



# 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.ARCOnline.net](http://www.ARCOnline.net)



Northwestern University Feinberg School of Medicine

Center for  
Community Health





The Night Ministry



Puerto Rican  
Cultural Center



Cambodian  
Association of IL



Health & Medicine  
Policy Research Group



Access Living



Heartland Alliance



Apostolic Faith  
Church



Chicago Youth  
Programs

## ARCC STEERING COMMITTEE

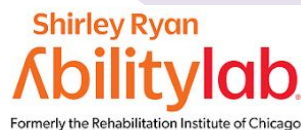
### *Government Agencies:*

Chicago Department Of Public Health,  
Chicago Public Schools



### *Northwestern Faculty & Academic Staff:*

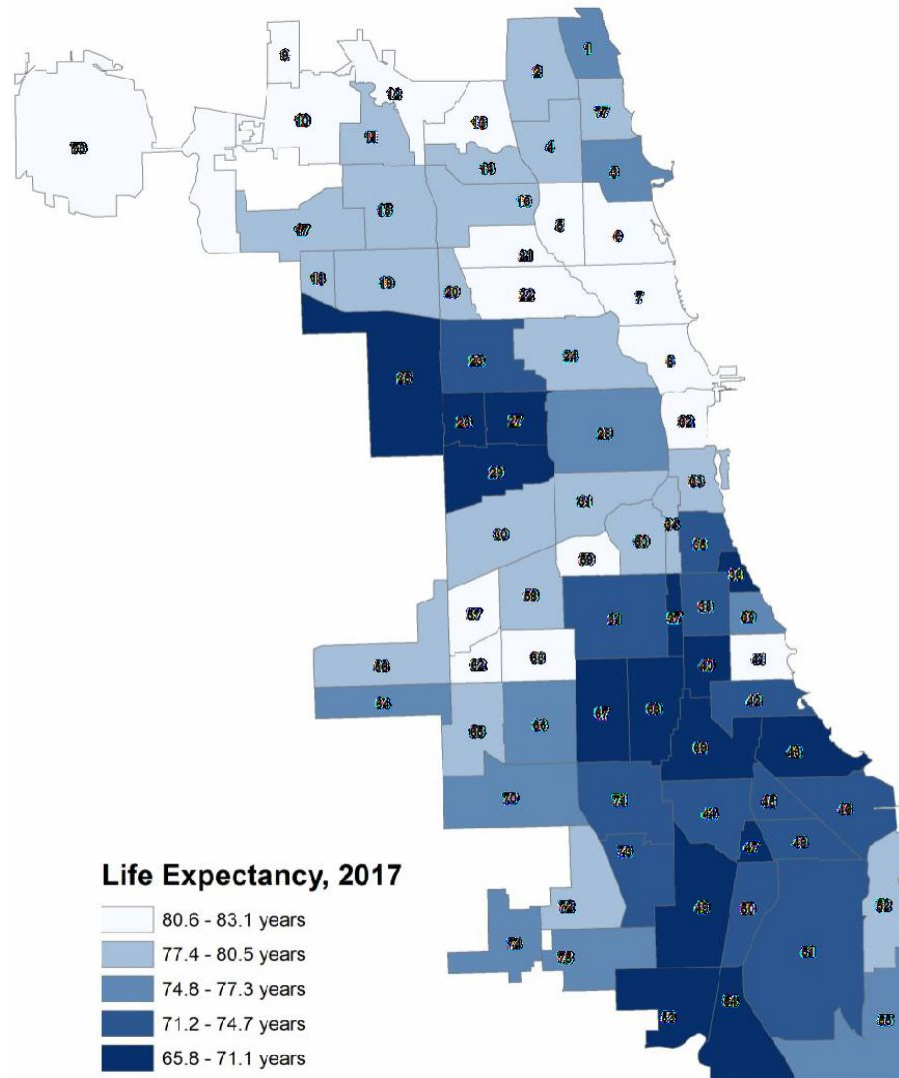
Lisa Azu-Popow MHA, Tara Gill PhD, Ashley Knapp PhD, Tarneka Manning MEd,  
Theresa Sukal-Moulton DPT PhD, Faith Summersett Williams PhD, Sarah Welch MPH



Formerly the Rehabilitation Institute of Chicago



# 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?



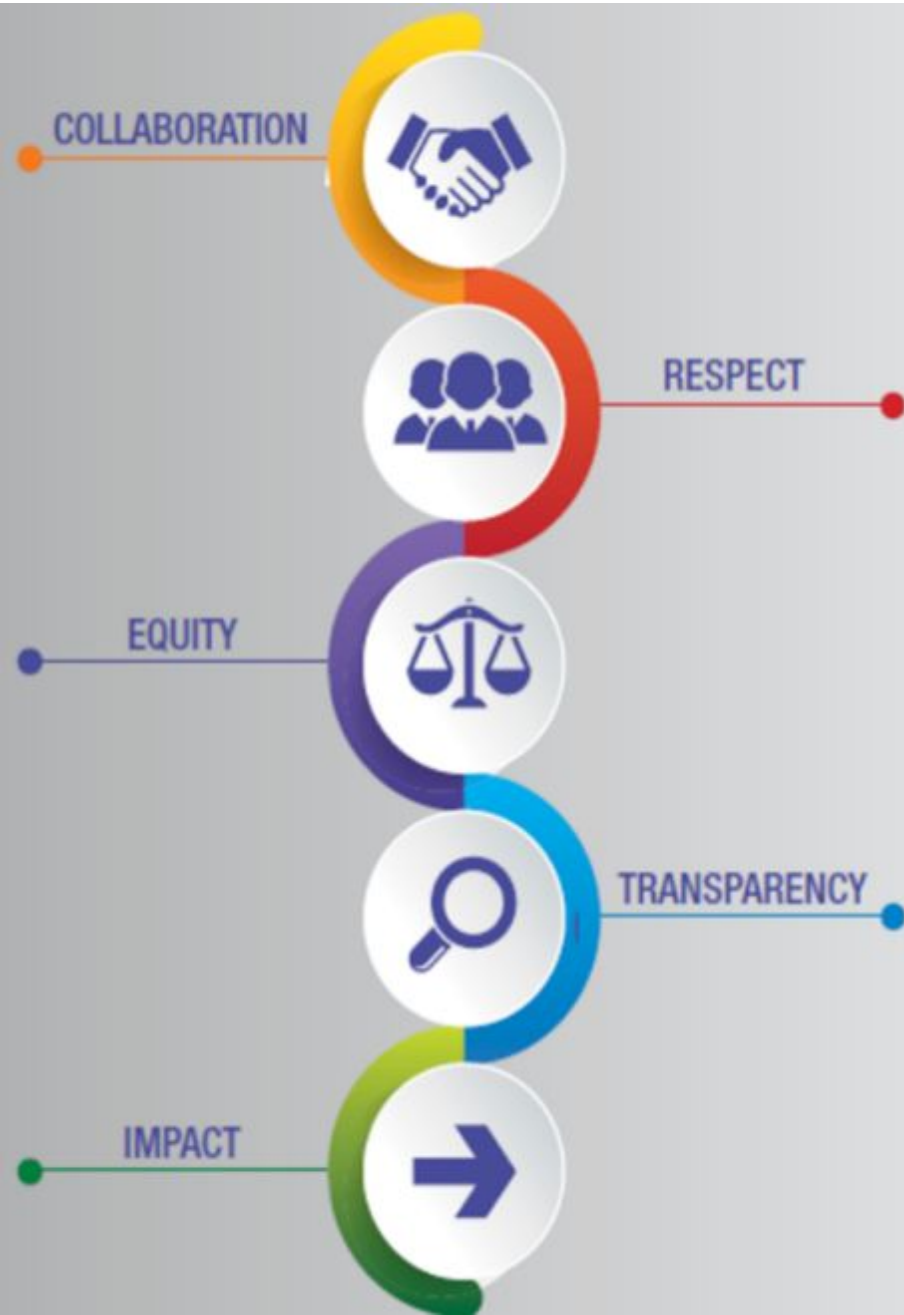
Partners/people impacted by the issue/topic

Partners/people who have power to make change based on findings

Individuals with lived experience vs community org

Most impacted by inequities

# Principles of Engagement



# 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



# 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

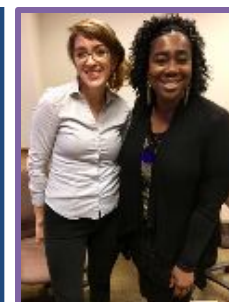


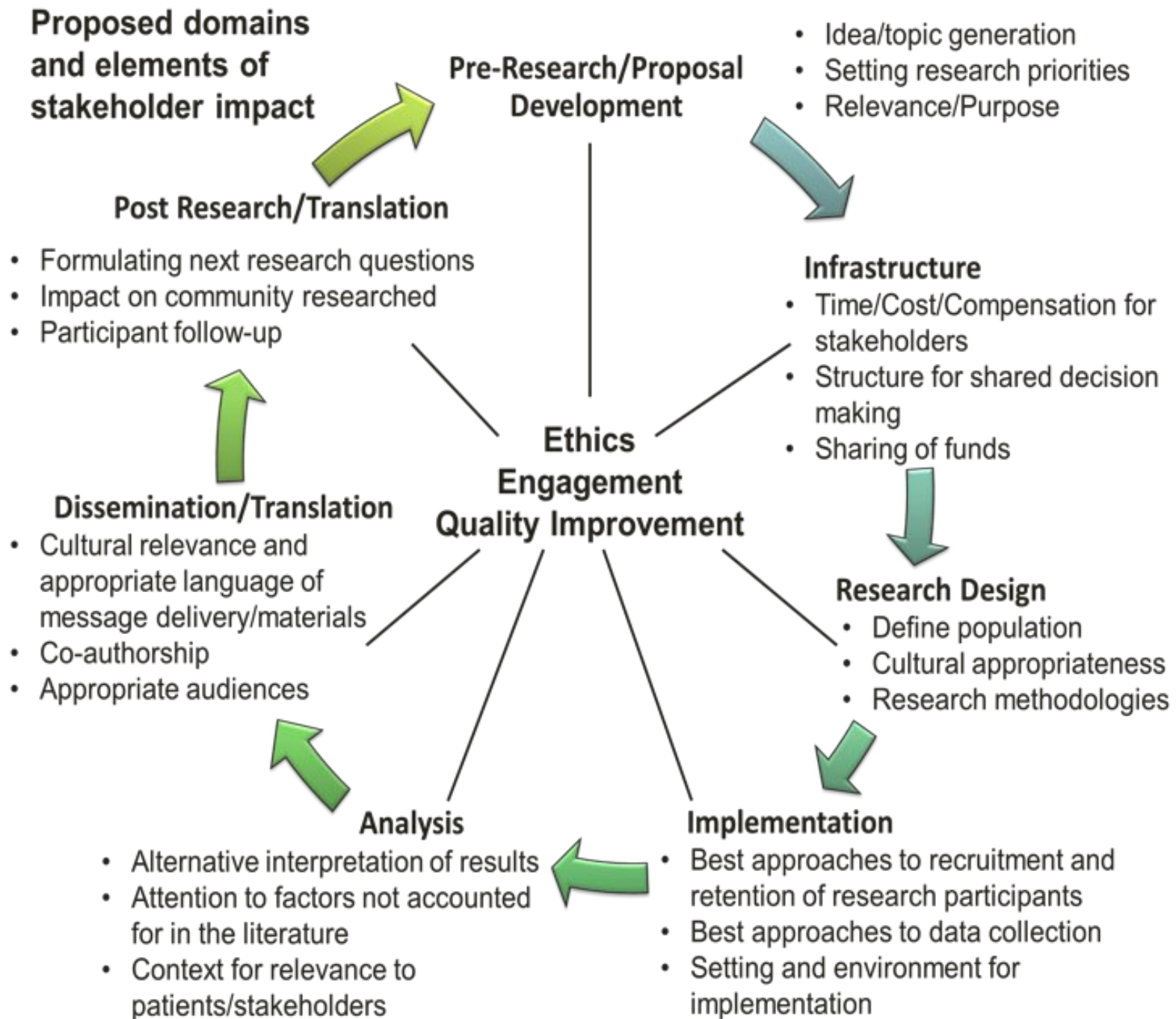
# Melvin Thompson



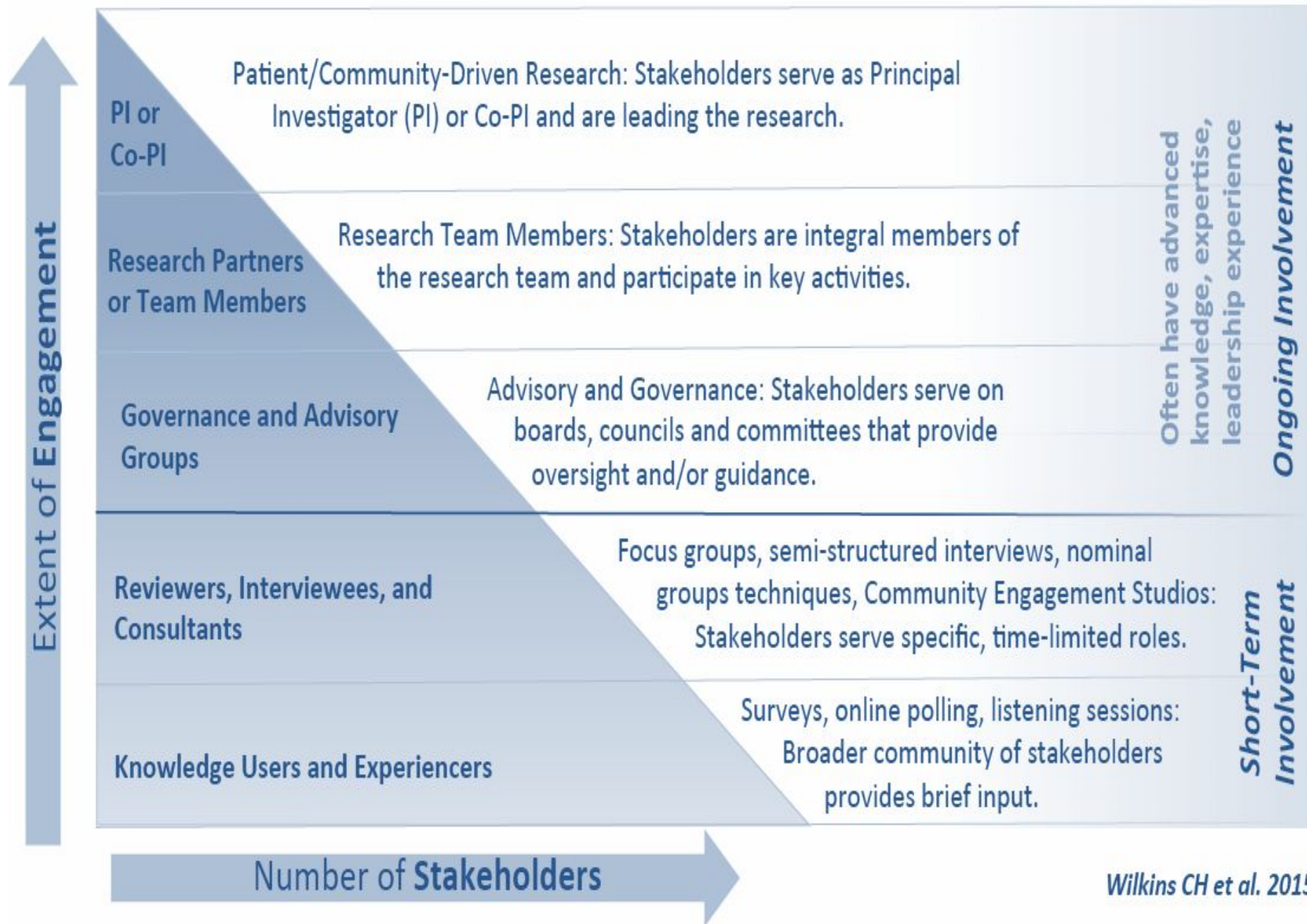
# Engagement Strategies

- **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



# 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



## Power Over

Power is finite.

One must use fear to hoard  
and protect power.

## Power With

Power is infinite.

Power expands when it is  
shared with others.

## Supremacist

Ability to control people people or things

Stems from scarcity consciousness

Requires acceptance of relationships of  
domination and submission: relative rank  
and privilege of being on top

## Liberatory

Ability to create what we want

Stems from abundance consciousness

Requires transformation of what one  
perceives as a limitation





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PMCID: PMC10130837

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PMID: [37125052](https://pubmed.ncbi.nlm.nih.gov/37125052/)

## Challenges and recommendations to improve institutional review boards' review of community-engaged research proposals: A scoping review

[Deborah Onakomaiya](#),<sup>1</sup> [Janet Pan](#),<sup>2</sup> [Timothy Roberts](#),<sup>2</sup> [Holly Tan](#),<sup>3</sup> [Smiti Nadkarni](#),<sup>2</sup> [Marina Godina](#),<sup>4</sup> [Jo Park](#),<sup>5</sup> [Marilyn Fraser](#),<sup>6</sup> [Simona C. Kwon](#),<sup>2</sup> [Antoinette Schoenthaler](#),<sup>2,7</sup> and [Nadia Islam](#)<sup>2,7</sup>



# 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/>

A screenshot of the CIRTIfication Online webpage. The header includes the University of Illinois Chicago logo and navigation links for UI Health, UIC.edu, Campus Map, Events, News, CTSA Program, and a search icon. A secondary navigation bar lists SERVICES, TOOLS (underlined), FUNDING, TRAINING, PARTNERSHIPS, PARTICIPATE, and ABOUT. Below this is a dark blue banner for the Center for Clinical and Translational Science with the tagline 'UI HEALTH IS UIC'S ACADEMIC HEALTH ENTERPRISE'. The main content area has a left sidebar with links: CIRTIIFICATION, Using CIRTIfication, In-Person Training, Online Training (highlighted in red), Partners, and Contact CIRTIfication. The main heading is 'CIRTIfication Online' with a breadcrumb trail: Tools > CIRTIfication > CIRTIfication Online. Below the heading is a photo of hands typing on a laptop keyboard. To the right of the photo is a text box: 'CIRTIfication Online is a free, web-based human research protections training program tailored specifically to the needs and roles of community research partners.' At the bottom, a paragraph states: 'The online version of CIRTIfication introduces learners to the basics of the research – the terminology, people, and methods. It also reviews the history of research abuses that has informed current ethical principles, rules, and regulations.'

# ARCC Resources



[www.ARCOnline.net](http://www.ARCOnline.net)

Anti-Racist Community-Academic Research [Reflective Practice Tool](#)

Seed Grants: [bit.ly/ARCCgrants](http://bit.ly/ARCCgrants)

[www.ARCResources.net](http://www.ARCResources.net)

Monthly Resources & Opportunities [listing](#)



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 engaged research and support building



## 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](#)



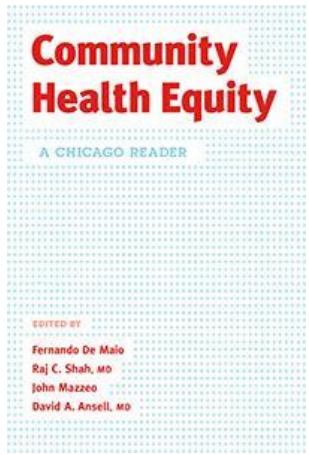
# Chicago Resources



Hospitals and Communities  
Improving Health Across  
Chicago and Cook County

- [2022 CHNA Report](#)

- Chicago Beyond- [Why Am I always Being Researched?](#)



- [Community Health Equity: A Chicago Reader](#)

- [Health & Medicine Policy Research Group](#)



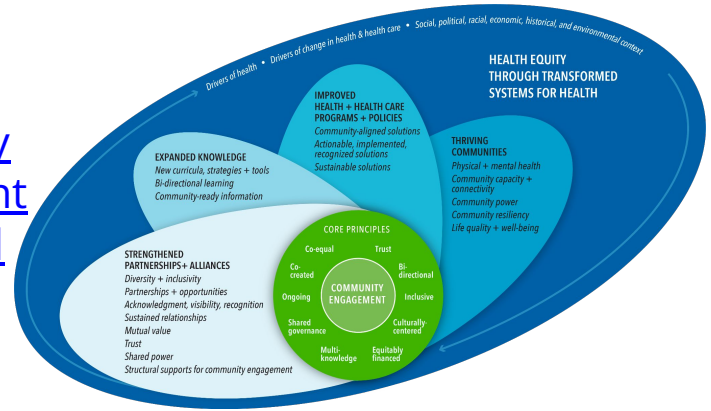
- [Chicago United for Equity](#)



# National Resources



## Assessing Community Engagement Conceptual Model







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