Nothing About Us, Without Us: The Basics of Community-Driven Research

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Intros

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Alliance for Research in Chicagoland Communities

Celebrating 15 years of engagement and action!

Catalyze & support research partnerships that honor, are driven by, & share power with communities to improve health & equity

www.ARCConline.net
17-year gap between Chicago communities
Whose story?

• Whose voices/experiences are valued? Who asks questions? Who makes decisions?

• How do communities see themselves represented as researchers? How do researchers see themselves in communities?

• Why would/wouldn’t communities want to engage in research? Why would/wouldn’t researchers want to engage communities in research?
Who is “The Community”? Who represents the community?

- Partners/people impacted by the issue/topic
- Partners/people who have power to make change based on findings
- Individuals with lived experience vs community org
- Most impacted by inequities
Community-Engaged Research

- Honors & centers expertise of communities (local, cultural, practice, lived experience experts) in collaboration with academics (scientific experts) to increase value of research for improving health & equity

- Broad spectrum: minimal to equal partnership in all aspects

Principles of Engagement
Community-engaged research

Orientation to research: changes role of researcher & researched. Who makes the decisions? Who has the power? What is the evidence the research has changed based on engagement?

**Key Principles**
- Address community/patient priorities
- Build on community strengths & resources
- Mutual respect of values. Power sharing & flexibility. Findings ‘translated’ & shared with partners to catalyze action
Melvin Thompson
Engagement Strategies

- **Leadership/shared leadership** (org, individual)- community driven or co-driven
- **Collaborating**: team members/partners, bridge/boundary spanners
- **Involving**: Governance & Advisory Groups- oversight and/or guidance
- **Consulting**: focus groups, interviews, testers, community arts
- **Listening**: Surveys, polls, listening sessions/storytelling, town halls
- **Informing**: Media
- **Observing**: Mapping, researching, observation, assessment
The Continuum of Community (Stakeholder) Engagement in Research

- **Patient/Community-Driven Research:** Stakeholders serve as Principal Investigator (PI) or Co-PI and are leading the research.

- **Research Team Members:** Stakeholders are integral members of the research team and participate in key activities.

- **Advisory and Governance:** Stakeholders serve on boards, councils, and committees that provide oversight and/or guidance.

- **Focus groups, semi-structured interviews, nominal groups techniques, Community Engagement Studios:** Stakeholders serve specific, time-limited roles.

- **Surveys, online polling, listening sessions:** Broader community of stakeholders provides brief input.

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Wilkins CH et al. 2015

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**Number of Stakeholders**

**Extent of Engagement**

**Ongoing Involvement**

**Short-Term Involvement**
Reflection BEFORE & during engagement

• What do you know about community before you engage?
• What do you know about yourself/your institution before you engage?
• Resources it takes to engage
• Understanding challenges
Moving from Engagement to Community Leadership

• Addressing racism & bias in community research partnerships
• Operationalizing shift in who leads
• Supporting community leadership
• Leveraging power & privilege
<table>
<thead>
<tr>
<th>Power Over</th>
<th>Power With</th>
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<tbody>
<tr>
<td>Power is finite.</td>
<td>Power is infinite.</td>
</tr>
<tr>
<td>One must use fear to hoard and</td>
<td>Power expands when it is shared</td>
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<td>protect power.</td>
<td>with others.</td>
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<table>
<thead>
<tr>
<th>Supremacist</th>
<th>Liberatory</th>
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<tr>
<td>Ability to control people</td>
<td>Ability to create what we want</td>
</tr>
<tr>
<td>people or things</td>
<td>Stems from abundance</td>
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<tr>
<td>Stems from scarcity</td>
<td>consciousness</td>
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<tr>
<td>consciousness</td>
<td>Requires transformation of what</td>
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<td>Requires acceptance of</td>
<td>one perceives as a limitation</td>
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<tr>
<td>relationships of domination</td>
<td></td>
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<tr>
<td>and submission: relative rank</td>
<td></td>
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<tr>
<td>and privilege of being on top</td>
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Challenges and recommendations to improve institutional review boards’ review of community-engaged research proposals: A scoping review

Deborah Onakomaiya, 1 Janet Pan, 2 Timothy Roberts, 2 Holly Tan, 3 Smiti Nadkarni, 2 Marina Godina, 4 Jo Park, 5 Marilyn Fraser, 6 Simona C. Kwon, 2 Antoinette Schoenthaler, 2, 7 and Nadia Islam 2, 7
Challenges

1. Community partners not being recognized as research partners
2. Cultural competence, language of consent forms, & literacy level of partners
3. IRBs apply formulaic approaches to CEnR
4. Extensive delays in IRB prep/approval potentially stifles relationships with community partners
Recommendations

1. Training IRBs to understand CEnR principles to streamline & increase flexibility of IRB review process

2. Identifying influential community stakeholders who can provide support for study

3. Disseminating human subjects research training that’s accessible to all community investigators
CIRTification Online

Free, web-based human research protections training program tailored specifically to needs & roles of community research partners.

Developed by UIC. ARCC staff & community partners & others from Chicago gave input on creation.

https://ccts.uic.edu/tools/cirtification/
ARCC Resources

www.ARCConline.net

Anti-Racist Community-Academic Research Reflective Practice Tool

Seed Grants: bit.ly/ARCCgrants

www.ARCCresources.net

Monthly Resources & Opportunities listing

Resources Directory

Resources to build, strengthen and sustain relationships.

The Resources Directory was developed and is maintained by the Alliance for Research in Chicagoland Communities (ARCC). The directory provides 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-integrated research and research-informed practice.
Northwestern Resources

- NU MSCI Community-Engaged Research & Anti-Racist Science Courses
- NU Racial Equity & Community Partnership grants
- NMH Community Health Needs Assessments
- NMH Grants & Donations
Chicago Resources

- Chicago Beyond- Why Am I always Being Researched?
- Community Health Equity: A Chicago Reader
- Health & Medicine Policy Research Group
- Chicago United for Equity

- 2022 CHNA Report
National Resources

Assessing Community Engagement Conceptual Model

[Image of logos and concepts related to health partnerships, equity, and trustworthiness.]
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