

Eugene Washington PCORI Engagement Awards

Expanding Access to Engagement Awards:
Public Panel Discussion of Challenges and
Opportunities for Small Organizations

June 2, 2021
4–5 pm ET

Agenda

- **Welcome and Introductions**
 - Amanda Barbeau, Senior Program Associate, Science
 - Greg Martin, Acting Chief Engagement and Dissemination Officer
 - Karen Martin, Program Director, Engagement Awards
- **Goals**
 - Courtney Clyatt, Senior Program Officer, Engagement Awards
- **Presentation of Findings and Discussion**
 - Kate Boyd, Program Officer, Engagement Awards
- **Final Comments**
- **Wrap Up**

Panelists



- **Scott Berns**, President and CEO, National Institute for Children's Health Quality, and Co-founder, The Progeria Research Foundation
- **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.
- **Crispin Goytia-Vasquez**, Program Manager, Icahn School of Medicine at Mount Sinai and Patient/Caregiver Principal Investigator for the INSIGHT network
- **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
- **Regina Greer-Smith**, President, Healthcare Research Associates, LLC

Eugene Washington PCORI Engagement Award Program

- Support projects to build a community of patients and other stakeholders equipped to participate as partners in patient-centered outcomes research/comparative clinical effectiveness research (PCOR/CER), as well as serve as channels to disseminate PCORI-funded study results
- Funding to support engagement in, and with, research, not to conduct research



Our Goals



- Elicit input from stakeholders—most with previous experience related to the PCORI application and contract lifecycle—with a focus on the Engagement Awards
- Assess challenges and other critical barriers that stakeholders may have experienced during the application and contract lifecycle
- 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

Key Findings



Engagement Awards : What is Working



Funding

- Supports engagement in research
- Utility in engaging populations not currently participating in research process

Communication with PCORI

- Conversations with Program Officers/PCORI Staff
 - Throughout the entire project period (pre-award, implementation, post-award)
- PCORI helpdesk response time

Engagement Award Support

- Flexible (e.g., COVID-19/rapid cycle announcements)
- Structured guidance and tools throughout award process (e.g., milestones/deliverables template; expectations of deliverables due on time)

Barriers to Engagement Awards



- Lack of **awareness** of PCORI EA awards
 - PCORI roadshows, advertising, innovative approaches to share PCORI EA mission and vision
 - PCORI is a known entity in research institutions; broaden the scope to encourage other applicants by increasing awareness
- Lack of **clarity** around what PCORI EA funds
 - Understanding the difference between PCOR versus community-based participatory research
 - Research versus research support
 - Clarify definition of PCOR/CER and why engagement in PCOR/CER is important
- **Administrative burden**
 - Time demand to put together an application
 - Administrative burden on community-based organizations
 - Understanding how to execute service agreements and subcontracts
- **PCORI website**
 - Can be difficult to navigate and can be intimidating
 - Links to FAQs

Discussion: Barriers

- WHAT ARE YOUR REACTIONS TO THESE FINDINGS?
- WHAT RESONATES WITH YOU?
- IN YOUR VIEW, WHAT IS MOST IMPORTANT FOR PCORI TO KNOW?

Recommendations



Recommendations

- Mentorship
- Flexible Funding Opportunities
- Matchmaking
- Accessibility of Materials
- Additional Resources
 - Step-by-step tutorials/checklists

Discussion: Recommendations

- WHAT ARE YOUR REACTIONS TO THESE FINDINGS?
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Final Product Ideas

- Replicable work
 - Toolkits, infographics, videos, training
- Strategic plan and/or research roadmap to outline the future of the organization and engaged research (e.g., 1-, 3-, 5-year plans)

Discussion: Final Product Ideas

- WHAT ARE YOUR REACTIONS TO THESE FINDINGS?
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Thank You



Contact Information



- Eugene Washington PCORI Engagement Awards
- <https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards>
- ea@pcori.org
- 202-370-9312