Reviewer’s report

Title: Co-producing a shared understanding and definition of empowerment with people with dementia

Version: 1 Date: 19 Jan 2019

Reviewer: Andrew Entwistle

Reviewer's report:

I draw the attention of the Authors to the following:

Co-production. This is usually involves lay people (with experience of health of social care) and professionals including academics in the involvement and management of a research proposal - that is, the lay people are an integral part of the research team - as distinct from 'tokens'. Here there are 7 senior academics and a total of 9 lay people (PWDs); The authors should explain the almost equal numbers of academics and lay people in what is really a simple exercise. Although this is post research I would have thought non-PWDs could have provided a different and useful perspective - including but not exclusively carers- for instance I suspect that claims of disrespect, patronising, absence of being listened to etc would be challenged or least the evidence evaluated. Even more problematical is the PWD statement about bed blocking; bed blocking is current problem in hospitals after medical treatment because patients can only be discharged if there is somewhere where the patient receives appropriate follow up care - usually with family or community. - which often it is not available hence the blocking. To say that 'no we are not bed blocking (wrt to hospitals and surgeries) our lives matter too' hence inferring that in the health environment their 'lives are considered not to matter' needs to be challenged by evidence. NHS England is absolutely clear that some of the PWD negative claims, opinions, experiences have no place in today's health care - ref Dame Sally Davies, INVOLVE, PILAR, UNTRAP, CRNs. I have no experience of health care in Northern Ireland so cannot comment - please note I am a PhD graduate of Queens, for which I have the highest respect and remain in contact by the various Queens literature.

9 PWDs were selected to take part in the co-production team. I would be interested to know the demographics of people with dementia in N Ireland - numbers, age profiles, gender, stage of diagnosis, distribution - rural vs town/city living, hence to provide a perspective to help understand better this paper.

Clarification is also needed on the selection criteria for the PWDs and including stages of dementia. The capacity to give informed consent implies 'early stage dementia'. So, I would have liked information on how the diagnosis was carried out; what gave rise to referral. Part of the diagnosis probably evaluated memory and a capacity for analysis of events, make decisions. The
strong impression I get is that the PWDs are strong on these values; but how representative are these 9 PWDs of the rest of the N Ireland dementia population?

I am not convinced that the inclusion of philosophy/sociology e.g. Foucault adds to the theoretical framework or ultimately to the outcome values of the project. For me they confuse understanding and evaluation.

The inclusion of citations about 'empowerment of one ...at the expense of another' (Clegg; Davenport.) is out of step with today's world of financial stress in the health service and funding for health care research; selection is done on the basis of 'best care' (NHS) and 'most promising research proposal' usually done by panels of professionals and lay people (PPI) e.g. RfPB.

Activism: I have no direct experience of the meaning of activism. I am actively involved in health research including with Alzheimer Soc.: this is the first time I have heard of 'dementia activist movement'. To avoid misunderstanding the authors need to provide clarification.

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