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ASCOT Easy Read: usability evaluation of an electronic adaptation

*A report from an electronic adaptation of the ASCOT ER
measure*

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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 and Social Care.

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.

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Introduction

This study is part of the ‘Engagement’ research programme within QORU (Quality and Outcomes of person-centred care policy Research Unit; www.goru.ac.uk), which aims to develop approaches to enable the participation and inclusion of people with intellectual, communication, and cognitive impairments in social care research to make sure that their experiences are reflected in the evidence-base.

ASCOT is a measure of social care-related quality of life (SCRQoL) for social care service users and their carers. The service user version captures quality of life in eight areas, referred to as ‘domains’: control over daily life, occupation, social participation and involvement, personal safety, personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, and dignity (Netten et al., 2012, Smith et al., 2017). ASCOT forms part of the annual Adult Social Care Survey (ASCS), which collects outcome data from users of social services funded by local authorities in England. The easy-read version of ASCOT has recently been revised (Turnpenny et al., 2018) and validated (Rand et al., accepted). The aim of this study was to adapt the revised ASCOT Easy Read for use in electronic format on devices such as tablets and test it with people with the target service user group – people with learning disabilities and/or autism.

Background

There is evidence suggesting that capturing the perspectives of people with learning disabilities in large surveys is uncommon (Williams et al., 2015). Indeed, a recent literature review has found that there is limited inclusion of people with learning disabilities in social care research (Beadle-Brown et al. 2012). Fujiura et al. (2012) highlight ‘the two contradictory themes in the treatment of self-report: the centrality given to personal perceptions and choices and the methodological concerns over the meaningfulness and validity of the self-reporting process’ (p. 352). While it is now widely accepted that many people with learning disabilities can reliably use a self-report instrument, in Emerson et al.’s (2013) words ‘where the limits lie for gaining valid subjective information in this population have not been adequately determined’ (p. 336).

The easy read version of the Adult Social Care Outcomes Toolkit (ASCOT-ER) aims to address this gap; its purpose is to collect information on how services affect people’s quality of life,

i.e. outcomes of social care services. This data can be used by various stakeholders in the social care sector. Service providers and practitioners can use it to measure and improve quality of services, whilst local authorities can monitor and evaluate services and inform commissioning, and ASCOT is also increasingly used in social care research and practice (see e.g. Callaghan, Brookes, & Palmer, 2017; Bauer et al., 2016; Whitehead et al., 2016). The Adult Social Care Outcomes Framework (ASCOF), which uses data from the ASCS to populate a number of indicators of social care in England, encourages the use of survey data (including the quality of life data collected through the ASCOT questions) for local decision-making and commissioning. Therefore, it is important that the views and experiences of all service users, including those with learning disabilities and autism are adequately captured and represented by the measure.

ASCOT Easy Read

The easy-read version of ASCOT was devised using common questionnaire development and pre-testing methods (e.g. expert panel, cognitive interviews) in conjunction with approaches to create accessible information for people with intellectual disabilities (Turnpenny et al., 2018). The aim of the revision was twofold: (1) to improve acceptability and face validity and also (2) to make the questionnaire more widely accessible (although acknowledging the limitations of using self-report in this population). To this end, the process was designed to ensure that the instrument was developed together with the intended target population, namely people with learning disabilities or on the autistic spectrum who use services.

Substantial changes were made based on feedback on various iterations of the original questionnaire from people with a learning disability and/or autism. These included revisions to the layout of each item, question stem, and response option; as well as new images sourced from CHANGE (www.changepeople.org), a disabled people's organisation that offers easy read information design. The process and main features of ASCOT-ER are discussed in detail by Turnpenny et al. (2018).

The psychometric properties of the revised ASCOT-ER as a self-completion questionnaire in a postal survey have recently been examined by Rand et al. (in press). They found moderate to strong correlations between the revised ASCOT-ER and measures of personal wellbeing (the Personal Wellbeing Index – Intellectual Disability (PWI-ID), Cummins & Lau 2005) and overall quality of life (NHS Digital 2017ab), and significant relationships between the

instrument and individual characteristics. Exploratory factor analysis confirmed the measure's unidimensionality, in line with the main ASCOT measure (Malley et al., 2012). Rand et al. also found good feasibility of the instrument, which coupled with the findings confirming the instrument's construct validity and unidimensionality, support the use of the revised ASCOT ER as a measure for collecting outcomes data from social care users with learning disabilities and/or autism.

Computer-assisted interviewing and web surveys

Computer-assisted interviewing and self-administered web surveys have become increasingly popular and dominant with the rapid development of technology over recent decades (Couper 2000). This section gives a brief overview of the concept of 'usability' and highlights some of the general findings related to 'usable designs' and specific considerations for computer-assisted questionnaires.

Usability or user-centred design is more than 'user friendliness' as it also considers factors such as the length of time taken to complete a task and the number and severity of errors (Couper 2000). Common usability problems and mode effects in computer-assisted interviews are attributed to design characteristics, most prominently the effect of different layouts.

Usability inspection and end-user evaluation are common approaches to usability testing (Couper 2000). Usability inspections are expert reviews – by three to five experts – of an instrument using a pre-defined set of usability and design principles. Although not the most reliable method, expert reviews are relatively easy to carry out and can identify salient design and usability problems. End-user evaluation methods encompass laboratory-based experiments and observation, and field-based usability evaluations. A key lesson from early observations is that the introduction of a computer (or similar device) can significantly affect the respondent-interviewer interaction, especially when interviewers experience difficulties with the device. Another key conclusion from these experiments is that 'seemingly minor differences in screen layout, design, or function can produce differences in the time taken to complete an instrument and in the number and type of errors made by users' (p. 392).

Field-based usability evaluations use paradata (automated auxiliary data generated from the process; different from metadata) and can be built into the design of on-line instruments.

Paradata provide valuable information about how respondents complete the instrument (e.g. time spent on items, changing answers etc.) and may draw attention to design problems.

Couper (2000) highlights that neither of these approaches will provide a fully comprehensive picture on its own, and the use of multiple approaches are recommended, depending on the complexity of the instrument and the availability of resources.

Tourangeou, Conrad, & Couper (2013) assert that self-report web surveys perform well in terms of observation / measurement errors compared to more traditional survey methods; even though they are more prone to non-observation (i.e. coverage, sampling, nonresponse) errors (p. 152). The following features have been shown to reduce measurement errors relative to other modes, primarily interviewer-assisted and postal surveys. These are all potential benefits when considering the electronic adaptation of ASCOT-ER:

- Visual (and more dynamic) presentation allows the incorporation of features that can help to clarify the meaning of questions (and answers);
- Interactive designs can provide different degrees of help and prompts;
- Self-administered web surveys can potentially reduce social desirability bias;
- Respondents can better control the pace of the survey, which in turn can reduce the cognitive burden of answering.

A further advantage of electronic instruments is that they allow the incorporation of accessibility and universal design features. In the light of the evidence, Tourangeou et al. (2013) recommend the use of certain design features:

- **Page navigation** is easier to use than scrolling through large amount of information;
- **White or light background**, no background graphics;
- **Clean, simple design** with no 'unnecessary' features that can potentially distract respondents;
- Important information displayed in the **top left of the screen** – the most prominent part of the screen – and text is justified left;
- **Visual separation** of different response options;

- **Definitions** of any technical terms. These features work best when respondents can access them easily, e.g. move mouse over a word rather than clicking or scrolling;
- **Prompts** to remind respondents of missed answers, feedback on the speed of answering (e.g. if too fast might indicate satisficing).

Usability considerations for people with learning disabilities

Emerging evidence on digital literacy, technology and internet use by people with learning disabilities highlight some design features that have the potential to enhance usability of online instruments in this group. Some of these are different from 'mainstream' recommendations, but by-and-large are consistent with easy read guidance. This section gives a brief overview of the specific usability and accessibility considerations for people with learning disabilities in online forms / questionnaires.

Poor mouse control and involuntary activation of the context menu (i.e. 'right click') are two main accessibility issues in relation to website navigation according to Williams (2013).

Rocha et al. (2015) found that touchscreen input is generally preferred to a computer mouse in terms of effectiveness, efficiency and user satisfaction, and it might also increase motivation to complete the task. However, as highlighted by Quezada et al. (2017) not all touchscreen operators are the same: autistic people found 'keystroke', 'tap', and 'touch' easiest to use; 'mental act' and 'gestures' presented the most challenges; and 'drag and 'swipe' were implemented but much slower than in the control group without autism.

When navigating websites, Rocha et al. 2012 found that people with learning disabilities pay more attention to images than to text links. They also express a preference for more factual 'object images' (i.e. those that provide a representation of objects) as opposed to 'action' and 'universe representative' images (i.e. those that refer to the sensation of action or function, or require extended/contextual knowledge) because they are easier to decode (Rocha et al. 2018).

Williams and Hennig (2015) highlight that people with learning disabilities are less able to skim webpages to locate relevant content because they access information serially.

Therefore, horizontal presentation of options/content might be more accessible than vertical menus. However, it is also emphasised that usability and user preferences do not

necessarily overlap: although people often express preference for images and large fonts, smaller fonts and no images are no less effective in facilitating information retrieval.

Williams (2017) examined the website preferences of people with learning disabilities and found that people with learning disabilities rated 'accessible' versions of mainstream websites less favourably compared to websites that were developed specifically for people with learning disabilities. Three common features of mainstream websites appeared especially difficult: hierarchical structure, the amount of (i.e. too much) information, and vertical layout of options. Although participants were generally positive about the use of pictures / images from both an aesthetic and a practical point of view, images were most useful for procedural and specific information. Paging is clearly preferred to scrolling, but this needs to be clear and use large icons and simple terms. The inclusion of audio is recommended to make websites more accessible for people with limited literacy (see Norah Fry Research Centre & RNIB Multiple Disability Services 2004; Waight and Oldreive 2016); even though Williams (2017) found no clear evidence on the use of audio; however, this might have been due to the specific design features of the website tested.

Few studies have directly compared computer-based with paper-based versions. In a two-group within-subject experiment Stock et al. (2004) found that participants needed significantly fewer prompts to complete an online questionnaire compared to a paper-based version. However, there were no significant differences in the number of errors recorded. Davies et al. (2017) also used a two-group within subjects design to test the utility and efficacy of a multimedia software system (ATLAS; Accessible Testing, Learning and Assessment System) for people with learning disabilities. They found that ATLAS performed significantly better on all three criteria: test-taking errors, assistance required, and time to complete.

In conclusion, the evidence suggests that accessible online instruments may support people with learning disabilities to self-report with greater independence and efficiency compared to traditional paper-based survey methods.

Aims

This project aimed to develop and test the usability of a digital version of the revised ASCOT Easy Read (ASCOT-ER) questionnaire with people with learning disabilities and autism.

Methods

Partnership: research team, developers, and service provider

The project was implemented in partnership between the research team and industry partners: PSSRU, Tizard Centre, Rescon Technologies (Rescon) and a service provider organisation. The same provider organisation was previously involved in the validation of the revised ASCOT-ER (Rand et al., in press) and expressed an interest in including the measure in Lincus, an existing online platform the organisation used for gathering outcomes information.

Lincus, developed by Rescon, is a digital platform designed for collecting health and wellbeing data enabling the user to track and monitor their progress in those areas (Gilbert and Dawson, 2014). The platform includes a module for staff allowing them to record information on behalf of the individual. This provides a useful case history and enables staff to monitor individuals' outcomes and devise appropriate interventions to support them (Gilbert & Dawson, 2014; Gilbert et al., 2013). Moreover, Lincus has been adapted for and tested with people with learning disabilities living in supported accommodation.

Adapting ASCOT-ER for Lincus could potentially help widen the use of the tool as an outcomes measure, particularly for care providers. Incorporating the tool into an existing electronic platform – such as Lincus – appeared more feasible in terms of resources than developing a stand-alone application. In addition, Rescon offered to support the project free of charge. Taking all this into account, the decision to involve Rescon as an industry partner and developing the electronic ASCOT-ER as part of Lincus was made.

Timeline and methods

It was planned that the project would consist of two main stages: the first stage was to adapt the ASCOT-ER for inclusion in Lincus, and the second to establish its feasibility and acceptability (with modifications, if needed) with people with learning disabilities through an iterative process of one-to-one cognitive interviews in two rounds of (25) interviews. The method of cognitive interviews is described by Willis, Reeve, & Barofsky (2005). This section provides a general overview of timeline and rationale: the original plans and why/how they changed. The methods and participants are described in more detail under *Round 1 testing* and *Round 2 testing*).

The project ran from March 2017 to August 2018, with development and testing taking place between May 2017 and February 2018. The project activities mainly followed the original plan; however, there were some changes due to factors beyond the control of the research team. Rescon commenced the digital adaptation work in March 2017. Prior to the start of the project, in February 2017, an agreement was signed between Rescon and the University of Kent, who holds the copyright of the ASCOT materials, giving the company permission to adapt ASCOT-ER into Lincus for the purposes of the project.

The first version of the adaptation was completed in May 2017. The research team reviewed the first version and asked Rescon to make some minor (formatting) changes (to ensure the consistency of font styles and spacing, and remove unwarranted format changes (i.e. coloured happy & sad faces) prior to group testing – in July 2017.

Following that, Rescon made some changes to the instrument between July and October 2017; however they notified the research team that they were unable to further support the project beyond that due to resource constraints.

For this reason, the decision was made to conduct only one round of the cognitive interviews. This was supported by the fact that the usability inspection by the research team and end-user evaluation by a group of people with learning disabilities or on the autism spectrum (group testing) of the first version of the instrument provided a lot of useful feedback, and consequently was treated as the first round of testing. The project timeline was amended to replace the iterative rounds of cognitive interviews with a two-phase end-user evaluation: group testing and one round of cognitive interviews.

The study received ethical approval from the Social Care Research Ethics Committee in October 2016 (16/IEC08/0029) as part of a wider QORU project to pilot the ASCOT-ER. Research governance approval was obtained from three local authorities – two county councils in the South East and South of England, and a London borough – also as part of the larger QORU project.

Round 1 testing

The first version of the electronic ASCOT-ER was adapted for the Lincus platform in May 2017. It was reviewed by a group of potential end-users (also referred to as ‘working group’) in July 2017. The aim of this initial round of testing was to highlight any potential issues and allow the developer to rectify these before one-to-one cognitive interviews. This chapter summarises the main experiences and feedback from the working group.

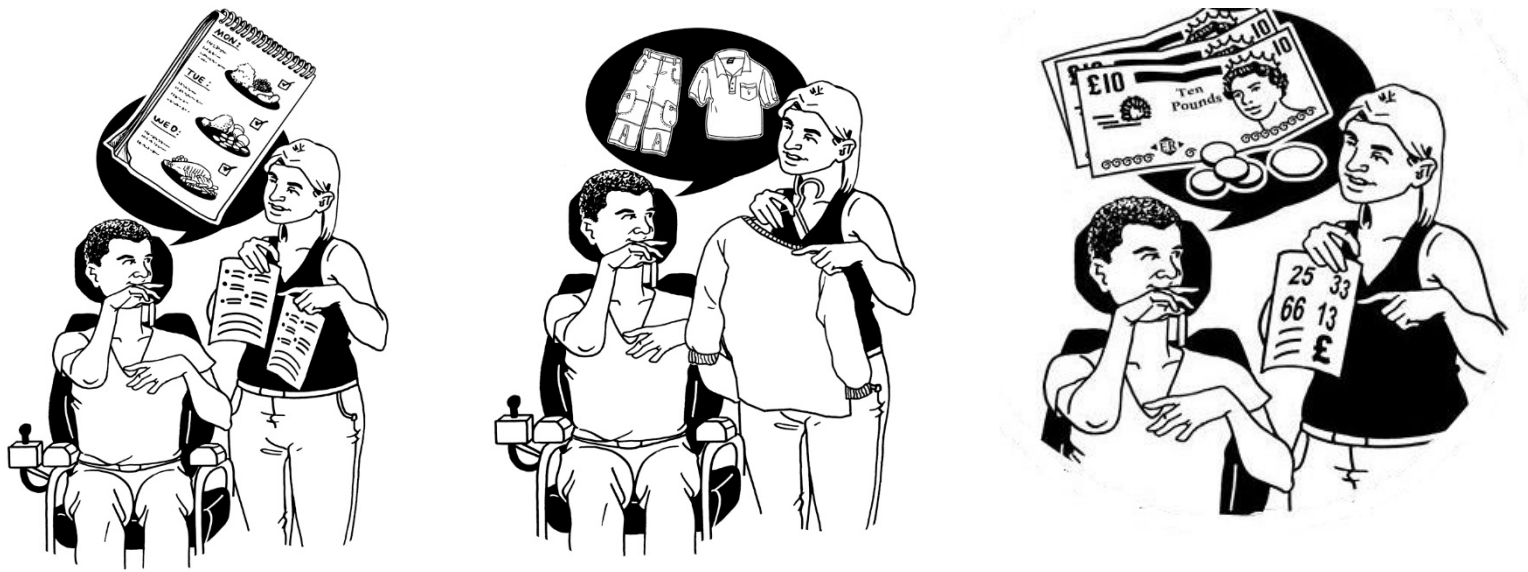
Participants

The working group consisted of six people with learning disabilities or autism and one support worker recruited via the Tizard Centre’s *Researching All Together* group and local social enterprise that employs disabled people. Participants had a range of abilities, but the majority were able to read and use some technology independently. They all had smart phones and some commented that they owned a tablet or laptop.

Materials

The original ASCOT-ER questionnaire was developed for and tested in an A4-size paper format. It contains nine questions, each on a separate page. Each question corresponds to one of the eight ASCOT domains, except for the personal safety domain that has two questions for safety inside and outside of the home. At the top of each page there are between one to three images representing the meaning of the question. Below the images, there is a brief description of what the question is about, which is followed by the question itself in bold font with an instruction underneath it: “Please tick (✓) 1 box”. There are four response options below the question, each with a tick box and a happy/sad face on the right of it. The faces represent the different levels of response options from the ideal state, a very smiley face, to high-level needs, very sad face with a tear. An example question from the paper questionnaire is shown in Figure 1 below.

Figure 1. An example question from the paper ASCOT ER questionnaire.



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.

The digital adaptation of the questionnaire followed the original paper-version as closely as possible. It did not incorporate additional design features allowed by the digital format. The layout and proportions were retained; however, there were some differences:

1. The happy/sad faces were filled with grey colour, as opposed to an outline in the paper version
2. The sad face representing the high-level needs response option (level four) differed slightly from the original version as it did not have a tear on the left side of the face
3. The first sentence of the question description is in a larger italicised font
4. The instruction under the question was changed from “Please tick (✓) 1 box” to “Please tick one box”
5. The tick boxes and smiley faces were moved further to the left of the response option wording than in the paper version.

The electronic version of the questionnaire contained some Lincus-specific features:

- **Pagination.** The option to view the whole questionnaire on one webpage. For long questionnaires users have to scroll down to see all the questions.
- **Toggling.** Users can switch the page view between the whole questionnaire presented on one page, and the questions presented one at a time (although due to the spacing of the text, respondents still have to scroll up and down the page to display the full list of possible answers). An orange ‘toggle page view’ button at the top of the top of the page allows users to switch between the different views. Both pagination and toggling involve a lot of scrolling up and down the page when completing the questionnaire.
- **Progress bar.** At the top of the page there is a progress bar, which in the case of the ASCOT questionnaire consisted of nine buttons representing the nine questions. The question that is being answered is highlighted in orange.
- **Non-response.** The electronic questionnaire does not allow non-response. Selected answers can be changed, but it is not possible to untick all boxes once an answer has been selected or submit the form without answering all questions. However, if questions are missed, there are no prompts asking respondents to select an answer, although it is not possible to submit the questionnaire with missing responses.

- **Submitting the answers.** At the bottom of the page there is a large 'submit' button with an arrow to the left of it (Figure 2). When an answer is selected, a blue arrow to the right of the button appears (Figure 3). Hovering over this arrow highlights it in orange and clicking on it moves the questionnaire to the next question (Figure 4). When the last question is answered, clicking on this arrow highlights the 'submit' button in orange (Figure 5). Upon clicking on the button, the user is taken to a 'complete survey' page (Figure 6) which consists of two fields at the top for entering date and time, and a large box beneath for entering free-text notes. Below the box there is a 'back' button and a 'submit' button. Clicking on this 'submit' button submits the whole questionnaire.

Figure 2. A screenshot of the 'submit' button before selecting an answer.

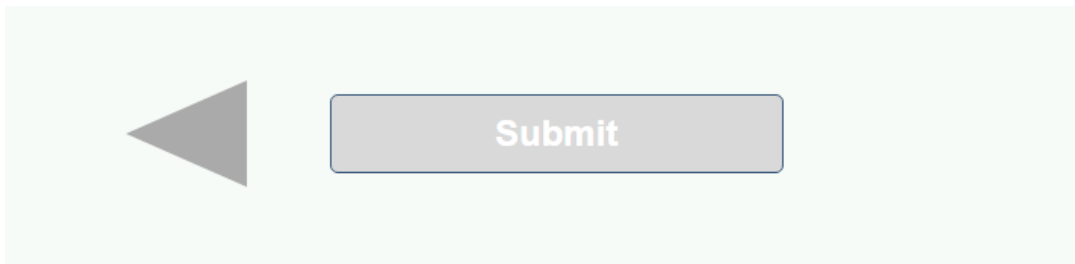


Figure 3. A screenshot of the 'Submit' button when an answer has been selected.

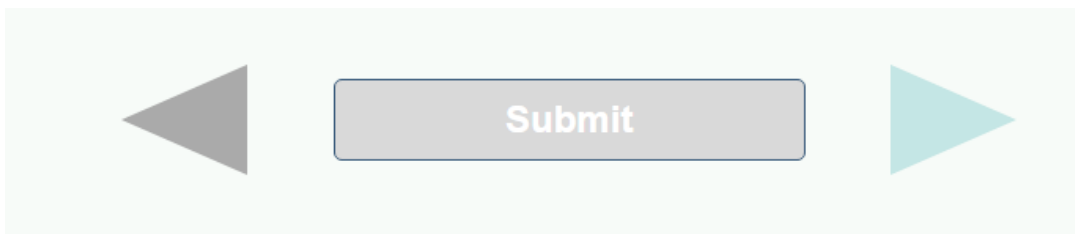


Figure 4. A screenshot of the 'Submit' button showing the arrow on the right highlighted in yellow when user hovers over it.

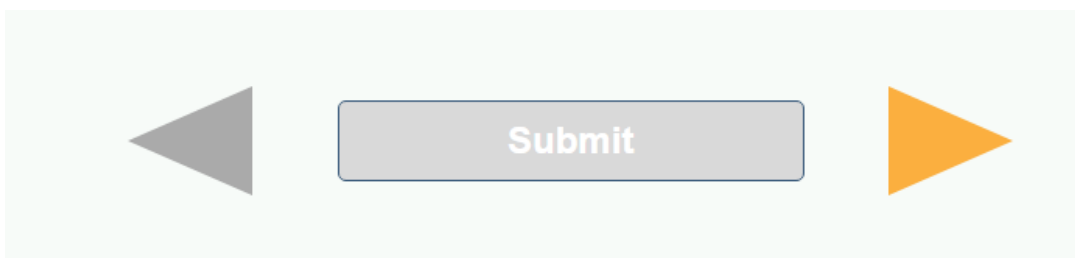


Figure 5. A screenshot of the highlighted 'Submit' button after the last question has been answered.

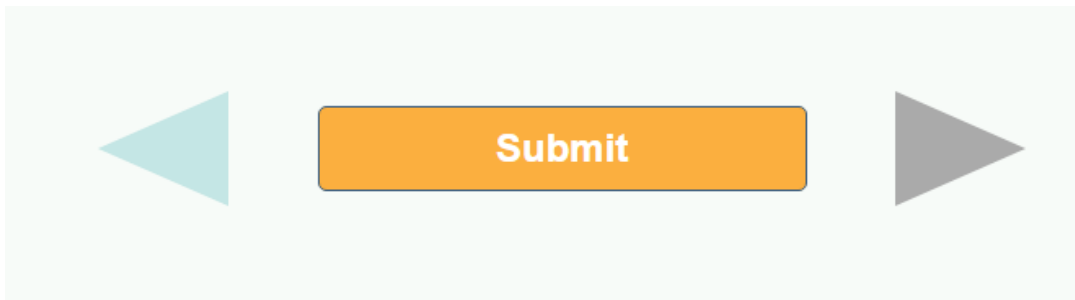
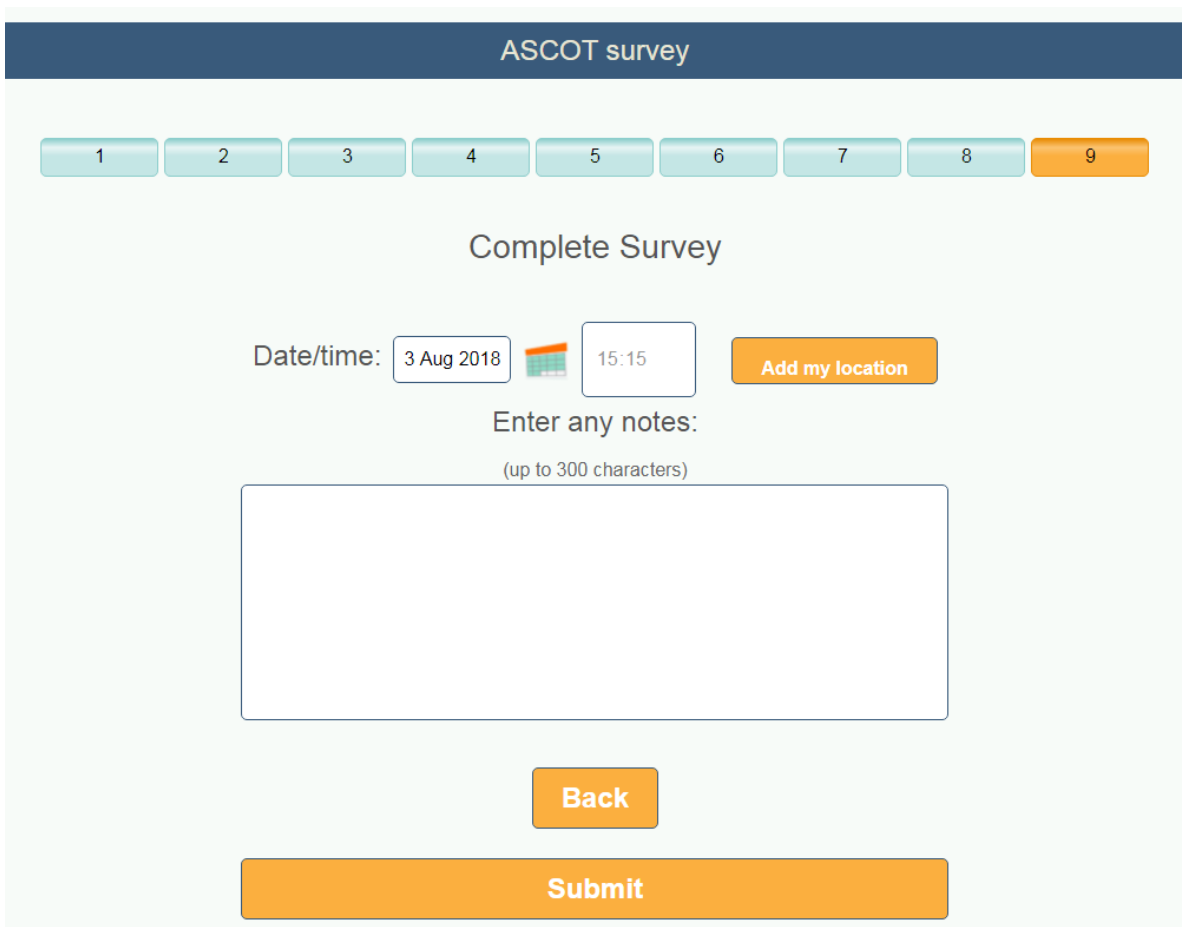


Figure 6. A screenshot of the 'Complete Survey' page.



Devices

The electronic questionnaire was adapted for use on a laptop in Google Chrome browser.

Three devices were used for testing:

- iPad mini 4, 4th generation (7.9")
- iPad Air 1 (9.7")
- Lenovo Yoga 2 touchscreen Windows laptop (13")

Procedure

Two members of the research team (K. Razik and A. Turnpenny) facilitated the meeting. The digital questionnaire in Lincus was pre-loaded in Google Chrome browser on the laptop and the two tablets used for testing. The facilitators explained the reasons for the meeting and asked the participants to complete the digital questionnaire on the devices they were assigned to. The two researchers talked the participants through the process of questionnaire completion, provided help and asked participants questions about the experience of questionnaire completion. The support worker also helped participants with the task. Researchers also took notes through the process, which were written up after the meeting. Participants' travel expenses were paid and they received £20 high street vouchers for their involvement.

Feedback from the working group

Most participants were able to read and understand the questions and response options and complete the questionnaire, although they all needed different degrees of help. Specific problems identified are described below.

Toggle page view

Participants in the working group commented that some people might not be aware of what the toggle view means. It would be useful to have an explanation or an easier phrase instead. Once the first question was submitted, they were able to see the progress of the questionnaire by the highlighted question number at the top of the page. One participant commented: 'Agree, it would be good if it said something like 'click to view one question at a time' or 'click to view all questions''.

Question heading

Participants found it easy to read the question headings even though they were italicised. However, the original version of the question headings are not italicised for compliance with easy read guidance. The research team therefore suggested that the font is not italicised.

Question stems

Participants commented that using bold in text was helpful. They found reading and understanding the question easy, although for longer stems text could be better spaced.

Instruction underneath the questions

Participants thought the paper-based version of the instruction – ‘Please tick (✓) 1 box’ - was easier to understand than its electronic equivalent – ‘Please tick one box’- because of the use of a tick symbol. They thought that some people might not know what a tick is and providing the tick symbol (✓) in the instruction would make it clear.

Position of boxes and smiley faces

Participants thought that the tick boxes and the happy/sad faces should be closer to the response options. They thought it was not clear which box referred to which response option and it was easy to tick the wrong box. This seemed to be less of an issue for the longer questions where the end of the statement was closer to the corresponding happy/sad face and the box.

Some participants expressed frustration and confusion over the fact that it was not possible to unselect all boxes once an option has been ticked. It appeared that they found it more demanding to switch their answer rather than starting the question again. They commented that they would like to be able to delete their selection and then select a new response.

One participant commented that it would be useful if upon selection the whole response was highlighted. It would make it easier for participants to visualise their response and make sure that they selected the intended answer.

Happy/sad faces

Participants understood the meaning behind the illustrated faces and were able to differentiate between the different levels of response that these represented. However, the majority expressed a preference for the faces on the paper version, saying that they were clearer. Two individuals (one looking at a laptop version, one using the iPad) commented that the grey filling made it more difficult to see the expressions and a white or other light coloured background would be better. One participant thought that the face associated with the lowest level response (high-level need) looked unhappy and angry. The participant did not have this opinion of the equivalent in the paper-based format and correctly identified that it was the most ‘unhappy face’.

Submitting an answer/moving to the next question

Participants said it was not clear how to submit an answer and move to the next question. It was not made clear that pressing the arrow at the bottom of the page after response selection would submit an answer. They recommended that it was made clear how to submit an answer and move to the next question. An explanatory text, such as, 'Please click here to save your answer and move to the next question' would be helpful.

Images

One of the two original images in Question 7 (social participation and involvement) was missing. Participants commented that having two images, as it is in the original paper-based version, would help them to understand what the question was asking about.

One participant commented that adding colour to the images would make the form look more interesting.

Submitting the questionnaire

- a) Some participants skipped questions (either on purpose or by mistake). When they tried to submit the questionnaire, they were not able to do it, but there was no message why. They found this confusing and recommended that a message was added to warn people that they missed some questions and told them either to go back and answer these or confirm that they wanted to leave these unanswered and submit the questionnaire.
- b) On the submission page, participants were not able to read the instructions above and below the free-text notes box because the font size was too small. However, more importantly it was unclear what they should write in the box. The support worker was also unsure what should be recorded there. It was suggested that it would be useful to indicate what information should be recorded in the box. The ASCS contains two questions about what help was received during survey completion. These were not included in the electronic version even though the majority of participants said they would ask somebody for help.
- c) Some people found it confusing that after they answered all the questions and clicked on 'submit', the questionnaire was not submitted and instead they were taken to the notes page and had to click 'submit' again.

Devices

We asked some participants to complete the questionnaire on multiple devices and there was a consensus that this was easiest on the Lenovo Yoga 2 touchscreen laptop (using the touchscreen function). The most difficult was on the iPad mini and, to a lesser extent the iPad Air, because the page had to be navigated sideways to read the question and reveal happy/sad faces and tick boxes corresponding to each answer option. Alternatively, using the zoom out function in Google Chrome made the font size too small to read.

Proposed revisions

The experiences of the working group in this first round of end-user testing highlighted that while some aspects of the questionnaire worked for the participants, changes were required to improve its usability. Participants were able to read the questions, select responses, move to the next questions and submit the questionnaire with varying levels of guidance and help from the researchers. This mainly consisted of verbal explanations, clarifications, and prompts. A number of features were highlighted in the process of group-testing that potentially required further clarifications or changes, and were shared with Rescon:

1) Provide better instructions:

- Add information clarifying what ‘toggle page view’ means, for example by adding the following text: ‘click to view one question at a time’ or ‘click to view all questions’
- Clarify how to submit an answer by for example adding instructions, such as ‘Please click here to submit your answer and move to the next question’;
- Add a message when questions are missed to telling users to either go back and answer the missed questions or to confirm that they wanted to leave the questions unanswered;
- Clarify that submitting the last answer does not submit the whole questionnaire, but takes the user to ‘Complete Survey’ page on which they can submit the whole questionnaire;

2) Improve formatting and layout:

- Remove the italics from the question headings;
- Use consistent spacing in question stems;
- Change the happy/sad faces to be identical with the paper-based version;

- Add the second image missing in question 7 (social participation and involvement);
- Position the happy/sad faces closer to the tick boxes for the shorter questions to make it easier to identify the box that corresponds to a particular answer;
- Match the wording ‘Please tick one box’ with the wording in the paper-based questionnaire ‘Please tick (✓) 1 box’;
- Allow changing font size to make completion easier on smaller tablets.

3) Make it possible to unselect an answer before selecting another response option.

Due to limited resources, the developer was able to address two of the issues identified: (1) the italicised question headings were changed to normal font and (2) the missing image in question 7 was added. A screenshot of the first question from the revised questionnaire in Lincus is presented in Figure 7. At this stage, we were also informed that the questionnaire was optimised for use on laptops and personal computers. Rescon were unable to deliver the adaptation for use on tablets due to unforeseen resourcing constraints.

Figure 7. A screenshot of the first question of the electronic ASCOT Easy Read questionnaire in Lincus.

The font is changed from italicised to standard

The screenshot displays the ASCOT survey interface. At the top left is the 'ASCOT' logo, and at the top right is a circular logo with 'ASCOT' inside. A dark blue header bar contains the text 'ASCOT survey'. Below this is an orange 'Toggle page view' button. A progress bar shows nine steps, with step 1 highlighted in orange. Three illustrations of people in wheelchairs are shown: one holding a large box, one holding a box and a bag, and one holding a box and a bag. The main text reads: 'This question is about choice in your daily life. Having choices 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 one box'. Four response options are listed with checkboxes and smiley face icons: '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.', and 'I have no choice. It is bad.'. A 'Submit' button and a back arrow are at the bottom. A 'Submit Feedback' button is in the bottom right corner.

Round 2 testing

To assess whether the digital version of the ASCOT ER is a feasible tool to collect social care-related quality of life information and to test the usability of the instrument, we conducted cognitive interviews with people with learning disabilities.

Participants

Offices of the participating provider organisation were contacted in the three local authority areas where the research was conducted. They received information packs for distribution among their eligible service users. Each pack contained a cover letter, participant information sheet, complaints form, pre-paid envelope and permission to contact form, whose aim was to indicate an expression of interest in research participation. Guidance regarding eligibility criteria was provided in the cover letters. The main criteria were as follows: service users aged 18 or over who had the capacity for informed consent and understand simple verbal explanations in English and answer simple questions about their everyday experiences.

Nine participants were recruited from one service. Participants' age ranged from 24 to 64 and the majority ($n=6$) were males. Overall, the interviewees had more severe disabilities than the working group participants. Only two interviewees could read. Four people had limited speech. Participants received £10 high street vouchers for the involvement in the study.¹

Settings

Six participants lived in a facility that was a mixture of a residential home and supported living, with 24-hour support. Of these, two people lived in a residential home and four people had their own flats, which were either shared or individual. Three participants lived in shared accommodation in the community. The interviews took place in participants' dwellings, either in their bedroom/sitting room or in shared living spaces as chosen by the individual.

¹ This reflected the difference between the time commitments of the two testing rounds. Working group participants had to travel to the University, while cognitive interview participants were interviewed on the premises of the service.

Materials and devices

The questionnaires were completed on a 14-inch Lenovo ThinkPad laptop with Windows 10 and Google Chrome 67 installed, and a Logitech wireless mouse. The questionnaires were completed online. The Huawei 4G Pocket Hotspot Mobile Wifi Pro dongle was used to connect to the internet. The interviews were recorded using an encrypted digital voice recorder and transcribed by a professional transcription company.

Procedure

Two research team members (A. Turnpenny and K. Razik) conducted the first three interviews together with one researcher interviewing and the other observing, to ensure consistency of approach. Three interviews were conducted by A. Turnpenny and three by K. Razik alone. All interviews took place in a service setting, in areas proposed by the participants: studio apartment, shared living areas, or bedroom. Participants could decide whether they wanted their support worker present during the interview: staff were present and involved (supporting communication) at four interviews; were present and involved minimally to support communication at one interview; were present for at least some of the time but not involved / doing something else at two interviews; and not present at two interviews. No other service users were present during the interviews.

The digital questionnaire in Lincus was pre-loaded in Google Chrome browser on the laptop. The laptop was placed for convenient use on tables where possible; however, in three cases a table or desk was not available, so the laptop was placed on the participant's lap or bed. A mouse was provided but in the majority of cases it was not used due to the level of disability ($n=5$) or the level of disability and inadequate space ($n=2$).

Participants were given the laptop with the first page of the questionnaire pre-loaded. Researchers asked whether participants would know what to do if they were asked to complete this questionnaire, and whether they would ask for help and from whom. The researchers then showed participants how to move to the next screen and how to select and submit an answer. Participants completed the questionnaire with help from the researchers and, in some cases, their support staff (see above).

As participants were completing the questionnaire, researchers asked questions about this experience. The interviews were guided by a framework, which encapsulated the main

themes of interest. The researchers also used participant observation structured by a topic guide to determine the feasibility and usability of the electronic questionnaire. Researchers supported participants to respond to the questionnaire, probing their understanding of the content and process, and observing the type of difficulties experienced, including the practical aspects of using a laptop for this purpose, a reflection on the interaction between the participant, researcher, and staff where present. See Appendix 1 for a full list of questions and Appendix 2 for details of the observation topic guide. Detailed field notes were prepared from the experiences of the cognitive interviews and observations.

Analysis

The analysis was based on the reading of interview transcripts and field notes, although relied more heavily on the latter because it captured more relevant and nuanced reflection on feasibility and usability. Meanwhile, transcripts were limited in that a number of participants had speech difficulties and used gestures to aid communication.

Findings

Field notes and interviews were analysed using an *a priori* framework based on usability considerations and the experiences of the group-testing: how intuitive was it to use the digital questionnaire, type of help needed, navigation of the questionnaire, and the overall experience of completing the digital questionnaire.

How intuitive is it to use the digital questionnaire

The participants did not find it intuitive to complete the questionnaire. When presented with the first page, no participants understood what was being asked of them and how to proceed to start the questionnaire. Participants could not work out how to submit an answer and move to the next question, or how to submit the questionnaire upon answering all the questions. At the beginning, it was not clear that when an answer was selected, an arrow appears to the right of 'submit' button at the bottom of the page and that clicking on the arrow progresses the questionnaire. Initially, all participants needed prompts and explanations from the researchers; however, with practice some participants learnt the process and needed less help with the procedure. On the other hand, some participants needed constant prompts to remain focused on the task and were not able to engage with the questionnaire independently.

All participants interpreted the happy/sad faces associated with the four response levels correctly and used them to identify their preferred answers. Four participants confirmed their answers by pointing to the corresponding face.

Participants – including those who could complete the questionnaire with limited help – were confused by the two-step final submission: clicking on ‘submit’ button in the last question did not submit the questionnaire; instead, they were presented with another screen that contained a box for notes. However, it was not clear for the participants what they were to do on this screen.

In addition, participants did not understand what ‘toggle page view’ meant. However, once the researchers explained that it enables the questions to be presented one at a time on the screen, they were able to track questionnaire progress by the question buttons at the top of the page.

Type of help needed

All participants stated that they would ask for help to complete the questionnaire and indeed they all needed differing levels and types of help.

Physical questionnaire navigation

The online questionnaire required a lot of navigation: scrolling up and down the screen, clicking boxes to select answers, clicking arrows to submit answers and move the next question, and clicking ‘submit’ button to submit the completed questionnaire. Although all participants had previous experience of using a tablet or less commonly a laptop, the majority (n = 8) had considerable difficulty using the mouse and the laptop touchpad for navigation. In some cases, participants’ level of physical disability meant that the mouse or touchpad navigation was inaccessible to them and they needed full support to select answers and navigate the questionnaire. Two participants displayed unwanted actions with the mouse (e.g. unintentionally clicking and selecting everything, window disappearing etc.). Although in this particular case they were not discouraged by these difficulties, these issues can have the potential to cause frustration and errors in the completion of the questionnaire.

Four participants did not want to engage with the physical navigation of the questionnaire on the laptop and asked the researcher to do this for them. They confirmed their answers by pointing to the corresponding face on the screen.

Support with questionnaire interpretation

All participants needed help with interpretation of the questions. Two participants who could read, needed help to clarify and confirm the meaning of the questions. For the remaining seven participants the researchers read out the questions and answers and explained the questions, providing examples to illustrate the meaning behind the questions if necessary.

Overall experience of completing the digital questionnaire

Completing the questionnaire on a laptop was challenging because finding an appropriate surface (e.g. a table or desk with a chair) was sometimes not possible. Researchers had to place the laptop on beds or laps, which prevented the use of the mouse and was generally somewhat cumbersome.

Conclusion

This project aimed to develop and test the usability of a digital version of the revised ASCOT Easy Read questionnaire with people with learning disabilities and autism. The literature demonstrates a range of benefits associated with web survey and computer-assisted questionnaire designs. It was hoped that an accessible online instrument developed and tested with people with learning disabilities would allow greater independence and efficiency in self-reporting social care-related quality of life.

The electronic adaptation of the instrument was carried out by an industry partner free-of-charge. This had implications in terms of time and resources allocated for the project. There was a static transposition of the paper format questionnaire to a webpage layout optimised for use on a laptop computer, without incorporating additional accessibility features permitted by the electronic mode (e.g. audio, font-size, spacing etc.).

Field-testing with people with learning disabilities highlighted various usability issues:

- The use of laptop for questionnaire completion was challenging for people with learning disabilities, the majority of whom had difficulties using the touchpad or the mouse for navigation;
- The layout of the page – particularly the need to scroll up and down to reveal the full question and answer options – was also problematic.
- The positioning of tick boxes further away from the answers made it more challenging for some participants – who could otherwise complete the questionnaire with minimal support – to make sure they selected the intended option.
- The lack of clear instructions on how to complete the questionnaire and the lack of opportunities to practice made participants more reliant on external help. This could potentially increase the risk of errors.

Nevertheless, the majority of participants were positive about the electronic questionnaire, and were familiar with the use of technology (e.g. tablet, mobile phone etc.). Computer-assisted self-reporting could have the potential in this group to support participation in research, however the approach/version tested in this project did not deliver this due to limitations in accessibility – primarily, due to the use of a laptop with mouse/touchpad.

The project also had some limitations, namely the use of experienced interviewers/researchers to facilitate the completion of the questionnaire; and the lack of resources to deliver the identified modifications to the initial questionnaire that may have improved its feasibility and accessibility. Furthermore, the questionnaire was developed for use on a laptop and not (as originally intended) on portable tablet devices.

To conclude, the use of the electronic version of ASCOT-ER developed in this project is not recommended on a larger scale. Further work is necessary to create a more accessible and easier-to-use version based on the experiences of this project. Although this project benefited from industry partnerships, funding was a barrier to study design. Future work needs to seed-fund the development of the electronic adaptation, as well as the testing and evaluation, rather than relying on partnership working alone. The new development should be for a tablet device and take a more experimental approach by testing versions and features in situations that more closely resemble the conditions in which people with

learning disabilities might be asked to complete the questionnaire – for example, observing people responding with support from staff or friends.

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Appendix 1: Question guide for the cognitive interviews

Questions used for the first page of the questionnaire.

- In your words, could you tell me what this is asking you to do?
- If you were asked to answer these questions, would you do it?
 - Probes: would you know how to do it? If yes, why? If not, why?
- Do you know what 'toggle page view' means? Could you tell me in your own words?
[probing question: did you click on 'toggle page view'?]
- How easy is it to read the question? [probes: is the size too big or too small?]
- Do you know how to choose an answer? What would you do to choose your answer?
[probe: What does 'please tick one box' mean'? do you understand 'please tick one box'?]
- Can you tell me what the smiley faces mean?
- Would you ask anyone to help you? / Would you fill it in on your own?
 - Probes if asking for help: who would you ask to help you? What would you ask them to help you with? Why?
 - Probes if filling it on their own: Do you think it's OK to ask for help if people need help?

As the participants went through the questionnaire, the focus was shifted to learning more about this experience; the following questions were used to facilitate data collection:

- What answer did you choose?
- What did you do to answer this question?
- Was it easy or difficult to answer the question?
- Did you know how to choose your answer?
- Could you read the text of the question?
- Were the smiley faces helpful to choose an answer? Did you know what each smiley face means?
- Did you know which answer went with which smiley face?
- What were you thinking when answering this question?

Appendix 2: Topic guide for the user experience observations

- Did participants need help?
- Who were they helped by?
- What type of help was given?
- How easy was it to complete the questionnaire on a laptop?
- How easy was it to use a mouse?
- How practical was it to use a laptop?
- How practical was it to use a mouse?
- How easy was it to navigate the questionnaire? Switching between page view/infinite scrolling etc.
- How intuitive was it to complete the questionnaire? Was it clear to participants what they had to do to answer the questions?
- Could they access and understand information on a laptop screen, using the layout provided?
- What was the overall experience (e.g. did people stay motivated/ get frustrated etc.) of completing the questionnaire?