Reviewer’s report

Title: Facilitating Non-tokenistic User involvement in Research. An Ethnographic Analysis from a Rehabilitation Research Project.

Version: 1 Date: 27 Feb 2019

Reviewer: Gordon Fernie

Reviewer's report:

This is an interesting and useful piece of research on a much-needed topic which we enjoyed reading. We think the article is good and some of the conclusions are novel. We particularly liked the idea that the service users you collaborated with were guests of your institution and what followed from that, especially the shared meal. Some areas of the article need more clarification and more detail, mainly around (i) consistency of terminology and (ii) methodology. These impact on your interpretation of and ability to speak with confidence about the legitimacy of your findings, as well as the reader's ability to practically take your findings and apply them.

(i) Consistency of terminology

1. We think that what the authors mean by tokenism, collaborative arena, representational artefacts and language games could be better defined to make the terms clearer for a general audience. This should appear at the very start of the paper where the terms are first used.

2. In the article it needs to be clearer about who users are much earlier - not until page 5 do we learn they are service users with traumatic brain injury rather than, for example, drug users in rehabilitation [note, at this point the acronym TBI for traumatic brain injury needs to follow as you use it later on line 293]. How the user panel were selected could also be mentioned earlier e.g. on page 5. Some background information on who these users were and their experience is important as we believe this could conceivably have impacted on their advice and your research. In turn this could affect the generalisability of the research to other contexts - is it important to involve users with experience outside of their own treatment e.g. as representatives of larger patient groups or charities?

3. The authors should be consistent when describing users: users, service users, participants, user participants, informants, and panel members are all used somewhat interchangeably (additionally in the discussion on line 521 - discussants and critical companions are added. Here an interesting reference you may wish to refer to is in Joy Hendry's book 'An Introduction to Social Anthropology: Sharing our worlds' (page 5, 2nd edition) the term "collaborator" is used to better describe the critical role the users played, as you speak to on line 521.
4. Related to point 3, in places more clarity is required about who is being referred to e.g. panel members vs researchers on pages 15 and 16, especially where pseudonyms are used (on p.341. is Marie a service user or member of the research team or both?)

5. Being consistent in your use of artefact, arena or continuing feature. The first two terms are common in anthropology and ethnographic work so the definitions are important, but on lines 218 - 222 the meal seems to become all three of these categories. Our understanding in reading this is that the meal is the artefact, and the act of sharing a meal is the area - though this could do with some clarification. Similarly on lines 383 & 384, stories are described as representative artefacts (are these different to your previous use of the term artefact?) when as described by your paper they would seem to be a continuing feature?

6. On lines 398-399 methods of promoting group dynamics and active participation are mentioned and a reference given. We recommend expanding on this as it is the main thrust of your article. Similarly on line 266 "visual techniques" to support an inclusive atmosphere and a positive tone are mentioned, and a reference given, but not expansion of examples of use within your own data collection. What are these visual techniques? These seem like good opportunities to share with the reader what you did and what worked well, so that lessons can be learnt from your reporting if a reader is hoping to apply your findings practically in their own user involvement groups.

(ii) Methods/empirical & how this relates to discussion:

Without knowing a bit more about the extent of the data collection (time period, volume of audio recordings and meetings, methods used during observations etc.) it is difficult to evaluate the reliability of your findings and the generalisability of your results. This could be addressed through brief clarifications to let the reader know the depth of your data collection and the scope of your data items. The answers to the questions below should hopefully be used to justify in your discussion why your findings are indeed based on a rigorous autoethnographic approach and are of potential use in the future to limit tokenistic involvement:

1. Timeframe over which data was collected, how many researchers were involved at each stage, was this consistent through-out? Was rapport built and did this play a role in data collection?

2. How many audio recordings of conversations & discussions did you use? Who was present for most of these conversations (i.e. was there a potential power imbalance which may affect the information people were comfortable sharing? What steps were taken to mitigate this?)?
3. What techniques were used during the observations referenced line 139, what detail was noted? How many people conducted these observations? What interactions were observed?

4. What are the short memos (line 142)? How short were they, who wrote them, and how many did you have?

5. You should include a brief evaluation of using meeting minutes as a data source alongside observations as they omit usual ethnographic data - this isn't a negative but something which should be acknowledged at least in the discussion.

6. How much was the honorarium paid to users?

7. Is reporting names rather than initials a conscious choice and if so you could expand about why?

Other notes:

- We recommend including a more substantive listing of the specific methodologies you found to be successful in reducing non-tokenistic involvement in a clearly presented way. This is more for the readers' benefit, so that your findings can easily be incorporated into future user interactions.

- In some sections the past tense should be used e.g. the description of the empirical material used.

- Lines 482 - 516 are very good! We appreciated what you were saying here and agreed with you.

- Line 47 - "also showed" should read "are also shown"

- Line 48 - we do not quite understand what you mean by "respect for participants was decisive".

- Line 333-4 - perhaps rephrase this - we don't fully understand what you mean.

- Line 372 - whose first impressions and immediate assumptions are referred to here?

- Line 484 - "concerns" should instead be "concern"

- Line 541 - "differentials" seems like an extra word?

- Line 543 - elucidation of instead of "elucidating the"

- Line 562 - we do not understand what this means. Perhaps elaborate?
Gordon Fernie, Centre for Healthcare Randomised Trials (CHaRT), University of Aberdeen

Dan Brunsdon, Health Services Research Unit (HSRU), University of Aberdeen

**Level of interest**
Please indicate how interesting you found the manuscript:

An article whose findings are important to those with closely related research interests

**Quality of written English**
Please indicate the quality of language in the manuscript:

Needs some language corrections before being published

**Declaration of competing interests**
Please complete a declaration of competing interests, considering the following questions:

1. Have you in the past five years received reimbursements, fees, funding, or salary from an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?

2. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?

3. Do you hold or are you currently applying for any patents relating to the content of the manuscript?

4. Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript?

5. Do you have any other financial competing interests?

6. Do you have any non-financial competing interests in relation to this paper?

If you can answer no to all of the above, write 'I declare that I have no competing interests' below. If your reply is yes to any, please give details below.

I declare that I have no competing interests.

I agree to the open peer review policy of the journal. I understand that my name will be included on my report to the authors and, if the manuscript is accepted for publication, my named report including any attachments I upload will be posted on the website along with the authors' responses. I agree for my report to be made available under an Open Access Creative Commons CC-BY license ([http://creativecommons.org/licenses/by/4.0/](http://creativecommons.org/licenses/by/4.0/)). I understand that any comments which I do not wish to be included in my named report can be included as confidential comments to the editors, which will not be published.
I agree to the open peer review policy of the journal