# Community Engagement Matters

... a brief introduction to Community-Engaged Research

Karen Glanz, PhD, MPH George A. Weiss University Professor Director, Community Engagement and Research Core

May 15, 2025









## **Objectives**

- Basic principles of community-engaged research
- Describe different approaches to community-engaged research
- Apply community-engaged research concepts to patient and provider engagement
- Understand practical and ethical challenges of including patients and providers as participants

## Background

- Center for Health Behavior Research
- UPenn Prevention Research Center
- Community Engagement and Research (CEAR) Core of Clinical and Translational Science Award (CTSA/ITMAT)
- Long history of conducting community-engaged research

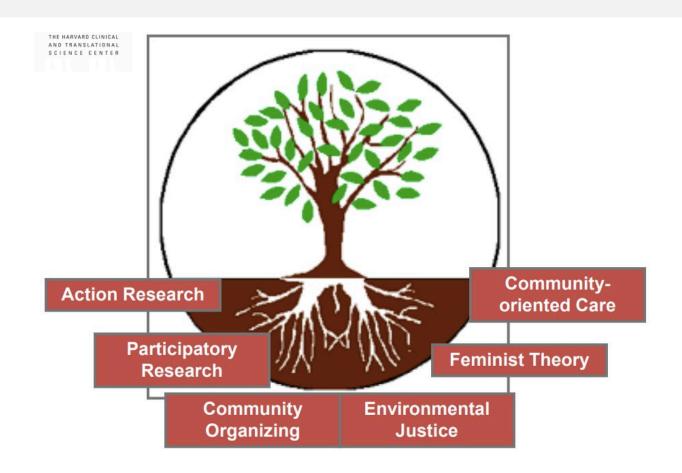




## Overview of Community Engagement (CE)

- Working definition:
  - "...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."
- General goals of Community Engagement
  - Build trust between academics and community members/organizations
  - Involve community members/organizations in research as participants and co-investigators
  - Create and maintain mutually beneficial relationships between researchers and participants
  - Improve overall health outcomes for relevant community/ies

## Roots of Community Engagement



https://catalyst.harvard.edu/pdf/regulatory/CEnR\_Webpage\_101\_Presentation.pdf

## Comparison of Research Types

	Traditional	Community-Engaged	CBPR
Research Objective	Based on epidemiologic data & funding priorities	Community input in identifying locally relevant issues	Full participation of community in identifying issues of greatest importance
Study Design	Design based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is culturally acceptable	Community intimately involved with study design
Recruitment & Retention	Based on scientific issues & "best guesses" regarding how to best reach community members	Researchers consult with community representatives on recruitment & retention strategies	Community representatives provide guidance on recruitment & retention strategies and aid in recruitment
Instrument Design	Instruments adopted/adapted from other studies. Tested chiefly w/psychometric analytic methods.	Instruments adopted from other studies & tested/adapted to fit local populations	Instruments developed with community input and tested in similar populations

## Comparison of Research Types

	Traditional	Community-Engaged	CBPR
Data	Conducted by academic	Community members	Conducted by members of the
Collection	researchers or individuals	involved in some aspects of	community, to the extent possible
	w/no connection to the	data collection	based on available skill sets. Focus
	community		on capacity building.
Analysis &	Academic researchers own	Academic researchers share	Data are shared; community
Interpretation	the data, conduct analysis	results of analysis with	members & academic researchers
	& interpret the findings	community members for	work together to interpret results
		comments & interpretation	
Dissemination	Results published in peer-	Results disseminated in	Community members assist
	reviewed academic	community venues as well as	academic researchers to
		scientific publications	disseminate results (public meetings,
			radio, etc.) in a timely manner &
			community members involved in
			dissemination. Results also
			published in peer-reviewed journals.

## What kinds of questions can be answered with CE research?

- Epidemiological or descriptive studies
  - What's true for this community?
- Creating practice-based evidence
  - Does this community-based and created program work?
- Creating evidence-based practice
  - Does this program or intervention work in a community setting?



## 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.

Principles of Community Engagement, Second Edition, 2011.

## **Models and Frameworks**

#### The Social Ecological Model



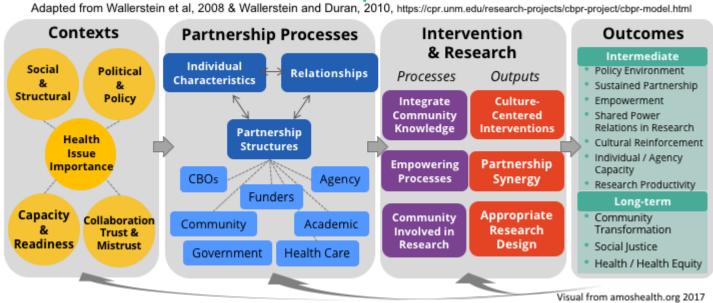
Principles of Community Engagement, Third Edition. 2025.

Salvo, D., Durand, C., & Jáuregui, A. Ecological Models of Health Behavior. In Glanz, Rimer & Viswanath (eds.), *Health Behavior: Theory, Research, and Practice*, Sixth Edition. San Francisco: Jossey-Bass, Inc., 2024.

### **Models and Frameworks**

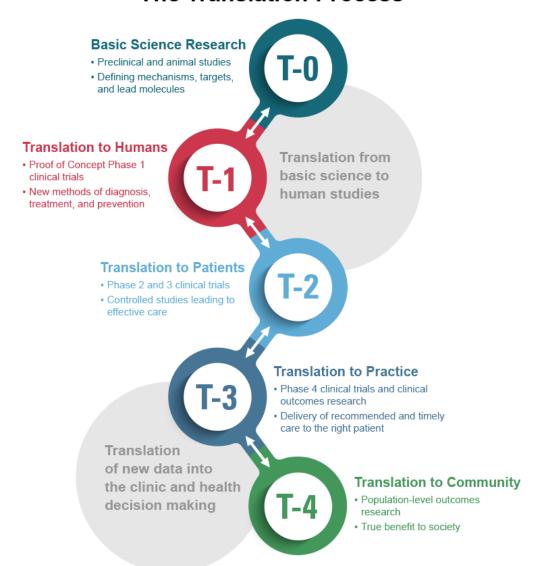
#### Community-Based Participatory Research

## **CBPR Conceptual Model**



Principles of Community Engagement, Third Edition, 2025.

#### **The Translation Process**



## Principles of Community Engagement

- **Principle 1.** Be clear about the purposes or goals of the engagement effort and the populations and/or communities you want to engage.
- **Principle 2.** Become knowledgeable about the community's culture, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experiences with efforts by outside groups. Be aware of each other's perceptions of past engagement activities.
- **Principle 3.** Build and maintain relationships and trust by working with individuals and/or community leaders.

## Principles of Community Engagement

- **Principle 4.** Remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it can bestow on a community the power to act in its own self-interest
- **Principle 5.** Establish a partnership with the community to create change and improve health.
- Principle 6. Recognize and respect diversity within the community.
- **Principle 7.** Identify and mobilize community assets and strengths by developing the community's capacity and resources to make decisions and take actions.



## Principles of Community Engagement

- Principle 8. Recognize that individuals and institutions must be prepared to release control and be sufficiently flexible to meet changing needs.
- **Principle 9.** Foster community collaboration and strengthen long-term commitment among the partners.
- Principle 10. Demonstrating trustworthiness is fundamental to sustaining successful community engagement.



## The Ethics of Community Engaged Research

- Community engaged research is based on relationships
  - Consider the power dynamics
- Limits of the IRB
- Ethical interactions among partners
  - Beyond official research subjects
- Dissemination plan
- Evaluating risks and benefits
  - Community consent



## Challenges and Barriers: Academic perspective

- Mismatch between academic and community interests and expectations
- Time investment
- Not traditionally prioritized by academia
- Expectations for dissemination of results
  - Community members often expect to hear about results soon after the research is completed; don't want to wait the months or years it takes to appear in academic journals

## Challenges and Barriers: Community perspective

- History of leaving community concerns and interests out of the research agenda, leading to caution on the part of communities
- Time: research is often an additional responsibility
- Unclear distinctions between research, advocacy and administrative change can lead to unrealistic expectations

### Penn and CHOP Resources: CEAR Core

- Who we are:
  - Part of the Clinical and Translational Science Award (CTSA), which is funded by the National Institutes of Health (NIH) and awarded jointly to Penn and CHOP
- What we do:
  - Facilitate initiatives in community-engaged research, collaboration, and multidisciplinary team science.

https://cear-itmat-upenn.org/



Hub for Community-Engaged Research



Training for Community
Partners in Research



**Pilot Grant Funding** 



Community Driven Research Day



Research Consultation

### Penn and CHOP Resources

- Community Engagement and Research Core
- Community-Driven Research Day
- Penn Medicine CAREs Grants
- Community Needs Health Assessment and Implementation



Community Engagement is at the heart of many of our activities...

## Funding Acknowledgements

- Clinical and Translational Science Award UL1TR001878 from the National Institutes of Health, National Center for Advancing Translational Sciences (CEAR Core)
- Health Promotion and Disease Prevention Research Center cooperative agreement 1U48DP006801 and 1U48DP006865, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$6.5 million (2024-2029). (UPenn Prevention Research Center)
- The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

### **Citations**

- Duke CTSI. Community Engagement Overview: Frequently Asked Questions. https://ctsi.duke.edu/community/community-engaged-research-initiative/resources-community-engaged-research/ceri-e-16
- Glanz K, Rimer BK, Viswanath V (Eds.). Health Behavior: Theory, Research, and Practice, Sixth Edition. San Francisco: Jossey-Bass, Inc., 2024.
- Ohio University Center for Community Engagement. Community-Engaged Research, 2025. https://www.ohio.edu/student-success/community-engagement/community-engaged-research
- NCATS Alliance. What is Translational Science, 2025. https://ncatsalliance.org/what-is-translational-science/
- Pasick R, Oliva G, Goldstein E, Nguyen T. Community-Engaged Research with Community-Based Organizations: A Resource Manual for UCSF Researchers, 2010. https://accelerate.ucsf.edu/sites/default/files/CE/guide\_for\_researchers.pdf
- Principles of Community Engagement, Third Edition, 2025.
   https://www.aamchealthjustice.org/media/8061/download?attachment

# Contacts and Consultations

#### Karen Glanz, PhD, MPH

Director, Community Engagement and Research Core Director, UPenn Prevention Research Center kglanz@upenn.edu

#### Krista Scheffey, MPH, MSW

Project Manager, Community Engagement and Research Core Deputy Director, UPenn Prevention Research Center Krista.Scheffey@pennmedicine.upenn.edu