Author’s response to reviews

Title: Working with public contributors to improve the patient experience at the Manchester Clinical Research Facility: An evaluation of the Experience Based Design approach.

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Author’s response to reviews:

Reviewer #1:

1. This article clearly presents the process and results of the study to evaluate patient experience at the Manchester Clinical Research Facility. The steps taken to ensure a collaborative team between staff and public contributors, including young persons, are noteworthy, resulting in a sense of ownership by all. It is also significant that, although Experience Based Design is a well established methodology, this appears to be the first example of the use of Patient and Public Involvement in co-designing an EBD project. The benefits and costs of this approach are well documented, and will form a good pattern for future similar projects.

We would like to thank reviewer one for their positive and encouraging comments.

Reviewer #2

1. It is welcome and encouraging to see this article describe in detail the application of a specific approach for involvement of people in research and to show how it can be evaluated. The references direct readers to useful resources especially the work done by the King’s Fund and at GSTT and King’s College NHS Foundation Trust.

We would like to thank reviewer #2 for their positive comments.
2. I would like more detail about how the decision to use EBD was made and if it was fully supported or if there were any dissenting voices. The limitations of patient satisfaction surveys is briefly mentioned but I'd like to know how the shift to EBD was made.

EBD was selected, as the team wanted an approach that allowed patients and staff to work together in a collaborative fashion to improve the patient experience of the Manchester Clinical Research Facility (MCRF). The team at the MCRF, including public contributors to the MCRF and clinical staff, attended quality improvement training focused on adopting an EBD approach to quality improvement before decided to adopt this approach. They discussed other potential approaches e.g. patient satisfaction surveys within the MCRF Involvement and Engagement working group and following the quality improvement training they felt that adopting an EBD approach was the most appropriate way of approaching this work to ensure that all stakeholders (patients, public and staff) had ownership over the process.

3. There are some reflections on the investment that is required to participate fully in EBD and I would suggest that the 5 themes reported in the results could be developed into a useful checklist when planning involvement for example factoring in time.

We thank the reviewers for their helpful suggestion and have developed a checklist for planning involvement using an EBD approach which we have incorporated into the manuscript.

4. I have questions about the selection of people who became involved and there are intriguing comments in the section comparing what emerged with existing literature where there were low levels of disagreement mentioned. It might be useful to understand the demographics of those who use the facility and the staff who work there. How diverse are these groups and what might it say about inclusion and exclusion of studies in MCRF? And how might that influence invitations to get involved?

The Manchester Clinical Research Facility is a generic adult and paediatric facility based at Central Manchester University Hospitals NHS Foundation Trust. It offers state of the art equipment, a team of specialist nurses and experience in supporting over six hundred commercial and academic studies across a wide range of disease areas. People from all over Greater Manchester access the facility.

The Manchester Clinical Research Facility has a working group which focuses on facilitating involvement and engagement across the MCRF. This has four public contributors, two young people who attend a local high school in Cheadle Hulme, and two adult public contributors who were recruited by advertisement to act as public members of the MCRF Involvement and
Engagement Group. All were selected due to having great interest in healthcare in and clinical research, and both the adult public contributors have experience as patients and carers.

All of the public contributors described above where involved in designing the study, collecting and analysing data and developing the action plan.

The MCRF has a large number of clinical trials running through it at any one time, and we attempted to collect patient stories from patients taking part in a number of different trials (including healthy volunteers).

5. Finally I was slightly anxious about the focus on developing the action plan and the creation of this document. I wanted to know more about what was revealed about the experience of using MCRF and what changes were suggested.

Although we feel that the primary focus of this paper is the evaluation of the public involvement aspects of the EBD approach, we have provided some additional information about the action plan.

6. One of the possibilities of EBD is that the ethos of co-design can and should be extended to involving people in designing and testing new ideas together. The post EBD role for the public contributors seems to be limited to monitoring and I worry about 'active documents' when the details of who could do what by when and how are hazy. Is anything improved? The introduction of processes for more real time and continuous improvement could be explored rather than risking a snapshot on a biannual basis.

Shortly after this work was undertaken the MCRF needed to submit for further National Institute for Health Research Funding to continue its work. This meant that this work needed to be paused until the funding decision was known. The MCRF has recently been successful in achieving further National Institute for Health Research Funding to continue its work (2017-2022). This is also likely to include an ongoing role for public contributors in examining patient experience.
Reviewer #3:

1. Who was invited to be involved in the project and what was the rationale for selecting these individuals?

See response to reviewer 2, question 4.

2. We are told that the members of the public are part of the Involvement and Engagement Group, but what relevant experiential knowledge did they bring to the project? Are they patients with experience of participating in trials?

All four public contributors had been members of the Manchester Clinical Research Facility Involvement and Engagement Group for between 1-2 years when this work was being undertaken. Therefore, they had considerable experience of discussing patient focused issues in relation to the MCRF for some time. One of the adult public contributors had experience of taking part in a clinical trial.

3. I am not in complete agreement with the authors' conclusions that given the complex nature of the task, it was necessary to recruit highly educated young people for the role. For example, I'm aware of an excellent involvement project where patients made a significant difference to the analysis of qualitative data, even though they were unable to read (they listened to recording of excerpts from transcripts - see Cossar, J. and Neil, E., British Journal of Social Work, 45, 225-240). This issue of essential skills may only be true if involved patients/members of the public are asked to do the same job as researchers, almost as an extra pair of hands, rather than seeking to develop a process that meets their needs and facilitates their meaningful contribution. From the details in this paper, I can't tell whether the process supported the public/young people to do the same job as the staff or whether it fully enabled them to offer their unique and distinct perspectives.

We thank the reviewer for this useful point and agree that it should be possible to involve a diverse group of young people in similar work in the future. We have commented on this point in the manuscript accordingly.

It is important to emphasize that all four public contributors were involved in designing the study approach from the start and we took into consideration the need to develop a process that met their needs and allowed them to meaningfully contribute.

4. This brings me to the second question I'd like to ask - how were staff and members of the public trained for this project? Did they receive identical training? Did the training support
involved members of the public to recognise that they might contribute very different views and perspectives and to keep their 'patient/ member of the public' hat on during the project? What patients/ the public offer is equal but different to health professionals/ researchers - did the training emphasise and enable this?

Public contributors received training to help to support them effectively in their role within the project. Therefore, not all received identical training if they were involved in different tasks. The emphasis of the training was on their being no ‘right or wrong’ answers and that all views and perspectives were valid. It was also emphasised that the work did not need to be approached in the same way as someone with formal research training would approach it.

5. To feel confident that this did happen, it would be really helpful for me to know precisely what the public/ patient members contributed to the project. How did they influence the thinking? What did they challenge during the project and what changed as a result? Without some of this detail of precisely what was different as a result of the involvement, it also possible to conclude that the impact may have been minimal - for example commenting on the language of a questionnaire- rather than identifying the questions that patients would want to ask. Was there constructive conflict? Were the patients/ members of the public genuine partners contributing to the conceptual development of the project - or did the process select and engage like-minded individuals so that opportunities for learning and impact were limited?

Public contributors were involved at all stages of this project.

1. They were involved in the decision regarding the approach to take to this work.
2. They lead on the development of the topic guides which included (thinking through the patient journey, mapping the journey and thinking of the emotions that patients may feel at each point as prompts for collecting patient stories
3. They had input into the decision of how to recruit (i.e. sending letters to all patients, asking patients to take part face to face on the wards, how many patients to collect stories from
4. Public contributors led the observations section of the project
5. Young people analysed the interview data and developed the first draft of the action plan
6. Public contributors helped to prioritise actions
Within the paper we discuss the fact that there was limited conflict and the potential reasons for this. Public contributors felt that they were listened to and that they were able to shape the project from the start.

Reviewer #4:

1. This paper will be of value to audiences interested in EBD as a method, and in ways of involving the public in both research and service improvement - thank you.

We would like to thank the reviewer for their positive comments.

2. Overall, my main comment is that it is important to make clear the difference between EBD as a method and what you mean by PPI - to help the average reader understand.

We have clarified our definitions within the background to this paper.

3. The EBD method involves patients and staff working together - not the public, unless you count family/carers of patients. Your paper is about teaching members of the public how to use the method and how successful this was. This is the focus - and what makes it different. It gets confusing in places where EBD and PPI are used interchangeably- for example p. 4 lines 34-43 where you say 'when considering the success of PPI within the EBD approach....respondents who had completed an EBD project said that the approach had 'really engaged patients". The barriers and facilitators were considered (to EBD as a method) in this same survey, and in other evaluations of EBD or EBCD projects.

We have hopefully clarified our references to EBD and PPI throughout the paper.

4. Secondly, it's important to distinguish between Experience Based Design (by the way box 2 says evidence based design) and Experience Based Co-Design. Papers by Glenn Robert or The King's Fund are about EBCD. (As are refs 4,12,13) Glenn Robert added the 'co' to emphasise how patients stay involved after improvements have been identified and work with staff to design, prototype, and test and finally implement the changes. Is your project going to continue to implementation with patients?

The aim is for the project to continue with involvement of patients in its implementation. The exact details of this will be clarified in the forthcoming months as the work is restarted following the successful funding application.
5. Reference 5 - is King's College London (not The King's Fund)

Thank you for identifying this error, we have amended the reference accordingly.