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## Conducting research in care homes and reliability of data reported by proxy.

NIHR Statistics Group, 5<sup>th</sup> Annual Conference, 24<sup>th</sup> June 2021.

Ann-Marie Towers, Reader in Social Care.

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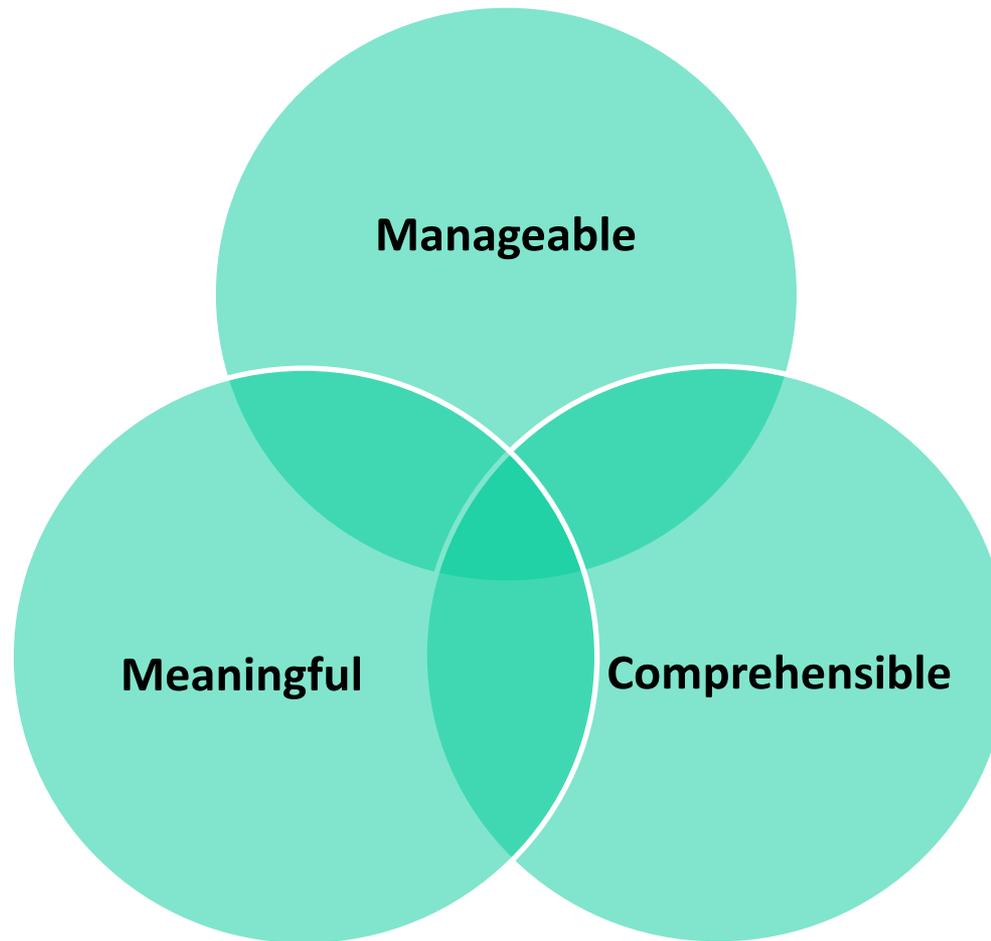
# Background

- 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 care home residents are at risk of exclusion or only having their perspectives represented by a proxy.
- Today:
  - present an alternative, mixed-methods approach;
  - explore the feasibility and justification of this approach by examining **missing data from the different sources** and **exploring divergence between final ratings and the perspectives of those interviewed.**

# Barriers to self-report in care homes

- **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?
- **Manageability:** too long, too structured, difficulty choosing a response option. Prefer open questions.
- **Physical and sensory barriers:** need someone to read the questions, be their scribe, alternate format needed (braille).

# 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

# Adapting your approach

- 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
- Example of how we have done this for the Adult Social Care Outcomes Toolkit (ASCOT).

# The ASCOT

- The ASCOT designed to measure social care-related quality of life (SCRQoL).
- Eight domains of SCRQoL.
- Structured questionnaire, 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
- View the tools here: <https://www.pssru.ac.uk/ascot/tools/>
- 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

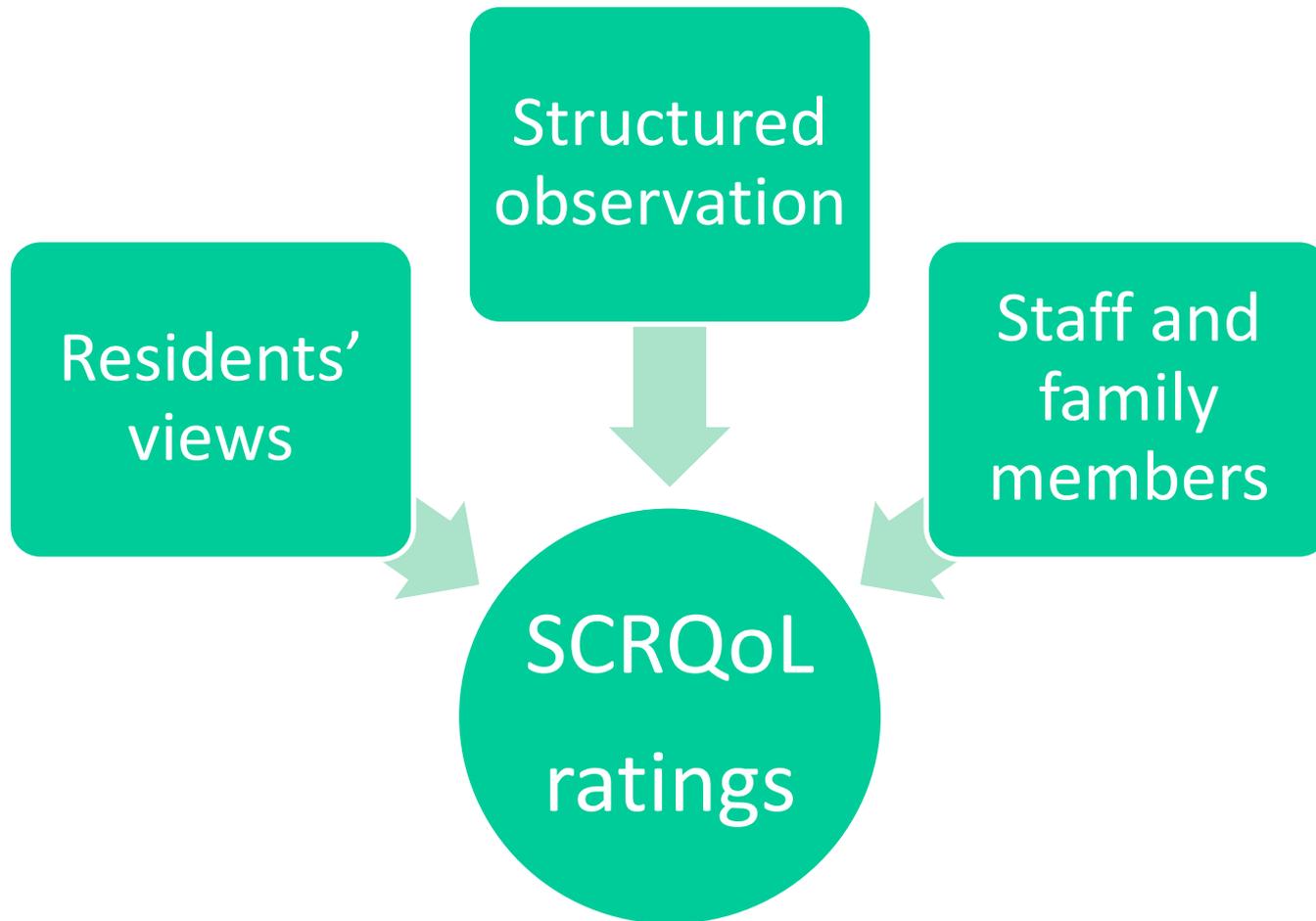
I have some control over my daily life, but not enough

I have no control over my daily life

# Mixed methods

- Single method of data collection not suitable in care homes:
  - 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



# Feasibility of the mixed-methods approach

- 1) Measuring and Improving Care Home Quality Study (MiCare HQ)  
<https://www.pssru.ac.uk/micarehq/homepage/>
  - Funded by NIHR HS&DR (report forthcoming)
- 2) Measuring Outcomes of Care Homes (MOOCH study)
  - Funded by NIHR SSCr
  - Towers, A., et al. (2019). A Cross-sectional Study exploring the relationship between regulator quality ratings and care home residents' quality of life in England. *Health and Quality of Life Outcomes*. <https://doi.org/10.1186/s12955-019-1093-1>

**Objective:** explore the feasibility and justification for the mixed-methods approach, by examining **missing data from the different sources** and **exploring divergence between final ratings and the perspectives of those interviewed.**

# The sample

Variable	MOOCH (n=293) Frequency (%)	MiCare (n=182) Frequency %	Combined (n=475) Frequency %
Female	197 (67.2%)	121 (66.5%)	318 (67.0%)
80 years +	214 (73.0%)	130 (71.4%)	344 (72.4%)
Nursing home	190 (64.8%)	98 (53.8%)	288 (60.6%)
Dementia	152 (51.9%)	87 (47.8%)	239 (50.3%)
Lacked capacity to consent	88 (30.0%)	61 (33.5%)	149 (31.4%)

# Resident interviews (self-report)

- Relying on self-report would have resulted in mostly missing data.
  - Less than a third of residents could self-report for a single domain.
- Easiest one for residents was 'Accommodation' (31.6% self-reported)
- Most difficult was 'Dignity' (only 21.7% could self-report).
- Resident and overall 'researcher ratings' (based on all evidence) were significantly associated across six of the eight domains (Cramer's  $V \geq .76$ ,  $p < .001$ )
  - Not dignity or personal safety domain (N for self-report was very low).
- The domain with the highest proportion of divergent ratings was *Dignity* (11 of 103 ratings, 10.7%) followed by *Food and drink* (14 out of 141 ratings, 9.4%). The other six domains had eight or fewer (<7%) divergent ratings.

# Staff Ratings (proxy report)

- Excludes dignity: only 7 domains in proxy interview.
- High rates of completion (91-94% at domain level).
- Weakly but significantly associated with researcher ratings ( $p < .05$ , Cramer's  $V \geq .12$ )
- Higher proportion of divergence - up to 58.8% (social participation).
- More likely to rate residents' QoL better.
- Staff interviews are important but offer a different perspective.
- Our ratings also based on what resident told us and what we observed.

# Family interviews

- Very difficult to recruit family members for face-to-face interviews.
- Pre-COVID, online video calls were not common place.
- 10% of the sample had family interviews.
- Significant, moderate associations between the family and researcher ratings ( $p < .01$ , Cramer's  $V \geq .39$ ), except for *Personal safety* and *Dignity*.
- Family tended to rate residents' QoL more poorly.

# Summary

- Researchers made ratings for all 475 residents, meaning we had quantitative data for everyone.
- Significant missing data from self-report (over two thirds)
- Easier to self-report on ‘tangible’ concepts (accommodation) – but still fewer than a third.
- Lots of partial information from residents.
- Staff interviews for all residents and most staff answered all domains.
- Family interviews harder to obtain.
- Ratings informed by residents’ views where possible, then observations and proxy perspectives.

# Discussion

- Care home population challenging to get non-clinical, quantitative data about.
- Offered an alternative method for doing this.
- Mixed-methods necessary and feasible with this population.
- Interpretation key:
  - Staff may over-estimate QoL/outcomes
  - Researcher has to balance lots of perspectives and use evidence to make a rating.
  - Is this reliable?
- Previous work shown excellent IRR with same team
  - **Towers, A., et al. (2019). *Health and Quality of Life Outcomes.***  
<https://doi.org/10.1186/s12955-019-1093-1>

# References/resources

**NIHR ENRICH:** <https://enrich.nihr.ac.uk/research-community/#preparing-research-studies>

**NIHR School for Social Care Research:** <https://www.sscr.nihr.ac.uk/event/nihr-sscr-webinar-inclusion-of-people-who-cannot-self-report/>

**ASCOT :** <https://www.pssru.ac.uk/ascot/tools/>

## Papers

Towers, A., Smith, N., Allan, S., Vadean, F., Collins, G., Rand, S., Forder, J., Bostock, J., Ramsbottom, H., Lanza, S., Cassell, J. (*forthcoming, 2021*). Measuring and Improving Care Home Quality (MiCareHQ): a mixed methods study. *Health Services and Delivery Research*

Towers, A., Palmer, S., Smith, N. and Collins, G. (2019). A Cross-sectional Study exploring the relationship between regulator quality ratings and care home residents' quality of life in England. *Health and Quality of Life Outcomes*.  
<https://doi.org/10.1186/s12955-019-1093-1>

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

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