Patient and Stakeholder Engagement in Research for Community Engagement

2018 Community Engaged Research Symposium
Wayne State University
Karmanos Cancer Institute

Yasmeen Long, MA
Program Officer, Eugene Washington PCORI Engagement Awards Program
February 5, 2018
Agenda

- Welcome and Introductions
- About PCORI
- Engagement in Research and Establishing Partnerships
- PCORI’s Engagement Rubric
- Engagement Award Program Brief Overview
- Q&A
Welcome!

Yasmeen Long
Program Officer, MA Eugene
Engagement Awards Program
Our Discussion for Today

• How does PCORI operationalize patient engagement and patient centeredness?
• How can you prepare to conduct patient and stakeholder engaged research for community engagement?
• Examples of Engagement Awards focused on community Engagement
About Us

• An independent research institute authorized by Congress in 2010 and governed by a 21-member Board of Governors representing the entire healthcare community.

• Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process.

• Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns.
Our Mission and Strategic Goals

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.

Our Strategic Goals:

- Increase quantity, quality, and timeliness of useful, trustworthy research information available to support health decisions.

- Speed the implementation and use of patient-centered outcomes research evidence.

- Influence research funded by others to be more patient-centered.
Who Are Our Stakeholders?

Payers
Clinicians
Caregivers/Family Members
Purchasers
Policy Makers
Patients/Consumers
Hospitals/Health Systems
Industry
Training Institutions
Patient/Caregiver Advocacy Organizations
How Do We Facilitate Patient/Stakeholder Engagement in Research?
Engagement: Promoting Patient/Stakeholder Participation in Research Processes

• Patients and stakeholders from across the entire healthcare enterprise are actively and meaningfully involved in the entire research process—from the development of research priorities to the dissemination of research findings.

• Patients are treated as partners in research, not just “subjects.”

• Engagement intentionally used as a tool to advance research in the areas of comparative clinical effectiveness research (CER) and patient-centered outcomes research (PCOR).
Engagement as a Path to Useful, High-Quality Research

- Topic Selection and Research Prioritization
- Proposal Review; Design and Conduct of Research
- Dissemination and Implementation of Results
- Evaluation
Engagement in Research

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Why Engage?

To influence research to be patient-centered, relevant, and useful

To establish trust and a sense of legitimacy in research findings

To encourage successful uptake and use of research results
Why Engage?

Neely Williams
Patient Co-Principal Investigator
Bariatric Surgery Study
Engagement Tools

- Engagement Rubric

- Planning the Study
- Conducting the Study
- Disseminating the Study Results
Partnering in Research

Planning of the study

Conduct of the study

Dissemination of study results
Partnering in Research

- Identify the research question
- Identify outcomes
- Craft study design
- Specify inclusion criteria
- Develop study materials

Planning of the study

Conduct of the study

Dissemination of study results
Partnering in Research

**Planning of the study**
- Identify the research question
- Identify outcomes
- Craft study design
- Specify inclusion criteria
- Develop study materials

**Conduct of the study**
- Assist with recruitment and retention
- Collect and synthesize data
- Make decisions about study adjustments
- Revise informed consent materials

**Dissemination of study results**
Partnering in Research

Planning of the study
- Identify the research question
- Identify outcomes
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Conduct of the study
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Dissemination of study results
- Co-present and co-author in traditional formats
- Develop non-traditional formats and methods
- Begin planning for dissemination at the beginning
Patient Influence on Dissemination

Patrick Corrigan, PsyD
Distinguished Professor of Psychology
Illinois Institute of Technology
Engagement Tools

- Engagement Rubric
- Sample Engagement Plans
- Compensation Framework
- “Budgeting for Engagement” guidance document
- Programmatic Funding (Eugene Washington Engagement Awards)
- Ambassadors Program (webinars, networking, training, matchmaking opportunities)
- Other application assistance/guidance for developing research proposals (Partner Biosketch, Applicant Training, Engagement FAQs, Applicant Town Halls)
- Post Award: Engagement Officers/Program Officers
- “Engagement in Research” website page
Embody the Six Engagement Principles

- Partnership
- Co-learning
- Reciprocal Relationships
- Trust
- Transparency
- Honesty
Eugene Washington PCORI Engagement Award Program

- An engagement funding opportunity -- not research awards
- Support projects that will build a community better able to participate in patient-centered research (PCOR) and comparative clinical effectiveness research (CER), as well as serve as channels to disseminate study results
- Also provide support for symposia, seminars, workshops, and other organized and formal meetings where individuals assemble to exchange information or explore issues or areas of knowledge related to PCOR/CER
- Projects will produce deliverables that are useful to awardees, PCORI, and the broader PCOR community for increasing patient and stakeholder engagement in PCOR and CER
Programmatic Aim

- Provide a platform to increase meaningful engagement of patients and other health care stakeholders throughout the research process from topic generation through the dissemination and implementation of research findings.

Freddie White-Johnson
Founder & President, Fannie Lou Hamer Cancer Foundation

Engagement Award:
The University of Southern Mississippi
Building on a culturally-sensitive network for PCOR/CER dissemination

Alan Alda
Alan Alda Center for Communicating Science, Stony Brook University

Engagement Award:
University of New Mexico Health Sciences Center
Making the Connection: Communication & Collaboration Skills for Creating PCOR Teams
EXAMPLES OF ENGAGEMENT AWARDS FOCUSED ON COMMUNITY ENGAGEMENT
“Engaging Black Faith Communities to Address Mental Health Disparities via Curriculum Development”

Overview

- Project to increase the capacity of faith communities, youth, and stakeholders to lead, design, and conduct their own PCOR/CER studies
- Engaging stakeholders to assist the project team in understanding the gaps in African Americans’ knowledge about PCOR/CER in mental health
- Collaboratively designing a training curriculum to prepare African American youth patients/advocates, faith and community leaders in the basic tenets of PCOR, CER and CBPR

Alfiee M. Breland-Noble, Ph.D., MHSc. Associate Professor
Department of Psychiatry
Georgetown University Medical Center

Project Collaborators:
NC Suicide Survivor Consultants;
Balance and Life Ministries; and
Community Advisory Board members (including teens) who represent 10 faith communities/organizations in the DC area and NC

Engagement Award Project, awarded July 2015
“Reducing Cancer Disparities by Engaging Stakeholders”

Objectives

- Develop a learning community with a common agenda related to reducing cancer screening-related disparities;
- Determine disparities in screening rates;
- Identify evidence-based approaches that increase screening and reduce screening disparities;
- Adapt effective intervention approaches for use in primary care practices;
- Disseminate a model approach to intervention adaptation in health systems;
- Evaluate learning community engagement and related outcomes.

Ron Myers, PhD
Thomas Jefferson University

Project Collaborators:
Two regional health systems (Lehigh Valley Health Network and Delaware Valley Accountable Care Organization); a patient and stakeholder advisory committee from each health system; insurers; a state and a local health department; regional employer groups; a national advocacy organization; a regional advocacy organization; and Children’s Hospital of Philadelphia

Engagement Award Project, awarded October 2015
Additional Engagement Awards

- **Racial and Ethnic Minorities**
  - *The Gathering for Pacific Islander Health*
  - *A Gathering of Good Minds: Engaging Native Americans in Wellness*
  - *National Hispanic Patient-Centered Research Agenda*

- **Rural Populations**
  - *Virtual Rural Oncology Community (V-ROC)*
  - *Rural Patient and Provider Perspectives on the Patient Centered Medical Home Model*

- **Individuals with Disabilities**
  - *Workshops to Transform the Health Care of Women with Disabilities*
  - *Speak for Yourself: Patient-Centered Research Network for People with Disabilities & Their Families*
Who Can Apply?

- **Private Sector**
  - Nonprofit and for-profit research organizations

- **Public Sector**
  - Universities and colleges; hospitals and healthcare systems; laboratories and manufacturers; units of state, local, or federal government

- **U.S. Organizations**
  - Must be recognized by the Internal Revenue Service

- **Foreign Organizations and Non-Domestic Components of U.S. Organizations**
  - May apply if there is demonstrable benefit to the U.S. healthcare system or U.S. efforts in the area of patient-centered research can be clearly shown

- **Individuals**
  - Not permitted to apply under this program
We expect that projects selected for an Engagement Award will further PCORI’s goals of promoting the relevance of research to target audiences and the uptake of research results by end-users. We are committed to using and sharing successful approaches.

Organizations that have previously received an Engagement Award are eligible to apply if their current/former project is being expanded, the content will be delivered in new formats, and/or the geographic breadth and/or audience reach will be broadened.
Engagement Awards Do Not Fund

• Out of Scope for an Engagement Award project:
  – Projects intended to improve patient engagement in non-research activities, such as healthcare service delivery, patient self-care, or patient-centeredness of care
  – Research studies (PCORI funds these studies through other opportunities)
  – Development of research proposals
  – Development of interventions
  – Validation of tools or instruments
  – Development of registries
  – Projects intended to increase the number of patients who enroll as subjects in research studies or registries
  – Development of decision aids or clinical practice guidelines
  – Meetings that don’t focus on PCOR or CER
From the Field
Engagement Resources:

- Engagement Rubric
- Budgeting for Engagement Activities
- Compensation Framework for Engaged Research Partners
- Sample Engagement Plans
- PCORI in Practice Webinar Series
Thank you!

Contact Information:

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