

Mandating patient and public involvement in research: is it cause for concern?

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ABSTRACT | BACKGROUND: Public and Patient Involvement [PPI] is a relatively new concept within the field of research. However, it involves a process whereby service users/patients are involved in every step of the research process. Recently, The Lancet Psychiatry and the Journal of Mental Health released a mandate for all future submissions to have PPI representation clearly documented in the manuscripts. This, although welcome, raises the fear of tokenistic practices in research production and dissemination. This has resulted in a space of contentious fluidity developing as researchers and indeed PPI representatives struggle to ascertain what exactly PPI is all about. Only when these questions are answered, will we, as scholars, determine whether to actively use the approach or let it die off like a burnt out candle.

KEYWORDS: Research. Patient and Public Involvement. Co-Production. Training.

This paper was born out of an initiative between two journals to ensure that new perspective authors ensure the active use of Public and Patient Involvement [PPI] as part of any future submission to the particular journals in question. PPI is a relatively new initiative within mental health discourse. However, in recent years, the idea of patient/service user involvement in the research process has become increasingly popular. Patient and Public Involvement [PPI] is a term that is defined in many different ways. However, for the purpose of this paper, the term describes research that is co-produced with the public who have particular lived experiences relevant to the research project.¹ The idea behind which is that such research would be more meaningful and have a greater impact for the end user/benefactor of the research process on the ground. The mechanism of action behind the use of PPI is through a process of in depth discussions with patients/service users regarding all facets of the research process.² This entails involving patient/service users in the co-production of every aspect of the research process from study design, to ethical approval, to involvement in active research activities and finally to paper write up and dissemination of the research findings. It involves utilising their experiences and centring them front and centre in every research activity. It is about recognising that experience as a knowledge set that can be used to enhance the research process, make it more meaningful and centred on the needs of the end user. Within mental health service provision, the co-production of services is already beginning to take effect with the implementation of the recovery movement within such services. The recovery movement does not only focus on the person's ability to live a life of their own choosing but also it examines the organisational change that is required to become recovery focussed.³ One such change is to ensure that services are tailored to the specific requirements of each and every service user to provide them with the best opportunity for growth and lasting recovery. Within mental health services this is accomplished by a process of co-production – where all stakeholders, including service users enter a collaborative medical partnership to not only improve their own treatment/care experiences but the service provided as a whole also.⁴ Although this idea of co-producing has been around, particularly

in mental health, for just over ten years now, the idea of utilising patient/service user experiences as a resource to more effectively navigate the research process is still at a formative phase of development.⁵

In March 2021, within Irish institutions, the PPI Ignite Network was established through state funding to promote excellence and innovation in PPI.⁶ The PPI Ignite Network was not only developed to promote excellence in PPI but also to prevent tokenism in research. Tokenism is a practice of presenting the appearance of patient/service user involvement when such individuals do not have any/much influence.^{7,8} However, tokenistic practices still do occur regardless of this, even in 2024, as noted by Rose and Beresford.⁹ For instance, in a systematic review conducted by Hammoud and colleagues¹⁰ which examined the reporting rate and quality of PPI contributions to patient safety research, they claimed, from a review of 8561 studies that only 6.1% of these studies documented the PPI adequately within the study – which Hammoud and colleagues further stipulates to have occurred only at the design stage of the research process.¹⁰

My own experiences of being involved in PPI resonates with that of Rose and Beresford.⁹ Despite the advancement of certain jurisdictions, like Ireland in regards to developing networks to support PPI, I fear that individuals who practise PPI, do so for only aspects of the research process and see PPI as a nice add on, rather than an essential aspect of the research process. From my experience, when PPI is used incorrectly, the main contributing factor for this is a lack of understanding of what PPI is all about – not just by the researcher, but also by the PPI representative as well. Other additional factors include the lack of proper recognition of lived experience as a knowledge set that could be tapped into along with utilising PPI representatives that do not have lived experience of the phenomenon under investigation. However, there is still hope in my opinion. When PPI works really well, the results can be transformative for both policy and practice. Take for instance, the PSI STAR HRB funded research programme which examines aspects of psychosis to improve care for those diagnosed with a psychotic illness.¹¹ Here PPI is embedded into the research programme, with PPI contributors, like myself, forming part of the

supervisory team, with the same responsibilities and level of involvement as the academic supervisors on the team, Despite this, this occurs in a minority of cases. Therefore, I am left pondering why the learning obtained from co-production in both the PSI STAR initiative and within the wider mental health services within an Irish context, has not been explored further within the discipline of PPI.

For me, the catalyst for writing this paper is twofold. Firstly, from my concerns that originate from my observations of PPI practices to date – especially with researchers seeing PPI as a nice add on to a project rather than being integral to it. Secondly, this paper stems from the recent press releases by both The Lancet Psychiatry and the Journal of Mental Health in January/February 2024 which stipulated a directive calling for the need for perspective authors to clearly document how PPI was involved and contributed to the paper. If authors failed to utilise PPI, they are required to provide a clear rationale as to why such experiences were not meaningfully involved in the research process. This announcement is set to cause changes on how high-quality research is designed, conducted and co-produced and will certainly pave the way for other journals to follow suit.

Although this is overall a welcome development in research practices which both journals should be commended on for, I as a lived experience researcher and PPI'er am concerned by this announcement. Yes, this is welcome. Yes, this will positively change the way one goes about research. However, my concern does not relate to the practice of PPI itself, but to the danger of such announcements possibly causing a spike in tokenistic PPI practices across academia. Particularly because such announcements come at a time where the academic community are still trying to fully grasp and understand the role of PPI in the research process. Additionally, training for PPI representatives is sparse, with exception of those conducted in America and Australia. Within an Irish context, only one training programme was identified through the University of Limerick, which is tailored for those who already hold an undergraduate degree.¹² This in itself is also worrying as not all individuals with experience of value to research will have the undergraduate

college education required to take part in such formal training activity in this area. As a result, the area of PPI is in a state of contentious fluidity as researchers still try to gain a formal understanding of what it is and how it can be valuable in research. Only when this state of contentious fluidity settles will one ascertain whether PPI as an empirical concept or idea will last or frizzle out like a burnt out candle. All one can do now is wait and see.

Conflicts of interest

The author declares a conflict of interest due to his role as a PPI representative on both the PSI STaR and PROGRESS research projects funded by the Health Research Board [HRB].

Indexers

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