

The evolution of the ASCOT-ER in England

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Background

- Measurement is a core government mechanism to manage accountability.
- The ASCOT is designed to measure social care-related quality of life (SCRQoL).
- Eight domains of SCRQoL.
- Structured questionnaire, produces a numeric score.
- Developed and tested with older social care users.
 - Able to take part in user experience surveys and interviews.

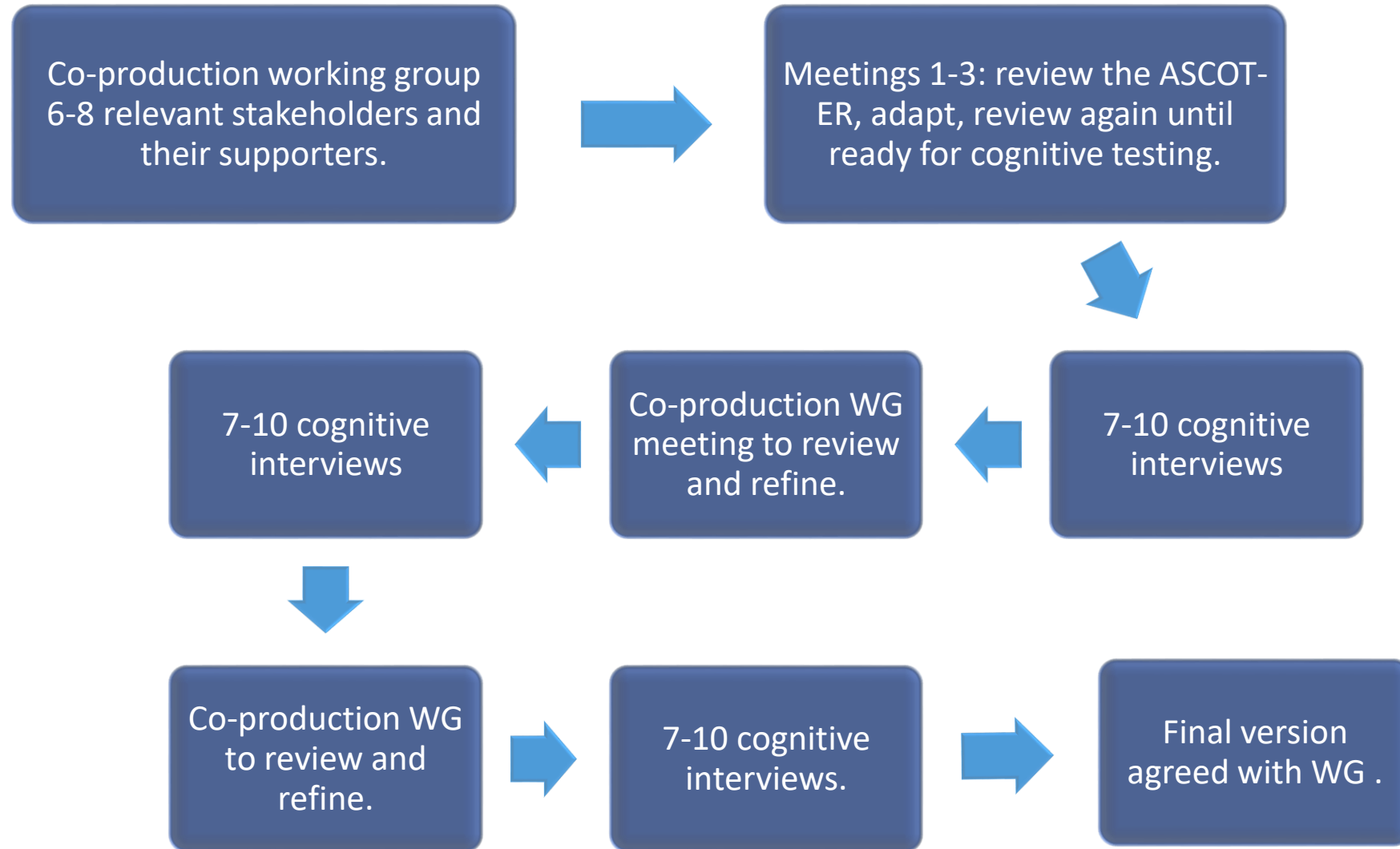
Background

- If measurement is to be rigorous, valid and unbiased, it must include the voices of those populations or individuals that are hard to include, or seldom heard.
- Structured format of surveys can be challenging for people with cognitive or intellectual disabilities which can lead to exclusion.
- Range of associated problems with any long term condition can make it more difficult for people to take part in research.
- For some individuals the risk of exclusion is high.
 - E.g., Adult Social Care Survey in England (ASCS) – exclusion of people unlikely to be able to self-report from sample.
- Need for an Easy Read version of the ASCOT.

Developing the ASCOT-ER

- An easy read version was developed as part of the Adult Social Care Survey (ASCS).
 - Undertaken under tight time pressures with the aim of minimizing differences for comparison.
 - Feedback from user groups suggested revision would be beneficial.
- Projects to revise and update the ASCOT-ER.
 - For people with intellectual and developmental disabilities (ID) and/or autism (2015).
 - Validity study (Rand et al., 2019).
 - For older people who need support due to cognitive decline (age related, cognitive impairment, dementia) (work ongoing).

Methods



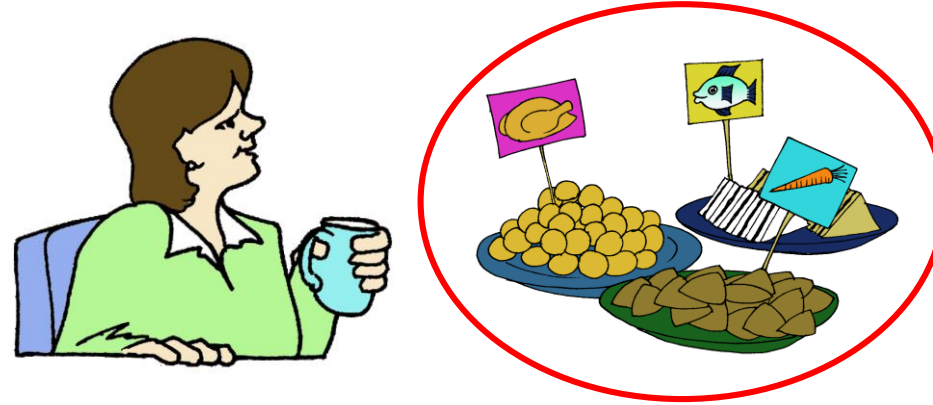
Easy Read best practice

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.

Illustrations

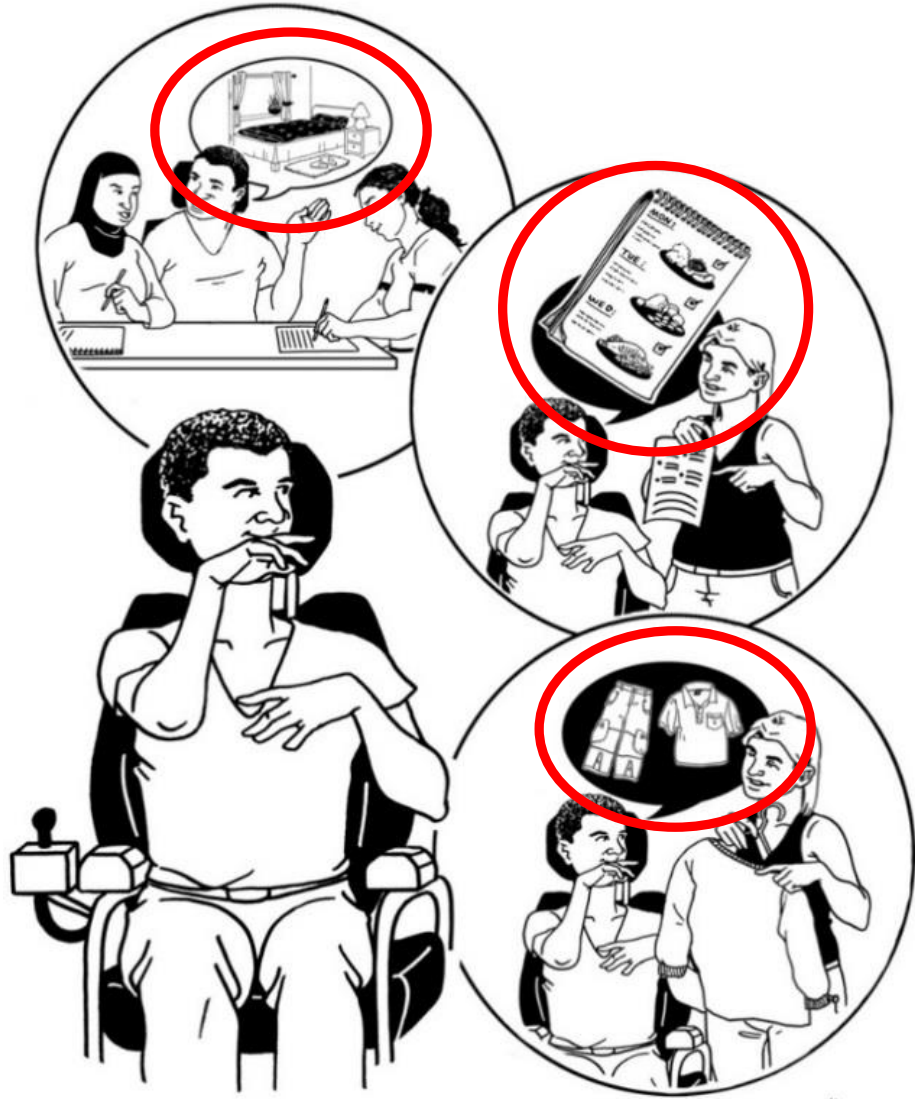
Food and drink domain:



Original

Revised





standing for more abstract concepts and

by black & white pictures.

ons. Pictures with a clear relevance to
o work best.

æ-level images (e.g. thought bubbles etc.)
y for people with autism.

Pictures: faces for response options

Original



Revised



Question phrasing and structure

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

Question phrasing & structure: example

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

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.

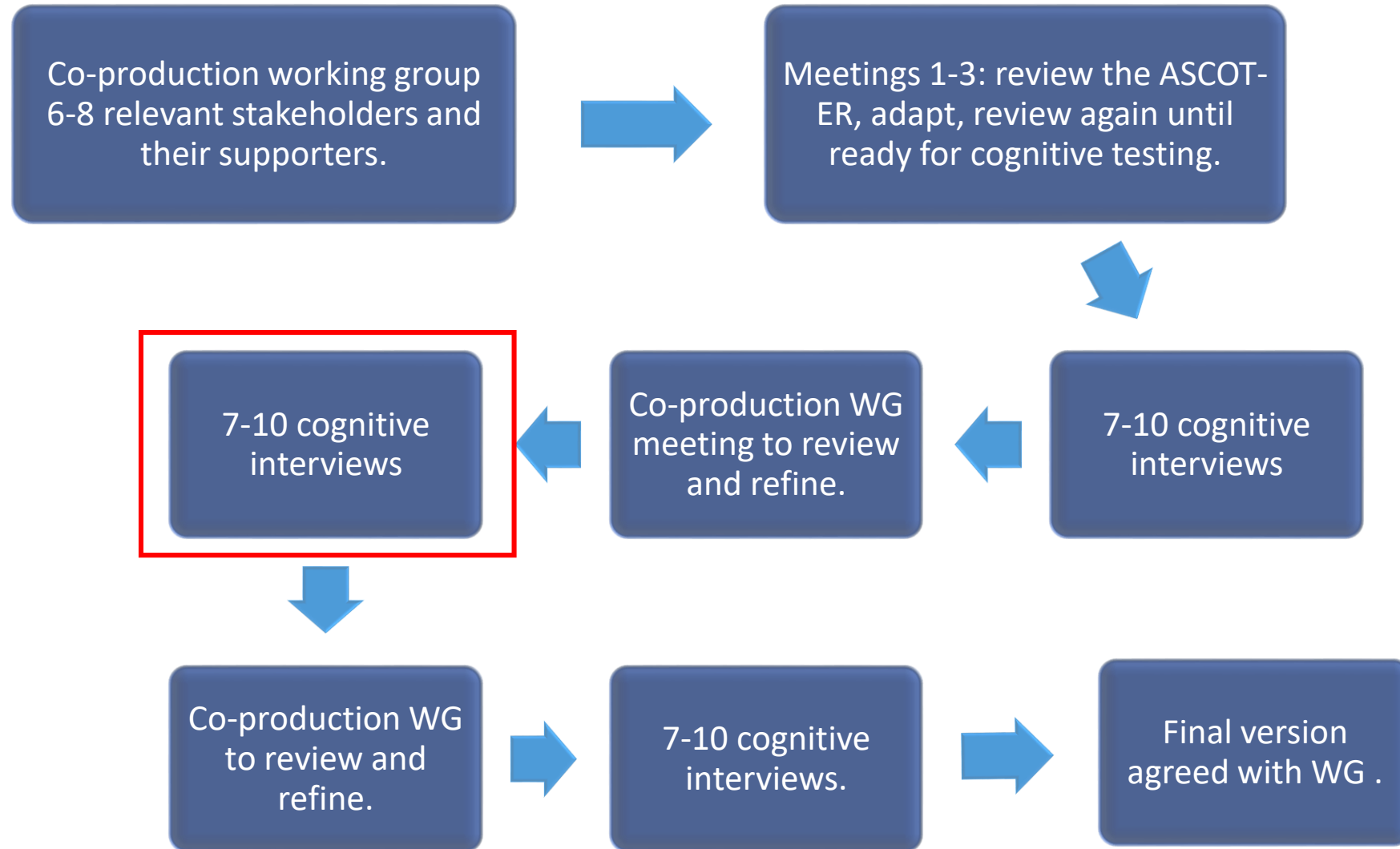
Being presentable means being clean, having clean clothes and feeling comfortable in what you are wearing.

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. 

ASCOT-ER for older people accessing social care

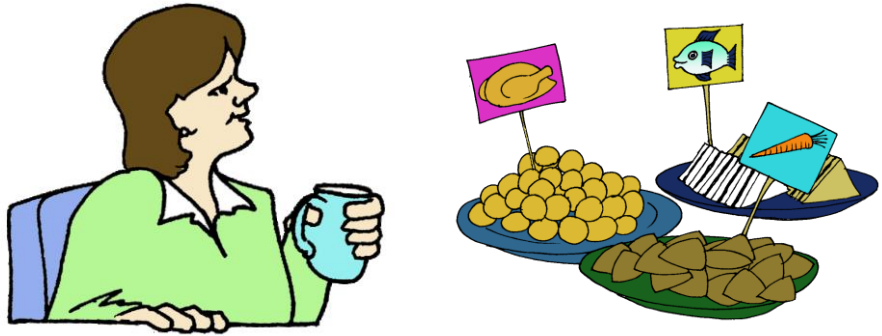


Easy Read for older social care users – working group (illustrations)

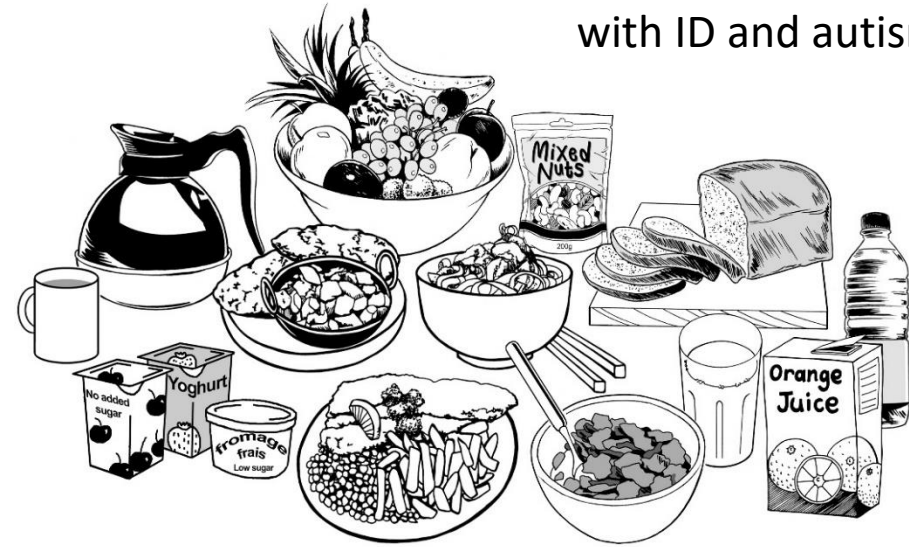
- Disliked illustrations
 - Not relevant or relatable
 - Could alienate responders
 - Reinforcing stereotypes (that older people need help)
 - Food and drink unclear
 - “is it about health, or a balanced diet?”
 - “Too busy, not big enough”
 - Too much detail
 - Disliked style
 - ‘Emoji style’ happy / sad faces for response options helpful

Illustration change – example

Original



ASCOT-ER for people with ID and autism



ASCOT-ER for older social care users

Easy Read for older social care users – working group (wording)

- Less need for lengthy or ‘wordy’ questions and response options.
- Move back towards standard ASCOT questions.
- Some words changed / added due to risk of misinterpretation or relevance.
- Some word ordering changed to reflect more relevant concerns for older people e.g. safety.

Easy Read for older social care users – cognitive testing (round 1)

- Conducted 6 interviews with individuals.
 - Areas covered included: Kent (3), Hampshire (1), Sussex (1) and London (1)
 - Higher end of cognitive impairment (as measured by mini cog)
 - Scores ranged from 0-3 (out of 5)
- Of the 6 people interviewed:
 - 6 white British,
 - 4 female, 2 male
 - Aged 72-89
 - Social care use: 5 using home care, 2 using community activities, 3 equipment (e.g. walking aids), 3 home adaptations, 2 other (dementia support group)
 - 5 pay for their social care, 1 pays a contribution

Easy Read for older social care users – cognitive testing (round 1)

Question ordering

- Control over daily life
 - Personal cleanliness
 - Food and drink
 - Accommodation
 - Safety inside the home
 - Safety outside the home
 - Social Participation (life)
 - Occupation (how you spend your time)
 - Dignity
- 
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 - Dignity

Easy Read for older social care users – cognitive testing (round 1)

Moving tick boxes and response prompts

How much control do you have over your daily life?





Please tick (✓) 1 box

I have as much control as I want.

I have adequate control.

I have some control, but not enough.

I have no control.

<input type="checkbox"/>	
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Easy Read for older social care users – cognitive testing (round 1)

Moving tick boxes and response prompts

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Next steps

- Round 2 of cognitive interviews
- 10 interviews being carried out in May
- Working group meeting 5 in June
- Round 3 of cognitive testing
- Final version to be agreed with working group
- Other outputs to include:
 - One page lay summary
 - Testimonial videos (co-production and ASCOT-ER tool)

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