

COMMUNITY ENGAGEMENT

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TRANSLATIONAL RESEARCH INSTITUTE (TRI)

Community Engagement Team



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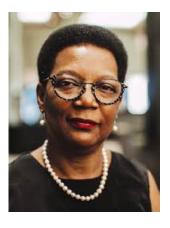
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OVERVIEW

Community engagement (CE) concepts

(definitions, importance, types)

TRI CE services and programs



IN THE CHAT:

What does community engagement mean to you?

WHAT IS COMMUNITY ENGAGEMENT?

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. (CTSA, 2011)



WHY IS COMMUNITY ENGAGEMENT IN RESEARCH IMPORTANT?

RESEARCHERS GAIN:

- Bidirectional relationships that build trust
- Contributions from diverse viewpoints and expertise
- Development of more informed and interesting research questions
- More effective designs
- More successful participant recruitment

COMMUNITIES GAIN:

- Influence and voice
- Research more focused on their pressing issues
- Capacity for positive change
- Access to new resources and opportunities

COMMUNITY ENGAGEMENT CONTINUUM

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

Outreach

Some Community Involvement

Communication flows from one to the other, to inform

Provides community with information.

Entities coexist.

Outcomes: Optimally, establishes communication channels and channels for outreach.

Consult

More Community Involvement

Communication flows to the community and then back, answer seeking

Gets information or feedback from the community.

Entities share information.

Outcomes: Develops connections.

Involve

Better Community Involvement

Communication flows both ways, participatory form of communication

Involves more participation with community on issues.

Entities cooperate with each other.

Outcomes: Visibility of partnership established with increased cooperation.

Collaborate

Community Involvement

Communication flow is bidirectional

Forms partnerships with community on each aspect of project from development to solution.

Entities form bidirectional communication channels.

Outcomes: Partnership building, trust building.

Shared Leadership

Strong Bidirectional Relationship

Final decision making is at community level.

Entities have formed strong partnership structures.

Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.

Reference: Modified by the authors from the International Association for Public Participation.

TRADITIONAL VERSUS PARTICIPATORY RESEARCH COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

CBPR is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.

(Viswanathan et al, 2004)







TRADITIONAL VERSUS PATIENT CENTERED OUTCOMES RESEARCH (PCOR)



Helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options.

What challenges do you think researchers face when working with community?

CHALLENGES TO COMMUNITY ENGAGED RESEARCH

- Distrust in research and/or research institutions
- Building relationships take time and effort outside of regular responsibilities
- High expectations for dissemination of results
- Differences between academic and non-academic cultures and priorities

SUPPORT SERVICES PROVIDED BY THE CETEAM

- Consultations
- Community connections/partnerships
- Technical assistance: Developing/implementing Community Advisory Boards (CABs)
- Community Review Boards (CRBs)
- Equipment Library
- Capacity building for community partnered research:
 - Do's and Don'ts of Community Engagement Workshop
 - Community Scientist Academy (CSA)
 - Community Partners Educated as Arkansas Research Leaders (CPEARL)
 - Community-Based Participatory Research (CBPR) Scholars Program

CE CONSULTATIONS

REQUEST VIA TRI PORTAL (TRI.UAMS.EDU REQUEST SERVICES GO TO SERVICES FORM)



- Advise researchers on incorporating CE into grants
- Trouble-shoot challenges related to engagement
- Help researchers develop new partnerships
- Advice and technical assistance on starting
 Community Advisory Boards

WHAT IS A COMMUNITY ADVISORY BOARD? DEFINITIONS VARY...

For example, Newman and colleagues:

CABs "often serve as a source of leadership in the partnerships of community-based participatory research (CBPR) and provide structure to guide the partnership's activities...[and] provide a mechanism for community members to voice concerns and priorities that otherwise might not enter into the researchers' agenda, and advise about suitable research processes that are respectful of and acceptable to the community."

(Newman et al, 2011)

WHAT IS A COMMUNITY ADVISORY BOARD?

DEFINITIONS VARY...

NCI's definition in relation to clinical trials:



"A group of non-scientist volunteers that serves as a link between a community and clinical trial researchers. A CAB may review and monitor clinical trials and help teach the community about the trials."

WHY CONSIDER A COMMUNITY ADVISORY BOARD? ENGAGEMENT OF THOSE AFFECTED IS IMPORTANT





- Provides lived experience perspective
- Builds relationships and trust
- Increases relevance and effectiveness of research questions, design, recruitment



FOR COMMUNITY:

- Builds relationships and networks
- Community priorities/issues
- Builds capacity for positive change
- Access to resources and opportunities



FOR FUNDING AGENCIES:

 May help fulfill requirements (e.g., PCORI, NIH, CDC...)

TRI COMMUNITY ADVISORY BOARD (CAB)

PROJECT/PROPOSAL REVIEWS

- **TRI CAB** Community representatives from around the state who advise TRI on issues that are important to different stakeholders.
 - Assist in prioritizing research initiatives
 - Increase TRI visibility at the community level.
- Review research proposals/projects for:
 - Importance to Community
 - Cultural Appropriateness/Sensitivity
 - Recruitment Strategies/Materials
 - Dissemination of Findings



TRI COMMUNITY ADVISORY BOARD (CAB)

PROJECT/PROPOSAL REVIEWS

Review options

- Full CAB Review (quarterly meetings) In-person presentation
- Subcommittee Review (schedule as needed between meetings) 3-4 CAB members participate in a conference call with the researcher(s) and CE team
- Letter of Support



COMMUNITY REVIEW BOARDS (CRB)

- Guidance session for researchers
- Provides immediate feedback
- May be done at any stage of your research
- Deepens understanding of the community of interest
- Assessment of feasibility and appropriateness of the project for the community
- Immersion into the cultural distinctions and possible historical issues



Dr. Snowden's Testimonial:

https://www.youtube.com/watch?v=VG KL0SJD60w

COMMUNITY REVIEW BOARDS (CRB) - EXAMPLES

Child obesity-related clinical trial

Dr. Jessica Snowden – Little Rock, LRSD CSA graduates

- Pediatric asthma
 - Dr. Tamara Perry
- COVID-19 Related Projects
 - Dr. Wendy Nembhard; Dr. Kris Patterson
- Second hand smoke in African American women
 - Dr. Pebbles Fagan Dumas
- FAITH Network Research Advocate Training
 - Drs. Keneshia Bryant-Moore, Martha Rojos (2 Marshallese Community/Springdale & Latinx Community/Conway)

EQUIPMENT LIBRARY

Step One: Request equipment via portal https://tri.uams.edu/request-services-2/

NEW ONLINE Request Process



- Link to REDCap survey will be sent to complete request
- Once survey is complete, a time will be scheduled to pick up the equipment
- Please allow at least 48 hours for this process
- Equipment can be loaned for up to 2 months

Inventory

















Laptops (and accessories)

iPads (and accessories)

LCD Projectors

LCD Projector Screen

iPad Docking Stations

Easels

iPad Covers

Portable PA System

Folding Table with Wheels

COMMUNITY SCIENTIST ACADEMY (CSA)

- Educate community members and/or patients on the research process
- Create a pool of stakeholders who can influence TRI's research by serving on steering committees, mentoring committees, review committees, research projects and in other leadership capacities.
- Covers the basics steps of the research process
- Features small group sessions with researchers
- Presented using lay friendly language
- Interactive
- Modified versions available



- Different formats available: From a 1-day intensive to weekly sessions over 6 weeks
- Curriculum can be modified based upon the need of the targeted participants

For more info see: Stewart et al, 2018

EXAMPLE: CSA NEW FORMAT LITTLE ROCK SCHOOL DISTRICT EXCEL PROGRAM





Spring 2019 – Pilot

- 10 week academy
- 26 Graduates
- PhotoVoice Project & Paper

Fall 2019 - *Current

- Modified sessions to 3 small groups
- Included Kahootz! & "games" for research content
- PhotoVoice Project

PROGRAMS TO SUPPORT CBPR

Community Partners Educated as Arkansas Research Leaders (CPEARL)

- One year leadership institute for community based organizational leaders
- Seed grant for community project
- Research mentoring and community consultation
- Piloted in 2020, Next round and New Changes for 2022 CPEARL

CBPR Scholar Program Due to pandemic moved from hybrid to all online version currently being piloted

- 9 month training program for a partnership between academic and community based researchers to receive Community Based Participatory Research (CBPR) training
- Develop meaningful, equitable partnerships
- Submit a scientifically sound funding proposal for targeted pilot funding of up to \$50,000 from the TRI.



Improving health literacy among monolingual Spanish patients



Assessing and addressing priority health concerns



Conscious discipline intervention for families with high ACES



Educational outreach to rural African American men



Peer advocates for criminal justice system navigation



Physical fitness for developmentally disabled young adults

2020 CPEARL - Organizations and Project Topics

CBPR SCHOLARS PROGRAM OVERVIEW

What is the time commitment of the participants?

- <u>I year commitment:</u> Complete 6 online modules, meeting with your academic and community mentors, monthly zoom content meetings, and meetings with community partner for activities
- 10 hours a month

What is the eligibility criteria?

- Each team IS REQUIRED to have the following members:
 - Primary researcher: UAMS faculty with a terminal degree (assistant professor or above) who
 has dedicated time and research experience
 - Community organization partner: 501c3
- Each team may have additional researchers/clinicians within and outside the UAMS (ex: UAPB, UALR, etc.) Multi-disciplinary team: we encourage multi-disciplinary teams to apply but this is not required.
- New partnerships: limited to no experience with CBPR
- Researcher: limited to no experience with this organization

2021 CBPR SCHOLARS

Academic Partners	Community Partner(s)	Target Population
Melissa Zielinski, Ph.D., Katy Allison, Ph.D	Arkansas Foundation for Suicide Prevention	Individuals currently Incarcerated
Gerry Ezell, M.D., Jennifer Naylor, Ph.D.	River City Ministries	Individuals currently Unhoused/Homeless or recently transitioned to housing
Eva Woodward, Ph.D., Jennifer Gan, Irenia Ball	Arkansas Freedom Fund	Rural Veterans
Brooke Montgomery, Ph.D	Our House, Inc.	Individuals currently Unhoused/homeless
Deanna King, M.D., Ph.D., Charia Hall, Au. D., Rachel Glade, Ph.D. (UofA- Fayetteville)	Arkansas Hands and Voices	Rural Hearing Impaired Children
Wendy Nembhard, Ph.D., Katie Brown, O.D., Kirk Leach, Ph.D. (UALR), Jennifer Gan, Leah Dawson, Ph.D., Joe Schaffner, Maria Ruvalcaba	Shepherds Hope	Spanish Speaking Community
Sanjay Maraboyina, M.D., Analiz Rodriguez, M.D., Ph.D., Cynthia Dillport, LCSW, and Harriet Farley, LCSW	Home for Healing Goodness Village	Rural Cancer Patients

THANK YOU!

For more information, contact us here:

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