Reviewer’s report

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

Version: 0 Date: 29 Jan 2017

Reviewer: Kristina Staley

Reviewer's report:

This article describes patient and public involvement in the application of an Experience Based Design (EBD) Approach to a review of participants' experiences in clinical trials, with the overall aim of making improvements to participants' experiences.

The paper describes how this project was carried out and the results of an internal evaluation of the involvement. The involved members of the public and young people report having been able to shape the EBD project and having had their voices heard. Staff and involved public felt they had benefited personally from the project. However, I think there are some important details missing. Without this information I feel unable to judge whether the project represents best practice in involvement - it may well do so - but I'd like to know more to be certain of that.

In common with many other publications and reports of involvement there is a lot of information about the process, but crucial detail missing that would help me judge the quality of that process. For example, I would find it helpful to know:

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

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?

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.

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?

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?

I see a lot of involvement that I wouldn't class as best practice because the room for patient influence has been restricted, by who was involved and how they were involved. I'm not concluding that this project was poor quality, but saying that with the information the authors have provided so far, it is impossible to tell. I would like to be reassured by a bit of extra detail, that this process did support meaningful and effective involvement.

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