

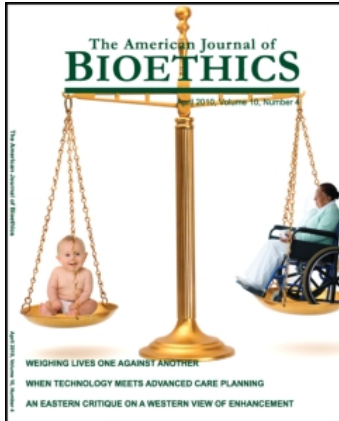
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### Community Members Employed on Research Projects Face Crucial, Often Under-Recognized, Ethical Dilemmas

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# Community Members Employed on Research Projects Face Crucial, Often Under-Recognized, Ethical Dilemmas

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Simon and Mosavel (2010) explore how proximity between study recruiters and potential subjects/ participants can influence research ethics and scientific integrity. They do this through reviewing the literature on peer-driven recruitment (PDR) and sharing their own experiences of a variant of PDR, that is, the employment of women from the local study communities to conduct a range of activities – including recruitment, data collection and local data dissemination - for a cervical cancer study. The authors highlight that having community members on their staff helped principal investigators (PIs) to learn about local norms and values and tailor the study recruitment plans and consent processes to the local context. On the other hand, their community staff members also faced significant practical, emotional and psychological stresses which were addressed through a range of interventions including the introduction of brief cross-checking questions to improve participant understanding of research and regular de-briefings for community staff members with a psychologist.

Two issues are immediately striking about the authors' paper. Firstly, how very different the PDR approaches they review are to their own 'variant' of employing community

based staff. As the authors say, their approach does not share any of the main characteristics of the PDR method, including direct knowledge of potential participants or snowballing processes with successive waves of recruitment. A pure PDR approach, we believe, should remain as it is described in the literature, as an exceptional approach to recruitment when there is no alternative method that enables some form of separation between personal relationships and friendships and those supporting recruitment into studies.

The second striking aspect of this paper is the familiarity of the authors' PDR variant, and its associated strengths and challenges. Working with research staff who are also members of the communities in which they undertake a variety of study related activities is common to many research institutions (Molyneux et al. 2009; Gikonyo et al. 2008; Molyneux and Geissler 2009). For example at our research centre in Kilifi Kenya, almost all of our community-based studies employ what we call 'field workers'. Field workers have a range of roles in studies very similar to those outlined for the cancer study. While they are often employed for practical reasons – for example because they can speak the same

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language as potential participants, are familiar with the village lay outs, are aware of local norms and values – the key role that they play at the interface between researchers and community members, and as members of both of these rather different worlds, is increasingly recognized. They play a crucial and often under-recognised and under-supported role in ‘doing ethics’ in the field. In establishing and maintaining interactions and relationships between study participants, non-participants in a community, and research staff, they also have a central role in the success and quality of the science itself (Molyneux and Geissler 2009).

Drawing on our own research we support the authors’ suggestion that the practical and ethical strengths and challenges that community-based staff or field workers face can differ according to how embedded they are in research communities (Gikonyo et al. 2008). At one end of the spectrum we have field staff who are employed from the local community to continue to live in their own homes and neighbourhoods over the course of the study, and at the other end we have community members employed to work across a large geographical area surrounding the research centre, and who typically live in a central town, and travel out to work in study communities every day. The more embedded fieldworkers are in a particular community, the more familiar they are with local social networks and norms, giving rise to the strengths and challenges noted by the authors in their variant of PDRs. However social networks are complex and multiple, even within relatively confined geographic areas. Individuals may have only partial or no access to some social networks in their neighbourhood with important implications for the wider acceptability of the research with which they are associated. In some instances, the actions of an individual field worker can strongly prejudice others’ attitudes to a study. In addition, their new status as ‘employee’ of an organization may impact upon these social networks and wider interactions. Furthermore fieldworkers—as people whose background and training is familiar and known—may be considered to have inadequate technical knowledge about a study, even after training. All of these factors have important implications for building up of trust between research institutions and communities involved in research, and for the nature of support and supervision required for field workers.

The familiarity of the authors’ PDR variant approach to involving communities, and of the issues raised in the paper, underlines its value. Specifically, we support the need to take seriously the authors’ experiences of the strengths of involving community members as staff, while minimizing the range of ethical and practical problems that may arise. We would strongly support from our own experience the need for participatory training of staff from the outset, including training on what health research is and how participants’ rights are protected in research. Role plays and demonstrations based on local knowledge and experience can help to develop a range of strategies for field staff to cope with both expected and unexpected scenarios. We also support the authors in arguing that this training can and should be ‘two way’: the researchers learning about local priorities

and concerns, and responding to them. Introducing and ensuring there is good quality, supportive supervision of field staff is also obviously key and we agree that enabling fieldworkers to access counselors can be valuable not only in relation to highly sensitive research topics, but also for more mundane research projects in areas where there are high levels of poverty, morbidity and mortality (Molyneux et al. 2009).

We would add to the authors’ recommendations around working with locally recruited community based staff in several ways. Firstly, we argue that there needs to be a professionalization of this cadre of staff’s work; a fundamental recognition of the range of contributions that they make to research, and the highly skilled work that they conduct. Professionalization of their work requires careful consideration of level and form of remuneration, and consideration also of future career directions and training needs (see also Molyneux et al. 2009). Second, we feel that with the exception of the PDRs mentioned above, there should be a deliberate effort across all field workers to separate recruitment itself from interactions with one’s own close social networks, in order to minimize the potential ethical problem of exploitation. Thus for example while community based staff may be involved in explaining elements of a vaccine trial to their neighbours and friends, the final consent process should be overseen by a more senior or external trial team member. Third, our experience suggests that there needs to be careful attention to the recruitment process for this key cadre of staff. Employment in low income settings can be a highly contentious issue, and selection of inappropriate people or inequitable systems of selection can be damaging to both communities and research institutions. We recommend introducing systems that are open and transparent (as opposed to based on, for example, community leader recommendation) wherever possible. Fourthly, we suggest a need for very careful attention to the relationship between this staff group and research coordinators or principal investigators. Staff need to feel able to raise the concerns that they are facing in order to be able to resolve them, and to be reassured that refusals by community members are not only acceptable, but potentially indicative of an ability to make a choice.

Clearly recommendations around involving community members as research staff should not undermine or be considered as a substitute to a wider carefully considered set of community engagement activities which might be needed by a study. Staff roles around informed consent processes give important support to, but cannot meet, the wider ethical goals of community engagement. One example of community engagement that shows the way these can be linked is through activities involving PIs and research supervisors in directly interacting with study participants in their homes and communities. This creates visibility, builds trust in communication systems within research teams and allows leaders to see and feel the challenging situations that field staff experience. However, in many studies, there are a range of individuals who can be involved in studies as part of community engagement, for example

community health workers and community leaders and representatives (Marsh et al. 2008). We conclude by noting that, given the relative power some of these individuals have in communities, many of the strengths and challenges of embeddedness apply equally – if not more strongly - to these groups. ■

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