

Patient-Centered Outcomes Research Institute Communications, Outreach and Engagement Committee (COEC) Report

PCORI Board of Governors
Baltimore, MD
March 5, 2012



COEC Members

- Sharon Levine, MD (Chair)
- Debra Barksdale, PhD, RN
- Robert Jesse, MD, PhD
- Grayson Norquist, MD, MSPH
- Ellen Sigal, PhD
- Harlan Weisman, MD
- *Gail Hunt*

COEC Report to the Board

- I. Public Feedback on the **Draft** National Priorities and Research Agenda
- II. National Patient and Stakeholder Dialogue – February 27, 2012
- III. Clinician Focus Groups
- IV. Incorporating Input into Revisions of **Draft** National Priorities and Research Agenda
- V. Stakeholder and Community Engagement Events Associated with Board Meetings
- VI. Connecting with PCORI

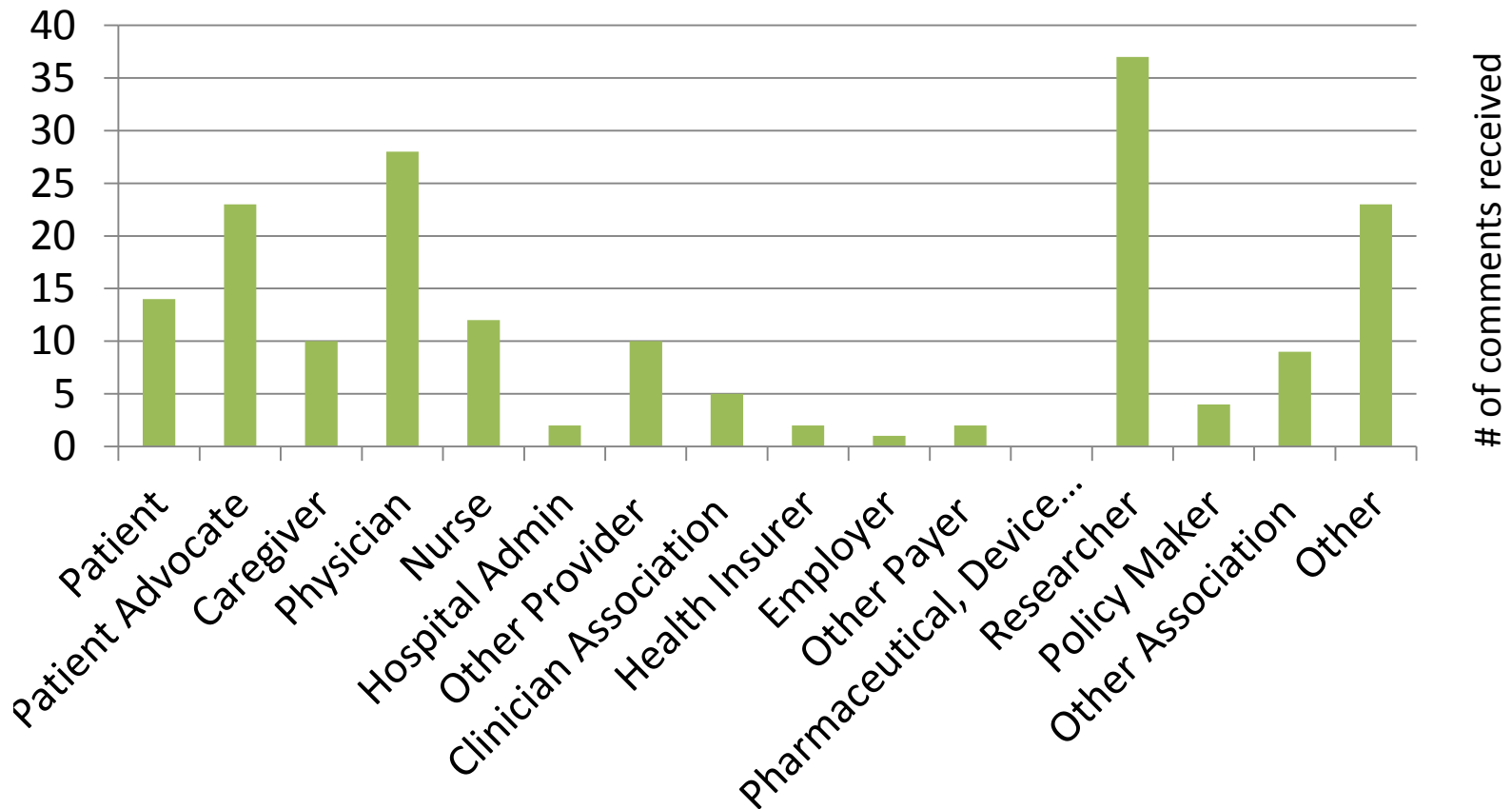
I. Public Feedback on the *Draft* National Priorities and Research Agenda

- **Formal public comment period**
 - January 23-March 15
 - www.pcori.org/survey/priorities-agenda
 - Responses received through www.pcori.org posted for public view on the website
 - Opportunity for feedback by mail

I. Public Feedback on the *Draft* National Priorities and Research Agenda

- **Comments received to date**
 - **101** comments received through March 1
 - Distribution of comments received:
 - By stakeholder type
 - By geographic location

Comments Received by Stakeholder Type



Comments Received by Geographic Location



II. National Patient and Stakeholder Dialogue – February 27, 2012

- More than **900** individuals pre-registered to participate:
 - **400** in person
 - **530** by webcast or phone
 - Actual participation exceeded **850**
- Watch the archived webcast on pcori.org
 - Visit *Past Meetings & Events* page



II. National Patient and Stakeholder Dialogue – Highlights

- Presentation by Board Member Harlan Krumholz on the draft National Priorities for Research and Research Agenda
 - “Our true North is our patients”
- Two panels:
 - **Patient and Caregiver Advocates** (American Cancer Society, Autism Speaks, National Alliance for Hispanic Health, National Alliance on Mental Illness, National Health Council)
 - **Clinicians and Other Stakeholders** (Aetna, American Academy of Family Physicians, American Medical Association, American Nurses Association, National Business Group on Health, PhRMA)

II. National Patient and Stakeholder Dialogue – Highlights

- **57** public comments or statements provided:
 - **11** panelists
 - **46** individuals in person
 - **8** individuals by phone
- Event Evaluations by those Attending In Person:
 - **90%** of respondents felt event was informative regarding the National Priorities and Research Agenda.
 - Just under **85%** felt panel discussions helped provide context for the National Priorities and Research Agenda.

Focus Groups – Additional Feedback on the Draft National Priorities and Research Agenda

- **Patient and Caregiver Focus Groups**
 - 12 groups in 4 cities, 96 participants
 - Reported on at Jacksonville Board meeting
- **Clinician Focus Groups**
 - 9 groups in 4 cities, 58 participants
 - Conducted February 8-16

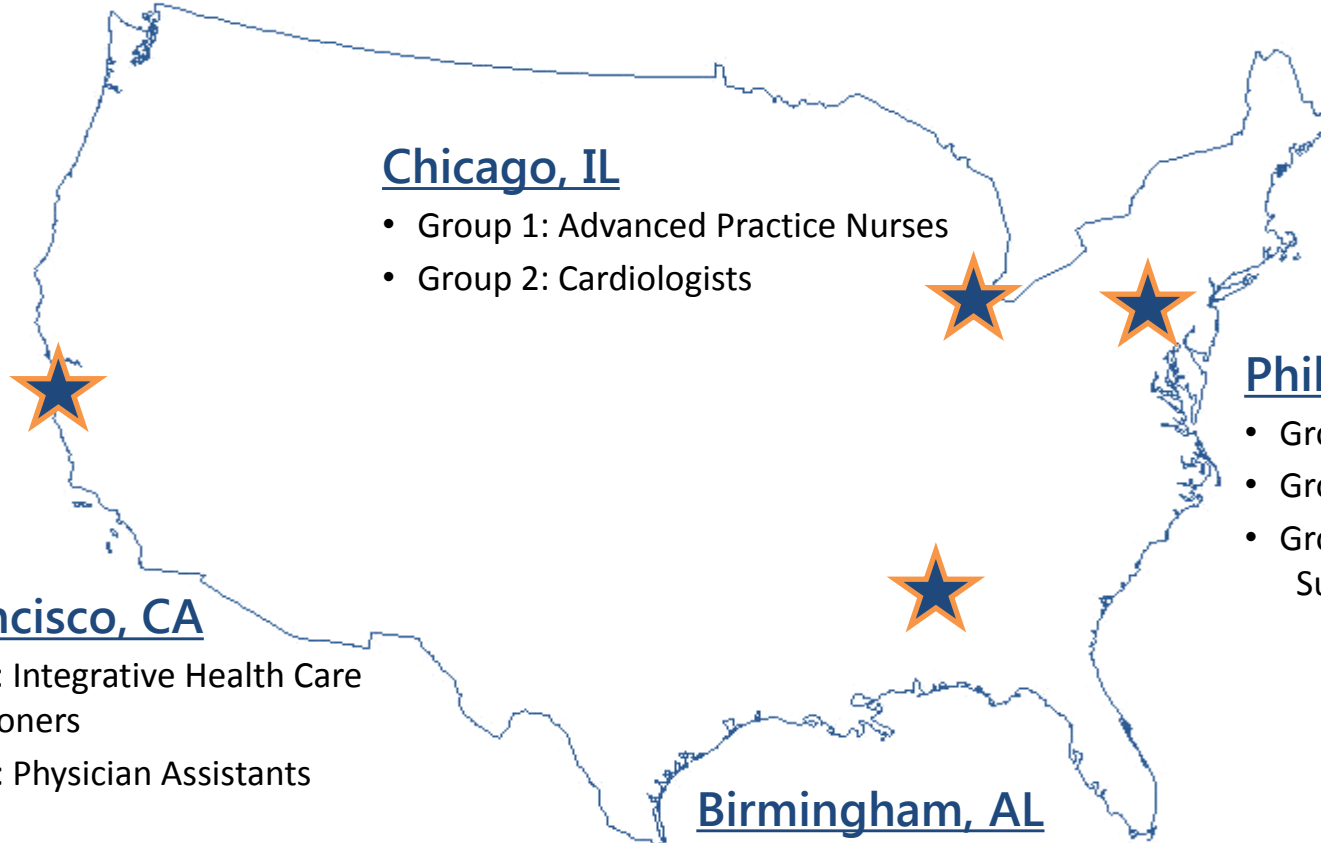
III. Clinician Focus Groups

Purpose, Objectives

- Obtain detailed feedback from clinicians discussing PCORI's draft National Priorities for Research and initial Research Agenda.
- Explore research priorities from the clinicians' perspective, their understanding and reaction to PCORI's proposed priorities and agenda, as well as general opinions about PCORI's work.
- Better understand practice needs, clinical issues, and how new research-based information can be helpful.

Focus Groups Nationwide with Clinicians

Physicians, nurses, physician assistants and integrative health care practitioners representing a mix of tenure, practice setting and specialties.



Chicago, IL

- Group 1: Advanced Practice Nurses
- Group 2: Cardiologists

Philadelphia, PA

- Group 1: Mix of Nurses
- Group 2: Psychiatrists
- Group 3: Orthopedic Surgeons

San Francisco, CA

- Group 1: Integrative Health Care Practitioners
- Group 2: Physician Assistants

Birmingham, AL

- Group 1: Registered Nurses
- Group 2: Primary Care Physicians

Key Findings from Clinician Focus Groups



Clinicians on "Medical Research"

- Clinicians have mixed feelings about research. They use and appreciate research, but have concerns about corporate agendas, FDA approval times, and feel several steps removed from research activity.
- Clinicians voluntarily articulate the need for many of the concepts behind "comparative effectiveness research" and "patient-centered outcomes," but this is not their language.

Impressions of PCORI

- One of the biggest stumbling blocks with clinicians is the perception that PCORI is too broad, too over-reaching, and thus too idealistic to have a meaningful impact.
- Another communications challenge is that healthcare costs, access, and payer decisions overshadow discussions about clinical effectiveness.

Research Agenda

- Clinicians, as did patients and caregivers in earlier groups, agree that "assessing options" and "communication" are priority areas for PCORI. Clinicians also prioritize "improving healthcare systems."
- Clinicians say that PCORI should start by focusing on one or two of its research priorities, and begin to build a track record.

Advice for Engagement

- Professional organizations are the preferred channel for these clinicians. They seem willing to engage with PCORI, if opportunities are convenient and specific to their practice/patient population/setting.
- Focus groups and online surveys are also mentioned as good ways to reach them.
- Many underscore that staying in touch will take diligence on PCORI's part.

How Would Clinicians Allocate Funding?

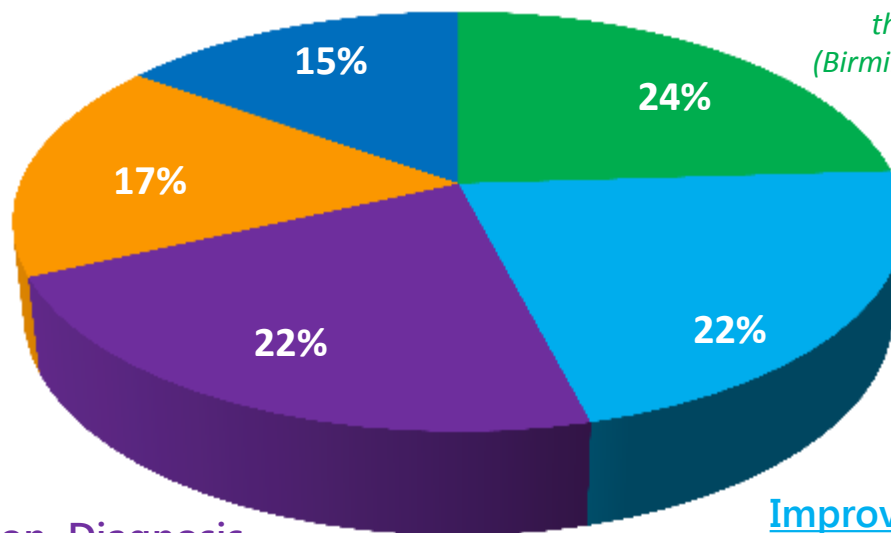


Accelerating Patient-Centered and Methodological Research

"We have universities that train researchers – Penn and Hopkins." (Philadelphia, Nurses)

Communication and Dissemination

*"I want my patients to be involved in their care. If they want to get involved, that makes my job easier because they're motivated to change."
(Birmingham, Primary Care Physicians)*



Addressing Disparities

*"If everything else is up and running, this should be a small thing."
(San Francisco, Integrative Medicine)*

Assessment of Prevention, Diagnosis and Treatment Options

"A lot of times the patients are the best ones to tell you if this works or that doesn't work, but nobody listens." (Birmingham, Registered Nurses)

Improving Healthcare Systems

"There is no coordination with anything. Everybody is doing their own thing. It seems like there is no communication. We are struggling with this." (Chicago, Cardiologists)

Focus Group Exercise: Pretend YOU are allocating PCORI resources. What percentage of resources would you invest in each area? (Your total needs to equal 100%.)

IV. Revising the Draft National Priorities and Research Agenda

- PCORI will review input received from:
 - Website survey and formal public comment process
 - National Patient and Stakeholder Dialogue
 - Patient, caregiver and clinician focus groups
 - Formal and informal feedback received by Board members and staff at PCORI-related events
- Report to be published on www.pcori.org summarizing input received explaining how input led to changes in the draft priorities and agenda.
- Revised National Priorities and Research Agenda to be presented for adoption by PCORI's Board of Governors during a special public meeting in April.

V. Soliciting Feedback on Stakeholder and Community Engagement associated with Board Meetings

- **Survey of Board Members on Past Stakeholder Events Underway (March 2011-January 2012)**
 - What have we learned?
 - Which formats have been most useful?
 - How have the results informed our work?
 - What can we accomplish this year?
- **Soliciting feedback from stakeholder/community participants**
- **Planning for 2012**
 - Analyzing upcoming metro areas, their unique demographics and health needs

VI. Ongoing Engagement and Feedback Process

- PCORI website – www.pcori.org
- Join PCORI's mailing list – www.pcori.org/subscribe
- Follow PCORI on Twitter [@PCORI](https://twitter.com/PCORI)
- Provide feedback at anytime – www.pcori.org/provide-input
- Request a speaker – www.pcori.org/contact-us



follow us on
twitter



Questions & Discussion