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Community Engagement and the Ethics of Global, Translational Research: A Response to Sofaer and Eyal

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In “The Diverse Ethics of Translational Research,” Neema Sofaer and Nir Eyal argue that ethical concerns about translational research, especially in global or transnational settings, have been based on studies of T1 research and that those objections do not apply to T2 research. They conclude that unlike T1 research, T2 research does not include the morally problematic features typically found in translational research: (1) special risks, (2) questionable benefits, (3) lack of informed consent, (4) financial conflicts of interest, (5) exploitation of global poor, and (6) increased disparities between developed and developing nations. From their examination of these six features, they develop a set of practical conclusions about funding and research oversight mechanisms.

Despite the strengths of the article in addressing a gap in the literature on research ethics and translational research, there is a marked absence: The voice of the global, or transnational, research participant. A consideration of how we ensure that research participants from among the global poor are heard is lacking in this discussion. This is troubling even for benign cases of T2 health services research. If a community will not or cannot use the health intervention or service because of a lack of infrastructure or a lack of trust in researchers and clinicians, then the research has provided no benefit. For example, researchers wanting to study the impact of pollution on the residents of Lawrence, MA, and their health assumed the community would willingly participate: The researchers did not work with the community to develop the study and were unprepared to answer questions about the selection of Lawrence as a research site and control of research samples and results (Silka et al 2008). Because they were incapable of providing sufficient information for informed consent, many residents refused to participate. When researchers fail to consider the concerns and needs of participants, especially those voiced by the global poor, even morally unproblematic health disparities and health services research might fail to meet ethical benchmarks and also fail to translate potentially beneficial interventions into practice.

One way to allow those voices to be present and considered when assessing the ethics of transnational, translational research is through the expanded use of community engagement techniques. Community engagement is a set of practices that creates mutually beneficial relationships between researchers and communities; these relationships are characterized by mutual respect between all parties and inclusive participation in decision making (Calleson, Jordan, and Seifer 2005; Green and Mercer 2001; Jones and Wells 2007). A range of community engaged research practices exists. At minimum, community-engaged research

occurs when researchers are “addressing a community-identified need, studying community problems and issues, and engaging in the development of programs that improve health” (Maurana et al. 2001, 215). Fully community engaged research occurs in community-based participatory research (CBPR), where communities are equal partners in determining research questions, identifying research methods, gathering data and presenting results (Green and Mercer 2001; Jones and Wells 2007; Ospina et al. 2004). In addition to receiving scholarly attention, funding agencies have begun providing guidelines—and more importantly, resources—for community engaged research because they recognize that engaging participants and communities enhances the potential to improve cross-cultural communication regarding research and its importance, to create and ensure the equity in research that is needed to improve health disparities, and to optimize the protection of research subjects (National Institutes of Health, 2009; CDC, 1997).

While community-engaged research does produce unique ethical challenges around issues of community representation, distribution of resources, and dissemination of sensitive information, most researchers have found these methods generally lead to robust ethical research practices (Brugge and Kole 2003; Marshall and Rotimi 2001). Ultimately, community engaged research practices can help address ethical concerns in global translational research like special risks, lack of informed consent, exploitation of the global poor, and increased disparities between developed and developing nations. While the special risks found in technologically intensive T1 research cannot be mitigated by community engagement, concerns about data ownership and confidentiality would likely be mitigated when the community is an equal partner of the researchers, especially in CBPR where they will play a role in disseminating research results. The lack of understanding that makes consent informed would potentially be minimized if communities are consulted from the beginning of the research process: Ideally, researchers would need to develop clear, cogent descriptions of their projects before the community and its representatives agree to collaborate further. Finally, global translational research using community engagement would produce agreements between communities and researchers that would provide long-term, enduring benefits to the community in the form of health services or money generated by the medical interventions produced by the researchers. While none of these positive aspects of community engagement can be absolutely guaranteed, community engaged research in developed countries has led to these results, and we believe that as long as researchers remain sensitive to the cultural issues that arise when researchers work across language and cultural barriers in developing countries similar benefits will accrue in global, translational research.

While we find Sofaer and Eyal's argument about the differences between T1 and T2 research compelling, we believe that they failed to identify a key strategy to ameliorate ethical problems in global, translational research. Community engagement allows for greater opportunities for dialogue between participants and researchers about research questions and increased transparency about methods and resulting products. These practices complement the practical suggestions Sofaer and Eyal make about regulatory oversight. While T1 and T2 research might require different levels of regulatory oversight and while different types of T2 research might also require different levels of oversight, all forms of global, translational research can benefit from practices like community engaged research that ensure the voices of Others, especially the global poor, are heard, and their ethical concerns and health needs are prioritized and that their concerns are taken seriously.

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