

Interviewing people with dementia

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Introduction



- ▶ An interview is *'a conversation with a purpose'* (Webb and Webb 1932, p.30)
- ▶ Way of gathering information, hearing individual perspectives and gathering stories
- ▶ 20 minute presentation reflecting on value of conducting qualitative interviews with people living with dementia in social care research:
 - ▶ Guiding principles, including ethical considerations
 - ▶ Interview process, including practical challenges
 - ▶ Considering what might help
 - ▶ Other methodological challenges
- ▶ Key reference: https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-methods-review_MR022.pdf



Why interview people living with dementia?



Greater interest from practitioners and commissioners



Traditional biomedical model of dementia challenged (Kitwood 1989)



Biopsychosocial model of dementia



People living with dementia should be more than a 'silent presence' (McColgan 2000)



Severity of dementia acknowledged as not only determinant



Interviews valuable medium to offer 'safe context' (Hellstrom et al 2007)

The image features a dark purple header bar at the top, which transitions into a black background. A bright pink rectangular tab is positioned in the upper right corner. Centered in the black area is the text "GUIDING PRINCIPLES" in a white, uppercase, sans-serif font.

GUIDING PRINCIPLES



MITIGATING
POTENTIAL
CHALLENGES



LANGUAGE AND
SPEECH



WHOSE VOICE?



WHAT ABOUT
INSIGHT?

The image features a dark purple header at the top, a black main body, and a pink tab in the upper right corner. The text 'ETHICAL CONSIDERATIONS' is centered in the black area.

ETHICAL CONSIDERATIONS

Mental Capacity Act 2005 (England and Wales) guiding principles about choosing and consenting to participate in research study

MCA Code of Practice useful to researchers, especially in their approach to capacity, consent and people living with dementia who may have fluctuating capacity

Obtaining consent not a one-off matter: apply “process consent” framework (Dewing 2007) – it complements MCA Code of Practice and widely used in research (McKeown et al 2010)

The image features a dark purple header bar at the top, which transitions into a black background for the main content area. A bright pink rectangular tab is positioned in the upper right corner. The text 'INTERVIEW PROCESS' is centered in the black area in a white, sans-serif font.

INTERVIEW PROCESS

Principles of conducting interviews



Are interviews the best way to answer the research question



Types of questions



Questions can be open-ended, closed questions, be careful with double questions and multiple choice questions



Developing interview topic guides



Sample size decisions – numbers and groups

Conducting interviews

- ▶ Access and recruitment
- ▶ Setting context and orienting participant
- ▶ Acknowledging anxieties about interviews
- ▶ Building rapport
- ▶ Communicating effectively – see next slide



Strategies to aid effective communication (Beuscher & Grando 2009)

Effects of dementia (possible)	Strategy
Attention and concentration lapses	Conduct interviews in familiar place Redirect conversation if possible
Decreased abstract reasoning	Restructure questions to concrete topics Use participant's wording that is familiar and comfortable to them
Difficulty with word finding	Give ample time to respond If participant seems uncomfortable, offer reassurance and help
Memory loss	Use reminiscence Provide cues
Repeating phrases or dwelling on a topic	Validate meaning Redirect conversation, if appropriate
Fatigue or anxiety or distress	Monitor for signs Offer to stop interview

What might help during interviews?



JOINT INTERVIEWS
WITH CARERS



INTERVIEW AIDS,
SUCH AS SIGNS,
VERBAL CUES



USING VIGNETTES



TALKING MATS

Other methodological considerations

Co-
researchers or
peer
researchers

Individuals
living with
dementia
writing first-
hand
accounts of
their lives

Thoughtful
analysis and
writing up of
findings to
describe and
present full
picture

The COVID-19 context

- ▶ Impact of social distancing, shielding and lockdown
- ▶ Likely to persist for vulnerable groups and places
- ▶ Research questions and methods will need careful planning and justification
- ▶ Possible greater reliance on informants – room for methodological development surely ?
- ▶ Care needed about (re)traumatising and distress – face to face but also telephone and virtual
- ▶ Potential value of re-analysing data
- ▶ Importance of archiving

Useful resources

- ▶ See our methods review – eg DEEP
- ▶ Look out for new MCA Code of Practice
- ▶ And key journals such as Dementia (SAGE) report new methods
- ▶ Much to learn from practitioners – their huge experience



The image shows the cover of a methods review report. The background is dark blue. At the top right, the NIHR logo is followed by 'School for Social Care Research'. The title 'Interviewing people living with dementia in social care research' is centered, with 'METHODS REVIEW' below it. There are three photographs: a man's face, a woman sitting in a chair, and an older woman with her hand to her face. The cover is decorated with various geometric shapes in teal, purple, and white.

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Interviewing people living with dementia in social care research
METHODS REVIEW

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Thank you!

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