Reviewer’s report

Title: Educational content and challenges encountered when training service user representatives as peer researchers in a mixed study on patient experience of hospital safety

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Reviewer: Janette Rawlinson

Reviewer's report:

An interesting article in an area of growing importance, using patients and public within research. The paper outlines a detailed experience of training lay people as peer research/reviewers and some of the challenges and opportunities from this situation.

Some phrases need amending as they do not read well from a native English speaker's perspective.

The manuscript draft abstract starts with a typo in the word 'Background (missing g)

Plain English Summary - needs some further work. 'Pedagogical' is not an everyday English phrase - and the phrase 'federated' makes no sense - federated to what or whom? A Federation is usually an association and I'm unclear what was meant in this context. These phrases are used in several other places within the document so need translating into more 'lay' language. e.g p12 line 2 - 'lied' should be 'lay' as 'lied' means not telling the truth.

use of English language - Abstract - line 24 - 'same rhythm' would be better expressed as 'with the same timing', or 'at the same time' or 'at the same pace' or 'in parallel'

p8 of document/p9 pdf - unclear what a 'mission head' is. (line 32) p6 line 13 ontological awareness also not plain English

This is a valuable paper p8 lines 48-51 shows direct impact and p9 lines 16-19 in particular are very valuable. The challenges of working with lay people and academia/researchers should not be underestimated but the opportunities and value/impact can be substantial. As more and more funding bodies insist on having patient/public involvement within any studies, finding ways to work more effectively will require considerable training in communications and understanding/appreciating the different values the different groups may have. There appears to be a balance of challenges experienced with learning for future initiatives. Views from the peer researchers would have been useful as a triangulation whether as direct quotes or themes arising as the work progressed.

Observations and suggestions to help peer researchers feel comfortable, confident and more effective are very valuable as this example demonstrates. For many years research has been undertaken by those who know the theory but may have not experienced the situation being researched. Therefore public and patient involvement can bring a different and valuable perspective, a realism from real world to help researchers in whatever context appreciate some of the complexities involved by the research subjects. Such involvement is encouraged in the UK at design of studies (to ensure improved recruitment and retention to
studies), ongoing role within the study and dissemination of the research findings. Such collaboration can offer useful insights to the researchers and bring a valued sense of purpose to participants. As such involvement develops in other countries especially Europe, such articles as this can offer helpful contributions for others.

p10 - lines 46-61 - it is quite often the case that patient/public volunteers will be beyond retirement age. The criticism for not handling this well seems totally focused on the individual concerned rather than the Centre for failing to anticipate this and handling it more sensitively especially given the pioneering nature of this work and naivete of some of the peer researchers involved, both to the work involved and the organisation. Expecting lay people to understand and anticipate the various organisational IT and payment systems is unrealistic as most have completely different systems, pay rates and expense policies. Having been involved in research for several years, the variation of expense/pay policies for involving members of the public can be bewildering. A biased/judgemental tone should be avoided within the article. Misunderstandings happen - it is how they are dealt with that can deter future public engagement, result in individuals feeling aggrieved and telling others which may impact on future 'peer researcher' recruitment/involvement so it is much better all round to recognise and acknowledge the upset and learn from the process. Was it made clear beforehand how and when peer researchers would be reimbursed? Some may be on limited incomes so if they have outlaid costs to take part, it is unethical to delay payments in any event. It would be useful to capture the learning for the organisation for any future peer researcher involvement to notify participants clearly before such situations arise.

p11 - good learning regarding the less than optimum recruitment methods - it's important to recruit based on competencies not just the fact that somebody has been a patient or expressed an interest so this point is useful for others planning to recruit patients/peer researchers.

One aspect that I found a little concerning was the academics' surprise that people completely unfamiliar with research would understand, after limited training, the need for adhering to a framework. In many sectors, it is usual for employees to work around a framework - ensuring core elements are deployed whilst attempting to make interactions more 'personalised'. This may have been the participants' norm hence not appreciating that veering from the research methodology has the ability to flaw the results. Citing the phrase that was able to persuade the participants of the need for impartiality is very powerful and reinforcing the need for a consistent approach (as detailed in p9 lines 29-32) about recording the results. Their training appears thorough from the table provided. Views from the peer researchers would have been useful as a triangulation whether as direct quotes or themes arising as the work progressed.

The findings should enable it to be more tailored in future to the gaps identified from this piece of work. Risks such as attrition had been mitigated by having a waiting list of participants for when one peer researcher dropped out - this is good practice. What was less clear was whether more than the 10 had undergone the training i.e. a pool of trained people from which the 10 were selected. Keeping in touch with the peer researchers by conference calls in addition to the face to face work seemed to have also proved valuable.

An unusual topic but one that will be of interest to researchers and members of the public already involved or considering involvement in future in such initiatives especially as some key learning
points have been identified for the respective parties. There appears to be a balance of challenges experienced with learning for future opportunities. The quantity of references cited demonstrates the ongoing interest in this area and provides additional learning for any organisation seeking to involve peer researchers in future.

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