The Patient-Centered Outcomes Research Institute – Who We Are and What We Fund

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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

How is Our Work Different?

• We fund research on which care options work, for whom, under which circumstances.
• We focus on answering questions most important to patients and those who care for them.
• We aim to produce evidence that can be easily applied in real-world settings.
• We engage patients, caregivers, clinicians, insurers, employers and other stakeholders throughout the research process.
• This makes it more likely we’ll get the research questions right and that the study results will be useful and taken up in practice.
Who Are Our Stakeholders?

- Payers
- Clinicians
- Caregivers/Family Members
- Purchasers
- Policy Makers
- Industry
- Training Institutions
- Hospitals/Health Systems
- Patients/Consumers
- Patient/Caregiver Advocacy Organizations
- Policy Makers

Our Research Focus

We Fund Comparative Clinical Effectiveness Research

- 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

We Fund Research That...

Focuses on high-priority conditions:

• Affecting large numbers of people across a range of population
• Placing a heavy burden on individuals, families, specific populations, and society
• Including rare diseases, which are difficult to study

We Fund Research That...

Pays particular attention to specific populations:

• Racial and ethnic minorities
• Older adults
• Low-income
• Residents of rural areas
• Women
• Children
• Individuals with special healthcare needs, including individuals with disabilities, individuals with multiple chronic diseases, and individuals whose genetic makeup affects their medical outcomes
• Patients with low health literacy/numeracy and limited English proficiency
• Lesbian, gay, bisexual, transgender (LGBT) persons
• Veterans and members of the armed forces and their families
We Also Work to Improve Research Methodology

In any study, methods matter. That’s why we’ve developed methodology standards that patient-centered CER should follow, at a minimum.

Methodology Standards: 11 Broad Categories

- Formulating Research Questions
- Patient-Centeredness
- Data Integrity and Rigorous Analyses
- Preventing/Handling Missing Data
- Heterogeneity of Treatment Effects
- Data Networks
- Data Registries
- Adaptive and Bayesian Trial Designs
- Causal Inference
- Studies of Diagnostic Tests
- Systematic Reviews

Snapshot of Funded Projects

Number of projects: 582
Amount awarded: $1.68 billion
Number of states where we are funding research: 41 (plus the District of Columbia)

As of March 2017

About Our Research Portfolio

As of March 2017
The National Patient-Centered Clinical Research Network (PCORnet)

- Improve the nation’s capacity to conduct clinical research faster, more efficiently and less expensively, with greater power
- Establish a large, highly representative, national patient-centered clinical research network with a focus on conducting randomized and observational comparative studies
- Support a learning US healthcare system, which would allow for large-scale research to be conducted with greater accuracy and efficiency within real-world care-delivery systems

Better Research through Engagement

Engagement as a Path to Useful, High-Quality Research

Topic Selection and Research Prioritization

Proposal Review; Design and Conduct of Research

Dissemination and Implementation of Results

Evaluation
Eugene Washington PCORI Engagement Awards

- Knowledge Awards increase knowledge about how consumers of healthcare information view, receive, and make use of PCOR and CER.
- Training and Development Awards build capacity for participating in PCOR and CER and create ways to connect patients, caregivers, clinicians, and other healthcare stakeholders with the research community.
- Dissemination Awards develop and strengthen channels for disseminating and implementing PCOR and CER findings.
- PCOR/CER Meeting and Conference Support Awards provide organizations with funding for meetings and conferences that align with PCORI’s mission and aim to facilitate expansion of PCOR and CER.

Awards of up to $250,000 per project, up to two years in duration

Getting the Word Out

Dissemination & Implementation (D&I) of Results

We have started a strong effort to encourage the healthcare community’s use of important results from the research that we fund.

We are committed to
- Enhancing awareness of evidence useful to people and organizations as they make health decisions
- Speeding the integration of this evidence into practice
Peer Review of Completed Research

• **Scientific Integrity**
  - By evaluating the integrity of the data and whether the data adequately support the conclusions.

• **Adherence to Methodology Standards**
  - The Awardee will report how the study incorporates the Standards.

• **Relevance and Usefulness**
  - Ask patient and stakeholder reviewers to speak to the usefulness of the results to people like them.

PCORI Research Investments in Child & Adolescent Behavioral Health

Randomized Comparison of Evidence-Based Protocols for Adolescents with ADHD in Specialty Care: Behavioral Only versus Integrated Behavioral and Medication Interventions

Engagement
• The study involves regular consultation with researchers, youth, family advocates (including school officials), therapists and supervisors from counseling centers, and families who have an adolescent with ADHD

Potential Impact
• Could improve practice because treatment protocols could be rapidly shared with therapists, treatment programs, and school mental health counselors without the need for much additional training

Methods
Randomized controlled trial

Aims to compare the effectiveness, in outpatient behavioral services, of academic interventions only versus integrated (academic plus medication) interventions for adolescents with ADHD. The study will compare the effects of these two treatment options on counseling attendance, medication use, behavioral problems, and quality of life.

Aaron Hogue, PhD
National Center for Addiction & Substance Abuse
New York, NY

Assessment of Prevention, Diagnosis, and Treatment Options, awarded September 2014
### Communication to Improve Shared Decision Making in ADHD Care

**Engagement**
- Caregiver and stakeholder partners have been research team members in the development of this study and will continue to provide input on the study.

**Potential Impact**
- This study will expand our evidence for effective electronic and in-person communication strategies for children with ADHD and their caregivers, teachers, and clinicians.

**Methods**
- Randomized controlled trial

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### Padres Electivos (Parent Activation): Skills Latina Mothers Use to Get Healthcare for Their Children

**Engagement**
- Parent focus groups on cultural influences and barriers to care inform intervention design, and parents provide feedback on the first iteration of the intervention.

**Potential Impact**
- Could change practice by providing evidence of the effectiveness of a culturally sensitive, advocacy-skills intervention to build activation among Latino families and improve use of services for their children with mental health conditions.

**Methods**
- Mixed methods approach

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### A Community-Based Executive Function Intervention for Low-Income Children with ADHD and ASD

**Engagement**
- Parent and teacher input throughout the project ensures that the treatments are acceptable to families and schools.

**Potential Impact**
- Could change practice by being the first evidence- and community-based executive function treatment for this group of school-age children that targets skills to make them more successful in their everyday lives and communities.

**Methods**
- Qualitative and quantitative methods
More projects

• The Family VOICE Study: A Randomized Trial of Family Navigator Services Versus Usual Care for Young Children Treated with Antipsychotic Medication (PI: Reeves)
• Comparative Effectiveness of State Psychotropic Oversight Systems for Children in Foster Care (PI: Crystal)
• Using Telehealth to Deliver Developmental, Behavioral, and Mental Health Services in Primary Care Settings for Children in Underserved Areas (Coker)
• Improving Patient-Centered Outcomes among Overweight and Obese Youth with Bipolar Spectrum Disorders Treated with Second Generation Antipsychotics (SGAs) (PI: DeBello)
• Evaluation of Parent-Based Interventions to Support Children after Traumatic Injury (PI: Ramirez)

How to Get Involved

Become a Merit Reviewer
• Review applications for research and attend review meetings

Become a Peer Reviewer
• Review reports on completed projects

Join an Advisory Panel
• Provide recommendations and advice about research and engagement

Become an Ambassador
• Share information about PCORI with others

Provide Input
• Respond to calls for public comment
• Suggest a patient-centered research question

Contact Us

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Thank You

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