

## Review Methods:

### Search Strategy:

A systematic search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid E pub Ahead of Print, Ovid Embase, Ovid PsycINFO, Ebsco CINAHL and Cochrane Library.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2012 to January 2018 restricted to English language studies. The search strategy was modified to capture index-ing systems of the other databases. (Search strategies available upon request).

To identify additional papers, the following websites were searched:

- [INVOLVE Evidence library](#)
- [National Cancer Research Institute](#)

Furthermore electronic tables of content for the last two years were scanned for Health Expectations Journal.

Reference lists of published reviews and included studies were checked for any relevant studies. The searches generated 195 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

### Inclusion:

- Studies that include strategy, models, guideline, toolkit, framework, evaluation, impact, performance, audit, procedure, codes of conduct, ethics, impact, challenges, facilitators, financing and training aspects of PPI implementation in cancer and palliative care research.
- Studies conducted in English languages
- Studies in the area of cancer and palliative care
- Studies involving adults only

### Exclusion:

- Studies set in non-Organization for Economic Cooperation and Development (OECD) countries
- Non-English language studies

### Study selection/Quality Assessment/Data

**Extraction:** Study selection was based upon review of the abstract by two independent reviewers. The full text was then assessed independently using a pre-designed eligibility form according to inclusion criteria. Quality assessment of the eligible studies was carried out by one reviewer using appropriate quality assessment checklists and checked by another reviewer.

Any discrepancies between the two reviewers were resolved by consensus or by recourse to a third reviewer. Study data was extracted by one reviewer and checked by another reviewer using a pre-established data extraction form.

## Context

The improved outcomes obtained in research by using PPI policy have been well recognized in health and social care research in general. Yet, it is not quite evident how different PPI models are applied and translated into practice in cancer and palliative care organizations. There is a need to explore the evidences on which model/ framework/ tools/ guidelines are advocated and followed while implementing PPI policy. It is also important to identify what are the outcomes of using these PPI framework/ tools/ guidelines. This review aims to identify existing models and outcomes of PPI in cancer and palliative care research. The established definition for **public involvement in research** was used: Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. ([NIHR INVOLVE 2017](#))

## Key Findings

The evidence base is limited, with only three studies identified as being relevant to the question. These studies outline features of an optimal PPI model, PPI facilitators (motivation; inter-relations; role of key persons; long-term organisational and professional support; experiential knowledge) and challenges (role ambiguity; attitudes and capacities; lack of resources; practical and emotional demands). In an optimal model, PPI should occur early during the research process, it should be flexible to include virtual as well as face to face methods and professionals should promote the contribution made to research by PPI. The main PPI impact categories reported by both patient representatives and professionals were quality of care, information development and dissemination, and policymaking. An optimal PPI model should stress the impact of PPI, however, this may be difficult to identify, with service-users concerned more with short term impact and professionals concerned more with long term strategic goals.

Quality of Evidence:

### A. Reliability

The evidence base is very limited. Three papers were selected, all were qualitative studies using in-depth interviews and focus groups. Two studies were conducted at university sites throughout the UK and one study was conducted in palliative care networks in The Netherlands. A total of 34 patient/public representatives and 17 professionals took part across all three studies. All PPI representatives were already involved in research.

### B. Consistency

The study conducted at The Cicely Saunders Institute (Daveson et al) identified four factors that an optimal model should consider, these factors shared similar themes to those reported in the Netherlands as facilitators and barriers to PPI (Haarsma et al). For example, ambiguity in role expectation was reported as a barrier to PPI (Haarsma et al), and it was reported that an optimal model should devote time to clarifying roles early on (Daveson et al). Professionals felt that service-users should be encouraged to add value to research by helping to improve research productivity, quality and relevance, but this was not identified as a priority for the users (Daveson et al). Similarly, Haarsma et al found that users found it hard to commit to long term, strategic processes and experienced more impact regarding short term solutions, whilst professionals perceived great benefit in the former. The study carried out across five UK university sites (Froggatt et al) also identified that more general and longer term impact was less visible to participants.

One of the barriers to PPI reported by Haarsma was that advice given by service-users had no follow-up. Similarly Daveson found that service-users wanted to see greater emphasis on what difference their involvement makes and reported that an optimal model should stress PPI impact, especially in research dissemination. However, Froggatt reported that identifying the difference made by the participants could be difficult.

The sense of reality and practical knowledge of being a patient that were identified as important contributions to research across five UK university sites (Froggatt et al) was also highlighted in the Netherlands study where it was found that professionals' recognition of experiential knowledge was very important to patient representatives, however, sometimes, participants felt they were not being taken seriously (Haarsma et al). The need for researchers to promote the contribution of service users was identified as part of an optimal model of PPI (Daveson et al) and professional expertise concerning the support of PPI was also identified as a PPI facilitator (Haarsma et al).

### C. Relevance

This rapid review reveals the dearth of examples and guidance in the rapidly emerging and evolving area of PPI. Whereas some barriers to effective PPI have been highlighted, there are few examples of PPI in real life practice especially within the area of cancer and palliative care. Some explanation for this is that PPI may be context specific, so one size may not fit all. However, any opportunities to share practice or case studies will add to the scarce body of literature and highlight good practice.

# What are the models and outcomes of Public and Patient Involvement (PPI) in cancer and palliative care research?

## Evidence Implications:

### Clinical:

The evidence base identified by the included studies reveals the paucity of evidence in the area of PPI in cancer and palliative care. There is a slowly developing field of evidence for PPI with ongoing research projects aiming to define best practice, or research priorities. Kearney et al has prioritised the research areas for PPI in the clinical trials context whilst Bagley et al have scoped UK clinical trials units looking at current models of practice. They found that PPI is an evolving field with many challenges, including resource, of both time and funding, training and full understanding of the intent of PPI, and a lack of consistency or standardisation.

This lack of published data highlights the potential importance for further research. Well-designed studies across all care settings are required to establish a robust evidence base.

### Policy:

Whether standardisation of PPI is an objective to aspire to is arguable but there is a recent move to at least establish shared standards at <https://sites.google.com/nih.ac.uk/pi-standards/home>, which will inevitably lead to performance outcomes and models of practice. This review will be updated in two years to monitor the effect of national standards on PPI models and outcomes as they embed in practice.

### Glossary:

**PPI:** Public and Patient Involvement

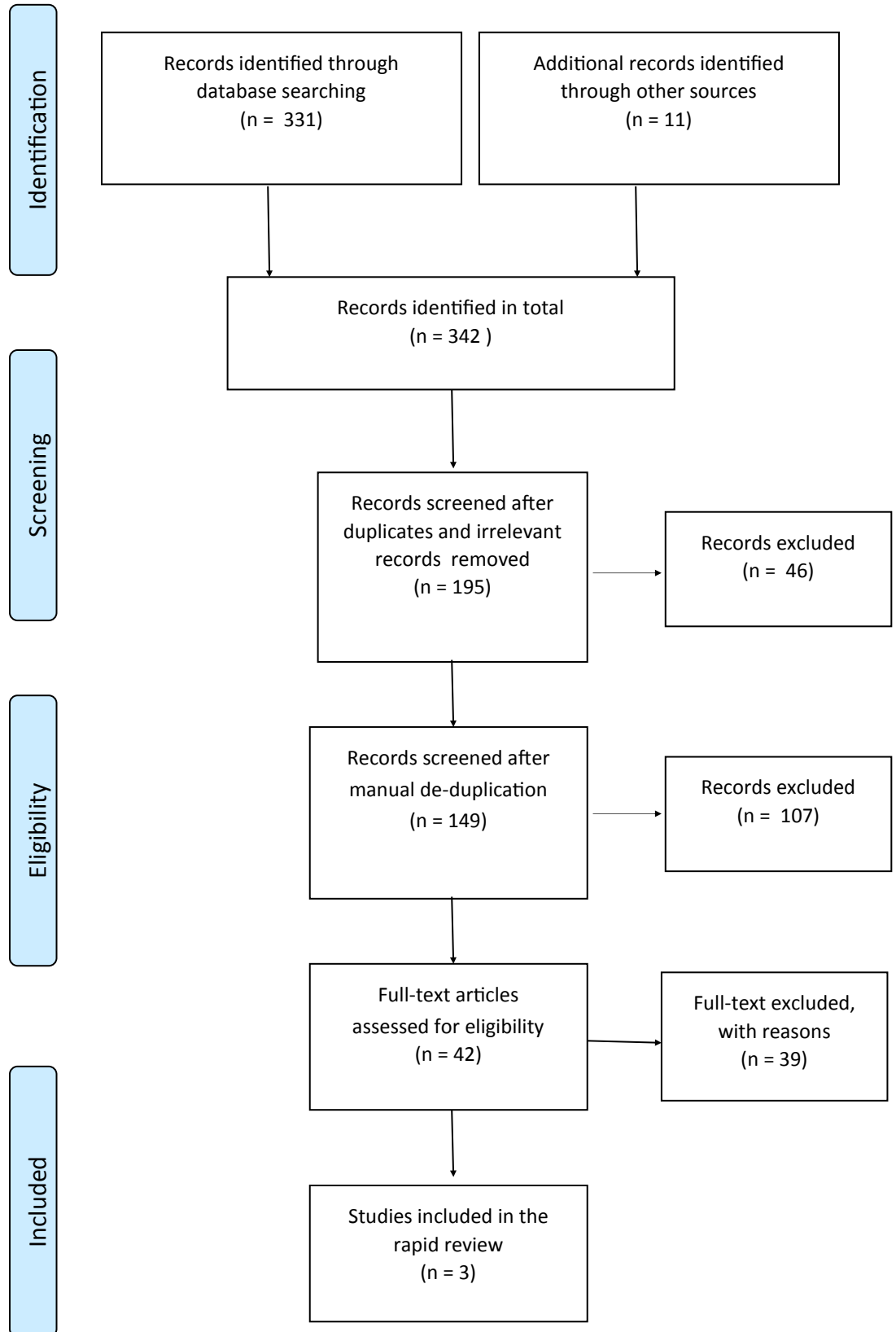
**OECD:** Organizations for Economic Cooperation and Development

**NIHR:** National Institute for Health Research

**CSI:** Cicely Saunders Institute

**CECo:** Cancer Experiences Collaborative

## Flow Diagram:



# What are the models and outcomes of Public and Patient Involvement (PPI) in cancer and palliative care research?

**Table 1: Characteristics of Included Studies**

<b>Daveson et al 2015</b>	<b>Study Setting &amp; Design – Cicely Saunders Institute (CSI) at King’s College London; Focus group with nominal group technique</b>
<b>Study Objective</b>	To determine an optimal user-involvement model in palliative care research that fulfils the needs of both users and researchers while acknowledging any potential diversity between these groups.
<b>Participants</b>	12 users (4 patients; 4 unpaid caregivers; 2 user advocates; 2 members of the public) and 5 researchers (1 clinical research nurse; 2 research assistants; 1 research fellow; 1 senior scholar) participated. Inclusion criteria were the ability to provide informed consent; to understand English to a degree that allowed workshop participation; active involvement in CSI palliative care research.
<b>Interventions/ Comparators/ Methods</b>	A consultation workshop using expert presentations, focus group discussions and nominal group technique was used to generate recommendations and form a consensus on priority setting to inform the components of a model of user involvement in palliative care research.
<b>Outcomes</b>	The proposed outcomes were: <ul style="list-style-type: none"> <li>To generate recommendations and form a consensus on priority setting to inform the components of a model of user involvement in palliative care research</li> <li>To identify areas of divergence between users and researchers</li> </ul>
<b>Summary of the Study Results</b>	Users and researchers agreed that an optimal model should consider the following: <ol style="list-style-type: none"> <li>Researchers need to promote the contribution of service-users, ensure their visibility and stress their impact, this sustains engagement and aids user satisfaction.</li> <li>Early involvement (from idea generation) to ensure meaningful involvement and impact.</li> <li>PPI models should be applied flexibly and be offered both via virtual and face to face methods.</li> <li>Service-users should also be encouraged to add value to research by helping to improve research productivity, quality and relevance, e.g. by avoiding researching an irrelevant need to the population.</li> </ol> <p>Areas of divergence: Users wanted their involvement to be more visible, including during dissemination, with a greater emphasis on the difference their involvement makes. Researchers wanted to improve productivity, relevance and quality through involvement.</p>
<b>Appraisal Summary</b>	Limitations: <ul style="list-style-type: none"> <li>Only users already involved in research and known to the CSI participated in this study.</li> <li>Senior investigators were missing from the consultation</li> <li>An ordinal ranking scale for the nominal group work was used rather than an interval scale. An interval scale would have allowed for a more thorough examination and understanding of the differences between the individual rankings.</li> </ul>

# What are the models and outcomes of Public and Patient Involvement (PPI) in cancer and palliative care research?

**Table 1: Characteristics of Included Studies (continued)**

<b>Froggatt et al 2014</b>	<b>Study Setting &amp; Design – Cancer Experiences Collaborative (CECo) at five UK university sites. (Lancaster, Liverpool, Manchester, Nottingham and Southampton); Qualitative study using semi-structured interviews</b>
<b>Study Objective</b>	To describe the experience of PPI participation in palliative care research following a cancer diagnosis.
<b>Participants</b>	8 participants (7 women, 1 man, aged 51 to 84) who had a cancer diagnosis and were involved in a nationwide supportive and palliative care research collaborative over a period of 6 years
<b>Interventions/ Comparators/ Methods</b>	An exploratory, qualitative study using semi-structured interviews (2 at home; 3 at host university; 3 by telephone). A thematic analysis of the transcribed data was undertaken, using template coding to match the original research objectives
<b>Outcomes</b>	Proposed outcomes were: <ul style="list-style-type: none"> <li>To describe the motivations of participation in PPI activities</li> <li>To consider the benefits to individuals of participation</li> <li>To identify the challenges for individuals of participating in PPI activities</li> <li>To describe the perception of the impact of their involvement upon the research process.</li> </ul>
<b>Summary of the Study Results</b>	<p><b>Benefits</b> Bringing a different, lay perspective into research, specifically through having the experience of being a cancer patient. They identified that a sense of reality and practical knowledge of being a patient were important contributions that could make a difference to the research; with a specific example such as their review of information materials. Personal gains were identified, in terms of users gaining knowledge, skills, confidence, and support (from others who had experienced cancer)</p> <p><b>Challenges</b> PPI activity made emotional demands (revisiting personal experiences) and practical demands (time commitment). The use of clinical language was challenging, however addressing this was identified as a contribution of PPI to the research, for example, through consultation about patient information sheets and questionnaires.</p> <p><b>Impact</b> Identifying the difference made by the participants could be difficult. Some specific examples of changes made in response to consultation activities were described (e.g. patient information sheets). However, more general and longer term impact was less visible to participants</p>
<b>Appraisal Summary</b>	Limitations: <ul style="list-style-type: none"> <li>Only users already involved in research participated</li> </ul>

# What are the models and outcomes of Public and Patient Involvement (PPI) in cancer and palliative care research?

**Table 1: Characteristics of Included Studies (continued)**

<b>Haarsma et al 2014</b>	<b>Study Setting &amp; Design – Palliative Care Network, Lindberg, Netherlands; Qualitative study (in-depth interviews and focus groups)</b>
<b>Study Objective</b>	To examine in depth the current practice of public involvement in palliative care.
<b>Participants</b>	14 patient representative members of PCN sounding board groups (12 female, 4 male, mean age 62.6) 12 professional members of PCN management teams (6 female, 6 male, mean age 50.4)
<b>Interventions/ Comparators/ Methods</b>	18 in-depth interviews and 3 focus groups analysed using critical incident technique and Arnsteins framework. Impact categories as well as facilitators and barriers were analysed using content analysis.
<b>Outcomes</b>	The proposed outcomes were: <ul style="list-style-type: none"> <li>• Patient representatives and professionals perceptions of the impact of public involvement in PCNs?</li> <li>• Perceived facilitators and barriers associated with public involvement in PCNs, according to patient representatives and professionals?</li> </ul>
<b>Summary of the Study Results</b>	<p>4 major impact categories:</p> <ol style="list-style-type: none"> <li>1. Quality of care</li> <li>2. Information development &amp; dissemination</li> <li>3. Policymaking</li> <li>4. Organisation-specific issues</li> </ol> <p>For both patient representatives and professionals, quality of care was the main priority issue and organisation-specific issues was ranked lowest. However, patient representatives perceived information development and dissemination as the second and policymaking as the third most important impact category, while professionals assigned the opposite ranking to these two categories. The greatest impact was reported by both groups in the preparation and implementation phases of decision making. The smallest impact was perceived in the evaluation and adjustment phases of decision making.</p> <p>Facilitators to PPI:</p> <ul style="list-style-type: none"> <li>• Motivation - Interested in palliative care as a topic; Advocacy for the very vulnerable and ethnic minorities:</li> <li>• Inter-relations - Sharing stories; Exchanging ideas and experiences</li> <li>• Key persons - Chairperson; PCN coordinator who was capable of communicating and coordinating issues from the sounding board to the professionals</li> <li>• Long-term support - Organizational arrangements; Professional expertise concerning the support of PPI</li> </ul> <p>Barriers to PPI:</p> <ul style="list-style-type: none"> <li>• Ambiguity in role expectation - Lack of clarity in the statutes; Operational vs. strategic (<i>patient reps experienced more impact regarding short term solutions, whilst professionals perceived great benefit in long term strategic processes</i>); One-way communication (<i>self-initiated advice by the sounding board dominated, and had no feedback</i>)</li> <li>• Attitudes and capacities - Volunteer vs. professional; Value of experiential knowledge. (<i>Professionals' recognition of experiential knowledge was perceived as lacking, they assigned more value to capacities, such as analytical skills and being able to think on an abstract level, than to experiential knowledge.</i>)</li> <li>• Lack of resources – Money; (New) members</li> </ul>
<b>Appraisal Summary</b>	<p>Limitations:</p> <ul style="list-style-type: none"> <li>• Self-selection aspect of recruitment process meant that participants were likely to be highly motivated</li> </ul>

# What are the models and outcomes of Public and Patient Involvement (PPI) in cancer and palliative care research?

## Included Studies:

Studies were included where it was reported that a member of the public was involved as defined by [INVOLVE](#). "Public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them".

1. Daveson BA, de Wolf-Linder S, Witt J, et al. Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative Medicine* 2015;29(10):939-49. doi: 10.1177/0269216315584875
2. Froggatt K, Preston N, Turner M, et al. Patient and public involvement in research and the Cancer Experiences Collaborative: benefits and challenges. *BMJ Supportive and Palliative Care* 2015; 5: 518-21. doi:10.1136/bmjspcare-2013-000548
3. Haarsma F, Moser A, Beckers M, et al. The perceived impact of public involvement in palliative care in a provincial palliative care network in the Netherlands: A qualitative study. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy* 2015;18(6): 3186-3200. doi: 10.1111/hex.12308

## Excluded Studies:

For full list of studies excluded at full text reading stage please contact [PaCERSWCRC@cardiff.ac.uk](mailto:PaCERSWCRC@cardiff.ac.uk)

## References:

Kearney A, Williamson P, Young B, Bagley H, Gamble C, Denegri S, Muir D, Simon NA, Thomas S, Elliot JT, Bulbeck H, Crocker JC, Planer C, Vale C, Clarke M, Sprosen T, Woolfall K. Priorities for methodological research on patient and public involvement in clinical trials: A modified Delphi process. *Health Expect*. 2017 Dec;20(6):1401-1410. doi: 10.1111/hex.12583. Epub 2017 Jun 15.

Bagley HJ, Short H, Harman NL, Hickey HR, Gamble CL, Woolfall K, Young B, Williamson PR. A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials - a work in progress. *Res Involv Engagem*. 2016 Apr 27;2:15. doi: 10.1186/s40900-016-0029-8. eCollection 2016.

## Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies
- List of excluded studies

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