

Towards Patient-Centered Outcomes Research

PCORI and PCOR

William Lawrence, MD, MS

Senior Clinical Advisor

Office of the Chief Engagement and Dissemination

Officer



About Us

- An independent research institute authorized by Congress in 2010 and governed by a 21-member Board of Governors 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






Our Mission and Strategic Goals



PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from **research guided by patients, caregivers, and the broader healthcare community.**

Our Strategic Goals:

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

We Fund Comparative Clinical Effectiveness Research (CER)



- Generates and synthesizes evidence comparing benefits and harms of at least two different methods to prevent, diagnose, treat, and monitor a clinical condition or improve care delivery
- Measures benefits in real-world populations
- Describes results in subgroups of people
- Helps consumers, clinicians, purchasers, and policy makers make informed decisions that will improve care for individuals and populations
- Informs a specific clinical or policy decision

Note: We do not fund cost-effectiveness research

Adapted from Initial National Priorities for Comparative Effectiveness Research, Institute of Medicine of the National Academies

We Fund Patient-Centered Outcomes Research



PCOR is a relatively new form of CER that....

- Considers patients' needs and preferences, and the outcomes most important to them
- Investigates what works, for whom, under what circumstances
- Helps patients and other healthcare stakeholders make better-informed decisions about health and healthcare options



What We Mean By...

“Patient-centeredness”

- The project aims to answer questions or examine outcomes that matter to patients within the context of patient preferences
- Research questions and outcomes should reflect what is important to patients and caregivers



“Patient and stakeholder engagement”

- Patients are partners in research, not just “subjects”
- Active and meaningful engagement between scientists, patients, and other stakeholders
- Community, patient, and caregiver involvement already in existence or a well-thought-out plan

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



Our Engagement Rubric— A Valuable Resource



Provides practical guidance to applicants, merit reviewers, awardees, and engagement/program officers on effective engagement in research

- **Planning the Study:** How patient and stakeholder partners will participate in study planning and design
- **Conducting the Study:** How patient and stakeholder partners will participate in the conduct of the study
- **Disseminating the Study Results:** How patient and stakeholder partners will be involved in plans to disseminate study findings and ensure that findings are communicated in understandable, usable ways
- **PCOR Engagement Principles:** Reciprocal relationships, co-learning, partnership, trust, transparency, honesty

Building a PCOR Community Nationwide



Our Eugene Washington PCORI Engagement Awards and Pipeline to Proposal Awards are not research awards but opportunities to build patient-centered outcomes research capacity.

Number of awards:

384*

**Amount
awarded:**

\$76 million

States with funded projects:

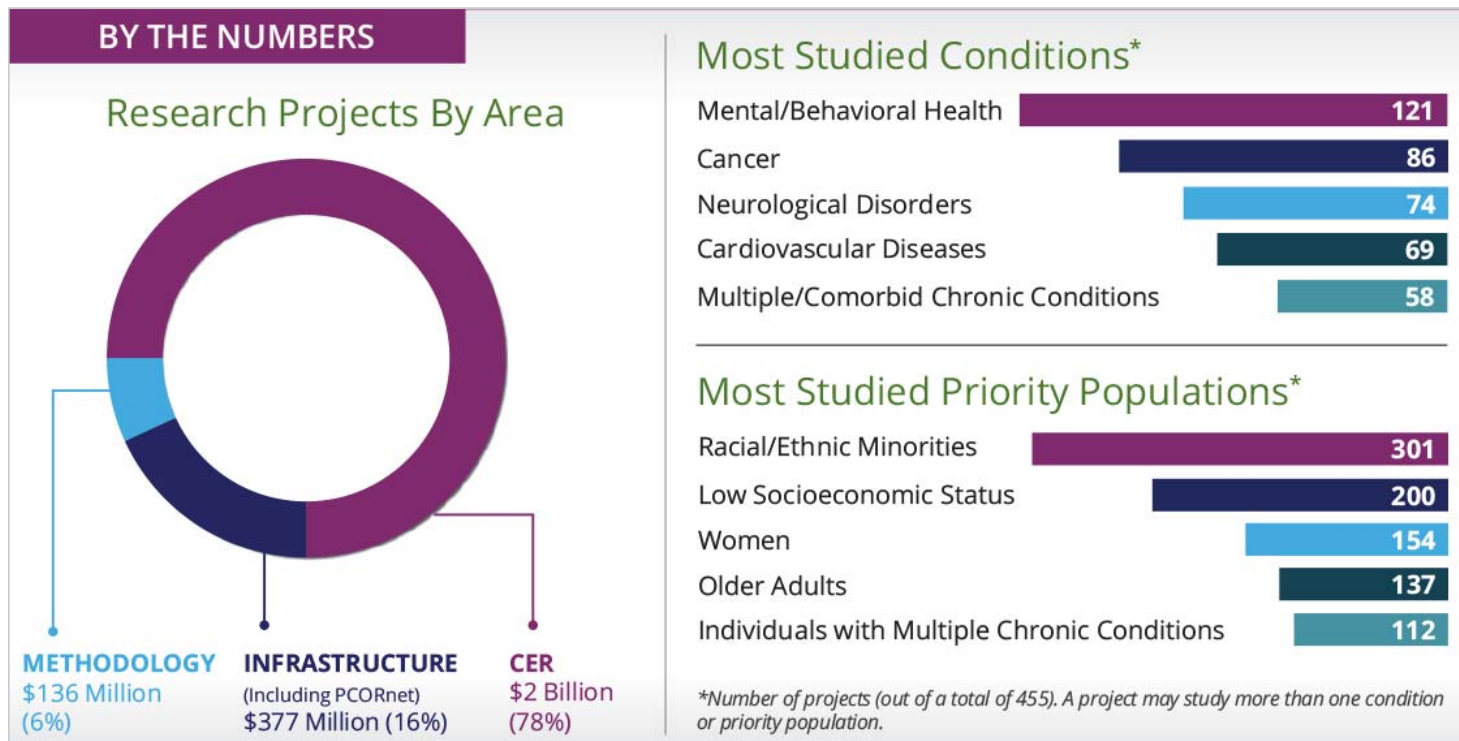
46

**(plus DC and
Puerto Rico)**

These awards support projects that promote meaningful involvement by patients, caregivers, clinicians, and other healthcare stakeholders in comparative clinical effectiveness research (CER).

*AS OF MAY 2019

About Our Research Portfolio



AS OF MAY 2019

Assessment of Prevention, Diagnosis, and Treatment Options



Seeks to fund research that:

- Compares the effectiveness of two or more options that are known to be effective but have not been adequately compared in previous studies
- Among compared population groups, investigates factors that account for variation in treatment outcomes that may influence those outcomes

Example – Anticoagulation for Atrial Fibrillation



RESEARCH

Real world effectiveness of warfarin among ischemic stroke patients with atrial fibrillation: observational analysis from Patient-Centered Research into Outcomes Stroke Patients Prefer and Effectiveness Research (PROSPER) study

Ying Xian,¹ Jingjing Wu,¹ Emily C O'Brien,¹ Gregg C Fonarow,² DaiWai M Olson,³ Lee H Schwamm,⁴ Deepak L Bhatt,⁵ Eric E Smith,⁶ Robert E Suter,⁷ Deidre Hannah, Brianna Lindholm, Lesley Maisch, Melissa A Greiner,¹ Barbara L Lytle,¹ Michael J Pencina,¹ Eric D Peterson,¹ Adrian F Hernandez¹

BMJ 2015;351:h3786.

Study Outcomes

12,552 STROKE PATIENTS
with **ATRIAL FIBRILLATION**



11,039 discharged on warfarin



1,513 discharged with no anticoagulation

Those who took warfarin as prescribed averaged



48 more days at home



13% lower risk of major adverse cardiovascular events

in the two years after their stroke

Contact Information

William Lawrence, MD, MS – Senior Clinical Advisor, OCEDO

 202-370-9415

 wlawrence@pcori.org

 www.pcori.org

 @pcori

 /PCORInstitute

 PCORI

 /pcori

Thank You!

