Reviewer's report

Title: Patient and public involvement in data collection for health services research: a descriptive study.

Version: 3 Date: 2 April 2015

Reviewer: Carole Mockford

Reviewer's report:

Major compulsory revisions

1. This paper is well written and interesting. It raises some important issues for research, and for funders on the benefits and challenges of involving service users in health research. I would like to see more detail on the research and governance procedures.

2. Some issues are mentioned which applied to the lay observers would also apply to researchers. It is not straightforward to involve lay people within the infrastructure which supports research yet, quite rightly, protects the vulnerable who are the focus of research. Some of the challenges mentioned in this paper are described as hurdles yet they are in place to protect the patient, and should also apply to the researchers, one example given was not being allowed into single bed rooms where there are infection control procedures in place. This may have reduced the availability for observation but is not specifically a problem arising from involving lay observers. This needs some clarification.

3. One of the key issues raised in this paper is that there was little time allowed by the research team to recruit and train the lay observers. This appears to be because involving lay observers was a late addition to the study after the study had started. It is not possible to rush this process, enough time has to be allocated to recruit and train the ‘right’ people for, what could be, quite sensitive observations. This needs to be better acknowledged. Also time has to be allowed for the research and governance approvals to take place and more description is required for what the team had to change or add for approval, these details are important to know for other research studies.

4. How to get lay researchers into an environment like a hospital where there are very vulnerable patients was a challenge for this study. It seems clear that being a lay observer is not really the role of a hospital volunteer and there is a tension amongst the hospital volunteer group and the lay observers because of this ‘way in’ to the hospital. What other ways were considered and rejected and why?

5. With regard to the lay observers, it is not stated if they were volunteers or if they were paid for the work they did. There is some discussion about the training, but it is not clear if the training they received was sufficient for them. Did they receive any kind of reward or recognition for the work they did? For example, did they receive a certificate?

6. Overall I think the paper raises some interesting issues and shares interesting
challenges which are common enough to challenge many research studies.

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests