Community-Engaged Research with UCSF Researchers

A RESOURCE MANUAL FOR COMMUNITY-BASED ORGANIZATIONS

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CTSI at UCSF

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

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TOPICS

PREFACE

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

NIH states that enhanced translation efforts should include *"outreach to underserved populations, local community and advocacy organizations, and health care providers."*[1] Going beyond "outreach," UCSF recognizes that strong and mutually beneficial *partnerships* between the communities UCSF serves and the University are essential to address the needs of community members, confront health and health care disparities, and produce 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. We invite community-based organizations and agencies to work with the CTSI Community Engagement Program to explore possible collaborative research opportunities to address the health and healthcare concerns of the communities and people you serve.

The Community Engagement Program prepared this manual to inform community-based organizations and agencies about the nuts and bolts of developing such research collaborations. We have included resources to facilitate this work and address some of the barriers to collaboration. The overall aim of this

A Note About Terminology

In this guide we use the terms *community-based organizations, CBOs* or *community agencies* to refer to:

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

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

- Faith-based organizations and institutions; and

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

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1 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*

document is to orient community-based organizations seeking to do research built on research partnerships with UCSF investigators. This manual is designed to inform, facilitate and support such partnerships so research can meet the needs of agencies, collaborative partners and participants. An *online companion manual* is available for UCSF investigators who would like to explore research partnerships with community-based organizations. While this manual refers to specific UCSF resources and projects, we hope the information it provides is generalizable to other institutions and can be a resource for agencies and organizations across the U.S.

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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 1

Why community research and what does it offer my organization?

"What is research, but a blind date with knowledge?"
— William Henry, British chemist

Some people think that health sciences research involves doing medical experiments with human beings. In general, UCSF researchers think of health-related research as discovering innovative solutions to difficult problems. A growing number of health sciences researchers at UCSF are interested in addressing the complex and difficult health problems faced by our communities.

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 discov-ery to practice is likely to lead to more rapid and more fully realized advances in the health of our communities.[2] UCSF researchers and community agency staff 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 research results into community programs (evidence-based practice), and to the integration of community knowledge, needs, and preferences into research (practice-based evidence).

You may be interested in working closely with researchers to:

- Describe the scope of public health priorities that can be addressed by community organizations and agencies,

- Answer questions about your own community and other communities or service populations,

- Identify better systems of health education and delivery,

- Learn how to conduct self-evaluation,

- Access resources to develop/adapt new programs and/or interventions that are culturally appropriate for their target populations,

- Conduct more rigorous research and/or evaluation of these programs,

- Educate researchers about issues facing your communities,

- Provide access to clinical trials for your clients or community,

- Obtain consultation and resources needed to conduct proven or promising interventions,

Know Your Research Partner

Many institutions in the Bay Area conduct clinical and health sciences research, including *Children's Hospital Oakland Research Institute (CHORI), Kaiser Permanente, Stanford University Medical School, University of California Berkeley School of Public Health* and *California Pacific Medical Center (CPMC)*. Many of the elements discussed in this document apply to collaborations with researchers from these and other institutions, while other elements will be specific to research conducted at UCSF. If you have questions about researchers who contact you regarding a partnership, it's important that you know about the places they work and understand the requirements of that institution before getting involved in a study.

- Have input into proposals for funding programs that impact your communities, and

- Gain access to a wider range of potential funding sources.

UCSF researchers may be interested in working closely with community organizations to:

- Identify research questions that matter to the community,

- Learn about community priorities, assets, needs, and capacity;

- Conduct research projects to address community priorities,

- Evaluate the impact of programs and interventions,

- Conduct effective outreach events,

- Provide community-based research training for students, fellows, and other junior researchers;

- Disseminate research findings.

The combined expertise and experience of local and regional organizations and UCSF researchers creates the groundwork for exciting partnerships. At the same time, the factors that make partnerships possible and productive also may generate confusion and misunderstanding. Different priorities, values and cultures can pose a challenge to partnerships. This guide will help community-based organizations sort out the advantages and challenges to collaborating in research studies.

The research we are discussing in this manual includes all kinds of questions about human health, including behaviors that cause disease or promote health; the design and quality of health services; and the effectiveness of treatments and health education. Ultimately, health-related research aims to advance knowledge in order to decrease human suffering. Research at UCSF includes learning about how patients are evaluated, treated and cared for in clinical settings *(patient-centered research or clinical research)* and how individuals or communities address barriers to achieving optimal health *(community-based research)*. More recently, the concept of community-based participatory research (CBPR), in which communities play major roles in defining the research questions and the interventions, has expanded the definition of research to include many different types of activities, including capacity building, network development, and policy action.

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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.

TOPIC 2

What is community-engaged research?

Learning about each other's interests and expertise is critical for effective partnership.

There are many types of collaborative activities that can take place between community organizations and UCSF researchers. At its core, community-engaged research recognizes that community-based organizations have credible, legitimate, and intimate understandings of the assets, concerns, values and activities of their constituents and communities. Oftentimes, community agencies and organizations are the places individuals share experiences and develop the relationships that define a community. Community members who have not been trained in research may not fully grasp the nuances of methods, theory, and study design, just as an "outsider" researcher can acquire knowledge and trust but may not fully learn all that is important about a given health problem or research question. 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.

Community engagement is about relationships, and relationships between community organization representatives and UCSF researchers can be structured along a continuum. As community-engaged research involves increased partnership activities between university researchers and community members and agencies, it is more likely to take place outside of academic settings and involve more diverse people and places.

Activities that fall at the low engagement end of this continuum include the following strategies to recruit community members to participate in studies:

■ Recruiting 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 CBOs from a particular community to develop recruitment materials and approaches that address the community'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.

Community-engaged research with community-based agencies answer 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)

A more engaged arrangement involves partnering with an agency or organization to assist more fully in implementing a study designed by the researcher. In this case, the agency may advise or function as a subcontractor to carry out a specific set of tasks required by the study. Agencies and organizations may participate in this way for the financial resources and/or because the arrangement otherwise benefits the organization or their clients or members.

Examples of this type of arrangement would be:

- CBO staff provides education or counseling services outlined in 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 uses the research intervention as a way to deliver program services.

In these situations, research staff would train CBO staff members and be in regular communication regarding program implementation and data collection.

Moving along the continuum toward greater engagement, researchers and community members can create 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 in the research project to ensure the community's involvement. One effective way a community perspective can be incorporated into a research project is through a Community Advisory Board (CAB). Participating on a CAB can take a lot of time, but it's one way to ensure that researchers hear and understand community input. (More detailed information about CABs is included below.) When CBOs partner with researchers, they may be able to arrange to have the researcher act as an advisor to the agency. Research 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, and

- Active problem solving.

At the greatest level of engagement, the researcher and CBO representative(s) enter into a partnership to jointly explore a problem that is of interest to all of them and to cooperatively develop the specific research question, methods, and a plan for decision-making as well as the equal and fair 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 research institutions, research that involves community engagement has a long history and is currently widely used. The most actively engaged kind of research is known by many names:

- Community action research,

- Participatory action research,

- Community-based action research,

- Empowerment evaluation, or

- Community-based participatory research (CBPR).

Community Advisory Boards

One way to engage in a research project is to participate in a community-based and oriented Scientific Review Committee (SRC), Community Advisory Board (CAB) or Scientific Advisory Board (SAB). These groups are established to review elements of the study. These groups can meet throughout the life of the project.

What is Community-Based Participatory Research (CBPR)?

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*[2]

Most CABs are comprised of leaders and other individuals representing various parts of the community, such as religious groups, schools or universities, media, clinicians, patients and non-profit or community-based agencies.

CABs are generally made up of no more than 20 people who serve as primary liaisons between the community and the researchers. Often a senior scientist or other member of the study staff will attend CAB meetings on a regular basis, indicating the CAB's importance in the study 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 researchers about 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 protocol and other documents to reflect 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.

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2 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

TOPIC 3

Why would my organization be interested in working with UCSF?

Community organizations may or may not be directly involved in health programs or have a history of doing research. However, community organizations are always engaged in activities that promote the well-being of a community. Most community organizations aim to:

■ Identify problems relevant to their clients and community,

■ Discover what contributes to those problems,

■ Deliver relevant and cost-effective programs,

■ Evaluate their programs, and

■ Seek additional funding to sustain or expand these programs.

The resources to accomplish all of these tasks may be scarce or completely unavailable. As a result, many organizations focus mainly on program implementation and fundraising. Collaborating with UCSF can give community agencies access to resources that are the traditional strengths of an academic institution:

■ Data gathering (to identify problems),

■ Literature review (to identify solutions),

■ Evaluations (to assess program effectiveness), and

■ Capacity building (to improve self-evaluation, outreach, and funding).

In addition, collaborative research grants may enable community organizations to expand the range of potential funding sources, create networking opportunities, and form strategic alliances. Equally important, community organizations can contribute to determining research priorities and ultimately shape the literature on what constitutes effective interventions. What is discovered today can have a positive impact on what funders and what organizations serving your population will do tomorrow.

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How do I find a research partner at UCSF?

The *Community Engagement Program* can help you:

☐ Find a potential collaborator with similar interests;

☐ Establish a relationship with UCSF researchers;

☐ Manage the steps of setting up a research project with a collaborative partner;

☐ Explore the degree of involvement that would work best for you and your organization.

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*.

TOPIC 4

Why is UCSF interested in working with community agencies in community settings?

Community input and participation are crucial, both in terms of generating knowledge and in acting to implement changes. When research is conducted in community-based settings, the results are likely to be useful and lead to the development of real program and policy changes. Community-based organizations and agencies provide real-world settings to implement new health care or health service programs and interventions. While community-based research poses logistical and conceptual challenges, its rewards are increasingly recognized by researchers. Academic research institutions and funders are beginning to invest resources in community-based research.

Community leadership can also lead to innovative approaches to increase access to health care or more culturally appropriate health education. Programs developed in the community can be studied and shared in order for others to learn about one agency's success or innovative approach. In addition, community organizations have more skills in implementation and dissemination than researchers. Many UCSF researchers are committed to collaborating and understand the value of partnering with community-based organizations to help learn about best ways to deliver health education programs and policy.

Bridging the gap between what researchers do and what community organizations do is often challenging. It involves bridging different cultures and belief systems and different organizational systems. Sometimes it involves the challenge of overcoming suspicion and distrust based on a history in which human subjects protocols were breached.

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.

Collaborative research tends to be more expensive and time-consuming than conventional research, but the result is almost always more relevant research leading to insights for all involved and better programs for those who need them.

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TOPIC 5

What might I need to know about how research is conducted at academic institutions?

Research is about discovery which, along with patient care and teaching, is a primary mission of academic medical institutions like *UCSF*. Health sciences researchers usually have a specific area of interest that is important to them. These interests may come from personal experience with a health issue or community or because of a larger interest in improving public health. Health sciences researchers can be social scientists, physicians, nurses, dentists, pharmacists, or laboratory scientists. They typically have special training in research methods.

At UCSF almost all research projects are funded by grants from the government (federal, state, or local), private foundations, or by pharmaceutical companies. The vast majority of UCSF researchers are supported by grants. Like community-based agencies, they raise the money for some or all of their salary and the salaries of their research team by obtaining grants. Researchers may be interested in pursuing a project with a community agency, but need to secure funding in order to conduct a full-scale collaborative research project. On the other hand, many academics also are willing to give talks, review proposals, or serve on boards of community agencies because they share a commitment to the same community or health concern.

After developing a research question or an idea for a new program or intervention, a researcher usually writes a proposal for grant funding in order to conduct the study. The potential funding agency reviews the proposal for significance, scientific rigor, feasibility, and innovation. A project that is worthwhile in every other way and that may appeal to a community organization may not get funded as a research project if it has been done in a similar way somewhere else. While the requirements differ from one source to another, some

issues apply generally. UCSF grants are managed by a central *Contracts and Grants Office*.

Built into academic research programs and institutions are structures and processes that maintain high ethical standards, support rigor, and encourage high quality work. These include governmental and institutional regulatory systems, peer review, and the standards that guide internal and external competitive funding processes.

To have successful careers, researchers must establish themselves as an expert in a particular area of inquiry, whether it be basic science, clinical, epidemiologic, or health services related. This is typically done by building a program of related research projects and presenting the findings of this research to peers at meetings and in professional journals. Academic promotion is based on demonstration of expertise as evidenced by securing funding for research projects, authoring significant publications, serving on committees of professional organizations (e.g. the American College of Obstetricians and Gynecologists) or government agencies (e.g. the National Institutes of Health), and providing education and mentoring for junior faculty. The infrastructure of academic institutions is designed to support inquiry and the standards of excellence that are a critical element of it.

The nature of a research team varies depending on the size of the project. The lead scientist on a research project is usually called the Principal Investigator (PI). He or she usually assembles a team that may include a Project Director, an Evaluator, and research assistant(s). We include more information on research staffing in Topic 10.

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TOPIC 6

What might a researcher need to know about my organization?

Researchers who approach you usually have some idea of why they want to collaborate. Those you are approaching may want to have an idea of your organization's mission, location, how long you have been working in the community, whom you serve, and the services you offer. A brochure, one-page fact sheet, or an informative website is usually sufficient for an introduction. If your organization has worked with researchers previously, a description of the project and the contributions of your organization would be helpful.

When the discussion about collaboration becomes more serious, information that will help the researchers may include your organizational structure, prior or current projects, and your role in networks or coalitions. The researcher may also want to know your incorporation status (non-profit, etc.), whether your organization can receive funds from governmental projects, and whether you have to have your own process for protecting participants in research.

Questions You Might Be Asked About Your Community-Based Agency or Organization:

- Who is served by this organization or agency?

- What services are offered?

- How is this organization staffed? Are staff members interested in or supportive of a research project?

- Does this organization belong to a network of similar organizations or agencies? Might the network be interested in participating in the research project in some capacity?

- Is the Board of Directors interested in this research project? Is the Board supportive of this project? What is the best way to determine support for the project?

TOPIC 7

What questions should I ask when considering partnering with a UCSF researcher? How do I know which researchers will be good collaborators?

As with many other partnerships, successful research collaborations are often dependent on qualities such as personality, commitment, and trust. You will need to make those assessments for yourself, and your doing so will help ensure your active participation in the establishment of this partnership. We can also help. Here are some questions to get you started. These questions in this section complement the questions listed on page 9.

- What level of involvement does our organization want to have in the development of the research question, design, implementation and dissemination?

- Does or could our organization have the capacity to do this research project?

- What type of capacity building could help our organization do this better?

- Does our organization have relationships with researchers that might inform who we would like to partner with in the future?

- Which skills or experiences would we prefer a researcher have in order to be sensitive to the needs of our organization?

Issues to Consider: Sustaining the Partnership

One common challenge to community-academic partnerships is making the relationship last. Community leaders often report that a researcher appears out of nowhere, requests community support for a particular project, and then disappears again at the conclusion of the project. This approach clearly leads to distrust the next time a different researcher (or the same one) reappears. In choosing a research

Questions to Ask of Potential Collaborators

For more questions to ask collaborators, see *Working Together: A Guide to Collaborative Research in HIV Prevention*. Page 17 lists useful questions for all research topics. Here are a few:

- Has this person collaborated with others before?

- How did the experience go?

- Does the researcher have the skills (i.e. language) needed for this project?

- Is the researcher aware of the basic needs of the population I work with?

- How will we share in recognition or any profits from research findings?

- How will we control or handle any impact the results may have on our client population?

- What rights will you have in case there are disputes about the use of the results?

partner, your organization should engage with a researcher who understands and subscribes to the guidelines outlined in this manual.

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 regular intervals, both 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. Both you and your researcher partner should be clear about current availability

What questions should I ask when considering partnering with a UCSF researcher? How do I know which researchers will be good collaborators?

and career plans and set out realistic expectations for continued engagement in current and/or future projects.

It is also a good idea to consider negotiating for funding in the proposal for sustainability. For example, funds might cover staff time to obtain licensing for the agency to pay for the delivery of a particular service in the future, to develop partnerships with other agencies that have resources to contribute to the support of a program or to approach a government funder that has resources.

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**Maintaining Good
Community-Campus Partnerships**

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. See the full text of the *CCPH Principles of Good Community-Campus Partnerships*.

UCSF has program personnel dedicated to establishing, strengthening and enriching a range of types of connections between Bay Area community organizations and the University. If you are interested in how these programs can help you stay connected to UCSF, see the *Office of University Community Partnerships* website.

TOPIC 8

What are the steps of collaborative research?

Community-academic research collaborations revolve around processes of joint decision-making about the four major steps of research:

- Design (research question, the research plan, and research methods);

- Implementation (the program delivery, data collection);

- Data analysis; and

- Dissemination (publishing, presentations, reporting and networking).

Mutual decisions can be made at each of these steps. Community-research teams differ in how they share decision-making authority. We recommend that collaborating partners identify a decision-making process that will keep the project on target and is appropriate to the needs and skills of the partners. At the outset and throughout the project, partners should discuss what decisions must be made, who will be involved in making decisions, as well as who makes final decisions and about which facets of the project. While ultimately the Principal Investigator is responsible to the funder to complete the deliverables and oversee the budget, there are many decisions that can be made together or by the community partner if a clear process for shared decision-making is put in place at the outset.

The Research Question

A collaborative process might take place to determine the precise questions the project will ask and try to answer. Community agencies and researchers could decide on the research question(s) to pursue together. They could convene a community forum or community advisory board to help set research priorities. For example, if the research topic is an exploration of high rates of asthma in a particular community, the CBO-researcher team could turn to community members directly to help set priorities for the research question and/or possible intervention. Community members may want researchers to investigate these questions:

- Are there adequate number of providers or systems of care for our community? What are the barriers to care?

- What is the quality of care provided to them?

- What are the assets and barriers that facilitate or get in the way of pursuing healthy behaviors?

Research Design and Methods

Good scientific research requires the use of particular methods to study a research question. You should discuss the methods of the research project in depth with your research partner and ensure that all staff affected by the data collection (receptionists, front desk staff, social workers, outreach staff, health education staff and others) have a clear sense of what will be required during the research project and have input into how to minimize disruption into their service delivery. The project budget should be structured to cover any resource requirements and ensure that program adjustments that are required of your agency are included.

A common methodological issue that arises is the use of *control groups*. When a study uses control groups, one group of community participants re-

ceives a new program or intervention being tested in the research project and another group doesn't receive the new program or intervention as a "control" or comparison group. The fact that a control group does not receive the new program or treatment can cause concern in the community because there is an assumption that one group is getting something beneficial and the other is not.

For example, a researcher may have created a video to communicate cancer risks in order to promote colon cancer screening among community participants. In order to prove that the video is effective in communicating the information and increase colon cancer screening, the researcher has to show the video to some participants but not others and measure what happens to both groups. Otherwise, if the video is shown to everyone, and cancer screening behavior increases, you cannot know for certain that it was the video and not something else (perhaps a news story about a famous person diagnosed with colon cancer) that led to the improvement.

From the point of view of the research participants, it seems intuitive that seeing a video is more beneficial than not seeing it. However, if the video does not really work, the comparison group actually ends up losing something (time spent watching the video). One way to deal with this problem is for the researcher to offer the video to the comparison group after the measurements have been made. Another solution is to offer the comparison group another educational tool on a different topic.

Another common issue to think about is the process of *randomization*, in which participants are not allowed to choose their group (intervention or control) but are assigned to a group by a random method. Randomization is a major principle of research because it helps to remove the influence of self-selection by a group that is different from those who do not choose to participate. Without randomization, you wouldn't know if a person who responded well

to a program did so because the program was really good or because the person was highly motivated and therefore participated in the program. If both motivated and unmotivated people attended the program, and all of them benefited, you can say that the program was very effective.

Because random assignment is an important concept for research, a researcher may not want to do the project or a funder may not want to fund it if participants can choose whether they want to participate in the intervention or to be in the control group. However, researchers with experience in community-based research often have solutions to this problem. One solution is to educate participants about the benefit of this method. Scientifically proving that an intervention or program is effective is key to making the case for sustained funding for it for everyone in the community. Another way to address the problems associated with randomization is to modify randomization or research design to give everyone some access to a service at a point in time that still allows the data to be collected.

A third common methodological issue is the *quantity of data* that researchers want to collect. Data required for a research project is more extensive that the usual program evaluation and process data that agencies are used to collecting to evaluate their programs. We encourage open negotiations between you and your research partner if these issues become challenges during the planning process.

Another issue which may come up is researchers' focus on defining the research terminologies and measurements. For example, researchers may spend time differentiating between terms like "knowledge" and "belief," or "intention" and "plan." Some of these debates will have no effect on your work or organization. Others may seem to slow down the pace of the project for no clear practical reason. Your input on these kinds of semantic debates matter be-

cause you will have experience in the ways terms are understood in your community. More important, you may know that some of the research measurements do not apply to your community or that the researchers have missed some crucial measurements in your community. Your role as a partner in this aspect of the research is essential.

Publications and Presentations

Community groups are often concerned about issues that arise from the requests from researchers related to sharing and publishing information from a joint project. A difficult reality of life for all academic researchers is that career advancement depends on obtaining grants and publishing the research results in scientific journals. Thus, they have a vested interest in presenting and publishing in scientific venues. There can be a benefit to community agencies from this process. In a community-university partnership, sharing published or unpublished research findings with the community can ensure a wider audience than academic presentations alone and may help to disseminate a beneficial program or intervention. A well thought out and carried out dissemination plan can serve to build and strengthen a trusting relationship between researchers and community partners. When regular updates and feedback are taking place, stakeholders have the opportunity to shape and apply the research as it is taking place.

Many researchers are enthusiastic about participating in research presentations in community venues. If this is important to you or your organization, you and your research partner should pursue these kinds of opportunities both to present and host presentations. Work with your research partner to create and plan presentations that are appropriate for your audience. Ask researchers about the opportunity for your staff to be trained to present at scientific venues.

Publishing and dissemination can reach those in government with authority to develop legislation to insure funding for a proven intervention. Another potential benefit is the opportunity for your staff to develop new skills through their participation in research discussions and the preparation of publications. Although authorship of scientific publications is usually determined by rigorous criteria, some of your staff members may qualify. If this is important to your organization, you should ask the researchers about the responsibilities of authorship. Publishing and presenting research findings can be considered part of a broader dissemination plan. See *these guidelines* for more information on dissemination. This is a time when your questions about who "owns" findings and how they are used will be at the forefront of your conversations with your research partner.

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About Publication

For more information on writing up research, see *Uniform Requirements for Manuscripts Submitted to Biomedical Journals*: *Writing and Editing for Biomedical Publication—Authorship and Contributorship.*

TOPIC 9

What kinds of rules and regulations do researchers have to follow?

Each research partnership will differ depending on the nature of the project and 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.

The IRB at UCSF is called the *Committee on Human Research* (CHR). The CHR reviews research proposals and grants permission for implementation, once the safety and privacy of study participants is established. The review process is intended to protect those who participate in research by providing oversight of issues such as study quality (*Is it good science?*), disclosure of risks and benefits (*If there is the possibility of any benefit or discomfort or risk to the participants, how will you let participants know about it?*), and the design and administration of consent forms (*Are the consent forms clear and explained in a consistent manner?*).

This process must take place, even if your CBO holds the main grant and the researcher is only working for you as an evaluator. The UCSF researcher is responsible for submitting the application to the CHR and following the regulations, but this process very likely will require your organization's input. CHR approval must be renewed annually, and changes in the research protocol must be submitted, reviewed, and approved as they occur. The *CHR website offers forms* that UCSF researchers are required to use for different types of human research.

Helping research participants understand what it means to participate in the study is the role of the consent process. Informed consent means that potential research participants are told in a clear, language-approriate way, about their participation in the research and agree, without coercion, to participate. This is one of the most important responsibilities of research teams. The UCSF CHR provides templates and examples of consent forms to assist researchers with the appropriate language for informed consent.

Consent procedures are especially critical when research is being conducted in a community-based agency setting. It is important that agency clients understand that they don't need to participate in a research project for them to continue to receive services from your agency. You should plan to work with your research partner to ensure that the consent procedures are very clearly explained in a way that your clients will understand. This is especially true when study procedures are complex, when a language other than English is spoken or read by research participants, or when the literacy level of participants is low. *Read about consent forms* on the CHR website. NIH offers information on *what makes a good consent form*. If community organizations want to learn more about research ethics, there is good information available online, such as this *curriculum for community representatives*.

Anyone handling research data about people will have to follow the laws that protect human participants in research (Health Insurance Portability and Accountability Act of 1996, or HIPAA). All community agency staff members who handle human/participant research information must be trained in HIPAA laws and procedures (See box on page 16). All research information is organized and closely safe-

On Conducting Human Research

The UCSF CHR requires that members of the research team, which may sometimes include you or your agency staff, 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 patient confidentiality and privacy. See *more information on HIPAA*, and more information on *HIPAA training at UCSF*.

guarded at UCSF in order to provide privacy protection for research participants.

Though IRB review usually takes no more than two or three months to complete, it can take longer, depending on the complexity of the study and number of groups that must provide final approval before a study can be implemented. Therefore, even after a research project has been funded, additional delays in implementation resulting from IRB approval and other bureaucratic requirements should be anticipated both at the beginning of a project, and sometimes even after implementation of the study has begun. IRB delays can be frustrating, but the proper human subjects review is an essential part of the research process.

On a final note, the findings of community-based research sometimes have implications for public policy. Researchers are expected to advocate for dissemination and implementation of their research results in the community. However, recipients of federal or state funds are prohibited from lobbying as part of these efforts (i.e., promoting specific legislation). UCSF researchers, who are employed by the State of California (and who might be funded by governmental grants), fall into this category, as are employees of government-funded community-based organizations. This can seem a fine line to walk in some circumstances, but it is legal for these employees to educate policy makers on the subjects of their research. For more information and consultation on research policy, read about the *CTSI Health Policy Program*.

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TOPIC 10

What structures and resources need to be in place to support collaborative research? How might they impact my organization?

Funding

A researcher may approach your organization after having received a grant. This may be the easiest type of collaboration because there is already funding available, so the most important part is to agree on the scope of work in relation to the available funding. However, the researcher is obligated to deliver to the funder the promised objectives and work plan, thus 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 your organization 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 organizations are often asked to write *letters of support* and a description of their capabilities and contributions to a project. 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 your clients may

participate, desired endpoints, and the allocated resources should take place at this stage. It is important to clarify with the researcher the scope of work and the budget. A researcher cango back to a grant administrator if there are questions about requirements of the budgeting process.

Once the grant is submitted, there is no guarantee that it will be funded. Sometimes it may take up to 6 to 12 months to find out funding status, as research grants usually go through a peer-review process by other scientists, followed by reviews from the funding agency. It is not unusual for a large grant to be revised and submitted up to three times or to multiple agencies before it is funded. The researcher should notify you when a revision or resubmission occurs particularly if there is an impact on your work. During this waiting 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.

A researcher may ask your organization to write a letter of support for a grant application. The letter of support usually names the grant and funding mechanism, describes your organization and its relationship with the researcher, and states what part your organization will play if the grant is funded. A letter of support is not a formal commitment. Once the grant is funded, the researcher should let you know the next step of formalizing the relationship.

Subcontract

While your organization and the UCSF researcher are responsible for drafting a subcontract, the formal legal agreement is between UCSF and your organization. As a result, there may be multiple revisions required to satisfy UCSF Contracts and Grants requirements. A subcontract in which your organization provides services to UCSF requires at minimum the overall scope of work, a timeline for deliverables, a listing of your staff, the proportion of their time spent on the project, their tasks, their salaries and benefits, other costs including indirect costs, and reporting requirements. In addition, other requirements 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 participants' protection guidelines, and prohibition on lobbying.

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 your organization are obligated to carry out the terms of the subcontract once the grant is funded. Waiting until after the grant is funded to create a subcontract agreement does entail the risk that the researcher may not go back to your organization after funding but has the advantage of not having to go through the entire process without assurance of funding. For these reasons, your organization may be asked for a memorandum of understanding.

Memorandum of Understanding (MOU)

A memorandum of understanding describes the types of deliverables and general timeline of the deliverables between the UCSF researcher and your organization. It is more formal than a letter of support and is signed by both the researcher and the leader of your clinic. *Read more information about MOUs*.

Accounting

The *UCSF Office of Contracts and Grants* must review the agreement between your organization and the researcher 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. Your organization must issue an invoice to the researcher, who then forwards it to UCSF Accounting, which then writes the check. This process can be slow, so organizations are advised to plan for delays in receiving funds. Timely delivery of funds can be facilitated by frequent communication between your organization and the researcher, but often these problems are out of the control of individual investigators.

Staffing

Since research often needs to be integrated into the regular activities of a community agency or activity, agency and research staff need to be in close communication with administrators, front line staff and participants throughout the course of the study. Key agency staff should meet with investigators on a regular basis to give and get input on new staff hires, the development of study tools, piloting instruments, involving and motivating agency staff to participate, and protecting patient rights and confidentiality.

Since most agency staff are busy with the daily demands of running a community-based organization, it is usually unreasonable to expect you to be responsible for principal activities of the research project unless you are given additional time to work on the project and will be compensated for your time.

Sometimes, new staff are hired for a research project. They may work primarily at the community site or at the university. In other situations, community agency staff are moved onto the research project and paid

for by research funds. All staff participating in the research project should be trained in and understand both the needs of the community services as well as of the research project. Research assistants typically:

- Undergo training in participant recruitment and interviewing techniques, research ethics, reporting procedures and policies and procedures to maintain confidentiality;

- Complete training in the intervention; and

- Attend frequent meetings with the project coordinator to discuss all aspects of the study, especially those that relate to participant interactions, recruitment and study procedures.

Counselors, outreach workers, school personnel, and other staff at your agency or institution may assist in a study by identifying eligible study participants, informing them of the study and giving them a flyer with information on the study. Agency staff can notify the research staff and/or refer patients who appear eligible for participation in a study.

Posters and leaflets explaining the study, outlining eligibility criteria and listing study contact information in the appropriate language(s) can also be displayed at the study sites. All screening and recruitment methods must be clearly spelled out in the CHR application and steps must be taken to insure that community members' information and confidentiality will be maintained by study staff. Sometimes agency staff may be asked to obtain consent from a potentially eligible patient for future contact, so that research staff can contact a client or member at a later time to determine if that person is a candidate for enrollment in the study.

It is helpful, but not necessary, for CBO partners to have or learn some research skills. A basic under-

standing of statistics and data analysis is helpful. UCSF either has or is developing the resources to help community partners learn about:

- Study Design
- Methodology
- Grant Writing
- Publishing
- Regulatory Issues
- HIPAA Administration
- Good Clinical Practices Research Policies

CHR's Human Research Protection Program offers *information about online research training*. The UCSF CHR's Human Research Protection Program (HRPP) offers training to research staff on Good Clinical Research Practice (GCRP). This *tip sheet* offers information on best practices.

UCSF projects may hire part-time casual workers from community-based organizations for specific tasks, such as outreach, data collection, and program activities. Individuals may also receive honoraria for participation in conferences or advisory board meetings. Research funds may be paid to organizations to deliver specified services.

Reporting

Researchers are obligated to report, usually on a semi-annual or annual basis, the progress of their work to the funder. Research partners may ask you to submit reports on behalf of your agency prior to the release of funds to your agency or to help them write their reports more accurately. The timing of reports and expectations for what reports contain should be made clear in your memorandum of understanding or subcontract.

Community Engagement Program
Clinical & Translational Science Institute
at the University of California San Francisco

TOPIC 11

What are some obstacles or drawbacks to participating in research that I should keep in mind?

- Limited time - there will always be pressure to accomplish the research protocol requirements mentioned here;

- Limited space - for outside research staff and equipment;

- Limited financial resources - for anticipated and unanticipated research costs.

Hopefully these potential obstacles or drawbacks will not outweigh the long and short-term benefits a research collaboration could bring your clients or members, your agency, and the communities you and UCSF serve. Your active 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 small or large steps at any point(s) along the continuum of engagement with a UCSF research collaborator.

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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!

COMMUNITY-ENGAGED RESEARCH WITH UCSF RESEARCHERS: A RESOURCE MANUAL FOR COMMUNITY-BASED ORGANIZATIONS **20**

Community Engagement Program
Clinical & Translational Science Institute
at the University of California San Francisco

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