Engaging Communities, Providers, & Patients in Research: Resources from Northwestern’s Center for Community Health

Jen Brown, Director, Alliance for Research in Chicagoland Communities
Who’s in the room?
Why would communities want to conduct or participate in research?

- Access to services/resources/treatments they wouldn’t have otherwise
- Describe scope of health priorities/issues in their communities. Answer ?s about their communities
- Develop/adapt programs/services that are culturally appropriate for their communities
- Conduct evaluation (describe impact/outcome) of their programs/services
- Collect data/stories that help make their case for policy advocacy/funding
Why would communities want to conduct or participate in research? 

Broader reasons

• Contribute to scientific knowledge about how things work/don’t work - doesn’t necessarily benefit their specific community/members

• Ensure research conducted includes representation of their community

• Act as gatekeeper to ensure research done on/in their community is respectful/useful
Why wouldn’t communities want to do or participate in 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 our community is really concerned with is gun and gang violence.

• How do we know our patients wont be treated like guinea pigs? Exploited like in the Tuskegee trials?

• The university implemented and evaluated a really nice program but then the money ended and the program right along with it.

• We don’t want to be anyone’s petri dish. My cousin had a bad experience in the hospital.
Why do universities want to do research with communities?

- **Need strong recruitment and retention** of research subjects- including diverse communities
- Greater demand by communities/regulatory for equity and research relevance- **address history of abuse/mistrust**
- **Limitations of current research approaches** to address NIH translational blocks
- Persistence of health disparities- **Understand importance of local/cultural context**
Community-engaged research

• Approach that calls for conducting research in a collaborative way involving partnerships between communities and academics in an exchange of expertise between academics, as scientific experts, and communities, as local and cultural experts.

• **Broad spectrum**: minimal collaboration to comm. orgs & researchers as equal partners in all aspects of the research
Community-engaged research: What it is and isn’t

- Orientation to research: changes role of researcher & researched
  - 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- Can be quantitative, qualitative, RCT
  - Solely community-placed- With Not In
  - Top-down or ‘outside expert’ approach

- Research That Matters: Goal is to influence change in community conditions, norms, systems, programs, policies, clinical practice
Spectrum

Inform

Consult

Involve

Collaborate

Empower

We will keep you informed

We will consider your input and give feedback about how it informed our decisions

We will ensure that your input is considered among the choices we implement

We will work together to decide and ensure everyone’s views are incorporated as much as possible

We will implement what you decide
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
Practice-Based Research

- **Practice-based research** is grounded in, informed by, and intended to improve practice with the goal of improving the health of patients.

- **Primary care practice-based research network**: Practice-based research networks composed primarily of primary care clinicians that focus their research and development activities on issues relevant to the primary care of patients.

- Originated in 1980’s as a strategy to study patients not normally seen at Academic Medical Centers
Patient-Centered Outcomes Research (PCOR)

“helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options.”

“...meaningful involvement of patients and other stakeholders in all steps of the process. Bringing together all stakeholders in the healthcare enterprise to set research priorities, with patients at the center....”
Who is “The Community”? Who represents the community?

**Community** - group of people united by at least one common characteristic, e.g. geographic proximity, shared interests, values, experiences, or traditions.
Community-engaged research is rewarding and growing

• Increasing legitimacy/support/interest from:
  – private and govt. funders
  – CTSAs, PCORI
  – journals
  – Job/fellowship announcements
  – university leaders
Examples

• Global Gardens Refugee Training Farm (Bhutanese & Burmese)
• 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
Translational research

T1: Basic (then animal) to Human

T2: Clinical trial to care

T3: to community

T4: to policy
Evolving understanding/practice of community engagement in research

• Community engagement required component in CTSAs

• For some:
  – Building on prior work and need for trust building, started at more collaborative end of spectrum

• For some:
  – Working to increase diverse recruitment in trials

• Move to address silos between CEnR researchers and not researchers

• IOM/NCATS reports
IOM/NCATS Reports of CTSAs

IOM Recommendation 6: Ensure CE in All Phases of Research: NCATS & CTSA Program should ensure that patients, family members, health care providers, clinical researchers, & other community stakeholders are involved across the continuum of clinical & translational research.

– ensure active & substantive community stakeholder participation in priority setting & decision making across all phases of clinical and translational research and in the leadership & governance of CTSA Program
How do we involve communities in research from early stage to late stage?
What we do and don’t know

- What does CE look like in all these phases?
- Most current CE professionals understand collaborative engagement in population/public health and health services
- Not as much knowledge or examples of CE in other parts of spectrum
- Need help of researchers in those other parts of spectrum about structures/possibilities there
- Need help of communities to understand how they would want to engage in these other phases (not just as subjects/participants)
Some examples

- Biobanks/Genome depositories
- Design of clinical trials (HIV/Cancer)
- Advice/assistance w/recruitment
- Patient navigators re: research participation
- PCORI
- CBPR/COMR
- PBR
Example from Cancer Clinical Trials

• Education Network to Advance Cancer Clinical Trials (ENACCT)
• Focus on increasing cancer clinical trial participation, particularly within underserved communities. Apply CBPR principles to cancer clinical trials
  – strengthening communication and recruitment &retention practices
  – implementing patient-centered policies/procedures to enhance recruitment & accrual;
  – ensuring access to trials as a measure of delivery of quality care;
  – partnerships between institutions & communities to create greater community awareness

• Association of Clinical Research Professionals (ACRP)
Mission: CCH cultivates and catalyzes engagement of academic and community partners in research to improve the health and healthcare of communities.

http://www.feinberg.northwestern.edu/sites/cch/
Practice-Based Research Program (PBR)

PBR fosters collaborative research between community-based practitioners and NU faculty. Two practice-based research networks, REACH and PPRG.

- **REACH**: 17 clinical sites affiliated with NU, including private practices and federally qualified health centers (FQHCs) with more than 160 member physicians.

- **Pediatric Practice Research Group (PPRG)**: regional network founded in 1984 as partnership of Ann & Robert H. Lurie Children’s Hospital of Chicago Dept. of Pediatrics and group of over 50 pediatric practices.
**Mission**: Promoting and supporting collaborative research partnerships between Chicago area community-based and faith-based organizations & Northwestern University that lead to measurable improvements in community health.

Guided by steering committee of 13 community and faith-based organizations, Chicago Public Schools, Chicago Department of Public Health, and 11 Northwestern faculty.

[www.ARCConline.net](http://www.ARCConline.net)
## Resources and Services

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National Resources

- Resources
- Skill-Building Online Curriculum

Progress in Community Health Partnerships Journal

- Patient and Family Engagement Rubric
- Sample Patient Engagement Plans

http://www.pcori.org/get-involved/what-is-engagement-in-research
Resources

• Monthly Resources & Opportunities Listings

• CCH Writing Retreats- next is Sept 22

• Chicago Consortium for Community Engagement (C3) Symposium, October 10

• Academic Research Staff Meetings
ARCC Resource Directory

The ARCC Resource Directory is an online website providing access to materials and resources to help interested community and faith-based organizations and academic partners to learn about how they can build capacity to conduct community-engaged research and support building, strengthening, and sustaining their partnership.

**Click here to access a brief guided video tour of the website.**

It was developed and is maintained by the Alliance for Research in Chicagoland Communities (ARCC). ARCC is guided by a steering committee of community- and faith-based organizations from across the Chicagoland area, public agencies, and faculty at Northwestern University. ARCC supports and promotes collaborative research partnerships between community-and faith-based organizations and Northwestern University that leads to measurable improvements in health. Learn more at ARCConline.net

Community-engaged research (CEnR) is an approach characterized by collaborative partnership development, cooperation & negotiation, & commitment to addressing local health issues. Engagement is on a broad spectrum from minimal collaboration to collaboration as equal partners (e.g. community-based participatory research (CBPR)).

Resources by Category