

Guidelines for Community Partnership Research: Executive Summary

Introduction

The purpose of this document is to provide guidelines to researchers and community organizations interested in partnering to ask research questions and conduct research that has both scientific and social value. This Executive Summary and the full Guidelines were prepared by the Community Research Alliance (CRA), an alliance of community-based organizations, with significant input from the Institute for Community Research, faculty of the University of Connecticut School of Medicine in Farmington, CT and the University of St. Joseph in West Hartford, CT, with support from the UCONN Connecticut Institute for Clinical and Translational Science (CICATS), 2013-2014.

In this document the phrase “research partners” refers to university or other institutionally-based researchers and community based organizations (CBOs); the latter may or may not have a working knowledge of or experience with research. We focus here on community-based research and other research that engages community members and organizations. This type of research is based on the premise that involvement of “end users” in the development of research questions, formulation of the study, research implementation, data analysis and interpretation, and dissemination of findings results in better research and better use of the research. “Community” refers to people in socio-geographic space (e.g., neighborhoods, alliances, informal groups) and the organizations that serve them. Larger institutions (e.g., city and state health departments, hospitals) may or may not be considered part of the “community” in community-based research, depending on how the community is defined in relation to the problem. While end-users may be any groups interested in a research topic or product, we emphasize engagement of those who are affected by health disparities stemming from structural, social, scientific and other inequities, and the community organizations that serve them. Our goal is to promote better research to address and resolve those health disparities. “Research team” refers to all those involved in conducting partnership research, including faculty, community researchers, CBO representatives, and people from affected communities.

This document was designed to facilitate collaborative community research and to increase the inclusion of end-users and others who experience health disparities in that research. As such, it is not intended to limit the types of research or community/research partnerships, nor to generate undue burden on any party, but rather to increase the likelihood of success to achieve the goals of both the researchers and the community. This Executive Summary should be used in conjunction with the full Guidelines for Community Partnership Research, which provides additional specification of the key points as well as brief examples of successful and challenging collaborations. Additional references are provided at the end of this document.

Guidelines Summary

I. Involvement of partners in the research process

- Research partnerships should be collaborative. This means joint researcher/CBO/agency negotiation of study topics, designs and approaches.
- Research teams should include all necessary partners by substantive area (intersectoral) and discipline (interdisciplinary) to ensure that the study addresses the key questions and factors.
- Investigators and staff should reflect the ethnic, racial and other characteristics of the study population, to represent the focus of the research and the community setting in which it takes place.

- The research team should develop clear and mutually agreed upon policies regarding joint ownership of data and dissemination of research results.
- The research partnership team should disseminate findings to all partners, including the community in which the study takes place.
- The research team should address and resolve issues of power and power differentials, and experiences of discrimination (e.g. by race/ethnicity, language, gender), disenfranchisement, stigma, exploitation, and distrust of research as a result of historical medical exploitation and experimentation. These factors, if unresolved, impede the trust required for good partnerships.

II. Developing an understanding of, respect for and commitment to the community where research takes place

- The study community should be clearly identified.
- Members of the study community should agree to the study and its importance.
- Members of the research team should demonstrate an interest in and commitment to working in and with the study community.
- Members of the study community and knowledgeable researchers should ensure that information and knowledge about the community is incorporated and applied in all phases of the research process (planning, implementation, evaluation, analysis and dissemination).
- The research team and members of the identified community should demonstrate a mutual understanding and respect for the culture(s) of the research partners and study community.

III. Relevance and benefit of the research

- All partners should agree on the relevance and benefits of the research.
- The research topic should be relevant and of benefit to the community or communities participating in the research.
- The research should identify and address health disparities experienced by the community or communities in which it takes place.
- Researchers and community members should share the responsibility of putting research into action for the benefit of the community as well as for the betterment of science.
- Researchers and community members should identify ways to link the research to community needs and interests in an authentic way

IV. Effective communication among partners

- Communication should be bi-directional; research partners should work to ensure the creation and implementation of policies and infrastructure that enable all partners to have an equitable voice in the research process.
- The research team should establish policies that foster open and effective communication and create a structure that supports conflict resolution if it occurs at any time throughout the research partnership.

V. The ethical conduct of research

- All members of the research team must be trained and certified in the protection of human subjects.
- The Institutional Review Board (IRB) conducting the review of the research should include local community advocates and university faculty familiar with community-based research on the review board. These advocates and community researchers can contribute to the review because they consider community as well as individual participant protection, understand politics of

research and inequities in research design, and are sensitive to vulnerabilities of research staff who may come from these communities.

- Attention should be paid to the risks and benefits of the study for project staff, individual participants, and for the community as a whole.
- The research team should work together to develop protocols and resources to address the potential effect on participants of discussing sensitive personal information (e.g. abuse of any kind, mental illness/suicide attempts – past and present) during the research process. These resources should include referrals to health and social services as needed, including those associated with the partner university and/or CBO.

VI. Recruitment in community settings

A. Engaging community-based organizations (CBOs) and the broader community in the recruitment process.

The research process will go more smoothly if a relationship with community members has been established prior to initiating any discussions about a specific research study.

- CBOs should not be seen as simply a tool for recruitment; interaction between researcher and CBOs is bi-directional.
- Researchers should meet CBOs and community members in the environment where the research is to take place to provide information about the project and answer questions about the research and why the study should be done in this setting. Open discussion will build trust between researchers and community and reduce the social distance between the community and the research institution.
- Researchers should work with CBOs to make the connection between the study with community concerns.
- Researchers and partnership teams should discuss with CBOs and their clients the real and perceived risks and benefits of the research.
- CBOs should have a clear understanding of the researcher's needs and expectations, and should clearly identify their capacities and limitations so that all members of the research partnership can realistically assess what support and collaborative effort can be expected and provided in order to maximize recruitment potential.

B. Recruiting prospective participants in the research – The researcher partners should work together to:

- Create opportunities to inform the community about the research and its utility;
- Provide credible reasons why community residents should participate;
- Make an effort to accommodate people's personal schedules to facilitate their participation in the research process;
- Develop strategies to share results of the research with the study community, including study participants.

VII. Capacity-building, resource sharing and sustainability

- The research partnership should promote co-learning and capacity building among all partners, including, but not limited to:
 - Funding;
 - Grant writing;
 - Improving organizational credibility;
 - Increasing knowledge of research ethics and individuals' rights as participants in research;

- Participating in all aspects of the research process (development, implementation, evaluation and dissemination).
- The research partners should negotiate agreements on resource sharing across the partnership initially and re-negotiate on an as needed basis over time.
- Research partners should work to:
 - Sustain community-university research relationships;
 - Advocate for resources to build and sustain research infrastructure especially as projects or studies come to an end;
 - Support and work toward funding for a longer term program of research at the organizational and broader community levels.

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