Author’s response to reviews

Title: Learning as an outcome of involvement in research: What are the implications for practice, reporting and evaluation?

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Dear Editors,

We were surprised to see these comments two months after we submitted our revised manuscript on 19 Dec 2018. They seem to repeat many of the issues we have already addressed. One specific comment asked for a change that we have already made that was underlined in the revised manuscript on 19 Dec. We have responded to the other comments below. We went to lengths to have the editors comments and our responses in different fonts so they would be easy to see, but the system removes this formatting change. We have therefore also included our responses as supplementary material.

This is the second time that as an author I have been asked to make changes that I have already made and to respond to comments I have already responded to. I am wondering why this is happening - it's as if the editors have not seen the responses we have made previously. Is there a breakdown in communication somewhere? I have yet to receive an explanation of what happened last time.

Editor: Thank-you for submitting a revised version of this paper. It is much improved. There is less repetition; the language flows better; it is more confident. The variety and range of reviewers’ comments have been considered, resulting in a more focused and coherent approach to the topic. The addition of the summary box makes for a much more authoritative presentation, and we are pleased to see the matter of representativeness is tackled.

Us: We are grateful for this and the many other positive comments from the reviewers. We did make an effort to be more confident and authoritative in the text and are reassured to hear that the reviewers believe we have done that.

Editor: The opening of the paper still needs a little improvement. You state in your comments to one reviewer that the paper is a commentary that does not fit into standard research reporting.
This useful statement would be better placed early in the paper itself, contextualising your standpoint and contribution.

Us: We assumed that as the article is described as a commentary and not a research paper, that this distinction would already be clear. We are pleased to see that the RIE journal includes a number of commentary articles where researchers and involved members of the public can report on their experience and learning. Our article fits into this same category.

However, in order to make this completely clear we have added this detail to the introduction (the text is added in red and in a different font on the latest version of the manuscript).

Editor: In another comment to reviewers you have said, “we are not reporting results of qualitative research and therefore do not need to reflect on our standpoint to the topic.” We wonder if you feel this purist statement is appropriate for a paper that is likely to have wide readership among patients and carers, given the views that you are seeking to publish?

Us: The original reviewer asked the following about us as authors, “Are they researchers themselves? If yes, I think that they should add some reflective views on their standpoint to the topic.” We explained that we are not reporting as researchers of involvement (although we are researchers in other, separate contexts) and are not presenting objective, qualitative data. We understand that when researchers present data as objective fact, it is important that they reflect on whether their perspective or standpoint has influenced that data and biased it in such a way that it can no longer be described as objective fact. Our starting point is that we are reporting on our subjective learning based on our experience of doing and enabling others to do involvement. So our starting point is reflective, and our views expressed in the paper are informed entirely by our particular perspectives. In the paper, we describe this difference between data and wisdom based on experience. We have already explained all of this in the text, and are confused by this comment. We are unclear as to how our response to the reviewer can be described as purist.

Editor: There are some strident statements towards the end of the paper, some of which are based on assumptions that readers may not share, even the assumption that there is in today’s world a moral/ethical aspect to inclusion of citizens in health and social care research.

Us: The discussion section is based on our views which others may disagree with. Whether this is perceived as strident or not may depend on the reader’s viewpoint. Some may perceive these statements as clear and strong expressions in support of their own experiences. We recognise that our views may be controversial, particularly when viewed through the lens of the dominant research culture. It is our intention to positively challenge these views. We note that other reviewers have not expressed this concern and have been very supportive of opening up this debate.

Editor: Moreover, for some patient advocates, there will be a view that this paper does not take forward the debate on how lay representatives can have a stronger influence in health and social
care research in the UK. The paper does offer interesting and useful insights into the processes, but without a critical approach that recognises the role of power relationships and how research knowledge is constructed.

Us; We agree with the reviewer that the issue of power is an important one. However, this paper purposefully does not address this issue. Power-sharing is a complex topic that would require proper exploration in considerable detail to do justice to its significance. We feel unable to address every aspect of involvement in a single article and have therefore focused on the issue of how involvement is being understood from researchers’ viewpoints.

We believe another article could potentially focus on the issue of power relations alone. Again, we see considerable confusion in practice, with researchers sometimes believing they need to give all the decision-making power to involved members of the public, in order to follow best practice. On the other hand, involved members of the public sometimes report feeling disempowered. We believe the issue therefore needs in-depth consideration, paying careful consideration to context. If we were to include one or two sentences on this issue, it would feel tokenistic.

Editor: Overall we would emphasise our view that your paper adds some important reflections to the academic discussion and we would like to see it published. We would urge you to consider our comments above, so that the eventual paper can be judged and discussed on its ideas and content, rather than on tone.

Us: We are unclear as to how to respond further to the comments about tone. We have already made changes to the discussion section in response to the first set of reviewers’ comments. We changed the wording of some of the sentences to be more suggestive of our conclusions than definitive. This comment also seems to contradict that of other reviewers who asked us to be more confident and authoritative in our presentation. It seems a hard balance to strike to reflect these very different views.

We are not convinced that all readers will read the article in the same way. We expect that people will have different responses depending on their starting place. We are aiming to challenge the dominant culture in a constructive, positive way, but that may seem ‘strident’ to people who are strongly immersed in the culture. If we can start a robust debate with this article, we will have achieved our goals.

Editor: One minor point. We would prefer to see “20+ years” expressed in words; perhaps “two decades”?

We have already made this change in the text. It was underlined in the version we sent you on 19 December, nearly two months ago. This is the second time that we have received comments from the editors that suggest they have not seen our previous responses to reviewers. Is there some communication breakdown happening at the journal or on the submission system? Please could you explain why this is happening?