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Trust and the Ethical Conduct of Community-Engaged Research

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Abstract

Community-engaged research (CEnR), which emphasizes equal participation of academic and community partners in research, seeks to improve public trust in science. Unfortunately, there is a dearth of rigorous empirical research on trust as a core component of ethical conduct of CEnR. Drawing on data collected from a project on the ethics of CEnR, this commentary discusses benefits and risks of trust and uses the concept of embeddedness to explain how public trust in science may be increased. We argue that in developing and maintaining trust, partners must balance scientific rigor with community relevance and cultural appropriateness of research. They must strike a balance between working with the same limited pool of trusted partners, which can speed research but slow wider acceptance of science, and extending their trust to new partners, which can broaden acceptance of science but slow research. Practitioners may facilitate the development of trust in science by gradually expanding the pool of partners they choose their collaborators from.

Keywords

Community-Engaged Research; Embeddedness; Research Ethics; Trust

One of the goals of community-engaged research (CEnR) is to improve public trust in medical science through equal participation and active engagement of academic and community partners in research conduct (Ross et al., 2010). Commonly defined as a process of developing “emotionally charged ties of dependence with other persons” (Giddens, 1991) and forming positive expectations about the behavior of others (Khodyakov, 2007), trust can

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facilitate joint action under conditions of uncertainty (Luhmann, 1988), when interests of involved parties overlap but are not identical (Hardin, 2002).

A lack of trust in science and the consequent underrepresentation of ethnic minorities in health research (Moreno-John et al., 2004) have been partly attributed to past ethical misconduct in research involving minority participants (Christopher, Watts, McCormick, & Young, 2008; Corbie-Smith, Thomas, & St George, 2002) because such studies violated the ethical principles of autonomy, beneficence, and justice stipulated in the Belmont Report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). CEnR practitioners work to counter mistrust in science by changing the research process in ways that empower and inform vulnerable communities (Lopez, Sharma, Mekiana, & Ctibor, 2012).

Indeed, many aspects of CEnR, including close collaboration between community and academic partners in all phases of research, prioritization of study topics important in the community, building community partners' research capacity, using culturally-competent research practices, and sharing research findings through culturally-appropriate means, may help build and sustain trust by reducing potential risks of cooperation and increasing academic and community partners' willingness to be dependent upon each other during the research process (Delemos, 2006).

Although trust is an important aspect of the partnership process (Schulz, Israel, & Lantz, 2003), context (Belone et al., 2014), and outcomes in CEnR (Viswanathan et al., 2004), it has yet to be considered *as a core component of ethical conduct of CEnR* (McDonald, Townsend, Cox, Paterson, & Lafrenière, 2008). Furthermore, research on trust in social and economic exchange suggests that reliance on trust can be risky due to the ever present possibility of non-cooperation and defection (Evans & Krueger, 2011; Molm, Takahashi, & Peterson, 2000). In this commentary, we synthesize the results of our recently completed empirical study on the ethics of CEnR, which relied on a literature review (Mikesell, Bromley, & Khodyakov, 2013), semi-structured interviews with 15 academic and 14 community partners working on CEnR projects (Bromley, Mikesell, Jones, & Khodyakov, 2015), and an online modified-Delphi panel with 63 academic and community stakeholders (Khodyakov, Mikesell, Schraiber, Booth, & Bromley, 2016), with our earlier theoretical work on trust (Khodyakov, 2007) to empirically describe trust as a core component of ethical conduct of CEnR, illustrate its benefits, explore potential risks of relying on trust during the research process, and propose how and why CEnR can increase public trust in science.

Community and Academic Perspectives on Trust

In CEnR, trust is a multi-faceted concept. Trust and trustworthiness have been used to describe the process by which participants come together to conduct research, make research decisions, manage interpersonal relationships, and generate the right kinds of project outcomes. In our online stakeholder panel (Khodyakov, et al., 2016), academic and community investigators agreed that all study team members must feel trusted and respected; and that their motives and decisions must be transparent. Indeed, of the nine ethical principles considered by the panelists, trust was the only one that stakeholders agreed

was critical to the definition of ethical research and easy to evaluate whether or not it had been achieved.

During interviews (Bromley, et al., 2015), we saw that academic partners often describe trust as having confidence that “research is scientifically valid.” “Trustworthy research,” one academic said, “really means that you understand that scientifically you’ve done the right thing.” For academics, trust in the scientific research process was perceived to facilitate work with new partners. Community partners often stressed interpersonal trust as a core component of ethical CEnR, emphasizing the need for all partners to deliver on their promises, “do the best job they can,” and “not act [in their own] interests.” But both stakeholder groups conceptualized trust as ensuring that the research is conducted “in the right way” and that partners “feel comfortable” with each other. Similarly, while community partners reported focusing on interpersonal trust and relationship building, they too noted concerns about scientific rigor, especially about the use and validity of study findings. Collectively, community and academic participants underscored the reciprocity in building trustworthy relationships among team members and generating trust in the research process, its outcomes, and science more generally. They argued that research quality may suffer without strong relationships. This reciprocal and reinforcing aspect of trust may be one reason it was placed at the center of a definition of research ethics. As one academic said, “relationship building and trust are a big aspect for ethical research.”

Benefits of Trust

Our interviewees suggested a number of positive outcomes of trust and explained the mechanisms through which these outcomes can be achieved in the context of conducting ethical CEnR. The first positive outcome is increased community willingness to participate in research. One community representative noted that by developing close relationships with a respected community partner, researchers were able *to identify and recruit hard to reach populations*. Interviewees said that having trust in investigators also helped participants engage in research that required them to provide sensitive information, such as their legal status or use of illegal substances. Participants also provided examples of how trust in CEnR could increase trust in data generated by a joint research project. By engaging in the research process, they reported that community partners better understood, evaluated, trusted, and ultimately accepted research and its findings. One community partner said: “We can now understand what data really look like, what these numbers really mean, and how to read these data. I think that’s where building trust is important: to be able to see that the data were valid.”

The second positive outcome of trust is **improved quality of research projects**, which could be achieved by making the study more culturally appropriate and its results more relevant to the community. For example, an academic partner working on a depression study designed to test how an intervention affected health-related measures noted that the study’s community partners insisted the intervention would likely affect risk of homelessness. Such an outcome is not typically measured in studies about depression. By trusting the instincts of community partners to include measures of such risk, investigators improved the relevance of study findings to a community that believed depression and homelessness were closely

linked. The results of this study informed a series of new efforts in the community to address homelessness by using community-academic partnered approaches.

The third positive yet unanticipated outcome of trust is a perception that **it can make the research process more efficient**. Interviewees said that trust helped community partners defer to their academic partners because they knew that community interests would be taken into account. “My community partner,” said an academic interviewee, “seems to be trusting my judgment more and more over time...She just defers to me. She will even say to me: ‘You can speak for me now,’ which is really weird because she has such a unique community perspective.” Trust breeds confidence in the decisions that partners make even if all team members have not been consulted, thereby increasing the efficiency of making partnered decisions. As an academic investigator put it:

My [community partner] can now channel her inner researcher and so it's far rarer that you'll hear her ask something that violates basic research principles...She'll caveat her comment with something like: “You may tell me that you can't do this for research reasons, but...” This makes it far more efficient. Similarly...it is less common that I will suggest something that is a complete non-starter in [a community setting]. For everyone involved, it is a tremendous improvement sort of in efficiency.

Interviewees also said that increased efficiency of the research process emerged from a shared expectation of mutually beneficial project outcomes. To use the words of an academic who has a long-standing relationship with a health service provider: “I do feel like trust is really, really important. I like to believe that at this point [my community partner] realizes that I certainly don't want to do anything that's going to get her into trouble, that I want to be respectful, and that I also want to do things that are useful for their company.”

Trust Risks

Nonetheless, trust can be a double-edged sword because too much trust could negatively affect interpersonal relationships among community and academic investigators, scientific integrity of their research projects, and ultimately public perception of science and medicine (Eyal, 2012). Reliance on trust in medicine and research exacerbates individual vulnerabilities, such as inability to protect personal interests in situations characterized by power differences among individuals, and could be harmful if researchers or doctors turn out to be untrustworthy (Rogers & Ballantyne, 2008).

Our findings and examples of trust benefits described above can help identify possible unintended consequences of overreliance on trust in the process of conducting CEnR. First, an emphasis on engaging and building personal relationships with community partners with different interests and abilities may create tension among community partners. Some community partners who contribute more time and effort to the project may not agree with the equal distribution of non-monetary benefits, such as recognition for participation. Academic partners may favor sharing benefits so as not to alienate community partners unable to fully engage with the project and to encourage them to become more engaged in future projects. Additionally, some community partners may express disillusionment that the

most vocal community partners ultimately dictate research decisions and processes, leaving the less vocal partners skeptical of the entire enterprise. Thus while CEnR processes encourage balanced representation of academic and community needs, there may need to be more effort to ensure that individual partners' needs are also being met.

Second, a desire to preserve trust among partners with overlapping but not identical goals and interests may compromise the objectivity of some research decisions. For example, community partners may describe study findings in a way that might be interpreted as a "marketing effort," whereas academic interpretation of results might contradict community perceptions of a problem. Similarly, community partners may object to using previously validated but culturally inappropriate scales, while academic partners may object to using culturally appropriate but non-validated scales.

Finally, although it may expedite decision-making, reliance on trust can also curtail discussion and debates. Academic partners may not suggest an idea that they feel community partners will reject; community partners may not ask for something that they believe "violates basic research principles." As a result, a valid and creative idea may be missed. Put another way, overreliance on trust may violate CEnR principles of engagement and equal power sharing.

Building Trust in Science as an Institution

Research suggests that while CEnR does not guarantee that community trust in science will be re-established, it can help community and academic investigators develop trustworthy relationships on their research team, which they may then extend elsewhere in the community and the academy (Christopher, et al., 2008; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). But how can CEnR projects improve public trust in science if trust on a CEnR team can increase risks?

To explain this, we use the sociological concept of embeddedness, or the idea "that behavior and institutions [are too] constrained by ongoing social relations" to be considered independently (Granovetter, 1985). The application of the concept of embeddedness would suggest that interpersonal relationships among CEnR partners reinforce trust in project-specific scientific choices and practices and may simultaneously affect, and ultimately increase, trust in science as an institution. By developing interpersonal trust among a relatively small group of academic and community investigators, CEnR partners can actively collaborate in all aspects of research, share expertise, divide decision-making power, and jointly own study findings. Doing so helps them build trust in the project-specific scientific research process and make all scientific research decisions (e.g., data analysis and interpretation) together in a way that is both transparent and broadly understandable, which then facilitates the development of trust in science in their community.

Indeed, CEnR research partnerships tend to reflect a network typically characterized by "strong" or "embedded" ties (Uzzi, 1997) among community and academic partners who prefer to work with partners from past successful projects. These strong ties generate the kind of trust people typically enjoy with their family members and very close friends

(Khodyakov, 2007). Partners whose relationships are characterized by strong ties express genuine concern for each other and believe that their relationships have intrinsic value. The basis for such trust is familiarity with the partner, which enables collaboration in research.

Interpersonal trust is both critical to the success of partnered research and time-consuming to develop. As a consequence, academic and community partners tend to work with the same partners to reduce the costs of building and maintaining trust. By relying on a dense network of strong ties, partners can effectively coordinate their behaviors by quickly exchanging fine-grained private information with each other, promoting collaboration and joint problem-solving, and reinforcing trust in the research process (Uzzi, 1997). Reliance on strong ties not only reduces transaction costs, but also guides the behavior of partners and creates shared expectations.

Although strong ties help partners reduce the risk of collaboration and expedite the decision-making process, overreliance on such ties has disadvantages. When a long-time partner cannot work on a project or a partner with different skills is needed, partnerships have to build relationship with new partners from the ground up and invest in building trust in the project-specific scientific research process, which is time-consuming. Establishing trust in “weak ties” (Granovetter, 1985; Uzzi, 1997), or acquaintances and individuals whom partners do not know personally, however, may be more beneficial because weak ties help partners access critical information and otherwise unavailable resources.

This tradeoff between efficiency and better access to valuable resources reflects the “paradox of embeddedness” (Uzzi, 1997) - weak ties can be more advantageous than strong ones, especially when partnerships face exogenous shocks, such as an urgent need to add a new partner. Indeed, trust in weak ties is particularly important for generating trust in science as an institution because collaboration with a wider network of research partners can expose a larger number of community representatives to research. However, relying on trust in weak ties can be risky. It requires partners to assume that new research team members are dependent and reliable, and that they will act in ways that will benefit, or at least not harm, the project and other partners.

Thus, CEnR partners have two options, both of which have shortcomings. First, they can continue working with the same, limited pool of partners whom they know well and with whom they have strong ties. This option, however, limits the number of community partners available for research, thereby slowing the development of trust in science as an institution because fewer community representatives will be engaged in research. The second option is for partners to extend their trust to weak ties by collaborating with new partners, hoping that following research procedures can help them develop trustworthy relationships with new individuals whom they do not know personally. This approach may expedite the development of trust in science as an institution; however, even developing weak ties of trust in new partners is a time-consuming process requiring resources that may not be readily available.

Consequently, CEnR project partners may benefit most from relying on a mix of strong and weak ties in each new project. By bringing in one or two new partners to each CEnR project,

research partnerships can expand their networks, which is crucial for building trust in science. At the same time, working with both old and new partners can help new partners understand how the partnership prefers to work together and reduce risks should a new partner turn out not to be trustworthy or a good fit for the existing partnership.

These conclusions raise several questions to be explored in future research. Among these: what is an appropriate mix of strong and weak ties for a CEnR project to maximize trust in science? Under what conditions can interpersonal trust successfully translate into trust in the research process and trust in science as an institution? Could successful CEnR projects be characterized by high levels of trust in scientific research process but low levels of interpersonal trust? The answers to these and other questions related to trust in CEnR warrant further exploration if we hope to improve public trust in science and conduct high quality, ethical, and rigorous CEnR.

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