



Patient-Centered Outcomes Research Institute



Program Development Committee

Report to PCORI

March 7, 2011



Purpose of Program Development Committee (from Charter)

....provide advice and assistance to the Board regarding the development of options for unique PCORI investments that will contribute to and accelerate progress in patient-centered outcomes research, the creation of a Charter for the Methodology Committee, and the identification of processes for PCORI work, interactions between the Methodology Committee and PCORI Board and staff, peer review, and ongoing interactions with stakeholders.



Objective #1: Conduct an environmental scan

Goal of environmental scan is to help PCORI determine where it can add unique value and to help PCORI establish the National Priorities

Include in Environmental Scan:

1. Ongoing comparative effectiveness research
2. Peer review processes that engage stakeholders
3. Patient-centered priority setting processes
4. Outcomes clinical research capacity and capability analysis
5. Overview of ARRA-funded research



Objective #1 (con't): Conduct an environmental scan


Six components of environmental scan:

1. **Who is doing what? (overview of organizations and research)**
2. **Capacity for outcomes research (What is it? What are the existing capabilities? Survey inventory and assess needs, including workforce)**
3. **Needs-based environmental scan of the research methodologies (both extant and non-existent) required to carry out PCORI research agenda (with Methodology Committee)**
4. **Major gaps in evidence**
5. **Stakeholder engagement processes**
6. **Stakeholder involved peer-review processes**



Objective #2: Develop the “Tier 1” planning grant process

- The PDC has determined that it would be productive to conduct some “capacity-building” research as we develop the national priorities and research agenda.
- The goal of the “tier 1” planning grant process is to inform the development of the National Priorities.
- First, we will frame a definition of Patient-Centered and Outcomes Research
- Next, with this framing, we will solicit projects that explore unmet patient needs in communication, knowledge and decision making; outcomes research infrastructure and methodology; and incorporation of the patient voice in the health care continuum.



Objective #2 (con't): Develop the “Tier 1” planning grant process

- **We plan to seek public comment on our ideas and seek other ideas.**
- **Example of type of research: #1 white paper on models for seeking patient engagement at various stages of activities (e.g., comments on research agenda, shaping questions for research, identifying patient-outcomes they value)**
- **Example #2: white paper on nationwide patient-centered research network with broad patient engagement**



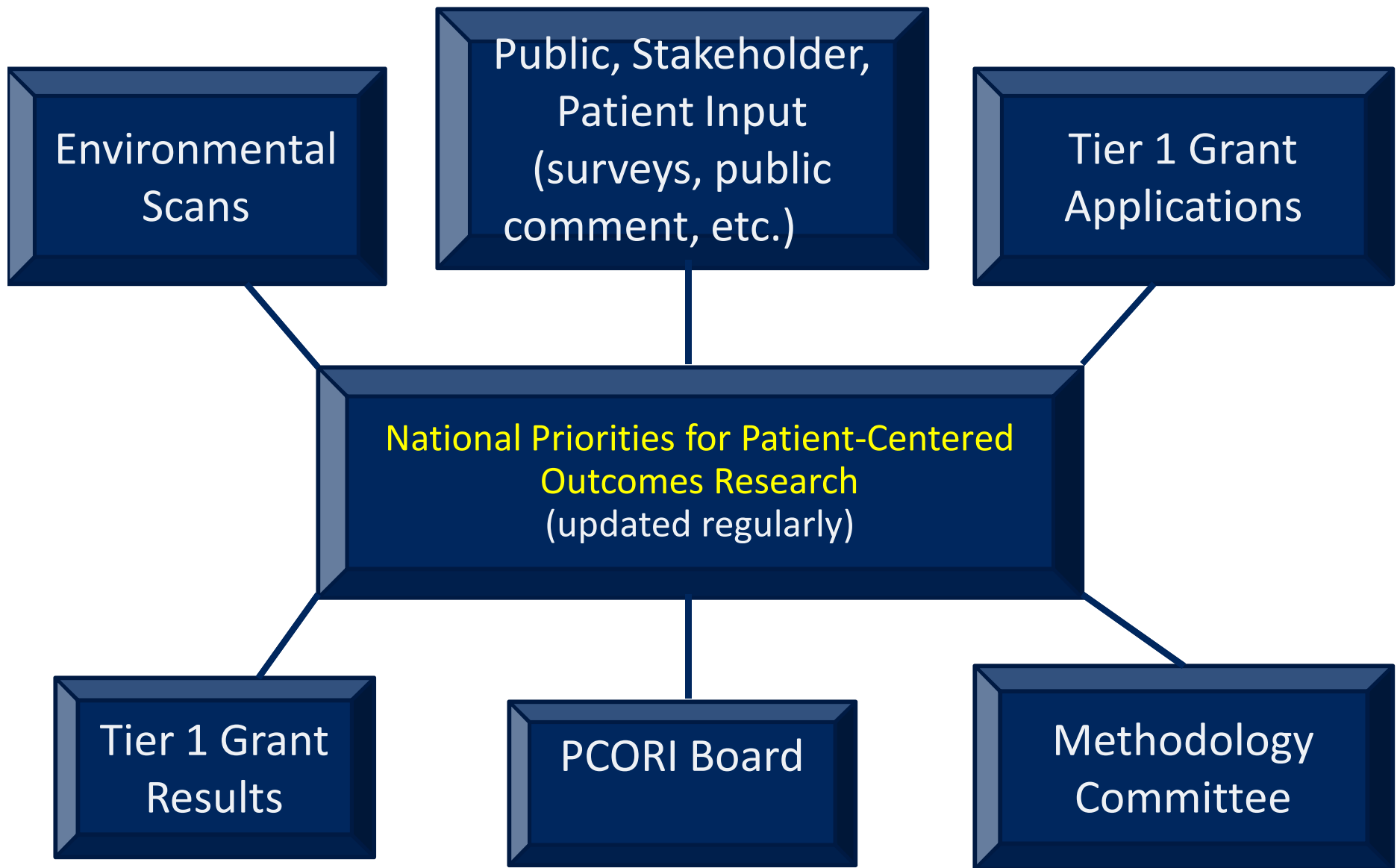
Objective #3: Establish the PCORI National Priorities

Six Key Sources of Input:

- **Public (public comment period, survey, other stakeholder outreach)**
- **The PCORI Board**
- **The Methodology Committee**
- **Environmental Scan**
- **Tier 1 grant proposals**
- **Tier 1 grant results**

Objective #3 (con't): Establish the PCORI National Priorities


- Working, in collaboration with other committees, to reach a common definition of “patient-centered outcomes research
- Have developed tentative criteria to consider for establishing national priorities
- Will review other priority-setting processes for comparative effectiveness research
- Will seek public comment on national prioritie





Objective #4: Develop the durable Core Research Agenda for Patient-Centered Outcomes Research

- **Develop the Grant process**
- **Assess administration through NIH vs. academic institution or private sector entity**
- **Develop patient-centered peer review process**



Objective #5: Identify and fund capacity-building research that will fill gaps in research methodology

- **Close coordination with Methodology Committee (e.g., overlap of Members; integration of staff; encourage participation by Board Members)**
- **Close coordination with Public Affairs and Communications Committee**
- **Focus on how to build-in patient input at every stage**
- **Consider white paper on dissemination and uptake methods**



Patient Engagement

- **Will work to support PCORI efforts to establish a patient-centered process with two-way communication channels.**
- **We plan to seek public comment on our early research plans that are designed to pave the way for developing national priorities and the research agenda.**
- **Eager to explore creative ways to engage patients beyond public comments, e.g., surveys, contests**
- **Conscious of a need to conduct a representative survey, and not to rely on the loudest voice. We aim to give patients a voice.**
- **Will work with PACC to develop process for patient input on specific research projects**



Tentative Criteria for Establishing National Priorities

- **Innovative research that advances the concept of patient-centered outcomes**
- **Disorders or areas where research will provide maximum healthcare value (considering prevalence, burden of disease, variation in practice patterns, high scientific opportunity, expressed needs and concerns of stakeholders)**
- **Research that employ principles of outcomes research**
- **Research with potential for multiplicative effect (such as live data for practice improvement, building platforms for future studies, method development)**
- **Health disparities research that focuses on priority populations**
- **Research in diseases and healthcare/delivery unlikely to be studied (absence of incentives or other barriers)**