SC CTSI

Resource for

Integrating Community Voices

into a Research Study

Community Advisory Board Toolkit

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Translating Clinical Practices and Innovations into Community Settings

A. Community Engagement and the Clinical and Translational Science Awards

The Clinical and Translational Science Awards (CTSA) were initiated in 2006 by the National Center for Advancing Translational Science (NCATS) branch of the National Institutes of Health. The more than 60 CTSAs provide the support and resources needed to assist academic health centers (AHC) with creating an efficient and supportive infrastructure to accelerate the translation of promising clinical practices and innovations into community settings. An important part of this infrastructure is the integration of community organizations, clinics and others into this process to ensure that the research conducted at these AHCs is meaningful to the populations for whom they are intended. CTSAs are required to have a structure, which can solicit and integrate community input into the research process; to do this successfully, research institutions must collaborate with community organizations to identify and understand public health needs.

The Southern California Clinical and Translational Science Institute (SC CTSI), the CTSA hub housed at the University of Southern California and Children's Hospital Los Angeles, developed this toolkit to provide investigators and others an overview of how to develop and maintain a community advisory board for research studies. We work and thrive in a community that is known for its diversity and creativity. As community-based researchers and community organizers, it is our role to harness the power of our diverse and creative communities to address our country's most pressing health problems. This toolkit is a small part of that effort and we hope it can contribute to the development of a meaningful and impactful research agenda at your own institution.

B. Community Engaged Research

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)." Many definitions of community exist; 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. For our purposes, we use a broad definition of community and the terms community or community partner are used interchangeably to include non-profit organizations, community clinics, hospitals, faith-based organizations, schools and community residents.

Principles of Community Engagement

- Begin with a research topic of importance to the community
- View community partners as knowledgeable and important contributors to research
- Allocate resources dedicated to building trust with community members

Community engagement can take on a range of shapes and sizes. Community-engaged research is characterized by the principles that guide the research and the relationships between researchers and the community, rather than the research methods. The traditional research approach often begins with the researcher developing the research question and 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 an academic institution to collaborate on exploring the research topic. However, it is often a university faculty member or an outside researcher who initiates a community partnership. The degree to which the community becomes involved in community-engaged research can vary greatly between partnerships.

For a researcher who wants to take a community-engaged approach to his or her work, there are a number of methods to do so. The goals and structure of a project's community engagement plan should be tailored to each individual project. Communities and researchers may collaborate by:

- Defining the problem
- Planning the research
- Data collection
- Intervention implementation
- Disseminating research results

However a project incorporates community engagement, there are some overarching goals and principles to consider:

- Develop a meaningful role for community partners with clearly articulated goals.
- Build collective community capacity (researcher and community member) to better address the research aims.
- Disseminate research findings that are translatable and meaningful to the community.

C. Community Advisory Boards

One common way to integrate community perspectives into a research study is to develop a community advisory board (CAB), which can play a number of roles in a research study. A CAB is typically comprised of community members who share a common identity, history, language, and/or culture by which the community's interests in research or program development can be conveyed (Israel, Checkoway, Schulz, & Zimmerman, 1994). CAB members are typically representatives from community organizations that serve your target population; or, in some cases they can be members of the lay community such as parents, patients or youth. However, special attention should be paid to lay member groups as these environments may not be as welcoming or supportive of their active participation. In those instances, the project team should consider ways to make this a more supportive environment such as 1:1 coaching with the lay members; setting ground rules that ensure equal participation and other ideas that may be appropriate.

The development of CABs in research studies has become increasingly common as funding agencies continue to place a greater emphasis on involving community members in the study design process and execution of research studies. Indeed, a more recent federal funding mechanism, the Patient Centered Outcomes Research Initiative (PCORI), requires patient and/or community involvement in the development and implementation of the study. Similarly, the Institute of Medicine's recent review of the Clinical and Translational Science Awards recommended the integration of community input in the full spectrum of a research study, including the development of research questions, research approach, recruitment and dissemination (Institute of Medicine, 2013).

These funders recognize that community involvement in research studies has a number of benefits such as:

- Ensuring the research topics or questions reflect a major concern of the community;
- Enhancing the relevance and application of the research data by all partners involved;
- Bringing together partners with different skills, knowledge and expertise to address complex problems;
- Enhancing the quality, practicality and visibility of the research by involving local knowledge; and
- Aiming to improve the health and well-being of the involved communities (Israel et al., 2005).

Despite the growing body of research focused on the involvement of community members in research and program development, not all researchers have embraced CABs, nor have CABs been entirely successful in every setting (Buck, Rochon, Davisdson, & McCurdy, 2004). In spite of the acknowledgement that CABs can be essential to the success of program and study design, limited information is available regarding how CABs are maintained in long-term research studies and to what end. Similarly, how CABs are developed, integrated and maintained vary across programs and studies. One of the most common questions and requests for consultations our Community Engagement program receives is – **how can I develop a CAB for my work?** While this is a valid request, we believe that this should be slightly reframed to – **how can I develop and nurture a CAB for my work that engages the community in a meaningful way that is beneficial to both the research team and the community members?**

In this toolkit, we provide an overview of how to develop a successful CAB, and focus on effective strategies for identifying members, integrating them into the research process, maintaining engagement and interest over time, and meeting facilitation. Throughout the document, we provide concrete examples of our own experiences with CABs. Particularly, we feature examples from a CAB that has been in place for ten years and has provided insights and feedback on more than seven different research studies focused on HIV prevention with young men who have sex with men (YMSM).

Using a CAB for Research Studies

A CAB can be used for a number of purposes in a research study. For example, a CAB may be formed prior to a grant submission to get input on the proposed methods and measures for a study. In some cases, a CAB may be formed once a project is underway and used as a mechanism to review materials and make recommendations. In an ideal community-engaged research study, a CAB is formed at the very beginning of the planning process for a grant to assess the extent to which the proposal addresses an identified community need and the appropriateness of the methods and outreach. However, this may not always be possible or necessary depending on the project scope and aims.

Please note that developing a CAB simply to say "I have a CAB" is not a prudent idea. When you develop a CAB, you develop a group that can keep you accountable. Thus, when developing a CAB, think about the role they can play in your research. CABs are a monetary and time investment for your team, the individual CAB members and their organizations. Therefore, it is imperative that you also think through your team's abilities to follow through on commitments or ideas.

CABs can be integrated into research studies through a variety of research activities, such as the following:

1. Research Question Development

Our YMSM CAB includes a diverse representation of service providers across the county. One of these individuals works closely with faith-based organizations and wanted to explore the relationship between religion and spirituality and young men's well-being. The general literature on this topic identifies higher levels of religiosity to be protective against substance abuse and other risk behaviors. In sexual minority populations, this is not as clear and in fact, some studies have found higher levels of religiosity to be a risk factor for risk behaviors. This interest in religiosity and spirituality led to a specific qualitative study to explore the meaning of religion and spirituality in the lives of YMSM.

2. Study Design: Young Men's Relationships Study Example

In a study focused on exploring the contexts and experiences of partner violence among YMSM, we experienced challenges in identifying the appropriate study design and approach. For example, we knew that we could not ethically or easily screen for partner violence during a typical recruitment event on the street or in designated venues. CAB members suggested we recruit young men for a study on relationships, and screen them for experiences with partner violence once they completed participation in the first part of the study. The result was a multi-phase study which allowed us to explore general relationship dynamics and challenges with young men in a safe space. A survey that was administered after these discussions helped identify individuals involved in partner violence who could then be contacted for additional data collection.

3. Instrument Development

Our YMSM CAB provided invaluable input on the creation of surveys and qualitative data collection guides. For example, one of the community members commented that he sees a lot of YMSM in his organization with eating disorders. As a result, questions about body image were included in a survey for a prior longitudinal study. In addition, another member indicated that religion can play both a positive and negative role in one's life and may be a source of homophobic messages. Thus, questions about religiosity and religious practices were also included in the survey.

4. Recruitment

In one of our studies with YMSM, our team faced challenges recruiting a sufficient sample of African American young men. We brought this issue to our CAB members who helped us identify local venues from which to recruit a diverse sample of YMSM. Previously unknown venues were brought to our attention, such as the House and Ball communities, a space where many African American YMSM – who do not frequent more traditional gay venues – congregate. Their collective knowledge of the city and the local youth gay scene was essential in helping us recruit a large and diverse sample of over 500 YMSM.

5. Intervention Development/Identification

A CAB for a study focused on asthma prevention and management among elementary school children was instrumental in identifying appropriate intervention methods. This group of health educators and providers reviewed a number of evidence-based programs to assess the appropriateness of their content for a population of children in afterschool programs. Another study, which was developed to adapt a curriculum to promote early identification of autism spectrum disorders in children of color, used advisory groups comprised of parents, providers and community health workers to develop the exercises and activities for a community-based intervention.

6. Data Interpretation and Dissemination

In several of our studies, we have invited CAB members to participate as co-authors on selected manuscripts. This can be done in a way that is not burdensome to your CAB and plays to their strengths. For example, in one CAB meeting, we brought the data analysis results back to the group and asked them to think about what it means. The resulting discussion included recommendations, as well as inferences into what the data might mean for our population. These conclusions provided the framework for the Discussion section of a manuscript that included all of the CAB members as co-authors.

CAB members can be involved in dissemination in other ways as well. For example, our YMSM CAB played a key role in ensuring the results from our team's research were disseminated to broader audiences. Staff members from the City of LA AIDS Coordinator's Office, which were a part of our CAB, helped our team organize a day-long community forum at City Hall to discuss the results and implications of one of our studies. CAB members served as panelists during the forum and provided their own expertise and insights. In addition, CAB members have also provided assistance in disseminating research at community events, such as Los Angeles Pride. During this event, our research team set up a booth with interactive games that integrated results from our research – reaching more than a 1000 youth.

Community Dissemination Activities at LA Pride Booth

Developing Your CAB

A. Staffing

It is best to have a single person be the point of contact for the CAB to ensure that communications are consistent across time. While an entire team may be involved in identifying potential members, the designated person should coordinate meetings, initiate contact, and ensure the CAB is running smoothly. In some cases, this can be a full time job with a Community Liaison (or similar title) being responsible for attending other community meetings, following up on action items and coordinating all community events. In most cases, this is not a full time job but the duties required for creating and maintaining the CAB should be clear and not underestimated. Keep in mind that time is required to build relationships and trust with community partners. Therefore try to maintain consistency in the organization's representative, and remember that partnerships are often made with individuals not organizations.

Generally, dedicating anywhere from 5% to 20% effort for CAB development and maintenance is sufficient. More time should be considered if high visibility in the community is required. This might mean your staff person serves on CABs/coalitions for other studies or programs. Allocating sufficient resources to this aspect of your work reflects a real commitment to the community and that their perspective is valued.

B. Develop Roles, Goals and Responsibilities

The role of the CAB can be determined by outlining the overarching goals of the partnership and setting ground rules for the CAB meetings. The rules and expectations can initially be set by the research team. During the first meeting, these rules can be discussed and refined with the CAB members and revisited during subsequent meetings. While not required, you may want to consider drafting by-laws or memoranda of understanding to clarify the agreements for both the research team and the CAB. A simple one-page document outlining goals, expectations, and agreements can also be developed in partnership with the CAB that outlines the collective agreements. This document can also be a great tool to use when explaining the CAB to potential members. Appendix A is an example of such an agreement.

Some common expectations that we have developed over the last ten years include:

- Regular and ongoing meetings attendance.
- Ability to commit to membership for the length of the study.
- Provide input about a variety of issues related to the study including: recruitment strategies, eligibility criteria, survey and interview guide development, and interpretation and dissemination of study findings.
- Being open to including goals that may be beyond your specific project (yet still relevant to the topic) that may be of interest to the group.

- Providing one-one on consultations on areas of expertise. For example, in a study where our team was tasked with recruiting Korean, Filipino, Chinese and Vietnamese YMSM, we reached out to a partner who had expertise with all of these groups for additional ideas on outreach and approach with this population.

C. Compensation and Recognition

Monetary incentives that recognize members' time are valuable and appreciated by CAB members. We recommend building these stipends into your project budgets. A stipend of $40-$75 dollars per two-hour meeting is recommended. This payment can be made directly to the individual or to his or her agency, whichever is preferred. Providing food and parking validation also ensure that members are not spending any of their own or their agency's funds to participate in the CAB.

Regular updates on what your partners have accomplished can build trust and confidence with community partners. As researchers, we often provide updates on what we have accomplished as a research team but may neglect to summarize the community's success. This can be done at a regular meeting or a special meeting designed to recognize their accomplishments. A small gift (e.g., plant, flowers) or certificates detailing their accomplishments can go a long way in building your relationships with the community.

D. Identify Potential Members

One of the most time consuming and important steps in CAB development is developing a list of potential members. This process should include your full team as well as any colleagues who work in similar areas. As a group, identify community organizations with an interest or experience in the topic of your research study. Once you have identified those organizations, the next step is to identify individuals within your target organizations who would be most appropriate for the CAB. Those individuals should **have some decision-making power, but may not be the upper management or director.**

Oftentimes, our instinct is to try to engage the executive director, political representatives (e.g., city council, County commissioner) or other leaders in order to have a list of CAB members with some name recognition. This is done in order to make a good impression with funding agencies. However, these individuals are often too busy to make a commitment to your CAB and also may not have direct knowledge of your target population. Before involving potential community partners, consider the following:

- What purpose would a community partner serve in the research?
- What role would a particular partner play?
- Does this partner have any potential conflicts of interest?
- Is this the right partner for this project?
- Will this person have the answers to the specific questions we have?

You will also want to consider to what extent your list of potential members represents a range of perspectives on the topic of interest. For example, if planning a study on family violence, you may want to include providers from shelters, mental health and other areas, law enforcement, faith-based organizations, etc. A broad representation of perspectives will strengthen your capacity to understand the issue being addressed.

An ideal number of CAB members is usually between 10-16 members. Any more members and meetings can be difficult to facilitate; any less and you may have some meetings with very few participants. We usually plan on about 60% of our members being able to attend most meetings.

Once you have identified potential members, the next step is to contact them. If someone on your team has an existing relationship with a potential member, have that person send an introductory email to introduce the idea of the CAB and the identified point person for CAB development. If no one has an existing relationship, phone calls and emails should be sent to the individual requesting an in-person meeting. This is a good time to send the one-page CAB goal sheet you developed to help contextualize the project and explain their potential role. These in-person meetings help to build rapport, introduce the topic and answer any questions about the CAB and the project. These meetings should be brief (about an hour) and a one-page summary of the research should be reviewed, as well as any other materials that are relevant for sharing. The meeting location should be convenient for the community partner; we recommend meeting at the individual's office or suggest a café that is near their office. A sample of a one-page description for an asthma study our team conducted can be found in Appendix B.

To avoid confusion around who is considered an active CAB member, make participation expectations clear and discuss members' abilities to disengage from the CAB if desired. You can consider developing a letter of commitment which spells out the expectations for each member and ask members to sign as a way of formalizing the membership (see Appendix C for an example letter).

When integrating new members, think about the rationale and be purposeful in your selections. A CAB should be representative of the target population, but it should also be sustainable and planned. Also, be intentional with your efforts to familiarize new members with the overall study, research questions, and other members.

When working with lay communities including parents, patients and/or pediatric/young adult populations, think about meaningful ways to include youth as community partners. A separate CAB for youth members may be more appropriate if youth are reticent to voice opinions with adult CAB members. Include youth in pilot testing of surveys and discussion guides. When sharing research findings with youth, ask them why they think a particular finding is important.

There are a number of partnership models for community-based research including community-based participatory research (CBPR), participatory action research (PAR) and, community-engaged research. Each of these models has different principles and expectations for conducting the research. Seek up-to-date references to help you identify the best model for your work. See Appendix D for a sample outline for a Community Partnership Model.

CAB Meeting Facilitation

A. Facilitation Skills

Meeting facilitation is an art, not a science. For consistency, the point of contact and coordinator of the CAB should also be the primary facilitator. The person in this role should be highly organized and adaptable to change, and have excellent communication skills. Facilitators are responsible for moving the discussion along and for keeping it on topic. ***The facilitator should participate very little in the discussion***.

In general, the role of the facilitator is to:

- Set a friendly and comfortable tone.
- Create an open environment in which people feel comfortable to express their perspectives.
- Greet each member and develop rapport; encourage cross communication with the group by introducing members to each other and engaging them in conversation.
- Take charge of the room.
- Be familiar with the agenda.
- Direct the discussion at a pace that allows all agenda items to be addressed thoroughly.
- Be flexible (rephrase) and move things on the agenda as needed.
- Make quick judgments about when and how to interject.
- Solicit input from all present.
- Assess when an item has been thoroughly discussed and identify the appropriate time to move on to the next agenda item.

A skilled facilitator:

- Invites a wide range of commentary by asking participants for experiences, thoughts, and definitions.
- Uses silence to his/her advantage. Give members a chance to think about the questions, and do not be afraid to wait until someone speaks.
- Limits his/her own participation once the discussion begins. After going through the introductory material, sets the stage by posing a question and allows the CAB to react for a few minutes with limited direction.
- Encourages participation while maintaining control.

When posing questions to the group, the facilitator should:

- Ask one question at a time
- Remain neutral
- Verify unclear responses
- Ask open-ended questions

CAB Meeting Logistics

Once you have identified your CAB members and met with them to explain the project and their role, it is time to schedule the first meeting. Try to find a date and time that is convenient to most people. It is unlikely you will find a date that works for everyone, but try to accommodate as many schedules as you can. Use a doodle poll (www.doodle.com) or similar mechanism to help with scheduling.

In-person meetings are preferred as they help to build relationships and create a friendly atmosphere. However, we know that oftentimes people are not able to make in-person meetings. Discuss with your team whether you want to allow members to call-in via phone or Skype. There are pros and cons to this; one advantage is it allows people to participate in different ways, but if people rely on this method too much, you may have fractured meetings and a non-cohesive group. This can result in a lack of rapport among members with less interactive discussions. Consequently, you may not get everything you need from the CAB.

Consider who from the study team should be present at the CAB meetings. You may want to limit participation in the meetings so that the meeting is not over-represented by the research team. At your first meeting, key individuals from the team should be invited to meet the CAB and introduce themselves. Subsequent meetings should have only those team members necessary (e.g., CAB coordinator, PI, project manager/director) so that the community members are the primary participants in the room.

A. Materials

Create a binder for each CAB member for him/her to keep all project materials. At the first meeting, you will likely review a number of project-related items and materials; CAB members can store these materials in their binders. Have tabs in your binder for items such as:

- Agendas
- CAB Roster
- Meeting Minutes
- Grant Proposal
- Data Collection Instruments
- CAB Goals and Responsibilities

Be sure to collect the binders after each meeting, as members often forget to bring the binders to the meetings.

B. Taking Notes/Minutes

Provide concise, written summaries of meetings to help CAB members reacquaint themselves with the prior discussion points or to catch up a partner who missed a meeting. Set a precedent at the first meeting to have a regular schedule for sending notes out to the CAB. An example schedule would be:

1 Week After the CAB Meeting

- Type meeting minutes and share with study team for feedback and inclusions
- Create a list of action items for yourself and others
- Email meeting minutes and next meeting date to the CAB and study team

Note-Taking Hints

With CAB members' permission, consider audio-recording the meeting so you have a complete record of the discussions. However, you should not rely on this method as the recording could get damaged or malfunctions may occur. The following are some hints for good note-taking:

- Create a form on which to write notes (a sample is included in Appendix E).
- Take notes strategically. It is usually practical to make only brief notes during meetings so that you appear engaged in the meeting. Rather than documenting every detail, write down key words and phrases that will trigger your memory when you expand your notes. When possible, document interesting, representative quotes word-for-word.
- Use shorthand. Because you will expand and type your notes soon after you write them, it does not matter if you are the only person who can understand your shorthand system. Use abbreviations and acronyms to quickly note what is happening and being said.
- Use large "Post-Its" for group discussions. Sometimes a group discussion can be captured using visual aids that the whole group can see and comment on. Posting these on the walls of the room allows the CAB to reflect and comment on ideas throughout the meeting.

C. Scheduling and Planning Meetings

Schedule meetings around your members' schedules, not the research team. Offer to have meetings on weekends or evenings to accommodate your partners' schedules. Consider a set meeting date (e.g., second Wednesday of the month) so that members can plan around CAB meetings.

We have found that lunch meetings typically work well for our CABs. Meetings should be no more than two hours long. One tip we have learned is that in spite of their best efforts, people are often late to meetings. We schedule lunch at 11:30 and then start the meeting at 12:00; that way we have time to eat and chat as people arrive.

Frequency of meetings will depend on your project goals and timeline. For some projects with well-developed CABs, we meet quarterly. Projects with short timelines may have monthly CAB meetings, and others may have bimonthly. Talk with your team and the CAB to think about the best schedule for your group.

Begin each meeting with a review of what has already happened on a project since the last meeting, and for new members, a brief overview of the project to date.

Some overarching things to consider when scheduling and planning meetings:

- Meetings should be scheduled based on the partners' availability, meaning evening or weekend meetings depending on your group.
- Meetings should be held at a location that is convenient for everyone. This may mean your offices or perhaps at a community partner's office.
- Provide a meal or light refreshments.
- Validate parking if necessary.
- Create a reasonable, achievable agenda with the majority of the time allocated for community partner participation. A meeting including only the research team reporting back to the CAB is not a good use of their time or yours. Use no more than 20-30 for project updates.
- Use the majority of the meeting for brainstorming, hearing feedback, and taking input from all those present.
- Routinely provide follow-up meeting summaries and action plans to CAB members.
- Be mindful of how you explain the research. Researchers often use a lot of jargon and acronyms in their speech. Speak in clear terms that everyone can understand.

In addition there are a number of logistical strategies that can be used to keep a CAB active and thriving. These logistics although seemingly very minor, in fact, seem to play a significant part in our success at sustainability.

- First, coordinate all meetings around the schedules of the CAB members, not the research team.
- When scheduling meetings, give 2-3 choices of meeting dates, 2-3 week advance notice, and meeting reminder calls and emails.
- Recognize special events in members' lives such as weddings, graduations, new jobs or other big events.
- Provide compensation for attendance, validated parking, and food at every meeting.
- Prior to each meeting, we provide a meeting summary from the previous meeting including any follow- up on identified action items as well as a draft agenda for the upcoming meeting.
- Make a conscious effort to update CAB members on how their suggestions have been incorporated in the study design and in the structure and goals of the CAB meetings.
- Attend your CAB members' events and meetings to put face time in with the community.
- Consider a project newsletter or Facebook page. See Appendix F for an example newsletter.

D. Agenda Setting and Planning

CAB agendas should be made to address your project needs. However, in the spirit of community engagement, you should also allocate a small portion of the agenda for members to provide updates on activities at their agencies, new projects or anything of interest. This is a good way to start the meeting so that everyone has a chance to talk.

Set up a regular timeline for communications and agenda planning to avoid forgetting important meeting items. A sample schedule is below.

1 Month Before the Meeting

- ☐ Send a meeting reminder to all members
- ☐ Solicit any agenda items from the CAB
- ☐ Draft a meeting agenda

3 Weeks Before

- ☐ Share agenda draft with project team (meeting and/or via email) and solicit agenda items/announcements

2 Weeks Before

- ☐ Email agenda and solicit RSVPs from CAB (if needed call or text for RSVPs)
- ☐ Confirm and coordinate any presentation needs (i.e. projector, screen, handouts) with any meeting presenters

2 Days Before

- ☐ Print all handouts including:
  - ☐ Agenda
  - ☐ Sign-in sheet
- ☐ Have parking validations ready
- ☐ Have any other meeting materials ready (i.e. projector, screen, flipchart etc.)
- ☐ Send meeting reminder

Meeting Day

45 minutes Before

- ☐ Arrive 45 minutes before the start of the meeting
- ☐ Set up the meeting room (e.g., materials, food, projector, laptop)

E. Maintaining CAB Engagement

Building community partnerships takes time and commitment, as well as consistent participation and communication by both sides. It is important to provide your CAB regular updates between meetings. For long-term projects (such as our longitudinal study that spanned five years), you want to avoid the trap of having a CAB that is present and active during the initial phase of the study and then tapers off.

There are a number of strategies you can use to maintain and engage your CAB. One strategy is to set a precedent for always discussing and revisiting the meaning and purpose of the research during the CAB meetings. This can be accomplished by continuing to discuss ways in which the research and its findings can be used to shape interventions targeted towards your population of interest.

Think about whether it would be appropriate to have a CAB member co-lead/facilitate the meetings. This can demonstrate co-leadership for the group and help integrate members. The co-lead may need some extra training on how to facilitate meetings but this is all in the spirit of capacity and partnership building.

Identify early on the motivations for CAB participation. Whether it be a personal or professional commitment, your members are invested in the work in some way and it is up to you to identify it and to remember it. Remind the CAB of how their participation makes a difference in these personal ways so that they feel invested in the work.

Consider initiating a CAB-led project. This can be an idea that is feasible and can be led by a CAB Member with minimal staff support. A CAB-led project should be considered once rapport is built and the group has identified common interests.

Additionally, having a committed and passionate CAB forces us, as researchers, to continually revisit our larger goals and reflect on whether our research practices align with those goals. It is also important to actively self-reflect on the level of privilege and power we have as researchers throughout the community engagement process.

F. Evaluation

Finally, in order to assess the healthiness of your CAB, we suggest a biannual evaluation of the group. This can be a simple survey that assesses the satisfaction, impact and relevance of the CAB for the members. You may also want to do one-on-one meetings to discuss the successes and challenges each member has experienced in his or her tenure on the CAB. Present these results back to the group so that they can be discussed and solutions identified as needed. In our assessment of the YMSM CAB, we found that several CAB members wanted to hear more from the project principal investigator. This information was relayed to the PI and she subsequently ensured she could attend CAB meetings and attend more community events to solidify her engagement.

References Cited

Buck, D. S., Rochon, D., Davidson, H., McCurdy, S. & the Committee of Healthcare for the Homeless. (2004). Involving homeless persons in the leadership of a health care organization. *Qualitative Health Research*, 14(4), 513-525.

Institute of Medicine, (2013). The CTSA Program at NIH: Opportunities for advancing clinical and translational research. Institute of Medicine, Washington, DC. Downloaded from: http://iom.nationalacademies.org/Reports/2013/The-CTSA-Program-at-NIH-Opportunities-for-Advancing-Clinical-and-Translational-Research.aspx

Israel, B. A., Checkoway, B., Schulz, A. & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Education Quarterly*. 21(2),149-170.

Israel, B.A., Parker, E. A., Rowe, Z., Salvatore, A., Minkler, M….Halstead, S. (2005). Community-based participatory research: Lessons learned from the Centers for Children's Environmental Health and Disease Prevention Research. *Environmental Health Perspectives*, 113(10), 1463-1471.

List of Appendices

Appendix A: CAB Member Agreement

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Appendix A: Cab Member Agreement

Goals for the Healthcare Community Advisory Board

The purpose of the Healthcare Community Advisory Board (HCAB) is to guide and inform the Community-based Research for Asthma Prevention and Management project led by the Office of Community Engagement (OCE) at the Southern California Clinical and Translational Science Institute (SC CTSI), Breathe California of Los Angeles County (Breathe LA) and Community Outreach Prevention and Education (COPE Health Solutions). Together we will commit to building community capacity in conducting research; developing mutually beneficial relationships; and/or identifying new funding opportunities to support our effort. The HCAB will:

1. **Identify existing pediatric asthma interventions**
   We will review and assess existing evidence-based and practice-based interventions that have been previously implemented and evaluated to address the specific intervention targets identified through this study.

2. **Assist in the review and analysis of the data collected through this study**
   This Community-based Participatory Research study will be implementing a Photovoice technique to better understand knowledge and perceptions of asthma risk factors, management, triggers and symptoms, and identify education and training needs for children and parents in the Los Angeles (LA) and Long Beach (LB) communities. Key-informant interviews will also be conducted with school and after program staff to inquire on asthma related protocol and barriers in school settings.

3. **Develop a set of recommended interventions and next steps**
   Based on the data collected through this study and on the expertise and experience of the HCAB members, we will develop a set recommended interventions and next steps for pediatric asthma in the LA and LB communities. This should result in a new grant proposal that would address pediatric asthma in other communities in Los Angeles County.

Healthcare Community Advisory Board Members

Los Angeles and Long Beach representatives can include:

- Community Organizations
- Physicians
- Nurses and other Healthcare Providers
- Community Clinics and Hospitals
- City Departments

Healthcare Community Advisory Board Meetings

- Attendance at the HCAB meetings will be for 2 hours during the months of January, March, May, July and September at the Carson Center, 801 E. Carson St., Carson, CA 90745 or another location convenient to our advisory members.
- Lunch will be provided.
- A $75 stipend, payable to you or your organization, will be provided to compensate you for your time at each meeting attended (only applies to non USC or CHLA staff/faculty).
- The first HCAB meeting will be held in January, date and time T.B.D.

Appendix B: One-Page Study Overview

SC CTSI
Translating Science into Solutions for Better Health

BREATHE CALIFORNIA of Los Angeles County

COPE HEALTH SOLUTIONS

Community-Based Research on Asthma Prevention and Management

This is a collaborative project between the **Southern California Clinical and Translational Science Institute** (SC CTSI) at USC, **BREATHE LA** (BLA), a community-based organization specializing in education and outreach around asthma and other chronic pulmonary conditions and the Camino de Salud from **COPE Health Solutions**, a non-profit organization designed to improve operations and integration of clinical care. This project builds upon the vision of the SC CTSI and its Community Engagement program to conduct research and improve health in the diverse urban environment of Los Angeles and its surrounding communities. The study takes place in Long Beach, California, a city particularly burdened with higher rates of childhood asthma, where asthma affects 22% of children age 5-17, compared with 15.6%, 18%, and 14.2% in LAC, CA, and the US respectively. Research also shows that parents of low-income children more likely to voice negative perceptions in their ability to manage their child's asthma, these parents also have lower expectations for their child's functioning with asthma, higher levels of worry and more competing family priorities. They are also less likely to receive counseling or an asthma management plan from their care providers or make an office-based provider visit for asthma treatment

While programs and education have been developed and implemented for children and parents affected by asthma, the rates continue to increase in our communities. This speaks to the need for additional research and community-engaged collaborative work to address this ongoing issue. This project will be accomplished through three phases. Given the evidence that exists of the growing issue of childhood asthma.

Phase 1 will determine community knowledge and perceptions of asthma triggers and management with the goal of nurturing the development of culturally relevant prevention education and interventions using a community based participatory research (CBPR) approach. Using a Photovoice technique, we implemented a CBPR study to better understand knowledge and perceptions of asthma risk factors, management, triggers and symptoms, and identify education and training needs for parents and families in our targeted geographic area. This was made possible through our collaboration with the **Boys and Girls Club of Long Beach**. This study also identified assets, strengths, and resources that are available to promote child health and well-being within the community.

Phase 2 will focus on refining the current BREATHE LA asthma curriculum to fit the existing evidence based models and adapt the curriculum to reflect the needs and suggestions identified in phase 1. In doing so we will promote the delivery of evidence-based approaches to treatment, prevention, and health promotion within our partner clinical and community agencies.

Phase 3 will entail a proposal of recommended interventions and next steps based on the information gathered in phase 1. We will form two community advisory boards (CAB); one comprised of health care providers (HCAB) and one other comprised of parents (PCAB). These partners, will assist in identifying recommendations based on the data collected in phase 1 and on their personal experiences and expertise.

For more Information contact

Marisela Robles
Community Liaison
Office of Community Engagement, SC CTSI
323-442-2105
mariselr@usc.edu

Appendix C: Partnership Letter

LETTER OF COMMITMENT FOR MEMBERSHIP COMMUNITY ENGAGEMENT ADVISORY COMMITTEE

Dear [NAME OF MEMBER]:
Thank you for agreeing to be a member of the Community Engagement Advisory Committee ("the committee") of the [YOUR ORGANIZATION] ("the institute"). We are looking forward to working together as we grow and expand the scope and reach of meaningful and responsive community partnerships and translational research in Los Angeles County. This letter will confirm the understanding and agreement between you and the institute with respect to your appointment as a member of the committee.

The [YOUR ORGANIZATION] hereby appoints you to the Community Engagement Advisory Committee to serve as a partner and advisor to the institute effective as of the date you sign this letter of agreement and will continue according to the terms of membership outlined in the letter below.

Background:
The committee will work with the [YOUR PROGRAM] ("the office") to guide and inform efforts of the institute to provide infrastructure, expertise and incentives to ensure meaningful and bi-directional academic-community partnered research.

Responsibilities:
The committee will operate as a formal mechanism that will identify and communicate to the institute community health-related needs, concerns, and priorities and will make recommendations for academic-community research partnerships to address those needs.

Members of the committee will participate in a collaborative and iterative process to establish research priorities, set goals, and ensure that the office and institute activities and research projects are responsive to the community's needs and interests. The committee will compliment recommendations made by the office's other advisory councils. Furthermore the committee will provide the office's leadership team with guidance and direction with respect to how office activities and resources will be prioritized and allocated.

Key Functions:
- Review of the office's resources, functions, services, research partnerships, research portfolio, productivity and progress made towards accomplishing goals and objectives.
- Identify new and novel opportunities for community partnerships, community research and dissemination projects targeting community and academic audiences.
- Identify community and academic education and training needs and opportunities.
- Identify strategies for building awareness about the institute and its resources.

Activities:

- Attend quarterly meetings to guide the office and inform the development of its research partnerships with community providers.
- Solicit input from community healthcare providers, community groups, policy-makers, and other key stakeholder groups regarding the community's health-related needs and/or concerns.
- Generate specific bi-directional education and co-learning experiences that promote knowledge flow from community practitioners to researcher & researcher to community practitioners.
- Identify potential community partners within institute targeted communities.
- Provide feedback regarding their perceived health and research needs/interests.
- Identify research questions and opportunities.
- Offer recommendations for resource allocation and community translation and dissemination of institute research findings that have relevance to community needs and practice.
- Provide examples of successful community-based initiatives; and of "less than successful" community initiatives.

Committee Membership:
Members are individuals who commit to attend at least 3 quarterly meetings.

Size and Diversity:
The committee shall consist of approximately 15-20 members that broadly represent different areas of community research and institutions such as:

(a) The institute's academic and clinical partner organizations;
(b) At least four community representatives;
(c) At least one policy maker; and
(d) At least one representative from a local philanthropic organization.

Term:
Membership terms will be for 2 years, with unlimited renewal.

Meeting Schedule:
The committee will meet a minimum of four times annually.

I hereby agree to the terms of membership and am fully committed to assuming the responsibilities defined above as an advisor and partner to the [YOUR ORGANIZATION].

BY:

NAME
TITLE
ORGANIZATION Date:

Appendix D: Community Partnership Model

I. Goals

To maintain a mutually beneficial relationship between the HYM research team and communities to:

1. Ensure that the research questions are relevant and reflect the current HYM populations and communities.
2. Build community capacity to better understand and address the needs of YMSM.
3. Identify new research opportunities/questions.

II. Challenges

1. *Time* – Agency staff members are often over committed, and many already participate in several CABs and local planning groups in town.
2. *Size* – We are targeting four (4) separate populations, each with their individual as well as shared communities. How do we develop a representative and productive membership?

III. Partnership Model

The HYM structure will combine multiple layers of collaboration to bring the most diverse perspectives to the project and ensure that lessons learned throughout the research will be readily accessible to HYM communities.

HYM community partnerships will include:

1. A diverse CAB
2. Consultants
3. Planning and advocacy groups

CAB

Participants will be diverse representing youth, their health/social service providers and their communities.

Representatives can include:

1. Local youth
2. Local youth HIV prevention experts
3. Non HIV related Social Service providers
4. Community leaders/activists

CAB Meetings

The CAB will meet 1 X month during the formative phase and during the beginning of the longitudinal study. Meetings may be shifted to quarterly, once the HYM team is in the field for a few months.

The purpose of these meetings will be to:

1. Build knowledge on the YMSM populations HYM will connect with through the venue-based recruitment.
2. Gain insight into the health behaviors of the young men who will be missed due to the recruitment strategy (e.g. drug trends).
3. Identify venues for recruitment.
4. Develop a name and identity for the research project that is meaningful to the local communities.
5. Share ongoing analysis.
6. Share findings from literature reviews.
7. Build connections between agencies and youth.

IV. Ad Hoc Topic Groups

During the course of HYM, specific individuals will be pulled together to explore certain topic areas and population needs. For instance, Asian-Pacific Islander (API) providers and community members may be pulled together to explore Filipino YMSM health needs, or club promoters may be gathered for discussions around recruitment and venue selection. These groups may meet only once, or across a period of time. The level of involvement will be defined by the complexity of the subject.

V. Community Workshops

Once the parent study is in the field, CAB members, other community partners and community representatives will be invited to meet as a group during HYM community workshops to explore complex and sensitive constructs (e.g. racism and homophobia, violence and victimization, etc.).

VI. Consultants

Some local experts may be asked and agree to collaborate on a more intensive level as a consultant. The scope of work and specific role these individuals will play is to be defined by the consultant, Principal Investigator and Project Director.

VII. Existing Meetings

To facilitate collaboration with key service and policy leaders, the HYM team will work with existing planning and advocacy groups. HYM participation in these groups may include time on meeting agendas to gather feedback on the project, as well as presentations and discussions around interim findings.

Represented Groups and Collaborations:

1. LA County HIV Prevention Planning Committee (PPC)
2. Youth Leadership Sub Committee to the PPC
3. Adolescent HIV Consortia
4. Asian Pacific Pride Council
5. Gay Asian Support Network
6. Latino HIV Coalition
7. API HIV/AIDS Caucasus
8. West Hollywood Providers
9. LAUSD LGBT Advisory Group
10. LA Men's Study Community Advisory Group
11. Mpowerment Project
12. Unity Fellowship Church
13. West Coast Ballroom Scene

Appendix E: Note Taking Template

Date		Group	
Time Started		Session Number	
Time Ended		Facilitator	
Number of Participants		Co-Facilitator	

Question/Discussion [Each question should have a separate area for notes]

Brief Summary/Key Points	**Notable Quotes**
Comments & Observations	

Appendix F: Sample Newsletter

Asthma Healthcare Community Advisory Board

Community-Based Research for Asthma Prevention and Management

Monthly Newsletter. Issue 4. June 2012

In this Issue

PhotoVoice Results

Dissemination

Upcoming Events and Opportunities

HCAB Meetings

Welcome HCAB Members to the forth issue of the HCAB monthly newsletter. Keep reading to find out what's been going on and how you and/or your organization can stay involved.

PhotoVoice Results

Our team has completed data collection at all three school sites! At the last HCAB meeting, you got a glimpse of the PhotoVoice themes from the first two sites. After reviewing the information from all the focus groups, the top 3 recurring themes in the children's focus groups are as follows: 1) triggers, with cigarettes as the most mentioned trigger, 2) solutions to identified asthma problems, and 3) things that may alleviate asthma symptoms. The three most recurring themes from the parents' focus groups were triggers, barriers to accessing healthcare, and issues related to advocacy. At the next meeting, we will present on these and other themes that emerged and discuss their meaning and how this information will be used to refine the asthma curriculum.

Dissemination

Community-based participatory research requires that the data gathered from its research activities are disseminated back to the communities from which the information came from. As we enter the second half of Phase I of our project, our goal is that the information gathered through the PhotoVoice project is distributed throughout our HCAB partner organizations and the community at large. A list of potential dissemination activities by priority is listed below:

1. Adapted BREATHE LA Curriculum
2. Patient Education Booklet with PhotoVoice images
3. Educational Presentation at stakeholder organizations
4. Photo Gallery of PhotoVoice images

If you or your organization is interested in any of the previously listed activities, please complete the dissemination activities form (attached) or email Hannah Valino at *hvalino@copehealthsolutions.org*.

Upcoming Events and Opportunities!

California Breathing will be having their two-day California Asthma Summit: Putting Research into Practice. The summit aims to bring together renowned asthma researchers and stakeholders to plan and develop strategies to address the burden of asthma. For more information, go to www.californiabreathing.org.

When: December 5-6, 2012
Where: UCSF Mission Bay Conference Center
San Francisco

- The American Lung Association's SCAMP CAMP is on 6/24/12—6/29/12. To request applications, contact Dana Weinberg, *dana.weinberg@lung.org* or (213) 384-5864 ext. 265. To volunteer, contact Luis Lechuga, *Luis.Lechuga@lung.org* or (619) 683-8660.

For more information, please contact:

SC CTSI
Katrina Kubicek
kkubicek@chla.usc.edu

Marisela Robles
mariselr@usc.edu

BREATHE LA
Neal Richman
nrichman@breathela.org

COPE Health Solutions
Charlene Chen
cchen@copehealthsolutions.org

SC CTSI Office of Community Engagement

BREATHE CALIFORNIA of Los Angeles County

COPE HEALTH SOLUTIONS

Community Engagement Team

Michele Kipke, PhD
Director
(323) 361-8424
mkipke@chla.usc.edu

Katrina Kubicek, MA
Assistant Director
(323) 361-8452
kkubicek@chla.usc.edu

Marisela Robles, MS
Community Liaison
(323) 442-2105
mariselr@med.usc.edu

Mayra Rubio
Administrative Assistant
(323) 442-1157
mayrarub@med.usc.edu

Alma Garcia
Research Ambassador
(323) 442-1916
almag@med.usc.edu

Sara A. Calderon
Research Ambassador
(323) 442-2664
saracald@med.usc.edu

SC CTSI

Resource for

Integrating Community Voices

into a Research Study

Community Advisory Board Toolkit