



Conceptualizing trust in community-academic research partnerships using concept mapping approach: A multi-CTSA study



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ABSTRACT

Objectives: Collaborations between communities, healthcare practices and academic institutions are a strategy to address health disparities. Trust is critical in the development and maintaining of effective collaborations. The aim of this pilot study was to engage stakeholders in defining determinants of trust in community academic research partnerships and to develop a framework for measuring trust.

Methods: The study was conducted by five collaborating National Institute of Health' Clinical and Translational Sciences Awardees. We used concept mapping to engage three stakeholders: community members, healthcare providers and academicians. We conducted hierarchical cluster analysis to assess the determinants of trust in community-academic research partnerships.

Results: A total of 186 participants provided input generating 2,172 items that were consolidated into 125 unique items. A five cluster solution was defined: authentic, effective and transparent communication; mutually respectful and reciprocal relationships; sustainability; committed partnerships; and, communication, credibility and methodology to anticipate and resolve problems.

Conclusion: Results from this study contribute to an increasing empirical body of work to better understand and improve the underlying factors that contribute to building and sustaining trust in community academic research partnerships.

1. Introduction

In community-academic research partnerships, a diverse group of stakeholders, commonly including community members, healthcare providers, and academic researchers, collaborate for the purpose of sharing authority and responsibility in planning and implementing research studies with a mutually beneficial research objective (Berge, Mendenhall, & Doherty, 2009; Lasker, Weiss, & Miller, 2001; Lindquist-Grantz & Vaughn, 2016). Research approaches that involve the community as an active partner in addressing health and social concerns are

ample and, since the latter part of the 20th century, have become increasingly recognized as an important model for health research (Andrews et al., 2012; Israel et al., 2013). These approaches are especially needed to engage racial and ethnic minorities who have been historically underrepresented in research studies and who have many reasons to mistrust health research, including cases of unethical research in the past (Ferreira and Fidji, 2011; Hodge, 2012; Scharff et al., 2010; Shern, Trochim, & LaComb, 1995a; Vaughn, Jones, Booth, & Burke, 2017).

The continuum of community participation in research ranges from

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outreach (some involvement, one-way communication), to consultation (more involvement, two-way communication, connections), to collaboration (community involvement, partnership/trust building), to shared leadership (strong bi-directional relationship, joint decision-making, trust) (Cottler, McCloskey, & Aguilar-Gaxiola, 2013; Israel, Schulz, Parker, & Becker, 1998). On this continuum, community-based participatory research (CBPR) is defined by shared decision-making and involvement of all partners in all aspects of the research project and has emerged as a particularly viable approach to improve trust and involvement of underrepresented groups in health research (Wallerstein & Duran, 2010). These community-academic research partnerships give everyone a voice in the research enterprise, which is also a tenet of social justice (Barnett et al., 2010; Carlton, Whiting, Bradford, Dyk, & Vail, 2009; Wright et al., 2011).

Prominent national and international health agencies such as the National Institutes of Health (NIH), Institute of Medicine (IOM), Agency for Healthcare Research and Quality (AHRQ), Patient-Centered Outcomes Research Institute (PCORI) and others, recommend conducting research driven by community-academic partnerships because of their potential to: a) improve the quality and relevance of research; b) increase community capacity to affect change; and, c) alleviate persistent health disparities in historically underserved communities (Butterfoss, 2006; Butterfoss, Goodman, & Wandersman, 1996; Jagosh, Bush, & Salsberg, 2015; Wallerstein et al., 2008). It is recognized that the success of community-academic research partnerships is largely dependent on the partnership's ability to create and maintain trust between a diverse group of stakeholders with varied interests, goals, and values (Nichols, Anucha, Houwer, & Wood, 2013). This is a particularly important factor for the success of research efforts in underserved communities (Christopher, Watts, AKHG, & Young, 2008). Yet, trust continues to remain a poorly understood aspect of community-academic research partnerships (Mayer et al., 1995).

Trust is a concept that has been empirically defined in various ways. A common definition of trust is “the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control the other party (Balkrishnan et al., 2003).” Many researchers note that the concept of trust must be understood from the perspective of all parties and within its context (Moreno et al., 2009; Northouse, 1979). In the context of community-academic research partnerships, researchers expound the importance of trust by sharing descriptions of the practices and principles they followed to achieve trusting relationships or by measuring trust as an important outcome of the participatory research process (Kane and Trochim, 2007; Plowfield et al., 2005; Shern, Trochim, & LaComb, 1995b). However, to date, few studies have identified empirically sound or practical measures of trust for community-academic research partnerships to build from.

To address this gap, we, a community-academic research partnership, conducted a multi-site, multi-institutional study with the purpose of developing a conceptual framework of trust in community-academic research partnerships. Our primary aim was to include the perspectives of major types of stakeholders in order to identify factors that contribute to trust within community-academic research partnerships from the perspectives of community members', academic researchers' and healthcare providers'. Our secondary aim was to evaluate the relative importance of the identified factors for creating and maintaining trust within partnerships as well as for improving public trust in research more generally.

2. Method

We used concept mapping, a mixed methods approach that uses structured participatory processes and rigorous data analyses to elicit, integrate, and organize the perspectives of multiple individuals into a conceptual framework. Additional information on the methods used in

this study are described by Frerichs et al. (Frerichs et al., 2016) Originally developed by Trochim, this method produces a conceptual framework for how a group views a topic. In 2005, Burke et al. introduced concept mapping as a participatory public health research method and since then it has been used to address a wide range of health topics in several community engaged research projects (Burke et al., 2005). The visual representation of the group's collective thoughts relative to a topic of interest (i.e. concept map) is a helpful tool in determining elements of complex or abstract concepts such as trust (Kane & Trochim, 2007). All research protocols were approved by the institutional review board at each collaborating site.

2.1. Setting

This study involved five NIH-funded Clinical and Translational Science Award (CTSA) grantees: University of North Carolina at Chapel Hill (UNC), University of Arkansas for Medical Sciences (UAMS), University of Florida (UF), University of California, Los Angeles (UCLA) and University of Pittsburgh (PITT). PITT served as the data coordinating site and facilitated trainings, data collection sessions, and analyses and reporting of the study findings. UNC, UAMS, UF, and UCLA, each recruited participants and collected data at their respective sites. A steering committee that included representatives from each CTSA, including both academic and community partners, met monthly via conference, to plan the study, review progress, and guide dissemination of study findings.

2.2. Participants and sampling

Respondent-driven sampling, a non-probabilistic sampling method, was used to identify key informants in three major stakeholder groups: (1) community members, (2) healthcare providers, and (3) academic researchers. Each CTSA recruited initial participants using existing research network and community research partner lists, and invited recruited participants to identify potential participants for invitation to the study. Each site also purposively sampled from populations most affected by health disparities within their respective regions. We recruited community members with and without previous experience in community-engaged research in order to obtain a more representative community perspective and mitigate potential selection bias of participants who are more inclined to participate and trust in health research. Healthcare providers had to self-identify as representing a healthcare agency (e.g., hospitals, public health department, primary care clinic), and have a primary role that was not academic research but have at least some experience in community-engaged research projects (e.g., co-investigator, data collection, research design, etc.). Similarly, academic researchers had to self-identify as having at least some experience in community-engaged research projects (Kruskal & Wish, 1978). All participants received incentives for their time and travel reimbursement for participation in the study.

2.3. Concept mapping procedures

All participants were asked to complete a brief, self-administered on-line questionnaire that included demographic variables (e.g. age, race, education) and years of community-engaged research experience. Each site followed the standard concept mapping research process, and the same cohort of participants from each CTSA site were involved in three major group activities: (1) brainstorming, (2) sorting and rating, and (3) analysis and interpretation (Everitt, 1980). At least one academic partner and one community member partnered as co-facilitators for all group sessions. Each facilitator completed a training webinar, led by the PITT data coordinating team on the concept mapping research process and session procedures.

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