SC CTSI

Toolkit for Developing Community Partnerships

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Toolkit for Developing Community Partnership

Southern California Clinical and Translational Science Institute
Community Engagement

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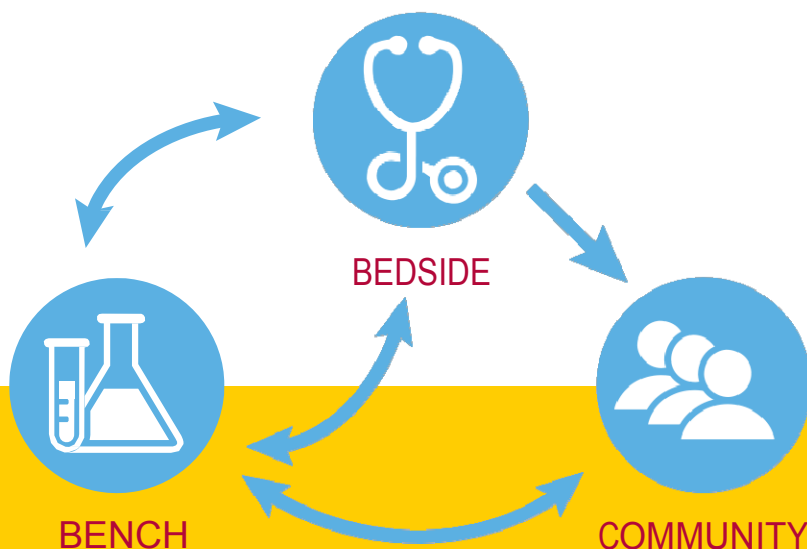
I. Introduction

About the SC CTSI

The Southern California Clinical and Translational Science Institute (SC CTSI) is a multi-disciplinary **translational research** partnership between the University of Southern California, Children's Hospital Los Angeles and the Los Angeles County Department of Health Services. The SC CTSI is one of 60 research institutes in 30 states and the District of Columbia that have been created by the US National Institutes of Health (NIH).

BEDSIDE

BENCH

COMMUNITY

The SC CTSI seeks to improve health within one of the world's most diverse urban environments and to gain knowledge that can be shared around the globe. Research will target obesity, diabetes, cancer, cardiovascular/thoracic disease, infectious diseases, HIV/AIDS, neurodevelopmental disorders, mental health and behavior conditions and other high-priority concerns.

About the CE

The Southern California Clinical and Translational Science Institute's Community Engagement (CE) is one of several programs that make up the SC CTSI. The CE is creating a new research infrastructure to support the development of community research partnerships, with the ultimate goals being to promote health, reduce disparities, increase access to care and to improve the quality of care delivered in Los Angeles County.

About *Toolkit for Developing Community Partnership*

The CE supports community-engaged research (CEnR) that brings researchers, clinicians and the community together to share their knowledge, skills and resources with a common goal of improving the health of Los Angeles communities. This guide is intended to be a resource for researchers, health care providers and the community who are interested in conducting community-engaged research.   The CEnR guide will outline the process and approach needed during every phase of a project (e.g. relationship building, proposal development, project execution and dissemination). Throughout this guide, various terms are used that you may or may not be familiar with. These terms appear in blue. Detailed explanation of these terms can be found at the end of this guide. We realized there is a lot of information already available on this subject which is why we have relied on the great work of community-engaged research experts (See References - page 27) to create this guide. The Community Engagement program is also available to provide consultations and technical assistance on the processes outlined throughout this guide.

The SC CTSI Community Engagement provides individual or group consultations on a variety of research design issues, partnership development and/or match-making services and training and technical assistance to academic researchers, clinical providers and community organizations.

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II. What is Community-Engaged Research?

Before we describe community-engaged research in detail, it is important to provide our definition for community and to explain what we mean by "research". Many definitions of community exist and most acknowledge a community is a group of individuals and/or organizations who are linked by specific geographical or political boundaries and share common interests, values, networks and/or demographic characteristics. In this guide, we use a broad definition of community and the term community or community partner is used interchangeably to include non-profit organizations, community clinics, hospitals, faith-based organizations, schools and community residents.

Research is also a very commonly used term that may have different meanings to different audiences. Research can be broadly defined as the search for knowledge, or as any systematic investigation, to establish new facts, solve new or existing problems, prove new ideas, or develop new theories. Research can take many forms, serve many purposes and be conducted in many settings. In this guide, research includes not only traditional **clinical research** in a laboratory setting, but also **applied research**, such as **program evaluation** and **quality improvement** measures in a clinical or community setting.

Community-engaged research is "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people (Centers for Disease Control and Prevention, 1997, p.9)." Community- engaged research differs from traditional research where the researcher initiates the research question and develops the study design with little or no community input. In community-engaged research, the community plays a role in defining the relevant research questions and a community member or organization may approach the university to collaborate on exploring the research topic. Frequently, however, it is a university faculty member or other outside researcher who wishes to initiate a partnership and involves the community. The degree to which the community becomes involved in community-engaged research can vary greatly between partnerships.

This guide was created to walk you through the steps of using a community-engaged approach to research.

Characteristics of Community-Engaged Research
(Horowitz, Robinson & Seifer, 2009)

- Community members and researchers contribute equally and in all or most phases of research.

- Trust, collaboration and shared decision making are integral parts of the process

- **Findings** and knowledge benefits all partners.

- Researchers and community members recognize each other's expertise in a bidirectional, co-learning process.

- Researchers embrace the skills, strengths, resources and assets of local individuals and organizations.

- The community is recognized as a unit of identity.

- Emphasis is on **multiple determinants** of health.

- Partners commit to long-term research relationships.

- Core elements include local capacity building, systems development, empowerment and sustainability.

A Comparison of Research Approaches

	Traditional	Community Engaged	Community-Based Participatory Research
Research Objective	Based on researchers' interests and funding priorities	Community input identifying locally relevant issues	Full participation of community in identifying issues of greatest importance
Study Design	Design based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is culturally acceptable	Community intimately involved with study design
Recruitment & Retention	Based on scientific issues and "best guesses" regarding how to best reach community members	Researchers consult with community representatives on recruitment & retention strategies	Community representatives provide guidance on recruitment and retention strategies and aid in recruitment
Instrument Design	Instruments adopted/adapted from other studies. Tested chiefly with psychometric analytic methods.	Instruments adopted from other studies and tested/adapted to fit local populations	Instruments developed with community input and tested in similar populations
Data Collection	Conducted by academic researchers or individuals with no connection to the community	Community members involved with some aspects of data collection	Conducted by members of the community, to the extent possible based on available skill sets. Focus on capacity building.
Analysis & Interpretation	Academic researchers own the data, conduct analysis and interpret findings	Academic researchers share results of analysis with community members for comments and interpretation	Data is shared; community members and academic researchers work together to interpret results
Dissemination	Results published in peer-reviewed academic journals	Results disseminated in community venues as well as peer-reviewed journals	Community members assist academic researchers to identify appropriate venues to disseminate results (public meetings, radio, etc.) in a timely manner and community members involved in dissemination. Results also published in peer-reviewed journals.

Case Study:

Lessons Learned From A Community-Engaged Research Project

"The most empowering University-Community Relationships are built with persistence, patience, non-condemnation and cultural sensitivity. Each partner desires positive health outcomes. Our mutual research, with its scientific preciseness and cultural relevancy, will direct us to insights that may ultimately reduce health disparities."

- Dr. Glovioell W. Rowland, USC Cancer Researcher and Minister

Our Body and Soul Program- Vignette

After receiving Pastoral permission to engage his congregation in the research program, I left my contact information at the church for his designee. This occurred in June. I heard nothing. In two weeks I called. In four weeks I visited the church office again to leave my information. By week five, I ran into the Pastor at a restaurant. I asked about his continued interest and about reaching out to his designee. He was clear that his church was committed and simply said, "Try reaching her again!"

It was not until the day after Labor Day that I received a return call. Mother Jones had been away on vacation, and had returned. She left again to attend a Family Reunion. In the meantime, she tried to shift the assignment to other leaders. She sheepishly told me, "I am so embarrassed, Dr. Rowland, that it has taken so long." I greeted her with joy—"So glad you called! Don't worry about the past; we are connected now. I would love to meet with you at your convenience!"

After several months of prayer and one-to-one organizational meetings at the church, Mother Jones paved the way to the Assistant Pastors, church office staff, the Men's, Women's and Children's Auxiliary Leaders and the Kitchen Committee. She formed the Body and Soul Church Committee. We mutually established research protocols, methods of subject recruitment, and the means by which research funds would be dispersed to the church. The Pastor was briefed and his approval received at pertinent junctures. In four months, we had the finest of research operations. In fact, this church was celebrated as a Success Story in the final version of the evidence-based, Body and Soul: A Celebration of Healthy Eating and Living —The Church Guide!, published by the National Cancer Institute, Centers for Disease Control, the American Cancer Society, and the Historical Black Colleges.

Faculty to community approaches must have: 1) the right mindset, 2) the goal of partnering early on in the research process, 3) the commitment to involve a diverse staff (ethnically and intergenerational) and 4) the ability to form a church-based leadership team who have the delegated authority to operate a research program.

The church sustained its Body and Soul health program after the research was completed by presenting the Church Financial Committee with a proposal to establish it as a new ministry with funding from the church's budget.

Relationship Building is Key!

Remember, we are guests—entering the church's ongoing calendar of activities and the personal calendars of church members and leaders. It is a privilege and an honor to engage in faith-based research.

Why Do Community-Engaged Research?

(Horowitz, Robinson & Seifer, 2009; Handly & Pasick et al., 2010)

- To facilitate the translation of research into meaningful health improvements for all communities.

- To facilitate the discovery of innovative solutions to difficult and current community health problems.

- To ensure that research questions, data and programs are based on community needs and meet standards of scientific integrity.

- To increase the relevance of research questions, data and programs devised and implemented in concert with those directly affected by the disease.

- To collaborate on a project that can improve sustainability, dissemination, replication and policy impact; community engaged research often has benefits that outlast research.

- To strengthen the research and program development capacity of all involved.

Benefits for Researchers
to gain entry into communities and to learn about community health needs, assets, and policy implications.

Benefits for Community Organizations
to gain access to university resources (e.g. library holdings, technological support, training opportunities) and knowledge about current evidence-based practices, and methods of program evaluation to create more opportunities for funding and collaboration.

Benefits for Clinical Organizations
to gain access to university resources (e.g. library holdings, technological support, training opportunities) and knowledge about current evidence-based practices, and methods of evaluating quality improvement measures to create more opportunities for funding and collaboration.

Challenge
Not every person works well-with evidence-based models ("round peg/square hole").

Possible Solution
Understand the population you are working with and adapt evidence-based models to meet the needs and/or reflects the characteristics of that population.

Challenge
Clinic/community providers don't understand how research teams function.

Possible Solution
Provide "Research 101" training for clinic providers and other community partners.

Community-engaged research is not for everyone, before starting a project, it's important that you seriously consider the following questions:

- Do I posses the patience needed to work with a diverse team, to learn things I may not know anything about and teach others my skills and experience?

- Do I have a burning, genuine curiosity about how people live and what other people's job entails?

- Do I posses or am I willing to learn the interpersonal skills necessary to build long-term lasting partnerships?

- Am I willing and able to mentor and inspire others?

- Do I have the ability to share control, to lead and be led?

- Do I want to make community concerns the focus of my research, project and/or program?

- As a researcher, am I able to supplement my scientific skills with humility?

- Do I have a commitment to self-evaluate, ensure an equal power distribution exists and develop a mutually respectful partnership with communities?

Challenges to Community Engaged Research

Research Time constraints (grant deadlines) faced by the Body and Soul Program

1) The research project started several months past the estimated timeline.

    a. The researcher might be ready to initiate the project, but the organization might not be ready. In this example, research was not a priority at that time. This is an example of the extensive time commitment required for Community-Based Research. Ultimately, this church became one of our success stories.

Learning curve (Interactive University-Community Collaboration)

1) A critical window is required to engage and receive community input on the entire research process (i.e. subject recruitment, data analysis, journal article co-authorships and conference presentations).

The Sustainability Factor (Body and Soul Program remains sustainable after 5 years)

1) Sequence: Building a partnership, introducing a research idea, performing the research, forming a new ministry, and assisting the church to successfully submit and receive their own grants as a Community Based Organization.

Be certain to engage in Capacity Building for the Community Partner

2) Sustainability also included connecting the church to resources from the American Cancer Society, the American Heart Association, American Diabetes Association and the California Department of Public Health.

III. Suggested Community-Engaged Research project Timeline

At least 6 months prior to starting your project:

Relationship Building Period

Each partner enters into a potential research collaboration with their own perspectives, needs and agendas; some of which may overlap but will also be different from those of the other partners (Israel, Eng, Schulz & Parker, 2005).

Understanding the community/clinic you want to work with

Outside researchers should plan to spend considerable time getting to know the community before they approach individuals, community clinics or organizations about partnering (Israel et al., 2005). Getting to know the community, its leaders, key players, needs and built environment will help in the process of identifying potential collaborators. Los Angeles is a big city with many opportunities to volunteer or participate in community events, meetings and in efforts organized by non-profit organizations. Finding local community events and groups can now easily be found online or you can visit local schools, churches and community/recreational centers.

Challenge
Community burn-out exists when there have been previous bad experiences with researchers.

Possible Solution
Build trust with communities early on *(before research is initiated)*. Invest in the communities and leverage relationships.

Challenge
Researchers may not have a real understanding of the needs of the population or even understand what population the agency serves.

Possible Solution
Get into the community early and "warm up the community," by participating in community events and activities. Also, have research staff representative of the communities you are working with.

www.healthycity.org is a free resource that provides California residents access to data maps through an easy to use online platform. Users can create and share maps for the purpose of program planning, grant writing and/or service delivery.

Challenge
Research participant stigma around a certain disease and/or about participating in research

Possible Solution
Provide community education around scientific literacy issues. Spend time in community to assess what concerns exist about research participation and address those concerns in a community forum or by other methods.

One way to better understand the community you want to partner with is by attending community and cultural events. The following are just some of the websites and organizations where you can find information about upcoming community events in the Los Angeles area. Local newspapers and magazines that are specific to particular communities or ethnic groups can also be a great resource. Contacting local non-profits and volunteering at their events or facilities can provide a greater insight about how people live day to day and it may also be an opportunity to begin building relationships and identify potential collaborators.

➡ Los Angeles City website- Community Event Calendar
http://www.lacity.org/SubMenu/CityEventsCalendar/index.htm

➡ Events in the Latino Community
www.latinola.com/calendar.php
or the Olvera St website where many festivals and events are held
http://olvera-street.com/index.html

➡ Events in the Chinese Community –
the Los Angeles Chinese Chamber of Commerce website
http://www.lachinesechamber.org/index.html

➡ Events in the Japanese Community – the Japanese American Culture & Community Center website
http://www.jaccc.org/events.php

➡ Community Health Events in Los Angeles-
http://events.la.com/los-angeles-ca/events/community+health+events+los+angeles

Identifying potential partners

Once an outside researcher really gets to understand the community, its members, organizations, needs and values, the next step is the identification of a potential partner. During this identification process, a researcher needs to ask him/herself important questions such as:

- Why do I want to work with a particular community or clinical organization? What are the benefits to us? What are the benefits to the community or organization? What is the mutual benefit?

- A researcher will also have to identify if the community or clinical organization has the capacity to do research. Does the organization have the staffing infrastructure, technology capabilities, etc.? A researcher should initially approach research ready organizations and could also work with less ready organizations to help build their future capacity.

- It is always easier to start a research relationship for a specific project if there have been previous positive connections with the community/clinic (or a researcher), through, for example, university services or centers, previous research collaborations, or referrals from trustworthy sources or through reputation (Israel, 2005).

Approaching the Community about a Project Idea

Researchers should approach the community with an open mind and recognize that the community members are experts in their community and have unique perspectives about the community's needs and assets. One of the best strategies to develop relationships with community members is to just show up; visibility is key to begin relationship building. You can attend community events, meetings, celebrations, etc. This will show community members that you are willing to meet on their "turf," rather than expecting residents to come to the university.

Approaching a Community Clinic about a Project Idea

Researchers should keep a couple of things in mind when approaching a community clinic or hospital. First, there are many demands on a clinician's time and conducting research is usually not a top priority. Clinics and hospitals have to see a certain number of patients per day, so any research conducted needs to have minimal disruption to clinic workflow. Discussing the potential project idea early on in the process (when there is still room for negotiation) will show the clinic partner that the researcher is respectful of their work and wants to minimize disruption to the clinic.

Challenge
Clinics and/or community organizations don't always have the infrastructure or capacity to conduct research (e.g. data analysis, technology, etc.).

Possible Solution
Assess the capacity the clinic/community organization has to conduct research. Understand the power differential. Work with clinics and organizations that are "research ready" and offer training and/or technical assistance to clinics/organizations that may need capacity building and are willing to learn how to do research.

Challenge
Too many competing demands on clinician's time; time conducting research takes time away from seeing patients.

Possible Solution
Clinic partners need to communicate to researchers how to be respectful of their work and their challenges. Engage in dialogue early on (program wise; budget wise); researchers need to understand the unique challenges of the particular clinic and find creative ways to conduct research and minimize clinic disruption, time commitment, and expense to clinic.

Case Study:

Working with the Los Angeles House and Ball Communities: Example of How a Research Idea Can Initiate from the Community and the Importance of Partnership Development

Community-engaged Work to Identify HIV Intervention Opportunities

Michele D. Kipke, PhD
Director of the Community Engagement program
SC Clincal and Transaltional Science Institute

What are Houses and Balls?

Houses are comprised primarily of African American men who have sex with men under the age of 30 who perform at "Balls" – competitions focused on dance, gender expression, sexuality and fashion. Balls are both forms of entertainment and also serve as venues that are "safe spaces" for African American young men who have sex with men to express themselves. In general, the House and Ball communities work together to develop and support a community involving primarily African American and Latino individuals of diverse sexual and gender identities.

The limited research with these communities suggests that HIV is a major public health concern as many affiliated with the House and Ball scene are living with HIV and often times are unaware of their HIV status.

How our Partnership Began

Our project began while recruiting research participants for another study involving young men who have sex with men. Our community advisory board, comprised of HIV service providers, youth and policymakers had identified the House and Ball communities as a popular venue for African American young men. After speaking with the local leaders about our research, several House leaders approached our research team, concerned about HIV-risk within their community, wanting to "serve as gatekeepers for this project to ensure that our community is fully active in its own knowledge gathering, analysis of data and the development of future interventions".

Thus, in partnership with the House and Ball communities, our team developed a research proposal for the National Institutes of Health to conduct community-engaged, mixed methods research. The overarching goal was to better understand how the social and cultural functions of the House and Ball communities may be related to HIV risk and protective behaviors. Ultimately, we wanted to develop an HIV prevention intervention designed for and by the House and Ball communities.

Challenge – Time Commitment

The relationship-building phase was key – it took us two years to obtain funding to launch this project. During that time, we attended community events, engaged the community in focus groups, attended meetings and generally took the time to develop a presence in the community. That is key. Without that time, we may not have been able to develop such strong partnerships. The House leaders waited for us to obtain funding, which we finally did! When funding was awarded, we had spent the time to get to know the communities – so taking the time to develop those relationships, even without funding, is important. Think about ways you can work with the community in the interim. For example, we provided space for community meetings, served as unbiased vote counters for their annual Awards Ball and supported all community activities.

Engage the Community in the Research Process

We then engaged them in helping us figure out the best way to collect data, what questions needed to be asked and how to actually collect the data. This was important as we were collecting data during their events and you don't want to be disruptive to their routines. Five years later, we have finished the first phase of the study – which included observations, interviews, surveys and focus groups – and are now working with the community to interpret our results and think through our next steps.

Intervention Design – Identifying Risks in the Community

This may be the most difficult phase, because your community members need to think through what is it about their communities that may put their members at risk – and for HIV that may mean drug use, alcohol consumption and sexual behavior. However, on the flip side, it can also be an experience that empowers the community to not only work to address those aspects of risk but also identify and embrace the sources of support that exist and build on those sources to create a safe and healthy environment.

Strategies for Researchers:

- Self-reflect on your capacities, resources and potential liabilities as academics or clinicians interested in engaging with the community or a clinical organization; this includes reflection on your institution's capacities, resources and potential liabilities as well and identifying historical and current relationships between the institution and the community or organization.

- Identify potential partners and partnerships through appropriate networks, associations and leaders

- Negotiate the health issue(s) for research; even if initiated by the university, issues and research questions can be reframed through the partnership.

Strategies for Community Members:

Approaching Researchers about a Project Idea

When approaching a faculty/researcher you need to recognize YOU are an expert in the community and you have a lot of skills/assets that researchers need. You need to be able to articulate those experiences and knowledge about the community.

In starting the dialogue about a potential project idea, it would be helpful if you are able to refer to past research collaborations that have taken place in your community, if you have a referral to the researcher from a trustworthy community source, or if you are knowledgeable about the researcher's professional reputation. However, if those connections are not in place starting a research relationship can be a process that is facilitated by a service provided by the university like the Community Engagement program.

Finding the right researcher is more than just identifying an expert on the community need you have identified. You need to be able to identify a researcher who can work with you and your community and the questions you want to address.

University websites can be a good first step as they often provide search options by research interest or expertise, department and school. The next step would be to schedule a meeting with a researcher to learn more about his/her interests in and experience working with the community.

Career Issues for Researchers:

It is important to understand the different roles, responsibilities, timelines and work pressures often faced by faculty and researchers. An academic re- searcher (especially junior faculty) is motivated by grant deadlines, student research assistant avail- ability during semesters and by faculty needs to produce manu- scripts and papers for tenure and promotion; whereas community or clinical partners are typically focused on completing research quickly so that results can be disseminated to satisfy programmatic or clinical goals, and to minimize disruption of client workflow.

Community-based, collaborative research can be both intellectu- ally gratifying and inspiring, as participants uncover connections between good science and tangible improvements in people's lives. University-based collaborators need to recognize these studies often require more time to formulate and conduct, and may result in less academically prestigious publications, com- pared to other types of research they may conduct.

University-based investigators advance in their careers (e.g. rank, tenure and compensation) based on the appraisals by senior colleagues and by leading experts in their fields, nationally and internationally. These appraisals look at research quality and at productivity. The CE urges university-based investigators to have candid conversations with their department chair, promo- tion or tenure committees and professional mentors about ways that their achievement in community-based research can earn the recognition that they deserve. One resource that faculty should consider is the Community Campus Partnership for Health (CCHP) which offers a number of resources for faculty including a link to a publication that provides a peer-reviewed process for non-traditional media (e.g., curricula, handbooks, videos) that can be used to bolster academic dossiers.
(www.ccph.info)

Challenge
Researchers and health-care providers have different goals: Capacity building doesn't lead to tenure, but publications do.

Possible Solution
Utilize multiple strategies to disseminate research findings and illustrate the impact of research and meet the needs of both the researcher and the community.   Traditional aca- demic dissemination (e.g. pa- pers, presentations, posters) and community-focused dissemina- tion (e.g. community forums, newspaper articles, radio an- nouncements) can also be used. Community-engaged research builds capacity in individuals to answer community questions.
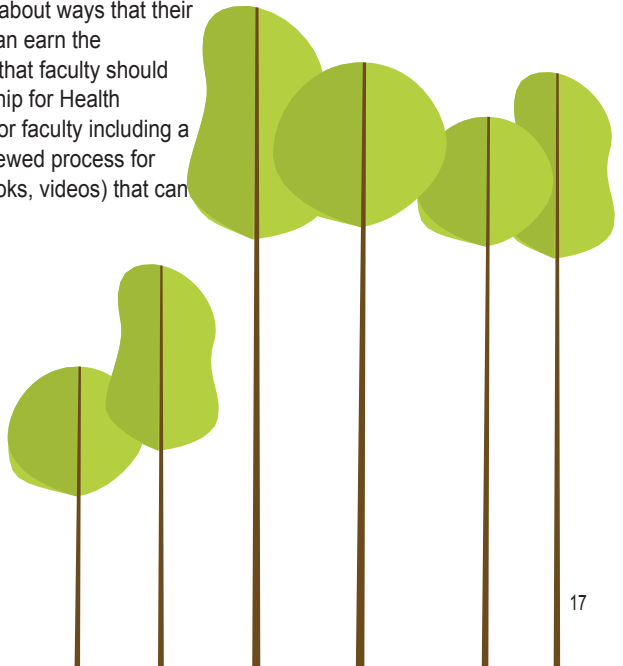
Funding Resources

Government
www.grants.gov
www.nih.gov

CBPR Oriented
www.cbcrp.org
www.cchp.info

Foundations
www.calendow.org
rwjf.org
unihealthfoundation.org

List of funding agencies at the Endowment website
www.calendow.org/Article.aspx?id=1284#additional
www.calwellness.org

USC/ University funding
www.sc-ctsi.org

Proposal Development Period

Developing research questions and protocols with partners

As previously mentioned, the degree of community involvement in any community-engaged research collaboration can vary widely. Ideally, the community or clinical partner is directly or indirectly involved with formulating the research question. This will benefit the research proposal because the community or clinical partner has an in-depth understanding of the characteristics and health needs of the community.

Community or clinic partners can play a very important role in all aspects of developing the research design including the review and selection of tools and assessments, recruitment and retention strategies, methods, and dissemination strategies being proposed. Community participation can help ensure that study goals are relevant to the population; that the means of accomplishing them are sensible; that the program considers the knowledge, attitudes, language, beliefs and practices of the target group and that results are shared, sustained and used for the good of the community.

Identifying funding resources

There are a variety of different sources that fund research including governmental agencies, local foundations and universities. Funding requirements at these agencies differ between agencies and may even differ between various grant programs within an agency. There are also specific agencies that primarily fund community-engaged research. An example would be the California Breast Cancer Research Program www.cbcrp.org that funds community-engaged research projects focusing on breast cancer, the environment and disparities. Another important resource is the listserv disseminated by the University of Washington. This listserv disseminates daily community-engaged research opportunities and was created in partnership with the Community-Campus Partnerships for Health www.ccph.info and the Wellesley Institute www.wellesleyinstitute.com.

Research information that is already available for the topic at hand

In this process, the research partner can take the lead as he/she has access to the university library and electronic databases and journals to conduct literature reviews. Free public databases to access scientific literature to develop proposals are also available for non-university affiliated partners.

The following list provides some of the free, public on-line resources that exist for conducting literature searches.

- Free full text archive of biomedical and life science journal literature at National Institutes of Health National Library of Medicine. www.ncbi.nlm.nih.gov/pmc/

- Google search engine that provides abstracts and full text journal articles www.scholar.google.com

- National Institutes of Health/National Library of Medicine database that provides consumer health information on a variety of topics. www.nlm.nih.gov/medlineplus/

- Free resource that provides California residents access to data maps for the purpose of program planning, grant writing and/ or service delivery. www.healthycity.org

- Free database that provides access to best current evidence on a wide range of clinical topics www.bestbets.org

Organize a meeting where everyone is able to speak openly, clarify expectations and concerns, and where questions are addressed from all parties.

- At this time, a draft memorandum of understanding (MOU) or a collaboration policy can be developed so that roles, responsibilities, expectations can be clearly defined for all parties; identify challenges that might occur and proposed solutions to meet those challenges. A MOU template can be found on the SC-CTSI website at www.sc-ctsi.org and look under "Collaborate with the Community"

- This can also be a time to identify the assets and skills in the group and see whether other partners are necessary to conduct the work.

- Discuss the budget- Define the specific resources each partner can contribute to the project through time, in-kind contribution, or with the use of grant funds (e.g. office space, project staff, training, etc.). Researchers should ensure that their community partners are compensated for their time and contributions and that budgets are developed transparently.

- Also talk about the proposal responsibilities and requirements. Assignments should be made so that each partner contributes to the proposal development. Timelines and a review process should also be discussed.

Challenge
Research is not a top priority at clinics.

Possible Solution
Create a university-based research and training center for the delivery of primary care. Determine how to effectively translate research into the primary care/community   clinic setting.   Determine specific strategies needed to change clinic culture to welcome new research initiatives.

Challenge
There is a lack of financial incentives for community/clinical practitioners since they are not able to bill for the work related to research.

Possible Solution
Understand the financial burden of community/clinical partners. Involve community/clinic partners early on in the planning stage (budget-wise, program-wise); all partners need to be fully informed and transparency is needed. Develop a compensation protocol for providers- offer communities/clinics   financial remuneration for their research participation.

Challenge

Working with community/clinical partners without burdening and/or disrupting their system.

Possible Solution

Learn about program culture (e.g. what's appropriate to do in clinic/organization and what is not) and outside influences that may be impacting the clinic/organization (e.g. understanding a clinic may have absorbed clients from a recently closed clinic).

Challenge

Clinics may be reluctant to invest time and manpower in research projects that don't reflect clinic needs and priorities.

Possible Solution

Identify clinic needs and priorities early on in the research development process. Work collaboratively with clinic staff to design research projects that will answer the researcher's research questions and will also address clinic needs and priorities.
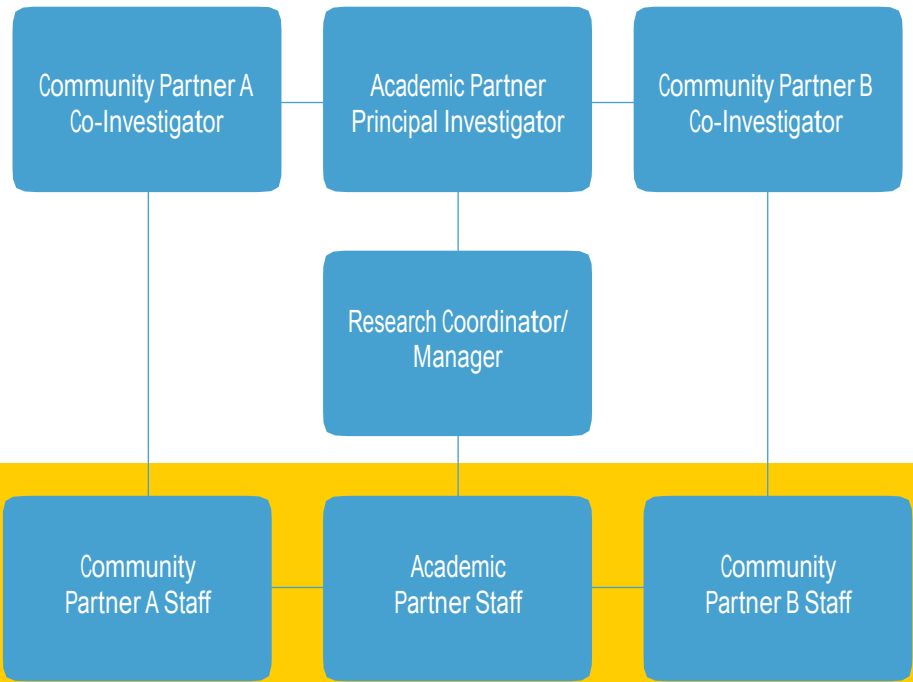
Develop a plan for mediation in case things go awry; it may be included in your MOU.

- Conflicts or differences in opinion are inevitable in collaborations. Developing specific strategies for effective resolution of conflict is essential to demonstrate a commitment to research goals and continue the partnership. Effective conflict resolution may actually strengthen the research partnership. A mediation plan may be included in your MOU or you can develop a separate mediation plan. A Mediation plan template can be found on the SC-CTSI website **www.sc-ctsi.org.**

Identify roles and responsibilities (e.g., are there co-principal investigators?)

- Develop a leadership team and an organizational chart, if necessary
  It would be helpful to also create a job description for each project member to specifically outline roles and responsibilities. This will ensure that expectations are clear and eliminate duplication of effort.

- Develop a contingency plan for staff turnover/leadership changes
  "Unexpected obstacles can surface, such as staff turnover or changes in leadership. Partnership means spending the time to develop trust and, most important, to develop the structures that support trust, so that a move in unexpected directions or setbacks can be seen as part of a long-term process that will continue (Israel 2005, p. 33)." This contingency plan may be included in the MOU.

- Make sure all parties understand the timeline to obtain funding
  Researchers are often used to waiting for a year or more for funding. This needs to be explained to the community partners. Make sure to manage expectations; don't try to accomplish everything in one proposal. Rome wasn't built in a day. Now you are ready to write a grant proposal or a **Letter of Intent (LOI).**

Sample Organizational Chart for
Community / Academic Research partnership

```
┌─────────────────┐   ┌─────────────────┐   ┌─────────────────┐
│ Community        │   │ Academic        │   │ Community        │
│ Partner A        │   │ Partner         │   │ Partner B        │
│ Co-Investigator  │   │ Principal       │   │ Co-Investigator  │
│                  │   │ Investigator    │   │                  │
└─────────────────┘   └─────────────────┘   └─────────────────┘

                      ┌─────────────────┐
                      │ Research         │
                      │ Coordinator/     │
                      │ Manager          │
                      └─────────────────┘

┌─────────────────┐   ┌─────────────────┐   ┌─────────────────┐
│ Community        │   │ Academic         │   │ Community        │
│ Partner A Staff  │   │ Partner Staff    │   │ Partner B Staff  │
└─────────────────┘   └─────────────────┘   └─────────────────┘
```

Congratulations – you were funded!

Now the real work begins…

Challenge

Inconsistent metrics are typically used in research; research focuses on outcomes and doesn't account for or measure the "value-added." This is needed for sustainability.

Possible Solution

Add a qualitative component to the research design including process evaluation measures, case studies, focus groups, key informant interviews, etc. These measures capture the "story behind the research."

An initial project meeting with all parties should be held prior to submitting any Institutional Review Board (IRB) documentation or other paperwork

Everyone should review the proposal and identify any questions about each step of the research process including:

- Data collection
- Tool development
- Sampling
- Analysis
- Dissemination

The team should establish regular meetings as needed and make sure that all parties agree to the schedule.

Regular meetings will establish consistent check-ins on project progress, address concerns and plan next steps. Communicating clearly and frequently during this phase is important.

Hiring of staff for the project should be made jointly

Even though project staff will be employees of the academic institution or the community/clinical partner, efforts should be made to gather feedback about potential hires from the partnering organization.

Dissemination:
After Data Collection and Analysis Ends

There should be real time and effort devoted to this phase; this is often a step that researchers omit and can create distrust in the community.

① ### Community Dissemination
Make sure that information is disseminated back to the community/clinical organization. Inquire about their preferred method (e.g., community forums, reports, web-based, etc.). Consider creative ways of disseminating the information such as media, local newspapers, community events, games, etc. Consider language as well; make sure your data are translated into the preferred language of the community.

② ### Project Sustainability
It is important to discuss project sustainability throughout the project period. Efforts should be made to develop a plan to identify supplemental funding sources to further the project after the initial funding period ends. This funding may come from the partner organization, a local foundation or from additional grant funding. Effective dissemination strategies (discussed above) leads to increased publicity and visibility, which in turn, may also lead to additional fund- ing from unexpected sources.

③ ### Wrap-up Meeting
A wrap-up meeting of the project should be considered to address final concerns, future projects and on-going communication In a traditional research project, normally the end of a project is also the end of the collaboration and relationship with those involved; however, in community-engaged research, an on-going relationship with collaborators is expected and encouraged. Many times the end of the first research project is only the beginning of the collaboration team, who will often explore other ways to work together.

④ ### Giving back to the community/community partner
According to Israel (2005), potential shorten-term benefits for communities might include training provided by outside researchers, grant writing assistance or technical assistance, which may or may not be directly related to the research.

Frequently Asked Questions

What are the incentives researchers can offer community partners?

For an academic there are many clear incentives for doing research. In fact, it is part of their job description. In order to get tenured faculty members must publish and therefore, conduct research. However, for community organizations and medical providers there are no set incentives, it can often be viewed as a burden. This is why it is important to develop an equal partnership where the benefits for both parties involved are clearly stated. Researchers can provide incentives such as including the community partner in the budget of the proposal and/or sharing the research findings with the community in a format that the organization can use in the work that they are doing (for funding or advocacy purposes). The researcher can also provide his/her expertise and time outside of the collaborative project as a consultant on another of the organization's projects.

Where can I find funding for my project?

Fortunately, funding for this type of research has increased in recent years. Community engaged research is becoming the focus of many funding agencies. Here are some funding resources:
- National Institutes of Health and other Federal Sources (www.grants.gov)
- Robert Wood Johnson Foundation (www.rwjf.org)
- Join the CBPR list serve (www.ccph.info)
- SC CTSI (www.sc-ctsi.org)

What are some of the challenges to conducting CEnR?

- Compared to traditional research CEnR can take much longer and requires more time commitment for a researcher. This is largely due to the relationship building required in this type of collaborative work.

- A common barrier researchers have to face is community burn-out when previous bad research experience exists. This is often due to researchers who view the community as non-active participants in their project who "parachute" into a community, collect data and leave never to be seen or heard from again.

- A lack of incentives for researchers from academic institutions to engage in this type of research is an issue for researchers. Although, the approach of doing research is changing, the academic structure and pressures to produce publications has not changed to accommodate researchers who are conducting this type of research and/or serving the community.

Why does this type of research take longer than traditional research approaches?

Traditional research does not require collaboration or community participation. Community-engaged research, on the other hand, is an approach where academic and community partnership is at its core. The building of trust between people is not something that happens overnight. Bringing together two or more individuals and organizations with different sets of priorities, experiences and skills is also a process that can take time. Unlike traditional research CEnR is often a medium through which long lasting relationships and collaborations are formed that last way beyond the timeline of a single project.

How can you work with a community partner without burdening and/or disrupting their system?

Clinics and other community organizations are often overwhelmed with clients, often beyond their staffing capacity. Therefore, asking them to partake in research can be a daunting proposal. Researchers can make the process of doing research an enjoyable experience for the community by providing monetary compensation, training for their staff, technical assistance, new software and extra research staff such as student interns.

Where can I find training or more information about CEnR?

Online information, articles and books about CEnR can easily be found online. The Community Engagement program also provides CEnR 101 workshops for faculty and community members as well as consultations and technical assistance on partnership formation and project development.
Here is a list of some online resources:
- Community-Campus Partnerships for Health
- Join the CBPR list serve

What's in for me as a researcher?

CEnR provides researchers with a unique opportunity to produce research that is relevant to the needs of the community and have an opportunity to take research findings to those who need them the most. This approach to research allows researchers to gain entry into communities and to learn not only about community health needs, but also about community assets. Partnering with the community on a research project will also increase the relevance of research questions, data and programs devised and implemented as a result of the research.

How and where do I start to do CEnR?

There are many resources available about CEnR (books, articles, guides, workshops etc.) The SC CTSI's provides a list of some of these resources on their website (www.sc-ctsi-org). The SC CTSI's Community Engagement program also offers one-on-one and group consolations for community and researchers in any phase of their research project (i.e. identifying a partner, developing research question and methods).

How do I approach a researcher about a research project?

Of course referring to previous research collaborators or referrals from a trustworthy source is always the best way of identifying a good partner. However, if those connections are not in place, starting a research relationship can be a process that is facilitated by a service provided by the university such as the SC CTSI's Community Engagement program. You need to be able to identify a researcher who can work with you and your community and the questions you want to address. Finding the right researcher is more than just identifying an expert on the community need you have identified. University websites can also be a good first step as they often provide search options by research interest or expertise, department and school. The next step would be to schedule a meeting to learn more about his/her interests in and experience working with the community or contact the CE for a group consultation.

How do I approach the community about a research project?

When approaching the community about a research project it is best that you begin by genuinely learning about the community and their needs. This can be done through your participation in community events and simply being present in community coalitions and forums. Often local organization, churches, schools and community centers are a great place to start. It is ideal when one project can help meet the needs of the community while at the same time answer the questions the research wants to explore. The only way to identify the commonalities between the researcher's interests and the community needs is through communication and relationship building. Services such as those provided by the Community Engagement program can also help facilitate a community introduction.

Glossary of Terms

Translational Research
Is a research approach that seeks to move the application of science from laboratory experiments through clinical trials to actual point-of-care patient applications in the community (e.g. "from bench to bedside to community").

Clinical Research
Is a type of research that determines the safety and effectiveness of new medications, medical devices and therapeutic treatments intended for human use for prevention, treatment or relieving symptoms of a disease.

Applied Research
Is a type of research that seeks to solve practical problems in real-world settings.

Program Evaluation
Is a type of research that seeks to determine effectiveness and efficiency of programs. Program evaluation typically involves quantitative (e.g. standardized questionnaires) and qualitative components (e.g. focus groups, interviews, etc.). Evaluations can also include process measures (e.g., tracking attendance, development of a program) and outcome measures that look at how the program or project has impacted individuals such as changes in behavior or knowledge.

Quality Improvement
Is the clinical application of research. Quality improvement measures are implemented in clinical settings for the purpose of analyzing and improving client care. These quality improvement measures may be evaluated and replicated in multiple clinical settings.

Findings
Refer to the results of a research project.

Multiple Determinants of Health
Are multiple personal, social, economic and environmental factors that influence health status.

Research Questions
Is the primary question (or hypothesis) that you want your research to answer.

Methods
In a research study, methods refer to study procedures and tools used (e.g., questionnaires, focus groups, surveys, interviews), the type of participants recruited, how participants are identified and enrolled and how research data are analyzed.

MOU
A memorandum of understanding (MOU) is a document created for the purpose of outlining roles, responsibilities and expectations of two (or more) collaborating organizations.

Co-Principal Investigator
A Co-Principal Investigator (Co-PI) is responsible (along with the primary "principal" investigator) for determining the scientific direction of a research project. Co-PIs are typically from a different organization than the Principal Investigator.

Grant Proposal
Is a formal request submitted to a funding organization to apply for funding.

LOI (Letter of Intent)
Is a brief letter often requested by funding agencies that describes your research proposal. This is submitted before your full proposal.

IRB
An institutional review board is an administrative board (usually found within a university setting) that is responsible for reviewing research studies to determine scientific integrity, participant safety, and study feasibility.

Data Collection
Is the process of preparing and collecting research data.

Tool Development
Is the process of research questionnaires and procedures needed to carry out a research study.

Sampling
Is a representative selection of a subset of individuals from within a population to estimate the characteristics of the entire population.

Analysis
Is a process of inspecting, cleaning, transforming and modeling research data with the goal of highlighting useful information, suggesting conclusions, and supporting decision making.

Dissemination
Is the sharing of knowledge by any appropriate means (e.g. publications, conferences, workshops, web-based activities, etc.).

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