Using questionnaires in interviews with people with dementia

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Spotlight on data collection

Background

Historical exclusion from research:

- People with dementia have been traditionally excluded from research

- Even research *about* dementia did not include the voices of people with dementia

- This began to change in the late 1990s….

Chapter Ten

'Nobody's ever asked how I felt'

Rebekah Pratt

Introduction

Interviewing people with dementia has become an increasingly important aspect of dementia research. Whilst the field has started to recognise the value of including people with dementia (Cotrell and Schulz 1993;

Quality of life for people with dementia: approaches to the challenge of measurement

JOHN BOND*

ABSTRACT

With the development of possible therapeutic interventions for people with dementia there is an increasing realisation among clinical and health service researchers of the paucity of appropriate outcome measures for people with dementia and their informal caregivers. The different perspectives on

Background

Policy context:

- Targets to increase the numbers of people with dementia taking part in research (Prime Minister's challenge on dementia, 2012)
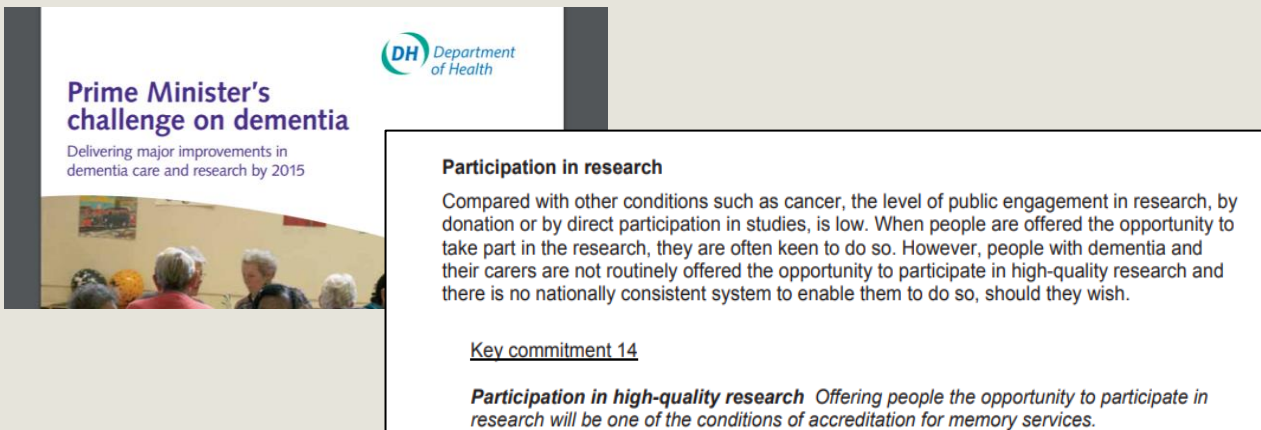
Rights based movement:

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

National Dementia Action Alliance, 2017

What does 'good practice' look like?

Most literature focusses on:

- Consent (Mental Capacity Act)

- Use of proxy data

Re data *collection*:

- Innovative qualitative methods like photovoice, or co-research

Emphasizing a person-centred approach:

'...*scholars emphasize sensitive, attuned and flexible communication approaches that enable researchers to adapt and respond to participants' needs and abilities*'
(Novek and Wilkinson, 2019)

What if we need something more structured?

'Structured interviews have a clear format, include specific wording of questions and the researcher needs to ask everyone the same question. … Not surprisingly, these are rarely used in social care research or dementia studies.'

Samsi and Manthorpe, 2020

- Standardised tools *have* been developed or adapted to collect data for trials and cohort studies. E.g. to measure:
  - Quality of life (DEMQOL, QOL-AD)
  - Cognitive impairment (sMMSE, MoCA)
  - Depression, anxiety (CSDD, RAID)
- Generic measures validated for use with people with dementia (EQ5D)
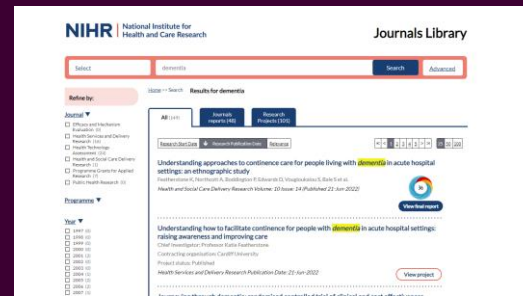- Usually administered face-to-face

My research questions

- *How do people with dementia experience structured interviews involving standardised measures?*

- *What factors influence:*
  - *The wellbeing of the participants (people with dementia and research workers)?*
  - *The answers given/recorded?*

- *How might this change over time as dementia symptoms progress?*
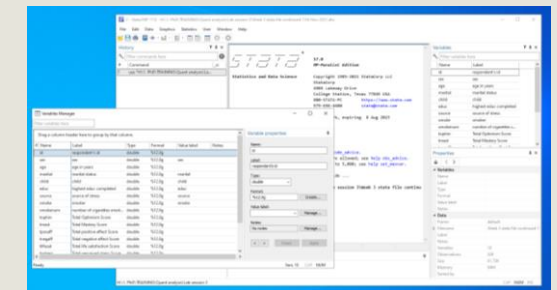
Methods

1. Systematic review of NIHR studies
   - How do authors report the data collection process?
   - Are any issues with data collection or completeness reported ?
2. Qualitative interviews and a focus group with researchers
3. Observations of data-collection for DETERMIND
4. Micro-interviews with DETERMIND participants and researchers
5. Mixed methods exploration of DETERMIND dataset, bringing it all together…

Findings from the review:

17 NIHR reports published (up to Nov 2021) of studies (n=22) using standardised data from people with dementia. These showed:

- Wide variation in response rates (associated with dementia severity and setting)

- Limited description of (or reflection upon) data collection processes

- Over 90% from participants with mild-moderate dementia

- Often below 50% where:
  - Dementia severity was moderate – severe
  - Data were collected in care homes or hospital settings

- What happened when data were collected (or where this was attempted and failed?)

The wellbeing of participants?

- Interview content - sensitive or negative questions? E.g. **DEMQOL**

First I'm going to ask about <u>your feelings</u>. In the last week, have you felt.......

7. sad?	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
8. lonely?	☐ a lot	☐ quite a bit	☐ a little	☐ not at all
9. distressed?	☐ a lot	☐ quite a bit	☐ a little	☐ not at all

- Interview context – could simply being interviewed cause anxiety?

This was indicated in several ways including <u>misunderstanding</u> questions and showing uncertainty about how to reply, giving answers that they seemed to think the interviewer wanted, conveying feeling <u>pressured</u> to say the right thing, and forgetting things during the memory 'test'…. Some participants expressed <u>distress</u> at the prospect of the interview itself, commenting that they were unsure about what to expect…

…for the patients, it was a bit too much when you're sat in the house. We only had, like, 90 minutes but I couldn't do the first one in less than 2 hours because he kept getting upset and <u>crying</u>, it was very difficult.

Clinical trials assistant, Allan et al. (2019)

Reflections in Abendstern et al. (2020)

Qualitative interviews and focus group with DETERMIND research assistants (n=16)

Researchers were concerned about:

- Fatigue
- Emotional impact
- Cognitive complexity

...well if I'm still getting confused surely the person with dementia at some point will also be confused because it's, to me it's not worded well...

RW01

...they'll say it was, it was exhausting, a lot of them do say that (laughter) they'll say, it's exhausting and it's made me think an awful lot about things...

RW02

...it's the content, it's quite an emotive, they're quite emotive questions, and there's also a lot of repetition in it which frustrates people...

RW04

Recommendations to DETERMIND

- **Cut non-essential measures to:**
  - Reduce overall duration
  - Ensure questions are being asked for a good reason

- **Ensure researchers understand those good reasons:**
  - It's hard for researchers to justify a question or measure to participants if they don't understand it themselves

- **Enhance the role of the PPI group:**
  - To pilot the interviews
  - To meet/train the researchers
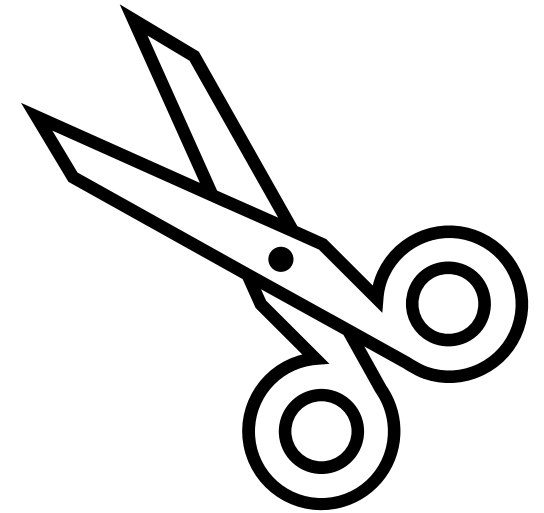
Example of removed questions:

The Emotion Regulation of Others and Self (EROS) Scale

To what extent have you used the following strategies to influence the way someone else feels over the past two weeks. It does not matter whether the strategies worked or not, just the extent to which you used them.

- I told someone about their shortcomings to try to make them feel worse

- I acted annoyed towards someone to try to make them feel worse

- I explained to someone how they had hurt myself or others, to try to make the person feel worse

"Horrendous!"

Member of the DETERMIND PPI group
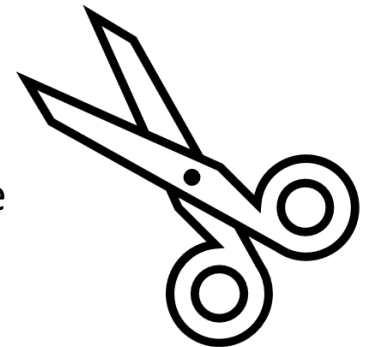
From observations (n=10) and micro-interviews (n=19):

What factors influence the answers given?

- How the participant is feeling
- Their dementia symptoms
- Their understanding of the type of interaction underway
  - Does it call for a long narrative answer, or one word from a scale?
- Other people (carers, the researchers)

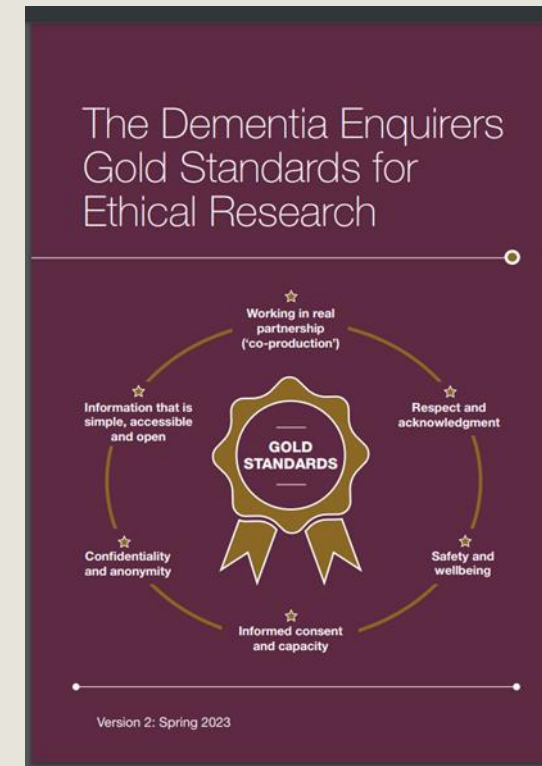**What factors influence the answers recorded?**

- What the participant says (or doesn't say)
- The design of the measures, with set answer options/scales
- The researcher's training and background
  - Ask it again/in a different way?
  - Leave it blank?
  - Pick the closest answer?

Implications?

Do we think enough about what lies behind our datasets?

- Only the answers that the research assistants select go into the final dataset

- Contextual influences tend to go unexamined in statistical analysis

- What are the implications for study findings?

Ethics – participant wellbeing is important in quantitative research too!

The Dementia Enquirers Gold Standards for Ethical Research

https://www.dementiavoices.org.uk/wp-content/uploads/2020/07/The-DEEP-Ethics-Gold-Standards-for-Dementia-Research.pdf

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Thoughts?

Questions?

DETERMIND
DETERMinants of quality of life, care and costs, and consequences of inequalities in people with dementia and their carers

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