

UCLA

UCLA Previously Published Works

Title

Trust in Community-Engaged Research Partnerships: A Methodological Overview of Designing a Multisite Clinical and Translational Science Awards (CTSA) Initiative.

Permalink

<https://escholarship.org/uc/item/8m12g59w>

Journal

Evaluation & the health professions, 43(3)

ISSN

0163-2787

Authors

Kim, Mimi M
Cheney, Ann
Black, Anita
[et al.](#)

Publication Date

2020-09-01

DOI

10.1177/0163278718819719

Peer reviewed

Trust in Community-Engaged Research Partnerships: A Methodological Overview of Designing a Multisite Clinical and Translational Science Awards (CTSA) Initiative

Evaluation & the Health Professions

1-26

© The Author(s) 2019


Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/0163278718819719

journals.sagepub.com/home/ehp



M. M. Kim¹ , A. Cheney², A. S. Black³, R. J. Thorpe Jr.⁴, C. D. Cene³, G. J. Dave³, J. Schaal³, S. Vassar⁵, C. Ruktanonchai⁶, L. Frerichs³, T. Young³, J. Jones⁷, J. Burke⁷, D. Varma⁶, C. Striley⁶, L. Cottler⁶, A. Brown⁵, G. Sullivan² and G. Corbie-Smith³

¹Center for Biobehavioral Health Disparities Research, Duke University, Durham, NC, USA

²Center for Healthy Communities, University of California, Riverside, CA, USA

³NC TraCS Institute, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

⁴Department of Health, Behavior, and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

⁵Department of Medicine, Division of General Internal Medicine/Health Services Research, David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, CA, USA

⁶College of Public Health and Health Professions and College of Medicine, University of Florida, FL, USA

⁷Health Policy Institute, University of Pittsburgh, Pittsburgh, PA, USA

Corresponding Author:

M. M. Kim, Center for Biobehavioral Health Disparities Research, Box 90420, Durham, NC 27708, USA.

Email: mimi.kim@duke.edu

Abstract

Community-engaged research (CEnR) builds on the strengths of the Clinical and Translational Science Awards (CTSA) framework to address health in underserved and minority communities. There is a paucity of studies that identify the process from which trust develops in CEnR partnerships. This study responds to the need for empirical investigation of building and maintaining trust from a multistakeholder perspective. We conducted a multi-institutional pilot study using concept mapping with to better understand how trust, a critical outcome of CEnR partnerships, can act as “social capital.” Concept mapping was used to collect data from the three stakeholder groups: community, health-care, and academic research partners across three CTSA. Concept mapping is a mixed-methods approach that allows participants to brainstorm and identify factors that contribute to a concept and describe ways in which those factors relate to each other. This study offers important insights on developing an initial set of trust measures that can be used across CTSA to understand differences and similarities in conceptualization of trust among key stakeholder groups, track changes in public trust in research, identify both positive and negative aspects of trust, identify characteristics that maintain trust, and inform the direction for future research.

Keywords

community-engaged research, translational science, community research partners, trust, CTSA

Background

There is an increasing focus on the potential value of academic–community collaborative partnerships that continue to gain acceptance as an appropriate approach to address health disparities in underserved and disadvantaged communities (Abdulrahim, El Shareef, Alameddine, Afifi, & Hammad, 2010). Trust is a necessary foundational aspect of any effective collaboration and successful community-engaged research (CEnR; Khodyakov, Mikesell, Schraiber, Booth, & Bromley, 2016). The effort described here reviews constructs of trust and describes a cross-Clinical and Translational Science Awards (CTSA) project that used concept mapping to better understand key elements of trust.

Trust is a measurable outcome of collaborative research (Israel, Schulz, Parker, & Becker, 1998). Once a foundation of trust is established, the

likelihood of enhanced cooperation between academic and community partners increases by fostering engagement in research with mutual benefit to both academics and community members (e.g., civic engagement). The process of building trust involves partners getting to know one another, recognizing each other's abilities and capacities, identifying and understanding one another's respective needs, and bidirectional transparency regarding expectations over time.

As clearly stated by the CTSA Community Engagement Key Function Committee Task Force (Clinical and Translational Science Awards Community Engagement Key Function Committee Task Force, 2011), the body of knowledge supporting the 1997 principles of community engagement has grown tremendously as well as the number of agencies and organizations involved in CEnR. But currently, there is little empirical evidence on the varied definitions and measures of trust in CEnR from a multidimensional perspective. Unlike the case examples provided in the 2011 CTSA report (Clinical and Translational Science Awards Community Engagement Key Function Committee Task Force, 2011), this methodological overview did not aim to evaluate a CEnR relationship in the context of intervention delivery or program evaluation efforts. Rather, this overview provides a case example of how to address and establish and sustain the core foundation of the CEnR—the relationship—by identifying determinants with corresponding standardized measures (Abdulrahim et al., 2010; White-Cooper, Dawkins, Kamin, & Anderson, 2007).

Objectives

Progress has been made to recognize the ethical obligation of mutual respect and the importance of redressing power difference in research; yet exactly how relevant these principles are to translational science is still unknown (Khodyakov et al., 2016). Furthermore, the current body of trust-focused empirical investigation has been limited by a unidirectional perspective of trust from either the community or an academic institution but not both equitably (White-Cooper et al., 2007). There is an apparent need for researchers to contribute to efforts that encourage meaningful change in the determinants of health using stakeholder engagement across sectors to align incentives to achieve common goals and establish a collective impact, adequately and effectively (Pastor & Morello-Frosch, 2014; Scott et al., 2014; Woolf, Zimmerman, Haley, & Krist, 2016).

Figure 1 presents the logic model to guide development of metrics for CEnR, as defined by the National Center for Advancing Translational

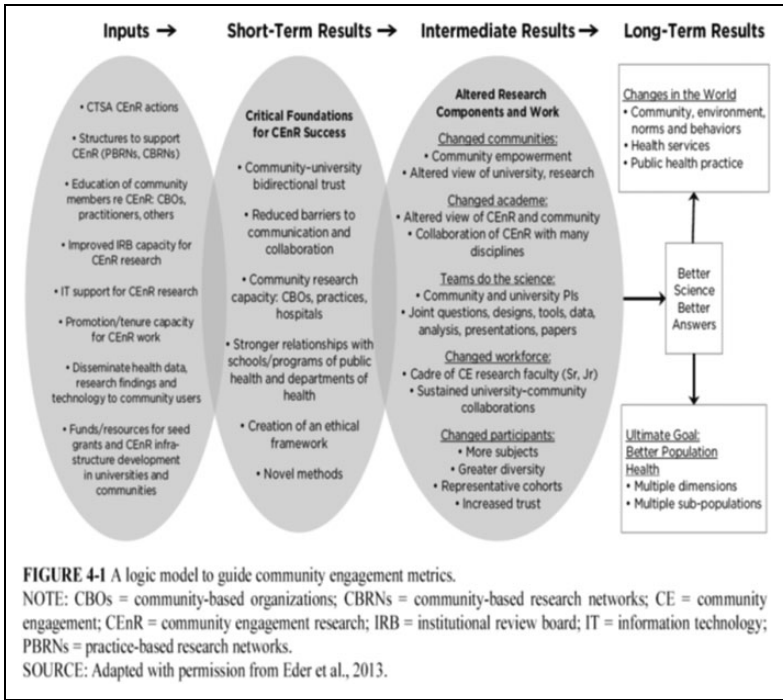


Figure 1. The logic model for development of metrics for community-engaged research.

Sciences (Leshner, Terry, Schultz, & Liverman, 2013). Equally important, the CTSA was designed to develop innovative solutions to improve the efficiency, quality, and impact of the process for turning observations in the laboratory, clinic, and community into interventions to improve the health of individuals and the public (<https://ncats.nih.gov/ctsa>). When considering the status of translational science according to the CTSA objectives, the effort presented here responds to the two metrics in the collaboration category (researcher collaboration and institutional collaboration) defined (Dilts, 2013; Rubio, 2013). Specifically, these metrics are related to the willingness of researchers to engage in multidisciplinary approaches to conducting clinical research and overcoming barriers to this research to affect the efficiency of research endeavors and “transform” the processes for practical translation of evidence (Dilts, 2013; Pincus, Abedin, Blank, & Mazmanian, 2013; Rubio, 2013).

Herein is a description of a case example of the process for designing a cross-CTSA community–academic partnership project involving multiple stakeholder groups and a participatory mixed-methods approach. This case example intends to provide a framework for other partnerships to gain insight into (1) the value of community–academic partnerships in research, (2) the immediate and larger impact outcomes that can be expected from community-engaged partnerships, (3) the extent to which CEnR approaches can directly respond to existing gaps in the empirical body of research work, and (4) the specific determinants of trust that should be targeted when building community–academic partnerships, and public trust, and the various metrics for measuring the development of trust.

We conducted a multi-institutional pilot study using concept mapping with community, health-care, and academic research partners to allow us to understand how trust, a critical outcome of CEnR partnerships, can act as “social capital.” In 2016, Woolf et al. conducted a community engagement program to explore the social and environmental factors that influence health in local communities, set priorities, and develop targeted action strategies to bring evidence to policy makers and change agents. Woolf et al. applied concept mapping techniques and methodologically established a foundation of authentic engagement with community-based stakeholders to define pathway diagrams that elucidated potential causal factors contributing to health outcomes and prioritize research questions. The efforts described here shared a similar emphasis on authentic engagement as the foundation for exploring our position. Specifically, we posit that with increased public trust in research, research can elicit different perspectives on the dynamics of trust as a partnership resource—contributing to the science on how the development of trust in CEnR can transcend the current unidirectional empirical perspective. The multisite effort described here focused on *increasing the understanding of and improving the assessment of the underlying factors contributing to building community–academic partnerships, public trust, and a collective impact in research from varying perspectives.*

Theoretical Framework

As we consider the various frameworks from which our adapted model was developed, Table 1 presents an overview and comparison of the influential models. Our hypothesis and corresponding adapted framework were informed by Putnam’s *theory of civic engagement* (Putnam, 1997; Putnam, Leonardi, & Nanetti, 1994), Bourdieu’s (2011) *theory of social capital*, and The forms of *capital for health* (Carpiano, 2006).

Table 1. An Overview of Conceptual Focus, Definition of Social Capital, and the Role of Trust Among the Influential Models of Civic Engagement, Social Capital, and Social Capital for Health.

Theoretical Framework	Conceptual Focus	The Construct of Social Capital	The Role of Trust in Building Social Capital
Putnam: Theory of civic engagement	Collective values and social integration	Features of social life that enable participants to act together more effectively to pursue shared objectives	The ethos of mutual trust between citizens emerges from a culture of mutual cooperation, vital social networks, equal political relations, and the tradition of citizen participation
Bourdieu: Theory of social capital	The role of actors engaged in struggle in pursuit of their interests	Driven by resource building and sharing	Individual pursuits create collective values and social integration. There is a resultant accumulation of trust as social capital accrues when individuals trust one another
Carpiano: Forms of social capital for health	Inter- and intracommunity factors that serve as structural antecedents	Socioeconomic conditions serve as strong determinants for behaviors that are usually considered threatening in addition to the overall deterioration of the urban landscape (respectively termed as social and physical disorder)	Trust is a resource, or a form of social capital, that is available within social networks and can be further developed and maintained through the process of mutual reciprocity

According to Putnam et al. (1994), trust extends beyond individual- and didactic-level interactions deeply into the multiple layers of social context. Putnam (1997) defines social capital as “features of social life—networks, norms, and trust—that enable participants to act together more effectively to pursue shared objectives.”

This multi-CTSA effort was based on the hypothesis that social cohesion begins to form within community-engaged partnerships because of engagement, social interaction, formation of networks, and recognition of shared goals. Based on the development of these isolated social relationships, individuals can begin to access valued resources that create varying forms of social capital. In our case, trust, which is a form of social capital, emerges from these interactions. As the social networks and social ties develop, then social capital (i.e., trust) increases providing more opportunities for those who might be part of the group but not intimately connected to the group to access those resources.

Closely related to Putnam's theory, Bourdieu asserts that social capital is driven by resource building and sharing. An important aspect of Bourdieu's theory of practice is that individual's *habitus* or more simply class/social positions shape access to valued resources (or capital) and that an individual acts/reacts within the constraints (i.e., relations of power) imposed on them. From this framework, there is an inherent assumption that diverse stakeholders, because of their social positions, offer varying and specific strengths. This assumption serves as the foundation of the potential value in engaging multiple stakeholders in the research process to access different resources/capital (e.g., academics to grant funding, community members to emic, or insider knowledge). Social capital, which results from social interactions within networks, ultimately, leads to the accumulation of trust as social capital and accrues when members trust one another. Finally, Capano's (2006) conceptual model links Putnam's seminal work with Bourdieu's notion of social capital to illustrate that trust is a resource or form of social capital that is available within social networks that can be further developed and maintained through the process of mutual reciprocity. Thus, we used these concepts of trust, social capital, and civic engagement in research to identify an adapted framework to examine how trust within CEnR partnerships can ultimately build public trust in research. Each is described further below.

Putnam's Theory of Civic Engagement

Putnam's theory provides a framework to understand how the flow of capital through social relationships can enhance cooperation among community members by fostering trust in each other. Putnam's theory focuses on three components of social capital: moral obligations and norms, social values (especially trust), and social networks (especially voluntary associations). Putnam's theory posits that a region establishes a well-functioning

economic system and a high level of political integration from the region's successful accumulation of social capital (Putnam et al., 1994). Putnam further posits that here in the United States, the cause of many social problems is the decline of social capital which has been apparent for the last three decades (Putnam et al., 1994). Siisiäinen (2000) identified Putnam's ideas as a continuation of a current within the American theory of pluralism and reminiscent of functionalist conceptions of social integration from the 1950s and early 1960s (Siisiäinen, 2003). The guiding question of the evolution of Putnam's theory, as identified by Siisiäinen (2000), is "what are the preconditions for the development of strong, responsive representative institutions and a prosperous economy?" After empirical investigation, Putnam concluded that in areas with a well-functioning local government and a prosperous economy, the public activity of citizens has created an atmosphere of mutual cooperation, vital social networks, equal political relations, and the tradition of citizen participation (Siisiäinen, 2000). Behind all of these phenomena radiates the ethos of *mutual trust* between citizens (Abdulrahim et al., 2010; Green, 1991; Putnam et al., 1994; Siisiäinen, 2000).

Pierre Bourdieu's Social Capital

Society as a plurality of social fields is the theoretical cornerstone of Bourdieu's theory. Social position within a field influences access to capital (economic, cultural, and social; Bourdieu, 1990; Siisiäinen, 2000). The forms of capital controlled by the various agents determine the chances of "winning the stakes in the game" (Siisiäinen, 2000). From Bourdieu's perspective, social capital is the result of a collective phenomenon. Furthermore, as posited by Siisiäinen (2000), bureaucratic organizations are an effective tool in *concentrating* social capital and transforming contributing members to organizational effectiveness. The formation of an association can create a sense of solidarity among a mass of persons by giving the association a "name" which, in turn, institutionalizes the capital that is being accumulated. Despite trust not being included as part of Bourdieu's language, this collective and individual investment parallels the concepts we include in our adapted model that directly address collective efforts in CEnR that are necessary in the development of social capital as a foundational aspect of building trust. Furthermore, as explained by Carpiano (2006) in a critical examination of Bourdieu's theory, Bourdieu's theory forces us to consider the existence of community social networks and the resources (potential or actual) within a network and individual residents'

abilities to draw upon the network for those resources in order to pursue and achieve a variety of goals. When comparing Putnam's and Bourdieu's theories, Putnam's idea of social capital deals with collective values and societal integration, whereas Bourdieu's approach is made from the point of view of actors engaged in struggle in pursuit of their interests. But, as concluded by Siisiäinen (2000), Putnam's theory of social capital is focused on the concepts of collective values and societal integration, but in contrast, Bourdieu's theory focuses on the role of actors engaged in struggle in pursuit of their interests (Siisiäinen, 2000).

Carpiano's Conceptual Model of the Influence of Neighborhood Social Capital on Health

Carpiano's (2006) framework examines structural antecedents of social capital, social cohesion processes that lead to social capital, social capital itself, and social capital outcomes. He draws from Bourdieu's (2011) work to identify a model of social structure that includes both inter- and intracommunity factors that serve as structural antecedents. The model Carpiano (2006) examines the impact of socioeconomic burden on the living conditions of inner-city neighborhoods as well as the social resources of residents (particularly those of racial/ethnic minority status). More specifically, Carpiano (2006) posits that socioeconomic conditions serve as strong determinants for behaviors that are usually considered threatening in addition to the overall deterioration of the urban landscape (respectively termed as social and physical disorder; Sampson & Raudenbush, 1999). These determinants can also serve as the impetus for isolating both residents and communities from mainstream society. This framework influences our adapted model because it aptly defines the foundational aspects of CEnR partnerships that have historically undermined the development of trust between community and academic stakeholders.

Our Adapted Framework for the Development and Enhancement of Trust, Social Capital, and Civic Engagement

In Figure 2, we draw from Carpiano's model of social capital and health—one that links Putnam's seminal work on civic engagement and Bourdieu's conceptualization of social capital—to create a conceptual framework illustrating proposed relationships between social capital and trust within community-based partnerships and public trust in research. In essence, social cohesion permits social capital to emerge and permeate through the social networks of community-based research partners and the larger

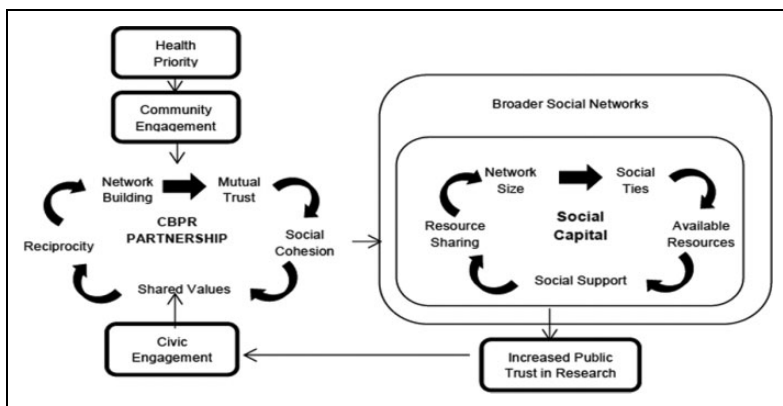


Figure 2. A framework for the development and enhancement of trust, social capital, and civic engagement adapted from Carpiano, Putnam, and Bourdieu.

community affecting how individuals perceive and approach research partnerships, and become involved in civic engagement, via research.

Sites and Partnerships

This multisite study involved five CTSA sites. Table 2 identifies the number of academic and community research members at each site and a brief geographic description of each site to identify the variation of sample participants across all the sites (with the exception of the University of Pittsburgh [PITT] which served as the data-coordinating site). The partners were located throughout the country and each site (excluding PITT) recruited stakeholders from varying settings including smaller southeastern urban settings (University of North Carolina [UNC]), large, urban settings (University of California, Los Angeles [UCLA]), moderate city and rural areas (University of Arkansas Medical Sciences [UAMS]), and moderate cities (University of Florida [UF]). The variation in sites supported recruitment of a broad stakeholder sample.

Using a CEnR Approach

A CEnR approach was integrated throughout this study's evolution from the onset of study conceptualization to study recruitment and currently during the dissemination of study results. In keeping with the CEnR framework of the study, the academic and community research partners established and maintained a collaborative professional relationship with consistent

Table 2. Overview of Partnering CTSA Sites, Research Team Composition, and Geographic Description.

Site	Number of Research Team Members	Number of Community Research Partners on Team	Geographic Location and Description of Stakeholder Locations
University of North Carolina at Chapel Hill	5	1	Research Triangle Park, NC (small, southeastern, urban areas around Chapel Hill, Durham, and Raleigh)
University of Arkansas for Medical Sciences—Little Rock	6	1	Southern United States, rural and urban areas
University of Florida—Gainesville	5	1	Gainesville, FL, medium size College town in central Florida and its surrounding rural communities
University of California—Los Angeles	4	2	Los Angeles, CA/large academic medical center and community clinics and community organizations throughout Los Angeles County
University of Pittsburgh	2	0	Data-coordinating site

communication on weekly team meeting calls that began prior to the start of the study and still continue. Figure 3 provides the overall governance structure of the multisite study. The research team established a data stewardship committee consisting of at least one academic team member and one community member from each site to review and monitor all deliverables in the form of grants, manuscripts, and presentations from the pilot work reported in this article with the objective of ensuring equity, conflict resolution, and multidisciplinary dissemination of study results. A formal *Authorship/Data Sharing Agreement* formalized the guidelines around all dissemination efforts including requirements of inclusion for this multisite initiative while also requiring community partner inclusion for all dissemination efforts. This multisite team achieved and has maintained a high level of success in building strong, collaborative relationships across the sites as evidenced by the works in progress and coauthorship on all deliverables.

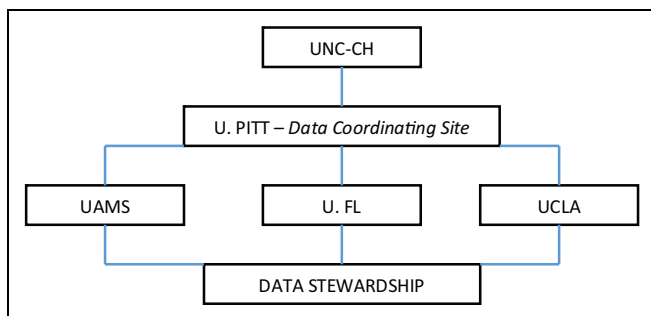


Figure 3. Overall governance structure.

Data-Coordinating Site

PITT investigators have extensive experience in research and projects that utilize the concept mapping approach (Burke et al., 2005). PITT led training webinars on data collection and management for each phase of the research and the Concept Systems Concept Mapping software (available at <http://www.conceptsystems.com/>, The Concept System[®] Software; Burke et al., 2005). The lead PITT investigator published the first article promoting the use of concept mapping as a participatory research method (Burke et al., 2005) and directed the PITT Department of Behavioral and Community Health Sciences (BCHS) Concept Mapping Institute. The BCHS Concept Mapping Institute is a recognized Concept Systems, Inc., center of practice and offers technical assistance and support to researchers interested in using the method (for additional details, refer to <http://www.publichealth.pitt.edu/behavioral-and-community-health-sciences/research-and-practice/centers/concept-mapping-institute>).

Method

Over the past decade, concept mapping has increasingly been used as a participatory research method in public health (Burke et al., 2005) to explore health topics including cancer screening (Ahmad, Mahmood, Pietkiewicz, McDonald, & Ginsburg, 2012), physical activity (Kelly, Baker, Brownson, & Schootman, 2007), health disparities (Risisky et al., 2008), and immigrant experiences (Haque & Rosas, 2010). Concept mapping was used to collect data from the three stakeholder groups: community, health-care, and academic research partners across three CTSA. Concept mapping is a participatory mixed-methods approach that allows participants to brainstorm

to identify factors that contribute to a concept and describe ways in which those factors relate to each other. Concept mapping is a process that traditionally involves six steps: (1) preparation, (2) generation, (3) structuring, (4) representation, (5) interpretation, and (6) utilization (Burke et al., 2005; Trochim, 1989). Concept mapping can involve participants at every level of research, so that they become research collaborators rather than solely providing responses to questions (Burke et al., 2005). Participants typically construct the questions that are used to collect data organize and prioritize data, label findings, and discuss their relevance. They become involved in the generation of ideas through the identification of conclusions and the application of findings. They can challenge results and plan strategic actions to apply the findings to their own or general situations (Burke et al., 2005; Trochim, 1989).

Study Overview

In order to accomplish these goals, the community–academic partners identified and prioritized various dimensions of trust with the intent of (1) defining an initial conceptual model of building and maintaining trust within a CEnR partnership from a multistakeholder-informed approach, (2) defining aspects of public trust in research that arise from CEnR partnerships and how they compare to existing frameworks, and (3) contextually defining a linkage between trust in CEnR partnerships and public trust in research. The CTSA grantees—UNC at Chapel Hill, UAMS, UF, UCLA, and PITT partnered on an inter-CTSA research project with the following aims:

- Aim 1:* Elicit community members', academicians' and health-care providers' understanding of trust to identify and define constructs of trust within CEnR partnerships.
- Aim 2:* Prioritize constructs of trust within CEnR partnerships and explore the relative importance of each construct for development and maintenance of CEnR partnerships and public trust in research.
- Aim 3:* Identify key indicators of trust and develop conceptual frameworks illustrating the pathways linking trust within CEnR to public trust in research via community connectors and the influence of civic engagement.

Figure 4 provides an overview of the concept mapping process and the project aims that guided this specific multisite, CEnR effort. More specifically, as part of the structured concept mapping process, study participants were asked to identify and prioritize various dimensions of trust with the

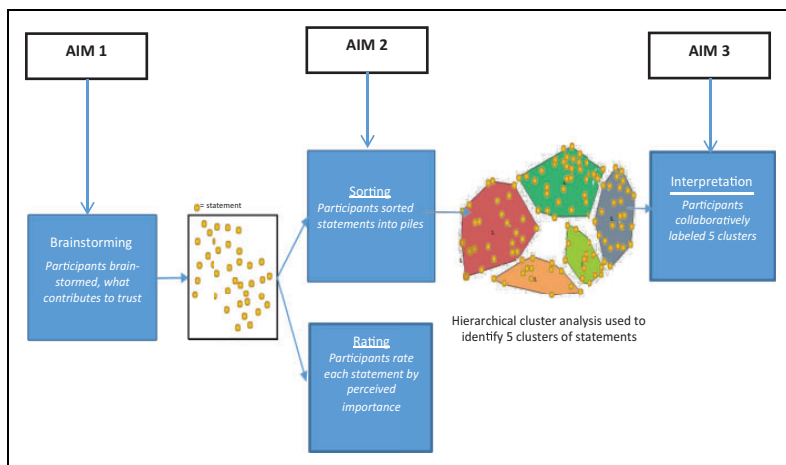


Figure 4. Concept mapping overview with project aims and corresponding study activities to address each aim.

intent of (1) defining a conceptual model of building and maintaining trust within a CEnR partnership, (2) defining aspects of public trust in research that arise from CEnR partnerships and how they compare to existing frameworks, and (3) contextually defining a linkage between trust in CEnR partnerships and public trust in research. The anticipated outcome of this effort was a visual concept map depicting the relationship of items contributing to trust and an initial set of measurable domains that identify the relationship between trust in CEnR partnerships and public trust in research. This research is an important first step in developing a set of measures of trust that can be used across CTSA sites to track changes in public trust in research. More specifically, our strong hope is for this case example and the data from the effort to inform the direction for the design of future measurement tools and the framework of future interventions that will focus on building trust and social capital within community–academic partnerships and public trust in research.

Recruitment and Reimbursement Practices for Study Participation

Table 3 provides an overview the project time line. Key stakeholder groups were defined according to mutual consensus across all partnering CTSA sites and included community members, health-care providers, and academicians (further described in “Sample Overview” section). All participants were recruited according to a respondent-driven, nonprobabilistic sampling

Table 3. Project Time Line.

Project Milestone	September	October	November	December	January	February	March	April	May	June	July	August	September
Participant recruitment													
Finalize data tools													
Finalize concept mapping protocol													
Train cofacilitators													
Data collection													
Data analysis													
Review data													
Dissemination plan													
Manuscript/proposal development													

Table 4. Reimbursement by Site.

Site	Study Activity Reimbursement Total/Rate	Other Reimbursement
University of North Carolina	US\$15/study activity	US\$10 for gas/activity when travel was greater than 60 miles total
University of Arkansas Medical Sciences	US\$15/hr for each study activity	US\$10 for gas/activity
University of Florida	US\$30/study activity	NA
University of California, Los Angeles	US\$40 (cash)/study activity	NA

method that identifies key informants and relies on these individuals to draw on their social networks to refer potential participants to the study (Heckathorn, 1997). This sampling method is often used to recruit participants from groups not typically engaged in research and ensured that a range of perspectives was represented for this effort. Inclusion criteria were (1) 18 years and older and (2) at least 1 year of CEnR experience. However, for the community member stakeholder group, we also included participants with no CEnR experience to increase the inclusion of this particularly valuable stakeholder group. All participants across all sites received reimbursement for their time and travel expenses for participation in the form of a gift card but reimbursement varied according to site specifics. Table 3 provides an overview of the varying reimbursement approaches across each study activity by data collection site. Table 4 presents an overview of reimbursement by site and activity.

Sample Overview

The originally identified target recruitment for each stakeholder group was 15–30 for community members, 15–30 for health-care providers, and 15–30 for academic researchers. The total recruited sample for this study was 156, from four different study sites, UAMS ($n = 54$), UCLA ($n = 27$), UF ($n = 33$), and UNC ($n = 42$) which surpassed the originally identified target enrollment needed to effectively analyze the data in the Concepts Systems software.

The final sample for each study activity is presented in Table 5. All participants completed a brief, self-administered questionnaire that

Table 5. Sample Size for Each Study Activity.

Activity	Community Members	Academics	Health-Care Providers	Total
Brainstorming	65	74	47	186
Sorting and rating	67	49	40	156
Interpretation	55	50	38	143

included demographic variables (e.g., age, gender, education) and research experience.

Results

Description of Concept Mapping Process

In order to address Aim 1, online and/or face-to-face group sessions were conducted at each site to identify the constructs and critical elements associated with trust in research. The decision between the two online and/or face-to-face methods was decided by each site based on the accessibility of participants to attend face-to-face sessions with variation across sites. Table 6 presents an overview of the number of sessions at each site for each study activity and the number of face-to-face and online sessions for each study activity by site.

During the first session, all participants were asked to complete a brief questionnaire that included demographic variables (e.g., age, gender, education) and research experience. Each site identified research team members who served as cofacilitators for face-to-face sessions. The facilitators completed a training webinar led by the PITT Concept Mapping Institute (data-coordinating site). The webinar provided information on how to collect data in each phase of the research, the kinds of follow-up questions to pose during sessions to illicit the appropriate data as guided by the study objectives, manage the data obtained from the brainstorming and pile sort and rating activities, and synthesize the study and corresponding analytic process of reaching the cluster concept map solution presented in the interpretation sessions.

All sites committed to disseminating the final results of the study efforts by providing a summary report of each activity both for their site and the overall study. The final report also included the final cluster solution that included the specific constructs within clusters and was distributed in person, via e-mail, and mailed to all study participants across all sites.

Table 6. Overview of Total Study Activity Sessions, Face-to-Face, and Online Sessions by Site and According to Study Activity.

Site	Number of Total Sessions/Site Across All Study Activities	Face-to-Face Number of Sessions by Activity	Online Number of Sessions by Activity
University of North Carolina			
Brainstorming	3		3
Sorting and rating ^a	37 ^a		
Interpretation	4		4
Presentation of results ^b	1	1	
University of Arkansas Medical Sciences			
Brainstorming	4	2	2
Sorting and rating ^a	54 ^a		
Interpretation	4	2	2
University of Florida			
Brainstorming	8	3	
Sorting and rating ^a	31 ^a	1	1
Interpretation	7	7	
University of California, Los Angeles			
Brainstorming	3		3
Sorting and rating ^a	25 ^a		
Interpretation	6	6	

^aSorting and rating is completed individually online (with the exception of UF). Therefore, only the total number of participants/site are reported. ^bUNC was the only site to conduct an in-person session to share overall study results and conduct a brief focus group to obtain feedback across all stakeholder groups on the study process and next steps based on this pilot effort.

Study Activity 1: Brainstorming

The first step in the Concept Mapping process, the brainstorming session, was focused on gathering responses from the research team on the project's focal question: *Based on your experience(s), list all the things that you think contribute to trust between community and academic partners in research?* The PITT investigators, as the data-coordinating site, facilitated the determination of the brainstorming focal question. The process of identifying the question began by providing example focal questions and probes from prior projects to all research team members across the four data collection sites. Then, data-coordinating center integrated the input from the four other sites and finalized the question.

The brainstorming activities included in-person, group sessions and online data collection via an online survey tool across all the sites (excluding PITT, the data-coordinating site). An online data collection tool was used to collect brainstorming responses from the research study focus prompt. Given the difficulty for some of the stakeholder groups at particular sites to identify a time to meet in person, the research team members felt an online method was the most practical source to gather input from all stakeholder groups for this first study activity. Thus, three of the four data-collecting sites conducted online brainstorming activities. Typically, the focal question elicits brief responses in the form of words or phrases. It is important to keep in mind that the brainstorming activity is not interested in understanding “why” the respondent nominates an item to the list. The “why” is explored later in the interpretation study activity.

This phase of data collection generated many brainstorming responses that were then consolidated into a single list by the data-coordinating center. Using deductive approaches to data reduction, duplicate items were removed in a standardized manner, items grouped based on common themes, and ultimately, a master list of themes was generated.

Study Activity 2: Sorting and Rating

The second step in the Concept Mapping process is to sort and rate the master list. This is an individually oriented activity, which allows for each participant to:

- (1) group the items into piles based on similarity among items and
- (2) rate the items using predetermined ratings scales

The ratings scales for this second activity were defined and finalized for this project by consensus from all members of the research team from the four data collections sites with guidance from the original rating scales suggested by the PITT team. The rating scales were identified as:

- (1) How IMPORTANT is each item for CREATING TRUST between community and academic partners in research?
- (2) How IMPORTANT is each item for MAINTAINING TRUST between community and academic partners in research?
- (3) How much INFLUENCE does each item have on the GENERAL PUBLIC’S TRUST OF RESEARCH?

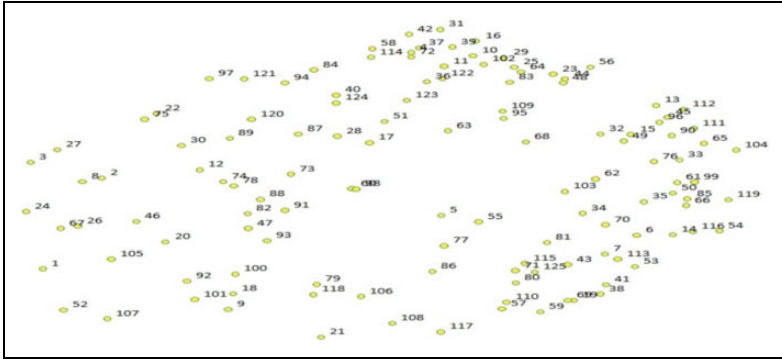


Figure 5. Point map.

This study activity included in-person group sessions and/or online independent data collection at each site. While the same instructions and tasks were provided to all participants regardless of in-person or online methods, the tasks were individually oriented and were not impacted by choice of facilitation approach. Those who participated via in-person, group sessions were in direct contact with the investigators facilitating the activities and those who completed activities online did so independently. All data gathered from the sorting and rating activity were then entered and analyzed by the coordinating center using the Concept Systems software (Kane & Trochim, 2007, which allowed for the visualization of results through concept maps) which are generated by multidimensional scaling and hierarchical cluster analyses (Kane & Trochim, 2007).

Data across all sites were used to first generate a point map depicting similarities of constructs and then cluster maps illustrating how specific items sorted together (as shown in Figure 5). In concept mapping, multidimensional scaling is used to create a point map. The point map is a two-dimensional picture of the similarity of the statements. As shown in Figure 5, the map illustrates similarities among items as individuated by the distance between each individual point that represents a single item in a cluster. Therefore, the points that are closest to each other are items that were grouped together most frequently. Items that are further away from each item are thought to be less similar.

Using hierarchical cluster analysis, distinct clusters of items are delineated, and a final cluster solution is decided on through group consensus. In our community-engaged process, the data-coordinating site gathered input for this analytic phase from all research team members across all

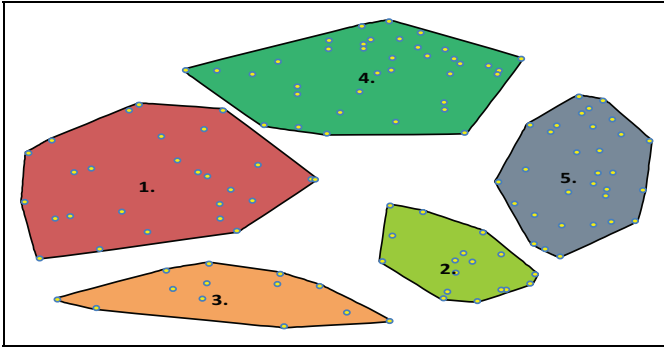


Figure 6. Example of five-cluster solution.

CTSA sites regarding the appropriate number of final clusters with an emphasis on capturing valuable conceptual data in response to the study objectives. Figure 6 provides a visual example of a hypothetical five-cluster solution that can emerge from the data collected in a concept mapping effort.

Study Activity 3: Interpretation

Participants across all four data collection sites were then asked to work in small groups among their stakeholder group to review the specific items within each of the five clusters. Small groups were determined according to the number of participants who registered for each session which were offered both in-person and online across all data collection sites.

Participants were first asked to name each cluster based on the theme of the items within each individual cluster. Each session group discussed their labels among their stakeholder peers with the objective of reaching a consensus on the name of that cluster. In second part of the interpretation session, we asked participants to work within the same group to illustrate, using pen and paper, relationships among items within clusters. Clusters were discussed in great detail, including the cluster itself and each item. Once the final cluster name was decided upon with consensus, participants were asked to identify, or visually illustrate on paper, relationships among items and an explanation of these identified relationships. Once all labels were collected across all sites and across all stakeholder groups, the research team members were asked to select their site's top choices of labels to submit to the PITT investigators for finalizing the cluster labels.

Cluster names were finalized through an iterative process with online input from each research team member and all study participants. A total of 21 cluster titles were proposed across all four sites for each of the five individual clusters. The proposed cluster titles were compiled by the coordinating center and sent via online survey to research team members at the data collection sites. Each team member was asked to identify his or her choices for the top three names for each cluster. The list of 21 cluster names was then distilled to a total of 20 possible titles across all five clusters (Cluster 1: 4 proposed titles, Cluster 2: 4 proposed titles, Cluster 3: 4 proposed titles, Cluster 4: 3 proposed titles, and Cluster 5: 2 proposed titles). The coordinating center then distributed a second online survey requesting each team member across all four sites to identify one final title for each individual cluster.

Discussion

This article provides a case example that examines trust as a critical outcome of CEnR partnerships and a methodological overview of the application of concept mapping for multisite, CEnR efforts. Future dissemination efforts can inform the evidence base on how critical trust is to CEnR partnership outcomes. Furthermore, future dissemination efforts should be aimed at illustrating how trust acts as social capital and permeates through partnerships into the community.

In this multisite effort, we learned that trust within CEnR partnerships can act as “social capital” or as a resource leading to increased public trust in research. While trust within partnerships has been identified as both an essential element and an outcome of CEnR, there is a paucity of literature that suggests that trust is a resource available in social networks that can lead to increased public trust in research (Bright, Haynes, Patterson, & Pisu, 2017). Our work is one of the first empirical efforts to better understand trust from a multistakeholder, CEnR framework. This effort is also the first, disseminated case example of a CEnR effort, to the best of our knowledge, to examine social capital as it relates to participation in research. As described by the CTSA in 2011, the Task Force described four key elements for development of a constituency to conceptualize the tasks of community engagement. The methodological process described here applies a similar process to conceptualize the tasks of community engagement by focusing on the fundamental concepts of building the single construct of trust. The methodological overview presented here intends to provide measurable domains that can be applied by other CTSA to understand differences and

similarities in the conceptualization of trust among key stakeholder groups, track changes in public trust in research, identify both positive and negative aspects of trust, identify characteristics that maintain trust, and inform the direction for future research.

Strengths and Limitations of Concept Mapping Approach for CEnR

As noted in previous publications, concept mapping is a method with notable limitations and strengths (Burke et al., 2005). The method is resource intensive (e.g., requires the use of computers and associated software) and the conduct of the in-person group activities necessitates the use of trained facilitators. In addition, the concept mapping process is a stepwise process that builds on prior activities and may require both a substantial time commitment from participants and investigators and coordination of several activities across multiple sites. Nonetheless, concept mapping is a unique participatory research method that uses multiple data collection approaches (e.g., brainstorming and sorting activities) and individual- and group-based activities to permit the exploration of complex ideas. A significant strength of the concept mapping method is the generation of visual maps displaying group consensus on the similarities of items and ideas. Concept maps and other visual representations (e.g., pattern matches) can be fairly easily understood by a broad range of participants from multistakeholder groups including doctors, academics, and community members. Furthermore, this multisite effort is an example of concept mapping's application for empirical investigation to explore trust specifically in CEnR partnerships. Overall, the concept mapping exercise successfully met the study's objectives by applying this mixed-methods approach to a multidisciplinary sample to facilitate a collaborative discussion in order to clearly define the measurable domains of trust.

Implications

The primary goals of this methodological overview are intended to serve as a first step from which multiple stakeholders can build. More specifically, we provide a study protocol for other multidisciplinary teams to build from to identify the specific relational aspects that are needed to create effective and trusting CEnR partnerships. Further, we intend to serve as a case example of the significant power of the concept mapping process as a mixed-methodological technique that fosters collaboration among several stakeholder groups across many dimensions of an outcome of interest; this

is particularly useful and appropriate when conducting research from a community-engaged framework. As executed by Dozier et al. (2013), concept mapping can serve as an initial step to guide the development of a more granular approach, such as social network analysis, to identify individual- and within-group differences from a multisystem level perspective to collectively impact practice and policy. Finally, we intend to share the value of this multistakeholder, multistep methodological, and multisite initiative as a significant and successful benchmark study for CEnR and more broadly, multistakeholder partnerships in research.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by a grants from the National Institutes of Health/ National Center for Advancing Translational Science through the Clinical & Translational Science Award Institutions of University of Arkansas for Medical Sciences (#UL1TR000039), University of California, Los Angeles (#UL1TR 000124), University of Florida (#UL1TR 000064), University of North Carolina (#UL1TR001111), and the University of Pittsburgh (#UL1TR000005).

ORCID iD

M. M. Kim  <https://orcid.org/0000-0003-2381-3453>

References

- Abdulrahim, S., El Shareef, M., Alameddine, M., Afifi, R. A., & Hammad, S. (2010). The potentials and challenges of an academic–community partnership in a low-trust urban context. *Journal of Urban Health, 87*, 1017–1020.
- Ahmad, F., Mahmood, S., Pietkiewicz, I., McDonald, L., & Ginsburg, O. (2012). Concept mapping with South Asian immigrant women: Barriers to mammography and solutions. *Journal of Immigrant and Minority Health, 14*, 242–250.
- Bourdieu, P. (1990). *In other words: Essays towards a reflexive sociology*. Palo Alto, CA: Stanford University Press.
- Bourdieu, P. (2011). The forms of capital. In I. Szeman, & T. Kaposy (Eds.), *Cultural theory: An anthology* (pp. 81–93). Madden, MA: Wiley-Blackwell.
- Bright, C. F., Haynes, E. E., Patterson, D., & Pisu, M. (2017). The value of social network analysis for evaluating academic-community partnerships and

- collaborations for social determinants of health research. *Ethnicity & Disease*, 27, 337–346. doi:10.18865/ed.27.S1.337
- Burke, J. G., O'Campo, P., Peak, G. L., Gielen, A. C., McDonnell, K. A., & Trochim, W. M. (2005). An introduction to concept mapping as a participatory public health research method. *Qualitative Health Research*, 15, 1392–1410.
- Carpiano, R. M. (2006). Toward a neighborhood resource-based theory of social capital for health: Can Bourdieu and sociology help? *Social Science & Medicine*, 62, 165–175.
- Clinical and Translational Science Awards Community Engagement Key Function Committee Task Force. (2011). *Principles of community engagement* (2nd ed.). Washington, DC: NIH.
- Dilts, D. M. (2013). A “three-plus-one” evaluation model for clinical research management. *Evaluation & The Health Professions*, 36, 464–477. doi:10.1177/0163278713499019
- Dozier, A. M., Martina, C. A., O'Dell, N. L., Fogg, T. T., Lurie, S. J., Rubinstein, E. P., & Pearson, T. A. (2013). Identifying emerging research collaborations and networks: Method development. *Evaluation & The Health Professions*, 37. doi: 10.1177/0163278713501693
- Green, L. W. (1991). Forum on youth violence in minority communities. Establishing a public-private partnership. *Public Health Reports (1974)*, 106, 242–243.
- Haque, N., & Rosas, S. (2010). Concept mapping of photovoices: Sequencing and integrating methods to understand immigrants' perceptions of neighborhood influences on health. *Family & Community Health*, 33, 193–206.
- Heckathorn, D. D. (1997). Respondent-driven sampling: A new approach to the study of hidden populations. *Social Problems*, 44, 174–199. Retrieved from <https://ncats.nih.gov/ctsa>
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.
- Kane, M., & Trochim, W. M. (2007). *Concept mapping for planning and evaluation*. Thousand Oaks, CA: Sage.
- Kelly, C. M., Baker, E. A., Brownson, R. C., & Schootman, M. (2007). Translating research into practice: Using concept mapping to determine locally relevant intervention strategies to increase physical activity. *Evaluation and Program Planning*, 30, 282–293.
- Khodyakov, D., Mikesell, L., Schraiber, R., Booth, M., & Bromley, E. (2016). On using ethical principles of community-engaged research in translational science. *Translational Research*, 171, 52–62. e51. doi:10.1016/j.trsl.2015.12.008

- Leshner, A. I., Terry, S. F., Schultz, A. M., & Liverman, C. T. (2013). *The CTSA program at NIH: Opportunities for advancing clinical and translational research*. Washington, DC: National Academies Press.
- Pastor, M., & Morello-Frosch, R. (2014). Integrating public health and community development to tackle neighborhood distress and promote well-being. *Health Affairs*, 33, 1890–1896. doi:10.1377/hlthaff.2014.0640
- Pincus, H. A., Abedin, Z., Blank, A. E., & Mazmanian, P. E. (2013). Evaluation and the NIH clinical and translational science awards: A “top ten” list. *Evaluation & The Health Professions*, 36, 411–431. doi:10.1177/0163278713507061
- Putnam, R. D. (1997). The prosperous community: Social capital and public life. *Frontier Issues in Economic Thought*, 3, 211–212.
- Putnam, R. D., Leonardi, R., & Nanetti, R. Y. (1994). *Making democracy work: Civic traditions in modern Italy*. Princeton, NJ: Princeton university press.
- Risky, D., Hogan, V. K., Kane, M., Burt, B., Dove, C., & Payton, M. (2008). Concept mapping as a tool to engage a community in health disparity identification. *Ethnicity and Disease*, 18, 77.
- Rubio, D. M. (2013). Common metrics to assess the efficiency of clinical research. *Evaluation & The Health Professions*, 36, 432–446. doi:10.1177/0163278713499586
- Sampson, R. J., & Raudenbush, S. W. (1999). Systematic social observation of public spaces: A new look at disorder in urban Neighborhoods. *American Journal of Sociology*, 105, 603–651.
- Scott, C. S., Nagasawa, P. R., Abernethy, N. F., Ramsey, B. W., Martin, P. J., Hacker, B. M., . . . Disis, M. L. (2014). Expanding assessments of translational research programs: Supplementing metrics with value judgments. *Evaluation & The Health Professions*, 37, 83–97. doi:10.1177/0163278713500984
- Siisiäinen, M. (2003). Two concepts of social capital: Bourdieu vs. Putnam. *International Journal of Contemporary Sociology*, 40, 183–204.
- Siisiäinen, M. (2000). *Social capital, power and the third sector. The third sector in Finland: Review to research of the Finnish third sector*. Helsinki, Finland: Finnish Federation for Social Welfare and Health. pp. 7–35.
- Trochim, W. M. (1989). Outcome pattern matching and program theory. *Evaluation and Program Planning*, 12, 355–366.
- White-Cooper, S., Dawkins, N. U., Kamin, S. L., & Anderson, L. A. (2007). Community-institutional partnerships: Understanding trust among partners. *Health Education & Behavior*, 36, 334–347.
- Wolf, S. H., Zimmerman, E., Haley, A., & Krist, A. H. (2016). Authentic engagement of patients and communities can transform research, practice, and policy. *Health Affairs (Millwood)*, 35, 590–594. doi:10.1377/hlthaff.2015.1512