Community Voices For Health

Leveraging Community-Engaged Research for Success: Findings from Researcher Interviews and Literature Scan

Background

Community Voices for Health aims to build stronger community engagement infrastructures—involving a broad range of people and especially those from marginalized and underserved communities—so their voices are heard in health policy decisions, their efforts to solve problems are supported, and their community networks are strengthened. This project will make community engagement more:

▲ **Inclusive and sustained**, by expanding engagement techniques and involving previously marginalized communities;

▲ **Informed**, through community-engaged research; and

▲ **Influential**, by creating strong, sustainable communication pathways between community members and policymakers.

The Robert Wood Johnson Foundation has provided funding for six organizations to lead 30-month projects in six states, with technical assistance provided by Public Agenda and Altarum.

A unique facet of this project is to strengthen consumer engagement and policymaking efforts using community-engaged research. To facilitate project success, we used the pilot phase to conduct informal researcher interviews and a web search/literature scan to better understand where and how community-engaged research has been used and to strengthen our understanding of best practices.

Our findings are presented below.

What is Community-Engaged Research?

Community-engaged research (CEnR) is a collaborative process between a researcher and community partners that creates and disseminates knowledge and creative expression with the goal of strengthening the well-being of the community.[1] A fundamental premise of community-engaged research is that community members and organizations have credible, legitimate, and intimate understandings of the assets, concerns, values, and activities of their communities.[2]

CEnR in Action: Neighborhood Health Scorecards in Birmingham, Alabama

Shape Bham is a multi-stakeholder collaborative that aims to combine demographic and health information with input from community stakeholders to integrate health and equity into the Birmingham City planning process at the neighborhood level. The collaborative created a "report card" to: (1) assess the health and quality of life of Birmingham neighborhoods; (2) make recommendations to the community planning "framework" process; and (3) track the progress in neighborhoods as the city does its planning.

During the planning phase of the project, researchers brought together groups of community residents to discuss assets and barriers that affected local quality of life. Using PhotoVoice, residents collected over 300 photographs of elements in their environment that hurt their quality of life, including damaged sidewalks and abandoned buildings in disrepair. Once the neighborhood scorecards were drafted, residents provided feedback on their format and usefulness. Revisions were made according to the community's response.

More information on Shape Bham's Neighborhood Health Scorecards and other examples of community-engaged research are available on the Community Voices for Health website. These projects illustrate the value of CEnR for integrating community knowledge, needs, and preferences into research and ensuring that results lead to local transformation.

Informal Researcher Interviews: Approach

Altarum interviewed researchers, advocates and community organizers (including some that were unfamiliar with the concept of CEnR) from June to August of 2019 to gather learnings related to community-engaged research. Our goal was to learn:

▲ How to clearly convey the research component of the Community Voices for Health project;

▲ What barriers might exist for researchers potentially interested in using community-engaged research approaches;

▲ Interviewees' reactions to case study examples and our organizing framework profiling diverse uses of community-engaged research; and

▲ Community-engaged research best practices.

The following researchers and advocates shared with us their diversity of experience and expertise:

Joe Sammen, Center for Health Progress (CO)	**Michael Oakes**, University of Minnesota School of Public Health (MN)
Jessica Greene, Baruch College, Marxe School of Public and International Affairs (NY)	**Janet Weiner**, University of Pennsylvania Leonard Davis Institute of Health Economics (PA)
Martin Gaynor, Carnegie Mellon University (PA)	**Hasshan Batts**, Promise Neighborhoods of the Lehigh Valley (PA)
Lisa Kirsch, University of Texas at Austin Dell Medical School (TX)	**Sirry Alang**, Lehigh University (PA)
Jonathan Oeverman, City of Grant Rapids (MI)	**Billy Kirkpatrick**, Five Horizons Health Services (AL)
Katherine Browne, Constellation Consulting (PA)	**Nina Wallerstein**, University of New Mexico Health Sciences Center's Center for Participatory Research (NM)

COMMUNITY-ENGAGED RESEARCH: LEARNINGS

Our informal interviews and literature scan revealed many important lessons, especially for those not previously familiar with CEnR. These are summarized into 10 key learnings below.

"Community Participation" Means Different Things to Different People

Informal interviews with experts who have engaged in a diversity of research projects shed light on the wide interpretation of the term "community participation." The spectrum of understanding ranged from a consultative approach (i.e., surveys and/or focus groups) to one that empowers community members to improve their own circumstances by designing the research process, developing measures, "owning" the data and disseminating the results. In the absence of examples that illustrate a broad, inclusive approach to engaging community members in research, community participation can easily be defined too narrowly. These definitions tend to rely too heavily on 'outreach' as the primary form of community involvement.

The International Association of Public Participation (IAP2) Spectrum of Public Participation is helpful for understanding the range of potential community involvement in a research project.

Outreach	Consult	Involve	Collaborate	Shared leadership
• Some community involvement • Communication flows from one to the other, to inform • Provides community w/ information • Entities co-exist • **Outcomes:** establishes communication channels & channels for outreach	• More community involvement • Communication flows to the community & then back, answer seeking • Gets information or feedback from the community • Entities share information • **Outcomes:** develops connections	• Better community involvement • Communication flows both ways, participatory form of communication • Involves more participation w/ communities on issues • Entities cooperate w/ each other • **Outcomes:** visibility of partnership established w/ increased cooperation	• Community involvement • Communication flow is bidirectional • Forms partnership w/ community on each aspect of project from development to solution • **Outcomes:** partnership-building, trust-building	• Strong bi-directional relationship • Final decision making is at community level • Entities have formed strong partnership structures • **Outcomes:** broader health outcomes affecting broader community

Increasing level of community involvement, impact, trust & communication →

"We will keep you informed."	"We will keep you informed, and listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the direction."	"We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision."	"We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible."	"We will implement what you decide."

Source: International Association of Public Participation (IAP2) Spectrum of Public Participation

Researchers and Community Members Have Different, But Equal, Expertise

Several factors contribute to creating an equal partnership between researchers and community members. For example, interviewees identified a need for clear and consistent terminology that acknowledges the different, but equal, contributions of researchers and community members. While researchers' expertise is often well-established, expertise from community members' lived experiences tends to be under-valued in community research. Use of alternative titles, like "content expert" and "context expert," helps convey equal power between the two parties, which is important for building trust, ensuring that outcomes are informed by the communities' lived experience, and providing a strong foundation for action at the project's conclusion.

Community Members Should be Included in All Phases of the Research

According to national experts, best practices for CEnR include creating an equal role for community members in each phase of the research project, as described in Table 1.

Table 1
Best Practices for Community Engagement in Research—A Checklist

RESEARCH PHASE	Was the community involved in:
RESEARCH QUESTION/DESIGN	Design Development?
	Proposal Development?
	Budget Development?
RESEARCH PROCESS	Participant Recruitment?
	Problem Solving?
	Staffing Decisions?
	Project Oversight?
	Data Collection?
	Data Analysis?
INTERPRETING RESULTS	Interpreting Findings?
DISSEMINATING RESULTS	Designing Dissemination Plan?
	Publishing or Presenting Findings?
OWNERSHIP OF DATA	Data Ownership?

Note: This checklist was adapted from C. R. Spears Johnson A. E. Kraemer Diaz T. A. Arcury, "Participation Levels In 25 Community-Based Participatory Research Projects," *Health Education Research*, Volume 31, Issue 5 (October 2016) and Wallerstein, Nina et al., Community Engaged Survey, *Engage for Equity: A National Study of Community and Academic Partnerships* (August 2016).

For the most part, we received positive feedback from interviewees regarding the list of potential roles for community members described in Table 1. However, questions were raised about community members' capacity to meaningfully contribute to all phases of research. For example, some interviewees expressed concern over community members' ability to productively participate in research design and analyses without formal training.

Marginalized Communities May Have a History of Distrust with Large Academic Institutions

Numerous interviewees described experiences in which researchers enter a community, collect and analyze data, and tell community members what their problems are. This "advice" is often unsolicited, confirms what community members already know, or fails to acknowledge other, more pressing, problems that residents face. Moreover, researchers often leave a community once the project is over, neglecting to offer solutions or provide resources to address the problems they have identified. Interviewees provided examples of large academic institutions that have alienated the urban communities in which they are located, causing many community members to distrust them.

Community-Engaged Research Requires Trust in Order to Build Working Relationships

One interviewee explained that overcoming distrust between marginalized communities and researchers requires researchers to adopt an attitude of truth and reconciliation, even if they were not involved in past projects that undermined trust. As mentioned previously, researchers must be willing to share their power and come to the table as equal partners in order to build meaningful relationships with community members.

Successful efforts might start with an individualized, passionate invitation for community members to participate. Researchers must create "an authentic sense of belonging" and allow community members the flexibility to decide the type of contribution that is best for them. Additionally, community members need to know that their actions are going to make a difference. Researchers must be prepared to answer the question "How is this going to matter?" Finally, once the project has concluded, researchers should return to the community and ask "Did we maintain the trust?"

Budgets are Value Statements

Empowering communities to improve their circumstances requires funders to change the way money is distributed. Uniquely, community-based participatory researchers at the University of New Mexico serve as the sub-contractor in their work with Native American tribal leaders. The tribal leaders are the principal investigators on the project—they communicate with the program officers, make the decisions, and own the data. This structure ensures that the research project is driven by, and ultimately benefits, the community.

At the very least, multiple interviewees expressed that community partners should be compensated for their time and expertise. Ideally, their compensation should be equal to that of the research partner to reinforce parity between the partners.

Research Design Should Reflect Communities' Wants and Needs

Community-engaged research requires research partners to be flexible in their approach. For example, a randomized controlled design is considered the gold standard in traditional research, but may be inappropriate for projects that involve addressing unmet community needs. One informant with experience in this area explained that it is impossible to maintain a community's trust if you withhold an intervention from a control group when people are in need. In these cases, a randomized lag design could be a good alternative.

Follow-Up Is Important

Many of the examples in our inventory of case studies[3] did not measure outcomes or describe follow-up activities once community needs were identified. Communicating results to the broader community and co-designing a plan to help address identified needs is critical to maintaining trust and sustaining community engagement in research.

Community-Engaged Research May Sacrifice Researcher Objectivity

One interviewee expressed concern that equal partnerships with community members could make it difficult for researchers to maintain objectivity, which is important when drawing conclusions from one's research. They also explained that there is a line between research and advocacy that, if crossed, can diminish a researcher's credibility among external audiences.

Considerations for Research Partners

Interviewees identified some potential barriers to researcher participation in Community Voices for Health, including:

▲ Possible diminished opportunity to publish findings in a peer reviewed journal (particularly for non-tenured academicians);

▲ Lack of familiarity with community-engaged research concepts; and

▲ Discomfort with sharing power with community members.

Tenured professors with independent funding streams have greater flexibility to engage in projects with relatively low funding or those that might not appear in peer-reviewed journals. These considerations are somewhat lessened for non-academic researchers.

Because this project focuses on raising the voices of underserved and marginalized communities, distrust in academic institutions is of central concern. Community members may be more comfortable partnering with local colleges and universities rather than larger research institutions. On the other hand, at some large institutions, community-engaged research is a well-developed field of inquiry. Additionally, younger researchers looking for fresh, novel research ideas may be willing partners.

To ensure a potential research partner is willing to meaningfully partner with a community, interviewees proposed asking the researcher the following questions:

▲ Has the researcher had a previous relationship with the community of focus?

▲ Will the researcher provide staffing or other resources to community organizations? If so, how will the staffer support the community organization?

▲ Who is identifying the research problem?

SUMMARY

Interviewees emphasized the importance of understanding the community-engaged research spectrum and recognizing the unique histories and experiences of community members as an asset to research. While researchers have academic expertise and can serve as 'content experts,' community members should also be regarded as 'context experts' to create an atmosphere of equality. Additionally, community members should play a role in all phases of the research and be compensated for their time.

Negative historical experiences highlight the need for relationship-building among researchers and community members—especially those from marginalized and underserved communities. Building trust requires researchers to adopt an attitude of truth and reconciliation, even if they did not create the damage.

Finally, co-owning research findings and demonstrating a commitment to solving problems (rather than solely documenting them) are critical to sustaining community engagement and supporting community-driven change.

The *Community Voices for Health* technical assistance team will use these learnings to support grantees as they develop plans for and implement community-engaged research projects and to inform a larger learning community.

Notes

1. Virginia Commonwealth University, Center for Community Engagement and Improvement, https://community.vcu.edu/faculty-support/ (accessed on Nov. 5, 2020).

2. Pasick, Rena, et al., *Community-Engaged Research with Community-Based Organizations: A Resource Manual for UCSF Researchers*, Clinical & Translational Science Institute at the University of California, San Francisco, C.A. (2010). https://accelerate.ucsf.edu/files/CE/manual_for_researchers_agencies.pdf

3. Altarum and Public Agenda, *Using Community-Engaged Research to Strengthen Resident Engagement in Health Decision-Making*, Washington, D.C. (2019). https://static1.squarespace.com/static/5d4c679727aefd0001ed91b0/t/5ed14ad031c1a80efe467b70/1590774481182/CER+Case+Studies+Examples.pdf

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