

COMMUNITY-ENGAGED RESEARCH

A Quick-Start Guide for Community-Based Clinicians

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About this Guide

This Quick-Start Guide is intended for community-based clinicians who 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 clinicians and UCSF-based researchers develop productive and mutually-satisfying collaborations that are relevant for clinical and public health practice.

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 practice;
- 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.

If after reading this Guide you are interested in pursuing a research partnership, you can contact the CTSI Community Engagement Program for more information about our services and tools to inform you along the way. We invite you to explore our website at:

www.ctsi.ucsf.edu/community

Introduction

Community-Engaged Research

As a clinician providing health care at a community-based practice, you might tend to see your work as very separate from that of an academic researcher. Yet in the course of a routine day, you've also undoubtedly found yourself asking questions that include elements of both clinical practice and research.

- *How can I best serve the needs of my patients?*
- *How can I access better treatments for my patients, or locate relevant clinical trials to which I can make referrals?*
- *How can I evaluate the effectiveness of my patient interactions and other clinical operations?*
- *How can I participate in developing better systems of clinical practice?*
- *How can I draw research attention to the important patient needs that I see in my practice?*



At the same time, researchers at UCSF are searching for ways to work more closely with community-based clinicians. At the simplest level, this may involve working with community-based practices to increase participant recruitment into clinical trials. But like their clinician counterparts, UCSF researchers also search for new ways to evaluate or measure clinical practice and outcomes, or to identify other health issues of importance to the community served by a practice or group of practices.

Introduction *(continued)*

**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.

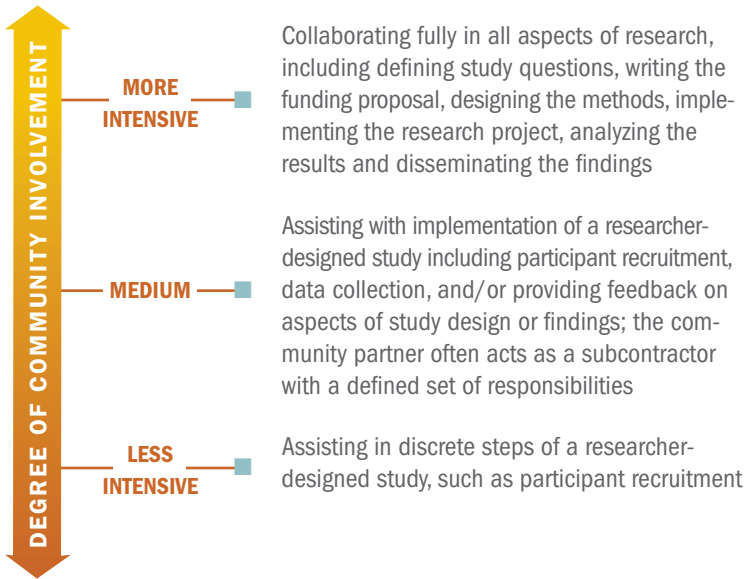
To foster these partnerships, the UCSF Clinical and Translational Science Institute's (CTSI) Community Engagement Program (CE) provides consultation, training, and other resources to build the capacity of both UCSF and local community organizations and clinical settings to conduct *Community-Engaged 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



By participating in the development of a research design or the implementation of a research study, community-based clinicians may have the opportunity to shape that research to address more effectively the concerns and needs of patients in a particular practice or group of practices.

Helping to Shape Research

Clinical research often takes place in specialized settings or with patient populations that do not reflect the diversity of healthcare needs and resources in our communities. The findings of research conducted in these settings may not be relevant or applicable to “real world” clinical practice situations. More “intensive” community-engaged research that is more reflective of clinical realities often takes place at community partner clinic sites.

Community-Engaged Research (continued)

The Premise of Community-Engaged Research

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 the communities they serve. These perspectives are vitally important in shaping and refining study questions, implementing strategies, and collecting, analyzing and disseminating data. In community-engaged research, clinical partners can participate in how a study is designed and conducted, how the study findings



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The IDEALL Study: Managing Diabetes in the Real World

Investigators at the UCSF Center for Vulnerable Populations recently partnered with San Francisco Community Health Network clinics to conduct the *Improving Diabetes Efforts across Language and Literacy* (IDEALL) study, a 9-month comparative effectiveness trial of two diabetes self-management support interventions. The study determined that using simple communication technology, as opposed to traditional approaches, was more effective in managing diabetes in underserved populations that have limited literacy and limited English proficiency.

Automated Telephone Self-Management Support (ATSM) was found to improve communication between patients and providers, facilitate a patient's self-management of their diabetes, and improve physical activity as well as overall physical and emotional function. ATSM also was found to promote patient safety and is as cost-effective as other accepted diabetes interventions, such as lipid and blood sugar control.

UCSF investigators are currently partnering with a broader network of clinics affiliated with the San Francisco Health Plan to further demonstrate the ATSM system's "real-world" applicability. The current project, entitled SMART-Steps (Self-Management Automated and Real-Time Telephonic Support), is evaluating a scaled-up version of the ATSM system on both patient-centered and clinical outcomes.

may be communicated and applied, as well as how they can be used to shape future research and practice.

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.

In addition to generating local benefits, SMART-Steps is expected to have far-reaching implications for priority populations disproportionately affected by chronic disease and faced with formidable communication barriers that make disease management especially challenging.

For more information about how clinics participate in the IDEALL study, go online at:

www.innovations.ahrq.gov/content.aspx?id=1863

and scroll down to *Adoption Considerations*.



What can community-engaged research offer my practice?

One of the most common questions from community-based clinicians is, “Why would my clinic be interested in working with UCSF researchers?” At CTSI, we’ve found that clinicians are most interested in partnering with UCSF researchers for the following reasons:

*Possible
Benefits
for
Partnering
Clinicians*

- To learn about new and potentially better evidence-based treatments or interventions for their patients,
- To understand the effectiveness of current treatments or practice improvements,
- To increase access to clinical trials for their patients who might benefit,
- To rigorously evaluate their own clinical practices and gain access to a wider network through which their effective practices can be disseminated,
- To draw more research attention to problems that affect their patients and that may be currently overlooked by academic researchers.

At the deepest level, clinical research offers community clinicians an opportunity to participate in processes of discovery that may benefit their practice, their patients, and their communities.

Why are UCSF researchers interested in working with community-based clinicians?

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. 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 program and policy changes. When research is conducted with community input and in community-based settings, the needs and real circumstances of patients and clinicians can be incorporated into the questions researchers ask and the solutions that are proposed.

Partnerships between community-based clinicians and UCSF researchers can advance clinical research by:

- Identifying research questions that are relevant to clinical practice and the community context;
- Increasing the diversity of participants in research studies, and improve recruitment and outreach;
- Improving the quality of research and patient education materials and protocols because they are informed by reality-based insights about clinical care, the busy clinical context, and patient experiences;
- Providing insights about the adaptation and uptake of protocols in the context of community health care delivery;
- Improving the dissemination and implementation of promising new discoveries;
- Increasing the generalizability of research findings.

*Possible
Benefits
for
Partnering
Researchers*



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Underserved Women with Breast Cancer at End of Life

End-of-life is a difficult issue to address even in the best of circumstances. For underserved women with breast cancer—who have few resources and limited access to quality health care—facing the end of life can be a lonely and fearful experience.

To help such patients at the Charlotte Maxwell Complementary Clinic in San Francisco and Oakland, Clinical Operations Manager Kendra Stone has teamed with Shelley Adler, PhD, at UCSF to conduct a quality-of-life study designed to find ways to reinforce these women's sense of meaning of their lives and to ease their concerns regarding death. The two Co-Principal Investigators contributed equally to the creation and design of the project at each phase, including writing the initial concept paper, the formal research proposal, and the development of their plans for dissemination and implementation.

Research team members from both UCSF and the clinic continue to work closely together, sharing in the decision-making in all aspects, including the analysis of the study data and dissemination of the findings. The clinic's participation in the research study is building its own capacity to identify and investigate future questions of interest to the community.

The Charlotte Maxwell Complementary Clinic, founded in 1991, offers complementary alternative medicine treatments to underserved women with cancer, and provides them with ongoing and consistent emotional, spiritual and political support.



What questions should I ask before partnering with a UCSF researcher?

As is true with other relationships, successful research collaborations often depend on personal qualities that result in commitment and trust. You will need to make those assessments for yourself. Doing so will help you decide which partnerships are worth pursuing and help ensure your active participation in the collaboration. We can also help. Here are some questions to get you started:

- *Is the researcher interested in a question that is important to my patients?*
- *Do I have the time to work with a researcher or research teams to bring this project into our practice?*
- *Are my office staff and colleagues interested in participating?*
- *How well does the researcher understand the needs of our practice and our patient population?*
- *How will the impact on the practice be compensated, including (but not limited to) funding?*



How might a research partnership affect my work?

Regardless of the level of participation in research, a partnership with academic researchers will necessarily involve commitment on the part of a community-based clinician or practice. At the most minimal level, a partnership will involve at least some commitment of time on the part of the partnering clinician. At its most involved, a partnership may require a substantial commitment of clinic resources, including both staff and provider time. Anticipating and planning for the commitment of resources will go far in supporting any research partnership.

An Initial Checklist

In general, the following should be in place in a community clinical setting to facilitate a satisfactory research partnership:

- A champion at the clinic to advocate for the project with clinic leadership and look out for the needs of the project in the face of competing priorities, programs and activities;
- Time to include all staff members impacted by the research project in discussions about the study;



- Appropriate staffing, including research assistants familiar with the clinical setting;
- Clear agreements about authorship, ownership of data, and the roles and responsibilities of all parties involved in the research partnership;
- A Memorandum of Understanding (MOU) to clarify agreements between the clinic and the researcher;
- A clear budget with equitable division of resources;

For more in-depth information on the topics found in this Quick-Start Guide, please see the online companion publication: *Community-Engaged REsearch with UCSF Researchers: A Resource Manual for Community-Based Clinicians* (http://ctsi.ucsf.edu/files/CE/manual_for_clinicians.pdf). This 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.



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 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

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 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

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