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Researchers' experiences and perceptions of working with patient and public involvement and engagement (PPIE) contributors and service users in mental health research: A scoping review

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ADMINISTRATIVE INFORMATION
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INTRODUCTION

Review question / Objective What is the evidence available on 'researchers' experiences and perceptions of working with patient and public involvement and engagement (PPIE) contributors and service users in mental health research?
* In this study, 'researchers are defined as mental health researchers' who have not been employed because of their lived experiences, and who do not identify as service users of mental health.

Background As affirmed by the World Health Organisation (WHO), and the National Institute of Health Research (NIHR) and Department of Health in the UK, patient and public involvement and engagement in research (PPIE) is an important human right for those on whom the consequences of the research will have most impact. 'Nothing

about us without us', has become the rallying cry of service users and carers, also called 'experts by experience' or EBEs, who have influenced policymakers in recognising that their involvement is axiomatic in research so that optimal patient-centred practice can be achieved.
There is also growing evidence that PPIE and co-production can have beneficial impacts at every stage of research, although it has been forcefully argued that reporting standards for PPIE impacts require concerted improvement. Nevertheless, there are abundant peer-reviewed reports and reviews, including from mental health research, of the benefits of PPIE to patient relevance, recruitment, data collection, analysis, and dissemination.
However, despite this positive evidence and overwhelming institutional support, there is an

acknowledged disjunction between policy commitment and the meaningful practice of PPIE. The possible causes for this (and its solutions) – specifically within mental health research – are the focus of this scoping review and the wider project of which it forms a part.

According to the most prolific and respected authors on this topic, the principal barrier to better collaboration with EBEs includes ‘systemic prejudice’ and negative attitudes. Chief among these is the downgrading of knowledge derived from lived, rather than learnt experience. It is therefore hardly surprising that both EBEs and researchers regard much PPIE as tokenistic, an effect which is amplified in mental health PPIE. This may be due to deficit-based attitudes towards mental health, and above all the more pronounced power imbalances between on the one hand professionals with the authority to detain, and on the other service users who may have been treated against their will.

It is also vital to acknowledge that mental health researchers, with limited lived experience of mental ill-health or of working with EBEs, can find themselves involved in just as much ‘emotional labour’, as service users. This can be because of the redistribution of power that is required in mental health PPIE and the adaptation of working practice this can involve.

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There has only been one review (Happell et al., 2018) on what has been identified as the principal barrier to meaningful mental health PPIE and working with experts by experience, namely nonconsumer (as the authors call them) researchers’ attitudes. This literature review included five papers, the latest published in 2016. Happell et al. (2018) concluded that the views of researchers ‘are pivotal for service user involvement [in mental health research], yet there is minimal knowledge available’ (p. 2015).

Since this review appeared there have been more in-depth qualitative studies on nonconsumer researchers’ experiences of co-production, as well as reflections on the optimal ‘dynamics’ or mechanisms for these encounters. However, as Happell herself observes, summarising the need for this scoping review and further work: ‘there is no indication of a systematic research approach to facilitate policy expectations for this type of research in mental health’.

Rationale In contrast, there is a rapidly growing in-depth literature exploring EBE participation, training, and attitudes to mental health research.

Arguably, this makes it even more pressing ‘to bring together consolidated knowledge on the views of other mental health researchers on service user involvement and co-production of mental health research’ (Happell et al. 2018, p. 2016).

Therefore, in part, this scoping review is a response to the calls for further research in Happell et al.’s literature review of 2018, echoed in other excellent primary empirical research they have produced since then. Their literature review examined peer-reviewed papers and grey literature written between 1996 and 2016. However, knowledge on the topic has grown and advanced since then, and it is vital that a systematic review captures more recent evidence. Much of this is in-depth primary data, produced by Happell and her collaborator Scholz. It has never been synthesised or analysed with the other papers this scoping review will be exploring.

Finally, this scoping review is needed because the views of mental health researchers of the dynamics, or mechanisms, of effective mental health PPIE – a particular interest of this study – have also never been systematically mapped. The future development of mental health PPIE is heavily dependent on the perceptions and therefore willingness of researchers to adopt it and work alongside EBEs. Thus, a scoping review is not only desirable, but urgently needed to to better understand the views and experiences researchers that could facilitate or hinder meaningful engagement with EBEs. In addition the review will direct future research, such as a full realist review and synthesis.

METHODS

Strategy of data synthesis Systematic electronic literature searches will be carried out within the following databases: MEDLINE, PsycINFO, Embase, and Web of Science. This search is restricted to the English language, and literature published after 2016, as this was the latest published paper featured in the Happell et al. (2018) literature review. The reference lists of included papers will be screened to identify eligible research, and key authors in the field will be contacted to ensure that publications which are in press or are near to completion are included. All review articles will be excluded from the screening process. However, the reference lists of relevant reviews will be screened to identify potentially eligible studies.

The search terms will be based on the main research question which was formulated in accordance with the population, concept, and context (PCC) framework. Thus, for the population of researchers who do not identify as service users and who are not employed because of their lived experience, search terms like mental health researchers, academic researchers, nonconsumer researchers, and 'allies', will be used, the latter being an important term Happell and Scholz use to describe nonconsumer researchers who promote PPI and co-production, often with extensive experience of working with EBEs. This deals with 'population' in the PCC framework.

The first concept is 'experience and perceptions'. This search will include the terms such as attitudes, views, reflections, perspectives, barriers, and facilitators. The second concept is PPIE for which there are many terms, such as PPI, co-production, collaboration, involvement, consultation, consumer research, service user research, community based participatory research in Canada and the US, and survivor research, although this is more of an historical term. Significantly, Happell and Scholz who are based in Australia and New Zealand, distinguish between PPI contributor/service user and non-service user researchers by using terms 'consumer' and 'nonconsumer researchers', though these appear to be more widespread in their use in Australia and New Zealand where Happell and Scholz are based. Finally, for the context element – 'mental health research' – search terms will be used reflecting research into different conditions, as well as by different disciplines (.e.g psychiatry, mental health nursing, occupational therapy etc.).

Eligibility criteria Included:

- i) published articles which include primary data and/or researcher opinions/reflections on working with EBEs.
- ii) qualitative studies collecting empirical data, reflective studies, editorials, opinion pieces, case studies, qualitative components of surveys and/or mixed method studies
- iii) studies written in English
- iv) articles explicitly focussed on the views, attitudes, perceptions, and experiences of researchers (who do not identify as mental health service users and who have not been employed because of their lived experience) of working with PPI contributors and service users in mental health research.
- v) In the case of mixed samples (e.g. mental health research mixed with other types of research), data needs to be extractable which focusses on mental

health research, or the views of mental health researchers specifically.

Excluded:

- i) purely quantitative studies and systematic, narrative, and literature reviews
- ii) studies that are only available in abstract form, or which are not available to the reviewers
- iii) studies featuring the views of mental health professionals who are not involved in research, for instance clinicians, practitioners, or service providers.
- iv) studies about views of PPIE in mental health services
- v) studies written in languages other than English
- vi) studies that focus on working with PPI contributors in general healthcare research
- vii) studies that focus on working with mental health PPI contributors who are exclusively under the age of 18.

We ended up excluding editorials and opinion pieces, in order to restrict bias towards the primary evidence which we were collecting.

Source of evidence screening and selection

Duplicated papers retrieved from the electronic databases will be excluded.

Title and abstract screening

Three reviewers (MC, CF, and HB) will double screen all titles and abstracts of papers found in the initial searches. Discrepancy will be resolved by a third reviewer not involved in the initial two votes.

Full-text review

Three reviewers (MC, CF, and HB) will double screen all full texts. Discrepancy will be resolved by a third reviewer not involved in the initial two votes.

After full-text evaluation, the papers meeting the eligibility criteria will be included in the scoping review. The selection process will be documented and visualised in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart, which will include the number of papers found, the reasons for excluding the papers at full-text screening, and the final number of included studies.

Data management A data extraction form is being developed, will be pilot tested on two studies, and adapted as necessary before the overall data extraction process begins. One reviewer (MC) will extract data from included papers using the data extraction form, with another reviewer (CF) checking 30% of these studies. If

agreement is poor, this will be discussed with a further member of the team (HB), followed by another round of data extraction to see if data is being extracted more consistently by the two independent reviewers.

The elements to be extracted are as follows: publication details—author, year of publication, journal, country, and study design; general study details—study objective, study sample and recruitment, healthcare setting, level of EBE involvement as defined by INVOLVE (e.g. consultation, collaboration, co-production); attitudes (including barriers and facilitators), experiences, perspectives, reflections including recommendations on working with PPIE contributors and service users.

Reporting results / Analysis of the evidence The findings will be synthesised according to the information provided by the extraction sheet. Following qualitative thematic synthesis of the content, I will be using the PAGER framework (Bradbury-Jones et al., 2021) to report Patterns, Advances, Gaps, Evidence for practice, and Research recommendations which will also form part of my Discussion and Conclusion section. The PAGER framework proved ill-suited to analysis of the evidence as there wasn't a sufficient quantity to allow for the 'advances and gaps' framework employed by PAGER. Instead we used qualitative content analysis.

Presentation of the results The publication types, years, and countries of the papers as well as their study objectives, methods of participation and measured outcomes will be described in a tabular form to provide an overview of the scope of the existing literature. At this point a concise quality appraisal will also be included highlighting some of the limitations (and strengths) of the evidence that I have collected and will be analysing.

Language restriction Only papers in English will be included in this review.

Country(ies) involved UK.

Keywords Mental health research; PPI; PPIE; co-production; patient and public involvement and engagement; consumer researchers; nonconsumer researchers; collaboration; consultation; attitudes; barrie.

Dissemination plans The review will be conducted complying with this protocol, and will be included in a proposal for a PhD to satisfy the requirements of a Master's degree in health and social care research. A paper based on the

scoping review will be submitted to appropriate journals, such as Health Expectations and the Journal of Mental Health, and the findings will be presented at conferences, such as the Mental Health Nurse Academics' international research conference, as well as being disseminated in summarised form as a Vlog on my Youtube channel. The scoping review will also provide a useful introduction to PPIE contributors who will be providing feedback and suggestions on my PhD proposal.

Contributions of each author

Author 1 - Max Carlish - Leading author: main writer, researcher, one of the reviewers.

Email: max.carlish@postgrad.manchester.ac.uk

Author 2 - Helen Brooks - The author is my academic supervisor on the dissertation of which this scoping review is a part. She will also be one of the reviewers.

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Author 3 - Cintia Faija - Cintia is an academic supervisor on my dissertation. She will also be carrying out the title, abstract, and full text screening, along with checking 30% of the data collection.

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Author 4 - Jo Howe - assisted with the screening of the full texts and also double checked MC's data extraction before he proceeded to extract data for the documents included in the final scoping review selection.

References

- Happell et al., (2018). 'Mental health researchers' views about service user research: A literature review.' *Issues in Mental Health Nursing* 39(12): 1010-1016.
- Bradbury-Jones, C. and Aveyard, H. (2021). 'The incomplete scope of scoping reviews: A framework for improving the quality of reporting'. *Journal of Clinical Nursing*, <https://doi.org/10.1111/jocn.15998>