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JOURNAL DISCUSSION
Improving Institutional Review of Community-Based Participatory Research Applications
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Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *J Urban Health*. 2007;84(4):478-493.

Those who promote community-based participatory research (CBPR) have long known that there are obstacles to its wider adoption. For example, Ahmed and colleagues cite several "institutional barriers" to CBPR, which include the objectification of the community in research, a lack of respect for community knowledge, and a limited understanding of CBPR, along with the perception that it lacks rigor, a lack of CBPR researchers to serve as mentors, and a dearth of available grants and incentives [1].

While Ahmed et al. made a significant contribution to our understanding of the difficulties facing a researcher interested in CBPR, Flicker et al. have recast the discussion and changed the way we should look at institutional influences on CBPR in their 2007 article "Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards" [2]. The article reports on a study in which the authors performed a content analysis of forms and guidelines used by institutional review boards (IRBs) and research ethics boards (REBs) in the United States and Canada, respectively. Their sample comprised 30 institutions that offered graduate-level public health training, due to their belief that institutions with schools of public health would be the most sympathetic to CBPR.

Flicker et al. found that the forms used by the IRBs and REBs they studied tended to favor a traditional biomedical research framework, and they concluded that, by taking a narrow view of research from the outset, ethics boards could unknowingly harm communities by treating traditional forms of research as the *de facto* standard. They close their article by offering suggestions for more CBPR-friendly language for use in IRB and REB forms and policies [2].

Ahmed et al. were offering new ways to think about barriers to CBPR, thus their recommendations were necessarily vague—"redefine scholarship" and "hire CBPR champions," for example [3]. Flicker et al. change the tone of the discussion by presenting specific instances of a real institutional bias favoring traditional research that not only have the potential to dissuade researchers from using CBPR, but also might hinder IRBs in determining what ethical CBPR actually is. While Ahmed et al.

do not discuss the bias present in the IRB approval process, the recommendations Flicker et al. suggest offer a concrete way to begin to address some of these concerns.

The alternative language Flicker et al. put forth is meant to redress specific CBPR-related deficiencies that the authors found in the IRB/REB forms that they studied. For example, none asked about community consent. Only three featured questions concerning power imbalances between researchers and participants. Four listed community risks and benefits, but phrased them as broadly "social" rather than as specific to a particular community. Only 5 of the 30 had questions about data dissemination or training for individuals who would have access to sensitive study-related information. Nineteen mentioned protecting vulnerable populations, but those primarily featured lists of "protected populations" recognized in the Code of Federal Regulations, Title 45, Part 46 on protection of human subjects [4]. More than half asked about sample size, but none wanted justification for inclusion or exclusion criteria.

Flicker et al. make the following recommendations for improving the CBPR approval process:

1. IRBs and REBs engaged in reviewing CBPR (and other community-based intervention) grants should be provided with basic training in the principles of CBPR.
2. IRBs and REBs should mandate that CBPR projects seeking ethical review must provide signed terms of reference or memoranda of understanding. These should clearly outline the goals of the project, principles of partnership, decision-making processes, roles and responsibilities of partners, and guidelines for how the partnership will handle and disseminate data.
3. IRBs and REBs should require researchers conducting CBPR to document the process by which key decisions regarding research design were made and how the communities most affected were consulted [5].

They also put forth alternatives for such IRB language as:

> Describe how and by whom participants will be approached and recruited. Include copies of any recruiting materials (e.g., letters, advertisements, flyers, telephone scripts). State where participants will be recruited from (e.g., hospital, clinic, school) [6].

They suggest that it could be changed to "What provisions have you put in place to ensure culturally-relevant and appropriate recruitment strategies and materials"[6]?

Another traditional item on an IRB approval form might be "Describe exactly how the research will be carried out" [6], for which the authors suggest the following alternatives:

> How will the community be involved in the research? At what levels?
> What training or capacity-building opportunities will you build in?

Will the methods used be sensitive and appropriate to various communities (consider literacy issues, language barriers, cultural sensitivities, etc.)? How will you balance scientific rigor and accessibility [6]?

Flicker et al. believe their recommendations will help IRBs and REBs to review CBPR protocols more effectively, remove some of the obstacles facing CBPR researchers in getting IRB or REB approval, and expose other researchers to CBPR themes and concerns by default when they use the same approval process [2].

The authors have made a valuable contribution to the field of CBPR. Changes in form and guidance language that nudge investigators to think about CBPR are worthwhile. More importantly, they continue the discussion concerning how institutional policies and guidance impact CBPR. Taken in that larger context, Flicker et al. build on the earlier conceptual work of Ahmed et al. and begin to give us concrete examples of ways that we can begin to remove barriers to CBPR practice.

References

1. Ahmed S, Beck B, Maurana C, Newton G. Overcoming barriers to effective community-based participatory research in US medical schools. *Educ Health (Abingdon).* 2004;17(2):141-151.
2. Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *J Urban Health*. 2007;84(4):478-493.
3. Ahmed et al., 145.
4. Protection of human subjects. 45 CFR 46. http://ohsr.od.nih.gov/guidelines/45cfr46.html. Accessed January 18, 2011.
5. Flicker et al., 487.
6. Flicker et al., 488.

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