Center for Community Health
Partnering with NUCATS to Offer Resources & Services for Patient & Other Stakeholder Engagement Across the Research Spectrum
The Need
What PCORI means by “engagement”
PC-1: Engage people representing the population of interest and other relevant stakeholders in ways that are appropriate and necessary in a given research context:

- Formulating research questions;
- Defining essential characteristics of study participants, comparators, and outcomes;
- Identifying and selecting outcomes that the population of interest notices and cares about and that inform decision making relevant to the research topic;
- Monitoring study conduct and progress; and
- Designing/suggesting plans for dissemination and implementation activities
PCORI’s Stakeholders

• **Patient** Partners: those with personal experience, including patients, family members, caregivers, and/or the organizations that are representative of the population of interest
  – *patient partners are not the same as patient “subjects”*
  – *patient partners are members of the research team and involved in the planning, conduct, and dissemination of the research*

• Other **Stakeholder** Partners: those with professional rather than personal experience, such as clinicians, purchasers, payers, industry, hospitals and health systems, policy makers, and training institutions
• Every PCORI Funding Announcement application requires an Engagement Plan, which is organized into 3 phases of the research process:
  – Planning the Study
  – Conducting the Study
  – Disseminating Results

• The PCORI “Engagement Rubric” provides guidance to applicants for completing an Engagement Plan
  – Defines PCOR Engagement Principles
  – Provides a variety of options for how to incorporate engagement, where relevant, into each phase of the research

### PCORI Engagement Principles

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<tr>
<th>Engagement Principle</th>
<th>Proposal must demonstrate...</th>
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<tr>
<td>Reciprocal Relationships</td>
<td>Roles &amp; decision making authority of all partners are defined collaboratively and clearly stated</td>
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<td>Commitment to Co-Learning</td>
<td>Clear goal for patients &amp; stakeholders to understand the research process and academics to understand and incorporate patient engagement &amp; patient-centeredness</td>
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<td>Respect for Partnership</td>
<td>The time and contributions of patient &amp; other stakeholders are valued with reasonable requests for time commitments &amp; fair financial compensation; priority populations are appropriately engaged &amp; cultural competence is demonstrated</td>
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<td>Trust, Transparency, Honesty</td>
<td>Major decisions are made inclusively; information is shared readily with all partners; stated commitment to open and honest communication of information that is meaningful and usable</td>
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Your “Readiness” Assessment
Are you ready to apply to PCORI?
• Have you sufficiently engaged patients and other stakeholders in planning the study?
  – Developing the research question and relevant outcomes to be studied
  – Defining the study population to be appropriately inclusive
  – Designing the procedures to minimize burden and maximize benefits
  – Identified when & how progress and findings will be communicated?

• Have you demonstrated that there is or will be “co-learning?”
  – Have patients/stakeholders been trained in research principles and practices?
  – Are people / organizations capable of the roles you have proposed?
  – Does each partner have biosketch?
  – What demonstrates that researchers are competent / capable of engagement?

• How have you (will you) make decisions in an engaged fashion?

• Do you have written agreements or letters from stakeholders demonstrating their level of involvement?

• Are you using fair compensation guidelines for stakeholders/partners?
Forms of Help from CCH
Center for Community Health (CCH)

• **Mission**
  To catalyze and support meaningful community and academic engagement across the research spectrum to improve health and health equity

• **Who we are**
  CCH is a hub for:
  – IPHAM’s home for Community engaged research teams & programs
  – NUCATS’ home for academic & community expertise to provide education, training, navigation & technical assistance for different forms of engagement in research

CCH Programs
- Alliance for Research in Chicagoland Communities
- Practice-Based Research Program
  - REACH
  - Pediatric Practice Research Group
What we provide...

CCH Resources & Services

Before the Research
- Education, Training, & Capacity Building
  - Online/written education
  - Workshops
  - Seed grants
  - Biosketch examples
- Finding & Developing Partnerships
  - Networking
  - Staff consultations
  - Partnership brokering
  - Partnership grants
  - MOU’s
  - Technical assistance for CABs / SCs

During the Research
- Proposal / Application Development
  - Staff consultations
  - Stakeholder
  - Academic Resource Panels
  - Proposal review
- Toolkit of examples
- Resource boilerplate
- Pilot grants

Evaluating & Maintaining Partnerships
- Best practice communication tools
- Compensation guidelines
- Technical assistance
- Partnership evaluation & troubleshooting

After the Research
- Translation & Dissemination
  - Partner consultations
  - Best practice examples
  - Technical assistance
  - D&I grants

Northwestern Medicine
Stakeholder-Academic Resource Panels (ShARPs)

- 2 hour session
- 6-8 stakeholders (1 academic)
- Group selected based on the research topic or community of focus
- Time & Location – flexible

- Research team presents 15 slides with 5-8 specific questions they want to ask the group
- CCH facilitator & note taker
- Recommendations provided to research team
Getting Started?

• CCH
  – Phone: 312-503-2275
  – Email: cch@northwestern.edu
  – Location: (appointment only) 750 N. Lake Shore Drive (Rubloff), Suite 680

• Visit us on the web
  – www.feinberg.northwestern.edu/sites/cch/
  – http://ARCCresources.net/
Additional Sources of Information

• CCH’s Key Considerations for Engagement -
  http://www.feinberg.northwestern.edu/sites/cch/research/faqs.html
• ARCC Online Toolkit: http://ARCCresources.net
• PCORI: http://www.pcori.org/funding-opportunities/what-we-mean-engagement