
Conference or Workshop Item:

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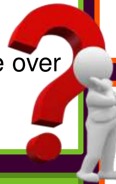
Exploring the process of data collection from people with dementia: a DETERMIND PhD

Research questions:

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

What factors influence:
a) The answers recorded?
b) 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)

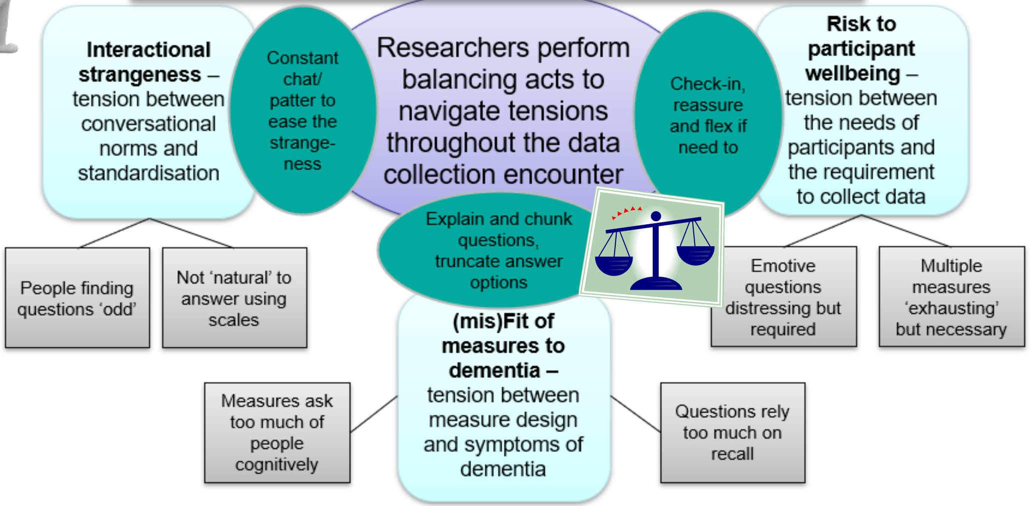
Findings

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



Researchers perform balancing acts to navigate tensions throughout the data collection encounter

Interactional strangeness – tension between conversational norms and standardisation

Constant chat/ patter to ease the strange-ness

People finding questions 'odd'

Not 'natural' to answer using scales

Risk to participant wellbeing – tension between the needs of participants and the requirement to collect data

Check-in, reassure and flex if need to

Emotive questions distressing but required

Multiple measures 'exhausting' but necessary

(mis)Fit of measures to dementia – tension between measure design and symptoms of dementia

Explain and chunk questions, truncate answer options

Measures ask too much of people cognitively

Questions rely too much on recall

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.

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