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Balancing Scientific and Community Interests in Community-Based Participatory Research

David B. Resnik, JD, PhD and

National Institute of Environmental Health Sciences, National Institutes of Health, Johns Hopkins University.

Caitlin E. Kennedy, PhD., MPH

Department of International Health, Johns Hopkins Bloomberg School of Public Health, Johns Hopkins University.

Abstract

Community-based participatory research is an approach to studying human populations that emphasizes extensive partnerships between researchers and community members. While there are many advantages of this approach, it also faces a number of conceptual and practical challenges, one of which is managing the conflict that sometimes arises between promoting scientific and community interests. This essay explores the potential conflict between scientific and community interests in several different stages of community-based participatory research, including research design, data interpretation, and publication, and makes some suggestions for practice and policy. To manage potential conflicts between scientific and community interests, investigators and community partners should enter into written agreements at the beginning of the study. In some cases, it may be necessary for a third party, such as a review committee from a supporting institution, the community, or a funding agency, to help investigators and community partners resolve disagreements. It may also be useful, in some situations, to publish a dissenting opinion when investigators and community partners cannot agree on how to interpret findings resulting from a study. These strategies may help address some of the challenges of implementing community-based participatory research.

Keywords

community based participatory research; ethics; openness; objectivity; publication; data sharing; data interpretation

Introduction

Community-based participatory research (CBPR) is an approach to studying human populations that emphasizes extensive partnerships between researchers and members of the community in all phases of investigation (O’Fallon and Dearry 2002). In the last decade, investigators have used the CBPR approach in epidemiology, genetics, clinical trials, public health, psychiatry, environmental health, health education, and other areas of biomedical and behavioral research (Sharp and Foster 2002, Savage et al. 2006, Horowitz et al. 2009, Shetgiri et al. 2009, Rhodes et al. 2009). CBPR has several advantages over traditional

approaches to research, which do not require extensive involvement of community members. CBPR can help to improve protections for human subjects and communities, build trust between investigators and community members, and enhance protocol development and implementation (Weijer and Emanuel 2000, O'Fallon and Dearry 2002, Dickert and Sugarman 2005, Marshall and Berg 2006, Flicker et al. 2007, Wallwork 2008, Watkins et al. 2009). CBPR may also improve the quality, validity, and relevance of research findings, and it can empower community members to advocate for program and policy changes that may be indicated as a result of the research (Israel et al. 1998).

Though CBPR has many advantages over traditional approaches, it is a labor-intensive activity that requires considerable time, effort, and resources. CBPR investigators face a number of conceptual and practical challenges, such as defining the community, choosing community partners, learning about the community's needs and traditions, educating the community about the research methods and questions, managing community advisory boards, dealing with disagreements with community partners, training research staff in CBPR, and finding sufficient funding and resources to conduct the research (Gilbert 2006, Flicker et al. 2007, Kennedy et al. 2009, Horowitz et al. 2009).

One of the challenges inherent in CBPR is managing the conflict that sometimes arises between the interests of scientists and the interests of community members. For example, if a study yields data or results that could harm the community or its members if disseminated publicly, investigators and community partners must balance the interests of the community and the interests of science when deciding whether (or how) to disclose this information (Weijer and Emanuel 2000, Dickert and Sugarman 2005). Investigators and community partners may disagree on how to strike an appropriate balance between scientific and community interests. This essay will explore these conflicts and make recommendations for practice and policy.

Community-Based Participatory Research

CBPR evolved in the 1990s in response to the growing recognition that investigators have ethical obligations to protect the communities they study from harm and promote their interests (Weijer and Emanuel 2000, Dickert and Sugarman 2005, Gilbert 2006). The regulations for reviewing research with human subjects in the U.S. and other countries protect the rights and welfare of individuals, not communities (Gilbert 2006). Accordingly, committees that oversee research with human subjects, such as institutional review boards (IRBs), focused on protecting individuals, not communities (Gilbert 2006). Many commentators, community activists, and researchers argued that ethical principles, such as justice and beneficence, support an obligation to protect communities from harm, even if the regulations do not specifically require it (Weijer and Emanuel 2000, Resnik and Sharp 2006). As investigators became accustomed to the idea of collaborating with communities, they began to realize that this strategy also makes sense from a scientific point of view. Partnering with communities can enhance the quality and effectiveness of research because community leaders and members are a valuable source of information and expertise (Israel et al. 1998). Community partners can also help to recruit human participants, reach out to disadvantaged or minority groups, and foster public support for research (Israel et al. 1998, O'Fallon and Dearry 2002).

This new approach to involving communities in research was variously described as community participatory research, community collaborative research, community involvement in research, and community consultative research before the name "community-based participatory research" became the preferred descriptor (Israel et al.

1998, Sharp and Foster 2000, Wallwork 2008). CBPR is guided by six principles (O’Fallon and Dearth 2002):

- Research projects involve active collaboration with community partners at all stages of research.
- Community participants and investigators learn from each other.
- Research projects address needs identified by the community.
- Results are disseminated in terms that are useful to the community.
- Research and intervention strategies are culturally appropriate.
- The community is the unit of identity.

Different models of CBPR involve community members in various ways. The simplest model is for investigators to work closely with community leaders and representatives, hire community liaisons as research staff, and hold focus groups or educational sessions with community members. In more complicated models, investigators form community advisory boards and/or community-based IRBs, which provide expertise or oversight (Gilbert 2006, Watkins et al. 2009, Kennedy et al. 2009).

Scientific Interests

Scientists have a number of different interests related to the conduct of research, including personal interests, such as credit, prestige or status; financial interests, such as career advancement, intellectual property, or stock ownership; social and political interests, such as environmental protection or public health promotion; and scientific interests (Latour and Wolgar 1986, Hull 1988, Longino 1990, Kitcher 2001, Resnik 2007). While it is important to understand all of the different interests that scientists may have related to research, in this essay we will focus on their interests as members of scientific professions.

A scientist’s primary interest as a member of a scientific profession is to advance human knowledge by describing, explaining, and predicting natural phenomena and discovering relationships between natural structures, events, and processes (Kitcher 2001). Scientific knowledge is valued for its own sake as well as for its practical applications in informing public policy and in providing the theories, concepts, and laws that are used in engineering, medicine, public health, biotechnology, aeronautics, agriculture, and many other fields (Kitcher 2003, Resnik 2007, 2009a, Pielke 2007).

To advance human knowledge, it is necessary for scientists to follow epistemological and ethical norms (or rules) for the conduct of research (Shamoo and Resnik 2009, National Academy of Sciences 2009). Adherence to epistemological and ethical norms is important for ensuring that research results are reliable and objective and that scientists are trustworthy (Resnik 2007). Trust is part of the ethical foundation of scientific research: scientists must be able to trust each other and society must be able to trust scientists (National Academy of Sciences 2009). Serious breaches of research norms, such as data fabrication, falsification, or suppression, undisclosed conflicts of interest, or abuse of human or animal research subjects, undermine the trustworthiness of scientists and the scientific profession itself (National Academy of Science 2009).

Three of the most important norms for scientific inquiry are honesty, openness, and objectivity (Shamoo and Resnik 2009). Honesty obligates researchers to be truthful in all scientific communications, including grant applications, presentations, and publications. Investigators should not fabricate, falsify, or deceptively manipulate data. Openness requires researchers to share data, results, and methods with other researchers and society. Scientists

should publish their work, not suppress it. Objectivity is the idea that beliefs, hypotheses, and theories should be based on evidence and rational argument instead of personal, social, political or other biases (Popper 1959, Kitcher 1993, Haack 2003, Resnik 2007). Scientists should be aware of how biases may affect their research and they should try to minimize their impact.

Although objectivity is one of the most important norms for scientific inquiry, scientists often fail to live up to this ideal. A variety of biases can influence research design, data analysis, publication, peer review, and other aspects of research (Kuhn 1970, Hull 1988, Longino 1990). For example, a large body of literature has documented how pharmaceutical, tobacco, and other companies have suppressed data and manipulated scientific research (Krimsky 2003, Angell 2004, Resnik 2007, Michaels 2008). Studies have also shown how racial, ethnic, and gender biases can affect research (Longino 1990, Gould 1981). Biases may operate at a conscious or subconscious level: investigators may not even be aware of how biases affect their work (Krimsky 2003, Resnik 2007, Institute of Medicine 2009). Even though unbiased research is often difficult to achieve, scientists should still strive for objectivity and should not intentionally skew or distort their research (Kitcher 1993, Haack 2003, Pielke 2007, Resnik 2007, 2009a).

CBPR and Scientific Interests

Following epistemological and ethical norms that help to advance human knowledge can be challenging when working for organizations or collaborating with partners who have interests that can be affected by the outcome of the research. A great deal of scholarship and commentary on research integrity in the last decade has focused on how collaborations with industry can impact scientific investigation, but other sorts of arrangements can produce similar results, including collaborations with communities. Community partners often have specific interests related to the outcome of research. First, though most communities have an interest in publishing research about the community, they also have an interest in protecting the community from adverse publicity, stigma, discrimination, and other harms that could result from the publication of findings that report medical or social problems in the community, such as HIV/AIDS, alcoholism, prostitution, cancer, genetic diseases, etc. Second, community partners have an interest in procuring benefits for the community, such as health care, education, environmental remediation, jobs, money, and intellectual property. (Sharp and Morris 2002, Dickert and Sugarman 2005, Minkler 2004, Flicker 2007). Though investigators may have similar interests and ethical obligations toward communities, these interests are counterbalanced by their interests in the advancement of science, publication, and career advancement (Hull 1988). When community members become part of the research team, as is the case in CBPR, there is the potential that their interests may interfere with scientific ones.

In CBPR, community partners are involved in all stages of investigation, including research design, subject recruitment, data analysis and interpretation, dissemination of findings, and implementation of policy. It is possible, therefore, that biases resulting from the interests of community partners could impact research, and that community partners and investigators may disagree about important issues pertaining to scientific inquiry. These disagreements may pit the interests of the community against the interests of scientists. It is also conceivable that investigators' objectivity will become compromised as they work closely with community partners and identify with their interests. This would be similar to the loss of objectivity that sometimes occurs when investigators become closely aligned with the interests of industry sponsors or collaborators (Krimsky 2003). Scientific organizations, federal agencies, and commentators have recommended a variety of strategies for minimizing the impact of industry influence on research, such as management of conflicts of

interest, independent review of research design and data analyses, careful attention to agreements that define publication rights and access to data, and registration of clinical trials in public databases (Krimsky 2003, Institute of Medicine 2009). Some of these strategies could also be applied to CBPR.

Study Design

Community interests may clash with scientific interests at the beginning of the research process, during the design of a study. One of the most important issues in planning a research project is determining the questions that the study will attempt to answer as well as its aims and objectives. By definition, CBPR addresses questions that are relevant to the needs of the community. However, community partners and investigators may have different perspectives on how research questions should be developed and framed, even though they both agree that questions should address community needs. Investigators may place a greater emphasis on designing studies that focus on important scientific and public health issues, while community partners may be more concerned with designing studies that focus on meeting community values or perceived community needs. For example, in an HIV treatment study in sub-Saharan country, investigators might be interested in studying the effectiveness of anti-retroviral drug therapy, while community partners might be more interested in examining the effectiveness of traditional, herbal remedies (Mills et al. 2005). Further, community partners may be more concerned with diseases that have distinct, perceivable signs and symptoms or acute onset, such as heart attacks, and less concerned with diseases or conditions that have generalized signs and symptoms, such as depression, or whose effects are not yet visible, such as Alzheimer's dementia. It is also possible that investigators may be interested conducting research that advances their career goals but does not offer significant benefits to the community.

It is important to note that selecting a research question is never a purely objective decision, because this choice always reflects the interests of the questioner(s), e.g. the investigator, institution, or research sponsor (Longino 1990, Resnik 2007). For example, a pharmaceutical company may be interested in comparing its new drug to competing products, a pesticide manufacturer may be interested in demonstrating that one of its chemicals is safe for humans when applied at a particular dosage, etc. Even though the choice of a research question always reflects the interests of the questioner(s), this type of bias should still be appropriately managed in CBPR, so that neither the interests of community partners nor the interests of investigators dominate the planning process. The research should have value to science and to the community.

Disagreements between community partners and investigators may also occur when choosing the methods used to answer research questions. Community partners may be interested in using methods that maximize medical or other benefits to community members that participate in the research, but these methods may compromise the scientific value of the research. For example, randomizing research subjects to different treatment groups (e.g. experimental vs. control) in a clinical trial helps to minimize biases related to human choices, beliefs, or other factors. Randomization is appropriate when there is genuine uncertainty concerning the merits of the different treatments. If a trial is not randomized, investigators might assign the patients with the best prospects to the experimental group, which could skew the outcome of the trial (National Cancer Institute 2004). Although randomization helps to minimize bias, community partners might prefer to allow research subjects to choose their own treatment in a clinical trial, because this would enhance their autonomy and might help to reduce risks (Marquis 1983). Non-randomized trials may be appropriate when investigators are interested in examining the long-term benefits and risks of standard therapies.

Community partners and investigators may also disagree about using placebo control groups in clinical trials. Placebo-control groups are used when it is necessary to determine whether an experimental therapy is superior to a placebo, such as situations in which there is no effective therapy or the standard therapy is barely more effective than a placebo (Emanuel and Miller 2001). The use of placebos is unethical when an effective therapy exists, according to some, because giving these subjects a placebo would violate the physician-investigator's duty to provide patients with optimal medical treatment (Miller and Weijer 2006). Many commentators argue, however, that it can be ethical to use placebos when an effective therapy exists, provided that subjects in the placebo group are not likely to suffer permanent harm, a placebo control group is necessary to achieve scientific rigor, and the clinical trial addresses an important public health question (Emanuel and Miller 2001). Since biomedical researchers, statisticians, policy analysts, and other commentators sometimes disagree about using placebos in clinical trials, it is likely that community partners and investigators will also disagree about the use of placebos, pitting the interests of the community against the demands of scientific rigor.

Disagreements may also arise when research does not involve a clinical trial or other intervention but involves observation of factors related to the health of the community, such as environmental exposures, diseases, and genetics. Community partners and investigators may disagree about the outcomes that should be measured, the methods used to measure outcomes, and returning research results to human subjects (Resnik 2009b).

When investigators and community partners have differences of opinion about the questions that will be addressed or the methods that will be used, they should work together to reach mutually acceptable solutions that promote good science and address important community values (Minkler 2004). In most cases, investigators and community partners should be able to design studies that satisfy their different goals. When they cannot reach consensus on important issues related to study design, it may be useful to allow an independent party, such as a review committee established by the research sponsor, the community, or a supporting institution, to mediate the dispute.

Data Interpretation

Once data collection is complete, disagreements may also arise concerning the interpretation of the data (Minkler 2004, Flicker et al. 2007). Data interpretation is often far from straightforward, because there may be several different ways of interpreting the data: the same dataset may be compatible with different hypotheses, theories, or explanations (Kitcher 1993, Haack 2003). For example, in the 1950s, numerous studies linked smoking to lung cancer, but many reputable scientists did not agree with this interpretation of the data, and general acceptance of the hypothesis that smoking causes lung cancer did not occur until the 1964 Surgeon General's report (Brandt 2009).

Community partners and investigators may disagree about how to interpret the data generated by a study. Community partners may endorse a portrayal of the data that is favorable to the community, while investigators may endorse a rendering of the data that is candid and neutral, regardless of how it could impact the community. For example, suppose that a CBPR study demonstrates different rates of HIV infection among different racial or ethnic groups in a community (Harawa et al. 2004). Community partners and investigators might disagree about the role of race or ethnicity in HIV infection, and whether other factors, such as income, education, culture, substance abuse, sexual preference, or social standing, play a more important role (Harawa et al. 2004). Community partners might favor an interpretation of the data that minimizes the role of race or ethnicity, for example, to avoid stigma or discrimination against the community (Minkler 2004).

Investigators and community partners who disagree about data interpretation should work together to reach mutually acceptable solutions that promote good science and address community concerns (Minkler 2004). If they cannot reach consensus about data interpretation issues, they could ask a third party to mediate their dispute, or, as a last resort, they could publish different interpretations of the data (Flicker et al. 2007). For example, an article reporting the results of a CBPR study could include the majority view's interpretation of the data as well as an addendum that reports the minority position, or a separate commentary could be published that presents an alternative view of the data.

Publication

Community partners and investigators may also disagree about issues related to the publication and dissemination of data and research results (Weijer and Emanuel 2000, Sharp and Foster 2000, 2002, Minkler 2004, Chen et al. 2006, Flicker et al. 2007). As noted earlier, community partners may oppose dissemination of findings that could cause harm to the community, which runs contrary to the scientific ethic of openness. Sometimes it may be possible to protect the community from harms related to publication by removing information that could be used to identify the community, such as the location of the community or demographic characteristics of the population. However, removal of identifying information may compromise the scientific value of the data, because other investigators may need the this information to review the research, analyze the data, replicate experiments or studies, or generate new hypotheses or theories (Minkler 2004, Flicker 2007). In many cases, removal of identifying information would completely vitiate the scientific value of the study because the identity of the community is inherently linked to the research questions. For example, it would not be possible to remove identifying information from a study of breast cancer genetics of Ashkenazi Jews without rendering the data and results virtually useless (Minkler 2004).

Some commentators have suggested that the best way to deal with questions related to the publication of research results is for investigators and community partners to reach a formal (written) agreement, at the onset of the study (Weijer and Emanuel 2000, Flicker et al. 2007, Minkler 2004, Horowitz et al. 2009). These agreements should address key issues related to publication and dissemination, such as drafting and review of manuscripts and press releases, authorship, timing of publications, venues for publications, sharing and storage of samples and data, disclosure of funding sources and conflicts of interests, and measures taken to protect the community from harm, such as removal of identifying information. Though written agreements may seem cumbersome and legalistic, they can be useful in establishing expectations up front and assuring both investigators and community partners that their expectations will be addressed. Agreements can be modified if warranted by the circumstances of the research.

Conclusion

Community-based participatory research is a valuable approach to studying human populations because it can enhance protections for human subjects, benefit communities, improve protocol design and implementation, build trust between investigators and the people they study, and foster public support of research. Though CBPR has several advantages over approaches to studying human populations that do not have significant involvement from community members, one of the challenges of CBPR is balancing scientific and community interests. Conflicts between scientific and community interests may arise at several stages of investigation, including research design, data interpretation, and publication. To manage these conflicts, investigators and community partners should consider entering into written agreements at the beginning of the study concerning key

issues related to research. In some cases, it may be necessary for a third party, such as review committee from a supporting institution, the community, or funding agency, to help investigators and community partners resolve disagreements. It may also be useful to publish a dissenting opinion, when investigators and community partners cannot agree on how to interpret findings.

While this commentary has explored some of the ethical and methodological dilemmas that can arise in CBPR, more research is needed. In particular, it would be useful to interview investigators and community partners involved in CBPR to understand their perspectives on these issues, e.g. whether they have had any conflicts over research design, data interpretation, publication or other issues relating to the conduct of research, and how they have resolved these conflicts. Additional research could provide useful guidance and identify best practices for CBPR to further improve this already valuable approach.

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