

Virtual Mentor

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CLINICAL CASE

Physician, Researcher, Neighbor—Conflicting Roles in Community-Based Participatory Research

Commentary by Carla C. Keirns, MD, PhD, MSc, and Florence Thiclin

Dr. Banks moved to the mixed-income neighborhood where he also works at the Dunlap Community Health Center. Outside of the clinic, he serves as a member of the neighborhood association and is getting to know many of his neighbors, little by little, through the association and potlucks and chance meetings in the grocery store. At the clinic, he's asked to be part of a community-based participatory research project to study "Safe Sex Practices in Dunlap, Zone 4," a topic he's long been interested in exploring. He anticipates that recruitment will go fairly easily since he has begun to build relationships within the community. When recruitment begins, he notices that he is getting strange looks from his neighbors, and his relationships with them are starting to appear strained.

After a couple of weeks of low recruitment numbers, Dr. Banks decides to offer an incentive. Quite a few people from the neighborhood consent to participate after word spreads of the grocery store gift card given upon completion of the 1-hour interview. His first several groups of participants are neighbors on his block, some of whom are married. Each interview is more difficult than the one before it, and he finds that he is left with little data after each.

After a few more unsuccessful interviews, Dr. Banks brings the matter up with his colleagues and community members. One whom he really trusts says, "Dr. Banks, you have to choose. Be a neighbor or be a physician-researcher. No one will open up to you as long as you are both. People feel that you might share whatever you learn about individuals with other neighbors."

"But it was clear on the consent form that no data on individuals would be released," Dr. Banks says.

"That's all fine," says his colleague, "But people don't trust you with their personal information. They don't want you to know."

Dr. Banks feels pulled in two directions. He doesn't think that data he's collected so far will be at all helpful. He really cares about the work he's doing and wonders if there is a way to exist in both worlds.

Commentary 1

by Carla C. Keirns, MD, PhD, MSc

Dr. Banks wants to improve the health of his community, reduce health disparities, contribute to scientific knowledge, and advance his career. As a physician-researcher, he hopes to do all of these through his personal clinical services at the Dunlap Community Health Center and community-based participatory research on the health challenges of his community. By moving into the neighborhood, going to potlucks, and getting to know the community, he has done all the right things to start a practice in community-based primary care and projects in community-based participatory research [1].

Physician, Researcher, or Neighbor?

The problem Dr. Banks faces now is one of role confusion [2]. As he was told, “Be a neighbor or be a physician-researcher. No one will open up to you as long as you are both.” The social rules of neighborly interaction vary from one community to the next, but generally include knowing each others’ spouses and children and may include school, church, or other community activities. At the same time, there’s an implicit understanding of respect for privacy: the role of neighbor is not easily compatible with knowledge of the sexual activities of everyone on the block.

In addition to the conflict between neighbor and researcher, Dr. Banks also faces a conflict between his roles as neighbor and physician, and another between his roles as physician and researcher [3]. Physicians working in close-knit communities, whether small towns or urban neighborhoods, have to manage relationships with people who may be simultaneously patients and neighbors, friends, and business associates. Managing these multiple roles to protect confidentiality and trust and avoid exploitation or misunderstanding requires balancing responsibilities and careful communication [4]. The intertwining of personal and professional relationships may sometimes require the physician to hold himself or herself apart from highly charged social interactions [5], particularly dating and sexual relationships, which are often most prone to miscommunication for both patients and physicians [6]. This may be particularly challenging for the physician who is unattached and has to decide whether to date within or only outside of the community.

“Are you my doctor or are you a researcher?” Are you advocating for the individual patients in the study, for scientific truth, for the pharmaceutical company or agency paying for the research, or for something else? These conflicts between loyalty to research participants and other stakeholders are often more apparent to community partners than they are to the researchers themselves. I have sat in research planning meetings in both the U.S. and Africa in which community members initiated explicit discussions of the incentives for researchers, asking about who was paying for research, what questions are being asked, who chose those questions and why, and what was the value to the individual researchers of doing and publishing the research in terms of their careers. These women—and they were all women, usually teachers

or nurses professionally—representing themselves and their communities, brought with them a more sophisticated awareness of the history of relationships between poor communities and researchers [7, 8] than the researchers themselves often did.

In Philadelphia, for instance, there is widespread community awareness of dermatologic and pharmaceutical research conducted at Holmesburg Prison that left many men with severe burn-like scars, and generated new products like Retin-A for acne [9]. Researchers, most of whom were raised or trained elsewhere because of the social dynamics of academic careers, do not learn of this community history from their fellow researchers and mentors, nor from their local neighbors. Community representatives frequently argue that researchers have been studying their communities for decades without either finding practical solutions to the health problems at hand—such as studies of diabetes in Native American communities [10-12]—or helping the communities gain access to health care, including the benefits of both the research in question and prior community-based research [13]. What is remarkable is not that the community representatives so often advance the critique that, due to structural injustice in access to health care, research benefits the researchers but neither the participants nor their communities, but that this criticism is always a surprise to the researchers. Seeing research as an intrinsic and communal good, researchers often fail to consider how the benefits of research reach—or do not reach—community members [14].

Community-Based Participatory Research for Health: What Can Dr. Banks Do?

Dr. Banks has worked hard to be accepted as an insider in Dunlap, a neighbor and a physician, and now wants to participate in community-based participatory research (CBPR) to improve the health of the community. The case description does not include a discussion of the origins of the study “Safe Sex Practices in Dunlap, Zone 4,” who planned it, and why.

Most important, who represents the community? What is the structure of Dunlap, demographically, economically, socially? These questions are essential to beginning any CBPR project because, especially in communities—usually economically disadvantaged and often ethnically diverse or composed primarily of members of historically discriminated-against ethnic groups—that face substantial health disadvantages, community leaders need to be identified and legitimate in the eyes of community members [15]. Balance may be necessary between groups to ensure representation and attention to issues which may affect one segment of a community more than others—as in U.S. cities where I have worked with both African American and Latino communities—and longitudinal relationships of trust and equality are essential to continuing collaboration between researchers and communities.

Next, who decided that sex was a good first topic for a new CBPR collaboration? Safer sex may be an important issue epidemiologically in Dunlap, as it would be in nearly any community, but CBPR principles require community participation in the selection of research topics, the choices of methodology, and the interpretation of

results. While safer sex may be a topic this CBPR collaboration could handle as a second or third project, once trust has grown and research protocols are more developed, it's probably too sensitive a topic for the first project unless the community itself identifies it as its most pressing health problem (as some communities indeed would have).

If the CBPR collaboration decides in the future to take up safer sex, Dr. Banks' status as an insider, as well as the value of his time as a clinician, suggest that they should probably consider the use of "outsider" professionals to serve as the interviewers, selected by both the local health experts such as Dr. Banks and the community partners, to increase protection of confidentiality. Failure to consider interviewer effects in sexuality research has been a confounding factor since the famous Kinsey studies of the 1940s, in which both male and female respondents were initially interviewed face-to-face by the same middle-aged male researcher, perhaps contributing to apparent underreporting of female respondents' admitted sexual activity and exaggeration of the responses of male subjects [16, 17].

Dr. Banks has several choices, all familiar to researchers in CBPR, sexuality research, and social science research more broadly. The work of building trust with a community is ongoing, and whether as a researcher or neighbor, asking about sex at the potluck is probably unwise. He can facilitate community health, participate in CBPR, and maintain his status as an insider in his community, but only if he acknowledges the conflicts inherent in these roles, and decides deliberately which specific activities would benefit from his direct participation, and which roles are best filled by others.

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Commentary 2
by Florence Thicklin

Dr. Banks displayed a lack of respect for his community by being insufficiently up front about his research; the community's lack of trust was demonstrated by their reluctance to share personal information.

Researchers can incorporate community engaged practices into traditional research projects through the community-based participatory research (CBPR) model. CBPR is:

a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities [1].

CBPR is a balancing act between two partners with emphasis on community engagement throughout the research process. While researchers must be mindful of fostering community relationships, they must avoid the development of unethical partnerships.

To earn trust, Dr. Banks must be transparent about his intentions to conduct research in his community. He attempted to achieve a level of acceptance by acculturating to his new community, but it isn't enough for him to just *be located* within it; the community must be a part of the development of, implementation of, and dissemination of findings from the research.

Had Dr. Banks used community social functions to create awareness of his intentions to conduct CBPR and invited community members to participate in research development, perhaps community concerns or mistrust of researchers would have surfaced. It appears that Dr. Banks got to know the community, but the community did not get to know Dr. Banks as a researcher. The level of community engagement for his study does not satisfy CBPR principles.

For Dr. Banks' research to be successful, it should benefit the community and not just further his personal research interests. As histories of indigenous communities demonstrate, "outside research teams swooped down from the skies, swarmed all over town, asked nosy questions that were none of their business and then disappeared never to be heard of again" [2]. Dr. Banks doesn't have to do that. He can overcome his neighbors' understandable distrust.

He can support programs that will provide practical applications of his research to benefit the community. He can involve community members in the development of research instruments; assure the protection, privacy, and confidentiality of research participants; hire and train community members as interviewers; and secure additional funds or resources to support other community initiatives [3]. He can acknowledge and describe the researcher's role in the study, obtain the community's permission to give credit for contributions to manuscripts for publications and study reports to sponsors, and include community members in presentations at professional meetings. If Dr. Banks follows the CBPR approach, he can continue to conduct his research, while serving and collaborating with the community.

Although Dr. Banks' study received institutional review board (IRB) approval, collaboration with the community was not standard. Its role was limited to that of subject, when it should rightly be a partner. The overall goal of the IRB CBPR ethics review is to ensure the community's appropriate participation in research, minimize

adverse impacts of research, and maximize the potential benefits to individuals and the community as a whole. An additional review to make sure these criteria are met can be carried out by a community advisory board [4]. Human protection concerns in CBPR are not just about the individual, but also inherently about respect for, beneficence toward, and just treatment of the community [5].

Dr. Banks must demonstrate that he is not just conducting another study with no commitment, but undertaking a community-engaged process with mutual benefits. The advantage to the CBPR approach includes Dr. Banks' ability to contribute scientific research, the community partners' knowledge of familial aggregation and cultural and historical community dynamics, and an empowering co-learning process that attends to social inequalities.

Using a memorandum of understanding (MOU) would increase the community's trust. This document establishes decision-making styles; intent to compromise among different philosophies; mutual respect; shared responsibilities; respect for diversity of gender, race, ethnicity, class, age, and so on; preferred language and definitions of terms; and ownership of data. Furthermore, partnerships can dissolve and need to plan a process for closure [6].

The participant screening process must also reflect these priorities. During this process, the researcher determines if potential participants meets eligibility requirements and if they will be compliant with study requirements. In addition to signing a consent form, participants should be given a verbal explanation of all of the elements of informed consent: the purpose of research (in this case, the sensitive nature of the topic), risks, benefits, alternatives, who will have access to the data, a certificate of confidentiality, and so on. The researcher must make sure the participant actually comprehends the study expectations. Participants' desire for privacy must be respected.

CBPR partners must work together to make sure the research is conducted with the best interests of the community in mind. The research must also be designed with a specific understanding of the community in which it is taking place. Researchers and community partners must establish agreed-upon values and goals and focus on measurable outcomes and accountability to each other. They must treat each other with respect, trust, sincerity, and commitment; make communication and mutual understanding a priority; balance power and share resources; and work to address the needs of all partners.

Is Dr. Banks' Community Too Small for Such Personal Research?

Small towns and communities must be considered for research; they should not be neglected on the basis of population size. But only a very carefully designed study will maintain the confidentiality and de-identification of study participants and not stigmatize or bring harm to the community. CBPR can be successful in small communities if partners practice the principles of good community-campus partnerships.

Terminating the study would be extreme and a disservice to his community. However, if Dr. Banks redesigns the study and integrates the principles and ethics of CBPR, he can fulfill his research objectives and meet the community's needs without being estranged from it.

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