

# MOVING FROM CONSULTATION TO PARTNERSHIP: STRATEGIES FOR MEANINGFUL PATIENT AND PUBLIC INVOLVEMENT (PPI) IN RESEARCH

Natalia Duda<sup>1</sup>, Isaiah Gitonga<sup>2</sup>, Siobhán Corrigan<sup>1</sup>, & Rebecca Maguire<sup>2</sup>

<sup>1</sup>*School of Psychology, Trinity College Dublin (Ireland)*

<sup>2</sup>*Department of Psychology, Maynooth University (Ireland)*

## Abstract

**Purpose:** We propose an interactive workshop to explore strategies for embedding patient and public involvement (PPI) throughout the research cycle, with the overarching goal of fostering meaningful collaboration and partnership between academics, practitioners, patients and members of the public. **Background:** Participatory approaches have gained significant recognition as a means of enhancing the quality, relevance and impact of research. While funding agencies and policy makers emphasize the importance of PPI, the practical challenges of involving contributors in research can lead to tokenistic or “box-ticking” practices. PPI partners often play consultative roles in the initial and end phases of projects, with little input in the entire research cycle.

**Key Points:** This workshop introduces the concept of embedded PPI, emphasizing patient and public empowerment through partnership. The session will provide a roadmap for co-creation of knowledge and provide strategies for meaningful involvement. Participants will be invited to explore benefits of and barriers to embedding PPI and will collaboratively identify strategies and skills for initiating and maintaining partnerships with stakeholders.

**Procedure:** The workshop will consist of an in-person presentation and discussion centered around implementing PPI across the research cycle. Participants will engage in a hands-on group activity in which they will identify challenges to and strategies in the context of their own research. Through case studies and scenarios, facilitators will share their experience of participatory research.

**Participants:** This workshop is designed for researchers, educators and students interested in enhancing the real-world impact of their research. 5-20 attendees are recommended for optimal interaction and discussion.

**Keywords:** *Co-design, participatory research, Patient and Public Involvement, partnership, science communication.*

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## 1. Introduction

Patient and Public Involvement (PPI) is increasingly recognized as a crucial element of research in health and healthcare. Defined by INVOLVE as research conducted 'with' or 'by' the public instead of 'to', 'for', or 'about' them (NIHS, 2021), PPI is driven by the recognition that engaging non-academic stakeholders can significantly enhance the quality, relevance, and impact of research (Gilfoyle et al., 2022; Greenhalgh et al., 2019). While still in its formative days as a normalized practice, participatory research recognizes that expertise comes in many forms and seeks to involve members of the community from the very beginning and through to the end of the research process (Chevalier & Buckles, 2019)

## 2. Challenges to embedded PPI

Although PPI is valued by contributors and researchers, its implementation frequently faces difficulties, resulting in superficial or tokenistic practices. Various obstacles, including organizational barriers, cultural differences, and logistical issues impede the successful execution of PPI. Ocloo and colleagues (2021) identified how perceptions of subordinate status among laypeople and uncertainties regarding participation goals act as barriers. Limited resources and institutional cultures that undervalue experiential knowledge further obstruct efforts, while concurrent pressures from funding agencies to incorporate PPI may lead to “box-ticking” practices (Aiyegbusi et al., 2023; Gilfoyle et al., 2022). Further, while inclusivity and equity are central to the ethos of PPI, marginalized populations often remain

underrepresented in initiatives (Dawson et al., 2018). Despite numerous frameworks and rationales proposed (Greenhalgh et al., 2019), there is also a lack of consensus on the best practices for PPI (McCoy et al., 2019). This is compounded by inconsistent reporting of measurable impact (Price et al., 2018).

Tokenism, where involvement in research is more symbolic than substantive, is a significant issue (Ocloo & Matthews, 2016). Despite the growing emphasis by funding bodies and policy makers on the importance of PPI, practical challenges in its implementation often result in superficial or non-involvement of non-academic stakeholders. In many cases, their role is consultative, or limited to endorsing pre-determined research agendas or providing feedback on findings, without meaningful engagement and partnership. This tokenism reflects a 'democratic deficit' in health research, where scientific knowledge is privileged over experiential knowledge (Pearce, 2021). Addressing these issues requires shifting from paternalistic attitudes to equal partnerships and confronting power dynamics and professional resistance (Liabo et al., 2022; Turnhout et al., 2020).

To ensure research is responsive to the needs and perspectives of its intended beneficiaries, it is crucial to involve stakeholders as partners in research. For PPI to be truly effective, it should be embedded into every stage of the research process (Figure 1), from identifying needs and formulating research questions to ensuring cultural sensitivity in methodologies, to collaborative analysis, implementation and dissemination of findings. This approach fosters an environment of continuous dialogue and co-learning, making partnership a cornerstone of meaningful and impactful research.

Figure 1. Embedding PPI in the research cycle.



### 3. Workshop

We will deliver an interactive workshop to explore strategies for embedding PPI throughout the research cycle, with the overarching goal of fostering meaningful collaboration and partnership between academics, practitioners, patients and members of the public. The workshop will draw on the PPI Ignite Network Values and Principles Framework (PPI Ignite Network, 2022) to provide a roadmap for embedded practices.

The objectives are to:

- Review the current practices and challenges of PPI in health research;
- Facilitate discussion and analysis of tokenistic practices in PPI by means of a vignette analysis;
- Develop a plan for partnership by evaluating strategies and skills for embedded PPI.

This workshop is designed to be an engaging blend of theoretical presentations and practical activities focused on embedding PPI in research. Through guided exercises and facilitated discussions, attendees will explore how to integrate PPI effectively into their own research, adapting principles and techniques to their unique contexts and challenges. The workshop is tailored for researchers, educators, and students who are keen on enhancing the real-world impact of their work. The workshop accommodates 5-20 attendees to ensure optimal interaction and discussion.

## 4. Conclusion

Embedding PPI in the research cycle is crucial for creating relevant, inclusive, and impactful research. This approach should not only enhance the quality and applicability of research findings but can also foster equity, diversity and inclusion and deeper stakeholder engagement. Our workshop is expected to significantly shift attendees' perspectives on PPI, equipping them with the knowledge and tools necessary to apply PPI principles in their future work, thereby fostering a more inclusive and engaged approach in research endeavors.

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