Community-Engaged Research with Community-Based Organizations

A RESOURCE MANUAL FOR RESEARCHERS

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This is one of a series of manuals developed by
the UCSF Clinical and Translational Science Institute (CTSI)
Community Engagement Program on conducting
community-engaged and translational research.

This guide was prepared by the Community Academic Research
Engagement (CARE) Committee of the Community Engagement Program.

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T O P I C S

PREFACE

"If we want more evidence-based practice, we need more practice-based evidence."

Lawrence W. Green[1]

Scientists in the United States have learned a great deal about the causes, treatment, and prevention of many diseases. Yet great scientific advances in research have not fulfilled their promise and potential for optimizing the health of our communities. It is especially evident that communities with persistent disparities in health outcomes have yet to reap the full benefits of progress in health sciences research.

In 2006 the National Institutes of Health (NIH) responded by instituting the *Clinical and Translational Science Awards* (CTSAs), a new funding program to address these discrepancies and facilitate the *translation* of important scientific discoveries into practice. The University of California San Francisco (UCSF) was one of the first recipients of a CTSA, and has since established the UCSF Clinical and Translational Science Institute (CTSI) to promote research and education in clinical and translational science at UCSF, at affiliated institutions, and in communities UCSF serves.

NIH states that an enhanced translation enterprise should include *"outreach to underserved populations, local community and advocacy organizations, and health care providers."* [2] Going beyond *outreach*, UCSF recognizes that strong and mutually beneficial partnerships between the communities UCSF serves and the University are essential to a translation process that addresses the needs of community members, works to address health and health care disparities, and produces more rigorous and applicable research.

In order to accomplish its mission, the UCSF CTSI established a *Community Engagement Program (CE)* to provide consultation, training, and other resources to build the capacity of UCSF and local community organizations and clinical settings to conduct community-engaged research. Community organizations and clinical practices are strongly encouraged to work with the CTSI Community Engagement Program to explore possible collaborative research opportunities to address the health and healthcare concerns of the people they care for.

The Community Engagement Program's Community Academic Research Engagement (CARE) Committee prepared this guide to inform UCSF investigators about the processes and steps involved in developing research collaborations with community-based organizations and institutions. We have included resources to facilitate this work and address some of the barriers to collaboration. The overall aim of this document is to orient UCSF researchers seeking to do rigorous research built on research partnerships with public and community-based agency staff. This guide is designed to inform, facilitate and support such partnerships so research can meet the needs of researchers, collaborative partners and participants. A companion guide is available on the UCSF CE website for agency staff who would like to explore such partnerships with UCSF investigators. While this document refers to specific UCSF resources and projects, much of the information it provides is generalizable to other institutions and can be a resource for investigators across the U.S. *[Back to Topics]*

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1   This statement is the theme of LW Green's website *here*. For more on his perspective about this statement, see Green LW and Ottoson J, *From Efficacy to Effectiveness to Community and Back: Evidence-Based Practice vs Practice-Based Evidence.* Proceedings from conference: From Clinical Trials to Community: the Science of Translating Diabetes and Obesity Research, 2004, National Institutes of Health, Bethesda, MD. Also, see Laflin M, and Black DR. An interview with Lawrence W Gree. *American Journal of Health Behavior*, 2003. 27(4):466-78.

2   U.S. Department of Health and Human Services, National Center for Research Resources (NCRR) Press Release, September 18, 2007. *NIH News: NIH Expands National Consortium to Transform Clinical and Translational Research 2007* (see *www.nih.gov/news/pr/sep2007/ncrr-18.htm*)

TOPIC 1

What is community-engaged research?

A fundamental premise of community-engaged research is that community-based organizations have credible, legitimate, and intimate understandings of the assets, concerns, values and activities of their constituents and communities. Oftentimes, these agencies and organizations are the places individuals share experiences and develop the relationships that define a community. An outside researcher can acquire knowledge and trust, but may not fully learn all that is important about a given health problem or research question, just as community members who have not been trained in research may not fully grasp the nuances of methods, theory, and study design. Fortunately, these diverse perspectives can be complementary, and often do find considerable common ground. Community-engaged research is anchored in these areas of mutual interest, need, and respect.

A Note About Terminology

In this guide we use the terms *community-based organizations, CBOs,* or *community agencies* to include such non-clinical entities as:

- Nonprofit 501(c)(3) or community-based organizations, i.e. *Sobrevivir al Cáncer (Surviving Cancer Coalition), Crisis Response Network, On-Lok Senior Centers;*

- Public agencies and governmental offices, i.e. *Health Equity Institute; San Francisco Unified School District; San Francisco Department of Public Health; Mayor's Office of Children, Youth, and Families;*

- Faith-based organizations and institutions; and

- Networks, associations or consortia of these agencies, offices, and organizations.

Community engagement is about relationships, and relationships between UCSF researchers and community representatives can be described as taking place along a continuum. As research becomes more community-engaged and involves community members and agencies more closely, it is more likely to take place outside of academic settings and involve more people and places the community values.

Community-engaged research with community-based agencies answers three basic types of questions:

- *What's true for this community? (epidemiological or descriptive studies)*

- *Does this community-based and created program work? (creating* **practice-based evidence***)*

- *Does this program or intervention work in a community setting? (creating* **evidence-based practice***)*

Activities that fall at the low engagement end of this continuum include participant recruitment strategies such as the following:

- 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 partner or intermediary.

Participant recruitment also can fall under a more collaborative place on this continuum. For example, a researcher can work with members of a particular community or CBO 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 to recruit study participants and to explain the study in a linguistically and culturally appropriate manner.

Moving along the continuum toward more engaged research are studies that convene 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.

At the next step of the continuum, for example, is an arrangement that involves solicitation of a CBO to assist in implementing a study designed by the researcher. In this case, the CBO may advise or function as a subcontractor to carry out a specific set of tasks required by the study. CBOs may participate in this way simply for the financial resources generated and/or because the arrangement otherwise benefits the organization or their clients or community.

Examples of this type of arrangement are:

- CBO staff provides education or counseling following a research protocol;

- A CBO provides the setting for a partnering clinic staff member to draw blood or do another lab test on-site; and

- A CBO integrates the research intervention into their program time.

In these situations, research staff would train CBO staff members and regularly check the quality of the work and the data being collected.

Moving along the continuum toward greater engagement, researchers and community members build an infrastructure to support opportunities for increased communication and mutual accountability. Collaboration takes place earlier and more often in the development of the research project. It is important, therefore, to set up structures to make those collaborative opportunities possible. One effective way to obtain community input into a research project is to develop and work with a community advisory board (CAB). CABs are explored in more detail *later in this guide*. Identifying CAB members and recruiting them can be demanding, but the rewards can be as great as the efforts required to create a successful CAB. Most researchers find it useful to enlist the help of one or more CBOs active in the community to get the process started. Nonprofit CBOs have their own Boards of Directors to oversee administrative and policy aspects of their organizations, and some also have community advisory boards to provide input on programs and activities. These members are generally representative of the ethnic, socioeconomic and cultural aspects of their communities. When researchers partner with CBOs, they may be able to arrange to have the CBO's community advisory board also act as advisor to the project. 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

- Developing dissemination plans to share research findings with the community.

At the greatest level of engagement, the researcher and CBO(s) 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 that this expertise is as valuable as the research skills provided by the university partner.

At UCSF and other health sciences research institutions, research at the low end of the engagement continuum has a long history and is currently widely used. Research that reaches into the more engaged areas of the continuum may be described as community-based in that the research takes place in communities and may be population-based when representative sampling is used. These should not be confused, however, with the most actively engaged model, known variously as:

- Community action research,
- Participatory action research,
- Community-based action research,
- Empowerment evaluation, or
- Community-based participatory research (CBPR).[4]

CBPR, which traces its origins to the 1940's, offers considerable potential for the translation of research into practice. A foundational premise of CBPR is that the more inclusion and community partnership that is systematically built into the research process, the more relevant and applicable research findings will be. That inclusion begins earlier in the research process and is more rigorously applied for the extent of the study, and sometimes beyond.

CBPR offers theory and methods for research in which the goals are improved community-based outcomes, and all phases of the project involve close collaboration between community stakeholders and academic researchers. The key features are a strong foundation of understanding, respect, and trust among the participating entities; a set of mutually agreed-upon goals; and a governance structure and rules of conduct that ensure that the process remains collaborative from goal generation to implementation and dissemination of results.

Participatory research is systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change.   *[Back to Topics]*

What is Community-Based Participatory Research?

CBPR is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change. CBPR involves:

- Co-learning and reciprocal transfer of expertise by all research partners with particular emphasis on the issues being studied with CBPR methods;
- Shared decision-making power; and
- Mutual ownership of the processes and products of the research enterprise.

— *U.S. Agency for Healthcare Research and Quality*[3]

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3 Viswanathan M, Ammerman A, Eng E et al. Community-Based Participatory Research: Assessing the Evidence. Evidence Report/Technology Assessment No. 99 (Prepared by RTI–University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication 04-E022-2. Rockville, MD: Agency for Healthcare Research and Quality. July 2004.

4 Faridi Z, Grunbaum JA, Gray BS, Franks A, Simoes E. Community-based participatory research: necessary next steps. *Prev Chronic Dis* [serial online] 2007 Jul [date cited]. Available *here*.

TOPIC 2

Why should I be interested in community-engaged research?

When researchers and representatives of community organizations engage in the process of discovery together, advances in scientific knowledge can be more finely tuned and immediately applicable to the lives of community members. When research is community-engaged, the path from scientific discovery to practice is likely to lead to more rapid and more fully realized advances in the health of our communities. UCSF researchers and community members have much to gain from partnerships dedicated to having a positive impact on the health of communities. Such partnerships are key to the translation of results into community-based practice (*evidence-based practice*), and to the integration of community knowledge, needs, and preferences into research (*practice-based evidence*).

There are many types of collaboration that can take place between community organization staff and academic researchers. For example, community agency personnel and researchers can work together to:

■ Identify new and better intervention and prevention efforts for community members;

■ Identify and support the development of better systems of health promotion and delivery;

■ Identify public health priorities that can be addressed by community organizations and agencies;

■ Develop educational programs for agency and organization staff;

■ Translate clinical questions into research projects that address important community needs.

Ultimately, intervention researchers are concerned with the development and testing of strategies that have the potential to promote health and prevent

What is "Health"?

Health is a broad concept, which we define here as the state of well-being and balance that individuals and communities experience when they are able to function at their full potential. This definition derives from the widely accepted definition of health used by the World Health Organization (WHO), which states that *"health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"* (WHO. Constitution of the World Health Organization Geneva, 1946). In more recent years, this statement has been modified to include the ability to lead a *"socially and economically productive life."* Some argue that health must be seen as a process of continuous adjustment to the changing demands of living and of the changing meanings we give to life.

disease in real-world settings. However, the long-standing fixation on randomized controlled trials to preserve internal validity, while appropriate for Phase One efficacy tests (*Does the intervention work under the most tightly controlled circumstances?*), is highly problematic in the Phase Two effectiveness test, designed to assess the impact of an intervention under real-world conditions.[5] In this phase of research, the outcome must fit the resources, needs, and characteristics of actual end-users, and thus the methods and intervention require adaptation to ensure this result. It is in this phase of research that collaborative research, with CBPR as its most rigorous model, can provide balance between "the scientific rigor of the Phase One study and respect for indigenous wisdom about the local situation."

5 U.S. Department of Health and Human Services, National Center for Research Resources (NCRR) Press Release, September 18, 2007. *NIH News: NIH Expands National Consortium to Transform Clinical and Translational Research 2007* (Available *here*)

According to Green and Ottoson, "The factors that clog the pipeline from research center-based clinical research to community-based practice are numerous:

■ The types of research products flowing from efficacy trials;

■ Bias toward internal validity in the effectiveness trial;

■ Oversimplification of the causal mechanisms at work in social and behavioral systems; and

■ Poor fit at the community-based practice end of the original efficacy trial research product."[6]

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. Those forces can represent causal and risk factors that interact and play important roles in creating inequities and disparities in the health and health care of vulnerable populations. Community-engaged research is well designed to take these issues into consideration and address them. Community members who are impacted by factors are usually uniquely able to identify them and likewise identify strengths and shortcomings of research interventions aimed at a health problem. For example, the effectiveness of a clinical service or program is impacted by very practical considerations like the dialects spoken in a community or the appropriateness or accessibility of a research or intervention site. Community members or agency leaders or clients who are willing to share their experience and insight are invaluable assets to a study when engaged from the outset as valued collaborators.

In order to address community concerns and gain buy-in, 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. For African Americans, such concerns are a lasting legacy of the syphilis experiments at Tuskegee. Sensitivity to a community's need for lasting benefit from a research study can help collaborative partners think creatively about ways to institutionalize effective interventions or programs after the study is completed. It may be a good idea to include this kind of plan in the initial proposal with an appropriate funding plan.

When social, cultural, and fiscal concerns are addressed, community involvement can lead not only to scientifically sound research by improving recruit-

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Examples of Community-Based Research Collaborations at UCSF:

■ *AANCART San Francisco* is a collaboration to promote cancer awareness activities and cancer-related research among 10 Asian ethnic groups in the greater San Francisco Bay Area region. Our local AANCART program is part of a national program of university-community research and training collaborations.

■ The *UCSF Center for AIDS Prevention Studies (CAPS)* has a long history of fostering collaborative community-engaged research. *This CAPS study of young black men who have sex with men* is one example of such a collaboration, testing community interventions to reduce sexual risk behavior and increase HIV testing.

■ The *ASPIRE project* is a collaboration of the UCSF School of Dentistry's CAN DO Center and Head Start to determine parental acceptability and preferences for preventive dental treatments for young Hispanic children.

■ UCSF's Schools of *Dentistry*, *Medicine*, *Nursing*, and *Pharmacy* host websites dedicated to research. Check these sites for other examples of community-engaged research.

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6 Green LW and Ottoson JM. From efficacy to effectiveness to community and back: evidence-based practice vs practice-based evidence. From *Clinical Trials to Community: The Science of Translating Diabetes and Obesity Research.* Conference Proceedings: January, 2004. NIH. Available *here*.

How do I find a community organization interested in collaboration?

The *Community Engagement Program* can help you:

- Find a potential collaborator with similar interests;
- Establish a relationship with community-based organization representatives;
- Manage the steps of setting up a research project with a collaborative 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.

To have a form faxed or mailed to you, please call **(415) 206-4048** *or email us at* *CEP@fcm.ucsf.edu.*

- Facilitates collaborative partnerships in all phases of the research;
- Integrates knowledge and action for mutual benefit of all partners;
- Promotes a co-learning and empowering process that attends to social inequalities;
- Involves a cyclical and iterative process;
- Addresses health from both positive and ecological perspectives;
- Disseminates findings and knowledge gained to all partners.

Key among these definitions, criteria and principles are the concepts of equity between researchers and community representatives in the form of shared power and decision-making and relevance: research that addresses real-world needs and produces real-world solutions. For more information on creating "the glue" that holds partnerships together, see *this online curriculum* from the Campus Community Partnerships for Health.

Community-based settings are particularly well suited for translational research because collaborative projects developed using community-based research methods minimize implementation barriers from the outset.   *[Back to Topics]*

ment and receptivity overall, but yields research that is more relevant than that conceived in the absence of community involvement. Further, such involvement builds trust and enhances the capacity of community members and groups to recognize and expand upon community assets and to address local problems.

According to Barbara Israel, a preeminent scholar in the field of community-based participatory research, principles that guide any one research endeavor are ideals for which the project can strive and are interrelated. The extent to which any research project can achieve any one or a combination of these principles will vary depending on the context, purpose, and participants involved in the process. Israel[7] provides these examples of CBPR principles as a starting point for working together:

- Recognizes community as a unit of identity;
- Builds on strengths and resources within the community;

Working Examples: Guidelines for Participatory Research

Campus Community Partnership for Health (CCPH) at the University of Washington has developed an excellent set of guidelines for collaborations between academic researchers and community partners. These guidelines can help you work with your collaborator to establish good communication and processes for decision-making. Click *here* to see the full text of the CCPH Principles of Good Community-Campus Partnerships.

Dr. Lawrence Green has also developed *guidelines for participatory research in health promotion.* These can be used to provide focus to the early development of a collaborative research project.

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7 University of Washington Community Campus Partnerships for Health. *Developing and Sustaining Community-Based Participatory Health Partnerships: A Skill-Building Curriculum.* [cited 2008; Available *here*]

TOPIC 3

Why would a community agency or network of agencies be interested in collaborative research?

Community agencies can benefit from research partnerships in several ways. First, as a collaborator on a grant, a CBO may gain access to resources to support new initiatives, and/or sustain or expand upon established aims. Many social service organizations, for example, may view new health programs as a way to respond to community needs and thereby enhance their role as a critical resource to the community members they serve. They also may learn about the effectiveness of programs they currently deliver. By partnering with the university in health research, an agency may enhance its advocacy strength, forging connections that give it a greater voice in the policy arena. Finally, demonstrating competence as a research grant partner is often the basis for an agency to obtain additional funding in related areas.

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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 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, 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.

TOPIC 4

What do I need to know about community-based organizations and the community setting?

As mentioned above, this document refers to a range of agencies and organizations within the broad term *community-based organizations*. The aim of this section is to orient researchers to some basic structural and functional elements of two types of these organizations. This kind of orientation should give researchers a good starting point from which to ask additional questions of potential research partners in an effort to maximize the assets and strengths CBO and agency representatives can bring to research collaborations. Similarly, CBOs stand to benefit from a grounding in the processes and constraints of research.

Non-Governmental Nonprofit Community-Based Organizations

Nonprofit community-based organizations are uniquely positioned to connect researchers with participants who stand to benefit from biomedical and health promotion research and are in touch with the context and reality of life of community members. They are also in a position to disseminate findings and participate in efforts to institutionalize effective programs or strategies.

An agency must meet and maintain certain operational and programmatic criteria and standards to be granted their 501(c)(3) nonprofit tax status by the state in which they do their work. Usually their work has developed in recognition of and response to local needs. CBOs range in size from multi-million dollar to small "mom and pop" operations that function primarily through volunteers. Their mission focuses on providing information, advocacy or services to address problems or issues. CBOs generally have mis-

sion statements that identify their core values, such as social justice or equal access to services; define target populations of particularly vulnerable groups; and express idealistic goals or outcomes. CBO Boards of Directors and staff tend to be strong advocates for their clients regarding the issues that inform the agency's mission and program work.

Like most academic researchers, nonprofits write grants to raise staff salaries and program funds. This dependence on grant funding means agencies that can afford to dedicate staff time to grant writing and management can focus on sustainability. Government agencies, on the other hand, receive most of their funding from local, state, and/or federal legislation. Most community-based CBOs are supported by a variety of sources, including government funds, private foundation grants, and individual donations. All of these resources are subject to funding cycles, changes in political priorities, and philanthropic trends. In the case of small organizations, funding is a constant concern and even small fiscal changes can make program planning difficult. Salary levels at non-governmental CBOs are generally lower than salaries in the for-profit or governmental sectors, so high staff turnover is a real challenge for program development and relationship building. In this context, it also can be difficult for staff to find the time or resources for long-range strategic planning and thorough process and summative, evaluation efforts.

Typically, the staff of a non-governmental CBO is headed by an executive director (ED), who supervises program directors and their staff, finance and marketing staff, capital (buildings, vehicles, etc.) and maintenance staff, and volunteers. The ED re-

ports to a Board of Directors, the body that holds legal and fiscal responsibility for the agency or organization. Many CBOs are committed to hiring local residents, peers and members of their target population to carry out their programs. To maximize resources, individual CBOs can leverage resources of other CBOs or agencies by joining forces within collaborations, networks or coalitions. Many of these groups find that together they can access funding or influence policies. Usually it's most fruitful for a researcher to contact the ED or a board member of a CBO or coalition of agencies to initiate an exploration of a research collaboration. That individual can begin the process of negotiating the partnership and getting buy-in from program staff, clients, and the Board. Eventually a collaboration agreement may be made involving a Memorandum of Understanding, subcontract, and other formal elements.

Another issue to keep in mind is the role of non-governmental CBOs in advocacy efforts. An agency like Planned Parenthood has a clear policy and legislative agenda and raises funds to promote it. As state government employees, UCSF faculty and staff may not in the course of their work directly advocate for a political position. On the other hand, they may provide information to educate policy makers. The issue of advocacy has implications for the packaging and use of research findings, which should be a point of negotiation between collaborators during the initial planning process. Research partners must stay aware of and maintain this boundary between the advocacy work that is permissible for agencies and their UCSF collaborative partner.

Government Agencies

If you are considering a collaboration with a government agency, it is also important to understand some basic elements of its management structure, which in turn determines how decisions are made and projects are approved. In this case, administrative directors, health commissioners or city supervisors will have to approve a collaboration. It is important to make direct contact, preferably in person, with these decision-makers at the outset. This kind of open and direct contact will facilitate the development of a realistic timeline for grant writing and alert you to any concerns that need to be addressed before requesting formal approval.

If research findings from a collaborative study could influence upcoming legislation supported by a CBO research partner, would it be allowable for the CBO staff to use those findings at legislative hearings? If a UCSF staff person is invited by a legislative panel to be present as an expert when a bill is being discussed, what can the staff person say? These questions may require consultation form a UCSF lawyer and careful wording of any statements.

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TOPIC 5

What questions might community-based organizations have about research or about a potential collaboration?

When you meet with staff from community-based organizations, they may have some fundamental questions about what you do and what you'd like to do. These questions can help you prepare for initial and ongoing conversations with potential partners:

- *What interests you about the population we serve?*

- *What do you want to accomplish?*

- *What is your training for this project?*

- *What makes our organization a good match for this project? What kind of help do you need?*

- *How do your ideas fit with our mission? How will the research help us?*

- *How will this project impact our work?*

- *Are you discussing this project with other potential research partners?*

- *Have you ever worked in the nonprofit (or public) sector before?*

- *What resources might be available to support our participation?*

- *Is your idea funded yet? If not, what steps are necessary to obtain funding? How long will it take? How can we participate?*

- *Is it necessary to have a control group?*

- *How are research projects typically staffed?*

- *How are research staff paid? Can agency staff be paid by a research grant?*

- *What kind of day-to-day and long-range decisions have to me made? By whom? How?*

- *How will we know if the research is having the desired impact?*

- *What will be the products of the research for our agency and for our community?*

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

TOPIC 6

What are the steps of community-engaged research?

The diagram on page 12 illustrates the steps of the process of developing, implementing and analyzing the results of a research study, and compares traditional research and community-based participatory (CBPR) approaches to each of them. While recognizing that this degree of engagement is not ideal or even appropriate for all research projects, we are comparing this most engaged model to illustrate the collaborative potential at each step. Each collaborative project should assess the level of engagement that is appropriate.

For each component or step, the CBPR model brings together the views and interests of stakeholders to build consensus that is built upon at the next step. Involving community partners in the earlier steps helps ensure the study has real and immediate relevance to the community. To make any degree of collaboration possible, partners should consider building collaborative mechanisms discussed in Topic 9.

In the early stages of a collaborative process, partners can formulate a research question together. Both partners contribute their expertise to the process, providing information, discovering any areas that require more preliminary examination and identifying process issues. This process is valuable not only in refining the question but also in building both trust and familiarity with one another's needs and understandings. Developing a research question involves learning about and considering the evidence currently available about the research question and a possible intervention.

After a proposal is written and submitted, partners face an uncertain future. During this waiting time, whether or not partners have to work on and submit revisions to the proposal, it is advisable for grant planning and collaboration work to continue so implementation can begin on schedule if you are successfully funded. Ongoing communication, planning, and meeting during this time can help the collaboration continue to grow and develop uninterrupted. Statements between partners such as *"if this grant is funded, then…"* or *"if this project is successful, then…"* should also be followed by *"if this grant is not funded, then…"* or *"if this project does not meet its objectives, then…"*

Note!
Keep in mind that the strictest definition of CBPR requires that the research and community partners decide together and equally on the research question, one that reflects a high priority to the community. It is still more often the case that, for many reasons (e.g. response to a particular RFA, a natural progression in one's research, etc.), the question is not jointly conceived. Approaching CBOs to generate support and interest in an already formulated, specific research question can lead to a collaborative project, but limits the extent to which the collaboration can be participatory because the most important element, the research question, is predetermined from the agency point of view. If, however, you wish to create a more participatory project and you come to the initial meeting with a research question in mind, use it as a starting place for discussion, negotiation and learning rather than a predetermined fact.

Conducting Research: A Comparison of Traditional Research and Community-Based Participatory Approaches

Traditional Research Model	Research Component or Step	Community-Based Participatory Model
Issues identified based on epidemiologic data and funding priorities	**Health concern(s) identified**	Full participation of community in identifying issues of greatest importance. *Increased motivation to participate in research process.*
Design based entirely on scientific rigor and feasibility; funding requested primarily for research expenses	**Study designed and funding sought**	Community representatives involved with study design and proposal submission. *Increased acceptability of study approach, include funds for community.*
Approaches to recruitment and retention based on scientific issues and "best guesses" regarding reaching community members and keeping them involved in the study.	**Participants recruited and retention systems implemented**	Community representatives provide guidance regarding recruitment and retention strategies. *Enhanced recruitment and retention.*
Measurement instruments adopted/adapted from other studies. Tested chiefly with psychometric analytic methods.	**Measurement instruments designed and data collected**	Measurement instruments developed with community input and tested in similar population. *Potentially sensitive issues handled better and increased reliability and validity of measures.*
Researchers design intervention based on literature and theory.	**Intervention designed and implemented**	Community members help guide intervention development. *Greater cultural & social relevance to the population served, increasing likelihood of producing positive change.*
Researchers report findings from statistical anaylsis and publish in peer-reviewed journals.	**Data analyzed and interpreted, findings disseminated and translated.**	Community members assist with interpretation, dissemination & translation of findings. *Greater sensitivity to cultural & social norms, climate and potential group harm; enhances potential for translation of findings into practice.*

The same collaborative, iterative process should hold true for the steps that follow:

- Data Collection;
- Delivery of Intervention or Program (if applicable);
- Data Analysis; and
- Dissemination of Findings.

Find out more!

The CTSI Resource Manual *An Introduction to Effectiveness, Dissemination, and Implementation Research* addresses research geared toward dissemination and implementation.

A key concern of community partners is whether and how the results of the study will be disseminated to all community members and to other community groups with similar interests. Collaborative partners often ask each other how to sustain an effective intervention when the research money is gone. This can involve the question of whether a clinical therapy can be made available, whether a counseling and education program can be continued or whether a service site can be maintained.

Partners also may want to know how the collaborative relationship can be maintained. We recommend that when a partnership between a community organization and a researcher is being considered, there should be a process to assess the needs and capacity of each at the outset and at regular intervals after the partnership is off the ground. Research partners should reassess how the partnership is progressing relative to the milestones set forth in the project proposal. This needs to be done in a consistent and explicit manner to avoid misunderstandings and distrust. A researcher should be clear about his/her availability and career plans and set out realistic expectations for continued engagement in current and/or future project. Community agency staff should do the same. A trainee should not commit to a lengthy involvement (although a successful project may increase the likelihood of staying longer). It is helpful to plan for institutionalization of a new intervention by building the CBO's capacity to sustain it or by identifying potentially low cost links to local (including UCSF) resources and personnel, such as medical or nursing students or a UCSF clinic. This may mean bringing these longer term collaborators to the table relatively early in the research process, as soon as the need for them is identified.

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Need more information?

If you have questions about these steps or would like consultation about how to collaboratively set up and implement these steps with a community partner, the Community Engagement Program can help. To request a consultation, *complete a consultation request form* and we will be in touch with you within a few days.

TOPIC 7

How do I gain entrée to the community I would like to engage in research?

This is likely one of the most common questions on the minds of researchers contemplating collaborative community-based research. Regardless of the model of community engagement, relationship building is a critical first step. If one is interested in using the CPBR framework, a relationship must be well established before any research question is formulated. If a researcher does not have such a connection to community gatekeepers, it may be realistic to consider an initial project a first or second step toward subsequent projects that will be truly participatory from their inception. If you are not ready for a CBPR study, consider starting somewhere else along the community-engaged continuum.

A researcher can gain entrée in a number of ways:

- Identify other UCSF researchers who have worked or currently are working on collaborative projects with a community partner.

- Ask to be introduced to individuals and groups that may be interested in developing their relationships with UCSF. Over time a researcher may develop a good reputation and become well known for his/her commitment to the issues of concern to the community. Such a researcher and her/his colleagues are much more likely to be respected by potential partners. This is the researcher to seek out when you want to initiate contact in those communities with which you would like to set up collaborative partnerships.

- Identify and approach UCSF clinicians working in a community, and ask them introduce you to individuals connected to community agencies.

- Identify existing community planning or action groups in the area of your research interest.

- Contact the *CTSI Community Engagement Program* for a consultation!

These groups can be identified via UCSF contacts or by contacting the local health department working on a particular health focus, e.g. AIDS or asthma or prenatal services. In this situation it can be valuable both to the researcher and to the planning or action group if a researcher joins and helps the group by providing data and evidence and identifying potential funding sources for their work. Following the CBPR model, if a potential for research funding arose, meetings could take place with community representation to identify a focus for research and formulate a question or questions of interest to both the researcher and community agency.

Using the internet to identify programs or groups interested in a general interest area may help broaden your search to include individuals and agencies that are not yet connected to the University.

Similarly, identifying gatekeepers can occur in a variety of ways. Researcher can seek out connections at community meetings, conferences or other gatherings or events to get acquainted with community members and learn more about their histories and priorities. Researchers can explore local resources, programs, and gatekeepers via the web and other media to identify groups who might be interested and have the capacity to participate in a research study. See also: *Getting Started from Scratch: Where to Begin?*

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TOPIC 8

What qualities and skills help a researcher conduct effective community collaborative research?

Because trusting and effective partnerships cannot be cultivated quickly, researchers must be willing to commit to the partnership over a long time frame. This requires *patience* in recognizing at the outset that a new study will be many months and sometimes years in development. As a result, *creativity* and *resourcefulness* are required in career planning and the prioritization of other commitments.

Among the personal qualities that help researchers work effectively in any community and with community partners, *respectfulness* and *humility* are paramount. Academic partners must recognize that their training and education provide only one piece in a complex array of skills needed to conduct effective community-based research. Respect is an essential antidote to distrust and resistance to health research that continues to inform communitites that experienced well-documented breaches of human subjects protocol in the past. It is evidenced by openness to, and serious consideration of, community input, by thoughtful listening, and by whole-hearted consideration of community proposals. Being able to incorporate community input and compromise on research questions and procedures in this way requires *flexibility*, another key quality.

Other qualities that help researchers develop credibility with community members include:

- Interest in and knowledge of the community, its history and hopes for the future;

- Demonstrated commitment to addressing important community issues;

- Interpersonal skills to invite and build ongoing access to community expertise and inspire enthusiastic community participation.

Knowledge of and commitment to ethics in research are required. These must be communicated in a way that assures participants of your commitment to the protection of their right to privacy and the confidentiality of research subjects. Over time, evidence of this knowledge and commitment will build and preserve trust in the research enterprise.

Finally, *dedication to building skills in health literacy* enables research and community partners to communicate effectively with one another. The ability to translate technical concepts into lay terms is critical in establishing trust, equal footing, and mutual understanding. When scientists cannot step out of their technical language and concepts in order to communicate clearly and openly in lay terms, they signal a power differential that can be difficult to bridge. It is helpful when the language used in conversations and presentations can be understood by all. Staff training for both the CBO staff on research methods and the UC staff on community/cultural issues can be built into the study budget and timeline.

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TOPIC 9

What administrative components of research partnerships with community-based organizations should I know about?

In general, the following structures and resources need to be in place to support collaborative research:

Funding

Community-engaged research requires careful and often lengthy planning, so the project timeline and budget should reflect this. Integrating various aspects of community engagement will have different budget implications. The deeper the engagement, the more likely it is to impact the project budget. Some CBPR grants allow a planning period where partners work to identify a research question and/or intervention strategy and then reapply for implementation funds. Funders approach contracting for this type of work in a number of ways: funding one partner with a *subcontract* and *memorandum of understanding (MOU)* with the other partner, or funding each partner separately with an MOU describing how they will work together and defining the roles and responsibilities of each. Depending on the level of engagement and the research question you're asking, a community-engaged research project could take 3-5 years.

A researcher interested in collaborative research may approach a community-based organization after having received a grant. This may make the project appealing to prospective partners committed to the research question because there is already funding available, so the next important step is to agree on the scope of work in relation to the available funding. However, because the researcher is obligated to deliver to the funder the promised objectives and work plan, there is less flexibility to accommodate

community input for defining or designing the research question. Community input is still important as a "reality check" on the proposed plans for data collection and research instruments (surveys, questionnaires, etc.), and a good researcher will incorporate community input and adjust the plans as needed.

Another scenario is that a researcher and community clinician are interested in the same topic and decide to write a grant proposal together. In this case, there is usually very little funding available for the work required to write a good grant. Community agency staff are often asked to write *letters of support* and a description of their capabilities and contributions to a project. The letter of support usually names the grant and funding mechanism; describes the agency or organization and its relationship with you, the researcher; and states the role each party will have if the grant is funded. A letter of support is not a formal commitment. Once the grant is funded, it's a good idea let your community partner know the next step of formalizing the relationship.

Sometimes, a memorandum of understanding is needed. Rarely, a subcontract needs to be signed prior to the submission of the grant. Usually at this point in the process, community partners only need to sign a form that reflects their *intent to subcontract*. This is a good time to clarify the goals of the project and the distribution of resources. Negotiations about the type of project, the methods of gathering data, how community partners may participate, desired endpoints, and the allocated resources should take place at this stage. It is impor-

What administrative components of research partnerships with community-based organizations should I know about?

tant to clarify with each person involved about the degree of certainty of the scope of work and the budget. Since a grant administrator may have to respond to granting restrictions for how the money can be spent, it is important that community partners partners know about what options are available to share resources with them.

Since grants can take a long time to get reviewed, it is important to maintain communication about the pending grant in those interim months and let agency partners know as soon as any funding decisions are known. During this time, it is advisable for grant planning and collaboration work to continue so implementation can begin on schedule if you are successfully funded. Ongoing communication, planning, and meeting during this uncertain time can help the collaboration continue to grow and develop uninterrupted.

Subcontract

It may make sense to discuss drafting a subcontract, the formal legal agreement between UCSF and partnering organizations. A subcontract in which your collaborative partner provides services to UCSF requires at minimum:

- The overall scope of work;
- A timeline for deliverables;
- A listing of participating agency staff;
- The proportion of staff time spent on the project, their tasks, their salaries and benefits;
- Other costs including indirect costs; and
- Reporting requirements.

Additional information may be necessary depending on the source of the funding. For example, recipients of subcontracts on federal grants have to agree to specified salary caps, human subjects protection guidelines, and prohibition on lobbying. Multiple revisions of subcontract agreements may be required to satisfy UCSF Contracts and Grants requirements.

A subcontract agreement may be needed either at the time UCSF is submitting the grant proposal or after the proposal has been funded. If submitted prior, this ensures that both UCSF and partner agency sites are obligated to carry out the terms of the subcontract once the grant is funded. A Memorandum of Understanding may also be developed with or without a subcontract in place.

Memorandum of Understanding (MOU)

A Memorandum of Understanding describes the types of deliverables and general timeline of the deliverables between the UCSF researcher and community organization. It is more formal than a letter of support and is signed by both the researcher and the agency leader. It will be important to determine who the appropriate person is to sign the MOU before the memo writing process begins. *Read more information about MOUs.*

Accounting

The *UCSF Office of Contracts and Grants* must review agreements between researchers and partnering agencies to make sure it follows regulations from the funding agency and UCSF. The Contracts and Grants office is also the office that receives the funds. Once funding is obtained by UCSF, funds flow from the University to subcontractors and partners.

Some CBOs, such as governmental agencies, have very sophisticated accounting and contracting departments that are accustomed to working with the University. A small nonprofit may have very small and not very sophisticated accounting systems, so UCSF may have to provide active guidance and oversight of accounting, including special reporting forms, training and monitoring. The cost of such services also should be taken into account.

What administrative components of research partnerships with community-based organizations should I know about?

Human Subjects Protection

Each research partnership will differ depending on the nature of the project as well as the researcher(s) and organization(s) involved. However, all UCSF researchers are required to follow rules and regulations that are specified by UCSF, their funders, and by state and federal regulators. Some of the most important regulations have to do with assuring that research does not harm study subjects, and that patient confidentiality is protected.

In the proposal writing phase, the researcher must obtain *Institutional Review Board (IRB)* approval for research involving people (see box). The IRB at UCSF is called the Committee on Human Research (CHR). All standard IRB and *HIPAA regulations* apply to community-based research. The purpose of the IRB is to make sure that the study has undergone appropriate scientific review, has an acceptable balance of risks and benefits for research subjects, follows appropriate methods of informed consent for research participants, and has appropriate systems in place to monitor patient safety and confidentiality as the research proceeds.

The UCSF Committee on Human Research

The UCSF *Committee on Human Research (CHR)* requires that all members of the research team, which may include you or staff from your CBO partner(s), take part in online training to assure that everyone who is involved in the study has an appropriate level of understanding of the principles of the safe conduct of research. Since 1996, this training has included education on requirements of the Health Insurance Portability and Accountability Act (HIPAA). HIPAA training is meant to assure that any research information that is derived from the medical record is handled appropriately with respect to participant confidentiality and privacy. See *more information on HIPAA*, and more information on *HIPAA training at UCSF*.

The protection of study participants is an area where it is useful to provide training and technical assistance to CBO partners. They should understand what will be required (and provided) to assure confidentiality and privacy of research participants. Time spent with your community partner is invaluable in determining and developing the best language, structure, and procedures for gaining consent. *Creating good consent forms* is an important issue. *Read about consent forms* on the UCSF CHR website. NIH also offers information on *what makes a good consent form*.

It is especially important to develop confidentiality guidelines and training on them when agency staff serve clients and track information for their own program purposes as well. It is often difficult to distinguish between service delivery and research data collection, and this distinction must be clear throughout the study to all staff involved.

Scientific Advisory Boards and Community Advisory Boards

As each section of this guide has pointed out, broad and meaningful support from the communities involved in the research is important to the success of community-engaged research. As the research idea moves closer to being a proposal, a community-based and oriented Scientific Review Committee (SRC), Community Advisory Board (CAB) or Scientific Advisory Board (SAB) can be established to review elements of the study. These groups might be convened only early in the study, or meet throughout the life of the project.

Most CABs are comprised of leaders and other individuals representing various parts of the community, such as agency clientele and staff, representatives of local health-related organizations or clinics, schools, religious groups, media, and other interested parties.

What administrative components of research partnerships with community-based organizations should I know about?

CABs are generally made up of no more than 20 people who serve as primary liaisons between the community and researchers. Often a senior scientist or physician and/or other member of the research staff will attend CAB meetings on a regular basis, a sign indicative of the CAB's importance in the research process.

CAB members may take on active roles in planning for and undertaking research projects. Examples of their numerous activities include:

- General community outreach and education;

- Support for volunteer recruitment by disseminating information about the study;

- Providing feedback on trial protocols, including criteria for participation, informed consent forms and processes, and volunteer recruitment and retention;

- Advising investigators regarding potential participants' perspectives about the study;

- Providing a safeguard (in addition to institutional ethics review committee) for participants' rights; and

- Representation at important national, regional and international meetings and conferences.

CABs may provide feedback on the actual study protocol, the informed consent document and any educational materials to be used in the community. Although these consultations are not part of the formal approval process, researchers may make changes to the study protocol and other documents to reflect this community input. This process helps to ensure that communities receive appropriate information, that their concerns are addressed and that the trial will run smoothly in the community. CAB meetings are a useful forum for addressing ongoing concerns and project progress. Depending on the community interests and needs and the project budget, the CAB may be able to garner resources and support from the study partners. This support may take the form of space for meetings, refreshments, staff to arrange meetings and take minutes, and stipends to compensate community members for their time.

Staffing

Since research often is integrated into the regular activities of agency sites, research staff work closely with each site to maintain dialogue between the investigators, CBO staff, administrators and others on-site throughout the course of the study. Investigators should meet with key staff on a regular basis to get input on hiring research staff, the development of study tools, piloting instruments, involving and motivating CBO staff to participate, and protecting participant rights and confidentiality.

Since most CBO staff are busy with the daily demands of delivering service, it is usually unreasonable to expect them to be responsible for principal activities of the research project unless staff are given additional time to work on the project and will be compensated for their time.

Depending on the stipulations of your funding source, CBO staff may be able to recruit and enroll study participants, or you and your community partner may choose to hire dedicated research staff for this project. It is important to remember that most agency staff do the work they do because of their commitment to delivering services to the community they serve, not to conducting research. Take time to include this in their feedback and input into the data collection methods. Not ensuring agreement and participation from frontline staff could prove to be the Achilles' heel of a study if they don't believe in it.

Reporting

Researchers are obligated to report, usually on a semi-annual or annual basis, the progress of their work to the funder. Reporting and accountability fol-

low the type of contracting relationships. For collaborative research each partner may write part of the report or the lead agency may write a draft and ask for input. If there is a main contractor and a subcontractor the timelines and expectations need to be clearly established. The timing of reports and expectations for what reports contain should be made clear in your memorandum of understanding or subcontract. The UC partner may need to provide training and technical assistance to the CBO in meeting the reporting requirements. On the other hand a public agency may have a very complex accounting and reporting system and may be able to provide training and technical assistance to the university partner.

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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.

TOPIC 10

What are the challenges of collaboration with a community-based partner?

Some of the obvious obstacles to progress in this area are the time and funding required to establish and maintain foundational relationships.

Time for planning

There are few infrastructure funds to support convening agency staff, community members and academic researchers to discuss and develop formal projects to answer questions of value to all in the group. Such meetings often occur after hours when everyone has other commitments, which is why progress can be slow. Building in longer timelines for planning can alleviate the pressure to get projects underway.

Time for conducting research

It is sometimes difficult for CBO staff to free up time in their day additional activities, such as research. These kinds of competing priorities can create tension between researchers and community staff. This is an example of a situation that can be addressed if regular communication has taken place from the outset and a foundation of trust has been built. For researchers accustomed to working in more research-focused settings, patience under these circumstances is important. A good research partner will value the CBO services and work to learn lessons about implementation from the community partner.

Traditional hierarchies in academic and social service organizations

Community-based agency staff members come from many educational and socioeconomic back-grounds. Some have advanced degrees and dedicate their skills to nonprofit organizations and institutions. Some come from disadvantaged communities or have recently received services from the community-based agency and are valued for their expertise in community dynamics and experience with the issue being addressed. Similarly, some researchers have deep connections to the communities in which they focus their efforts, inspired to give back by conducting research into the health of their own community. Others have few connections to the community, but bring an interest in health research. In all cases, it's important to assess the strengths and limitations of people who will be collecting data, interacting with community members, designing outreach materials and research instruments. If anyone on the team is not skilled in their role or doesn't believe that the research enterprise is valuable, the quality of the data can suffer. Poor data collection means that the researchers and community members won't get the answers to their collective research questions, and the contribution to community health won't happen. It's important to take time to ensure that all members of the research time are well trained, understand the value of their role, and feel able to ask for help or provide feedback about what is or is not working.

Change in expectations from exclusively publication-driven outcomes

Investigators need to learn to negotiate between their own research agendas and the needs identified by the research team, thereby building in 'win-win' or 'piggy back' proposals that are more inclusive. This may take more time and will often require more

resources than a more traditional single purpose study. Offering training in research skills to interested collaborators can also help bring together different research ideas into more practical studies, and this requires resources and commitment.

Hopefully these potential obstacles or drawbacks will not outweigh or override the long and short-term benefits of a research collaboration. Your ac-

tive collaboration in a research partnership means the discoveries you make are more likely to be translated into action and better outcomes for more people. The *CTSI Community Engagement Program* can help you as you take any number of small or large steps at any point(s) along the continuum of engagement with a community partner.

TOPIC 11

What is known about the effectiveness of community-engaged research?

"Community-based research in and of itself will not resolve broader social issues, such as racism and economic inequalities. Differences in beliefs and social inequalities enter into community-based research relationships, just as they do in other forms of research. That they are made explicit in community-based research, and that the research process attempts to grapple with them and their implications for the construction of knowledge and the development of effective strategies for change, enhances the potential for community-based research to address social inequalities associated with differentials in health status."

— Barbara Israel[8]

Community-based participatory research, CBPR, the model that requires the most community engagement, is still developing and has rapidly growing interest and support among research scholars. An extensive literature on CBPR theory and methods is available. While the concept of equal participation between researchers and community partners is widely recognized as a core principle, there is no one absolute agreed-upon set of guidelines on the development or evaluation of CBPR proposals, and suggestions as to resources required for successful collaboration vary widely. This is a literature that does not lend itself to meta-analysis or even ready synthesis in terms of the effectiveness or rigor of CBPR studies. Yet the literature reflects numerous successes and insights.

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Resources and Tools for CBPR

Community Campus Partnerships for Health has a website that serves as a clearinghouse for resources on community-based participatory research (CBPR). The site offers compilations of tools and instruments, as well as literature to support high quality community-engaged research. Be sure to check out the *UCSF CTSI Community Engagement Program website* as well for updated resources (literature, sample supporting documents, presentations, funding opportunity listings) on community-engaged health research.

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8 Israel, BA, Schulz, AJ, Parker, EA, et al. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Ann Rev Pub Health*, 19, 173-202.

What do I need to know to obtain funding for a collaborative study?

The first step toward funding a project is the identification of funders who at best promote the use of community-engaged research and have demonstrated that support with their track records. The Centers for Disease Control and Prevention, the National Institute of Environmental Health Sciences, and the National Cancer Institute have been leaders in funding federal CBPR initiatives. Interest across the federal government continues to grow in the form of RFAs, toolkits, and reports. However, according to the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality, reviewers can be unfamiliar with or even skeptical about community-engaged or CBPR approaches.

Thus, the second key step is to write a proposal that scrupulously documents all supporting evidence for the study's community-engaged or CBPR model and methods.

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TOPIC 13

How do I write a competitive proposal to conduct CBPR?

"In recent years, national organizations, funding agencies and researchers have called for a renewed focus on an approach to public health research that recognizes the importance of social, political and economic systems to health behaviors and outcomes. This renewed focus is due to many converging factors, including our increased understanding of the complex issues that affect health, the importance of both qualitative and quantitative research methods, and the need to translate the findings of basic, interventional, and applied research into changes in practice and policy.

"As a result, participatory models of research, in which communities are actively engaged in the research process through partnerships with academic institutions, have become central to the national prevention research agenda as articulated by the Institute of Medicine, the Centers for the Disease Control and Prevention (CDC), Research!America, Partnership for Prevention, the Public Health Foundation and others. "

— Community-Campus Partnerships for Health

Lawrence Green[9] has developed *review criteria and a rating scale* to help researchers and their partners assess the extent to which their project design is participatory and action-oriented.

Criteria for successful proposals have also been developed by the Community-Campus Partnerships for Health (CCPH) including the following:

■ 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;

■ 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.[10]

See also: *Show Me the Money: Securing and Distributing Funds*, an online curriculum module to help partnerships identify and secure funding, and decide how to distribute funding resources.

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9   Agency for Healthcare Research and Quality. Community-Based Participatory Research – Assessing the Evidence– Evidence Report/Technology Assessment Number 99, 2004.
10 Israel, BA, Schulz, AJ, Parker, EA, et al. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Ann Rev Pub Health*, 19, 173-202.

TOPIC 14

What do I need to know about publishing a collaborative study?

Authorship is a key element of disseminating research findings and publishing is an important professional incentive, especially for academic researchers. 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. Often the determination of authorship is decided in the MOU or as publications are being planned. Conflict may arise when authorship decisions are deferred until the results are submitted for publication. If community partners cannot or choose not to be formal co-authors, a published acknowledgement of the contribution of community partners is a good alternative. Sometimes agency settings are acknowledged or site administrators may be one of many authors (i.e., a research study group).

It is important to recognize that a variety of strategies can be used to disseminate research that has been conducted (or is currently being conducted) in an academic-community partnership. As with other elements of community-engaged research, the earlier and more explicitly plans and decisions about dissemination are made, the more effective dissemination efforts will be. Wherever a study lies on the engagement continuum, thoughtful, consistent and thorough dissemination can demonstrate commitment and enhance trust between research collaborators. Ongoing information sessions or meetings, for example, can provide critically important status updates about a project and thereby provide a forum for the airing of collaborator and participant questions. As with the issues and conditions described above concerning authorship, a well thought out planning and implementation process should take place for presentations of research findings at community agency meetings, academic conferences, and other venues.

For collaborators in more "intensively" engaged studies, a list of journals that publish CBPR studies developed by the Council on Linkages between Academic and Public Health Practice[11] may be of interest. As the frequency of CBPR increases and the quality of these studies improves, more journals are taking part. Before deciding to submit an article to a journal, we suggest that you survey the most recent examples of CBPR papers to assess journal style(s) of and options.

A limited number of studies representing a complete and fully evaluated intervention – an observational study or an epidemiologic study that can be generalized beyond the participants involved – have been published to date.

Limiting factors appear to include:

■ The categorical nature of most federal funding;

■ Funding period length and flexibility; and

■ Page limitations of journals.

There was little evidence to indicate that high-quality scores in community collaboration are associated with low-quality research scores.

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11 Public Health Foundation: Council on Linkages Between Academia and Public Health. Journals That Publish Practice.   [cited 2008; Available *here*]

Community-engaged research challenges the traditional notion that researchers alone can and should initiate, design, and conduct studies to improve community health. Including and valuing community expertise can help researchers improve the focus and relevance of interventions, ensure that study designs are more responsive to external validity and feasibility issues, and disseminate findings more broadly with providers and policymakers who can use research results. Community-engaged research is based in trusting relationships in which the skills, experience, and perspectives of both researcher and community members are seen as critical to the success of the project.

A range of possible ways to include community input are described in this guide because our goal in the Community Engagement Program is to help you consider options for integrating community perspectives into your work. Whether you have a one-time community input forum, convene a Community Advisory Board for the life of your study, collaborate with a community agency or institution for participant recruitment, or partner with a community agency as a full collaborator, the CTSI Community Engagement Program can help you navigate community engaged research. *[Back to Topics]*

How Do I Contact the
CTSI Community Engagement Program?

You can reach us by email: *CEP@fcm.ucsf.edu*

You can reach us by phone: **(415) 206-4048**

Visit us on the web at:

www.ctsi.ucsf.edu/ce

Fill out a consultation *request form* online!

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UCSF

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