https://doi.org/10.1016/j.colegn.2019.08.002

**Title page (anonymous)**

## Title

# Involving consumers with palliative care needs and their families in research: a case study

## Running head

Co-designing palliative care research

## Abstract

Background: There are significant policy imperatives to involve consumers at the outset of and throughout research. How best to achieve this in an authentic and meaningful way is elusive, particularly within the palliative care population.

Aim: To determine how best to engage people with palliative care needs and their families in co-designing a qualitative study to better understand how to improve care of the dying in the acute care setting.

Methods: A case study design informed this work, informed by pre-determined research questions that focused on consumers advising on participant experience within the research, rather than research methodology *per se.*

Findings: Eleven consumers contributed across five panel meetings. Analysis of documented feedback led to four key areas of protocol change: *Getting the language in the recruitment materials and information and consent forms right; Developing a feasible and acceptable recruitment strategy; Opportunities to more clearly articulate the explicit value of this research for patients and families; Support strategies for participants.*

Discussion: Authentic consumer engagement requires time and effort; however, the outcomes are well worth the invested time and energy. Key foci outlined within this case study to enhance authenticity included: collaboration; preferencing the consumer voice; adequate preparation to support consumer engagement; and openness to all feedback provided.

Conclusion: Co-designing research with consumers enabled the outcome to be feasible for implementation, without any modifications required. Ensuring relevance and consumer-centredness for the expanding palliative care evidence base is essential and can only be achieved through meaningful partnerships with consumer representatives.

**Keywords:** Community participation; Palliative care; Case report; Consumers; Patient engagement; Quality and Safety.

## Summary of Relevance

*o Problem or Issue*

- Policy imperatives call for consumer engagement in the design and implementation of research;
- Achieving meaningful and authentic engagement across palliative care populations is unclear.

*o What is Already Known*

- People with palliative care needs, and their families / carers are keen to contribute to research;
- The need for early engagement with consumers, clarity of role at the outset, the valuing of consumer contributions and supporting flexible methods for participation is outlined.

*o What this Paper Adds*

- This short report outlines one approach to meaningful consumer engagement in co-designing a research protocol that sought to understand the experiences of patients with palliative care needs, and their families/carers, of hospital care.

## Introduction

There is a growing international policy imperative for involving consumers at the outset of new research and implementation projects in order to improve their quality, relevance and impact (Canadian Institutes of Health Research, 2011; Cancer Australia and Cancer Voices Australia, 2011; National Health and Medical Research Council, 2016; NHS Health Research Authority, Health and Care Research Wales, & NHS Research Scotland, 2017; Scholz, Bevan, Georgousopoulou, Collier, & Mitchell, 2019; The National Institute for Health and Care Excellence, 2014). The United Kingdom has led significant work in this area, with additional policy and study work evident from Canada, the United States and more recently, Australia (Brett et al., 2014). However, achieving authentic consumer (‘patient, carer and/or family’) engagement continues to be challenging in many contexts (Ball, Amelia Harshfield, Asha Carpenter, Adam Bertscher, & Sonja Marjanovic, 2019; Brett et al., 2014; Daveson et al., 2015; Hubbard, Kidd, Donaghy, McDonald, & Kearney, 2007; Oliver, Kothari, & Mays, 2019). A recent review found that integrating consumers’ perspectives into projects designed to reform the Australian health system and/or care delivery has evolved significantly over the past 20 years in relation to their work in developing, implementing and evaluating such work (Consumer Health Forum of Australia, 2015 ). However, the need to develop evidence to inform methods for effective consumer representation is noted as a priority (Consumer Health Forum of Australia, 2015 ). National Health and Medical Research Council policy recommends that health and medical researchers consider and plan for how they involve consumer representatives in the development, conduct and communication of their studies (National Health and Medical Research Council, 2016). The uniqueness of every new research project demands targeted consumer involvement from the outset (National Health and Medical Research Council, 2016).

Engaging consumers focused on palliative care in the conceptualisation and development of research protocols has been noted as important for over a decade (Bradburn & Maher, 2005;

Scholz et al., 2019). Involving such consumers in new research initiatives increases the person with palliative care needs' sense of empowerment, of legacy and of meaning to their days whilst living with a terminal illness (Bloomer, Hutchinson, Brooks, & Botti, 2018; Bradburn & Maher, 2005). Recent consumer focused research has added to our understanding of the perspectives and experiences of people with palliative care needs, their family and/or carers, in relation to research participation (Aoun, Slatyer, Deas, & Nekolaichuk, 2017; Bloomer et al., 2018; Harrop et al., 2016; Pessin et al., 2008; Scholz et al., 2019; Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006; White & Hardy, 2010).

A 2010 systematic review found positive outcomes from research participation for people with palliative care needs and their families particularly in relation to altruism and personal gain (White & Hardy, 2010). However, this same review notes the importance of participant autonomy and the need for trial design to be as simple as possible (to enable participant understanding), data collection processes to be minimal to prevent burden on the participant and no noted financial burden (White & Hardy, 2010). One large study of family carers identified that participants described positive experiences both from an inward-directed perspective (sharing of experience, ability for reflection, validation of role) and an outward-directed perspective (connection with others) (Aoun et al., 2017). A more recent integrative review published in 2018, examining the perspectives and experiences of dying people in relation to research participation outlines four themes: (1) the value of research, (2) desire to help, (3) expression of self and (4) participation preferences (Bloomer et al., 2018). Beneficial aspects to participation including validation of self-worth, altruism and social interaction are well described for both people with palliative care needs and their family carers (Aoun et al., 2017; Harrop et al., 2016; Pessin et al., 2008; Scholz et al., 2019; Terry et al., 2006). Participation preferences were noted to include the desire to be approached by a clinician familiar to the patient or family, for involvement within comparator trials and to be involved in research that is not too burdensome for the person both in relation to time investment and/or invasiveness of proposed interventions (Bloomer et al., 2018).

Despite this guidance, there is little evidence to guide clinical researchers as to how best to involve consumers in palliative care clinical research (Daveson et al., 2015; Scholz et al., 2019; White & Hardy, 2010). A consultation workshop (incorporating expert presentations, discussion and nominal group work to develop recommendations) focused on this particular issue, suggests that optimal engagement with consumers focused on palliative care in meaningful research participation, depends on the following attributes:

1) Researchers being clear at the outset about a consumer's role and valuing the contribution and difference consumers make to the research outcomes;

2) Early engagement to aid productivity, quality and relevance;

3) Flexibility is essential, incorporating multiple methods for participation (virtual and face to face) to account for health fluctuations, alternate priorities and responsibilities; and

4) Assisting consumers to focus on improved productivity, quality and relevance in line with a researcher's agenda is important (Daveson et al., 2015).

This short report outlines one approach to engaging consumers focused on palliative care in co-designing a research protocol that sought to understand their experiences of hospital care including [for some] stays where a family member died. This case study informed a broader program of sequential mixed methods research (Andrew & Halcomb, 2009) focused on how to support system level improvements in care for people with palliative care needs in the hospital setting, and their families/carers.

Aim: To determine how best to engage people with palliative care needs and their families in co-designing a qualitative study to better understand how to improve care of the dying in the acute care setting.

## Methods

An exploratory case study design informed this work (Baxter & Jack, 2008; Yin, 2003) and involved people with palliative care needs, bereaved carers and cancer survivors. Pre-determined research questions were articulated, clear boundaries in relation to the case outlined and varied data sources used to enhance understanding (Baxter & Jack, 2008). Of note, the two predetermined research questions provided clarity about the purpose for consumer input with their focus maintained on participant experience within the research, rather than research methodology *per se.* The research questions for this case study were:

1. What do consumers perceive to be the best strategies for identifying, approaching and recruiting people with palliative care needs, and their families, and supporting participation within research focused on optimal hospital-based palliative care?
2. Do consumers perceive this program of research to be important, and if so, how can we best promote this work to a non-clinical audience?

Ethical approval was not required in the development of this research protocol. Regular presentations to and feedback from consumer panels (n=5) occurred throughout protocol design with adaptations in response to consumer feedback (Goodyear-Smith, Jackson, & Greenhalgh, 2015) made until consensus was achieved. Consumer panels were drawn from two organisations, one being from a tertiary academic environment's consumer advisory group and the other from a Translational cancer research network's consumer panel. Members of both organisations' consumer groups included: people living with cancer, cancer survivors, people with palliative care needs and bereaved carers. Ensuring adequate preparation for meaningful consumer engagement occurred through sending draft documentation for review prior to panel meetings and using organisational templates for standardised information provision. These templates allowed unique study information to be presented in a manner that provided consumer representatives with some consistency of format and data type.

Descriptive analysis of data from field notes taken within each panel informed research team discussions and case study outcomes. Ensuring openness to feedback, even when a difference between lay and clinical perspectives occurred, was prioritised throughout all discussions. That is, decisions were led by consumer perspectives in relation to the research questions set out (consumer participation strategies and communication options). Steps taken to ensure prioritisation of the consumer voice included noting and reviewing every individual's feedback; accepting all feedback given in relation to language used to describe our population – that is valuing all concerns voiced; openly reviewing all protocol-related changes needed to address noted areas of consumer concern and ensuring consensus prior to document finalisation. Difficulties in instituting these approaches included the fact that not all consumer representatives were present across all panel discussions and the need to truly embrace feedback given, even when it did not align with clinical thinking, was challenging. However, the lessons learned from such an approach were profound, with the consumer perspective echoing the perspective of screening clinicians and potential participants.

## Results

Eleven consumers (inclusive of bereaved carers (n=7), people with palliative care needs (n=2) and cancer survivors (n=2)) contributed, with six attending more than one panel. Five panel meetings were conducted and detailed field notes documented at each one. Each panel meeting included a 20 minute discussion about this particular piece of work. Analysis of documented feedback led to four key areas of change centering upon improving the participant's experience from recruitment through to participation. Specifically, feedback focused on the following:

1. *Getting the language in the recruitment materials and information and consent forms right;*

Consumers were asked for advice about appropriate terminology to describe the study population in written study materials. As the study aimed to recruit patients with palliative care needs, with a likely prognosis of 12 months of less, this needed to be clearly and sensitively articulated in the protocol, ethics application and the participant information sheet. Consumers were adamant that terms such as "advanced, progressive illness; advanced and non-curable health conditions; people approaching the end of their lives" would be too confronting for many patients with palliative care needs and their family members. After several panel discussions, and iterations of the participant information sheet, consumers suggested that using the term 'serious chronic illness', was the preferred terminology as it was most likely to be acceptable to potential participants and unlikely to cause unnecessary distress.

However, this broader term presented challenges for the research team as it did not sufficiently describe people admitted to hospital who were likely to have a prognosis of 12 months or less. However, keeping with co-design principles the team acknowledged that it was important to honour and privilege this consumer feedback and to include the preferred term 'serious chronic illness' in all paperwork seen by potential participants. The screening strategy was devised to enable identification of people with a prognosis of 12 months of less (and their families) by senior clinicians in accordance with predetermined prognostic screening tools, including the Supportive and Palliative Care Indicators Tool (SPICT$^{\text{TM (The University of Edinburgh)}}$) and Australia-modified Karnofsky Performance Status (AKPS) (Abernethy, Shelby-James, Fazekas, Woods, & Currow, 2005). As a result, the inclusion criteria became clearly defined (Table 1) and used language that was specific to the target population. This eligibility criteria provides clear guidance to the clinician's screening patients for this study as well as providing them with a conversation script to honestly discuss the study with potential participants without causing distress. The wording focuses on the fact that participants are living with a serious chronic illness but does not refer to it as an advanced illness, prognosis or whether the illness is curable or not. This consumer guided advice enabled the team to navigate the complexity of not needing to detail prognostic information within the recruitment paperwork.

Table 1: Inclusion and exclusion criteria for the study

| **Inclusion criteria** | **Exclusion criteria** |
|---|---|
| • Clinical indicators of one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT$^{\text{TM}}$ (The University of Edinburgh))<br>• Australia-modified Karnofsky Performance Status (AKPS)(Abernethy et al., 2005) score between 30 and 70<br>• 1 or more admissions to hospital within the previous 12 months<br>• Patient aware they have a serious chronic illness<br>• Patient is comfortable talking about their serious chronic illness and related care needs<br>• Willingness to give verbal informed consent and willingness to participate in and comply with the study<br>• Family member / carer of someone with advanced dementia who has had at least 1 hospital admission within the previous 12 months<br>• Bereaved family member or carer whose loved one had at least 1 admission to hospital in their last 12 months of life and their bereavement is within 2 years | • Patients less than 18 years of age<br>• Patients and / or family members / carers who cannot converse in English<br>• Patients with cognitive impairment that impairs their ability to describe prior hospitalisations and care experiences |

*2. Developing a feasible and acceptable recruitment strategy;*

Initial recruitment strategies discussed with consumer representatives included the use of databases to identify people with palliative care needs, and their families. However, the consumer representatives advised that recruitment should be completed by people who knew a patient’s care well and were actively involved in their care provision. The reasons for this were twofold: 1) To ensure people approached were comfortable with talking about their illness and aware of their diagnosis; 2) Consumers felt it would be most appropriate for the first contact to be made by someone whom potential participants knew rather than a stranger. This consumer advice was also prioritised and an approach using chronic care coordinators, nurse consultants, nurse practitioners or medical physicians, working with people who met the screening criteria, was developed. This presented the challenge of possible ‘gatekeeping’ in relation to study participation. However, the benefits of limiting potential distress for this vulnerable population were felt to outweigh the risk of missing eligible people who would have welcomed participation but were not given the opportunity to do so by their care coordinator. We also tried to offset this risk by providing support and education for the screening clinicians in relation to the importance of providing people with opportunities to participate.

*3. Opportunities to more clearly articulate the explicit value of this research for patients and families.*

Consumers provided feedback in relation to the difference they perceived between the way this study was discussed during face to face panels and how they felt when reading the initial written study protocol, participant information sheets and consent forms and invitation letters. The face to face discussions allowed an element of the study to emerge that was not as obvious in the written materials, with feedback provided that the passion and energy to drive improvements in palliative care provision within the hospital setting, as a result of this study, were not evident within the paperwork presented. They suggested ensuring that all written study information be very patient and family centred and to remain focused on the reasons for undertaking this research. Suggestions also included clearly articulating how the research provides important insights into what is most important to patients with palliative care needs, and their families, to enable optimal care and how to measure this, and why the team is so passionate about answering these questions. The consumers cautioned against using too much jargonistic language, such as ‘system level improvements’ and to avoid dry, policy language. They encouraged the development of a lay research summary, which has been crafted and refined based on their subsequent feedback.

*4. Support strategies for participants;*

Initial support strategies articulated within our study protocol included linking the patient and/or their family member back to their local general practitioner for support as required. However, the consumer advice was to also list the supports that their specialist teams could provide, given the patients we would be talking with are likely to have complex illnesses and be known to at least one specialist clinical team. Consumers felt such people often had closer ties with their specialist treating teams at this time than their general practitioners. This was useful feedback and easily integrated into the study protocol and the patient information sheet.

The Human Research Ethics Committee reviewed the research protocol detailing the proposed screening, recruitment, consent and participation strategies in relation to the identified vulnerable population, being those with palliative care needs and their families, in October 2018. This ethics submission was accepted without changes, despite the vulnerability of the population and sensitivity of topics to be explored in interviews, and screening and recruitment for this study is now underway. The language changes made at the suggestion of consumers, have resonated well with screening clinicians who noted that without such changes, their ability to recruit effectively would have been significantly impacted. Furthermore, our initial ideas of recruiting via databases and providing paperwork naming advanced illness and palliative care needs has been noted by screening clinicians as an approach they would have been unhappy to be involved with, as so many of their patients have varied perspectives on their illness, prognosis and the meaning of palliative care. Therefore, the consumer perspectives resonated with the perspectives of clinicians working closely with patients with palliative care needs, and their families.

## Discussion

This case study outlines how one research team worked with consumer representatives to co-design a research protocol focused on palliative care. There is substantial literature outlining the value of integrating the consumer perspective into research design and implementation centering around impacts on quality (Brett et al., 2014; Daveson et al., 2015; Scholz et al., 2019; Woolf et al., 2016), appropriateness (Brett et al., 2014; Canadian Institutes of Health Research, 2011; Cancer Australia and Cancer Voices Australia, 2011; Scholz et al., 2019), relevance (Daveson et al., 2015; National Health and Medical Research Council, 2016; Scholz et al., 2019; Woolf et al., 2016), impact (Canadian Institutes of Health Research, 2011; National Health and Medical Research Council, 2016; Scholz et al., 2019; Woolf et al., 2016), improved outcomes and experiences for patients and families (Cancer Australia and Cancer Voices Australia, 2011; National Health and Medical Research Council, 2016), ethical respect for vulnerable populations (Woolf et al., 2016) and developing a research active nation (Daveson et al., 2015; National Health and Medical Research Council, 2016). However, barriers to such participation have also been noted, including a lack of clarity about the purpose and role of a consumer representative (Ball et al., 2019; Nathan, Johnston, & Braithwaite, 2011; National Health and Medical Research Council, 2016), inadequate preparation for consumer representatives (Ball et al., 2019; Consumer Health Forum of Australia, 2015 ; National Health and Medical Research Council, 2016; Woolf et al., 2016), tokenism (Ball et al., 2019; National Health and Medical Research Council, 2016), and tension in relation to the balance between lay and clinical perspectives (Ball et al., 2019; Beckett, Farr, Kothari, Wye, & le May, 2018; Martin & Finn, 2011; National Health and Medical Research Council, 2016; Scholz et al., 2019).Planning participation and role definition carefully and in view of each unique study’s requirements is essential to enable such barriers to be overcome (Ball et al., 2019; Cancer Australia and Cancer Voices Australia, 2011; National Health and Medical Research Council, 2016). This case study addressed such concerns through: collaborating to co-design a research protocol with clarity about the purpose for consumer engagement focusing on participant experience within the research, rather than research methodology *per se*; carefully considering how to value the consumer voice; ensuring adequate preparation for meaningful consumer engagement through sending draft documentation for review prior to meetings; ensuring openness to feedback even when a difference between lay and clinical perspectives was noted and felt challenging. This process was time consuming and required work; however, the outcomes of a feasible and acceptable screening and recruitment strategy for a vulnerable population (being those with palliative care needs) were well worth the invested time and energy. Discussions with screening clinicians continue to underscore the importance of the change in our early thinking in relation to language and planned approaches to access our defined population; that was fully precipitated by consumer co-design. Although some of the feedback provided at the commencement of the protocol co-design was difficult to hear and accommodate, the principals of committing to meaningful consumer engagement and prioritising their feedback in relation to the pre-designed feedback questions enabled successful discussions, consensus building and eventual protocol finalisation.

Significant progress in relation to meaningful engagement with consumer representatives within research design, conduct and reporting has occurred over the past decade (Ball et al., 2019; Woolf et al., 2016), with some of this progress credited to the work led by the Patient-Centered Outcomes Research Institute (PCORI) (Frank, Basch, & Selby, 2014; Selby, Forsythe, & Sox, 2015). PCORI is a non-governmental organisation, established in 2010 in the United States, with a noted mandate to '*improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed* *health decisions' (Patient-Centered Outcomes Research Institute, 2017)* and they do so in a variety of ways, one being to ensure engagement of patients and family members across all stages of the research cycle. However, the need to continue to look at each unique study and how co-design can enhance question generation, protocol design, implementation and dissemination is vital, with some areas of research perhaps benefitting more than others (Oliver et al., 2019). Consumer participation is widely recognised as important within cancer services and cancer research (Cancer Australia and Cancer Voices Australia, 2011); however, the progression of this within palliative care remains emerging (Bloomer et al., 2018) and therefore careful consideration about how to achieve this is important. This case study provides evidence of one such approach which worked well for this particular study. Like so many areas of healthcare, a personalised approach to meaningful consumer participation is essential to ensure this work can reach its potential (Oliver et al., 2019). This can be challenging and requires significant effort; however, when successfully achieved, it can vitalise work, enhance its relevance and increase its application into practice (Woolf et al., 2016).

## Strengths and limitations

The strength of this work lies within the clear establishment of aims for consumer participation, informed by the predesigned research questions. This enabled clarity about the purpose of the consumer role which helped the team to provide the consumers with the necessary content to make an informed contribution. This step, in turn helped to focus the consumer panel discussion to optimise the consumers input in a timely way. Furthermore, the upfront clarification of consumer role enabled the research team to privilege the consumer's feedback in relation to the set research questions and this informed discussions and consequently outcomes. The limitation of the approach taken was that the team did not seek consumer feedback about the engagement process and actual experience of contributing to co-designing the research protocol. Although all consumer representatives appeared to interact comfortably and consensus on the preferred wording and framing of the research protocol was achieved, it would have been useful to have sought consumer feedback about the processes used and outcomes gained.

Recommendations for future research

This short report highlights the importance and value of meaningful consumer engagement at all stages of the research process, from the initial idea, through to the development of the concept through to implementation into practice. However, this report demonstrates the importance of clearly articulating the consumer representative’s role and for this role to be understood by both the consumers and the research team. This short report describes one method for establishing research questions specifically for the consumer roles focused on appropriateness of the study question through to accessibility and experience for potential participants within the proposed study. It would be helpful to research such approaches more systematically through establishing mechanisms for consumer feedback in relation to approach taken and ability for meaningful engagement for all involved.**Conclusion**

Significant policy work outlines the importance of engaging with consumers throughout the development and implementation of research. Preferencing consumer data and engaging meaningfully with consumer representatives has enabled this case study to remain focused on that which is of most importance to people with palliative care needs, and their families. Co-designing a research protocol with consumers focused on palliative care enabled the outcome to be feasible for implementation within a clinical setting, without any modifications required. Ensuring relevance and consumer-centredness for the expanding palliative care evidence base is essential and can only be achieved through meaningful partnerships with consumer representatives.

## Acknowledgments

We would like to acknowledge the support provided by the (title blocked for anonymity) Consumer Advisory Group and the consumer advisors within the (title blocked for anonymity). This research is supported by an Australian Government Research Training Program Scholarship. This scholarship had no involvement in research design, conduct, manuscript preparation or choice of journal for submission.

## Author contributions

All authors (XXXX blocked for anonymity) contributed to manuscript preparation, editing and finalisation. The initial research design was developed by XXXX (blocked for anonymity). The co-design process outlined involved all authors, as did related consensus discussions.

## References

Abernethy, A. P., Shelby-James, T., Fazekas, B. S., Woods, D., & Currow, D. C. (2005). The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliative Care, 4*(1), 7. doi:10.1186/1472-684x-4-7

Andrew, S., & Halcomb, E. J. (Eds.). (2009). *Mixed Methods Research for Nursing and the Health Sciences*. West Sussex, United Kingdom: Blackwell Publishing Ltd.

Aoun, S., Slatyer, S., Deas, K., & Nekolaichuk, C. (2017). Family caregiver participation in palliative care research: challenging the myth. *Journal of Pain and Symptom Management, 53*(5), 851-861.

Ball, S., Amelia Harshfield, Asha Carpenter, Adam Bertscher, & Sonja Marjanovic. (2019). *Patient and public involvement in research: Enabling meaningful contributions.* Retrieved from Santa Monica, CA. https://www.rand.org/pubs/research_reports/RR2678.html.: https://www.rand.org/pubs/research_reports/RR2678.html.

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The qualitative report, 13*(4), 544-559.

Beckett, K., Farr, M., Kothari, A., Wye, L., & le May, A. (2018). Embracing complexity and uncertainty to create impact: exploring the processes and transformative potential of co-produced research through development of a social impact model. *Health Research Policy and Systems, 16*(1), 118. doi:10.1186/s12961-018-0375-0

Bloomer, M. J., Hutchinson, A. M., Brooks, L., & Botti, M. (2018). Dying persons' perspectives on, or experiences of, participating in research: An integrative review. *Palliative Medicine, 32*(4), 851-860. doi:10.1177/0269216317744503

Bradburn, J., & Maher, J. (2005). User and carer participation in research in palliative care. In: Sage Publications Sage CA: Thousand Oaks, CA.

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations, 17*(5), 637-650.

Canadian Institutes of Health Research. (2011). *Canada's Strategy for Patient-Oriented Research. Improving health outcomes through evidence-informed care* Retrieved from Canada: http://www.cihr-irsc.gc.ca/e/45850.html:

Cancer Australia and Cancer Voices Australia. (2011). *National Framework for Consumer Involvement in Cancer Control*. Retrieved from Cancer Australia, Canberra, ACT.:

Consumer Health Forum of Australia. (2015 ). *"Unique and essential": A review of the role of consumer representatives in health decision-making Deakin ACT: Consumer Health Forum of Australia*. Retrieved from Available from: https://chf.org.au/sites/default/files/role-of-reps-health-decision-making-2015.pdf

Daveson, B. A., de Wolf-Linder, S., Witt, J., Newson, K., Morris, C., Higginson, I. J., & Evans, C. J. (2015). Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative Medicine, 29*(10), 939-949.

Frank, L., Basch, E., & Selby, J. V. (2014). The PCORI perspective on patient-centered outcomes research. *Jama, 312*(15), 1513-1514.

Goodyear-Smith, F., Jackson, C., & Greenhalgh, T. (2015). Co-design and implementation research: challenges and solutions for ethics committees. *BMC medical ethics, 16*(1), 78.

Harrop, E., Noble, S., Edwards, M., Sivell, S., Moore, B., & Nelson, A. (2016). "I didn't really understand it, I just thought it'd help": exploring the motivations, understandings and experiences of patients with advanced lung cancer participating in a non-placebo clinical IMP trial. *Trials, 17*(1), 329.

Hubbard, G., Kidd, L., Donaghy, E., McDonald, C., & Kearney, N. (2007). A review of literature about involving people affected by cancer in research, policy and planning and practice. *Patient Education and Counseling, 65*(1), 21-33.

Martin, G. P., & Finn, R. (2011). Patients as team members: opportunities, challenges and paradoxes of including patients in multi-professional healthcare teams. *Sociology of Health & Illness, 33*(7), 1050-1065.

Nathan, S., Johnston, L., & Braithwaite, J. (2011). The role of community representatives on health service committees: staff expectations vs. reality. *Health Expectations, 14*(3), 272-284.

National Health and Medical Research Council. (2016). Statement on consumer and community involvement in health and medical research. In: Australian Government Canberra.

NHS Health Research Authority, Health and Care Research Wales, & NHS Research Scotland. (2017). *UK policy framework for health and social care research*. Retrieved from NHS Research Authority website: https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/:

Oliver, K., Kothari, A., & Mays, N. (2019). The dark side of coproduction: do the costs outweigh the benefits for health research? *Health Research Policy and Systems, 17*(1), 33.

Patient-Centered Outcomes Research Institute. (2017). Retrieved from https://www.pcori.org

Pessin, H., Galietta, M., Nelson, C. J., Brescia, R., Rosenfeld, B., & Breitbart, W. (2008). Burden and benefit of psychosocial research at the end of life. *Journal of Palliative Medicine, 11*(4), 627-632.

Scholz, B., Bevan, A., Georgousopoulou, E., Collier, A., & Mitchell, I. (2019). Consumer and carer leadership in palliative care academia and practice: A systematic review with narrative synthesis. *Palliative Medicine*, 0269216319854012.

Selby, J. V., Forsythe, L., & Sox, H. C. (2015). Stakeholder-driven comparative effectiveness research: an update from PCORI. *Jama, 314*(21), 2235-2236.

Terry, W., Olson, L., Ravenscroft, P., Wilss, L., & Boulton-Lewis, G. (2006). Hospice patients' views on research in palliative care. *Internal Medicine Journal, 36*(7), 406-413.

The National Institute for Health and Care Excellence. (2014). *Patient and public involvement policy*. Retrieved from London, United Kingdom:

The University of Edinburgh. SPICT. Retrieved from https://www.spict.org.uk/

White, C., & Hardy, J. (2010). What do palliative care patients and their relatives think about research in palliative care?—a systematic review. *Supportive Care in Cancer, 18*(8), 905-911.

Woolf, S. H., Zimmerman, E., Haley, A., & Krist, A. H. (2016). Authentic engagement of patients and communities can transform research, practice, and policy. *Health affairs, 35*(4), 590-594.

Yin, R. (2003). Case Study Research: design and methods, Thousand Oaks, 3. In: Aufl.