Dear Dr Staniszewska,

Many thanks to the reviewers for their very helpful comments. We have responded to their concerns below and have made amendments to the text of the paper where required.

Reviewer #1:

The approach of considering the impact of involvement on researchers is useful. The article would benefit from the following:

- including a clear research question (I note that you state that it is a discussion of a specific part of an evaluation, but there must have been a research question that guided your method).
The aim of the evaluation was to gather learning for Parkinson’s UK as to whether their pilot project had worked well and what might be improved. The organisation used this learning to develop their PPI practice and policy within their research department. We therefore sought the views of a purposive sample of researchers and volunteers who had taken part in the pilot, to address the question of whether and how this work might be continued. We have made this clearer in the Introduction.

- a more appropriate source for your definition of 'learning'. I consider Wikipedia to be a guide, not a source. The Oxford English Dictionary, for example, would be more credible while remaining consistent with your understanding of learning. However, even with that source, a dictionary definition can serve as a helpful warning to readers and authors that an element of our work could be better informed.

This is an important point and links to an additional comment and response below.

- including information about how coding was informed and checked during thematic analysis

KS carried out the initial thematic analysis which was checked and confirmed in meetings with IAV and CN and initially members of the Steering Group. A couple of sentences explaining this has been added to the Methods section.

- information about the number of interviewers

There was one interviewer, KS, which has been added to the Methods section.

- clarity about participant numbers. For this particular research question, were just 8 interviews relevant? I have no problem with the number but in the abstract the inclusion of '16' suggests that it was a larger group, but then on reading the paper I wondered if the 8 patient/carer interviews were not the subject of this research question.

We have amended the abstracts and methods section to make it clear that only 8 of the original interviews were included in the analysis for this piece of work.

- In 35 suggests that on the basis of information being 'new' to researchers, they will learn. Regrettably, I feel it is unlikely that humans learn every time they are exposed to new information and therefore these sentences should be re-written.
We have amended this sentence to suggest that researchers will often learn from their experience of involvement. Based on our experience, this does happen and is often described as a ‘lightbulb moment’. This is very important. The researchers who experience such a moment are the ones who then state that they will never do another project without involvement. We conclude that a key question around improving the quality of involvement processes is to develop ways to support better learning and more lightbulb moments, for example by better preparing researchers to be open to new ideas and to better prepare patients to share their relevant experiential knowledge.

- A key limitation to this work is that learning is really under conceptualised and hangs on a Wikipedia definition and yet it is central to your discussion. I feel this really needs to be reflected on as 'learning' is a huge field of research and future work would need to consider how we better define learning in this environment, eg it may need to draw on the considerable volume of work about shared learning and decision-making, and how we measure learning (as in this paper it is self-reported learning and we cannot be sure of intrinsic or extrinsic pressures to be positive about the experience).

This is an important issue. There is indeed a vast literature around learning. We have attempted to find relevant papers, but this has proved challenging as we are not experts in learning theory. Much of the literature seems to relate to how individuals learn in different ways and what this means for education, or how organisations learn and what this means for developing organisational policy and practice and business success.

We wanted to propose that what researchers learn through involvement is more than factual information about life with a condition. The experience of working with patients/ carers and learning from them also changes researchers’ attitudes, perceptions and values. We have found a reference that relates to this broad definition of learning from the field of psychology and have included this in the text. We hope this is an improvement on the Wikipedia definition (see above).

This paper is a commentary on what we have observed. We are aware it is not a research paper testing an academic theory. We would very much appreciate an opportunity to work with academics with experience of learning theory to help us conceptualise what learning means in the context of involvement in research. We offer these ideas in the hope it will stimulate further work in this area. We have amended the text to make this more explicit.
Reviewer #2:

This is an important, well conducted and well written piece of research. The findings from the study have important implications for the measurement of the impact of public involvement in research. I would like the authors to consider addressing the following minor discretionary points:

Were there any differences noted between the insights obtained from carers as distinct to those from patients?

Yes there was one difference as described in the text. The researcher was looking at the cognitive and psychological problems experienced by people with Parkinson’s. Originally the researcher was going to interview only patients. The carers’ shared an insight that was not put forward by the patients i.e. sometimes it’s the carer who has a better idea of the individual patient’s mood and cognitive problems, for example, people are not always aware of their own memory relapses. The study design was therefore changed to include additional interviews with carers.

Do the authors think that the findings of their study, have any specific implications for coproduction or for joint researcher and patient/carer joint learning?

We do believe the findings have implications for training and supporting researchers and patients/carers to enable them to work together in a way that encourages mutual learning. KS is currently working with colleagues at Exeter and the University of West England to develop these ideas. It is too early to include the findings in this article.

Reviewer #3: Your results are exactly the same I found out regarding my work as an patient representative with physicians. They are very thankful to become feedback from patients and caregivers. Sharing experiences is often an unique possibility for a doctor to learn about the concerns of the patient. It helps them to understand the needs of a patient in different ways. Thank you for your research!

Reviewer #4:

This is a good, clear, concise paper which ably demonstrates the impact of public involvement on researchers. The authors are highly expert and credible in their field and Parkinson's UK has a strong track record of developing robust public involvement as part of its research funding. Of particular merit are the examples of impact provided along with supporting quotes. I have only
two suggestions - publication is dependent on neither but the paper might feel more rounded were the amendments made. They are as follows:

1. While I entirely accept that this is a paper looking at the impact of public involvement on researchers I did wonder whether there was a place for the inclusions of some comments and perspective from the patients/carers interviewed. Did their impressions match those of researchers? We're they aware of the impact their insight and experience had made?

We asked both the researchers and involved patients/carers about their perceptions of the impact of the involvement on the research. In some cases, their views were very similar as efforts were made to feed back to patients/carers about what had changed subsequent to their involvement.

We did not ask patients/carers about what they saw as an impact on the researchers, although some did briefly report observing researchers being surprised or acknowledging learning new information. Likewise we didn’t ask researchers to comment on the impact on the volunteers. We were asking each party to describe their own subjective experience of the involvement process.

By focusing on what researchers learn from involvement we are seeking to understand the link between what gets discussed during the meetings with patients and the public, and subsequent behavioural changes or actions on the part of researchers. So this work had a very specific focus. Future evaluations may want to explore the ways in which mutual learning enhances the impact of involvement.

2. The authors make a valuable point about face-to-face contact (or digital equivalents). I think this should be captured in the main conclusion.

We have amended the abstracts to include this point from the main conclusion.

Many thanks,

Kristina Staley
Isabelle Abbey Vital
Claire Nolan