‘Nothing about us without us’: The Value of involving Older People, including those with Dementia, when developing Technological Innovations to Support their Health and Well-being

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Abstract
Policy in the UK advocates that people remain in their own homes, as active members of their local communities, for as long as possible into later life. Yet for many the scene painted is very different; as increasing numbers of people are developing long term conditions, impairments or disabilities which mean that they require care and support in later life. Dementia is just one example of a condition that is impacting on experiences of later life. To overcome some of these health challenges a plethora of technology has been developed to support people to remain in their own homes. Yet take up of this technology by older people, including those with dementia, is not wide spread.

This paper examines what we might learn from talking to people about their experiences of using technology. Data is drawn from two projects that explored, in different ways, the potential of technology for maintaining independence and enabling people to remain at home for longer. The first discussed use of information and communication technology to support mobility in later life in interviews with twenty older people. Whilst the second explored use of assistive technology to support people with dementia by reducing their risk of being injured or dying from fire at home, in four focus groups with people with dementia, carers and professionals.

An overarching theme from both projects was the purpose [of the technology] in the participant’s everyday life – a solution for some, whilst for others alien objects with little or no value. Drawing on the experiences of people with dementia also raises ethical and moral questions with regard to when introducing such technology is appropriate, and for whom. For example, it may seem suitable for a carer to introduce technology at, or after, a crisis point; however the benefit may be overshadowed if introducing the technology makes the person with dementia confused or distressed.

Focusing on the perspectives of older people, including those with dementia, provides unique insight into the lived experience of such groups. The challenges of later life and dementia care force us to careful consider what we might take for granted in circumstances where physical and cognitive abilities are unaffected. This paper therefore discusses how involving older people, including those with dementia, is crucial in developing technological innovations that make a positive difference to their lives, and should happen from the outset as ideas develop. It is recommended that policy makers, designers, practitioners and researchers work collaboratively with older people and their families to develop technology that is effective in supporting their use of indoor and outdoor environments. Some suggestions of methods of collaborative approaches will also be included.

Keywords: Older people, dementia, technological innovations, lived experience, ethics, well-being.