Community-Based Participatory Research (CBPR) 101

These slides present the basic principles of CBPR, as well as background on why and how this approach to research is used, benefits, etc. design.
Why would communities want to conduct research?

- Describe scope of health priorities/issues in their communities
- Answer questions about their communities or service populations
- To develop/adapt new programs and/or services that are culturally appropriate for their communities
- Conduct evaluation of their programs
- Collect data/stories that help make their case for policy advocacy/funding
Some experiences communities may have had with research

• It’s called ‘Helicopter Research.’ They flew in, took our personal info, took off. We never got anything back.

• The academics got a grant for reducing smoking but what we’re really concerned with is gun and gang violence.

• Did they need to do that big long study to ‘prove’ what we already knew?

• The professor can’t just walk in with the expectation of creating a partnership. It takes time to understand each other and make sure we won’t be exploited.

• The university implemented and evaluated a really nice program but then the money ended and the program right along with it.
Why community-engaged research?

• Persistence of health disparities, Importance of local/cultural context – Need to make sure health programs/research findings work in real community settings

• Greater demand by communities for equity and research relevance- history of abuse/mistrust

• Limitations of current research approaches to address research translational blocks
What is community-engaged research?

• Approach characterized by collaborative partnership development, cooperation & negotiation, & commitment to addressing local health issues

• Broad spectrum:
  – Some incorporate few elements of comm. engagement/minimal collaboration
  – Others involve comm. orgs & researchers as equal partners in all aspects of the research
Spectrum

Inform
Consult
Involve
Collaborate
Empower
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. 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

How can you tell if a research project is community-placed or participatory? Who made the decisions?
Principles of CBPR: Maximum Engagement

- Builds on strengths & resources within community
- Facilitates collaboration in all phases of research
- Commitment to addressing local health issues
- Brings knowledge gathering & action together for mutual benefit of all partners
- Academics & community learn together –both are empowered
- Disseminates findings to all partners

How can communities be engaged in the phases of research?

• **Find partners/form team:** Identify/engage potential collaborators. Build participatory partnership structures (MOU).

• **Form research Question:** Share community issues/priorities. Identify community questions or give feedback on academic questions. May include assessing community strengths/dynamics. Supplement literature review with local history/politics.

• **Planning study:** Seek $ together. Advise on appropriate research plans/methodologies: data collection tools, participant incentives, recruitment, logistics, & how to tailor methods to specific community/cultural context. Review proposal drafts.
How can communities be engaged in the phases of research?

- **Conducting Research**: Promote study in community. Hired to collect data. Address implementation problems.

- **Analyzing data**: Trained to assist (e.g. ‘data cleaning’). Assist with interpretations of findings. Get input on interpretation of findings from broader community (residents, other organizations, policy makers). Discuss possible actions/interventions
How can communities be engaged in the phases of research?

• **Sharing findings**: Disseminate appropriately in community (easy to understand language, town hall forums, fact sheets, media, policy briefs). Assist in presenting findings in academic venues (conferences, journal articles).

• **Taking Action**: Figure out what actions should be taken based on findings (e.g. conduct more research, translate into new/revised policies, mobilize people behind issue, lend support to current programs or show need for new programs, or seek further funding).
Community-Engaged Research: What it is and isn’t

• An Orientation to research: changes the role of researcher and researched
  – How can you tell if research is community-placed or community-engaged?
  – Who makes the decisions? Who holds the power? Choice of issue/design, gets money, owns data, dissemination venues

• **Not** a method or set of methods
  – Typically thought of as qualitative
  – Fewer other examples, but promising

• Goal is to influence change in community conditions, norms, systems, programs, policies

• Communities may be patients with specific health condition, families/caregivers, health care professionals, racial/ethnic, geographic, identity (LGBT), etc.
Benefits of Community-Engaged Research

- Research agenda (diversity of topics)
- Research design and delivery (tools, recruitment)
- Research ethics (consent, ethical acceptability)
- Impact on communities (CBOs, participants)
  - Enhancing effectiveness of interventions
  - System change outcomes (policy change, practice/program changes, community capacity and empowerment)
- Impact on faculty
- Impact on broader community/practice
Examples

- Global Gardens Refugee Training Farm (Buthanese & Burmese)
- African American Faith-based Caregiver (focus on Alzheimers)
- Dissemination of HIV Prevention Info in Social Networks
- Violence Prevention in Schools in Roseland
- Asthma verification/medication access in Chicago Public Schools
- Hep C Vaccination in African Americans
- Clinician understanding of needs of children with life-limiting illnesses and their families
- Coordination of Care for Uninsured in DuPage County
- Medicaid Primary Care Experiences for People with Disabilities
Community-engaged research is rewarding and growing

- Making research matter in the community
- Growing “movement”
- Increasing legitimacy/support/interest from:
  - university leaders
  - private and govt. funders
  - journals
  - Job/fellowship announcements
Community-engaged research is not for everyone

• Challenging

• Time-consuming

• Requires compromise

• Not always understood/supported by community or university leaders- pay for colleagues’ errors

• It’s not just about community change/action, it’s also about research and rigorous process.

• It’s not just about research and grants and papers, it’s also about relationship-building and trust.
Local Connections

Chicago Consortium for Community Engagement

www.c3ctsa.org

Chicago CBPR Network

http://groups.yahoo.com/group/Chicago_CBPR_Network/