

1  Community-Based Participatory Research Curriculum for General Pediatrics Fellows

Session 1

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3  What is Community-Based Participatory Research (CBPR)?

"A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings".

--W.K. Kellogg Foundation (2001)

4  What is CBPR?

- An orientation to research that alters researcher-community relationships
- CBPR is NOT:
  - "Community-placed" research
  - Sporadic or symbolic inclusion of communities
  - Basic research

5  Why CBPR?

- Growing recognition that "traditional" research approaches have failed to solve complex health problems
- Community demands for research addressing locally identified needs

## 6 Development of CBPR:

### Conceptual & Historical Roots

- Action Research (1940's, Social Psychology): Bridging gap between theory and practice by involving stakeholders within organizations
- No community/social change element to Action Research
- Continues today as action science, insider-outsider research, educational action research, and collaborative action research

## 7 Development of CBPR:

### Conceptual & Historical Roots

- Participatory Research and Participatory Action Research (1960's, Sociology, Anthropology, Community Planning): Involving citizens in research and community development process with an explicit community/social change focus
- Origins in the Third World—Africa, South America, Asia
- Influenced transformation of research relationship from communities as objects as study to communities and active participants

## 8 Development of CBPR:

### Conceptual & Historical Roots

Other Influences:

- Feminist Theory: promoting increased voice for women often marginalized by research
- Community Organizing: recognizing ordinary citizens' ability to promote community change
- Community-Oriented Primary Care: health professionals and community members working together to diagnose and treat a community

## 9 Development of CBPR:

### Conceptual and Historical Roots

- Numerous influences creating "post-positivist" research paradigm characterized by "...the increased visibility of research designs that are interactive, contextualized, and humanly compelling because they invite joint participation in the exploration of research issues".

--Lather, 1986, p. 259

## 10 Present Day Context of CBPR

- CBPR becoming inclusive phrase to characterize participatory research approaches with an explicit social change focus
- CBPR taking place in Public Health, Medicine, Psychology, Sociology, Anthropology, Urban Planning, and other disciplines
- Increase in:
  1. Public and private funding for CBPR
  2. Academic institutions practicing and promoting CBPR
  3. Non-academic institutions promoting CBPR

- 11  Present Day Context of CBPR:  
Public and Private Funding
- National Institute of Environmental Health Sciences (NIEHS): ongoing program announcements for “community-driven research”
  - Centers for Disease Control (CDC): first-time program announcement in 2002 to support community based participatory prevention research
  - Agency for Health Care Research and Quality (AHRQ): small grants for participatory research
- 12  Present Day Context of CBPR:  
Public and Private Funding (cont...)
- W.K. Kellogg Foundation: ongoing support for Community Health Scholars Program that trains postdoctoral fellows in CBPR
  - Annie E. Casey Foundation, Ford Foundation, Robert Wood Johnson Foundation: fledgling support for community-driven research projects
- 13  Present Day Context of CBPR:  
Academic Institutions Practicing and Promoting CBPR
- Policy Research and Action Group (PRAG): four-university consortium in Chicago working with community-based organizations
  - CDC Urban Health Centers: three centers emphasizing participatory, community-based approaches to studying and addressing health concerns
  - Center for Community Partnerships  
(U. of Pennsylvania)
  - Community-Campus Partnerships for Health (U. of Washington)
- 14  Present Day Context of CBPR:  
Non-Academic Institutions Promoting CBPR
- LOKA Institute (Amherst, MA)
  - Institute for Community Research (Hartford, CT)
  - Applied Research Center (Oakland, CA)
  - Highlander Center (Tennessee)
- 15  Rationale For Conducting CBPR
- 1.Improves the quality and validity of research
  - 2.Enhances the relevance and usefulness of research data for all partners
  - 3.Joins together partners with diverse skills, knowledge, and expertise
  - 4.Strengthens the research and program development capacity of partners
- 16  Rationale for Conducting CBPR (Cont...)
- 5.Increases possibility of overcoming distrust of research
  - 6.Provides additional funds and possible employment opportunities for community partners
  - 7.Aims to improve health and well-being of communities, both directly through examining identified needs, and indirectly through increasing control of research process

- 17  **Exercise**
- What are the strengths, skills, competencies, and insights that community stakeholders could bring to your research project?
  - What are the strengths, skills, competencies, and insights that you bring to your research project?
- 18  **Remaining CBPR Curriculum Sessions**  
Trajectory of a CBPR Project
- 19  **Community-Based Participatory Research:  
Curriculum for General Pediatrics Fellows**  
Session 2  
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- 20  **What is Community-Based Participatory Research (CBPR)?**  
“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings”.
- W.K. Kellogg Foundation (2001)
- 21  **Trajectory of a CBPR Project**
- 22  **Initiating a CBPR Research Project**  
Goals of This Lesson:  
1.To identify key steps in starting a CBPR project  
2.To highlight challenges associated with starting a CBPR project  
3.To highlight potential solutions for dealing with challenges
- 23  **Initiating a CBPR Research Project: Key Steps**  
1.Select the community with which to work  
2.Select key community partners  
3.Create joint ownership of study  
4.Determine research question(s)  
5.Design research study  
6.Insert sustainability and action steps

- 24  **Select the Community With Which to Work**
- Initial step in CBPR
  - Community is characterized by “a sense of identification and emotional connection to other members...shared values and norms...common interests, and commitment to meeting shared needs”. [Israel, Schulz, Parker, & Becker, 1998]
  - *Community is the unit of identity* (CBPR Principle)
  - Several distinct communities within East Baltimore

25  **Select The Community With Which to Work: Challenges and Facilitators**

1

Challenges:

- Distrust of academic institutions
- Distrust of researchers from “outside” the community
- Understanding communities’ social, economic, & political landscape

2

Facilitators:

- Forge relationships with existing CBPR projects
- Books, newspapers, other media & published reports describing community landscape

26  **Select Key Community Partners**

- Identify stakeholders that need to be “at the table”
- Having the “water cooler conversation” with identified community stakeholders
- Discussing potential research without creating a university—community dichotomy
- *Builds on strengths and resources of community* (CBPR Principle)
- *Address health from an ecological perspective* (CBPR Principle)

27  **Select Key Community Partners**

Exercise: Stakeholder identification for pediatric [XXX] intervention

Who needs to be “at the table”  
Why are they important?

28  **Select Key Community Partners**

1

Challenges:

- Time involved in meeting and recruiting key partners
- Community dynamics
- Overextended community stakeholders

2

Facilitators:

- Entrée through existing CBPR projects
- Community meetings/forums
- Monetary incentives for participation during planning

29  Create Joint Ownership of Study

- Determine roles and responsibilities of partners
- Discuss fiscal considerations
- Discuss ownership of data and process for interpreting data
- Create structures and processes for communication between university and community

30  Create Joint Ownership of Study

1

Challenges:

- Unequal power dynamics may persist

- Unequal distribution of grant money

2

Facilitators:

- Develop agreed upon norms and processes
- Develop plans to evaluate partnership process
- Community partner submits grant or becomes subcontractor

31  Determine Research Question(s)

- “Those who are in control of problem definition are likely to control the entire research process”. [Selener, 1997]
- Generating questions based on “expert” and “local/citizen” knowledge
- *Co-learning process as both parties learn about phenomena of interest* (CBPR Principle)

32  Determine Research Question(s)

1

Challenges:

- Tight deadlines for grant submissions

- Researcher expertise vs. community need (research vs. service)

2

Facilitators:

- Creation of Community Advisory Board

- Researcher providing in-kind services or resources to community

33  Design Research Study

- CBPR does not limit choice of research design and/or methods
- Intervention and/or research?

Exercise: Determine an appropriate research design for a study to prevent substance abuse among homeless men who receive meals from a community-based organization

34  Design Research Study

1

Challenges:

- Scientific rigor vs. community acceptability
- Unfavorable results could hurt community organizations' funding

2

Facilitators:

- Provide intervention to initial control group (\$ permitting)
- Discuss advantages of rigorous design for future funding
- Discuss potential for unfavorable results

35  Insert Sustainability and Action Steps

- Long history of researchers promising, but not producing, data that will benefit communities
- *Long-term commitment from all partners* (CBPR Principle)
- "Are academic irrelevant?" [Stoecker, 1997]

36  Insert Sustainability and Action Steps

1

Challenges:

- Reduction or elimination of grant money
- Staff turnover in community organizations

2

Facilitators:

- Money and/or infrastructure established early in CBPR project
- Creation of clear mission/vision statement for CBPR project

37  Community-Based Participatory Research: Curriculum for General Pediatrics Fellows

Session 3

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38  Data Collection in CBPR

1. Data Collection to help communities identify their strengths and assets as well as

problems or issues to address

2.Data Collection to study the problem or issue selected as “phenomenon of interest”

39  **Helping Communities Identify Strengths/Assets and Problems/Issues to Address**

- “Start where the people are” when determining research questions
- Involving communities during earliest phases of research project provides more depth than reviewing statistical data alone

40  **Data Collection Approaches To Identify Strengths/Assets and Problems/Issues to Address**

- 1.Walking and windshield tours
  - observing community on foot or by car and recording these observations
- 2.Interviews with key informants
  - formal and informal leaders as well as “ordinary citizens”
3. Guided discussions (e.g., focus groups)

41  **Data Collection Approaches To Identify Strengths/Assets and Problems/Issues to Address (cont...)**

- 4.Delphi Process
  - individual survey done in-person or via mail to identify key community issues; iterative process to prioritize key issues
- 5.Nominal Group Technique
  - group process done in-person to prioritize key community issues

42  **Data Collection To Study The Problem or Issue Selected as “Phenomenon of Interest”**

- No limitations to data collection methods that can be used (e.g., quantitative vs. qualitative) as long as agreed upon and understood by community

43  **Key Considerations During CBPR Data Collection**

- 1.How are instruments decided upon and developed?
  - Valid, reliable instruments vs. tailoring to local context?
  - Do “researcher” concepts/constructs need to be reworded/rephrased?
  - Processes for creating instruments?

44  **Key Considerations During CBPR Data Collection (cont...)**

- 2.Who collects the data?
  - Is it possible to hire and train community residents?
  - Does using community residents slow down the study?

- 45  Key Considerations During CBPR Data Collection (cont...)  
3. Institutional Barriers
- IRB requirements (e.g., consent forms, research compliance training)
  - Will funding source allow instruments to be modified and/or community residents to be hired?
  - Are opportunities to publish diminished by modifying instruments?
- 46  Community-Based Participatory Research: Curriculum for General Pediatrics Fellows  
Session 4  
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- 47  Community-Based Participatory Research: Action Orientation
- Three components of CBPR:
    1. Research (i.e., study of health issue)
    2. Education (i.e., knowledge gained by researchers and community)
    3. Action
- 48  Action = Making Research Count for the Community  
How to make research count?
- Are a community's needs met through a research study?
  - Do the community and researcher benefit from a research study?
  - Action does not lag behind research/theory
- 49  Ways that CBPR Can Count for the Community
- Helping document and/or sustain effective programs, services, and interventions
  - Translating interventions (efficacy → effectiveness)
  - Promoting public policy and advocacy
- 50  Ways that CBPR Can Count for the Community (cont...)
- Creating products to help keep community organizations viable (ex.) brochures, fliers, videos, newsletters
  - Promoting individual- and community-level empowerment
- 51

## Processes to Ensure that CBPR Counts for the Community

1. Ongoing discussion with community about early analyses and emerging findings
2. Joint interpretation of research findings
3. Discussions at start of research project about research products

### 52 Challenges to Making Research Count for the Community

1. Contrasting cultures (i.e., community vs. university) with divergent expectations and timelines for research products
2. Ebb and flow of data collection and analysis
3. Researchers need to focus on action and policy implications of research as well as journal publications

### 53 Challenges to Making Research Count for the Community (cont...)

4. Ownership of data
5. Community understanding of statistical analyses
6. Community may focus on issues that research deems to be of lesser importance/statistical significance