Using a CBPR Approach with Health Literacy Research for Community or Patient Stakeholder Engagement

HARC VIII

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Introductory Activity –

1. Continuum of community-engaged research (CEnR) including CBPR
2. Relevance of CEnR and CBPR
3. Strategies for incorporating engaged research in traditional project designs
4. Application of CEnR to FOAs
COMMUNITY & CONTINUUM
Definition of Community

- Basic definition of community: “those who have a shared identity”
  - People with shared experience, such as gender, racial/ethnic identity, sexual orientation, disability or health condition, or online community
  - Neighborhood/geographic proximity
  - Emotional connection, shared values or norms, common interest or shared need (i.e., religious affiliation)
  - Institutions and individuals representing selves or organizations
Community Engaged Research (CER)

- APPROACH to research
- Can be incorporated into most research designs
- Done well, it adds to research strategy
- Can be used with interventions, education, clinical guideline development
- CER, CEngR, CEnR…..
Community Engagement

- Range of levels of engagement

- **Collaborative** effort between community partners and program planners/researchers

- Community members **involved** in topic selection, design of research/program development, dissemination of findings to improve use of research

- Community representatives have a **voice and role in the process**

- Work **benefits a community**

- National Institutes of Health & PCOR
Definition of Community-Based Participatory Research

- Collaborative approach to research and practice that equitably involves all partners in the research/planning and implementation process
- Recognizes the unique strengths that each brings
- Combines knowledge with action and achieving social change to improve health and eliminate disparities

The W. K. Kellogg Foundation, 2001
http://www.cdc.gov/pcd/issues/2007/jul/06_0182.htm
# Ladder of Participation: Community Engaged Research

<table>
<thead>
<tr>
<th>Community Placed</th>
<th>Community-Based</th>
<th>Community-Engaged</th>
<th>Community-Participatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment plans,</td>
<td>Focus groups or surveys to</td>
<td>Task forces or Workgroups work</td>
<td>Workgroups, Action Boards where</td>
</tr>
<tr>
<td>programs in the</td>
<td>obtain community perspective</td>
<td>together to get things done</td>
<td>important decisions are made about</td>
</tr>
<tr>
<td>community, tailored</td>
<td></td>
<td></td>
<td>project</td>
</tr>
<tr>
<td>media campaigns</td>
<td></td>
<td></td>
<td>Community gets share of financial</td>
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</tbody>
</table>
<pre><code>                                                             |                                      | resources and equal voice in decisions    |
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- **Consultation, Input**: Seek viewpoints, ideas, strategies from community to be considered in research. Cooperation.
- **Involvement Collaboration**: Community works with researchers to solve problems. Involved in discussions and have a voice. Power of final decisions still often with researchers.
- **Partnership**: Striving for equity of all involved, all involved benefit from participation. Shared goals and values, shared decision making, resources, and responsibility, co-learning.
- **Empowerment**: Communities and representative partners’ increase control over factors and decisions that affect lives/health issues. Action that is explicitly aimed at social political change.

*Jurkowski, 2016*
Communication Flow for Ladder of Participation

Level 1: Low level of public involvement and influence
- Inform or Educate
- Communications

Level 2: Mid level of public involvement and influence
- Gather Information
- Listening

Level 3: High level of public involvement and influence
- Discuss
- Consulting

Level 4: Engage
- Engaging

Level 5: Partner
- Partnering

Adapted from Patterson Kirk Wallace

Power

There is no justice in the world.

There is some justice in the world.

The world is just.
Community Collaboration must Recognize Power

- Disenfranchised and marginalized populations
- Community organization exists to facilitate a way of life that affects people and social systems
- Privileged provide access to power and wield it to reproduce structures of control
Discussion

How do you think health literacy and power are related?

How does power impact your health literacy work?

How does power influence your work with communities?
Power Comes into Play

- Interpersonal communication
- Access to resources
- Definition and acquisition of knowledge
Definition of Stakeholders

- Persons with past/current illness experience, family/caregivers/advocacy groups (PCORI)
- People with vested interest at various levels; constituents; “Representative” of a sub-group
- Are those most affected by the research involved?
- Are those who have a stake in the research/problem involved?
  - Consideration of who impacted by research or issue addressing
    - Community leaders- informal or formal
    - City Council members or staff, faith leaders/ organizer or advocate/nonprofit or school leaders/staff
“Community” Representation

- Grass tops
- Grass stalks
- Grassroots
CBPR for Cultural Tailoring and Sensitivity

- Learned patterns of thought, communication, beliefs and behavior shared
- Norms and expectations
- Professional and organizational culture
- Family and social group culture

- Cultural liaison
- Identify and include in research and intervention
Direct Benefits to Research

- Gain unique knowledge and skills (form of researcher empowerment)
- Improve participation
- Refine recruitment protocols
- Improve adherence to treatment
- Tailor materials and programs to culture and community
- Identify new potential relationships between independent and dependent variables
Direct Benefits to Research

- Identify innovative research or program evaluation questions and ethical considerations
- Ideas for mediators or different outcome measures
- Improve interpretation of and meaningfulness of findings
- Improve translation and feasibility
- Sustainability
- Dissemination - relevance to patients & community members
Direct Benefits to Research and Clinical Practice

- Patient satisfaction and trust
- Community ownership or buy-in
- Reduction in medical errors
- Belief that programs are important and therefore should be attended and funded
Benefits to Broader Community

- Capacity for managing health issue
- Improvements in knowledge, understanding of importance of topic
- Skill building
- Medical/health care knowledge
- Empowerment
- Social networking
- Satisfaction with care
- Greater dissemination to local community
Do you think CBPR can help build health literacy skills of the community? If yes, how?

What about other related literacies, such as research literacy?
Challenges of CBPR

- Time to build relationships
- Different skills than how PhDs and MDs are trained
- Concern about introducing bias
- Managing conflicting agendas
- Determining which stakeholders
- Worries about null results or inconvenient findings
- Sustainability
Group Activity #1

Discussion at tables

What types of community partners could you engage in your project?

What are some of your challenges and some benefits to an engaged process?
STRATEGIES
Community Engagement

- Creating a Setting
- Infrastructure
- Structural supports

Suicide Prevention Coalition in WY
Structures for Engagement

- Advisory
- Boards
- Workgroups
- Co-Investigators

**Meeting people where they are...**
CAC or Project focused Workgroup

- Committee structure
- Define roles
- Decision making process

- i.e. Community Advisory Board
Principles for Participation

1. Community recognized as having a unique identity
   - Acknowledge multiple cultures in community and social and economic factors

2. Emphasizes local relevance of public health issue and ecological perspective
   - Policy, organizational, and community factors; family and individual knowledge, behaviors, and beliefs all influence health.
   - Unique characteristics help or make it difficult for families to stay healthy

https://depts.washington.edu/ccph/cbpr/u1/u11.php
3. **Builds on strengths within community**
   - All communities, cultures, and organizations have strengths. They need to be leveraged

4. **Facilitate collaborative and equitable partnership in all phases**
   - Active listening, shared decision-making

https://depts.washington.edu/ccph/cbpr/u1/u11.php
Principles for Participation

5. Promotes co-learning and capacity building for researchers and partners
   - Community has expertise; Researchers and community learn from each other
   - Participation can lead to new abilities, skills or opportunities for organization and individuals

6. Participatory process is a cyclical and iterative process
   - Strategy for flow of communication

https://depts.washington.edu/ccph/cbpr/u1/u11.php
Principles for Participation

7. Broad dissemination of findings/knowledge gained
   - Findings of research and curriculum available beyond academic journals and written in an understandable format

8. Acknowledge long-term process and commitment to process
   - CAB members need to be at meetings to share in decision making for the duration of the work

https://depts.washington.edu/ccph/cbpr/u1/u11.php
Facilitating Participation

- Incentives
- Child care
- Provide food
- Cultural sensitivity
Strategies for Engagement

- Working meetings
- Qualitative methods modified for feedback
- World Cafes
- Delphi Method (for building consensus)
- Concept Mapping

**Consider including capacity building- facilitate networking

**Recognition (and discussion) of power differentials
Discussion

Do you think CBPR can be applied to...

...all types of research?

...all types of settings, even online?
CBPR: Clinical Trials and Evaluation

- Protocols more:
  - inclusive of family and support networks
  - feasible for consistent participation
- Processes for design (RCT, Stratifications)
- Recruitment materials
- Interpretation of findings
- Communication of findings in non medical terms disseminate to wider audience
- Recommendations for scale up
CBPR: Assessment and Evaluation

- Define purpose
- Interpret literature for tailoring evidence-based programs to local cultural context
- Introduction and length of a survey
- Identify theoretical concepts and help choose measures
- Order of survey questions
- Translation
- Administration strategies
- Program design- curriculum design and implementation
- Discuss relationships between measures
- Interpret finding
- Write or present findings
Burning Questions?
Group activity #2

At tables, review project summaries

Discuss specific ways to incorporate CBPR or CEnR

Come up with specific ways to incorporate CBPR or CEnR in different sections of grant proposal.

- Background, Innovation, Research Strategy, Budget, Human Subjects
CBPR

- Community Campus Partnerships for Health: Community-Based Participatory Research
  - https://depts.washington.edu/ccph/commbas.html

- UCSF Accelerate: Community-Engaged Research Presentations and Tools
  - https://accelerate.ucsf.edu/research/community-tools

- AAPCHO: CBPR Toolkit
  - http://www.aapcho.org/resources_db/cbpr-toolkit/
Health literacy and CBPR

  - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4498535/

  - http://eric.ed.gov/?q=A+Community-based+approach+to+health+literacy+using+participatory+research&id=EJ768235


- Shaw, S.J. Addressing minority health access through community-based health literacy research. University of Arizona.
  - http://mhdi.unl.edu/Susan%20Shaw%20Powerpoint.ppsx
Grants and CBPR

- Community-Campus Partnerships for Health: Tips & Strategies for Developing Strong Community-Based Participatory Research Proposals

- Community-Campus Partnerships for Health: Examples of Funded Proposals
  - [https://depts.washington.edu/ccph/commbas.html#FundedProposals](https://depts.washington.edu/ccph/commbas.html#FundedProposals)

- Community-Campus Partnerships for Health: Tips & Strategies for Funding Community-Engaged Research (CEnR).
  - [http://www.feinberg.northwestern.edu/sites/cch/docs/arcc/CCPHGrantWritingResources.pdf](http://www.feinberg.northwestern.edu/sites/cch/docs/arcc/CCPHGrantWritingResources.pdf)

- ARCC: Sample Proposals and Partnership/Project Cases Studies
  - [http://arccresources.net/category/sample-proposals-partnership-case-studies/](http://arccresources.net/category/sample-proposals-partnership-case-studies/)
PCOR grants

- AHRQ: Community-Based Participatory Research, Lessons for Stakeholder Engagement in Patient-Centered Outcomes Research

- PCORI: What We Mean By Engagement
  - [http://www.pcori.org/funding-opportunities/what-we-mean-engagement](http://www.pcori.org/funding-opportunities/what-we-mean-engagement)

- PCORI: Engagement Rubric

- PCORI: Sample Engagement Plans
Articles of Interest

THANK YOU!

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