Understanding Patient and Stakeholder Engagement Roles for Participating in “Research Done Differently” with the Patient-Centered Outcomes Research Institute (PCORI)

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Objectives of Today’s Presentation

• Provide overview of how PCORI defines patient and stakeholder engagement

• Illustrate types of stakeholders that could/should be engaged in PCORI project

• Offer concrete suggestions on how to obtain patient and stakeholder engagement pre-award and after obtaining funding
• Independent non-profit research organization authorized by Congress as part of 2010 Patient Protection and Affordable Care Act (ACA)

• PCORI helps people make informed healthcare decisions and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community
PCORI Funding Opportunities

• Five portfolios/priorities for research:
  – Assessment of Prevention, Diagnosis, & Treatment Options
  – Improving Healthcare Systems
  – Communication and Dissemination Research
  – Addressing Disparities
  – Improving Methods for Conducting Patient-Centered Outcomes Research

• Other funding opportunities outside the five portfolios
Outside PCORI’s 5 Portfolios

Funding for pre-research & non-traditional researchers (e.g. patient groups & community-based organizations seeking partnerships w/academic medical centers)

-Pipeline to Proposal Awards to develop partnerships and patient-centered research proposals

http://www.pcori.org/funding-opportunities/eugene-washington-pcori-engagement-awards/
PCORI Review Criteria
(Basis of awarding PCORI contract to researcher/patient/stakeholder teams)

• Five main review criteria
  – Impact of the condition on health of individuals and populations
  – Potential for study to improve health care and outcomes
  – Technical merit
  – Patient-centeredness
  – Patient and stakeholder engagement
PCORI Review Process

• All proposals reviewed by four individuals: two researchers, one patient, one stakeholder

• Patient-centeredness and stakeholder engagement reviewed by all individuals; other aspects of research plan only reviewed by researchers
Patient-Centeredness
(as defined by PCORI)

Proposal demonstrates patient-centeredness at every stage of research. Addresses the following questions:

– Is the research focused on questions that affect outcomes of specific interest to patients and their caregivers?

– Does the research address one or more of the key questions mentioned in PCORI’s definition of patient-centered outcomes research?

– How credible are claims that engaged patients and stakeholders will exert meaningful influence on the design and conduct of the research, to ensure patient-centeredness of the questions and outcomes addressed?
Patient & Stakeholder Engagement  
(as defined by PCORI)

The proposal integrates patients and stakeholders in the development of research plan and in key elements of conducting the research. Addresses the following questions:

– Does proposal describe how patients and stakeholders were or will be identified and engaged in the research?

– Are roles of patients and key stakeholders significant in formulating study’s research questions, hypotheses and design and in the study’s conduct and dissemination of results?

– Are roles proposed for patients and stakeholders in any planned dissemination or implementation plans meaningful and likely to be effective?

– If engagement is not applicable to proposed research, does the application justify why it is not?
Recruiting Patients, Caregivers, Stakeholders

Pastors in PCOR Research Ministry
Southland Ministerial Health Network
Partnering for Patient-Centered Outcomes Research
Apostle Carl L. White, CEO and Ministers of the SMHN
Defining Terms

• Who is the community?

• Who are considered patients, caregivers, stakeholders?

• What is comparative effectiveness research (CER)?
Why should patients/caregivers/stakeholders/communities be interested in research? PCORI?

- Describe scope of health priorities/issues in their communities
- Answer questions about their health conditions or communities
- Conduct evaluation of current programs/treatments
- Develop/adapt new programs/treatments/services that are culturally appropriate for their communities
- Collect data/stories that help make the case for policy advocacy/funding of their health issue/condition
Who are the patients/stakeholders that need to be engaged?

Considerations in selecting:

– Funder requirements (e.g., PCORI, NIH)
– Objectives of project
– Type of input needed
– Importance of obtaining broad spectrum of perspectives
– What type of input is needed pre-award, during project, and post-award
What can maximize likelihood that patients/stakeholders will collaborate?

• Clearly defining roles and responsibilities of patients/stakeholders

• Clearly articulating what they will gain—“what’s in it for me?”

• Developing sound bites/materials that can be used to recruit
  – Linked to project goals, roles/responsibilities, and what members will gain
Approaching patients/stakeholders

- Build on Existing Relationships
- Referrals/recommendations from colleagues*
- Shared Interest/Common Goals
- Commitment and Willingness
- Equal Standing
- Shared Decision-Making

*CCH can provide assistance
Questions patients/stakeholders may ask researchers

– Who are you?
– Why are you here?
– What’s your experience/relationship with us and how a disease/condition impacts us? Experience with engagement?
– Are you committed to a long-term relationship after the research?
– What is the research topic/project?
– What’s in it for us/our community? Is the research of interest to us? How will we benefit from the research project/findings?
– What are my roles and responsibilities?
– How do we equally engage/participate?
– What does our relationship look like?
Developing Patient/Stakeholder Engagement Plans

THE S.T.A.R. INITIATIVE
STRATEGICALLY TARGETING APPROPRIATE RESEARCHERS

Framework for Developing Patient/Stakeholder Engagement

• Engagement plans should discuss patient/stakeholder involvement during three phases:
  – Pre-award
  – During project
  – Post-award
Mechanisms for facilitating engagement pre-award

• Getting to know each other/building relationship

• Input on additional patients/stakeholders to involve

• Feedback on proposal design, description of patient/stakeholder groups

• Data collection on interest in/issues related to issue being researched (focus groups, survey, town hall)

• Review of drafts/proposal components. Provide letters of support.
Mechanisms for facilitating engagement pre-award

• Develop a Memorandum of Understanding or Letter of Agreement to document agreements concerning roles/responsibilities, data use/access, etc.

• Establish mechanisms for communication among researchers/partners during project

• Form an engagement advisory or steering committee to provide feedback/input throughout project
Types of Engagement During Project

• Input on:
  – Data collection methods
  – Study protocols
  – Measures/instruments that are feasible/acceptable
  – Recruitment/retention strategies
  – Preparation of study materials
  – Sites for study implementation
  – Data interpretation

• May be able to hire patients/stakeholders as part of research team to collect data or implement interventions

• Continuation of advisory/steering committee comprised of key stakeholders
Types of Engagement

Post-Award

• Developing sustainability plan for program/service/intervention

• Assisting in dissemination of study findings to key stakeholders (e.g., patients, patient advocacy organizations, policy-makers)
  – Dissemination plan a requirement of PCORI applications
Vision: The CCH will drive meaningful and lasting improvements in population health through leadership, participation, and support for the principles and practice of community-engagement.

Mission: CCH cultivates and catalyzes engagement of academic and community partners in research to improve the health and healthcare of communities.

Connected to Institute for Public Health and Medicine (IPHAM) and Northwestern University Clinical and Translational Sciences (NUCATS) Institute.
Alliance for Research in Chicagoland Communities

Mission: Growing equitable & collaborative partnerships between Chicago area communities & Northwestern University for research that leads to measurable improvements in community health
**Practice-Based Research Program (PBR)**

**PBR** fosters collaborative research between community-based practitioners and NU faculty. Two practice-based research networks, REACH and PPRG.

- **REACH**: 17 clinical sites affiliated with NU, including private practices and federally qualified health centers (FQHCs) with more than 160 member physicians.

- **Pediatric Practice Research Group (PPRG)**: regional network founded in 1984 as partnership of Ann & Robert H. Lurie Children’s Hospital of Chicago Department of Pediatrics and enthusiastic group of over 50 pediatric practices.
Upcoming CCH & ARCC Events

• **CCH Manuscript Writing Workshop, December 4, full day.** Dedicated space and time for attendees to focus on their own manuscripts.

• **ARCC Workshop: Guidance on Policy and Priority Areas for Conducting Health and Wellness Research at Chicago Public Schools. Dec 12, 1:30-4 pm.** Session speakers will include representatives from CPS Research and Review Board and Office of Student Health and Wellness.

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Contacts

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