

# ADVISORY PANEL ON PATIENT ENGAGEMENT MEETING

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*Via GoToWebinar*

*Spring 2022 Meeting*

May 16, 11:30am-5:00pm EDT



# Welcome

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**Kristin Carman**

Director, Public & Patient Engagement

**Neely Williams**

Chair, Advisory Panel on Patient Engagement

**Karen Fortuna**

Co-chair, Advisory Panel on Patient Engagement



# Housekeeping



- Meeting is available to the public and is being recorded
- Members of the public are invited to listen to this teleconference and view the webinar
- No public comment period is scheduled
- A meeting summary and materials will be made available on PCORI's website following the meeting
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information on future activities

# GoToWebinar Housekeeping



- Attendees are in listen-only mode
- Submitting questions/comments (PCORI PEAP)
  - Type "I have a question/comment"
- Panelists (PCORI PEAP) can mute/unmute themselves and turn on/off camera
  - Please keep yourself on mute when not talking
- If you need to leave the meeting early, please send Lisa a note so we aren't concerned that you are having connectivity issues

# Advisory Panel on Patient Engagement



**Donald Adams, Jr.**

*Representing: Patients, Caregivers, and Patient Advocates*



**Geri Baumblatt**

*Representing: Patients, Caregivers, and Patient Advocates*



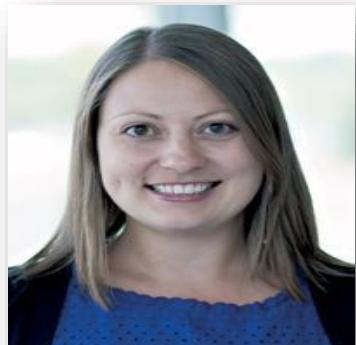
**Russell Bennett**

*Representing: Patients, Caregivers, and Patient Advocates*



**Jen Brown**

*Representing: Patients, Caregivers, and Patient Advocates*



**Beth Careyva**

*Representing: Researchers*



**Tracy Carney**

*Representing: Patients, Caregivers, and Patient Advocates*



**Karen L. Fortuna**

*Representing: Researchers*



**Crispin Goytia**

*Representing: Patients, Caregivers, and Patient Advocates*

# Advisory Panel on Patient Engagement



**Melody Goodman**

*Representing: Researchers*



**Una Lee**

*Representing: Clinicians*



**Lauren Lessard**

*Representing: Researchers*



**Margarita Holguin**

*Representing: Patients, Caregivers, and Patient Advocates*



**Alma McCormick**

*Representing: Patients, Caregivers, and Patient Advocates*



**Al Richmond**

*Representing: Patients, Caregivers, and Patient Advocates*



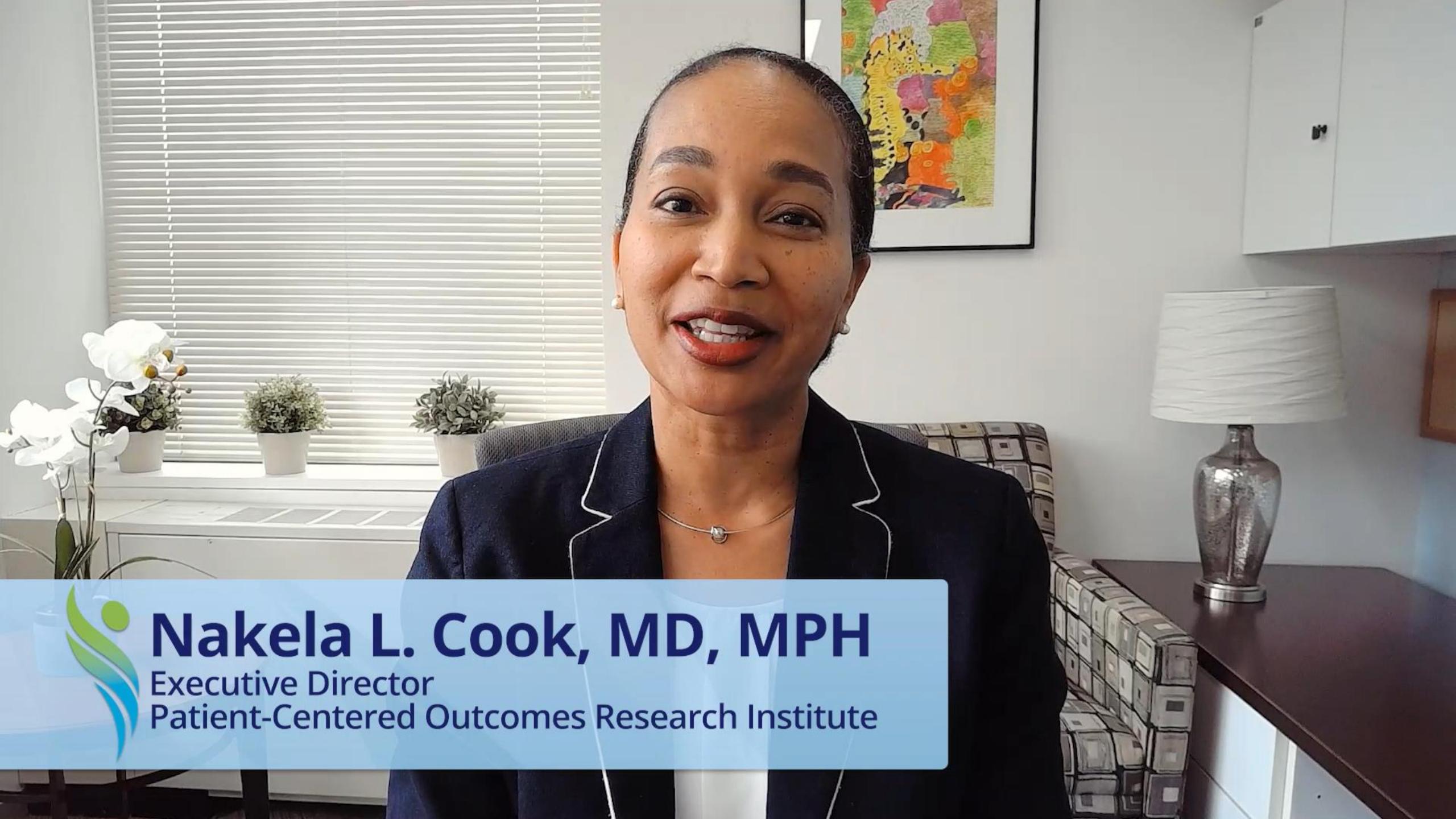
**Rupa Valdez**

*Representing: Researchers*



**Neely Williams**

*Representing: Patients, Caregivers, and Patient Advocates*



**Nakela L. Cook, MD, MPH**

Executive Director  
Patient-Centered Outcomes Research Institute

# The PCORI PEAP Team



**Kristin Carman**  
Director,  
Public and Patient  
Engagement



**Brendaly Rodríguez**  
Senior Engagement Officer,  
Public and Patient  
Engagement



**Meghan Berman**  
Program Associate II,  
Public and Patient  
Engagement



**Aleksandra Modrow**  
Program Manager,  
Public and Patient  
Engagement

# As per our Charter...



- “The Advisory Panel on Patient Engagement (PEAP) will advise and **provide recommendations** to PCORI’s Board of Governors, Methodology Committee, and staff to help plan, develop, implement, improve, and refine efforts toward meaningful patient-centered research.”
- “Members of the PEAP will assure the highest **patient engagement standards** and a **culture of patient-centeredness** in all aspects of the work of PCORI.”

# PEAP Chairs



**Neely Williams**

Chair

Administrator, Community  
Partners' Network, Inc

*Patients, Caregivers, and Advocacy  
Organizations*

[neely.williams1@gmail.com](mailto:neely.williams1@gmail.com)



**Karen Fortuna**

Co-chair

Assistant Professor of Psychiatry, Geisel  
School of Medicine at Dartmouth  
College

*Researchers*

[karen.l.fortuna@dartmouth.edu](mailto:karen.l.fortuna@dartmouth.edu)

# Agenda



## Part I (EDT):

- 11:30 AM – Opening Remarks and Roll Call
- 12:00 PM – Update on Strategic Planning: PCORI's Strategic Plan
- 12:30 PM – Stretch Break
- 12:45 PM – Update of the PCORI Engagement Rubric: Preliminary Findings for Discussion
- 2:15 PM – Lunch Break

## Part II (EDT):

- 2:45 PM – Healthcare Cost and Value: Addressing the Full Range of Outcomes
- 3:30 PM – Stretch Break
- 3:45 PM – PCORI Updates
- 4:15 PM – PEAPs in Action: Engagement Stories
- 4:45 PM – Announcements and Wrap-Up
- 5:00 PM – Adjourn

# Update on Strategic Planning

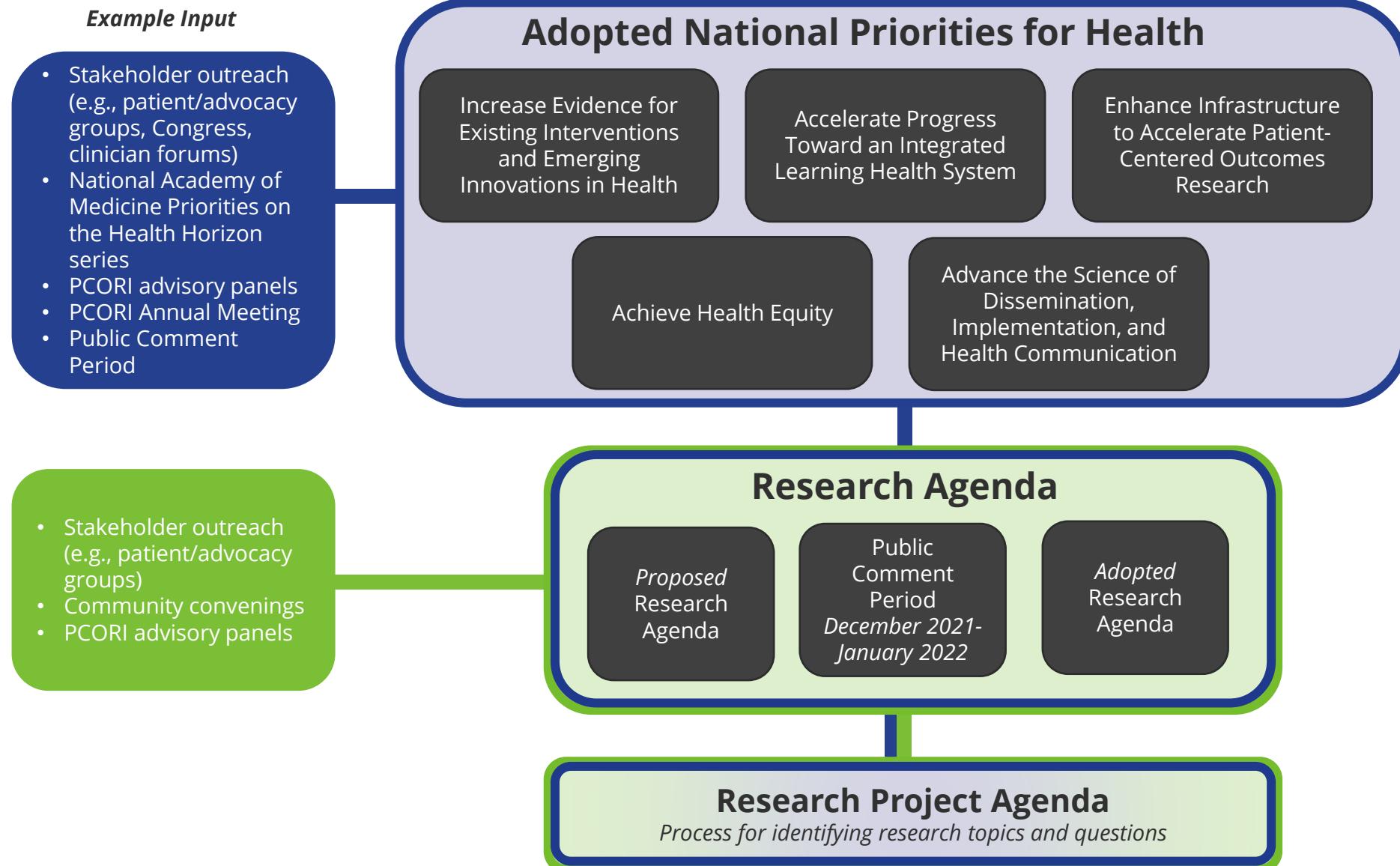
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## PCORI's Strategic Plan

Laura Lyman Rodriguez  
Deputy Executive Director for  
Strategy and Planning



# Stakeholder and Public Input Inform Work



# Adopted National Priorities for Health

## Increase Evidence for Existing Interventions and Emerging Innovations in Health

**Goal:** Strengthen and expand ongoing comparative clinical effectiveness research focused on both existing interventions and emerging innovations to improve healthcare practice, health outcomes, and health equity.

## Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research

**Goal:** Enhance the infrastructure that facilitates patient-centered outcomes research to drive lasting improvements in health and transformation of both the research enterprise and care delivery.

## Advance the Science of Dissemination, Implementation, and Health Communication

**Goal:** Advance the scientific evidence for and the practice of dissemination, implementation, and health communication to accelerate the effective sharing of comparative clinical effectiveness research results for public understanding and uptake into practice.

## Achieve Health Equity

**Goal:** Expand stakeholder engagement, research, and dissemination approaches that lead to continued progress toward achieving health equity in the United States.

## Accelerate Progress Toward an Integrated Learning Health System

**Goal:** Foster actionable, timely, place-based, and transformative improvements in patient-centered experiences, care provision, and ultimately improved health outcomes through collaborative, multisectoral research to support a health system that understands and serves the needs and preferences of individuals.

# When We Last Communicated



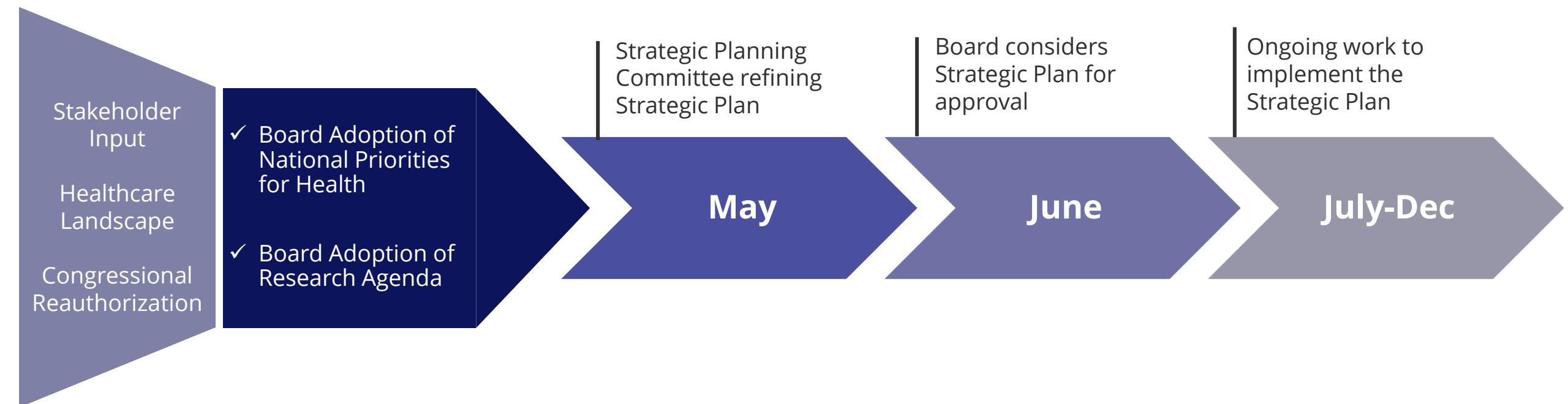
- This panel considered the proposed Research Agenda and how it could support a research portfolio to meet current and future needs. Feedback was provided via survey- thank you!
- Panel members shared insights regarding PCORI's future work including:
  - It is important for health equity to be embedded throughout the research cycle including those developing, supporting, and leading the research
  - Representation matters when it comes to those conducting the research and those participating in the research.
  - Collaboration across organizations, disciplines, and data, will be a key aspect for advancing the work.
- This was integrated with input from other convenings, meetings, and discussions.

# Adopted Research Agenda

Fund comparative clinical effectiveness research that:

- Fills patient- and stakeholder-prioritized evidence gaps and is representative and inclusive of diverse and underrepresented patient populations and settings
- Advances the achievement of health equity and elimination of disparities with an emphasis on overcoming the effects on health and healthcare outcomes of racism, discrimination, and bias
- Builds the evidence base for emerging interventions by leveraging the full range of data resources and partnerships
- Examines the diverse burdens and clinical and economic impacts important to patients and other stakeholders
- Focuses on health promotion and illness prevention by addressing health drivers that occur where people live, work, learn, and play
- Integrates implementation science and advances approaches for communicating evidence so the public can access, understand, and act on research findings

# Anticipated Timeline



# Developing a Comprehensive Approach



- Core Strategic Plan document
- Digital format (e.g., clickable, interactive webpages)
- Printable “at-a-glance” handouts (e.g., two-page PDFs)

## Accessibility



- Demonstrate how PCORI achieves its mission
- Opportunity for stakeholders to see themselves in PCORI's vision
- Serve as a communication tool
- Serve as the basis for PCORI's next phase

## Purpose



- Patients and caregivers
- Researchers and clinicians
- Congress and GAO
- Healthcare purchasers, payers, industry, hospitals and other health systems
- Broader health community

## Audiences



# Outline of Substantive Components in Strategic Plan



- **Introduction and A Bold Vision for PCORI's Second Decade**
  - Shares, briefly, PCORI's history and how we envision continuing our work such as the continued importance of diversity, equity, and inclusion and being responsive to an evolving health care and research landscape
- **A Holistic Approach to Generating and Disseminating Patient- Centered CER**
  - Describes a comprehensive set of activities (e.g., funding CER, engagement, D&I, infrastructure) that flow from the National Priorities for Health and facilitate the generation and dissemination of evidence to improve clinical decision making
  - Includes the National Priorities for Health and Research Agenda
- **Measuring Success and Monitoring Progress**
  - Provides general approach for assessing PCORI's progress towards the National Priorities for Health

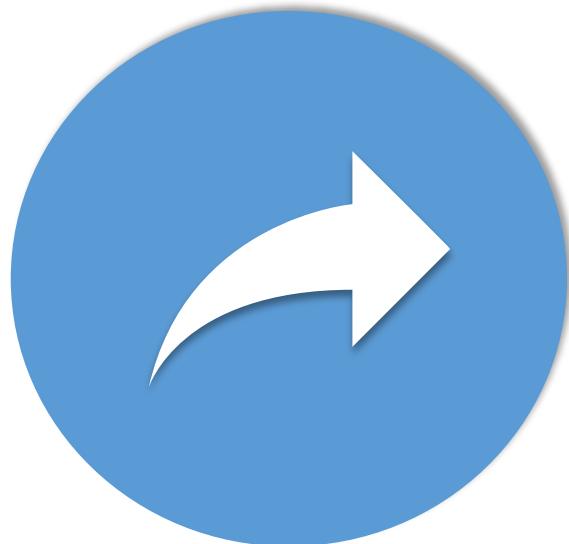
# Moving Towards Implementation Planning



- We are excited to *begin discussions* with Advisory Panels related to implementation planning. To start, we would like your input on strategic opportunities related to the Strategic Plan and Research Project Agenda (RPA).
- We are particularly interested in hearing about promoting an effective, transparent process for developing the RPA. Currently, this is in a *transition* and we are considering opportunities to revise the process with an eye towards enhancing ability to be *nimble, adaptive, and responsive* to changes in the health environment.
- Aim for Research Project Agenda process that is:
  - Stakeholder-Driven
  - Responsive
  - Transparent
  - Systematic
  - Efficient



# Anticipated Next Steps



- Use feedback garnered from discussions to inform our process considerations along with actionable steps for implementation
- Share update on process development with this panel at a future meeting

# Beginning Discussions to Help Inform Implementation Planning



- What are meaningful ways to engage with stakeholder communities represented on this panel to solicit ideas and inform topic development (e.g., convenings, surveys, webinars)?
- How would a responsive, transparent Research Project Agenda development process be reflected from your perspective?
- How could PCORI demonstrate relevance to stakeholder communities represented by this panel?
- Are there innovative ways you see organizations tracking community needs and concerns?



# Stretch Break

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12:30- 12:45pm EDT



# Update of the PCORI Engagement Rubric

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Preliminary Findings for Discussion

Kristin L. Carman  
Director, Public & Patient Engagement

Michelle Johnston-Fleece  
Senior Program Officer, Public & Patient  
Engagement



# Engagement Rubric



## Planning the study



## Conducting the study



## Disseminating study results

### POTENTIAL ACTIVITIES

- Developing research questions
- Selecting relevant outcomes
- Define study population characteristics

### POTENTIAL ACTIVITIES

- Drafting or revising study materials
- Participating in study recruitment
- Participating in data analysis

### POTENTIAL ACTIVITIES

- Identifying partners for dissemination
- Participating in dissemination efforts
- Presenting information about the study

### REAL-WORLD EXAMPLES

- Patient organization surveys members on treatment preferences
- Clinicians suggest a third arm to study based on variability in practice

### REAL-WORLD EXAMPLES

- Patients develop informed consent to make it understandable to participants
- Patient representative serves on data safety monitoring board

### REAL-WORLD EXAMPLES

- Research team holds stakeholder summit to speed implementation of findings
- Research team introduces study at a patient advocacy conference to inform community of the research



### PCOR Principles

Reciprocal Relationships • Co-Learning • Partnerships • Transparency, Honesty, Trust

**Reciprocal Relationships:** Demonstrated when roles and decision-making authority of all research partners are defined collaboratively and clearly stated

**Co-Learning:** Researchers help patient partners better understand the research process, and researchers will learn about patient-centeredness and patient/stakeholder engagement

**Partnerships:** The time and contribution of patient and other stakeholder partnership is valued and demonstrated through compensation, cultural competency, and appropriate accommodations

**Transparency, Honesty, Trust:** Major decisions are made inclusively and information is shared readily among all research partners

# Engagement Rubric Update

- The [Engagement Rubric](#) was originally developed in 2014 to provide Awardees with *guidance* on **how** and **when** to engage stakeholder partners.
- The next version of the Engagement Rubric will:
  - Be a **cross-departmental and multi-stakeholder** effort
  - **Use knowledge developed** in the natural laboratory created during PCORI's first ten years
  - **Address facilitators and barriers** to engagement
  - Provide **guidance and tools** to support engagement
  - Reflect PCORI's **key priorities for advancing engagement** – both within PCORI and in the field, including diversity, equity & inclusion



The ultimate goal of the Rubric is to promote and support meaningful and sustainable engagement in CER/PCOR, and to influence research to be more patient-centered, relevant, and useful.

# Update of the PCORI Engagement Rubric

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## Preliminary Findings for Discussion

**Tania Dutta**

Senior Researcher, AIR

**Melissa Henry**

Senior Technical Assistance Consultant, AIR

**Jennifer O'Rourke Lavoie**

Patient Partner

**Lee Thompson**

Principal Technical Assistance Consultant, AIR

# Agenda

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1. Provide an overview of the project including the role of the PEAP
2. Share preliminary themes from an environmental scan on “external” engagement guidance
3. Share a draft vision for the updated PCORI Engagement Rubric (referred to as updated Rubric)
4. Engage in interactive discussion throughout

# What Do We Want to Achieve Today?

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Engage in **bi-directional sharing and learning** to shape updates to the PCORI Engagement Rubric.

- What do researchers and stakeholders need to work together on teams and on projects?
- What is most relevant to include in the updated Rubric?
- What should the updated Rubric do and for whom?

# About the Project

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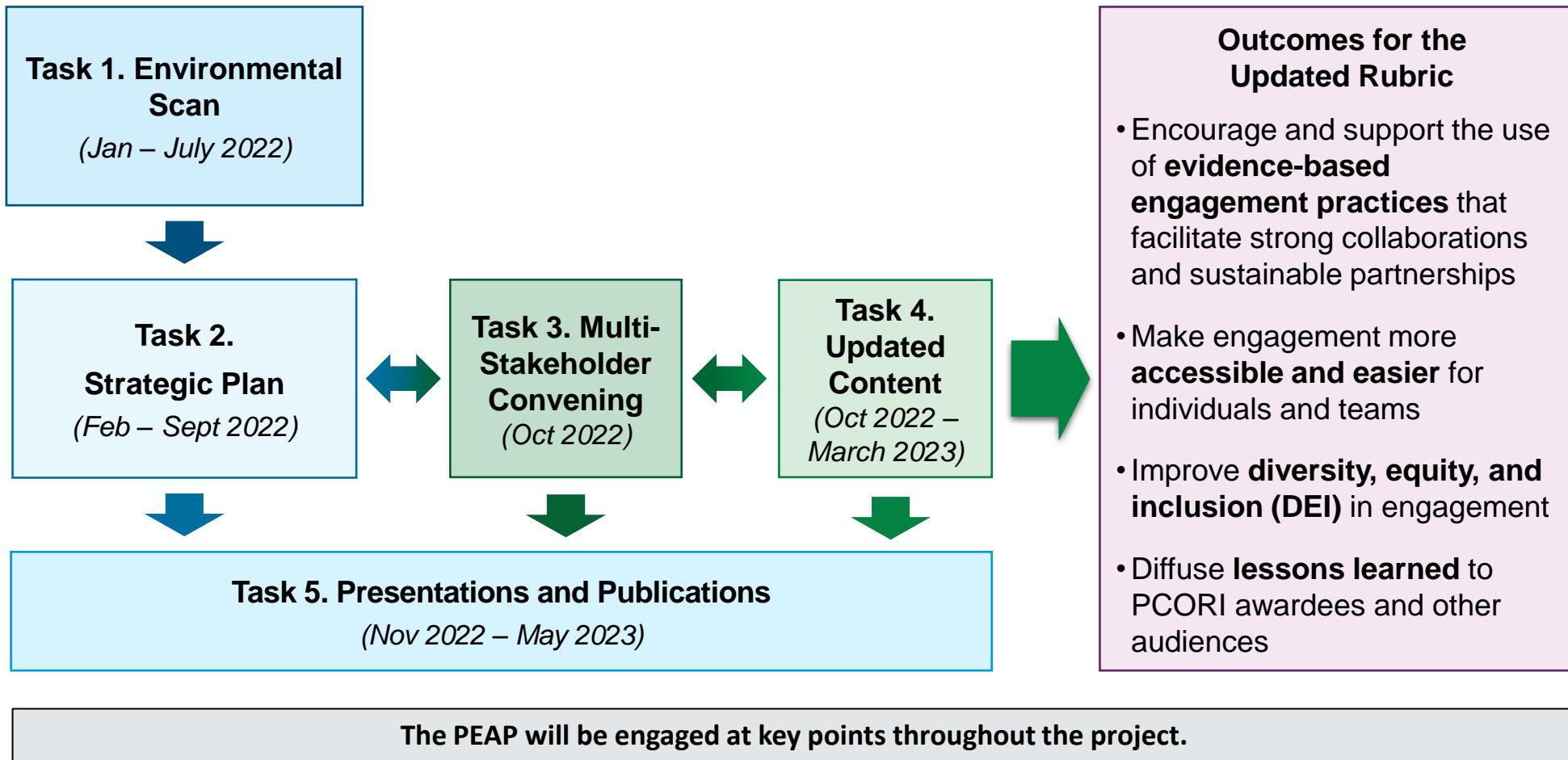
# Project Goal and Objectives

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- **Goal:** Update the PCORI Engagement Rubric to reflect growing knowledge and experience within the field since 2014 (when the Rubric was first released)
- **What does PCORI want to accomplish with the updated Rubric?**
  - Provide **stronger and practical evidence-based guidance** on how and where PCORI awardees can engage with stakeholders
  - Encourage and support **sustainable and equitable partnerships** between researchers and stakeholders
  - Model a **collaborative and stakeholder-driven process** to update the Rubric
  - Demonstrate PCORI's **leadership** in the field of engagement and **commitment** to diversity, equity, and inclusion (DEI)

The ultimate goal is to **promote and support meaningful and sustainable engagement** in CER/PCOR, and to **influence research to be more patient-centered, relevant, and useful**.

# Overview



# Task 1. Environmental Scan

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# Task 1. Environmental Scan

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**Goal:** To examine engagement policies, requirements, and guidance external to PCORI to understand their relevance to PCORI-funded research and inform the process of updating Rubric.

## Research Questions:

1. What guidance related to engagement is most relevant to PCORI-funded research?
2. How has engagement guidance been implemented, including barriers, facilitators, and lessons learned?
3. What has been the impact of such guidance?
4. What are the gaps related to engagement in research?

## Activities:

- Literature review of external guidance
- Up to 30 key informant interviews (KIIs) with engagement and DEI experts
- 4 focus groups with PCORI research and engagement awardee PIs and patient partners

# Preliminary Findings about External Guidance

Most of the guidance comes as **guidelines and recommendations** and emphasizes the need to amplify patient and stakeholder voices throughout the research process. Stakeholders are involved in developing and communicating engagement guidance.

Barriers to Using Guidance	Facilitators to Using Guidance
<ul style="list-style-type: none"><li>• Cost and time burden on stakeholders</li><li>• Limited funding</li><li>• Limited knowledge of and/or practice in engagement by researchers</li><li>• No requirement or incentive for researchers to engage</li></ul>	<ul style="list-style-type: none"><li>• Monetary and practical support for patients and stakeholders</li><li>• Building trust through respect and transparency</li><li>• Training researchers and stakeholders on how to implement the guidance</li></ul>

# Preliminary Findings about Gaps or Needs the Updated Rubric Could Address

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1. Provide information about the **minimum time and resources** it takes to “do” engagement with options at each phase
2. Provide **just-in-time resources** for stakeholders and patient partners
3. “Champion” **equity** in engagement
4. Communicate the **value of engagement in research**
5. Need resources and guidance to effectively engage with **diverse stakeholders**

# Discussion

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1. What are your **reactions** to these preliminary findings?
2. In what ways could these preliminary findings **inform** updates to the Rubric?
3. What **additional information** would be helpful to identify and/or highlight to inform updates to the Rubric?

# Task 2. Strategic Plan

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# About the Strategic Plan

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- **Purpose:** Facilitate strategic discussions to determine how to build on the current PCORI Engagement Rubric using:
  - Guidance identified in the environmental scan report
  - A synthesis of PCORI's research and resources on engagement
  - PCORI staff's practice-based experience with engagement in research
- **Outcome:** A strategic plan that aligns with PCORI's goals, mission, standards and values and will be used to guide the convening and content development

# Key Questions

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The strategic planning process is intended to answer these questions:

1. Who are the **intended audiences**—both internal and external to PCORI—of the updated Rubric content?
2. How should the updated Rubric content be conceptualized and expanded to **meet current and future needs** and advance the science of engagement?
3. How **prescriptive** should the updated Rubric content be to successfully communicate PCORI’s expectations for engagement and help PCORI awardees meet these expectations?
4. What **formats** should be used to present the updated Rubric to meet the needs of different audiences?

# Assessment of Current Rubric (by PCORI staff)

Strengths	Limitations
Is simple, clear, easy to understand and follow, and accessible	Too simple; does not account for nuances of engagement, such as study type, award type, and various types of stakeholders
Makes the process of engagement clear, especially for new PIs	Focuses more on transactions between researchers and stakeholders rather than relationships that happen over time
Provides a framework or map for engagement with “guardrails”	Does not provide specific guidance on what research teams should do to practice meaningful engagement (which leads to variation and can create burden)
Explains PCORI’s engagement principles clearly and concretely with actionable, real-world examples	Assumes researchers have already engaged with and developed relationships with patients and other stakeholders; does not address how to identify and develop relationships with partners (pre-engagement)
Can be used by multiple audiences for multiple purposes (e.g., to influence funders to be more patient-centered)	Does not help users with important actions, such as getting started, applying the information, or addressing specific engagement-related problems
	Is static and does not allow users to filter or interact with it to find the most relevant information (such as an evidence map)
	Does not include enough information related to diversity, equity, and inclusion

# Goals of the Updated Rubric

The goals of the updated Rubric are to: (1) promote and support meaningful and sustainable engagement in CER/PCOR and (2) influence research to be more patient-centered, relevant, and useful

- The updated Rubric will achieve these goals by:
  - **Communicating what PCORI means** by meaningful engagement
  - **Encouraging and inspiring research teams to engage diverse stakeholders** in ways that reflect PCORI values and principles
  - **Supporting bi-directional learning** to continue to build the evidence base for engagement

# Intended Audiences and Potential Uses of the Updated Rubric

Audience	Use
<b>PCORI applicants and awardees</b>	Understand PCORI's expectations for engaging stakeholders and what success looks like from both the researcher and the stakeholder perspective
<b>PCORI staff</b>	Promote a shared understanding of engagement so that staff can help awardees problem-solve
<b>External audiences</b>	Promote and advance the science of engagement

# Guidance in the Updated Rubric

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- The updated Rubric should provide information and guidance that addresses what, why, and how including:
  - principles;
  - considerations in addressing those principles; and
  - different options or actions to implement the principles.
- Guidance should be illustrated by real-world examples that address common engagement challenges and represent the diversity of stakeholders engaged and topics that PCORI funds.
- The updated Rubric should also include links to relevant resources.

# Examples of Minimum Expectations

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- Research teams should use a variety of methods to engage with stakeholders.
- Stakeholder partners should be reflective of the population(s) being studied and impacted by the study, including those who may be “outside” of the healthcare system.
- Research teams should decide together how decisions will be made.
- Research teams should regularly evaluate its engagement plan and activities.
- All team members – researchers and partners – should receive appropriate training to support them in their roles.
- All stakeholder partners should be compensated equitably.

# Discussion

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1. What **minimum expectations** for engagement should the updated Rubric communicate?
2. What should be **expectations v. guidance v. considerations** (e.g., must, should, could)?
3. How should PCORI **communicate** these expectations (e.g., requirements)?
4. What should the updated “Rubric” **be** (e.g., format, name) to encourage accountability and innovation among new and more experienced teams?



Advancing Evidence.  
Improving Lives.

## Lee Thompson

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# Lunch Break

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2:15- 2:45pm EDT



# Healthcare Cost and Value

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Addressing the Full Range of Outcomes

Greg Martin  
Acting Chief Engagement & Dissemination Officer

Kristen Giombi  
Research Economist, RTI International

Olga Khavjou  
Research Economist, RTI International



# Agenda

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# Agenda



- Overview of PCORI Activity
  - Greg Martin, Acting Chief Engagement and Dissemination Officer
- Current Learnings
  - Olga Khavjou/Kristen Giombi, RTI
- Discussion

# Overview

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## PCORI Approach to Healthcare Cost and Value: Framework for Activities

### Collection of the Full Range of Outcomes

PCORI can ensure the appropriate and relevant data are identified and collected in PCORI awards

Support broadening of PCORI guidance to awardees through literature reviews, patient & stakeholder focus groups to clarify types of potential burdens, costs, and economic impacts to be included in PCORI-funded research, and data sources

Develop guidance for capture of specific types of potential burdens or costs consistent with a patient-centered perspective, as a basis for PCORI guidance to awardees and the field

### Informing the Value Conversation

PCORI can help advance patient-centered approaches to the value conversation by supporting understanding of stakeholder perspectives on what constitutes “patient-centered value”

Conduct a landscape review of current stakeholder statements, perspectives, and frameworks around value

Convene patient and stakeholder groups to identify the components or attributes necessary in “patient-centered value”

### Supporting Policy Priorities

PCORI can consider undertaking specific activities that contribute to priority policy goals (i.e., generating evidence to inform healthcare value discussions)

Consider placing an emphasis on research focused on emerging technologies/therapies

Consider building upon evidence synthesis capabilities to provide more timely information

# Update on Activities and Deliverables

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## Landscape Review

- How are different stakeholder communities defining “patient-centered value”?
- Where are the similarities and where are the differences?

# Value Attributes

Category	Attribute	Patients/ caregivers	Clinicians	Policymakers	Payers	Purchasers	Life Sciences Industry	Hospital/ Health System	Researchers/ Funders	Number of Stakeholders
Life and social impact	Emotional/mental status/well being	36							31	2
	Fatigue									2
	Physical abilities/well being/independence									2
	Insurance value (physical and financial risk)									1
	Future planning							5		2
								20		
		36	22	7	10	10	5	20	31	

# Informing the Value Conversation



## Identifying the Components of Patient-Centered Value

- What does patient-centered value mean to different communities?
- What elements, attributes, or components do different stakeholders consider to be part of value measurement?

# Discussion

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# Questions for the Panel



- Do the direction, activities, and goals resonate with you?
- Will the activities meet the informational needs of your stakeholder community?
- What additional considerations should be kept in mind as we proceed?

# Stretch Break

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3:30– 3:45pm EDT



# PCORI Updates

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**Kate Boyd**

Senior Program Officer, Eugene Washington PCORI Engagement  
Awards

**Courtney Clyatt**

Senior Program Officer, Eugene Washington PCORI Engagement  
Awards

**Michelle Johnston-Fleece**

Senior Program Officer, Public & Patient Engagement

**Karen Martin**

Director, Eugene Washington PCORI Engagement Awards



# Science of Engagement Initiative

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Michelle Johnston-Fleece  
Senior Program Officer, Public &  
Patient Engagement



# Science of Engagement Initiative



## Key Questions to Be Answered

- **What defines successful engagement, and for whom?**
- **How can engagement be measured? What indicates that a study is patient-centered?**
- **What are the approaches that support and achieve successful engagement, particularly for underrepresented populations?**
- **Under which conditions do approaches work best, and how should they be modified and resourced for different contexts, settings, and communities?**
- **Which approaches should be combined to achieve engagement aims?**

## First PFA Priority Areas

**Development and/or validation of measures, including rapid measure development**, to capture structure/context, process, and outcomes related to both engagement and research, from both the stakeholder and investigator perspective.

**Development and/or testing of engagement approaches** to generate evidence on which specific aspects of engagement are most effective, either alone or in combination, and how effectiveness varies by context, particularly for underrepresented populations.

## Key Dates

### **ONLINE SYSTEM OPENS**

- July 12, 2022; 9am (ET)

### **TOWN HALL**

- July 19, 2022, 12 – 1pm (ET)

### **LETTER OF INTENT DEADLINE**

- August 9 by 5pm (ET)

### **APPLICATION DEADLINE**

- November 15 by 5pm (ET)

### **MERIT REVIEW**

- Late February/early March 2023

### **AWARDS ANNOUNCED**

- TBD

### **EARLIEST START DATE**

- TBD

## Funds and Project Period

### **FUNDS AVAILABLE: UP TO \$4.5M**

- Rapid Measurement Studies: Up to \$1.5M
- Development and Testing of Engagement Approaches: Up to \$3M

### **TOTAL DIRECT COSTS**

- Rapid Measurement Studies: Up to \$500,000
- Development and Testing of Engagement Approaches: Up to \$1.5M

### **MAXIMUM PROJECT PERIOD**

- Rapid Measurement Studies: Up to 2 years
- Development and Testing of Engagement Approaches: Up to 3 years

# Science of Engagement Initiative – Discussion



- What are additional opportunities for promotion of this funding announcement?
- What are the key questions you think we may receive from the field on Town Hall or via email?

# Eugene Washington PCORI Engagement Award Program

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Kate Boyd

Senior Program Officer, Eugene Washington PCORI  
Engagement Awards

Courtney Clyatt

Senior Program Officer, Eugene Washington PCORI  
Engagement Awards

Karen Martin

Director, Eugene Washington PCORI Engagement Awards



# Engagement Award Program

## Commitment



- Meet the needs of diverse stakeholders
- Expand our reach

# Pre-Announcement Overview



The new Engagement Award: Building Capacity for Small Organizations to Engage in PCOR/CER funding opportunity will support two-year projects that enable small organizations and their communities to build capacity and skills to participate in the PCOR/CER process.

# Pre-Announcement Overview



- The projects will leverage each awardee organization's unique perspectives and experiences to **build the knowledge, competencies, and abilities** of the organization and its community to be meaningful partners with researchers throughout all phases of the PCOR/CER process.
- Awardees will be required to participate in a **learning network** throughout the project period. The learning network will provide an opportunity for awardees to receive **technical assistance** on their projects, share expertise and experiences, and offer lessons learned.
- Two-year projects; up to \$250,000 total (direct and indirect).

# Eligibility

## Applicant Organizations



- Must have an average yearly operating budget of \$1.5 million or less over the past two fiscal years.
- Must be tax-exempt under section 501(c)(3) of the Internal Revenue Code *or* have a fiscal sponsor that is tax-exempt under section 501(c)(3) of the Internal Revenue Code.
- May not have received a total of over \$100,000 through previous awards from the Eugene Washington PCORI Engagement Award Program. Funds received as a subcontractor on an award do not count towards this total.
- Must demonstrate a) current relationships with researchers and/or existing research networks; and b) current relationships with patients and other stakeholders who have a connection to, expertise in, or lived experience with, the topic area.

# Release Date



Funding Announcement Release Date: **July 19, 2022**

# Promotion of Funding Opportunity



- Goals:
  - Reach new audiences with connections to small organizations not yet familiar with Engagement Awards
  - Inform small organizations that were not successful with prior Engagement Awards applications
  - Inform small organizations that have received \$100,000 or less in funding from prior Engagement Awards

# Discussion



- What recommendations do you have for promoting the funding opportunity?

# Engagement Stories

**Beth Careyva, MD MHSA**



Your health deserves a partner.

# Agenda

- Describe my role and trajectory with engagement
- Discuss lessons learned from three Patient and Stakeholder Advisory Committees

# My Roles

- Physician
- Researcher
- Health Care Executive



# Catalyst Moment

- Why I believe in patient engagement

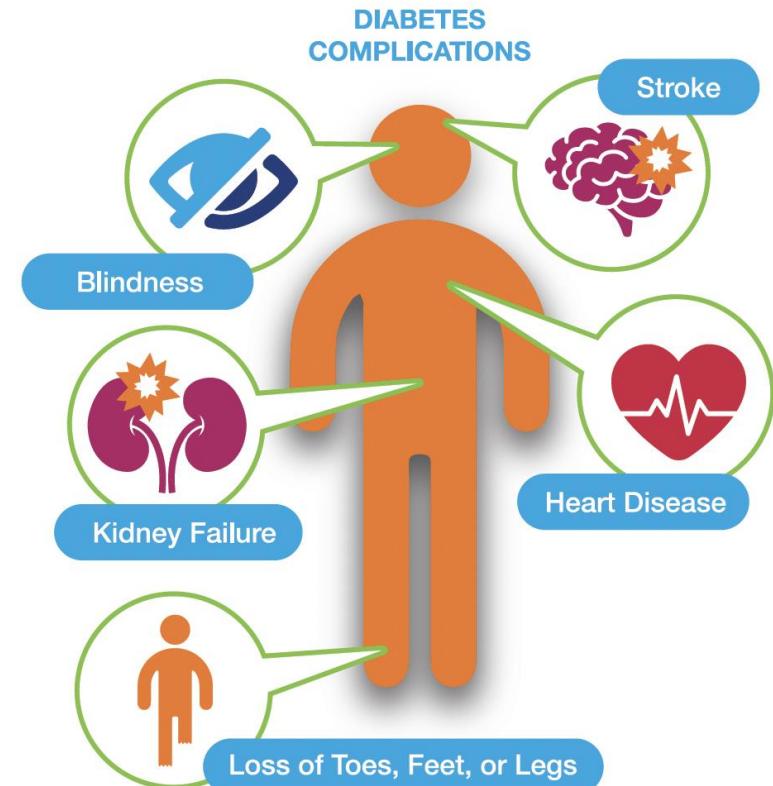
## Prediabetes

### PREDIABETES FACTS

1 in 3 adults have Prediabetes

7 out of 10 adults with Prediabetes develop Diabetes

You can make changes to prevent Diabetes!



## Core Areas of Research

- Cancer Screening in Vulnerable Populations
  - Colon
  - Lung
- Diabetes Prevention

*Improving the health of vulnerable populations*

## Patient and Stakeholder Advisory Committees (PASAC)

1. RCT of colon cancer screening in primary care practices - PCORI
2. Learning health system to address colon and lung cancer screening in underserved populations - PCORI Engagement Award
3. Creation of Prediabetes Decision Aid - Pool Trust

*What has been your experience with engagement?*



# PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# FINAL RESEARCH REPORT

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## Does Decision Support by Phone Increase Colorectal Cancer Screening in Hispanic Patients?

Ronald E. Myers, PhD<sup>2</sup>; Brian Stello, MD<sup>1</sup>; Randa Sifri, MD<sup>2</sup>; Constantine Daskalakis, ScD<sup>2</sup>; Sarah Hegarty, MPhil<sup>2</sup>; Melissa DiCarlo, MPH, MS<sup>2</sup>; Melanie Johnson, MPA<sup>1</sup>; Beth Careyva, MD<sup>1</sup>; Alicia Rivera<sup>1</sup>; Kyle Shaak, MPH<sup>1</sup>; Lucas Gordils-Molina<sup>1</sup>; Evelyn Gonzalez, MA<sup>3</sup>; Rosa Ortiz<sup>3</sup>; Liselly Diaz<sup>1</sup>

# PASAC

- Reviewed and tailored protocols and materials for cultural appropriateness
- Contributed to dissemination of results including community health fair



*People learn about colon cancer at a health fair in Allentown, Pennsylvania. At the fair, research team members shared study results. (Courtesy of Melanie Johnson, Lehigh Valley Health Network)*

[Explore Our Portfolio](#)



Share

Conference: Dissemination

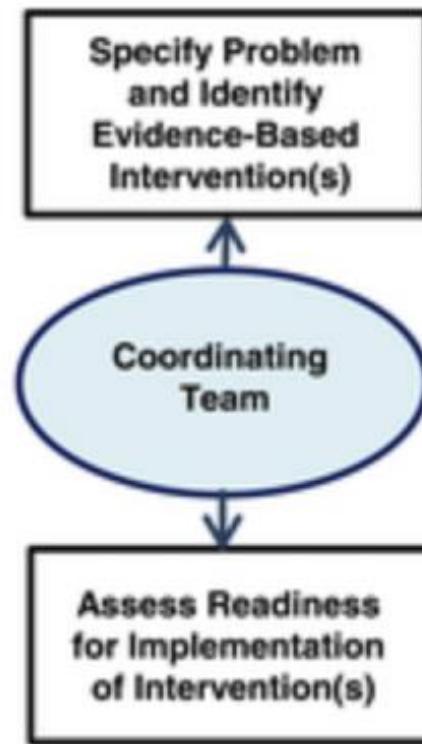
Completed

# Reducing Cancer Disparities by Engaging Stakeholders

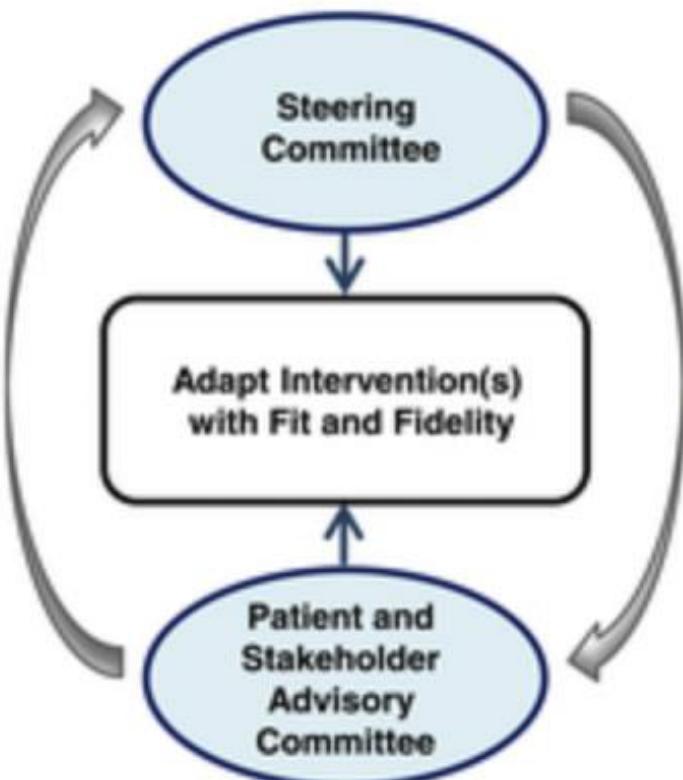
# Reducing Cancer Disparities by Engaging Stakeholders (RCaDES)

- Learning community model to engage patients and stakeholders
- Project Lead: Ronald Myers, PhD

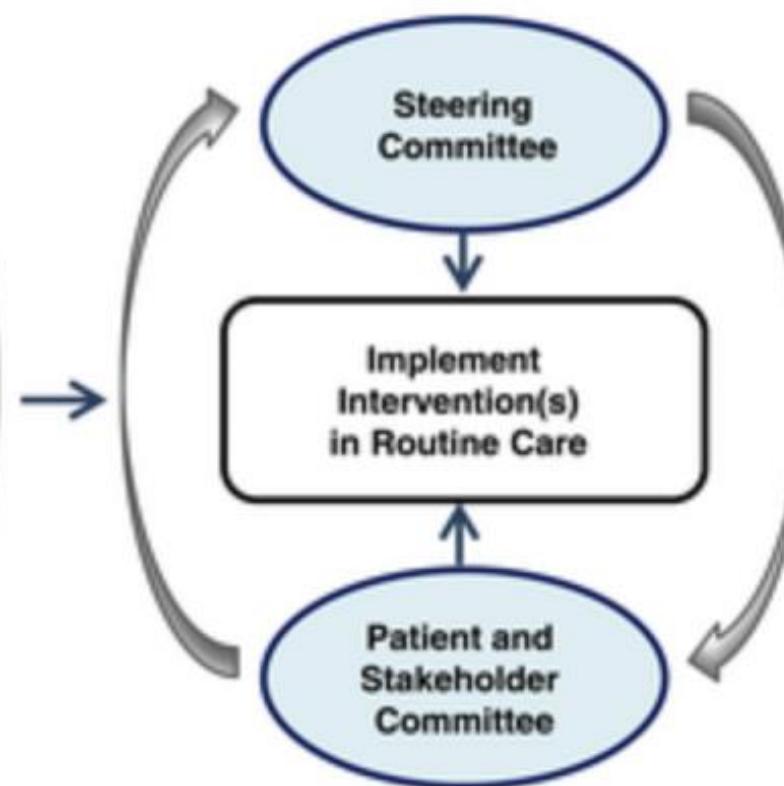
### Synthesis



### Translation/Adaptation



### Implementation/Maintenance



Learning Community Intervention Champions

Conduct Intervention Adaptation/Implementation Process, Outcomes and Cost Evaluations

## PASAC

- Participated in curriculum on cancer screening, language, and channels of delivery
- Conducted community member interviews
- Shared feedback to inform adaptation of interventions



*Colon Cancer*

Colon cancer is the fourth most common cancer in the United States. It is the second leading cause of cancer deaths in men and women. The good news is that colon cancer is preventable and treatable. If you are 50 years of age or older, you should be screened for colon cancer. If you are younger than 50, you should be screened if you have a family history of colon cancer or if you have certain symptoms. If you are at high risk for colon cancer, you should be screened earlier and more frequently.

*Cancer de Colon*

El cáncer de colon es el cuarto cáncer más común en los Estados Unidos. Es la segunda causa más común de muerte por cáncer en hombres y mujeres. La buena noticia es que el cáncer de colon es prevenible y tratable. Si tienes 50 años o más, debes ser examinado para el cáncer de colon. Si tienes menos de 50 años, debes ser examinado si tienes un historial familiar de cáncer de colon o si tienes ciertos síntomas. Si estás en alto riesgo de cáncer de colon, debes ser examinado más temprano y más frecuentemente.

*Signs and symptoms*

*Síntomas y signos*

*Screening*

*Exámenes*

*Colonoscopy*

*Colonoscopia*

**BRIEF REPORT**

# Designing and Evaluating a Prediabetes Shared Decision Aid

*Beth A. Careyva, MD, Kyle Shaak, MPH, Nicole M. Burgess, BS,  
Melanie B. Johnson, MPA, Elaine Seaton Banerjee, MD, MPH, Yoonjie Chung, MD,  
Allison N. Davis, and Colleen Payton, PhD, MPH*

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# PASAC

- Co-created prediabetes decision aid
- Participated in development of study plan and inclusion criteria
- Reviewed results and modified decision aid

# Lessons Learned

- Structured agendas
- Draft materials to respond to rather than create
- Between meeting communication
- Balanced composition of the group
- Need for skilled facilitators to balance voices

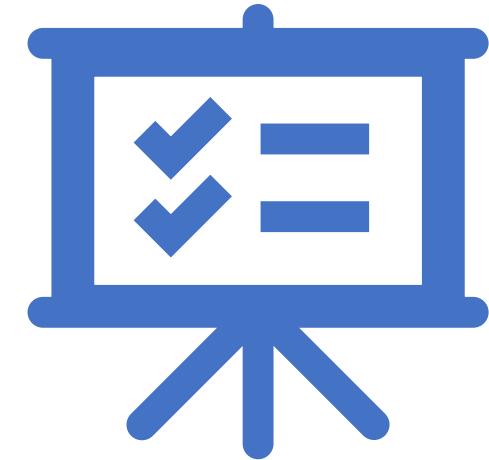
## Future Opportunities

- Engage participants sooner
- Expand role of participants
- Address patient and community member retention
- Develop novel strategies to sustain engagement between meetings



# Conclusion

- Engaging PASACs informed development, implementation, and dissemination
- Further study is needed to optimize longitudinal engagement and evaluation



# Discussion

1. What within this resonated with your experience?
2. What have you done differently that you found to be effective?
3. What other engagement strategies are you considering within hybrid communication (virtual and in person)?

# Thank You!

[Beth\\_a.Careyva@lvhn.org](mailto:Beth_a.Careyva@lvhn.org)

[Beth.Careyva@gmail.com](mailto:Beth.Careyva@gmail.com)



Your health deserves a partner.

# Announcements

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# Studying PCORI's Patient-Centered Approach (PCA) Workgroup

## Update on Recent Activities



- The PCA Workgroup advises on PCORI's evaluation agenda and staff-led projects that assess the effectiveness of PCORI's approach or build evidence about promising practices for patient-centered research

### **Workgroup activities since the November 2021 PEAP meeting**

<b>November 2021</b> <i>Virtual meeting</i>	Advised on plans and priorities for a scoping review of engagement literature to identify knowledge gaps and inform improvements to PCORI's Engagement in Health Research Literature Explorer
<b>February 2022</b> <i>Virtual meeting</i>	Advised on plans for a project examining diversity and representativeness of participants in PCORI-funded research projects
<b>March 2022</b> <i>Offline review</i>	Advised on protocol for an environmental scan of engagement policies, requirements, and guidance outside of PCORI to inform update of the PCORI Engagement Rubric

# Upcoming Events



## Mark your calendars!

- Upcoming Board Meetings (*June 13 & 14, July 26, September 19 & 20, December 13*)
- PEAP Meeting (*October 25*)
- PCORI Annual Meeting (*October 26-29*)



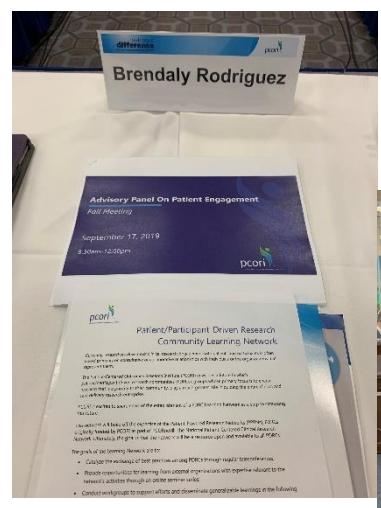
## Thank you to:

- Beth Careyva
- Tracy Carney
- Crispin Goytia
- Neely Williams

*Celebration forthcoming!*

# PEAP Alumna: A Journey

- First Contact: PCORI Latina Roundtable
- Ambassador
- PEAP Member
- Engagement Awardee
- Conferences & Projects





*Thank you to Lisa Stewart for her  
invaluable contributions to this  
panel over the past several years!*

# Adjourn

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# Post-Meeting Survey



- Don't forget!
  - Post-meeting survey: <https://survey.alchemer.com/s3/6791529/PEAP-Spring-2022-Meeting-Post-Event-Survey>
- Your feedback will be carefully considered when planning future meetings
- Feedback incorporated to-date:
  - Shorter presentations from PCORI staff
  - Greater opportunity for input/feedback
  - More time for breaks during virtual meetings