

# Guidance for Forming/Supporting on Community Advisory Boards for Research



*Developed by the Alliance for Research in Chicagoland Communities (ARCC)*

*In addition to the points below, you may be interested in the slides & video recordings of two workshop sessions on this topic hosted by ARCC in March 2016. These are included at the end of the document.*

For the purposes of this document, we will refer to the community advisory board as a CAB. A group you form may go by a different name or be composed of different types of members (e.g. community only, community and academic, other types of stakeholders). Membership will be further discussed below.

## **Defining a CAB**

A group of people who represent the interests/perspectives of communities, patients, or other stakeholders that may be impacted by a research project or findings.

## **Deciding to Form a CAB**

- Self/research team reflection on why you want to form a CAB?
  - o Leadership/input/sounding board
  - o Connections
  - o Feasibility/practicality of scientific ideas/research design
  - o Guidance on participant burden
  - o Communicate community priorities/needs/resources/questions
  - o Problem solving
  - o Requirement
- What makes a CAB a good fit versus another type of engagement structure/mechanism?
  - o Important to establish new group or possible to get feedback from an existing CAB?
- May need to engage different stakeholders or bodies at different times. E.g. discussions about sustaining an intervention after a research project ends may engage different stakeholders like public agencies, elected officials, payers, etc.
- CAB serves as a bridge between the research team and the community/research participants. Between science and community needs. Translation/balance. What researchers want to get done vs impact communities want to see.

## **Things to consider/develop before seeking members**

- What are CAB members being asked to do? Possible roles/responsibilities, expectations
  - o Feedback on research method/approach feasibility
  - o Feedback on recruitment/retention design/challenges
  - o Connections to other possible collaborators, recruitment sites, research participants
  - o Interpretation of research findings
  - o Dissemination/implementation of research findings
- Typically academics see the purpose of CABs to assist with the research completion- advise on design/recruitment, connection to possible research participants, etc. In contrast, CAB community members often see their primary roles as protecting research participants, providing oversight, and ensuring communities benefit from the participation and research findings. Important to discuss and be on the same page.
- Compensation- monetary (for period of time, piece of work, per meeting/task), other compensation (parking/transportation, food, child care, etc.). Payment to individual or organization. Consider what model of compensation (e.g. per meeting, annual/bi-annual).
- What are the benefits being provided to community? research outcomes, compensation, expertise/engagement of academic partner, access to other university resources (meeting rooms, etc.)

- What are you willing to offer to 'give back'? Learn about/get involved with their organization/community, connect them with other possible resources, give a talk to community partner organization/community, write a letter of support for community partner grant submission
- Will CAB members serve as individuals or as representatives of an organization?
- Consider type/Level of engagement- level of power/authority- Will be CAB be advisory or have decision making power?
- What level of transparency will you have with the CAB? What are you willing to share? Proposal, budget, other members being invited/who have accepted?
- It is important to understand the level of effort necessary for initiating and maintaining a CAB. An optimally-functioning CAB can be time-consuming and intensive. Consider the amount of time that a CAB may require of the PI, research team members, and support staff. If the research team cannot realistically support a CAB, it may be better to hold focus groups to learn about specific community/patient perspectives.

## Membership

- Choose selection criteria that reflect the goals of the research and intended function/purpose of CAB.
- Who? What perspectives, stakeholders are you seeking? Who is impacted by the research? Who would be involved in acting on research findings?
- What type of skills/experience are you seeking in members? Do members need to have past experience with research or just expertise/experience on the health topic/condition or community/population being served? What type of representation are you seeking- geography, race/ethnicity, etc.?
- How will you identify people to invite?
  - Past relationships
  - Referrals from existing community partners. Purposive snowball approach.
  - Referrals from CAB members who accept
  - Referrals from colleagues
  - Connections through the Center for Community Health
- Who selects CAB members? PIs, research team, include input from existing community partners or CAB member who accept first?
- Size of CAB- how many members?
- How to invite?
  - Email, in-person meeting, phone call.
  - Screening
  - Invite by PI or staff. PI invite may get better/quicker response and unless potential members know the staff person.
- Recognize that recruiting and retaining CAB members is an ongoing process, not a one-time event.
- How will member turnover be handled? Staff turnover within CAB member organizations? Potential turnover of member organizations that cannot continue.
- Invest up front in engaging members. Value of face time.
- Be clear in invitation about items above- expectations/roles, time commitment (# of meetings, time outside of meetings), etc.
- Consider what the perception/reputation of Northwestern/research is for the CAB members you want to recruit.
- Why do members decide to accept invitations to serve?
  - Personal connection/relationship with researcher (or person inviting them) or another member/invitee of the CAB
  - Research topic is related to person's individual interests or professional mission (passion for the topic)
  - Possibility for benefit or future benefit/collaboration to person's organization/community/work (access to university resources)
  - Their current available time/capacity

- Make connections (with other members, university, etc.)
- Opportunity to give input/make change (contribution to organization mission/community)
- Opportunity to learn/build personal/professional capacity (about health topic and/or about research or universities in general)
- Protect community interests- prevent exploitation/ensure community benefit
- Monetary compensation

### **Structure/Process**

- Signed Letter of Agreement (LOA) between research team leadership and CAB members may minimize potential misunderstandings/future conflict. Can include roles/responsibilities of CAB member/of research team staff, compensation, how conflicts will be handled (e.g. if responsibilities aren't being met).
- Staff support: consider the type and amount of effort it may take to organize and support your CAB. Meeting scheduling, preparation, follow up, payment, support, etc. Can be helpful to have a portion of time from an administrative or research staff person.
- Who facilitates the CAB/meetings? Who is the main contact person for CAB member questions/issues? Who organizes the CAB and sets up the logistics/engages CAB members, etc.? Consider who is the right fit for one or more of these roles. May be the PI, may be a research or administrative staff person, may be someone hired or contracted with from the community, may be a member who's asked/compensated to serve as a chair.
- Will the CAB have Leadership/committees or work groups? Chair, co-chair, etc.
- Consider CAB/meeting logistics- meeting space, parking validation, transportation assistance, child care, food, permission to record (audio/video/photo). Consider what you will need to provide to support CAB member engagement. For example, a CAB engaging veterans found that many had support animals and it was important to have pet food and other resources to support their participation. Schedule meetings far in advance, consider regular meeting time e.g. 1<sup>st</sup> Monday of the Month.
- Will CAB establish/adopt ground rules, by-laws, procedures, decision making process?
- Be Flexible- CABs have personalities. They may want to different things from each other. Some may want structure, some won't.

### **Planning for meeting(s)/member engagement**

- After members accept invitation
  - o Begin/continue building relationship/connection
  - o Send thank you/introductory/welcome letter/email. Remind members of research project background, expectations, compensation, etc.
- How often/long should CAB meetings be?
- In-person vs phone/online input from CAB members
  - o Meet first time in person, front load in-person meetings (perhaps first 2-3)
  - o Can then perhaps alternate with phone meetings and/or getting input over email or through online surveys
- 1<sup>st</sup> meeting
  - o Introduce other research team members, people they may be contacted by
  - o Let CAB members ask questions
  - o <http://arccresources.net/wp-content/uploads/2014/09/CAB-start-up-considerations1.pdf>
- Orientation- What background will CAB members need?
  - o Research project specifics (focus of research, protocol basics, funder, deadlines, research participants, etc.).
  - o Who is on the research team and CAB?
  - o Expectations/responsibilities of board members- type of engagement (advisory vs. decision-making)
  - o Basics of research design/terminology/acronyms

- Basics of university/funding structure/requirements/timeline (IRB, grant requirements/management, university indirects, categories of NIH funding, university structure (centers, departments, OSR, members of research team, CCH, etc.). It can be helpful to share what can be modified at the research project level vs what cannot (especially if it's a multi-site study) because sometimes CAB members will have suggestions/input that's outside of the control/scope of the research team/project.
- What will be engagement/communication with individual CAB members?
- Show investment in your members- come to their community events, show up.
- Setting the tone/trust- state upfront but also remind members throughout. At initial meeting(s), may want to establish or discuss ground rules for the CAB to create safe space for honest input/critiques.
  - Ask questions
  - Value of community input/knowledge. CAB must know/feel that researchers value their voice/input.
  - Researchers set the tone by being open/**transparent** themselves. Demonstrate, not dictate. How do researchers behave with CAB? Shows whether community can trust you.
  - Open to positive/negative/honest/hard feedback
  - Okay to disagree, conflict is okay.
  - Acknowledge that research team may not be able to act on all input/recommendations.
  - Give time for feedback, time for reflection/percolation.
  - Must balance between research team input/expertise and CAB member input/expertise
  - Consider ways to engage quieter members- round robin, also allow input by email, one on one phone call. Opportunity for members to share input confidentially or outside of meetings.
  - Clarify that though every idea will be heard, not every idea will be implemented.
- Connections among members and between CAB members and research staff
  - What is the mix of members? Representatives from grassroots community-based organizations, faith-based organizations, public agencies, patient advocacy organizations? Patients, caregivers, community members/residents? Clinicians? Representatives from larger institutions or businesses- hospitals/health systems, pharmaceutical companies, insurance company? Academic/scientific experts? If a diverse group across categories, consider how these various members would understand each other, work together, be comfortable with each other, etc.?
  - Board members may work better together when they know and trust the others they work with. Helpful for people to understand their perspective in relation to other peoples. What is the expertise they bring to the table?
  - Take time at meetings to network, engage in ice breakers, etc.
  - Create a contact sheet/roster that includes each board and staff member, their project role, the organization/topic they represent, contact info, photo, website/social media. This can be a document that people refer to at all future meetings.
- What types of questions or topics can CAB be asked to assist with?
  - Feedback on research method/approach feasibility/practicality
  - Feedback on recruitment/retention design/challenges, Guidance on participant burden
  - Connections to other possible collaborators, recruitment sites/incentives, research participants
  - Interpretation/analysis of research findings
  - Dissemination/implementation of research findings to community and other relevant audiences
  - Problem solving
- Follow up
  - Notes/minutes after meetings
  - If time, phone check in with members who weren't present
  - Will help members stay engaged and remember what was decided, actions they committed to taking, etc.
- At every meeting
  - Consider what materials members need for the meeting- agenda, background, acronym cheat sheet, etc.?

- Give materials in advance- respect CAB member time
- Remind of goals, remind of key players/roles, progress/accomplishments until now, current place in project timeline, how past feedback has been incorporated, where we're headed. Being repetitive can be helpful when this is something that CAB members spend such a small percentage of their time focused on.
- Feedback from members on presented topics/questions. Be targeted/specific in your requests, not too broad in your questions or you may get silence.
- Not necessarily at every meeting, but good to reinforce the tone/collaborative environment.

### **Addressing conflict/issues**

- How will lack of member engagement be handled? Will compensation be withheld if meetings are not attended or tasks are not completed?
- How will CAB handle conflict among members or between members and research team? E.g. issues related to research, working relationship, personal conflict (racism, sexism, other –ism)
- Important to consider the reality of doing research vs. achieving community change.
- Avoid or resolve some conflicts by going back to agreed upon principles/MOU/LOA, decision-making process etc.
- More resources related to conflict resolution: <http://arccresources.net/2013/12/building-healthy-partner-relationships/>

### **Evaluation and Celebrating Success**

- Consider ways of getting feedback about how the CAB is going. At the end of meetings, can do a quick read of positives/negatives or deltas.
- Consider doing periodic assessments of the partnership trust/process. One example free tool: Wilder Collaboration Factors Inventory Survey (20 research-tested success factors): <https://www.wilder.org/Wilder-Research/Research-Services/Pages/Wilder-Collaboration-Factors-Inventory.aspx>
- Include opportunity to discuss results of evaluation during a meeting.
- Celebrate project accomplishments, things working well, accomplishments of CAB members/research team unrelated to the research project.
- Acknowledge contributions, express thanks/gratitude.
- Sustainability- does the CAB continue after the specific research project ends?
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### **Resources**

- Community-Campus Partnerships for Health (CCPH)- [www.CCPH.info](http://www.CCPH.info)
- Patient Centered Outcomes Research Institute (PCORI): <http://www.pcori.org/get-involved/what-is-engagement-in-research>
- CCPH Community-Based Participatory Research Curriculum: [www.CBPRcurriculum.info](http://www.CBPRcurriculum.info)
- Resources for CAB members- Research 101 (design/methods), Glossary of Research Terms & Acronyms, University 101 (ethics, finances, grants process, promotion & tenure) available at [www.ARCCresources.net](http://www.ARCCresources.net)

### **Acknowledgement of sources/interviewees**

- Interviews with:
  - Leo Castillo
  - Gina Curry
  - Marcus Murray
  - Kirsten Peachy
  - Frank Penedo
  - Shyam Prabarakarn
  - Yaa Simpson
  - Erin Wymore

- Buchanan, David; Reddy, Priscilla; Sifunda, Sibusio; James, Shamagonam; and Naidoo, Nasheen, "The role of community advisory boards in health research: Divergent views in the South African experience" (2010). *UMass Institute for Global Health Faculty Publications*. Paper 1.
- [http://scholarworks.umass.edu/umigh\\_faculty\\_pubs/1](http://scholarworks.umass.edu/umigh_faculty_pubs/1)
- <http://heapro.oxfordjournals.org/content/30/2/328.long>
- [http://www.solvingdisparities.org/sites/default/files/CAB\\_tips.pdf](http://www.solvingdisparities.org/sites/default/files/CAB_tips.pdf)
- [www.CBPRcurriculum.info](http://www.CBPRcurriculum.info)
- [http://www.cdc.gov/pcd/issues/2014/14\\_0014.htm](http://www.cdc.gov/pcd/issues/2014/14_0014.htm)



## Forming & Supporting Community Advisory Boards for Research



CCH Workshop: March 16, 2016

Video Recording: <http://bit.ly/2zXlwho> (Unfortunately, audio starts few minutes into workshop, slides visible starting ~3 minutes)

# Plan for the Session



- Introductions
- Panel Discussion
- Q&A
- Resources and Wrap up







# Deciding to Form a CAB

- Self reflection:
  - why?
  - what makes a CAB a good fit?
  - Why this form of engagement?
- Things to consider/develop before seeking members:
  - Expectations/roles & responsibilities
  - Benefit to members/compensation
  - What info you are willing to share
  - What you already know/don't know about potential members/communities or perspectives they represent



# Panel Presentation

- Dr. Shyam Prabhakaran, Associate Prof, Neurology, Northwestern Feinberg School of Medicine
- Marcus Murray, Executive Director, Project Brotherhood
- Yaa Simpson, Community Epidemiologist & Bioethicist, The Association of Clinical Trials Services (TACTS)





# Forming & Supporting

- Membership
  - Size, who to invite, how to invite
- Structure/Process
- CAB member engagement
  - After accepting invite/Orientation
  - Meetings/Engagement outside meetings/Follow-up
  - Setting the tone
- Addressing conflict
- Evaluation



# Guidance for Serving on Community Advisory Boards for Research



CCH Webinar: March 25, 2016

Video Recording: <http://bit.ly/2A0DSgx>

*(Unfortunately, audio cuts out from ~3 to 19 minutes)*

# Plan for the Session



- Introductions
- Panel Discussion
- Q&A
- Resources and Wrap up



# What is a Community Advisory Board?

A group of people who represent the interests/perspectives of communities, patients, or other stakeholders that may be impacted by a research project or findings.

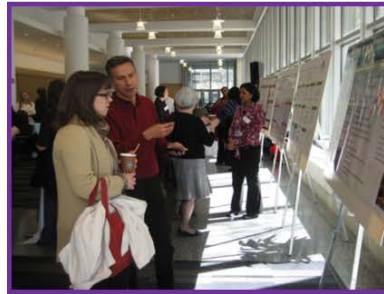
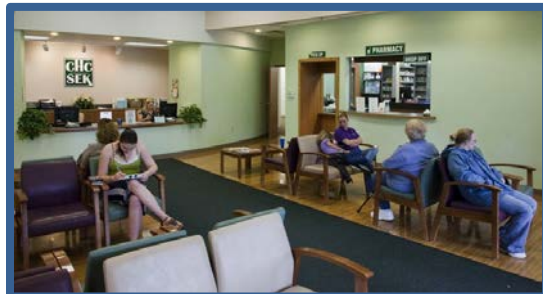
# Why do research teams form CABs?

- Leadership/input/sounding board
- Connections to communities/research participants
- Feasibility/practicality of scientific ideas/research design
- Guidance on participant burden
- Communicate community priorities/needs/resources/questions
- Problem solving
- Requirement of funder



# Panel Presentation

- Marcus Murray, Executive Director, Project Brotherhood
- Yaa Simpson, Community Epidemiologist & Bioethicist, The Association of Clinical Trials Services (TACTS)
- Rev. Kirsten Peachy, Director, Congregational Health Partnerships; Co-Director, The Center for Faith & Community Health Transformation; Director, Advocate Health Care







# Considering

- Membership- who else is invited? Serve as individual/organization?
- Roles & Responsibilities/Expectations
  - Time (meetings, phone calls, other work)
  - Required expertise/knowledge
  - Provided training/background
  - Decision making vs. advisory
- Benefits
  - Monetary (compensation, expenses)
  - Contacts/networking
  - Contributions to your mission/community
  - Access to university resources



# Joining

- Preparation/Orientation
- Structure/Process
  - Who will you work with?
  - LOA/MOU
  - Logistics
- Engagement (Meetings, Phone, Email)
- Benefits (Monetary (compensation, expenses), access to resources, connections)

Other roles community partners play in research

# Resources on

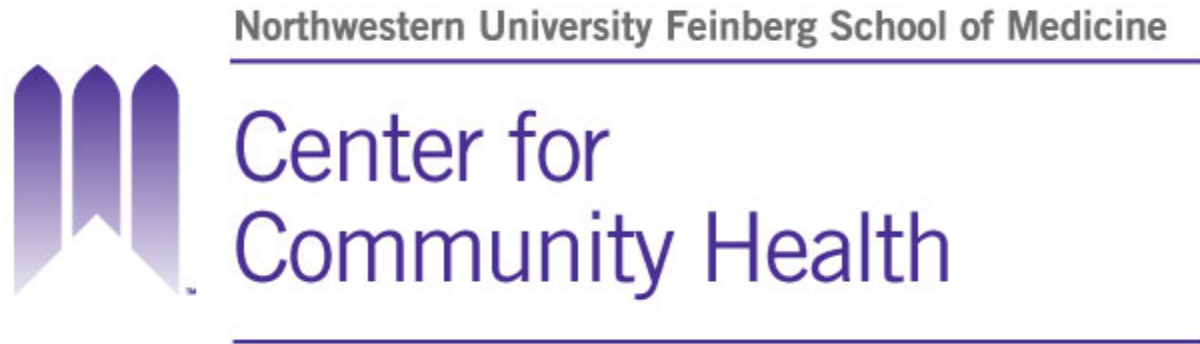
[www.ARCResources.net](http://www.ARCResources.net)



- Research 101 (design, methods)
- Glossary of Research Terms & Acronyms
- University 101 (ethics, finances, grants process)



# Institute for Public Health and Medicine's



Mission: CCH cultivates and catalyzes engagement of academic and community partners in research to improve the health and healthcare of communities.

<http://www.feinberg.northwestern.edu/sites/cch/>

# Practice-Based Research Program (PBR)

Fosters collaborative research between community-based practitioners and NU faculty.

## Networks

- REACH: 17 clinical sites affiliated w/NU, including private practices & FQHCs w/ more than 160 member docs
- Pediatric Practice Research Group (PPRG): regional network founded in 1984 as partnership of Lurie Children's & group of over 50 pediatric practices



# Alliance for Research in Chicagoland Communities



Guided by steering committee of 13  
community & faith-based organizations,  
Chicago Public Schools, Chicago Dept of Public  
Health, and 10 Northwestern faculty

[www.ARCOnline.net](http://www.ARCOnline.net)

Northwestern University Feinberg School of Medicine

Center for  
Community Health

Northwestern University Feinberg School of Medicine

Institute for  
Public Health & Medicine

Northwestern University

**NUCATS**  
Clinical and Translational Sciences Institute

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# ARCC Resources

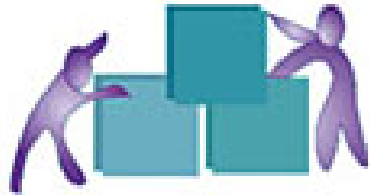


- **Online ARCC Resource Directory:**  
[www.ARCCresources.net](http://www.ARCCresources.net)

A screenshot of the ARCC Resource Directory website. At the top left is the ARCC logo. To the right is a search bar with a "Search" button and a link to "Visit arconline.net". Below the logo is a purple navigation bar with "RESOURCE DIRECTORY" on the left and "ABOUT", "NAVIGATING THE SITE", and "CONTACT/LINKS" on the right. The main content area has a heading "ARCC Resource Directory" followed by a paragraph describing the directory. Below this is a link to a video tour. Further down is another paragraph about the organization. On the right side, there is a vertical list of five colored buttons with right-pointing arrows: "All Resources" (grey), "Resources for Community Partners" (orange), "Resources for Healthcare Providers" (purple), "Resources for Academic Partners" (green), and "Resources for Teams" (blue).

- **Monthly Resources and Opportunities [listing](#)**

# National Resources



**Community-Campus  
Partnerships for Health**

Transforming Communities & Higher Education

[www.ccph.info](http://www.ccph.info)

- Resources
- Skill-Building Online Curriculum

## Progress in Community Health Partnerships Journal



Patient and Family Engagement Rubric

Sample Patient Engagement Plans

<http://www.pcori.org/get-involved/what-is-engagement-in-research>





Northwestern University Feinberg School of Medicine



Center for  
Community Health

[CCH@northwestern.edu](mailto:CCH@northwestern.edu)

<http://www.feinberg.northwestern.edu/sites/cch/>

