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Elevating Patient and Public Involvement and Engagement in Research: Highlighting the publication gap, ensuring the under-served do not become the under-published

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ABSTRACT

Sharing good practice in Patient and Public Involvement and Engagement (PPIE) often only happens at a local level, with insufficient relevant publications reaching wider audiences, despite the progress made by a few journals. Much of this work remains ‘grey literature’ and fails to gain traction in academia. Our editorial aims to highlight this barrier and showcase examples of good practice PPIE, to raise much needed visibility. The under-publication of PPIE activity and its role in successful research perpetuates the lack of consistent funding and trained staff. To advance, PPIE must be recognised and published as a meaningful contributor to research more widely.

Introduction

This editorial aims to highlight the impact of Patient and Public Involvement and Engagement (PPIE) in research and the publication barrier, arguing for greater visibility of PPIE activity, to strengthen research quality. PPIE is increasingly being recognised as an essential component of high-quality health research. Yet, despite its acknowledged value, examples of effective practice infrequently extend beyond local initiatives. Much of this work remains informal and under-published, circulating as 'grey literature' with limited academic reach. In 2012, Brett's[1] scoping review found just 66 studies which included the impact of PPIE and whilst he remarked "the positive impacts identified enhanced the quality and appropriateness of research", he also commented that the evidence base remains weak.

Ocloo[2] shared the barriers and challenges to delivering meaningful PPIE activity, highlighting power imbalances, the lack of inclusion and diversity across research overall as well as structural obstacles. PPIE practitioner colleagues and public contributors, continue to address these issues and attempt to break down these barriers by building trust with communities, contributing appropriate resources and creating institutional commitment to non-tokenistic and productive PPIE. Research is now starting to reap the benefits of PPIE due to these efforts, Park[3] demonstrated that PPIE can meaningfully contribute to evidence synthesis as well as to primary studies. However, there is still a gap between the amount of PPIE activity taking place, versus the amount which is published. Petticrew[4] researched the difference in rates of publication between qualitative research and quantitative research (specifically from conferences) and found they are now published at similar rates, so why is so little PPIE activity published?

Why Publication Matters

Publishing Patient and Public Involvement and Engagement activities is essential for validating the contributions of patients and the public, sharing best practice and informing policy and funding decisions. As Seals[5] highlights, visibility in peer-reviewed literature ensures that effective approaches to engagement and coproduction are not siloed, but instead can be critically evaluated, adapted, and scaled. Villaba's[6] paper demonstrates how existing literature on patient experiences can be developed into tools, such as the Health Experience Insight Cards, however without publication, work such as this, risks being undervalued and underrepresented in the evidence base. A robust publication record also fosters recognition within the academic community, helping to embed PPIE in training, research governance, and evaluation frameworks, as well as ensuring financial investment. Publication has always been a mark of legitimacy and should be utilised to amplify the voices of those historically underrepresented in research, instead of becoming yet another barrier to inclusion.

Discussion

Despite its contribution to research, the publication barrier limits PPIE from becoming more visible in research literature. PPIE activity is currently shared most widely at a local level; documented in local reports shared with the communities involved, conference presentations or shared via communications channels. These outputs, while valuable, rarely undergo peer review or reach a wider academic audience. Mockford's[7] systematic review found a lack of details on PPIE activities in published works, concluding "the absence of evidence does not indicate an absence of impact" and calling for development of the evidence base through improved reporting tools. For PPIE to become recognised for its contribution to research, journals need to include the topic in their publications more regularly. Discussed as a methodology, published PPIE examples and case studies would encourage further development and expansion.

In the United Kingdom, the National Institute for Health and Care Research (NIHR) mandated the inclusion of a "designated PPIE Lead" in all funding applications (Chappell[8]), which has led to growth in this vital area. The hidden labour Papoulias[9] describes as involved for PPIE colleagues actioning PPIE responsibilities, is arguably another contributing factor to the lack of PPIE-specific published articles. Watermeyer[10-11] describes the labour involved for public engagement as being reduced to non-academic skills, with the lack of sufficient regard, creating a "boundary block". This lack of recognition for PPIE work undersells the so-called 'soft skills' and just how vital they are to research progression, adding to the damaging narrative that PPIE has little or no place in published journals.

To illustrate the impact of PPIE, this article highlights examples of how involvement and engagement has influenced research design and delivery. The following examples demonstrate that when PPIE is embedded and utilised, it adds huge value and strengthens research outcomes. Fryer[12] and colleagues coproduced a Community Researcher Tool Kit through combining recent projects within local communities. By recognising the impact of involving public contributors, they were able to build on PPIE and strengthen their approach by working with Community Researchers. The four contributing studies each included underserved communities and the same coproduction approach with Community Researcher Link Workers. This demonstrated the model's effectiveness, whilst addressing the need for inclusive research and representative evidence. Fryer and colleagues first published reports on the contributing studies, on the Deep End Research Alliance website to share the results with the communities that coproduced the projects. However, now that the resulting toolkit has also been published in an academic journal, they have noted an increase in interest and enquiries [personal communication, Dr Kate Fryer].

The PPIE in the PATHWAY project which Capobianco[13] and colleagues delivered, improved study documents and co-developed dissemination materials. The project supported PPIE contributors to develop new skills whilst providing the research with patient voice and perspectives. As a result of taking part in the pilot of the home-based manual, public contributors stated that they understood their own mental health conditions in more depth "I didn't know until we started getting the paperwork, what it was [anxiety and depression]". This demonstrates the full power of PPIE, making significant improvements to research studies and to the public contributors involved. Shields[14] shared the PATHWAY project as a case study example to explain the benefits of PPIE across research stages and highlighted the disparity between the growing recognition of PPIE's contributions to research, compared with the limited number of published works sharing good practice. Providing evaluation of their PPIE approach, comprehensively outlined the challenges overcome and showcases how PPIE methodology can contribute to published works.

Publishing more PPIE projects in academic journals would give the field more gravitas and lead to the financial investment needed, evidenced by Ahmed[15] and colleagues. Conscious of previous research relationships with communities historically being "extractive", they instead focussed on building reciprocal relationships with communities, which lead to a community-based research project. The work demonstrated the need for financial support, both for participation payments for public contributors and to cover additional costs such as childcare. Working with communities and compensating them accordingly, led to trust being built and to the overall success of the project "adequately resourcing PPIE is crucial to its' success".

Understanding the gap in PPIE literature, Mathieson[16] conducted a scoping review in 2025, into the evidence-based interventions PPIE has contributed to healthcare. The search generated 918 articles (535 after removing duplicates) with only 12 meeting the inclusion criteria. These 12 eligible studies identified 8 different types of PPIE activity which was further broken down into 3 categories: collaborating, consulting and informing/ inspiring. The scoping review brought to light the inconsistent reporting of PPIE and the issue of under-publication. The authors conclude by stating "our understanding of the impact of PPIE in implementation research could be improved by better reporting and evaluation of activities in peer-reviewed articles."

These examples collectively illustrate that PPIE can be successfully integrated across diverse research contexts, they also highlight the need for systematic documentation and publication to share lessons learned, to support replication, and to strengthen the overall evidence base for PPIE.

Conclusion

To advance and invest in Patient and Public Involvement and Engagement, the academic community must prioritise visibility. Researchers, funders, and journals alike can contribute by requiring reporting of PPIE activities, offering flexible formats to accommodate engagement outputs and committing to rigorous, publishable documentation of involvement processes. We recognise this journal's efforts to raise the profile by creating this PPIE-specific issue and recommend that the field remains consistently in the journal's contents in future, to acknowledge and support the continued progress public contributors bring to research. Increasing publication will transport PPIE from local circulation of good practice to recognised evidence, ensuring that patients and the public are not only consulted but are credited in research.

Without adequate visibility, PPIE will remain under-utilised and research risks falling short of truly inclusive practice.

Conflicts of Interests Statement:

The authors have no conflicts of interest to declare.

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