Identifying the Challenges in Community-Based Participatory Research Collaboration
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The modern framework for consent and research is, like much of western philosophy, based upon the individual [1]. Individuals must be informed about the risks and potential benefits of involving themselves in research, and they must consent, individually, to participating in such research. As John Donne wrote, however, “no man is an island” [2], and, in many cases, it is communities as much as individuals that share the risks and benefits of research.

In recent years, an understanding of the importance of engaging communities in research has grown. A widely discussed model for engaging communities is community-based participatory research (CBPR) [3]. This model pairs academic researchers and community members; both partners should have active roles in shaping the research’s aims, design, and implementation.

In theory, CBPR offers benefits to academic researchers, the community involved in the research, and individuals in the community. Researchers may benefit from a better understanding of the community, allowing for better research design. The community can help shape research design and ensure that the actual needs of the community are taken into account. Individuals may have the opportunity to participate in research they would not have known about except through a community organization, and the community may empower individuals to share their ideas and concerns about the research. In many cases, the community may receive direct benefits during the study (e.g., through greater access to health care) and afterward, from greater understanding of cause-effect relationships the study has uncovered, increased attention to preventing or managing problems affecting the community, and so on.

In practice, however, CBPR often differs from this ideal: the demands of academic research, such as including a control group in many study designs, may not be liked or tolerated by some communities, and researchers may not be able (or willing) to accommodate all the needs of the communities they wish to study. Misunderstandings about the goals, benefits, or process of research can strain—or even sever—the relationship between communities and researchers.
Careful planning, with discussions and shared decision making, is therefore essential before engaging in community-based research. In “The Challenges of Collaboration for Academic and Community Partners in a Research Partnership,” Ross et al. provide a useful guide to ensuring that the partnership is successful. The authors helpfully organize the article along the lines of an actual research project, from finding a community partner or researcher, developing and conducting the research, and disseminating findings. They have produced a document that is easy both to read and to browse, and it is clear they endeavored to make their discussion useful for both professional academics and prospective community partners.

Ross et al.’s primary advice is that, because trust is essential for a successful partnership, open communication and planning in advance of the start of work is crucial. Their “points to consider” in each section ask important questions that serve as starting points for important discussions between researchers and community partners. Although some of these ideas seem relatively intuitive and straightforward, others might not be at all obvious to researchers or communities embarking on their first CBPR project. For example, in addition to describing the risks to individuals and communities who choose to participate in the research, Ross et al. also ask readers to consider the risks to “non-participating community members” [4].

This highlights an important difference between community-based research and traditional research. It is possible to imagine situations in which individuals who are not eligible or who elect not to participate in the research find their ties to the community weakened or their voice in the community marginalized. Risks such as these, which occur only in community-based research, may be easy to overlook for researchers trained in the more traditional, individual-based human subjects research.

The shift from screening individuals to participate in research to evaluating whether a community is suitable for participation requires a number of additional steps. Ross et al. differentiate between structured communities (they give the example of a church group) and unstructured communities that may need to be structured to some extent prior to conducting research (they give the example of evaluating health care needs of abused women) [5], noting that there may be concerns of legitimacy and agency when a community is fundamentally unstructured.

What Ross and her coauthors do not provide, however, is advice on overcoming many of the challenges they identify. Although an issue can be identified in a bullet point, fully understanding it is more difficult, and crafting a solution can prove to be even more difficult. After reading much of Ross et al.’s advice, the reader is left asking the question “how?”

For example, one of the authors’ points for community consideration in finding an academic research partner is “Does the academic researcher have the skills, experience, and resources necessary for the specific research project?” By definition, community partners lack the academic skills, credentials, and experience to conduct the research themselves. Research on jurists’ interpretation of expert testimony
shows that nontrained members of the public are not able to determine the qualifications of an expert effectively [6]. In this light, it is unclear how the community is supposed to evaluate the credibility of researchers. There is evidence that in such situations, people rely on simple heuristic clues: does the person look, sound, and act the way one would expect a creditable expert to look, sound, and act [7]?

Questions like this highlight the larger issues of power imbalance that may occur between researchers and members of the community. While an equal partnership between researchers and the community is a goal of CBPR [8], it is unclear whether such a goal is actually attainable and whether communities ultimately benefit as much as possible from such research [9]. As Ross et al. note, in many cases, only the researchers are eligible to be principal investigators, given the demands of the grant award process [10]. Even if money is supplied to community organizations, as the authors suggest may be possible, this may understandably be viewed by community participants as money from the researcher-partners given to the community-partner, a “handout” instead of an equal share.

Of the solutions that Ross et al. do propose, some seem made to contain legal liability rather than to foster trust and active partnerships. They propose, for example, documenting agreed-upon terms in a memorandum of understanding or other written document “delimitating the expectations of both parties and documenting the terms of agreement” [11]. Given that researchers are almost certainly more able to envision what activities will actually need to occur through the course of the research, such a document may well conform more to the desires and expectations of the researchers than of the community, which will probably be experiencing the research process for the first time.

In conclusion, although the promise of partnership in CBPR is tantalizing, careful consideration and work are required. Ross and her coauthors helpfully outline many of the concerns that must be addressed, but many of the questions they pose do not have easy answers, and it is unclear how well communities will be able to answer the questions themselves if called upon to become research partners. Even with the careful planning that Ross et al. advocate, CBPR may still fall well short of being a truly equally empowered partnership.

References


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