Research Partnerships with Community Health Centers

This document contains background and questions to consider when forming and building research partnerships involving community health centers and research teams. Includes considerations related to community health center research motivation, infrastructure, partner identification, capacity building, etc.
Why do universities want to do research with CHCs?

- Many researchers have been collaborating on research but often this is in spite of the University, not with support/structure
- $ Money $
- Required to (Funders like CTSA/PCORI*)
- Current approaches aren’t working
- CHCs/communities are demanding it
- Enlightened self-interest
CHCs see different people/conditions than academic medical centers

Typical Month of Healthcare in the U.S.

- 1,000 persons
- 800 report symptoms
- 327 consider seeking medical care
- 217 visit a physician's office (113 visit a primary care physician's office)
- 65 visit a complementary or alternative medical care provider
- 21 visit a hospital outpatient clinic
- 14 receive home health care
- 13 visit an emergency department
- 8 are hospitalized
- <1 is hospitalized in an academic medical center

Why do CHCs want to conduct research?

• Improve patient outcomes
  – Describe health priorities/issues/assets
  – Reduce health disparities/Culturally appropriate
  – Patient centered

• Improve care delivery
  – Quality improvement

• Representation/Gatekeeper

• Policy advocacy/funding
Why don’t CHCs want to do research?

- ‘Helicopter Research’
- Topical mismatch
- Ethical concerns/respect
- Time- everything is secondary to patient care
- No implementation sustainability
So how do you address these issues?
Community-engaged research (CEnR)

• Approach for conducting research in a collaborative way
• Partnerships between communities and academics
• Exchange of expertise between academics (as scientific experts) and communities (local, cultural, practice experts)

• **Broad spectrum**: minimal collaboration to equal partners in all aspects of the research
• Newer field, term not used even 10 years ago
Community-engaged research (CEnR):

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
CEnR Principles

- Focus on addressing local health issues/priorities
- Builds on strengths & resources within community
- Facilitates collaboration in all phases of research
- Mutual respect of values. Power sharing and flexibility.
- Academics & community learn together – both are empowered
- Disseminates findings to all partners
  - Strives for results that mobilize resources, influence systems, & catalyze new policies, programs, & practices
Inform
- We will keep you informed

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

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

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

Empower
- 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 (PBR)

- Grounded in, informed by, and intended to improve practice with the goal of improving the health of patients
- **PBR Networks**: groups of primary care clinicians & practices working together to answer community-based health care questions and translate findings into practice
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....”
# Research vs QI

<table>
<thead>
<tr>
<th></th>
<th>Research</th>
<th>Quality Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal</strong></td>
<td>Advance general knowledge/test hypothesis. Improve care.</td>
<td>Improve of patient care-monitor/correct practice</td>
</tr>
<tr>
<td><strong>Patient risk</strong></td>
<td>IRB review</td>
<td>IRB not required</td>
</tr>
<tr>
<td><strong>Applicability</strong></td>
<td>Generalizable</td>
<td>Only to local CHC</td>
</tr>
<tr>
<td><strong>Design</strong></td>
<td>Rigid, fixed protocol</td>
<td>Adapt over project</td>
</tr>
<tr>
<td><strong>Timeline</strong></td>
<td>Longer process towards change</td>
<td>Immediate change/sustained improvements</td>
</tr>
<tr>
<td><strong>Mandate</strong></td>
<td>Optional</td>
<td>Required</td>
</tr>
<tr>
<td><strong>Population</strong></td>
<td>Subset of individuals</td>
<td>All patients receiving particular treatment</td>
</tr>
<tr>
<td><strong>Dissemination</strong></td>
<td>Published/shared- journal</td>
<td>May only be internal</td>
</tr>
<tr>
<td><strong>Benefit</strong></td>
<td>May or may not benefit directly</td>
<td>All expected to benefit directly</td>
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So you’re convinced....

• How do you make the research you’re already doing work for CHCs/patients/academics?
• How do you make sure future research is great for CHCs/patients/academics?
• Lots of questions to consider......
• Important to take time to do some naval gazing, reflection, internal assessment
• Some questions you can answer on your own, many are things your health center/research team should discuss together
How does your CHC think about research?

• Why is your CHC interested in research?
• How does research fit with your CHC’s mission?
• How does your CHC currently use research?
• How does research contribute to your CHC’s decision making?

WHAT IS YOUR MISSION?
What’s your research status quo?

• How is your CHC currently involved in research? Do you know or track what research is currently taking place at your center?

• How is research involvement/use supported by your CHC (leadership, board, frontline staff, patients)?
  – Included in executive priorities or organizational roadmap?

• What are your CHC’s research priorities/agenda?
  – What research questions do you have?
  – Proactive or reactive?

• Who at your CHC decides on research participation?
  • If you’re not already engaged in research, why do want to?
  • Who gives input/participates in research design?
As an academic, why do you want to engage partners in research?

• What is the appropriate type of engagement for your research (may differ by project)?
• Who will be impacted by your research/findings?
• How will engaging add to your research success/outcomes?
  – appropriate design/focus
  – rigor
  – acceptance by a community/ethics
  – recruitment/retention
  – feasibility for success and sustainability
  – Impact/action
How do you want to be involved in research?

• Level of engagement you are interested in/open to?
  • Site for conducting?
  • Site for recruiting?
  • Collaboratively conducting research with external partners?
  • Creating a research department?

• Only on your identified priorities or other research topics too?

• What capacity does your CHC have to engage in research (fiscal, skills)?

• What type of research are you interested in (health services, behavioral, clinical trials)?
Who are your CHC’s current or possible research partners?

• Do you already have relationships with researchers or do you need to find research partner(s)?

• Are you looking for a long-term relationship or for single project?

• What info about your CHC/patients will you want to share with possible research partners?

• What info will your CHC want to know about possible research partners?
For academics: Who and how do you want to engage?

• Who are the groups or people you want to engage?
• Do you already have relationships with these groups or people or do you need to find partner(s)?
• What info about you/your research team will you want to share with possible partners?
• What info will you want to know about possible partners?
What do you want in a partner?

A survey with CHCs said these things are important:

• trust
• engaging CHC leadership
• transparency
• understanding the community
• clear and compelling benefit to CHC

What can contribute to these?

What are important to academics?
What are challenges or barriers you want to avoid/address?

• How can your CHC ensure that research collaboration is positive and beneficial for your CHC?

• How can your academic research team ensure that research collaboration is positive and beneficial for you?

• What challenges or conflicts could come up? How can you avoid these? How would you handle them?
What policies or processes do you have that support research collaboration?

– Research purpose/principles?
– Template MOU? Partnership agreements/contracts?
– Research review board/workgroup/staff?
– Review process?
– Questionnaire researcher must submit when wanting to conduct research at or with your CHC?
– Policies re:
  • budget/resource allocation
  • data access/ownership
  • dissemination, etc.
For academics: what policies or processes do you have that support research engagement?

- Community advisory board?
- Space for community meetings?
- Engagement purpose/principles?
- Template MOU? Partnership agreements/contracts?
- Lay language explanation/website/brochure of research interests?
- Engagement staff?
How are your patients impacted by research?

• How are they involved in the proposed research?

• Does the budget reflect your CHC’s/patients contributions? (CAB/patient support, budget for dissemination, budget for indirect costs for space for research implementation)

• How will findings be shared with your patients?

• Does it minimize disruption of clinic workflow/patient care?
How is research benefiting your CHC?

- Is it providing a needed service for your patients? Is it sustainable to your CHC?
- Will it raise capacity of your staff and community?
- Will the research be valuable to your CHC practice?
- Will researchers better understand your CHC/community/patients?
- Is the research bringing resources/funding to your CHC?
What organizational research capacity will your CHC need?

- **Staff w/ capacity**
- **Research knowledge & skills**
- **Value on research participation/use** (interest, buy-in, leadership)
- **Identified research priorities/agenda**
- **Mechanisms for dissemination**
- **Navigation** (university/funder systems)
- **Research policies/procedures** (MOU, rules of engagement)
- **Access to funding & resources/fiscal capacity**
- **Partnership skills** (negotiation/collaboration skills, Connections/relationships)
- **Depth** (# of staff, administrative support)
What engagement capacity will your academic research team need?

- Community knowledge
  - Politics/Players
  - Community priorities/interests
  - History

- Engagement skills
  - Humility, compromise, listening, power sharing, flexibility
  - Connections/relationships

- Ability/material to explain complex concepts in laypersons terms

- Support of your dept/leadership/administration
What capacity will your university develop to support your engaged research?

- Institutional leadership (dept. chairs, deans, provost)
- Subcontracts with community organizations
- Institutional Review Board
- Institutional support structures
- Promotion and tenure
- Academic pipeline

How does engagement happen not just at a project level but also in centers, institutes, schools, university-wide structures?
What capacity will other institutions develop to support your engaged research?

Funders

- Design of call for proposals
- Staff training
- Review process/criteria/panel members/training
- Grant administration rules ($ for food!)

Academic journals

Public Agencies- How are we ensuring capacity/ability/interest to make evidence-based policy?
What’s out there to help you do this?
Institute for Public Health and Medicine’s

Northwestern University Feinberg School of Medicine

Center for Community Health

**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/](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**: 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
**Alliance for Research in Chicagoland Communities**

**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 10 Northwestern faculty.

[www.ARCConline.net](http://www.ARCConline.net)
National Resources

www.ccph.info
- Resources
- Skill-Building Online Curriculum
- Listservs
- IRB and Ethics

Progress in Community Health Partnerships Journal
Research Training Catalog- http://eclinician.org/NACHC/


Building Research Partnerships with CHCs: Toolkit for Academics

http://www.nachc.com/
• Patient and Family Engagement Rubric

• Sample Patient Engagement Plans

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