Involving people living with dementia in research: collaboration and facilitation

Katie Davis – ESRC PhD Student
University of Manchester

Supervisors: Professor John Keady, Dr Caroline Swarbrick & Dr Penny Bee
Neighbourhoods and Dementia
people, spaces and places

• The first Prime Minister’s Challenge on Dementia (2012)
• Initial challenge set out 14 key commitments around three key areas
  ▫ Driving improvements in health and care
  ▫ Creating dementia friendly communities that understand how to help
  ▫ Better research
• The Neighbourhoods study [2014-2019] is funded under key commitment 12 of the first Prime Minister’s Challenge on Dementia, a commitment of funding for social science research.
• Chief Investigator – Professor John Keady
Work Programmes

- WP 1 - Member Involvement
- WP 2 - Generating neighbourhood profiles of cognitive ageing and service use
- WP 3 - Development of a dementia core outcome set
- WP 4 - Neighbourhoods: Our People, Our Places
- WP 5 - Evaluating dementia training in NHS hospitals
- WP 6 - Living life and doing things together
- WP 7 - Deaf with Dementia Life-Stories
- WP 8 - Health and well-being

www.neighbourhoodsanddementia.org  @nbdem
Work Programme 1

• Led by Dr Caroline Swarbrick

• ‘Member Involvement’ is a partnership between groups of people living with dementia, academic researchers and service providers.
Involving people living with dementia in research: a participatory study

• Literature Review
  ▫ A narrative review identified that although participatory research is beginning to be utilised within the field of dementia care, the voice of people with dementia is often lost or not recognised.

• Co-researcher
  ▫ ‘Co-’ incorporates collaboration, cooperation and community in a move away from the term ‘user’ or ‘participant’ (Swarbrick et al., 2016)
  ▫ ‘Nothing about us, without us’
Involving people living with dementia in research: a participatory study

- **Aim:** To form, develop and conduct a co-operative inquiry with people living with dementia

- **Objectives:**
  - To explore the creation of a co-operative inquiry with a group of people living with dementia and how this is subsequently facilitated
  - To develop an action output that had meaning and resonance for the formed group
  - To examine the facilitators and barriers in working collaboratively with people living with dementia in research
  - To evaluate the position of researcher reflexivity during the different stages of the co-operative inquiry.
Co-operative Inquiry

- What is co-operative inquiry?
  - Research ‘with’ rather than ‘on’ people
  - Co-operative inquiry is an approach to participatory research and human inquiry that involves cycles of action and reflection through clearly defined phases and is defined as a ‘a way of working with other people who have similar concerns and interests to yourself’ (Heron and Reason, 2006, pp. 144).
Co-operative Inquiry

Phase 1 - A group of co-researchers come together to explore an agreed area of human activity

Phase 2 - The group apply their agreed actions in their everyday life

Phase 3 - The co-researchers become fully immersed in the experience

Phase 4 - The co-researchers re-assemble to consider their original questions

Cycles of action and reflection in the co-operative inquiry process (Adapted from Heron and Reason (2006))
The Co-operative Inquiry

- Recruited from the Open Doors Project in Salford
- Six members including people living with dementia and care partners
- Developed a play script around stigma and included the group’s own negative AND positive experiences of living with dementia
http://www.mistermunro.co.uk/
Facilitators

Creativity

Activism

Support

Flexibility

Relationships
Summary & Recommendations

• Research ‘with’ rather than ‘on’ people
  ▫ Focus on what is important to the group

• Start early!

• Establish relationships

• Ensure support is available

• Embrace the creativity
Thank you

Email: Katie.davis@manchester.ac.uk