In addition, ASCOT is used by a number of Local Authorities in their internal evaluations and research, as well as assessments and reviews. ASCOT measures social care-related quality of life across eight areas or 'domains' identified as central to SCRQoL by service users:

- Accommodation, cleanliness and comfort – The person using the service feels their home environment, including all the rooms, is clean and comfortable.
- Control over daily life – The person using the service can choose what to do and when to do it, having control over their daily life and activities.
- Dignity – The negative and positive psychological impact of support and care on the personal sense of significance of the person using the service.
- Food and nutrition – The person using the service feels they have a nutritious, varied and culturally appropriate diet with enough food and drink they enjoy at regular and timely intervals.
- Occupation – The person using the service is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities.

- Personal cleanliness and comfort – The person using the service feels they are personally clean and comfortable and look presentable or, at best, are dressed and groomed in a way that reflects their personal preferences.
- Safety – The person using the service feels safe and secure. This means being free from fear of abuse, falling or other physical harm and fear of being attacked or robbed.
- Social participation and involvement – The person using the service is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends, family and feeling involved or part of a community should this be important to them.

In 2012 an Easy Read version of ASCOT (ASCOT-ER) was developed for use by people with learning disabilities completing the ASCS. However, due to the tight time pressures, this development was undertaken without pre-testing. Feedback from ASCS respondents and other user groups of ASCOT suggested that ASCOT-ER required revision.

## 1.2 AIMS

This study aims to develop and test<sup>2</sup> a robust Easy Read version of ASCOT, building on the previous work of a preliminary (un-tested) version that was developed in 2012. In particular, this research aims to ensure that an ER version is consistent with the standard version of ASCOT, and that the ER version is adapted to the needs of respondents with learning disabilities: the wording and pictures provide all the necessary information in an easy-to-understand format, such that respondents are able to answer the questions.

We employed a combination of conventional survey pre-testing methods with approaches to create accessible information for people with learning disabilities. The intention is that this will also reduce the degree to which people need external help to be able to respond to the questionnaire – 92% of respondents with learning disabilities reported that they received help in the Adult Social Care Survey in 2011 – and thus lessen potential bias (see Apps & Malley, forthcoming).

This report includes Annexes but is also accompanied by a separate Appendix document<sup>3</sup>.

## 2 BACKGROUND

This section gives a very brief overview of the use of surveys with people with learning disabilities, with particular attention to potential issues and biases and ways to deal with them. It also

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<sup>2</sup> We use the term *pre-testing* in this Report to signify that we are not reporting full validity and robustness testing, which will be covered in subsequent work (see Collins 2003).

<sup>3</sup> Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT) – Appendix.

introduces the concept of Easy Read information and the approach taken by the research team to the adaptation of the text.

## 2.1 SURVEYS AND PEOPLE WITH LEARNING DISABILITIES

The appropriateness of using self-report questionnaires with people with learning disabilities depends on a number of factors. Responding to a survey question has been described in terms of a four-stage cognitive processing model (Tourangeau, 1984 cited in Krosnick, 1991):

- 1) Interpreting the meaning of the question;
- 2) Searching memory and retrieving relevant information;
- 3) Integrating information into a summary judgement;
- 4) Reporting summary judgement, selecting between response alternatives.

This cognitive process can be quite challenging and is often compromised, resulting in bias or problematic responding, an effect also known as satisficing (Krosnick & Presser, 2010; p. 265). Difficulties with the use of self-report surveys by people with learning disabilities can arise at any of these stages and are relatively well documented in the literature (e.g. Finlay & Lyons, 2001; Finlay & Lyons, 2002; Heal & Sigelman 1995; 1996).

The use of complex sentence structures – such as passive voice and negatively worded structures, ambiguous wording in question phrasing, difficult/long/unfamiliar words – is likely to be challenging for respondents with learning disabilities. Difficulties can also arise with:

- questions that require a judgement or recall of time, frequency, degrees or quantities, direct comparisons;
- socially reflexive questions;
- abstract concepts and generalised judgements, including questions about general feelings;
- potentially difficult or unfamiliar content that asks respondents to consider themselves or their experiences in an unfamiliar way (Finlay & Lyons, 2001).

Fitting responses into pre-defined answer options can be a challenging task for some people with learning disabilities as it requires abstract thinking. As a result of poor literacy skills, postal questionnaires often have to be presented orally, or respondents must rely on help from carers or supporters to read and interpret the questions. Some question formats are less suitable for oral presentation, and reliance on external help can result in social desirability bias in reporting potentially sensitive content (Krosnick & Presser, 2010).

Satisficing has been described as a continuum, with weak satisficing referring to the less than optimal performance on cognitive tasks and strong satisficing involving the omission of complete stages altogether (Krosnick & Presser, 2010). Selecting the first or last answer that seems to constitute a reasonable response – or primacy and recency effects – are a common form of weak satisficing. Acquiescence response bias (“yeah-saying”) can be both an example of weak and strong satisficing and is considered a widespread bias in interviews with people with learning disabilities (Finlay & Lyons, 2002; Heal & Sigelman, 1995; Krosnick, 1991), although contested by some (Rapley

& Antaki, 1996). Forms of strong satisficing include non-differentiation in rating tasks, selecting 'I don't know' or neutral responses, and selecting an answer more or less randomly (Krosnick, 1991).

Satisficing has been associated with task difficulty, respondent ability and motivation (Krosnick, 1991). Various strategies have been recommended to improve the validity of responding by people with learning disabilities. Task difficulty can be reduced by the use of visual (pictorial) representations, clear and simple question phrasing and formats, and the use of clarifying questions (Finlay & Lyons, 2002; Hartley & MacLean, 2006). Interviewers or other sources of additional support can greatly reduce task difficulty by offering additional explanations; however, they might introduce bias and raise issues around social desirability, compliance and validity (Antaki, Young & Finlay, 2002).

The screening of respondents with learning disabilities has also been recommended as a way of improving the validity and reliability of data by excluding those who do not have the ability to respond appropriately (Finlay & Lyons, 2001; 2002; Hartley & MacLean, 2006), although this is not always practicable in larger-scale surveys.

Finally, people with learning disabilities are not a homogenous group and have very different needs and abilities. Therefore, features that might work for some people can be potentially problematic for others. In the words of Finlay and Lyons (2001), people with learning disabilities "may be too heterogeneous in terms of personal history and linguistic and cognitive abilities for any single questionnaire to be valid for the whole population" (p.329).

## 2.2 WHAT IS EASY READ?

Easy Read is a type of accessible information characterised by plain language, simple layout and format, and the use of images to illustrate key messages in the text. Sometimes Easy Read is referred to as "Easy Words and Pictures" or "easy information" or "easy-to-read". Easy Read is one way of making information more accessible for people with learning disabilities; however, it is not the only way, and many people would still require support to read and understand Easy Read information. Other ways of making information more accessible include the use of video and audio materials and face-to-face communication (Oldreive & Waight, 2013; Walmsley, 2010).

There are no common or minimum standards for producing Easy Read information. Easy Read publications can be found in a variety of formats and styles: the most common are black and white drawings (such as the images produced by CHANGE<sup>4</sup>) and photos (such as Photo Symbols). At the start of the project, the research team produced a brief overview of the main UK and international guidance on Easy Read information to help the development of the revised questionnaire (Turnpenny & Richardson, 2013). There is no evidence for the effectiveness of different Easy Read formats in facilitating understanding of written information and different groups/organisations express a preference for different types. Most of the research on the use of symbols is with children

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<sup>4</sup> <http://www.changepeople.org/about-change/what-we-do/>

in the context of augmentative and alternative communication (see e.g. Schlosser & Sigafos, 2002). We might expect that high iconicity black & white line drawings and photos would work similarly well in Easy Read documents – photo symbols working better when they depict something very specific (e.g. who they will meet, what they will see, etc.) but in some contexts they might cause difficulties for people with autism because they can be taken very literally. Given the main use of ASCOT-ER in user surveys, there were also concerns about the reproduction of photo images in high-enough quality. Therefore, based on a combination of these theoretical and practical considerations, the decision was made to use black and white drawings in the revised ASCOT-ER. The research team worked with CHANGE, an organisation led by people with disabilities, to develop images for the revised questionnaire.

### 3 METHODS

The overall methodology of the study was based on general survey questionnaire development and pre-testing methods (e.g. Collins, 2003; Presser, Rothgeb et al., 2004). There is little information in the literature on the best ways to develop or adapt surveys and questionnaires for self-report by people with learning disabilities; therefore this project has adapted a combination of conventional survey pre-testing methods with approaches to create accessible information for people with learning disabilities.

Rather than embark on a wholly new conceptual development phase, the study used the previous ER version as the starting point. The project then used various qualitative methods to redesign and cognitively test the revised ASCOT-ER. In particular, working group and focus group meetings were held to explore issues (such as misunderstandings, inconsistent interpretations, adequacy of images etc.) with the previous ER questionnaire, identify appropriate question formats, and refine pictures and wording using a structured approach. The use of focus groups allowed us to concentrate on individual ASCOT domains and gather a range of feedback from a wider cross-section of the population with learning disabilities or autism in a relatively short period of time. This informed further revision of the questionnaire, which was cognitively tested in in-depth interviews. Thematic analysis (Braun & Clarke, 2006) was used to explore respondents' understanding and interpretation of the questionnaire.

The project received a favourable ethical opinion from the Social Care Research Ethics Committee (SCREC) in April 2013. Following this, research governance approval was obtained from three Local Authorities in the South East of England where participants were recruited.

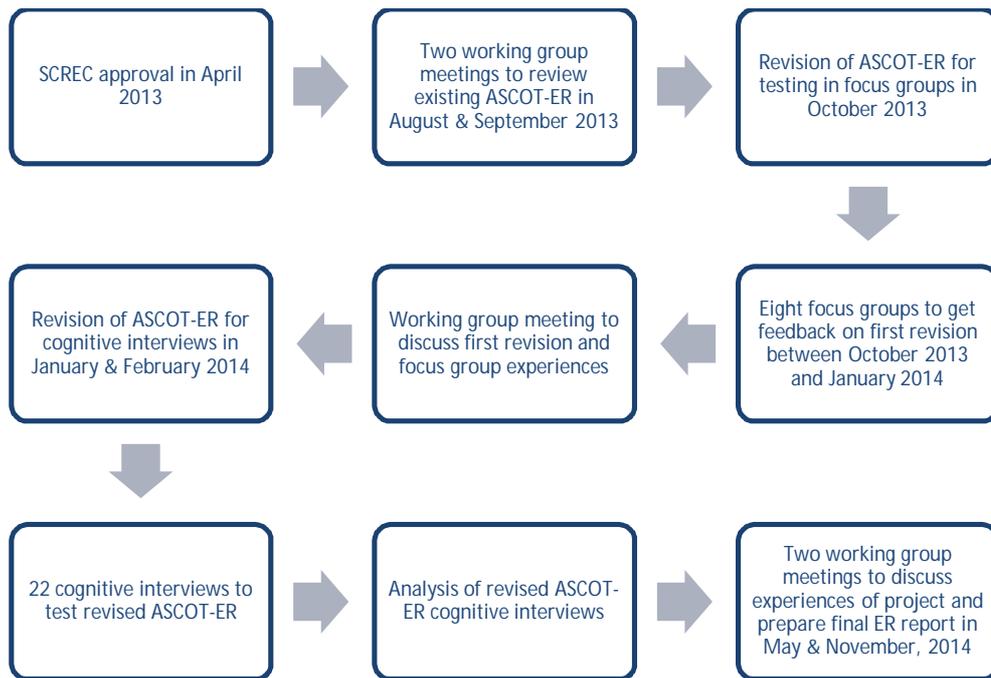
The core research team consisted of five researchers from the Personal Social Services Research Unit and the Tizard Centre, University of Kent. The study methodology involved a number of components in order to redesign, evaluate and pre-test the ASCOT-ER questionnaire:

- a working group,
- focus groups, and
- cognitive interviews.

People with learning disabilities or autism were involved in each project phase as participants. All participants received a £20 gift voucher as recognition for their time and input to the project. They were also reimbursed any travel expenses (including travel expenses of support staff) that were associated with the project.

The stages and timeline of the project are shown in Figure 1. As this was a first stage project, aiming to re-design and pre-test a questionnaire, it worked with English as the only language.

**Figure 1 Main project phases**



### 3.1 WORKING GROUP

A working group consisting of people with learning disabilities or autism was set up to assist the research team. The purpose of the working group was to guide development and revision of the questionnaire at every main stage and to provide feedback on draft versions. Working group participants were kept up to date with developments via a newsletter. Two meetings were held to discuss the previous Easy Read version and gain feedback on any potential issues that needed clarifying or simplifying in the questionnaire. Two meetings asked for feedback on subsequent revisions.

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### 3.1.1 RECRUITMENT AND PARTICIPANT CHARACTERISTICS

To recruit working group participants, Easy Read information material was sent to people with disabilities working at a local social enterprise, which had a good working relationship with the Tizard Centre through previous projects. After being informed about the project, those who expressed an interest in getting involved were invited for an informal meeting with the research team. The aim of this meeting was to introduce the research team as well as the project and the role of the working group. Information was presented using simple language and in an Easy Read format, and participants had the opportunity to ask questions about the project.

Five people with learning disabilities or autism decided to be part of the working group. All five were male, four of them worked for a local social enterprise – therefore knew each other – and were supported by a member of the organisation to attend the meetings. The fifth participant had been involved in previous research projects with the Tizard Centre. Working group participants had different levels of needs and abilities: some lived independently with minimal help, and others had higher needs and required more intensive support. All had capacity to consent and were able to communicate verbally in English. Two people had literacy difficulties and were unable to read.

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### 3.1.2 WORKING GROUP METHODS

A 'staggered reveal' approach was designed to provide a structured format to facilitate group discussion. This approach involved showing participants first just the picture that was above a question, then the picture plus the question wording without giving the answer categories, and then the whole item (i.e. the picture, question wording and possible answer categories). This method helped to explore, in a systematic way, the adequacy of the pictures, the clarity of questions and answers, any difficulties in understanding or responding, and how well questions reflected the content of the domains. It also provides an insight into how participants interpret and answer the questions, and how their personal experiences match the answer options. For a detailed description of the method see Appendix 1.

Working group meetings were run by members of the research team and lasted between one and a half and two hours. Discussions were audio-recorded, with participants' permission, and additional notes were taken. Recordings were not transcribed verbatim, but detailed notes were prepared after each meeting. Notes were analysed to identify any issues with the questionnaire (findings from the working groups are presented in Chapter 4) that fed into the first round of revision of the questionnaire.

## 3.2 FOCUS GROUPS

Eight focus groups with 32 participants with a learning disability and/or autism were conducted between November 2013 and January 2014. The aim of the focus groups was to gain feedback on the first revision of ASCOT-ER concentrating on three main questions:

- do the revised pictures adequately depict the domain;
- are questions and answer options easy to understand and understood correctly and consistently by participants;
- are answer options adequate and do they discriminate between different individual experiences?

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### 3.2.1 RECRUITMENT OF FOCUS GROUP PARTICIPANTS

Participants were recruited through self-advocacy organisations and service providers. Information materials, including an Easy Read information sheet, were sent to organisations asking them to inform their members/service users who were eligible and potentially interested in taking part in the focus groups. The eligibility criteria were:

- capacity to consent;
- ability to communicate in English – not necessarily verbally – with or without support.

Receiving social services – residential care or support in one’s own home – was not a requirement for focus group participants.

Focus groups were held either on the premises of organisations or at the University of Kent, if that was the preferred option. This helped to minimise difficulties associated with travel and unfamiliar environments. Participants in each focus group came from the same organisation and in all but one group they all knew each other. Support workers who knew participants well from each organisation were present during sessions.

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### 3.2.2 FOCUS GROUP PARTICIPANT CHARACTERISTICS

All 32 people that took part in the focus groups had capacity to consent, could express themselves verbally and were able to contribute to discussions in English. Not all participants were able to read and some had additional needs (e.g. visual impairment). Participant characteristics were gained by an Easy Read self-report questionnaire. When necessary, researchers read out questions and answers for participants, but other than this no other help was provided to fill in the questionnaire. For each question, the option of not answering the question was always given. Therefore the data below does not always encompass that of 32 individuals; one individual chose not to complete the questionnaire and others chose not to answer some questions throughout.

The mean age of participants was 38 years (range 19-77 years), 18 were male (58%), 17 (57%) had a learning disability, five (17%) had autism or Asperger Syndrome, and three (9%) described themselves as having both a learning disability and autism/Asperger’s. Of those who answered a question on ethnicity (n=28), all were either “White British” or “White other” (n=1).

In terms of living situation, of those who answered the question (n=30), nine people (30%) lived with their family, seven (23%) lived in a place of their own, five (18%) lived in a place of their own with

other people, six (20%) lived in a home provided by the organisation that supported them, and two people (7%) lived somewhere else. Eight people (30%) were supported by paid staff or personal assistants (PA) some of the time, eight (17%) were supported by paid staff/PAs all of the time, six (20%) were supported by family all of the time, or part of the time (n=3, 10%). Some had a mixture of paid staff and family support (n=2, 7%). One person said that someone else supported them, while two had no support and a further two did not want to answer the question.

Table 1 gives an overview of the areas where participants were getting either paid or unpaid (family) support. Two people indicated that they did not have any support at all and 16% (n=5) stated that they did not receive any support in the identified areas but had other types of support (e.g. employment services etc.). Twenty-two percent only received limited support, whereby they were supported in two or fewer areas out of the 10 areas listed. Sixty percent of people were supported in five areas or more, with 25% receiving more extensive support, in eight areas or more.

**Table 1 Areas where focus group participants were getting support**

<b>I get help to...</b>	<b>N (=27)</b>	<b>%</b>
do my shopping	20	74
prepare my meals	17	63
see the people I want to see	15	56
feel safe	15	56
do the things I want to do	15	56
feel in control of my life	14	52
clean my home	14	52
get out and about	12	44
move around my home	5	19
be clean or dressed	5	19

### 3.2.3 FOCUS GROUP METHODS

Focus groups used the same staggered reveal approach as working groups, with some minor changes (see Appendix 1). An additional ranking exercise was also conducted in focus groups that aimed to explore whether participants were able to use four-point scales adequately (Appendix 2).

Focus groups covered two to five of the ASCOT domains, most often three; therefore each domain was tested in at least two focus groups. Sessions lasted between one and a half and two hours. Discussions were audio-recorded, with participants' permission, in six of the eight focus groups; two groups asked not to be recorded. Additional written notes were taken by researchers in each session. Recordings were not transcribed verbatim, but detailed notes were prepared after focus group meetings and analysed thematically to check for misunderstandings, inconsistent interpretations, concept coverage and adequacy of images. Based on these notes, further revisions were made to the questionnaire before cognitive testing.

### 3.3 COGNITIVE INTERVIEWS

Cognitive interviewing is commonly used as a way of pre-testing survey instruments (Collins, 2003). Cognitive interviews provide a view of the processes elicited by the questions of a questionnaire (Presser, Couperet al., 2004). They use two main techniques – “think aloud interviewing” and probes – to explore the thought processes involved in interpreting and answering questions (Presser, Couper et al., 2004). The aim of the cognitive interviews was to test the second revision of the questionnaire. They took place between March and May 2014.

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#### 3.3.1 RECRUITMENT

Participants for cognitive interviews were recruited through five organisations operating in the South East of England: two self-advocacy groups, two social enterprises providing employment opportunities and independent living services and a residential care provider. Three of these organisations had been involved in the focus groups and were already familiar with the project. Information materials, including an Easy Read information sheet, were provided to all organisations.

Organisations were asked to recruit individuals who:

- had capacity to consent;
- were able to communicate in English – not necessarily verbally – with or without support;
- were receiving social services: either residential care or support in their own home;
- had not taken part in the focus groups.

Cognitive interviews were held on the premises of organisations to help minimise difficulties associated with travel and unfamiliar environments.

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#### 3.3.2 COGNITIVE INTERVIEW PARTICIPANT CHARACTERISTICS

Twenty-two people with learning disabilities and/or autism took part in the cognitive interviews. All participants had capacity to consent, were verbal and able to contribute to the cognitive interview in English. Participant characteristics were gathered using an Easy Read self-report questionnaire. For participants who could not read and/or write, researchers read out the questions and/or marked answers. For each question, the option of not answering was always given. Therefore some of the data below does not encompass the total sample of 22 individuals.

The mean age of participants was 39 years (range 24-70 years), and 13 (59%) were male. Of those who answered the question (n=19), 17 people (90%) described themselves as having a learning disability, one person (5%) had autism or Asperger Syndrome, and one (5%) had both a learning disability and autism or Asperger's. One individual had an additional visual impairment and another participant had a hearing impairment.

Of the 21 participants who answered the question about ethnicity, one person (5%) described themselves as “Black or Black British Caribbean”, two (10%) had other White backgrounds, while the majority (n=18, 86%) identified themselves as “White British”.

In terms of living arrangements, the majority of participants who answered the question (53%, n=10) lived in a home provided by the organisation that supported them (i.e. a residential home). Table 2 gives an overview of the living arrangements of individuals.

**Table 2 Living arrangements of cognitive interview participants**

	<b>N (=19)</b>	<b>%</b>
Lives with family	4	21
Lives in a place of their own	4	21
Lives in a place of their own with others	1	5
Lives in a home provided by the organisation that supports them	10	53

**Table 3 Support arrangements of cognitive interview participants**

	<b>N (=22)*</b>	<b>%</b>
Family all of the time	6	27
Family some of the time	4	18
Paid staff/personal assistants all of the time	8	36
Paid staff/personal assistants some of the time	8	36

*\* Participants could select more than one option; therefore the total number of responses is higher than the number of respondents.*

The majority of people were supported by paid staff or personal assistants either all of the time (36%, n=8) or some of the time (36%, n=8). Support arrangements are summarised in Table 3. Six participants (27%) reported having family support only, either full- (n=4) or part-time (n=2), and three of these participants also lived with their family. Although our inclusion criteria indicated that only people who were receiving formal social care services were eligible to take part in the interview, we decided to retain these participants in the sample for pragmatic and ethical reasons. Two participants reported their support in a seemingly inconsistent manner: they said they were supported by their family full-time and had part-time paid support. One of them lived in a care home. Both of these participants had a very close relationship with their family.

All but one participant (n=21) provided information about the support they were receiving at the time of the interview (see Table 4). Two participants (10%) said they had no support in any of these areas, and three people (14%) were receiving support in only one or two areas (shopping and meal preparation; cleaning home and meal preparation; feeling in control). Just under half of the participants (48%, n=10) reported support in five or more areas, with a third (n=7) receiving help in eight or more and one person in all ten areas.

**Table 4** Areas where cognitive interview participants were getting support

I get help to...	Number (N=21)	Percent
do my shopping	16	76
clean my home	14	67
prepare my meals	13	62
see the people I want to see	12	58
feel safe	12	58
do the things I want to do	12	58
feel in control of my life	10	48
get out and about	9	43
be clean or dressed	4	19
move around my home	2	10

### 3.3.3 COGNITIVE INTERVIEW METHODS

Cognitive interviews in this study used a face-to-face semi-structured interview format. Traditionally, cognitive interviews consist of “think-aloud” prompts with some probing questions. The two techniques put different cognitive demands on respondents – “think-aloud” techniques are considered cognitively more demanding (Collins, 2003) – therefore any “think-aloud” prompts were used alongside probing questions in this study (Appendix 3). Supporters could be present during the interview if this was requested by the participant; four participants requested this but no supporters intervened or prompted participants in the interview.

Before the interview, participants were reassured that there were no right or wrong answers, and the researcher asked questions to find out more about what they were thinking about in considering their response. Participants had the option to read the questionnaire themselves, read them together with the researcher or for the researcher to read them out. The researcher then encouraged the participant to think aloud and asked probing questions to explore how they arrived at the answer. Interviews typically lasted between 30 and 90 minutes, and all but one were audio-recorded with participants’ permission. Recordings were transcribed verbatim for analysis. In addition to this, researchers prepared field notes summarising any observations on respondents’ behaviour and the circumstances of the interview. Transcripts and field notes, alongside ASCOT questionnaire data, were transferred to NVivo for thematic analysis. Transcripts were coded using a simple frame consisting of codes for each domain, images, smiley faces, misunderstandings, difficulties with interpretation, and any other relevant category including potential bias. Data was then analysed by domain using matrix queries.

## 4 FINDINGS FROM PRE-TESTING THE RE-DESIGNED ASCOT-ER

This section examines in detail the process of the development and re-design of the ASCOT-ER. The analysis was led by three main questions that were also guiding the re-design:

- 1) Do the pictures help respondents to answer the questions, particularly:
  - a. How well do the pictures reflect the content of the questions?
  - b. Do the smiley faces help respondents to choose an answer? Is the difference between them clear?
- 2) Are the questions and response options easy to understand and are they interpreted consistently and in accordance with the domain descriptions by respondents?
- 3) Are respondents able to answer the questions? Are their answers based on their experiences? Is there any evidence of systematic bias in responding?

Findings are presented in three parts: firstly, looking at issues related to each of the ASCOT domains (section 4.1); secondly, presenting the experiences related to the use of the four-point scale response format (section 4.2); and finally in section 4.3 summarising findings related to the validity of the revised questionnaire.

### 4.1 DOMAIN-SPECIFIC FINDINGS

The section presents the initial question drafting (taken from the original ASCOT-ER version), along with issues identified in the original. We then report the findings and changes made following the working group, focus groups and the cognitive interviews. The original questionnaire can be found in Annexe 1; the version tested in focus groups is included in Annexe 2; and the one used in the cognitive interviews is in Annexe 3.

#### 4.1.1 FOOD AND DRINK

##### **Pictures**

In the first phase of development with the working group, members had some difficulty interpreting the images for the food and drink question used in the original Easy Read questionnaire (see Annexe 1). Whilst they identified a person drinking and plates of food, there was a consistent view among the group that the pictures of food on the plate itself (as opposed to the placard/sign on the plate) did not resemble the food it was supposed to be, as indicated by the sign. For example, one member stated: *“that doesn't look like chicken – it's just round balls”*. This created some confusion as to what people were looking at and subsequently supposed to think about in relation to the question. Another issue was whether or not they were two separate images or part of the same image. A number of members of the working group described how the woman in the first image was *“looking at the food because she's hungry”*. It was not clear to the working group that these images were separate and this again created some difficulty in interpreting them for the question. While all

members of the working group identified that *“the woman in the picture is having a cup of tea”*, the question relates to all drinks and it is possible that *only* depicting tea in the image limited the way that people were thinking about what they drink (i.e. reducing this to exclusively thinking about tea/coffee or hot drinks they have). Looking at the images, two members of the group thought that the question would be about *“your favourite food and drink”*, while others agreed that it would be *“about food and drink”* without commenting any further.

Following synthesis of the responses, the images used in the original easy read document were replaced with one single image to encompass food and drink that could be consumed across the day for testing in focus groups (Annexe 2). Initially, participants were shown a version of the image without any writing or words on the depicted produce (e.g. the words ‘Orange Juice’ written on a drawing of a drink carton) to test whether this would be less confusing for those with low or no literacy skills. However, consensus was that a version with no words would detract from the use and interpretation of the image. One participant summarised this: *“it looks weird without the words on, I can’t read them but I am still used to seeing the words on things”*.

In the cognitive interviews, the amended pictures worked well and prompted respondents to think about the variety of foods and drinks that they have and like or dislike. All but one respondent said that they liked the picture.

The individual who did not like the picture found it *“hard to understand”* due to the many small details (Box 1).

#### **Box 1**

- A: The pictures were confusing.  
Q: Okay, what’s confusing about the pictures?  
A: You can’t tell what they are.  
Q: Can’t you?  
A: No.  
Q: In this top picture here?  
A: Yeah. You can’t tell what the food is.  
Q: Can you not? Can you tell what any of it is?  
A: You can tell the plates are, but not the food.

*(Participant 18)*

#### **Question and answers**

Working group members were asked to look at the original wording of the question (Annexe 1) and answer in their own words. Answers focused on *what* they eat and drink without thinking about the standard of food or how satisfied they were with it. People did not consider whether it was timely, whether or not they had as much as they needed, or whether it was healthy, balanced and fulfilled nutritional requirements – all aspects of food and drink that people should consider when answering the question. Some members of the group had difficulty in answering the question, saying that they needed more information, that it was not very clear, and that they were unsure as to whether the

question related to breakfast, lunch or dinner. When asked to look at the category responses and choose an answer, members of the working group were able to do this with some support. Group members had some difficulty choosing a response due to some of the issues outlined above, and in particular that *“the pictures did not really help them”*.

Following the discussion in the working group, the wording of the question was amended to improve clarity and reflect that, while the question relates to people being able to eat and drink what they *like*, in addition they should consider whether they are able to have a healthy and balanced diet that meets all their nutritional requirements and is culturally appropriate, as well as whether they are able to eat and drink in a timely manner (Annexe 2).

The amended question wording appeared to be understood by participants in the focus groups, and more attention was paid to the variety and balance of the food and drink that people were consuming. The frequency and quantity of food was not discussed, possibly because the groups were fairly independent (could prepare their own food) and had enough food.

A variety of responses reflected different experiences among focus group participants. Some ticked the top option ('I get all the food and drink I like when I want') and commented that they lived on their own so *“when I want something, I get it”*, while another other participant commented on the variety of foods that they ate. A few people picked the third option ('I do not get all the food and drink I like when I want'): a participant who lived with their family commented that they had to eat what their mum cooked. Others mentioned dietary needs of family members (e.g. diabetic) and lack of money (i.e. cannot afford to have take-away as often as they would have liked it) as reasons for their response.

The majority of cognitive interview participants appeared to understand the question and responded appropriately. Seventeen out of 22 respondents picked the top answer ('I get all the food I like when I want'), four picked the second answer ('I get enough of the food and drink I like when I want'), and one person picked the bottom answer ('I do not get any of the food and drink I like so I might get ill'). All respondents said that the question was easy and no difficult words were highlighted. When asked why they picked a particular answer, most of them justified this adequately (see Box 2 & 3).

#### **Box 2**

A: 'Cause she [carer] doesn't stop us drinking or eating.

Q: Yeah.

A: Whenever you're feeling hungry you can just go and grab something out of the fridge.

*(Participant 19; top answer)*

**Box 3**

- A: For me I'd just go--, get all the food and drink I want when I want.  
Q: Yeah, okay.  
A: So if I get a bit of peckish--, hungry I just go and get some food and a drink.

*(Participant 10; top answer)*

**Box 4**

- A: That one.  
Q: So I do not get any of the food and drink I like so I might get ill?  
A: Yeah, I get ill sometimes.  
Q: You get ill sometimes?  
A: Yeah.  
Q: And is that because of what you're eating and drinking, or not eating and drinking?  
A: No, it's--, I can't eat too much.  
Q: Okay, you can't eat too much, and is that--, why is that, that you can't eat too much?  
A: I've been told by my carers.  
Q: You've been told by your carers that you can't eat too much?  
A: Yeah, somebody came and talked about it.  
Q: Okay, so you don't get to have the things that you want to eat?  
A: No, no.

*(Participant 6)*

There was a mixed response in terms of the impact of dietary restrictions on levels of satisfaction. One of the respondents had diabetes and was not allowed certain drinks, but this had no impact on their satisfaction. Meanwhile, the other participant who had dietary restrictions indicated high levels of unmet needs, and was the only person who selected the bottom option (Box 4).

### Box 5

A: I get enough food and drink I like when I want.

Q: Okay, why did you choose that answer, what were you thinking about when you chose that answer?

A: I can eat the food what I want.

Q: Okay. And can you tell me why you chose this answer and not this answer? What do you think is the difference between "I get all the food and drink I like when I want", or "I get enough of the food and drink I like when I want"?

A: I eat enough food.

(Participant 2)

Three of the four respondents who selected the second option seemed to find the term "enough" confusing and this led to problematic answers (Box 5).

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## 4.1.2 PERSONAL CLEANLINESS AND COMFORT

### Pictures

When reviewing the original version (Annexe 1), participants in the working group were able to describe what they saw in the pictures. One participant described these as: *"a lady and probably a man, the lady putting a top on and the second person brushing their hair and looking in the mirror"*. Similarly, another described the pictures as *"people getting ready to go out"*. This was a common theme among the group, and other comments related to people grooming themselves and getting ready. However, participants did not equate this to personal care *per se*, and washing, showering or bathing was not mentioned by anyone in the group. Prior to seeing the worded question, some participants thought that the question would be about *"being presentable, tidy and smart in the way you feel"* while other comments included *"looking after yourself"* and *"getting up and getting dressed"*. After the working group, only minor changes were made in the pictures – the original pictures were replaced by black and white images from the CHANGE picture bank – but the concept remained the same.

The revised images were then tested in two focus groups (Annexe 2). Participants most often commented that the images were about "getting ready" or "going out". Many participants simply described what they saw on the pictures and commented on that, often attributing a context (getting ready to go to a party, etc.). No participant could guess the question based on the pictures only.

The images used in the question were heavily leading participants to a context of 'getting ready to go out' or 'go to a party' without considering personal care. Therefore the pictures were changed to depict additional stages of daily activities to show washing, brushing teeth/hair and dressing, including one person being supported to do this.

### Box 6

- Q: What was useful about the pictures, what do you think?  
A: Knowing what presentable means.  
Q: Okay.  
A: Because you had your explanation, and also the pictures.  
Q: Yeah.  
A: They're in the shower.  
Q: Yeah.  
A: Then you've got another person brushing their hair.  
Q: Yeah.  
A: And you've got another person looking in the mirror, so obviously, that's to do with looking nice and fresh, and radiant.

(Participant 15)

Cognitive interview participants could identify what the pictures were showing, and the majority of them commented that they were useful in helping them understand and answer the question (Box 6).

### Question and answers

Answering the original question in their own words (see Annexe 1), participants in the working group discussed the importance of keeping clean, as this phrase is used in the question. Participants also discussed being "*clean, smart and tidy*" and also whether people were 'happy' with what they were wearing. This was in terms of whether or not it was comfortable, and whether they had a choice about what to wear and "*being satisfied with what you have*".

Predominantly, participants chose the top response category ('I feel clean and I like the way I look') when answering the original question, with the exception of one participant who chose the second option ('I quite like the way I feel and look, it's OK'), although was unsure as to why they chose this option. When outlining reasons for why they had answered the question the way they had, participants referred again to a context of going out to meet friends and having choice.

In conjunction with comments made by the working group, the question wording was amended to include specific reference to being clean, having clean clothes and feeling comfortable in what people are wearing. It also introduced and defined the idea of 'being presentable' (see Annexe 2). This term was chosen over others (such as being 'clean and tidy') because this would introduce two terms which could individually take on different meaning in selective contexts.

In focus groups the word 'presentable' was highlighted as being potentially difficult for people to understand, but perhaps more important was that participants felt it depended on context: for example, one participant stated: "*it depends how you feel in the morning*". In the cognitive interviews (Annexe 3), nearly all respondents commented that they had never heard the word "presentable" and it was potentially difficult to understand for 'other people'. However, all but two respondents understood it without additional explanation or prompts, and responded adequately.

The words and pictures were mentioned as particularly helpful. Two participants misunderstood the question and thought about how they feel when doing 'presentations' (Box 7 & 8).

**Box 7**

Q: So you've ticked the third one. So you think that you feel a bit presentable, but it could be better?

A: Yeah.

Q: Why do you think you've chosen that one?

A: Erm, 'cause I think I, when I do presentations at school I do get a tad nervous.

*(Participant 19)*

**Box 8**

Q: Can you tell me a bit about what kind of things you were thinking about when you were thinking that you feel presentable?

A: Presenting to people.

Q: Okay. In what way do you think?

A: When I go out to schools and present to little kids.

*(Participant 18)*

Fifteen out of the 22 participants selected the top level, usually referring to keeping clean, wearing clean and comfortable clothes, and choosing what to wear (Box 9 & 10).

**Box 9**

A: I would most probably be the top one.

Q: The top one.

A: 'Cause I always wear what I feel comfortable in each day.

*(Participant 4)*

**Box 10**

A: I'll tick I feel very presentable.

Q: Okay. Right, and why did you choose that answer?

A: Because I'm always clean, I've always got clean clothes on, I'm always washed and dressed, and I always try to look nice.

*(Participant 15)*

One respondent who said they felt a “bit presentable” provided a clear justification, although this highlights the difficulty of separating personal satisfaction from social expectations in some domains (Box 11).

**Box 11**

Q: So this next one, this question is about being presentable.

A: Right. It isn't always me.

Q: [Laughs]. Okay, well we'll see, you can answer the question.

A: I never bath always anymore.

Q: No? Okay. So being presentable means being clean, having clean clothes and feeling--,

A: No, I wear these for a whole week.

[...]

Q: You've put yourself on the third level there, and is that just because you feel like you could be dressed a bit better or?

A: Yeah. Sometimes I don't want to look smart, sometimes I wear like this or something.

Q: Yeah, but is that kind of just 'cause you want to though?

A: Yeah. Sometimes I don't always want to look smart. Then you get moaned at if you smell or something and don't wear nice clothes.

*(Participant 13)*

Three of the four people who said they felt “quite presentable” and the person who did not feel presentable could not explain why they picked that answer. They might have been affected by bias arising from the wording of the answers, or they might have been relying on the smiley faces to help them answer. This is illustrated by the example in Box 12.

### Box 12

- Q: This question is about being presentable, being presentable means being clean, having clean clothes and feeling comfortable in what you are wearing, how presentable do you feel?
- A: I feel good because I've been--, 'cause this morning I had a wash before I got my dressed clothes on so I did do that today so I got--, 'cause I got ready for the day see and then I know that's a simple thing to do isn't it, to get smartened up ready for something today.
- Q: Okay, can I read out the answers maybe you can pick one; I feel very presentable; I feel quite presentable, it is okay; I feel a bit presentable, it could be better; I do not feel presentable at all, it is really bad; so which answer would you choose?
- A: Presentable, this one that--, which one's the good one, the one down here?
- Q: No, it's down here: I feel very presentable, or I feel quite presentable, it is okay.
- A: It's okay this one, yeah.

(Participant 3)

#### 4.1.3 ACCOMMODATION CLEANLINESS AND COMFORT

##### Pictures

Participants in the working group highlighted some issues with the original picture used for this question (see Annexe 1). Initial thoughts and comments on the picture were based around the assumption that it was a residential care setting. One participant described the picture as *"sitting by the fire in an old people's home"*. When probed as to why it was this setting, the participant stated that *"the man has white hair"*. It was also noted that *"it must be cold because they're sat by the fire"*, but it was unclear as to whether or not this was an additional factor that contributed the assumption that this was a residential care setting. Other comments also focused on people keeping warm, sitting on chairs, relaxing and talking. When prompted, participants agreed that the picture did not look like or remind them of their own home but that *"it looked nice"*.

The disconnect between looking at the picture and equating it with their own home was problematic for interpreting the question and what aspects of home are considered when choosing an answer. As a result of discussions within the working group, the image was amended to show someone 'thinking' about their own home using a thought bubble (see Annexe 2). However, focus group participants almost unanimously viewed the thought bubble as confusing, and participants were distracted by the character depicted as thinking about their home. After discussions in this phase, it was agreed that the character should be removed and also that a contrasting picture could be introduced i.e. one image of a 'clean/tidy' room and another of a 'messy/unclean' room. These images were taken for testing in the cognitive interview phase.

In the cognitive interviews, most participants identified that the pictures depicted a living room and a kitchen (Annexe 3); however, some of them missed the clean/tidy vs dirty/messy aspect, or identified the kitchen as clean, although this is unlikely, in itself, to have affected the response.

### **Question and answers**

Looking at the original Easy Read question (see Annexe 1), all of the participants in the working group answered it by choosing the top level. When prompted about the kinds of things they were thinking about in answering, some participants described some of the tasks they do around the house (help cleaning the kitchen floor, gardening etc.). One participant appeared to struggle with differentiating between answer categories two and three, but when asked whether they would prefer three response options rather than four the participant stated that four was better *“because it gives people more choice”*.

In general, participants appeared to find considering both aspects of their home related to the question (being clean *and* nice) difficult. When answering the question, participants stated that they were mostly focusing on just one of these (cleanliness), as this was the more tangible element of the question. In response to this, the question wording was amended to include the term ‘comfortable’ (as in the original domain definition), and also amended to include definitions of both clean and comfortable to help people to think about these aspects of their home when answering the question.

When testing the amended question in the focus groups and cognitive interviews, particular attention was paid to difficulties arising from the complexity of the domain and the level of generalisation required from participants to consider aspects of cleanliness and comfort, as well as different living areas within their – often shared – accommodation. In the focus groups the question and response options appeared to be easy to understand for participants. The conflation of the terms clean and comfortable in the response categories was not raised as an issue by focus group participants, who were able to choose an answer that reflected their experience. Based on these findings, the domain was retained as a single question and taken forward for testing in cognitive interviews (see Annexe 3).

The majority (15 out of 22) of cognitive interview participants said that their home was clean and comfortable, and seven said their home was quite clean and comfortable. The emphasis of responding was on cleanliness.

Some participants were able to consider various aspects of cleanliness and comfort in their answer, while others found this more difficult, partly because they lived in shared accommodation (Box 13 & 14).

### Box 13

A: That's a tricky one. [Pause]. Quite clean.

Q: Quite clean and comfortable. What sort of things were you thinking about when you answered that? Were you thinking about just your room or were you thinking about the other rooms in the house?

A: I don't live in a house.

Q: You live in a flat?

A: Yeah, there's about seven residents in total.

*(Participant 5)*

### Box 14

A: It's a shared home.

Q: It's a shared home. So when you're thinking about it being a shared home how would you answer this question of how clean and comfortable your house is?

A: I have to remind them to clean the bath and flush the toilet and make sure it's all clean.

Q: Okay. So you have to remind the others. So if you had to pick an answer which one would it be? Which one fits best?

A: Most probably that one.

Q: Say my home is quite clean and comfortable, okay. So the second one down. Okay. So which rooms were you thinking about when you were answering that question?

A: My room would be really nice and tidy.

Q: Okay. Okay, so your room would be the first one but when you were thinking about all of the house you put the second one, okay, and which rooms were you thinking about?

A: The bathroom.

*(Participant 4)*

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#### 4.1.4 SAFETY

The question in the original Easy Read questionnaire included how safe people felt both at home and outside their home (see Annexe 1). Discussions with the working group revealed two main issues with the original question. Firstly, the question asked the respondent to consider how safe they feel at home and in the local community, and give a response based on considering both. This was not only cognitively difficult for most participants but also potentially leading to systematic bias. People stated that they would give a different response to the question depending on whether it related to inside or outside the home. For example, one participant explained that he felt safe in his home but

was much more anxious when outside due an incident in which he had been the victim of an assault. Secondly, members of the working group found the original question structure with a-b points confusing. They thought that people had to answer either option a) or b) separately.

These issues led the working group and research team to agree that the question should be divided into two separate questions: one relating to safety inside the home and one relating to how safe people felt when they were outside in their neighbourhood and local community. A single-item (amended) version was tested in one of the focus groups to seek further validation to the decision to split the safety domain into two questions. Feedback from this group was clear, and participants unanimously advocated splitting the question to differentiate between safety inside and outside of home.

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#### 4.1.4.1 SAFETY AT HOME

##### **Pictures**

The original pictures for the single safety questions were meant to encapsulate the general concept of feeling safe and unsafe (see Annexe 1). The abstract nature of 'feeling safe' coupled with the objective of the pictures to encapsulate safety both in and out of home made them difficult to interpret for participants in the working group. In discussion it was agreed that the images should be amended to represent more accurate and recognisable aspects of safety. Suggestions included *"someone falling over"* as well as *"someone is fearful or worried, for example because they are being bullied"*. The revised version of 'safety inside the home' was tested in a focus group and initially contained an image of someone falling out of a wheelchair (Annexe 2). However, participants expressed that they were primarily more concerned about security at home. Specifically, many participants mentioned concern with burglary, anti-social behaviour and harassment by neighbours or housemates. This image was thus replaced to reflect this (Annexe 3) and taken forward for testing in the cognitive interview phase.

Respondents generally found the pictures useful, although admittedly not all of them looked at the pictures when selecting an answer. All respondents could adequately identify what the images depicted and they prompted some people to share their thoughts (Box 15).

##### **Box 15**

A: I see that lady's got that chain on her front door. Yeah, because you can't be too careful who bangs on your front door. That's why every night when I get home now, I always lock my front door and lock my chain on, so I know that I feel safe and I'm thinking to myself no one can get in or anything, or...

(Participant 21)

## Question and answers

During focus groups the amended question for safety at home was understood by all respondents in a consistent way and they were able to answer adequately. In the cognitive interviews, 16 out of 22 respondents picked the top answer, five people said they felt quite safe at home and one person chose the bottom answer and said that they were worried and did not feel safe at all at home. This case was later followed up with the respondent's supporter.

One of the respondents who had visual impairment and said they felt quite safe explained their answer (Box 16).

### Box 16

A: For this one I'm going to put "I feel quite safe in my home".

Q: Okay. Thanks. So what were you thinking about when you chose that answer?

A: Erm--, just the, my house in general.

Q: Hmm-hmm.

A: And sometimes if my mum puts something down and she doesn't tell me that she's put it down, I fall over.

Q: Right. Yes. So you don't always feel safe because you're afraid you might fall over?

A: Yes.

Q: Is that what you're saying?

A: Yes. Or getting hurt. That's why I put I feel quite safe in my home.

*(Participant 15)*

Those who picked the top answer explained why they felt very safe at home (Box 17 & 18)

### Box 17

A: The top one.

Q: The top one. Okay. So why--, what were you thinking about when you answered that question?

A: 'Cause we've got all safety locks on our windows, we've got all them on the doors.

Q: Okay, so you were thinking about the locks on the windows when you were thinking about safety.

A: And if anyone comes round from companies we have to ID them and if they come in they have to sign in the book. ... We've got all security alarms, we've got an intercom.

*(Participant 4)*

### Box 18

Q: So you've answered the top one. So what were you thinking about when you said that you feel very safe in your home? What kind of things were you thinking about around safety?

A: Just making sure everything's--, lights switched off or--, even before I go to bed, everything's locked up and I always make sure to keep myself safe that way, everything's switched off, the electric and that, and my back door's locked and my front door's locked.

(Participant 21)

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#### 4.1.4.2 SAFETY OUTSIDE HOME

##### Pictures

Images for safety outside the home initially focused on both positive and negative aspects of feeling safe outside one's home/in the community (see Annexe 2). However, focus group participants explained that the 'positive' image was unclear and confusing. Discussion in focus groups centred on the difficulty of illustrating safety in a 'positive' sense, given its abstract nature. Due to this difficulty, it was agreed that this image should be amended to depict an additional negative aspect of safety outside the home. Suggestions here included using an image to depict feelings of intimidation in the community as this was one of the greatest concerns that participants reported regarding feeling safe outside. One participant suggested using a picture of *"a group of youths hanging around"* (see Annexe 3).

Cognitive interviews confirmed that the new images worked well; respondents associated the images with feeling safe/unsafe in the community.

##### Question and answers

During focus groups the amended question for safety outside the home was understood by all respondents in a consistent way and they were able to answer adequately. Some focus group participants with autism pointed out that they had some difficulty in selecting a single answer because how safe they felt in the community depended on the time of day and the area they visited.

### Box 19

A: I feel safe, like, in the mornings I go to [...], and then on Friday I come here and that and it's like when I go out, like, there's no, like, kids.

(Participant 10, top answer)

In the cognitive interviews, there was a variety of answers: out of the 21 respondents who answered this question, two said they did not feel safe enough, six said they felt quite safe and 13 respondents felt very safe. Some of those who said they felt very safe never or rarely went out on their own or

changed their behaviour (e.g. they do not go out after dark etc.) due to safety concerns (Box 19 & 20).

#### **Box 20**

A: I do feel safe when I go out, because when I do my shopping I always make sure I maybe walk down the road or anything where other people are walking, in other words as the same side the road as I am. I wouldn't walk down on the road on my own. It's alright during the day but when it starts getting dark, I don't think I'd like to do it on my own in the dark because I would panic.

*(Participant 21, top answer)*

There were some concerns from the core research team that the new pictures focused too heavily on the security aspect of the question and thus respondents might ignore other aspects of feeling safe (i.e. not worrying about accidents). There was no evidence of this in the cognitive interviews. Two respondents had additional needs (visual impairment) and both of them talked about their concern regarding accidents (Box 21).

#### **Box 21**

A: I'm going to tick I do not feel safe enough when I go out.

Q: Okay. So why did you say that one?

A: Because of uneven pavement, and 'cause I can't judge kerbs and steps. And if I don't know the layout or the area because it's new and I get disoriented about things that nine times out of ten I would fall over.

Q: Yeah, yeah.

A: And especially if somebody was to like come behind me or attack me. I wouldn't see them.

Q: Hmm.

A: So that's why I answered I don't feel, I do not feel safe enough when I go out.

Q: Okay, but then sometimes when you go out you do feel safe?

A: Yes.

Q: And when would those times be? When do you feel safe when you go out?

A: When I'm with my mum or when I'm with my PA lady. Or I'm with my friends. When I'm on my own I don't feel safe.

Other participants also reflected on various aspects of safety (Box 22).

### Box 22

A: If I go out of the house with road safety and all that, it feels to me that I'm always safe as when I'm being independent and I can look over the road where the car was. And I sometimes do feel safe when I literally go out of the house. Say if I'm going to see mum today. I feel safe in me if I get on a bus to go somewhere. I am pretty good for going out of the house being safe going somewhere when I have to meet someone. So I'm going to say I feel quite safe when I go out really because I'm going to say the second answer to it because I do feel the same, that I do like to go out and I'm always quite safe but I can see spotting dangerous things though.

(Participant 9)

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#### 4.1.5 SOCIAL PARTICIPATION AND INVOLVEMENT

##### Pictures

Members of the working group agreed that the original images for this question (Annexe 1) were difficult to interpret. Some members of the group identified that the first (left-side) picture depicted family but the second (right-side) was much more confusing, and participants had difficulty identifying what was going on or the scenario that was illustrated. One member described this image by saying: *"the woman has her mouth open and doesn't look very happy"*. The image did not appear to be conveying any sense of 'social participation', and other group members were equally unsure as to what the image was trying to portray. When asked what they thought the question would be about, most working group members were not able to answer. One participant suggested that it would be about *"how to look after people and looking after others"*.

It was agreed that the images needed to be improved to make them clearer. New images were developed in conjunction with CHANGE (Annexe 2), and these were taken forward for testing in two focus groups. Participants in the first group stated that *"this one was really easy"*, that one of the pictures was about socialising and friends, while the second picture showed *"somebody who was lonely, left out and maybe depressed"*. The second group did not find the pictures as straightforward as the first, possibly condition-specific to autism. Some participants here focused on the small details in the pictures and found these distracting (i.e. the clock in the second picture), and this led some participants to think that the question would be about family life and time keeping. After this, the clock was removed from the image prior to cognitive testing (Annexe 3).

No problems were reported with the pictures in the cognitive interviews. The majority of respondents associated the images with social participation, such as having friends or family around or feeling lonely and left out (Box 23).

### Box 23

Q: Yeah, what do you--, what do you think about those pictures? What do you think they're about?

A: Reminds me of having friends round.

Q: Okay, so this picture, the first picture reminds you of having friends round. What about the second picture, what do you think is happening there?

A: He feels on his own.

(Participant 4)

### Question and responses

Looking at the wording, the working group were happy with the question and understood the term 'social life' (Annexe 1). One participant stated that he would choose the second option and explained that he *"doesn't go out with friends that often but go out with family more often"*. Similarly another member of the working group drew a distinction between friends and family, commenting that *"it depends who you're talking about, it varies, because I see friends during the week and family at weekends"*. The original question specified 'time you spend with friends and family' and, while it is important that respondents consider both of these aspects of their social life, to reduce any confusion related to conflating these terms it was agreed to amend the wording to 'spending time with people you like' (Annexe 2). This version was tested in the subsequent focus groups.

Participants in focus groups described the question as *"straightforward"* and easy to understand, and all participants were familiar and happy with the term 'social life'. There were a variety of responses that reflected people's experiences, and participants understood the differences between the response categories. One participant picked the top answer because she goes out to discos and enjoys the company of others; another participant answered the second option because they only see family twice a year and explained that they would like to see them more. A third participant chose the third option because their school friends do not live geographically close to them and, while they have some friends locally, they would like to have a more active social life.

**Box 24**

- A: Hmm, that's a difficult one. [Pause].
- Q: Okay. So you picked 'I see the people that I like but not enough, it could be better.'
- A: Yeah.
- Q: Okay, what sort of things were you thinking about, who were you thinking about when you answered that question? Were you thinking about friends or family or community, or everybody?
- A: [Pause]. I'm not sure.
- Q: You're not sure, okay. When was the last time you saw your friends?
- A: Ooh, a long time ago.
- Q: A long time ago, okay.
- A: Yeah, going to be quite a few years now.
- Q: Okay. Do they live near here or do they live a long way away?
- A: I'm not sure now.
- Q: Okay, when was the last time that you saw your family?
- A: [Pause]. I haven't got a family now.
- Q: You haven't got a family, okay.
- A: I've still got sisters and a brother, but not--,
- Q: So you've got sisters, when was the last time you saw your sisters?
- A: Last year.
- [...]
- Q: Okay, do you know when you'll see them?
- A: Not yet.
- Q: Okay, so is that okay with you? Would you like to see more of them?
- A: Yeah.

*(Participant 5)*

Respondents in the cognitive interviews also reported a variety of experiences. The majority (59%) picked the top answer, six respondents (27%) said they saw the people they liked sometimes, one said they did not see people enough and another did not see people they liked at all. The majority of people appeared to understand the question and responded appropriately (Box 24).

It appeared that the phrasing of the answers was problematic for some respondents. The use of "sometimes" and "it's great" was potentially confusing for some (Box 25 & 26).

### Box 25

- A: I see the people I like sometimes, it's okay.  
Q: Hmm-hmm.  
A: Because I do like to be on my own sometimes.  
Q: Okay. So does that mean that you see people as much as you want to?  
A: Yes.

(Participant 15)

### Box 26

- A: I would, I definitely would like to see more of my own family, my big family too.  
Q: You ticked the top answer didn't you? I see as much as I want, it's great. Given that you would like to see them more would you still say it's the top answer? Are you still happy with that?  
A: I am quite happy with the top answer, I see people that I like as much as I want, it's great. I'm going to say it's great to see, whether it is a big family or seeing more family when I want to.

(Participant 9)

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## 4.1.6 OCCUPATION

### Pictures

When members of the working group looked at the pictures of the original Easy Read questionnaire (Annexe 1), these predominantly invoked the notion of 'hobbies' and 'favourite things to do'. As such, when asked what they thought the question would be about, members of the working group stated that it would be about *"interests and hobbies"*. There was no mention of other activities that may occupy people's time, such as employment or volunteer work, caring for others or other everyday activities such as household chores, cooking etc. Given that the domain addresses all of these activities (as well as leisure time/hobbies), this was identified in the working group as an issue that needed to be addressed, and new images were developed to include these aspects of the domain for testing in focus groups (See Annexe 2). Amended images included depictions of people playing sport, doing gardening and working at a computer.

Participants in the focus groups had a tendency to concentrate on the depicted activities and participants correctly identified these. However, the majority of participants still thought that the question would be about hobbies or what people like doing, or in some cases exclusively about the activities shown. Therefore, further amendments were made to the images to show other elements of the domain more clearly, particularly paid and unpaid work. Also, the decision was made to

include three pictures to reflect the different aspects of the domain: formal employment, unpaid work, caring for others and leisure activities. The new pictures were then tested during the following phase of cognitive interviewing (see Annexe 3).

The pictures were notably less clear than other domains', but the majority of respondents could identify what the pictures depicted. Participants who were in employment could more easily identify the middle picture (someone working in a store/supermarket) than those for whom this was a less relevant area. Only one respondent commented that the pictures were *"a bit jumbled up"* and there were too many things going on. The same respondent found other pictures confusing too.

### **Question and responses**

Similar to the question on safety, members of the working group struggled to understand the written format of this question and what it was asking people to do (see Annexe 1). As with safety, this was attributable to the alphabetical list of the different elements of the domain that the question was asking people to think about when considering their answer. However, members of the working group found these categories confusing, and again were unsure as to whether they should answer these separately; one participant commented that: *"it feels like lots of different questions"*.

It is important that respondents consider all aspects of the occupation domain, and it was agreed by the working group that we could continue to include these in the question but present them in a different format. The wording of the question was therefore amended to encourage people to consider all activities in their daily lives (not just leisure), and incorporated the use of bullet points rather than an alphabetical list to describe these (Annexe 2).

In the focus groups it was clear that participants were considering a much greater range of activities when answering the question, specifically work, college and leisure activities. Participants appeared to understand differences between the response categories and were able to choose an answer that reflected their own situation.

The majority of cognitive interview respondents (76%) selected the top answer "I spend my time how I want", 19% (n=4) said they do enough of the things they like and one participant (5%) selected the third answer "I do some of the things I like".

The variety of responses seemed to reflect the variety of experiences and feelings about daily activities among respondents, and most people understood and responded appropriately (see Box 27). Respondents talked about a variety of things they do, including work, college, community groups and classes, and leisure activities. The Occupation domain is the longest question, and some respondents needed to read the question and answers more than once; nonetheless no-one needed further explanation or highlighted difficult words.

### Box 27

- Q: Okay, what were you thinking about when you chose that answer?  
A: [Pause].  
Q: What sort of things do you do in your free time--, what things do you do?  
A: Not a lot at the moment.  
Q: Not a lot, okay.  
A: Not at the moment.

(Participant 5, second answer)

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## 4.1.7 CONTROL OVER DAILY LIFE

### Pictures

The original images for this question were problematic (see Annexe 1). In particular, the first picture depicting someone choosing their house/somewhere to live appeared to dominate thought processes. Members of the working group focused on this image and assumed that the question would be exclusively about living arrangements or housing: *“is it about where you live, or where you want to live?”* The second picture showing someone being helped to ‘choose’ was interpreted as *“someone getting help with something”* or *“helping someone to read”*. While these contexts relate loosely to the question, when asked what the question would be about, group members predominantly stated that it would be looking for a house/choosing where to live. It was agreed that new images would be developed to better depict the idea of having choice and control over your daily life.

The new image developed for this question (see Annexe 2) was shown to three focus groups. Participants in these groups were able to identify that the picture was about support and helping an individual to make choices: what to wear, what to eat, where to live etc. However, some participants (particularly those with Asperger’s syndrome) found the level of detail in the picture difficult to process. These participants reported that the thought bubbles were confusing: some participants thought that they were the main character’s thoughts, while others thought that he was telling others what he wanted. Some of the more relevant details (such as choosing from a menu) were overlooked, potentially due to the complexity of the images. Participants in the focus group suggested that the pictures in the bubbles should be simpler and display single images rather than bubbles within bubbles and so on. These amendments were made – the single picture was split into three pictures (see Annexe 3) – and subsequently tested in cognitive interviews.

The revised pictures were also problematic for some; a minority of respondents commented that they found them useful, but the majority could not identify what the pictures depicted. Those who identified “money, clothes and food” were not able to say how this was related to making choices. Furthermore, some respondents thought that the pictures were about telling someone what to do or helping someone (Box 28).

### Box 28

A: I was a little bit confused at first.

Q: Okay, what was confusing about it?

A: When I saw them.

Q: When you saw the pictures, okay. What is it about the pictures that you find confusing?

A: Because it looks like she's telling him what to wear, how much he's allowed, what he can and can't eat.

(Participant 4)

Some respondents thought that this question was related to the level of support they needed – perhaps because the pictures depicted an individual with higher support needs – and framed answers in terms of their level of independence and abilities (Box 29).

### Box 29

Q: Okay, and did you look at the smiley faces at all when you were answering the question... and did they help you at all when you were choosing your answer? Why did they help you? How did they help you?

A: It shows what level of support that you need.

Q: Okay, so it shows what level of support you need.

A: That's high support needs, that's medium and that's low.

(Participant 4)

## Question and responses

Some members of the working group, influenced by the images, focused on the idea that the question was directly related to *“choosing where to live and looking for a house”*. However, other members did relate the question to other aspects of having choice and control. One member, choosing the top response, explained that this is because: *“I get to do what I want and as long as I tell my mum I can go out when I want”*. Other members agreed and, while discussions continued to centre on housing and choosing where to live, other aspects such as going out, shopping and choosing what to eat were all mentioned as choices people can make. One member of the group said that he would choose the second option because: *“it's a bit difficult to explain things. It's hard to explain things to people so I don't have as much choice”*. Another member, talking about what the question was about, linked it to whether or not people have or receive help to make choices in their lives; he stated: *“it's about choice in life, do you need help in choice”*. In general, the working group agreed that the question needed to be made clearer by providing additional detail about what is meant by having control in your life.

During focus groups there were some continued issues regarding interpretation of the question, particularly for individuals with Asperger's syndrome. A number of participants from this group held

the view that the question was not specific enough because there are a large number of areas that a person can have control over. The group also highlighted that *"no one can ever have perfect control of their life"* because there are always limitations placed on an individual such as family commitments, employment or other statutory authorities. Participants in focus groups were generally drawn to discussing 'having choice' and being listened to when making choices rather than having control *per se*. This led to a number of participants suggesting that the question should be changed, and specifically worded to be about choice rather than control. In addition, a number of participants with learning disabilities had some problems with using the term 'control', as this was viewed as pejorative by some, for whom this implied 'being controlled' or having someone 'being controlling of them'. In response to these findings, the wording was amended to exclude the term 'control' and instead use 'choice'. This was tested in the following phase of cognitive testing (See Annexe 3).

The question about choice was the first question tested in the cognitive interviews. The majority (68%) said that they had as much choice as they wanted, five respondents (23%) said they had enough choice and two (9%) said they had some choice but wanted more. All but one respondent appeared to understand the question and respond appropriately. There was some confusion and hesitation, but this appeared to have been due to the fact that this was the first question (Box 30).

### Box 30

Q: So, you've ticked three there, you've ticked the first three boxes. We only ask you to tick one box.

A: Oh okay.

Q: So which one do you think would be the best answer for you? If you think about all the choices that you have.

A: Yeah.

Q: Do you think that you have as much choice as you want, and that is great? Or do you think you have enough choice, it is okay. Or do you think that you have some choice, but you'd like some more? Do you think you can choose just one?

A: Yeah, that one.

Q: That one? So we're going to go for the third one. So just put a cross through those ones. And you're going to go for that third one?

A: Yeah.

Q: Yeah? Okay. So why do you think the third answer? I have some choice, but I would like more. Why do you think you've picked that one? Why is that the best answer for you?

A: I think it gives other, 'cause other people might want more choice, I think more explaining.

*(Participant 19)*

Respondents talked about a variety of experiences, such as choices about what to eat, what to wear, going out, activities and work-related choices (see for example Box 31).

### Box 31

A: That one there, I have as much choice as I want it is great.

Q: Yeah, that top one?

A: Yeah.

Q: Okay. And can I ask what you're thinking about when you're answering that question?

A: I choose which job I like.

Q: You choose which job?

A: Yeah. And I'm allowed to make choices.

(Participant 14)

## 4.1.8 DIGNITY

### Pictures

In the working group it was clear that the images used in the original Easy Read question for dignity were not illustrative of the concept (Annex 4). While members of the group were able to describe what was happening in the images: *"someone has got their hand up and is saying 'wait' because they are busy looking at something else"*, only one member of the group was able to ascertain that this related to a negative illustration of dignity or respect: *"It looks like he's being rude. He is trying to talk and the other person has his hand up and is not listening"*. However, another member took the contrary view and described the image as *"showing respect because the person is waiting their turn to speak"*. One consequence of including a diverse and representative range of characters in the illustrations was that some members of the working group focused on these as a substantial element of the question. Here, for example, one member of the working group focused on the different ethnicities of the illustrated characters and speculated that the question would be about discrimination on the basis of ethnicity. One comment regarding the second (positive) dignity picture assumed that this was showing a scenario where *"someone has passed away, one woman is upset and the other is talking to her"*.

Once the worded question had been revealed, members of the group agreed that the pictures 'made more sense' but maintained the view that they needed to be improved. Specifically, members of the group had difficulty relating the images to being treated 'without dignity', and therefore this 'negative' image was initially withdrawn from testing with individuals in focus groups, and replaced with an image to depict someone being treated 'with dignity' (see Annexe 2).

In focus groups, participants had difficulty with the 'positive dignity' image of a person bringing a cup of tea/coffee to an individual sat down on a sofa. Participants agreed that this picture *"just looks like someone serving someone"* or even invoked notions of one person taking advantage of another, one

participant commented that *“he’s just being lazy because he can’t be bothered to get up and get his own drink – he should go and get his own”*. Participants suggested that to represent dignity *“a picture should show people helping each other, they should be shaking hands or with one arm around someone to show support”*. This view was shared by all in the focus group, and the research team agreed to make further amendments for future groups. An additional ‘positive’ illustration of dignity was developed in conjunction with CHANGE, as well as an additional ‘negative’ one for testing in focus groups. The amended images were re-tested in two focus groups with different participants; they received positive feedback from participants and were taken forward for testing in the cognitive interviews.

Another issue was that the question is about *paid* support, and it was necessary to convey this more clearly in the images. Therefore, amendments were made to accommodate this and provide added clarity.

Cognitive interview respondents generally found the pictures helpful and they seemed to convey the idea of being treated with or without respect (Annexe 3). Many respondents could identify staff in the pictures, although not all (Box 32 & 33).

#### **Box 32**

- A: Yeah, that's the one that goes with the very bottom.  
Q: What do you think is going on here?  
A: The lady she's meant to supporting isn't treating her nicely so, so she's very sad, and upset about it. She's more interested in talking to the other man that's working with her.  
Q: Hmm-hmm. And what about this one?  
A: That's where the lady is treating the man nicely and they're talking to each other, having a cup of tea.

*(Participant 14)*

#### **Box 33**

- Q: What do you think about these pictures?  
A: We'd be sitting round the table chatting to each other.  
Q: Okay. So do you think they're chatting in both pictures?  
A: That one they're not but this one they are.  
Q: Okay, what do you think is happening in this picture?  
A: They're not being very kind to who they're supporting.

*(Participant 4)*

Overall, while the new pictures were an improvement on the previous version (largely by amending illustrations of caregivers to include people in ‘uniforms’), however the issues reflect the difficulties in depicting abstract concepts using Easy Read images.

## Question and responses

Initial discussion in the working group centred on the meaning of 'dignity', which all members appeared to be happy with (see Annexe 1). One member commented that *"dignity is about respecting people"* and another stated that *"you should treat others how you would like to be treated"*. When asked to answer the question in their own words, everyone was able to answer but with agreement that it depends on the context, and to whom the question is referring to. One participant said: *"it depends on what you mean, who is asking the question and who you are talking to"* and this was a common theme among the working group. When asked to select one of the answers, members of the group were able to do this but again context was viewed as important. When asked, participants reported thinking about a range of people and not just paid staff; these included friends, family, people from college, people from the neighbourhood and work colleagues. It was agreed in the working group that some amendments would be made to the wording to clarify who people should be thinking about when answering the question.

During the focus groups a number of people reported having difficulty with the word 'respect' and it was agreed that this would be removed, and the definition of dignity re-worded as 'being treated nicely and kindly' (Annexe 3). Further issues were again reported with context, and as a result a further amendment was made to replace "people who support you" with "paid support" as a broad term to include support workers and personal assistants, the two most common types of support staff among people receiving social care services. Another issue raised was regarding the term 'how people treat you'. Some focus group participants suggested that this could be misinterpreted to mean rewarded or incentivised, therefore this was specifically asked about during the cognitive interview phase. Finally, people with learning disabilities who use social services usually come into contact with more than one paid staff member, who might have a different attitude towards supporting people. Therefore, answering the question requires a high level of generalisation that might be difficult for some respondents with learning disabilities. Although this did not come up in the focus groups as a problem, testing in the cognitive interview paid particular attention to this.

Sixteen respondents answered this question in the cognitive interviews; four respondents had no paid support, one respondent could not select a single response because they were supported by different people who treated them differently, and one person had to leave before the interview finished.

Two out of the 16 who responded said that they were quite happy with their paid support, while the remaining 14 were very happy. The issue of misinterpreting the phrase 'how people treat you' was specifically probed, but none of cognitive interview participants interpreted this as being rewarded or incentivised. The potential difficulty of having to aggregate a response to cover a number of paid support also did not emerge as a problem during cognitive interviewing, but this may be related to relatively high levels of cognitive ability or lack of multiple paid support staff. However, there were some problems with interpreting the question and answers: three participants seemed to interpret the question in terms of general happiness (see for example Box 34 & 35). This might have been due to the primacy effect of answers – focusing on the first part of the answer (I'm very happy) and ignoring the second part ("with the way my paid support treat me").

**Box 34**

- A: I'm happy 'cause I like coming here so.  
Q: Yeah, okay.  
A: Yeah.  
Q: So you're thinking about coming here and the fact that you enjoy coming here?  
A: Yeah.

*(Participant 19)*

**Box 35**

- A: I am happy 'cause I am happy 'cause I do like doing something like if I am happy I know like if I wanted to go out then it's nice 'cause I know how happy I am 'cause I enjoy, I like to visit our friends don't we?

*(Participant 3)*

The other issue was related to understanding the term "paid support". One respondent understood paid support as benefit payment and responded accordingly (Box 36).

**Box 36**

- A: I don't know, one of these two.  
Q: Yeah, one of the top two. What kinds of things are you thinking about when you're thinking about answering?  
A: I don't know. I've got no money for this weekend, I'm poor. My benefits are terrible, my benefits did not go in.

*(Participant 13)*

Another respondent pointed out that they do not pay for their support, although this did not seem to affect their answer (Box 37). Nevertheless, the majority of respondents understood the question and responded appropriately.

**Box 37**

- Q: Okay, that's great. Who were you thinking about when you chose the answer?  
A: I don't pay for my support.  
Q: You don't pay for it, but who were you thinking, do you have only one support worker or are there more people who come in to support you?  
A: Three.  
Q: Three, okay. And when you chose this answer were you thinking about all three of them or just one of them, or two of them?  
A: All three of them.

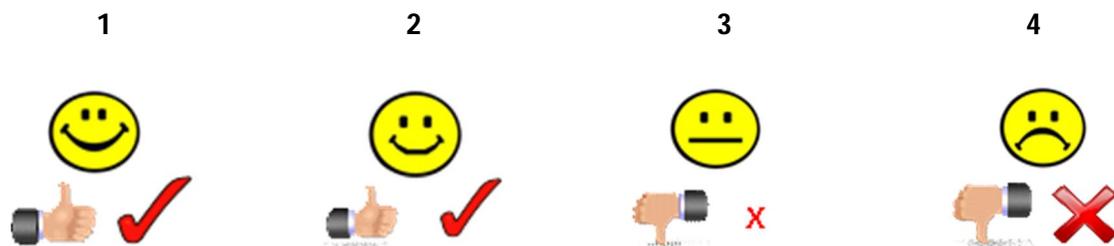
*(Participant 3)*

## 4.2 FINDINGS RELATED TO THE USE OF SCALES AND VISUAL AIDS

A central issue in the use of self-report ratings with people with learning disabilities is whether they can reliably distinguish between the categories and assign themselves to an answer. Therefore, particular attention was paid during focus groups and cognitive interviews to the use of scales.

In terms of the visual representation of response categories, the illustrations that coincided with each category in the original Easy Read questionnaire contained three images to help respondents in choosing an answer: smiley/sad faces; thumbs up/thumbs down; and ticks/crosses (see Figure 2).

**Figure 2 Visual representation of response categories in the original ASCOT-ER**



Initially, working group members thought these were all helpful to people answering the questions. However, when this was probed and the working group began to unpick how the symbols were helpful to people and which (if any) they were predominantly using, unanimously group members stated that they were using the happy/sad faces. Furthermore, a number of members suggested that the ticks/crosses could confuse people as to whether they should put a tick or cross in their chosen response or that they may be encouraged to put ticks/crosses in each of those boxes. Similarly when discussing the thumbs up/thumbs down in more detail, members of the working group explained that they were not able to differentiate between the top two and bottom response categories, and that this could become problematic for respondents when working out which was 'the best' and which was 'the worst' of these answer categories. There was also a major issue identified in relation to the happy/sad faces, namely that the third response category appeared to be 'too neutral' and should in fact be a 'slightly sad' face as this appeared to be in conflict with the meaning of this response category.

In light of these comments, also supported by available Easy Read guidance, it was agreed that the ticks/crosses and thumbs up/thumbs down illustrations would be removed and the happy/sad faces amended for testing in the next phase. The new illustrations were developed in cooperation with CHANGE and included various versions. The aim was to make sure that the images were easy to differentiate and clearly different from each other. The only difference between the version used in focus groups and cognitive interviews was the positioning of the teardrop in image 4 (see Figure 3).

**Figure 3** Visual representation of response categories in the revised ASCOT-ER



To assess if respondents were able to understand and, potentially, use four-item scales, a ranking exercise was conducted in the focus groups (for a description of the method see separate report, Appendix 2). Thirty-one focus group participants completed this task. Sixty-eight per cent of participants (n=21) ordered the show cards correctly from “best” to “worst”, and 71% (n=22) from “most frequent” to “least frequent”. Some participants said they relied on words only, others used both words and pictures, and others pictures only. A common difficulty was distinguishing between “quite” and “very”.

In the focus groups there was no evidence that participants were choosing answers based on their preference for any of the smiley faces. They used the happy/sad faces to support their choice of answer, and the general feedback was that the pictures were helpful. People were familiar with the imagery in everyday situations: for example, many participants reported using smiley/sad faces in text messages etc. Nevertheless, some commented that smiley/sad faces were “childish”, while others highlighted the absence of a neutral response/face as problematic.

We also explored the use of thumbs up/down in some early focus groups, but the general consensus was that happy/sad faces are easier to understand because they are more “standard”.

In the cognitive interviews, happy and sad faces appeared to be useful for many respondents when selecting an answer, and the differences between the four levels were clear (see for example Box 38).

**Box 38**

A: That's where you're extremely happy. That's where, and that's where you're a little happy. That's being sad, and that's being upset.

*(Participant 14)*

However, some respondents found it difficult to distinguish between the four levels, and probing revealed some issues around the use and interpretation of happy/sad faces (Box 39 & 40).

**Box 39**

Q: How did they [smiley faces] help you? What do you think they mean?

A: Does one mean happy?

Q: Happy, and what's the next one?

A: Happy.

Q: Okay, and the next one?

A: Is it happy?

Q: Happy, and what about this one, the last one?

A: Is it happy?

*(Participant 7, top level)*

**Box 40**

A: They're both happy and these are both sad.

Q: Yeah, they're both happy and they're both sad. Is there any difference between these two, the two happy ones?

A: I don't think so, no.

*(Participant 8)*

One respondent liked the very smiley face and commented on this throughout the interview. This has potentially biased their responses (see Box 41). However, there was no sign of similar bias among the other respondents.

**Box 41**

Q: So can I ask you what were you thinking about when you chose that answer?

A: It made me have a smile, it made me happy.

Q: So you were looking here, were you--,

A: Yeah.

Q: At this smiley face?

A: Yeah.

*(Control)*

Q: So what were you thinking about when you chose that answer?

A: I like it all. It's my favourite. My favourite face in the whole world.

Q: The smiley picture is your favourite face?

A: Yeah.

Q: Is that why you're ticking the top one?

A: Yeah.

*(Accommodation)*

A: It's all right. Been a bit awesome.

Q: It's been awesome that one.

A: It is awesome.

Q: Okay. So that top smiley picture is awesome.

A: Yeah.

*(Social participation)*

*(Participant 17)*

### 4.3 VALIDITY OF THE REVISED QUESTIONNAIRE

To analyse the validity of the revised ASCOT-ER questionnaire, two main approaches were used. First, we looked for patterns in responses, particularly respondents who consistently selected the same answers throughout the questionnaire. Four respondents were identified who selected the top answers for all questions. These cases were then analysed in more detail to look for signs of bias or other problems with validity in interview transcripts and interviewer field notes. Two of these respondents were confident readers and had low levels of support: one was getting support in two of the ten areas listed in the participant characteristics form and the other had support in three areas. Both completed the questionnaire with no or minimal help and appeared to be responding appropriately without any evidence of bias in the interviews. They were able to distinguish between the answer options and justified their choice of answers. (Box 42).

**Box 42**

Q: Okay, so for this one you answered, I get all the food and drink I like when I want.

A: Yes, but within the budgeting I've got.

Q: Okay. Yeah, so you have a budget for your--,

A: Yes.

Q: For your food. And so given that you've got a budget you're happy with the food and drink you can get with that? You can get enough food and drink?

A: Sometimes I might go to ASDA to get some more food.

Q: Okay. And what sorts of food and drinks were you thinking about when you answered the question?

A: I like microwave food.

Q: Hmm-hmm.

A: Then sometimes I go out, erm, go to a restaurant, or I'll go to the fish and chip shop.

*(Participant 16)*

The other two respondents were receiving more support – in eight and nine out of 10 areas respectively – and possible bias was noted by interviewers in field notes in both cases. One of these respondents liked the very smiley face, which might have caused biased responding (see Box 41). Field notes for the other respondent highlighted that they “wanted to please and get it right”. They wanted staff to sit in at the interview and kept looking at them for the answers. They also had difficulty distinguishing between the four answer options (see Box 39) and selecting one of them because of relatively higher levels of cognitive impairments (Box 43).

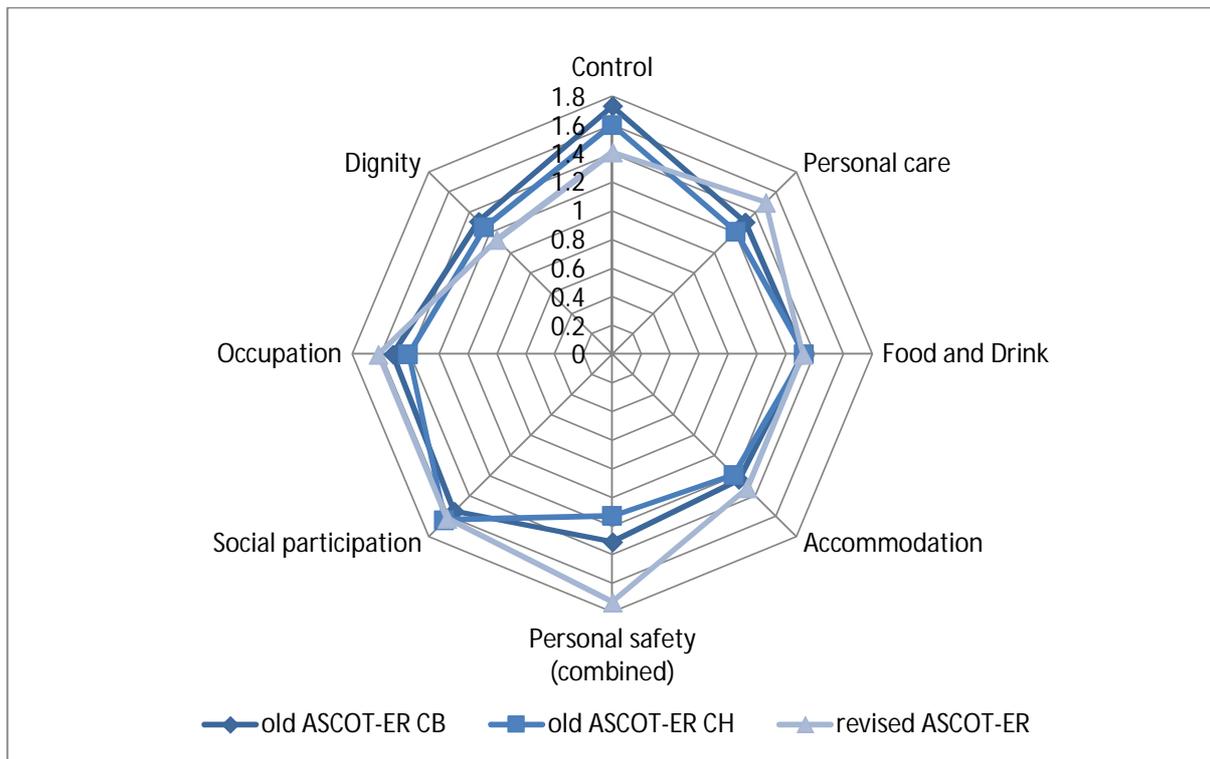
**Box 43**

- Q: Okay, so please tick one box. I feel very presentable. I feel quite presentable, it's okay. I do feel a bit presentable, it could be better, or I do not feel presentable at all, it is really bad.
- A: Presentable.
- Q: Presentable?
- A: Yes.
- Q: So which one would you choose?
- A: Presentable.
- Q: What, I feel very presentable or I feel quite presentable?
- A: Presentable.
- Q: Okay, so having a look here, because this might help you, which one would you pick?
- A: Is it that one?
- Q: Well I don't know, how do you feel? Which one would you choose?
- A: Presentable.
- Q: So yeah, the first one, okay, wonderful. So why did you choose the top one?
- A: Nice and clean isn't it?

*(Participant 7)*

The quantitative analysis of the revised instrument's validity has been limited by the small sample size; therefore any findings presented here must be interpreted with caution. Figure 4 shows that domain scores were broadly similar in ASCS and cognitive interviews, with some notable exceptions: control, safety and personal care. The difference in the number of observations should be noted (ASCS had 5,000+ respondents while the same number was 16-22 in the cognitive interviews).

**Figure 4 Comparison of ASCOT-ER domain scores in the ASCS 2010/11 and 2011/12, and cognitive testing**



**Notes for Figure 4:**

ASCS scores reported by Rand, S. (2013). QORU Engagement (E003) Milestone 1 Report. The Adult Social Care Survey 2010/11 and 2011/12: Easy Read Version. (Unpublished report). ASCOT coding for individual domains is 1=ideal state (best score), 2=no needs, 3=low-level needs, 4=high level needs (worst score). Overall SCROoL score is calculated by reverse scoring domain scores from 0 (worst score) to 3 (best score).

In the revised ASCOT-ER there was no single Safety domain. Single safety score was computed by taking whichever score was higher (worse) for safety at home/safety outside the home newly created domains. Six participants had different scores for safety at home and safety outside the home; five scored worse for safety outside the home.

Cronbach’s alpha, a co-efficient for assessing internal consistency of scales, was 0.634 (n=16) for the revised nine-item questionnaire. This is lower than for the original eight-item ASCOT-ER community-based version ( $\alpha = 0.721$ ) and care home version ( $\alpha = 0.706$ ). While in the original ER questionnaire none of the items would have increased the Cronbach’s alpha value if omitted, in the revised questionnaire there were three such items: food and drink, accommodation and safety outside the home (Table 5). However, it might be argued that quality of life is an inherently multi-dimensional concept and some ASCOT domains are even arguably in tension to some degree (e.g. control and safety).

**Table 5** Item-total statistics for the revised ASCOT-ER

	Corrected item-total correlation	Squared multiple correlation	Cronbach's Alpha if item deleted
Control	.563	.861	.545
Personal cleanliness and comfort	.428	.896	.574
Food and drink	.052	.822	.685
Accommodation	.130	.458	.641
Safety at home	.461	.737	.585
Safety outside the home	.066	.618	.662
Social participation	.528	.914	.537
Occupation	.318	.483	.605
Dignity	.570	.881	.582

## 5 DISCUSSION

The methodology for gathering data and developing the new tool was designed to be inclusive to ensure that, as far as possible, the new Easy Read version of the ASCOT was developed in conjunction with people that could potentially be asked to complete it. At the same time, the project followed the more conventional stages of pre-testing survey instruments with a working group (expert panel) and cognitive testing. Experiences suggest that this worked quite well and it is indeed possible to design and test questionnaires with the involvement of people with learning disabilities. Participants in the working group were also asked to reflect on their experience of being part of the project; an account of this can be found in Appendix 4 and this appeared to have been a positive experience for the group.

Overall, substantial changes and improvements were made to each domain which included changes to illustrations, wording of question stem, wording of answer responses and the visual representation of response categories (i.e. happy/sad faces). On reviewing all changes in the final working group, participants unanimously agreed that the newly developed version was, overall, more accessible and conceptually easier to understand than the previous version. Changes for each domain question are summarised below.

- Control: redesigned pictures; amended wording of question stem; amended wording of response categories; redesigned response category pictures.
- Personal cleanliness and comfort: redesigned pictures; amended wording of question stem to introduce and define 'being presentable'; amended wording of response categories; redesigned response category pictures.
- Food and drink: redesigned single picture; amended wording of question stem; amended wording of response categories; redesigned response category pictures
- Accommodation cleanliness and comfort: redesigned pictures; amended wording of question stem to define 'clean' and 'comfortable'; amended wording of response categories; redesigned response category pictures.
- Safety: question split into two separate questions (safety inside the home and safety outside/in the community); redesigned pictures; amended wording of question stem; amended structure of question; amended wording of response categories; redesigned response category pictures.
- Social participation and involvement: redesigned pictures; amended wording of question stem; amended wording of response categories; redesigned response category pictures.
- Occupation: redesigned pictures; amended wording of question stem; amended structure of question; amended wording of response categories; redesigned response category pictures.
- Dignity: redesigned pictures; amended wording of question stem to introduce paid support element; amended wording of response categories; redesigned response category pictures.

The revised ASCOT-ER questionnaire appeared to work for the majority of cognitive interview respondents but – as expected – not for everyone. It is clear that there is a sizeable group of people with learning disabilities who are not able to self-report subjective quality of life using a structured questionnaire. There was no information about the receptive and expressive language skills of participants or their cognitive abilities (e.g. IQ scores); however, people who were getting more intensive support (e.g. lived in staffed homes, getting support in more areas etc.) clearly had more difficulties with the questionnaire and needed more support to work through the form.

The focus groups and cognitive testing identified some of the difficulties people with learning disabilities had when completing a structured questionnaire. Some people found it difficult to use a four-point scale and, while some of these people might have been able to respond more easily using a three-point scale, for others semi-structured interviews would have worked better. In the focus groups, just over two thirds of the participants could rank four show cards in the correct order from "best" to "worst" and from "most frequent" to "least frequent" (see Chapter 4.2 and Appendix 2). Some limitations should be acknowledged here: notably the task was not performed under laboratory conditions, and some participants might have found the noise and the time pressures distracting. Also, the lack of context for the show cards might have been challenging for some participants.

The cognitive interviews also highlighted potential issues around social desirability and "framing" of answers (Antaki, Young & Finlay, 2002). Respondents were not always selecting from the available answer options, had difficulty assigning themselves to a single option or their selection was not clear (Box 44). This behaviour could create contradictory answers that often end up being discarded as invalid responding (an example of this is people who "misreported" their support arrangements in

the participant characteristics survey) or lead supporters to “help” people select answers and thus potentially create bias.

Other methods for collecting ASCOT data, particularly for individuals with higher levels of cognitive impairment (including the use of a semi-structured interview and an observational approach), are being developed as part of the QORU programme. However, one of the biggest challenges in developing such measures is establishing when to implement such tools and to whom. Such decision making would require some form of pre-administration screening of individual service users to determine their understanding and competence to use the measure (Emerson, Felce & Stancliffe, 2013).

#### **Box 44**

Q1: This question is about being presentable, being presentable means being clean, having clean clothes and feeling comfortable in what you are wearing, how presentable do you feel?

A: I feel good because I've been--, 'cause this morning I had a wash before I got my dressed clothes on so I did do that today so I got--, 'cause I got ready for the day see and then I know that's a simple thing to do isn't it, to get smartened up ready for something today.

Q1: Okay, can I read out the answers maybe you can pick one; I feel very presentable; I feel quite presentable, it is okay; I feel a bit presentable, it could be better; I do not feel presentable at all, it is really bad; so which answer would you choose?

A: Presentable, this one that--, which one's the good one, the one down here?

Q1: No, it's down here, I feel very presentable, or I feel quite presentable, it is okay?

A: It's okay this one, yeah.

*(Participant 3)*

In a recent study, Apps & Malley (forthcoming) showed that having help in responding to surveys had a significant impact across a range of ASCOT domains and total scores for people with physical or sensory impairments and other vulnerable client groups. They found that different sources and types of help had a different impact on outcomes. For example, help from a care worker had the strongest impact, and it was associated with the reporting of more favourable outcomes. Help from outside the household had weaker but still significant effects, and it was associated with less favourable outcomes. They also found that the effect of type of help (e.g. reading, translation, writing the answers etc.) was smaller than the effect of source of help.

Reducing the need for help when completing ASCOT was one of the aims of this project. The majority of cognitive interview respondents (n=16; 73%) said that they would answer the questionnaire with help from family or paid carers, and only six people (27%) said they would complete it without help. This result should be treated with caution given the low number of participants and the hypothetical nature of the question, so would certainly warrant further investigation when used on a much wider scale.

The cognitive interviews also highlighted broader issues around reporting subjective satisfaction by people with intellectual disabilities. Subjective well-being and satisfaction show high levels of stability in individuals over time, and they reflect dispositional traits more than actual life circumstances (Cummins 2003; Hatton 1998). High ratings of subjective satisfaction or well-being can potentially hide poor life circumstances or services (Hatton & Ager 2002), as is illustrated in Box 45.

#### Box 45

Q1: Okay, great. Can you tell me what choices were you thinking about when you picked that answer [top answer]?

A: When [laughs] with the choices that I like, you know like with being on the--, days like we're out like we often choose where we want to go and it's like--, it's like either, it's either one of the places to go otherwise you don't know which one to go for, and like say if I chose to go somewhere like if I'm choosing to go to a dance at night you can't go out in the day 'cause if you choose to go out in the evening instead of going out in the day that's what we've been doing because we've been choosing nights out. I've chose to go to a dance at night 'cause I know in the morning it's like say instead of being out during the morning or the day or whatever they'll like say, "I'm going to pick the evening 'cause it's the evening where we go to a dance at [name] Hall," and I've been like, "Yeah, that's a good thing to go to," 'cause that's an evening out, that's an evening thing to go to 'cause you can't choose both, 'cause you can't go out in a day and go out at night, so that's why I'd rather pick the going out in the evening 'cause you can have a good time.

(Participant 3, top answer)

Iterative testing can often lead to the temptation to continue the process, constantly making minor changes and adjustments while potentially not making any significant further progress or improvements, even after the fieldwork phase has been completed. This is perhaps acutely the case when targeting a cohort of people with varied and complex needs, such as individuals with learning disabilities and/or autism. Here, cognitive interviews highlighted some issues that could indeed warrant further investigation in the revised ASCOT-ER questionnaire. These are:

- Pictures for the *Control over daily life* domain. Illustrating abstract concepts in an Easy Read format is particularly challenging. Preliminary analyses of the previous Easy Read version of ASCOT to explore the construct validity and internal reliability in the *Interpreting the Impact of Adult Social Care (IIASC)* study highlighted that the *Control* domain would require some further work to ensure that it does fall within the construct of care-related quality of life (Rand, 2014). Overall, the revised pictures for the *Control* question worked relatively well in

the pre-tests (see also Figure 4 and Table 5), but could potentially benefit from further testing in the next phases.

- Additional sentences for answer options (i.e. "It is great" etc.). These were confusing for some participants in the final phase of cognitive testing. However, these are used to distinguish between scale points.
- Use of the phrase "enough of" in the *Food* domain. This can be confusing for some respondents. Further work could explore alternatives that appropriately reflect the content of the domain.

Inevitably, people will have different preferences for general style, colour, size and so on, so it is important to recognise this and acknowledge that the aim here is to develop something that 'most' of the targeted population can use and respond to. These findings suggest that the changes and amendments made to the ASCOT-ER constitute an improved version that is fit for purpose among people with learning disabilities who can provide self-report data.

There were some limitations of this work to consider. It has been recognised that methods used to conduct cognitive interviews can influence the data produced (DeMaio & Landreth, 2004; Presser, Couper et al., 2004). Interviewers' contributions can shape interviews by providing confirmation, functional remarks, expansive probes and feedback, as well as re-orientate and keep respondents motivated (Presser, Couper et al., 2004). The probes and remarks of a skilled interviewer might have helped some people to remain motivated and provide valid responses to the questionnaire (Box 46).

This was a small-scale study and participants were not representative of the population of social care users who would receive ASCOT as part of the Adult Social Care Survey. Because the main aim was to cognitively test the questionnaire, participants were potentially more able than the general service user population.

#### Box 46

- Q: What did you think about the form?
- A: For me, without your help it would have been a bit hard for me to go through it.
- Q: Okay. Why is that? Just to stop you on that point. Why would it be hard for you to do without support?
- A: Because some, er, the writing's not big enough for me to see.
- Q: So you would need bigger writing?
- A: Yes.
- Q: Hmm-hmm.
- A: And some, without your explanation, some of the questions that you have asked were a little bit difficult.
- Q: Hmm.
- A: And that you really had to think about.
- Q: Hmm-hmm.
- A: Not just think, oh right yeah, I'll tick that and say that.

*(Participant 15)*

Cognitive testing and the growing body of literature on self-report by people with learning disabilities has also highlighted two areas where future work could potentially improve the validity and reliability of ASCOT-based surveys. It remains to be seen whether the revised questionnaire has reduced the need for external help; however, a large proportion of respondents with learning disabilities are likely to require some form of help. There is increasing evidence that external help can be a source of bias in self-report by people with learning disabilities. Therefore, developing clear guidance (e.g. prompts etc.) for those who help respondents could have the potential to improve validity. Also, the level of help required by respondents with learning disabilities can vary greatly and even with adequate help some people will not be able to respond to a self-report questionnaire. Introducing some form of screening to identify these respondents and using alternative ASCOT instruments (i.e. informant-based, observational etc.) could potentially improve validity. Whether such screening is feasible within a large national survey implemented by local authorities needs careful consideration.

## 6 CONCLUSION

The aim of this project was to develop and (cognitively) test an Easy Read version of ASCOT. This work started with the preliminary version of ASCOT-ER. Our findings suggest that the ASCOT-ER has made it easier for people with learning disabilities to interpret and answer the questions. In this way, the research contributes to the aim of improving the engagement of groups of people that are under-represented in the evidence and in the Adult Social Care Survey.

Findings also indicate that the revised Easy Read version adequately represents the ASCOT domains and the standard questionnaire. However, ASCOT-ER might benefit from further systematic testing, particularly around validity and reliability. Whilst there has been work to establish the construct validity of the core (non-ER) version of ASCOT, there may be questions as to (a) whether the revisions made to produce an ER version impact on validity, and (b) whether ASCOT (in ER form) is valid for people with learning disabilities. Therefore, proposed future work would include exploring the construct validity of ASCOT-ER by looking at the relationship between responses to the individual items and other indicators that we would expect to be theoretically related to these concepts (e.g. other quality of life and wellbeing measures). This could be done through systematic use of the tool, linking with the development of ASCS to ensure the results drew on and informed the survey as well as the ASCOF.

Ideally, the use of this ER version of the ASCOT questionnaire should not only improve response rates in the ASCS but also help to ensure that what is being communicated (by all respondents) better reflects the underlying aims of the instrument.

## REFERENCES

- Antaki, C., Young, N., & Finlay, M. (2002). Shaping Clients' Answers: departures from neutrality in care-staff interviews with people with a learning disability. *Disability & Society, 17*(4), 435-455.
- Apps, M., & Malley, J. (forthcoming). *The effect of help in completing the Adult Social Care Survey 2011 on Adult Social Care Outcome Framework indicators*. Personal Social Services Research Unit, University of Kent. Canterbury.
- Atkinson, A. (2005). Atkinson review: final report. *Measurement of government output and productivity for the National Accounts*. Basingstoke.
- Beadle-Brown, J., Ryan, S., Windle, K., Holder, J., Turnpenny, A., Smith, N., Richardson, L. & Whelton, B. (2012) *Engagement of people with long term conditions in health and social care research: Barriers and Facilitators to capturing the views of seldom heard populations*. Canterbury.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Cabinet Office (2010). *Inclusion health: Improving the way we meet the primary health care needs of the socially excluded*. London.
- Collins, D. (2003). Pretesting survey instruments: an overview of cognitive methods. *Quality of Life Research, 12*(3), 229-238.
- Department of Health (2010). *Transparency in outcomes: a framework for adult social care*. London.
- Cummins, R. A. (2003). Normative life satisfaction: Measurement issues and a homeostatic model. *Social indicators research, 64*(2), 225-256.
- DeMaio, T. J., & Landreth, A. (2004). Do different cognitive interview techniques produce different results?. In.: Presser, S., Rothgeb, J. M., Couper, M. P., Lessler, J. T., Martin, E., Martin, J., & Singer, E. (2004). *Methods for testing and evaluating survey questionnaires* (Vol. 546). John Wiley & Sons. 89-108.
- Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and developmental disabilities, 51*(5), 333-348.
- Finlay, W.M., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*(3), 319-335.
- Finlay, W.M., & Lyons, E. (2002). Acquiescence in Interviews with People Who Have Mental Retardation. *Mental Retardation, 40*(1), 14-29.
- Forder, J., Malley, J., Rand, S., Vadean, F., Jones, K. & Netten, A. (2014). Identifying the impact of adult social care: Interpreting outcome data for use in the Adult Social Care Outcomes Framework. PSSRU Discussion Paper No. 4633. Personal Social Services Research Unit, University of Kent. Canterbury.

Hartley, S.L., & MacLean, W.E. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research*, 50(11), 813-827.

Hatton, C. (1998). Whose quality of life is it anyway? Some problems with the emerging quality of life consensus. *Mental retardation*, 36(2), 104-115.

Hatton, C., & Ager, A. (2002). Quality of life measurement and people with intellectual disabilities: a reply to Cummins. *Journal of Applied Research in Intellectual Disabilities*, 15(3), 254-260.

Heal, L.W., & Sigelman, C.K. (1995). Response biases in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research*, 39(4), 331-340.

Heal, L.W., & Sigelman, C.K. (1996). Methodological issues in quality of life measurement. In: Schalock, R. (1996). *Quality of life: conceptualization and measurement*. Vol. 1, 91-104. AAMR.

Krosnick, J.A. (1991). Response strategies for coping with the cognitive demands of attitude measures in surveys. *Applied Cognitive Psychology*, 5(3), 213-236.

Krosnick, J.A., Presser, S. (2010). Question and Questionnaire Design. in: *Handbook of Survey Research*. 2nd edition. Emerald. pp.263-313.

Makai, P., Brouwer, W.B.F., Koopmanschap, M.A., Stolk, E. A., & Nieboer, A.P. (2014). *Quality of life instruments for economic evaluations in health and social care for older people: A systematic review*. *Social Science & Medicine* 102(0): 83-93.

Netten, A., Burge, P., Malley, J., Potoglou, D., Towers, A. M., Brazier, J., Flynn, T., & Forder, J. (2012). *Outcomes of social care for adults: developing a preference-weighted measure*. *Health Technology Assessment*, vol 16, no 16.

Oldreive, W., & Waight, M. (2013). Enabling access to information by people with learning disabilities. *Tizard Learning Disability Review*, 18(1), 5-15.

Presser, S., Couper, M. P., Lessler, J. T., Martin, E., Martin, J., Rothgeb, J. M., & Singer, E. (2004). Methods for testing and evaluating survey questions. *Public Opinion Quarterly*, 68(1), 109-130.

Presser, S., Rothgeb, J. M., Couper, M. P., Lessler, J. T., Martin, E., Martin, J., & Singer, E. (2004). *Methods for testing and evaluating survey questionnaires* (Vol. 546). John Wiley & Sons.

Rand, S.(2014). *The Construct Validity and Internal Reliability of the ASCOT Easy Read Measure of Social Care-related Quality of Life*. *Internal Draft Paper 4858*. PSSRU, University of Kent. Canterbury

Rapley, M., & Antaki, C. (1996). A conversation analysis of the 'acquiescence' of people with learning disabilities. *Journal of Community & Applied Social Psychology*, 6(3), 207-227.

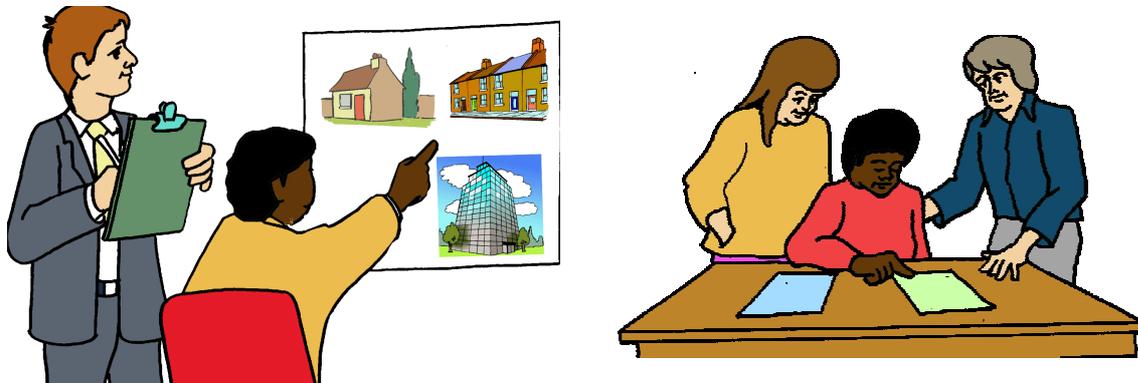
Schlosser, R., & Sigafoos, J. (2002). Selecting graphic symbols for an initial request lexicon: Integrative review. *Augmentative and Alternative Communication*, 18(2), 102-123.

Smith, T.W. (2004). Developing and evaluating cross-national survey instruments. In. Presser, S., Rothgeb, J. M., Couper, M. P., Lessler, J. T., Martin, E., Martin, J., & Singer, E. (2004). *Methods for testing and evaluating survey questionnaires* (Vol. 546). John Wiley & Sons. 431-452.

Turnpenny, A., & Richardson, L. (2014). *How to produce Easy Read information. A review of available guidance*. Tizard Centre, University of Kent. Canterbury. (internal draft paper)

Walmsley, J. (2010). Access in mind: A review of approaches to accessible information for people with learning disabilities. In. Seale, J., & Nind, M. (Eds.). (2010). *Understanding and promoting access for people with learning difficulties: Seeing the opportunities and challenges of risk*. Abingdon: Routledge.

### Control over daily living



**1. How much control do you have in your life?**

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

Please tick (✓) 1 box

I make all the choices I want



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



I make some choices but not enough



I do not get to make any choices



## Personal Cleanliness and comfort



2. When it comes to keeping clean, and how you look (for example your clothes or your hair) how do you feel?

Please tick (✓) 1 box

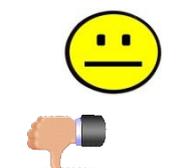
I feel clean and I like the way I look



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



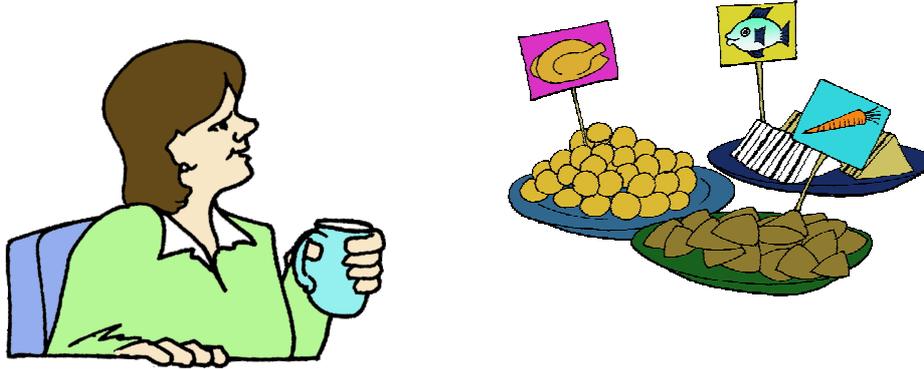
I feel a bit clean and tidy, but not enough



I do not feel at all clean or tidy



## Food and Nutrition



### 3. What do you get to eat and drink?

Please tick (✓) 1 box

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



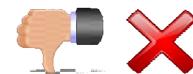
I get enough food and drink



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



I do not get all the food and drink I need, and I think this might make me ill



## Accommodation



### 4. What do you think about your home?

Please tick (✓) 1 box

My home is as clean and nice as I want



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



My home is not clean or nice enough



My home is not at all clean or nice



## Safety



### 5. How safe do you feel?

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

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

Please tick (✓) 1 box

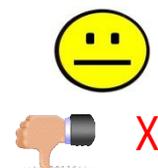
I feel very safe



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



I do not feel safe enough



I do not feel safe at all



## Social participation and involvement



### 6. How do you feel about your social life?

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

Please tick (✓) 1 box

I see my friends and family as much I want



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



I do see friends and family, but not enough



I feel lonely because I do not see my friends and family



very much or at all

## Occupation



### 7. How do you spend your time?

When you are thinking about how you spend your time, please include:

- anything you like doing
- work, whether you get paid for it or not
- looking after others.

Please tick (✓) 1 box

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



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



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



I do not do any things I like



## Dignity



### 8. How do you feel about the way other people treat you?

Please tick (✓) 1 box

The way I am helped and treated makes me feel better about myself



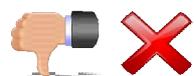
The way I am helped and treated does not change the way I feel about myself



The way I am helped and treated sometimes makes me feel a bit bad about myself



The way I am helped and treated makes me feel very bad about myself





This question is about control over your daily life.

Control means that you can choose what to do.

It also means that you can decide when to do things.

**How much control do you have over your daily life?**

Please tick (✓) 1 box

I have as much control as I want. It is great.



I have enough control. It is OK.

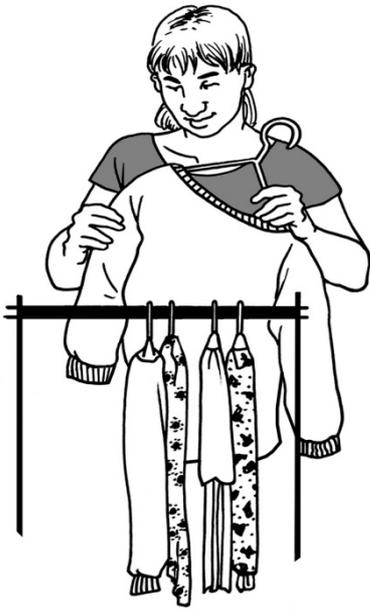


I have some control. But I would like more.



I have no control. It is bad.





This question is about being presentable.

Being presentable means being clean, having clean clothes and feeling comfortable in the clothes you are wearing.

### How presentable do you feel?

Please tick (✓) 1 box

I feel very presentable.

I feel quite presentable. It is OK.

I do feel a bit presentable. It could be better.

I do not feel presentable at all. It is really bad.



This question is about what you eat and drink. Think about if:

- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

**What do you think about what you eat and drink?**

Please tick (✓) 1 box

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

I get some of the food and drink I like when I want.

I do not get all the food and drink I like when I want.

I do not get any of the food and drink I like so I might get ill.



This question is about how clean and comfortable your home is.

Having a clean home means that the kitchen, bathroom, bedrooms and all other rooms are clean and tidy.

Having a comfortable home means that you like how your home looks and feels.

### **How clean and comfortable is your home?**

Please tick (✓) 1 box

- |  |                          |   |
|--|--------------------------|---|
| My home is as clean and comfortable as I want. | <input type="checkbox"/> |  |
| My home is quite clean and comfortable.        | <input type="checkbox"/> |  |
| My home is not clean and comfortable enough.   | <input type="checkbox"/> |  |
| My home is not clean and comfortable at all.   | <input type="checkbox"/> |  |



This question is about how safe you feel at home.

Feeling safe means that you are not worried about:

- Being bullied or abused.
- Falling or getting hurt.
- Being attacked or robbed.

### How safe do you feel at home?

Please tick (✓) 1 box

I feel very safe at home.



I feel quite safe at home.

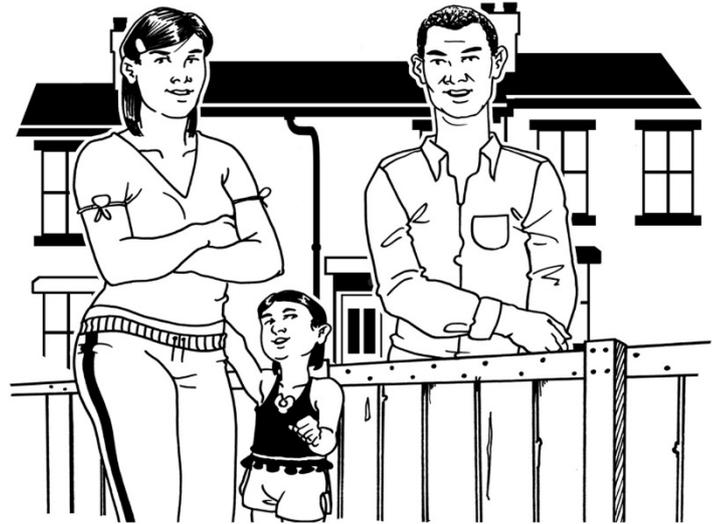


I do not feel safe enough at home.



I do not feel safe at all at home.





This question is about feeling safe when you go out.

Feeling safe means that you are not worried about:

- Being bullied or abused.
- Falling or getting hurt.
- Being attacked or robbed.

**How safe do you feel when you go out?**

Please tick (✓) 1 box

I always feel safe.



I feel safe most of the time.



I feel safe some of the time.



I never feel safe.





This question is about your social life.

Social life means spending time with people you like.

This could be friends, family or people in your community.

**How do you feel about your social life?**

Please tick (✓) 1 box

I see the people I like as much as I want. It is great.

I see the people I like sometimes. It is OK.

I see the people I like but not enough. It could be better.

I do not see the people I like at all. And I feel lonely.



This question is about how you spend your time.

Think about all the things you do during the day. For example:

- Gardening.
- Cooking.
- Going to work.
- Playing a sport.

Think about if:

- You can choose the things you do.
- You enjoy the things you do.
- You have enough things to do.

**How do you feel about the way you spend your time?**

Please tick (✓) 1 box

I spend my time how I want. It is great.



I do enough of the things I like. It is OK.



I do some of the things I like. But I would like to do more.



I do not do the things I like. It is really bad.





This question is about dignity.

Dignity means being treated nicely and with respect.

**How do you feel about the way people who support you treat you?**

Please tick (✓) 1 box

I am very happy with the way people treat me.



I am quite happy with the way people treat me.



I am a bit unhappy with the way people treat me.



I am very unhappy with the way people treat me.



Control over daily life



This question is about choice in your daily life.

Having choice means that you can decide what to do.

Think about the choices you have.

**How do you feel about choice in your daily life?**

Please tick (✓) 1 box

I have as much choice as I want. It is great.



I have enough choice. It is OK.



I have some choice. But I would like more.



I have no choice. It is bad.





This question is about being presentable.

Being presentable means being clean, having clean clothes and feeling comfortable in what you are wearing.

**How presentable do you feel?**

Please tick (✓) 1 box

I feel very presentable.



I feel quite presentable. It is OK.



I feel a bit presentable. It could be better.



I do not feel presentable at all. It is really bad.





This question is about what you eat and drink. Think about if:

- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

**What do you think about what you eat and drink?**

Please tick (✓) 1 box

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

I get enough of the food and drink I like when I want.

I get some of the food and drink I like when I want, but not enough.

I do not get any of the food and drink I like so I might get ill.

*Accommodation cleanliness and comfort*



This question is about how clean and comfortable your home is.

Having a clean home means that the kitchen, bathroom, bedrooms and all other rooms are clean and tidy.

Having a comfortable home means that you like how your home looks and feels.

**How clean and comfortable is your home?**

Please tick (✓) 1 box

- |  |                          |   |
|--|--------------------------|---|
| My home is as clean and comfortable as I want. | <input type="checkbox"/> |  |
| My home is quite clean and comfortable.        | <input type="checkbox"/> |  |
| My home is not clean and comfortable enough.   | <input type="checkbox"/> |  |
| My home is not clean and comfortable at all.   | <input type="checkbox"/> |  |

*Safety inside the home*



This question is about how safe you feel in your home.

Feeling safe means that you are not worried about:

- Being bullied or abused.
- Falling or getting hurt.
- Being attacked or robbed.

**How safe do you feel in your home?**

Please tick (✓) 1 box

I feel very safe in my home.

I feel quite safe in my home.

I do not feel safe enough in my home.

I do not feel safe at all in my home.



This question is about feeling safe when you go out in your local area.

Feeling safe means that you are not worried about:

- Being bullied or abused.
- Falling or getting hurt.
- Being attacked or robbed.

**How safe do you feel when you go out?**

Please tick (✓) 1 box

I feel very safe when I go out.	<input type="checkbox"/>	
I feel quite safe when I go out.	<input type="checkbox"/>	
I do not feel safe enough when I go out.	<input type="checkbox"/>	
I do not feel safe at all when I go out.	<input type="checkbox"/>	

*Social participation*



This question is about your social life.

Social life means spending time with people you like.

This could be friends, family or people in your community.

**How do you feel about your social life?**

Please tick (✓) 1 box

I see the people I like as much as I want. It is great.

I see the people I like sometimes. It is OK.

I see the people I like but not enough. It could be better.

I do not see the people I like at all. And I feel lonely.

Occupation



This question is about how you spend your time.

Think about all the things you do during the day. You could think about:

- Your free time.
- Going to work, college, or volunteering.
- Housework.

Think about if:

- You can choose the things you do.
- You enjoy the things you do.
- You have enough things to do.

**How do you feel about the way you spend your time?**

Please tick (✓) 1 box

I spend my time how I want. It is great.



I do enough of the things I like. It is OK.



I do some of the things I like. But I would like to do more.



I do not do the things I like. It is really bad.



*Dignity*



This question is about dignity.

Dignity means being treated nicely and kindly.

**How do you feel about the way your paid support treat you?**

Please tick (✓) 1 box

- I am very happy with the way my paid support treat me.  
- I am quite happy with the way my paid support treat me.  
- I am a bit unhappy with the way my paid support treat me.  
- I am very unhappy with the way my paid support treat me.  