Reviewer’s report

Title: Engaging Patients and the Public in Health Research: Experiences, Perceptions and Training Needs among Manitoba Health Researchers

Version: 0 Date: 09 May 2019

Reviewer: Mary Newburn

Reviewer's report:

My feedback as a reviewer on the submitted article is as follows:

This paper addresses and interesting and important subject but I feel uses an inadequate methodology and the questions addressed are too narrow. A realist approach asking questions along the lines of 'What matters (and/or is valued or useful) to whom, why and in what circumstances?', would have been better. This rather limited mainly quantitative approach to the question seemed inadequate to really exploring the issues in a way that would make a substantial contribution to knowledge.

At one point the authors suggest that researchers early in their career may be preoccupied by the need for 'publication, productivity and tenure'. I felt that this paper was might be influenced by the same preoccupations, rather than a genuine interest in PPI in research. The authors refer to 'theoretical domains framework' and a 'determinants of implementation behaviour' questionnaire, which sounds impressive, but was not referred to in the results of discussion sections in relation to the (design) or analysis of the collected data. There was a tantalising reference to appreciative enquiry and 'discover, dream, design, destiny', but little evidence of how this was applied and reflection on its utility.

1) I would have liked to know who these researchers were. What were their academic disciplines? Were they doctors (if so of which branch of medicine), nurses, midwives, psychologists, health service researchers, social scientists)? While their length of service may be on interest, so is the background and the values /methodologies of their discipline.

2) I would equally have liked to know much more about the PPI in this study. The Patient and Public Engagement Collaborative Partnership was not explained, yet this is surely of central interest to an article exploring PPI in research. Who set it up? Who funds it? Who are the PPI participants? How did they get involved in PPI in research? What health areas are they experienced in? Had they had generally positive or mixed experiences of being engaged and involved in research, or not? Were they 'experts by experience'? I would like to hear some of their words verbatim.
3) The plain English summary needs to be re-drafted. For example, 'IAP2 spectrum' is a far cry from plain English. I cannot believe that there was serious PPI involvement in writing and/or refining the summary. (It was ungrammatical in sentence 2; and the phrase 'research process' was used twice not really clear what this was adding; the last sentence was not well crafted and clear.

4) The English was rather clumsy throughout. It would be helpful to have a native speaker who is committed to accessible language to edit it further so that service users, non-native English readers and the public generally (researchers, funders, non-researchers, etc) can read it with ease. All research should be written in accessible English. In particular I picked out as needing refinement/simplification: 'the need for adequate resources to embed patients and the public early on in the research process'. (Services users don't want to be 'embedded'. This is not respectful language. It shows insufficient awareness and reflexivity (and/or poor use of English). Primary research 'pillar' meant nothing to me and was irritating because obscure. The word 'disinterested' was used incorrectly. For 'lack of interest in'. The sentence on p21 beginning 'The basic and biomedical realm was an area in question by health researchers...' was unclear. Later on, 'applicable to apply for competitive funding' should have been 'eligible'. What is 'good merit'? What are 'supports' (plural)? Support is a collective noun. There was a good deal of jargon that was unhelpful. For example, can 'a number of modalities' not be explained in a more direct and straightforward manner?

5) It would be helpful to say more about 'patient directed' research. It is insufficient to simply refer to patients doing 'final decision making'. This part of the paper suggested to me that the authors were not very familiar with the literature and debates around involvement/codesign and patient-led research.

6) I was puzzled by the power calculation. I'm not convinced that this was necessary or appropriate. If it was, it needed better explanation. If there was a hypothesis informing the power calculation, this was unclear.

7) The point about PPI being used most by mid-career researchers doing mixed methods research was really interesting. Those who use mixed methods often explore both what and why/how questions. It seems likely to be no coincidence that mixed methods researchers value and practice PPI in research. This could usefully be explored a little, explicitly, in this paper.

8) This study (research subject) would be improved by a full commitment to a mixed methods approach and asking a broader, more holistic range of related questions.
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