Involvement in Palliative Care and End of Life Research
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Background

Involvement* of those with experience of using palliative care services is now an important and mandatory part of health and social care research, including palliative and end of life care. Those with direct experience of using palliative care and end of life care (patients, carers, friends or family members), such as in hospices and care homes, can enhance and shape research (Goodman et al., 2011). Involvement in these research areas, has its own challenges and innovative approaches are needed.

Seeking involvement from people with experience of care at an early stage of research development is key to ensure the research is user friendly, feasible and has relevant outcomes.

We ran a joint workshop focussing on palliative and end of life care research to enable researchers to receive face to face comments from people with experience of palliative and end of life care on their research projects in a ‘dragon’s den’ style session.

* or Patient and Public Involvement (PPI)

Involvement ‘Dragon’s Den’ Style

A one day workshop: Presentations, exercises and sessions on involvement, UK Standards, which were co-presented by researchers and PPI contributors (including Marie Curie Research Voices).

Attendees: 18 comprising 6 PPI contributors and 12 researchers

Before workshop: A short lay summary of each of the research ideas was circulated to PPI contributors before the workshop

The Dragons Den Session: Each researcher/team ‘pitched’ their research idea to a small group of Marie Curie Research Voices and an external PPI contributor. Research at early stage of research cycle.

Who took part? 1 or 2 researchers from a research team
3 PPI contributors
1 facilitator

Timing: 5 minute presentation by researcher
15 minute discussion between researchers and PPI contributors

How? Facilitator takes notes of discussion and give to researchers afterwards

What next? Evaluation forms at end of workshop
Evaluation form 4 months after workshop

Feedback (Mathie et al, 2018): Results of the evaluation sent to PPI contributors so they could see how useful their input had been.

Resources: All researchers and PPI contributors were provided with a pack of INVOLVEMENT resources.

Early involvement - Proposal Design

Evaluation of the Workshop

Evaluation Response Rate:
On day: 88% (16 out of 18) 4 months: 50% (6 out of 12 researchers)

Value of the workshop on scale of 0 to 10 (6 not valuable, 10 extremely valuable)

Understanding of PPI
22 out of 16 increased their understanding of Patient and Public Involvement (4 stayed the same)

Change: 11 out of 16 said they would make a change as a result of the workshop (4 PPI contributors said N/A).
The one who would not change explained “my approach was strongly endorsed but I would refine and extend as a result of today” (Researcher)
4mths follow-up: 6 out of 6 said they had made changes

Unexpected Outcomes
“an unexpected outcome, i.e. the networking that has followed – today will be my fourth example of contact with folk involved with the initiative” (PPI contributor)

Learning for Next Time

• Longer Dragon’s Den discussion
• More structured discussion for remaining participants whilst Dragon’s Den sessions happening
• Separate room for Dragon’s Den sessions
• Pilot of Dragon’s Den worked well, repeat again.

References:

CLAHRC EoE PPI in Research Theme Website: https://www.clahrc-eoe.nhs.uk/research/research-themes/patient-and-public-involvement-ppi/