PCORI’s Role in Creating a Research Agenda to Reduce Disparities and Improve Health Outcomes

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Director, Addressing Disparities Program

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“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.

About PCORI

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

Committed to continuously seek 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 health care decisions, and improves health care delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care 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 Health Care Community

- Patients/consumers
- Caregivers
- Physicians, nurses and clinicians
- Hospitals and health systems
- Health plans
- Health services researchers
- State and federal health officials
- Pharmaceutical, device, and diagnostic manufacturers
- Private payers
- Employers
Patient-Centered Outcomes Research (PCOR) helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options.

“Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”

“What are my options and what are the potential benefits and harms of those options?”

“What can I do to improve the outcomes that are most important to me?”

“How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?”
What is Patient-Centered Research?

Does the proposed research compare the effects of treatment options that matter to patients?
- Are these realistic choices faced by patients or other decision-makers?

Does the research focus on outcomes of interest to patients and their caregivers?
- Outcomes of interest might include: health, health-related quality of life, functioning, symptoms, safety from medical harm, survival and satisfaction with care.
Engagement as a path to rigorous research

<table>
<thead>
<tr>
<th>Patients and Stakeholders</th>
<th>Tell Us What PCORI Should Study</th>
<th>Review Proposals and Partner in Research</th>
<th>Tell Us How We Are Doing</th>
<th>Help Us Share the Findings</th>
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<tbody>
<tr>
<td><strong>Tell Us What PCORI Should Study</strong></td>
<td>What questions are most important? (research prioritization)</td>
<td>Review research proposals for impact and patient-centeredness</td>
<td>How can we improve on what we are doing and how we are doing it?</td>
<td>How do we best communicate important research findings?</td>
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<td><strong>What outcomes should be studied? (topic generation)</strong></td>
<td>Participate in conducting research</td>
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From priorities to research patients can use
National Priority Areas

1. Addressing Disparities
2. Communication and Dissemination
3. Assessment of Prevention, Diagnosis, and Treatment Options
4. Improving Healthcare Systems
5. Infrastructure and Methods
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**.
2002 (IOM) Plenty of Evidence that Disparities Exist
ACA and Addressing Disparities

*Patient Protection and Affordable Care Act*

*March 23, 2010*

…identify national priorities for research, taking into account factors of disease incidence, prevalence, and burden in the United States (with emphasis on chronic conditions); **gaps in evidence in terms of clinical outcomes; practice variations; and health disparities in terms of delivery and outcomes of care**; the potential for new evidence to improve patient health, well-being, and the quality of care…

…review the extent to which research findings are used by healthcare decision makers, **the effect of the dissemination of such findings on reducing practice variation and disparities in health care**…

Evolution of Disparities Research

- From minority health to disparities in health; describing the problem

- Understanding the Causes
  - Social Determinants
  - Healthcare Determinants

- Intersection of Disparities and Quality

- Place Matters
Now What?

Time to move beyond describing the problem to eliminating disparities in health and health care.
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
Addressing Disparities Program Goal
### Conceptual Framework - Barriers and Mediators of Equitable Healthcare

#### Barriers
- **Personal/Family**
  - Acceptability
  - Cultural
  - Language/literacy
  - Attitudes, beliefs
  - Preferences
  - Involvement in care
  - Health behavior
  - Education/income
- **Structural**
  - Availability of appointments
  - How organized
  - Transportation
  - Financial
- **Health Status**
  - Mortality
  - Morbidity
  - Well-being
  - Functioning

#### Use of Services
- **Visits**
  - Primary care
  - Specialty
  - Emergency
- **Procedures**
  - Preventive
  - Diagnostic
  - Therapeutic

#### Mediators
- **Quality of Providers**
  - Cultural competence
  - Communication skills
  - Medical knowledge
  - Technical skills
  - Bias/stereotyping
- **Appropriateness of care**
- **Efficacy of treatment**
- **Patient adherence**

#### Outcomes
- **Health Status**
- **Equity of Services**
- **Patient views of care**

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Citation: Lisa A Cooper, et al. Designing and Evaluating Interventions to Eliminate Racial and Ethnic Disparities in Health Care *JGIM*, 2002
What if we thought about better communication as a target for QI?

Dyad focused (technical skills):
- Motivational interviewing
- Teach-back
- Clear language
- Cultural competency
- Etc.

Systems focused
- Appreciative inquiry
- Community engagement
- Team-based care
- Build teach-back into forms and processes
- Provide resources to respond when pts fail a teach back
- Provide educational materials, videos, interpreter services

Patient-Centered Communication

Conceptual Framework
The Intersection of Health Literacy with Health Care Improvement

Hasnain-Wynia R and Wolf MS (2010)
*Health Services Research*
### Addressing Disparities Program

**Advisory Panel Prioritized Topics**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Short Name</th>
<th>Topic</th>
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<tbody>
<tr>
<td>FIRST</td>
<td>Health communication associated with competing treatments</td>
<td>Compare the effectiveness of clinician/patient and organizational 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>SECOND</td>
<td>Heart attacks among racial &amp; 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>THIRD</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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<td>FOURTH</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>FIFTH</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: Progress Toward Goal

**Broad PFAs:**
- 23 funded research contracts (Cycles I-III)
- 71 new applications awaiting review (11/21/2013)

**Targeted Topics:**
- Treatment Options for Uncontrolled Asthma in African-Americans and/or Hispanic/Latinos: Review 11/11/2013
- Three topics being refined:
  - Obesity Treatment Options. PFA development
  - Perinatal Care (in collaboration with IHS). Workgroup 10/24/2013

**Overarching topic:** Compare the effectiveness of clinician/patient and organizational health communication models on improving outcomes
Conditions and Diseases: Cycles I-III

- Chronic conditions: 12
- Mental health: 6
- Sexual/reproductive health: 2
- Infectious disease: 1
- Non-condition specific: 1
- Injury/trauma: 1
Disparities Population: Cycles I-III (Not mutually exclusive)

Addressing Disparities Program Priority Populations
- Racial/Ethnic Minorities
- Low Socioeconomic Status or Economically Disadvantaged
- Rural
- Disabilities
- Limited English Proficiently
- LGBT
Study Design for Main Analysis: Cycles I-III

- RCT: 9
- RCT, Mixed: 9
- Secondary data analysis: 2
- Observational: 2
- Quasi experimental: 1
Addressing Disparities Portfolio: Examples

- **Culturally-adapted decision aid**
  - Help Latina’s decide whether to get the HPV vaccine.

- **Language-appropriate mobile app**
  - Educate Asian Americans about Hep B and C

- **Telemedicine**
  - Increase access when in-person visits are difficult

- **Literacy-adapted CBT group therapy**
  - Help low literacy patients with chronic pain.

- **Integrative medicine group visit model**
  - Address chronic pain among low income patients

- **Group therapy for cancer survivors AND their caregivers**
  - Improve QOL, stress and family conflict.
Reducing Disparities with Literacy-Adapted Psychosocial Treatments for Chronic Pain: A Comparative Trial

Engagement

• Intervention and materials will be guided by patient, provider and expert feedback, and a Research Board will provide study oversight.

• Community members will recruit participants.

Potential Impact

• Could change practice by providing intervention for reducing pain and depression in chronic pain patients with low income and low health literacy.

Methods

• Research is completed through a mixed methods approach and a randomized controlled trial.

Conducts a community-based randomized controlled trial comparing three treatments for chronic pain among patients at Federally Qualified Health Centers: 1) usual care, 2) pain education, and 3) health literacy-adapted cognitive-behavioral group therapy.

Beverly E. Thorn, PhD
University of Alabama-Tuscaloosa

Addressing Disparities Research Project, awarded December 2012
Nueva Vida Intervention: Improving QOL in Latina Breast Cancer Survivors and Their Caregivers

Engagement

• Patient and caregiver focus groups will inform design and help refine intervention.

• Academic institutions and patient advocacy groups will collaborate on dissemination.

Potential Impact

• Could change practice by providing an intervention that can close the established quality of life gap between Latina and non-Latina breast cancer survivors.

Methods

• Research is completed through a randomized controlled trial.

Studies the use of group support sessions for Latina cancer survivors and their caregivers. Survivors and caregivers assigned to intervention group will attend separate group sessions twice a month to discuss different quality of life issues such as side effects, stress management and impact on family.

Kristi Graves, PhD
Georgetown University

Addressing Disparities Research Project, awarded May 2013
Cultural Tailoring of Educational Materials to Minimize Disparities in HPV Vaccination

Engagement
- Seeks input from a Community Advisory Board (CAB) comprised of parents of Latina adolescents and young adult Latinas.

Potential Impact
- Could change practice by increasing HPV vaccination rates among Latinas, and creating a blueprint for improving vaccination rates among underserved communities.

Methods
- Mixed methods including focus groups followed by a randomized controlled trial.

The project focus is to increase HPV vaccination rates among Latinas, who have the highest risk for developing invasive cervical cancer. The long-term aim is to compare three different approaches to helping Latinas make decisions about the HPV vaccine.

Amanda Dempsey, MD, PhD, MPH, University of Colorado-Denver

Addressing Disparities Research Project, awarded December 2012
A Patient-Centered Intervention to Increase Screening of Hepatitis B and C Among Asian-Americans

Engagement

• Patient/provider focus groups to create and pilot test app.

• Patient Advisory Councils, community advocacy groups and hospital administrators to serve in advisory roles

Potential Impact

• Could change practice by expanding our understanding about how to use technology-based interventions to improve quality of care in diverse patient populations.

Methods

• Research is completed through a randomized controlled trial.

Develops and tests an interactive mobile app to increase the rate of Hep B and C screening among Asian Americans. Trial will test effectiveness of app by comparing its use in combination with a physician panel notification vs. the physician panel notification only.

Tung Nguyen, MD  
University of California San Francisco

Addressing Disparities Research Project, awarded May 2013
Two Paths to Research Funding

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

**Patient/Other Stakeholder Initiated**
- PCORI and stakeholders generate and prioritize questions based on review criteria
- PCORI issues specific funding announcements for highest priority topics
- Researchers partner with patients and stakeholders to develop proposals
- Peer review prioritizes applications by level of alignment with criteria

Diverse research portfolio answering key questions for patients and clinicians
PCORI Merit Review Criteria

Applicants must respond to the five PCORI Merit Review Criteria within the Research Strategy.

1. Impact of the condition on the health of individuals and populations

2. Potential for study to improve healthcare and outcomes

3. Technical Merit

4. Patient-centeredness

5. Patient and stakeholder engagement
We want to know what health care question you may be facing.
Help determine what we fund

Advisory Panels & Working Groups

PCORI Reviewers
Facilitating patient partnership in research

Ambassadors

Engagement Awards
Tell Us How We’re Doing

- Public Comment Periods
- Roundtables and Workshops
- info@pcori.org