



Introduction & Overview of Patient Engagement

Sue Sheridan, MBA, MIM

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 |
| Policyholder | 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?



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 | <ul style="list-style-type: none">➤ Panelist introductions |
| Patient Engagement Advisory Panel Charge & Work Plan | <ul style="list-style-type: none">➤ Share meeting objectives and overall vision for the panel➤ Facilitate the development of a vision document➤ Write the panel scope of work together |
| Brainstorming | <ul style="list-style-type: none">➤ Begin considering PCORI-pedia (notecards are available for idea sharing)➤ Share pre-meeting activity responses |
| The Roles of Patients in Research | <ul style="list-style-type: none">➤ Share and discuss what is meaningful patient engagement in research |
| Matching Patients and Stakeholders with Researchers | <ul style="list-style-type: none">➤ Share and discuss best practices in matching patients and researchers |
| Evaluation of Engagement Efforts | <ul style="list-style-type: none">➤ Current evaluation strategies➤ The potential role the panel could play in this capacity moving forward |



Advisory Panel on Patient Engagement Charge & Work plan

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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. Patient-Centered Outcomes Re-



pcori

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

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

Idea Capture

- ➊ 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

Sue Sheridan, MBA, MIM

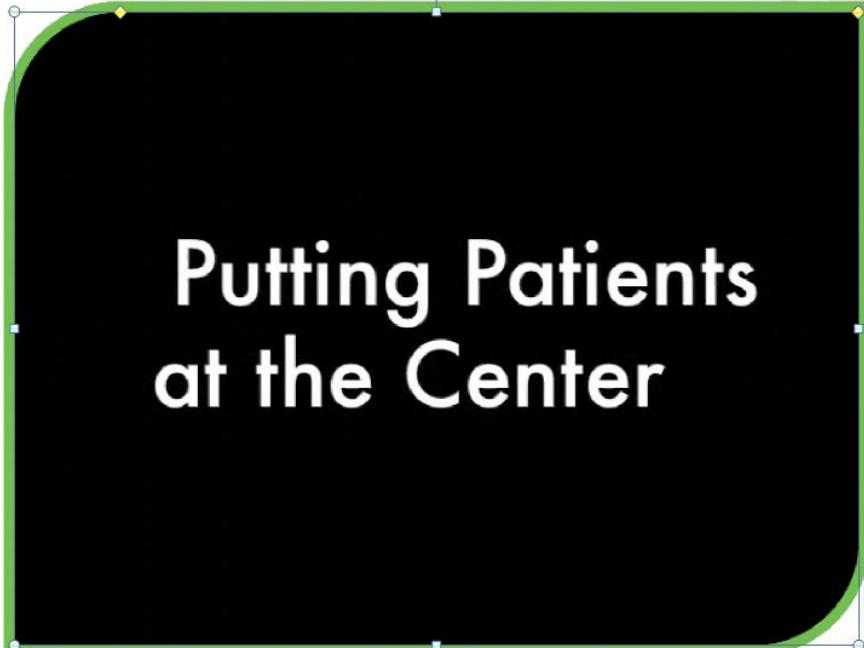
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Putting Patients at the Center



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



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
Advisory Panel Kickoff & Training
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Patient-Centered Outcomes Research Institute

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