Reviewer's report

Title: Co-producing public involvement training with members of the public and research organisations in the East Midlands: Creating, delivering and evaluating the lay assessor training programme

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Reviewer: Kristina Staley

Reviewer's report:

This is a very good example of using co-production to develop a training programme to support involvement in research. The training has been well-received by participants and has supported enhanced involvement in the review of research materials. It offers a process for others to follow in developing training for people who get involved in research. However, I am curious about the term 'lay assessor' and how the purpose of assessment is being understood. It would be helpful to have more contextual information to understand who took part in the training and what type of research they are reviewing. I note that the example of the Northwick Park study was included - does this mean that the assessors are only looking at early trials involving members of the public (rather than patients with a specific health condition)? If yes, then I think this needs to be made explicit in the text. If no, then I would have further questions about the role of reviewers. The text seems to suggest that the training was targeted at any patient/member of the public which is fine - but does this also mean that the understanding of the role of lay assessor is that any 'lay' input is appropriate - I wonder if such an approach may underplay the importance of relevant patient experiential knowledge in certain contexts. I recently undertook an evaluation of a panel of mental health service users who reviewed research materials which showed there are several layers to assessment. On one level there were comments that related to making the information lay-friendly - a job that potentially any member of the public could do. On another level, there were some patient-specific issues, for example recognising that participants in research may need additional travel expenses for taxis if their condition makes it impossible for them to drive or use public transport - an issue that affects many patients. Then there was the top level, which were condition-specific comments. This was where patients were bringing their experiential knowledge to the task. These were issues that patients with other conditions would not be aware of. For example, when reviewing a patient information sheet that explained what having an MRI scan would involve, most people in the panel thought the information clear and accessible. However they did not have schizophrenia - the condition being studied. The patient with schizophrenia on the panel, on reading that music would be played through headphones whilst in the scanner, commented that he would need to know exactly what piece of music would be played to avoid feelings of paranoia. This example nicely illustrates that patients will have information needs that only they will know about, because they have lived experience of a health condition. (Ref: Kristina Staley Joanne Ashcroft Lisa Doughty George Szmukler, (2016),"Making it clear and relevant: patients and carers add value to studies through research document reviews", Mental Health and Social Inclusion, Vol. 20 Iss 1 pp. 36 - 43 Permanent link to this document:http://dx.doi.org/10.1108/ MHSI-09-2015-0037) It is not clear to me whether this distinction between the different contributions of expert patients/members of the public was made during the training - this is a
wider issue than the development of the training itself - but I believe an important learning point for assessors to understand their role. If appropriate, I would like this to be clarified in the text, as this article is also contributing to the literature on the purpose of lay review. In a similar vein, I'm curious about how the role of lay assessor is understood in relation to the role of lay members on ethics committees. In my view the role is quite different for the reasons above. So I am also curious about how this is being conveyed in the training. There has been a recent publication on this issue including a joint publication by INVOLVE and the HRA which may be pertinent here. I think it would be important to add some detail to the introduction and discussion to contextualise this project and open up discussion points around purpose as well as practice in developing the role of lay assessors - as there will be assumptions about purpose that will have informed the whole approach. I would find it helpful if these assumptions were made explicit. On a minor note, I published a critique of the Ives paper referenced on page 7. I'd be grateful if the authors might consider including this - the reference is: Staley K. (2013) There is no paradox with PPI in research. Journal of Medical Ethics, 39, 186-187.

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