Patient and Stakeholder Engagement in Research

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Welcome!

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Session Objectives

- Differentiate between patient-centeredness and patient engagement

- Provide an overview of PCORI's Engagement Rubric

- Discuss the role of the Engagement Officer at PCORI

- Review additional engagement resources available through PCORI

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We Engage Patients and Other Stakeholders at Every Step

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PCORI Merit Review Criteria

During a rigorous merit review process, proposals are evaluated to assess:

- Impact of the condition on health of individuals and populations
- Potential for improving care and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement

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What Are Patient-Centeredness and Patient Engagement?

Patient-Centeredness

Patient Engagement

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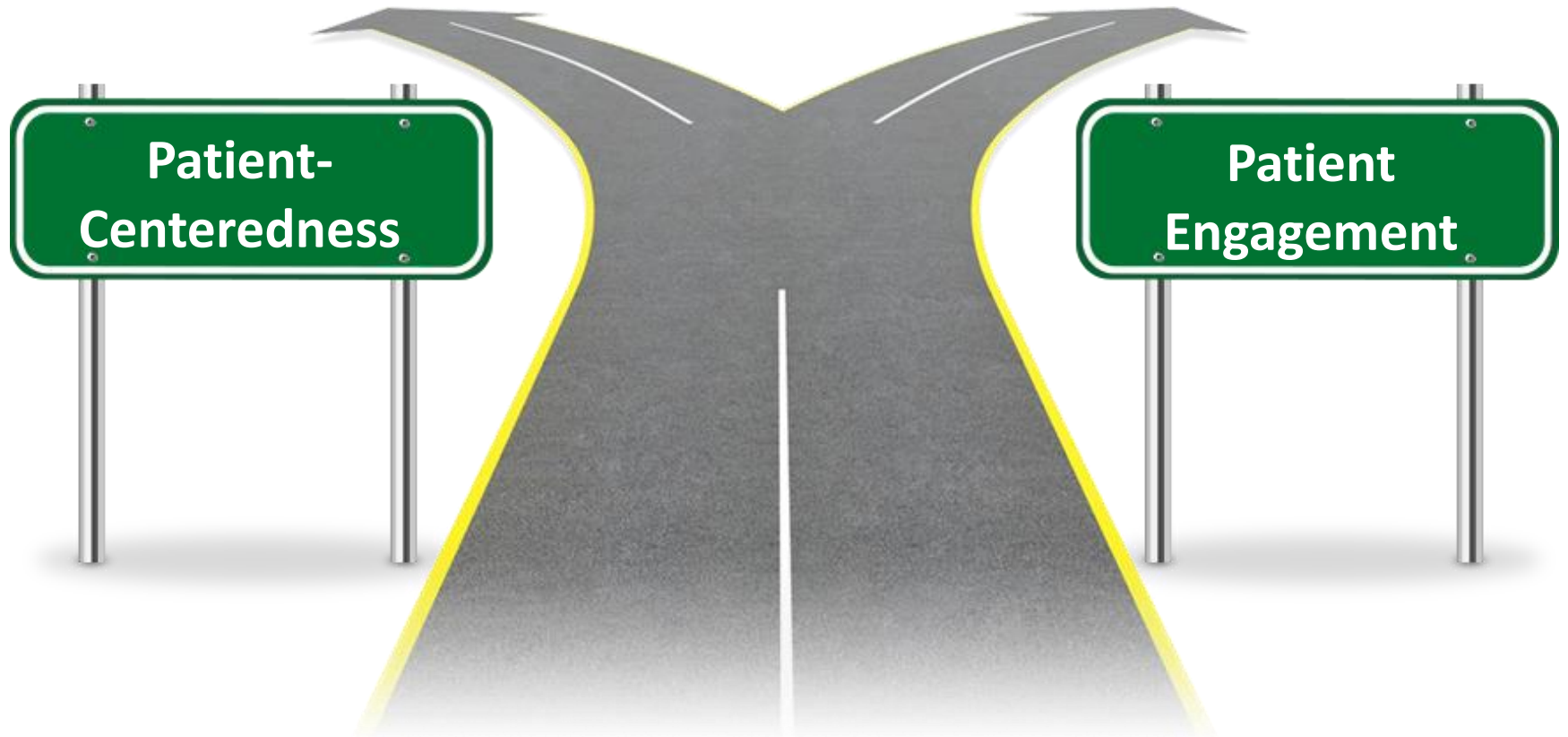
Patient-Centeredness vs. Patient and Stakeholder Engagement

- Patient-Centeredness:

  Does the project aim to answer questions or examine outcomes that matter to patients/caregivers and patient/caregiver organizations?

- Patient and Stakeholder Engagement:

  Are patients/caregivers and other stakeholders–and patient/caregiver and stakeholder organizations–involved as partners in research?

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Show Your Work
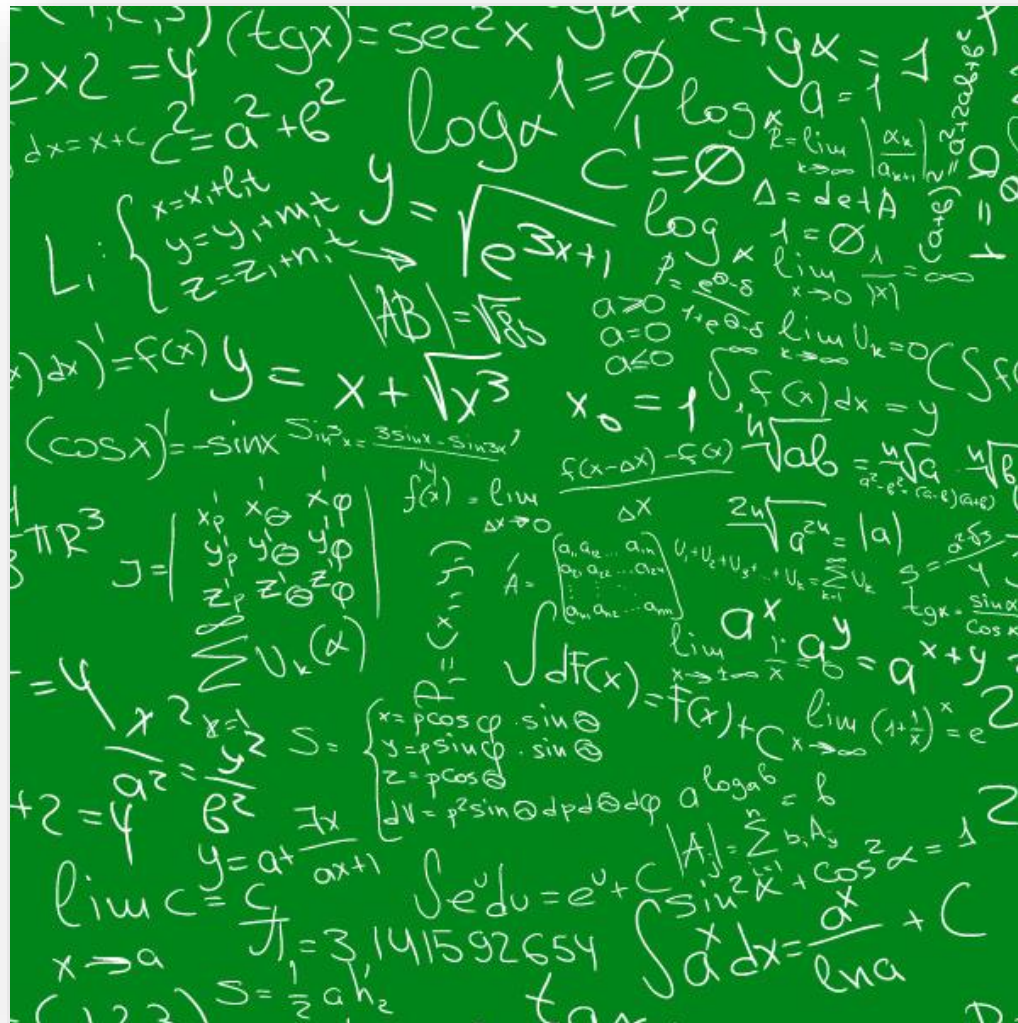
The Rubric

Why develop a rubric?

What is the rubric?

How will the rubric be used?

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Overarching Rubric Principles

- The rubric is a collection of examples, intended to provide guidance to applicants, merit reviewers, awardees, and engagement/program officers.
- It is not intended to be comprehensive or prescriptive.
- Applicants can choose to include some (but not all) activities illustrated, and they can include additional innovative approaches not included.
- The examples provided are from real PCORI-funded projects.

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Elements of the Rubric

Planning the Study

Conducting the Study

Disseminating the Study Results

PCOR Engagement Principles

Planning the Study

- Potential activities include but are not limited to:

  - Identifying the research question and outcomes

  - Drafting study protocol

- Examples:

  - "Mental Health" study name and materials amended by partners

  - Diabetes study: clinician partners amended study design to more accurately reflect real-world practice settings

Conducting the Study

- Potential activities include but are not limited to:

  - Recruitment and retention of study participants

  - Data collection

  - Data analysis

- Examples:

  - Patient partners in cancer imaging studies amended inclusion criteria to be more reflective realistic patient actions

  - Parent partners in pediatric psychiatry study are delivering components of the intervention
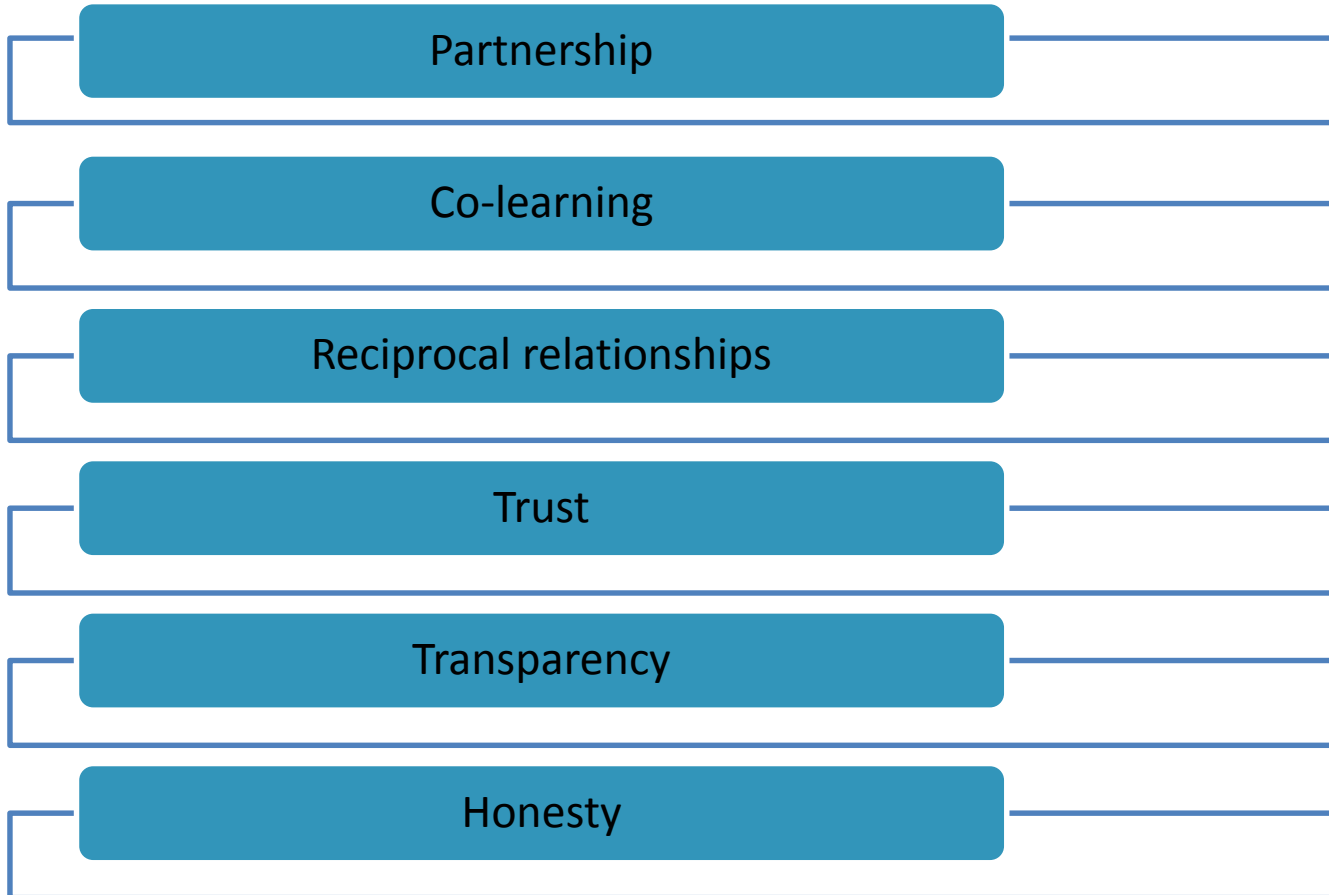
Disseminating Study Results

- Potential activities include but are not limited to:
  - Co-authoring publications such as journal articles
  - Co-presenting at conferences
  - Using social media outlets

- Examples:
  - Neurology study results are being shared at a neurology patient advocacy organization conference
  - Patient partners are co-authoring journal articles on a pain study

Embodying the Engagement Principles

Six Engagement Principles

Partnership

Co-learning

Reciprocal relationships

Trust

Transparency

Honesty

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Embodying the Engagement Principles (Cont'd)

- Real-World Examples

    - Providing financial compensation to patient and stakeholder partners

    - Providing training opportunities for patient, researcher, and stakeholder partners

    - Scheduling and locating meetings at mutually accessible times and locations

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Engagement Resources
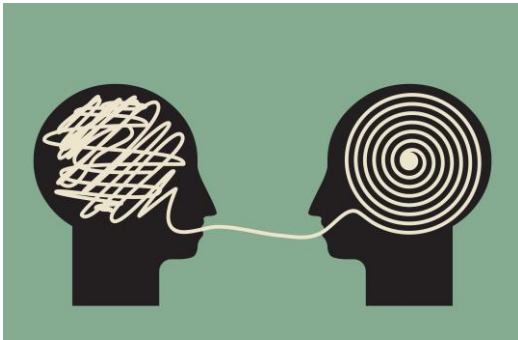
- **PCORI's "Engagement Rubric"**

  http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf

- **Sample Engagement Plans**

  http://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf

- **PCORI Compensation Framework**

  http://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf

- **Engagement in Research website page**

  http://www.pcori.org/content/engagement-research

- **PCORI's Methodology Standards PC-1 to PC-4**

  http://www.pcori.org/assets/PCORI-Methodology-Standards1.pdf

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Putting the Rubric to Work

Greater understanding of engagement	Stronger engagement in proposals	Strong engagement during research?

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Engagement Officers

Engagement Officers, working closely with Program Officers, will support active portfolio management by

- Helping Awardees to outline engagement milestones
- Participating in the Awardees' kickoff and interim phone calls with research team members, including key patient and stakeholder partners
- Facilitating communication between Awardees to troubleshoot engagement challenges
- Gathering promising engagement practices from the portfolio to feature in webinars and for use in updating or expanding the Engagement Rubric

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Engagement Programs

Engagement Awards Program

- Launched in February 2014
- A programmatic funding opportunity−*not* research awards
- Provides support for projects that lead to better integration of patients and other stakeholders into the healthcare research process
- Also supports Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER) meetings and conferences
- Program budget $15.5 million (FY 2015)
- Awards up to 2 years in duration; $250,000 total costs
- Funds organizations
- Funds awards through contracts rather than grants; PCORI programmatic involvement with awardees throughout the post-award process

Engagement Awards

Support projects that do one or more of the following:

Knowledge Awards	Training and Development Awards	Dissemination Awards
• Increase the patient and stakeholder community's knowledge of PCOR and CER and/or • Increase PCORI's knowledge of patient and stakeholder PCOR and CER needs	• Build capacity for engaging in PCOR and CER and/or • Connect patients and stakeholders with the research community and cultivate the relationships for PCOR and CER	• Develop and strengthen partnerships and channels for disseminating PCOR and CER findings

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Recently Funded Engagement Projects

- **Engaging Patients in Bladder Cancer Research Prioritization**
  - *Bladder Cancer Advocacy Network* is working with their online community to create a sustainable infrastructure for conducting research prioritization with bladder cancer patients.

- **70x2020 Colorectal Cancer Screening Initiative**
  - *University of Mississippi Medical Center* is leading local community health advocates, primary health care providers, and public health officers to introduce stakeholders in the Mississippi Delta region to the concepts of PCOR and CER and engage them in designing research.

- **Pathways to Partnership: Communication and Collaboration Skills for Creating PCOR Teams**
  - *University of New Mexico Health Sciences Center* is developing and implementing training aimed at addressing barriers to patient and stakeholder engagement in research.

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Recently Funded PCOR/CER Meetings and Conferences

- Conference on Statistical Issues in Pragmatic Clinical Trials

- Nontuberculous Mycobacteria Research Consortium Stakeholder Engagement and Planning Meeting

- Conference on Science of Dissemination & Implementation

- Summit on Advanced Illness Care: Driving Change through Leadership, Evidence, and Action

Engagement Awards <u>Not</u> Intended to Support

- Research projects

- Planning/pilot studies

- Demonstration projects

- Evaluations of programs or interventions

- Validation of tools or instruments

- Provision of health care

- Recruitment of study subjects

- Development of registries or activities to increase participation in registries

- Development of decision aids or clinical practice guidelines

- Meetings that are business as usual, without focus on PCOR or CER

For More Information

Engagement Awards

Web Page: www.PCORI.org/eugene-washington-awards

Email Address: ea@pcori.org

Contact Number: 202-370-9312

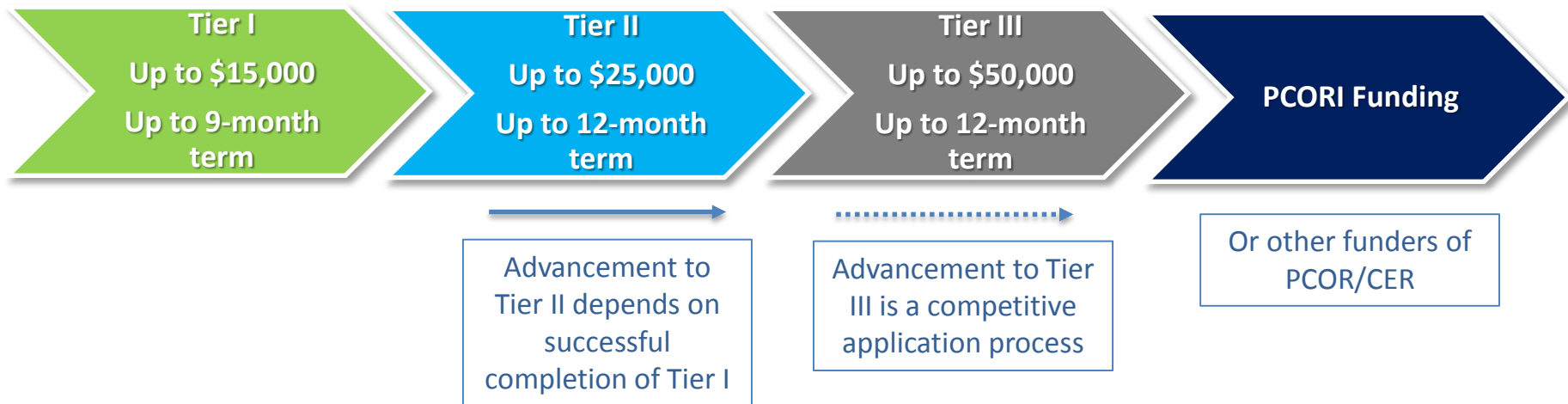PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Pipeline to Proposal Awards

Our Pipeline to Proposal Awards initiative aims to build a national community of patients, stakeholders, and researchers who have the expertise and passion to participate in patient-centered outcomes research, or PCOR, and to create partnerships within that community that lead to high-quality research proposals.

Three-Tiered Process

Tier I	Tier II	Tier III	PCORI Funding
Up to $15,000	Up to $25,000	Up to $50,000	
Up to 9-month term	Up to 12-month term	Up to 12-month term	

Advancement to Tier II depends on successful completion of Tier I

Advancement to Tier III is a competitive application process

Or other funders of PCOR/CER

Strengthening PCOR Nationwide

Our *Pipeline to Proposal Awards* encourage PCOR in comparative clinical effectiveness research.

Number of projects:
Tier I – 77
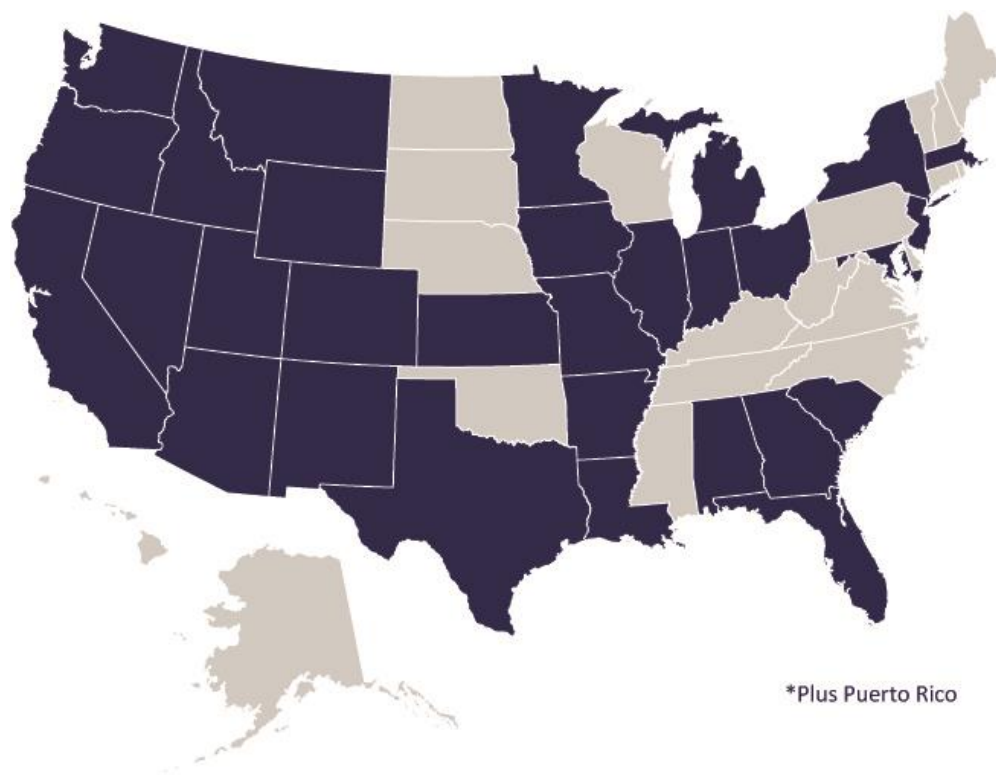Tier II - 27

Amount awarded:
$1,813,999
(Tier I Cycles 1 & 2 and Tier II Cycle 1)

Number of states where we are funding projects:
30 states and Puerto Rico

As of March 27, 2015

*Plus Puerto Rico

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Ambassador Program

PCORI has created a volunteer initiative that aims to unite health and healthcare stakeholders around the promise of PCOR while offering opportunities for training, partnership, and knowledge sharing with other Ambassadors, PCORI staff, and other external partners that support PCORI's mission.

Learn more here:

http://www.pcori.org/get-involved/become-pcori-ambassador

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Questions?

Thank You!

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