

Thoughts on reporting public and patient engagement and involvement in research in the Journal of Advanced Nursing (Editorial)

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TITLE PAGE

- **Short informative title**

Thoughts on reporting Public and Patient Engagement and Involvement in Research in the Journal of Advanced Nursing

- **Short running title**

Reporting Public and Patient Engagement

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- **Conflicts of interest**

None to declare.

Thoughts on reporting Public and Patient Engagement and Involvement in Research in the Journal of Advanced Nursing

Historically, patient stakeholders (patients, families and caregivers) have been the subject of research, mere datapoints in the research enterprise. Researchers used participants' data and rarely considered other contributions they could offer. Over the last 15 years, this perspective has changed, as researchers and funding agencies now acknowledge that patients and the public have capacity to design, implement, and share relevant and meaningful research (Manafa et al., 2018). This fundamental paradigm shift from paternalism, towards democratic partnership, provides a new and exciting opportunity for patients and the public where they work alongside researchers as team members.

Ultimately, involving patients and the public throughout the lifecycle of research is simply seen as the 'right thing to do' as research must be relevant to the lives of the people affected by its outcomes. Patients and the public can impact patient-and family-centred care principles by mobilizing and legitimizing the experiential knowledge of patients and ensuring research focuses on patient concerns (Manafa et al., 2018). Public and Patient Engagement and Involvement in Research (PPEI) overlaps with the Triple Aim mandate of healthcare by addressing more effective care, a better patient experience, and improved per capita costs. Accordingly, ethical review boards and funding organisations increasingly require researchers to actively involve patients and the public in their research.

Recently, the Journal of Advanced Nursing (JAN) made PPEI a requirement for reporting. This includes: a paragraph at the end of the abstract titled "Patient or Public Contribution" containing details of how patients, service users, care-givers or members of the public were involved in your study; or a paragraph at the end of the abstract titled "No Patient or Public Contribution", if these details are not necessary or do not apply to the work, with a statement of why. This timely initiative increases awareness of this orientation towards research.

In 2014, the BMJ introduced PPEI reporting mandates. In response, there was a 10-fold increase in the proportion of papers reporting PPEI (Price et al., 2018). However, it should be noted that only a small proportion (n=16 out of 125 articles; 11%) included PPEI activity; substantial variation in the clarity of reporting was observed (Price et al., 2018). Thus, PPEI reporting guidelines are not the magic bullet; there are deeper issues with uptake and structured reporting of PPEI practices. However, JAN's new reporting guideline is a critical step towards making PPEI more widespread and transparent through emphasising the importance of integrating meaningful PPEI into the dissemination phase.

JAN's new guidelines support that there is no one-fit-all approach to PPEI; it can occur at different levels. At lower levels patients are 'consulted', where they provide advice and feedback on specific research activities, which may or may not be, incorporated. PPEI at this level is common. For example, in a study of 200 projects conducted in primary care, about half had evidence of patients reviewing patient information leaflets (i.e. 'consulted') (Blackburn et al., 2018). Greater opportunities exist for patients and the public to build alliances and move beyond this level of engagement. At higher levels of engagement

patients and the public are co-researchers and ‘collaborate’ whereby they are on equal footing with researchers on all aspects of the project, actively contributing to decisions about research design, acceptability, relevance, conduct and governance from study conception to dissemination (Hoddinott et al., 2019). Occasionally, patients lead or do the research (Hoddinott et al., 2019). Participation at this level is rarer; in a study of PCORI projects, patients were collaborators on 53% of project, or co-leaders on 6% of projects (Forsythe et al., 2016). There is no right level of PPEI, and each author is encouraged to reflect on and plan for appropriate levels of PPEI for their study.

By the same token, authors may report that PPEI did not occur at all. Having no PPEI should never result in immediate rejection from a journal; as this may perpetuate tokenistic PPEI practices by researchers who try to ‘tick a box’ to meet journal guidelines. Instead, PPEI reporting guidelines should encourage a research culture of reporting meaningful PPEI at a level appropriate for each study. It is important to plan PPEI early, well before the dissemination phase. This helps to guarantee that PPEI is genuine, has been a part of the project's development from the beginning, and is not just an addition after all the decisions have been made.

There are other considerations that could enhance reporting of PPEI. GRIPP2 is an evidence-based reporting checklist that lists PPEI concepts that should be reported to enhance the quality and transparency of PPEI (Staniszewska et al., 2017). The GRIPP2 is not only useful for retrospective reporting but can be used at the outset of the study to plan PPEI in the study. Ultimately, by using GRIPP2 to share lessons learnt (i.e. what worked well and what did not work well), we can bridge gaps and enhance understanding, allowing other researchers to understand how to do PPEI (Staniszewska et al., 2017). Further, by improving PPEI reporting, we can improve synthesis of PPEI in systemic reviews and the evidence based for this approach (Staniszewska et al., 2017).

JAN’s new guideline also raises another important reporting consideration: acknowledging patient and public contribution when they author or co-author publications. The BMJ instructs authors to thank patients and the public involved in the acknowledgement sections. However, patient authorship is expected to increase because patients, the public and funders support this practice. Oliver et al. (2022) suggest that for authorship patients should meet the following criteria: “A person who lives with or is affected by a disease or condition (i.e. a broad definition of patient that includes those with lived conditions or receiving health or social care, caregivers, family members and members of patient advocacy groups who represent them); A person who provides unique and valuable input from the patient perspective to the publication; A person who meets all the criteria required for authorship (e.g. criteria from the International Committee of Medical Journal Editors [ICMJE])” (Oliver et al., 2022, pp.2). This highlights the importance of authorship conversations early in partnerships; patients and the public should be informed of ICMJE conditions and what this means for their involvement. Most Editors-in-Chief (69.2% ($N = 74$)) support patients being co-authors on publications (Cobey et al., 2021). However, they hold mixed views about whether ICMJE criteria should be revised to more inclusive of patient co-authors (Cobey et al., 2021).

As this practice increases, the field may benefit from a way to track and report this practice. A research group suggests that using the term “Patient Author” in the patient author affiliations would facilitate PubMed searching to easily identify patient author and co-author practices (Oliver et al., 2022). These researchers report that using the term “Patient Author” in affiliations has increased 9-fold (Oliver et al., 2022) and there are calls for this requirement to be added to the GRIPP2 checklist (Jones et al., 2021).

We are pleased JAN is proactive in taking a meaningful approach to PPEI. Such an approach builds on JAN’s other initiatives such as involving community members in the peer review process when submissions are received about minoritized groups (Jackson & Moorley, 2022). JAN provides a service that includes a range of voices/perspectives and the new reporting guidelines ensures JAN’s published discourse reflects its position on PPEI. Researchers are encouraged to reflect on what meaningful PPEI looks like in their study; research projects have a range of methodologies and the activities in which patients engage (i.e. reviewing materials, collecting data, disseminating findings), the phases of the research they engage in (i.e. active, start-up and close-out phase), and their level of engagement (i.e. consulted, collaborators, or co-leaders), will differ. The JAN PPEI reporting guidelines are a pertinent shift in the cultural expectations around reporting, that we hope will change the visible presence of patients and the public in the generation of disciplinary knowledge.

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