



Co-Designing an Accessible Adult Social Care Outcomes Toolkit for Older People: Towards More Inclusive Self-Reporting





Disclaimer

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The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Why does care-related quality of life matter?

- 2.2 million older people in England require support with at least one activity of daily living, with needs met variously by family, friends, or social care services (Reeves et al., 2023)
- > 0.5 million older people rely on publicly funded social care (King's Fund, 2024a)
- 33.2% of social care in community settings is self funded
- Along with 48.9% places in care/nursing homes (ONS, 2022; 2023)
- It is therefore important to capture care-related quality of life



What is ASCOT?

- The Adult Social Care Outcomes Toolkit (ASCOT) is an outcome measure, capturing social care-related quality of life.
- This means it measures the aspects of QoL most impacted by social care:
 - Control over daily life
 - Personal cleanliness and comfort
 - Clean and comfortable home
 - Food and drink
 - Personal safety
 - Relationships with family and friends
 - Occupation (doing things you value and enjoy)
 - Dignity
- <https://www.pssru.ac.uk/ascot/>



What tools does ASCOT offer?

SCT4

4-level self-completion tool

INT4

4-level interview tool

CH4

4-level mixed-method tools
in care homes

- Residents' view
- Structured observation
- Staff and family member view

Carer SCT4

4-level self-completion tool
for family/friend carers in
community settings

Carer INT4

4-level interview tool for
family/friend carers in
community settings

SCT4 Proxy tool

4-level proxy-report version
for completion by someone
who knows the person well

CWRQoL

4-level self-completion tool
for people working in adult
social care

SCT4 Easy Read

4-level self-completion tool
for people with intellectual
disabilities

Used internationally:



UK

DK

FI

AT

JP

CN

NO

ES

NL

AU

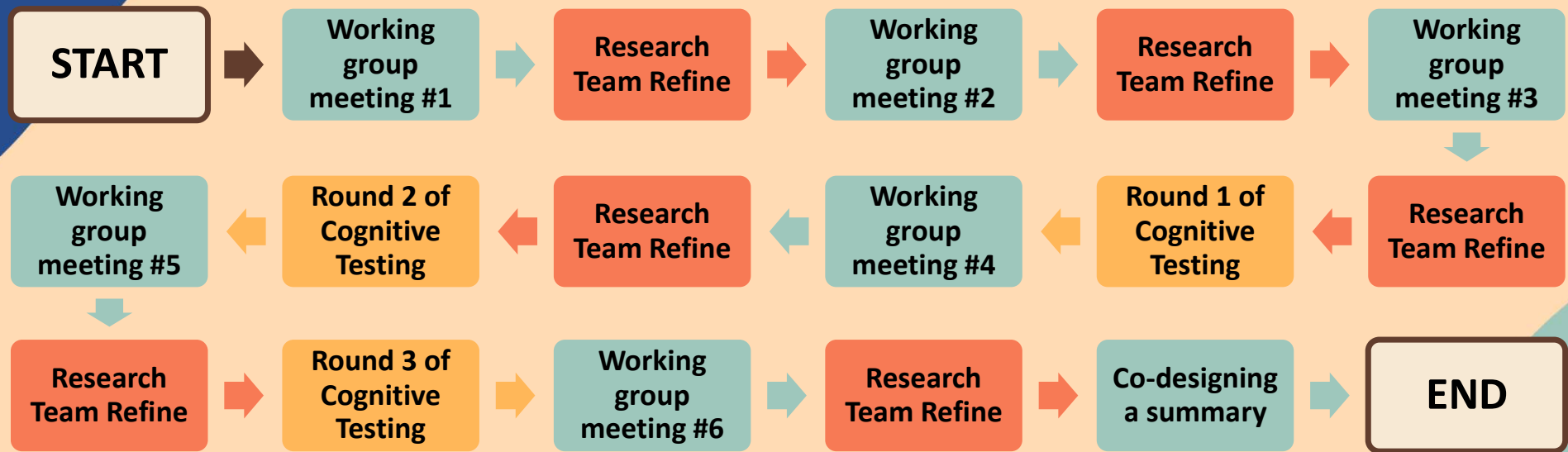
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Why was an easy-read version for older people needed?

- Some older people find the standard questionnaire difficult to complete, this might be due to:
 - Mild-to-moderate dementia
 - Cognitive impairment
 - Unfamiliarity with surveys
 - Other age-related needs
- There already was an 'easy-read' ASCOT tool for adults with intellectual disabilities
 - The ASCOT team had many requests to use this with older people living in the community

How was the toolkit developed?



Working group: 8 older people (many living with dementia, some did not have personal experiences of social care input), 6+1 meetings

Cognitive testing: 25 older social care users (each person tested once only), latter rounds focussed on increasing ethnic diversity



testing with people who can find surveys difficult.

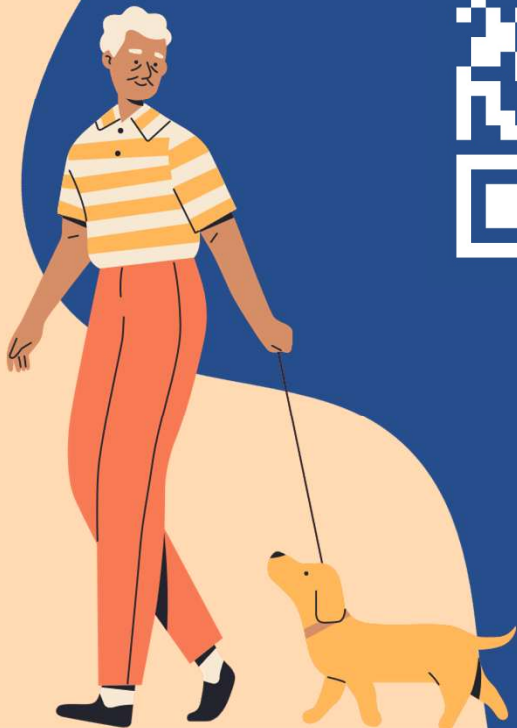
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Project
Overview

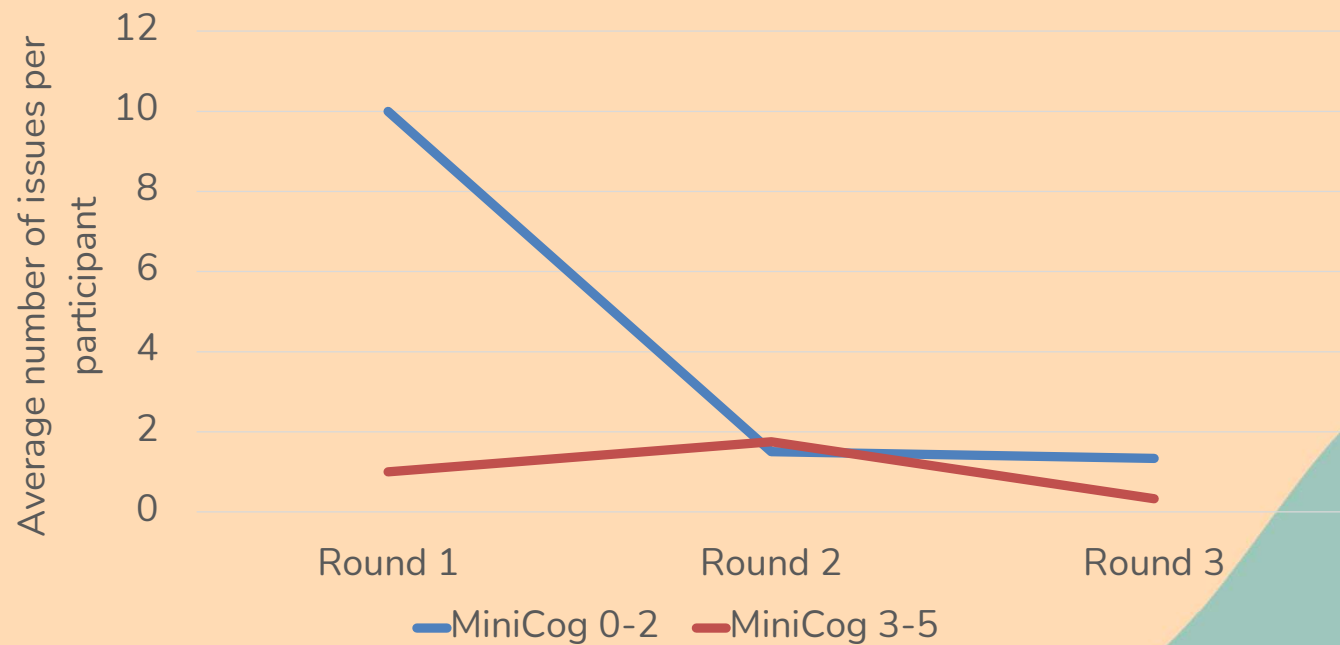


Reflections from the
working group



Cognitive Testing Results

Frequency of issues by cognitive impairment



Issues assessed:

- Comprehension
- Recall
- Judgement
- Response Mapping
- Prompt required

NB: small sample size!

What is different about the new version?

- Many elements of the tool have changed because of the iterative refinements:
 - Use of images
 - Re-ordering of, or addition of (more relevant) prompts for questions
 - Changes to the wording of response options
 - Removal of qualifiers in response options (“It is ok.”)
- The tool is more relevant, more understandable and easier to respond to than ever before for this group of people.









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 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 often enough. Sometimes I'm hungry or thirsty.
-  I do not get any of the food and drink I like. I am often hungry or thirsty.



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 only 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 often enough. Sometimes I'm hungry or thirsty.
- I do not get any of the food and drink I like. I am often hungry or thirsty.

What difference do we hope this will make?

- ASCOT is an internationally used outcome measure for social care.
- This co-designed easy-read toolkit will enable more people to report the impact of services on their quality of life.
- Care providers and commissioners can use the tool to assess how well services are meeting people's needs.
- The tool has already been licensed for use by the British Red Cross to evaluate the impact of their services across the UK with 10,000 older people.



THANK YOU

R.Mikelyte@kent.ac.uk

