

# Strategies for Community & Stakeholder Engagement in Research

IPHAM Seminar, November 10, 2016

## Session Video Recording

- A video recording of this seminar can be viewed online:
  - <https://mediasite.fsm.northwestern.edu/Mediasite/Play/f6178457566a47e18475d7b9265286d31d>
- Please note that the session begins at the 11:10 mark and that unfortunately the audio is out from 11:11 until 22:40.

# Community-Engaged Research (CEnR)

- Approach for conducting research in a collaborative way
- Bidirectional exchange of expertise between academics (scientific experts) and communities/stakeholders (local, cultural, practice experts) that results in informed decision-making about design/conduct/use of research.
- **Broad spectrum:** minimal collaboration to equal partners in all aspects of the research



# Why would universities want to engage communities & stakeholders in research?

- \$ Money \$
- Required to
- Current approaches aren't working
- Communities are demanding it
- Enlightened self-interest

Researchers as compared to institutions

# Why do communities want to engage in research?

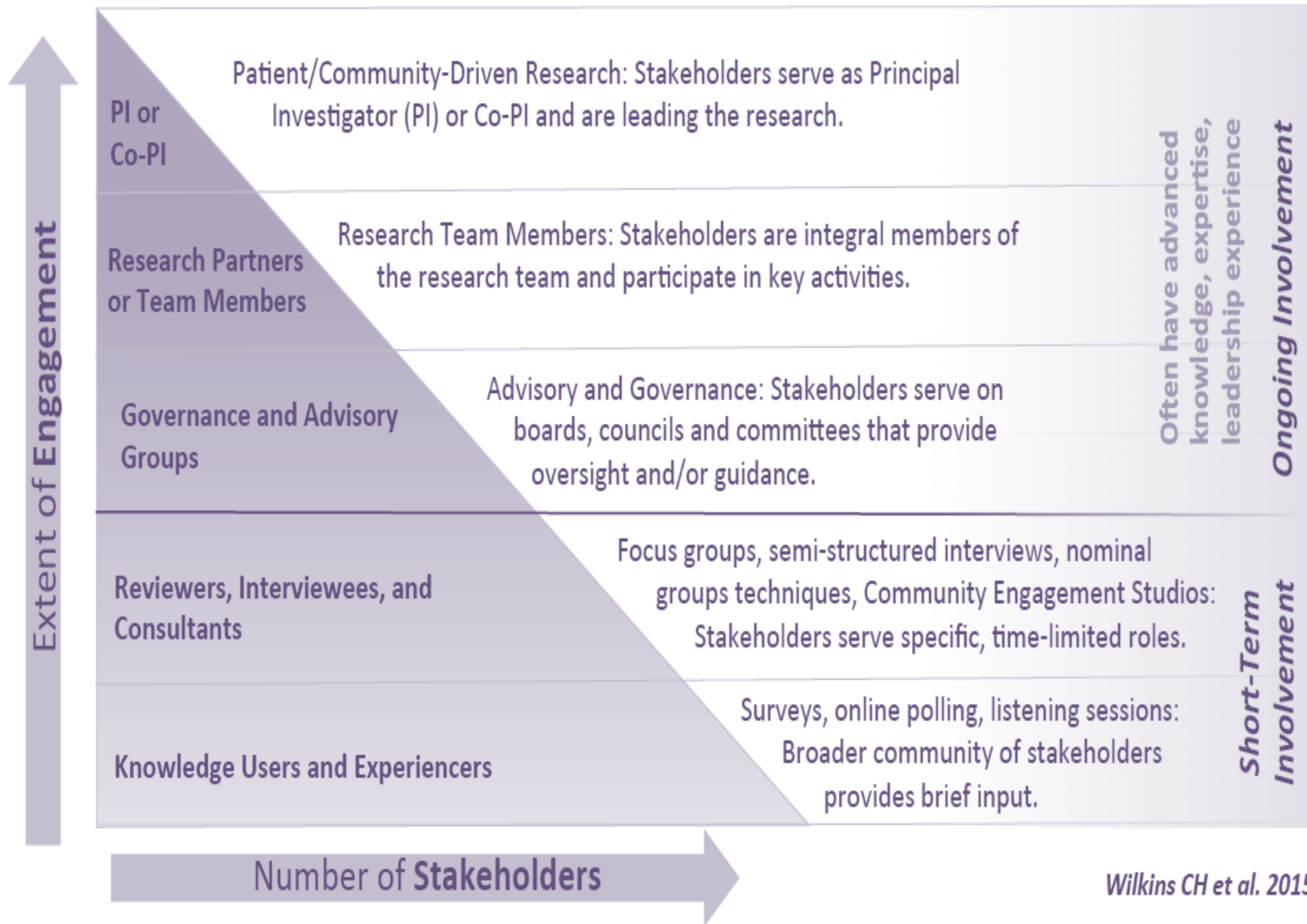
- Community-centered research questions
- Improve outcomes/service delivery
  - Describe health priorities/issues/assets
  - Reduce health disparities/culturally appropriate
  - Develop/adapt/evaluate programs/services
- Representation/Gatekeeper
- Policy advocacy/funding- funders requiring more evaluation, data, evidence-based interventions
- Community benefit- connections, reputation, workforce development

# Why don't communities want to engage in research?

- Topical/priority mismatch- irrelevant
- Mistrust/Ethical concerns/Lack of respect
- Time/cost
- 'Helicopter Research'/No implementation sustainability



# The Continuum of Community (Stakeholder) Engagement in Research





# Why do you want to engage stakeholders in research?

- 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





# Who do you want to engage in research?

- Who will be impacted by your research/findings?
- Stakeholders may include:
  - Patients/community members
  - Community-based organizations (local/natl.)/coalitions
  - Faith-based organizations
  - Patient Advocacy Organizations (local/natl.)
  - Public agencies (local, regional, federal)
  - Healthcare providers/hospitals/clinics/health systems/payers



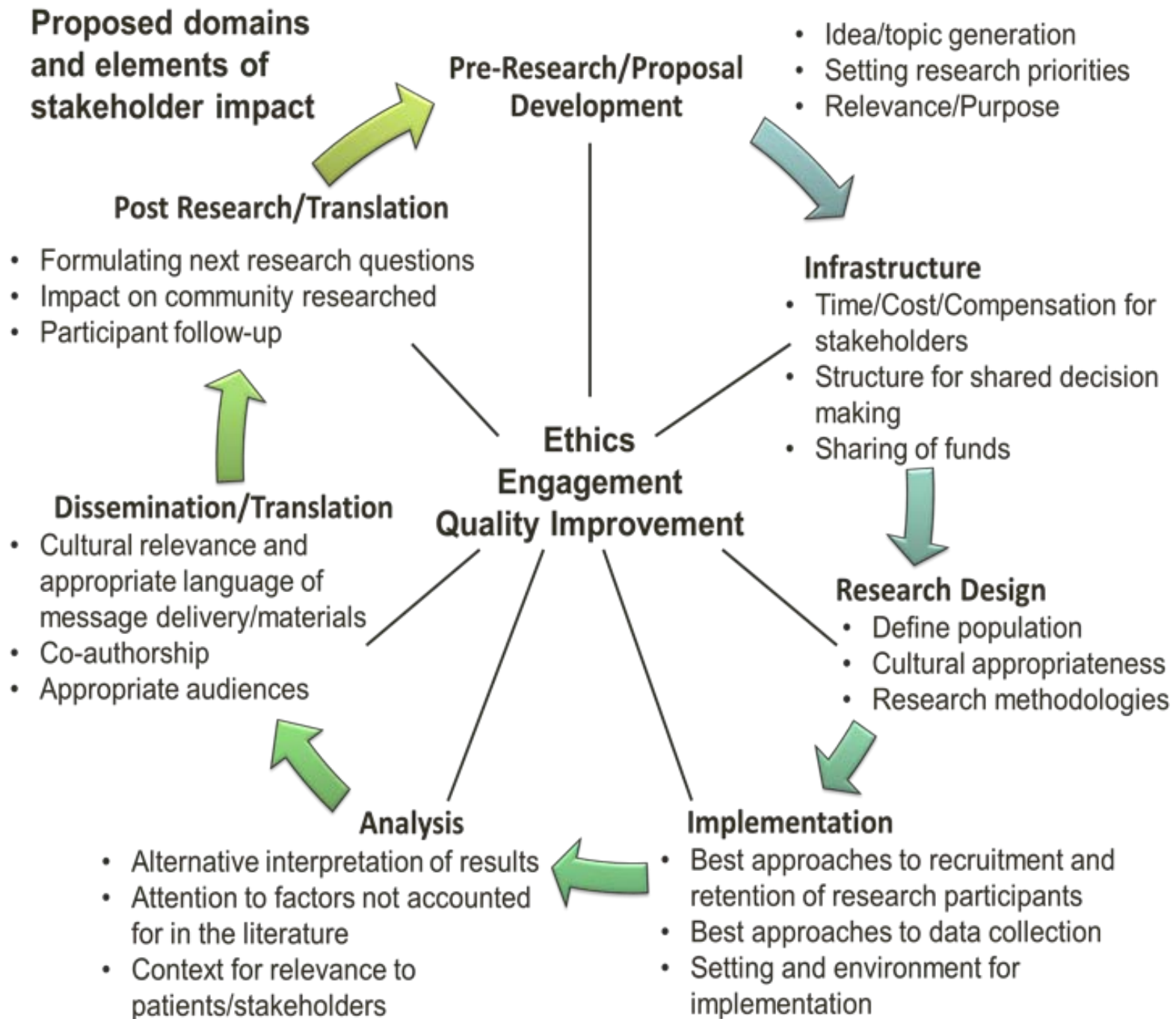
# How do you want to engage stakeholders in research?

- Extent/type of engagement?
  - Site?
  - Decision making team member/collaborator?
  - Advisor?
  - # of stakeholders?
  - What are you interested in/open to? What are stakeholders interested in/open to?
- Only on identified priorities or other research topics too?
- If on funded project, what does funder require/allow?

# When do you want to engage stakeholders in research?

- Pre-Research
- Research Design/Conduct
- Post-Research- Dissemination/Usability





# How do you begin to identify and engage stakeholders?

- Who are groups or people you want to engage? Difference in engaging organizations vs. individuals
- Do you already have relationships with groups or people or need to find them? Are there existing connections with others in your network/institution?
- What info about you/your research team will you share with possible stakeholders?
- What info will you want to know about possible stakeholders?
  - How do they think about/value/use research?
  - Do they have capacity/experience for engaging in research?
  - At organizational level: who makes decisions about research involvement/use?
- What benefits are there to stakeholders?

# What resources will you need to engage stakeholders in your research?

- Funding- stakeholder compensation, meeting expenses
- Engagement skills (PI/team/staff) or guidance
  - Ability to explain complex concepts in laypersons terms
  - Humility, compromise, listening, power sharing, flexibility
  - Connections/relationships
- Community knowledge- Politics/Players, Community priorities/interests, History
- Time
- Policies/procedures/Infrastructure- MOU or agreement
- Support of dept/leadership/administration



# Panel

- **Paris Davis**, MBA, PhD, Executive Director, Pastors4PCOR; Exec Dir, Total Resource Community Development Organization
- **Rebecca Johnson**, PhD, Research Assistant Prof, Buehler Center on Aging, Health & Society/Medical Social Sciences, Feinberg School of Medicine
- **Matthew O'Brien**, MD, Assistant Prof, General Internal Medicine & Geriatrics, Feinberg School of Medicine
- **Christine Stake**, DHA, Project Manager, Department of Surgery, Lurie Children's Hospital

# Center for Community Health



# Center for Community Health Resources

- Partnership brokering & development- patient & stakeholder engagement
- Workshops/seminars, team training, online resources- Writing retreats- next one on January 12
- Funding assistance- ARCC/PBR seed grants, NUCATS dissemination & implementation pilot grants
- Consultation, proposal review & support- Stakeholder Academic Resource Panels



# Alliance for Research in Chicagoland Communities Resources

- Monthly Resources & Opportunities Listings
- [www.ARCCresources.net](http://www.ARCCresources.net)



Visit [arconline.net](http://arconline.net) »

## RESOURCE DIRECTORY

[ABOUT](#) [NAVIGATING THE SITE](#) [CONTACT/LINKS](#)

### 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](http://ARCConline.net)

Community-engaged research (CErR) 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)).

All Resources



Resources for  
Community Partners



Resources for  
Healthcare Providers



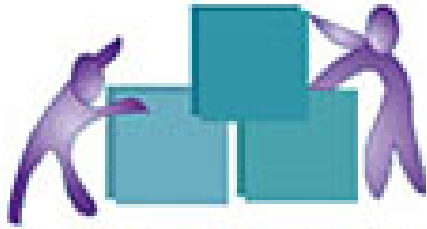
Resources for  
Academic Partners



Resources for  
Teams



# National Resources



## Community-Campus Partnerships for Health

Transforming Communities & Higher Education

[www.ccph.info](http://www.ccph.info)

- Resources
- Skill-Building Online Curriculum
- Listservs
- IRB and Ethics

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>





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<http://www.feinberg.northwestern.edu/sites/cch/>

