



Partnering with Public Health Institutes for Community Engagement: Bringing Patients, Researchers and Systems Partners to the Table

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Patient-Centered Outcomes Research Institute

About PCORI

pcori.org

Why PCORI?

- Research has not answered many questions patients face.
- People want to know which treatment is right for them.
- Patients need information they can understand and use.



PCORI Has a Broad and Complex Mandate

“The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions** by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed **through research and evidence synthesis...and the dissemination of research findings** with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services...”

-- from *Patient Protection and Affordable Care Act*



PCORI Is Accountable for Changing Practice

“(g) FINANCIAL AND GOVERNMENTAL OVERSIGHT. ...

(2) REVIEW AND ANNUAL REPORTS.

...

(iv) Not less frequently than every 5 years ... the overall effectiveness of activities conducted under this section ... such review shall include an analysis of the **extent to which research findings are used by health care decision-makers**, the effect of the dissemination of such findings on **reducing practice variation and disparities** in health care...”

-- from *Patient Protection and Affordable Care Act*






Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from **research guided by patients, caregivers and the broader health care community.**



Our Focus

Comparative Clinical Effectiveness Research

-  Patient-centered
-  Answering questions that matter to patients and other clinical decision makers
-  Comparisons of outcomes that matter to patients

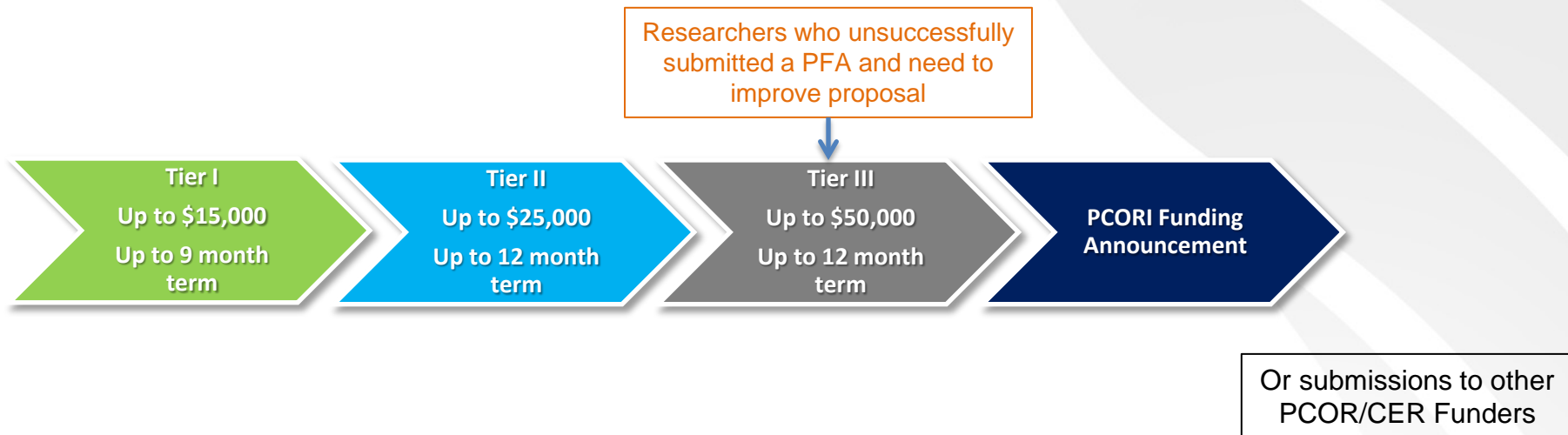
PCORI Emphasizes *Engagement* for Getting to Practical, Useful Research



History of the Pipeline to Proposal Initiative

- Idea came from patients and stakeholders at Engagement Workshop
- Purpose is to build a community of patients and stakeholders who have the expertise and passion to participate in PCOR, and create partnerships within communities that lead to high-quality research proposals.
- Awards available to individuals or groups of patients, other stakeholders, or researchers.

Pipeline to Proposal Awards



Tier I Pipeline Awards (Up to \$15,000 for up to 9 months)

Available to individuals, consumer/patient organizations, clinician(s), researcher(s) or a combination of the above to support:

- Community building around an area of research interest to improve outcomes for patients
- Creation of structure and communication strategies
- Develop an understanding of PCORI, and “research done differently”



Tier II Pipeline Awards (Up to \$25,000 for up to one year)

Available to emerging research/non-research partnerships to support:

- Data network and registry development
- Development of infrastructure
- Generation and refinement of research question through community events, town hall meetings, etc.



Tier III Pipeline Awards (Up to \$50,000 for up to one year)



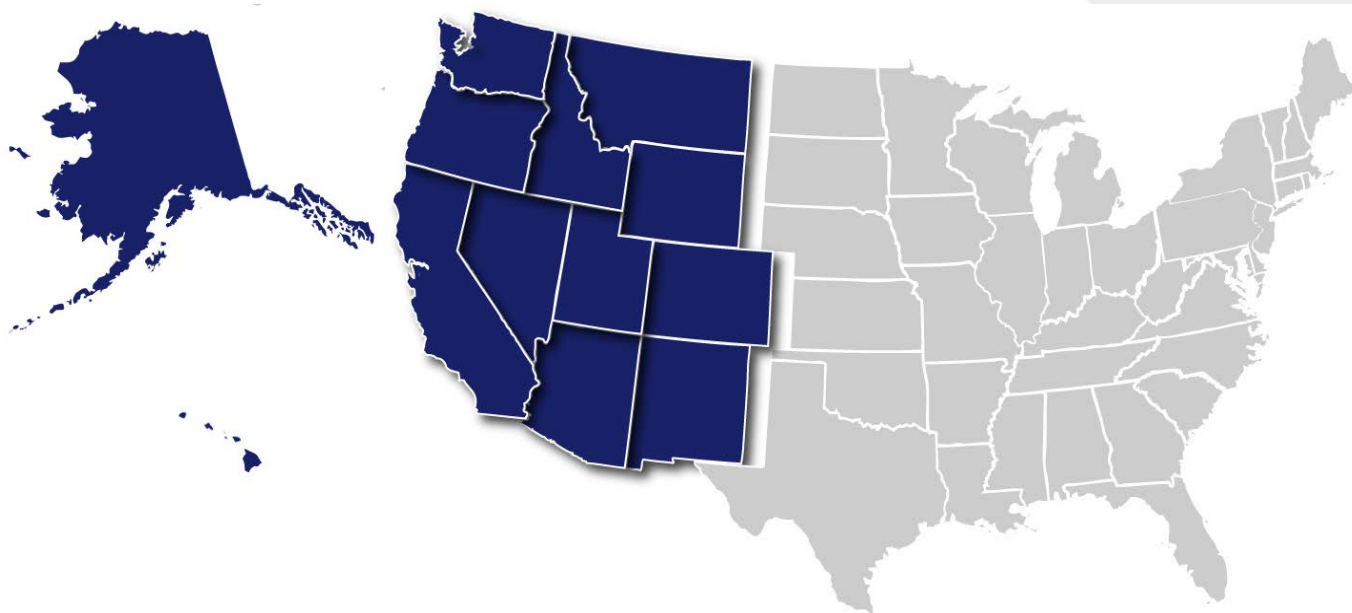
Available to advanced research/non-research partnerships, including those who submitted PCORI proposals and were not funded, to support:

- PCORI research proposal (re)submission focusing on development of engagement plan
- Research partnership skill development

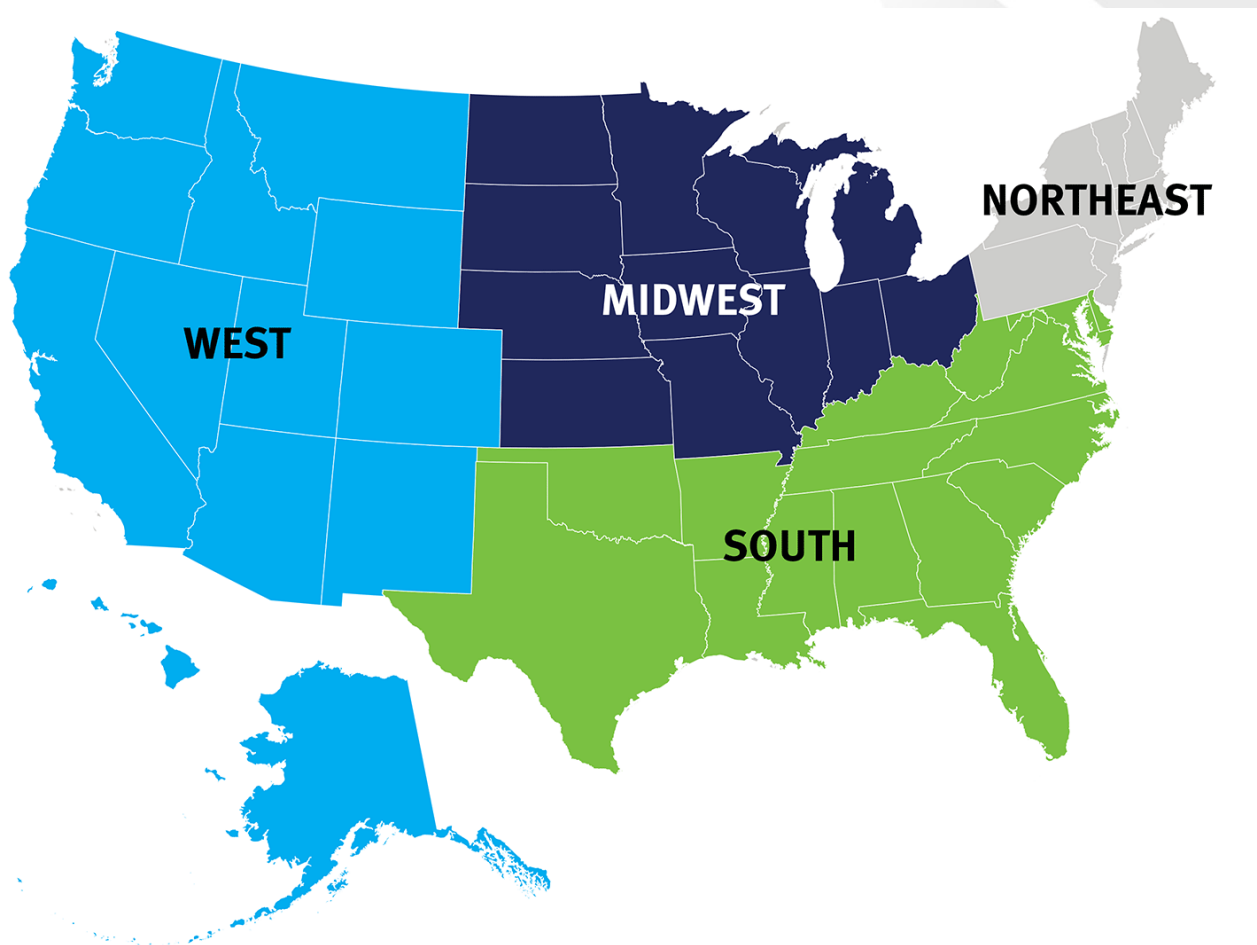
First Thirty Tier I Awards Announced


December 23, 2013

Western Region Tier I Pipeline Pilot



Regional Breakdown for Pipeline Awards





The National Patient-Centered Clinical Research Network (PCORnet)

Clinical Data Research Networks

System-based networks, such as hospital systems

- 11 Networks
- \$76.8 Million Awarded

Patient-Powered Research Networks

Patients with a single condition form a research network

- 18 Networks
- \$16.8 Million Awarded

Coordinating Center

Provides technical and logistical assistance under the direction of the Steering Committee and PCORI staff





Pragmatic Clinical Studies and Large Simple Trials

Seeks to fund investigator-initiated research that compares two or more alternatives for:

- Addressing prevention, diagnosis, treatment, or management of a disease or symptom
- Improving health care system–level approaches to managing care; or
- Eliminating health or healthcare disparities.
- Research topics of particular interest identified by stakeholders or questions included in IOM’s Top 100 Topics for CER or AHRQ’s Future Research Needs.

Opportunity Snapshot

Number of Anticipated Awards: Six to Nine

Funds Available: \$90 Million

Maximum Project Duration: 5 Years

Maximum Direct Costs Per Project: \$10 Million

Supporting Engagement as a Tool to Advance Research

pcori.org/engagement

Engagement Goals

Build a Patient-Centered Outcomes Research Community



Engage the PCOR Community in Research



Promote Dissemination and Implementation



Eugene Washington PCORI Engagement Awards

*Awards of up to \$250,000
to provide “wrap-around”
support and enhance
impact of PCORI’s
research initiatives.*

Objectives

- Engage new groups who have not previously been involved with PCORI
- Develop new mechanisms for disseminating research findings
- Promote research done differently by supporting engagement and partnering in the conduct and usage of comparative effectiveness research

Three Types of Awards

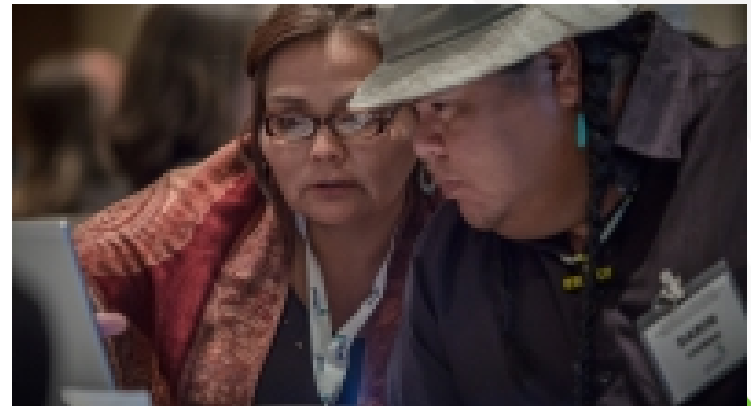
- Knowledge
- Training and Development
- Dissemination and Implementation

How to Get Engaged in PCORI Activities

pcori.org/get-involved/

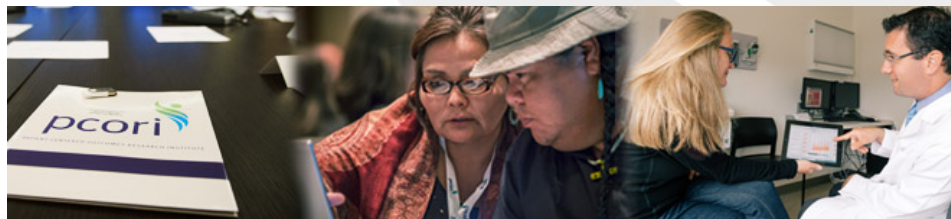
Regional Workshops

- Hosted around the country
- Learn from participants the health issues of most importance in their regional of the country, and among their community
- Participants are introduced to PCORI, and clinical comparative effectiveness research
- Next Regional Workshop:
Minneapolis, Minnesota, June 18-19



Webinar Series: PCORI in Practice

- Offers the public an opportunity to learn about:
 - promising practices of meaningful engagement in research
 - The research we fund
 - How to get involved
- Archived on our website
- Upcoming webinars include:
 - Exploring PCORI: Highlighting Opportunities for Nurses
 - June 12, 2014 1:00Pm – 2:30pm ET
 - Register here: <http://www.pcori.org/events/exploring-pcori-highlighting-opportunities-for-nurses/>





Thank You

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