Author’s response to reviews

Title: Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement.

Authors:

Louise Locock (louise.locock@abdn.ac.uk)

Susan Kirkpatrick (susanfkirkpatrick@gmail.com)

Lucy Brading (Lucy.brading@liverpool.ac.uk)

Gordon Sturmey (strmgord@aol.com)

Jocelyn Cornwell (jocelyncornwell@pointofcarefoundation.org.uk)

Neil Churchill (neilchurchill@nhs.net)

Glenn Robert (Glenn.robert@kcl.ac.uk)

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Author’s response to reviews:

Reviewer #1: The study and its methodology were well thought-out and executed, and I hope the findings will be put to practical use to improve patient involvement.

Thank you – no action required

Reviewer #2: This is a very interesting piece of work and describes how patient and public involvement contributes to a novel experience-based co-design approach. The conclusions are thought-provoking too. I did find the article a little difficult to follow and I hope that my perspectives on the 'flow' and clarity of the article are helpful.

1. Plain English Summary

I wonder whether the summary could be improved in places, removing jargon and somewhat UK-specific colloquial speech. I hope my suggestions below are helpful:

First paragraph:
Replace 'collect and analyse data' with 'carry out the research and analyse, or make sense of, the results.' Replace 'typed-up interviews' with 'written copies of interviews'. Instead of referring to what would be useful for the NHS to know about (and would a non-UK reader necessarily know what NHS stands for?), how about framing it in terms of what would be relevant to improving patient care and what would help healthcare staff in improving care? In addition, the summary assumes that the reader knows what patient or service user involvement is.

Response: We have left ‘collect and analyse’ but have sought to explain better what ‘data’ means. We have taken out NHS and clarified what kind of improvement we mean. However, we think for this particular journal our explanation of what is meant by ‘patient or user involvement in health research’ is sufficient.

Second paragraph:

Refers to researchers and then researcher later on. Was it one or more than one researcher who analysed the interviews? Replace 'had done their own analysis of the interviews' with 'had analysed the interviews'. 'NHS quality improvement' is jargon. What does that mean? Improve the quality of patient care?

Response: changed to ‘research team had analysed the interviews’ and changed wording around quality improvement.

Third paragraph:

Replace 'spotted some new things the researcher had missed' with 'found other themes'. 'Lots of documents' reads a bit bland. 'a good way forward' is colloquial.

Response: Changed to ‘new details the researcher had missed’. (It was sometimes a question of emphasis rather than whole new themes’.

2. Clarifying methods and results

The article is not presented under the headings of Background, Methods, Results and Discussion. This format is a specific requirement of the journal for methodology articles. Following this format will also help in more clearly describing your methods and the outcomes of the PPI. As it stands, I feel that there is a lack of detail in the methods in places and that the outcomes are buried in amongst the methods description.

Response: we have restructured as suggested

For example, in Workshop 1, the finding that the process of engaging with all the material took longer than planned is presented in a continuous feed with describing the workshop agenda and then discussing why this process took longer than planned. More descriptive detail about training
for public partners and how these PPI opportunities were advertised (e.g. flyers and posters with which groups and organisations, community notice boards in which locations, which PPI involvement network?) might be useful.

Response: restructured. Detail about the specific recruitment routes for the two client groups is covered in the section on each workshop (for example the INVOLVE young people’s mental health advisory panel, and a regional PPI network). We think giving details about exact location of networks and community noticeboards may be too detailed for an international readership, however. Do the editors agree?

LB's own reflections are of interest, but do disrupt the 'flow' of the whole story in developing the PPI. Moving these reflections to a separate results section would help. As it stands, it is not that easy to pick out the important learning points that the team gained from workshop 1 and used to modify their approach to workshop 2.

Response: restructured as suggested

Also, it would be interesting to learn more about how the public partners developed a grasp of the idea of a touchpoint. Would it be possible to provide an illustrative example of discussions the public partners had about a specific touchpoint?

Response: we have added an example on p.20 of how a small comment about interaction with care may be embedded in a narrative that seems to be primarily about feelings and symptoms.

Workshop 2 is not that easy to follow either. The change to the agenda, compared with workshop 1, is explained but I ended up spending time flicking between the two agendas and trying to compare them myself. Am I right in thinking that the key difference is in asking the group to identify what they think are the key touchpoints based on their own experiences, rather than by reading transcripts? How exactly was this done as this appears to be an important development of the methodology? What about the draft trigger film? This was done for workshop 2 but not workshop 1. Can this decision be explained in the context of learning from workshop 1?

Response: yes, this was a key difference. We hope by restructuring and reducing word count this is now clearer.

3. Other points

I would be interested to know why the team chose 'Experiences of stroke' and 'Experiences of young people with depression'. This isn't really expanded upon.

Response: we have added an explanation about seeking to include both mental and physical health and different age groups, and priority topics for NHS England.
An article by Jennings et al (BMC Psychiatry (2018) 18:213 https://doi.org/10.1186/s12888-018-1794-8) was published very recently. The authors may find this of interest, particularly in comparing their own PPI with the Collaborative Data Analysis approaches that the team identified from their critical review. Could be a nice discussion point and illustrate their work in a wider context.

Response: Thank you – this was a really helpful suggestion which we have incorporated in both the background and the discussion.

Subtitle - Running the workshops and learning from the process:

* P.15 Line 9: "We worked with two very different sets of narratives…” - in what way were they different?

Response: this section has been deleted as part of reducing word count

* P.15 Line 14 to 34: This isn't described very clearly - parts of interview transcripts are described as 'segments', 'selections' and 'extracts'. I am not sure how these differ and how they were selected by the researchers.

Response: we have amended to ‘extracts’ throughout

The training provided to the public partners is only very briefly described and, from the way it is written, I am not sure whether ‘participants reading segments of interview transcripts…’ is part of the training or is part of the co-discovery work itself.

Response: It was not part of training so we have deleted a paragraph here which may have been confusing.

The people involved in the workshops are variously described as 'attendees', 'participants', 'service users', 'people', 'users'. Consistency would help, as well as perhaps avoiding the term 'participants' due to potential confusion between PPI and participation.

Response: Yes, agree – ‘participants’ was meant to refer to ‘workshop participants’ but the potential for confusion with research participation is a good point. We have variously used ‘those attending’, ‘attendees’, or ‘service users’, depending to some extent on context.

I am not sure about the term 'co-discovery'. The authors claim it is used elsewhere in a different discipline. Also, PPI is awash with different terminology. Do we need another 'co-'? And what is being 'discovered'? I appreciate this is a personal opinion but wonder why something more descriptive like 'collaborative analysis' couldn't be used.

Response: We have removed co-discovery from the title and the article, and deleted some related paragraphs.
The first paragraph under the subtitle 'Patient and public involvement and data analysis' states that 'Qualitative data analysis may appear more intuitive and approachable than, say, quantitative analysis such as logistic regression or mathematical modelling'. This is a subjective viewpoint and wonder whether this statement should be removed.

Response: We changed ‘qualitative analysis’ to ‘analysing patient stories’ to emphasise what may appear more intuitive about it than technical quantitative work.

It is interesting to read that the approach developed here is being applied to another project (Box 4). The authors emphasise the need to avoid reinforcing exclusion of minority perspectives. Do they suspect this could have been an issue with the methods they developed? Just wondered why this point was emphasised here.

Response: In response to reviewer 3 we have removed this box.

Reviewer #3: Better understanding of how to meaningfully involve patients and members of the public in different aspects of research and quality improvement processes is a very important and topical issue. The work reported is a valuable example of an attempt to involve patients in the development of trigger films based on modifications to an established EBCD methodology.

Though not extensive or entirely novel in many ways, there is valuable reflection and learning in this manuscript that warrants sharing with the broader community of researchers, improvers and PPI partners. In its current form however, the manuscript is much too long, provides too much unnecessary detail, and begins to lack a clear focus from about page 9 onwards. The attempt to provide transparency in the reporting is to be commended, but this could still be achieved with far fewer words and less minute detail.

Response: in response to reviewer 2 we have restructured methods and results which we hope will help with clarity of focus. For more specific changes, see below.

Some essential detail is missing - who facilitated the workshops and how for example.

Response: we have explained that we facilitated the workshops ourselves on p.16.

I was also not convinced that the lengthy explanation of EBCD and the work related to the current manuscript is entirely necessary. This background information, provided from line 1 on page 10 through to line 50 on page 12, is a particular example of where the manuscript could be shortened. I found myself disengaging from the manuscript at this point and then felt I had eventually reached 'the point' again at line 18, page 13 (the question addressed by the reported study). The quality of the written English is of a high standard, but some sections of the manuscript are very complex and not readily accessible or easy to understand, others are quite
drawn out and at times repetitive. As well as room for the manuscript to be much more succinct throughout, clarity in what is being reported in this manuscript is an issue. There is a sense that the manuscript is trying to do too much.

Response: we have considerably shortened the sections on EBCD and HERG/Healthtalk.

It was difficult to stay with the original aim of the activity reported, sometimes because the authors provide reflection on the workshop processes before fully describing what they did and how it was done and sometimes because it is not clear what they were actually wanting the workshop participants to do. Description of the analysis process, pages 13 from line 48 to line 12 on page 14 is very complex and difficult to follow. 'The aim' of the workshop/s is stated in several places and isn't always consistent. At line 51, page 14, it is unclear which 'process' the verbal feedback from workshop participants relates to - is this the whole day or the process of involving them in the thematic analysis or the sense-checking? Outcomes and impacts are distributed amongst description of process. Outcomes and impacts not directly related to the research question are reported (which is fine), and discussed in more (and unnecessary) detail than some of the actually quite interesting and key reflections on the learning from the study itself about involving patients in 'the qualitative analysis of patient narratives' (as the title states).

Response: we have separated the description of the methods of the workshops from reflection on findings, which we hope will address these points about clarity and succinctness.

In the discussion section a completely new study is introduced and reported on.

Response: removed as suggested.

The manuscript would greatly benefit from significant editing to provide a much clearer structure and focus, and much more succinct reporting of key elements of delivering the workshops, the learning that was gained from that, and the authors' subsequent reflections on what worked well, and what could be done differently.

Response: see above re separation of methods and results to address this

It remained unclear to me what the authors' rationale was for 'training' participants in 'qualitative research methods' when the aim was to get a 'lay' perspective on the transcript data and themes. Providing them with understanding of the approach to analysis is one thing but it seems the purpose of the training was to help them to engage in and apply a qualitative process to the data (rather than reflecting on the data or themes from the perspective of their lived experience)?

Response: we have included some critical self-reflection on ‘training’ on p.27. While we think training for PPI partners is important to reduce power differentials, we ourselves were probably unclear about what training was needed and why.
It is also unclear if anything new was 'co-discovered' and if so, what this was. The authors mention 'nuances' and 'emphases' but do not elaborate on what these were, how they contributed conceptually or otherwise to the interpretation of the data and so on.

Response: we have added a few words on p.20 and p.25 to clarify – most of the differences between user and researcher perspectives were not large.

The discussion section of the manuscript felt rather labored in places (the whole of page 25, though interesting, is superfluous to the aim of the study really), and some statements are not supported by published literature (lines 5 to 20 on page 24, lines 1 to 12 on page 25 are examples).

Response: We have made clearer that those statements emerge from our findings rather than literature. The discussion seems to us to be an important part of our conclusions.

What do 'assemble user reflections' (line 22 page 25), and 'chime sufficiently' mean? (line 32 page 25),

Response: ‘assemble’ changed to ‘elicit’. ‘Chime sufficiently with’ changed to ‘adequately reflect’.

and could you explain statements like 'this sensitizing approach would be equally enlightening in more theoretical sociological analysis' for the non-sociologist and lay reader?

Response: we have explained more about the very applied nature of our project but deleted this particular comment.

Line 50, page 25 - a completely new study is introduced and explained. This should either be removed or incorporated into the body of the manuscript as part of the exploratory study. Referring to this later workshop as a follow on study informed by the learning the manuscript is reporting on is fine, but the study itself should not be reported here and especially since box 4 presumably provides unpublished data/information?

Response: removed as suggested

Page 27 line 12. What was/is the 'valuable layer' that the 'lay' partners contributed. This has not yet been clearly articulated in the manuscript (or else it has but is lost amongst the detail). Lines 26-31, what were the 'nuances and emphases' that the authors found when comparing what the researcher and the users 'could see in the data'?

Response: We hope that this may be more evident now, and have repeated here a couple of the key insights from users – though we also note that much of their analysis chimed with our own.
Elaborating on these findings and also on the authors very interesting ideas about 'including early conversation and guidance on the expected content of the analysis' would greatly improve the value and contribution of this manuscript. What might this look like in practice?

Response: We had hoped our Box 4 was in effect doing this – showing the steps we have been through in another project to put flesh on the bones of the analytic conversation approach. However, we have replaced this with more discussion of the Jennings et al best practice framework. Although this was not available to us at the time we undertook the project, it has similar conclusions and articulates for us the process we also felt was most appropriate.

Did the users describe their role as being one of 'a map and a compass’? and did they mean this just in the context of what they were asked to do in the workshops or could they generalize this to the context of any qualitative analysis of data drawn from service user experience?

Response: no, this was our interpretation and we have reworded it slightly to make this clearer.

The discussion section spans 5 pages yet it is the last page and a half that begins to hold the reader's attention most. More elaboration on the ideas proposed in these final pages of the manuscript, and how this all sits within the published literature, would provide a much more focused and valuable summary of the work reported.

Response: We hope that by removing box 4 and incorporating reflection on the new Jennings et al paper recommended by reviewer 2 we have made clearer what the contribution of the paper is.

Reviewer #4: Hello, this is a well-written paper, however, I think it should be shortened and made more concise.

Response: thank you – chimes with other reviewer comments about shortening, which we have addressed above.

In addition, except for the the different patient groups - what is the real difference between this paper and reference 25? Reference 25 is written as a research paper and structured that way.

Response: reference 25 (our previous NIHR study on accelerated EBCD) did not include user involvement in analysis. This was only done in the ESRC-funded study we report in this paper. But hopefully that will be more obvious now we have taken out much of the description of the EBCD study.

The new paper seems to be a ramble of what happened and should be shortened throughout. The reflective part was good but did not address all the issues that were raised through the paper. Despite PPI, there seemed to be a general lack of awareness as to what would be suitable training for lay people to accomplish analysis.
Response: in response to reviewer 3 we have added some critical self-reflection about our approach to training.

In addition, there is no consideration of the welfare of people with long-term health conditions - this should be raised in the reflection.

Response: there is a section on p.27-8 [in current track changes version] which addresses issues of fatigue and concentration, cognitive impairment, and the potential to find transcripts upsetting. This is one of the reasons why we recommend a lighter touch analytic conversation, which we hope would help address welfare issues.

There is concern that PPI can become experts when they have had a little training and therefore are no longer true PPI.

Response: this is a long-running debate outwith the scope of this paper, but we do reflect on the length and detail of training provided, and why despite our wish to use it to reduce power differentials it may not have had the desired effect.

Research with PPI should be co-production - even in writing of manuscripts.

Response: we agree, which is why we have two user co-authors, and had a user co-investigator on the team.

The second paragraph of the abstract is written in a technical, inaccessible way. What are touch points/trigger terms, what do you mean? Line 35 of the discussion provides a much better description of the analytic task.

Response: ‘touchpoints’ are explained in the abstract as ‘key moments of healthcare experiences’, and the purpose of a ‘trigger’ film is explained as something that is ‘used to spark codesign discussions’. These issues are elaborated in the text, but inevitably within the word count of an abstract some detail has to be omitted.

Abstract Method - who was involved, how many, how were they recruited, what criteria was used?

Abstract results - what themes were similar, what new insights?

Abstract conclusion - again lack of insight into what lay people, especially those with long-term health conditions can do, especially when they are brought in for just one part of the research process.

Response: we do not have space in the abstract to add more detail.

"user reflections" - what do you mean?

Response: added short explanation
Background

line 33-37 is clunky. The whole section should be shortened.

Response: simplified wording

PPI

This could be shortened and more detail added about frameworks used for PPI input. The authors talk of health research and there NIHR have produced a framework. There should be more evidence about where PPI has been used or not within the framework. See: Patient-Centred Outcomes Research Institute [https://www.pcori.org/]. Involve: Public involvement in research: values and principles framework. In. Eastleigh: INVOLVE; 2015. P. 8 line 16 - shows that even PPI have different ideas and stories that will shape research analysis.

Response: we were not setting out to describe PPI across the research cycle, but to look only at one commonly neglected area, involvement in data analysis.

line 38 - why include PTE method?

We included this because it is relevant literature on past efforts to involve users in analysis.

P. 10 What is EBCCD? - should not be shortened title line 14-19

Response: We now have it in full again in the sub-heading.

- researcher chose film clips - hardly PPI! Shown later to not represent what the PPI felt were the important points. Need care here.

Response: we think this may be a misunderstanding. We specifically wanted to compare what happened if users were involved in analysis with what the researcher found. In EBCD this is not normally done, and we are simply describing that fact.

P. 11 Weakness - not using local film clips takes the research out of context and may not be as pertinent to the PPI. line 30 - PPI found the films chosen by the researcher to be too negative and not reflect their own views. Lack of PPI - should be added to limitations

Response: again this is a description of standard practice in EBCD, which is not PPI, and is not the main focus of this article

P. 17 line 10 - typo

Response: ‘this way’ changed to ‘the way’
P. 24 line 35 - PPI had previously been upset whilst taking part in the research - what were the safety features for this study? Was counselling offered to those affected? Again, also lack of insight into PPI

Response: This was reporting on a different project, not the one described in this paper. However, we have added that they were well supported by a clinical nurse specialist, and chose to continue their involvement.

Reviewer #5: The paper covers a subject of importance, thank you for your effort on it.

The training of the patients (one day) was quite limited. It is difficult to evaluate the benefit of patient involvement with a limited selection of patients, who have no time to prepare the topic.

Response: this reviewer takes a different view to other reviewers that we were perhaps already trying to do too much training. We agree with other reviewers and feel that longer training would not have helped.

Further explanation on the exact topic of interest (icl. which video was viewed- you gave a link with a list of videos, I could not find which was used, and what you really expect from patients) would have been more helpful.

Response: we have given a link to our whole list of trigger films. We could change this to two links to only the two topics considered in the workshop, but would prefer to give people a link to a wider range of films.

FROM THE CO-EDITORS-IN-CHIEF:

We would ask the authors to pay particular attention to the comments of the reviewers that would allow the paper, the summary and the abstract to be more accessible to a wider (lay) readership.

Response: amendments made as suggested by reviewers