Foundations in Community-Engaged Research: Rationale and Theory

Eugenia Eng
University of North Carolina at Chapel Hill

DeWanna Hamlin
Wake Forest School of Medicine

Scott D. Rhodes
Wake Forest School of Medicine

Seminar Series Objectives

- Describe the underlying rationale for community-engaged research.
- Outline theories and strategies designed to increase community-engaged research.
- Identify methods aligned with community engaged research.

Outline for Today’s Seminar

- Our respective pathways to community-engaged research to enhance health equity.
- The continuum of community engagement.
- Factors important to approaching and establishing partnerships with a community.
- Examples of key components and values of and outcomes from community-engaged research to enhance health equity.

Series

- **Today**: Foundations in community-engaged research: Rationale and theory
- **October 3, 2017**: An introduction to photovoice as a method aligned with community-engaged research
- **November 14, 2017**: Citizen science: A novel and emerging method to knowledge generation
- **December 14, 2017**: Recruitment and retention of “hard-to-reach” populations: Successful strategies to increase the participation of Latinos in research

DeWanna
Community-Engaged Research Continuum

ON IN WITH

Courtesy of Nina Wallerstein, DrPH
NM CARES Health Disparities Center, 2011

Conflict, Contradictions, and Change by Design

Duality of a Bowl

Space, Room, Freedom, Opportunity

Boundary, Border, Control, Limitation

Contradictions

Study design, budget, and proposal reflects community ownership and authenticity

Study design and budget proposed reflects review of scientific literature and feasibility
**Contradictions**

Effective and sustainable interventions are informed by the concerns, culture, and assets of participating community.

Interpretation, dissemination, and translation of findings aimed at transferability through CBO channels of communication.

**Arnstein's ladder of citizen participation**


**Health Equity and Social Justice**

- **At the core of community engagement is a commitment to health equity and social justice.**
- **Health equity** is the absence of systematic, unjust disparities in the determinants of health among communities with different levels of social advantage or disadvantage.
- **Social justice** generally refers to the idea of creating an egalitarian society or institution that is based on the principles of equality and solidarity, that understands and values human rights, and that recognizes the dignity of every human being.

**Equality vs. Equity**

- Participation of lay community members, organization representatives, local businesses, and academic researchers
- Relationships are critical
  - “Be early, stay late”
  - If you mess up, own it and apologize
- Unflagging commitment, cooperation, and negotiation to identify, work towards, and meet goals/aims
  - Transcends 1 project
- Transparency, and open and honest communication
- Assume best intentions

**Values of Community-engaged Research**
Values of Engagement, continued

- Multidirectional exchange of information, learning, and capacity development
- Willingness to be uncomfortable
- A focus on community empowerment
- Assets orientation
- Conflict among partners as a catalyst to improve processes and outcomes
- Shared power and resources
- Action orientation
- Celebrate, celebrate, celebrate!
- Ongoing reflection

Who’s at the table?

- Where is the table?
  - Place matters
  - Community vs. institution
- Whose issues/agendas are at the table?
  - Values
  - Agendas
- Who sits at the table?
  - Representation
  - Historical mistrust/inequities
- Who “sets” the table?
  - Guidelines
  - Decision making
  - Budget
  - Control
  - Structure
  - Shared power/collaboration

Road to Engagement

A road to engagement

In the beginning...

Defining the Problem

Selecting Partners

The Greensboro Health Disparities Collaborative

A community-academic-medical partnership which conducted
Cancer Care and Racial Equity Study (CCARES)
NCI 5-R21-CA119979-01
and
Accountability for Cancer Care through Undoing Racism and Equity (ACCURE)
NCI 1-R01-CA150980-01A1

Undoing Racism™ Framework

- Challenges participants to analyze the structures of power and privilege that hinder social equity
- Prepares them to be effective organizers for justice
- Provides a historical and institutional understanding of and shared definition for racism
Organized its membership
Held its first meeting
Held Undoing Racism Workshop

May 2004
• Internalized Racial Oppression/Superiority in Health Care focus group

June 2004
• Undoing Racism Workshop

Sept 2004
• CBPR Training
• Full-Value contract signed
• Grant-writing sub-groups formed

Research Questions:
• Did African American and White women with breast cancer in Guilford County, NC, receive cancer treatment that was the same?
• If the breast cancer care was not the same, how was it different and what could have been the reasons?

Qualitative Methods in CCARES
• Critical Incident Technique

Cancer Care and Racial Equity Study (CCARES)

Who are the partners?
Greensboro Health Disparities Collaborative 2008
Conclusions

Community-engaged research is a democratic process; brings diverse partners, experiences, and perspectives together to promote social justice; and increases the relevance and translation of research into health impacts.
- Builds bridges
- Addresses needs, priorities, and assets
- Ensures more informed understanding of health phenomenon
- Produces efforts that are more likely to be culturally congruent, effective, sustained, translatable, and disseminable
- Promotes study designs that are just and “do-able”
- Recruitment and retention rates may be higher
- Measurement may be more precise
- Data collection may be more acceptable, complete, and meaningful
- Data analysis and interpretation may be more accurate
- The underlying factors of social injustices and inequities may be affected

“Communities deserve the best science.”
- Dr. Flavio Marsiglia, Arizona State University

And the best science comes about from working together in authentic partnership, building on knowledge, experiences, and perspectives

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Thank You

Eugenia Eng
Eugenia_Eng@unc.edu

DeWanna Hamlin
DLTHamlin@yahoo.com

Scott D. Rhodes
SRhodes@wakehealth.edu

http://northwestahec.wfubmc.edu/mura/www/?utm_campaign=none&utm_source=redirectlink&utm_medium=none/#/event/52918

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