

# When conventional self-report is difficult: alternative methods to support inclusion in research.

Ann-Marie Towers, Reader in Social Care.

CENTRE FOR HEALTH SERVICES STUDIES



EXCELLENCE  
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# Background

- Gathering the views of the public, patients and service users is a fundamental aim of social research.
- Experience, satisfaction and QoL of service users are important indicators of service quality.
- Methods often rely on the person being able to self-report.
- Many social care users at risk of exclusion.
- Some 'inclusion' issues relate to access (identifying people, finding them, recruiting them), beyond scope of today.
- Focus here is on enabling inclusion after recruitment.
- Look first at conventional self-report methods....

# Questionnaires

- Quantitative methodology.
- Can reach large numbers of people.
- Usually postal/online.
- Consented at start of survey.
- Relatively inexpensive to administer.

# Barriers to inclusion

- **Consent:** can the respondent understand the aim of the survey, what you will do with their data and how you will store it?
- **Comprehension:** do they understand the questions and response options? Are they able to choose one that best represents how they feel?
- **Mode/layout/format:** might be confusing and lead to the person missing questions, ticking multiple options or giving up.
- **Physical and sensory barriers:** need someone to read the questions, be their scribe, alternate format needed (braille).
- **Submitting responses:** can the person *understand* how to return it? Are they *physically able* to get it back to you (post)?

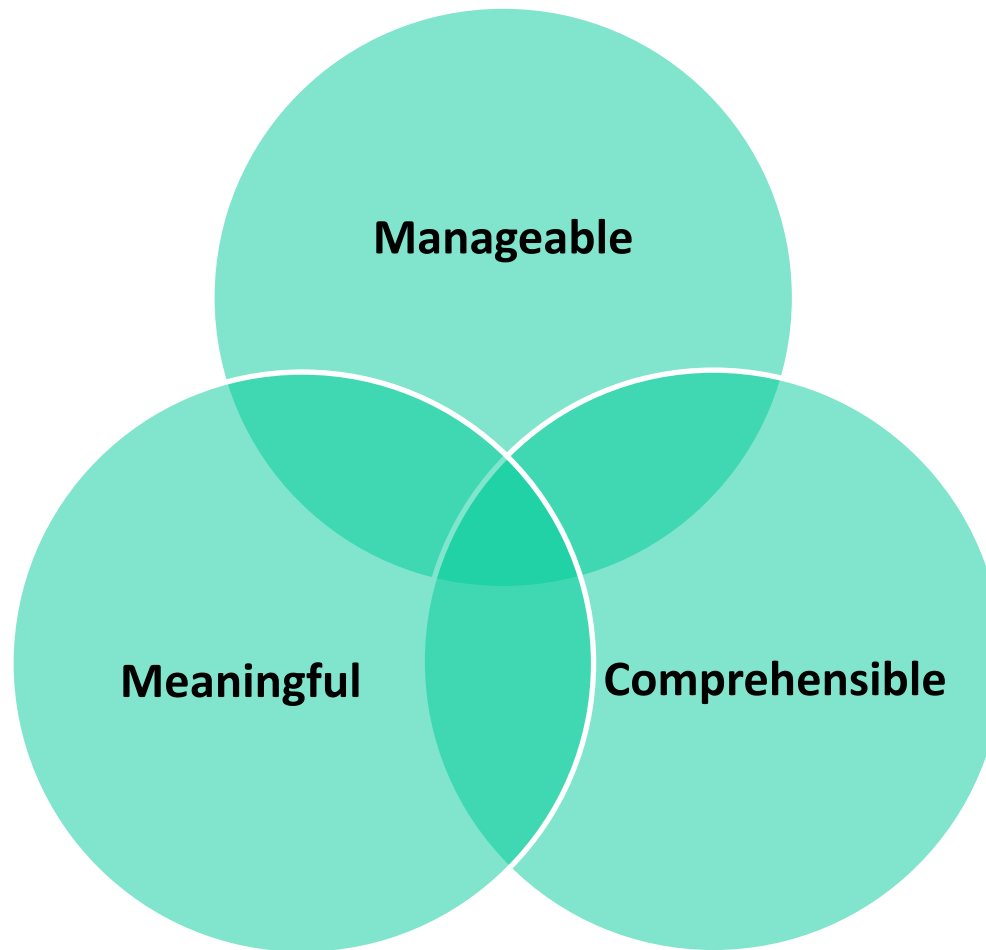
# Structured Interviews

- Face-to-face/telephone/online.
- Can be used alongside postal/online to support inclusion.
- Consent often in advance and on the day.
- Interviewer can support understanding, provide clarification and prompts.
- Good option for those who require some practical assistance (reading/scribing).
  - Often informal carer or paid carer will help but not always appropriate, depending on topic.

# Structured Interviews: barriers to inclusion

- **Comprehension:** standard question wording and response options might still difficult to understand.
- **Manageability:** too long, too structured, difficulty choosing a response option. Prefer open questions.

# Research participation should be...



# What does Manageable, Meaningful and Comprehensible look like?

I'm visually impaired

I can't hear your question

I need someone to write for me

I can tell you how I feel in my own words

I need you to make it easier to understand

I need lots of breaks

I can choose between things using my eyes

I need someone to answer for me

You can see how I feel but I can't tell you



# Depends on the person and their needs.

- A single study can't do everything!
- Know your sample and the likely barriers to inclusion.
- Can be limited by 'validated' instruments and tools.
  - Can you adapt the questions?
  - Can you change the layout and format?
  - Does mode of administration matter?
  - COSMIN standards for PROMs
- Some examples we've used drawing on our work with the Adult Social Care Outcomes Toolkit (ASCOT).
- <https://www.pssru.ac.uk/ascot/>

# The ASCOT

- The ASCOT designed to measure social care-related quality of life (SCRQoL).
- Eight domains of SCRQoL.
- Structured questionnaire, preference-weighted, quantitative analysis.
- Developed and tested with older social care users
  - Could self-report (home care users)
  - Able to take part in user experience surveys and interviews
- Take a look at an example

# Example



## four-level self-completion questionnaire (SCT4)

### 1. Which of the following statements best describes how much control you have over your daily life?

*By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want.*

***Please tick (☑) one box***

I have as much control over my daily life as I want

I have adequate control over my daily life

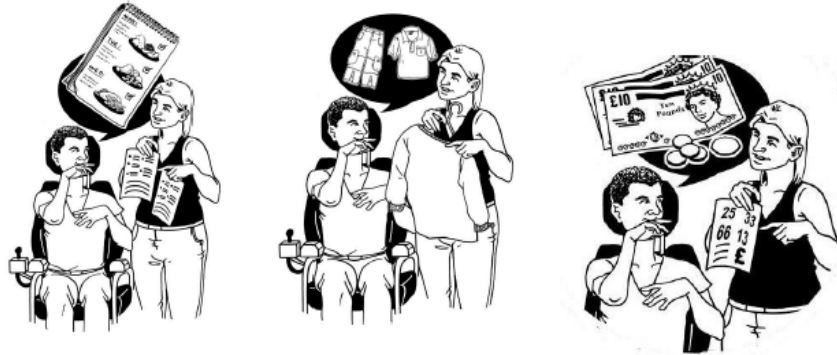
I have some control over my daily life, but not enough

I have no control over my daily life

# ASCOT Easy-Read

- Working group of adults with intellectual disabilities and autism.
- Simplified wording and sentence structure.
- Images and symbols to aid understanding
  - Topics
  - Response options
- Followed COSMIN standards for Patient Reported Outcome Measures.
- Piloted and validated with service users .
- Example.....

# ASCOT-Easy Read







This question is about choice in your daily life.

Having choice means that you can decide what to do.



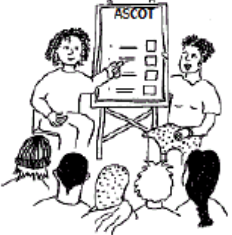
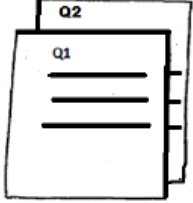
Think about the choices you have.

**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. | <input type="checkbox"/> |  |
| I have enough choice. It is OK.               | <input type="checkbox"/> |  |
| I have some choice. But I would like more.    | <input type="checkbox"/> |  |
| I have no choice. It is bad.                  | <input type="checkbox"/> |  |

# Don't forget the instructions....

	<p><b>We are asking you to help us.</b></p> <p>This is a form asking you some questions. A form that asks lots of questions is called a questionnaire.</p>
	<p>We use questionnaires when we want to ask lots of people the same questions.</p>
	<p>This questionnaire is called the Adult Social Care Outcomes Toolkit. We call this form ASCOT.</p>
	<p>There is a different page for each question we want to ask you.</p>

# Supported interviews

- Sometimes ‘easy-read’ alone is still not enough.
- People need additional ‘scaffolding’ to help them stay on track and understand.
- Work in Australia led by Dr Lyn Phillipson
- Piloting the ASCOT-ER with older adults who struggled to self-complete the SCT4.
- Easy-read helped but a ‘supported interview’ needed by many to make self-report *manageable*.
- Staggered reveal method:
  - Images, then question, then responses.
- Applied for funding to undertake content validity study here.

# Mixed methods

- Many care home residents struggle with self-report.
- Physical, sensory and cognitive impairments.
- Single method of data collection not suitable:
  - Some can self-report
  - Some can have a conversation but not a full interview
  - Some cannot tell you how they feel at all.
- How do we collect comparable information for quantitative analysis?
- Used a mixed-methods toolkit to gather evidence and the evidence informs a 'rating'.



# ASCOT Care Homes Toolkit (CH4)

- Structured observations of all participating residents
  - Communal areas
  - 2 hours per 5-6 residents
  - Rotate around
  - Make notes relating to the domains.
- Interviews with residents
  - Whatever level appropriate for the resident
  - From a whole interview to a bit of a chat (prompts provided)
- Proxy perspectives
  - Staff (always)
  - Family (where possible)

# Impact on inclusion

- Two studies:
  - Measuring and Improving Care Home Quality Study (MiCare HQ)  
<https://www.pssru.ac.uk/micarehq/homepage/>
  - Funded by NIHR HS&DR
  - Measuring Outcomes of Care Homes (MOOCH study)
  - Funded by NIHR SSCR
- What data did we collect on each resident across the two studies?
- How many would have been excluded had we relied on self-report?

# Impact on inclusion: results

- 475 older care home residents across both studies
- About half had diagnosis of dementia.
- Mixed methods: scores for all 475 residents (no missings)
- Resident interviews:
  - Mostly missing data
  - Easiest domain was 'accommodation' – 31.6% self-report
  - Need an answer to every domain to get a score.
- Staff interviews:
  - 91-94% response rates per domain but a different (proxy) perspective.
- Family perspective for around 10% of residents.
- Report out soon (peer review)

# Proxy-report

- For some people, self-report is not possible.
- Proxy report offers a pragmatic alternative.
- Not ideal but better than excluding the person altogether.
- Two types: Proxy-patient and Proxy-proxy
- Can be helpful to measure both and treat them as distinct perspectives.
- Approach used in the ASCOT-Proxy.
- New study validating it with informal carers of people with dementia <https://www.fundingawards.nihr.ac.uk/award/NIHR200058>

# ASCOT-Proxy tool



## four-level self-completion proxy questionnaire (SCT4 proxy)

**6. This question is about how much control the person you are representing has over his/her daily life.**

*By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want.*

*Please say what you think in the first column. Then say how you think the person you are representing would answer in the second column. Please write in the comments box if you wish to add anything to your answer.*

The person I am representing has...

*Please tick (☑) one box for each column*

	<i>My opinion</i>	<i>How I think this person would answer</i>
As much control over his/her daily life as s/he wants	<input type="checkbox"/>	<input type="checkbox"/>
Adequate control over his/her daily life	<input type="checkbox"/>	<input type="checkbox"/>
Some control over his/her daily life, but not enough	<input type="checkbox"/>	<input type="checkbox"/>
No control over his/her daily life	<input type="checkbox"/>	<input type="checkbox"/>

# Summary

- Looked at some of the methods we can use to make research participation:
  - Manageable
  - Meaningful
  - Comprehensible
- Focused here on work with the ASCOT, with a view to being able to undertake quantitative analysis.
- Lots of qualitative methods may also be helpful, including qualitative interviewing, discourse analysis, ethnographic methods and action research.

# References

## ASCOT development

Netten A, Burge P, Malley J, Potoglou D, Towers A, Brazier J, Flynn T, Forder J, Wall B (2012) Outcomes of Social Care for Adults: Developing a Preference-Weighted Measure, *Health Technology Assessment*, 16, 16, 1-165 DOI: <http://dx.doi.org/10.3310/hta16160>

## Easy Read

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Rand S, Towers A, Razik K, Turnpenny A, Bradshaw J, Caiels J, Smith N. (2019) Feasibility, factor structure and construct validity of the easy-read Adult Social Care Outcomes Toolkit (ASCOT-ER), *Journal of Intellectual & Developmental Disability 2019:1-14*, DOI: <https://doi.org/10.3109/13668250.2019.15921266>

## Supported interviewing and Easy Read

Phillipson, L., Smith, L., Caiels, J., Towers, A. and Jenkins, S. (2019). A cohesive research approach to assess care related quality of life in older people with cognitive impairment: Lessons learned from adapting an Easy Read survey. *International Journal of Qualitative Methods*. <https://doi.org/10.1177/1609406919854961>

## Care home/mixed methods

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## Proxy

Caiels, J. Rand S. Crowther, T. Collins, G. Forder, J. (2019) Exploring the views of being a proxy from the perspective of unpaid carers and paid carers: developing a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT), DOI: <https://doi.org/10.1186/s12913-019-4025-1>

# Disclaimer

The views expressed are those of the author(s) and not necessarily those of the NIHR, NHS or the Department of Health and Social Care or its arm's length bodies or other government departments.



# Thank you for listening

## Contact

[A.Towers@kent.ac.uk](mailto:A.Towers@kent.ac.uk)

Twitter: @AmmTowers @ascot\_pssru @CHSS\_Kent

ASCOT website: [www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot)

ASCOT mailbox: [ascot@kent.ac.uk](mailto:ascot@kent.ac.uk)

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