

# PATIENT & COMMUNITY ENGAGED RESEARCH

Group Technical Assistance  
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Environment

# WEBINAR OBJECTIVES

1. Distinguish between traditional research and Community and Patient Engaged research, and how it has evolved over time
2. Describe a brief history of Community and Patient Engaged research
3. Explain why Community and Patient Engaged research is relevant to P2P projects
4. Recognize challenges and barriers to successful Community and Patient Engaged research
5. Identify best practices in Community and Patient Engaged research

# WHAT IS COMMUNITY ENGAGED (CE) RESEARCH?

“Research that involves connecting broad groups of people connected by neighbourhoods, special interest, or other characteristics to better understand issues they have identified as affecting their well-being and that of their community”

*North Carolina Clinical and Translational Sciences Institute*

	Traditional Research	Community Engaged Research
<b>Research Objective</b>	Based on epidemiologic data and funding priorities	Community input in identifying locally relevant issues
<b>Study Design</b>	Design based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is culturally acceptable
<b>Recruitment &amp; Retention</b>	Based on scientific issues and “best guesses” regarding how to best reach community members	Researchers consult with community representatives on recruitment and retention strategies
<b>Instrument Design</b>	Instruments adopted/adapted from other studies. Tested chiefly with psychometric analytic methods.	Instruments adopted from other studies and tested/adopted to fit local population
<b>Data Collection</b>	Conducted by academic researchers or individuals with no connection to the community	Community members involved in some aspects of data collection
<b>Analysis &amp; Interpretation</b>	Academic researchers own the data, conduct analysis and interpret the findings	Academic researchers share results of analysis with community members for comments and interpretation
<b>Dissemination</b>	Results published in peer-reviewed academic journals	Results disseminated in community venues as well as peer-reviewed journals

# CE RESEARCH QUESTIONS

How are research questions generated?

- ▮ Then: hierarchically by a “top-down” approach
- ▮ Now: collaboratively through consensus-building

What types of questions are funded?

- ▮ Then: funding for pre-clinical research and clinical trials only
- ▮ Now: funding for clinical implementation and population health research also

What are the roles of patients and community in generating research questions?

- ▮ Then: research subjects
- ▮ Now: research subjects, research influencers, and RESEARCHERS

# HOW DID CHANGE HAPPEN? A VERY BRIEF HISTORY

**1932-1972:** Tuskegee Syphilis Study

**1947:** The Nuremberg Code

**1960s and 1970s:** Civil Rights, other social justice movements in the US, Empowerment Model

**1979:** The Belmont Report

**1986:** NIH Policy on Inclusion of Women and Minorities in Clinical Research

**Late 1990s:** Formal beginning of Community-Based Participatory Research

**2006:** Clinical and Translational Science Awards (CTSAs) launched by NIH

**2010:** Affordable Care Act, PCORI established

# Patient Engaged Research uses CE principles to assess priorities and CE processes to answer questions.

- ▢ CE methods are used to identify topics of interest to patients and caregivers, and address related research questions
- ▢ Both lead to more long-term, sustainable interventions and improvements because people are involved and invested in the process and outcomes
- ▢ Takes place in clinical or community settings with application/intervention occurring in clinical settings
- ▢ Overarching goal is to improve patient health outcomes
  - ▢ Benefits parallel those of CE research, but *may* be more specific to patient populations utilizing the healthcare system

# CE RESEARCH & PCOR QUESTIONS

PCORI Funding Priorities	CE Research Areas
Assessment of Prevention, Diagnosis, and Treatment Options	Projects that address critical decisions that patients, their caregivers and clinicians face
Improving Healthcare Systems	Projects that address critical decisions that face health care systems, the patients and caregivers who rely on them, and the clinicians who work within them
Communication and Dissemination Research	Projects that address critical elements in communication and dissemination among patients, caregivers and clinicians



# DIFFICULTY OF CE IN PRACTICE

“Involving the community” is a concept that seeds anxiety for many institutions, from federal agencies to area schools, churches, and non-profits.

These institutions may not know where to begin or they may worry about the implications of not being in control of the relationship - especially when examples of successful, genuine engagement are hard to find. Shallow approaches can engage other community members but inevitably preserve the status quo.

When a community is authentically engaged in dialogue and collaboration, their boundaries can expand. Community assets are acknowledged, respected, and mobilized.”

*NACCHO Roots of Health Inequity*

# DIFFICULTY OF CE IN PRACTICE... YOU SAID IT!

- TIME
- Award administration
- Fiscal administration
- Communication
- Ongoing engagement and commitment
- Competing priorities
- Disturbs the normal way of working
- IRB
- Unclear guidelines
- Sustainability of resources
- And more...

# EXAMPLES OF OVERCOMING BARRIERS IN CE RESEARCH

## **1. Acknowledge the challenges of CE research and develop solutions early**

- ▮ A community organization was struggling to maintain funding, so they created a network of institutions to increase capacity while also building opportunities for enhanced public participation in research.
- ▮ This multi-faceted group has allowed for a consistent flow of resources and given community a voice in health research.

## **2. Mobilize a community's existing assets, both people and institutional resources**

- ▮ Academicians looking to develop a weight loss intervention engaged fitness professionals at community recreation centers to partner on all aspects of study design, implementation and dissemination.
- ▮ As a result, participants lost more weight than controls.

## **3. Establish consistent project-wide goals but modify objectives based on local conditions**

- ▮ In response to the needs of a community who noticed a spike in cancer rates, a project included the collection of biospecimens in one county enrolled in a large study, against the advice of the funder, who deemed the activity too costly.
- ▮ Mutual trust and benefit allowed for successful implementation of this study and future research partnerships.

*Adapted from Principles of Community Engagement (Second Edition)*

*Donna Jo McCloskey et al (2011)*

# RESOURCES

A Quick Start Guide to Conducting Community Engagement from the Southern California Clinical and Translational Science Institute Office of Community Engagement [http://oprs.usc.edu/files/2013/01/Comm\\_Engaged\\_Research\\_Guide.pdf](http://oprs.usc.edu/files/2013/01/Comm_Engaged_Research_Guide.pdf)

CE Research 101 from the North Carolina Clinical and Translational Sciences Institute <http://portals.tracs.unc.edu/index.php/research101>

Community Engaged Research Resource Page from University of Southern California <http://oprs.usc.edu/initiatives/cm/>

National Association of County and City Health Officials (NACCHO) Roots of Health Inequity <http://rootsofhealthinequity.org/>

NIH Research Ethics Timeline (1932-Present) by David Resnick <http://www.niehs.nih.gov/research/resources/bioethics/timeline/>

Principles of Community Engagement (Second Edition) by Donna Jo McCloskey et al for the Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement [http://www.atsdr.cdc.gov/communityengagement/pdf/PCE\\_Report\\_508\\_FINAL.pdf](http://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf)

QUESTIONS?  
THANKS FOR JOINING US!

See you Wednesday, July 15  
12:30 pm Mountain/11:30 am  
Pacific  
Partnership & Coalition  
Development