

# Kent Academic Repository

## Full text document (pdf)

### Citation for published version

Turnpenny, Agnes and Caiels, James and Whelton, Beckie and Richardson, Lisa and Beadle-Brown, Julie and Crowther, Tanya and Forder, Julien E. and Apps, Joanna and Rand, Stacey (2016) Developing an Easy Read version of the Adult Social Care Outcomes Toolkit. *Journal of Applied Research in Intellectual Disabilities*, 31 (1). e36-e48. ISSN 1360-2322.

### DOI

<https://doi.org/10.1111/jar.12294>

### Link to record in KAR

<http://kar.kent.ac.uk/58659/>

### Document Version

Author's Accepted Manuscript

#### Copyright & reuse

Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

#### Versions of research

The version in the Kent Academic Repository may differ from the final published version.

Users are advised to check <http://kar.kent.ac.uk> for the status of the paper. **Users should always cite the published version of record.**

#### Enquiries

For any further enquiries regarding the licence status of this document, please contact:

[researchsupport@kent.ac.uk](mailto:researchsupport@kent.ac.uk)

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at <http://kar.kent.ac.uk/contact.html>

## DEVELOPING AN EASY READ VERSION OF THE ADULT SOCIAL CARE OUTCOMES TOOLKIT (ASCOT)

Agnes Turnpenny<sup>1\*</sup>, James Caiels<sup>2</sup>, Beckie Whelton<sup>1</sup>, Lisa Richardson<sup>1</sup>, Julie Beadle-Brown<sup>1</sup>, Tanya Crowther<sup>3</sup>, Julien Forder<sup>2</sup>, Joanna Apps<sup>4</sup>, Stacey Rand<sup>2</sup>

### **Author information:**

<sup>1</sup> Tizard Centre, University of Kent, Canterbury, UK

<sup>2</sup> Personal Social Services Research Unit, University of Kent, Canterbury, UK

<sup>3</sup> NatCent Social Reserch, London, UK

<sup>4</sup> Canterbury Christ Church University, Canterbury, UK

### **\* Corresponding author:**

Any correspondence should be directed to Agnes Turnpenny, Tizard Centre, University of Kent, Canterbury CT2 7LR, UK (e-mail: [A.V.Turnpenny@kent.ac.uk](mailto:A.V.Turnpenny@kent.ac.uk)).

### **Disclaimer:**

This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

### **Acknowledgements:**

We would like to thank everyone who participated in focus groups and cognitive interviews, as well as the organisations that helped to organise and host these. We would also like to thank all the members of the working group who are: Allan Finn, Gareth Bailey, Kevin Saxton, Mark Flavell, and Jason Robson. Special thanks also to Karen Smeed from Tuck by Truck for helping to facilitate these sessions, to CHANGE for developing the new pictures, and to Juliette Malley, Ann Netten, Ann-Marie Towers and Nick Smith for providing additional support and expertise on ASCOT.

**Key words:**

ASCOT, quality of life, intellectual disability, autism, Easy Read, survey

**Abstract***Background*

This paper reports the experiences of developing and pre-testing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT) for self-report by people with intellectual disabilities.

*Method*

The study has combined survey development and pre-testing methods with approaches to create accessible information for people with intellectual disabilities. A working group assisted researchers in identifying appropriate question formats, pictures and wording. Focus groups and cognitive interviews were conducted to test various iterations of the instrument.

*Results*

Substantial changes were made to the questionnaire, which included changes to illustrations, the wording of question stems and response options.

*Conclusions*

The process demonstrated the benefits of involving people with intellectual disabilities in the design and testing of data collection instruments. Adequately adapted questionnaires can be **useful tools** to collect information from people with intellectual disabilities in survey research; however its limitations must be recognised.

## 1 Introduction

Most research underpinning the evidence-base of policy and practice in health and social care tends to favour groups that can access and understand information more easily: people who are able to respond to standardised interviews and communicate their thoughts (Beadle-Brown *et al.* 2012). Although inclusive research has been rapidly growing since the early 2000s, the inclusion of the views of people with intellectual disabilities in large surveys remains uncommon (Williams *et al.* 2015). It requires, among other things, robust but adapted data collection techniques. This paper aims to contribute to these by adapting and improving an existing measure for use by people with intellectual disabilities and autism.

The Adult Social Care Outcomes Toolkit (ASCOT) (Malley *et al.* 2012; Netten *et al.* 2012; Makai *et al.* 2014) is a standardised tool used to collect data on adult social care outcomes. It measures social care-related quality of life in eight domains: control over daily life; dignity; food and drink; accommodation cleanliness and comfort; occupation; personal cleanliness and comfort; personal safety; social participation and involvement. As far as possible it seeks views from service users themselves and is based on the idea that those in the best position to comment on whether services are meeting a given need are the persons in receipt of those services (<http://www.pssru.ac.uk/ascot/>). The ASCOT is used as part of the Personal Social Services Adult Social Care Survey (ASCS) in England, an annual postal survey of service users (<http://www.hscic.gov.uk/socialcare/usersurveys/>).

There is an existing Easy Read version of ASCOT that has been used in the ASCS since 2010/2011 (<http://www.hscic.gov.uk/socialcare/usersurveyguide1011>). This was developed under time constraints and with the aim of minimising changes to the wording of the main ASCOT questionnaire. New Easy Read guidance published since then (Department of Health 2010b) as well as feedback from local authorities and survey participants suggested that a revision of the questionnaire was timely and justified to make it more user-friendly (e.g. HSCIC 2015, p. 8 and p. 18).

This paper reports the experiences of developing and pre-testing a new Easy Read version of ASCOT. The main purpose of this paper is to describe the inclusive process of developing an Easy Read questionnaire with the support and input from people with intellectual disabilities.

## 2 Background

It is estimated that up to 90% of people with intellectual disabilities have communication difficulties, with around half of these thought to have significant communication deficits (Baker *et al.* 2010). Communication problems can affect expressive, understanding, as well

as functional and social interaction skills (Bradshaw 2011, pp. 96-97). However, there is a dearth of robust and contemporary prevalence figures.

The challenges of using self-report questionnaires with people with intellectual disabilities are well documented in the literature (e.g. Finlay & Lyons 2001; Finlay & Lyons 2002). The use of complex sentence structures – such as passive voice and negatively worded structures; ambiguous wording in question phrasing; difficult, long or unfamiliar words – is likely to be challenging. Difficulties can also arise with questions that require a judgement or recall of time, frequency, degrees or quantities, and direct comparisons. Socially reflexive questions, abstract concepts and generalised judgements as well as unfamiliar content can also be problematic (Finlay & Lyons 2001). Fitting responses into pre-defined answer options requires abstract thinking, so it is potentially difficult for some people with intellectual disabilities.

Written self-report questionnaires can present particular challenges for people with intellectual disabilities, some of whom might have limited or no literacy (Katims 2001). Reading is a complex skill that involves lexical decoding as well as literal and inferential comprehension (Fajardo et al. 2014). Previous research has shown that reading is a specific area of difficulty for many individuals with intellectual disabilities (Conners 2003).

Thus, written questionnaires often have to be presented orally for people with intellectual disabilities. Certain question formats are less suitable for oral presentation, which in itself can be challenging as it requires consistently high levels of attention as well as matching the speed of their cognitive processing to the speed of speech delivery (Cummins 2005). The use of external help to read or interpret questions can also result in social desirability bias in reporting potentially sensitive content (Krosnick & Presser 2010).

Various strategies have been recommended to improve the validity of responding by people with intellectual 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). Additional explanations by interviewers or other sources of support can also reduce task difficulty; however, they might introduce bias and raise issues around social desirability, compliance and validity (Antaki *et al.* 2002; Elliott *et al.* 2008). The screening of respondents with intellectual disabilities has also been highlighted as a way of improving the validity and reliability of data by only including those who have the ability to respond appropriately (Finlay & Lyons 2001; 2002; Hartley & MacLean 2006).

Making information easier to understand for people with intellectual disabilities is increasingly seen as a personalised process (Oldreive & Waight 2013; Goodwin *et al.* 2015). Buell (2015) notes three key issues in relation to the design and delivery of accessible information. First, the importance of good design: the analysis of the intended target

audience and the inclusion of their representatives in the production team. Second, the way people understand information and ideas is a complex cognitive process that is unique for each individual based on their personal experiences, linguistic and cognitive abilities. Finally, Buell highlights the heterogeneity of the target audience and warns that “over-reliance on a universal design is unrealistic and probably ineffective” (p. 88). Features that might be helpful for some people can be problematic for others (Finlay & Lyons 2001).

Ways of making information accessible include the use of video and audio materials, face-to-face communication and Easy Read materials (Oldreive & Waight 2013; Walmsley 2010, 2013). Easy Read is characterised by plain language, simple layout and format, and the use of images to illustrate key messages in the text. There are no common standards for producing Easy Read information, although there are national and international guidelines (e.g. Department of Health 2010b; Inclusion Europe 2014). Easy Read publications can be found in a variety of formats and styles: the most common being black and white drawings and photographs. Images can be used to illustrate single words or concepts as well as abstract or complex ideas – a whole sentence or a paragraph. Different groups or organisations express a preference for different styles (i.e. photographs or drawings). However, there is a lack of robust, empirical research to support the use of Easy Read and available evidence on the effectiveness of different modalities and formats is limited and inconclusive (Fajardo *et al.* 2014; Hurtado *et al.* 2014). A common criticism is that Easy Read information favours more able individuals and it is inaccessible to large groups of people with more severe intellectual disabilities (Goodwin *et al.* 2015; Oldreive & Waight 2013).

### **3 Aims**

The aim of this study was to develop and test a new version of the ASCOT Easy Read questionnaire (ASCOT-ER), building on an initial (un-tested) version. Specifically, the aim was to create an instrument that is easy to understand and minimises task difficulty for respondents with intellectual disabilities.

Having help to complete outcome measures is one way to enable people to take part and ‘have a voice’ but this can also create bias. So another aim of this study was to reduce the need for help as far as possible.

### **4 Methods**

There is little information in the literature on the best ways to develop or adapt surveys and questionnaires for self-report for people with intellectual disabilities. This project has combined conventional survey development and pre-testing methods (Collins 2003) with approaches to create accessible information. The project received a favourable ethical

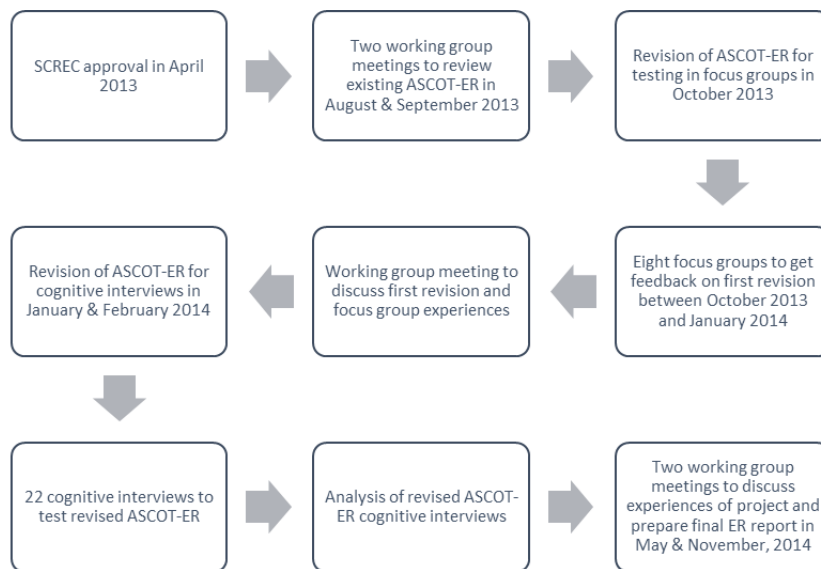
opinion from the Social Care Research Ethics Committee in England (Reference: 13/IEC08/0015).

Given the main use of the Easy Read ASCOT questionnaire in large scale postal surveys, the use of Easy Read format with plain text and pictures seems appropriate and justified. Based on theoretical and practical considerations it was decided that black and white drawings would be used in the questionnaire. Grove (2014) argues that photographs of actual people can be distracting because users have to learn to substitute a more abstract idea; therefore, graphic images can be less confusing for abstract ideas. From a practical point of view, black and white graphic images are easier to reproduce in high quality than photographs. The research team worked with CHANGE, an organisation led by people with disabilities, to develop illustrations for the revised questionnaire. The aim was to identify or – where necessary – create images that are easily guessable and convey the content of each domain (Dada, Huguet & Bornman 2013).

The study used the existing version of ASCOT-ER as the starting point and then employed various qualitative methods to redesign and cognitively test the revised instrument (see Fig. 1):

- 1) A working group consisting of people with intellectual disabilities and/or autism and acting as an expert panel assisted researchers in identifying appropriate question formats, pictures and wording in various iterations of the instrument. The purpose of the first working group session was to review the existing ASCOT-ER and make an assessment regarding its usability among people with an intellectual disability and autism. The second working group focussed on making changes based on this initial assessment for testing in the focus groups. Then, each stage of testing was followed by presenting subsequent findings to the working group (third and fourth sessions) and discussing suggested changes as a result of these findings. The fifth and final working group session discussed the final report and reflected on the experiences of being involved in the project.
- 2) Eight focus groups with a total of 32 participants with an intellectual disability and/or autism were conducted to gain feedback on the first revision of the ASCOT-ER. Each focus group tested two or three domains – using the approach described in the *Methods* section – and each domain was tested at least twice in different focus groups.
- 3) Twenty-two one-to-one cognitive interviews were conducted with people with an intellectual disability and/or autism in testing the second revision of the instrument.

**Figure 1: Main project phases**



### *Recruitment and characteristics of participants*

All participants, including the working group, were recruited through self-advocacy organisations and service providers for people with intellectual disabilities in the South East of England. They all had capacity to consent, could express themselves verbally and were able to contribute to discussions in English.

The working group consisted of five men with an intellectual disability or autism. They had different levels of needs and abilities: some of them lived independently with minimal help, and others had more support. Two people were unable to read. Information about the characteristics of focus group and interview participants was gathered using a self-report (Easy Read) questionnaire (Table 1).

[Table 1 about here](#)

### *Working methods*

A 'staggered reveal' approach was designed to provide a structured format to facilitate working group and focus group discussions. It consisted of first showing participants only the picture that was associated with a question, then the picture and the question stem without the response options, and lastly the whole item (question stem and responses). These were shown to each participant on separate sheets of paper with each 'reveal' (turning over to next sheet) gradually containing more of the question in its entirety. Each



stage involved questions about the adequacy of the pictures, and the clarity of questions and answers. This enabled researchers to consistently structure notes, analysis and feedback from participants and helped both researchers and participants to focus on and consider each element of the question i.e. pictures, question stem and question response options. It also helped to explore, in a systematic way, difficulties in understanding and cognitive processing.

A ranking task was carried out before focus group discussions that aimed to explore whether participants were able to use four-point visual scales adequately. People were asked to order two sets of four show cards starting from “best” to “worst” and “most frequent” to “least frequent” without any context. All show cards had happy or sad faces and text (Fig. 2).

The cognitive interviews used a face-to-face semi-structured interview format and were conducted by the research team. Traditionally, cognitive interviews combine “think-aloud” prompts with probing questions (Presser, Couper *et al.* 2004). However, the two techniques put different cognitive demands on respondents; “think-aloud” techniques are considered cognitively more demanding than probing questions (Collins 2003). Here, all “think-aloud” prompts were followed up by probing questions to explore respondents’ understanding of the questions, and how and why particular answers were selected.

Working group and focus group discussions as well as cognitive interviews were audio-recorded with participants’ permission. Working group and focus group discussions were summarised in detail after each meeting. Notes were thematically analysed to check for misunderstandings, inconsistent interpretations, concept coverage and adequacy of images. The findings from these were incorporated into the revisions of the questionnaire (see Fig. 1).

Cognitive interviews were transcribed verbatim for analysis. Field notes were prepared summarising observations on respondents’ behaviour and the circumstances of the interview (e.g. presence of supporters). Transcripts and field notes from cognitive interviews, alongside responses for the ASCOT-ER questionnaire were transferred to NVivo for thematic analysis (Braun & Clarke 2006). Transcripts were coded using a combination of attribute coding (Saldaña 2013, pp. 69-72) and structural coding (pp. 84-87) with a frame consisting of codes for domains, images, visual response scale, misunderstandings, difficulties with interpretation, requests for clarification, and contradiction/potential bias.

### *Analysis*

The analysis of materials from the working group, focus groups and cognitive interviews was led by three main questions that also guided the overall revision of the questionnaire:

- 1) Can participants understand the questions and response options? Are they interpreted in accordance with the domain descriptions and answered in a way that is relevant to the context? Are questions and responses options interpreted consistently across respondents?
- 2) Are respondents able to answer the questions, in particular:
  - a. Are their answers based on their experiences?
  - b. Is there any evidence of systematic bias in responding?
- 3) Do the pictures help respondents to answer the questions, particularly:
  - a. How well do the pictures reflect the content of the questions?
  - b. Does the visual response scale help respondents to choose an answer? Is the difference between the response options clear?

## **5 Findings from pre-testing the revised ASCOT-ER**

This section presents the main findings from the development and cognitive testing of the questionnaire in focus groups and individual interviews, concentrating on three areas: the interpretation of questions; the use of the four-point scale response format; and any evidence of bias.

### *Findings related to understanding and interpreting the questions*

#### Food and drink

The question wording (Fig. 3) was understood by focus group participants and cognitive interview respondents. Responses reflected different experiences, and attention was paid to the variety and balance of the food and drink that people were consuming, as intended by the domain description. Those who selected the top option ('I get all the food and drink I like when I want') often commented that they lived on their own or prepared their own food so "*when I want something, I get it*". Others mentioned the variety of foods that they eat. A few people picked the third option ('I do not get all the food and drink I like when I want') and explained the reason (e.g. they have to eat what their mum cooks, cannot afford take-away food as often as they would like it etc.).

For three cognitive interview respondents the difference between "all the food and drink" (top answer) and "enough of the food and drink" (second answer) was potentially unclear:

Q: Why did you choose that answer (*I get enough of the food and drink I like when I want*)? 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.

*(Female, lives in her own home with support)*

### Personal cleanliness and comfort (Being presentable)

This domain asks respondents to consider how presentable they feel. Being presentable is explained as being clean, having clean clothes and feeling comfortable in what one is wearing. In focus groups and cognitive interviews the word ‘presentable’ was highlighted as being potentially difficult and nearly all respondents commented that they had never heard it. However, all but two respondents understood the question without additional explanation or prompts – other than the explanation provided in the question stem – and responded adequately. Two participants misunderstood the question and thought about how they feel when doing ‘presentations’ as part of their self-advocacy work. Most participants selected the top answer referring to keeping clean, wearing clean and comfortable clothes, choosing what to wear, and trying to “look nice”.

### Accommodation cleanliness and comfort

This question asks respondents to consider how clean and comfortable their home is and it was understood without any difficulty by focus group and cognitive interview participants. Responses emphasised the cleanliness aspect of the question and some participants living in shared accommodation were able to integrate various aspects of this into their response.

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.

*(Female, lives in shared home)*

### Personal safety

The safety domain and the original question included how safe people felt both at home and outside their home considering various aspects of safety such as abuse, being a victim of crime and accidents. Discussions with the working group revealed that this was cognitively too challenging because most reported feeling very different at home and in the community. For example, one participant explained that he felt safe in his home but was more anxious when outside because of being the victim of a previous assault.

These considerations led the research team to split the original question into two questions: one relating to safety inside the home and the other to how safe people feel when they are outside in their neighbourhood and local community. The new questions were understood by all respondents in a consistent way and they were able to answer adequately, commenting on various aspects of safety – including accidents – and personal experience.

### Social participation and involvement

This question asks participants to consider how they feel about their social life, which is explained as spending time with people they like including family, friends and people in the community. 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’. Similarly, cognitive interview participants appeared to understand the question and responded adequately reflecting on their experiences of seeing and keeping in touch with people important to them.

## Occupation

This domain encourages respondents to consider all activities in their daily lives. To encompass this complexity bullet points are used in the question to list the main areas respondents are encouraged to think about when answering this item. As a result, this is the longest question in the questionnaire and some respondents needed to read (hear) it more than once to process it fully. Nevertheless, participants did not need any further explanation nor did they highlight any difficult words. Participants were considering a range of activities when answering the question, including work, college, community groups and leisure activities, which reflected the original content of the domain. Responses seemed to reflect the variety of experiences and satisfaction with daily activities.

## Control over daily life

Control over daily life was one of two domains (alongside *Dignity*) that presented particular challenges during the development of ASCOT-ER. Control over daily life is defined as “the service user can choose what to do and when to do it, having control over his/her daily life and activities”. The first iteration of the question used and explained the term “control” in the question stem. However, a number of difficulties with this were highlighted during the focus groups: a number of participants – particularly those with Autism – held the view that the question was not specific enough and therefore difficult to answer.

Other participants with intellectual disabilities found the term ‘control’ confusing, and it was sometimes viewed in a pejorative context – ‘being controlled’ or having someone ‘being controlling of them’. In most cases participants were generally drawn to discussing ‘having choice’ and being listened to when making choices rather than having ‘control’. Participants suggested that the question should be changed, and specifically worded to be about choice rather than control. The question was amended and tested in the cognitive interviews where all but one respondent appeared to understand it and responded appropriately.

## Dignity

The dignity domain is defined as “the negative and positive psychological impact of support and care on the service user's personal sense of significance”. An early version tested in focus groups included the term ‘respect’ (“dignity means being treated nicely and with respect”) and this term was highlighted by participants as problematic. As a result of suggestions from the groups this was removed and the definition of dignity re-worded as ‘being treated nicely and kindly’. Because the question refers to social care support, “paid support” was used as a broad term to describe types of support staff. A further concern was that people with intellectual disabilities who use social services often come into contact

with more than one paid staff member, who might have a different attitude or approach towards supporting people. Therefore, answering this question potentially requires a high level of generalisation that might be difficult for some respondents; cognitive testing paid particular attention to exploring this.

In the cognitive interviews there were some problems with interpreting the question and answers. Three participants understood and answered the question in terms of general happiness, ignoring the part of the answers about paid support. One respondent pointed out that they do not pay for their support, while another understood paid support as benefit payment and responded accordingly. One respondent could not select a single answer:

A: I want to put two down here.

Q: Do you? Which two did you want to put?

A: This one and this one [two top answers].

Q: Why did you want to put two on that answer?

A: She is very kind to me.

Q: Who is very kind to you?

A: Support.

Q: Your support worker?

A: Yes.

Q: Okay. So why did you also want to put the second one?

A: 'Cause they get put, erm, the [...]

Q: So you would answer differently for different people that support you?

A: Yes.

*(Male, lives in his own home with paid support)*

#### *Findings related to the use of scales*

A central issue in using self-report ratings with people with intellectual disabilities is whether they can reliably distinguish between response categories and assign themselves to an answer.

The ranking task was completed by 31 focus group participants. Most participants ordered the show cards correctly from “best” to “worst” (n=21), and from “most frequent” to “least frequent” (n=22). However, when it came to specific response options, longer descriptors were found to be more useful than those consisting of one or two words, commonly used in Likert-type scales. Participants suggested that longer descriptors provided more information and helped them identify the most appropriate response.

Feedback highlighted that happy and sad faces were helpful because people were already familiar with the imagery from everyday situations (e.g. sending text messages).

Nevertheless, some commented that they were “childish”, while others highlighted the absence of a neutral response and face – the ASCOT measure uses a four-point scale – as problematic.

Some participants had difficulty distinguishing between the four levels of the response scale, more specifically between the two happy and two sad options. This emerged clearly in some cognitive interviews:

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.

*(Male, lives in a care home)*

Initially concerns were raised in the research team that the use of happy and sad faces might lead to bias by encouraging some people to select answers based on their preference for certain images. As an alternative the use of thumbs up/down was explored in some early focus groups, but interpretation and illustration here were problematic given that the measure uses a four-point scale. Overall consensus in the working group was that “smileys” are easier to understand because they are more “standard”. In the focus groups there was no evidence that participants were choosing answers based on their like or dislike of particular images. However, one cognitive interview respondent liked the happy face associated with the top response and commented on this throughout the interview and selected the top answer for all questions:

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?

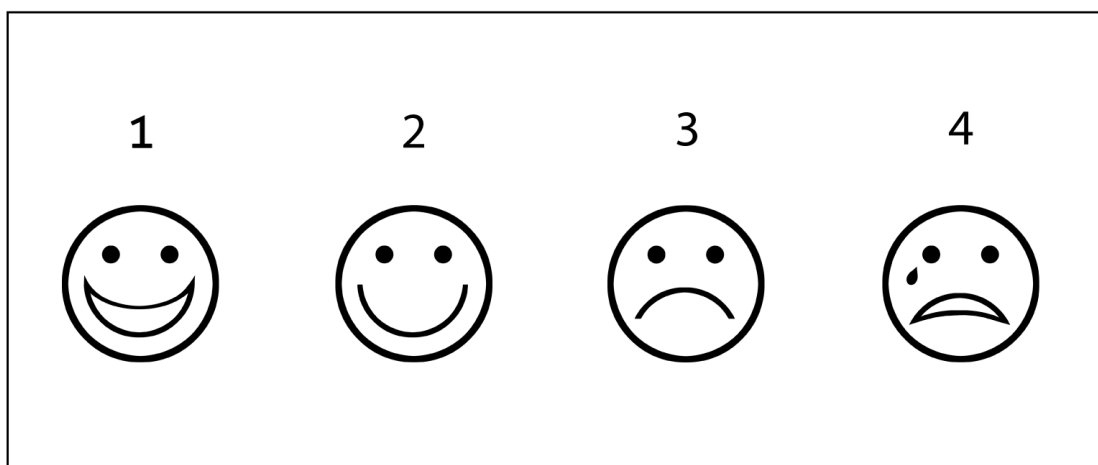
A: Yeah.

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

A: Yeah.

*(Male, lives in a care home)*

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



*Findings related to the validity of the revised questionnaire*

The analysis of cognitive interviews also looked for patterns in responding, particularly among respondents who consistently selected the same level response throughout the questionnaire. There were four participants who selected the top answer for all questions. Two of these respondents were confident readers and had low levels of support. Both completed the questionnaire with minimal or no help and appeared to be responding appropriately without any apparent contradictions or evidence of bias in the interviews.

The other two respondents were receiving more support – in eight and nine out of 10 areas – and possible bias was noted by interviewers in field notes in both cases. One respondent explained that they liked the “very smiley face”, which might have caused biased responding (see above). Field notes for the other respondent highlighted that he “wanted to please and get it right”, and asked for staff to sit in at the interview and frequently referred to them by looking at them for the answers.




## 6 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 who 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 consisting of people with intellectual disability and/or autism (expert panel) and cognitive testing. We believe the result of this process demonstrates the benefits of involving people with intellectual disabilities in the design and testing of data collection instruments. Feedback highlighted difficulties in the interpretation of words and images, and helped to improve the questionnaire using revised iterations in a systematic way.

Substantial changes were made to the original ASCOT-ER questionnaire, which included replacing the illustrations as well as changes to the wording of question stems and response options, based on feedback from the working group and focus groups. To improve the clarity of the presentation each item has been formulated using the same structure: one to three images at the top of the page intended to provide a pictorial representation of the domain, a brief introduction that explains the main concepts and any difficult words identified by participants, followed by the question and response options (see Fig. 3). The response scale has been presented vertically with a descriptive statement and corresponding visual representation.

**Figure 3: Question format of the revised ASCOT-ER questionnaire**



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.  😞



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.  😞

Finding out about the kinds of things people are considering when processing questions and preparing answers was crucial in relation to the main aim of improving the original ASCOT-ER. Conducting the study in this way has also helped us to identify those domains that can be more challenging and potentially more problematic in creating bias that might need to be controlled for, especially in large scale surveys.

Easy Read is sometimes criticised for being a “cosmetic device, as likely to confuse as to inform” as well as “dumbing down complexity” (Walmsley 2013, pp. 17-18). These were real issues as some of the feedback highlighted in the early stages of the process. However, involving people with intellectual disabilities and autism in the revision of the questionnaire has helped to address these by identifying and including images that are both acceptable and relevant to the majority of participants.

The revised ASCOT-ER questionnaire appeared to work for the majority of cognitive interview respondents but – as expected – not for everyone. The experiences of the project confirmed that adequately adapted self-report questionnaires can be a useful tool to collect information from people with intellectual disabilities in survey research. However, it is important to recognise the limitations of data collection instruments that rely on reasonably high levels of verbal communication in research with people with intellectual disabilities. There is a sizeable group who are not able to self-report subjective quality of life using a structured questionnaire and for them different methods are needed to support engagement in research (Beadle-Brown *et al.* 2012).

While there was no information about the expressive and understanding skills of participants or their cognitive abilities (and we recognise this as a limitation of the study), it was evident that people who were receiving more support had increased difficulties with the questions and needed more help to complete the form.

ASCOT requires a four-point response scale (see Netten *et al.* 2012) and this was kept for the revised Easy Read version to maintain comparability with other versions. Some respondents found it difficult to use a four-point scale and, while some of them might have been able to respond using a three-point scale, for others semi-structured interviews are likely to have worked better. Abstract questions, such as those about control over daily life and dignity, presented more difficulties to respondents than questions related to concrete everyday experiences (e.g. food and drink).

Respondents did not always select their answer from the available options, had difficulty assigning themselves to a single option or their selection was not clear. This can lead to contradictory answers that result in being discarded as invalid responding or supporters “helping” people to select an answer and thus potentially creating bias (Antaki & Rapley 1996; Antaki *et al.* 2002). Having help from a care worker has been associated with reporting more favourable outcomes among people with physical and sensory impairments

(Elliott *et al.* 2008), and people with intellectual disabilities (Rand & Malley 2016). Reducing the need for help in completing the ASCOT questionnaire was one of the aims of this project. It is not possible to draw any firm conclusions on whether the project has achieved this, given the small number of participants. The majority of cognitive interview respondents (n=16) said that they would answer the questionnaire with help from family or paid carers, and only six people said they would complete it without assistance. On the one hand, this could be because some people with intellectual disabilities might lack the self-confidence to complete such a form independently, as opposed to lacking the skills necessary for this task. On the other hand, it also highlights the limitations of Easy Read information and that there is a sizeable group of people who, while being able to respond to a questionnaire also need support to do this for various reasons, including limited literacy or cognitive skills. This issue warrants further investigation and future work could also focus on developing clear guidance for those who help respondents to complete forms in order to improve the validity of data and reduce potential bias.

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 presence of the interviewers may have helped respondents with intellectual disability in a way that would not be reflective of a self-completion survey.

Another limitation relates to the development of ASCOT-ER as part of the ASCS in that participants were not necessarily representative of the population of social care users who would receive the survey. Because the main aim was to cognitively test the questionnaire, participants were potentially more able than the general service user population. Other methods for collecting ASCOT data for individuals with higher levels of cognitive impairment are being developed (e.g. Talking Mats for ASCOT, semi-structured interview and structured observation). However, one of the biggest challenges in developing such measures is establishing when to implement the different 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 *et al.* 2013). Whether such screening is feasible in a large national survey such as the Adult Social Care Survey needs careful consideration.

## **7 Conclusion**

The aim of this project was to develop and (cognitively) test an Easy Read version of ASCOT. Specifically this related to answering three research questions:

1) Can participants understand the questions and response options? All questions and response options were understood by most participants. Terms such as 'social life' and being 'presentable' were well understood and questions were interpreted in a consistent way such that they conformed to the domain descriptors and the relevant context. A small minority of participants had difficulty distinguishing between levels (response options) for some questions.

2) Are respondents able to answer the questions? All participants were able to answer the questions. In most cases participants related their answers to personal experience reflecting on day to day activities and experiences such as eating different foods, having accidents, living with others, feeling safe or unsafe, seeing friends and family and integrating these aspects into responses. Nonetheless a small number of participants had difficulty choosing a response (especially for more abstract questions) and one participant exhibited behaviour which could result in systematic bias in responding in consistently choosing the top response because of affinity with the 'happy face'.

3) Do the pictures help respondents to answer the questions? Feedback suggested that happy and sad faces were helpful to participants in choosing response options. Many likened this to using an emoji in a text message or using other social media and this helped with interpreting meaning. However some commented that they were "childish" and one participant consistently chose the top response due to the corresponding image.

Overall our findings suggest that most participants were able to use and engage with the ASCOT-ER to interpret and answer the majority of questions at some level. In this way the research contributes to the wider aim of improving engagement for groups that are under-represented in the evidence about social care and in the Adult Social Care Survey. However, other factors will influence how easily questions are interpreted, understood and answered such as the level of intellectual disability, whether or not people receive help to complete questions and the degree of this help. We therefore recommend that ASCOT-ER would benefit from further systematic testing, particularly around validity, reliability and reducing potential sources of bias.

## References

- Antaki, C., & Rapley, M. (1996). Questions and answers to psychological assessment schedules: Hidden troubles in 'quality of life' interviews. *Journal of Intellectual Disability Research, 40*(5), 421-437. DOI: 10.1046/j.1365-2788.1996.779779.x
- 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. DOI: 10.1080/09687590220140368
- Baker V., Oldnall L., Birkett L., McCluskey G. & Morris J. (2010). *Adults with Learning Disabilities (ADL): Royal College of Speech and Language Therapists Position Paper*. RCSLT, London.
- 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.
- Bradshaw, J. (2011). Between you and me: communicating effectively with people with learning disabilities. In. Carnaby, S. (Ed.), *Learning disability today* (3rd ed.). GB: Pavilion Publishing & Media (pp. 95-108)
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Buell, S. (2015). A commentary on "First-hand experience of accessible information". *Tizard Learning Disability Review 20*(2), 88-91. DOI: 10.1108/TLDR-12-2014-0042
- 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.
- Connors, F. A. (2003). Reading skills and cognitive abilities of individuals with mental retardation. *International Review of Research in Mental Retardation, 27*, 191-229.
- Cummins, R. A. (2005). Issues in the systematic assessment of quality of life. In. Hogg, J., & Langa, A. (2005) *Assessing Adults with Intellectual Disabilities: A Service Providers' Guide*, 9-22.

Dada, S., Huguet, A., & Bornman, J. (2013). The iconicity of picture communication symbols for children with English additional language and mild intellectual disability. *Augmentative and Alternative Communication, 29*(4), 360-373. DOI: 10.3109/07434618.2013.849753

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.

Department of Health (2010b). *Making written information easier to understand for people with learning disabilities. Basic guidelines for people who commission Easy Read information*. Revised edition. Department of Health, London.

Elliott, M. N., Beckett, M. K., Chong, K., Hambarsoomians, K., & Hays, R. D. (2008). How Do Proxy Responses and Proxy-Assisted Responses Differ from What Medicare Beneficiaries Might Have Reported about Their Health Care?. *Health services research, 43*(3), 833-848. DOI: 10.1111/j.1475-6773.2007.00820.x

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. DOI: 10.1352/1934-9556-51.5.333

Fajardo, I., Ávila, V., Ferrer, A., Tavares, G., Gómez, M., & Hernández, A. (2014). Easy-to-read Texts for Students with Intellectual Disability: Linguistic Factors Affecting Comprehension. *Journal of Applied Research in Intellectual Disabilities, 27*(3), 212-225.

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. DOI: 10.1037//1040-3590.13.3.319

Finlay, W.M., & Lyons, E. (2002). Acquiescence in Interviews with People Who Have Mental Retardation. *Mental Retardation, 40*(1), 14-29. DOI: 10.1352/0047-6765(2002)040<0014:AIWPW>2.0.CO;2

Goodwin, J., Mason, V., Williams, V., & Townsley, R. (2015). Easy Information about research: getting the message out to people with learning disabilities. *British Journal of Learning Disabilities, 43*(2), 93-99. DOI:10.1111/bld.12128

Grove, N. (2014). "Practical understanding: an approach to making ideas accessible", paper presented at the IASSID Europe Congress, Vienna, 14-17 July.

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. DOI: 10.1111/j.1365-2788.2006.00844.x

HSCIC (2015). *Personal Social Services Adult Social Care Survey, England, 2013-14. Survey feedback report*. Health and Social Care Information Centre (retrieved from: [http://www.hscic.gov.uk/media/13277/Adult-Social-Care-Survey-England-2013-14-Feedback-survey-report/pdf/ASCS\\_2013-14\\_SurveyFeedbackReport\\_v1.0.pdf](http://www.hscic.gov.uk/media/13277/Adult-Social-Care-Survey-England-2013-14-Feedback-survey-report/pdf/ASCS_2013-14_SurveyFeedbackReport_v1.0.pdf))

Hurtado, B., Jones, L., & Burniston, F. (2014). Is Easy Read information really easier to read?. *Journal of Intellectual Disability Research*, 58(9), 822-829. DOI: 10.1111/jir.12097

Inclusion Europe (2014). *Information for all. European standards for making information easy to read and understand*. Inclusion Europe, Brussels (retrieved from: <http://easy-to-read.eu>)

Katims, D. S. (2001). Literacy Assessment of Students with Mental Retardation: An Exploratory Investigation. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(4), 363–372. Retrieved from <http://www.jstor.org/stable/23879898>

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. DOI: 10.1016/j.socscimed.2013.11.050

Malley, J., Towers, A., Netten A., Brazier, J., Forder, J., Flynn, T. (2012). An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people, *Health and Quality of Life Outcomes*, 10(21). 1477-7525. DOI: 10.1186/1477-7525-10-21

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*, 16(16). DOI: 10.3310/hta16160

Oldreive, W., & Waight, M. (2013). Enabling access to information by people with learning disabilities. *Tizard Learning Disability Review*, 18(1), 5-15. DOI: 10.1108/13595471311295950

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. DOI: 10.1093/poq/nfh008

Rand, S., & Malley, J. (2016). The factors associated with care-related Quality of Life of adults with Intellectual Disabilities: Implications for Policy and Practice. *Health and Social Care in the Community*. Advance online publication. DOI: 10.1111/hsc.12354

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. DOI: 10.1002/(SICI)1099-1298(199608)6:3<207::AID-CASP370>3.0.CO;2-T

Saldaña, J. (2013). *The Coding Manual for Qualitative Researchers*. SAGE. (2<sup>nd</sup> edition)

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.

Walmsley, J. (2013). Commentary on “Enabling access to information by people with learning disabilities”. *Tizard Learning Disability Review*, 18(1), 16-19.

DOI:10.1108/13595471311295969

Williams, V., Ponting, L., & Ford, K. (2015). A platform for change?. *British Journal of Learning Disabilities*, 43(2), 106-113. DOI:10.1111/bld.12123



Table 1: Participant characteristics

	Focus group	Cognitive interview
Total participants	32	22
Female	13	9
Age range		
20-39 years	16	13
40-59 years	4	5
60 years or over	4	3
Prefer not to say	8	1
Disability		
LD	17	17
Autism	5	1
Both	3	1
Prefer not to say	7	3
Ethnic background		
White British	27	18
Other	1	3
Prefer not to say	4	1
Living arrangement		
Lives with family	9	4
Own place, alone	7	4
Own place, with others	5	1
Staffed home	6	10
Other	2	n/a
Prefer not to say	1	3
Support arrangement		
Has paid support	16	16
Number of areas <sup>1</sup> where getting support		
0-1	10	3
2-4	7	8
5-7	7	3
8-10	8	7

<sup>1</sup> These include assistance with shopping, cleaning, preparing meals, socialising, keeping safe, engagement in activities, mobility at home and in the community, making decisions, personal hygiene and getting dressed.