Researching Dementia:
A practical approach to inclusion

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for
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Understanding Dementia

- Move away from the standard paradigm of understanding dementia
- Holistic approach
- Concept of personhood “a standing or status that is bestowed on one human being, by others, in the context of relationship and social being” (Kitwood, 1997)
- Dementia as a disability
In recent years there has been a move away from proxy measures. Also a conscious move to undertake psychosocial research. Including the person with dementia in the research process; (i) places value on their perspectives (ii) furthers our understanding of the experience of dementia (iii) empowers the individual.
How were people with dementia included in ENABLE?

- Recognition that individuals with dementia were;
  (i) first people
  (ii) second people with dementia
  (iii) third research participants

- Informed consent, revisited at each interview stage
- Brod’s Dementia Quality of Life Scale (T0, T2 & T3)
- Quality of life qualitative questions (T0, T2 & T3)
- Questions on use and usefulness (T2, T3 & T4)
How were people with dementia included in ENABLE?

Questions on date of birth and opinions of on the existence of memory problems at baseline (T0)

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<th>No</th>
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<tbody>
<tr>
<td><strong>PWD memory problem:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>own opinion</td>
<td>73</td>
<td>5</td>
</tr>
<tr>
<td>carer opinion</td>
<td>79</td>
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*Person with dementia and carer opinion of memory problems at T0 (N=80)*  
*Data missing from 2 persons with dementia*
A practical approach to inclusion

This practical approach is based on 5 countries experiences including researcher field notes and questionnaires

- Research challenges
- Benefits of including people with dementia
- Factors effecting participation
- What makes a good researcher?
- Preliminary guidelines for researchers
Research Challenges

- Disclosure, do people know they have dementia?
- Communicating with people with dementia
- Carer’s as gatekeepers
- Adapting questionnaires
- Individualised nature of dementia - no one-way is standard
- Differentiating carer’s and people with dementia’s experiences
- People with dementia have good and bad days
Benefits of including people with dementia

- Important to get persons' views on ways to best support their day-to-day living
- Provides insight into the human interface of dementia and technology
- Provides insight into the lived experience of dementia
- Data on use and usefulness of the ENABLE devices
- Results show a positive correlation between carer and persons with dementia’s responses to product use at T2 (therefore good and accurate informants)
- Legitimises person’s feelings and experiences
Factors that influenced participation; our findings

- Persons level of cognitive impairment (part of inclusion criteria)
- Interview conducted in an environment familiar to the person i.e. their own home where they feel safe and more confident
- Researcher relationship with the person with dementia
- Respondents willingness to take part in the research
- Carers willingness for respondent to take part in the research
- General positive attitude by carer and person with dementia
- Incentive of free assistive device
What makes a good dementia researcher?

• Take a person-centred approach
• Have good listening skills and be calm
• Build rapport with respondents,
• Be patient
• Be understanding
• Recognise the rigour involved in scientific research
• Be aware of the words and expressions used - keep it simple, too much explanation can be confusing
• Be sensitive to how the person is coping
• Know when to stop
Preliminary guidelines for researchers

• Accessible research design
  Mixed methods
  Longitudinal study, people have good and bad days
  Flexibility in research design
  Awareness of sensitivity in issues being explored
  Allow greater time for data collection (Hubbard, Downs & Tester, 2003)
  Short, simple questions as open-ended as possible
  Create an open environment (Cotrell & Schulz, ‘93)
  Appropriate language
  Trained researchers
• Recognise the importance of carer as gatekeeper
• Respect the person
• Build rapport and trust
• People with dementia have rights (Downs, ‘97), the right to have a point of view and the right to participate
• Be dementia aware
• Be disability aware
• Address ethical considerations
• Avoid placing any additional burden on the person or their carer
“Asking people with dementia their views may be difficult, but it does not mean it cannot be done” (Goldsmith, 1996)