PCORI's Engagement in Research Requirements and Engagement Related Funding Opportunities: A Discussion

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pcori®

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Welcome!

Lia Hotchkiss
Director,
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Engagement Awards Program

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Engagement Awards Program

- A programmatic funding opportunity – *not* research awards
- Provides support for projects that will build a community better able to participate in PCOR/CER as well as serve as channels to disseminate study results

Develop Community Skilled in PCOR → **Involve Community in Research Processes** → **Engage Community in Dissemination of PCOR findings**

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Engagement Awards Program

- Awards up to 2 years in duration; up to $250,000 total costs
- Funds organizations
- Funds awards through contracts rather than grants; PCORI programmatic involvement with awardees throughout the post-award process
- Projects will produce deliverables that are useful to awardees, PCORI, and the broader PCOR community for increasing patient and stakeholder engagement in PCOR/CER

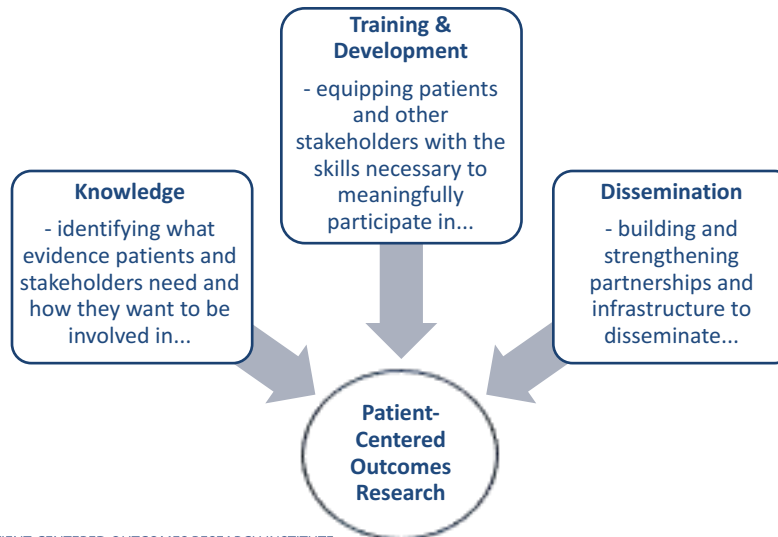| **136**	**$26.3**	**35**
Engagement Awards Made	**Million Awarded**	**States with Engagement Awards**

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Engagement Award: Knowledge, Training and Development, and Dissemination Awards

Training & Development

- equipping patients and other stakeholders with the skills necessary to meaningfully participate in...

Knowledge

- identifying what evidence patients and stakeholders need and how they want to be involved in...

Dissemination

- building and strengthening partnerships and infrastructure to disseminate...

Patient-Centered Outcomes Research

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Engagement Award (EAIN): Research Meeting and Conference Support

- Support meetings/conferences that align with PCORI's mission and strategic plan, and facilitate expansion of PCOR/CER in areas such as, but no limited to:
  - **Research Design and Methodology**
    - Methodological and technical issues of major importance in the field of PCOR/CER are addressed, or new research designs/methodologies are developed.
  - **Research Development**
    - Potential topics for PCOR/CER are explored with relevant patients, caregivers, clinicians, and other healthcare stakeholders.
  - **Dissemination and Implementation**
    - Emerging PCOR/CER research findings and methodologies are shared; findings are considered for their potential impact on clinical practice and research; strategies for integrating the findings are discussed.

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Examples of Funded Engagement Award 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.
- **YouthBuild: Trainings and Resources for Research Partnerships Involving Adolescents**
  - *Children's Hospital of Philadelphia* is building a set of interactive, web-based trainings and toolkits to help youth and researchers create research partnerships and conduct PCOR together.
- **Improving Care for Critically Ill Patients & Families Through Research Dissemination/Implementation**
  - *Society of Critical Care Medicine* is creating an e-community to engage clinicians, patients and families to share strategies for identifying and implementing PCOR to improve care.*

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Examples of Funded Meeting/Conference Support Awards

UNC Center for Maternal and Infant Health

4th Trimester Project

Cerebral Palsy International Research Foundation

HealthInsight

Cholangiocarcinoma Foundation
3-minute video recap:
https://www.dropbox.com/s/vt9goc8m4egbwfy/CCF%202016%20v1.1.mp4?dl=0

From the Field

Danielle Lavallee, PhD, PharmD
Research Assistant Professor
University of Washington,
Department of Surgery
What excites me about the Eugene Washington awards is that often times we fund research but very rarely do we stop and say what infrastructure is needed to do this research and do it successfully.

And so the Eugene Washington awards, in my opinion, give people an opportunity to really think about how do we build and sustain research but by building infrastructure. And but not necessarily doing research but figuring how do we get to the next phase of patient engagement or how do we do other things that aren't research but will support research. So I think this mechanism for funding is really critical for PCOR to be successful in the long run.

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Engagement Awards <u>NOT</u> Intended to Support:

- Projects solely intended to improve patient engagement in healthcare service delivery,
- Projects intended to increase the number of patients who agree to be research subjects or participants
- Research studies
- Planning or pilot studies
- Projects designed solely to validate tools or instruments
- Delivery of health care
- Development of registries or recruitment of research or registry participants
- Development of decision support tools or clinical practice guidelines
- Meetings that don't focus on PCOR or CER
- Full-fledged projects to translate PCORI research findings into products and/or disseminate PCORI research results
- Projects proposed by PCORI-funded investigators to prepare for applying (i.e. "bridge funding") to the Limited PCORI Funding Announcement: Dissemination and Implementation

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For More Information

Engagement Awards

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

- Email Address: ea@pcori.org

- Contact Number: 202-370-9312

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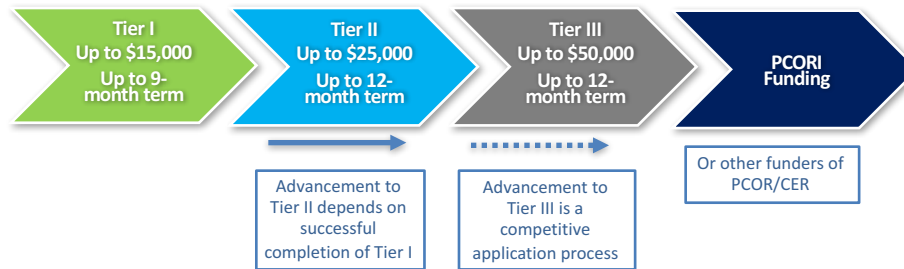
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Pipeline to Proposal Awards

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.

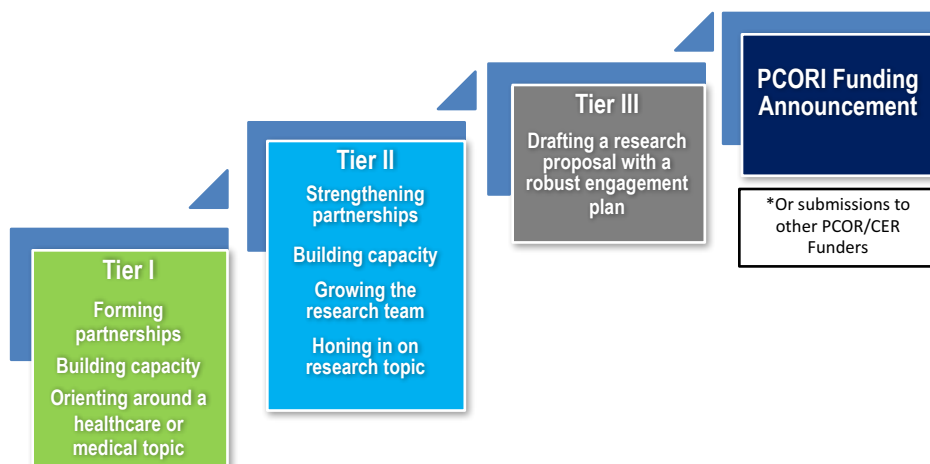PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

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Three-Tiered Process

Tier I	Tier II	Tier III	PCORI
Up to $15,000	Up to $25,000	Up to $50,000	Funding
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

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Capacity-Building: Pipeline to Proposals

Tier I

Forming partnerships

Building capacity

Orienting around a healthcare or medical topic

Tier II

Strengthening partnerships

Building capacity

Growing the research team

Honing in on research topic

Tier III

Drafting a research proposal with a robust engagement plan

PCORI Funding Announcement

*Or submissions to other PCOR/CER Funders

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From the Field…

Ronnie Sharpe, Founder, CysticLife
Our project for the Pipeline to Proposal was to establish a patient-centered research community for cystic fibrosis. And for us, what was even more important is to make it a patient driven research community. As a patient, I've been involved in research studies, whether they were clinical, whether they were QI projects, but to actually have the opportunity to drive this research project as a patient. This is certainly my first experience driving the research from A to Z. I think the biggest gap in research has always been patient-centered researchers thought up as eventually we'll get the patient to the center. And eventually our ideas will trickle down to the patients, so then we'll call it patient centered.
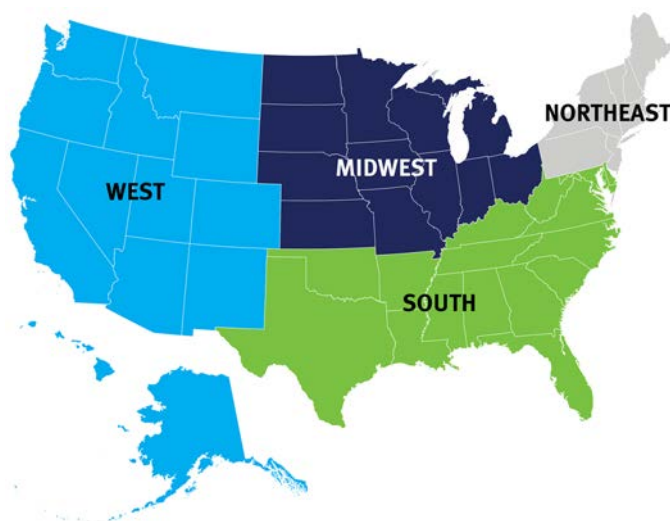
This has given us an opportunity to be the creators of the experience and the structure by working with most importantly other patients in the community. And then we chose who to bring in and drive the research from the inside out, instead of from the outside in. When we described the project to our patient community, the response was greater than I could've ever imagined. Our email had the highest click rate of any emails we ever sent out. And so I think just the biggest thing I've learned is that you've got to be prepared when your showing something new to your community—that the response could be even greater than you anticipated. And now, what are you going to do with that response? And how are you going to harness that passion, and put other patients in the best position to drive this research along with the community?

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Regional Breakdown for Pipeline Awards

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Strengthening PCOR Nationwide

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

Number of projects awarded:
Tier I – 123
Tier II – 71
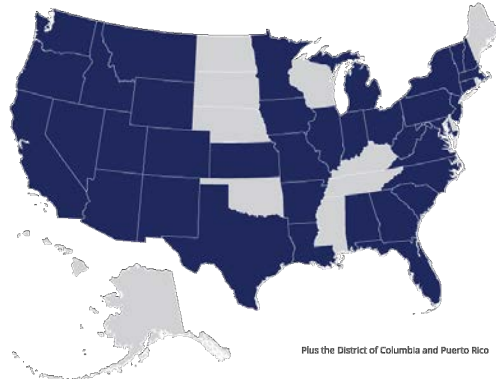**Tier III - 22**

Amount awarded:
$4.7 Million
(Tier I Cycles 1 , 2 & 3 and Tier II Cycles 1 & 2, Tier III Cycle 1)
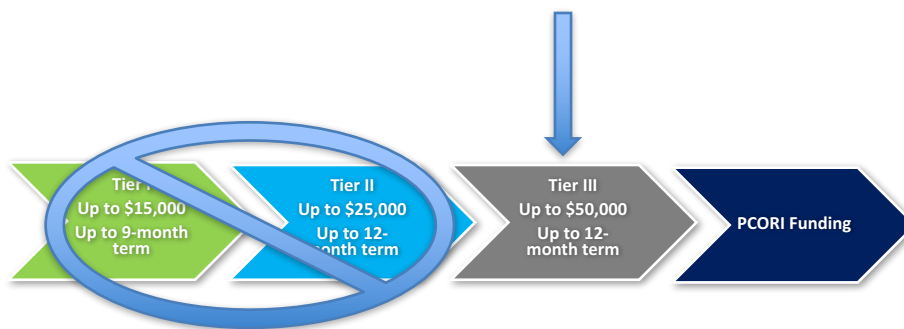
Number of states where we are funding projects:
37 states, District of Columbia and Puerto Rico
As of July 1, 2016

Plus the District of Columbia and Puerto Rico

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Independent Tier III

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

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Pipeline 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

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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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Questions?

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Thank You

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