

A National Collaborative Study of Community-Based Processes for Research Ethics Review

Community-based participatory research (CBPR) is increasingly recognized by NIH, researchers and community groups as a critical approach to understanding and addressing racial, ethnic, socioeconomic and environmental health disparities.¹⁻⁵ In CBPR, community members and researchers collaborate to conduct research that builds capacity, leads to knowledge that directly benefits communities and influences policies that affect health. Numerous studies have demonstrated how CBPR can help to translate research into practice and policy by engaging members of populations that are affected by the health conditions being studied as partners in the research process.⁴⁻⁶ CBPR is especially well-suited to overcoming deeply engrained histories of mistrust that many vulnerable populations have of health research.⁷ Indeed, the building of mutually respectful relationships between researchers and community members is not only central to countering historical trauma related to research,⁷ but also the validity and utility of research findings.⁵

With the substantial federal investments being made in CBPR, more community groups are being approached by researchers who want to conduct research in their communities, and more community groups are initiating their own research.⁸ On one level, the funding for CBPR is a welcomed sign that it is being viewed as a rigorous, legitimate and effective approach to research. On another level, it raises genuine concerns in communities that have been harmed by research and have experienced CBPR in practice as no more than being expected to recruit participants into investigator-initiated and designed clinical trials.⁸ To ensure the ethics and integrity of the research in which they and their communities are engaged, a growing number of community groups have developed their own research ethic review processes that operate independently or in conjunction with institution-based Institutional Review Board (IRBs).⁹⁻¹² In the first systematic study of these processes, we identified 109 community groups across the U.S. with such processes in place, described their challenges and benefits, and documented the ethical issues they consider that institution-based IRBs normally do not.^{13,14} While our study findings revealed the important role these processes could play in ensuring the ethics and integrity of CBPR, their actual contributions are not known. In the proposed study, we are collaborating with five community-based processes for research ethics review identified through our earlier study in order to understand the research ethics and integrity issues that arise in (a) the research proposals they review; (b) institution-based IRB reviews of the same proposals; and (c) the actual conduct of the research reviewed.

The specific aims of our study are:

1. To articulate the research ethics and integrity considerations, experiences and outcomes of community-based processes for research ethics review. We will accomplish this aim by analyzing data obtained through observation of a review process meeting, structured interviews, focus groups and reviews of documents from community groups that operate these processes.
2. To assess similarities and differences in the research ethics and integrity issues raised by community-based processes for research ethics review and those raised by institution-based IRBs that review the same study proposals. We will accomplish this aim by conducting a content analysis of the specific feedback documents on study proposals that have undergone review by a community-based process for research ethics review and an institution-based IRB.
3. To determine the research ethics and integrity issues experienced by research teams whose study proposals were approved and compare those with the issues raised in the reviews. We will accomplish this aim by conducting a content analysis of structured interviews and focus groups with community and academic members of research teams whose approved studies are underway and comparing the findings with the content analysis of the feedback they received on their study proposals.
4. To identify and disseminate promising practices for assuring the ethics and integrity of CBPR to community groups, researchers, institution-based IRBs, funding agencies and policy makers. We will accomplish this aim by synthesizing findings from across the case studies into practical, applied products that are extensively peer reviewed by members of the key audiences we aim to reach prior to their dissemination.

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For More Information

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