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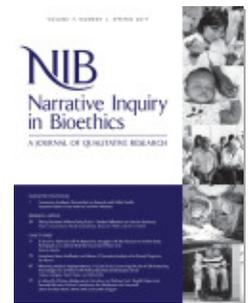
A Deep Dive into Community Engagement

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Narrative Inquiry in Bioethics, Volume 7, Number 1, Spring 2017, pp. 41-45
(Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2017.0014>



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Commentary

A Deep Dive into Community Engagement

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Conflicts of Interest. The author reports no conflicts of interest.

Abstract. Community engagement offers opportunities to enhance the value of health research. Through engaging with community partners, researchers can pursue projects that produce meaningful benefits for study populations. At the same time, engagement presents challenges for everyone involved. High-quality engagement requires attending to the choice of community partners, the ethics of engagement, education for researchers and community partners, project planning, and the distinct knowledge that experienced research subjects can contribute to engagement activities.

Keywords. Research Ethics, Community Engagement, Patient-Centered Research, Human Subjects

Community engagement is here to stay. As the narratives in this collection demonstrate, what was once a startling innovation is becoming an accepted, indeed expected, element of health research. This is a welcome development, in my view. I am convinced that researchers, clinicians, and ethicists can learn a great deal from patients, subjects, and community members. When it's done well, engagement adds meaning and value to health research.

The narratives included here are also evidence that people involved in engagement activities are becoming more sophisticated. These authors exhibit a nuanced understanding of the rewards and challenges, as well as a refreshing honesty in discussing what can be an uncomfortable

situation for traditional experts in research and health care.

Underlying community engagement and related efforts, such as participatory and patient-centered research, is a more egalitarian vision of health studies. Engagement and related initiatives can give real meaning to the "participants as research partners" rhetoric that is so popular today. But sharing power with study subjects and their communities isn't always easy. It takes humility and strength to practice true engagement.

Through reviewing narratives like the ones in this issue, research teams can enhance the quality of their own engagement efforts. They can also discover how to address practical problems, such as the low enrollment and high drop-out rates that

make studies more difficult to complete. The narratives also show how engagement enables research teams to detect and address ethical problems that could otherwise go unnoticed.

In this commentary, I call attention to important insights contained in the narratives. I describe positive features of engagement, then I consider some challenges engagement presents. I close with recommendations for researchers, clinicians, ethicists, and community partners participating in engagement activities.

Engagement's Contributions

The research literature describes a number of contributions that community engagement can make. Community members can provide information about which health problems are most important for research to address, as well as the most productive way to study those problems. Community members' personal knowledge about study populations and health conditions enables them to identify potential problems with study proposals, too. They can also furnish advice on interpreting study findings and can help determine how research results should affect health care practice (Dresser, 2001, pp. 28–29; Tinetti & Basch, 2013).

Community engagement can have practical benefits, too. Community members may be reluctant to enroll in studies if they think researchers have given insufficient attention to their interests and concerns. In contrast, recruitment procedures and materials developed in cooperation with community partners can increase study enrollment. Community partners can also alert investigators to problems that could lead participants to disregard study requirements or prematurely withdraw from studies (Dresser, 2001, pp. 32–33; Dresser, 2016, pp. 87–122). And improved subject recruitment and cooperation can offset any added costs of community engagement (Ludman et al., 2010).

The narratives in this issue attest to engagement's benefits and rewards. For example, Saksena and McMorro report that engagement led them to a research project that would be valuable to Congolese refugees living in their community. The

community contributed significant resources to the project, too, such as space to conduct interviews and a bus enabling study participants to travel to project interviews. A community member took the role of interpreter, becoming "a critical bridge" in subject recruitment and retention.

Engagement also gave several narrative authors a better understanding of the people they worked with. Thomas, Kaiser, and Svabek learned about common attitudes community members had toward researchers. Their interactions with community members taught them about "the power of The Personal," too. To produce high-quality information, everyone had to interact at a human level. Members of the research team had to talk about their goals and their lives in ways that old-school researchers might regard as unprofessional. Their experience suggests that maintaining professional distance can in some cases lessen the quality of the data researchers obtain in their projects.

Engagement enables investigators to gain insights into subtle interactions that can affect a person's attitudes toward research and health care. Mason supplies a vivid example in her account of a project on stigma faced by parents who are HIV-positive. One day a member of the project's consumer advisory board took her aside. He wanted to talk about a disturbing interaction he had had with a mental health clinician who worked with his teenage daughter. The clinician had "made a face" when the father mentioned knowing Mason. The father was afraid the clinician now suspected that the family was involved in Mason's HIV project. The father was worried the clinician was biased against HIV-positive people and would no longer want to work with his daughter.

Small reactions like that of the clinician in this incident can have a huge impact on patients, families, and research subjects. Medical and research professionals need to know about the potential effects of their everyday behavior, and engagement is a good way to learn about them.

Some of the authors in this issue also discovered that participants didn't necessarily give research projects the priority that investigators hoped they would. Subjects were sometimes late

to appointments or sought to reschedule at the last minute. Some researchers also felt that their own time and efforts were less appreciated than they should have been.

Although some authors were disappointed by subjects' behavior, their reactions are strikingly similar to reactions that subjects have to the way that they are treated in research. Subjects complain about wait times and inconvenient schedules, too. Subjects are not passive data sources, they are agents with their own concerns and commitments. Researchers shouldn't be surprised if subjects give higher priority to their personal needs and responsibilities than to research requirements. Researchers engaging with communities can discover how to design and conduct studies that promote subjects' cooperation and commitment (Dresser, 2016, pp. 44–122).

Engagement Challenges

Although community engagement can lead to improvements in health research, engagement also imposes new demands on those involved in the research enterprise (Dresser, 2001, pp. 33–35). Engagement challenges traditional notions of research expertise, because it recognizes community members as experts. Through research partnerships, investigators are forced to confront their own limitations. Engagement supporters believe that sharing authority with communities is a reasonable corrective to the unfair control researchers have traditionally exercised. But engagement skeptics worry that such sharing can compromise research quality, reducing the chance that studies will contribute to public health improvements.

Giving communities a say in research can also threaten investigators' interests in advancing their careers. It can be difficult to convince funders to support unconventional projects and to publish the results of such projects. Engagement can add burdens and complexity to the research process, as well. As two early adopters warned, engagement and participatory research efforts require "openness, critical self-awareness, iterative learning, humility, patience, respect, and empathy toward the community" (Cornwall & Jewkes, 1995, p. 1668).

Writers in this issue are open about the challenges they faced. Reporting on her talks with members of the Amish community, Farrar confesses that the "information made me realize that there is still so much I don't understand." Feedback like this can be hard to hear, but it can also be essential to conduct worthwhile research. Other narrative authors admit that it's hard to confront the limits of their training and expertise. They recount situations in which they were overwhelmed by problems and uncertainties. They describe their mistakes and what they learned from them.

Researchers aren't the only ones facing engagement challenges. Several narratives refer to challenges community partners faced in fulfilling their responsibilities. But since the narratives come primarily from investigators who initiated the projects, the personal perspective of community partners is largely absent. An exception is the essay by Rayner and Jenkins. In a project on health care for transgender and gender-nonconforming individuals, Rayner and Jenkins occupied dual roles—each of them was both a professional and a community member. As community members, they had access to valuable information relevant to the project. But they also experienced conflicts related to their dual roles and overlapping identities.

Conflicts like these are often reported by community members who become part of a research effort. In this situation, it can be hard to preserve their independence and legitimacy as community representatives. Others in the community may suspect that engagement partners are being co-opted into the research establishment (Epstein, 1996, pp. 330–53). Researchers seeking community involvement primarily for its public relations value may neglect the views of community members, too. And as several of the essays point out, community members can struggle with the time and effort it takes to be part of engagement activities (Dresser, 2001, pp. 36–37).

Improving Engagement

Although there have been significant advances in the design and practice of engagement, further

progress will require heightened attention to five areas. The first involves the choice of community partners. Most communities are made up of people with diverse attitude and beliefs. Community leaders and activists are often involved in engagement activities, but they don't always have the perspectives of less visible community members. Research teams should develop strategies for communicating with an array of community members, including those who are vulnerable and disadvantaged. Engagement activities won't fully succeed unless they include a reasonably representative sample of community members.

Second, although community engagement can help make research more ethical, engagement itself raises ethical issues (Dresser, 2016, pp. 215–17; Participants in the Community Engagement and Consent Workshop, 2013). For example, if community partners offer unqualified support for a project, others in the community can develop relaxed attitudes toward study participation, failing to attend to the disclosure process that underlies informed consent. Community partners can also be overly protective, depriving community members of opportunities to participate in what they believe are worthwhile projects. Justice and fairness issues can arise when community members have conflicting opinions on how to handle a particular research matter. What criteria should determine the ultimate decision and who should be involved in reaching that decision? The ethics of engagement is an underdeveloped area, meriting more attention than it has so far received.

Third, engagement education needs to improve. Researchers, including those in this issue, often comment on how poorly prepared they are to participate in and respond to community engagement. For example, Bravo, Gutierrez, and Young acknowledge their initial missteps in an engagement project, missteps that reflected their inaccurate assumptions and lack of appreciation for engagement's complexities. Their observations suggest that courses on community engagement should be part of the formal health research curriculum.

Community partners need education, as well. In some projects, community partners must learn about the science and medicine relevant to a health

problem. Most need information about the structure of planned engagement activities and the role they will be expected to play (Boiven, Lehou, Burgers, and Grol, 2014). Without adequate training, community partners can become frustrated, leading them to question whether engagement activities are worth their time and effort. Engagement won't work unless researchers and community partners understand the background information that is relevant to their projects.

Fourth, everyone involved in engagement must recognize the importance of planning. Different projects call for different types of community engagement. Project goals and duties vary, as well. In her narrative, Wilbricht describes the preliminary work that she and her community partners did, including drafting "a community partnership agreement prior to any data collection, in which we outlined each party's goals, interests, and responsibilities." Although flexibility must be preserved, addressing these and other matters early in the process is likely to pay off later.

Fifth, researchers and community partners should recognize the distinct contributions that can come from people who know what it is like to be a research subject. The engagement literature tends to emphasize inclusion of community members in general, without differentiating between people who have experience as research subjects and those lacking that experience. But personal experience as a research participant gives people special insights that others lack. I learned this myself when I was a cancer patient invited to participate in a treatment trial. Even though I was a research ethics scholar and teacher, as well as a longstanding Institutional Review Board member, personal experience made me much more aware of ethical and practical considerations that can influence patients' choices about research participation (Dresser, 2012, pp. 70–85; Dresser, 2017, pp. ix–xi).

Conclusion

Community engagement creates opportunities to magnify the benefits that health research produces. It offers new knowledge to research professionals,

knowledge that can boost the quality of their work. At the same time, research professionals must take engagement seriously. Engagement must not be attempted without proper preparation, or tacked onto a project at the last minute. Engagement is a complex and often dramatic alternative to conventional health research practices. In the coming years, research professionals and their community partners should continue to evaluate their efforts, with the aim of refining this exciting research development.

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