

# COMMUNITY-ENGAGED RESEARCH

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## A Quick-Start Guide for Community-Based Organizations

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## About this Guide

This Quick-Start Guide is intended for community-based organizations that may be interested in partnering with academic researchers at UCSF to conduct community-based research. The Guide is a product of the Community Engagement Program of the UCSF Clinical & Translational Science Institute (CTSI). One of the Program's primary aims is to assist both community-based organizations and UCSF-based researchers in the process of developing effective and mutually-satisfying collaborations on community-based research.

In this Quick-Start Guide, you will find:

- Reasons why community-engaged research can be effective, and why funding agencies are increasingly supportive of strong community-research partnerships
- Types of information you need to know and the questions you need to ask in deciding whether a community-research partnership is right for you and your organization
- Information on how the CTSI Community Engagement Program can help you whether you decide to take small or large steps toward partnering with an academic researcher on a community-based study.

If after reading this Guide you are interested in pursuing a community-research partnership for your organization, please contact the CTSI Community Engagement Program for more information. We also invite you to read the extended online Resource Manual on this topic and explore our website:

**[www.ctsi.ucsf.edu/community](http://www.ctsi.ucsf.edu/community)**

The online companion Resource Manual ([http://ctsi.ucsf.edu/files/CE/manual\\_for\\_agencies.pdf](http://ctsi.ucsf.edu/files/CE/manual_for_agencies.pdf)) examines each of these issues in detail, and includes much more extensive information about the questions you need to ask, and the steps you need to take, to enter into a partnership for community-engaged research.

## Introduction

# Community-Engaged Research

Without a doubt, managing a community-based organization (CBO) or institution is a complex and busy undertaking. Amid the daily pressures of serving clients, managing staffing, fundraising, keeping track of community needs and forecasting future areas of concern, it isn't surprising that incorporating a research agenda into these activities may be near the bottom of the to-do list.

And yet, it's compelling to think about the possibilities for your staff and your organization's mission when you consider a research collaboration: creating research results that can directly inform program implementation and create evidence for evaluation, participating in setting research priorities, advocating for community needs in academic research, developing staff skills, and increasing access to academic networks and research funders.

Unfortunately, efforts to bring research and community-based service delivery together often lack adequate resources, planning and communication, leading in turn to common complaints by community-based organizations:

- *Researchers aren't looking at the problems that are most important to my community.*
- *Researchers come up with solutions that are not relevant to my community.*
- *The research results don't help me make my organization more effective.*



### Introduction *(continued)*

- *We aren't fully involved in planning or decision-making.*
- *Researchers may not keep us updated on study progress or findings.*
- *Study recruitment and data collection add to our staff workload, but our time isn't compensated.*
- *We don't see any additional access to funding opportunities.*

### **CTSI Community Engagement Program at UCSF**

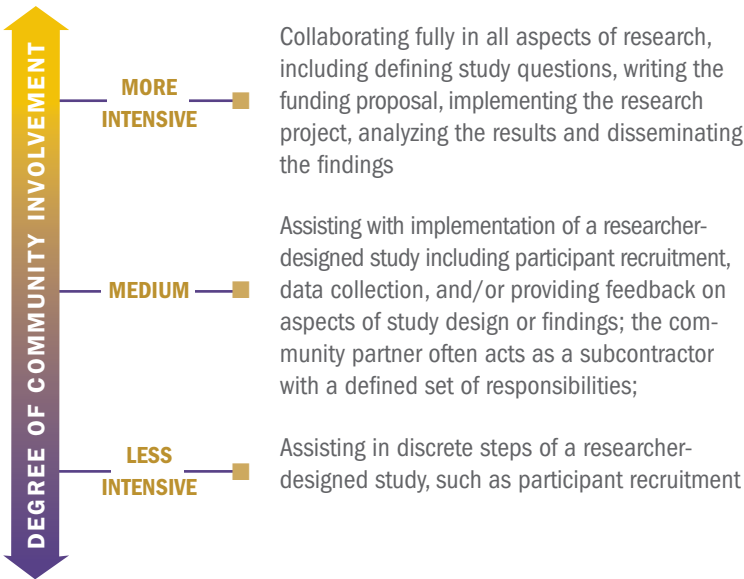
At UCSF, we recognize that strong and mutually beneficial partnerships between the university and the communities it serves are essential to the translation of research into meaningful health improvements for all communities. To foster these partnerships, the UCSF Clinical and Translational Science Institute's (CTSI) Community Engagement Program (CE) provides consultation, training, and other resources to build the capacity of both UCSF and local community organizations and clinical settings to conduct *Community-Engaged Research*.



# What is community-engaged research?

**C**ommunity-engaged research describes research that incorporates community input in any phase of the research process. The extent of this input can range from simply helping researchers define and clarify their research questions, to much more involved collaboration in defining the research question, implementing the research project, analyzing the results and sharing the findings.

*A Continuum of Possibilities*



Community-engaged research that is more “intensive” often takes place at community partner sites. Community partners might include any type of community-based institution, including CBOs, religious institutions, schools or school districts, or public health departments. Community partners might also be individual community members associated with an advocacy or grass-roots community group. For the purpose of this Guide, we’ll refer to these groups as CBOs, while acknowledging that there are differences within these organizations that must be understood before research partnerships can be formed.

*Community Partners*

Community-Engaged Research (continued)

*The Premise of Community-Engaged Research*

The fundamental premise of community-engaged research is that community stakeholders have critical, useful and intimate understandings of the concerns, values, assets and activities in their communities. When CBOs are engaged as partners in research, they bring these perspectives to help shape and refine study questions, implementation strategies, and data collection plans. They also play an important role in identifying how the study results may be applied to practice, and how the results can be used to shape future research directions.

Health research can be seen as discovering innovative solutions to difficult problems. When researchers and CBO representatives engage in this process of discovery *together*, the results are more finely-tuned and immediately applicable to the lives of community members, and hence have a greater likelihood of improving the health of our communities.

*The Culture Contains the Seed of Resistance...*  
Miranda Bergman and O'Brian Thiele  
1984  
Balmy Alley  
San Francisco



## What can community-engaged research offer my organization?

One of the most common questions from CBOs is, “Why would we be interested in working with UCSF researchers?” At CTSI, we believe that community agencies have much to gain from research partnerships that are designed to improve the health of communities. Such partnerships are key to integrating community knowledge, assets, needs, and preferences with the research study. Partnering with UCSF researchers can help community organizations:

- Identify and measure problems relevant to their own clients and community,
- Discover what contributes to those problems,
- Deliver relevant and cost-effective programs,
- Evaluate their current programs, and
- Access additional funding sources to sustain or expand these programs.

CBOs typically focus primarily on service delivery, program implementation and fundraising. By taking part in community-engaged research, CBOs can often gain access to resources to undertake activities that are the traditional strengths of an academic institution:

- Data gathering (to identify problems)
- Literature review (to identify potential solutions)
- Evaluation (to assess program effectiveness)
- Capacity building
  - Adapting or undertaking new programs,
  - Providing access to clinical trials for community members,
  - Obtaining consultation and other resources to improve your programming, and
  - Increasing your organization’s outreach and fundraising opportunities.

Through collaborative research projects, CBOs may be able to identify additional potential funding sources, form new networking opportunities and strategic alliances, and raise their visibility in

What does community-engaged research offer? (continued)

shaping research priorities and adding to the research literature on what constitutes effective programs or interventions.

COMMUNITY-ENGAGED RESEARCH

CAN DO and Children’s Oral Health

Dental caries is the most common chronic disease among children, especially in low-income and certain minority group families. The disease is very difficult and expensive to treat in young children, but is also largely preventable. At UCSF, the Center to Address Disparities in Children’s Oral Health (nicknamed CAN DO) conducts research to compare methods to prevent dental caries in children and seeks ways to apply evidence-based protocols to community primary care and social service settings.

One of the primary aims of CAN DO is to forge new partnerships with dental, medical and primary care colleagues, as well as with the federally-funded Women, Infants and Children (WIC) health and nutrition program, to create effective ways of improving children’s oral health in non-traditional settings.

“For the past seven years, we have been working with communities to understand and prevent early childhood caries,” says Dr. Jane Weintraub, professor and chair of UCSF’s Division of Oral Epidemiology and Dental Public Health, and CAN DO’s principal investigator. “Now we want to disseminate the information we’ve gathered and get it incorporated into clinical practice and health policy.”

CAN DO enlisted the help of CTSI’s Community Engagement program to:

- identify clinical practices to work as community partners;
- develop the research design for one of the research projects funded through the Center;
- design a community liaison program that would frame the outreach activities of the Center.

*In December 2008, the UCSF School of Dentistry received a seven-year \$24.4 million grant from NIH to continue CAN DO’s innovative programming to prevent early childhood tooth decay.*





## Why is UCSF interested in working with community-based organizations?

One of the most common criticisms of academic center-based research is that it is often difficult to apply the results to community-based practice. That is, the findings often do not *translate* well into real-world practices that can improve the health of individuals and communities.

Increasingly, researchers at UCSF recognize that community input and participation in research are crucial to generate results that are more likely to be useful and lead to real and sustained changes in health outcomes. When research is conducted in community-based settings, the needs and real circumstances of both community members and community institutions can be incorporated into the questions researchers ask and the solutions that are proposed.

While community-based research poses logistical and conceptual challenges, the rewards are increasingly recognized by academic researchers and the groups that fund them. The result is a growing investment in research efforts that incorporate community-engaged research partnerships.

## Is a community-engaged research partnership right for my organization?

The answer to this question depends on consideration of several factors:

- *What are my expectations with respect to the partnership? How much input do we want to have in the research process? Do we have an informed understanding of what research involves?*
- *Do we trust that the researcher is interested in our input? Have we developed a trusting relationship?*
- *Will following a research protocol work with our organization's service delivery and other activities?*
- *What needs to be in place to facilitate a successful research partnership? Do we have (or can we get) the necessary time, personnel, and funding to take part in a research collaboration?*

The companion Reference Manual examines each of these issues in detail, and includes extensive lists of questions that can help you clarify what you'll need to do, as well as the benefits you might hope to reap, from a research partnership. In addition, the CTSI Community Engagement Program can help you take steps toward conducting research with a UCSF partner. See the back of this Guide for information on the services we offer and how to contact us. To get you started, consider the following questions:

*"What does my organization expect from a research partnership?"*

Research partnerships can take many forms, and therefore have varied levels of expected investments and benefits on the part of the participating CBO. One of the most common possibilities involves a researcher who already has funding for a specific research project and who asks your organization to participate in conducting the study. In this situation, the next step is to negotiate roles (*Who will do what?*), how you'll work together, and what resources will be available

to make sure all are fairly compensated. With a funded project, the researcher must deliver to the funder the promised objectives and work plan, which leaves less flexibility for your organization's input for defining the research question, or designing data collection and implementation strategies.

At the other end of the spectrum, you might decide to start a research partnership with a UCSF researcher based on a mutual interest or concern. In this case, your organization and the researcher may decide to write a funding proposal together. This gives you more input in determining research questions, and data collection and program strategies, as well as negotiating staffing and budget allocations. The major difficulty of this level of involvement, however, is that there are considerable "up front" costs in the time and effort required to prepare a grant proposal, with no guarantee of a receiving funding to do the project.

*"Is conducting research a good fit with my organization's mission of service delivery?"*

Research is a primary mission of academic institutions like UCSF. Researchers must follow strict regulations for all aspects of a study's design and implementation. These include specific governmental and institutional regulatory systems that all UCSF researchers are required to follow. Some of these have to do with ensuring that research does not harm study participants, and that research participant confidentiality is protected.

What does this mean for your organization? As a research partner, you would need to follow these same regulations, especially with respect to informed consent procedures, monitoring research participant safety, as well as maintaining the security and confidentiality of research participant information and data.

The type of study design may also impact how you offer your programs. For example, some study designs may call for certain services being available for some clients and some might be offered a particular service that is not offered to others.

These are considerations that make a research study different from service delivery, and that may influence your organization's decisions to take part in research.

*“What structures and resources need to be in place for my organization to support community-engaged research?”*

Taking part in a research partnership almost always requires agency staff time and attention, and perhaps physical space, supplies and equipment. Is there someone in your organiza-



COMMUNITY-ENGAGED RESEARCH

Zero Breast Cancer

In 1995, statistics about extraordinarily high rates of breast cancer in Marin County, California spurred a group of local women to form a grassroots organization to investigate the problem. Realizing they needed to combine their lived expertise with academic methods and models, they set out to find investigators for research partnerships. That original group of community advocates has become Zero Breast Cancer, a nonprofit organization dedicated to finding the causes of breast cancer through community participation in the research process.

“Community-based participatory research, or CBPR, is our gold standard,” explains Janice Barlow, Zero Breast Cancer’s Executive Director. “We aim to have the community at the table from the formation of the research question to the publication, dissemination, and application of the findings.”

The group first partnered with UCSF epidemiologist Margaret Wrensch in 1997 to study the relationships between breast cancer and adolescent development, geographic location, socioeconomic status, and other environmental factors. They secured pilot funding from the California Breast Cancer Research Program to conduct one of a handful of studies on factors in adolescence that impact breast cancer risk. Full

Tara Gill Photography

(except photo #2 courtesy of Janice Barlow)

tion who can advocate for these allocations? Are there clear agreements about roles and the responsibilities of all parties in the research partnership?

The companion Reference Manual includes more details about the types of resource expenditures clinics can expect with various levels of research partnership. In addition, the CTSI Community Engagement Program can help you as you take steps toward engaging with an academic partner in a research endeavor.

funding led to the Adolescent Risk Factors Study (2000-2002); findings from this and subsequent studies have been published in peer-reviewed publications. By generating useful data, Zero Breast Cancer's initial research succeeded in laying a solid foundation for fundraising and community participation in ongoing community-partnered research.

Currently (2009), Zero Breast Cancer is a key community partner in the Bay Area Breast Cancer and the Environment Research Center (BABCERC), a collaboration funded by the National Institute of Environmental Health Sciences and the National Cancer Institute. BABCERC is exploring how chemical, physical, and social factors in the environment interact with genetic factors to affect mammary gland development and the onset of puberty. BABCERC partners also include researchers, scientists and advocacy groups from UCSF, Kaiser Permanente, the California Department of Human Health Services, and Lawrence Berkeley National Laboratory. UCSF epidemiologist Robert Hiatt is BABCERC's principal investigator.

In the course of their work in the BABCERC partnership, Zero Breast Cancer and their academic partners have turned to the CTSI Community Engagement Program for:

- Group consultation on disseminating research to multiple audiences;
- Training on research dissemination strategies;
- Training for community-based organizations on creating evidence for research and evaluation.



## The CTSI Community Engagement Program can help you:

- Find an academic partner with similar interests;
- Establish a relationship with an academic partner;
- Manage the steps of setting up a research project with a partner;
- Explore the degree of involvement that would work best for you.

We ask that you fill out a Consultation Request Form to help us learn more about you, your organization and your interests. After you submit a form, you'll hear back from us within a few days with next steps. The form can be completed online at:

***[www.ctsi.ucsf.edu/consult](http://www.ctsi.ucsf.edu/consult)***

To have a form faxed or mailed to you, please call:

**(415) 206.4048**

or email us at:

***[CEP@fcm.ucsf.edu](mailto:CEP@fcm.ucsf.edu)***

## Publications and Online Resources

The CTSI Community Engagement Program at UCSF maintains a resource library of printed and online resources for researchers and members of the wider community who may be interested in community-engaged research. We recommend that you access not only the resources directly relevant to your own affiliation, but also those directed toward your intended partner.

### PUBLICATIONS

#### Quick-Start Guides

*Community-Engaged Research: A Quick-Start Guide for Researchers*

*Community-Engaged Research: A Quick-Start Guide for Clinicians*

*Community-Engaged Research: A Quick-Start Guide for Community-Based Organizations*

#### Resource Manuals

*Community-Engaged Research with Community Clinicians: A Resource Manual for Researchers*

*Community-Engaged Research with Community-Based Agencies and Organizations: A Resource Manual for Researchers*

*Community-Engaged Research: A Resource Manual for Community-Based Clinicians*

*Community-Engaged Research: A Resource Manual for Community-Based Organizations*

*An Introduction to Effectiveness, Dissemination and Implementation Research*

### ONLINE RESOURCES

You can find these publications and more information about partnering with UCSF researchers at:

[www.ctsi.ucsf.edu/community](http://www.ctsi.ucsf.edu/community)

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