Reviewer’s report

Title: Investigating the patient safety issues for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study

Version: Date: 2 February 2014

Reviewer: Pauline Heslop

Reviewer’s report:

This article describes the findings from a study of patient safety issues for people with intellectual disabilities in NHS acute hospitals. The article has potential, but requires revision before it is ready for publication.

Major Compulsory Revisions

There is considerable scope for the article to be tightened up, with increased precision required in a number of areas. In part this is about the use of language; in other places in the article, it is about the description and interpretation of the study. The majority of my comments relate to this overarching issue. Places where I think that clarification and precision should be improved are described below, and together constitute major compulsory revisions.

• The abstract. The phrase ‘harmful healthcare’ is emotive and deserves clarifying. Do the authors mean healthcare that is harmful in its intention, delivery or consequences?

Also in the abstract, the authors suggest (in the findings) patient safety issues that ‘may be’ or are ‘potentially due’ to certain factors. Again this needs to be clarified, and more precision is required based on the findings of this particular study.

• A much clearer definition and explanation is needed as to what the authors understand to be ‘patient safety issues’. An overview (drawn from the literature) is given in Table 1, although I do not understand the authors’ distinction between the issues and the contributory factors (e.g. poor recognition of swallowing difficulties could be a contributory factor and the patient safety issue would be choking or aspiration). Nor are ‘never events’ either mentioned or included in the list of safety issues. The potential issues in Table 1 are also different from those described in Tables 2 and 3, leading to further confusion. The article would be considerably improved if there was a clear discussion in the introductory text about what defines and constitutes a patient safety issue and why, perhaps with categorisation of types of issue.

Clarification is required regarding the methods of the study.

• The author should describe how many questionnaires were returned by family carers and paid care staff separately.

• Other than mentioning the observation of in-patients with intellectual disabilities,
there is no mention about how this was undertaken, the information gained from doing so, and whether this was a useful way of obtaining data. This requires clarification or a note to state that the data is being reported elsewhere.

- The rationale for the inclusion of items in interview schedules and questionnaires should be given. For example, why were the specific patient safety incidents as described in Table 3 chosen? How was the wording of each item selected, and does it adequately identify patient safety issues (for example, the use of ‘certain tests or treatments’ rather than ‘essential tests or treatments’). Why was the time period of 3 years used?

- No mention is made about how the interview participants were identified and recruited, or by whom or where the interviews were undertaken. This requires amending.

The section about data analysis also requires clarification – who was the multi-disciplinary team that undertook the data analysis? Was the coding in NVivo predetermined, or were new codes added as different themes emerged? Was the coding double checked by different researchers?

Regarding the findings: I am unclear about the selection of the four particular safety issues described in the results. Are these the issues that occurred most frequently (and if so are they presented in order of frequency with which they were reported) or are they the issues that the authors suggest are the most important? Placing ‘lack of basic nursing care’ first suggests that it is of most concern, but the wording ‘several carers and hospital staff’ (in relation to an assumed 272 incidents) leads to a lack of clarity with this assumption. In addition, the section about ‘delayed investigations and treatment’ only seems to refer to ‘several’ examples.

In addition, clarification is required in the results section in relation to:
- The phrase ‘lack of basic nursing care’ requires justification. Was this a complete lack, or was it inconsistent, inadequate or poor quality provision?
- The quotations do not always describe the issue at point e.g. p.11 the fact that a person was inappropriately given a drink whilst waiting a theatre slot has little to do with misdiagnosis.
- The explanation about delays to investigations and treatments in relation to the Mental Capacity Act also requires more attention to detail. The Mental Capacity Act should be implemented at all times, not just after a patient’s capacity has been established (p.13). It would also be appropriate not to go ahead with tests or treatments without patient consent – what would be of concern would be inappropriate delays in the decision-making process about what would be in the person’s best interests. Finally the assumption that junior staff would be more likely than senior clinical staff to misunderstand the MCA or lack confidence in using it must be questioned. It may well be that junior staff have received more recent training than senior medical staff and would be expected to be more up-to-date.
- DNAR should be referred to as Do Not Attempt Cardiopulmonary Resuscitation
(DNACPR) to distinguish this treatment from other forms of resuscitation e.g. fluid resuscitation.

The Discussion does not clearly follow on from the findings presented in this paper, leading to some confusion on the part of the author. For example:

- In the findings (and described in Table 1), diagnostic overshadowing is described as a patient safety issue, but in the discussion it is described as a contributory factor.
- The authors report that ‘gaps in access, treatment and care’ remain (p.16), but gaps in access have not been addressed in the findings of the study.
- The discussion about acts of omissions and acts of commission is interesting but confusing. The authors note that acts of omission are thought to be twice as prevalent as acts of commission, but this is not reflected in the findings of the study where acts of commission (providing the wrong care) are emphasised more.

Minor Essential Revisions

The Table numbers given in the text do not refer to the correct Tables. Tables 2 and 3 should be reordered into a logical order, for example with the types of incidents most commonly reported placed first.

Discretionary Revisions

The discussion could usefully explore a number of issues raised in the paper. First, why, for example, were issues described by interviewees on p.15 not reported or acted upon? If an order not to resuscitate a person was inappropriately based on staff assumptions about the quality of life of a person, why did the ward manager not challenge this? There seems to be two issues here – the occurrence of the patient safety issues, and whether or not patient safety issues are reported. The authors could usefully disaggregate these issues.

The second issue that could be usefully expanded on in the discussion relates to what could be done to address the problems identified. The authors suggest that healthcare providers should be encouraged to scrutinise the provision of care and treatment with expert coordination of care, but the basis for this assertion is not clear. I would suggest that a more focused discussion could be presented that is based on ways of preventing, reporting and monitoring patient safety issues.

Finally, one of the potentially interesting aspects of this paper is the perceptions of different patient or professional groups about what constitutes a patient safety incident. This could usefully be drawn out a little more.

Level of interest: An article of importance in its field

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