Reviewer’s report

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

Version: 0 Date: 03 Apr 2019

Reviewer: Magdalena Skrybant

Reviewer's report:

Thank you for inviting me to review this paper, which I think will be relevant, in particular, to researchers engaged in methodological research. For researchers in this area, it can be challenging to conceptualise how and at what stages in the research cycle public involvement can add value. This paper can help identify a) how researchers in this area can be supported to work in partnership with patient and public contributors to shape research design and delivery and b) further research that needs to be undertaken to better understand how patients and the public can be involved in methodological research.

The paper is also of relevance to people that help coordinate and facilitate public involvement (Public Involvement Leads), reviewers of research (e.g. lay reviewers for funding applications), and public contributors involved in research.

General Comments
I thought the paper was interesting and addresses an important issue: how to involve the public in methodology-focused research. Whilst the paper described discussions at the MiRoR meeting and subsequent discussions, I did feel there should be more clarity on what the next steps should be (e.g. what specific training/support could be developed/provided for this group and who could develop this; what topics should be incorporated in this training/support; how this can be rolled-out) and what further research needs to be undertaken to better understand this area. An important consideration could be how to involve members of the public in designing and delivering this training/support.

I do think that the paper would benefit more from a more detailed explanation early on of methodological research and identifying how this research differs from clinical research and how this presents a challenge for researchers involving public contributors. I didn't feel that this was addressed properly until p.9 (in the Journal Club section). Moreover, whilst the focus is on early career researchers, discussions and strategies developed for involving the public in methodological research would be of benefit to researchers at any stage of their career.

As the focus is on Early Career Researchers, I think there needs to be greater exploration of what specific needs this group have and how these can be addressed. You do state that these are the 'next generation' of researchers, which is a very valid point, but are there any other considerations about this group?

Towards the end of the paper, you discuss engagement with the wider public with research. You
describe the need for researchers to increase their skills and develop a range of strategies for
game. Whilst this is important, I did feel there needed to be a stronger link to the main focus of
the paper - public involvement rather than engagement - and I did feel that there was a great
opportunity missed here. In research projects with a strong methodological focus, there are great
benefits to working in partnership with patients and the public to communicate these messages
effectively and disseminate findings.

Specific comments are detailed below.

Abstract:
- I think you need to be clear here that MiRoR has a focus on methodological research. You do
  spell the acronym out (in the Main Body), but it's not immediately obvious to an unfamiliar audience
  the nature of this research. I think some examples of the types of research researchers in this field
  undertake would be beneficial.
- In the conclusion, I think you need to highlight the fact this is training for early stage
  researchers in the field of methodology research. There is a wealth of training on involvement that is
  accessible to researchers, but as you highlight in the paper, it can be more challenging to conceptualise
  public involvement in some of these projects.

Plain English Summary
- 25-26 - I think this would benefit from more detail about 'Methods in Research on Research'
  with a few examples provided. This would give readers a better understanding, early on, about the
  nature of research projects this group focus on.
- 27 - suggest 'The outputs enabled the ESRs that attended the event to learn more about the value
  of PPI …'
- 28 - I found the phrase 'consider it within their own research' to be a bit weak. I think the
  statement could be stronger - rather than just consider whether to involve public contributors, the
  statement should reflect when and how public contributors can be involved in research to add value.
- 31 - I would remove 'in short'
- 43 - I would use 'enhance our partnerships with public contributors'
- 43 - For the plain English Summary, I would use 'share' rather than 'disseminate'

Background (p.4)
-5-6 - What about waste of public resource/charity funding that is used to finance the research?
- 13-14 - I'm not sure that the word 'guiding' does justice to the contributions of public contributors.
  You could consider using 'shaping' perhaps?
-17 - I think you should use the correct definition of involvement from NIHR INVOLVE (INVOLVE
  defines public involvement in research as research being carried out 'with' or 'by' members of the public
  rather than 'to', 'about' or 'for' them.). This is the definition most people would be familiar with and it
  can be accessed here: (https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-
  2/)
- 22 - With reference to partnership working, NIHR INVOLVE have produced some guidance on co-
  production of research, which could be worth highlighting: https://www.invo.org.uk/wp-
Whilst is appreciate that this is an International audience, this guidance has been quite impactful.
26-33 - In terms of what funders are looking for, presumably the relevance of a particular research
project to members of the public is also important. It might also be worth mentioning at this point that
many funding bodies have lay reviewers to review bids who will scrutinise how the public have been
involved in shaping the design of the study and how they will be involved in the project moving forwards.

46 - You talk about the 'developing area' of PPI and you could mention here that there are attempts to improve the experience of involvement. For example, NIHR INVOLVE have published some Standards on Involvement (https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/) and papers have been published recently on considerations for the ethics of involvement (e.g. Pandya Woods https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0058-y)

I did also feel that there would be benefit to mentioning current efforts to better report public involvement in research (e.g. Staniszewska https://www.bmj.com/content/358/bmj.j3453) so people are aware of how public have been involved in research and what works/doesn't work in what contexts (thereby further reducing research waste).

53 - I wasn't clear on what the term 'participant involvement' meant. NIHR INVOLVE has a clear distinction between research participants and those involved in research. I wasn't sure if you meant user-researchers here?

56 - I would use 'one size fits all approach' rather than 'mechanism'. I also think that you need to emphasise that the approach to meaningful public involvement should be determined through ongoing discussions between the researchers and public contributors about what is most appropriate/relevant.

(p.5)

4-7 - The language here is very 'research' focused and can be very confusing. Rather than 'what patients to recruit as research partners', why not say 'who to involve as research partners', 'when to involve people', 'how to get people involved', 'how to keep public contributors involved in the project'.

21 - You introduce Early Stage Researchers at this point. A clear definition of this group would be welcomed.

27 - You talk about researchers producing 'more valid and relevant research evidence'. I feel a reference would be merited here. You have included Brett and Staniszewska (2014) in the references, but there are others that could be used (e.g. Wilson et al, 2015, RaPPORT study - https://core.ac.uk/download/pdf/30710021.pdf) I also think you could make a stronger point here: earlier training and skills development on value of public involvement, and adopting these practices early on, will help involving public contributors become a natural way of working rather than a 'tick box' exercise that needs to be done in order to secure research funding.

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7-8 - More detail about the nature of training to public contributors would be welcome (or a link to further information).

11-12 - In addition to exploring how the role of the public contributor is different to the role of the researcher, was there exploration of how the knowledge of the public contributor complements the knowledge of the researcher and how both contributions are necessary to co-produce the research?

15-16 'There was conversation about what are the most appropriate studies and time points in which PPI should be utilised'… I think that there are some people that would take issue with this statement. I think that there is a case to be made for involvement in all projects, but detail on how and when public contributors are involved is very much dependent on the nature of the project and where the public contributors and researchers feel public involvement can add most value.

Prioritisation of hot topics

36 -48 - I think there needs to be more discussion/explanation about the James Lind Alliance and the Priority Setting Partnerships. You could provide more detail on the thorough process of reaching
consensus on the priorities and the range of conditions. However, it's important to be aware that this is an international audience and not all conditions have had a Priority Setting partnership, so other methods of identifying research priorities should be considered. This doesn't, necessarily, have to be on a grand scale: it is important, however, for researchers to establish that the research is of relevance to patients/public and that the research outcomes will benefit patients/public.

Actions and Initiatives (p.8)

36 - 37 - When you talk about public involvement aims of the NIHR, you could mention initiatives such as 'People in Research' (a platform for people to find out about opportunities for involvement) or perhaps 'Patient Research Ambassadors' (organised by the Clinical Research Network). You could also highlight NIHR campaigns such as 'I am Research' https://www.nihr.ac.uk/news-and-events/support-our-campaigns/i-am-research/ that are part of the strategy to increase awareness of research.

38 - Whilst the RDS do support researchers in applications, which includes supporting researchers to do meaningful public involvement, I would remove the words 'to help meet this goal' at the start of the sentence because this might be confusing.

Mind the Gap

54 - You mention 'JLA' but you haven't mentioned the acronym earlier when you discuss the James Lind Alliance.

Journal Club (p.9)

21-22 - You mention here the challenges of involving public contributors in the projects the MiRoR group undertake and how these projects differ from clinical research projects. I think this is very important and needs to be brought out much earlier in the paper.

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In highlighting the examples from ESR 13 and ESR 15, you describe the ways that data collected from patient participants would enhance the studies. Whilst I don't disagree, the focus of the paper is public involvement and you could explore whether discussions in the journal club explored how more meaningful public involvement at an earlier stage of the research cycle may have prevented these groups from being excluded from the initial data collection.

50 - In discussing ESR 2, is it worth exploring why the group felt that there was 'no scope' for PPI. You highlight in the paper the importance of public in prioritising research and identifying research relevance and also in sharing research. Were these opportunities for involvement explored at all in the discussions in the journal club?

p.11 - 1 -4 'For some projects however, the purpose of PPI in the design and conduct of the research is not evident, particularly those with a strong statistical focus'. I. think that there. are some that would challenge this statement and, as mentioned above, there is scope for public involvement in identifying the relevance of a research project and in sharing the findings. Hannigan (2018) has published an interesting paper on public involvement in quantitative research, that can be accessed here: https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12800

Closing the gap - Challenges and concerns p. 12

20-21 - Whilst there are ongoing debates about 'professional patients' and representativeness of public contributors, I do feel that you also need to highlight the importance of public involvement reflecting
the diversity of communities and challenges of involving those under-represented in research.

29-30 - In exploring the various skills required at different stages of research, you could also consider the different roles of public contributors. A useful paper to consider is Crocker (2016), which explores different 'types' of public contributors and how they can add value to the research process: https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12479

Discussion

52 - Consider using 'impact on patients' rather than 'patient impact'
54 onwards - The sharing of research is an important point and I would feel that this would benefit from more detailed exploration in the main body of the paper rather than in the discussion. Moreover, I think the role of public contributors in working in partnership with researchers to communicate research effectively needs much more development.
It is not clear whether the flyers and videos about the ESR research are co-produced with public contributors. If not, isn't this a missed opportunity?

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