COMMUNITY-ENGAGED HEALTH RESEARCH
Experiences from the San Francisco Bay Area

San Francisco State University

Center for Research on Gender and Sexuality
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- Web-Based Survey
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I. EXECUTIVE SUMMARY

Community-based organizations (CBOs) face serious barriers in gaining access to and applying scientific information about the populations they serve and the effectiveness of their work. Rarely do CBOs, let alone community residents, have (1) access to the complex language of science and research and (2) a good understanding of what science and research mean for their work and the health of their community. Since the mid-twentieth century, health researchers and scientists have advocated community-based, participatory, collaborative, and action research as strategies to employ scientific principles and practices in pursuit of a more equitable society. Community-engaged research (CER) has a range of desirable consequences for the research process, including improving participation rates, strengthening research external validity, increasing the likelihood for follow-up, and building capacity within individuals and communities most affected by health disparities. CER also brings together rigorous public health research and practice to address social and environmental injustice and differences in health.

This report presents evidence-based knowledge of how to build and sustain community engagement in health research efforts to inform both researchers and community stakeholders. We identify the range of activities used to engage community in research endeavors, while increasing our understanding of the reasons for CER, barriers to CER, and when CER may be contraindicated. We clarify distinctions between community engagement, community action research, community-based participatory research, and other related terms. We also catalog and define “best practices” for community engagement. Drawing on existing literature and data gathered in interviews, focus groups, and surveys with academic researchers, institutional review board members, funders, and community research partners in the Bay Area, we examine current practices and principles in CER, with a particular focus on three shared principles: mutually beneficial inquiry, commitment to social change, and meaningful community involvement.

The general conclusions from this report are as follows.

• Researchers are more engaged with agencies and community organizations than with individual community members. Agencies and CBOs provide CER teams a research infrastructure. Over three fourths of researchers work with community organizations to disseminate findings (90%), recruit participants (83%), explore the implications of the study (79%), and generate research ideas (76%). There is also significant agency and organization engagement in the interpreting results (72%), and helping to prepare grant proposals (66%). Over half of researchers primarily engage community members as research team members or to facilitate the recruitment of research participants.

• Survey participants rated potential benefits of CER. An overwhelming majority of respondents argues that CER improves the recruitment of hard-to-reach population (91%), helps define community relevant research questions (88%), and help develop better community interventions (85%). A majority of participants definitely agree that CER results in highly relevant research, creates innovative research questions, helps in the interpretation of findings and in the translation of research in action, and create external validity to the research.

• Three principals emerge as critical from our work with Bay Area CER researchers: (1) a commitment to increase the capacity available to community partners, equipping them to work in partnership with researchers and, ultimately, to pursue their own research and social
change agendas; (2) engagement in research that make a positive impact, addresses social problems, and effects desired social change; and (3) the creation of meaningful partnerships throughout the study, including equipping community members, agencies, and organizations to work in partnership with researchers and, ultimately, to pursue their own research and social change agendas.

- The challenges in achieving such meaningful community involvement are numerous. Academic researchers struggle to sufficiently train and supervise collaborators, and community collaborative research can provide short-lived and often disappointing access to formal training and legitimate sources of income. Authorship and publication were of particular concern to our respondents. Few academic researchers receive any training in how to negotiate authorship with any collaborators—academic or community-based. Similar problems may arise around community partners’ meaningful access to data and other resources central to the process of inquiry. Staff turnover at agencies and CBOs may undermine community agencies’ and organizations’ commitment to long-term collaborations. Moreover, funders’ expectations of deliverables may compromise the reflection that CER otherwise promises.

- These challenges may discourage researchers from participating in CER. Our sample of researcher experiences with CER argues that the most important barrier for researchers to do CER is the time commitment necessary to develop a project with a community. Almost 80 percent of survey respondents believe the time required is a serious barrier to doing CER. Sixty-one percent consider funding pressures an additional serious barrier to building the foundation for CER, and over half cite inconsistent deliverables between academia and community as a barrier to researchers.

- Although most researchers fear that community engagement could affect the scientific validity of the work, this issue was less important to our sample of researchers with CER experience. About a third of experienced researchers see the difficulty to maintain scientific objectivity as a serious barrier to CER. Reflecting the need for training, capacity building, and building trust as important elements of CER, over half of experienced researchers mentioned community’s lack of understanding of academia, push-back on necessary methodological tools, ideas that are not supported by literature or funders, and a concern that community members may misunderstand research findings as somewhat representing barriers to CER.

In their discussions of how to respond to these challenges, researchers, community partners, funders, and practitioners in our sample identified a series of best practices that allow CER participants to balance academic and community concerns, build relationships, define roles and responsibilities, navigate differences, and ensure access to data and dissemination. These practices will help community and academic partners pursue CER that is characterized by the utmost quality and that addresses the most pressing public health concerns and the needs of the most vulnerable populations.
II. INTRODUCTION

A. Purpose

The Health Equity Institute at San Francisco State University (SF State), in collaboration with SF State’s Cesar Chavez Institute and Center for Research on Gender and Sexuality, embarked on a project for the Research Division of Kaiser Permanente to explore current nomenclature, definitions, and best practices in the engagement of community voices and expertise in the health research enterprise.

Community engagement research (CER) has a range of desirable consequences for the research process, including improving participation rates, strengthening research validity, increasing the likelihood for follow-up, and building the capacity of individuals and communities most affected by health disparities (Viswanathan, Ammerman, Eng, et. al, 2004). For Bay Area researchers committed to CER, still lacking is a clear definition and distinction of the types of CER available, how each type is defined, and case studies that highlight best practices in CER in the Bay Area.

Despite the many promises of CER, community-based organizations (CBOs) face serious barriers in accessing and applying scientific information about both the populations they serve and the effectiveness of their work. Rarely do CBOs, let alone community residents, have (1) access to the complex language of science and research and (2) a good understanding of what science, research, and CER might mean for their work and the health of their community.

Our project, guided by our shared missions of achieving health equity, sought evidence-based knowledge of how to build and sustain community engagement in health research efforts to inform both researchers and community stakeholders.

The primary aims of this project were the following:

- To identify the range of activities used to engage community in research endeavors;
- To increase understanding of the reasons for CER, barriers to CER, and when CER may be contraindicated;
- To clarify distinctions between community engagement, community action research, community-based participatory research, and other related terms; and
- To catalog and define the identified “best practices” for community engagement among local researchers, funders, and community representatives.

With its concentration of universities and research centers; diverse racial, sexual, and gender communities; activist organizations; immigrant communities; and access to federal, state, county, and private foundations, the San Francisco Bay Area has an especially robust community of public health researchers and a particularly active roster of community stakeholders and partners. Not surprisingly, CER—its rewards, challenges, and accomplishments—has become central to public health research and practice in the Bay Area.

In the following pages, we explore CER in the United States and in the San Francisco Bay Area. Drawing on existing literature and data gathered in interviews, focus groups, and surveys with academic researchers, institutional review board members, funders, and community research partners, we examine current practices and principles in CER, with a particular focus on three shared principles: community capacity building, research in support of social change, and meaningful community involvement. Throughout this report, we explore the many ways CER challenges conventional scientific practice, requiring academic researchers to rethink their professional
priorities while maintaining scientific rigor and integrity. We close with conclusions and recommendations, including some of the best CER practices our respondents identified.

B. Background

Since the mid-twentieth century, health researchers and scientists have advocated community-based, participatory, collaborative, and action research as strategies to employ scientific principles and practices in pursuit of a more equitable society (Wallerstein and Duran 2008). In the last few decades, such community-engaged strategies have gained legitimacy and support in public health research, advocacy, and practitioner communities (Mercer and Green 2008; Minkler and Wallerstein 2008). Enthusiasm for such rigorous community engaged public health research “reflects [its] potential for bridging gaps between research and practice, addressing social and environmental justice and enabling people to gain control over determinants of their own health” (Cargo and Mercer 2008:325). For those seeking public health research that is methodologically innovative and rigorous, responsive to community needs, and quickly effective in the fight against entrenched health disparities, CER offers a significant and exciting step forward.

CER represents one effort to redress power imbalances and even exploitation in the history of social and medical science (Bell 2006; Heron and Reason 2006; Smith 1999). CER has already proven successful in promoting the interests of vulnerable populations and helping to identify and evaluate effective policies and interventions in prisons (Fine et al. 2001; Grinstead, Faigeles, and Zack 1997). Collaborative and community-based interventions offer a particularly important opportunity to address the sexual, racial, gender, and socioeconomic inequalities that put many communities at risk of poor health outcomes (Gutierrez and Lewis 2005).

One of the most prominent forms of CER is community-based participatory research (CBPR). Drawing on the work of Israel, Schulz, Parker, and Becker (1998), W. K. Kellogg Foundation, a major funder, has defined CBPR as follows:

> CBPR in health is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.

CBPR has long been recognized as a critical approach to addressing complex health issues that arise in part from an unequal distribution of resources. CBPR aims for societal transformation toward health equity, including changing academic-community relations; incorporating community participation, decision-making, and values; and addressing inequitable distribution of social determinants. To accomplish these goals, core national CBPR principles have been proposed, including genuine partnership and co-learning; capacity-building of community members in research; applying findings and knowledge benefiting all partners; and long-term partnership commitments.

CBPR and CER alter the conventional relationship between researchers and community members. Academic researchers work with people who might otherwise be only “research subjects” to identify “problems of mutual concern and consequence” (McTaggart 1997, 27; see also Lewin 1946). These people act as “co-researchers” and participate in research design, implementation, and/or dissemination to take action that will effect meaningful social change in their lives (Tandon, Kelly, and Mock 2001). Participants’ contributions represent an opportunity to strengthen the research process by increasing its internal and external validity, accessibility, and ability to effect meaningful social change (Cahill 2007; Fine et al. 2003). CER promotes collaborative partnerships that allow
new theories to emerge and increases the likelihood that empirically-grounded interventions will be feasible and appropriate to community needs (Schensul 1999).

In this altered relationship between researcher and community, CER also represents a fundamental challenge to the scientific process. The paradigm launches community partners into roles that scientific practice does not conventionally provide for (Minkler and Baden 2008; Wallerstein and Duran 2008; Wright and Treacher 1982). Ethnic, racial, sexual, and socioeconomic differences between academic researchers and their co-researchers may only exacerbate challenges posed by differences in training and preparation (Pinto et al. 2007). Thus, partners must together achieve meaningful collaboration in which researchers and community partners teach and learn from one another, work together to shape the study’s process and outcome, enjoy equitable access to data and other study resources, and share both responsibility and credit for the study. CER that involves such meaningful collaboration will “embrac[e] both science and local experience” (Gómez, Hernandez & Faigeles, 1999; Pinto et al. 2007, 53).

Embracing science means maintaining research integrity, which requires “the adherence by scientists and their institutions to honest and verifiable methods in proposing, performing, evaluating, and reporting research activities” (Rhoades 2002, 467). Misconduct can occur across a range of research practices, all of which undermine the quality, relevance, usefulness, and trustworthiness of science. Those practices include ensuring shared access to data and other resources, to promote transparency and collaboration; promoting responsible data selection, interpretation, and reporting, to ensure honest, accurate findings; training and mentoring of researchers, to pass on norms, expectations, and practices, practice non-discrimination, serve as exemplars of research ethics and integrity, and promote rigorous attention to research integrity and ethics; and assigning authorship, to reflect responsibility for findings and not simply the claiming of credit (Bird 2006; Hansson 2000; Institute of Medicine 2002; Iverson, Frankel, and Siang 2003; Sigma Xi 2000).

In CER, academic researchers ideally share access to data and other resources central to the process of inquiry; however, academic researchers have greater access to resources situated in the university (Chataway 1997; Minkler 2004; Wallerstein 1999). Reaching consensus about what constitutes adequate training and mentoring is always contentious, and perhaps more so for researchers and community-based collaborators working across starkly different institutions and social hierarchies (Elden and Levin 1991). Collaborations among people with disparate training, experience, and comfort as authors and who answer to different audiences complicate the already difficult issue of authorship (Parker et al. 2005). Finally, the emphasis in CER on collaboration raises questions about what constitutes meaningful collaboration.

Ultimately, participation from community members introduces new priorities and complicates existing ones in health research: researchers become accountable to multiple communities and thus multiple and perhaps conflicting sets of ethical duties (Welch 1993) as members of the research, lay, provider, consumer, and evaluation communities work together and blur boundaries that conventionally separate their spheres of work and accountability (Minkler and Wallerstein 2008).

Increasingly, public health researchers navigate a professional landscape in which CER figures as a significant option and expectation. In the last fifteen years, CBPR and other models of CER have become “central to the mission of health professional schools” (Seifer, Wong, Gelmon, and Lederer 2008:5). More and more, funders, community members, practitioners, and others expect researchers to consider community interests and assets as they design, conduct, and disseminate research.
III. METHODOLOGY

To learn more about CER in the San Francisco Bay Area, we interviewed and surveyed academic researchers, community partners, grant makers, and institutional review board members from area universities, foundations, CBOs, and government agencies between October 2009 and February 2010. Our protocol was reviewed by the SF State Institutional Review Board and was considered exempt because the information gathered related to persons’ opinions regarding professional/work practices, the results were intended for local assessment and not for broader generalization, and the protocol did not involve the collection of personal information.

A. Qualitative Interviews and Focus Groups

We conducted 15 interviews and 2 focus groups with a total of 22 key informants, including academic researchers, funders, community research partners, and Institutional Review Board members at Bay Area universities, foundations, community-based organizations, and government agencies. Participants were identified and intentionally selected to represent a range of experience with CER.

The open-ended interview guide included the following questions:

- How do you define community-engaged research (CER)?
- How would you describe the particular sort of CER you do? How would you distinguish that from other CER?
- What are the existing barriers to conducting CER?
- What are some strategies for successfully challenging those barriers?
- What are the plusses and minuses of CER?
- What difference does CER make in your work?
- When is CER not the best choice for a research project? When is it a good choice?
- What motivates you to choose CER in your work?
- What would you identify as some best practices in CER?
- Tell me a story about a time that CER seemed to really work. A time it didn’t?
- What is the ideal trajectory of a CER project?

For funders only
- Have you made CER a priority in your calls for proposals? Why or why not?

For Institutional Review Board members only
- What challenges do you face in reviewing and approving CER proposals?
- When, if ever, have you thought that CER would improve a protocol?

Five trained SF State graduate students with interest and experience in health research, community-engaged scholarship, and participatory data collection and analysis conducted the interviews and focus groups. A staff member with the SF State Health Equity Institute conducted interviews as well. Interviewer training included an overview of project aims and design, discussion of CER, and practice in open-ended interviewing with key informants. After each focus group and interview, the
Interviewers used their notes and an audio recording of the interview to produce an extensive written summary of the conversation.

Interview analysis included a review of all written summaries and a selection of original audio recordings. Interviews were coded for themes including (but not limited to) the themes explored in this document.

**B. Bay Area Investigator Survey**

A brief (10-item) web-based survey (see Appendix A) was created in SurveyMonkey™ to assess experience with CER among a convenience sample of researchers in the San Francisco Bay Area. Items included closed-ended and open-ended responses.

An initial list of 75 local health-focused investigators was developed. Investigators received an email invitation to participate in an anonymous web-based survey and were also asked to forward the invitation to other colleagues conducting health research in the Bay Area. Individuals were given a two-week window for completing the survey and a reminder was sent to the original list a day prior to the deadline. A total of 42 investigators accessed the survey, and 34 surveys were completed.

Analysis of this survey was limited to descriptive statistics (frequencies, means, and distributions). Qualitative responses were collated based on themes, where appropriate.

**C. Sample**

Our overall sample included the following participants.

**Table 1. Number and type of participants**

<table>
<thead>
<tr>
<th>Total academic researcher survey respondents</th>
<th>34</th>
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<tr>
<td>Total interview and focus group participants</td>
<td>22</td>
</tr>
<tr>
<td>Academic researchers</td>
<td>13</td>
</tr>
<tr>
<td>Community researchers and partners</td>
<td>5</td>
</tr>
<tr>
<td>Grant makers</td>
<td>2</td>
</tr>
<tr>
<td>Institutional Review Board members</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>56</strong></td>
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IV. ANALYSIS

A. Shared Principles Across Spectrums of Engagement

Throughout the existing literature and in our interviews and focus groups, CER appears under a range of names, including participatory research, participatory action research, action research, community-engaged scholarship, community-involved research, community-responsive research, community-based participatory research, democratizing research, research justice, and stakeholder engagement. Many of these terms are overlapping; some represent umbrella terms for the broader enterprise of bringing research into greater conversation and collaboration with community concerns; and still others represent distinct philosophies and methodologies of community engagement. This proliferation of terms points to how new, active, and generative the CER undertaking has proven to be. Each term represents another attempt to best articulate a re-imagined research process.

In our recruitment of survey, interview, and focus group participants, we made a special effort to reach out to people with experience in CER. Thus, most of our survey respondents pursue some form of CER: 80 percent of respondents are engaged in either CER or community-based participatory research, what many consider a more formalized and stringent form of CER. Fewer researchers describe their work as community action research, work that is “often coupled with an intervention and iterated to improve services” or “has specific activist/anti-oppression goals.” This high proportion of CER practice reflects our targeted sample of researchers likely to be pursuing CER. A population-based sample of health researchers would likely show that the majority of health researchers have little experience with CER.

Figure 1. How investigators define their community engagement

Figure 2 illustrates the role and activities in which Bay Area survey respondents report they typically work with community partners, whether individual community members or agencies and organizations.
In their work with individual community members, researchers primarily engage the community as research participants. Fifty-two percent of our respondents also worked with community members as research team members, and 55% rely on community members to facilitate the recruitment of research participants.

Agencies and organizations provide CER teams an infrastructure and resource set that individual community members cannot. Not surprisingly, survey respondents report that they engage more often with agencies and organizations than with individual community members. Over three fourths of them work with community organizations to disseminate findings (90%), recruit participants (83%), explore the implications of the study (79%), and generate research ideas (76%). There is also significant agency and organization engagement in the interpreting results (72%) and helping to prepare grant proposals (66%).

Ultimately, these roles and activities can be arranged along what one focus group participant—a university-based researcher with a long history of conducting CER—described as a “spectrum of engagement.” Indeed, as illustrated in Figures 3 and 4, our data suggest two spectrums—one of collaborative activities and another of community roles.
At different points along these spectrums, researchers might seek informal input and feedback from stakeholders; others might establish a formal community advisory board (CAB) that receives financial remuneration for meeting regularly to review study progress and to make recommendations regarding next steps. Some CE researchers may make a special effort to recruit community members—especially those from traditionally underrepresented groups—as study participants; others may involve community members as research team members participating actively in the collection and analysis of data, holding decision-making power in the study’s governance, and paid for their efforts like other members of the research team.

Many participants suggested that CBPR incorporates the roles and practices at the far ends of the spectrums of engagement. A survey respondent explained the progression of her engagement with community:

*In the past, I engaged in mostly community-engaged research, where I approached community agencies about their interest in collaborating on research projects that I was already pursuing. More recently, I have been doing community-based participatory research, where my community partners and I jointly develop research projects of mutual interest, and where the community partners are active members of the project team with respect to data collection, analysis, interpretation, and dissemination.*

Like other forms of CER, CBPR strives for health equity. Unlike other CE scholars, CBPR researchers have formally proposed core national principles, including genuine partnership and co-learning; capacity-building of community members in research; applying findings and knowledge benefiting all partners; and long-term partnership commitments.

These principles characterize the work of the Bay Area researchers, partners, and funders we interviewed, whether they described their work as CBPR or CER more broadly. Indeed, our data suggest that every point along the spectrums of engagement shares three commitments.

- *Community capacity building:* CER increases the capacity available to community partners, equipping them to work in partnership with researchers and, ultimately, to pursue their
own research and social change agendas. Academic partners and grant makers bring, for example, training opportunities, infrastructural resources, and access to new professional networks in order to support community partners’ work.

- research in support of social change: CER takes up questions in an effort to make a positive impact, address an identified social problem, and effect desired social change. Community and academic research partners aim for study designs and findings that will prove quickly useful in shaping public policy, interrupting harmful practices, introducing new programmatic priorities and plans, or shifting public understanding and discourse in ways that challenge inequitable distribution of resources and healthy outcomes.

- meaningful community involvement: CER involves community partners throughout the study, including the development of research questions, study design, data collection and analysis, dissemination, and implementation of study recommendations. Not every project benefits from community participation at each step; however, even in those moments in which the community is less involved, the CE researcher will remain accountable to the principles and practices of CER.

One academic researcher described CER as a “dance” in which academic and community partners learn to work with each other in an intimate series of moves, gestures, and responses. Ideally, each turn helps to build trust in and knowledge of oneself and the other, and each step involves a new and gratifying series of principled negotiations between academic and community partners.

Following, we explore these principles at length before considering what they imply for research practices and standards.

Principle 1—Community Capacity Building

Community and academic partners consistently reported a shared commitment to increasing the capacity and infrastructure of community-based organizations and agencies that confront health disparities and serve disenfranchised populations. One educator and practitioner who had collaborated with a number of CER scholars reported in her interview that through CER she had come to value the people she served more than she had previously. As she learned new ways of communicating with the people she served and became comfortable talking with researchers, she felt empowered as an educator and as a woman of color. An academic researcher with a number of ongoing CER projects speculated that, because community-based educators and practitioners so often work within a sense of crisis, CER can offer a special opportunity to pause, talk about the issues shaping their work, and reflect on new ways to respond. As a survey respondent described,

Targeted communities themselves become self-critical and more thoughtful about not only who they are, but what they are trying to become. . . . It is an interesting revelation.

Such thoughtfulness reverberates throughout community partners’ work. Another community researcher, new to CER and already involved in two grant writing efforts, was excited to learn that CER had helped her nonprofit staff translate their ideas into programs. Already, participating in CER had helped improve programs as she and her staff put their ideas into action.

CER also has the potential to make those new programs sustainable. As numerous survey, interview, and focus group participants noted, through CER, community partners can become more competitive when seeking grants and funding—with academic partners and on their own.
Additionally, multi-year research grants can provide a different source of funding and help CBOs become more sustainable when planning beyond a single funding year.

Benefits may also be more indirect. For example, community partners will have access to training opportunities as they participate in research design, data collection and analysis, and dissemination efforts. They will likely discover new employment opportunities as their networks and skill sets grow. Academic CE researchers also routinely work to benefit community partners in ways that are only indirectly related to the research project—for example, tutoring youth participants, donating office supplies, or introducing community partners to other CE researchers and grant makers in order to increase the community’s capacity to address its own needs.

And, of course, a central practice in the spirit of conducting mutually beneficial CER is the dissemination of findings that are swiftly useful to community partners. Review processes, publication timelines, and scientific criteria often mean that research published in conventional venues is unlikely to meet the needs that lead a community member, agency, or organization to join a CER partnership. In order to ensure that CER is useful to the community, academic researchers will produce additional documents and presentations that are time-sensitive and easily digestible. Such products include newsletters, PowerPoint presentations, brochures, and fact sheets.

Other academic researchers encourage community partners to add questions to surveys, allowing them to collect quantitative, even longitudinal, data on questions of immediate interest and relevance. One academic researcher makes her surveys available and generates frequency tables and cross tabs for community partners. As another interview participant, a community-based health educator, explained, such a resource is invaluable.

“We always need good data. That could be demographic data, that could be health data, that could be other data. Just uncovering things that we haven’t been thinking about in the community. But it would be too expensive for us to actually hire a research firm to actually do some of this work . . . It’s cost prohibitive.”

Ultimately, as one academic researcher noted, CER is mutually beneficial, promoting both learning and increased capacity for both academic and community partners.

**Principle 2—Research in Support of Social Change**

For some researchers, CER represents an approach to redress power imbalances and even exploitation in the history of social and medical science (Bell 2006; Heron and Reason 2006; Smith 1999). Collaborative and community-based interventions offer a particularly important opportunity to address the sexual, racial, gender, and socioeconomic inequalities that put many communities at risk of poor health outcomes (Gutierrez and Lewis 2005).

Respondents argued that health disparities research, in particular, requires research that falls along the CER spectrums of involvement. As one academic public health researcher asserted,

*One can’t do disparities research from 30,000 feet.*

Another CE health researcher argued,

*There is really no other way—you either do it with the community or not at all.*
Community involvement signals community support, and that support is necessary to easing people’s fears that researchers will use findings that neglect or even worsen community suffering.

At its best, CER does more than not make things worse—it supports meaningful and desired social change. As one academic researcher with an established research program described, CER has allowed her to do “more innovative work, more important work, more relevant work; and personally it makes me feel like I am making a difference.” Academic and community partners come to learn from each other, talk in a similar language, and recognize the potential for change. As one academic researcher argued in an interview, through such collaboration, CER eliminates the need for translation and reduces the gap between research and practice. CER teams simultaneously conduct formative data collection and explore possible health interventions, for example, feeding risk survey data to community partners so they can confirm its accuracy and meaningfulness or, in another example, presenting preliminary findings stakeholder meetings in order to think immediately about implementation strategies, including media campaigns, educational workshops, and changes in health care policy. Our participants argue that CER produces richer data because people with an investment in the research are involved in every aspect of the research process.

Survey participants rated potential benefits of CER (see Figure 5). An overwhelming majority of respondents argues that CER improves the recruitment of hard-to-reach population (91%), helps define community relevant research questions (88%), and help develop better community interventions (85%). A majority of participants definitely agree that CER results in highly relevant research, creates innovative research questions, helps in the interpretation of findings and in the translation of research in action, and create external validity to the research.

For example, CER may improve external validity, offering practice-based evidence that generates evidence-based practice. As one CE researcher claimed, research that takes place in the real world and is of, by, and for the real world will be more meaningful and effective and relevant in the real world.

The CE researchers we interviewed acknowledge that it remains difficult to quantify the difference CER has made in the community and have identified such measurement as an underdeveloped area of research. In order to best capitalize on the principle of research in support of social change, CE scholars will do well to study the impact and promise of their efforts with community partners.
Figure 5. Benefits of CER

<table>
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<tr>
<th>Benefit</th>
<th>Percentage</th>
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<tr>
<td>Improves recruitment of hard-to-reach populations.</td>
<td>91%</td>
</tr>
<tr>
<td>Helps define community-relevant research questions.</td>
<td>88%</td>
</tr>
<tr>
<td>Better Interventions are developed.</td>
<td>85%</td>
</tr>
<tr>
<td>Results in highly relevant research.</td>
<td>75%</td>
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<tr>
<td>Creates more innovative research questions.</td>
<td>70%</td>
</tr>
<tr>
<td>Helps with Interpretation of findings.</td>
<td>70%</td>
</tr>
<tr>
<td>Helps translate research into action.</td>
<td>63%</td>
</tr>
<tr>
<td>Creates external validity.</td>
<td>55%</td>
</tr>
</tbody>
</table>

**Principle 3—Meaningful Community Involvement**

CER is about discovering and addressing the needs of the community with the community. Over and over, our study participants asserted that, in CER, academic researchers work with the community to develop the question, to seek an answer, and to turn that answer into a solution to a vexing social problem. CER that involves such meaningful collaboration will “embrac[e] both science and local experience” (Pinto et al. 2007, 53). CER partners must together achieve meaningful collaboration in which researchers and community partners teach and learn from one another, work together to shape the study’s process and outcome, enjoy equitable access to data and other study resources, and share both responsibility and credit for the study.

At the far ends of the spectrums of involvement, community partners are involved in every step and decision in the research process—the development of the research questions, programs, and assessments; the interpretation of the results; and publication and other dissemination. At these ends of the spectrums, the community and PI have equitable decision-making power and community members are paid. Even if they neither seek nor achieve that level of involvement, CER academic researchers and grant makers keep community concerns in mind as they identify research questions, design studies to address those questions, and disseminate findings.

The challenges in achieving such meaningful community involvement are numerous. Academic researchers struggle to sufficiently train and supervise collaborators, and community collaborative
research can provide short-lived and often disappointing access to formal training and legitimate sources of income.

Authorship and publication were of particular concern to our respondents. Limited experience with analysis, writing, and dissemination and challenging life conditions can make it difficult for collaborators to contribute to data analysis and dissemination. Other challenges may arise when CER partners unexpectedly assert an authorship of the work. As one survey respondent described,

*Some agencies agree to participate and then don’t want their data shared in publications. Or a high-ranking official agrees to participate only if they have the right to review manuscripts AND be listed as an author . . . a senior author.*

Few academic researchers receive any training in how to negotiate authorship with any collaborators—academic or community-based. They have few models of how best to navigate competing interests in determining authorship. Community members may want to put everyone’s name on the paper, even if that does not correspond to the publishing and authorship guidelines. Academic researchers may struggle with the sense that they will not receive adequate professional credit for a co-authored paper that, in fact, required more time and effort than many single-authored pieces.

Similar problems may arise around community partners meaningful access to data and other resources central to the process of inquiry. One interview participant presents a set of questions: Who owns the data? What does it really mean to say that the community owns the data: Does it mean giving a disk of all the data? Does the research protocol allow you to do that? It is not always feasible for academic researchers to hand over data to another person or institution without knowing what will be done with it.

Such questions bump right up against a question posed by a community-based health educator who partners regularly with academic researchers. She stated,

*If you are using the term “community” in this research, then the community should have access to it.*

Some community partners worried in interviews that they and their peers do not easily achieve such access. Academic researchers often have a difficult time relinquishing control. Community partners may not insist on equitable partnerships because they want and need to be involved in grant-funded efforts. Staff turnover may undermine community agencies’ and organizations’ commitment to long-term collaborations. Funders’ expectations of deliverables may compromise the reflection that CER otherwise promises.

The challenges here are significant. Researchers and community partners must work together to ensure that they conduct research with integrity, achieving both quality science and meaningful collaboration among partners. Most of our survey respondents believe that any successful CER effort requires time. As one stated,

*What makes community work hard is the time factor—it takes much longer to foster and work in relationship than to work alone. Funding for these kinds of research projects is not sufficient, but overall, funding is not sufficient for most research projects. I think it is the time factor, the establishment of trust, that does not get factored into the research equation.*
CER partners must be able to troubleshoot, to sensitively and caringly deal with problems that come up, and to maintain some faith that they can succeed. Ultimately, the hope is that people come to feel that the time and effort and information committed was worthwhile to people involved and has promise for a better future.

B. Implications for Health Science and Research

CER partners share a commitment to leveraging academic and community resources to understand and alleviate social inequities and negative health outcomes. Consistently, the CE researchers we interviewed from academic and community locations reported that such attention to health and other social disparities introduces new priorities and complicates existing ones in discussions of research integrity: researchers become accountable to multiple communities and thus multiple and perhaps conflicting sets of ethical duties (Welch 1993) as members of the research, lay audiences, providers, consumers, and evaluation communities work together and blur boundaries that conventionally separate their spheres of work and accountability (Minkler and Wallerstein 2008).

Some see this with great trepidation. Academics must prioritize bringing in grants, being published, or securing tenure over building relationships with community partners and supporting meaningful social change. Researchers may struggle to maintain “scientific integrity” when community partners are involved. Robust sample sizes may be difficult to achieve; and randomization may be even more elusive when “dosage” or implementation is unlikely to occur equally across all conditions. Some may also feel that academic/community collaboration challenges the scientific process, and much of the scientific community remains skeptical that community members can assume the roles that CER calls for and still maintain the integrity of scientific practice (Minkler and Baden 2008; Wallerstein and Duran 2008; Wright and Treacher 1982).

We asked survey respondents about the factors that could contribute to the decision not to participate in CER. The highest rated concerns among researchers with CER experience focus on external pressures (see Figure 6). Almost 80 percent of survey respondents believe the time commitment required to develop a project with the community is a serious concern in doing CER. Sixty-one percent argue that funding pressures do not allow researchers to build the foundation for supporting this work. Over half of researchers cite inconsistent deliverables between academia and community as a barrier for researchers.

Although most researchers fear that community engagement could affect the scientific validity of the work, this issue was less important to our sample of researchers with CER experience. About a third of experienced researchers see the difficulty to maintain scientific objectivity as a serious barrier to CER. Reflecting the need for training, capacity building, and creating trust as an important part of CER, over half of experienced researchers mentioned community’s lack of understanding of academia, push-back on necessary methodological tools, ideas that are not supported by literature or funders, and a concern that community members may misunderstand research findings as somewhat of a barrier to CER.
Figure 6. Reasons for not conducting CER

Those academic researchers who pursue CER must be willing to confront these and other significant challenges. Navigating skepticism and scrutiny, indeed, becomes a requisite task for CER researchers. As one survey respondent explains,

*Community-engaged research requires researchers to often move outside of their comfort zone, in a way that other modes of doing research does not. By this, I mean going to neighborhoods they may not go to, talking to people they may not otherwise talk to, having their professional (and personal) status and objectives questioned and scrutinized. There is a lot of distrust of research and researchers in many communities and so doing engaged work can be challenging for people. You have to be willing to put yourself “out there” and you have to have good people skills, which is something that not all researchers possess.*
In an interview, an established CE researcher who has acted as principal investigator on numerous federally and privately funded projects asserted that one of the greatest lessons CER offers is in “cultural humility.” Contrasting cultural humility with cultural competence, this researcher explained that one cannot hope to be competent in another person’s culture. Instead, CE researchers should adopt a practice of self-reflection and examine and keep in check preconceptions, remain open to learning about others’ cultures, and develop genuine partnerships.

Such openness may foster humility and insight, but it also raises difficult questions. One public health educator who had co-led a CER project with an academic researcher speculated that academic researchers may be reluctant to ask themselves,

What would really happen [to scientific inquiry] if you made your participants your partners?

The public health educator suspected that academic researchers would have to rethink their notions of status and science and, in doing so, relinquish some power—a likely uncomfortable prospect. An academic researcher with an established CER program said that successful CER academic researchers will wear “two hats: a service hat and a researcher hat” as they collect and analyze data that promote community interest, enhance analytic understanding, but do not advance research careers.

The benefits of such efforts will not be immediately apparent to all academic researchers. One interview participant advocated trainings to help researchers shed commonly held beliefs that they are the experts and develop instead learn to value the community as a source for knowledge production. These trainings would encourage a rethinking of relationships that are counterproductive to CER and, this participant argued, to sound and meaningful research.

CER is also not the best approach for every research project. One responded presented the following set of questions he/she considers when deciding whether to engage the community on his/her projects:

Will it benefit the research? Will it benefit the community members/agencies? Can it harm the community members/agencies? How hard will it be to get the right kind of engagement?

While another reflects on the methodological approach

In constructing research, it is important to consider the connection between the research questions and methodological approach. The consideration of working collaboratively with an agency or with a community should emerge from this. If the project is to intervene in knowledge making, produce knowledge from the ground up, then community engaged or action research is necessary and just.

Ultimately, the benefits to academic researchers extend beyond the formal research setting. CE researchers reported that they find their work particularly gratifying. One academic researcher with a long-term CER program that includes acting as PI on empirical studies and as mentor to junior scholars reported that CE scholars seem happier and more passionate than their colleagues. He asserted that CE scholars are routinely re-energized through their contact with the community. It may be exhausting, he argued, but it is exciting.
V. CONCLUSIONS AND RECOMMENDATIONS

This report sought evidence-based knowledge of how to build and sustain community engagement in health research efforts to inform both researchers and community stakeholders. We sought to identify the range of activities used to engage community in research endeavors, while increasing our understanding of the reasons for CER, barriers to CER, and when CER may be contraindicated. We have clarified distinctions between community engagement, community action research, community-based participatory research, and other related terms, suggesting “community-engaged research,” or “CER” as an umbrella term to encompass the range of practices and strategies adopted by San Francisco Bay Area researchers’ local, national, and international efforts.

Three principles characterize CER: a commitment to build the capacity of community partners, to pursue research that promotes positive social change, and to ensure meaningful community participation throughout a CER project. The nature of that capacity, change, and participation will shift according to the needs, experience, resources, and goals of community and academic partners.

For many, these principles will represent a fundamental challenge to health science and research practice. Scientists conventionally enjoy a degree of autonomy in their research programs, and much of the research community considers that autonomy necessary to equipping scientists to serve community needs with rigor and integrity (Welch 1993). CER straddles a difficult line between scientific integrity and community needs and rights. Useful CER sets the stage for collecting data that reflects the experiences of the community and engages them in interpreting how best to address those experiences and emergent needs. Identifying and addressing the obstacles to research integrity and rigor are critical to ensuring that CER characterized by the utmost quality addresses the most pressing public health concerns and the needs of the most vulnerable populations.

In conclusion, we offer a resource for academic and community researchers, funders, and Institutional Review Board members considering, pursuing, or supporting CER—a list of “best practices” for CER, culled from our interview and survey data.
Best Practices in Community-Engaged Research

Balancing Academic and Community Concerns

Remember that the best community-engaged research (CER) meets community needs and satisfies intellectual interest. Neither motivation must give way entirely to the other, but both motivations must make room for the other.

Revisit regularly the complementary value of research and practice. Consider how the two best inform each other, how the tensions between them can be productive and generative, and how partners can contribute to the success of both.

Be aware of and accountable to local institutional conditions and reward structures. Research organizations do not always value CER processes and products; for example, tenure and promotion committees may be unsure what value to assign CER. Work with committee members and senior colleagues to ensure that CER is appropriately recognized.

Remain responsive to—but not beholden to—concerns about the scientific validity and rigor of CER. Insist upon valid findings, while also helping colleagues to rethink restrictive understandings of validity. Pursue qualitative and quantitative data collection, adopting those methods that will encourage the participation of all team members and produce results that stakeholders will find compelling and convincing.

Talk with the local Institutional Review Board to clarify expectations for CER proposals. For example, does your work need review, or does the board consider it a needs assessment? How can you best allow for the contingencies and fluidity that are inherent and valuable to CER?

Building Relationships

Make a long-term commitment to building and maintaining trust. Such trust will yield multiple benefits, provide groundwork for multiple studies, and ensure meaningful and sustained community/academic collaboration.

Join or, if necessary, establish networks of academic researchers and community members who share interests and commitments and who will offer ongoing opportunities for collaboration and input into the design, conduct, and dissemination of research.

Listen carefully in informal and formal meetings of these networks for evolving research interests. The questions that emerge from these long-term and organic relationships will reflect the most trusting and collaborative spirit of CE.

Devote some time to getting to know one another outside of meetings and other formal settings. Share meals, attend one another’s celebrations, and talk to one another about interests and concerns without the immediate goal of advancing the research project.

Make clear, sustained, and frank communication a priority of all community/academic relationships. With this sort of communication, questions, findings, and dissemination plans will necessarily reflect shared commitments and equitable processes.

Defining Roles and Responsibilities

Ensure that research team leaders—for example, principal investigators and executive directors—take the time to build relationships across institutions. Their presence will signal to all team members that relationships are the products of genuine interest and not simply an instrumental gesture to be pawned off on less powerful members.
Clearly define partners’ roles and decision-making power. Role definitions should include the expectations as well as anticipated benefits, challenges, and rewards. When defining decision-making power, consider equity, when partners need to consult one another, and the extent of partners’ discretion.

Write and sign memoranda of understanding (MOUs) that detail roles and expectations. The best MOUs will expire, requiring partners to renew the MOU and, in the process, revisit the terms of the collaboration in order to improve, celebrate, or renegotiate their partnership.

Recognize academic researchers’ special responsibility to approach community partners with, on the one hand, humility about what they need to learn and, on the other, a recognition that it is not community partners’ responsibility to teach them everything they need to learn.

Conduct consistent and rigorous evaluation of CER outcomes and practice. Maintain a critical if appreciative eye when considering process and impact, learning from successes and failures.

**Navigating Differences**

Pay close attention to how social identities and differences inform CE collaboration. Consider, for example, how educational disadvantage make it difficult for people to participate fully or how gender, racial, or economic privilege may make it important for others to intentionally make room for their partners.

Keep in mind researchers’ reputation for exploiting the people they study. Whether deserved or undeserved, many collaborators bring this history to their CER and worry that they might be treated as guinea pigs or that they will not benefit from the research.

Ask before beginning CER whether community partners have the infrastructure, well-being, and resources necessary to participate meaningfully. Consider the same issues for the partnership itself—what are the material conditions necessary to our success? How can we create them if they do not yet exist?

Share resources as possible. Meaningful resources might include training in research and writing skills, access to professional networks, office supplies, support when applying for additional funding, and more.

Ask research partners what meeting times and locations will be convenient and comfortable for them. For community members, this will often be their offices or neighborhoods. Similarly, ensure that you’re communicating through media that are mutually accessible and satisfying, whether that’s in person, email, telephone, text, or conference call.

**Ensuring Access to Data and Dissemination**

Establish clear and mutually satisfying agreements about partners’ access to the data. Work with the local Institutional Review Board to ensure agreements comply with all necessary integrity and ethical guidelines while still promoting a spirit of openness and collaboration.

Strive to produce additional research projects that will be quickly useful to community partners. Such products might include literature reviews that CBOs and government agencies can use in funding proposals, program design, or program implementation.

Involve community partners in writing and dissemination processes to help ensure accurate presentation of data. Community partners might agree to, for example, co-author manuscripts, co-present at conferences, review early drafts, approve final versions, or be identified in acknowledgements.
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