

Mobilize a Community Advisory Board

UCLA CTSI Community Engagement & Research Program Partnered Research “How To” Series

OVERVIEW

Community Advisory Boards, or CABs, are central to research projects that engage diverse communities. CAB members serve as partners in the research continuum to support study design, outreach to the community, tailor program materials, support analysis, disseminate findings, and provide critical insights to help researchers understand more about the population of interest or improve research impact. CAB members may serve as co-investigators, consultants, or subcontractors.

WHAT IS A COMMUNITY ADVISORY BOARD?

A group that brings their expertise and lived experiences to help research projects align more closely with community priorities. Other names for CABs include Community Action Board, Community Consultant Panel, and Community Advisory Committee.

DEVELOPING A CAB:

Goals and purpose: The goals of the CAB may include various objectives along the research continuum. Examples include community-based or population-specific guidance and strategies on:

- Study design to improve the community relevance of recruitment, methods, treatment, and outcomes
- Recruitment strategy and materials to improve interest
- Identifying and reducing participation barriers and increasing strengths for improving the diversity of research participants, cultural or socioeconomic tailoring, feasibility, and more.
- Improving interventions or implementation strategies that are more applicable or feasible
- Data interpretation and dissemination

While goals and objectives may evolve over time, especially in response to feedback, initiating the CAB with a defined purpose and clear expectations is crucial.

Identifying types of CAB expertise: Depending on the research aims, identify your stakeholders and the feedback you would like on your project. Community experts can offer valuable insights into cultural factors, community norms, common questions, and concerns within the community and guide the tailoring of language, messaging, and communication strategies to engage with the community effectively. Depending on what insight would support advancing your work, the CAB may include community members, patients, individuals with lived experience, caregivers, healthcare providers, or other stakeholders.

Refine qualifications: Consider what you seek in a CAB member, including various expertise, experiences, and perspectives to advance your study. Areas of expertise include a line of work such as a position at an organization, community involvement or advocacy, or experience with the project topic. Experts can also be patients who can provide insight into specific health issues. Once you determine eligibility, contact your internal network to see if they have any recommendations or nominations. The CTSI CERP program may also support matchmaking!

PROJECT CONSIDERATIONS

COMMITMENT: Determine how long you will need your CAB members to serve on the board, how frequently you plan to meet (ex: 1x a month), and how long each meeting will be held (ex: 1.5 hours per meeting).

COMPENSATION: Determine how much you can pay your CAB members for their time in the CAB and communicate hourly or consultant pay from the beginning.

CAB SIZE: Determine the number of people you need for your CAB to cover desired expertise, which will allow for proper participation in all CAB meetings (time for everyone to speak up). Most importantly, ensure the budget will cover the number of CAB members for their commitment to your study.

WHAT IS COMMUNITY EXPERTISE?

- Understand cultural factors and community norms
- Bring up community-relevant questions and concerns
- Sharing barriers and facilitators for participation
- Promote framing, messaging, and communication strategies that resonate with the community
- Ideas for partnerships, connections, networking, outreach



Inviting CAB members: Draft personal invitations to each CAB member outlining the role, responsibilities, commitment, and compensation. Send invites and provide sufficient time for prospective CAB members to respond. Provide contact information for questions and offer to meet with prospective CAB members to answer questions. Often, some community members may be new to research, and explaining the research purpose and goals of the CAB clearly (and the types of community expertise you are looking for) is essential to gain buy-in and reduce power dynamics. We recommend beginning recruitment efforts at least *two months early* to allow for network-building, screening, interview (if applicable), scheduling, presentation preparation, etc.

GENERAL CAB COMMUNICATIONS

Clear, easy-to-understand communication is critical to building trust and rapport with your CAB members. Pick one lead to communicate with them, organize meetings, send reminders of meetings, and inform them of any changes. Initial discussions should involve icebreakers and lay language introductions to the project or research to allow for equal footing between investigators/researchers (technical expertise) and CAB members (community, culture, socioeconomic, lived experience, or other knowledge).

Encouraging inclusive participation through facilitation:

To encourage participation from all CAB members throughout your project, develop structured discussion questions for the CAB to discuss at each meeting. Build and reiterate previous discussions to advance the work. Be open and transparent about research gaps and improvement areas for the CAB to weigh in. Allow time and space (*silence is OK!*) for CAB members to speak up or think before responding. When it's comfortable, call on CAB members to make sure everyone has a chance to talk. Create ground rules so that all CAB members are asked to respect each other's opinions and allow each other to speak. Consider facilitators who help to highlight or reflect the overall CAB group, including cultural congruency.

Promote transparency: It is important to address and be transparent about any contemporary or historical context between researchers and communities. Acknowledge limitations, past/current harms, and motives and encourage reflections on improving and building relationships between researchers and communities. Celebrate wins and strengths and be honest about losses or challenges.

PREPARING FOR THE FIRST MEETING

- Communicate the purpose, expectations, and goals of the meeting
- Schedule the meeting several weeks in advance
- Post and send out agenda and meeting invites to appropriate people
- Prepare the meeting presentation and confirm who will facilitate the meeting and lead the presentation

MATERIALS and RESOURCES

Create concise materials informing CAB members about the project. Materials can consist of a member directory, a briefing booklet outlining the project, CAB goals, and a glossary of terms or acronyms related to the study.

Below are some points to consider as you create your materials:

- Make sure materials are free of jargon.
- Translate documents if needed.
- Send materials ahead of time. The members should receive briefing materials **before** the first meeting.

THINGS TO KEEP IN MIND

- Consider whether you want to meet in person or virtually. Assess comfort levels, transportation time/compensation, and physical and geographic accessibility. Select meeting days/times that most group members will be available.
- Solidify ground rules that will set the tone for future meetings (i.e., ensuring a safe space to share thoughts, group respect for different opinions, creating time and space for all to speak if desired)
- Consider accessibility in your CAB, including language translation, literacy, font size in presentations/materials, and use of new technology. Ensure that there are language provisions for monolingual CAB members (ex: Spanish-speaking only members)
- Consider who is not at the table and who is not represented in your CAB.

CHALLENGES THAT COME WITH COMMUNITY ADVISORY BOARDS

- Effectively translating research or project details into lay language, digestible discussion points for optimization of the CAB for project/research improvement.
- Gaining community trust.
- Improving community engagement in research among historically underrepresented groups.
- Transparency in effectively communicating the *unknown* risks and benefits of study participation.
- Time in researcher and community capacity building (i.e., researchers learning about community



preferences or barriers or community members learning about research procedures, risks, and benefits).

- Understand your organization's payment timelines and set up payments with your CAB members in advance to ensure timely payment.

SOLUTIONS TO ADDRESS CHALLENGES



- Community engagement and trust-building strategies may include:
 - To catalyze background information, create a lay language toolkit and capacity-building sessions on clinical trials or research basics (including sharing common pitfalls, gaps, or concerns) before the first CAB meeting.
 - Providing updates and education on the topic (i.e., health disparities, how the research is essential, ethics in research).
 - Weekly reflections and opportunities for questions and feedback.
 - Clarity in goals, strengths of a CAB, and proper recognition and validation of feedback, even if change is difficult or presents obstacles.
- Established partnerships with relevant community organizations or members.
- Compensation for CAB members is commensurate with their time commitment and expertise, including representation and knowledge of populations who may be considered underrepresented in research to promote optimal and equitable inclusion.