PCORI: Request for Proposals: Engagement Award Special Cycle: Building Capacity for PCOR/CER in Intellectual and Developmental Disabilities

Unrestricted funding opportunities

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Website: https://www.pcori.org/funding-opportunities/announcement/engagement-award-

special-cycle-building-capacity-PCOR-CER-IDD-2021

Submission Limitations: None

Foundation Deadline: Full proposals are due May 24, 2021, 5:00 p.m. EST

Please contact your RAS unit *and* Nicole Dancz to inform them of your intent to submit.

Overview

The Patient-Centered Outcomes Research Institute (PCORI) plans to award up to \$25 million in fiscal year 2021 as part of the Eugene Washington PCORI Engagement Awards. These awards are for research support projects. This program does not fund research studies. The Eugene Washington PCORI Engagement Awards support projects that encourage active, meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders as integral members of the patient-centered outcomes research/comparative clinical effectiveness research (PCOR/CER) enterprise.

This special funding opportunity will support projects that enable organizations and communities to build their capacity and skills to participate across all phases of the PCOR/CER process on topics that address health outcomes related to intellectual and developmental disabilities (IDD). Projects will also provide an understanding of the impact of stakeholder engagement strategies within different settings and stakeholder groups focused on this special area of interest.

In the context of the Engagement Awards program, capacity building to support research refers to the following types of projects:

- Projects that focus on building the knowledge, competencies, and abilities of patients and other stakeholders to be meaningful partners in PCOR/CER with researchers throughout the research process, from topic selection through design and conduct of research to dissemination or implementation of results.
- Projects that strengthen the skills of researchers to be better partners with patients and other stakeholders involved in PCOR/CER.
- Projects that support the expansion of use or adoption of existing engagement tools and resources to build capacity for PCOR/CER in a new population or geographic area.
- This is an opportunity to build capacity for stakeholder engagement with PCOR/CER in IDD on topics such as:
 - o Addressing health equity and advancing IDD health outcomes for vulnerable populations
 - Leveraging community-based and patient-centered models of care delivery
 - Challenges related to clinical care delivery and access
 - o Telehealth solutions
 - Transition to adulthood
 - o Caregiver needs and access to wraparound support
 - Patient needs and preferences
 - o Other relevant topics related to IDD health outcomes with appropriate justification are welcomed.

Funding

- Award total costs may not exceed \$250,000 (Direct + Indirect Costs).
- Maximum project period is 2 years.
- Earliest start date is September 2021.
- The length of the project period and budget amount must be justified by the level of activity that will occur during the project and all projects must be at least 18 months in duration.

More Information

PCORI's reauthorizing legislation in 2019 included two new research priority areas, one of which centers on individuals with intellectual and developmental disabilities (IDD). These new priority areas provide more focused opportunities for engaging diverse stakeholders and facilitating PCOR/CER that is critical in understanding and addressing the needs of those impacted by these conditions.

Developmental disabilities are chronic disabilities that originate at birth or in the developmental period and cause impairment in physical, learning, language, and/or behavioral areas. Intellectual disabilities, which fall under the umbrella term of developmental disabilities, involve limitations to cognitive function (reasoning, learning, problem solving) and adaptive behavior. Not all developmental disabilities include limitations in cognitive ability.

This Engagement Award funding announcement offers an opportunity for organizations and community groups to build capacity and skills for patient-centered outcomes research and comparative clinical effectiveness research (PCOR/CER) in IDD, as well as understand the impact of stakeholder engagement within different settings and stakeholder groups focused on this special area of interest.

In the context of the Engagement Awards program, capacity building to support research refers to the following types of projects:

- Projects that support organizations with strong ties to patients, caregivers, clinicians, and/or other stakeholders
 who have a connection to, expertise in, or lived experience related to the focus area to equip them to engage as
 partners in PCOR/CER. These projects will focus on building the knowledge, competencies, and abilities of their
 community to be meaningful partners with researchers throughout the research process from topic selection
 through design and conduct of research to dissemination or implementation of results.
- Activities might include, but are not limited to:
 - Educating and training stakeholders on the fundamentals of PCOR/CER; establishing a sustainable collaborative or learning community; engaging stakeholders to identify important patient-centered outcomes, prioritize PCOR/CER topics or themes, and/or develop a research agenda; capturing stakeholder perspectives on emerging PCOR/CER needs and barriers/facilitators to patient-centered research.
 - o Multi-stakeholder convenings, meetings, and conferences that include patients, caregivers, researchers, clinicians, purchasers, payers, health system leaders, and other stakeholders.
 - o Convenings designed with the active involvement of patient and community groups and organizations to bring diverse stakeholders together around a central focus or theme that unifies stakeholders.
 - Convenings that include one or more of the following priority/focus areas: (a) facilitating discussion around patient-centered research design and development of PCOR, (b) sharing engagement methods, and/or (c) dissemination of research findings.
- Projects that strengthen the skills of researchers to be better partners with patients and other stakeholders involved in PCOR/CER.
 - Applicants must clearly explain how the capacity that is developed through an award will be applied to existing or planned PCOR/CER partnership opportunities.
- Projects that support the expansion of use or adoption of existing <u>engagement tools and resources</u> whenever possible, rather than develop new products and tools. Projects may implement available tools, processes, or programs, alone or in combination, in a new population or geographic area—for example, a new network of clinicians, patient advocates, and academic researchers.
 - o If this project is using a PCORI-funded engagement tool/resource, applicants should identify the existing engagement tool/resource that this project will be scaling or adopting by listing the: (a) Tool Name, (b) Project Title, (c) Project Lead Name, (d) URL to project page. Applicants should anticipate seeking a letter of support from the tool/resource originator should a full application be invited.
 - O Applicants should identify and describe all tools/trainings/programs that will be used as part of the project, as well as share the evidence base for the resources that will be used.

Submitting a Successful Application

- Rationale that there is a need for additional patient and/or stakeholder capacity to participate in IDD-related PCOR/CER with a clear and direct link to participation in research opportunities.
- The intended impact of the proposed project.
- The organization's relationship to the population and/or context and track record in engagement.
- Commitment from the patient and/or stakeholder communities to be involved in the project and clear patient and/or stakeholder involvement/leadership in all stages of the proposed work.
- Evaluation metrics for assessing the success of the engagement strategies.
- Plans for sustainability/next steps after the project period has ended. Future funding from PCORI should not be
 assumed. If the project does not lend itself to sustained activities after the project period concludes, provide
 justification.
- If using or adopting a PCORI-funded engagement tool or resource:
 - Description of the engagement tool(s) or resource(s) selected and justification for its continued and expanded use. Provide information about prior use/implementation of the tool(s) or resource(s), including any data on its effectiveness to build capacity for patient and stakeholder engagement in PCOR/CER.
 - o Approval to use and, if applicable, adapt tool(s) and resource(s) from the relevant copyright owner of the tool(s) and/or resource(s) in the form of a written letter of support with the full proposal submission. This will typically be from the awardee institution of the original PCORI award. The relevant owner must grant the applicant rights to the engagement tool(s)/resource(s) sufficient to carry out the project.

Review Process

- Applying for this award is a one-stage process unlike applying for other Engagement Awards. A full proposal is
 required at the time of submission. An LOI is not required. Specific requirements and guidance to complete a
 successful application are found in the full funding announcement, submission instructions, and submission
 checklist.
- Proposals must be submitted by the application deadline of May 24, 2021 at 5 pm ET. PCORI may request
 additional information from the applicant after the initial review of the full proposal. PCORI aims to provide a
 final programmatic approval decision on the full proposal, via email, within 10 weeks of the application deadline.
 If the full proposal is programmatically approved, a PCORI staff member will coordinate arrangements to begin
 budgetary review and contracting negotiations.
- To select high-quality patient-centered projects, PCORI's Engagement and Contract Management and Administration teams and internal and external subject matter experts (as necessary) will review all applications.

Review Criteria

- Program Fit
- Project Plan and Timeline
- Qualifications of the Project Lead, Personnel, and Organizational Capabilities
- Patient and Stakeholder Engagement Plan and Collaborators
- Past Performance
- Budget/Cost Proposal