“You’ve Got to Understand Community”: Community Perceptions on “Breaking the Disconnect” Between Researchers and Communities

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PURPOSE

The Environmental Justice Partnership (EJP) was formed in 2003 to bring together researchers from Johns Hopkins and members of the surrounding urban community for increased, equitable partnerships and sustained dialogue, particularly in relation to research conducted in the local community. The EJP includes a Community Board of East Baltimore leaders and community based organizations, Johns Hopkins faculty and staff, and graphic art designers from the Maryland Institute of Art. In an effort to know how best to apply the principles of community-based participatory research (CBPR) to future research partnerships between Johns Hopkins and the local East Baltimore community, The EJP stressed the importance of learning community stakeholders experiences and views on research. Through this project, and in close partnership between the community and Johns Hopkins researchers, the EJP conducted focus groups with East Baltimore residents and interviews with other community leaders and representatives of community-based organizations. The goal of these focus groups and interviews was to learn experiences, attitudes, and recommendations about research in their community.

RECOMMENDATIONS FOR POLICY AND PRACTICE

Implementing CBPR guidelines equitably can be difficult and creates many challenges. The first challenge is to be correct in how to approach the community where the research is targeted. These challenges surface between researchers and communities when it comes to identifying the community leader or who speaks for the community. CBPR remains a work in progress because researchers have acknowledged that to do good research, finding and using the best approach to gain entry to a community is important. Communities have to see the need for the research, and the researcher needs to be able to deliver the research findings back to the participating community. To do this a working relationship must be established so that partners can learn about and understand each other’s needs. In addition, collaborative partnerships facilitate learning about the unique history of the community, its cultural values, and its priorities. In short, our research specifically found the following steps to help the process.

1. Researchers should do what they can to learn about the community, listen to community views and priorities, and try to understand the community.
2. Researchers should spend time in the community.
3. Researchers should increase how much they communicate with communities and should emphasize transparency.
4. Researchers should think about sustainability from the start and build capacity development into research projects.
5. Researchers should always disseminate their findings, through a variety of mechanisms.

Additionally, that community residents and representatives want to be more involved and want to ensure they are not exploited is consistent, not only with the principles of CBPR, but also with the growing ethics literature on respectful engagement of communities, especially underserved and/or disadvantaged communities. Indeed a small, but growing literature states that
researchers have responsibilities not only to minimize harm, engage in meaningful informed consent, and avoid exploitation of individual subjects, but that these ethics obligations apply to targeted research communities as well.

Knowing how to develop and define meaningful engagement or sufficient benefit to a research community is complex; an important first step, however, is recognizing such goals to be not merely aspirational, but morally mandated as well. It may be that community expectations for more are well founded, and it also may be true that the institution may do well to better publicize the contributions that it already makes, for example, through dissemination of research results.

Not only does increased dissemination improve visibility of researchers’ contributions, but it increases access to important information to prevent or treat health problems. In addition to dissemination, researchers should increase their interaction with community participants and residents as a whole during all stages of research. Interaction between researchers and community members often is constructive and positively viewed. The most negative impressions seem to come when rumors can continue and actual exchange is limited at best. This kind of interaction will also better guide researchers to make sure research is most appropriate, and meets needs of the community. Interaction will also help researchers to understand the context in which research is done and will help to know which avenues are best for dissemination. Additionally, academic institutions need to make greater effort to involve communities regularly in their community-based research to identify community priorities and concerns. Institutions may want to develop strategies for their affiliated researchers to facilitate partnership building. Especially for large academic institutions in urban settings, such efforts may help to bridge distance between researchers and community to promote the shared goal of improved public health.

**HOW FINDINGS SUPPORT RECOMMENDATIONS**

Recommendations come directly from the study participants suggestions. Through the conduct of eight focus groups and 17 interviews, this research project gave several East Baltimore residents and stakeholders the opportunity to reveal their views about research and how it can best be implemented. Consistently we heard that community interaction and involvement during all stages of research were critical, and attention to dissemination and sustainability afterward must be key components of any CBPR projects. In addition, participants gave specific advice on how to reach out to the community. For example, community representatives and residents suggested that researchers should walk around the community and listen to community priorities and needs. They also gave ideas on specific ways to disseminate information. For example, participants said face-to-face interactions or discussions were best, but that creating understandable materials was a key component to any educational campaign. Community stakeholders also suggested that researchers be honest and up front about their needs and limitations. Another important finding was that community residents with direct, personal experience with research tended to have more positive views about research than respondents with no personal experience. It would be important to learn if that finding holds true in other urban communities as well.