

Update from Patient-Centered Outcomes Research Institute (PCORI)

Joe V Selby MD MPH
Executive Director

National Comparative Effectiveness Summit
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What's In a Name?



Understanding the choices patients face



Aligning research questions and methods with patient needs



Providing patients and providers with information for better decisions

MISSION STATEMENT

(adopted July 17, 2011)

The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed health care decisions – and improves health care delivery and outcomes – by producing and promoting **high integrity, evidence-based information – that comes from research guided by patients, caregivers and the broader health care community.**

Working Definition of PCOR

(posted July 2011)

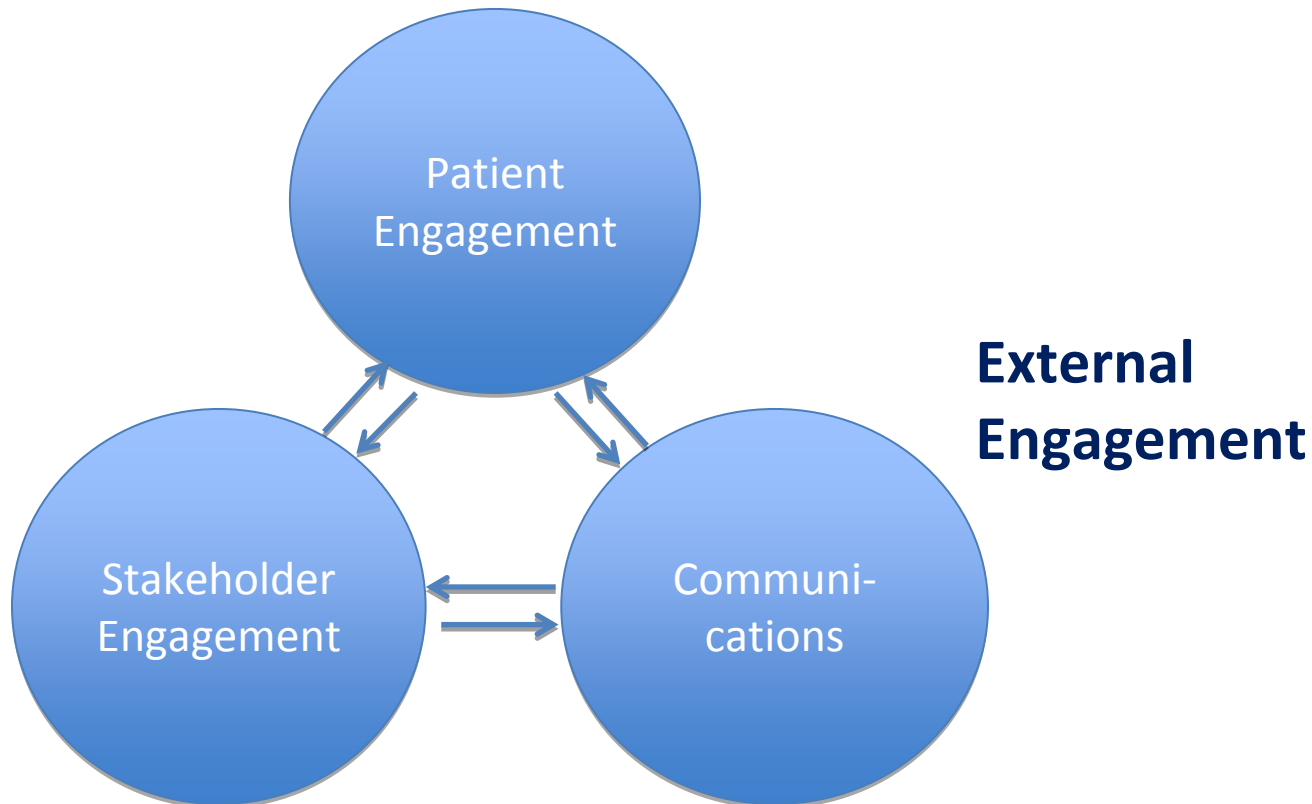
Patient-Centered Outcomes Research (PCOR) helps people make informed health care decisions and **allows their voice to be heard in assessing the value of health care options**. This research answers patient-focused questions:

1. “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
2. “What are my options and what are the benefits and harms of those options?”
3. “What can I do to improve the outcomes that are most important to me?”
4. “How can the health care system improve my chances of achieving the outcomes I prefer?”

Patient Engagement

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- Patient-Engagement Working Group formed
- Job Description for Director of Patient Engagement drafted and posted
- Directors of Stakeholder Engagement and Director of Communications added



Methodology Committee Structure

Methodology Committee

Co Chairs: Sherine Gabriel, MD, Mayo Clinic & Sharon-Lise Normand, PHD, Harvard Medical School

Report Assimilation

Patient-Centeredness

Methods to incorporate the patient perspective into all phases of PCOR

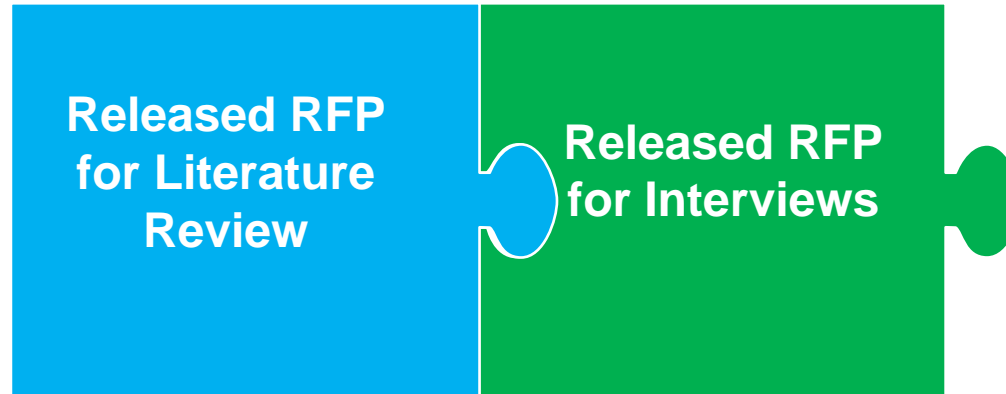
**Research
Prioritization**

Methods to inform prioritization of new research studies

Research Methods

Methods for using data, design, and statistical analyses to conduct PCOR

Patient Centeredness Workgroup Progress



Released RFP
for Literature
Review

Released RFP
for Interviews

“Review and Synthesis of Evidence for **Eliciting the Patient’s Perspective in Patient-Centered Outcomes Research**”

“Expert Stakeholder Interviews to Identify Evidence for **Eliciting the Patient’s Perspective in Patient-Centered Outcomes Research**”

PCORI Pilot Projects Areas of Interest

Developing, testing, refining, and/or evaluating new or existing methods (qualitative and quantitative) for **incorporating the perspectives of patients** or other stakeholders into the development of national priorities.

Developing, testing, and/or **refining existing methods for bringing together patients, caregivers, clinicians including non-traditional partners, and other stakeholders** in all stages of a multi-stakeholder research process, from the generation and prioritization of research questions to the conduct and analysis of a study to dissemination of study results

Developing, refining, testing, and/or evaluating **patient-centered approaches**, including decision-support tools, for translating evidence-based care into health care practice in ways that account for **individual patient preferences for various outcomes**.

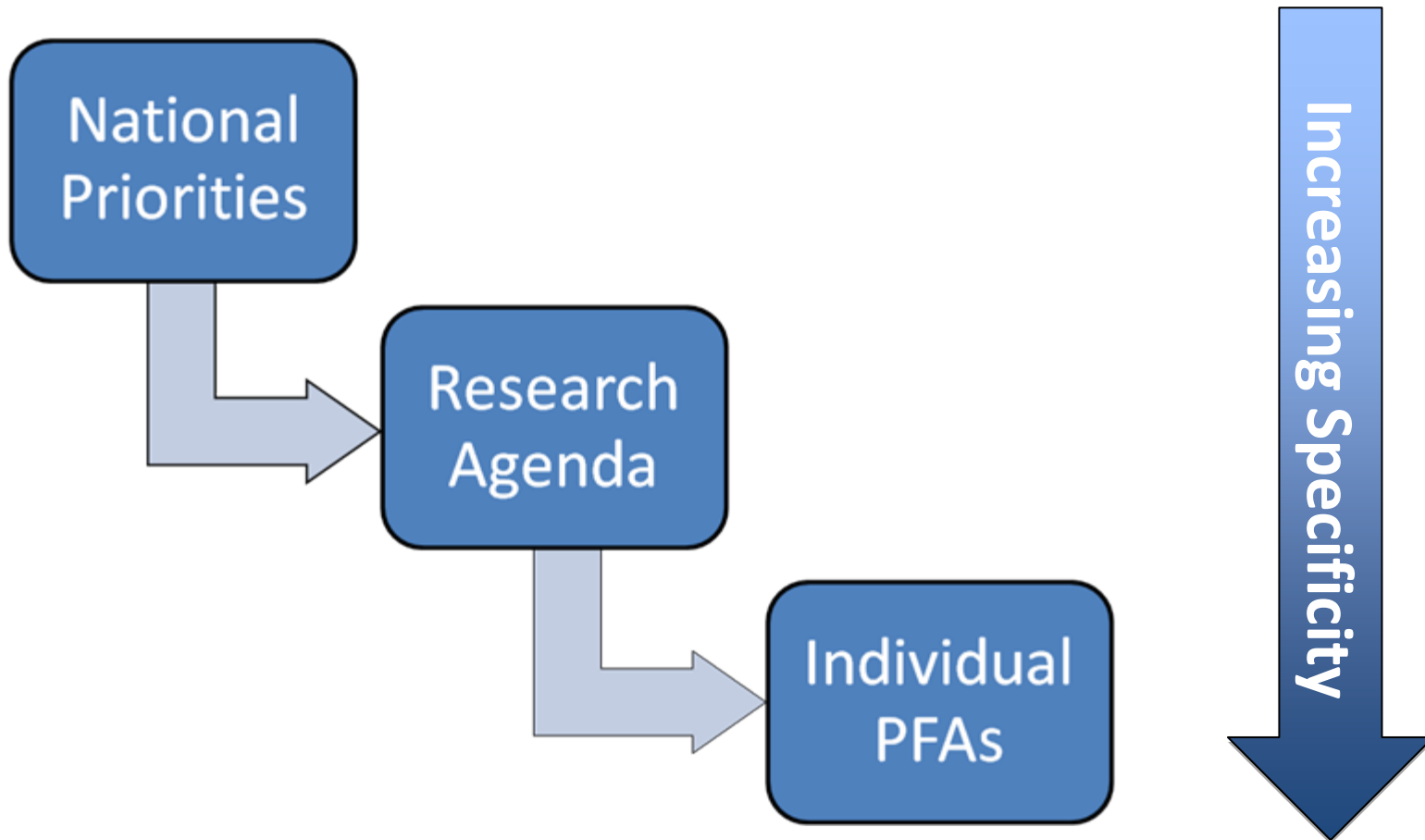
PCORI Pilot Projects Areas of Interest

Identifying, testing, and/or evaluating **patient-centered outcomes instruments**. This may include predictive tools (eg: instruments that measure or predict outcomes of interest to patients) or identifying standards for measurement properties of patient-reported outcomes.

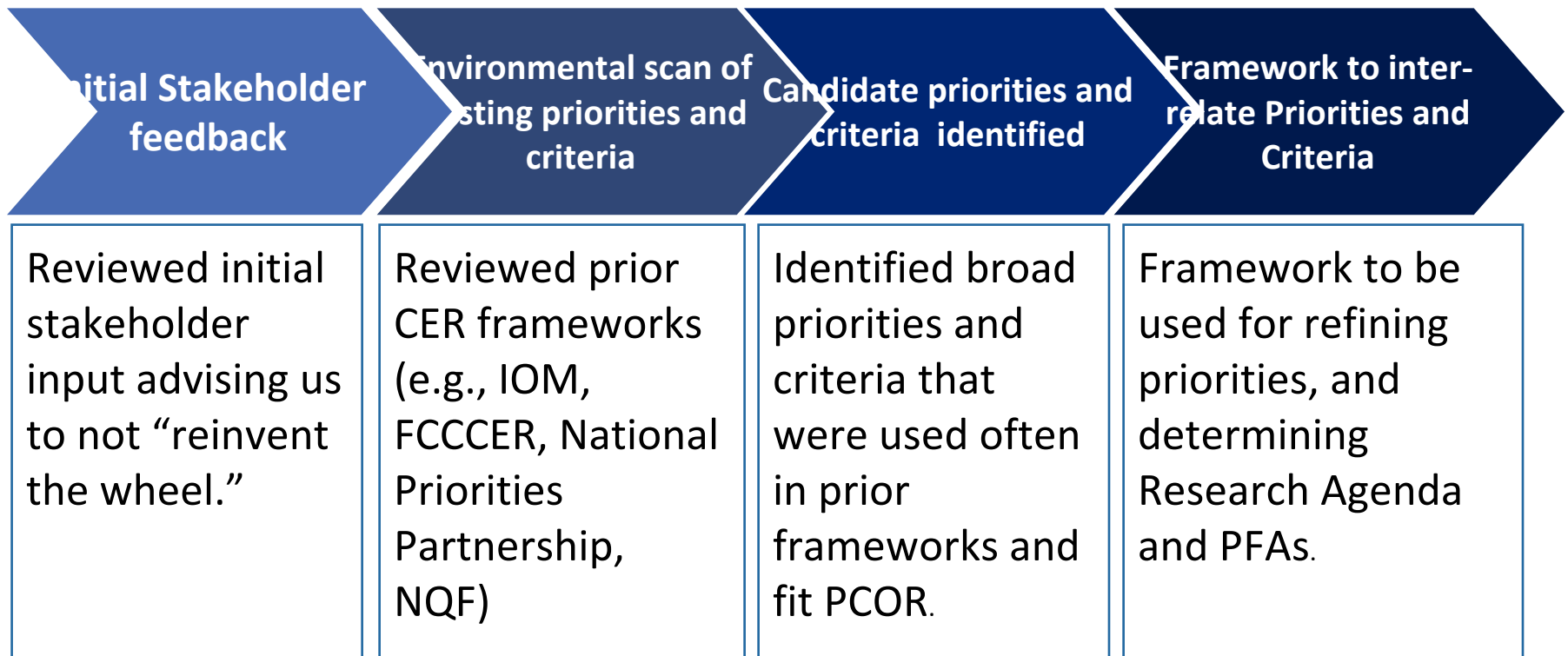
Identifying, testing, and evaluating methods that can be used to **assess the patient perspective** when researching behaviors, lifestyles, and choices within the patient's control that may influence their outcomes.

Identifying, testing, refining and/or evaluating methods for studying the **patient-care team interaction in situations where multiple options for wellness, prevention, diagnosis or treatment exist**.

Defining PCORI's National Priorities for Research is the critical beginning



Development of a National Priorities Framework



Ten candidate priorities consistent with prior efforts

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Source	Prevention	Acute Care	Chronic Disease Care	Palliative Care	Care Coordination	Patient Engagement	Safety	Appropriate Use	HIT to improve pt. experience	Impact of New Technology
IOM 2009: Priorities for CER	√		√	√	√	√	√	√	√	√
Federal Coordinating Committee for CER	√	√				√	√		√	
AHRQ National Quality Strategy	√		√			√	√			
AHRQ Effective Health Care Program	√	√	√	√	√			√		
National Quality Forum	√	√	√	√	√	√	√		√	
National Prevention Council	√					√				
National Priorities Partnership	√		√		√	√	√	√		

Framework to Develop PCORI National Priorities



Existing Priority Areas

- Prevention & Screening
- Acute Care
- Chronic Disease Care
- Palliative Care & Pain Management
- Care Coordination
- Patient Engagement
- Safety
- Appropriate Use
- Health Information to Improve Patient Experience
- Impact of New Technology

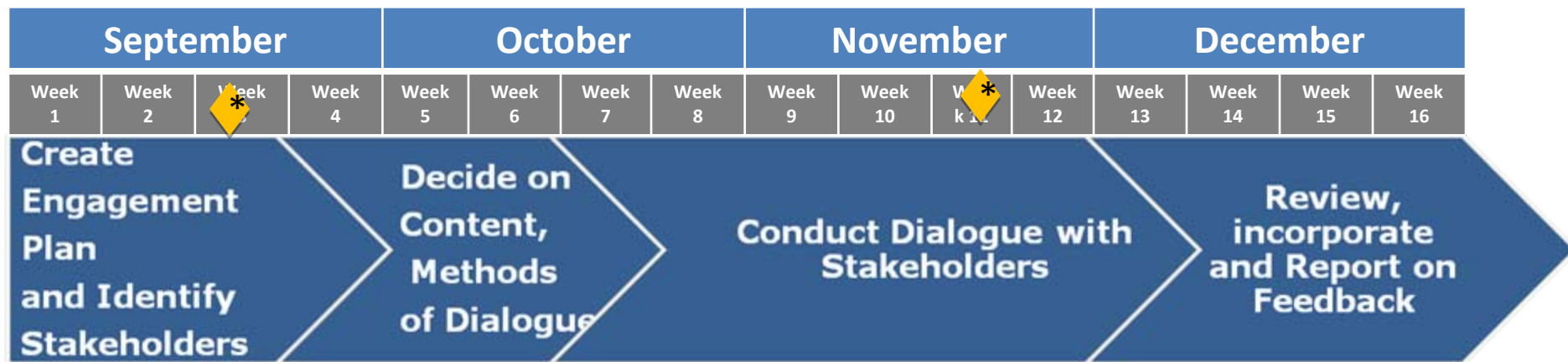
Proposed PCORI Criteria

- Impact on Health of Individuals and Populations
- Probability of Improvability via Research
- Inclusiveness of Different Sub-populations
- Current Gaps in Knowledge / Variation in Care
- Impact on Health System Performance
- Current Health Disparities
- Potential to Influence Decision-Making at Point of Care
- Responsiveness to Expressed Needs
- Advances CER Methods
- Fits the Definition of PCOR

In Statute

PCORI National Priorities

Proposed Stakeholder Engagement Timeline



 **Board Meetings**



pcori

Stakeholder Engagement - Guiding Principles

Balanced Representation

Obtain feedback from a diverse and representative range of patients, health care stakeholders and the general public

Transparency

Enable an open engagement process that makes clear how participants can get involved and how their input will be incorporated

Facilitate Participation

Provide easy, accessible forums for participants to provide feedback equitably

Who are PCORI's stakeholders?

Key Stakeholder Groups	
PATIENTS	PROFESSIONAL ORGANIZATIONS
<ul style="list-style-type: none"> Individuals with Illnesses Families Caregivers Patient Organizations/ Advocacy Groups General Public 	<ul style="list-style-type: none"> Providers & Practitioners Health Systems Employers Payers Research Community Federal/State/Local Government Congress Life Sciences Industry

To what extent will PCOR be CER?

- **Incorporating a stronger patient focus will help to ensure that:**
 - ✓ The questions are practical, and usually comparative
 - ✓ The variety of outcomes important to patients are not overlooked
 - ✓ The patients studied come from relevant settings and are representative
 - ✓ Possibilities of heterogeneity in effectiveness are examined

To what extent will PCOR be CER?

Questions in PCOR Definition	Is this CER?
“Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”	+/-
“What are my options and what are the benefits and harms of those options?”	+
“What can I do to improve the outcomes that are most important to me?”	+
“How can the health care system improve my chances of achieving the outcomes I prefer?”	+