

PCORI Advisory Panels

Anne Beal, MD, MPH, Chief Operating Officer
Sue Sheridan, Acting Director, Patient Engagement
Susan Hildebrandt, Director, Stakeholder Engagement
Sharon Levine, Chair, COEC

PCORI Board of Governors Meeting
Washington, DC
September 24, 2012



Questions for Board Consideration

1

Is this the right scope for advisory panel activities?

2

Please comment on the proposed number and type of panels.

Advisory Panels: What the Law Says

- The Institute may appoint permanent or ad hoc expert advisory panels as determined appropriate to **assist in identifying research priorities and establishing the research project agenda**
- The Institute shall appoint expert advisory panels in carrying out **randomized clinical trials** under the research project agenda
- In the case of a research study for **rare disease**, the Institute shall appoint an expert advisory panel

Advisory Panels: Purpose

- Advisory Panels will assist PCORI staff and Board in:
 - Modeling robust patient and stakeholder engagement efforts,
 - Refining and prioritizing specific research questions,
 - Providing other scientific or technical expertise
 - Addressing other questions that may arise relevant to PCORI's mission and work

Advisory Panels: Framework

- Each Advisory Panel will have
 - A unique charter and duration
 - Clearly defined scope of work
- Membership on each Advisory Panel will be based on ensuring those with appropriate expertise are selected to satisfy the scope of work established in its charter
 - We are developing a plan for compensation of members

Proposed Advisory Panels

- Patient Engagement
- Assessment of Prevention, Diagnosis and Treatment Options
- Health Disparities
- Improving Healthcare Systems
- Communication and Dissemination
- Infrastructure*
- Randomized Clinical Trials*
- Rare Diseases

First Panels: First Half of 2013

Patient Engagement

Assessment of Prevention, Diagnosis, and Treatment Options

Health Disparities

Improving Health Care Systems

Future Panels: Second Half of 2013

Communication and Dissemination

Infrastructure

Randomized Clinical Trials*

Rare Diseases*

Advisory Panels: What the Law Says

An expert advisory panel shall include representatives of practicing and research clinicians, patients, and experts in scientific and health services research, health services delivery, and evidence-based medicine who have experience in the relevant topic and, as appropriate, experts in integrative health and primary prevention strategies.

Composition

- Advisory Panel size will be 10-21 panel members, depending on the panel's purpose
- Membership of each Advisory Panel will be selected based on the scope of work established in the charter

Composition (continued)

- Panel may have a non-voting liaison from the PCORI Board of Governors or Methodology Committee as appropriate
- An Advisory Panel Chairperson will be selected from among the Panel members by the PCORI Board of Governors
- Members will be appointed for 1-year terms, with an opportunity for reappointment

Conflict of Interest

- PCORI will consider implications for panel members' eligibility for future PCORI funding in creating Advisory Panels
 - The role will be advisory and participation will not affect eligibility for funding
 - We will have firewalls similar to those surrounding the Methodology Committee regarding access to information
 - Advise members before appointment about potential impact on eligibility for PCORI funding if they might receive non-public information
 - Explore options to promote transparency of proceedings
- We will clarify that Advisory Panels' roles are to provide input to the Board and staff, not to make decisions

Advisory Panel Establishment Process

1

Staff Draft and Submit Charter for an Advisory Panel

- Board, MC, and/or PCORI staff identify the need to establish an Advisory Panel
- Staff initiates request for an advisory panel by submitting a panel-specific charter

2

Board Reviews the Proposed Advisory Panel Charter

- Board may authorize charter (proceed to step 3)
- Board may request revisions to the charter (return to step 1)

3

Staff Activates Nomination and Selection of Panel Participants

- Staff initiates open call for nominations, via the PCORI Web site and other communications
- Nominees submit an expression of interest, via the PCORI Web site
- Staff evaluates nominees, per evaluation criteria unique to the panel charter

4

Board Approves Panel Participants

- Staff selects and proposes a panel roster to the Board
- Board authorizes and approves the panel roster

First Panels: First Half of 2013

Patient Engagement

Assessment of Prevention, Diagnosis, and Treatment Options

Health Disparities

Improving Health Care Systems

Proposed Panel: Patient Engagement

- Purpose: Assure the highest patient engagement standards and patient-centeredness in all aspects of PCORI's work
- Term: 1 year
- Membership: Between 10–21 members with 75% patients, caregivers, and advocacy organizations and 25% researchers and other stakeholders
- Advisory Panels will provide advice and make recommendations to PCORI and help inform decisions of the Board of Governors, the Methodology Committee, and Institute staff, as requested

Proposed Panel: Patient Engagement

Selection Criteria

- Patients and caregivers who can represent the collective voice of their communities/networks
- Online communities and organizations with extensive reach into high priority populations
- Represent underserved/disparate populations and those with rare diseases
- Experience in patient-centered research/proposal review
- Involvement in systems improvement
- Community- or state-based

Questions for Board Consideration

1

Is this the right scope for advisory panel activities?

2

Please comment on the proposed number and type of panels.

BOARD VOTE:

Recommend Approval to Develop Advisory Panels

- Patient Engagement
- Assessment of Prevention, Diagnosis and Treatment Options
- Health Disparities
- Improving Health Care Systems