Reviewer’s report

Title: PPI in research: a reflection from Early Stage Researchers

Version: 0 Date: 22 Apr 2019

Reviewer: Tracey Williamson

Reviewer's report:

Thank you for submitting your commentary which I enjoyed reading. I particularly welcomed your clear structure and writing style and examples to illuminate points made. The topic is of interest to a wide readership including those who like me, are interested in gaining an appreciation of the benefits an initiative such as MiRoR can bring to the Early Stage Researcher community. The particular focus on your recent workshop in Croatia where wasteful research was considered, deserves a whole commentary on it as it affects many researchers and the communities they serve. For me a key strength of a paper is whether it makes the reader think or act differently and it has heightened my awareness of my own need to minimise wasteful research.

In my opinion the commentary is close to publication standard and there are very few changes I would suggest.

On page 9 line 54, you say the example given is obvious. To who? Either explain why it is obvious or better still say it is a good example and justify.

On page 10 lines 30-38 did make me wonder if the project had captured attitudes and beliefs of the Early Stage Researchers before the course for comparison later? No problem if not. Their reflections are important nonetheless. Just check that the quote you use best illuminates the point you are making.

On page 11 lines 1-12 I would reverse the ordering as you talk about 'the latter' before talking about 'the former'.

On page 11 lines 15-30 it is suggested that this research type makes PPI unfeasible. Some studies lend themselves more readily than others for sure. Some patients are interested in hearing about reporting of research and its occasional distortion and some read research reports directly or access a plain language digest of a study or institution's programme of research. As you say yourself on page 11 line 45, there are dissemination opportunities as a minimum. Therefore if a patient is affected somewhere down the line there is an opportunity for PPI. What I would add is that just like we have seen assistive technology developed then a use for it sought/forced, we don't want to force a fit of PPI where it is not likely to be beneficial. There is a risk of wasteful PPI just like wasteful research perhaps?

On page 12 lines 1-19 you note that some research can be less accessible for public members wishing to be involved and this is where experienced PPI representatives can be helpful. On line 19 being 'representative' is not the goal and there is argument against seeking a 'typical patient'. There are times
when a highly trained or experienced PPI representative is what is needed and I would always steer away from the term 'usual suspect'. It is good that the group are aware that tokenism exists and can hopefully steer away from this, instead thinking carefully about who to involve and why (what experience do they have, what characteristics, what role are they needed for etc). Also i'd like to flag how family carer's perspectives are often overlooked - they are often supporting the patient and so have valuable insights or there are implications for themselves. They shouldn't usually speak for a patient either.

On page 12 lines 31-35 I am unclear what you mean so perhaps rephrase? I understand funders may have advice on use of lay language but i do not know what guidance and support they could give to researchers with regards to recruitment and engagement in research and peer review.

Your Discussion section is appropriate. You rightly point out the challenges and merits of PPI in methodological work (page 12 line 44). It is good that awareness has clearly been raised amongst workshop participants and influenced them earlier in their careers to think about PPI and to do this at an early stage in their research planning.

The question I am left with is what is the likelihood of many future researchers being able to undertake development around PPI in such an intensive and possibly costly way as the MiRoR project? This makes it imperative that you disseminate well so that as many others as possible can learn through your experiences. This commentary will go some way to achieving this. Thank you.

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