

# Post Workshop - Helpful Resources

## PPI Within the Context of Palliative Care Research

AIHPC Online Workshop 31 March 2022

On the island of Ireland PPI refers to Personal and Public Involvement or Public and Patient Involvement in research. PPI in palliative care research actively supports and facilitates people with life-limiting conditions, their families, carers, and members of the public with an interest in palliative and end of life care to be involved in all stages of palliative care research.

In March 2022, AIHPC delivered an online workshop to support Palliative Care Research Network and Early Career Researcher Forum members to build capacity within PPI. **This post-workshop document highlights recommended reading, resources and tips shared by speakers, panel members and attendees at this event.**

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## Top Tips

To support people's involvement in palliative care research consider the following:

### Challenges facing people's involvement and potential barriers:

- People with life-limiting conditions may be experiencing pain, fatigue, and other symptoms related to their condition. They may also have difficulty with their mobility, ability to communicate or to understand due to cognitive impairment. Such needs can cause a barrier to participation if not considered and catered for.
- People may have caring responsibilities, as well as family and/or work commitments. Availability of time and the importance of their time must be considered, and activities designed to meet their needs.
- People commuting from rural areas, long distance or any distance may pose a challenge for their involvement. Consider geographical location and ways of catering to individual's needs.
- People who experience time lags on reclaiming expenses attached to attending PPI events can cause a barrier for their participation, particularly if due to illness and/or caring commitments household income has been impacted.
- People who are bereaved family members/former carers can have their emotions triggered due to their involvement and sensitivity is needed. Consider whether people who are recently bereaved (within at least 6 months) should be involved.
- People can feel that their contributions may not be valuable or valued and this can deter engagement. Consider ways to reassure people that their contributions are welcomed and valued.

**Budget:** Ringfence a dedicated budget for PPI. To plan for and achieve inclusivity, when budgeting for PPI consider the needs of different people with varying mobility, communication and cognitive needs and the supports you may need to put in place to facilitate everyone's engagement in PPI activities.

**Time:** Ensure there is dedicated time for PPI. Building relationships with your PPI contributors is essential. Ideally have a dedicated PPI coordinator who will collaborate with PPI contributors consistently throughout the research, at PPI events, and outside of those events. At the beginning of your research allocate time for listening which will allow you to get to know individual contributors, their individual needs, stories and experiences. The time you need to set aside for listening to your contributors inside and outside of PPI events cannot be underestimated.

It is important to be transparent with people about how much of their time will be required to be involved in the research project (Johnson et al. 2021). Also, remember PPI contributors are volunteers and some may enjoy the social aspect of group participation. Ensure you allocate time within PPI activities that will allow those who want to the opportunity to get to know other members of the PPI panel. It is recommended when planning PPI activities whatever amount of time you have built into your plans to add more to the schedule, to ensure you have enough time, particularly if any person has communication or cognitive impairments (McMenamin et al. 2021).

### Preparing for PPI activities:

- Offer flexibility for participation (Johnson et al. 2021). For example, if a person is not available to attend a group event, whether online or face-to-face, offer them the opportunity to comment on a post event document or make contributions in advance of the group event.
- Consider individuals training needs. For example, do members of your PPI panel need support around digital literacy, do they understand common research terms, or should a glossary be provided and/or explained? To participate in specific research activities capacity building may be required.
- Consider the needs of individuals when planning face-to-face events, the proximity of public transport to venues, parking proximity at venues and accessibility within a venue.

- Consider the language you use carefully, the pace at which activities are moving and ensure you have supports in place if emotions are triggered. It is recommended a minimum of two facilitators attend PPI activities. If a person needs to step out for a moment this will allow one of the facilitators to step out with them for support. At face-to-face events identify a quiet space you can go to within the venue if needed (Shé et al. 2021).
- Remember to always communicate to people they can withdraw at any time.

**Making the value of PPI contributors input clear:** Feedback to people about how they impacted the research project through their contributions. Examples of doing this include communicating what insights the research team gained from a PPI event, providing a post event document which captures PPI contributors' perspectives on the topic of discussion and by communicating how the research is going to move forward based on contributions.

## Recommended Reading

Johnson H, Ogden M, Brighton LJ, et al. **Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation.** *Palliative Medicine*. 2021;35(1):151-160. doi:[10.1177/0269216320956819](https://doi.org/10.1177/0269216320956819) [accessed 14 April 2022]

McMenamin, R., Griffin, M., Grzybowska, B., & Pound, C. (2021). **Working together: experiences of people with aphasia as co-researchers in participatory health research studies.** *Aphasiology*, 1-22. [doi.org/10.1080/02687038.2021.1923948](https://doi.org/10.1080/02687038.2021.1923948) [accessed 14 April 2022]

Shé, É.N., Gordan, A., Hughes, B. et al. **"Could you give us an idea on what we are all doing here?" the Patient Voice in Cancer Research (PVCr) starting the journey of involvement in Ireland.** *Res Involv Engagem* 7, 63 (2021). [doi.org/10.1186/s40900-021-00301-1](https://doi.org/10.1186/s40900-021-00301-1) [accessed 14 April 2022]

Murphy E, Tierney E, Ní Shé É et al. COVID-19: **Public and patient involvement, now more than ever** [version 1; peer review: 2 approved]. *HRB Open Res* 2020, 3:35 [doi.org/10.12688/hrbopenres.13067.1](https://doi.org/10.12688/hrbopenres.13067.1) [accessed 14 April 2022]

Brighton, L.J., Pask, S., Benalia, H. et al. **Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research.** *Res Involv Engagem* 4, 14 (2018). [doi.org/10.1186/s40900-018-0097-z](https://doi.org/10.1186/s40900-018-0097-z) [accessed 14 April 2022]

Seddon, K., Elliott, J., Johnson, M. et al. **Using the United Kingdom standards for public involvement to evaluate the impact of public involvement in a multinational clinical study.** *Res Involv Engagem* 7, 22 (2021). <https://doi.org/10.1186/s40900-021-00264-3> [accessed 25 April 2022]

Reynolds, J., Ogden, M. & Beresford, R. **Conceptualising and constructing 'diversity' through experiences of public and patient involvement in health research.** *Res Involv Engagem* 7, 53 (2021). [doi.org/10.1186/s40900-021-00296-9](https://doi.org/10.1186/s40900-021-00296-9) [accessed 14 April 2022]

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. **GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research.** *BMJ* 2017; 358:j3453 [doi.org/10.1136/bmj.j3453](https://doi.org/10.1136/bmj.j3453) [accessed 14 April 2022]

Ogden, M. **"Reflections from a Public Patient Involvement member on being part of an out-of-hours community palliative care research study."** *EAPC Blog*, 2 February 2022 [accessed 14 April 2022]

Foley G. **Video-based online interviews for palliative care research: A new normal in COVID-19?** *Palliative Medicine*. 2021;35(3):625-626. doi: [10.1177/0269216321989571](https://doi.org/10.1177/0269216321989571) [accessed 14 April 2022]

## Useful Resources

- [PPI in Palliative Care Research](#), The Palliative Hub – Professional/Research Zone
- [eLearning: 'What is Public and Patient Involvement \(PPI\)?'](#), Trinity College Dublin (TCD) PPI Ignite Introductory Module
- [Making a start: A toolkit for research charities to being a PPI relationship](#), Health Research Charities Ireland and TCD
- [UK Standards for Public Involvement](#), Supported by the UK Public Involvement Standards Development Partnership
- [Guidance for Researchers: Feedback from Researchers to PPI Contributors](#), Centre for Research in Public Health and Community Care (CRIPACC), University of Hertfordshire
- [PPI Spectrum of Involvement](#), IHRF
- [PPI Ignite Network](#)
- [Voices4Care](#), AIIHPC
- [Age-positive free image library](#), The Centre for Ageing Better
- [Engaging with disabled people: An event planning guide](#), (2018) Equality and Human Rights Commission UK
- Disability support services in individual universities can offer advice and guidance.
- [PPI in Research Support Small Grant Scheme](#), HSCR&D PHA Northern Ireland
- [Research Ethics Service and Research Ethics Committees](#), Health Research Authority, UK
- [National Office for Research Ethics Committees](#), ROI