Community-Based Participatory Research Slides Text Version

Slide 1
Community-Based Participatory Research: Lessons for Stakeholder Engagement in Patient-Centered Outcomes Research

June 19th, 2013

Slide 2
Welcome

Penny Mohr, MA

Senior Vice President, Program Development

Center for Medical Technology Policy

Image: Photograph of Penny Mohr.

Slide 3
AHRQ Community Forum

- To expand stakeholder involvement in comparative effectiveness research in AHRQ's Effective Health Care Program
- To advance methods for gathering public input on value-based healthcare questions
- Learn more: http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/ahrq-community-forum

Image: Photograph of a speaker at a workshop or conference.

Slide 4
Today's Goals

- To bring together experts in the fields of CBPR and stakeholder engagement in PCOR
- To discuss ways in which key lessons from CBPR can enhance stakeholder engagement methodology
- To encourage greater dialogue and resource sharing between the CBPR and PCOR research communities going forward

Slide 5
Webinar Speakers

Patricia Deverka, MD, MS, MBE

Senior Research Director

Center for Medical Technology Policy

Dwyan Monroe

Community Outreach Trainer/Patient Representative

C. Daniel Mullins, PhD

Professor

Department of Pharmaceutical Health Services Research

University of Maryland School of Pharmacy

Image: Photographs of each of the speakers.

Slide 6

Webinar Speakers
Madeleine Shalowitz, MD, MBA
Research Associate (Associate Professor) of Pediatrics
University of Chicago, Pritzker School of Medicine
Director, Center for Clinical and Research Informatics
NorthShore Research Institute
Nina Wallerstein, DrPH, MPH
Professor, Public Health Program
University of New Mexico School of Medicine
Image: Photographs of each of the speakers.

Slide 7
Webinar Agenda
- Introduction to CBPR and Stakeholder Engagement in PCOR: Nina Wallerstein, Madeleine Shalowitz, and Pat Deverka
- Understanding the Similarities and Differences Between CBPR and Stakeholder Engagement in PCOR
- Drawing on CBPR Lessons for PCOR
- Engaging Underrepresented Populations: Daniel Mullins and Nina Wallerstein

Slide 8
General Discussion and Questions from the Audience
- We will respond to questions from the audience during the last 15 minutes of the webinar, but encourage the submission of questions throughout.
- Please use the chat feature to type and submit your questions. The webinar facilitator will share your question with the audience, and ask the speakers to respond.
- We will do our best to respond to everyone, but our time may be limited.
- We will follow up on any questions we are unable to address after the webinar has concluded.

Slide 9
Community Based Participatory Research: Principles and Conceptual Framework
Nina Wallerstein, DrPH
Professor, Public Health Program
University of New Mexico

Slide 10
Community Based Participatory Research (CBPR) Definition
Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.

Slide 11
Continuum of Community Based Research: N.M. CARES Health Disparities Center, University of New Mexico

Image: The words "on, in, with" are each in a box, above an arrow pointing to the right, in which the words "continuum of research" are contained.

Slide 12

CBPR Principles

- Recognizes community as unit of identity
- Cooperative and co-learning process
- Systems development & local capacity building
- Long term commitment
- Balances research and action
-
- Israel et al, 1998 and 2008

CBPR Principles for Tribes

- Tribal systems shall be respected and honored
- Tribal government review and approval
- Tribally specific data shall not be published without prior consultation; data belongs to tribe
- Core Values: trust, respect, self-determination, mutuality of interests, perspective taking, reciprocity

Slide 13

CBPR Conceptual Logic Model

Adapted from: Wallerstein, Oetzel, Duran, Tafoya, Belone, Rae, "What Predicts Outcomes in CBPR," in CBPR for Health from Process to Outcomes, Minkler & Wallerstein (eds). San Francisco, Jossey-Bass, 2008); and Wallerstein & Duran, CBPR contributions to intervention research: The intersection of science and practice to improve health equity. Am. J. Public Health; S1, 2010: 100, S40-S46.

Image: Chart of the CBPR Conceptual Logic Model

Within the area labeled "Contexts" are the groupings:

- "Socio-economic, Cultural, Geography & Environment"
- "National & Local Policies/Trends/Governance"
- "Historic Collaboration: Trust & Mistrust"
- "Community Capacity & Readiness"
- "University Capacity & Readiness"
- "Health Issue Importance"

Within the area labeled "Group Dynamics" are the groupings:

- "Structural Dynamics"
- "Community"
- "Individual Dynamics"
- "University"
- "CBO's"
- "Relational Dynamics"
- "Agencies"

Within the area labeled "Intervention/Research" are the groupings:

- "Fits Local/Cultural Beliefs, Norms & Practices"
- "Reflects Reciprocal Learning"
- "Appropriate Research Design"

Within the area labeled "Outcomes" are the groupings:

- "System & Capacity Charges"
- "Improved Health"

Slide 14

Research for Improved Health (RIH): NIH Study of Community-Academic Partnerships

Aims: To advance science of CBPR to achieve equity 2009-2013

- Test CBPR Conceptual Model hsc.unm.edu/SOM/fcm/cpr/cprmodel.shtml
- Literature Review of measurement tools/metrics
  - 258 articles; 46 studies; 224 process/outcomes measures
- Project code of ethics and integrity, protocols for students, publications, communication, tools: http://narch.ncaiprc.org

Develop New Instruments and Data Collection

- Case Studies: 7 diverse communities
- Internet Survey: 294 partnerships from 2009 Reporter database
- http://iwri.org/health/resources/cbpr-resources/community
- Key Informant (KI) Survey for PI/PD: Factual Data
- Community Engagement (CE) Survey: Perceived Perspectives of Partners

Slide 15

Examples: Community Engaged/Key Informant Scales: Predictors

- Context (10)
  - Community Capacity, Project has what it needs to work effectively towards its aims
- Alignment with CBPR Principles (8)
  - Builds on resources and strengths, equitable partnerships, etc.
- Core values (4)
  - shared understanding of the missions and the strategies
- Power dynamics (9)
  - Power sharing, influence, decision making
- Dialogue, Listening, co-learning
  - Conflict resolution, emotional intelligence
- Partner Research Roles (13)
- Community Engaged Research Index (CERI)
  - Trust Typology
  - From Mistrust to Ideal Trust

Slide 16

Outcomes:

Partnership Synergy (5)

- Come together and work well

Culture Centeredness (5)
- Community theories, ownership, etc.

Personal, Political, Professional Level Outcomes (13)
- New knowledge, relationships, power, visibility, skills, etc.

Concrete & Perceived Outcomes (8)
- Index of Perceived Community/Policy Level Outcomes (IPCPLO). Improved services, policy change, health improvement, etc.

Slide 17

Image: Photograph of a billboard for TB awareness.

Slide 18

Metrics: Trust Indicators

Image: Table of "Types of Trust" and "Defining Characteristic"

Content of the table:
- Critical Reflective Trust: Trust, in this partnership, is at the place where mistakes and other issues resulting from differences (in culture; power) can be talked about and resolved
- Proxy Trust: Members of this partnership are trusted, because someone who we trust invited them, therefore we trust them.
- Functional Trust: Members of this partnership are working together for a specific purpose and timeframe, but mistrust may still present.
- Neutral Trust: We are still getting to know each; there is neither trust nor mistrust.
- Unearned Trust: Trust, is based on member's title or role with limited or no direct interaction prior to this project. Examples of title or roles may include: a community outsider, a physician, or community organizers.
- Proxy Mistrust: Members of this partnership are not trusted because someone who we do not trust invited them, therefore we mistrust them.
- No Trust: Members of this partnership do not trust each other. It is likely that trust will not develop.

Slide 19

CBPR Value System for Program Development, Evaluation and Information Sharing in a Health System Environment

Madeleine U. Shalowitz, MD, MBA
Research Associate (Associate Professor) of Pediatrics, University of Chicago, Pritzker School of Medicine
Director, Center for Clinical and Research Informatics
NorthShore University Health System

Slide 20

The Health System's Perspective

Image: There is an image of 5 gears, each of which represent a health system perspective: Payor, Health System, Culture/society, family, and Patients. An arrow extends from the gears pointing to the phrase "Health Outcome"

Slide 21

The Patient's Perspective

Image: The words "stress" and "support" point to "parent," "relationship," and "child," are encircled in an area labeled "family." This is in turn encircled in an area labeled, "community," which is nested in an area labeled "culture" and "society."

Slide 22

Be Well Lake County

- NorthShore University Health System's signature community benefit program since 2009
- Comprehensive diabetes management for adult, medically underserved, Type 2 Diabetics in Lake County, IL
- A partnership between NorthShore University Health System and the Lake County Health Department

Slide 23

Program Development: Clinical Collaborative development among NorthShore, community health department service providers, patient input and data in an iterative process over time

- Comprehensive primary care visits medication and testing supply assistance
- Subsidized subspecialty care access from NorthShore physicians
- Medical nutrition therapy and diabetes education
- Patient input
    - Fitness programs
    - Community garden
    - Retinal screenings

Slide 24

Based on provider and patient input, we added a food security measure and learned that almost 57% of the patients with type 2 diabetes in Lake County did not have adequate food.

Study Question

Do patients who don't have enough food have worse diabetes control?

Slide 25

Initial Results: Growth Curve Estimated HgbA1c By Food Insecurity Status (n=255)

Not having enough food interferes with glucose control despite comprehensive diabetes care. Interference with glucose control increases over time

Shalowitz et al. APHA 2010

Image: Graph of the HgbA1c by month for food secure and food insecure patients.

Slide 26

CBPR Organizational Structure

(NICHD Community Child Health Network– Lake County)

Image: Boxes are all connect to each other through arrows. Contents of each box are:

- Academic Steering Committee

- Community Advisory Committee
- Northwestern University
- NorthShore
- Community Health Center
- Lake County Communities

Sample PCOR Adaptation

Boxes are all connect to each other through arrows. Contents of each box are:

- Payor/Provider Steering Committee
- Community Advisory Committee
- Payor
- Health System
- Patients
- Family and Communities

Slide 27

Patient–Centered Outcomes Research and Stakeholder engagement

Patricia Deverka

June 19th, 2013

Slide 28

Definitions of CER and PCOR

Definition of CER

The generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care. The purpose of CER is to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at both the individual and population levels.

Source: Institute of Medicine

Definition of PCOR

Patient–Centered Outcomes Research (PCOR) helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options.

PCOR has the following characteristics:

- Actively engages patients and key stakeholders throughout the research process.
- Compares important clinical management options.
- Evaluates the outcomes that are most important to patients.
- Addresses implementation of the research findings in clinical care environments.

Source: PCORI

Slide 29

Barriers to involving stakeholders in CER

- Confusing terminology
- Lack of shared understanding of what it means to "successfully" involve stakeholders in research

- Limited data regarding impact; systematic evaluation rare
- Timing; restrictions on availability of stakeholders
- Training needs for all stakeholders to maximize participation
- Concerns that process will add time and costs to project plans

Sources: Guise, O'Haire, McPheeters, et al. A practice-based tool for engaging stakeholders in future research: a synthesis of current practices. J Clin Epidemiol. 2013 Jun;66(6):666-74. doi: 10.1016/j.jclinepi.2012.12.010. Epub 2013 Mar 13. and CMTP experience

Slide 30

Conceptual model for stakeholder engagement in comparative effectiveness research

Source: Deverka, Lavallee, Desai et al., JCER 2012; 1(2): 181-94

Stakeholder: Individuals, organizations or communities that have a direct interest in the process and outcomes of a project, policy or research endeavor – including patients and consumers, healthcare providers, payers and purchasers, policy-makers and regulators, industry representatives, researchers and research funders.

Stakeholder engagement: An iterative process of actively soliciting knowledge, experience, judgment and values of individuals selected to represent a broad range of direct interests in a particular issue for the dual purposes of 1.) creating a shared understanding and 2.) making relevant, transparent and effective decisions.

Image: Chart of "Types of Evidence"

Slide 31

Typology of stakeholder engagement

Image: Image of a group of people talking around a table, from which the words "Minimal public involvement, Consultation, Collaboration, and Control" extend. Each of these words have a longer description:

- Minimal public involvement
    - Researchers are the drivers of the project. Researchers respond to public action by providing information or inviting the public for consultations and collaborations on their terms.
- Consultation
    - Public is encouraged to provide diverse and in-depth views, perceptions, preferences, experiential knowledge and ideas.
- Collaboration
    - Public is empowered to become active partners in an ongoing public-clinician collaboration.
- Control
    - The public is the driver of research projects. Researchers participate on the terms of the public.

Finally, there are two arrows pointing to the figure, with the words "stakeholder engagement" in them.

Slide 32

Similarities and Differences Between CBPR and PCOR

Madeleine Shalowitz and Pat Deverka

Image: Photographs of the speakers.

Slide 33

What are the similarities and differences between CBPR and PCOR?

Slide 34

CBPR and PCOR: How much do they have in Common?

- CBPR
- Goal:
- Combine knowledge and action for social change; focus on topics of importance to community
- Intervention/Research Design:
- Reflects commitment to true partnership with community
- Outcomes:
- *Transform social and economic conditions
- *Reduce health disparities
- *System and capacity changes
- PCOR
- Goal:
- Help people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options.
- Intervention/Research Design:
- Reflects predominately consultation, trying to move to collaboration
- Outcomes:
- *More useful evidence for clinical and health policy decision-making
- *Shift the research agenda (system and capacity changes)
- Improved
- health outcomes
- Participation of individuals outside the traditional scientific paradigm
- Characterized by mutual respect and trust

Slide 35

Reaction from the patient perspective

Dwyan Monroe

Community Outreach Trainer/ Patient Representative

Image: Photograph of the speaker.

Slide 36

Discussion Questions

Are there enough similarities to allow us to draw lessons from CBPR about how to better engage stakeholders in PCOR?

Slide 37

Discussion Questions

What are the strategies for effectively equalizing the power structure between researchers and other stakeholders that allow for shared decision making?

Slide 38

Discussion Questions

Given the differences in the time frame between PCOR and CBPR, what lessons can we draw about how to sustain engagement over the long term?

Slide 39

Discussion Questions

What are the strategies for measuring the impact of stakeholder engagement on project and patient outcomes?

Slide 40

Discussion Questions

What are some successful dissemination strategies for bringing the results back to the community?

Slide 41

Engaging underrepresented populations

C. Daniel Mullins and Nina Wallerstein

Image: Photographs of the speakers

Slide 42

Reaction from the patient perspective.

Dwyan Monroe

Community Outreach Trainer/ Patient Representative

Image: Photograph of the speaker

Slide 43

Discussion Questions

What are some essential lessons about engaging underrepresented populations in CBPR that would be applicable to PCOR?

Slide 44

General Discussion and Questions from the Audience Please remember to use the chat feature to type and submit your questions. The webinar facilitator will share your question with the audience, and ask the speakers to respond.

We will follow up on any questions we are unable to address after the webinar has concluded.

Slide 45

Thank You for Participating!