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Co-creating the living well with dementia message

Dementia is a long-term medical condition, which affects not only the person with dementia it also has a profound impact upon their informal carers (Alzheimer's Society, 2014). In the UK, dementia is national priority, currently there are 850,000 people with dementia and this figure is predicted to double and then triple over the next thirty years potentially placing an enormous strain upon the UK's health and social care budget (Alzheimer's Society, 2014). Recent societal strategies/policies have started to reframe dementia as a public health issue; considering ways to reduce acquiring the condition – prevention, and promoting living well with the condition – the health promotion message (World Health Organisation [WHO], 2012; Department of Health [DH], 2009).

The following narrative will describe a research process, which aimed, through the medium of film, to co-create 'a living well with dementia message'. This work was underpinned by an earlier and related research process, which effectively asked people living with dementia across a City to describe their experiences of living with dementia (Cosijn, 2015). The majority of the respondents highlighted that being given a dementia diagnosis was a negative experience, especially in terms of the associated stigma.

The themes of this research were then presented to a research steering group containing people living with dementia. After a period of reflection the group recognised that the living well with dementia message had become lost. On this basis, the group were keen to use their own personal narratives to promote the living well message and where possible reduce stigma (Murphy et al., 2015). To achieve these twin aims it was agreed the medium of film would have the most utility especially if uploaded onto the web. Baruch et al. (2017) highlights a strength of using film in this way is that it gives people living with dementia an authentic voice and one that can challenge stigma. To capture this authentic voice, the films were co-created by a specific project group, which predominantly consisted of people living with dementia. Their role included the scripting and reviewing of the films, and appearing within the films as positive role models (Greenop & Smith, 2016).

The first step in the film-making process was to create a working environment that engendered a real-world understanding of need - an open innovation space (Stahlbrost & Bergvall-Kareborn, 2011). To engender a user-centric understanding, the project team facilitators, listened to people living with dementia as they talked about their ideas for a series of films (Weber, 2011; Estey-Burt & Baldwin, 2014). This phase allowed the facilitators the opportunity to begin working people living with dementia, the drivers of the project, to co-design a specific solution or way forward. The film workstream framed by a strong collaborative process met for a minimum of six fortnightly co-creation sessions, their progress being monitored and supported by a larger open innovation group (Woods et al., 2013). To move the process on from the data and ideas stage to a real-life solution it was essential people living with dementia were actively engaged as equal partners (Weber, 2011). This ethos was progressed by the facilitators continually ensuring through a robust crosschecking procedure that their understanding of a shared experience was the same as the person who shared the experience (Smith, 2015). Continually crosschecking meant that the whole of the person was valued irrespective of their age or condition, thus ensuring a person-centred and co-equal approach (Estey-Burt & Baldwin, 2014). The strength of people living with dementia being centrally involved in co-creating solutions is that the solution is more likely to be useful, useable, and compatible with real need (McKeown, Clarke & Repper, 2006).

The workstream outcome involved facilitating people living with dementia to commission a company through a tendering process to produce the films as required. After checking the quality and suitability of the films met the original aims the open innovation group signed off the films for wider distribution. Currently the Service User Reference Forum for Dementia Website hosts the films. - <https://surfdementia.org/>.

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