

Involving people living with dementia in research: collaboration and facilitation

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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

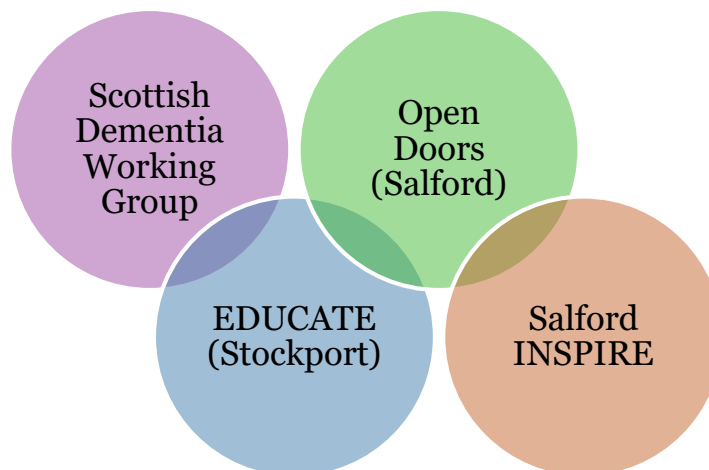


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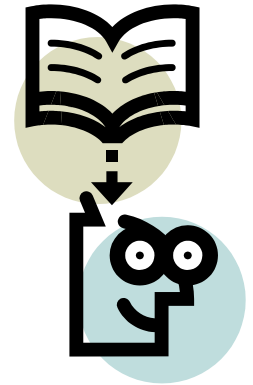
Work Programme 1

- Led by Dr Caroline Swarbrick
- ‘Member Involvement’ is a partnership between groups of people living with dementia, academic researchers and service providers.



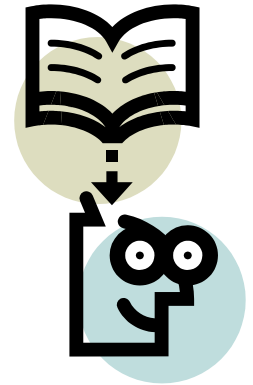
Involving people living with dementia in research: a participatory study

- 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.

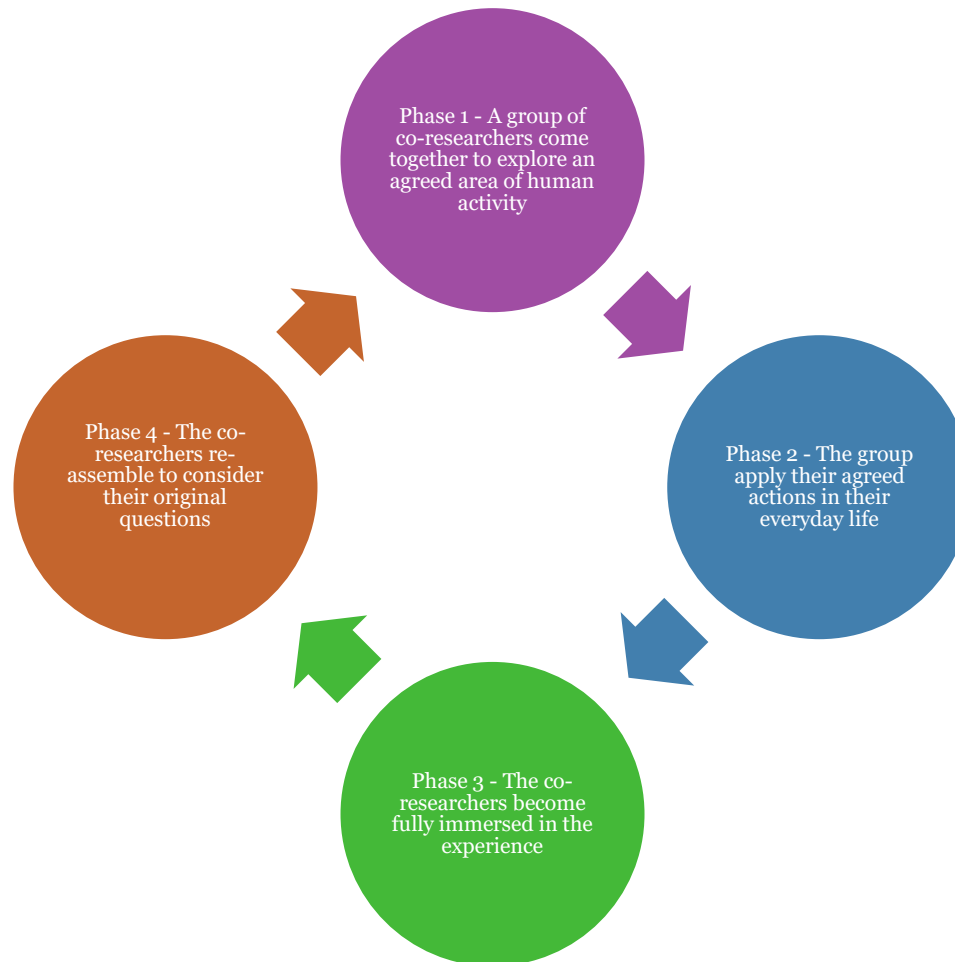


Co-operative Inquiry



- 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



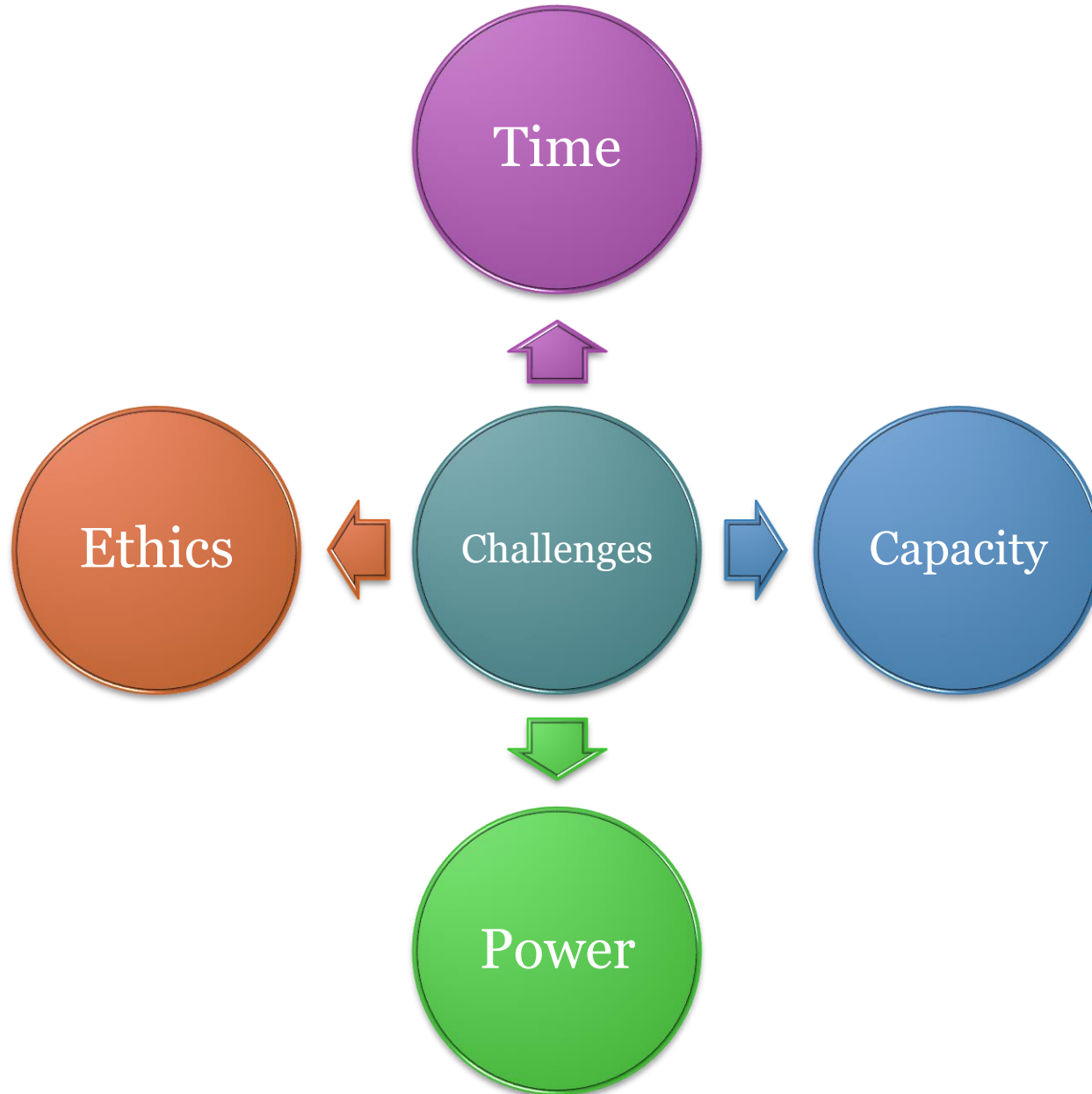
Cycles of action and reflection in the co-operative inquiry process (Adapted from Heron and Reason (2006))

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









Thank you



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