



Expanding Access to Engagement Awards: Challenges and Opportunities for Small Organizations

Prepared by the Engagement Awards Team

May 2021

Table of Contents

Goals	3
Key Findings	4
Engagement Awards: What is working.....	4
Barriers.....	5
Recommendations	5
Final Product Ideas.....	6
Appreciation.....	6

Goals

The Eugene Washington PCORI Engagement Award program is committed to continual improvement and ensuring that the program is accessible to all organizations, including small organizations that may not have research, particularly patient-centered outcomes research/comparative clinical effectiveness research (PCOR/CER) experience, infrastructure, funds, or staff capacity to produce competitive letters of intent (LOIs) and proposals and/or implement the size and scope of projects typically awarded through current Engagement Awards funding opportunities.

As part of this commitment, the Engagement Awards team conducted 13 interviews in April and May 2021 to solicit feedback from current and previous Engagement Awardees and stakeholders. The goals of the interviews were to:

- Elicit input from stakeholders, including those with previous experience related to the PCORI Engagement Awards application and award lifecycle.
- Assess challenges and other critical barriers that stakeholders may have experienced during that process.
- Identify potential solutions to ensure that the PCORI Engagement Award program is equitably accessible to all, including small organizations and investigators who are new to PCOR/CER.

A public panel discussion will be held on June 2, 2021 for interviewees to respond to the findings of the interviews. The recording will be posted to the PCORI website after the event. The goals of the public panel are to:

- Share broad themes identified during the interviews.
- Provide an opportunity for interviewees to respond to the findings and continue the discussion as a group.

Feedback from both the stakeholder interviews and the public panel discussion will inform future considerations by PCORI to refine the Engagement Award program.

Interview Questions:

The following questions were asked during the interviews to identify areas of opportunity for improving the program, potentially expanding it to reach broader groups of stakeholders more effectively and equitably and highlighting the tools and mechanisms that may better support them in successfully applying for Engagement Awards funding.

Section 1: Background Information

- Tell us a little bit about yourself. What organization do you work for? What type of organization is it? What is your previous experience with research? PCOR/CER?

Section 2: Experience with PCORI EA funding

- If you have applied for Engagement Awards funding before, what was your experience? Do you recall what you found to be most challenging? Do you recall any aspects of the process that were easier or more intuitive or user-friendly?

Section 3: Technical Assistance

- What types of technical assistance would be helpful as you move through the PCORI Engagement Awards application and award process?

Section 4: Determining Success of an Engagement Award from the perspective of a potential awardee

- At the end of a PCORI Engagement Award, what are ideal final deliverables, products or best outcomes for your organization/health topic area/stakeholder groups?

Key Findings

Key findings were organized into two major themes: (a) components of the Engagement Awards that are currently working and (b) barriers.

Engagement Awards: What is working

Funding: All participants acknowledged the role that PCORI plays in supporting engagement in research and recognize its utility in engaging populations that otherwise would not be participating in the research process.

Communication with PCORI: Most participants were pleased with the communication offered by PCORI. For example, many participants indicated that conversations with Program Officers and PCORI staff throughout the entire project period (from letter of intent program fit calls to check in calls) were helpful. The PCORI helpdesk response time was also indicated as helpful by some participants.

Support: Support offered by the Engagement Awards team was also indicated as helpful during the award process. For example, some participants mentioned the flexibility of the Engagement Awards team (especially during COVID-19) as well as structure offered by existing materials (milestone/deliverable tables and expectations of reports due on time) as useful tools to keep the project on track during the award period.

Barriers to Engagement Awards

Most awardees noted that a **lack of awareness** of PCORI Engagement Awards is a major barrier to reaching those who might be interested in applying. It was noted that PCORI tends to be a known entity in research institutions and increasing awareness would broaden PCORI's scope to reach other potential applicants.

All awardees mentioned that **clarity and accessibility** around what the Engagement Award program funds is paramount. For example, an accessible definition of PCOR/CER would be helpful as well as a clear connection to *why* engagement in PCOR/CER is important for research. Other barriers mentioned included: lack of clarity around how PCOR and Community-based participatory research (CBPR) are different with regard to research approach and understanding the difference between research and research support.

Many awardees also noted the **administrative burden** the application process places on smaller organizations. Participants noted, for example, the amount of time that it takes to put together an application and a lack of understanding, or less experience, regarding how to execute service agreements and sub-contracts.

The **PCORI website and portal** were also described by some participants as difficult to navigate.

Recommendations

The Engagement Awards team asked questions to help understand how processes can be improved to ensure PCORI funding mechanisms are accessible for all organizations to participate as stakeholders in PCOR/CER. The following ideas were mentioned as potential technical assistance that would be helpful for applicants and awardees.

Mentorship was mentioned by many participants as a way for new applicants and new awardees to learn from and with those who have gone through the Engagement Awards process. Participants suggested that mentorship between former and current awardees would have been helpful during the application process and during the implementation of the award. One participant also mentioned providing discrete funding for mentors as Technical Experts.

Participants suggested offering more **flexible opportunities** to obtain technical assistance, by expanding the type of allowable expenses within an award budget or through a PCORI-contracted organization. Topics for these types of flexible opportunities include: grant/application writing, data analysis, sustainability (targeted bridge funding), technical experts, and continued scholarships for the annual meeting and other ways to engage with PCORI.

Some participants brought up **matchmaking** as a way for awardees to engage with research partners, share information, and connect to groups doing similar work to build a network of engaged researchers.

All participants mentioned improving the **accessibility of materials** that PCORI provides to applicants and awardees. The materials mentioned included the funding announcements, key definitions, and the letter of intent online template. Participants also suggested that PCORI provide more education to applicants to ensure the materials are accessible.

Additional resources such as step-by-step tutorials and checklists were also recommended by some participants as potential areas of technical assistance. These tutorials/checklists could be used for LOI development, budget development, the creation of the workplan, and the development of milestones/deliverables (outputs). Some participants mentioned that better or increased communications with Contracts Management would be helpful as well as improved accessibility to the PCORI online portal.

Final Product Ideas

At the end of a PCORI Engagement Award, PCORI would like to know what final deliverables or outcomes would best support the continuation of engagement in PCOR/CER.

Most participants mentioned **replicable resources** such as toolkits, infographics, videos, and trainings as outputs. Almost all participants mentioned sustainability in the form of **a strategic plan and/or research roadmap** to outline the future of the organization with engagement in research.

Appreciation

The Engagement Awards team would like to thank the following individuals for participating in the interviews and contributing their perspectives and expertise:

Scott Berns, President and CEO, National Institute for Children's Health Quality (NICHQ), and Co-founder, The Progeria Research Foundation (PRF)

Jen Brown, Co-director/Co-founder, Alliance for Research in Chicagoland Communities at Northwestern University

Laverne Morrow Carter, President, Research, Education and Social Solutions, Inc. (REESSI)

Crispin Goytia-Vasquez, Program Manager, Icahn School of Medicine at Mount Sinai and Patient/Caregiver Principal Investigator for the INSIGHT network

Libby Hoy, Founder/CEO, PFCCpartners

Alma McCormick, Executive Director, Messengers for Health

Fatema Mirza, Executive Director, Worry Free Community

Kasha Morris, Secretary and Co-founder, Tango2 Research Foundation

Al Richmond, Executive Director, Community-Campus Partnerships for Health

Deneen Robinson, Policy Director, The Afiya Center

Brendaly Rodriguez, Director, Chula Vista Community Collaborative

Luke Smith, Executive Director, El Futuro

Regina Greer-Smith, President, Healthcare Research Associates, LLC