Latino Roundtable Discussion

July 23, 2013
9:00 AM – 3:00 PM
Housekeeping

- Webinar participants can provide input via the webinar “chat” feature or via e-mail (latinoroundtable@pcori.org).

- Submitted questions will be discussed during the public comment periods at 11:45 AM (ET) and 2:15 PM (ET).

- Additional input and comments are welcome through Friday, July 26, at 5 PM (ET) via e-mail at latinoroundtable@pcori.org.
Welcome and Overview of PCORI

Anne C. Beal, MD, MPH
Deputy Executive Director and Chief Officer for Engagement
Latino Roundtable
July 23, 2013
About Us

An independent non-profit research organization authorized by Congress as part of the 2010 Patient Protection and Affordable Care Act (PPACA).

Committed to continuously seeking input from patients and a broad range of stakeholders to guide its work.
Our Mission and Vision

Mission
The Patient-Centered Outcomes Research Institute (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.

Vision
Patients and the public have the information they need to make decisions that reflect their desired health outcomes.
PCORI’s Board of Governors Represents the Entire Healthcare Community

PCORI Board of Governors, March 2012, in Baltimore, MD
"The purpose of the Institute is to assist patients, clinicians, purchasers, and policy makers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis that considers variations in patient subpopulations and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of medical treatments, services.

Our Core Duties

- Establish national research priorities
- Establish and carry out a research agenda
- Develop and update methodological standards
- Disseminate research findings
## National Priorities for Research and Research Agenda

<table>
<thead>
<tr>
<th>Assessment of Prevention, Diagnosis, and Treatment Options</th>
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<tr>
<td>• Comparisons of alternative clinical options to support personalized decision making and self-care</td>
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<td>• Identifying patient differences in response to therapy</td>
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<td>• Studies of patient preferences for various outcomes</td>
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<tr>
<th>Improving Healthcare Systems</th>
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<td>• Improving support of patient self-management</td>
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<td>• Focusing on coordination of care for complex conditions and improving access to care</td>
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<td>• Comparing alternative strategies for workforce deployment</td>
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<th>Communication and Dissemination Research</th>
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<tr>
<td>• Understanding and enhancing shared decision making</td>
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<td>• Alternative strategies for dissemination of evidence</td>
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<td>• Exploring opportunities to improve patient health literacy</td>
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<tr>
<th>Addressing Disparities</th>
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<td>• Understanding differences in effectiveness across groups</td>
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<tr>
<td>• Understanding differences in preferences across groups</td>
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<tr>
<td>• Reducing disparities through use of findings from patient-centered outcomes research (PCOR)</td>
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<tr>
<th>Accelerating PCOR and Methodological Research</th>
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<tr>
<td>• Improving study designs and analytic methods of PCOR</td>
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<tr>
<td>• Building and improving clinical data networks</td>
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<td>• Methods for training researchers and patients to participate in PCOR</td>
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<tr>
<td>• Establishing methodology for the study of rare diseases</td>
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Criteria for Research, from the PPACA

- Impact on Health of Individuals and Populations
- Addresses Current Gaps in Knowledge/Variation in Care
- Patient-Centeredness
- Improvability through Research
- Impact on Healthcare System Performance
- Rigorous Research Methods
- Inclusiveness of Different Populations
- Potential to Influence Decision Making
- Efficient Use of Research Resources
What Makes PCORI Funding Different?

- User-friendly announcements to encourage broader range of applicants
- Patient and stakeholder engagement plan
- Dissemination and implementation assessment
- Reproducible and transparent research plan
- PCORI criteria outlined by statute
- Rigorous methodology standards
PCORI Does Not Fund Research That….

- Studies cost-effectiveness
- Studies causes of disease
- Does not measure patient-centered outcomes
- Does not compare approaches to improving patient-centered outcomes
- Studies questions that have already been answered or are in the process of being answered
Figure 1: Traditional Process

Investigator-Generated Research Just One Part of the Process

- PCORI issues broad funding announcements
- Researchers partner with stakeholders to generate questions
- Researchers, stakeholders apply review criteria in their applications
- Peer review prioritizes applications by level of alignment with criteria

Diverse Research Portfolio answering key questions for patients and clinicians
PFA Cycle I and II Awards

Cycle I Awards
25 projects in 17 states
$40.7 million (over 3 years)

Cycle II Awards
51 projects in 20 states
$88.6 million (over 3 years)
Funded Projects

Pilot Projects

Addressing Mental Health Needs of Rural African Americans

Assessment of Prevention, Diagnosis, and Treatment Options

Cycle II: Generating Critical Patient-Centered Information for Decision Making in Localized Prostate Cancer
Cycle II: Treatment Preference and Patient-Centered Prostate Cancer

Improving Healthcare Systems

Cycle II: Improving Healthcare Systems for Access to Care and Efficiency by Underserved Patients

Communication and Dissemination Research

Cycle I: Extension Connection: Advancing Dementia Care for Rural and Hispanic Populations

Addressing Disparities

Cycle I: Long-Term Outcomes of Community Engagement to Address Depression Outcomes Disparities
Cycle II: Padres Efectivos (Parent Activation): Skills Latina Mothers Use to Get Healthcare for Their Children
PCORI’s First Targeted Research Topics

- Identified several high-priority, stakeholder-vetted topics for targeted PFAs
- Jumpstart PCORI’s long-term topic generation and research prioritization effort
- Leverage stakeholder input from before PCORI’s existence
- Allow us to build on our engagement work

Research Topic:

Treatment of severe asthma in African Americans and Hispanics/Latinos

Letter of Intent Due: 8/1/13

Maximum Budget: Year 1, up to $500,000 total cost; Year 2, up to $1.75 million total cost; Year 3, up to $1.75 million total cost

Maximum Project Period: 3 years
PCORI’s Two Paths to Funding Research

Figure 2: Unique Process

Patient/Stakeholder-Led Approach

- PCORI and stakeholders generate and prioritize questions based on review criteria
- PCORI issues specific, funding announcements for highest priority topics
- Researchers and stakeholders develop responsive proposals
- Peer review prioritizes applications by level of alignment with criteria

Diverse Research Portfolio answering key questions for patients and clinicians
Introductions
Patient-Centered Outcomes Research Opportunities

9:45 AM – 10:30 AM
Addressing Disparities Program

Adaeze Akamigbo, PhD, MPP
Senior Program Officer, Addressing Disparities
July 23, 2013
Addressing Disparities: Mission Statement

PCORI’s Vision, Mission, Strategic Plan

Program’s Mission Statement
To reduce disparities in healthcare outcomes and advance equity in health and health care

Program’s Guiding Principle
PCORI is not interested in studies that describe disparities; instead, we want studies that will identify best options for eliminating disparities.
Addressing Disparities: Program Goals

Identify Research Questions
- **Identify** high-priority research questions relevant to reducing long-standing gaps in disparate populations

Fund Research
- **Fund research** with the highest potential to address healthcare disparities

Disseminate Best Practices
- **Disseminate** and facilitate the adoption of research and best practices to reduce healthcare disparities
## Advisory Panel Prioritized Topics

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<thead>
<tr>
<th>Rank</th>
<th>Short Name</th>
<th>Topic</th>
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<tbody>
<tr>
<td>1</td>
<td>Health communication associated with competing treatments</td>
<td>Compare the effectiveness of clinician/patient health communication models on improving outcomes in minority populations, patients with low literacy and numeracy, people with limited English proficiency, underserved populations, and people with disabilities.</td>
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<td>2</td>
<td>Heart attacks among racial and ethnic minorities</td>
<td>Compare the effectiveness of health interventions (including place-based interventions in community health centers) to enhance the “Million Hearts” program and reduce major vascular events among the economically disadvantaged, including racial and ethnic minorities and rural populations.</td>
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<tr>
<td>3</td>
<td>Hypertension in minorities</td>
<td>Compare the effectiveness of different delivery models (e.g., home blood pressure monitors, utilization of pharmacists or other allied health providers) for controlling hypertension in racial minorities.</td>
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<tr>
<td>4</td>
<td>Interventions for improving perinatal outcomes</td>
<td>Compare the effectiveness of multi-level interventions (e.g., community-based, health education, usual care) on reducing disparities in perinatal outcomes.</td>
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<tr>
<td>5</td>
<td>Reduce lower extremity amputations in minorities</td>
<td>Compare the effectiveness of interventions on reducing disparities in lower extremity amputations in racial and ethnic minorities.</td>
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Addressing Disparities

**Program Goals**
- Identify high-priority research questions
- Fund research that will have an impact
- Disseminate/ implement best/ promising practices

**Impact/Outcomes**
- Tell a comprehensive story about our effort and impact
- Identify best/ promising practices for research and implementation
- Identify research outcomes that translate to improved health outcomes

**PCORI Goals**
- Increase information
- Speed implementation
- Influence research

Ongoing Internal and External Programmatic Evaluation
Addressing Disparities: Projects to Date

• 14 studies and growing just for broad announcements
• Range of projects will grow and change over the next year
Addressing Disparities: Broad Funding Announcements

14 studies funded under the Addressing Disparities program

- Long-term outcomes of community engagement to address depression outcomes disparities, UCLA, Los Angeles, CA
- Comparative risks and benefits of gender reassignment therapies, Emory, Atlanta, GA

14 other studies address disparities issues in other program areas

- Patient-centered trauma treatment for PTSD and substance abuse: Is it an effective treatment option? University of New Mexico, NM
- Extension Connection: Advancing dementia care for rural and Hispanic populations, University of Iowa, Iowa City, IA
Addressing Disparities: Targeted Funding Announcements

PCORI Funding Announcement: Treatment Options for African Americans and Hispanics/Latinos with Uncontrolled Asthma

<table>
<thead>
<tr>
<th>Action</th>
<th>Date</th>
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<tbody>
<tr>
<td>Funding Announcement Release</td>
<td>Tuesday, June 18, 2013</td>
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<tr>
<td>PCORI Online System Opens</td>
<td>Monday, July 1, 2013</td>
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<td>Applicant Town Hall Session (Webinar)</td>
<td>2:00 to 5:00 p.m. (ET) Tuesday, July 9, 2013</td>
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<tr>
<td>Letter of Intent Deadline</td>
<td>5:00 p.m. (ET) Thursday, August 1, 2013</td>
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<tr>
<td>Application Deadline</td>
<td>5:00 p.m. (ET) Wednesday, September 18, 2013</td>
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<tr>
<td>Merit Review</td>
<td>October to December 2013</td>
</tr>
<tr>
<td>Awards Announced</td>
<td>December 2013</td>
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Group Photo and Break

10:30 AM – 11:00 AM
Health and Healthcare Issues in the Latino Community

11:00 AM - 11:45 AM

Public Comment at 11:45 AM
LUNCH
12 Noon - 12:30 PM
Health and Healthcare Issues in the Latino Community
(continued)

12:30 PM – 1:00 PM
Immediate Engagement Opportunities at PCORI

Susan Sheridan, MBA, MIM
Director, Patient Engagement
Latino Roundtable
Patient and Stakeholder Engagement in Patient-Centered Outcomes Research

Advise Us as to What PCORI Should Study:
- What questions are most important? (research prioritization)
- What outcomes should be studied? (topic generation)

Tell Us How We Are Doing
- How can we improve on what we are doing and how we are doing it?

Review Proposals and Partner in Research
- Review research proposals for impact and patient-centeredness
- Participate in conducting research

Help Us Share the Findings
- How do we best communicate important research findings?
Engagement Workshops and Regional Events

Workshops

- **Transforming Patient-Centered Research: Building Partnerships and Promising Models**
  - Helped to bring together consumers, patients, caregivers, advocacy groups, researchers, and other stakeholders in an effort to start building a patient-centered research community
  - Held October 27–28, 2013, in Washington, DC

- **What Should PCORI Study? A Call for Topics from Patients and Stakeholders**
  - Helped to bring together the broad range of healthcare stakeholders to share and discuss important future topics of patient-centered outcomes research
  - Held December 4, 2012, in Alexandria, VA

Regional Events

- **The Power of Partnership in Research: Improving Healthcare Outcomes in Rural Settings**
  - Helped to build a patient-centered research community in the central states
  - Held March 9–10, 2013, in Wichita, KS

- **Upcoming: The Power of Partnership in Research: Improving Healthcare Outcomes in Underserved Communities**
  - August 31 – September 1, 2013, in Memphis, TN

Upcoming workshops posted at: [http://www.pcori.org/events](http://www.pcori.org/events)
Advisory Panels

- Included clinicians, researchers, patients, and other experts with appropriate experience and knowledge to help PCORI achieve its goals.

- Meaningful patient engagement in:
  - Research activities
  - Identifying research priorities and topics
  - Conducting randomized clinical trials
  - Performing special research studies

- First training was held April 19–20 in Washington, DC

- Second Patient Engagement Meeting: September 2013 in Washington, DC
Suggest a Research Question

We want to know what healthcare question you may be facing.

Your input can help us refine our research agenda.

Suggest a Patient-Centered Research Question

Every day, patients and people who care for them must make healthcare decisions. They may have to choose between two or more options for preventing, diagnosing, or treating a health condition. Or, they might need to decide between doing, or not doing something. For these situations, the Patient-Centered Outcomes Research Institute (PCORI) was created. PCORI funds research to help patients make the best decisions about their health care.

We at PCORI want to know what health care question or decision you may be facing. We want to hear from you. Your input can help us refine our research agenda.

Whether you are a patient with a health condition, a caregiver for someone who needs care, or a researcher, we invite you to share your questions about options faced by patients. We also are interested in hearing about areas where we need to improve care for your patients, or as a researcher, we invite you to submit questions about options faced by patients, we also are interested in hearing about areas where we need to improve care delivery, address disparities in health care, or improve the communication of information. Please see PCORI's National Priorities for Research.

Suggesting a research question is the first step in a five-part process for funding. We will carefully consider each question and, along with patients, identify which ones we will study as part of our portfolio of patient-centered research.

This will be an ongoing feature on the PCORI website. So, please feel welcome to check back and suggest additional research questions in the future.

Is your question about a certain disease, behavior or health condition?

If yes, please name the disease, behavior or health condition. If no, leave blank and continue.
Become a Reviewer of Funding Applications

- PCORI invites professional and lay audiences to be reviewers of research applications
- Help us support research that will be both scientifically rigorous and truly patient-centered
- Learn more and apply online: www.pcori.org/get-involved/reviewers/
Become a PCORI Ambassador

- The Issue: The public is welcome to submit research questions, sign up to serve as reviewers for our funding applications, attend our engagement events, apply to be a advisory panelist or be involved as a research partner in one of our funded proposals.

- The Request: Attendees at our October Patient Workshop asked for a way to be more formally engaged with PCORI and stated that we had a room of “ambassadors,” if we choose to seize the opportunity.

- The Goal: To help PCORI raise awareness about PCOR and recruit patients, consumers, community members and other stakeholders to get involved in research.
Create PCOR Community
- Build a sense of community
- Increase the community’s knowledge of PCOR and PCORI
- Develop trust

Engage PCOR Community in Research
- Transcend from partners in care to partners in research
- Develop a well-informed, networked, PCOR-ready community

Disseminate and Implement Research Findings
- Identify and develop creative new pathways for dissemination and implementation
- Create trust, legitimacy, and uptake of PCORI’s research findings
Engagement Awards

Knowledge Awards
- Landscape reviews
- Background papers
- Efforts to share information on PCORI and PCOR
- Gaining knowledge of the current state of CER

Training and Development Awards
- Pipeline to Proposals
- Data Challenge
- Researcher Outreach
- Identification of best practices for engagement outreach

Implementation Awards
- Surveys and Evaluation
- Dissemination and Implementation
- Any project to promote PCORI's impact
Tier I Pipeline Awards (Up to $15,000 for 9 Months)

Available to individuals, consumer/patient organizations, clinician(s) or researcher(s) or a combination of the above to support:

- Community building
- Creation of structure and communication strategies
- Development of an understanding of PCORI and “research done differently”
Tier II Pipeline Awards
(Up to $25,000 for 1 Year)

Available to emerging research/non-research partnerships to support:

- Data network development
- Development of infrastructure
- Generation of research questions through community events, town hall meetings, etc.
Tier III Pipeline Awards
(Up to $50,000 for 1 Year)

Available to advanced research/non-research partnerships—including those who submitted PCORI proposals and were not funded—to support:

- PCORI research proposal (re)submission
- Research partnership skill development
Three Tiers

Tier 1 - Primarily patient and stakeholder applicants

Tier 2 - Researchers who unsuccessfully submitted a PFA and need to improve Patient Engagement Plan

Tier 3 - PCORI Funding Announcement

Or submissions to other PCOR/CER funders
Join Us at www.pcori.org
Discussion

Public Comment at 2:15 PM
Wrap-up

2:30 PM – 2:55 PM
Closing Remarks
Thank You for Your Participation