



# Development, Implementation, and Evaluation of a Community Engagement Advisory Board

Phoenix A. Matthews, Ph.D.

Professor and Clinical Psychologist

Co-Director, Recruitment, Retention & Community Engagement Program

Center for Clinical and Translational Science

University of Illinois at Chicago

# Introduction

- Professor of Clinical Psychology, College of Nursing at the University of Illinois at Chicago
- Co-director of the Recruitment, Retention, and Community Engagement Program (RRCEP) at the UIC Center for Clinical and Translational Science (CCTS).
- Research interests are on identifying determinants of cancer-related health disparities with a focus on African American and LGBT populations.
- My current research focuses on the use of community-based and culturally targeted health promotion interventions to reduce risk factors associated with cancer disparities including smoking cessation treatments.

# Objectives

- The purpose of this presentation is to describe the formation, operation, and evaluation of a community engagement advisory board (CEAB) that serves as a resource of the University of Illinois at Chicago's (UIC) Center for Clinical and Translational Sciences (CCTS).

# Opening Voice: The Value of Community Engagement

*“It’s really important, I believe, to be the voice of those that we don’t usually hear. That’s the residents. That’s the people in the community who we are trying to impact their lives. I’m here, speaking not only for the university but I’m really an advocate for community residents.”*

- CEAB Member



# Background

- Since 2006, the National Institutes of Health (NIH) has supported the Clinical and Translational Sciences Awards (CTSA) program which are designed to improve public health by translating basic science findings to clinical and community settings.<sup>1,2</sup>
- Community engagement is central to the mission of the CTSA program.<sup>3</sup>
- The focus on community engagement was in response to several key factors:
  - increasing health disparities<sup>4,5</sup>
  - the length of time required to translate research into practice<sup>6</sup>
  - failures in recruiting for clinical trials<sup>7</sup>
  - difficulties in moving from efficacy to effectiveness research.<sup>7</sup>

# Definition of Community Engagement

- Community engagement can be understood as a process aimed at establishing “*collaboration between institutions of higher education and their larger communities for the mutually beneficial exchange of knowledge and resources in a context of partnership and reciprocity.*”<sup>8</sup>
- At its core, community engagement seeks to achieve equitable, meaningful, active community participation in all phases of the research process.<sup>9</sup>

## COMMUNITY ENGAGEMENT



# Benefits of Community Engagement

- Benefits to the research endeavor:<sup>10,11</sup>
  - increased relevance and appropriateness of research questions and approaches
  - higher participation rates
  - increased external validity
  - decreased loss to follow-up
- Benefits at the community level: <sup>12</sup>
  - community engagement can lead to improved health and health behaviors among disadvantaged populations.
  - development of individual and community resources and capacity



# Community Engagement: Voices from the Community

## Examples of benefits for the research endeavor:

*“What the committee has shared with these researchers is really from the perspective of the community. Understanding the culture, understanding the language, understanding what will work, what won’t work, and voicing that, so that the investigators can listen to [understand] what we’re saying.”*

*“They [researchers] wanna know how we feel and how do they access your community. [CEAB members can] Be that gatekeeper. Tell ‘em what language to use. Who should come to the alley [potential locations for recruiting participants]. How you should present it [the objectives of the research study], you know? I hope we get it across here to the researchers.”*

## Examples of community benefit:

*“When I walk out of here some days, I’m thinking like, “Man, they’re really lost in terms of what they’re trying to do.” Then I walk out of some meetings. They’re right there. They’re almost there. They’re doing some really good stuff. It’s [the project] going to be impactful.”*

- CEAB Members





# Community Advisory Boards

- The establishment of community advisory boards is a proven strategy for increasing community engagement in research.<sup>13</sup>
  - Community advisory boards (CABs) are typically homogeneous groups assembled from a particular community for a particular research project.<sup>14</sup>
  - Community engagement advisory boards (CEAB) differ from a CAB in several important ways:
    - they advise on a range of research issues across a variety of research protocols.<sup>15</sup>
    - may also differ in the diversity of types of expertise on the board (lay community members, leaders of community organizations, research staff, and researchers)
    - developed for the purpose of bidirectional capacity building.<sup>16</sup>

# Function: RRCEP CEAB

- In 2009, the UIC CCTS established the community engagement advisory board (CEAB) as a working group within the Recruitment, Retention and Community Engagement Program (RRCEP).
- As a core component of the RRCEP, the CEAB was developed as a resource to support and advise researchers at UIC who engage in community, clinical and translational science.

# Function: Over of CEAB Program

- The CEAB is a free consultation service provided to UIC faculty, fellows and students.
- The CEAB board is overseen by:
  - two faculty co-directors of the RRCEP
  - a staff member that is the point of contact for researchers and CEAB members
  - a former CEAB member who serves as the community-academic liaison.



# Operations: Board Formation and Composition

- There are two standing CEAB boards that meet on alternating months.
  - Each board has approximately 15 members who serve three-year terms.
- Members include directors and providers of respected CBO's, patient and community advocates, faculty, research staff, IRB members, representatives of national organizations and city government.
- A deliberately chosen mix of academic and community representation ensures that each consultation can be evaluated in terms of scientific merit, community relevance, importance to patients, and human subjects concerns.
  - The current composition of the CEAB membership is 64% community based and 36% academic researchers (n=31).

# Current Composition of CEAB Committee (N = 31)

## Populations Represented/Served

- Racial/ethnic minority groups
- LGBT populations
- Disability communities
- Low-income
- Immigrant

## Type of Expertise

- Health disparities
- Social justice and advocacy
- Community engagement
- Research methods

CEAB Members



## Community Areas Serviced

- 45% of all Chicago community areas represented

## Professional and Community Roles

- Lay community members
- Academic researcher or staff
- Community or social services
- Local government

# Operations: Onboarding and Training

## *Voices from the Community:*

*“Coming in cold, and not really having training – I kinda had a sense, but I didn’t really know what the expectation would be of me, personally. What can I bring? What can I share? What could I possibly add to the conversation?”*

*- CEAB Member*



# Operations: Onboarding of New Members

- All members are provided with introductory training sessions.
- The training includes:
  - a lay orientation to the research process
  - research terminology
  - types of research approaches
  - principles of community engaged research
  - ethical considerations and human subjects training
- In addition, we orient members to the format and expectations of the actual consultation sessions and provide organizational items such as binders, action pages and consultation abstracts.





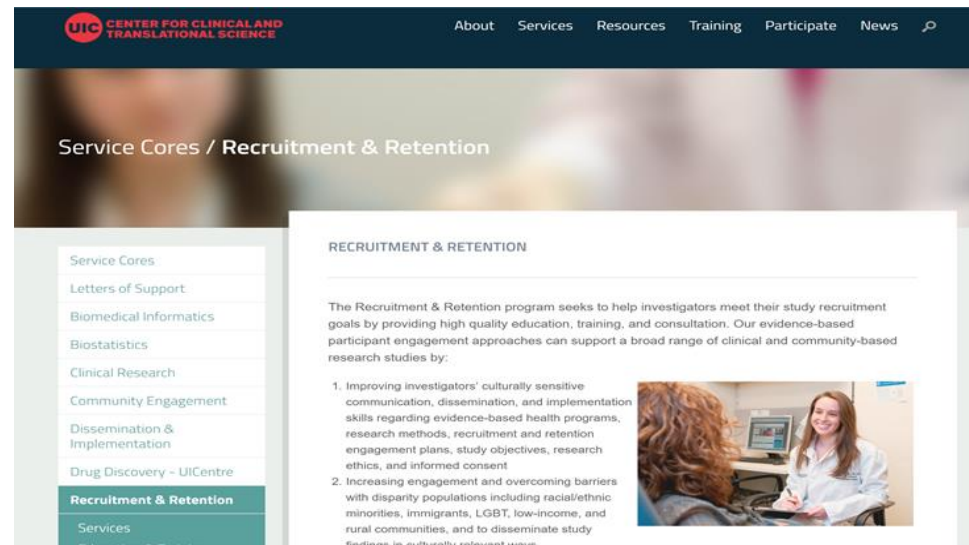
# Operations: Rapport Building and Continued Engagement

- Ongoing communication and rapport building with the CEAB members is essential to the success of the consultation program.
- Communication via email and phone occurs on a regular basis, including save-the-dates, meeting reminders, meeting preparation materials, and thank you cards.
- Members are also notified about university events and share with one another information about organizational and community events.
- Individual members and/or subgroups are invited to participate in other consultation activities when specific expertise is needed (e.g., forming collaborations with immigrant organizations).



# Operations: Outreach to Campus Researchers

- A range of activities are used to advertise the CEAB consultation service.
  - Interested researchers can directly request a consultation via the CCTS webpage.
  - Staff also send out direct advertisements for the service using faculty listservs.
  - Promotional materials are also included at all relevant CCTS activities.
  - Referrals from consultees or from directors of other CCTS programs.



# Operations: Format & Management of Consultation Meetings

- CEAB consultation meetings last about 2 hours and typically include 1-2 consultations of 30-45 minutes each.
- At each meeting, breakfast is provided, parking is complimentary, and \$50 gift cards are provided for services rendered.
- Prior to the first consultation, CEAB members have refreshments, check in with other CEAB members, and are oriented to the meeting agenda and upcoming consultation sessions.
- For each consultation, the researcher gives a brief presentation using slides to provide an overview of the study goals and objectives and to highlight the 2 or 3 key questions for the consultation.
- Members ask clarifying questions, engage in discussion regarding the consultation issues and offer recommendations to the researcher.

# Operations: Pre-Consultation Preparation of CEAB Members

- A reminder email or text is sent to CEAB members 2-weeks prior to meetings.
- To facilitate pre-meeting preparation, the CEAB members are emailed the following information one week prior to consultations:
  - the meeting agenda
  - an abstract summarizing the research problem and reason for the consultation
  - two-three specific consultation questions to consider
  - any additional supporting materials (i.e., recruitment flyers) provided by investigators.
- Printed copies of all materials are also made available for members at each CEAB meeting.

# Operations: Pre-Consultation Preparation of Investigators

Voices from the community:

*“I’ll say, very respectfully, sometimes I’ve seen the expressions on some of the [faces of] investigators [are] like deer in headlights. I really have. I say that in all due respect.”*

*“They don’t understand some of the things [about community engagement] that we take for granted.”*



# Operations: Pre-Consultation Preparation of Investigators

- CEAB staff work very hard with investigators to increase consultation readiness.
  - Following a request for a CEAB consultation, the investigator first completes an abstract that concisely and in lay terms describes their study goals and the specific focus of the consultation.
  - This abstract serves as a valuable tool for the CEAB members to learn about the research and to prepare for the meeting.


UIC CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE	
Community Engagement Advisory Board   DATE	
Your name and title:	
Title of your research study:	
What is the funding source of this study, or what funds will you be seeking?	
Your research – in 200 words or less, and in lay terms, please describe your overall program of research and how you came to be involved in this area of research:	
Your focus – in 200 words or less, and in lay terms, please describe what problem(s) you seek to address in this research study:	
What are the key terms and definitions for this research study?	
In one paragraph and in lay terms, briefly describe your study methods:	
What types of study participants are you looking for, i.e. your eligibility requirements?	
In what community areas will your study be implemented?	
Have you identified community partners for collaboration on this project? If yes, please list:	
What are the anticipated benefits of your research to the community?	
Please list the specific questions in which you seek input from the CEAB board?	
1.	
2.	

The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.



# Operations: CEAB Consultation Abstract

## ABSTRACT

- Introduce researcher
- Describe project
- Key terms
- Study objectives and methods
- Participant criteria
- Community engagement
- Consultation Questions

 <b>CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE</b>	
Community Engagement Advisory Board   DATE	
Your name and title:	
Title of your research study:	
What is the funding source of this study, or what funds will you be seeking?	
Your research – in 200 words or less, and in lay terms, please describe your overall program of research and how you came to be involved in this area of research:	
Your focus – in 200 words or less, and in lay terms, please describe what problem(s) you seek to address in this research study:	
What are the key terms and definitions for this research study?	
In one paragraph and in lay terms, briefly describe your study methods:	
What types of study participants are you looking for, i.e. your eligibility requirements?	
In what community areas will your study be implemented?	
Have you identified community partners for collaboration on this project? If yes, please list:	
What are the anticipated benefits of your research to the community?	
Please list the specific questions in which you seek input from the CEAB board? 1. 2.	
<small>The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health</small>	

# Operations: Investigator Presentation of Research Project

- Investigators are required to complete an abstract and standardized powerpoint
  - Investigators are coached if their abstract and/or powerpoint are not targeted to a lay audience.
- The template for the powerpoint presentation includes: 
  - title and introduction of researcher (why focus on the specific research topic)
  - problem area focusing on (big picture of  what this research will contribute to)
  - specific aims of the study
  - population interested in recruiting and WHY
  - methods
  - potential benefits to the individual participants, community at large or patient populations
  - specific consultations questions
- Goal is to keep the presentation brief (≤ 10 slides) to allow for questions and discussion.

# Operations: Post Consultation Procedures

- Staff members take detailed notes that are given to investigators:
  - key recommendations
  - potential community collaborators
  - pertinent websites, email addresses and phone numbers
- 2 weeks post consultation, staff members contact the researchers to ask if they need an additional individual consultation to review the recommendations of the CEAB members and to develop a specific plan of action.
- Investigators are also invited back to the CEAB for further consultation, to provide an update on their research (this is strongly encouraged) and/or to seek input from the board members on a new research project.
- CEAB consultees are also asked to complete a web-based satisfaction questionnaire immediately after their consultation.



# Number and Types of CEAB Consultations Provided

- From October 2009 - January 2017, N = 123 consultations have been provided to UIC investigators from 17 different departments, institutes or colleges.
- Consultations have fallen into the following categories:
  - 1) reviewing recruitment materials and providing advice on recruitment and retention of a wide variety of patient populations (14%);
  - 2) recommending modifications to measurement tools to make them culturally appropriate for specific ethnic groups (13%);
  - 3) reviewing research protocols to provide advice on components involving recruitment and community partnerships (55%);
  - 4) recommending appropriate means of disseminating research results (13%); and
  - 5) advising on the development of community advisory boards (5%).

# Evaluation: Investigators

- A satisfaction questionnaire was developed in collaboration with the Evaluation and Tracking (E&T) team to survey investigators receiving a CEAB consultation.
- Online surveys are sent via email to investigators immediately after the CEAB meeting and at one-year follow-up to obtain feedback regarding the satisfaction and effectiveness of the consultation services received.



# Voices from the Community: Provide Feedback

CEAB members discussed that they would like to hear how investigators evaluated the consultations in order to refine the feedback they are providing and to determine whether additional types of expertise should be sought for inclusion on the advisory board. As they stated:

*“It would be nice to have some type of evaluation of our service, whether it’s useful or whether it’s not. If there some other way that we can improve it would be nice to know that. Otherwise, we’re just hitting, taking aim in the dark.”*

*“Well, sometime I feel I talk a lot here. I’m not sure how often it’s effective”.*



# Evaluations: CEAB Member Experiences

A total of 106 respondents across all years completed a survey of their experiences providing CEAB consultations.

Table 1: Community Engagement Advisory Board Member Survey (2010-2016, N = 106)																
Survey Question	Yes		No		Not at all		Slightly		Moderately		Very		Extremely		Not Sure	
	%	N	N	%	N	%	N	%	N	%	N	%	N	%	N	%
<b>Benefit of Consultations Offered</b>																
How helpful are consultations to researchers	-----		-----		0% (0)		0% (0)		6% (6)		36% (38)		54% (57)		4% (5)	
Do consultations improve a researcher's project	-----		-----		0% (0)		3% (3)		6% (6)		46% (49)		34% (36)		11% (12)	
Recommend a consultation to a researcher	98% (104)		2% (2)													
<b>Overall Satisfaction with CEAB membership</b>																
Feel welcome as a member	-----		-----		0% (0)		0% (0)		3% (3)		34% (36)		63% (67)			
Feel comments are valued	-----		-----		0% (0)		2% (2)		10% (11)		64% (67)		24% (25)			
Level of satisfaction with membership	-----		-----		0% (0)		0% (0)		2% (2)		41% (44)		57% (62)			
Plan to continue as a member	91% (98)		2% (2)												7% (8)	
<b>Increased Capacity as a Result of membership</b>																
How much have you learned	-----		-----		0% (0)		1% (1)		15% (16)		40% (42)		44% (47)			
Have you been able to apply new information to your setting	79% (82)		13% (14)												8% (8)	
Have you been able to make new community linkages*	51% (49)		29% (28)												20% (20)	
Have you been able to expand your networks*	76% (72)		11% (10)												13% (13)	

# Evaluation: Benefits of CEAB Membership

- Contributed to an increase in personal knowledge:  
*“Individually and, I think, for the community, the research projects have often time informed me of the latest scientific theories about treatment and so on, about things that are associated with positive outcomes.”*
- CEAB members felt that their involvement increased their capacity to bring resources to the communities and organizations that they represent:  
*“For the years I’ve been here, its allowed me to be able to take back of lot of what is going on in the UIC community that’s not always taken back to the people who need it the most. . . not just to patients and consumers but even to my peers and people who don’t get to participate.”*
- Enhanced their ability to secure their own funding for community engagement:  
*“Well, for me, I got my own study. Had it not been a member of this board, I would not have had access to the type of consultations that I received. It made a real difference in what I’ve been able to do.”*



# Conclusions

- Community engagement is essential to the successful translation of interventions and other healthcare advances into community settings.
- The CEAB at UIC's CCTS provides one model for providing community engagement and consultation to assist investigators with their translational science goals.
- More research should be conducted to evaluate and improve the experiences of community advisory board members as they contribute to engaging communities and advising researchers at all (and especially the early) stages of the translational continuum.

# Dissemination of CEAB Information

- Matthews, A.K. et al., (In Press). Development, implementation and evaluation of a community engagement advisory board: Strategies for maximizing success. *Journal of Clinical and Translational Science*
- Matthews, A.K., et al., (In Press). A community engagement advisory board as a strategy to improve research engagement and build institutional capacity for community engaged research. *Journal of Clinical and Translational Science*
- Matthews, A.K., et al., (In Press). Evaluation of three approaches for increasing patient engagement in clinical research: Feedback from a community engagement advisory board. *Journal of Clinical and Translational Science*
- Matthews, A.K., et al., (Under Review). Ready or not? Observations from a long-standing community engagement advisory board about investigator competencies for community engaged research. *Journal of Clinical and Translational Science*



# References

1. IOM (Institute of Medicine. 2013. The CTSA Program at NIH: Opportunities for advancing clinical and translational research. Washington, DC: The National Academies Press.
2. CTSA Principal Investigators. (2012). Preparedness of the CTSA's structural and scientific assets to support the mission of the National Center for Advancing Translational Sciences (NCATS). *Clinical and translational science*, 5(2), 121.
3. CTSA Community Engagement Key Function Committee (2011). Principles of community engagement (2<sup>nd</sup> ed., No.11-7782, Duke CTSA, grant number UL1RR024128: NIH Publication). Bethesda, MD: National Institute of Health.
4. Krieger, N., Kosheleva, A., Waterman, P. D., Chen, J. T., Beckfield, J., & Kiang, M. V. (2014). 50-year trends in US socioeconomic inequalities in health: US-born Black and White Americans, 1959–2008. *International journal of epidemiology*, 43(4), 1294-1313.
5. Singh, G. K., & Siahpush, M. (2014). Widening rural–urban disparities in all-cause mortality and mortality from major causes of death in the USA, 1969–2009. *Journal of Urban Health*, 91(2), 272-292.
6. Morris, Z.S., Wooding, S., Grant, J. (2011). The answer is 17 years, what is the question: Understanding time lags in translational research. *Journal of the Royal Society of Medicine*, 104, 510-520.
7. Krall R. US Clinical Research. Proceedings of Third CTSA Clinical Research Management Workshop, June 21–22, 2010; Bethesda, MD.
8. [Cyril S](#), [Smith BJ](#), [Possamai-Inesedy A](#), [Renzaho AM](#). Carnegie Foundation. What is Community Engagement. <http://nerche.org/index.php>
9. Task Force on the Principles of Community Engagement (2011). Clinical and Translational Science Awards Consortium. Principles of community engagement (11-7782).
10. Leung MW, Yen IH, Minkler M. Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *Int J Epidemiol*. 2004; 33(3): 499–506.
11. Bodison, S. C, Sankare, I., Anaya, H., Booker-Vaughns, J., Miller, A., Williams, P, Norris, K. (2015). Engaging the community in the dissemination, implementation, and improvement of health related research. *Clinical and Translational Science*, 8, 814-819.
12. O'Mara-Eves, A., Brunton, G., McDaid, G., Oliver, S., Kavanagh, J., Jamal, F., ... & Thomas, J. (2013). Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. *Public Health Research*, 1(4).
13. Newman, S.D., Andrews, J.O., Magwood, G.S., Jenkins, C., Cox, M.J., Williamson, D.C. (2011). Community advisory boards in community-based participatory research: A synthesis of best processes. *Preventing Chronic Disease*, 8(3), A70.
14. Gonzalez-Guarda, R. M., Jones, E. J., Cohn, E., Gillespie, G. L., & Bowen, F. (2017). Advancing Nursing Science Through Community Advisory Boards: Working Effectively Across Diverse Communities. *Advances in Nursing Science*, 40(3), 278-288.
15. Cramer, M. E., Lazoritz, S., Shaffer, K., Palm, D., & Ford, A. L. (2017). Community Advisory Board Members' Perspectives Regarding Opportunities and Challenges of Research Collaboration. *Western Journal of Nursing Research*, 0193945917697229.
16. Pinto, R. M., Da Silva, S. B., Penido, C., & Spector, A. Y. (2011). International participatory research framework: triangulating procedures to build health research capacity in Brazil. *Health promotion international*, 27(4), 435-444.

# Contact Information

**Hello**  
my name is

Phoenix A. Matthews

[Aliciak@uic.edu](mailto:Aliciak@uic.edu)

<https://www.nursing.uic.edu/faculty-staff/phoenix-alicia-matthews-phd>

# Closing Voice: The Value of the CEAB

*“We’re still learning, but we’re at the level where we need to be, so we can intelligently work together, and also get out of it what’s needed to really advance our quality of life in our community.”*

*- CEAB Member*

