

# Implementing a Patient, Family Caregiver and Public Involvement Model for Palliative Care Research in order to influence Clinical Care, Policy and Funding

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## Background:

At the Cicely Saunders Institute, we want to produce evidence-based palliative care solutions for patients and their families by conducting relevant, high quality research with a true focus on the current concerns and needs of patients and families in receipt of palliative care (PC). The only way we can do that is if we work together with patients, their carers, the public and researchers to plan and conduct our research.

## Our aim:

To develop and implement a Patient, family and Public Involvement (PPI) model and business plan for PC research that allows sustained involvement to produce high-quality research with findings relevant to patients and families that influence clinical care, policy and funding.



## Methods:

Patient advocates and researchers took part in a nominal group exercise to establish how PPI in PC research should be delivered. Salient recommendations emerged and were used to iteratively develop a PPI model (including a business plan) for implementation. This PPI implementation model was developed further, refined and agreed by consensus with an executive board of a leading PC research centre (Cicely Saunders Institute, King's college London), which comprised clinical leads and international researchers. The implementation of subsequent workshops was systematically reviewed in order to determine components essential to implementation.



## Main findings from the first workshop:

The nominal group exercise revealed that involvement should:

- ...be in the whole research continuum
- ...be inclusive and widely advertised
- ...be flexible (pick and mix)
- ...not be tokenistic
- ...be two-way



These and further findings are accepted for publication in Pall Med 2015, Daveson et al: *Results of a transparent expert consultation on patient and public involvement in palliative care research*

## Results:

An overall structure for the PPI model was developed and three potential business plans were reviewed by the executive in order to agree on the final implementation approach. The components of the business plans were: aim, outcomes, structure, costs, and resources. One model was agreed (see below). They differed mainly in the frequency of face-to-face workshops and associated costs. Review of the implementation approach at subsequent workshops revealed that PPI model implementation depends on: operational and strategic leadership from research staff; consistent relationship-based work with participants, which involves acknowledging the value of their clinical care experiences; a blended means of involvement (e.g. face-to face and virtual platforms); and sufficient resources to support implementation.

## Conclusion:

Implementing PPI in PC research requires commitment of researchers and lay-members, excellent leadership and a continuous professional relationship with all collaborators. With a carefully designed business plan, PPI can be sustained beyond the limits of individual projects, despite limited resources. These findings highlight the potential for optimising the value of clinical experiences within research settings in PC.

## Business Plan

Aim	Face-to-face - Upskill service-users (15 minute presentation); Speed-dating to link in individual service-users with projects; Researchers opportunity to get feedback; Induct new members
Outcomes	
Structure	3 face-to-face meetings per annum
Face-to-face	Interactive, un-moderated discussion with resource upload
Virtual	
Costs	£540 per meeting including: - £150 for one co-facilitator including preparation time - £300 Travel reimbursement (first in, first served with max. 15 participants @ £20 per participant) - £90 refreshments (£6 per participant)  Annual cost: £1620 based on INVOLVE guidelines
Resources	Research assistant (Grade 5): 2 hours per week = £32 gross (29,600.10 per annum incl. London Allowance / 12 = 2466.68 / 4 = 616.67 / 37.5 = 16 * 2 = £32) Admin support (Grade 4): 2 hours per week = £28 gross (25310.40 per annum incl. London Allowance / 12 = 2109.20 / 4 = 527.30 / 37.5 = 14 * 2 = £28) Staff cost: £78pw / £312pcm / £3744pa (gross pay + 30% (NI and Estates) included)
Total costs per annum	£5364

## The Patient, Family and Public Involvement Model & Business Plan:

The tables on the left and below show the components of the involvement business model that was agreed by the executive board and taken forward in subsequent workshop.



Outcome	Aim	Intervention	Service users win	Researchers win
Service users are able to use the new skills in order to provide the researcher with a critical review	Up-skill service-users	Teaching on research specific tasks for example: • What is an informed consent? • What does randomisation mean and what it is good for?	<ul style="list-style-type: none"> <li>Insight into research process</li> <li>Being able to share an objective opinion with researcher</li> </ul>	Competent and reliable feedback from service user
Service users and researcher match-up according interest and skills	To facilitate pick-and mix recommendation	Speed dating model	Service user is linked to his / her area of interest and can commit according to his / her lifestyle priorities	Very motivated involvement / commitment from service user
To fulfil requirement of service user involvement in application processes meaningfully	Researcher gets meaningful feedback for their grant proposal / ethics application	Structured feedback in writing to the researcher	Service user gets acknowledged in the application	Improved quality of research proposal / ethics application
To include as many members of the public as possible	To welcome new members	Introduction( i.e.): • What does the CSI do? • Why is research and dissemination crucial?	<ul style="list-style-type: none"> <li>Know the distinction between research and practice</li> <li>Find a project which also addresses their motivation to contribute</li> </ul>	More people talk about the high quality research the CSI conducts

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