



Using ASCOT with older adults living with dementia

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Dementia in the UK

- Number of people in UK living with dementia is estimated to be 850,000 (2015)
- Forecast to rise by 40% by 2025 and 157% by 2051
- 1.3% of the population live with dementia
- Prevalence varies a lot across age groups
 - 65-69 1.7%
 - 75-79 6.0%
 - 85-89 18.3%
 - 95+ 41.1%

Dementia and social care

- 70% of care home residents are living with dementia
- UKHCA estimate that 60% of people receiving home care are living with dementia
- Cost of dementia
 - Social care (both public and private) 10.3 billion
 - Health care 4.3 billion
 - Cost of unpaid care 11.6 billion

Characteristics of dementia

- Not a illness but a syndrome (a group of concurrent symptoms by a number of different illnesses)
- Different people affected in different ways
- Kitwood 'Personhood'
 - Neurological impairment
 - Health and physical fitness
 - Biography
 - Personality
 - Social psychology
- People live with dementia rather than being defined by it

Characteristics of dementia

- Memory impairments
 - remembering events
 - living in the past
 - recognising people and places
 - recognising objects
 - disorientation in time and space
 - difficulty taking in new information
- Communication impairments
 - losing the ability to use or understand language both spoken and written
 - word substituting
 - echolalia

People living with dementia and participation in research

- Lots of work on dementia relies on the voice of carers, either as the focus of that work or as a proxy
- Examples of inappropriate methods being used with people living with dementia e.g. self-completion surveys – low response
- Some studies excluded people with dementia

People living with dementia and participation in research

- Work over the past twenty years has challenged this
- Debates have moved from *why* people living with dementia should be included in research, to *how* people living with dementia can be included in research (Pesonen et al. 2011)
- “... in far more cases than is commonly accepted, communication with people [living with dementia] *is* possible. It is not always easy, and it can be a time-consuming and frustrating process, but it is a process well worth persevering with. The rewards are considerable..” (Goldsmith 1996 p9)

ASCOT tools

- **Mixed Methods Care Home ASCOT (CH3)**
- **Semi-structured ASCOT interview** (Nick Smith)
- **ASCOT Mixed Methods in the Community** (Julie Beadle-Brown, Lisa Richardson, Nick Smith, Agnes Turnpenny & Beckie Whelton)
- **ASCOT Talking Mats** (Jill Bradshaw, Ann-Marie Towers & Nick Smith)
- **ASCOT Easy Read** (James Caiels, Agnes Turnpenny, Beckie Whelton, Lisa Richardson, Julie Beadle-Brown, Tanya Crowther, Joanna Apps, Juliette Malley & Stacey Rand)
- **ASCOT Proxy** (James Caiels, Stacey Rand & Grace Collins)

Mixed methods care home ASCOT (CH3)

- Uses mixed methods:
 - Observation of residents' lived experience
 - Interviews with residents
 - Interviews with family and friends
 - Interviews with staff
- Evidence used to rate Social Care Related Quality of Life (SCRQoL)
- Designed for use with people living with dementia and people with learning disabilities

Mixed Methods Care Home ASCOT (CH3)

- Everyone can participate
- But how actively?

- Original resident interview was a structured interview
- Experience of using the tools prompted shift towards less structured interviews

Semi-structured ASCOT interview

- A growing body of work suggests that qualitative interviews are a more appropriate method
- Reflects our experience
- Study in 2013-14 to develop a semi-structured ASCOT interview
- 60 interviews carried out in care homes

Semi-structured ASCOT interview

- Interview schedule structured around ASCOT domains
- Uses prompts to guide interview rather than fixed questions
- Encourages participants to talk about quality of life in their own words
- Examples of food and drink prompts:
 - What do you think about the food you get here? What is the food like?
 - How was lunch/breakfast today?
 - Where to do eat your meals?
 - Tell me what happens at mealtimes?
 - How would you get a snack outside of mealtimes?
 - If you want a drink, how do you get one?
 - How much choice do you get the food you get to have here?

Semi-structured ASCOT interview

- INT: *What about food?*
- RES: *I haven't got an appetite so I always have to push my grub down but it's very--, it's nicely done, it is, it's--, good cooks here.*

- INT: *Do you get to choose what you have to eat?*
- RES: *Er, no you don't get a choice, It just arrives.*

Semi-structured ASCOT interview

- Limitations
 - Interviews did not always cover every domain
 - Some participants did not recognise that they either lived in a care home or received support
 - Some participants did not respond 'on topic'
- Every interview valuable to understanding lived experience and SCRQoL
- Semi-structured interviews work when well combined with other approaches – so added to our mixed methods toolkit
- A range of techniques for improving participation
 - Flexibility
 - Listening
 - Timing
 - Location
 - Acceptance

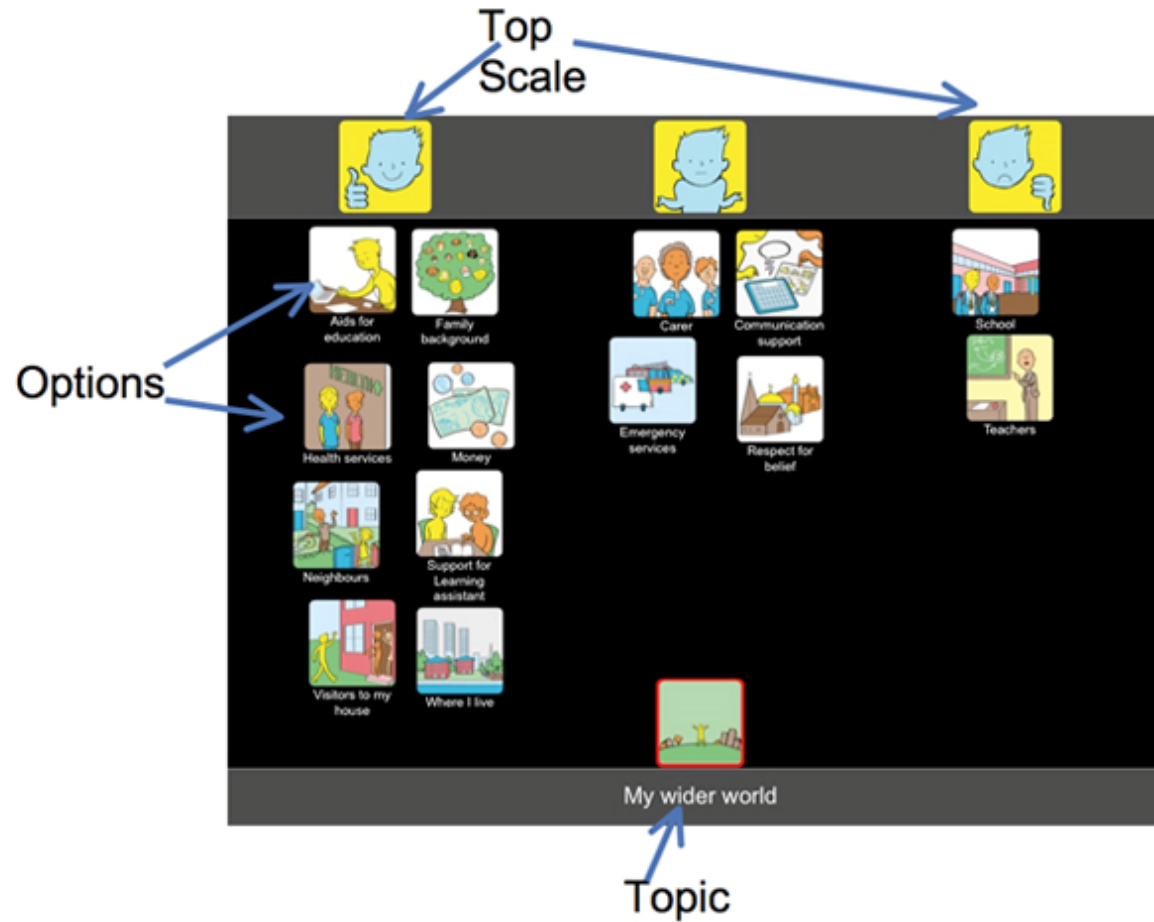
Mixed Methods in the Community

- Explores the feasibility of using observation in a community setting combined with user and Carer interviews
- Can we carry out observations in people's own homes?

ASCOT and Talking Mats

- A visual communication tool developed by Stirling University
- <http://www.talkingmats.com/>
- Uses 3 sets of communication symbols – topics, options and a visual scale - to support conversations

ASCOT and Talking Mats



ASCOT and Talking Mats

- Small project to develop and test and set of cards that is based around ASCOT domains of SCRQoL
- 2 phases
 - Developing the set of symbols
 - Testing the mat with people who live with dementia and people with learning disabilities
- Part of a mixed methods approach

ASCOT Easy Read

- Designed for (and tested with) people with intellectual and learning disabilities
- Easy read is an approach used with people who live with dementia
- Organisations who have produced easy read documents for people living with dementia included:
 - CQC
 - Cornwall County Council
 - Thurrock Council

ASCOT Proxy

- A tool designed for enabling either informal or formal carers to answer SCRQoL on behalf of the person they look after
- Proxy views are not the same as the views of the person being cared for
- Tension between giving people a voice and taking it away
- Use as a last resort

Main points

- People living with dementia can have a voice
- The right approach and tools can help enable this
- There are a range of ASCOT tools which aims to help enable people living with dementia to participate directly in research