COMMUNITY ENGAGEMENT IN RESEARCH

DAY TWO: CBPR/PCOR INTRODUCTION

CBPR/PCOR WORKSHOP AIMS

- Develop and fortify working knowledge of Community-Based Participatory Research (CBPR) & Patient-Centered Outcomes Research (PCOR)
- Discuss opportunities and challenges for using a CBPR/PCOR approach in research with those involved in the criminal justice system

QUESTIONS TO CONSIDER THROUGHOUT THE DAY

- How does the historical and political context of the criminal justice system impact research?
- How could you as a patient, clinician, or policymaker become involved in research and the development of interventions?
- How could you/how do you incorporate CBPR/PCOR in your research agenda? What's the first step you need to start?
- What support from your institution or organization might you need to utilize a CBPR/PCOR approach to improve the health of justice-involved persons?

WHY ENGAGE COMMUNITY MEMBERS (NON-RESEARCHERS) IN RESEARCH?

- Addressing health disparities has had limited success

  →especially in disadvantaged communities

What can people from the community offer to the research process?

CBPR DEFINITION

*"A **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 and has the aim of combining knowledge with action and **achieving social change**…"*

W.K. Kellogg Community Health Scholars Program

PURPOSE OF CBPR

*"The intent in CBPR is to transform research from a relationship where researchers **act upon** a community to answer a research question to one where researchers work **side by side** with community members to define the questions and methods, implement the research, disseminate the findings and apply them."*

Campus Community Partnerships for Health (CCPH) CBPR Curriculum, 2006

CBPR CHALLENGES TRADITIONAL RESEARCH

- Who are the “experts”?
- Who designs the research?
- Who’s hired for the project?
- Who collects the data?
- How analyzes the data? Who interprets the findings?
- Who owns the data?
- How will the data be used?
- How will the results be disseminated?
- Who receives funding?

DEGREE OF PARTNERSHIP IN COMMUNITY-BASED RESEARCH

CBPR/PCOR Continuum

Community Placed

Community Compliant

Directed Consultation

Mutual Consultation

Co-Investigation

Community Based Participatory Research

- Researcher goals primary emphasis
- Community organization facilitator
- Low involvement of community partner
- Publishing scientific papers key product

- Community goals primary emphasis
- Research a vehicle for action
- Very high engagement of both
- Publishing secondary

KEY PRINCIPLES OF CBPR

- Community as experts
- Builds on strengths & resources of the community
- Facilitates collaborative partnerships in **ALL** phases of the research
- Integrates knowledge and action for mutual benefit of all partners
- Promotes a co-learning and empowerment of the community
- Disseminates findings and knowledge gained to all partners

CBPR: WHAT IT IS AND WHAT IT ISN'T

- An orientation to research
  - Fundamentally changes the role of researcher
- CBPR is not a method or a set of methods
  - Often thought of qualitative but includes quantitative, too!
- CBPR is applied approach
  - Goal: to influence change in community health, systems, programs, or policies

BALANCING RESEARCH AND EXPERIENTIAL CAPACITY

- Research terminology and skills create immediate power imbalances
  - Historically, rationale for research "experts" to drive and own the process
  - Funding and history of race, power and privilege reinforce power imbalances

- *Co*-Capacity Building is an essential part of CBPR
  - Power imbalances are discussed openly
  - Community context, history, and trust just as important to conduct research
  - Understanding/building capacity is part of the process
  - Academic and community co-researchers learn side-by-side

INCLUSIVE RESEARCH DESIGN

- Question formulation
- Seeking funding
- Developing methodology (surveys, focus groups, evaluations, etc)
- Data collection
- Data analysis
- Data interpretation
- Dissemination

INCLUSIVE RESEARCH DESIGN

<u>Question formulation and seeking funding</u>

- Research questions that drive study design – chosen to yield data most useful for community and systems change.
- Grant/funds sought ***after*** community planning process
  - inclusively engage multi-sector stakeholders
  - community leaders, CBOs, academic, business, grassroots, policymakers, faith-based, etc.

INCLUSIVE DATA COLLECTION

- Methods – guided by community
  - Feasible – match available resources
  - least burdensome to community members
- Community members hired and trained to collect primary data.
- Field protocols guided by community: selection, recruitment, consent, safety, communication, tracking response rates.

INCLUSIVE ANALYSIS

- Includes multiple perspectives, anticipates technology/capacity needs, and maintains scientific rigor.
- Whenever possible, community is supported to conduct data analysis.
  - Hired and trained to be member(s) of the analysis team.
- Interpretations of findings are strengthened through active discussion and community participation.

INCLUSIVE DISSEMINATION

- Findings are disseminated to all partners and the community, in plain language
- Opportunities for discussion
- Acknowledges ownership of knowledge
- CBPR partners and community leaders are involved as authors, co-authors, presenters, co-presenters
- The data itself are shared and used for multiple purposes (grant proposals, advocacy campaigns, program planning, etc.).

WHAT DOES INCLUSIVE DISSEMINATION LOOK LIKE?

- Community briefs
- Neighborhood Town Hall Meetings
- Press conferences, local media coverage
- Presentations to elected officials
- Peer-reviewed publications
- Conference presentations
- Data requests

New Haven Health Survey

CARE

Community Forum

Learn about health changes in New Haven!

Where: ConnCAT

4 Science Park, New Haven, CT 06511

9:30AM	Registration and light breakfast
10:00AM	Program begins (promptly!)
11:15AM	Small group sessions – work with your neighbors to take action in your community • Groups facilitated by Community Mediation • Featuring live illustration sponsored by Artspace
1:00PM	Healthy and delicious lunch

Each neighborhood that participated in the survey will be eligible to apply for a **$1500 grant from CARE**

SATURDAY, MAY 7 9:30AM - 1:30PM

RSVP to reserve your space! ***letitia.charles@yale.edu*** or 203-737-5270

CBPR CHALLENGES: ACADEMIC-COMMUNITY SKILLS MISMATCH

- Academic researchers often lack community history, context, or credibility needed for community research
  - Few training programs teach/encourage this
  - Few academic institutions support nurturing community partnerships beyond funded projects
- Communities and community-based organizations (CBOs) often lack the infrastructure or skills needed to conduct research
  - Lack of a pipeline to research jobs/careers in communities experiencing health disparities
  - Few CBO research capacity building programs

DEFINITION OF PATIENT-CENTERED OUTCOMES RESEARCH (PCOR)

Patient-centered outcomes research (PCOR) studies questions and outcomes that are meaningful and important to patients and caregivers. PCOR is based on the belief that patients have unique perspectives that can change and improve the way in which questions about healthcare are asked and answered.

- Patient-Centered Outcomes Research Institute

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

- An independent nonprofit, nongovernmental organization located in Washington, DC, was authorized by Congress in 2010 through the Affordable Care Act
- Mandate is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions.
- Comparative **clinical effectiveness research, or CER**, that addresses the questions and concerns most relevant to patients
- Involve patients, caregivers, clinicians, and other healthcare stakeholders, along with researchers, throughout the process
- **The goal is to determine which of the many healthcare options available to patients and those who care for them work best in particular circumstances**

PCORI FUNDING PRIORITIES

- Assessment of Prevention, Diagnosis, and Treatment Options
- Improving Healthcare Systems
- Communication and Dissemination Research
- Addressing Disparities
- Accelerating Patient-Centered Outcomes Research and Methodological Research

WHAT ARE THE END GOALS OF PCORI-FUNDED WORK

- For patients: provide information about which approaches to care might work best, given their particular concerns, circumstances, and preferences
- For clinicians: focus on providing evidence-based information about questions they face daily in practice
- For policymakers, produce evidence that can help them make the best decisions on how to improve health outcomes for their constituents/patients.
- For researchers, build a base of useful evidence for improving outcomes in high-burden, high-impact conditions

WHAT DEFINES A PCOR QUESTION?

PCORI's goal is to fund the development of research projects that answer a series of key questions from the patient perspective:

- What should I expect will happen to me?
- What are my options and what are the potential benefits and harms of those options?
- What can I do to improve the outcomes that are most important to me?
- How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?

PCORI AND JUSTICE INVOLVED POPULATIONS

- **Coming Home Project**: This is a 3-year prospective randomized comparative study of the efficacy of patient navigation on health education, health-related quality of life, health care utilization, and medical outcomes in formerly incarcerated individuals.
  - Do patient navigators improve the health education impact and quality of life of the individual? and
  - Do patient navigators improve patient health care utilization and self-management of chronic diseases?
- **Philadelphia jails**: 3-year prospective randomized comparative study of the efficacy of navigation and Naltrexone on 3 month relapse rates (receive XR-NTX before reentry with follow-up XR-NTX at NET Steps after reentry, or told to report to NET Steps after reentry for their first dose)
- **The Share Project**: Build capacity of stakeholders to engage in patient centered outcomes research

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SIMILARITIES AND DIFFERENCES BETWEEN CBPR & PCOR

CBPR

- Community partnership
- Social justice orientation
- Capacity strengthening
- Long-term commitment
- Reduce health disparities

CBPR/PCOR

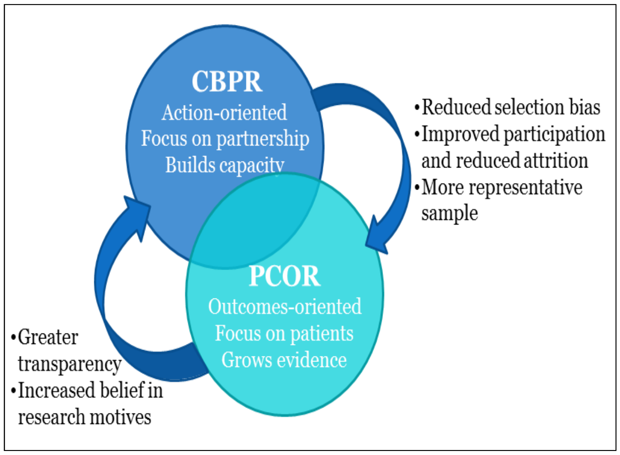
- Involvement of individuals not traditionally part of the research process
- Outcomes that are most important to stakeholders
- Trust & relationship building
- Focus on improved health outcomes

PCOR

- Patient focused
- Patient/caregiver involvement in medical decision making
- Patient/caregiver/clinician/policymaker as co-investigator

COMBINING CBPR & PCOR

- CBPR and PCOR are approaches to research
- Both emphasize the involvement of those affected in the research process
  - Design
  - Data collection
  - Data analysis
  - Dissemination
- Both focus on results of research
  - Outcomes
  - Use of results to improve health

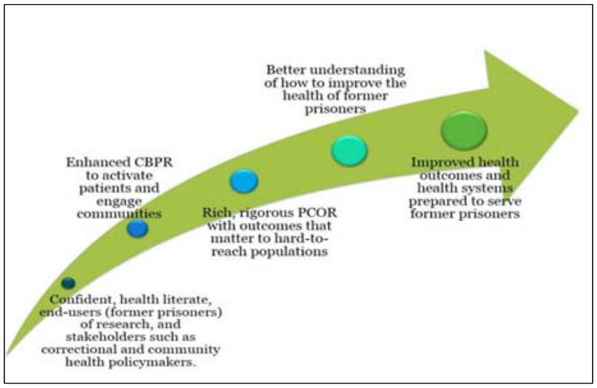


CBPR & PCOR IN CRIMINAL JUSTICE AND HEALTH RESEARCH

Goals of CBPR & PCOR

- Involve patients, clinicians, and policymakers not traditionally part of research process
- Build capacity of all stakeholders to equally participate in the research process
- Improve relationships between the patients (former prisoners), policymakers, clinicians and researchers
- Value variety of backgrounds, experience, and expertise
- Improve health outcomes and health systems

Applying CBPR/PCOR in The Share Project



EXERCISE

- Break into groups – assign vignettes
- Discuss how to better incorporate principles of CBPR/PCOR into traditional research
- Report back