Reviewer's report

Title: Consulting communities on sharing sickle cell disease findings in international health research: Views and values of residents in coastal Kenya.

Version: 1 Date: 12 July 2013

Reviewer: Matthew Hunt

Reviewer's report:

Thank you for the opportunity to review this manuscript. The paper describes a qualitative research project exploring views and experiences of different stakeholder groups related to disclosure of Sickle Cell (SC) findings in research projects in Kenya. The manuscript is well written and the study is clearly presented. The results of the study are compelling and offer important insights into processes of community consultation and, in particular, community perceptions related to genetic research findings.

In regards to the paper’s structure, I would suggest that the authors consider making a clearer division between the results and discussion components of the paper rather than integrating them in a single section as is now the case. This is not a change that I consider essential, but I believe it would help situate the reader and might also help push forward the discussion of the findings by making clearer the intersection between discussion and results. Beyond separating it from the findings, my other recommendation for the discussion component of the paper would be to further develop it in relation to several aspects of the findings that currently are mentioned but not taken up in a sustained fashion yet seem to be very salient (e.g. page 13 – how sharing information could empower families to create demand for better services; page 14 – conflation of carrier status between conditions and implications; page 16 – influence on gendered blame of knowing carrier status before marriage).

Minor Essential revisions

1. In the 2nd sentence of the background section, the authors report relationships between SC and increased malarial resistance. The implications of this relationship should be further explained for readers who are unfamiliar with this context – why is SC screening included in pneumonia, HIV and malnutrition studies?

2. Longevity data is given at the end of page 4 but it is unclear whether this is country, regional or community level data.

3. Bottom of page 5: “diagnostic misconceptions of research” is unclear. Also could add ‘lack of’ prior to “the resources needed for…”

4. The manuscript lacks a clear statement of a research question(s) related to the analysis of the community consultations (though general objectives of the consultation are listed). A succinct statement of research question(s) would be
useful.

5. Methods: I’m not certain what ‘framework analysis’ entails. The authors should explain this approach and add a methodological reference if possible.

6. Page 9: the authors refer to a key feature that is described elsewhere. There is no citation of where this has been discussed.

7. Page 9 bottom: unclear why “substantial explanation of the cause of SC disease” is italicized.

8. Page 10: Is describing paternity as “misaligned” the correct terminology?

9. Top of page 11: sharing information is described as having a positive impact on other family members and the wider community. This is quite general. What sorts of benefits are involved?

10. Top of 13: “risks if screening were available” change were to was.

11. Top of 15: “influential in their groups” – rephrase

12. Middle of 20: placeholder “XXX” – replace?

Discretionary revisions:

1. At the end of the background section, the authors refer to the empirical project as a form of community consultation as part of community engagement activities. A brief explanation of what community consultation entails, and how it fits under the broader umbrella of ‘community engagement’ would be helpful.

2. Methods: A distinction between deductively derived and inductively generated themes is made. As a reader, I’d be interested to know which themes were generated inductively and which were not.

3. Page 9: I suggest adding a brief paragraph at the beginning of the findings that maps out the analytic structure. This would help the reader see how the components of the analysis fit together.

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