

Patient and Stakeholder Engagement

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Program Officer, Eugene Washington PCORI Engagement Awards

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Welcome!



Yasmeen Long

Program Officer, Eugene
Washington PCORI
Engagement Awards

Our Discussion for Today

- How does PCORI operationalize patient engagement and patient centeredness?
- How can you prepare to conduct patient and stakeholder engaged research?
- How can you clearly explain your plans for patient and stakeholder engagement in your PCORI proposal?



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About PCORI

- An independent research institute authorized by Congress in 2010. Governed by a 21-member Board 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.



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The Research We Fund is Guided by Our National Priorities for Research



Assessment of
Prevention, Diagnosis,
and Treatment Options



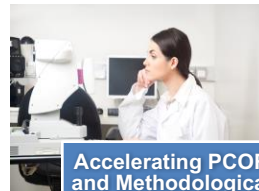
Improving
Healthcare Systems



Communication &
Dissemination
Research



Addressing
Disparities



Accelerating PCOR
and Methodological
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



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Why Engage?



Well, after having insurance coverage I made the decision along with that of my surgeon to have the surgery and the type of surgery that I had was Roux-en-Y. That landed me slap dad as they would say in the middle of the process being you know a patient and having always been a health advocate person.

And from that perspective of being a patient when the opportunity came along for me to work on projects related to obesity, it was just a natural fit. When I started this process, I was really centered on the outcomes for patients, but I am recognizing that these outcomes really are for all the stakeholders...for the clinicians who vest their time and energy in doing this work as well as for those who the services from the clinicians. Everybody wins if we are able to develop a better process and that's my hope for this project.



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What Makes Us Different?



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Merit Review



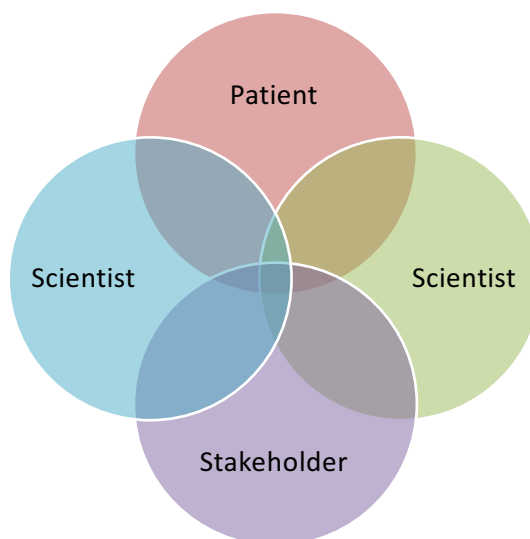
- 1: Potential for the study to fill critical gaps in evidence**
Is associated with a *significant burden in the US population* (prevalence, mortality, morbidity, individual suffering, or loss of productivity)
- 2: Potential for the study findings to be adopted into clinical practice and improve delivery of care**
Has the potential to lead to *meaningful improvement in the quality and efficiency of care* and to improvements in outcomes important to patients
- 3: Scientific merit (research design, analysis, and outcomes)**
Has a research design of sufficient technical merit to ensure that the *study goals will be met*
- 4: Investigator(s) and environment**
Assess the appropriateness (e.g., qualifications and experience) of the investigator(s)/team and the environment's capacity (e.g., resources, facilities, and equipment) to support the proposed project.
- 5: Patient-centeredness**
Focuses on questions relevant to *outcomes of interest to patients and caregivers*
- 6: Patient and stakeholder engagement**
Includes patients and other healthcare stakeholders as *partners in every stage of the research*



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Panel Composition



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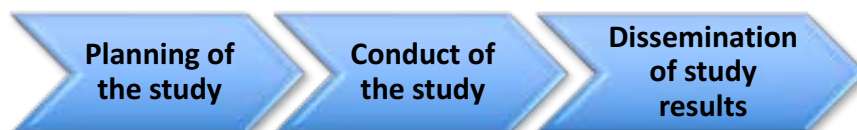
Partnering in Research



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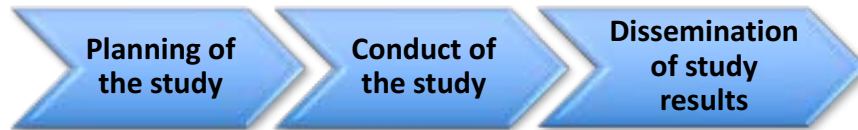
Partnering in Research



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Partnering in Research



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



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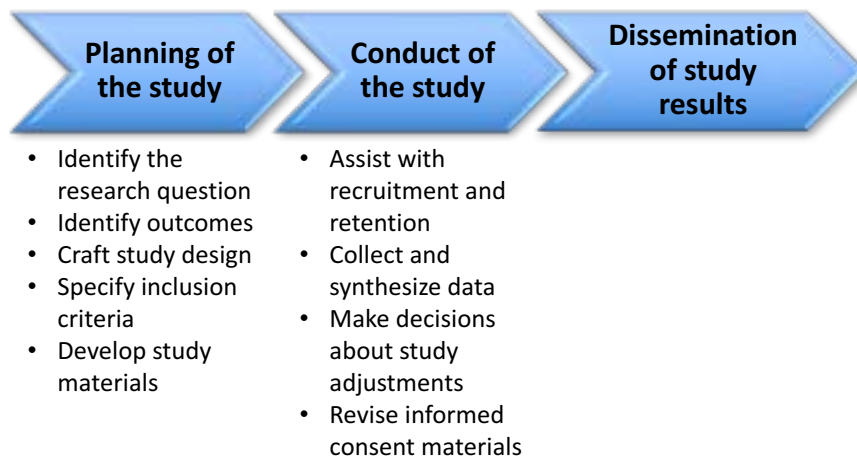
Patient Influence on Planning



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Partnering in Research



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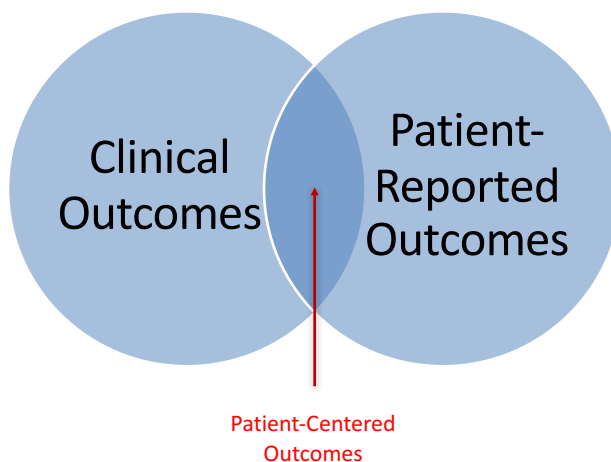
Patient Influence on Conduct



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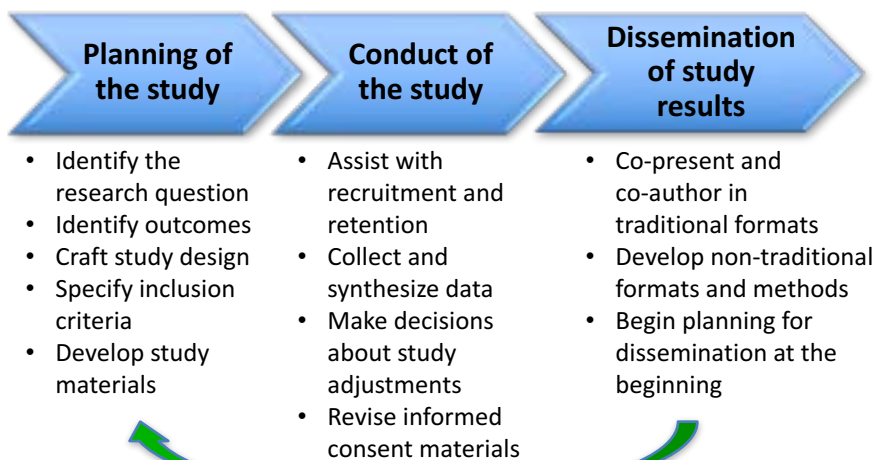
Patient-Centered Outcomes



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Partnering in Research



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Patient Influence on Dissemination



It is important to include the patient voice within research because they are the ones that know the best solution for their problems. It gets them involved throughout the whole process and they are able to help us devise a solution.

I have been working the field for twenty-five years. I specialize in services for people with serious mental illness. I know a lot, but frankly I'm not black. I'm not Latino. I'm not homeless and if we are going to provide programs for those people for my brothers and sisters citizens then they have to be leading the charge. You know I think they have two big roles. Roles in research coming in...so in partnering with Sonia and folks coming in they hit me with questions I never thought of, but they have even bigger roles going out. Its advocates like Sonia that are going to take our wisdom off the shelf and use it. So that is even more important.



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How Do We Facilitate Patient Engagement in Research?



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Engagement Tools



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Engagement Tools

- Engagement Rubric



Planning the Study



Conducting the Study



Disseminating the Study Results



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Engagement Tools

- Engagement Rubric
- Sample Engagement Plans



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Engagement Tools

- Engagement Rubric
- Sample Engagement Plans
- Compensation Framework
- “Budgeting for Engagement” guidance document



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- Programmatic Funding (Pipeline to Proposal Awards and Eugene Washington Engagement Awards)



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Engagement Tools

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- Programmatic Funding (Pipeline to Proposal Awards and Eugene Washington Engagement Awards)
- Ambassadors Program (webinars, networking, training, matchmaking opportunities)



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- Post Award: Engagement Officers



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- “Engagement in Research” website page



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- PCORI’s Methodology Standards PC-1 to PC-4



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How is this application process different?

- Engagement Plan
- Partner Biosketch
- Partner Compensation
- Description of research question and outcomes
- Provision of partner names
- Milestone development
- IRB approval



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Lessons Learned from the Portfolio

- Start with the goal, not the rule
- Ask first, exclude second
- Keep the “unusual suspects” in mind
- Engagement is relational, not transactional
- For proposals: Show your work!



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Embody the Six Engagement Principles

Partnership

Co-learning

Reciprocal
Relationships

Trust

Transparency

Honesty



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The Last Word...



Its hard to imagine ever doing another study where I don't start out with patients and families first. Its absolutely changes the way you look at a project and the way you do business and I hope don't ever do another one without patient and family engagement.



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Engagement Funding Opportunities



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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



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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

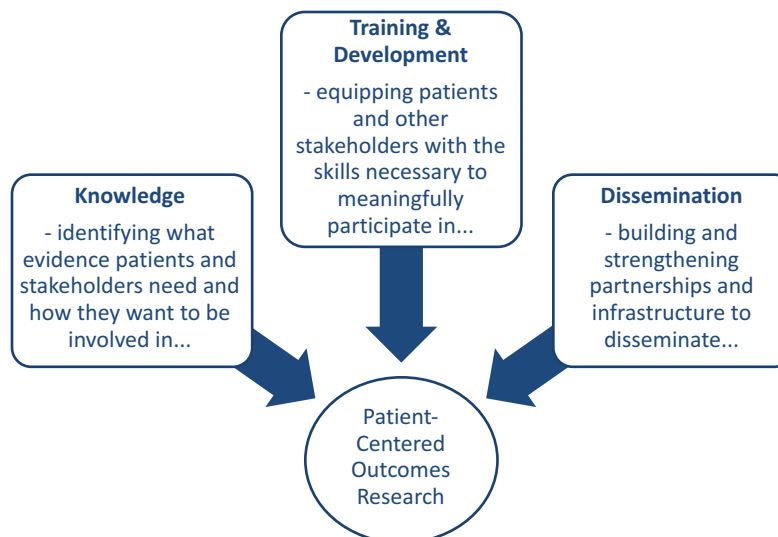
195	\$38.5	37
Engagement Awards Made	Million Awarded	States with Engagement Awards (plus Puerto Rico and Washington DC)



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



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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 not 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



Cholangiocarcinoma Foundation
3-minute video recap:
<https://www.dropbox.com/s/vt9qoc8m4egbwfy/CCF%202016%20v1.1.mp4?dl=0>

From the Field



Danielle Lavalley, 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 NOT 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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Pipeline to Proposal Awards (P2P)

- **Mission:** The P2P program aims to build a national community of patient, stakeholder, and researcher partnerships that have the expertise and passion to participate in patient-centered outcomes research within their communities that leads to high-quality research. In addition, the P2P program is a funding mechanism to develop and strengthen the engagement in proposals submitted for funding.
- **Purpose:** Build capacity and cultivate the development of proposals with sound scientific rigor and **robust patient engagement**.



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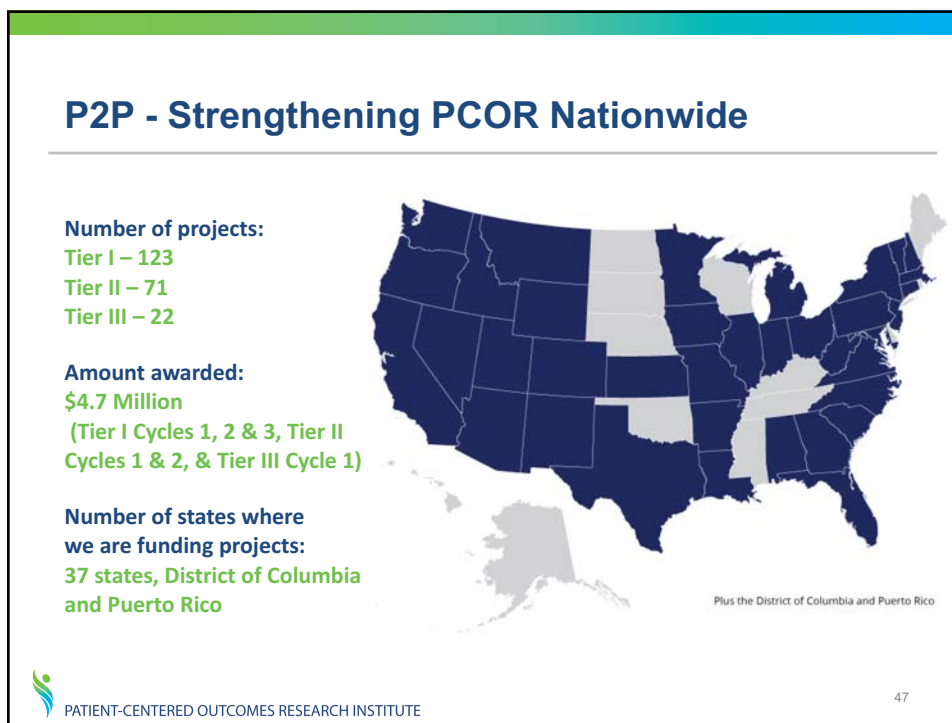
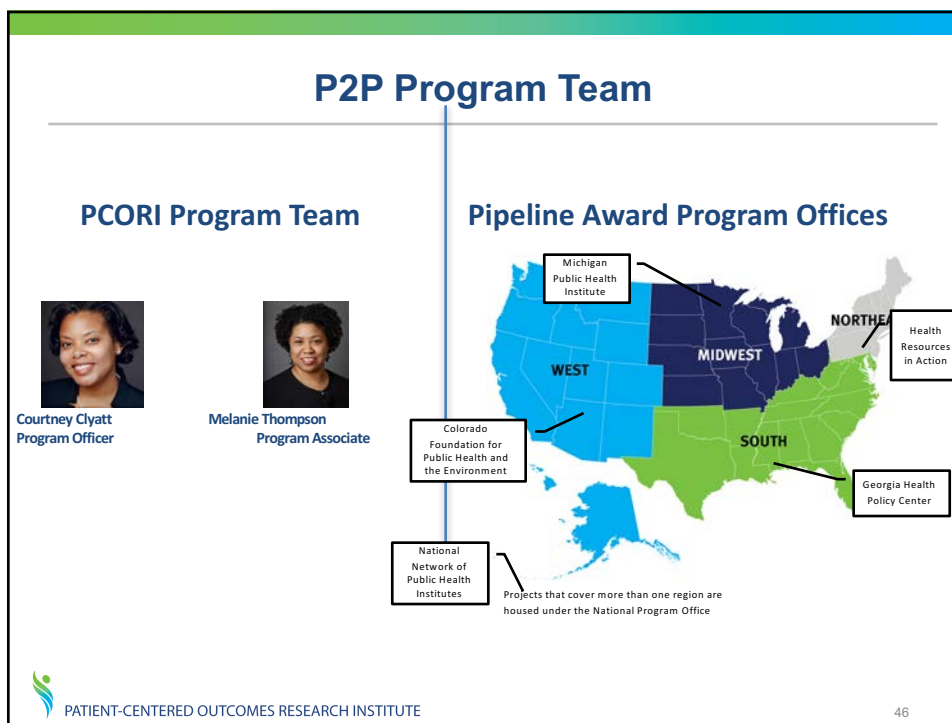
Overarching Goals of P2P

- Enabling the non-researcher community (including individual patients) to drive partnership development and research project (flip the funding)
- Developing research partnerships, infrastructure and a diverse, skilled PCOR community especially in underserved and underrepresented communities
- Creating a robust Dissemination and Implementation network that recognizes the PCORI brand
- Submission of high quality PCOR/CER proposals to PCORI and other funders with strong engagement plans
- Learning about promising pre-engagement practices and methods in the P2P (P2P as a learning laboratory) and share with broader research community

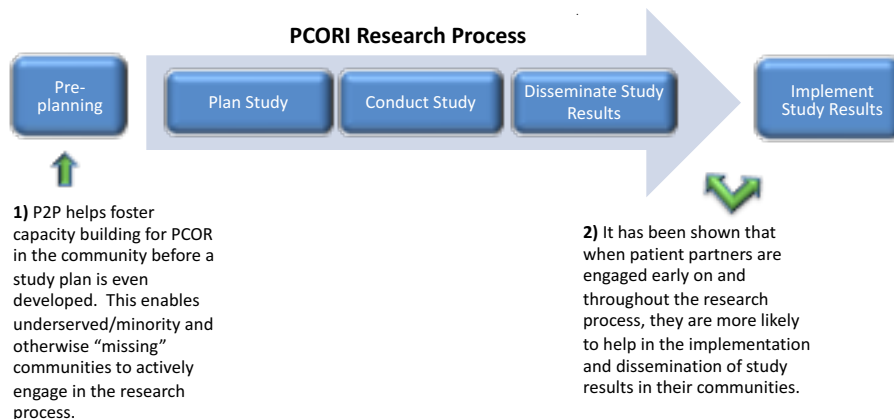


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P2P Awards Strengthen the PCORI Research Enterprise



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Examples of Pipeline to Proposal (P2P) Projects

- ***The Hispanic Family Asthma Outcomes Research Network***
 - **Nuestra Salud, LLC (NS)**, serves the Hispanic and Spanish-speaking population of New Mexico. Lung health, particularly asthma care in children and smoking cessation, has been surfacing as an issue that our community would like to address. As an advocate organization, our staff, families, and patients need training and support to build our capacity to participate more fully in developing comparative effectiveness research (CER) questions, participate in the design and evaluation of the research findings, and make sure our efforts are valued.
- ***Promoting Patient-Centered Research in the Puget Sound Asthma Coalition***
 - **Washington State University College of Nursing.** The purpose of this project is to promote patient-centered research in the Puget Sound Asthma Coalition (PSAC). The PSAC is a multi-organizational effort to improve the quality of life for individuals, families, and communities affected by asthma.
 - Quote from a P2P Awardee - “Our partnership has definitely been strengthened through this project....But this project has qualitatively and quantitatively changed our partnership to the point where we are now brainstorming outside the advisory council about how we can strategically improve Korean American’s health....”



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Examples of Pipeline to Proposal (P2P) Projects

Tier III – CER Proposal Development for \$50,000 over a 12-month period

- **A Community Partnership for Patient-Centered Outcomes Research in Type 2 Diabetes- University of Utah** - The goals of this PCORI Tier III award are to 1) increase the breadth of stakeholder involvement on the CAB, 2) refine CER questions and determine an appropriate funding mechanism for these questions, 3) conduct a systematic literature review to inform the design of the proposed new clinical research study, 4) design a clinical research study and submit a letter of intent.
- **Taking Care of Our Parents: A Collaborative Team Model to Support Caregivers and Elderly Community Members – Leaving Well** - In Tier III, project team seeks to identify ways that primary care provider teams can be engaged to assess evolving caregiver needs, help connect caregiver/patient dyads to community resources, and assist in training caregivers for the medically related tasks they perform.

Tier II – CER Question Development and Research Partnership Maturation for \$25,000 over a 12-month period

- **Patient-Led Multiple Sclerosis Research Community – The Board of Trustees of the University of Illinois** -Tier II project will support the Patient-Led Multiple Sclerosis Research Community in developing research study ideas to answer patient-selected comparative effectiveness research (CER) questions
- **Stakeholder-Driven Veteran's Suicide Protection Advisory Group – University of Colorado Denver - College of Nursing** - Stakeholder-Driven Veterans' Suicide Protection Advisory Group (VSPAG), partnership team, and key stakeholders will refine comparative effectiveness research (CER) questions into a single research question addressing—through a diverse series of engagement activities—protective factors against suicide in the veteran population.



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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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Pipeline Awards Not Intended to Support

- Research projects
- Planning/pilot studies or gathering pilot data
- 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
- Activities requiring IRB approval/informed consent of participants



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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

Yasmeen Long, MA
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Engagement Awards



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