

Involvement in Palliative Care and End of Life Research

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with Marie Curie Research Voices

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Background

Involvement* of those with experience of using 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 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

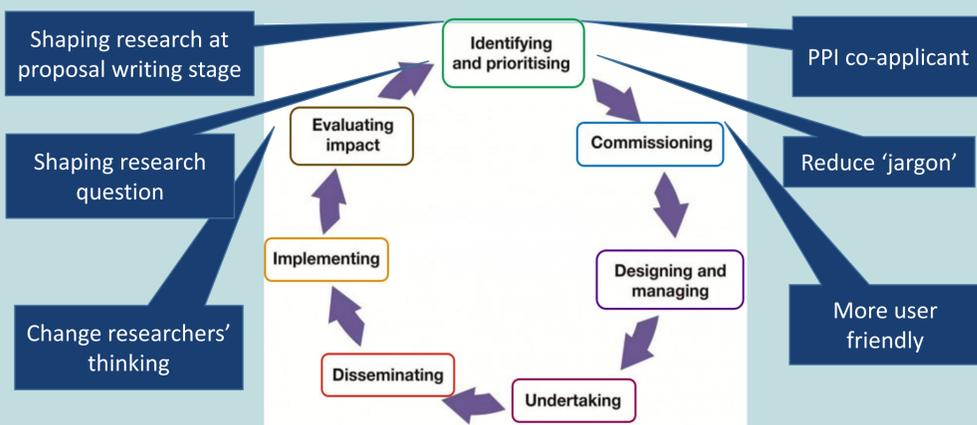
Feedback (Mathie *et al.*, 2018):

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



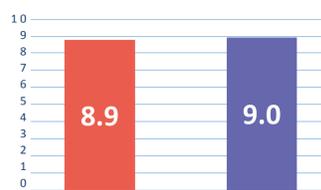
Evaluation of the Workshop

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 (0 not valuable, 10 extremely valuable)



On the day (researchers and PPI contributors) 4mth follow-up (researchers)

Understanding of PPI

12 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)

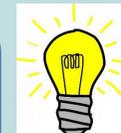
Researchers' Views

It has changed our way of thinking regarding control of the project. Carers who were going to be members of our PPI panel have now agreed to chair this and to take a lead on recruitment of participants (4 mths)

We have changed our proposal to address some of the points raised and have increased our engagement with the PPI group (4 mths)

Comments alerted us to the level of jargon that remained in our proposal - despite us having thought we had made it relatively user friendly (4 mths)

I attended with limited understanding of public/patient involvement - I am now much clearer on the 'true' meaning of involvement and the multiple stages where this can and ideally should occur. I will be much more mindful of this in the early stages of planning future projects (4mths)



I thought these sessions were excellent. It was extremely valuable to have a sit down, face to face discussion about the planned research and to hear the views of the PPI. While I think it is important that these sessions are condensed it would have been helpful to have a little longer (4 mths)

It was really helpful to have a group discussion with several PPI members contributing from their experience - personal and involvement in previous projects especially around wording and practical issues plus ethical concerns raised by reviewers....Really helpful to be engaged in genuine respectful co-construction of ideas around how to address this. I just wish we had more time (4 mths)

I found the workshop to be a good combination of presentations and time for discussion. The size of the group was also beneficial. The 'dragons den' sessions were extremely valuable and helped shape my second round application. I also found the time to talk to other researchers while waiting for dragons den sessions to be really interesting and helpful. It is so rare to get a chance to sit down as a small group and discuss the issues, share experiences and ideas in the way that was made possible in the workshop. Over all the day inspired me to speak to our PPI co-applicant on our current study to see if he would be willing to write an article for publication about his experiences. We are currently in the process of doing this (4 mths)

I will work with PPI contributors to set out some roles and expectations – to help full engagement and future proof the research study. Will also apply for Research Design Service money for our PPI group (on the day)

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:

Goodman, C., Mathie, E., Cowe, M., Mendoza, A., Westwood, D., Munday, D., Wilson, P., Crang, C., Froggatt, K., Illiffe, S., Manthorpe, J., Gage, H. & Barclay, S Talking about living and dying with the oldest old: public involvement in a study on end of life care in care homes. 2011, <https://bmc-palliat-care.biomedcentral.com/articles/10.1186/1472-684X-10-20>
Mathie E, Wythe H, Munday D, Millac P, Rhodes G, Roberts N, Smeeton N, Poland F and Jones J. Reciprocal relationships and the importance of feedback in patient and public involvement: A mixed methods study. Health Expect. 2018; 21:899-907. <https://doi.org/10.1111/hex.12684>
Mathie E, et al. Guidance for Researchers: Feedback. University of Hertfordshire, CRIPACC, Hatfield; 2018. p. 15. http://www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf.

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

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