Reviewer's report

Title: Experiences with community engagement and informed consent in a genetic cohort study of severe childhood diseases in Kenya

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Reviewer: Nhlanhla Mkhize

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Overview

It is not unusual that community engagement is reduced to superficial information of the community in question about the study to be undertaken. In this paper, which presents on community engagement and informed consent processes in a genetic study of children affected by severe childhood disease, the authors present a unique model of community engagement, characterised by a high degree of relationship building with the community under study. The KEMRI Welcome Trust Research Programme in Kilifi (Kenya) has developed a model of community engagement which is based on action research, incorporating reflection and feedback. In this study, the authors analyze documentation involving meetings with a wide range of stakeholders, including field researchers, in order to understand the strengths and challenges of community engagement with particular reference to informed consent, communication processes and the contribution of the field workers to the ethics process on the ground, the challenges they experience and how they address them. The paper succeeds not only in showing that relationship building facilitates the research process; it also highlights the crucial role played by the field workers on the ground, the personal challenges they experience (e.g. pressure to recruit as many participants as possible, personal inadequacy at times) as well as their potential contribution to the development of informed consent material. The study also highlights that major ethical issues from the perspectives of researchers or the international community (e.g. storage of samples) may not be perceived as such by community members. The researchers discuss the findings with reference to social science research. They also present recommendations to strengthen community engagement.

Recommendation

I found the article to be well-written. It makes a significant contribution to the community engagement literature. It is recommended that it be accepted for publication subject to minor corrections of an editorial nature.

The article: Background

The authors present a detailed background to the study. The action research model, characterised by action and reflection, theory and practice, is described. The study background, the Kilifi Genetic Birth Cohort, which investigates the
relationship between genetic factors and childhood diseases, is presented. The Kilifi community is described. The authors are successful in establishing the study context.

Methodology

Methods involved an analysis of various documents including minutes/notes taken in meetings with various stakeholders (e.g. local residents, religious leaders, village elders, field workers). While these groups were purposely selected, it is evident from the diversity that the authors were also aiming at maximum variation sampling and information redundancy (judging by the numbers involved) as additional criteria to test the adequacy of their sampling. Discussions held with community liaison groups added strength to the research process by way of methodological triangulation.

Findings, discussion and conclusions

The findings relating to the filed workers are very interesting. In a way, they indicate that fieldworkers are actively involved in translating the study at the local context and hence their role is not limited to data collection; they have a meaningful role to play. Their positioning as junior members of the team is a source of anxiety and this needs to be addressed. The authors show that field workers could play an important role supporting the informed consent process as well as community understandings of research. The study findings are discussed in relation to contributions by local chiefs and community members. Therapeutic misconceptions about research are noted and problematized. The findings are presented in a manner that is easy to follow and could be readily translated into a format for oral presentation in community meetings (the disseminations aspect of community engagement). The discussion focuses on long term capacity building in order to facilitate community workers’ understanding of the research process. The authors succeed in their discussion to problematise issues related to the methods and depth/intensity of community engagement. I found the conclusions to be consistent with the study findings.

Suggested Editorial Corrections

1. I recommend that the article be published as it stands. However, I note that the article is accompanied by a photograph of participants in a community/consultation meeting. It is not evident if the participants have consented to the publication of this image. The authors need to clarify this.

2. On page 7 of the article, the abbreviation AL is confusing. Does it refer to one of the authors? If this is the case most probably it should read AM (Albert Mlamba).

Thank you for the opportunity to review this interesting article