

# Update from Patient-Centered Outcomes Research Institute (PCORI)

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Executive Director

**Advancing Comparative Effectiveness Research  
under Health Reform**

October 19, 2011



# 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)

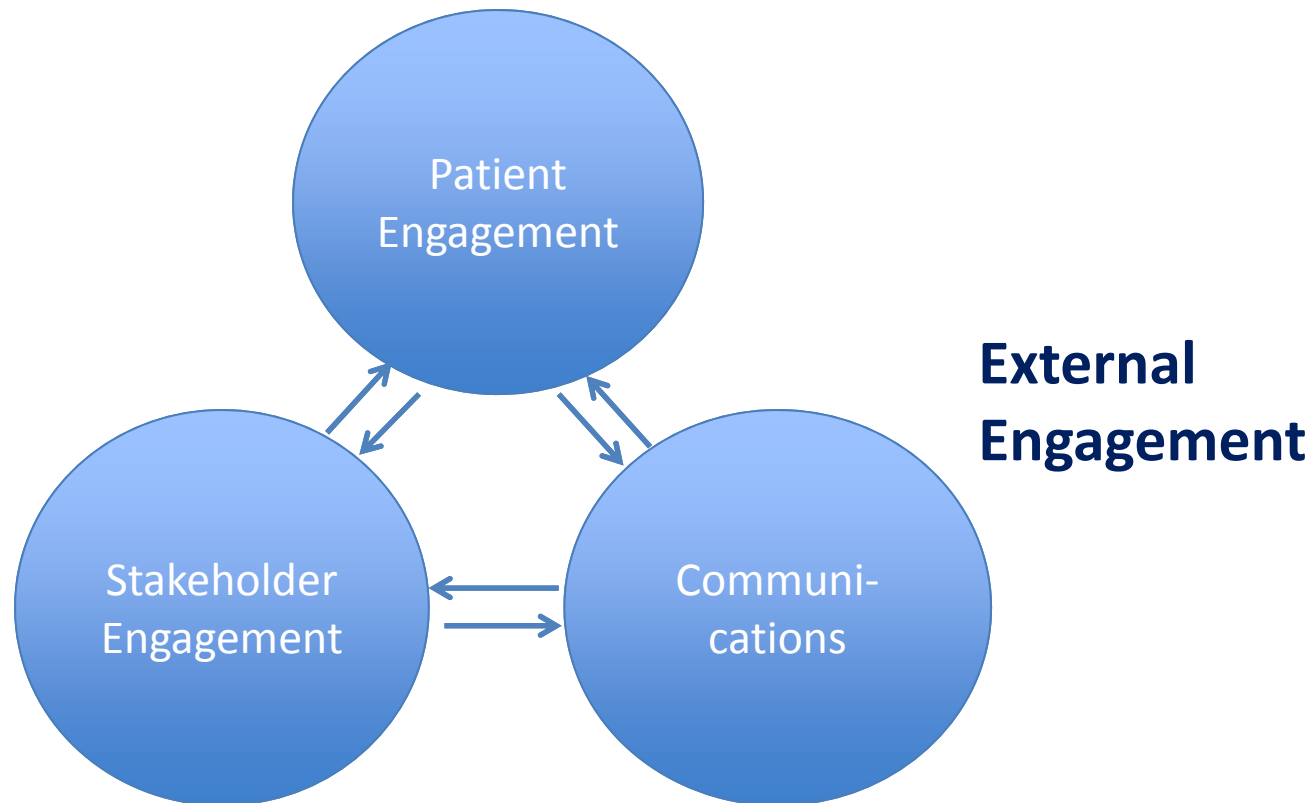
Patient-Centered Outcomes Research (PCOR) helps people make informed health care decisions and **allows their voice to be heard in assessing the value of health care options**. This research answers patient-focused questions:

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

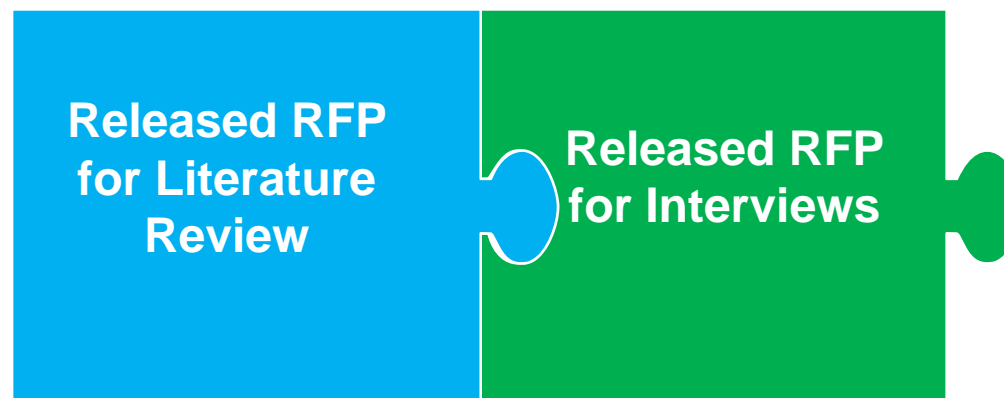
**Research Prioritization**

**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



“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

Due: 12/1/11



## 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

Due: 12/1/11

## 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**.

# To what extent will PCOR be CER?



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- **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

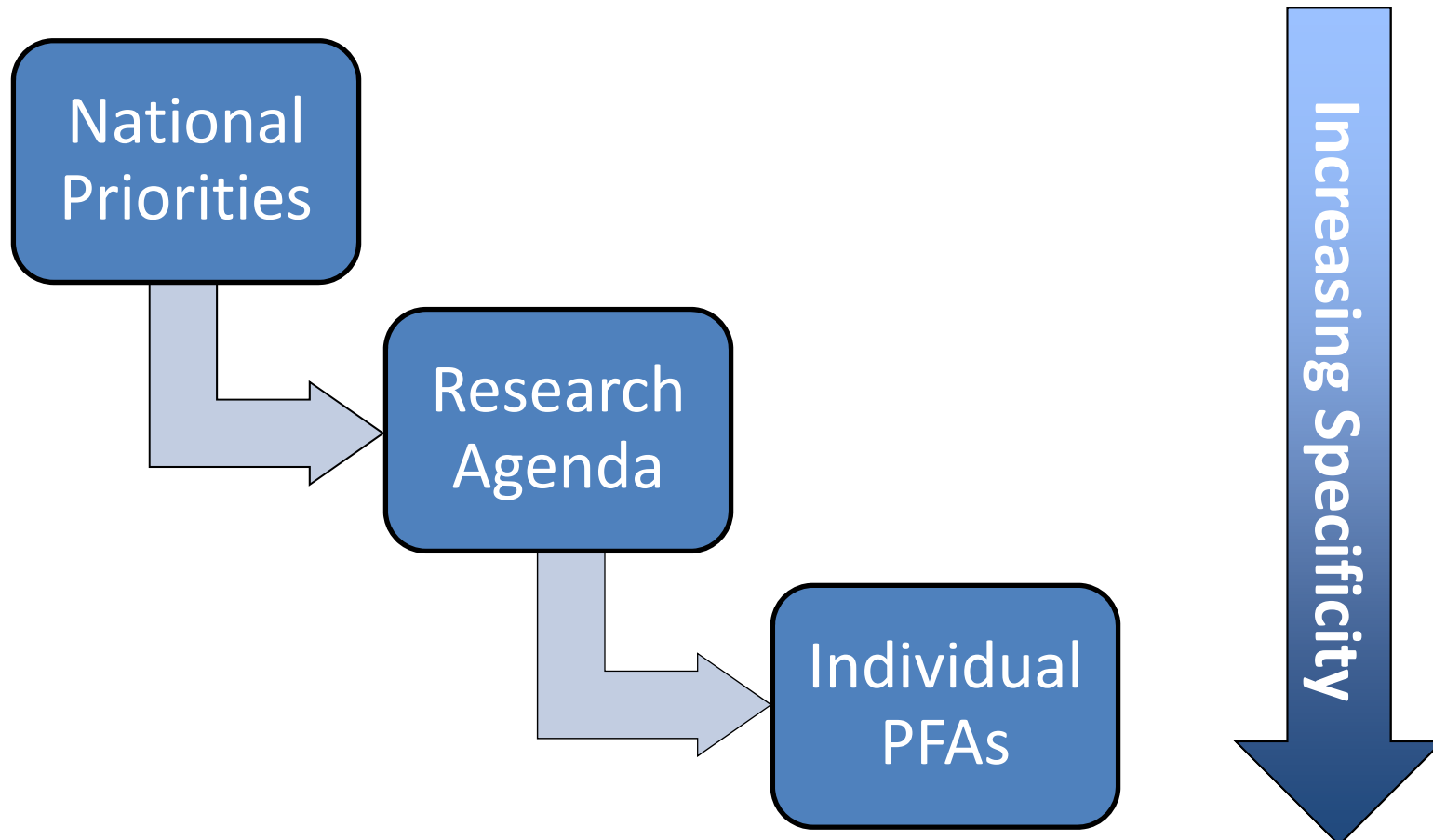
# To what extent will PCOR be CER?



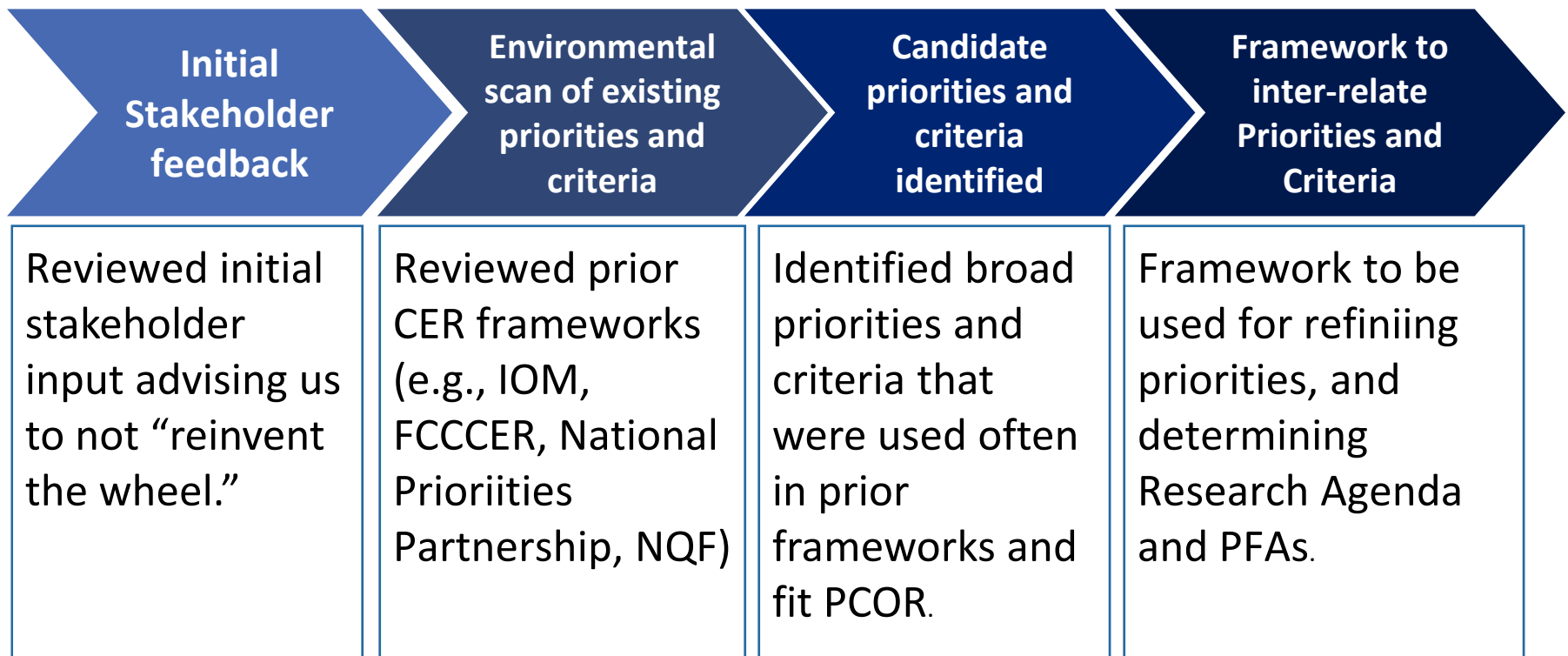
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Questions in PCOR Definition	Is this CER?
“Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”	+/-
“What are my options and what are the benefits and harms of those options?”	+
“What can I do to improve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

## 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 for Refining PCORI National Priorities and Developing Research Agenda



## Priority Themes

**Clinical Effectiveness**

**Patient-Centered Outcomes**

**Improving Healthcare Systems**

**Communication & Dissemination**

**Fairness / Addressing Disparities**

**Accelerating Patient-Centered Research**

## Proposed PCORI Criteria

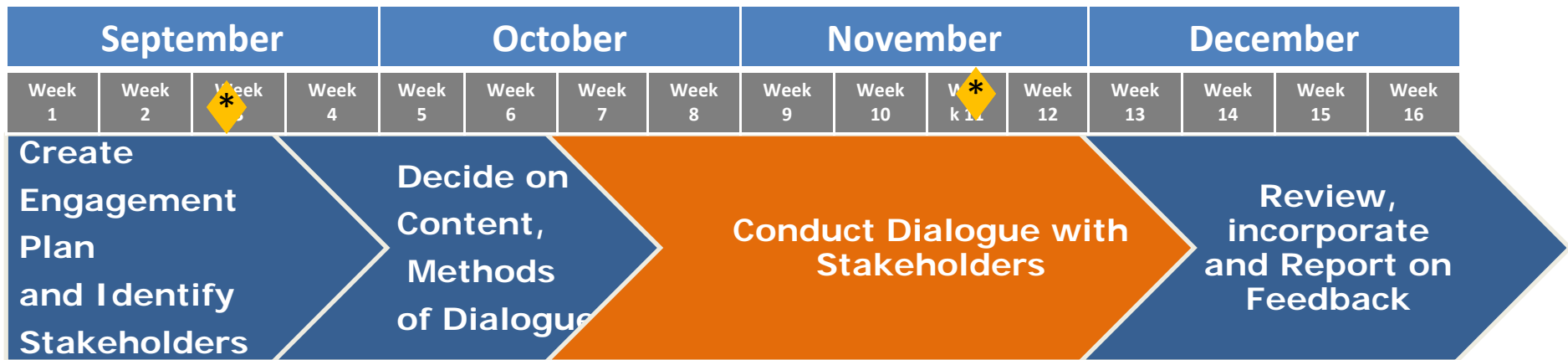
- Impact on Health of Individuals and Populations
- Probability of Improvability via Research
- Inclusiveness of Different Sub-populations
- Address Current Gaps in Knowledge
- Address Variation in Care
- Improved Health Care System Performance
- Current Health Disparities
- Potential to Influence Decision Making
- **Novel Use of Technology**
- **Efficient Use of Research Resources**

In Statute

PCORI  
Criteria

**PCORI Research Agenda**

# Proposed Stakeholder Engagement Timeline



\* Board Meetings



# Who are PCORI's stakeholders?



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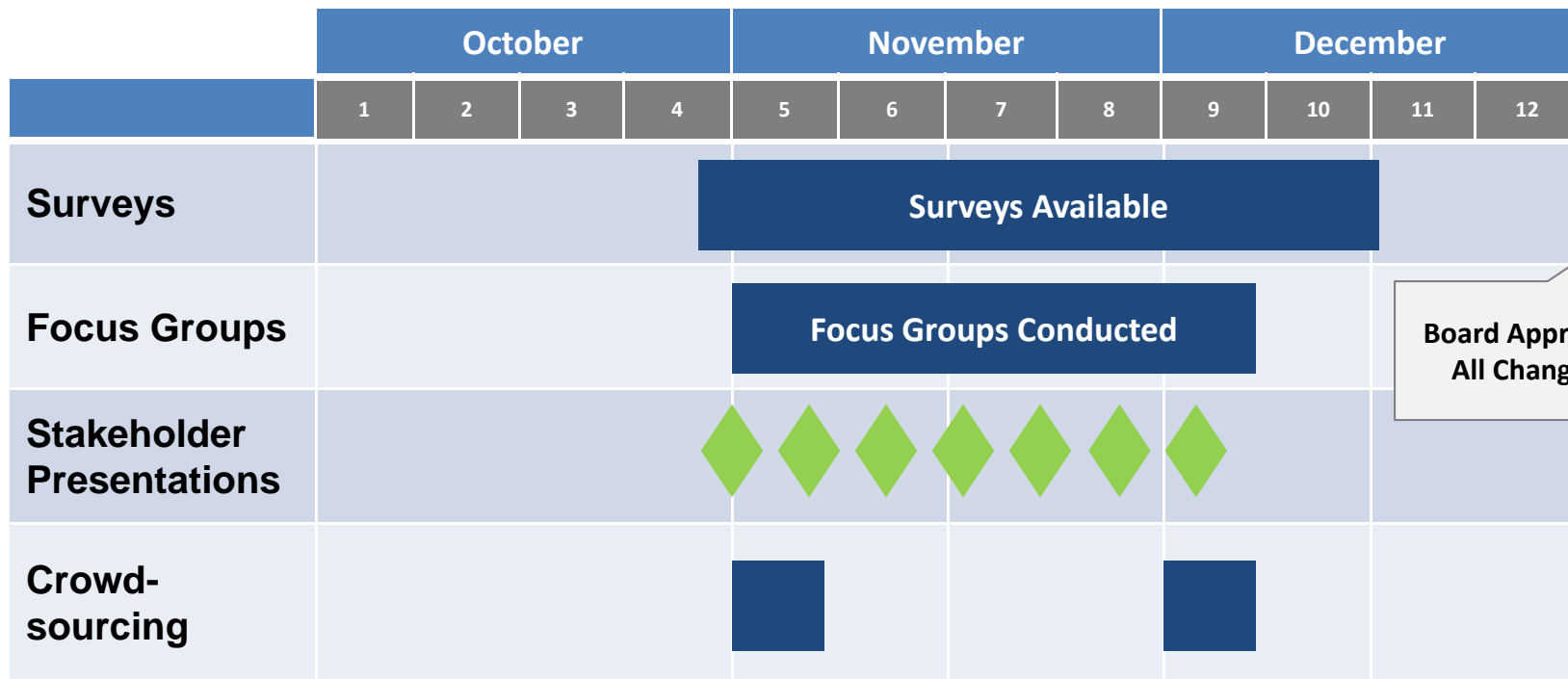
## Key Stakeholder Groups

PATIENTS	PROFESSIONAL ORGANIZATIONS
Individuals with Illnesses Families Caregivers Patient Organizations/ Advocacy Groups General Public	Providers & Practitioners Health Systems Employers Payers Research Community Federal/State/Local Government Life Sciences Industry

# Stakeholder Engagement - Methods and Timeline



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Board Approves All Changes



# Fundamental Questions on Research Agenda



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- Will PCORI's Research Agenda (and ?? funding announcements ) remain condition-neutral?
- To what extent will PCORI solicit and fund dissemination research- vs. effectiveness research?
- To what extent will PCORI invest in CER infrastructure - and what kinds?
  - Large clinical databases? Registries? Patient networks?
- To what extent will PCORI look to partner with NIH / AHRQ / Foundations to fund certain types of activities (e.g., ancillary studies associated with large clinical trials)?
- Will PCORI fund large clinical trials ourselves and if so, what proportion of the budget should be dedicated to this?
- How will PCORI address research on rare diseases? For example registry building to facilitate recruitment for clinical trials?