



Promoting participation of people with intellectual and developmental disabilities in social care research: Developing an Easy Read version of ASCOT

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QORU and Engagement programme

- Engagement is one of a number of programmes running under QORU.
 - Application, Measurement, Service Delivery
- Measurement is a core government mechanism to manage accountability.
- If such measurement is to be rigorous, valid and unbiased, it must include the voices of those populations or individuals that are reluctant to take part, hard to include or seldom heard.

Engagement programme – background

- Research on the impact of social care at PSSRU.
- Personal Social Services Adult Social Care Survey (ASCS).
 - Annual survey of social care service users receiving services funded wholly or partly by Social Services.
- Not everyone can answer for themselves, even with support.
- 14.5% of service users in 2012 receiving the ASCS had a learning disability.
- 71% of service users reported having help to complete the questionnaire.

Engagement programme

- Range of associated problems with any long term condition can make it more difficult for people to take part in research.
- Structured format of surveys can be challenging for people with cognitive or intellectual disabilities which can lead to exclusion.
- For some individuals the risk of exclusion is high.

Programme strands and aims

- Easy read version
 - Develop an easy read version of ASCOT for self report
- Proxy version
 - Develop a proxy version of ASCOT for formal and informal Carers
- Semi-structured Interview version
 - Develop a semi-structured interview version of ASCOT
- Mixed method approach
 - Explore feasibility of using observation in a community setting combined with user and Carer interviews

Easy Read (ER) Version

- An easy read version was developed as part of the ASCS.
 - Undertaken under tight time pressures with aim of minimizing differences for comparison.
 - Feedback from user groups suggest revision would be beneficial
- Aim of this project was to revise and update the ER version.
 - Improve the clarity of the ER version in order to maximise response rates and minimise the need for support from Carers.

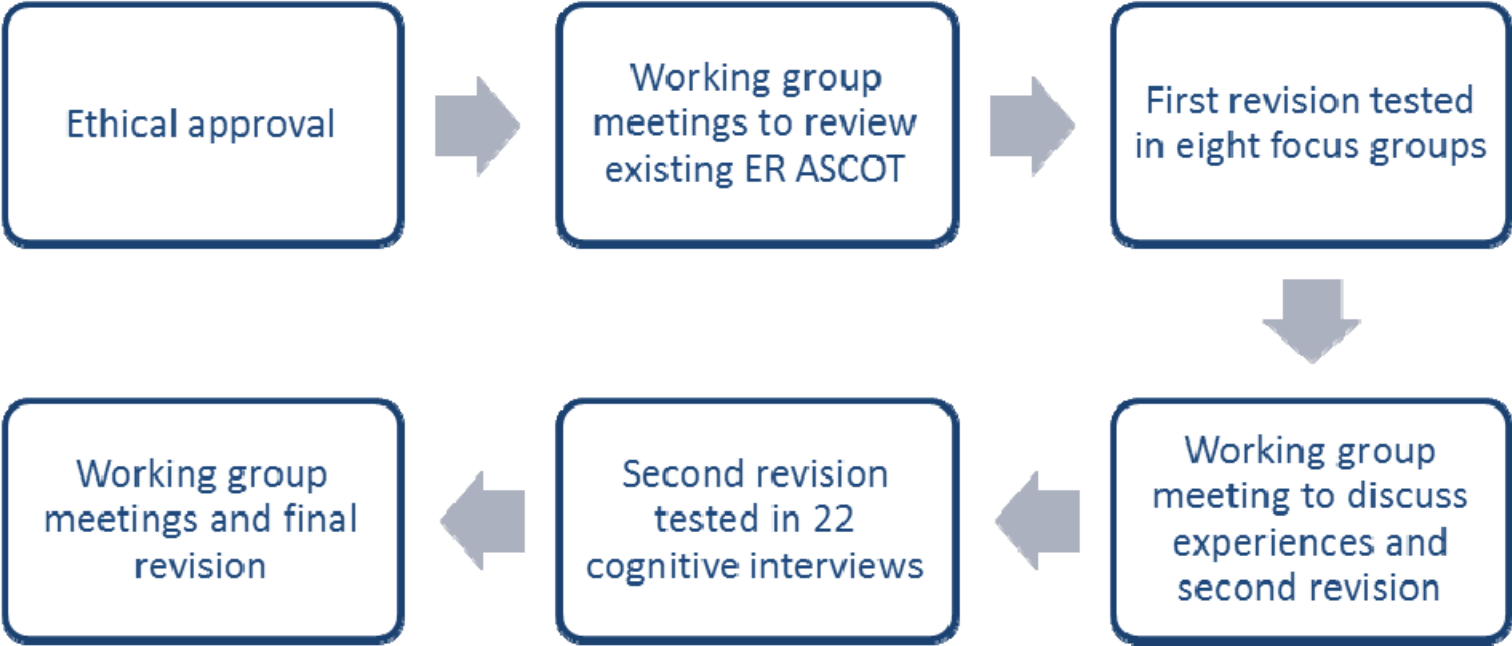
Easy Read best practice

A type of accessible information characterised by:

- plain language;
- simple layout and format; and
- the use of images to illustrate key messages in the text.

Sometimes Easy Read is referred to as “Easy Words and Pictures” or “easy information” or “easy-to-read”.

Methods and process



Staggered reveal method

- A structured approach to facilitate group discussion.
- Used in both the working group and focus groups.
- Main steps:
 1. Picture shown and discussed
 2. Question revealed and answered in own words
 3. Full item revealed and answered

Ranking exercise & cognitive interview

Ranking exercise:

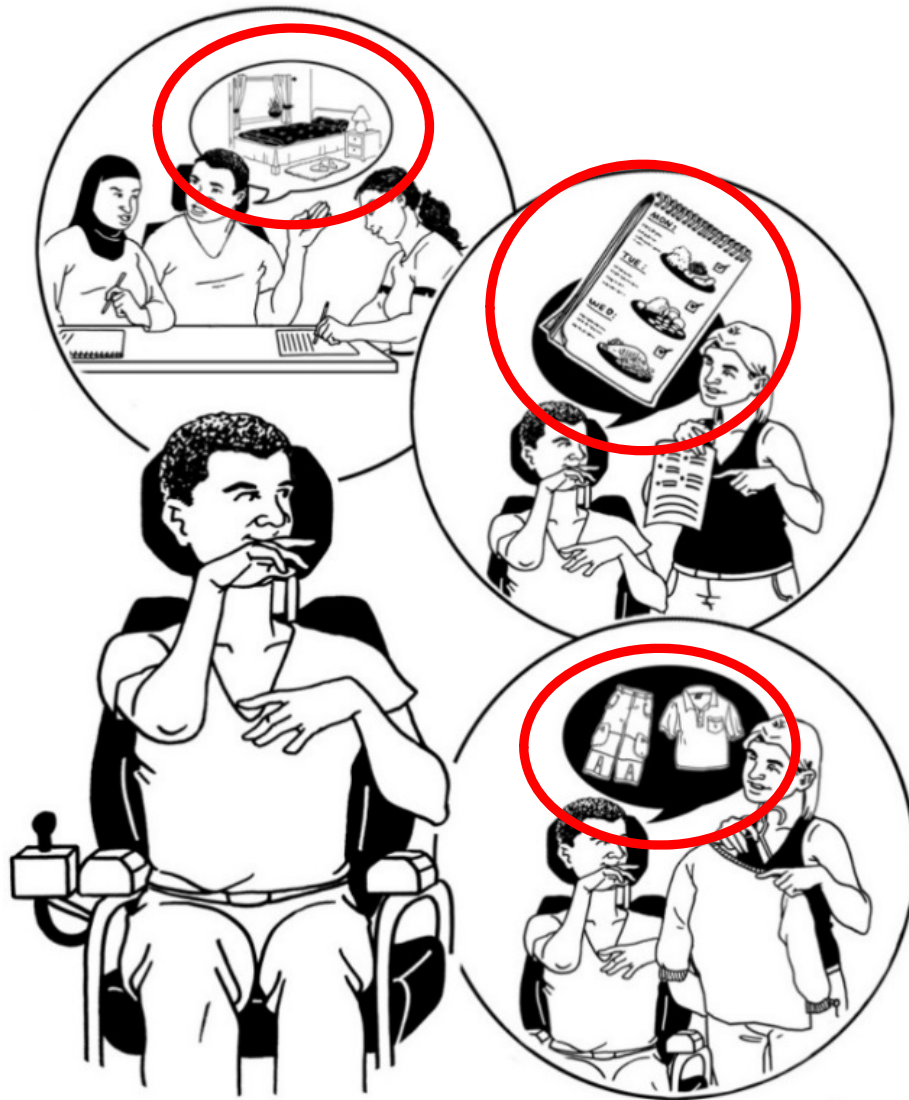
- Order two sets of four show cards starting from “best” to “worst” and “most frequent” to “least frequent”. All show cards had smiley/sad faces and text.

Cognitive interview:

- Semi-structured face-to-face interview format.
- Participants prompted to “think aloud” as they answer the questions.

Analysis

- Five focus groups and 21 cognitive interviews were audio-recorded. In the remaining focus groups and interviews detailed notes were taken.
- Focus groups were not transcribed but detailed summary notes were made from recordings.
- Cognitive interviews were transcribed verbatim and transferred to Nvivo for analysis.
- Questionnaire data from cognitive interviews analysed using descriptive statistics.



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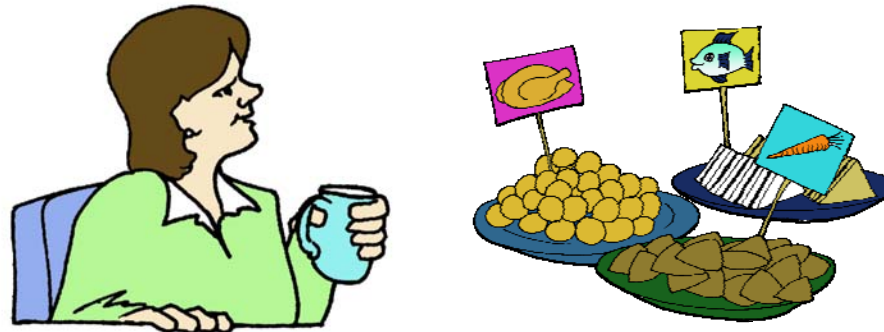
l by black & white pictures.

ons. Pictures with a clear
ences seem to work best.

re-level images (e.g.
confusing, particularly for

Pictures

Food and drink domain:



Version 1

Revised



Pictures

Safety domain:



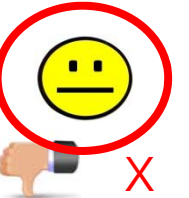
Version 1

Revised



Pictures: faces for response options

Original



Revised



Results: question phrasing and structure

- Followed general guidance on easy-to-understand/plain text:
 - Short sentences;
 - Active voice;
 - Bullet points (but we avoided numbered lists);
 - Simple words or more difficult words explained.
- Question stems longer than in standard questionnaires.
- Longer answers seem to work better than simple one-two word phrases often used in Likert scales.

Question phrasing & structure: example 1

Original:	Revised version:
How do you feel about the way other people treat you?	This question is about dignity. Dignity means being treated nicely and kindly.
The way I am helped and treated makes me feel better about myself.	How do you feel about the way your paid support treat you?
The way I am helped and treated does not change the way I feel about myself.	I am very happy with the way my paid support treat me.
The way I am helped and treated sometimes makes me feel a bit bad about myself.	I am quite happy with the way my paid support treat me.
The way I am helped and treated makes me feel very bad about myself.	I am a bit unhappy with the way my paid support treat me.
	I am very unhappy with the way my paid support treat me.

Question phrasing & structure: example 2

Original:

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

I feel clean and like the way I look.

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

I feel a bit clean and tidy, but not enough.

I do not feel at all clean or tidy.

Revised version:

This question is about being presentable.

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

How presentable do you feel?

I feel very presentable.

I feel quite presentable. It is OK.

I feel a bit presentable. It could be better.

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









Original and revised domain question

Personal Cleanliness and comfort



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

Please tick (✓) 1 box

- I feel clean and I like the way I look 

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

- I feel a bit clean and tidy, but not enough 

- I do not feel at all clean or tidy 


Personal cleanliness and comfort







This question is about being presentable.

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

How presentable do you feel?

Please tick (✓) 1 box

- I feel very presentable. 
- I feel quite presentable. It is OK. 
- I feel a bit presentable. It could be better. 
- I do not feel presentable at all. It is really bad. 

Limitations

- No information about the expressive and receptive language abilities of participants.
- Small sample size (developmental study).
- Not all participants were using services.

Further information

For more information QORU website:

<http://www.qoru.ac.uk/about/research/engagement/>

Full report:

<http://www.qoru.ac.uk/publications/>

Personal Social Services Research Unit

<http://www.pssru.ac.uk>

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