

Enhancing Patient and Public Involvement and Engagement in Cancer Research: The Inclusive Prehabilitation Study

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Abstract

Background

Patient and Public Involvement and Engagement (PPIE) is essential to ensure research is relevant to stakeholders (NIHR 2024). Numerous standards and tools to record PPIE activities exist. However, few nursing researchers publicly report their PPIE activities (Price et al. 2018). Here we outline the approach of the NIHR-funded, Inclusive Prehabilitation (I-Prehab) study, to enhance PPIE activities throughout and ensure meaningful contributions from diverse communities.

Methods

PPIE was integral from initial protocol development and funding application. Led by a multidisciplinary team including nurses, PPIE is crucial to the co-production stage of I-Prehab education, which involves reaching diverse groups. Activities are logged using the Public Involvement in Research Impact Toolkit (PIRIT), which records public contribution and impact in relation to PPIE standards (Newman et al. 2023).

Results

The I-Prehab study PPIE approach involves online and in-person meetings as follows:

- **PPI Co-applicants (n=3):** Contribute to study design and award, attend monthly meetings, advise on processes and data interpretation.
- **Public Advisory Group (PAG) (n=8):** Meet thrice yearly to advise on processes, support data collection, and co-production.
- **I-Prehab Community (n=25):** Email group invited to ad-hoc opportunities, including reviewing documentation and data interpretation.
- **Co-production:** Involves community representatives to engage diverse groups including cancer support, underprivileged and ethnic communities.

PPIE is enhanced by a coordinator, funded through the research grant, with reimbursement of PPIE contributions in line with PPI standards. The PIRIT tool enables a clear record of PPIE activities and showed each activity related to at least two of the five PPI standards, most commonly 'working together' and 'inclusive opportunities'.

Conclusions

The I-Prehab study includes significant funding for PPIE allowing a multi-tiered approach to enhance PPIE and meet standards. Nurses' understanding of diverse health experiences enables the participation of diverse communities throughout the project, essential for the co-production of inclusive prehabilitation practices.

References

National Institute of Health Research 2024. NIHR Standards for Public Involvement. Available at: <https://www.nihr.ac.uk/> [Accessed 20.01.2025].

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Price, A. et al. 2018. Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study. *BMJ open* 8(3), p. e020452.

Lead presenter biography

Nichola is a Senior Lecturer in Physiotherapy at Cardiff University, undertaking teaching and research. She is currently leading the PPIE of the interdisciplinary inclusive prehabilitation for patients with cancer, funded by the NIHR. She leads research capacity building at Velindre NHS trust and co-leads the Community for Allied Health Professionals Research (CAHPR) Cymru, to strengthen research capacity, capability