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Exploring the process of data collection from people with dementia: a DETERMIND PhD

Research questions:

How do researchers and people with dementia experience structured interviews involving standardised measures?

What factors influence:

- The answers recorded?
- The wellbeing of participants?

How might this change over time as dementia progresses?



Methods:

- ❖ Review of NIHR reports (complete)
- ❖ Interviews and focus group with DETERMIND researchers (complete)
- ❖ Observations of data collection visits (ongoing)
- ❖ Micro-interviews with people with dementia and researchers (ongoing)
- ❖ Exploration of DETERMIND quantitative data (ongoing)

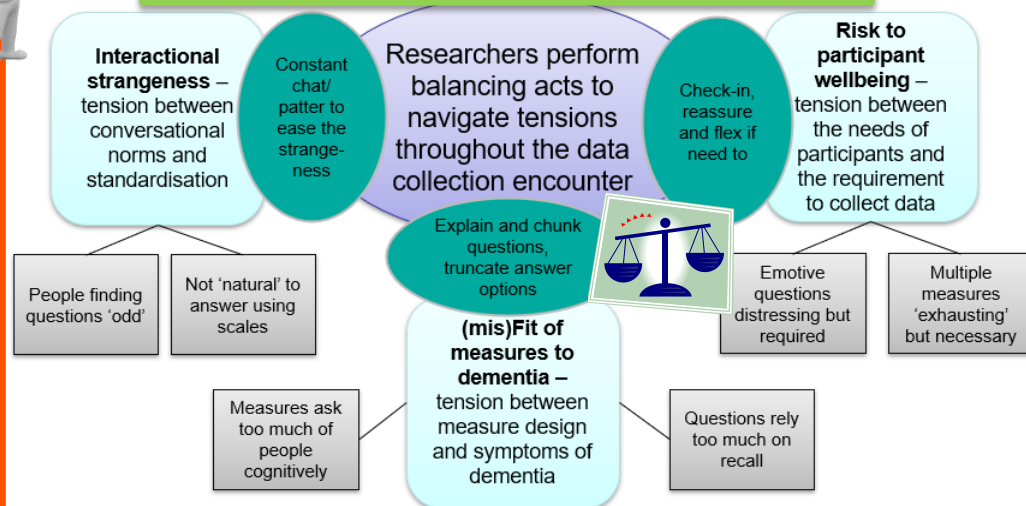
Findings

The review of NIHR reports found:

1) Wide variation in data completeness; 2) Limited reporting of data collection processes; 3) Possible risks to participant wellbeing.

Qualitative interviews and focus group with researchers (n=16): Using standardised measures with people with dementia is not straightforward. Researchers perform a balancing act to ensure participant wellbeing and tackle interactional strangeness, whilst also striving to meet project requirements including data completeness and adherence to standardisation (Figure 1). This can be tiring, labour intensive work with implications for researcher wellbeing.

Figure 1: Thematic map of the data collection process



Observations (n=10) and micro-interviews (n=20):

People with dementia generally report positive experiences of the data collection process, but observations suggest some experience anxiety and fatigue, and can struggle with certain question formats and content.



Researchers work flexibly, constantly evaluating situations and adapting their approach. This takes considerable skill, and could clash with requirements for strict standardisation.

Kate Gridley is a Research Fellow at the University of York. She is currently undertaking a PhD linked to DETERMIND funded by an NIHR SSCR career development award, due to be completed in 2025. kate.gridley@york.ac.uk

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