Methodological issues in tracking res

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Today

- Research with people with dementia – broad challenges
- Findings from a safe walking project
- Methodological challenges for tracking and assistive technology resea

Including people with dementia in research

- Many people with dementia want to be included in research and experience positive outcomes from participation
- The NIHR report that in the UK in 2014/15 nearly 22,000 people with dementia took part in research, a 58% increase on the previous year and a total of 202 studies were open for recruitment
- The Alzheimer's Society Research Network is a team of over 250 carers, former carers and people with dementia who take an active role in assessing funding applications and monitoring ongoing projects
- Scotland, England, Australia and the USA all have networks that actively recruit people with dementia and their carers into research.

Capacity and consent

- Capacity should be assumed until demonstrated otherwise
- Capacity is situation specific
- Using ‘process consent’ methods enables more people with dementia to be included in research (Dewing 2008)
- For people with dementia deemed unable to give consent consultee advice can be sought to enable participation.

Safe walking and dementia – funded by NIHR i4i

- User engagement to understand the wishes and needs for a safe walking device of people with dementia and their family carers
- 12 people with dementia, 3 caregivers and 5 older people in two focus groups, one in Scotland and one in England.
- Two researchers facilitated each group, audio recordings were fully transcribed, data were analysed using a qualitative, thematic approach.

McCabe and Innes (2013)

Methods to engage with people with dementia

- Focus groups held in familiar place with (mostly) familiar group of people
- Tea, cakes and fruit provided to give a sense of occasion
- Lots of time for warm-up and process consent
- Pictures and objects (GPS trackers) were used to prompt conversation and generate ideas.

Findings

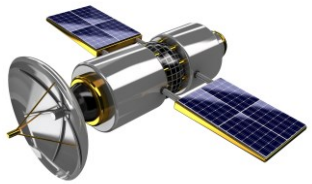
- People with dementia and family carers were very interested to learn more about trackers and share their views
- Focus on what trackers looked like and how they would be worn, wish for them to be discrete
- General acceptance and interest in trackers as a good option to enable independence and to keep people safe
- People with dementia and their carers reported positively on their engagement within the research and offered meaningful contributions to the project.

Some broader methodological issues: Black boxes and tangled networks

- Current methods, such as RCTs, often take a ‘black box’ approach to technology research which can limit understanding of the potential barriers and outcomes
- Technology does not act alone – it is dependent on human interaction within a network
- The complexity of these networks makes research challenging.

Outcomes

- Depression
- Anxiety
- Well-being
- Safety
- Falls
- Getting lost
- etc.



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BE THE DIFFERENCE

Realist evaluation – an option

- What works for whom in what circumstances
- Contexts – what are the key features of individual contexts that influence technology use? (living arrangements, support needs, age, gender, care support provided, carers/relatives)
- Mechanisms – what resources can people draw on to make technology work for them? (confidence to interact with technology, technology that doesn't require interaction, appropriate support from care workers)
- Outcomes – what outcomes can be expected from given pairs of context and mechanism? (avoid move to residential care, go out walking, increased independence).

For a telecare example see Berge 2016a and 2016b

Reflections and recommendations

- People with dementia are enthusiastic and often able to consent to take part in research
- Time and some imagination are needed to engage them effectively
- Technology research needs to open the black box and employ methodologies that allow us to do this
- Evidence about the use of tracking technology with people with dementia will improve with more complex, mixed methods studies.

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Thank-you

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