Title: DEEP: the engagement, involvement and empowerment of people with dementia in collective influencing

Author: Litherland, R. og Williamson, T.


Abstract:
Purpose – The purpose of this paper is to discuss the mapping processes and lessons learned in a project to scope the user involvement activity of groups of people with dementia across the UK.

Design/methodology/approach – Data was gathered using a mapping questionnaire designed with help from people with dementia, in-depth interviews and through a filming process at two national events. A total of 32 groups completed the main questionnaire and five groups were interviewed.

Findings – The collective voice of people with dementia is at a relatively early stage. Groups are at different stages on their journeys and many (completely understandably) prioritise peer support, and local rather than national action. But user-led groups are growing in number and confidence. They ask for support in capacity-building, networking and learning from each other so they can increase their influence over attitudes, policy and services.

Research limitations/implications – The paper relies on self reports from groups the authors were able to identify. Originality/value – Research that looks at the mechanisms that support the involvement of people with dementia is still in its infancy. This paper combines data and findings from a wide range of groups to provide recommendations about how to improve the involvement of people with dementia.

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