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

<table>
<thead>
<tr>
<th>Extent of Engagement</th>
<th>Ongoing Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PI or Co-PI</strong></td>
<td>Often have advanced knowledge, expertise, leadership experience</td>
</tr>
<tr>
<td><strong>Research Partners or Team Members</strong></td>
<td>Stakeholders are integral members of the research team and participate in key activities.</td>
</tr>
<tr>
<td><strong>Governance and Advisory Groups</strong></td>
<td>Advisory and Governance: Stakeholders serve on boards, councils and committees that provide oversight and/or guidance.</td>
</tr>
<tr>
<td>** reviewers, interviewees, and consultants**</td>
<td>Focus groups, semi-structured interviews, nominal groups techniques, Community Engagement Studios: Stakeholders serve specific, time-limited roles.</td>
</tr>
<tr>
<td><strong>Knowledge Users and Experiencers</strong></td>
<td>Surveys, online polling, listening sessions: Broader community of stakeholders provides brief input.</td>
</tr>
</tbody>
</table>

**Number of Stakeholders**

Wilkins CH et al. 2015
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
  o Ability to explain complex concepts in laypersons terms
  o Humility, compromise, listening, power sharing, flexibility
  o Connections/relationships

  o 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

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)).
National Resources

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
cch-consult@northwestern.edu

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