

Developing Meaningful Engagement of Community Partners in Research

Guidance for developing a Community Advisory Board (CAB) for Research Projects

Overview

A Community Advisory Board (CAB) is a group of community members who share a common identity, history, symbols and language, and culture that act as collaborators and multisector partners in public health or community-based participatory research (CBPR).¹ Community partnerships are defined by the relationships that institutions have with communities and how communities are engaged as partners in research². Building a CAB or engaging an existing CAB is one way that researchers can gain valuable insight from different perspectives to enhance their research questions, design, recruitment plan, or dissemination of findings back to the community¹. It takes time to develop a cohesive group of community engaged collaborators; however, here are three guiding principles to consider when developing community-academic partnerships: (1) create and sustain multiple partnerships; (2) promote bi-directional partnerships; and (3) commit to action and research8. According to Nass et al.⁵, there are four different levels of partner involvement in public health research:

- 1. Minimal public involvement: Researchers are the drivers of the project. Researchers respond to public action by providing information or inviting the public for consultations and collaborations on their terms
- 2. Consultation: Public is encouraged to provide in-depth community views, perceptions, preferences, experiential knowledge and ideas
- 3. Collaboration: Public is empowered to become active partners in an ongoing public-clinician collaboration
- 4. Control: The public is the driver of research projects. Researchers participate on the terms of the public

Effective community engaged research requires partner-level control where members of the public are involved from the beginning to end of the research process. Community engagement requires participation with members that represent perspectives and priorities of the community³. The benefits of community engagement range from strengthened bidirectional partnerships to improved health outcomes (see Figure 1)^{1,2}.

Benefits of Community Engagement in Research



Figure 1. Spectrum of community engagement and its benefits on public health research. Adapted from National Academy of Medicine.4

How to Create a Community Advisory Board (CAB) for Research Projects^{1,5,7}

1. <u>Determine your Community and Multisector Partners</u>. This can include individuals who have a direct interest in the process and outcomes of a project, policy or research endeavor, including community residents, faith-based organizations, patients/community members with lived experiences, social service organizations, patient advocacy groups, healthcare systems, and academic researchers (see Figure 2).



6. Figure 2. Examples of collaborators in community-based research. Adapted from the Nature Health Research Policy and Systems Journal

- 2. <u>Identify and Select Community and Multisector Partners that Need to be "At the Table."</u> Challenges:
 - Relationship-building takes time to meet, engage, and build trust with key collaborators
 - Encountering and understanding the history and landscape of community groups and organizations (e.g. new CBOs versus established CBOs)
 - Distrust of academic institutions and researchers "outside" the community
 - Understanding communities' social, economic, and political landscape
 - Defining community of interest
 - Ensuring the participation of overextended collaborators

Facilitators:

- Identify community champions and engage them into developing a partnership
- Ensure research team and university staff have the skills needed to build bridges with the communities of interest
- Host learning exchanges (e.g. setting up a community forum or listening sessions for researchers to learn from the community and understand the community; host panels to include community representatives)
- Read books, newspapers, other media & published reports describing community landscape
- Enter through existing community-engaged projects and/or CABs (e.g. consider relationships that are already in place to bring research questions to existing partnerships/CABs)
- Host community meetings/forums
- Provide monetary incentives for participation during planning to compensate for time, knowledge and expertise
- 3. <u>Foster Mechanisms for Community Engagement</u>. Examples of mechanisms include agreeing upon and articulating processes to support community engagement, which is critical to ensuring bi-directional benefit. Community engagement is an iterative, reflective process that allows for evolution (see Figure 3).

Challenges:

- Unequal power dynamics may persist between researchers and community
- Unequal distribution of grant money or resources

Facilitators:

- Develop agreed upon norms and processes (e.g. of meeting protocols and decision-making processes)
- Determine roles and responsibilities of all collaborators (e.g. Memorandum of Understanding or Partnership-Agreement)
- Discuss fiscal considerations (e.g. community partner can submit grant; determine if community partner can be a grant subcontractor; determine amount of grant overhead/indirect)

- Agree upon ownership of data and process for interpreting data
- Evaluate partnership process at regular intervals (e.g. annually)

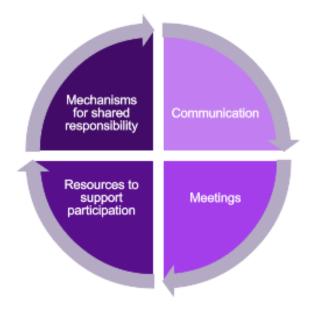


Figure 3. Adapted from the from the Urban Institute Community Voice and Power Sharing Guidebook.⁷

4. <u>Define the Problem & Research Question(s) with the Community Partner.</u> Consider a co-learning process as both parties learn about a phenomenon of interest.

Challenges:

- Tight grant deadlines
- Research-based vs. Community need
- Researcher & community disagreement on most important problem and/or research questions Facilitators:
- Ongoing input, listening sessions, and learning exchanges with CABs, community collaborators
- Researcher providing in-kind services or resources to community (e.g. attend community events, volunteer, attend and contribute to galas)
- Researcher flexibility/community recognition of funder priorities
- 5. <u>Determine a Research Design.</u> Community engagement is not a research design, it is an approach. It does not limit the choice of research designs (e.g., experimental, quasi-experimental). *Challenges:*
 - Scientific rigor vs. community acceptability
 - Unfavorable results could affect community organizations' funding

Facilitators:

- Delayed intervention design (to allow everyone to eventually receive intervention)

- Discuss advantages of rigorous design for future funding
- Discuss potential for unfavorable results
- 6. <u>Select Instruments and Curriculum.</u> Community collaborators often co-design study measures and intervention components.

Challenges:

- Valid, reliable instruments/"evidence-based" curriculum vs. tailoring to local context
- "Researcher" constructs may need to be rephrased
- Opportunities to publish in peer-reviewed journals may be diminished

Facilitators:

- Use of multiple measures
- Pretest surveys in community
- Qualitative methods to help design quantitative instruments
- Opportunities to publish in community-centered journals or other formats (e.g. community reports and briefs, white papers or policy briefs) to expand reach beyond the research community
- 7. <u>Data Collection & Intervention Delivery.</u> Community input and resources help remove barriers that could compromise intervention efficacy (e.g., inclusion of bilingual speakers on research teams) Challenges:
 - Limits on community organization time to engage in research
 - Evolved community context may shift priorities away from research engagement

Facilitators:

- Engage community collaborators in identification of appropriate venues for delivery and data collection and study team/staff
- Hire/train community members for data collection
- Integrate intervention delivery into community organization workflows
- 8. <u>Analysis, Interpretation, Action.</u> Consider the practical benefit to community collaborators and multisector partners for engaging in research. Research is translational to community & public health practice. Ensure a balance of relevance and rigor in research design as well as recognition, respect, and impact in dissemination.

Challenges:

- Prioritization of peer-reviewed publications by academic partners
- Limited capacity/interest of community collaborators to engage in analysis/dissemination Facilitators:
- Ongoing discussion with community about early analyses and emerging findings
- Joint interpretation of research findings
- Committees/workgroups to assist with interpretation of findings
- Discussions at start of project about intended research products

9. Maintaining CAB Engagement:

Challenges:

- Time involved in meeting & recruiting key collaborators
- Cutting down the number of meetings and identifying the correct representative at each CBO
- Community dynamics
- Ensuring participation of community collaborators

Facilitators:

- Selection of Health Priorities: promote participation in research processes due to the local relevance of selected health issue and ground health issues in relevant socioecological context
- Funding & Study Design: allocate funding to the community and promote community buy-in and acceptance of study procedures
- Recruitment & Retention of Participants: implement acceptability and feasible recruitment strategies; enhance recruitment and retention
- Development of Data Collection Tools & Data Collection: foster linguistic, cultural and contextual relevance of measures
- Development & Implementation of the Intervention: Develop intervention and implementation strategies tailored to the local community context, improve implementation outcomes (e.g., acceptability, feasibility, sustainability) and intervention outcomes (effectiveness), leverage existing community infrastructures in the intervention
- Data Analysis, Interpretation, Dissemination & Data translation: Align analyses and interpretation
 with community lived experiences, avoid perpetuating false narratives through misinterpretation of
 data, improved dissemination to community through non-academic channels, enhanced
 translatability from research to practice

Tips for Supporting Work with CABs¹

- Align missions of CAB members early on and review the goals and mission of the project at each meeting to reaffirm objectives.
- Establish trust and expectations (e.g. begin with face-to-face meetings, co-identify goals)
- Consider accessible and appropriate methods of communication for collaborators (e.g. virtual or conference calls to supplement face-to-face meetings, toll-free conference number)
- Allow time to let collaborators and investigators understand the mission, their roles.
- Consider co-leadership or alternate leadership at meetings between an investigator and key collaborators.
- Develop a memorandum of understanding (MOU) including responsibilities for academic and community partner
 - o Include financial compensation details
 - o Include appropriate financial/rates of compensation with members and appropriate methods of reimbursement (e.g. small grant/voucher program, gift cards) for partner involvement
- Determine and resolve any barriers (e.g. for specific populations older adults, language and translation needs) or institutional specific requirements for financial compensation or transportation for partner participation.
- Plan for adequate time to enhance a culture change
 - Establish CAB in the pre-award period if possible to build in sufficient time for culture change and alignment before research timeline begins
 - o Multiple meetings may be needed to learn to share decision making power and define roles.
 - The CAB is an evolving entity so all participants should be flexible and willing to adapt the CAB as needed (ex. include other collaborators not initially involved).
 - o Consider including confidential methods to obtain feedback from CAB members
 - Find a respected leader who reiterates the importance of authentic partner engagement and shared decision-making power.
- Intellectual property issues
 - Meet with institutional legal advisors early in the process.
 - o Include community collaborators in intellectual property issues.
 - Discuss interpretation of data, authorship dissemination plans upfront.



References/Resources:

- 1. Halladay JR, Donahue KE, Sleath B, Reuland D, Black A, Mitchell CM, Breland CE, Coyne-Beasley T, Mottus K, Watson SN, Lewis V, Wynn M, Corbie-Smith G. (2017). Community Advisory Boards Guiding Engaged Research Efforts within a Clinical Translational Sciences Award: Key Contextual Factors Explored. Prog Community Health Partnersh;11(4):367-377.
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- 3. Lavallee DC, Lawrence SO, Avins AL, Nerenz DR, Edwards TC, Patrick DL, Bauer Z, Truitt AR, Monsell SE, Scott MR, Jarvik JG. Comparing three approaches for involving patients in research prioritization: a qualitative study of participant experiences. Res Involv Engagem;6:18. doi: 10.1186/s40900-020-00196-4.
- 4. Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies. (2022). Assessing Meaningful Community Engagement: A Conceptual Model to Advance Health Equity through Transformed Systems for Health. NAM Perspectives. Commentary, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/202202c.
- 5. Nass P, Levine S, and Yancy C. (2012). Methods for involving patients in topic generation for patient-centered comparative effectiveness research an international perspective. Research Priorities White Paper for the Patient-Centered Outcomes Research Institute (PCORI-SOL-RPWG-001).
- 6. Boaz A, Hanney S, Borst R, et al. (2018). How to engage stakeholders in research: design principles to support improvement. Health Res Policy Sys: 16, 60. https://doi.org/10.1186/s12961-018-0337-6
- 7. Arnos D, Kroll E, Jaromin E, Daly H, Falkenburger E. (2021). Community Engaged Methods: Tools and Resources for Project -Based Community Advisory Boards, Community Voice and Power Sharing Guidebook. Urban Institute. PDF.
- 8. Chau TS, Islam N, Tandon D, Ho-Asjoe H, Rey M. (2007). Using community-based participatory research as a guiding framework for health disparities research centers. Prog Community Health Partnersh;1(2):195-205. doi: 10.1353/cpr.2007.0007.

Other Resources:

Resource Title	Source	Author(s)
Developing a Community Advisory Board for Research Toolkit	https://sc-ctsi.org/resources/developing-a-community-advisory-board-for-research-toolkit	Southern California Clinical and Translational Science Institute
Tools and Resources for Project-Based Community Advisory Boards	https://www.urban.org/research/publication/tools-and-resources- project-based-community-advisory-boards	Urban Institute
Case example of Research project with a CAB	Garbers S, Falletta KA, Srinivasulu S, Almonte Y, Baum R, Bermudez D, Coriano M, Iglehart K, Mota C, Rodriguez L, Taveras J, Tobier N, Grosso A. (2020). "If You Don't Ask, I'm Not Going to Tell You": Using Community-Based Participatory Research to Inform Pregnancy Intention Screening Processes for Black and Latina Women in Primary Care. Womens Health Issues;30(1):25-34. doi: 10.1016/j.whi.2019.08.004.	Garbers et al.
Manuscript on community based participatory research	Israel B, Checkoway B, Schulz A, Zimmerman M. Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational and community control. Health Educ Q. 1994;21:149–170.	Israel et al.
Evaluation of community academic partnerships in research	Evaluation of community academic partnership functioning center for the elimination of hepatitis b health disparities. 2011.	VanDevanter et al.
Community Engagement Populations Terminology	https://www.linkedin.com/pulse/time-adopt-new-word-stakeholders-marie-gettel-gilmartin/	Marie G. Gilmartin
Community Engagement Populations Terminology	https://www.forbes.com/councils/theyec/2022/08/24/stakeholder-engagement-needs-a-rethink-heres-what-will-replace-it/	Dave MacLeod

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