



# Co-designing an Easy-Read Measure of Care-Related Quality of Life:

Reflections on involving people  
living with dementia and their  
supporters





## 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?

- 1 in 11 people aged 65+ in the UK have dementia.
- As the dementia progresses, many will need support from adult social care services:
  - 60% of people receiving homecare live with dementia
  - 70% of people who live in care homes live with some form of dementia
- 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

## 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

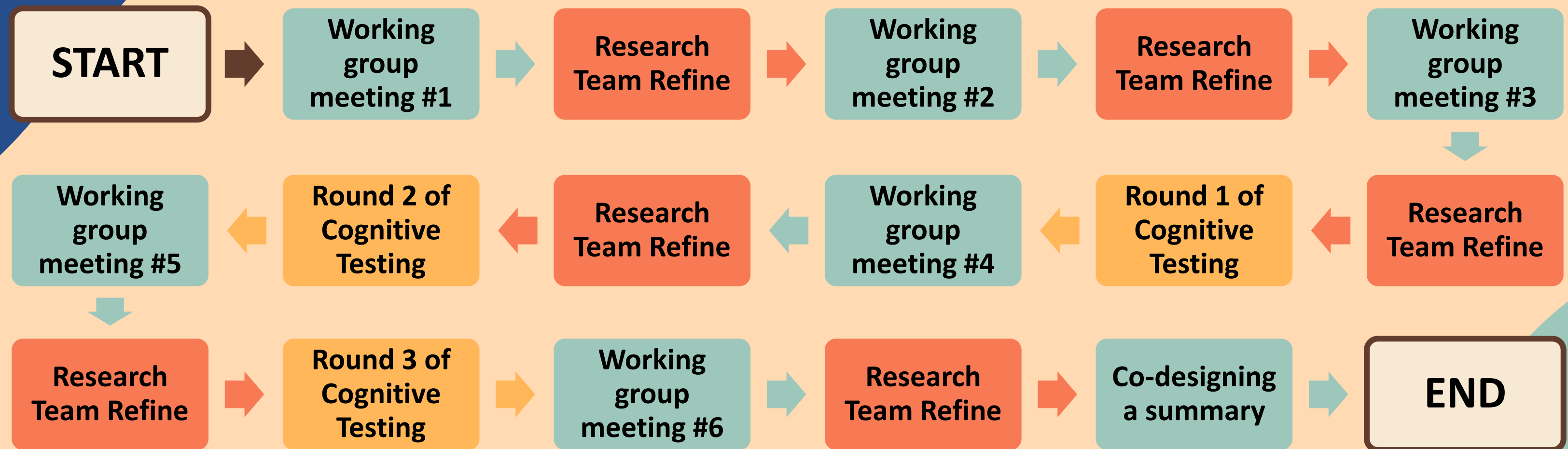
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# Why was an easy-read version for older people needed?

- 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 (half 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



A man with short brown hair and glasses is speaking. He is wearing a light blue and white vertically striped button-down shirt. The background is a soft-focus image of a landscape with green hills and a blue sky. The video is framed by a blue and orange border on the left and top, and a teal and orange border on the right and bottom.

testing with people who can find surveys difficult.



# WATCH OUR VIDEOS IN FULL



Project  
Overview



Reflections from the  
working group

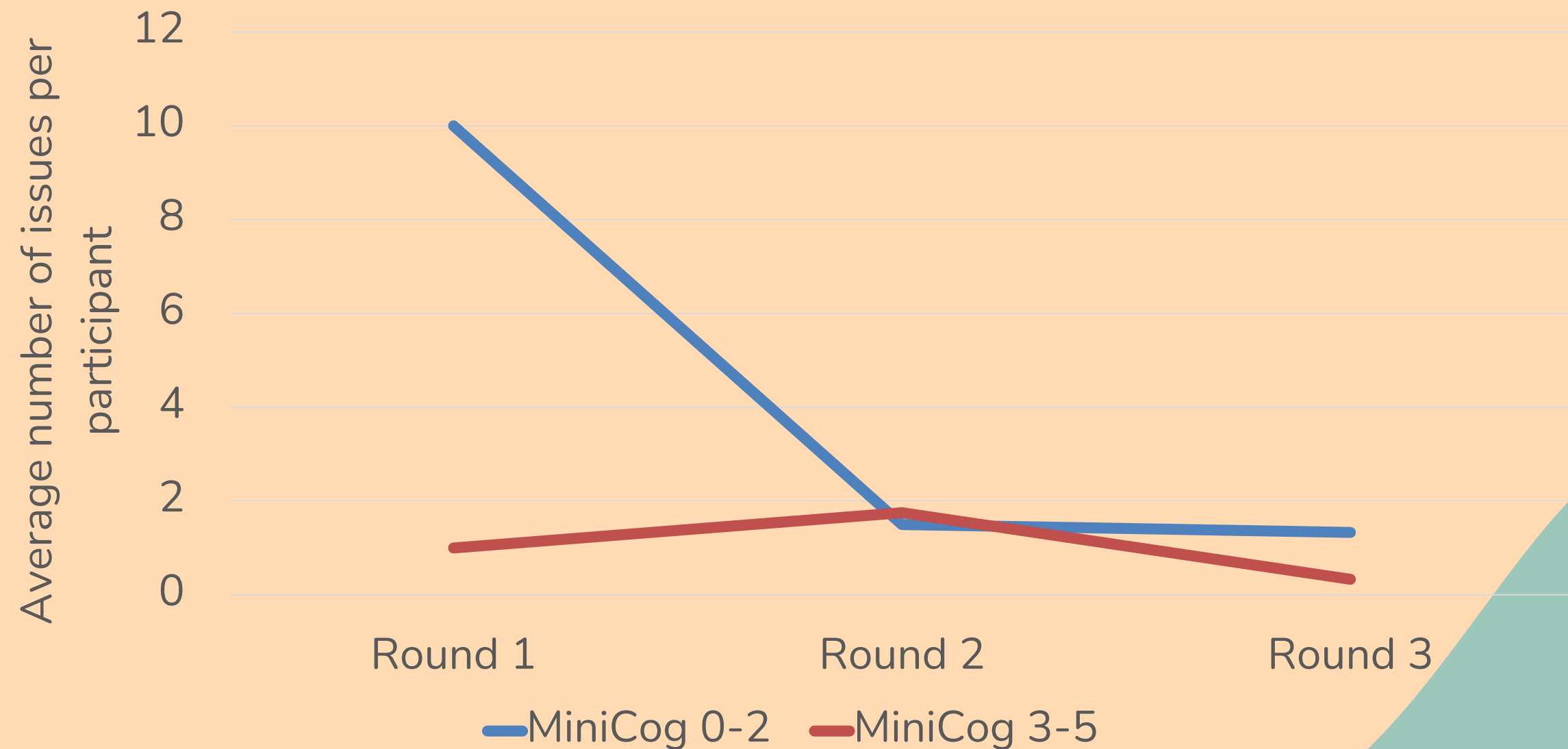


# Cognitive Testing Results

Issues assessed:

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

Frequency of issues by cognitive impairment



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.





## Why did the Working Group members get involved?

- Ability to contribute and make a difference
- Wishing to help others in similar circumstances (even if no direct benefit for self; even if any change will take a long a time)
- Local project (in-person, easy to get to)
- Ability to take part together with supporter
- Existing relationships with one team member

*“I don't care if it doesn't benefit me, but I do care if it benefits other people, even if it's a long way in the future, to me, that is more important than it benefited me” (EbyE3)*

## Why did the WG stay involved?

- Collaborative process and positive group dynamics, even when opinions diverged
- New knowledge and new perspectives gained (from researchers and other working group members)
- A sense of meaning from ability to contribute
- Interest in the iterative process of the project (i.e. cognitive testing rounds and how the group's redesigns will be received)

*“I personally felt a great deal of attachment to the illustrations, but it was good for me to know that they weren't going to be used [...] I was reminded of the process and the views of [cognitive testing participants] and how, in fact, the piece of work was far more important than my own personal thoughts on what I've contributed” (EbyE1)*





## Would WG members recommend getting involved in research to others?

- Unanimous suggestions that others should get involved
  - Some had already spoken about importance of involvement in research to their friends/families
- WG members stressed:
  - Enjoyment of the process
  - Empowering experience of being treated as an equal

*“I'm really glad to be able to come and talk to my friends [,,,] and if it means that people have a better understanding of how decisions are made and whether they might want to also participate in research projects like I have been doing, then I think that must be a really good thing” (EbyE5)*

# 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

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