

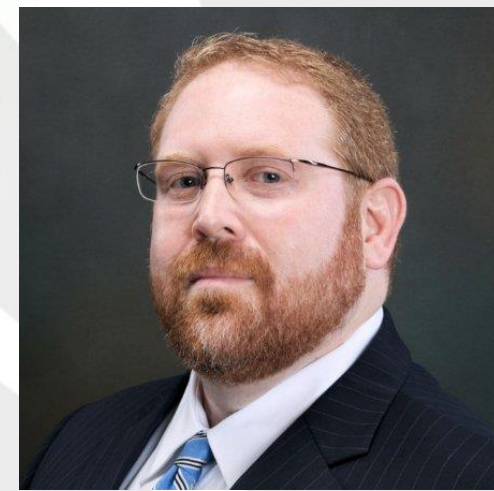


PCORI Evaluation Group

Sixth Meeting
Friday May 23, 2014

Patient-Centered Outcomes Research Institute

New Member: Steve Blum

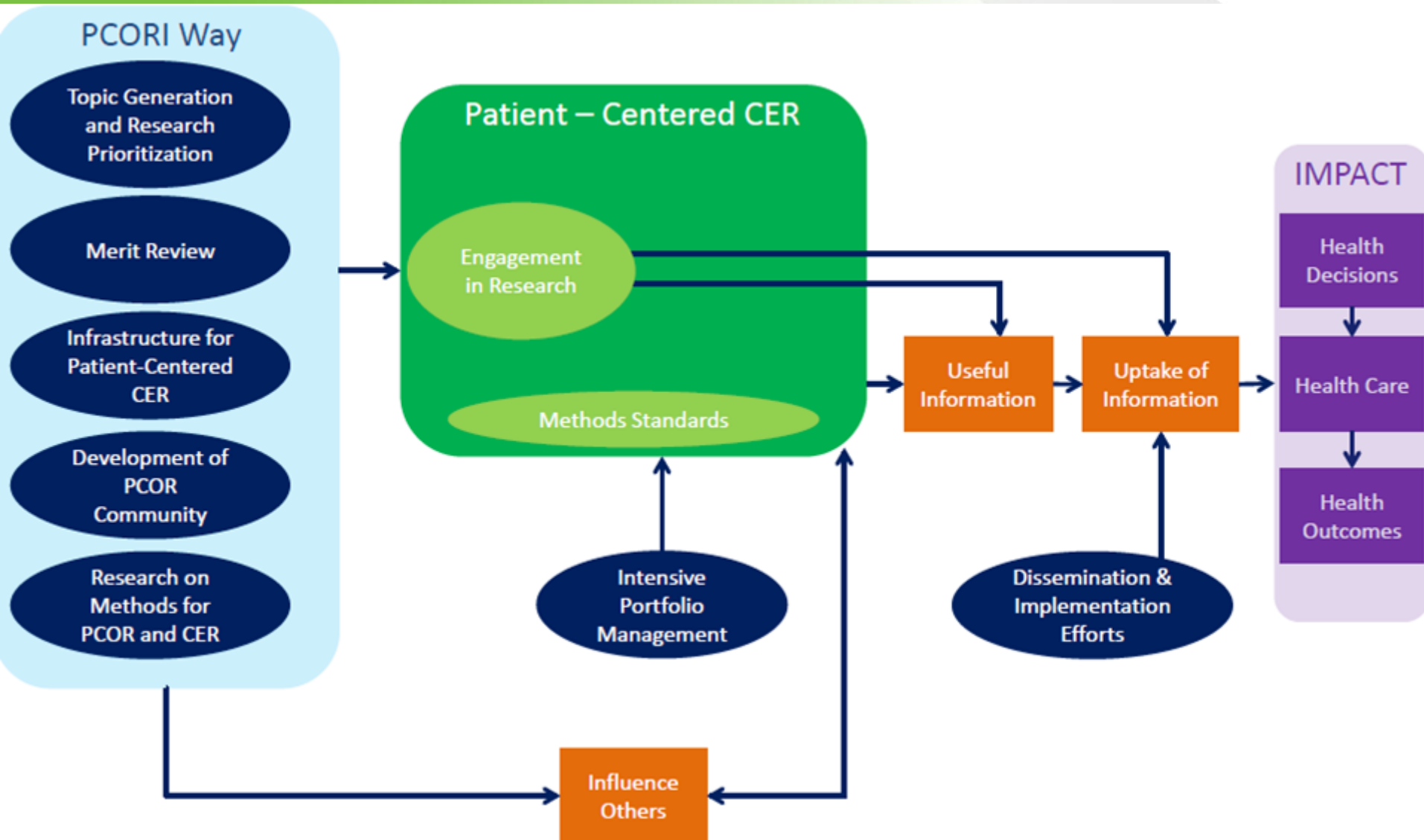


- Member of PCORI Patient Engagement Advisory Panel
- Director, Patient Reported Outcomes at GlaxoSmithKline – responsible for providing strategic and technical support for patient-reported outcomes and other clinical outcome assessments across a range of therapeutic areas.
- Health Economist and Outcomes Researcher with over 20 years of pharmaceutical industry experience
- Active member of ISPOR/ISOQOL. Active participant in Critical Path Institute (C-Path) PRO Consortium: co-chair of Communications sub-committee, former co-chair of Depression Working Group. Co-chair PROMIS Industry Interest Committee

Agenda for Today

- Review current data collection plans and activities at PCORI
 - Identify additional ways in which to quantify progress toward goals
- Review Draft Survey Plan: Researcher Survey

Model for Evaluating the Overall Impact of PCORI



PCORI Data Collection and Evaluation

**Impact of PCORI
Portfolio**

Merit Review

**Best Practices in
Research
Engagement**

PCORI Events

**Patient and Other
Stakeholder
Knowledge,
Attitudes and
Behavior**

Information Collection at PCORI

Data Collection	Purpose
1. Portfolio Impact	
Analysis of portfolio data	To track usefulness of PCORI funded projects.
2. Merit Review	
PCORI Merit Review – Reviewer Survey	To obtain perspectives of the merit review process from scientist, patient, and other stakeholder reviewers; to improve internal merit review at PCORI; to contribute to the study of stakeholder inclusion in merit review.
PCORI Funding Applicant Survey	To understand application experience and identify areas for improvement.
PCORI Research Letter of Intent (LOI) Survey	To understand why those who submitted an LOI but not a full application did not submit a full application.
Reviewer Focus Groups	To obtain perspectives of merit reviewers on the merit review process; permits follow up on results from survey. Information is used to improve internal merit review processes at PCORI; information intended to contribute to the study of patient and other stakeholder inclusion in merit review.



Information Collection at PCORI

Data Collection	Purpose
3. Engagement in Research	
We-ENACT (Ways of Engaging – Engagement ACTivity Inventory)	To describe engagement of patients and other stakeholders in PCORI funded projects. Results will be used to identify best practices and guide applicants.
Net-ENACT Inventory	To describe engagement of patients and other stakeholders in networks funded through PCORnet. Results will be used to understand how networks implement engagement, identify best practices, and determine the effects of engagement on research.

Information Collection at PCORI

Data Collection	Purpose
4. Engagement Events	
<p>PCORI events: surveys pre- and post-</p> <ol style="list-style-type: none">1. Engagement Webinar2. Memphis Workshop3. Wichita Workshop4. April Advisory Panel5. Webinar Evaluation: Promising Practices of Meaningful Engagement in the Conduct of Research6. Webinar Evaluation: PCORI Pipeline to Proposal7. Webinar Evaluation: PCORI Engagement Awards8. October Workshop9. December Workshop10. Albuquerque event	<p>To track PCOR activities of workshop participants subsequent to events; to improve effectiveness of PCORI events.</p>

Information Collection at PCORI

Data Collection	Purpose
5. Stakeholder Views	
InCrowd	To collect information on patient and primary care clinician attitudes and knowledge regarding comparative effectiveness research and engagement in research.
AIR Clinician Survey	Nationally representative surveys to collect information on attitudes toward CER and engagement in research from primary care clinicians.
AIR Patient Survey	Nationally representative surveys to collect information on attitudes toward CER and engagement in research from chronic disease and rare disease patients.
AIR Researcher Survey	To collect information about CER research practices, determinants of funding application submission, and to collect perceptions of PCORI programs.
HINTS -PCORI questions included in next round	HINTS collects nationally representative data routinely about the American public's use of cancer-related information. PCORI items address use of comparative health information.
Stakeholder data collection via focus groups and interviews regarding PCORI's progress	To collect opinions of stakeholder communities about PCORI's progress, to solicit input on future directions for PCORI.

Scientific Survey Project: Objectives

- To understand patient, health care provider, and researcher
 - attitudes toward and perceptions of CER.
 - understanding of and attitudes toward patient and other stakeholder engagement in research.
- To understand barriers to and facilitators of use of CER results in health decisionmaking and clinical practice.
- To develop methods to facilitate use of CER in health decisionmaking and clinical practice.

Scientific Survey Project

- Guided by multi-stakeholder advisory board and sample specific working groups
- Development of flexible item pools to be used across related efforts
- Project Timeline:
 - Cognitive testing: April – May 2014
 - Data collection: June – August 2014
 - Results available: October – November 2014

Scientific Survey Project

- 🌐 Patient survey: nationally representative sample of patients with chronic or rare conditions
 - N = 1000 – 1500
- 🌐 Clinician survey: nationally representative sample of Primary Care Clinicians (MDs, PAs, NPs)
 - N = 1400
- 🌐 Researcher survey:
 - N = 500

AIR Researcher Survey Domains – Slide 1 of 3

CURRENT RESEARCH/INFLUENCES ON FUTURE RESEARCH

- Most recent funded research project, general category
- Experience with PCORI research priority area
- Type of research institution in which currently conducting research
- Importance rating of various factors in deciding whether to pursue a funding opportunity
- Importance rating of various factors to career advancement at your institution

COMPARATIVE EFFECTIVENESS RESEARCH (CER)

- Familiarity with CER
- Experience with CER/Type of CER conducted
- Reasons for not conducting CER
- Value rating of CER to the clinician community

PATIENT-CENTERED CER

- Experience with Patient-Centered CER
- Reasons for conducting Patient-Centered CER
- Reasons for not conducting Patient-Centered CER

AIR Researcher Survey Domains-

Slide 2 of 3

ENGAGING PATIENTS/CAREGIVERS IN RESEARCH

- Importance rating of factors for engagement in research
- Overall interest in engagement in research
- Perceived Facilitators
- Perceived Barriers
- Experience
- Roles patients/caregivers have played in research
- Value of patients/caregiver engagement in research

ENGAGING PRACTICING CLINICIANS IN RESEARCH

- Same as above

AIR Researcher Survey Domains-

Slide 3 of 3

ATTITUDES REGARDING PCORI

- Familiarity with PCORI
- Influence of PCORI on the field
- Influence of PCORI on engagement in research
- Experience applying for PCORI funding
- Perceived difficulty of PCORI funding requirements
- Perceived facilitators of application for PCORI funding

AIR Researcher Survey items

7. How important are each of the following factors when you are deciding to pursue a specific funding opportunity for your research?
8. How important are the following to career advancement at your institution?

AIR Researcher Survey items

15. Which of the following are reasons why you have conducted patient-centered
16. Which part of the definition do you see as most relevant to the reasons you have conducted patient-centered comparative effectiveness research?
17. Which of the following are reasons you have not conducted patient-centered comparative effectiveness research?

AIR Researcher Survey Items

19. How familiar are you with including patients and/or caregivers as partners in research, to help decide what research is done and how it is done?
21. How important are each of the following factors in determining whether you would involve patients and/or caregivers as partners in your research?
22. Overall, how interested would you be in involving patients and/or caregivers as partners in your research?
23. How much would each of the following factors would facilitate your involvement of patients and/or caregivers as partners in your research?
24. How much do you think each of the following factors would hinder your involvement of patients and/or caregivers as partners in your research?

AIR Researcher Survey Items

25. Have you ever engaged patients and/or caregivers in the planning, design, monitoring, interpretation, or dissemination of a research study?
26. What role(s) have patients and/or caregivers played in your research study or project?
27. Overall, how valuable was engaging patients and/or caregivers to your research?
28. How familiar are you with engaging practicing health care providers as partners to decide what research is done and how it is done?
29. How valuable do you think health care providers' involvement in the following activities could be to your research?

AIR Researcher Survey Items

37. How familiar are you with PCORI?
38. Have you ever interacted with PCORI in some way (applied for funding, served as reviewer, attended public event, etc.)?
39. Has PCORI influenced your decision to conduct patient-centered comparative effectiveness research?
40. How much has the existence of PCORI influenced you to consider involving patients or non-academic practicing clinicians as partners in your research?
41. Have you or your team ever applied for funding from PCORI?
42. Have you or your team ever had your research funded by PCORI?
43. Which of the following are reasons that you have not applied for PCORI funding?
44. How difficult was it for you to respond to the following PCORI application criteria when proposing your study design?
45. What could PCORI do to encourage researchers to involve patients and health care providers as partners?

Feedback on Draft Researcher Survey

- Are we capturing the right domains? What additional information might we want from the researcher community?
- Target: Should we try to recruit researchers with low awareness of CER?

Thank you for your input!