
COMMUNITY ENGAGEMENT IN RESEARCH

UAM TRANSLATIONAL RESEARCH INSTITUTE'S RESEARCH AND CAREER DEVELOPMENT SERIES

Presented Fall 2018 by:

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TRANSLATIONAL RESEARCH INSTITUTE (TRI)

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OVERVIEW

- Community engagement (CE) concepts
(definitions, importance, types)
- Community engagement strategies
- TRI CE services



HOW DO WE DEFINE COMMUNITY?

- Does your research involve anyone outside of your institution?
- If so, who? Do you consider them as “community”? What is their role?
- If not, do you think you should be engaging others in your research? Why or why not?

EXERCISE:

Find someone you don't know or whom you know the least.

2-3 minutes total sharing time (1-2 minutes each)

When you hear the bell, find another partner and repeat sharing...

DEBRIEF

- What did you hear? How are we defining community?
- Is there a difference between communities and stakeholders?
- Who defines what “community” means?
- Who represents “the community”?



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

TYPES OF COMMUNITY ENGAGEMENT IN RESEARCH

- More traditional collection of formative data or place-based research
- One time community review of research (Joosten, 2015)
- Community advisory boards (Wilkins, 2013)
- Community-based participatory approaches with formal partnerships and engagement throughout issue selection, study design, study implementation and dissemination (Minkler, 2008; Israel, 2005)
- Community-initiated research driven by the community itself (Tau Lee, 2008)



KEY PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH

- Recognizes community as unit of identity
- Builds on community strengths and resources
- Facilitates collaborative, equitable partnerships
- Promotes co-learning and capacity building among all partners
- Balances between research and action for mutual benefit
- Emphasizes local relevance and ecological perspective
- Involves systems development through cyclical, iterative process
- Disseminates findings/knowledge to all partners
- Involves long-term process and commitment
- Addresses issues of race, ethnicity, racism, and social class and embraces cultural humility.



(Israel et al, 2005; Wallerstein, et al, 2018)

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)



STRATEGIES INCORPORATING BEST PRACTICES FOR ENGAGEMENT

- Compensating those we engage for the time and effort they contribute (Black, 2013);
- Identifying community needs and priorities (Minkler and Hancock, 2008; Issel, 2009)
- Formalizing community partnerships through written agreements (Pivik, 2011)
- Shared allocation of resources (Cain, 2014)
- Building both community and researcher capacity for engagement (Calzo, 2016; Huang, 2017)
- Addressing barriers to participation such as language, transportation and childcare (Bonevski, 2014)
- Using guidelines to assess the participatory nature of proposals aiming to engage intended users of the research (Mercer, 2008; PCORI, 2016)
- Shared decision-making and involvement in dissemination of findings, including returning results to participants (Israel, 2005; Long, 2016; Purvis, 2017).

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.

COMMUNITY ENGAGEMENT CONTINUUM

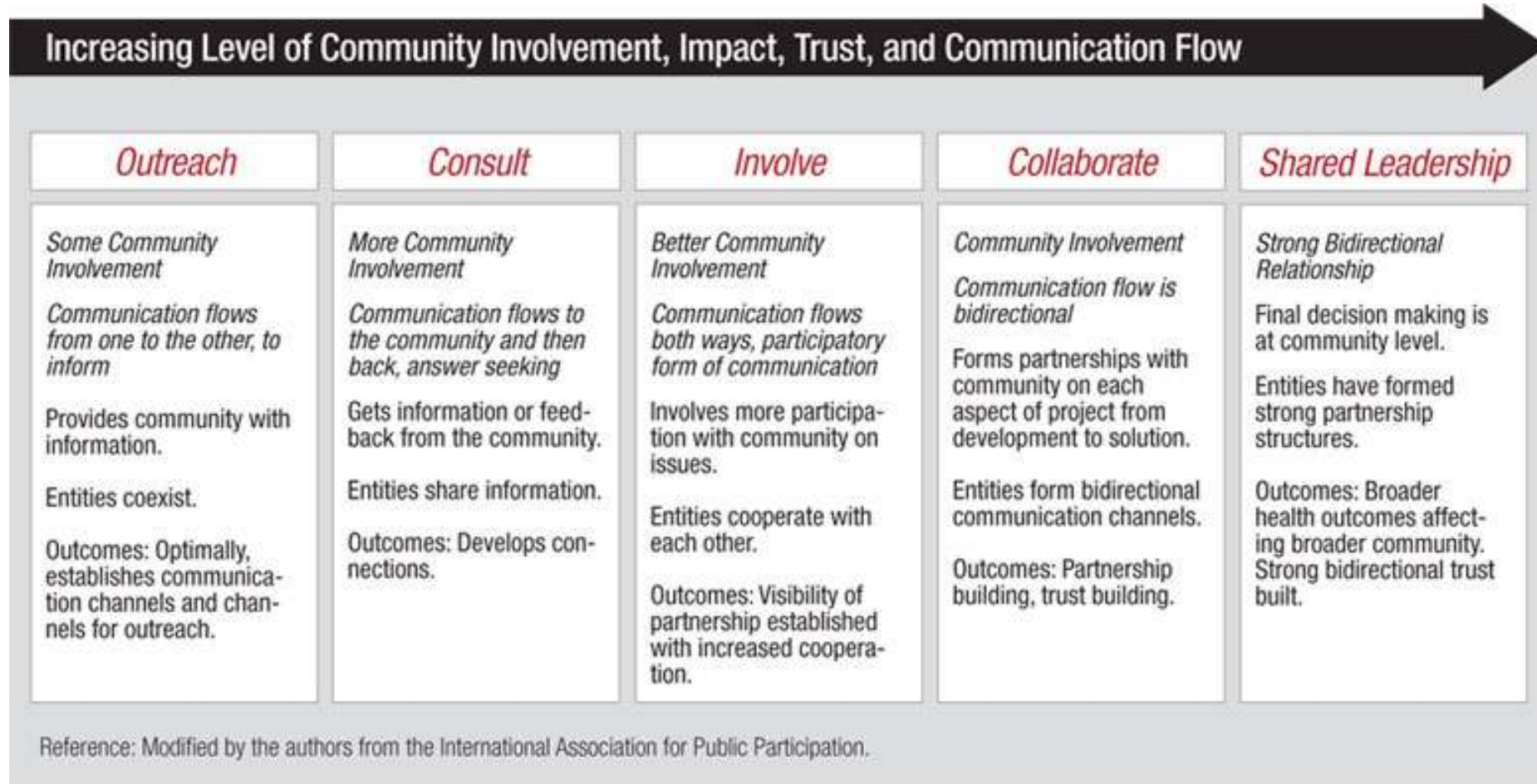


Figure 1.1. Community Engagement Continuum (CTSA, 2011)

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 CE TEAM

- Consultations
- Help researchers develop contacts with pre-identified populations
- Advice and technical assistance on starting Community Advisory Boards (CABs)
- Community Review Boards (CRBs)
- Do's and Don'ts of Community Engagement Workshop
- Equipment Library
- Community Scientist Academy (CSA)
- CSA Toolkit
- Arkansas Community Researcher Training (ArCRT)
- Community Partner Celebration



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.”

(NCI)



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



FOR RESEARCHERS:

- 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...)

CAB EXAMPLES OF POSITIVE IMPACT

- **Translational Research Institute CAB**
 - Community Partner Celebration
 - Community Scientist Academy
- **Arkansas Prevention Research Center CAB**
 - Dos and Don'ts of Community Engagement Workshop
- **Transform Health Arkansas**
 - Partnership members co-developed survey, recruited for and ran summits to identify priorities
- **FAITH in the Delta**
 - Faith Task Force recruited churches to participate in survey



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



COMMUNITY REVIEW BOARDS (CRB) - EXAMPLES

- iClick 911 – Dr. Aliza Brown
- Pediatric asthma – Dr. Tamara Perry
- Surrogate decision-making for ICU patients – Dr. Thomas Cunningham
- Smoking among African American women breast cancer survivors – Dr. Pebbles Fagan



DO'S AND DON'TS OF COMMUNITY ENGAGEMENT



- 4 hour workshop for researchers and research staff
- Uses storytelling and reverse role play
- Conducted by TRI CE Staff and Community Partners
- Covers three domains of CE:
 - Entering the community
 - Accommodating the realities & constraints of community-based organizations
 - Disseminating results

For more info see: Coffey et al, 2017.

EQUIPMENT LIBRARY

Requests are to be submitted in the TRI Portal

Dell Tablets (9)

iPads (50)

iPad Chargers (15)

LCD Projector

LCD Projector Case

LCD Projector Screen

DVD Burner and Duplicator

Video Camera

Dell Laptop Bags (3)

iPad Docking Stations (3)

iPad Covers (3)

OtterBox (25)

Folding Table with Wheels (4)

Panel Tri-Fold Display Boards (6)

Pop Up Tents

Room Partition

Portable PA System



ARKANSAS COMMUNITY RESEARCHER TRAINING (ARCRT)



- ArCART, a new human subjects training video, is available for community members working in partnership with UAMS faculty researchers.
- The online ArCART is a community-friendly course that was produced as an **ALTERNATIVE** to Collaborative Institutional Training Initiative (CITI) training.
- ArCART is intended for community partners **WITHOUT** a science background.

TRI modeled the CIRTification program from the University of Illinois at Chicago. They have a several session, F2F program. We converted it to online modules.

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

For more info see: Stewart et al, 2018



CSA TOOLKIT

AVAILABLE ONLINE SOON!

UAMS
UNIVERSITY OF ALABAMA
AT MONTGOMERY

Community Scientist Academy Toolkit

A Comprehensive Guide to Create and Facilitate a Community Scientist
Academy at your institution



Translational Research Institute Community Engagement Team
UNIVERSITY OF ALABAMA AT MONTGOMERY | 2019-2020

- Introduction
- Background/Purpose
- Start-up Issues to Consider
 - Gauge Community Interest
 - Determine Target Population
 - Determine Length/Dates/Time
 - Select Location
 - Identify Guest Researchers
 - Create Budget
 - Roles and Responsibilities of Sponsors and Trainers
- Curriculum & Session Structure
- Marketing and Recruitment
- Participant Registration
- Logistics
- Graduation
- Evaluation
- Appendices
 - Sample Budget
 - PowerPoint Presentations (Sessions 1-5)
 - Sample Marketing Materials
 - Sample Registration Form
 - Sample Graduation Program
 - Sample Graduation Certificate
 - Sample Pre-/Post Evaluation Tools
 - Sample Feedback Survey
 - Sample Participant Interest Form

COMMUNITY PARTNER CELEBRATION (CPC)

The UAMS Community Partner Celebration (CPC) is a campus wide celebration honoring our outstanding community partners that have helped make our various endeavors possible, whether it involves research, education and training, or services.

The following awards are presented at the CPC:

- Community Partnership Student Award
- Institutional Health Partner Award
- Community-Based Organization of the Year Award
- Community Advisory Board of the Year Award
- Chancellor's Community Research Partner Award



The Translational Research Institute will host its sixth annual “UAMS Community Partner Celebration” on **November 16, 2018**.

WE ARE CURRENTLY ACCEPTING NOMINATIONS FOR THIS YEAR'S CELEBRATION!!

To nominate your community partner, please visit the TRI website's Community Partner Celebration Page.

If you have any question, please contact, Rachel Hale, rbhale@uams.edu

THANK YOU!

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