Pipeline to Proposal Awards Initiative: Inaugurating PCORI’s Engagement Awards Program

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Note: This document is retained for archival purposes only. Information related to this program has changed. For current information, please see PCORI’s Pipeline to Proposal Award page, available at http://www.pcori.org/funding-opportunities/pipeline-to-proposal-awards.
About PCORI

PCORI was authorized by the Patient Protection and Affordable Care Act of 2010 as a non-profit, nongovernmental organization and is charged with helping patients, clinicians, purchasers, and policy makers make better informed health decisions by “advancing the quality and relevance of evidence about how to prevent, diagnose, treat, monitor, and manage diseases, disorders, and other health conditions.” It does this by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

PCORI’s strong patient-centered orientation directs attention to individual and system differences that may influence research strategies and outcomes. PCORI is charged with producing useful, relevant clinical evidence through the support of new research and the analysis and synthesis of existing research.

PCORI is committed to transparency and a rigorous stakeholder-driven process that emphasizes patient engagement. PCORI uses a variety of forums and public comment periods to obtain public input to enhance its work.

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Opportunity Snapshot

The Patient-Centered Outcomes Research Institute (PCORI) has launched a funding initiative to facilitate involvement of patient, stakeholder, and research communities in patient-centered outcomes research.

The Pipeline to Proposal Awards is designed to create opportunities for patients to partner with other healthcare stakeholders and become more engaged in the research process. This program will allocate resources through three successive tiers of awards designed to promote interest and capacity for the development of patient-centered outcomes research proposals.

The Pipeline Awards will be managed by five Intermediate Funders (IFs) who will help patient, stakeholder, or research group awardees build strong multi-stakeholder communities and partnerships.

The long-term goals of this initiative are to support the submission of high-quality patient-centered outcomes research proposals and to advance a nationwide network of communities that are equipped and eager to participate in research that helps patients and those who care for them make more informed decisions.
I. Background

The Patient-Centered Outcomes Research Institute (PCORI) was created to conduct research to provide information about the best available evidence to help patients and their healthcare providers make more informed decisions. PCORI’s research is intended to give patients a better understanding of the prevention, treatment, and care options available and the science that supports those options.

PCORI has identified five cross-cutting areas where health research is needed to give patients and those who care for them more information to support decision making. PCORI’s National Priorities and Research Agenda can be applied to and used to advance the quality of information for any health condition or disease where evidence is lacking or current decision making is suboptimal. The five priorities were developed in light of PCORI’s statutory requirements, its working definition of patient-centered outcomes research (PCOR), and previous research prioritization efforts. These National Priorities for Research encompass the patient-centered comparative clinical effectiveness research PCORI will support in its funding announcements:

1. Assessment of Prevention, Diagnosis, and Treatment Options
2. Improving Healthcare Systems
3. Communication and Dissemination Research
4. Addressing Disparities
5. Accelerating Patient-Centered Outcomes Research and Methodological Research

On October 27–28, 2012, PCORI invited 150 participants from across the country to a workshop titled Transforming Patient-Centered Research: Building Partnerships and Promising Models. Three-quarters of the participants self-identified as patients, caregivers, or patient representatives, while the remaining participants represented other stakeholder groups, many of them researchers. They met in Washington, DC, to offer ideas on best practices for patient engagement in research and to envision a future culture of patient-centered outcomes research where research is conducted in partnership with consumers/patients, caregivers, and the broader healthcare community.

In his closing comments, Joe Selby, MD, MPH, executive director of PCORI, remarked that the “readiness” of the patient and stakeholder community at the workshop “affirmed PCORI’s working assumption that the patient community is up to the challenge of playing its part in transforming the research enterprise.” Workshop participants shared, however, that few resources have been directed to patient, community, or other key stakeholder groups for capacity building, support, or infrastructure development for engagement in research as partners and that the majority of

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1 Available at pcori.org/research-we-support/priorities-agenda/
2 A workshop report and webcast are available at pcori.org/events/transfoming-patient-centered-research-building-partnerships-and-promising-models/?type=past
funding for research has been allocated to scientific and academic entities and to large healthcare
delivery systems in the United States. One of the key recommendations that emerged from the
workshop participants was the concept of Engagement Awards designed to facilitate involvement
of patient, stakeholder, and research communities in patient-centered outcomes research—as
partners.

II. Pipeline to Proposal Awards

The purpose of the Pipeline to Proposal Awards initiative is to build a national community of
patients, stakeholders, and researchers who have the expertise and passion to participate in
patient-centered outcomes research, and to create partnerships within that community that lead
to high-quality research proposals. Below, we describe the goals, how these awards fit within
PCORI’s mission, the funding structure for all three tiers, and the role of IFs.

What Are the Goals?
PCORI’s strategic goals for the Pipeline to Proposal Awards include:

• Strengthening relationships between researchers, patients, and stakeholders, particularly
  in communities that have historically been underrepresented in research.
• Building the capacity for community partnerships to create research questions and submit
  patient-centered research proposals that can be considered for PCORI funding.
• Cultivate the field of patient-centered outcomes research by increasing the number of
  patients, researchers, and other stakeholders who have the ability to participate in
  patient-centered outcomes research.
• Identify the most promising methods for engaging and communicating with patients,
  researchers, and other stakeholders in patient-centered outcomes research and
  communicate those lessons to current and future PCORI awardees.

How Will the Pipeline to Proposal Awards Contribute to PCORI’s Mission?
The Pipeline to Proposal Awards must support PCORI’s mission to help patients and those who care
for them make better informed healthcare decisions. All awardees will receive PCORI-created
trainings to ensure that they carry out their work in a way that adheres to the Institute’s guiding
principles of patient-centeredness, collaboration, and embracing diversity. Finally, the work
undertaken must meaningfully contribute to PCORI’s long-range goals to:

• Substantially increase the quantity, quality, and timeliness of useful, trustworthy
  information available to support health decisions
• Speed the implementation and use of patient-centered outcomes research evidence
• Influence clinical and healthcare research funded by others to be more patient-centered

How Will the Pipeline to Proposal Awards Be Implemented?
The Pipeline to Proposal Awards will be conducted through the funding of three successive
tiers of awards, with each tier designed to take another step toward producing community-led, patient-centered outcomes research proposals. **Tier I Pipeline Awards** will fund community-building and engagement projects. **Tier II Pipeline Awards** will develop research capacity, create new partnerships, and build the infrastructure needed to conduct research, and **Tier III Pipeline Awards** will fund the development of high-quality research proposals that can be submitted to PCORI (see Illustration 2).

**Illustration 2: Pipeline to Proposal Awards Funding Tiers**

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**Tier I: Pre-Engagement/Community-Building Projects (up to $15,000 per award)**

In Tier I Pipeline Awards, PCORI is focused on building the community of patients, stakeholders, and researchers who can participate in patient-centered outcomes research.

Tier I awards can be given to any individual patient, stakeholder, or researcher—or group of patients, stakeholders, or researchers—oriented around a particular issue that can ultimately lead to a comparative effectiveness research question, even if that question cannot yet be articulated.

The Tier I awardees will be asked to conduct the following activities over nine months:

- Build relationships within communities that are based on shared interest among patients, health organizations, clinicians, and researchers.
- Create structures (e.g., advisory councils) and communication strategies that may include setting up of social media platforms or using online forums to connect community members.
- Develop an understanding, through the use of PCORI-created trainings, of PCORI’s commitment to enhancing the use of patient-centered, evidence-based information.
- Identify specific parties who are interested in research collaboration and development of a proposal for a Partnership and Infrastructure Development Project (Tier II Pipeline Awards).
**Tier II: Partnership and Infrastructure Development Projects (up to $25,000 per award)**

Funding for Tier II Pipeline Awards will be available to groups, including Tier I awardees, that have successfully established partnerships between patient partners and research partners, and have demonstrated an interest in developing a patient-centered outcomes research proposal. Applicants who have not applied for or received a Tier I award may also be eligible, as long as the desired qualifications for partnership and demonstrated commitment to advancing patient-centered outcomes research are met.

Tier II awards invest in the development and maturation of research partnerships that can accomplish the end goal of creating a high-quality proposal that can be considered under PCORI’s primary research funding announcements. The awards are designed to support new or emerging research partnerships, the development of research infrastructure, and the generation of research questions and research priorities. The award period is 12 months.

Funding should be used to convene workshops, town hall meetings, virtual webinars, and other methods of communication within the community partnerships. The awards will also support partnership infrastructure development, such as governance and communications needs.

To qualify for a Tier II award, applicants must have both patient partners and research partners, with other types of partners strongly encouraged.

Applicants may request up to $25,000 in direct costs. PCORI expects that a significant portion of the funds will be allocated to the non-research partner and will carefully review proposals with a consideration of equity in allocation of resources.

**Tier III: Proposal Development Projects (up to $50,000 per award)**

Funding for Tier III Pipeline Awards will be available to groups, including successful Tier II awardees, that are well equipped to develop a PCORI research proposal but would benefit from additional assistance, particularly with regard to building the patient engagement component of the study design.

Applicants who have not applied for or received a Tier I or Tier II Pipeline Award may also be eligible provided that the desired qualifications for Tier III applicants are met. Applicants for Tier III Pipeline Awards may also be previously unsuccessful applicants for PCORI research funding. Special focus would be given to those who have submitted proposals to PCORI and were not funded but received recommendations from PCORI to strengthen the research partnership plan.

Tier III awardees are required to have a partnership between a patient and research partner in place, with other types of partners strongly encouraged.

Applicants may request up to $50,000 in direct costs. PCORI expects that a significant portion of the funds will be allocated to the non-research partner and will carefully review proposals with a consideration of equity in allocation of resources. Ideally, collaborative proposals will be based on partnerships that have demonstrated working success in the past. Projects must be completed within 12 months, and a PCORI research proposal must be prepared and ready for submission.

See Illustration 3 for a summary of funding tiers.
What Is the Role of Intermediate Funders in Pipeline to Proposal Awards?

IFs will be responsible for providing technical support and monitoring the operational and programmatic performance of the Pipeline awardees, as well as completing the financial accounting and administration duties. A monitoring report will be provided to PCORI on a regular basis to ensure that its investment in community building is serving the intended goal.

Each IF must have extensive experience requisite to offer technical assistance to the project and to manage small awards to recipients with little funding experience. The anticipation is that each of the five IFs may manage the awards in slightly different ways, and PCORI welcomes IFs to employ successful models they have used in the past. However, it is critical that the core principles of
PCOR and overarching goals of the Pipeline to Proposal Awards are adhered to by Pipeline awardees and IFs. Therefore, PCORI will provide the IFs with guidelines for both the financial and operational and programmatic management of the Pipeline awards.

PCORI will select the IFs by mid-April 2014.

PCORI expects and encourages each IF to pursue its own strategy for distributing funding and managing its awardees. One anticipated benefit of using IFs is the opportunity to compare and evaluate different methods for building diverse and effective communities. The IFs will also be asked to play a role in communicating their work with a broad group of stakeholders to amplify the impact of the Pipeline awards.

### III. A Model: How the Pipeline Awards Can Work Effectively

Outlined below is a description of how PCORI envisions all three tiers of awards being effectively utilized by patients, researchers, or other stakeholders to meet PCORI’s goals. *The organizations discussed in these examples are fictional and used for illustrative purposes only.*

#### Patient Awardee

Sunshine Health Institute in Colorado (an IF) awards $15,000 Tier I Pipeline Award to a small group of patients with osteoarthritis who, due to lack of effective medical treatment, have been sharing ideas about different ways to combat their pain and immobility. The group recruits interested clinicians to join them and—using the funding—rents meeting space for convening partners from around the region. The group also uses the award to purchase software and hardware to facilitate e-communication.

During the nine-month grant period, with oversight by the Sunshine Health Institute and PCORI, the Arthritis Cluster convenes once per week, grows its group to include 75 arthritis patients, appoints a leadership council, and drafts a plan for how it will move forward in identifying comparative effectiveness research issues of most importance to its members, including the best nonsurgical treatments for knee osteoarthritis.

Upon winning a Tier II Pipeline Award, the Arthritis Cluster forges partnerships with local clinicians and non-clinician stakeholders and researchers with interests in nonsurgical treatments for knee osteoarthritis. With oversight by PCORI, the group develops a governance and communications mechanism to share information about its primary research issue and continues to invite new members (from the patient, stakeholder, and researcher groups) to join. The group uses the Tier II funding to prepare the communications plan, to continue convening in-person meetings, and for software and hardware to continue building its e-community.

Having received a Tier III Pipeline Award, the now well-coordinated Arthritis Cluster begins honing in on specific comparative effectiveness research questions around nonsurgical treatment of knee osteoarthritis and vets these ideas through collaboration with other patient, stakeholder, and researcher groups. The group uses Tier III funding for three site visits to explore other similar
groups’ efforts in arthritis management. The group also uses the funding to build evaluation and communication/dissemination plans and to cover the administrative costs associated with the project director’s role.

The ultimate output from Tier III is a well-vetted research proposal with a strong engagement component that can be submitted to PCORI in response to a funding announcement. Additional outputs would be patient-centered outcomes research proposals to other funding entities, as well as shared learning among the patient, stakeholder, and research communities about the process of building community and orienting around an important research topic.

**Stakeholder Awardee**

Sunshine Health Institute in Colorado (an IF) awards a $15,000 Tier I Pipeline Award to a small local health department that, due to a large influx of type 2 diabetes patients (caused in part by the area’s food desert, economic hardship, and abundance of fast-food restaurants), has begun brainstorming more effective ways to engage its patients in disease management techniques. The group uses Tier I funding to pay for meeting costs, including travel expenses for its partners, and for multiple in-person gatherings of patients and stakeholders. The group also uses the grant to cover administrative expenses associated with the project director’s role.

During the nine-month grant period, with oversight by the Sunshine Health Institute and PCORI, the health department team convenes once per week, grows its group to include 50 of its diabetes patients, appoints a leadership council, and drafts a plan for how it will move forward in identifying comparative effectiveness research issues of most importance in managing diabetes. The team members draw largely from the input of the group’s patient partners on the best ways to tackle disease management obstacles, given the community’s specific challenges.

Upon receiving a Tier II Pipeline Award, the group, now coalesced as the Diabetes Consortium, forges partnerships with additional local clinicians and non-clinician stakeholders and researchers with interests in diabetes management. With oversight by PCORI, the group develops a governance and communications mechanism to share information about its primary research issue. The group also continues to invite new members (from the patient, stakeholder, and researcher groups) to join. The Consortium uses its Tier II funding to travel to three different sites where similar diabetes groups are working on patient-centered interventions; the group also uses the funding to cover three focus groups to further refine the research issues in play.

Having received a Tier III Pipeline Award, the now well-coordinated Diabetes Consortium begins honing in on specific comparative effectiveness research questions around the most effective patient-driven disease management techniques and vets these ideas through collaboration with other patient, stakeholder, and researcher groups. The group uses Tier III funding for two major convening meetings of project partners, for administrative costs associated with the project director’s role, and for a community survey to measure the baseline for the research proposal.

The ultimate output from Tier III is a well-vetted research proposal with a strong engagement component that can be submitted to PCORI in response to a funding announcement. Additional outputs would be patient-centered outcomes research proposals to other funding entities, as well
as shared learning among the patient, stakeholder, and research communities about the process of building community and orienting around an important research topic.

**Researcher Awardee**

Sunshine Health Institute in Colorado (an IF) awards a $15,000 Tier I Pipeline Award to a local researcher who lost his mother very quickly to a rare disease. He is interested in trying to connect nationally with others impacted by the disease and develop a comparative effectiveness study evaluating the best treatment options available for the condition. The researcher uses the funding to purchase software and consulting services to establish a large e-community; he also uses the funding to convene two in-person meetings of patients and stakeholders.

During the nine-month grant period, with oversight by the Sunshine Health Institute and PCORI, the researcher builds a network of 45 patients and 35 stakeholders affected by or interested in this rare disease. The group appoints a leadership council and drafts a plan for how it will move forward in identifying comparative effectiveness research questions evaluating available treatments for the disease. The plan is drawn largely from the input of its patient partners, with great care given to the outcomes of treatment that matter to patients beyond survival, such as treatment side effects.

Upon winning a Tier II Pipeline Award, the Rare Disease Collaborative continues to invite new patients, stakeholders, and interested researchers into its network. With oversight by PCORI, the group develops a governance and communications mechanism to share information about its primary research issue. The group uses Tier II funding to engage communications experts in creating a master dissemination plan. The group also uses the funding to pay for travel and other related costs for an in-person meeting of the members of the Collaborative.

Having won a Tier III Pipeline Award, the now well-coordinated Collaborative begins honing in on specific comparative effectiveness research question around the most effective and least caustic treatment for the rare disease. The group uses Tier III funding for software and hardware to maintain a robust online community, as well as for in-person meetings and partner travel.

The ultimate output from this tier is a well-vetted research proposal with a strong engagement component that can be submitted to PCORI in response to a funding announcement. Additional outputs would be patient-centered outcomes research proposals to other funding entities, as well as shared learning among the patient, stakeholder, and research communities about the process of building community and orienting around an important research topic.