




## What's Trust Got To Do With It? Ensuring Meaningful Community Engagement

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# What's Trust Got To Do With It? Ensuring Meaningful Community Engagement

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Kraft and colleagues (2018) are right to stress the significance of building trust with research participants, especially those who come from traditionally marginalized communities with a history of exploitation in research. We applaud their qualitative study of this topic, as it appears to be an important scholarly contribution. However, we are concerned that their discussion of the importance of their findings seems to revolve around a very limited view of community engagement.

Community-engaged research (CEnR) has been defined as “a bi-directional effort to respectfully and effectively translate clinical research into the community” (Ross et al. 2010, 7). CEnR can refer to a range of activities, including using focus groups, hiring community members to serve as research liaisons, or seeking approval or other feedback from community advisory boards (CABs) that oversee research done with members of their own communities. In contrast, researchers who practice community-based participatory research (CBPR), a more involved form of CEnR, typically seek to include community members in every stage of the research process. This involves selecting and honing a research question, determining a method that is congruent with community norms and values, analyzing research results in terms of community needs and priorities, and disseminating results to participants and other community stakeholders. In other words, CBPR involves ensuring that research studies are both scientifically sound and contextually meaningful.

Kraft and colleagues suggest that community engagement is an important, but insufficient, tool, without acknowledging that trust-building is often one of the central goals of CEnR. This is foundational; active engagement does not happen when one party mistrusts the other (i.e., in the absence of bidirectional trust). Wallerstein and Duran (2006) recognize this and suggest that integrity and humility are the two most important values underlying the practice of community engagement, without which researchers could not hope to overcome mistrust and build long-term research relationships that yield valid and meaningful results that can be turned into change that is sustainable.

When viewed through the lens of trust-building as its justification, CEnR can be seen as an overarching orientation toward research that at the very least already offers a framework from which to approach the issues raised by Kraft and colleagues. In many cases, the CEnR and CBPR literature also offers specific guidance. The most obvious is community engagement used as a tool to promote Kraft and colleagues’ first and third recommendations (“address the role of history and experience on trust” and “address cultural values and communication barriers”). The CBPR literature on these topics is voluminous.

A well-developed CEnR risk model (Ross et al. 2010) can be used as a starting point to “engage concerns about potential group harm.” The authors of this model differentiate groups from communities. Groups are made up of individuals with shared characteristics (e.g., race or disease). Communities, on the other hand, are structured groups. They might initially have been formed around a particular characteristic, but eventually developed to the point of having “internal structure, identifiable leadership, and sustain themselves over time” (Ross et al. 2010, 8). Communities can be local, but might also not have any shared geography. Some communities, such as American Indian tribal entities, are quite old, while others are new.

Individuals can be in several groups or even groups and communities simultaneously, since the common characteristics that define group membership might overlap for many groups. Some groups might claim members who do not wish to identify with them. A group could also develop structure simply so that it is easier to do research. Homeless drug users or teen mothers who live with persistent domestic violence, for example, likely do not self-identify with these specific labels, yet may be recruited into a research sample because of those combinations of characteristics. Conversely, the process of identifying to participate in research studies could be internally motivated out of a desire to attract a researcher with whom to collaborate, or to obtain the financial or clinical benefits of participation, or may be externally motivated by a researcher approaching the community (Ross et al. 2010).

These distinctions are important when paired with the different levels of risk from Ross and colleagues’

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framework. These include “process risks to well-being” (risks contingent upon the conduct of the research), “outcomes risks to well-being” (risks linked to findings or outcomes), and “risks to agency” (which include undermining autonomy [Ross et al. 2010, 8]). Each of these three types of risk is associated with a level at which potential harms can occur: the individual, individual by group association, and also at the community level. Individuals *qua* individuals not only retain their status in this framework, but also take on the possibility of a new level of risk, individuals *qua* group. Similarly, benefits occur at the same levels and along the same lines.

Process risks to individual well-being encompass much of the physical and psychological harms with which IRBs are typically concerned. The effects of blood draws, by causing bruising or contributing to anemia, are an example. Outcome risks to individual well-being highlight the effects of the research when results are reported. This could include knowledge about a genetic predisposition to disease that causes psychological harm or even a worsened clinical state brought on by participating in the study that now precludes the participant from qualifying for other therapies as a patient. The individual can also experience risks to agency, for example, when genetic material is used for purposes for which the participant did not consent (Ross et al. 2010).

Risks to individuals by group association occur along similar lines. Ross and colleagues contend that this can be a problem even for people who did not participate. For example, to explain process risks at this level, they describe how a participant’s cultural community might stigmatize the person because of his or her participation. Conversely, individuals who were not study participants could be influenced by a tendency to diagnose symptoms a certain way and thus could be harmed by an improper diagnosis. For instance, a study showing high rates of sexually transmitted infections (STIs) in urban centers could influence providers to assume almost any vague symptoms are STI related. Outcome risks occur similarly; for example, reported genetic predispositions can harm individuals in a group regardless of their participation. Risks to agency for the individual by group association could take the form of pressure to participate by other community members because they see the research as addressing a community need (Ross et al. 2010).

Risks to community are categorized similarly, but reflect potential damage to those things that make a group a community: structure, function, and moral/sociopolitical agency. Process risks arise during group participation and could result from disagreements that disrupt cohesiveness. Likewise, study results can impact community identity, such as what might happen when genetic predisposition to stigmatizing disease is reported. Similarly, group agency can be undermined when its preferences for data use are ignored (Ross et al. 2010).

Of the issues raised by Kraft and colleagues, the recommendation to “integrate patient values and expectations

into oversight and governance structures” is the most difficult to address. First, there are often considerable institutional-level barriers to promoting meaningful community engagement, which will likely require a shift in academic culture to address (Ahmed et al. 2004). But having a more nuanced model of group harms raises an additional question: How do we address the tension between individual consent and group identity?

Gehlert and Mozersky (2018) suggest that this tension is particularly challenging for unstructured groups. Deliberative democracy governance models (including CABs) are appealing for communities with recognizable structure, leadership, and shared identity. However, these governance models could actually hinder consent for individuals from groups without such structure. For example, there is no reason to expect a CAB to represent a group’s values when members do not belong to a well-defined community (and the group structure can be daunting; at the very least, it requires knowledge of some level of agreement on the value of specific ends that affect everyone in that particular community). Unfortunately, on the other hand, there is also evidence that individuals often place more importance on shared identities, irrespective of how representative they may be. Salant and Gehlert (2008) found that socially isolated African Americans in Chicago who did not belong to a structured community made health care decisions based primarily on their group identity, rather than based on their experiences as individuals. Their perceptions of their individual risk for developing cancer were based on the shared history of their group heard over the life span, which the authors refer to as collective memory, rather than on their own behavior and characteristics. In other words, they could not focus on their own risk because of self-messages about the history and experiences of African Americans as a group.

Overall, Kraft and colleagues have made an important contribution to the literature. Our chief concern is that their recommendations could benefit from a more robust model of community engagement. CEnR and CBPR are grounded in a process of active engagement that meaningfully involves participants in the research process and offer a valuable toolkit for trust-building. ■

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# Including Everyone but Engaging No One? Partnership as a Prerequisite for Trustworthiness

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In “Beyond Consent: Building Trusting Relationships With Diverse Populations in Precision Medicine Research,” Kraft and colleagues (2018) address several important issues for biobanking in the Precision Medicine Initiative (PMI). For one, their perceptive analysis alludes to the tension often found between individual autonomy and trust, as notably described by British philosopher Onora O’Neill (2002). Their article also brings to the fore a refreshing discourse that has historically received scant attention in bioethics—namely, the loss of trust in health care, which has recently been described as a “profound crisis” globally (Nie et al. 2017). While Kraft and colleagues’ findings certainly provide a starting point for developing institutional trustworthiness and engaging diverse populations, I wish to pose a subtle but significant question of clarification in this commentary: What exactly is the nature of the “trusting relationship” the authors wish to foster?

The PMI’s All of Us Research Program (PMI-AURP) has proclaimed as “core values” that its cohort should “reflect the rich diversity of the U.S.” and that “participants are partners” in research (National Institutes of Health [NIH] 2016). These laudable values, however, require certain procedural commitments that Kraft and colleagues leave underdeveloped or dismiss entirely. The concept of engagement, for instance, is often mentioned but hardly explicated, which can have serious implications for the relationship researchers develop with study participants.

My concerns echo those of Sabetello and Appelbaum, who worry that a “top-down model of engagement” may perpetuate itself in the PMI if scientific experts alone continue to “control the agenda, framing of needs, and research decisions” (2017, 21). Although Kraft and colleagues’ call to address cultural and language barriers with minority groups can help to mitigate this concern, I worry the communication

they prescribe is largely unidirectional and may instead exacerbate the existing hierarchical relationship. For example, demanding “clear communication of the value of unrepresented minority groups in the research, as well as the specific risks and benefits that relate to their communities” (Kraft et al. 2018, 14) suggests that the risks, benefits, and value of a study are obvious; the onus is merely on researchers to explain these finer points to skeptical demographics. Instead of encouraging a bottom-up model of engagement, the authors seem to accept the status quo that researchers should build “trusting relationships with the patients who are integral to their research agendas” (16) for the sole reason that patients are integral to their—that is, the researchers’—agenda.

Ironically, the authors do explicitly mention one bottom-up model of engagement with their brief discussion of deliberative democracy. But without further exploration, they trivialize the merits of deliberative modes of engagement for fostering trust by instead emphasizing the need for “institutional commitment to diversity, inclusion, and responsible oversight” (Kraft et al. 2018, 12). This seems, in some respects, to have it backward: Community engagement through deliberative democracy itself arguably demonstrates a genuine commitment to the very standards they claim to uphold. As Sabetello and Appelbaum note, “Deliberative democracy serves as a tool to increase governmental accountability and public trust” (2017, 21). Indeed, biobanking initiatives outside of the United States have recognized the value of deliberative democracy as “a pre-requisite to building trust” (Moodley 2017, 330) and its ability to “contribute to trustworthy governance” (Secko et al. 2009, 788). Kraft and colleagues wisely note that engaging a truly representative group, especially while sifting out ulterior motives from genuine concerns, poses a significant challenge for deliberative means of democracy. This challenge is inevitable but surmountable, however.

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