COMMUNITY ENGAGEMENT
COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)

What is Community Engagement?

• 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. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices (CDC, 1997, P9)

• Community engagement can take many forms, and partners can include organized groups, agencies, institutions, or individuals. Collaborators may be engaged in health promotion, research, or policy making.

Culture and Community Engagement

• “A complex integrated system of thought and behavior shared by members of a group – a system whose whole pattern allows us to understand the meaning that people attach to specific facts and observations.” Christie Kiefer (2007)

• Communities are not homogeneous entities; they are made up of diverse groups with different histories, social structures, value systems, and cultural understandings of the world.

• To achieve successful collaboration with a community, all parties involved need to strive to understand the point of view of “insiders,” whether they are members of a neighborhood, religious institution, health practice, community organization, or public health agency.

• Acknowledging diversity in background, experience, culture, income, and education and examining how society produces privilege, racism, and inequalities in power should be central to the process of community engagement.
Community Participation

— Whatever people’s motivations, obtaining meaningful communication participation and having a successful, sustained initiative require that engagement leaders respect, listen to, and learn from community members. An absence of mutual respect and co-learning can result in a loss of time, trust, resources, and, most importantly, effectiveness (Henry, 2011; Miller et al., 2005; Minkler et al., 2009)

— The potential benefits of participation for community members, academics, and health professionals include opportunities for networking, access to information and resources, personal recognition, learning, a sense of helping to solve community problems, improved relationships among stakeholders, increased capacity for problem solving, and contact with hard-to-reach populations (Butterfoss, 2006)

THE ETHICS OF COMMUNITY ENGAGED RESEARCH

• Debates about the ethics of clinical research are not new (Chen et al., 2006; Emmanuel et al., 2000; Levine, 1988), but community-engaged research (CEnR) studies demonstrate that IRBs generally do not incorporate the principles of CEnR into their considerations, even for studies that are community engaged (Flicker et al. 2007), and some have questioned whether the current IRB system is appropriate to provide oversight for all forms of CEnR.
Part of ethical conduct is developing a legitimate and serious dissemination plan for the findings of the proposed research that will meet the needs of both communities and researchers.

University Researchers should involve Community partners as early as possible in discussions about the potential uses of all data to be collected, including a dissemination plan for the sharing of the research findings with the wider [non-academic] Community, and should develop a process for handling findings that may reflect negatively and thus cause harm to one or both partners (CARE, 2009, P. 3)

ENGAGING AND MAINTAINING COMMUNITY INVOLVEMENT
How do you engage a community in a randomized clinical trial or a drug trial?

Take-Home Messages

• Engaging the community in RCTs is challenging but possible.
• Engaging and seeking input from multiple key stakeholders (e.g., grocery store owners, health care providers, and families) is an important strategy.
• Collaboratively developing an MOA can enhance communication and build new partnerships in studies that are restricted by time and are predefined.
• An MOA can serve as a valuable guidance document and useful tool throughout a study as an agreed-upon point of reference for researchers and community members (Davis et al., 1999; Davis et al., 2003)

How do you overcome historical exploitation?
Take-Home Messages

• Recognize that there may be a history of exploitation in the community and therefore a distrust of research and researchers.
• Employ a variety of participation strategies.
• Allow extra time for building relationships and trust.
• Seek approval from tribal or other local review groups.
• Include customs in interventions.
• Demonstrate respect and inclusion to the fullest extent possible (Davis et al., 1999; Gittelsohn et al., 2003)

How do you maintain community engagement throughout the research?

• Engagement needs to occur as the ideas for research are being formed and the procedures are being identified.
• Taking the community’s priorities into account increases the opportunity for engagement.
• Being a regular presence in the community may enhance research efforts.
How do you engage a community organization as a partner in exploratory health research?

Take-Home Messages

- Establish a collaborative research relationship may involve a different level of engagement than a collaborative outreach relationship.
- Organizations have their own responsibilities that have to be met independently of any research.
- Communicating regularly and often to keep all partners aware of priorities within the respective institutions is important.
- Working collectively to proactively create relationships and put procedures in place can help sustain the research when the community organization staff changes.
- It should be understood that, despite the time limits for research, partnerships must be flexible.

How do you engage the community when there are cultural differences (race or ethnicity) between the community and the researchers?
Take-Home Messages

- Act on the basis of value-driven, community-based principles, which assure recognition of a community-driven need.
- Build on the strength and assets of the community of interest.
- Nurture partnerships in all project phases; partnership is iterative.
- Integrate the cultural knowledge of the community.
- Produce mutually beneficial tools and products.
- Build capacity through co-learning and empowerment.
- Share all findings and knowledge with all partners.

How do you work with a community when there are educational or sociodemographic differences between the community and the researchers?

- Be explicit that drafts mean that changes can be made and that feedback is both expected and desired.
- Have more face-to-face meetings, especially when discussing points about which there may be disagreement, because telephone conferencing does not allow for nonverbal cues and makes it more difficult to disagree.
- Figure out ways to be scientifically sound in locally appropriate ways.
- Acknowledge and discuss power imbalances.
- Ensure that all partners' voices are heard and listened to, create settings for open and honest discussions, and communicate perspectives clearly.
- Help partners understand when they are being disrespectful or might be misinterpreted.
- Discuss differences even after a proposal is submitted.
- Improve communication by establishing agreed-upon deadlines and midpoint check-ins, using online brainstorming strategies, specifically requesting feedback with time frames, and facing issues directly so that everyone understands them.
- Provide community partners with time and opportunities for developing designs for proposals, and provide training for community partners if they lack knowledge in some areas of research design.
- Set aside time for university partners to learn about the community partners' knowledge of the community and what expertise they bring to a specific project.
- Acknowledge expertise within the partnership explicitly and take advantage of it when necessary.
How do you engage a community when there are cultural, educational, or socioeconomic differences within the community as well as between the community and the researchers?

Take-Home Messages

• Evaluate your process on an ongoing basis and discuss results as a group.
• Assure recognition of a community-driven need through strong and fair leadership.
• Make concerted efforts to draw out and acknowledge the voices of all participants.
• Create specialized committees.
• Engage participants in the choosing of new board members (especially former participants).

How do you start working with a community?
Take-Home Messages

• Community partnerships are not built overnight. A trusting partnership is developed over months or years.
• A partnership does not depend on a single grant, or even a succession of grants. The partnerships continues even when there are no grants.
• A partnership means that resources and control are shared. The academic institution or government agency must be prepared to share funds with the community. The community should be the "senior partner" on issues that affect it.
• Community representatives should primarily be people who live in the community. The programs and projects implemented by agencies, schools, and other entities affect the community, but their staff often live elsewhere.

How do you set up and maintain a community advisory board?

Take-Home Messages

• Engagement in effective community coalition boards is developed through multi-directional learning of each partner’s value and needs.
• Community coalition boards are built and sustained over time to ensure community ownership through established rules and governance structures.
• Trust and relationship building are both central to having neighborhood and research experts work together to shape community-engaged research agendas.
• Maintain a community coalition board requires ongoing communication and feedback, beyond formal monthly or quarterly meetings, to keep members engaged.
How do you overcome differences in financial practices between the academic institution and the community?

Take-Home Messages

- “splitting budgets in half” is too blunt a tool for the delicate work of building equal partnerships. Exploring more nuanced mechanisms to balance power between community and academic partners is critical.
- Make no assumptions about the capabilities of the institution (university or CBO) or how it functions.
- University and CBO partners need to come to agreement on all processes and timetables that might be involved.
- Foster open communication with those affected to maintain organizational and personal credibility.

• Community organizing is based on the principle of empowerment, community competence, active participation, and “starting where the people are” (Nyswander, 1956, as cited in Minkler, 2005, P. 27). As Labonte et al. (1996) state, imposing one’s own notions of health concerns over the community’s risks several disabling effects. These include being irrelevant to the community, creating feelings of powerlessness in the community, complicating individuals’ lives, and channeling local activism away from important challenges towards less important ones.