

27th Alzheimer Europe Conference
“Care today, cure tomorrow”
Berlin, Germany - 2 -4 October 2017

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ABSTRACT

Co-developing end-of-life resources: an equal and reciprocal relationship

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Involving people with dementia (PwD) in the development of new resources to help support their care at end-of-life requires a sensitive approach recognizing not only disability but also empowering and supporting capability. Some models of patient and public involvement (PPI) identify a spectrum of participation modes (e.g. Arnstein, 1969; Savory, 2010). Indeed there has been a discernable shift in PPI thinking from ‘doing to’, through ‘doing for’ to ‘doing with’ patients, i.e., from ‘coercion’ to ‘co-production’ (The New Economics Foundation, 2014). However, a recent review of PPI models currently being deployed concluded these were still too narrow, indeed often tokenistic, not acknowledging equality and diversity issues (Ocloo & Matthews, 2016). In the SEED study, concerned with the development of an intervention to increase the chances of a good death for PwD (SEED), designers joined the more traditional dementia, palliative and nursing care specialisms in the research team. The designers introduced methods and tools to involve all the key stakeholders (i.e., the PwD, family carers, the healthcare team and nurse specialists) in the design of new resources concerned with facilitating discussion and improving shared decision-making around key end-of-life plans. Specifically, through the nature and design of the workshops and use of participative tools these approaches were intended to better empower PwD and their family carers in this co-development process, to help open up their agendas in this very sensitive area. This presentation highlights key findings arising from this co-development process which enabled the PwD and family carers to voice their particular issues. Rather than outcomes being determined through a top-down ‘consultation’ model, the authors debate the value of a ground-up ‘collaborative’ model where new resources can be developed in a more equal and reciprocal partnership with PwD and their family carers.

Arnstein, S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*. 35 (4), 216-224

New Economics Foundation (2014). Co-producing wellbeing. Why it matters and how to do it. Available at: <https://prezi.com/eitdkealy8t/co-production-theory-and-practice/>

Ocloo J, Matthews R. (2016). *BMJ Qual Saf*. 25 (8). Available at: <http://dx.doi.org/10.1136/bmjqs-2015-004839>

Savory, C. (2010). Patient and public involvement in translative healthcare research. *Clinical Governance*. 15(3), 191-199

SEED. Available at: <https://research.ncl.ac.uk/seed/>