

## Notes from the Editor (*Journal of Palliative Medicine*)

### **Title: Opportunities and challenges in patient and public involvement and engagement (PPI) in palliative care research**

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### **Background**

The findings of a recent review suggested that the evidence for PPI (increasingly including an ‘engagement’ component as PPIE) in palliative care research lacked rigour, was primarily concerned with cancer, and has not increased in numbers of publications over time<sup>1</sup>. Should this be something we – as palliative care researchers and practitioners – need to address?

Patient and public involvement in general research and health services in the United Kingdom is well established and has foundations in public involvement in hospital and health care governance over past decades. In Europe, PPI has been described as unevenly implemented with well-developed practice in some Northern European settings but less so elsewhere. PPI has been shown to contribute to all aspects of the research pathway including setting the research agenda, assisting with research design, and involvement in analytic and dissemination processes, among others<sup>2</sup>. However, involving those facing progressive illness and approaching the end-of-life as active research collaborators has been described as potentially problematic. Whilst this may be the case, our local experience suggests that well conducted PPI can have positive outcomes, and that engaging patients and the public helps ensure that research priorities align with the real-life needs and concerns of those receiving palliative care. In this short piece, we reflect on the benefits and challenges of PPI in palliative care research and why we consider it a valuable asset in our research practice.

### **What progress has occurred and what might the barriers be?**

PPI in general research terms was highlighted as a policy priority in the UK with the establishment of the National Institute for Health Research (NIHR) in 2006. The NIHR are a major funder of health and social care research training and have close collaboration with patients and the public as a core guiding principle<sup>3</sup>. They require all research grant applications to demonstrate how PPI will be addressed, and other funders of research have followed suit<sup>4</sup>. These requirements have led to the increased development of PPI in many areas of health and social care and internationally<sup>1,9</sup>. European Commission funded programmes such as Horizon 2020 also prioritise and encourage ‘citizen engagement’ in research and innovation as exemplified in the [EU Mission on Cancer](#), a major strategic research and policy initiative across the European Union. But what of palliative and end of life care research specifically?

As noted above, there is some suggestion that there has not been much progress in PPI in palliative care research. If this is indeed the case, what might be creating the block? We know that people with palliative care needs and those close to them may be considered ‘vulnerable’ both as participants in research studies and as PPI partners. It is also recognised that involving people who may be experiencing disabling illness can be challenging and time-consuming, requiring considerable infra-structure and resource commitment from both researchers and PPI collaborators<sup>6</sup>. Paternalism and the negative aspects of gatekeeping in palliative care research participation have been well documented and commented on with a recent review concluding that greater – not less – dialogue with patients themselves was required to begin to overcome these obstacles<sup>7,8</sup>.

For patients and carers who may be invited to participate as PPI partners in palliative care research projects, barriers may also include frailty and intermittent or serious illness, tiredness, or a reluctance to talk about sensitive issues around dying and death. There may also be unease about creating additional burden at a critical life point or conflicting demands on a person's time, sparking a need for ethical considerations to be taken into account. In addition, researchers may lack skills in PPI or manifest beliefs about the ability of lay people to understand 'complex' research processes and associated jargon. Barriers to PPI can also be viewed in structural terms where no clear mechanisms and resources for PPI are in place, including recompense for the time of those participating. Research grant applications frequently fail and timeframes from inception to completion of projects may prevent those with serious progressive illness being realistically able to commit to the process.

Other barriers to greater PPI involvement in palliative care research include the nature of power and tokenism, alongside considerations of diversity and 'representation' in research collaborations. PPI partners may feel marginalised or disempowered if their contributions are undervalued or overshadowed by the expertise of researchers or healthcare professionals. Striking a balance between expertise and experiential knowledge is essential to avoid tokenistic approaches and foster genuine collaboration, but this may be difficult to achieve. Additionally, achieving meaningful representation of diverse patient populations can prove difficult in palliative care research and in PPI terms. Patients from marginalised or underrepresented groups may face barriers to participation, such as language difficulties, cultural differences, or socioeconomic constraints. Consequently, there is a risk of inadvertently excluding voices that reflect unique experiences and perspectives whilst privileging those without these limitations.

While patient and public involvement is applauded for its potential to enhance research relevance and quality, its impact on research outputs and inherent value remains a subject of debate. Some have argued for a more critical approach in which the positive aspects of PPI are presented as a given with little or no exposition of less desirable outcomes. Russell and colleagues in their conceptual review of the effect of a focus on measurement in PPI outcomes, question the value and outline the ‘skewing’ effect of what they describe as the institutionalisation of the field represented in the UK standards for PPI developed by the National Institute for Health Research. They argue for further research which examines the possible negative aspects of PPI and the ways this might increase inequalities by suppressing some voices while strengthening others<sup>10</sup>.

### **Why is PPI in palliative care research important and what are the benefits?**

Despite the challenges outlined above, we believe there is benefit to be gained in working in partnership with service users in our palliative care research projects. Indeed, we have no choice if we are to be successful in designing and obtaining significant funding for our work. PPI is embedded in UK health research policy and requires that we find ways of ameliorating the challenges and maximising the added value to our research efforts. Achieving this goal means engaging with our PPI partners in a way that moves beyond asking an opinion on a participant information sheet or recruitment flyer. We need to actively addressing the challenges to involvement throughout the research process from the topics and research questions we initially pose to disseminating research findings and all stages in between.

In attempting to counter what they describe as ‘marked inequalities’ in palliative care, Mitchell and her colleagues developed a framework specifically designed to enhance

diversity and inclusivity in palliative care research<sup>11</sup>. Such an approach can be seen to counter the critique of PPI that it fails to address representation and diversity concerns and can also begin to expose and illuminate inherent power differentials between research professionals and PPI partners. This points, conversely, to one of the stated benefits of PPI in health care research in that it can empower patients and caregivers to become active contributors rather than passive recipients of care and research participation. Moreover, engaging the public in research promotes awareness and advocacy for improved palliative care services, potentially driving positive change within healthcare systems and policy development more generally.

PPI can enhance methodological rigour by enabling diverse perspectives and promoting collaborative approaches in co-design and co-production. These may aid the development of research methodologies that are culturally sensitive, inclusive, and reflective of the complexities of palliative care contexts so supporting their relevance across diverse patient populations. In particular, this is pertinent to palliative care research in non-resource rich global contexts where research approaches and practice which are long established in the ‘developed’ world may have little traction elsewhere.

Linked to this is the notion that PPI in palliative care research aligns with the ethical imperatives of respect for autonomy, beneficence, and justice which can be viewed through a global as well as a local lens. Engaging service users in all aspects of research from the initial topic and research questions through dissemination and implementation enables the palliative care research community to uphold principles of inclusivity and transparency which fosters trust and mutual respect. By involving those with lived experiences, researchers can gain insight into the complexities of palliative care beyond clinical parameters or received wisdom. This facilitates the development of patient-centred interventions and services that

better address the holistic needs and preferences of service users promoting dignity, autonomy, and quality of life.

## **Conclusion**

The involvement of patients and the public in palliative care research offers many benefits, including patient-led research agenda and questions, potential empowerment, opportunities for methodological diversity, and ethical integrity. However, this collaborative undertaking is not without its challenges. Issues of representation, power imbalances, ethical considerations, and impact on research outputs are complex factors that need to be considered when seriously engaging in PPI partnerships. Dealing with these challenges requires a commitment to inclusive and transparent research practices that prioritise the voices, experiences, and well-being of our public partners. The [RE-EQUIPP project](#) in the UK which examined the integration of primary and palliative care services had PPI at its centre producing a ‘recipe book’ of recommendations aimed at researchers and public partners. We invite readers to examine their current practice in relation to PPI and seek innovative and creative ways of entering genuine and democratic partnerships with service users and the public appropriate to your particular socio-cultural contexts. Successful palliative care research collaborations have the potential to advance knowledge, improve service delivery, and promote dignity and quality of life for those with life limiting illness.

**[1599 words]**

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