

The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress

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Abstract

Background: The past two decades have been marked by increased community involvement in the research process. Community-engaged research (CEnR) is increasingly promoted in the literature, and academic programs with a community-academic partnership focus. Community-based participatory research (CBPR) is an approach to frame equitable community involvement in research and is a critical component of the CEnR continuum. As with CEnR, noted benefits of using CBPR expressed in the literature, which include enhancing the relevance and application of the research data, expertise to complex problems at all stages of research, overcoming community distrust, and improving community health. This article presents a community engagement (CE) model that includes seven defined designations for CEnR. In addition, this model includes equity indicators and contextual factors for consideration at the various levels of engagement along the continuum.

Methods: The CE model described in this article combines the principles of CE and CBPR in conjunction with a

continuum model. The continuum integrates a focus on health equity and contextual factors providing perspectives from both community and academic partners at each point of engagement.

Conclusions: A broadly defined CEnR continuum will allow researchers, community members and organizations to readily identify 1) where they are on the continuum of CEnR, 2) appropriate access points to enter the continuum based on existing contextual factors, and 3) actions to promote progression on the continuum. Funders have the opportunity to specify the appropriate level of CE needed to accomplish the goals of their identified priorities.

Keywords

Community-based research, Community engagement, Collaborative approaches, Research process, Participatory research

CENR

CE, defined by the Centers for Disease Control and Prevention is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”¹ The overarching aim of CE is to improve population health by building trust, enlisting new resources and allies, creating

better communication, and creating longstanding collaborations.¹⁻³ The principles of CE have not fundamentally changed in the past two decades. The nine principles of CE were adapted from Centers for Disease Control and Prevention and published in the second edition of *Principles of Community Engagement* by the Community Engagement Key Function Committee Task Force.⁴ The principles were organized in

three sections, including 1) considerations prior to beginning engagement, 2) necessary considerations for engagement to occur, and 3) considerations for engagement to be successful. To date, more agencies and organizations are involved in promoting CE and CEnR yielding substantial increases in published reports on the effectiveness of CE in research.^{4,5}

CE in research has emerged as a priority for several federal agencies. Funders began requiring community involvement beyond advisory boards, which often served superficial roles that were not integral to the conduct of the actual work. For example, the Clinical and Translational Science Awards, a program of the National Institutes of Health, designed to develop innovative solutions to improve the efficiency, quality and impact of the process for translating observations from the laboratory into communities' interventions that improve the health of the public. Clinical and Translational Science Awards program academic institutions are required to engage patients and communities in every phase of the translational process.⁶ Similarly, the Prevention Research Centers funded by the Centers for Disease Control and Prevention are a network of 26 academic research centers that are required to work with communities to develop, evaluate, and implement major community changes that can prevent and control chronic diseases.⁷ The Patient-Centered Outcomes Research Institute (PCORI) is a leader in the engagement of community and other stakeholders in the field of healthcare research with a focus on community and patient-stakeholder engagement.^{8,9} PCORI underscores their belief in equity among researchers, patients, and other stakeholders, emphasizing the value of patient expertise. PCORI has published 20 peer-reviewed articles highlighting the value that community and patient engagement has in research concerning health systems.⁸ National Institutes of Health, PCORI, and other research financing institutions have embraced the concept of CE in research. The trends of CE more broadly may create a shift in how researchers across disciplines see the role of community, patients and other stakeholders.

CBPR is a higher order example of CEnR. Israel et al.¹⁰ define CBPR as “a collaborative approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute unique strengths and shared responsibilities to enhance understanding of a given

phenomenon and the social and cultural dynamics of the community and integrate the knowledge gained with action to improve the health and well-being of communities.”¹⁰⁻¹² A 2004 systematic review of 185 CE articles published from 1999 through 2003 found increases in high-quality articles defined by rigorous research methods and adherence to CBPR principles of community collaboration.⁵ A subsequent systematic review (2000–2009) drew similar conclusions about the increase in published CBPR reports in addition to focusing on the effectiveness of CBPR studies as measured by positive changes in communities.¹³ Authors speculated that this trend was attributable to more targeted funding and special journal issues on this theme.⁵ These results showed that interventions, which included CE, have the potential for greater improvements in health; however there are variations in both the quality of the research methods and the actual degree of CE in the research process. Although the review of seminal CE studies established metrics to assess research rigor and adherence to CBPR principles, the metrics may have created a rigid standard which unintentionally serves as a barrier to CEnR more broadly.

HEALTHY FLINT RESEARCH COORDINATING CENTER (HFRCC)

Flint, Michigan, has been an epicenter of CE in research (including CBPR) for more than 25 years, yet there continue to be challenges understanding the stages of engagement, the role of equity, and how the historical context impacts CE. In 2016, the Healthy Flint Research Coordinating Center (HFRCC) was created as a partnership of local community leaders and university researchers to coordinate research efforts in Flint, Michigan (www.hfrcc.org).¹⁴ The HFRCC consists of an academic core with three university partners (Michigan State University, University of Michigan–Flint, and University of Michigan–Ann Arbor), and a Community Core led by two partners organizations (The Community Based Organization Partners and the National Center for African American Health Consciousness). The HFRCC was formed in direct response to concerns by community residents over the increased research in Flint owing to the water crisis.^{14,15} The HFRCC lessens the burden of research on community through collaborative efforts by 1) vetting research via the Community Based Organization Partners' Community Ethics Review Board (CERB), 2) decreasing redundancy in research

by creating an online catalogue of historical and active projects via the Flint and Genesee County Project Index, 3) offering trainings with bi-directional learning between community and academic partners, 4) providing access to Flint-area data via an online data repository Open Data Flint, and 5) hosting community dialogues to bolster the community's voice in guiding and setting a research agenda for Flint. The objective of this report is to introduce a broader framework of CEnR developed by founding members of the HFRCC.

METHODS

This framework is grounded in previous research on public engagement and public participation. Two prevailing models were developed to represent different levels of public engagement in society, including municipal sectors and in more recent decades, the scientific community. The International Association of Public Participation uses a continuum to measure public participation using five main domains of participation.¹⁶ Likewise, Arnstein's eight domains in the "ladder of citizen participation" served as a more direct predecessor for engagement continuums relevant to science and research.¹⁷ As citizen engagement in various sectors, including science, has increased over time, the need for specific models to characterize and contextual the continuum of CE in research has also grown.

Building on these previous frameworks, the current report defines a continuum of CE in research. Researchers, community members and funders could benefit from a more tailored perspective and clear definitions along a continuum of CE in research. This would allow researchers and community partners to 1) identify where they are on the CEnR continuum, 2) assess appropriateness of the research for varying degrees or stages of CEnR, and 3) provide actionable leverage points related to context (e.g., strength of relationships) and equity (e.g., distribution of resources) to support the success of community-academic partnerships.

Although there are many forms of CEnR, CBPR has emerged as the most commonly cited form and arguably the gold standard. Through the development of CBPR, much has been learned about the pitfalls and challenges of effective CEnR. One specific challenge identified is time. The length of time required to establish relationships and build trust with community may be a deterrent to researchers under pressure

to publish their research.¹⁸ Another challenge is sustainability. Maintaining time, resources/funding, morale, and power dynamics often associated with experiences of discrimination and racism present challenges to sustainability.¹⁶ The current CEnR continuum builds on the lessons learned from CBPR, which is identified as one point on the continuum.

Expanding the concept and language of CEnR could strengthen its value and provide evidence previously considered to have less scientific legitimacy, as it fell short of the CBPR ideals. It provides a clearer pathway for community partners to identify where their participation falls within research. A clearly defined continuum also enhances the community partners' ability to interact with investigators, with equal knowledge and understanding of the points of engagement. Using this framework, funders have the opportunity to specify the appropriate degree of CE required to accomplish the goals of their identified priorities. Furthermore, researchers interested in conducting CEnR have greater flexibility and can more readily identify appropriate entry points for community involvement without the stigma of not meeting the CBPR standard.

Expansion and Adaptation of the Framework

This framework was developed, in large part thru direct observations of community and academic partners in a variety of HFRCC CE activities related to the generation of research ideas, the conduct of research, and dissemination of research findings. The continuum of CEnR (Figure 1) was expanded and enriched, in part, by adding equity indicators and contextual factors based on the authors previous experiences and publications.^{19,20} The listening and vetting during public presentations lead to additional modifications to the framework. These changes were important to represent the key roles of equity and context^{10,20-22} in shaping research outcomes¹⁹ and influencing the strength of collaboration between the community and academic partners.²³ This adaptation more closely aligns with the principles of engagement. The authors propose that equity and context should be positioned at the center of planning, implementing and disseminating research for successful engagement to occur. The CEnR framework, including the background contextual factors and downstream equity indicators was developed and used as our CEnR continuum.

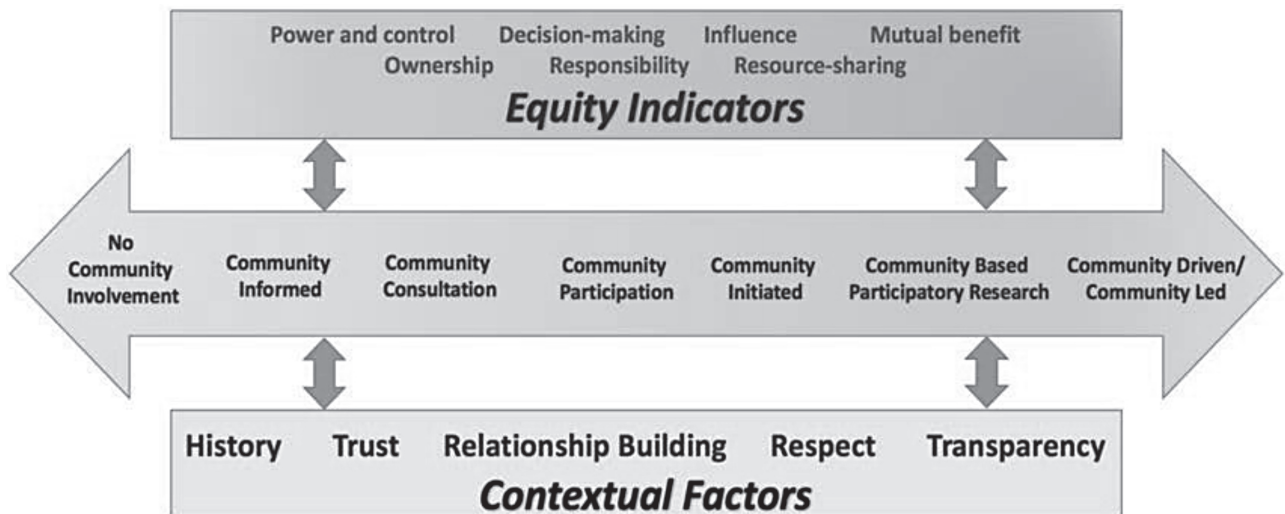


Figure 1. Continuum of Community Engagement in Research

The CEnR continuum was presented and vetted by both community and academic researchers during multiple HFRCC's research partnership events attended by more than 300 participants from multiple sectors. In the first two years of the HFRCC, it was shared with community residents during community dialogue sessions led by the HFRCC community core. The community dialogue sessions included community residents, academic partners, government institutions as well as philanthropic organizations. Engaging with participants and listening to their feedback identified the need to include community and institutional perspectives as well as equity and contextual factors. These perspectives are necessary to better understand the varying dynamics that often arise in community-academic (and other institutional) partnerships.

Defining the CEnR Continuum

Viewing CEnR in the context of a continuum demonstrates that such engagement can range from consultation with community partners to community driven research. CBPR has nine underlying principles: 1) recognizes community as a unit of identity, 2) builds on strengths and resources within the community, 3) facilitates collaborative, equitable involvement of all partners in all phases of the research, 4) integrates knowledge and action for mutual benefit of all partners, 5) promotes a co-learning and empowering process that attends to social inequalities, 6) involves a cyclical and iterative process, 7) addresses health from both

positive and ecological perspectives, 8) disseminates findings and knowledge gained to all partners, and 9) involves a long-term commitment by all partners.^{10,11} Our continuum places CBPR at the far right of the CEnR continuum, legitimizing research conducted with different levels of CE.

Over time, the level of community involvement may increase and become more meaningful to partners, thus the collaboration may move along the continuum⁴; however, there is no inherent value placed on research regardless of where it falls along the continuum; for example, some CE is better than none. The CEnR continuum (Figure 1), displays the various points of CEnR ranging from no community involvement to community led/driven research.

This framework highlights contextual factors that may influence and affect the points of engagement listed on continuum. These contextual factors include history, trust, relationship building, respect and transparency. Contextual factors, when considered by the partners, may affect the type of engagement and the overall results of the research. The framework also identifies equity indicators that affect CEnR. As relationships between partners are formed, transparency must be present, and trust developed. During this time, the critical conversations necessary to strengthen and build the partnership should be guided by the identification of contextual factors and equity indicators (power and control, decision making, resource sharing and ownership). These factors should be considered and addressed by the partners

to lessen potential negative reactions when they arise. Critical discussions around control, ownership, and decision-making processes make CEnR distinct from traditional research, in which issues of power dynamics are often topics considered inappropriate or uncomfortable. This continuum holds the promise of encouraging researchers to become more open to engaging community in research.

Defining Involvement and Activities on the CEnR Continuum

Figure 2 provides examples of the level of activity and involvement of partners at each point of engagement. The titles express the type of engagement, that is, “community informed” indicates that information is extracted by a researcher, from the community, knowingly or unknowingly, and is used to inform and make decisions as part of the research process. “Community consultation” is when the community provides guidance and/or advice regarding the research and gives feedback to the researchers. “Community participation” is the point at which community members are actively involved, in addition to the first two phases; for example, community members are serving on community advisory boards or engaging in recruitment efforts. “Community initiated” specifies that the community may engage a researcher based on the community’s research priorities. At this point, a community may not necessarily be directly engaged in the research design, data analysis, and/or dissemination phases of the research process. CBPR addresses issues of inclusion and equity, while underscoring community participation in all phases of the research process (from identifying the research topic to disseminating research findings). Finally, “community

driven” is the point at which community seeks the support of the researcher to assist in research identified and led by the community. Each point identified along this continuum clearly depicts the distinct points of engagement. Figure 2 also shows the activities and actions of the researcher at each point of engagement along the continuum.

Defining Perspectives and Experience on the CEnR Continuum

The CEnR continuum provides a visual representation of the engagement landscape without a subjective value attachment and avoids placing greater value on any particular point. This continuum provides guidance to researchers who desire to work with community partners. In addition, it helps to identify where they are, or could be, in their level of engagement. It also offers opportunities for expanding or enhancing engagement as appropriate and/or if desired.

Figure 3 provides an explanation of how the various forms of CEnR shown in Figure 1 manifests from either the perspective of the community or the researcher. For example, at the community informed point: a researcher attends a community event and hears what residents are saying about a specific issue. The researcher then designs a research project guided by the information they heard during the event. The residents who participated in the event may not be aware that what they shared was used to inform the researcher’s project. In this instance, though the researcher utilized this information to develop the project, they didn’t ask the residents to partner or participate in any capacity. From the perspective of the researcher, they were “informed” by the community. However, community members have described this behavior

Community Involvement/Activity						
Community is not included in any aspects of the research	Community informs the research and may or may not be informed or included (or know they're informing)	Community provides input and feedback to researchers to inform the research	Community has some active role in the research	Community initiates the research agenda/priorities	Community shares equally in decision-making and ownership	Community leads and owns the research
No Community Involvement	Community Informed	Community Consultation	Community Participation	Community Initiated	Community Based Participatory Research	Community Driven/Lead
Researcher works independent of community	Information is gleaned from the community which informs the research 'ear hustling'	Researcher consults with community and includes community in the research (front end or back end)	Researcher includes community in the research in a defined role	Researcher responds to specific needs or asks from community	Researcher shares equally in decision-making and ownership with community	Researcher supports community identified research efforts or serves no role
Researcher Involvement/Activity						

Figure 2. The Continuum of Community Engagement in Research: Involvement and Activity

<i>Community Perspective/Experience</i>						
We do not know about this project	We may or may not be aware of this project but our information informed it	Researchers met with us to present the project and asked for our input	Researchers provided opportunities for us to participate (e.g., recruitment, community advisory board)	We told researchers what questions we need answers for	We participated in all aspects, equitably	We fully own the research
No Community Involvement	Community Informed	Community Consultation	Community Participation	Community Initiated	Community Based Participatory Research	Community Driven/Lead
We had no contact with the community	We sat in on a meeting and learned a great deal	We met with several community organizations, they shared their concerns and gave us suggestions	We have a defined role(s) for community to participate in the research	We created the research in response to community identified issue(s)/question(s)	We developed the project together with community partners	The community is in charge and we support their efforts when asked
<i>Researcher Perspective/Experience</i>						

Figure 3. The Continuum of Community Engagement in Research: Perspective and Experience

of overhearing an idea from an individual or group and acting on that idea without their knowledge, as “ear hustling.” Figure 3 also aids community and researchers to better understand each other’s perspectives and provide insight for their actions, intentional or unintentional. This continuum is designed to inform partners of ways to approach and engage each other in activities that could result in more effective CEnR.

DISCUSSION

CEnR allows for the development of partnerships between researchers and community. It supports and integrates the expertise of community and researchers seeking to improve the community through research. This framework was created with both community and academic partners within the HFRCC, vetted, presented, and revised with input from community and academic participants from the broader community.

The HFRCC coordinates research efforts in Flint using this continuum as a guide to bring community and academicians to a broader understanding of how they can enter collaboratively into research. This continuum is complementary to existing and frequently cited approaches to CEnR, and seeks to validate other forms of CEnR, while providing distinctions between the various points of engagement. This continuum emphasizes the importance of the various points of CE represented along the continuum. It gives community and researchers the opportunity to discuss the point of engagement they intend to undertake and describes the expectations for CE in completing the research. These descriptions are dependent on the contextual factors and are informed by the knowledge,

needs and resources held by community members as it relates to the research question(s).

Although this continuum outlines the various types of CE, there are opportunities to define strategies to engage community and institutional partners in research. Such strategies may include a combination of educational resources tailored to inform community residents about the potential values of research. In addition, they could provide community members with educational and didactic opportunities to learn how to develop and conduct research studies. The CEnR continuum supports working with academic institutions and federal funding agencies to ensure community benefit through partnered research to enhance the translation of research findings into various community contexts.

FUTURE DIRECTIONS

The CEnR continuum resulted from the need for communities and academicians to identify and understand the various points of engagement in research. It is important to note that this continuum supports the necessary rigor to assure validity of the research while supporting the community in better understanding research frameworks and approaches. This continuum honors the capacity and expertise within the local context by its residents and provides an in-depth opportunity to understand the social context that frames the interpretation of research findings. In addition, community-partnered frameworks provide an opportunity to account for changes that occur in the community that may not be as easily captured in research literature for any particular topic.

CONCLUSION

We hope this continuum serves as guidance for those seeking to improve community conditions through community-academic research partnerships. We hope to underscore the potential for significant and equally important community health improvements with multiple forms of CEnR. To the extent possible, this information can be shared with health-focused community organizations to enhance their understanding of their potential roles in public health research. We anticipate that this continuum will also be adopted by schools of public health and health departments to more effectively engage with communities. We further hope to increase confidence within the scientific community that community expertise and engagement is a credible approach to solving problems within the community. We propose this could potentially increase the likelihood that identified solutions are sustainable and plausible within that the community context.

This CEnR continuum recognizes multiple points of engagement and will serve as a tool to inform partners at which point their efforts are on the continuum and the various perspectives and activities associated with their level of engagement. It places CBPR as an essential point of engagement on the continuum, preserving and safeguarding it in its truest state, while distinguishing it from other credible forms of CEnR that may not hold true to all the CBPR principles. Furthermore, the continuum introduces equity indicators and contextual factors in relation to CE. Understanding how these indicators and factors affect each point of engagement will aid community-academic partnerships as they collectively participate in the research process. This is especially important in addressing the crucial dynamics around equitable and respectful relationship building which are important elements along the CEnR continuum.

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