Reviewer's report

Title: A qualitative analysis of information sharing for children with medical complexity within and across health care organizations

Version: 2

Date: 10 December 2013

Reviewer: Anton Miller

Reviewer's report:

Please note that, though this may be a revision of the manuscript “A qualitative analysis of information sharing for CMC…”, this is first time I am reviewing this work.

I would note that the topic of information sharing for CMC is relevant and important, so new insights can be very helpful. The design to seek information from different kinds of sources/stakeholders is a strength (though the execution is slightly weakened by having only 3 interviews from privacy administrators).

Despite these strengths, I have a number of reservations about this paper. At the highest level, the context and rationale for the study are not convincingly explained. While it may be true that “knowledge about the sharing of written care plans remains limited” (pg 3, line 14), there have been many studies of electronic and personal health records, both important ways to share information, and the barriers and facilitators for their use, which actually overlap with present findings and barriers, including privacy, security, interoperability, institutional cultures etc (e.g. Beard et al JAMIA 2012; McGinn et al BMC Med 2011; Tang JAMIA 2006; Bates, Health Affairs 2005; Silvester Med J Austral 2009 etc.). None of this literature is referenced, and so the real rationale for the present study is not clear unless it is specifically to look at sharing of written care plans. This needs to be clarified. Also, the present findings are not placed in a context alongside other literature (even if this is from adult practice), though the authors do refer to barriers to information sharing identified in the children with special needs literature. I think there should be reference to what is known in the field more broadly, and then perhaps focus in this area, and whether it might be expected to differ from the larger field, and explain in this way what this study was intended to add. These points might also require revisiting or restating the claim that “this” is an understudied area warranting use of a grounded theory approach to data analysis.

Methods

Data collection:

It would be helpful to have more information on the interviews: scope, form, content, structure; and whether interview content was comparable across sources or not.

Data Analysis:
It would be helpful to have more information on how coding was done. It seems only three (out of 50 something interview) were coded by more than one person. Is that adequate for triangulation? Who coded all the others? These gaps make it hard to tell if resulting themes truly represent a 'best interpretation' of the data obtained.

Results

There was something unedifying about the way the findings are presented. A lot of details and elements are presented in a somewhat scattered way, but without much effort to synthesize and integrate. And where this is done, it is not clear sometimes how the authors batched things as they did. A couple of specific examples:

Lack of Common Language (under Theme 2: Focus on Episodic Care) is not well situated under Focus on Episodic Care, but is related to some other notion of care that is fragmented across sites.

Similarly under Organizational Priorities: refers to care across settings, each of which may have different policies, but this is not, to my view, a problem of Organizational priorities.

Other issues with data organization and presentation:

Figure 1: some sub themes/elements are mentioned/ described further in text, others not (e.g. Causal Conditions under Common Platforms)

(e.g. does Marginalized Families really fit under Theme Common Platform?)

Does Different Language across Organizations fit under Focus on Episodic Care (above)?

Finally, why is there a Fig 1 for Barriers but no counterpart for the section on Facilitators?

Discussion

Much of the discussion is quite wide-ranging and goes beyond study findings. Some comments do not even appear to belong in Discussion, e.g. bottom of pg 14: “Frontline HCPs were less conservative…”. This seems more like a study finding, but I was not aware of such comparisons while reading the Results section (possible that I missed it).

It would be helpful to concentrate the discussion on new insights from this study: e.g. that parents are not very worried about privacy or confidentiality; that there are differences in priorities among stakeholders, and related findings.

Limitations

Perhaps note that health care for CMC is not actually all in the realm of physicians and hospitals sources; there are many other players such as community based therapists. It would be interesting to know their views on information sharing too.
Carefulness

More care needed in checking for typos and accuracy and completeness of references

Typos
pg 6 line 4: privacy 'statues'.

References
Refs #8 – please check if this is the correct reference. It does not look correct.
Ref #14 is incomplete
Ref #27: should there be an URL link?

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