COMMUNITY-ENGAGED RESEARCH

A Quick-Start Guide for Researchers

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About this Guide

This Quick-Start Guide is intended for academic researchers at UCSF who are interested in community-based partnerships for 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 help academic researchers develop effective and mutually-satisfying collaborations with community-based organizations, clinicians or other community stakeholders.

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;

- information you need to know and the questions you need to ask in deciding whether a community-research partnership is right for your research study;

- information on how the CTSI Community Engagement Program can help you whether you decide to take small or large steps toward conducting research with a community partner.

If after reading this Guide you are interested in pursuing a community-research partnership, please contact the CTSI Community Engagement Program for more information. We also invite you to explore our website at:

www.ctsi.ucsf.edu/ce

that provides much more extensive information about the questions you need to ask and the steps you need to take to undertake community-engaged research.
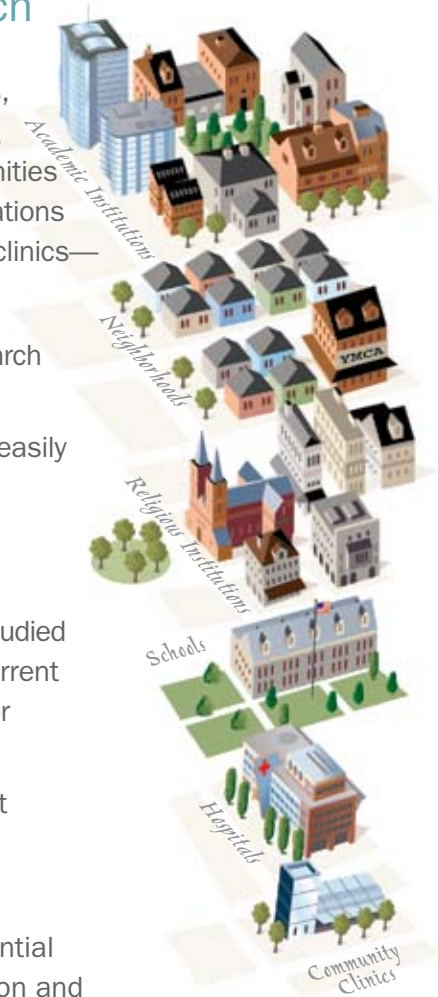
Introduction

Community-Engaged Research

F or academic health sciences investigators, community-engaged research is appealing for several reasons. By engaging with communities —whether through schools, non-profit organizations or religious institutions, community or private clinics— researchers may be able to:

■ incorporate critical insights into their research questions or interpretation of their data;

■ conduct research that can translate more easily to real world settings and impact health;

■ design more culturally- and language-appropriate interventions;

■ include populations that have been understudied and are not adequately represented in current data about a health problem, treatment or intervention;

■ increase the size of participant recruitment pools or make participant enrollment more efficient.

These advantages are accompanied by potential challenges that, without adequate anticipation and planning, can create problems for a research study. Some of the obvious challenges or obstacles to community-engaged research concern the time and funding required to establish and maintain productive relationships. Some view health research with suspicion because of well-documented breaches of human subjects protocol involving their communities in the past. Other challenges include negotiating the differences between the expectations of academic and community-based settings. The elements of these two cultures and how they can affect a research study

Introduction *(continued)*

are explored in more depth in our full guide *Community-Engaged Research: A Resource Manual for Researchers.*

The potential benefits of having community-grounded science often outweighs the potential barriers to a research collaboration. Active collaboration in a research partnership means discoveries are more likely to have direct application to the improvement of health and lives under real-world circumstances.
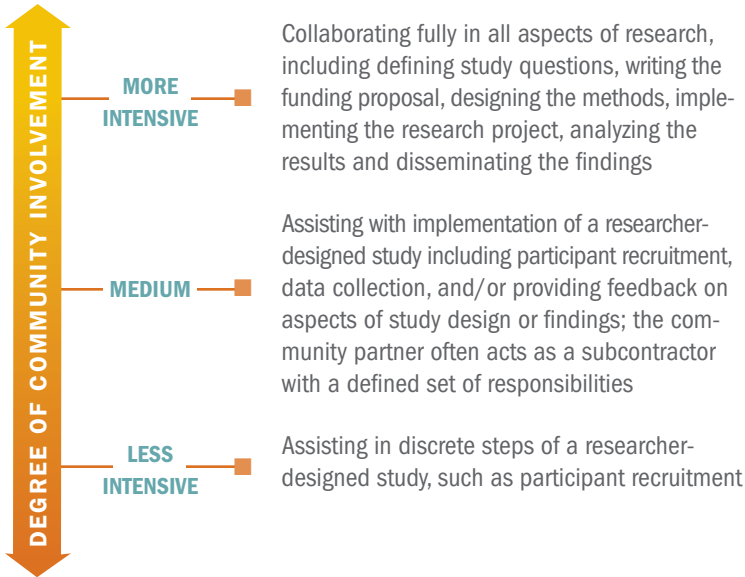
CTSI Community Engagement Program at UCSF

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?

Community-engaged research describes a continuum of possibilities for research conducted with community partner participation. Examples of such possibilities include:

A Continuum of Possibilities

DEGREE OF COMMUNITY INVOLVEMENT

MORE INTENSIVE — Collaborating fully in all aspects of research, including defining study questions, writing the funding proposal, designing the methods, implementing the research project, analyzing the results and disseminating the findings

MEDIUM — Assisting with implementation of a researcher-designed study including participant recruitment, data collection, and/or providing feedback on aspects of study design or findings; the community partner often acts as a subcontractor with a defined set of responsibilities

LESS INTENSIVE — Assisting in discrete steps of a researcher-designed study, such as participant recruitment

Potential community partners may include community clinicians (physicians, nurses, dentists, pharmacists, alternative medicine practitioners and others), non-profit community-based organization (CBO) staff, community institution representatives (*ie,* schools and religious institutions), or community advocates. Community-engaged research that is more "intensive" often takes place at community partner sites. Note that working in these different settings requires different protocols, so understanding the context of your community partner's work is the key to getting started.

Community Partners

The fundamental premise of community-engaged research is that community-based clinicians or service providers have critical, useful and intimate understandings of the concerns, values, assets and activities in their communities. When

The Premise of Community-Engaged Ressearch

Community–Engaged Research *(continued)*

community stakeholders 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 add value in identifying how the study results may be applied and how they can be used to shape future research directions.

Health research can be seen as discovering innovative solutions to difficult problems. When researchers and community 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.

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.

Why should I pursue community-engaged research?

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 and funders recognize that community input and participation in research are crucial to generate results that are more likely to be useful and lead to real practice and policy changes. When research is conducted in community-based settings, the needs, questions and real circumstances of community members, clinicians and CBOs can be integrated with the research questions asked and the solutions that are proposed.

"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.

What kind of studies lend themselves to community-engaged research?

In choosing to partner with community stakeholders, you may be able to address more effectively certain types of research questions:

Type of Community-Engaged Research Studies

- *Epidemiological or descriptive studies:* What particular health characteristics, needs or disparities exist?

- *Evidence-based practice:* To what extent can evaluated programs or treatment approaches be applied in an actual or different community setting? How do they need to be changed to be effective in community practices or organizations?

- *Evaluation or practice-based evidence:* Are community programs meeting their goals? Are they effectively addressing patient and community issues and needs?

Increasingly, major foundations and federal funders recognize the importance of practice-based and community-engaged research, and more funds are being allocated to this kind of research than ever before. NIH and AHRQ requests for proposals have specifically called for community-engaged and practice-based research in recent years, and the NIH CTSA initiative was in part designed to promote more research that takes place in community-based practice settings.

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

What are the challenges of community collaboration that I need to anticipate?

Some of the obvious challenges to community-engaged research include the time and funding required to establish and maintain an effective partnership. Trusting relationships cannot be cultivated quickly, and all parties must be prepared to commit to the partnership over a long time frame.

Providing services is typically the main priority of clinicians, service providers, teachers, health educators, and others. Introducing a research project into this mix requires careful planning to anticipate many of the common pitfalls of community-engaged research:

- *Community partners and researchers may be unfamiliar with and unprepared for the demands and requirements of each other's research or practice.* Research activities may conflict with service delivery, and protocol require-ments (*e.g.,* random assignment) may clash with your partner's culture of service provision.

- *Community partners and research teams may require additional training, staffing, or administrative resources to carry out study activities.* These demands may affect the structure and allocation of study budgets.

- *Community partners and researchers may assign different priorities to research study activities*, impacting the time required for study planning and implementation.

- *Collaboration may lead to a clash between academic and community partner cultures.* Differences in decision-making hierarchies between academic and community-based settings may be problematic. For example, you may find your study procedures must be vetted by your partner organization's CEO or Board of Directors. Community partners in turn need to adhere

Considerations for Planning

Challenges of Community Collaboration *(continued)*

to UCSF internal review boards and the requirements of human subjects protection considerations.

■ *Academic and community partner priorities may not align.* Conflicts may arise among the competing agendas of clinical and/or social service delivery on the part of the community partner and the publication-driven academic demands for replicable procedures and protocols on the part of the research partner.

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)

The potential challenges of community–academic partnerships deserve careful attention. When executed with foresight, respect and careful planning, an academic-community partnership can yield useful and mutually-satisfying results, leading to more rapid and fully-realized advances in the health of communities.

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.

How can I initiate a working relationship with a community-based partner?

This is one of the most common questions on the minds of researchers contemplating community-engaged research. *Entrée* is the critical first step of building a working relationship with a partner. You may be successful at gaining entrée through shared concerns or interests. For example, you may be able to partner with a neighborhood church based on a shared concern over the health status of its congregation, or the issue of neighborhood crime and violence. In partnering with a community clinic, you may gain entrée by addressing a topic, such as HIV/AIDS, that may be a particularly strong concern of that clinic's patient population.

You might seek out community partners who already have a track record of having participated with other researchers on related projects.

And sometimes community organizations or community-based clinicians may initiate the contact with you, based on your research interests.

Ways to Get Started

A researcher can get started working with community partners in a number of ways:

- Identify other UCSF researchers who have worked or currently are working on collaborative projects with a CBO or community clinic partner. Ask to be introduced to individuals and groups that may be interested in developing their relationships with UCSF.

- Identify and approach UCSF clinicians working in a community. Ask them to introduce you to other interested individuals working in clinical or community settings.

■ Identify existing community planning or action groups in the area of your research interest and ask if they might be interested in collaboration.

■ Contact the CTSI Community Engagement Program for a consultation!

For more in-depth information on the topics found in this Quick-Start Guide, please see these two online companion publications: *Community-Engaged Research with Community-Based Clinicians: A Resource Manual for Researchers* (*http://ctsi.ucsf.edu/files/CE/manual_for_researchers_clinicians.pdf*) and *Community-Engaged Researcher with Community-Based Organizations: A Resource Manual for UCSF Researchers* (*http://ctsi.ucsf.edu/files/CE/manual_for_researchers_agencies.pdf*).

These Resource Manuals examine the protocols and considerations for conducting community-engaged research in more detail and includes lists of questions that can help you clarify the benefits you and your partner might hope to reap, as well as the implications for planning, decision making and budgeting that follow from a community–research partnership. In addition, the CTSI Community Engagement Program can help you as you take steps toward engaging with a community partner in a research endeavor.

The CTSI Community Engagement Program can help you:

- Find a community collaborator with similar interests,

- Establish a relationship with a community partner,

- Manage the steps of setting up a research project with a partner,

- Determine the best research methods and methods training design for your study,

- Design an outreach or dissemination plan for your research process and findings,

- Frame your community-engaged funding proposal so it is competitive,

- 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 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/research/ce-consult

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

(415) 206.4048

or email us at:

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 Resarch: 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 community-engaged research at:

www.ctsi.ucsf.edu/research/community

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