

# How can I best work with community members to enhance my research and its impact on the community?

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## 1.0. Community-Engaged Research Basics

### ▼ 1.1. What is community-engaged research?

Community-engaged research is research in which community input is incorporated in the development of the question, implementation of the project, analysis of the results and/or dissemination of the findings to community stakeholders. A fundamental premise of community-engaged research is that community stakeholders, such as clinicians and agency staff have credible, intimate and necessary understandings of the assets, concerns, values and activities of their constituents and communities.

### ▼ 1.2. What are some of the advantageous of community-engaged research, and why should I consider it?

"Traditional" research methods are limited when confronted with the need to discover what works or what is workable in complex "real life" contexts. Health status and health care delivery are part of complex socioeconomic forces that shape "real life" for communities and populations. *Translational research*, aims to determine whether research findings from homogenous populations and settings are generalizable to more diverse ones such as those encountered in "real world" practices. This generalizability is also referred to as *effectiveness* or *external validity*. Information about effectiveness enables clinicians, communities and policymakers to make decisions regarding the design of services and estimate the public health impact of the interventions being tested. Engaging community providers and clinicians in the conduct of translational research is the best way to ensure that the implications of service delivery settings are well-understood and incorporated into study. Community-based settings are particularly well suited for translational research because collaborative projects developed using practice-based research or community-based research methods minimize implementation barriers from the outset.

### ▼ 1.3. How do the steps of community engaged research compare with the steps of traditionally conducted research?

The table below spells out seven key steps of conducting collaborative practice-based research. The table focuses on community clinical partners, but the principles are relevant for community agency or institutional partners, as well.

Below is a chart to that summarizes differences between these models.

<b>Community-Based Participatory Model</b>	Full participation of community in identifying issues of greatest importance.	Community representatives involved with study design and proposal submission.	Community representatives provide guidance regarding recruitment and retention strategies.	Measurement instruments developed with community input and tested in similar population.	Community members help guide intervention development.	Community members assist researchers with interpretation, dissemination and translation of findings.
	<i>Increased motivation to participate in research process</i>	<i>Increased acceptability of study approach, include funds for community</i>	<i>Enhanced recruitment and retention</i>	<i>Potentially sensitive issues handled better and increased reliability and validity of measures</i>	<i>Assures greater cultural and social relevance to the population served, increasing the likelihood of producing positive change</i>	<i>Assures greater sensitivity to cultural and social norms and climate and potential group harm and enhances potential for translation of findings into practice</i>
						
<b>Research Component or Step</b>	Health concern(s) identified	Study designed and funding sought	Participants recruited and retention systems implemented	Measurement instruments designed and data collected	Intervention designed and implemented	Data analyzed and interpreted, findings disseminated and translated

						
<b>Traditional Research Model</b>	Issues identified based on epidemiologic data and funding priorities.	Design based entirely on scientific rigor and feasibility; funding requested primarily for research expenses.	Approaches to recruitment and retention based on scientific issues and "best guesses" regarding reaching community members and keeping them involved in the study.	Measurement instruments adopted/adapted from other studies. Tested chiefly with psychometric analytic methods.	Researchers design intervention based on literature and theory.	Researchers report findings from statistical analysis and publish in peer-reviewed journals.

▼ 1.4. What are the kinds of questions that can be addressed by community engaged research?

It is helpful to break down the broad arena of community-engaged research with community stakeholders into three basic types of questions: (1) Epidemiological or descriptive studies: What's true for this clinic or agency and patient/client population? What are the health characteristics / needs / disparities in these settings or with these populations? (2) Creating evidence-based practice: Does this evaluated program or treatment work in a clinical setting? What changes are needed so that this program or treatment can work in the community setting it is intended for? How can this intervention be brought to scale in new and different communities? (3) Creating practice-based evidence: Does this community-created program work? Does this practice-based program or treatment improve health outcomes, and for whom does it work for and not work? Does this clinic intervention meet public health or community objectives?

▼ 1.5. Are there different levels of community engagement I might consider?

Yes, community engagement between UCSF researchers and community organization representatives/community clinicians can be described as taking place along a continuum. Please see below for examples of community engagement along a continuum from low engagement to a full partnership.

▼ 1.5.1 What are some participant recruitment activities with various levels community engagement?

Participant recruitment activities that fall at the low engagement end of this continuum include: intercepting potential participants on the street or other venue; conducting random phone sampling; posting flyers on the street or in a newspaper; and other forms of ad-hoc interactions between participants and research staff. These methods are designed and conducted at the discretion of the researcher, often without any involvement of a community organization partner or intermediary.

Participant recruitment also can fall under a more collaborative place on this continuum. For example, a researcher can work with staff of community based organizations (CBOs) or with clinicians serving a particular community to develop recruitment materials and approaches that they know will work well to address the constituent population's strengths or needs. CBO staff can also participate in posting and marketing recruitment information. Researchers can hire CBO staff or research nurses to recruit study participants and to explain the study in a linguistically and culturally appropriate manner.

▼ 1.5.2 Besides recruitment, what other important roles might community stakeholders play in a research project?

Researchers can engage community stakeholders through focus groups or forums: (1) at the outset to identify key themes and issues in the population or community; (2) at the end of the study to report back initial findings and conduct preliminary data analysis with the community.

One effective way to obtain community input into a research project is to develop and work with a community advisory board (CAB). CABs can have a range of responsibilities that include: reviewing proposals and other materials; providing input on the research protocol and project design; providing a bridge to a target population; active problem solving; and develop dissemination plans to share research findings with the community.

At the next step of the continuum is an arrangement that involves solicitation of a community partner to assist in implementing a study designed by the researcher. In this case, the community partner may advise or function as a subcontractor to carry out a specific set of tasks required by the study. Community partners may participate in this way for the financial resources generated, because the arrangement otherwise benefits the organization or their clients or community, and/ or because the clinic/ organization is interested in influencing research taking place in the community and learning research skills.

▼ 1.5.3 How can I form a full partnership with community stakeholders?

At the greatest level of engagement, the researcher and CBO(s) or clinicians enter into a partnership to jointly explore a problem that is of interest to both entities and to develop cooperatively the specific research question, methods, and a plan for decision-making as well as the equitable sharing of resources and findings. This approach embodies the belief that the community partner is an expert in terms of knowing how to work effectively with a particular population and how a particular program or treatment is best offered, and that this expertise is as necessary as the research skills provided by the university partner.

## 2.0. Getting Started & Important Considerations

### ▼ 2.1. What will community stakeholders want to know?

Community stakeholders want to know first and foremost if there is something in the research that will specifically benefit their patients/clients. They will want to know how the study might have an impact on their organization/ clinic and patients/clients, whether or not there will be lasting benefits, and if they will have to allocate additional staff time to complete the study protocols.

#### ▼ 2.1.1. What will community stakeholders want to know on behalf of their patients/clients?

On behalf of their patients/clients, community stakeholders will want to know:

1. Why should research be a high priority (i.e., why is it more important than other work I might do)?
2. Is there a quality improvement component to the research that will positively impact my practice/organization?
3. How does this research get past the disease-oriented perspective and demonstrate a patient-centered approach?
4. What is expected of patients/clients?
5. Which patients/clients are eligible and who is not? Why? Why not?
6. What are the potential risks and benefits for my patients/clients, both short and long term?
7. Will I get the results of any tests that are done on my patients/clients during the study?
8. What would happen if my patient/client gets randomized to a control group?
9. What if my patient/client gets a complication from participating in the study?
10. What happens to my patient/client when the study is over?

For some community stakeholders, randomization of their patients/clients to control groups is not acceptable, and there have been many ideas for modifying randomized designs, such as staggering intervention exposure and cross-over designs, that can address this major concern. It is also important to realize that community stakeholders may object to their patients/clients being randomized to the intervention if there are not staff resources to cover the time to conduct the intervention itself.

#### ▼ 2.1.2. What will community stakeholders want to know on behalf of the clinic/organization?

On behalf of the clinic/organization, community stakeholders want to know:

1. What is expected of staff?
2. Do we have adequate staff to perform research functions?
3. Will the research team bring in outside staff to perform part of the protocol?
4. What kind of training is required?
5. Will the practice be compensated for additional time the protocol requires of clinic staff?
6. How much time and space will study procedures take?
7. Will the research interfere with the flow of patients/clients through our clinic/organization?
8. Are the medical and clinic directors, program managers, and front line staff on board?
9. Who will own the data and findings?
10. How will the clinic/organization be recognized in any publications?
11. Are the materials and the researcher culturally competent?

It is important to build and establish as much clinic/organization-wide support for the project as possible. It may cause problems at the clinic/organization if only one person wants to participate, so it is critical to meet with and learn about the needs and concerns of other members early in the process. It is important to compensate them and build in equitable incentives for their involvement.

### ▼ 2.2. What key principles create the foundation for productive community-engaged research?

Barbara Israel, a preeminent scholar in the field of community-based participatory research offers these examples of community-based participatory research (CBPR) principles as a starting point for working together: recognize community as a unit of identity; build on strengths and resources within the community; facilitate collaborative partnerships in all phases of the research; integrate knowledge and action for mutual benefit of all partners; promote a co-learning and empowering process that attends to social inequalities; involve a cyclical and iterative process; addresses health from both positive and ecological perspectives; and disseminate findings and knowledge gained to all partners.

## 3.0. Research Design & Specific Studies

### ▼ 3.1. What are research design considerations when conducting community-engaged research?

In order to address community concerns, researchers may have to consider alternative designs when setting up protocols. A cross-over protocol, for example, may allay participant concerns about being treated like guinea pigs, a common ramification of the more traditional requirement for control groups in research that "invades" rather than collaborates with communities and leaves little of use after the research is completed.

Conducting community-engaged research has an impact on the types of research design choices made. Options include conducting ethnographic, descriptive, observational, intervention, or implementation research. Considerations include sample selection (random, purposive, convenience, snowball); the unit of analysis (individual, setting/ community, practice cluster); use of appropriate matched control or comparison group; cross-sectional, longitudinal, or wait-list design; qualitative, quantitative, or mixed methods. Each of these choices will have an impact on and be impacted by the setting in which the research is being carried out. These choices are best made with community consultation to ascertain how realistic

each choice will be. For example, a longitudinal study might be feasible in a controlled clinical setting with a stable patient population, but this might not be feasible for a highly transient clinic setting. Similarly, an intervention might be feasible in the context of a research project with large participant incentives and dedicated research staff, but not be feasible in a natural setting—the one which will ultimately be the location of the intervention once the research is completed.

Community input can make the research better. Cross-training will allow both the researcher and community partner understand and balance the needs of the research and the needs of the practice in order to conduct rigorous, useful research with public health impact.

#### 4.0. Step-by-Step Guide for Community-Engaged Research

##### ▼ 4.1. Please describe my options

STEP	Action Items for Collaborative Partners	Possible Benefit for Community Clinician Partner	Possible Benefit for Research Partner	Research Challenges and Caution Areas:
<b>Step 1: Groundwork for Partnership</b>	<p>Assemble research team. Team should include community clinicians, clinic staff and other community members who are decision-makers and can move project forward with research collaborators.</p> <p>Develop consensus on ethics and operating principles for the research, including protection of patients and clinic staff as well as clinic-level functioning.</p> <p>Set up a patient advisory board if possible, to be involved throughout the research process.</p>	<p>Groups that are formed can focus on several objectives in addition to the research so that resources can be used efficiently. For example, setting up a clinic database for identifying study patients can also be used for reminders for screening and preventive visits. Additional staff can help patients fill out insurance forms in between study activities.</p>	<p>Motivation in determining areas of focus and need will translate into activated collaborators who will see the project through.</p>	<p>Challenge: Time it takes to pull together a group.</p> <p>Caution: Ensure that the project is not perceived as conducting research 'on' the clinicians and their community, or in 'using' their clinic for research.</p>
<b>Step 2: Identify Research Area</b>	<p>Full participation of community clinicians and advisors in identifying issues of greatest importance and where new knowledge could create most benefit.</p>	<p>Relevance to and resonance with daily work and larger views on patients and community.</p>	<p>Establishing a consensus regarding areas of focus will translate into activated collaborators who will see the project through.</p>	<p>Challenge: Can be difficult to facilitate and focus and reduce conflict when different ideas cannot all be brought into sync.</p> <p>Caution: Ensuring this phase is well perceived as "fair" and "ethical" is the most critical step and cannot be rushed.</p>
<b>Step 3: Generate Study Questions</b>	<p>Community clinicians and advisors involved in writing process and details of determining what questions are feasible to address.</p>	<p>Relevance, as above.</p>	<p>Ownership of the ideas as demonstrated by research questions will motivate clinicians and staff about the research belonging to their goals for patient outcomes.</p>	<p>Challenge: Fitting ideas for questions to fundable projects, especially if different than researchers' expertise and interests.</p> <p>Caution: Validation of all questions, even those not do-able, is critical for showing respect to clinicians and advisors. Creating a mechanism so that ideas not used in current project are not lost, is important.</p>
<b>Step 4: Design and Implement Study</b>	<p>Researchers need to communicate the relevance of specific designs to address study questions yet be open to modifying design with more community acceptable approaches, such as delayed/staggered intervention enrollment vs. control group. Community-acceptable approaches may involve gathering focus group or other qualitative narratives.</p> <p>Recruitment strategies likely best developed with clinician and advisor ideas for effective ways to reach patients and keep them actively involved.</p> <p>Pilot testing with review of findings and revisions through clinicians and advisor feedback.</p>	<p>Actively building on unmet needs and therefore contributing beyond the patient-by-patient level, in parallel with community oriented primary care principles.</p>	<p>Project details less likely to fall through the cracks and lose momentum and day to day research operations will likely be more smooth because of this sustained interest by clinicians and staff (and community).</p>	<p>Challenge: Keeping integrity of the research design when community clinicians and staff also feel ownership, as in keeping randomization protocols in place, even with wait list designs. Balancing time and cost considerations with goals to find the 'best' answers. Hiring local staff and training them to do research is important but complex at times.</p> <p>Caution: Pilot test findings may result in new ideas or changes that may delay the project.</p>
<b>Step 5:</b>	<p>Community members should review findings and interpret in</p>	<p>Clinicians and advisors will likely find results 'resonate' with</p>	<p>Community clinicians and</p>	<p>Challenge: Interpretations of data by non-researchers may</p>

<b>Analyze and Interpret Data</b>	local social and cultural context to inform developing dissemination strategy. Clinicians will want to see their clinic or patient data, so strategies to disaggregate by local area, if possible, while protecting privacy will need to be ensured.	previous views, or, if they contradict them, may find new knowledge generating useful to challenge preconceptions.	advisors will find smart ways to translate findings into local knowledge sharing and ideas for dissemination.	be different and will require some thoughtful negotiation and mutual learning. Be mindful that local findings will be of primary interest to clinicians too.  Caution: Presentation of findings for this discussion of interpretation should allow for alternative interpretations, rather than present data as 'final'.
<b>Step 6: Implement Results</b>	Follow-up strategies to build on results should also have a community review process, with original group and also with additional identified stakeholders that may play a role in future work.	Pride in accomplishments and validation of work with new energy to follow-up if changes are occurring as a result of research.	Longevity of research collaborations and sustaining of projects over time.	Challenge: Writing additional grants while projects are underway to sustain continuity.
<b>Step 7. Disseminate Findings</b>	Community clinicians and advisors as authors on scientific papers and presenters in community and broader settings.	Recognition and authority related to community work, extension of COPC ideas.	Findings will reach larger audience and generate interest among new stakeholders, including policy makers and health systems players.	Challenge: difficult to develop an equitable balance as writing research papers is not a strong interest of many community clinicians, and other dissemination strategies will be more of interest.

## 5.0. Writing a Competitive Community-Based Participatory Research (CBPR) Proposal

### ▼ 5.1. How do I write a competitive proposal to conduct CBPR?

The Community-Campus Partnerships for Health (CCPH) has developed the following criteria for successful proposals which are outlined below: funding should be shared by research and community partners with percentages clearly detailed; linkages between community-defined priorities and the research focus are clearly described; equal attention is devoted to research methods and the building/sustaining of the partnership and community participation; and emphasis is placed on community capacity building in the form of job creation, cultivation of leadership skills among community members, sustaining programs following the conclusion of grant funding, and training of community members in research methods.

For additional guidelines and criteria see: Agency for Healthcare Research and Quality. [Community-based Participatory Research: Assessing the Evidence](#) Evidence Report/Technology Assessment Number 99, 2004.

Authorship and presentations are key elements of disseminating research findings. These [guidelines for successful dissemination](#) are very helpful to collaborative research partners. Because agency staff who contribute intellectual content to the research can qualify for co-authorship, researchers and community partners should decide up front what role each will have in preparing manuscripts. A similar process should take place regarding presentations of research findings at community agency meetings, academic conferences, and other venues.

## 6.0. Contacts for Further Help

### ▼ 6.1. How can the CTSI Community Engagement Program help me find a community organization or clinics interested in collaboration?

The Community Engagement Program can help you: **find** community partners with similar interests; **establish a relationship** with a community agency, institution, group of stakeholders, or practice-based research network; manage the steps of **setting up** a research project in community settings; develop rigorous, practical **study designs** that are responsive to community interests; and **explore** the degree of involvement with community that would work best for your research.

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. To have a form faxed or mailed to you, please call 415.206.4048 or email [CEP@fcm.ucsf.edu](mailto:CEP@fcm.ucsf.edu) .