Application of Community Engagement/CBPR Principles Metrics and Measures to Patient–Centered Comparative Effectiveness Research

CER Scientific Retreat, MUSC

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Context for Integrating Community and Patient Engagement

- IOM 2013 Report to NCATS: Recommendation 6:
  - “ensure patients, family members, health care providers, clinical researchers, and other community stakeholders are involved across the continuum”

- Patient Centered Outcomes Research (PCOR)
  - Within Comparative Effectiveness Research Agenda
  - Patient and Stakeholder Engagement

- “Continuous Patient Engagement”: 10 steps
  - Patients Prioritize Research Topics/Questions/Outcomes
  - Data Collection/Analysis/Interpretation/Dissemination
  - Provide Reality Check

Mullins et al, JAMA, April 18, 2012
RATIONAL: Need for Community-Engaged and Community-Based Participatory Research (CBPR)

- Challenge of research mistrust: historic/current
- Challenge of bringing evidence to practice
  - Internal validity insufficient for translational research
  - External validity: Implementation/Role of context in diverse communities
- Challenge of what is evidence
  - Evidence-Based Practice (Academic) vs.
  - Practice-/Indigenous-/Community-Based Evidence
- Challenge of sustainability and translating action and policy
Principles of Community Engagement


http://www.atssr.cdc.gov/communityengagement/
Community engagement is the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being.

CTSC Community Engagement

Community Engagement Continuum

Outreach
- Some Community Involvement
- Communication flow is from one to the other to inform
- Provides community with information
- Entities co-exist
- Outcomes: Optimally establishes communication channels and networks for outreach

Consult
- More Community Involvement
- Communication flow to the community and then back, answer seeking
- To get information or feedback from the community
- Entities share information
- Outcomes: Develops connections

Involve
- Better Community Involvement
- Communication flows both ways, participatory form of communication
- Involve more participation with community on issues
- Entities are cooperating with each other
- Outcomes: Visibility of partnership established

Collaborate
- Community Involvement
- Communication flow is bi-directional
- Form partnerships with community on each aspect of project from development to solution
- Entities form bi-directional communication channels
- Outcomes: partnership building, trust building

Shared Leadership
- Strong Bi-directional Relationship
- Final decision making is at community level
- Entities have formed strong partnership structures
- Outcomes: Broader health outcomes affecting broader community. Strong bi-directional trust built

Reference: Modified by DJ McCloskey and from the International Association of Public Participation
Continuum of Community Based Research:
N.M. CARES Health Disparities Center
University of New Mexico
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.

(W.W. Kellogg Foundation, 2001; Minkler and Wallerstein, 2008, pg. 6)
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
- Cultural Humility: Lifelong reflection on power and privilege/co-learning

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

Israel et al, 1998; Minkler et al, 2013
“Research for Improved Health”
Cross-Site Multicultural CBPR

Purpose:
1) To identify facilitators and barriers to effective CBPR across diverse populations and settings
2) To test conceptual model and associations partnering & outcomes
3) to advance the science of CBPR to reduce health disparities

Partners:
1) National Congress of American Indians Policy Research Center (M. Villegas, PI)
2) University of Washington (B. Duran, co-PI)
3) University of New Mexico (N. Wallerstein, co-PI)

NIH/NARCH Funding (2009-2013): NIGMS, NIDA, NCRR, NCI, NIMHD, OBSSR (with Indian Health Service)
Early Accomplishments

- Interactive Model linked to instruments and to variables/measures:  [http://fcm.unm.edu/cpr/cbpr_project.html](http://fcm.unm.edu/cpr/cbpr_project.html)
- Literature review of measurement tools/metrics
  - 258 articles: 46 unique studies; 224 process/outcome measures
- Project code of ethics and integrity, protocols for students, publications, communication, tools:  [http://narch.ncaiprc.org](http://narch.ncaiprc.org)
- Mixed Methods Research: Internet Survey/Case Studies
Diverse health issue, geographic region, populations: American Indian/other communities of color/social identity who face disparities.

- At least 3-year partnership history with projected research for at least 2 years;
- Successful intervention, capacity-building, or policy research.

Methods:
- Focus Groups and Partnership meeting observation
- 13-18 Interviews (university and community)
- Brief Partnership Survey: self-administered

CBPR Conceptual Logic Model: 2013


Contexts
- SES, Culture, Education, Place, Environment
- Policy Trends Funding/Governance/Institutions
- Historic Collaboration: Trust & Mistrust
- Community Capacity & Readiness
- University Capacity & Readiness
- Health Issue Importance

Group Dynamics & Equitable Partnerships
- Structural Dynamics
- Individual Dynamics
- Relational Dynamics

Intervention & Research
- Fitting Local/Cultural Beliefs, Norms & Practices
- Co-Learning/Partnership Synergy
- Appropriate Research Design

Outcomes
- System & Capacity Changes
- Improved Health
- Disparities
- Social Justice

- Changes in Policies/Practices
- Changes in Power Relations
- Cultural Renewal
- Partner/Agency Capacities

- CBPR System & Capacity Changes:
  - In Universities & Communities
  - Sustainable/cultural-centered interventions/Broader reach
  - Changed Power Relation/Empowerment
  - Collective reflection/Critical thinking
  - Cultural revitalization & renewal
  - Health Outcomes:
    - Transformed social/economic conditions
    - Reduced health disparities
National cross-sectional survey of all federally funded CBPR projects

(criteria = working with community partner or CAB, or any level of community engagement. If unsure, left in sample)

Extramural funded studies in 2009 NIH RePORTER database

A “research” project with at least 2 years of funding (not training grants or pilot studies)

- Mechanisms: R01, R18, R24, R34, RC1, RC2, U01, U19, U26, U28, U54
What is the variability across different dimensions of model?

What are associations between partnership processes and CBPR outcomes?

Two Surveys:

- **Key Informant** (~15 minutes):
  - Taken by Principal Investigator/Program Director

- **Community Engagement** (~ 30 minutes)
  - Taken by PI/PD, 2\textsuperscript{nd} academic investigator, and 2–4 community partners

Conducted from 12/2011 – 8/2012
Key informant Survey: Predictors
http://iwrri.org/health/resources/cbpr-resources/community/

- **Project Demographics and Features** (49)
  - PI team and partners ethnicity, position, gender, SO, etc.
  - Partnership dates, funding, type of research, # of partners, staff diversity, etc.

- **Resource/Decision sharing** (4)
  - Who decides hiring, budgets, resources shared

- **Research Integrity** (4)
  - Confidentiality/IRB training, approval decisions

- **Partner Research Roles** (13)
  - Community Engaged Research Index (CERI)

- **Governance** (15)
  - Formal MOU’s & DSOA’s, dissemination approvals, $, conflict resolution

- **Formal Training** (8)
  - Racism/sexism/privilege/cultural humility/CBPR-collective reflection

- **Contact info for Partners**
Community Engagement Survey: Predictors

- **Context** (10)
  - Community Capacity, Project has what it needs to work effectively towards its aims

- **Social & Human Capital** (3)
  - Knowledge, skills, connections

- **Alignment with CBPR Principles** (8)
  - Builds on resources and strengths, equitable partnerships in all phases of the research, emphasizes what is important to the community, 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

- **Governance Mechanisms**
  - Competency of leadership in diversity, communication, planning, efficiency, financial management, etc.
Outcomes: KI & CE

- **Partnership Synergy (Proximal) (5)**
  - Come together and work well

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

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

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

- **Health Outcome**
RIH Survey Response Rates

- Key Informant Survey by academic PI: 68.7% (N = 200)
- Com Eng Survey by academic PI: 70.5% (N = 141)
- Com Eng Survey by academic & community partners: 76.5% (N = 310)
Case Study Research Questions

- How do context/group processes/individual issues shape facilitators and barriers to effective CBPR?

- How do differing contextual conditions and perceptions/meanings interact with partnering processes to produce differing outcomes?
7 Case Studies

- Healing of the Canoe:
  - Youth Life Skills/Substance Abuse—Washington tribes

- Men on the Move:
  - Cardio-Vascular/Sustainable Agriculture/Rural—AA

- Lay Health Worker Intervention:
  - Colorectal Cancer Screening/San Francisco–Chinatown

- South Valley Partnership Environmental Justice
  - Semi–urban, Southwest – Latino

- Cancer Coalition and Tribal Approval Processes
  - Rural – Plains Tribe

- Bronx Faith–Based Initiative
  - Diabetes and Medical Apartheid

- Center for Deaf Health, Rochester
Trust Measures and Questions

Quantitative Survey: Two scales
- Views on how trust has evolved (type/when)
- Level of trust between team members
  - Trust of decisions, comfort asking others to take responsibility,

Qualitative Case Studies Questions:
- How do you describe trust in this partnership?
- Has it changed over the life of the partnership?
  - If so, how has it changed?
## Metrics: Trust Indicators

<table>
<thead>
<tr>
<th>Types of Trust</th>
<th>Defining Characteristic</th>
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<tbody>
<tr>
<td><strong>Critical Reflective Trust</strong></td>
<td>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.</td>
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<tr>
<td><strong>Proxy Trust</strong></td>
<td>Members of this partnership are trusted, because someone who we trust invited them, therefore we trust them.</td>
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<tr>
<td><strong>Functional Trust</strong></td>
<td>Members of this partnership are working together for a specific purpose and timeframe, but mistrust may still present.</td>
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<tr>
<td><strong>Neutral Trust</strong></td>
<td>We are still getting to know each other; there is neither trust nor mistrust.</td>
</tr>
<tr>
<td><strong>Unearned Trust</strong></td>
<td>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.</td>
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<tr>
<td><strong>Proxy Mistrust</strong></td>
<td>Members of this partnership are not trusted because someone who we do not trust invited them, therefore we mistrust them.</td>
</tr>
<tr>
<td><strong>No Trust</strong></td>
<td>Members of this partnership do not trust each other. It is likely that trust will not develop.</td>
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Cultural-Centeredness

- To what extent was the community partner's knowledge, culture, and voices included in research processes?
- To what extent does your project fit local/cultural beliefs, norms, and practices?
- How well did this project engage reciprocal learning and capacity building?

- Mohan Dutta
Have you noticed a change in your...

Harmony?  Breath?  Energy?

IT MAY BE TB!  505-722-
Cultural-Centeredness Scales

- Voice in Research:
  - Partner Research Roles/Community Engaged Research Index
    - ie., in problem-definition/grant writing/choosing research methods/
      recruiting/data collection/interpretation/writing reports and articles

- Power Relations/Voice in Partnership:
  - Reflexivity: Have increased research participation/talk about research
  - Decision-Making: Feel comfortable with opinions being heard

- Outcomes:
  - System Changes: Resulted in policy changes/improved health/
  - Community Capacity: Partnership with skills and expertise to work
    towards aims/Partnership has legitimacy
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<th>What Predicts Preliminary CBPR Outcomes?</th>
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<tr>
<td><strong>Capacity</strong>: Project has what it needs to work effectively towards its aims</td>
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<tr>
<td><strong>Alignment of CBPR Principles</strong>: Builds on resources and strengths, equitable partnerships in all phases of the research</td>
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<td><strong>Level of Involvement</strong>: Task roles and communication (CERI)</td>
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<td><strong>Communication/Dialogue</strong>: Degree to which partners cooperate to resolve disagreements</td>
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<td><strong>Stewardship</strong>: Use of financial &amp; in-kind resources</td>
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<td><strong>Partnership synergy</strong>: Partners ability to develop goals, recognize challenges, respond to needs, work together</td>
</tr>
<tr>
<td><strong>Trust</strong>: Level of trust at the beginning of the partnership</td>
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Why CEnR/CBPR Important (NIH): Recommendations for Improved Science

- Increased research trust
- Research questions community relevant
- Intervention strategies integrate community evidence with scientific evidence
- Enhanced recruitment/response/retention rates
- Enhanced reliability/validity instruments
- Greater accuracy and culturally-centered interpretation of findings
- Strengthened community capacity/assets
- Increased sustainability of evidence-based and culturally-centered research
Recommendations to Assure Community Benefit

- Promote Community Capacity in Research
- Change Power Relations: data/$
- Create Shared Analysis and Reporting
  - Not “ventriloquism,” but multiple spaces so the lived experience of our partners can be heard and validated (Spivak 1990).
- For Academics:
  - Integrate Community Engaged Scholarship
  - Return to CBPR principles:
    - Show up; Be who you are; Social Justice; Listen
      (AJPH, Northridge, 2003)
Contact Information

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