



Introduction & Overview of Patient Engagement

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Director, Patient Engagement

Advisory Panel Kickoff & Training

April 19, 2013

Patient-Centered Outcomes Research Institute

Who are we as a group?

Stakeholder Group	#
Patient, Caregiver & Patient Advocate	13
Researcher	2
Clinician, Physician	2
Clinician, Occupational Therapist	1
Clinician, Nurse	1
Industry, Pharmaceuticals	1
Policymaker	1

What brings you here?

- 🌐 Please introduce yourself to the group:
 - Name
 - Where are you from?
 - Why did you decide to support PCORI's work in this area?



HELLO
my name is

Questions to Consider

- 🌱 Creating a community – what is the role of this advisory panel?
- 🌱 What is true patient-centeredness?
- 🌱 What does success look like?
- 🌱 What is your experience?



Agenda for Today

Session	Objective
Introductions & Patient Engagement Overview	➤ Panelist introductions
Patient Engagement Advisory Panel Charge & Work Plan	➤ Share meeting objectives and overall vision for the panel ➤ Facilitate the development of a vision document ➤ Write the panel scope of work together
Brainstorming	➤ Begin considering PCORI-pedia (notecards are available for idea sharing) ➤ Share pre-meeting activity responses
The Roles of Patients in Research	➤ Share and discuss what is meaningful patient engagement in research
Matching Patients and Stakeholders with Researchers	➤ Share and discuss best practices in matching patients and researchers
Evaluation of Engagement Efforts	➤ Current evaluation strategies ➤ The potential role the panel could play in this capacity moving forward



Advisory Panel on Patient Engagement Charge & Work plan

Sue Sheridan, MBA, MIM

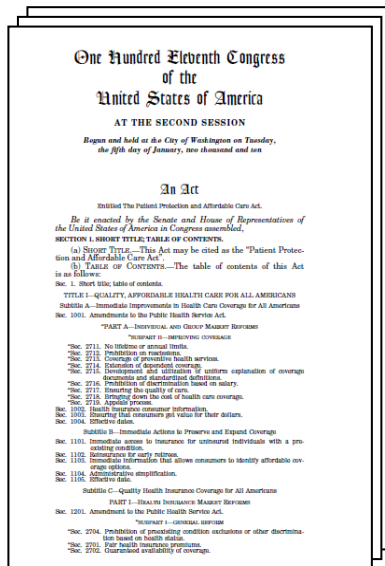
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PCORI's Broad Mandate



Purpose Of PCORI

“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.

Source: Affordable Care Act. Subtitle D—Patient-Centered Outcomes Research.

PUBLIC LAW 111–148—MAR. 23, 2010.

Advisory Panel on Patient Engagement Charge

- Advise on processes to identify research topics and **priorities that are important to patients**;
- Advise on all aspects of **stakeholder review of applications** for PCORI funding;
- Provide general recommendations to PCORI and externally on the **conduct of patient-centered research**;
- Advise on methods to **evaluate the impact of patient engagement in research**;
- Assist and advise PCORI on **communications, outreach, and dissemination of research findings**; and
- Provide advice on other questions and areas of interest that may arise that are relevant to PCORI's mission and work.

Meeting Objectives

- Familiarize panelists with PCORI's mission, national priorities, and the purpose and function of the Advisory Panels
- Inform panelists on all of PCORI's engagement opportunities
- Train panelists in research prioritization
- Review recommendations on best practices in patient engagement in research outlined in the final workshop report and offer additional input
- Receive advice and recommendations on the Engagement Awards and Ambassadors Program
- Collaboratively develop a pledge for the panel, as well as a work plan and expectations of panelists for Year 1

Meeting Outputs

- Patient Engagement Panel vision document
- Patient Engagement Panel work plan
- Edits to PCORI Ambassadors Program and the Engagement Awards
- Recommendations and enhancements for best practices in patient engagement in research
- PCORI-pedia – definitions for PCORI terms

Advisory Panel on Patient Engagement Work Plan

- Identify goals to work toward over the next 12 months





Brainstorming

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Review Responses to Pre-Meeting Activity

- 🌐 What is the biggest hope I have for patient-centered research?
- 🌐 What does success look like for patient engagement in PCORI's research?

Idea Capture

- This is an opportunity to share any additional ideas, hopes, and goals you may have for the Patient Engagement Advisory Panel





The Roles of Patients in Research

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Putting Patients at the Center

**Putting Patients
at the Center**

The Roles of Patients in Research

- What is meaningful patient engagement in research?





Matching Patients and Stakeholders with Researchers

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Methodology Standards Associated with Patient-Centeredness

- PC-1 Engage people representing the population of interest and other relevant stakeholders in ways that are appropriate and necessary in a given research context. Stakeholders can be engaged in the processes of:
 - Formulating research questions;
 - Defining essential characteristics of study participants, comparators, and outcomes;
 - Identifying and selecting outcomes that the population of interest notices and cares about (eg, survival, function, symptoms, health-related quality of life) and that inform decision making relevant to the research topic;
 - Monitoring study conduct and progress; and
 - Designing/suggesting plans for dissemination and implementation activities.

Video Clip: Ming Tai Seale



Review Criterion 7: Team and Environment (Current)

The 8 Merit Review Criteria:

1. Impact of the Condition
2. Innovation/Potential for Improvement
3. Impact on Healthcare Performance
4. Patient-Centeredness
5. Rigorous Research Methods
6. Inclusiveness of Different Populations
- 7. Team and Environment**
8. Efficient Use of Resources

- Are the investigators appropriately trained and experienced to carry out the planned studies?
- Is the work proposed appropriate to the experience level of the principal investigator?
- Does the study team have complementary and integrated expertise?
- Is their leadership approach, governance, and organizational structure appropriate for the project?
- **Are relevant patients and other key stakeholders of the study information appropriately involved in the design and implementation of the study?**
- Do the experiments proposed take advantage of unique features of the scientific environment or employ useful collaborative arrangements?
- Is there evidence of institutional or other support?

Video Clip: David Thorn



DAVID THOM

FACULTY AT USCF, DEPARTMENT OF FAMILY COMMUNITY MEDICINE

Challenge Background

- PCORI is committed to meaningful patient, caregiver, and stakeholder engagement as a tool for rigorous research.
- PCORI funding announcements require that patients be fully engaged throughout research process.
- Engagement is among the criteria PCORI uses to score applications.

The Challenge

- Develop a “matching” system that can connect researchers and potential patient partners.
- Solution could be:
 - A well-articulated conceptual model.
 - An adaptation of existing matching protocol.
 - A prototype or an entirely new Web-based service or app.
 - Some combination of these approaches, or something else entirely.

The Challenge

- Two first-place awards:
 - Conceptual model – \$10,000
 - Prototype of app – \$40,000
- Winners' work may be considered for additional PCORI support, depending on outcome of the review process.
- Submission materials: slide deck (5 slides), overview doc (5 pgs), video demo (5 min), link to working app (optional)

Evaluation Criteria

- Technical feasibility, usability, and scalability of the proposed conceptual model/prototype.
- Differences in ways patients, caregivers, and researchers understand, describe and seek answers to problems or issues they face.
- Maximizing patient-centeredness and scientific rigor.
- Particular challenges of serving hard-to-reach audiences: ethnic and racial minorities, rural populations, the elderly, physically challenged people, and non-English speakers.

Timeline

- Submission period began: December 14, 2012
- Submission period ended: April 15, 2013
- Winners notified: May 15, 2013
- Winners announced: at a major national health conference in the spring of 2013

Video Clip: Dr. Vinod Bhutani/Kris Schulze





Evaluation of Engagement Efforts

Lori Frank, PhD

Director, Engagement Research

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Vision for Engagement Research

Evaluation is fundamental to understanding and improving all that PCORI does.

Engagement Research ensures that PCORI **understands and maximizes the impact of its research funding** to help people make informed healthcare decisions and improve healthcare delivery and outcomes.

Goals for Engagement Research

- Evaluate **research engagement** by PCORI awardees to identify and support best practice
- Evaluate impact of PCORI **funding**
- Establish a **survey research** function to inform PCORI programs
- Evaluate PCORI **engagement and outreach programs**

Elements for Evaluation of Research Engagement from PCORI Workshop

- Define success
- Determine goals of engagement by research phase
- Establish feedback channels
- Address patient and researcher parity
- Assess patient and researcher perceptions of the value and appropriateness of engagement