Welcome

Kristin Carman
Director, Public and Patient Engagement

Gwen Darien
Chair, Advisory Panel on Patient Engagement

Neely Williams
Co-chair, Advisory Panel on Patient Engagement

Agenda

Part I (EDT):

- 11:30 AM – Remarks and Roll Call
- 11:50 AM – PCORI's Strategic Planning: Proposed National Priorities for Health
- 12:50 PM – Panel Discussion: Rethinking Systems that Support Research and Engagement for Achieving Health Equity
- 1:20 PM – Lunch Break

Part II (EDT):

- 1:50 PM – PCORI Updates
- 2:10 PM – Expanding Access to Engagement Awards: Challenges and Opportunities for Small Organizations
- 2:40 PM – Researching Engagement: What do we need to Know?
- 3:10 – Stretch Break
- 3:30 – Assessing the Effectiveness of Different Approaches for Combating Institutional Racism
- 4:00 – Announcements and Farewell
- 4:15 – Adjourn

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 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
  - 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

How to Ask Questions – Panelist Instructions

You are muted

Type "I have a comment" in the chat

File Options View Help 🌐▾

Attendees still on hold

Start broadcast

☑ Record on start

▶ Audience view 100%

▶ Sharing

▶ Webcam

▶ Audio

▶ Dashboard

▶ Attendees: 1 of 1001 (max)

▶ Polls (0/0)

▶ Questions

▶ Handouts: 0 of 5

▼ Chat

[Type message here]

To: All - Entire Audience ⌄ Send

PEAP Tech Session #1

Webinar ID: 149-787-971

GoToWebinar

How to Turn on Your Webcam – Panelist Instructions

Click to turn webcam on/off. Icon is green when on.

File   Options   View   Help   ⊕▾

Attendees still on hold

Start broadcast

☑ Record on start

▶ Audience view   100%

▶ Sharing

▼ Webcam

Share My Webcam   Webcams ⌄

▶ Audio

▶ Dashboard

▶ Attendees: 1 of 1001 (max)

▶ Polls (0/0)

▶ Questions

▶ Handouts: 0 of 5

▶ Chat

Test Webinar

Webinar ID: 997-665-123

GoToWebinar
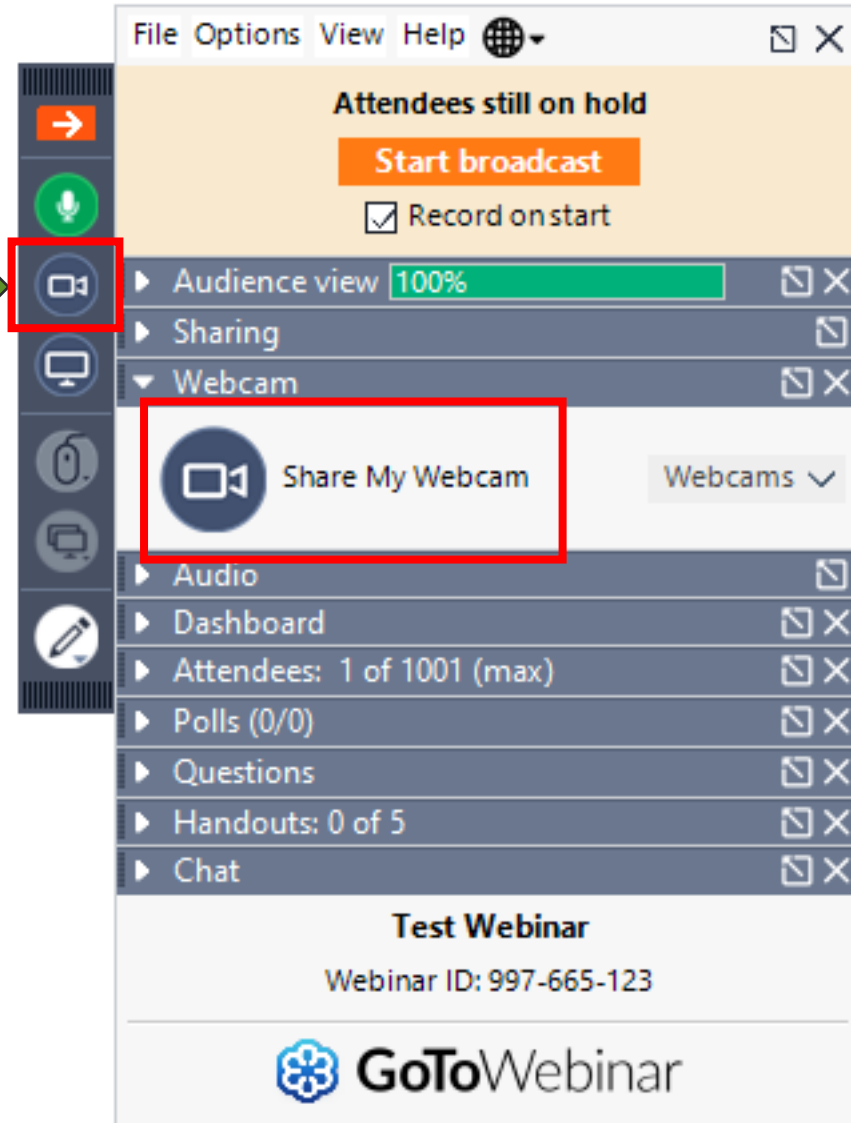
The PCORI PEAP Team

Kristin Carman
Director,
Public and Patient
Engagement

Lisa Stewart
Senior Engagement Officer,
Public and Patient
Engagement

Meghan Berman
Program Associate II,
Public and Patient
Engagement

Aleksandra Modrow
Program Coordinator,
Public and Patient
Engagement

PEAP Chair and Co-chair

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Gwen Darien

Chair

Executive Vice President, Patient Advocacy

Patient Advocate Foundation

Representing: Patients, Caregivers, and Patient Advocates

Neely Williams

Co-chair

Administrator

Community Partners' Network, Inc.

Representing: Patients, Caregivers, and Patient Advocates

Roll Call - Advisory Panel Members

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Jennifer Canvasser
Patients, Caregivers, and Advocacy Organizations

Beth Careyva
Researchers

Tracy Carney
Patients, Caregivers, and Advocacy Organizations

Gwen Darien
Patients, Caregivers, and Advocacy Organizations

Sarah Donelson
Industry

Karen L. Fortuna
Researchers

Maureen Fagan
Clinicians

Marilyn Geller
Patients, Caregivers, and Advocacy Organizations

Crispin Goytia
Patients, Caregivers, and Advocacy Organizations

James Harrison
Researchers

Roll Call - Advisory Panel Members

Jill Harrison
Patients, Caregivers, and Advocacy Organizations

Margarita Holguin
Patients, Caregivers, and Advocacy Organizations

Matthew Hudson
Patients, Caregivers, and Advocacy Organizations

Alma McCormick
Patients, Caregivers, and Advocacy Organizations

Al Richmond
Patients, Caregivers, and Advocacy Organizations

Anita Roach
Patients, Caregivers, and Advocacy Organizations

Umair Shah
Policy Makers

Sandy Sufian
Patients, Caregivers, and Advocacy Organizations

Neely Williams
Patients, Caregivers, and Advocacy Organizations

PCORI's Strategic Planning

Proposed National Priorities for Health

Kristin Carman
Director, Public and Patient Engagement

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Purpose of Today's Conversations

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Purpose

- Update on strategic planning process
- Opportunity to engage with the proposed National Priorities for Health and to gather perspectives

Goal

- Identify synergies among the National Priorities and consider what those may mean for the Research Agenda
- Identify critical needs and areas to address through the Research Agenda
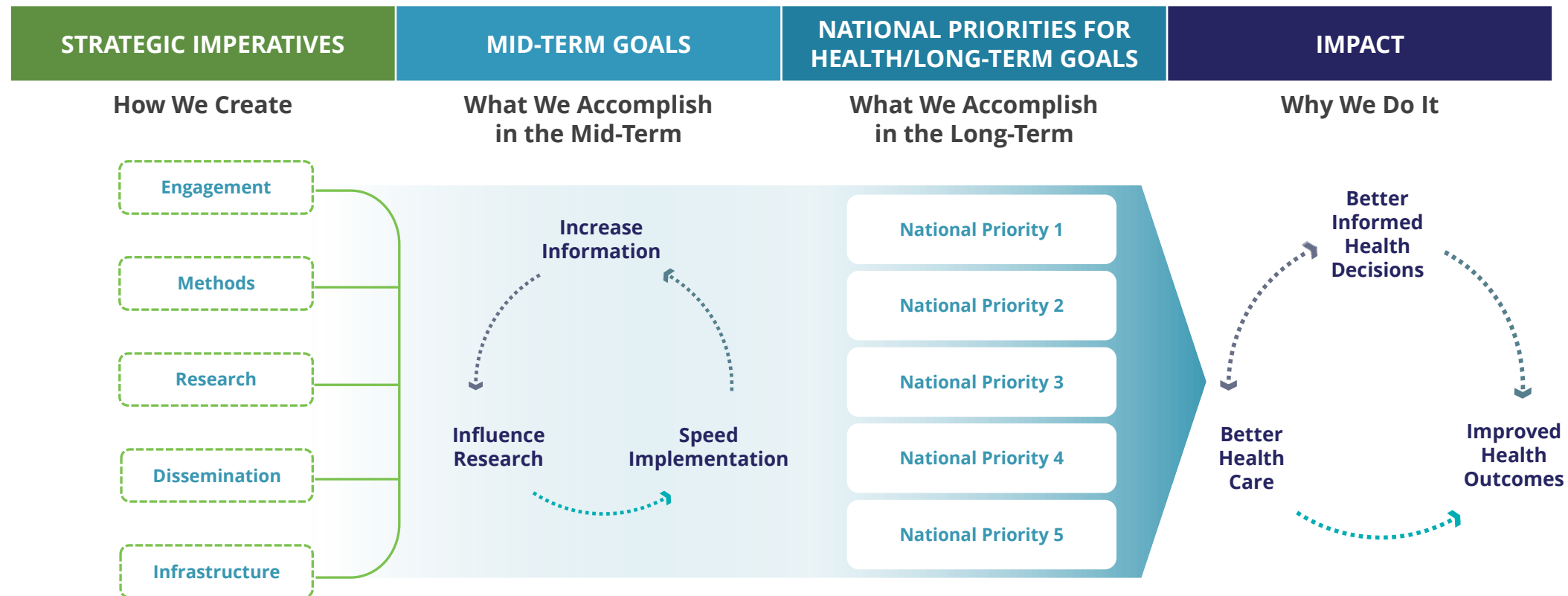
Scope of Strategic Planning Activities

Strategic Planning

- ## National Priorities
- Research Agenda
- PCORnet® strategic vision for PCORI's next phase
- Methodology Committee focus for PCORI's next phase
- Commitment Planning and strategies to increase funding
- Scenario Planning based on the changes in landscape and environment
- Priorities from reauthorizing legislation
  - Maternal morbidity and mortality
  - Intellectual and developmental disabilities
  - Full range of outcomes data

Moving Towards the Research Agenda

National Priorities

- Broad areas that include the patient-centered comparative effectiveness research (CER) PCORI supports
- Reflect priorities of patients, stakeholders, and the broader healthcare system
- Transparently demonstrate rationale for PCORI investments

Research Agenda

- More specific topic areas that address research priorities
- Establishes framework through which PCORI makes investments
- Articulates and reflects evolving evidence needs of patients, stakeholders, and the broader healthcare system

Topic Development

- Process of ongoing cultivation and refinement of specific topics and/or sub-questions
- Questions refined with input from patient and stakeholder partners
- Articulates focused areas for funding

Picking Up From When We Last Spoke

- In October 2020, the PEAP considered the revised strategic framework and what the reframing meant for National Priorities.

- What we heard from the panel:
  - Addressing **disparities** is more important than ever
  - Consider **implementation science** and how patient-centered outcomes research could be integrated with this domain
  - Importance of **communication** in research and in practice, particularly around how to communicate uncertainty in clinical outcomes
  - Consider supporting a **learning health system** as this could be relevant for PCORI's work

- This was reinforced and complemented by input from other convenings, meetings, and discussions.
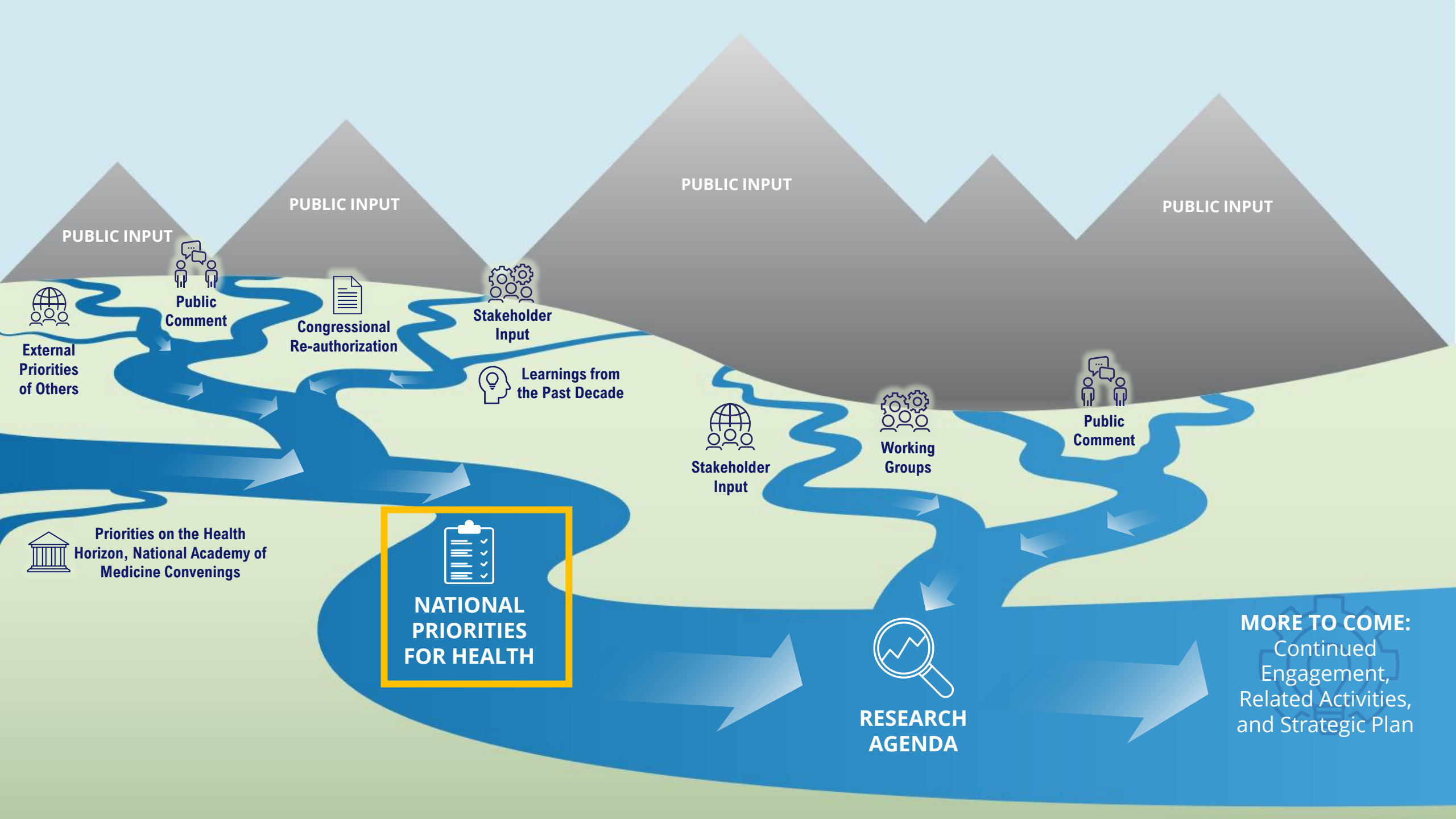
PUBLIC INPUT

PUBLIC INPUT

PUBLIC INPUT

PUBLIC INPUT

External Priorities of Others

Public Comment

Congressional Re-authorization

Stakeholder Input

Learnings from the Past Decade

Stakeholder Input

Working Groups

Public Comment

Priorities on the Health Horizon, National Academy of Medicine Convenings

NATIONAL PRIORITIES FOR HEALTH

RESEARCH AGENDA

MORE TO COME: Continued Engagement, Related Activities, and Strategic Plan

Developing National Priorities for Health

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- The themes below resulted from across the inputs
- At its April 2021, meeting, PCORI Board of Governors supported developing and further shaping these themes for National Priorities for Health
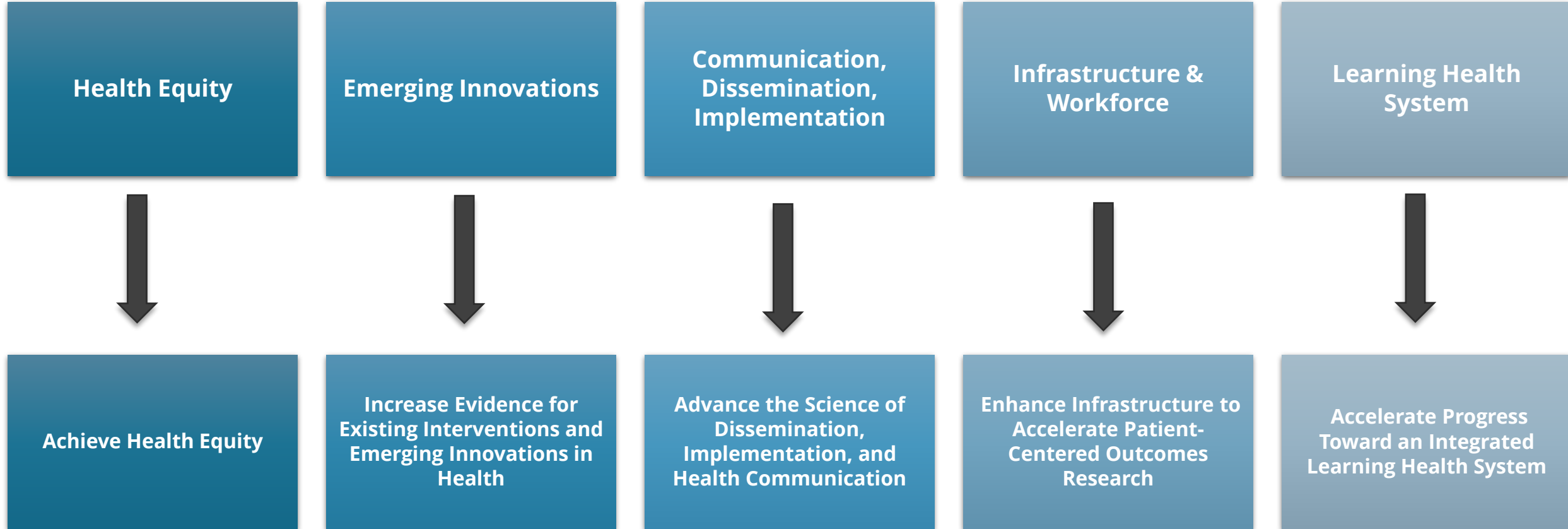
Health Equity	Emerging Innovations	Communication, Dissemination, Implementation	Infrastructure & Workforce	Learning Health System

Going from Themes to National Priorities

Themes

| Health Equity | Emerging Innovations | Communication, Dissemination, Implementation | Infrastructure & Workforce | Learning Health System |

| Achieve Health Equity | Increase Evidence for Existing Interventions and Emerging Innovations in Health | Advance the Science of Dissemination, Implementation, and Health Communication | Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research | Accelerate Progress Toward an Integrated Learning Health System |

Proposed National Priorities for Health

Proposed National Priorities for Health
Creating Synergistic Opportunities for Progress

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- At its June 2021, meeting, PCORI Board of Governors approved the National Priorities for Health to be posted for public comment which opened last month
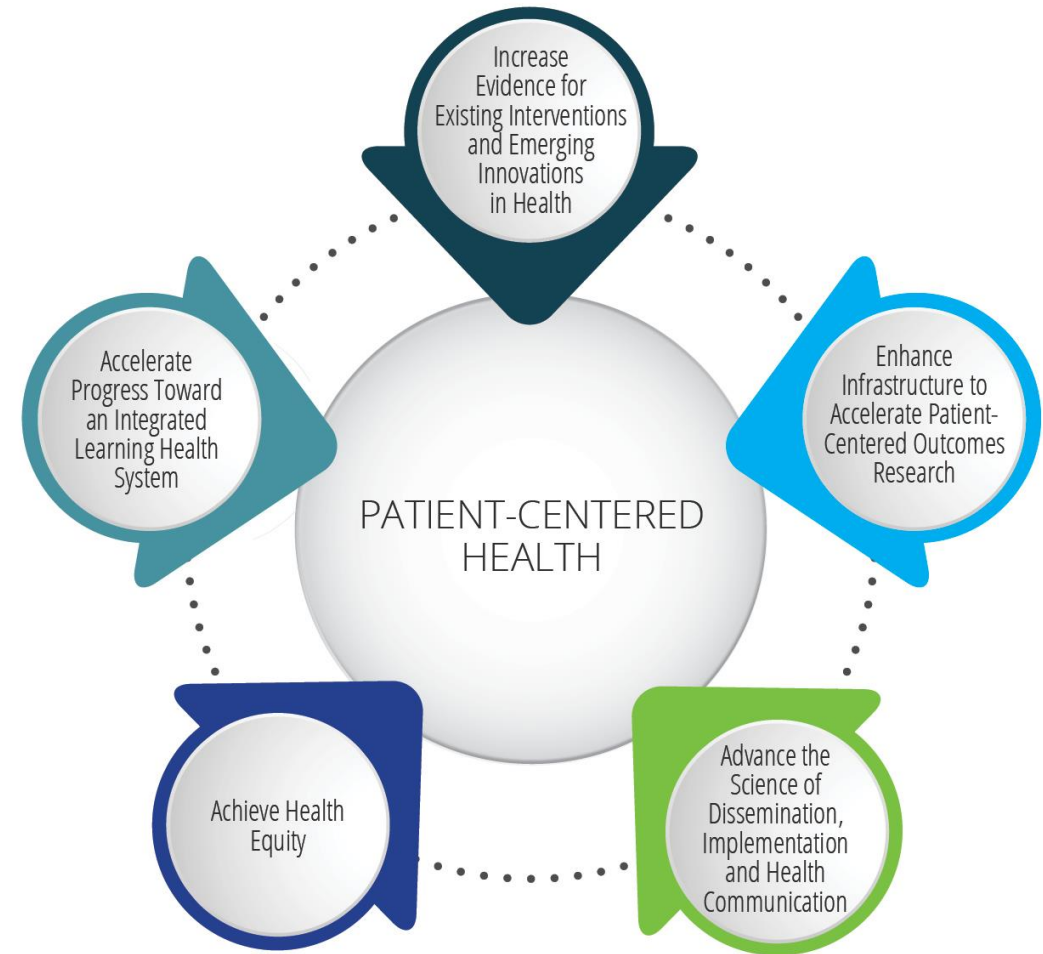
Looking Forward to Hearing From You

- What are critical needs and areas to address through the National Priorities?

- What synergies exist among the National Priorities? What might those mean for the Research Agenda?

- Imagine 5 years in the future, what potential impacts could these National Priorities for Health have on comparative clinical effectiveness research? Are there specific areas that PCORI could make a real impact on in this timeframe?

Proposed National Priorities for Health
Increase Evidence for Existing Interventions and Emerging Innovations in Health

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

Strategies to address this priority include:

- Monitor the research landscape for potentially high impact innovations

- Evaluate existing and emerging innovations in clinical care interventions, systems changes, healthcare delivery, technologies, public health, and social determinants of health

- Study unintended consequences, adverse events, barriers to care, burdens and economic impacts, and widened disparities in care outcomes associated with existing and emerging innovations

- Expand scope of stakeholders engaged in pcori's work from topic inception through implementation of the results

- Emphasize inclusion of populations who are underserved, under-represented, and disadvantaged in CER research

- Support CER of evidence gaps in diverse populations, geographic areas, and settings to foster equitable uptake practices

Proposed National Priorities for Health
Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research

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

Strategies to address this priority include:

- Develop and expand the universe of engaged patients and communities and representative leadership, research workforce, and clinician partners
- Advance the accessibility and utilization of real-world data
- Build synergies and leverage current work within health systems and by stakeholders
- Integrate patient-centered outcomes research findings into learning health systems

Proposed National Priorities for Health
Advance the Science of Dissemination, Implementation, and Health Communication

Advance the scientific evidence for and the practice of dissemination, implementation, and health communication to accelerate the movement of comparative clinical effectiveness research results into practice

Strategies to address this priority include:

- Fund CER studies of delivery or implementation strategies
- Communicate research findings effectively and in ways tailored to diverse audiences
- Actively deliver information to targeted audiences to use to inform healthcare discussions and decisions
- Promote the uptake of research findings into practice, to contribute to improved healthcare and health
- Engage stakeholders and communities in strategic partnerships across diverse settings to improve the uptake of evidence

Proposed National Priorities for Health
Accelerate Progress Toward an Integrated Learning Health System

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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 serves the needs and preferences of individuals

Strategies to address this priority include:

- Fund multi-sector interventional CER focused on health outcomes and grounded in the context of specific settings, communities, and needs

- Implement research on precision and personalized medicine and whole-person health into practice

- Incorporate the full range of outcomes to influence value that encompasses diverse outcomes and perspectives among patients, families, caregivers, and providers

- Formalize partnerships to ensure an integrated learning health system that meets the needs of patients and caregivers

- Use data analytic and informatic tools to inform and enable real-time decision making

Proposed National Priorities for Health
## Achieve Health Equity

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Expand stakeholder engagement, research, and dissemination approaches that lead to continued progress towards achieving health equity in the United States

Strategies to address this priority include:

- Fund CER to improve health outcomes for individuals of all backgrounds

- Strengthen efforts to support inclusive and diverse stakeholder engagement

- Disseminate and implement research findings with the intention of informing broader health equity strategies

- Collaborate with health, research, advocacy, social service, educational, and other organizations to reduce health inequities

- Identify and fund novel ways to support the professional development and increase the engagement of investigators of color, investigators with disabilities, and populations who are historically under-represented in research endeavors

Looking Forward to Hearing From You

- What synergies exist among the National Priorities? What might those mean for the Research Agenda?

- Imagine 5 years in the future, what potential impacts could these National Priorities for Health have on comparative clinical effectiveness research? Are there specific areas that PCORI could make a real impact on in this timeframe?
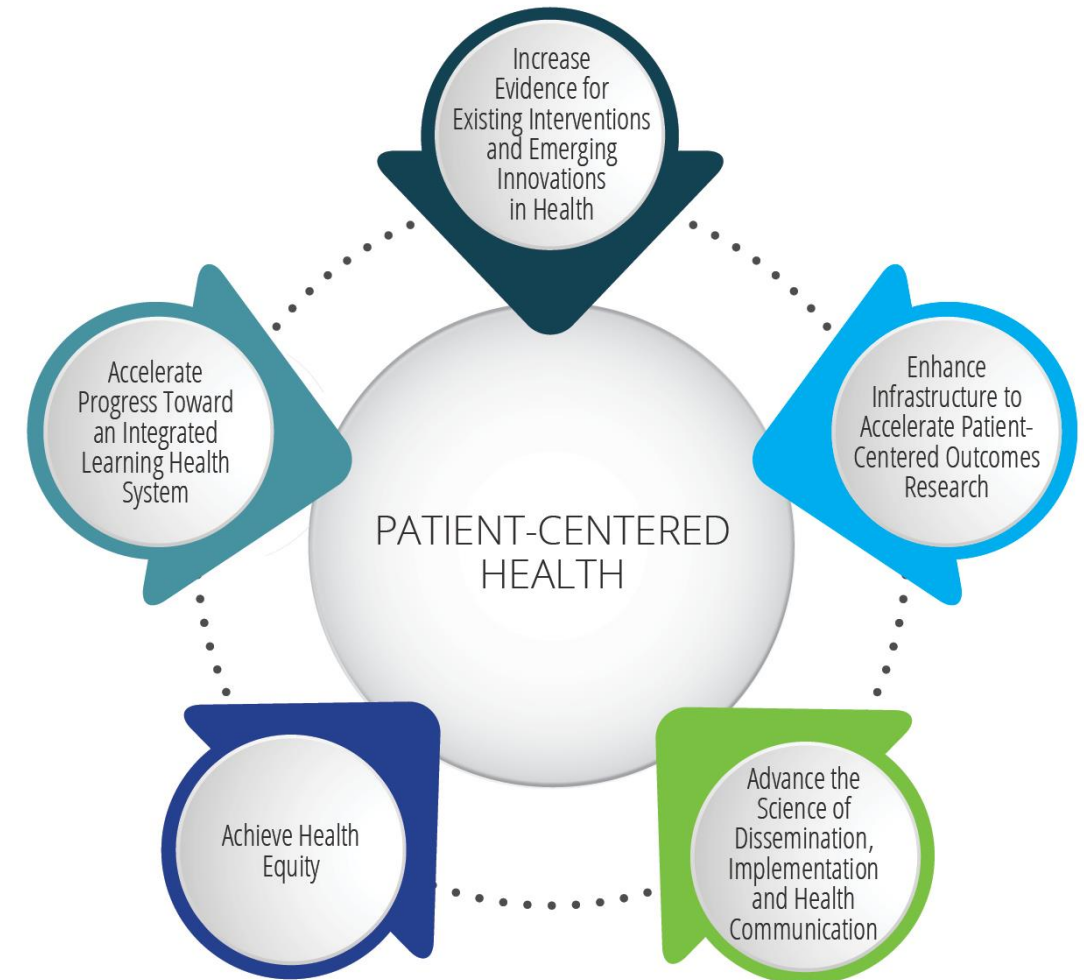
Public Comment Period

- Proposed National Priorities for Health

- [Submit comments](#) during PCORI's 60-Day Public Comment Period **(June 28 – August 27)**

- [pcori.org/nationalprioritiesforhealth](#)

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PROPOSED NATIONAL PRIORITIES FOR HEALTH

Regional Stakeholder Events

- Three Regional Events throughout August – October
  - West Virginia
  - Colorado
  - Maryland

- Partnering with community leaders, these events are an opportunity to engage new patient and stakeholder audiences and gather unique and diverse perspectives.

Advisory Panel Perspectives

Rethinking Systems that Support Research and Engagement for Achieving Health Equity

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Discussion

- As we look toward a future of investing in new approaches, what should be the blueprint for research organizations and partnerships that are equity-focused?

- How should they be structured and operate?

- Are there examples from other sectors to learn from?

Lunch Break

1:20 – 1:50pm EDT

PCORI Updates

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

William Lawrence
Senior Clinical Advisor, Office of the Chief Engagement
and Dissemination Officer

Kristin Carman
Director, Public & Patient Engagement

1.

Building Effective Multi-Stakeholder Research Teams

Building Effective Multi-Stakeholder Research Teams: Available Now!

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The goal of the *Building Effective Multi-Stakeholder Research Teams* **website** is to provide practical guidance to help stakeholders and researchers work together as equal partners.

Engaging Stakeholders to Be Active Members of the Team

Working Together as an Effective Multi-Stakeholder Team

Access the website at **www.pcori.org/research-teams**

Website Topics

Engaging Stakeholders	Working as a Team
Inclusion: The Starting Point for Effective Teams	**Best Practices in Multi-Stakeholder Team Science**
• Addressing Bias and Exclusion • Establishing and Maintaining Trust • Enabling Multiple Points of View	• Creating a Shared Vision • Defining Roles and Responsibilities • Establishing Team Norms
Best Practices in Engaging Stakeholders	**Leading and Contributing to Team Decisions**
• Planning for Collaboration • Preparing Team Members for Partnership • Practicing Effective Communication	• Leading and Contributing to Productive Meetings • Team-Driven Decision Models and Processes • Building Synergy Through Productive Disagreement
Addressing Contextual Challenges to Engagement	**Solving Challenges and Barriers to Teamwork**
• Institutional Barriers to Stakeholder Engagement • Individual Challenges to Stakeholder Engagement • Solving Common Engagement Problems	• Collaborative Problem Solving • Negotiating Conflict • Sustaining Engagement

Resource Examples

Fostering an Inclusive Team Culture
ACTIVITY GUIDE WITH WORKSHEET

What You Need to Complete This Activity

- **A facilitator:** Anyone on the team can play this role by following the directions in the Activity Guide and Worksheet.

- **A worksheet note taker:** Anyone on the team can do this by taking notes in the worksheet to capture the team discussion.

- **A copy of the worksheet** for each team member.

Your team will need about 1 hour to complete this activity, depending on the number of team members who participate. Your team can meet in person or virtually, following the step-by-step directions.

Activity Goal

Upon completing this activity and worksheet, your team will have identified tasks or practices that contribute to a team culture that reflects the perspectives and backgrounds of its members.

Who Should Participate and When?

This activity is best done by the entire team. It is valuable to complete this activity early in the team's formation so that all team members are able to contribute in meaningful ways from the start.

Why This Matters

Fostering an inclusive team culture can help all team members feel welcomed and valued. Those members who feel included are more likely to stay on the team and contribute to tasks and activities. An inclusive environment can also encourage all team members to share their true thoughts and ideas, which can help the team better understand and respond to stakeholders' needs. An inclusive environment can lead to greater use and uptake of research results by patients and stakeholders within the healthcare community.

1

Best Practices in Multi-Stakeholder Team Science
Following Team Norms

Menu | Exit

Decision Point 1

Background

How can the conflict between the art therapist and the family caregiver be addressed?

Make a selection

- **The art therapist ignores the caregiver** and focuses on interacting with the other team members.

- **The art therapist asks the Engagement Coordinator to help** by reminding the entire team of its norms.

- **After the meeting, the art therapist asks to speak privately with the caregiver** to better understand what is causing the conflict.

Submit

‹ PREV

Resource Examples, cont.

Patient-Centered Outcomes Research

The Benefits of Multi-Stakeholder Engagement

How to Use the *Benefits of Multi-Stakeholder Engagement* Slide Deck

- This slide deck was developed by the Patient-Centered Outcomes Research Institute (PCORI) as part of the Building Effective Multi-Stakeholder Research Teams website (https://www.pcori.org/events/2020/building-effective-multi-stakeholder-research-teams).

- It is organized into four sections:
  I.   What is patient-centered outcomes research (PCOR)?
  II. Why engage patients and other stakeholders in PCOR?
  III. How can multi-stakeholder engagement improve the research process and results?
  IV. How can organizations support multi-stakeholder engagement in PCOR?

Lesson 3: Keep **communicating**

Thank You!

- Questions?
  - Contact Michelle Johnston-Fleece
    - mfleece@pcori.org

2.

Engagement Rubric Update

Engagement Rubric Update

- The <u>Engagement Rubric</u> 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** 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.

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.

Opportunities for PEAP Engagement

- Sharing other organizational policies, frameworks
- Key informant interviews/focus groups
- Stakeholder convening meeting
- Input at PEAP meetings
- Ad hoc consultation

3.

COVID-19 Update

PCORI's COVID-19 Portfolio:
122 Enhancements, 9 Targeted Research Studies, and 25 Special Cycle Engagement Awards

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122 Enhancements Awarded, *$34.8 million*

53
Engagement Award
Enhancements
$7 million

13
D&I
Enhancements
$5.8 million

47
Research
Enhancements
$19.2 million

8
Methods
Enhancements
$2.3 million

1
PCORnet
Enhancement
$526,020

34 New Awards in Research & Engagement, *$33.5 million*

25
Engagement Award
Special Cycle
$3.7 million

9
Targeted Research
Studies
(COVID tPFA)
$29.8 million

Information current as of June, 2021

Increasing Vaccine Confidence among Long-Term Care Workers PFA

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- Using FAST PFA mechanism; will follow more rapid review and award timeline

- PFA posted April 13, 2021

- Up to 3 years

- Up to $5,000,000

- What interventions are effective in increasing COVID-19 vaccine confidence and uptake among LTC workers?

ACTIV-6

- ACTIV-6 is a randomized, blinded, and placebo-controlled Phase III platform trial to test the efficacy of repurposed medications to treat COVID-19 in the outpatient setting.
  - 5-8 arms determined by existing ACTIV medication prioritization committee
  - Conducted under an IND
- PCORnet is leading ACTIV-6, serving as the Clinical Coordinating Center, Data Coordinating Center, and contributing approximately 40 vanguard sites.
  - Leverage HERO-HCQ experience
  - Enhance patient-centeredness
- To enroll 15,000 patients across estimated 80+ sites

Horizon Scanning COVID-19 Supplement

- **COVID-19 six priority issues**
  - Devices
  - Prognostic/Risk factor
  - Diagnostic
  - Health Systems
  - Treatments
  - Vaccines
- Bi-weekly Scan (COVID-19 Only)
- COVID-19 Status Report
- COVID-19 High Impact Report
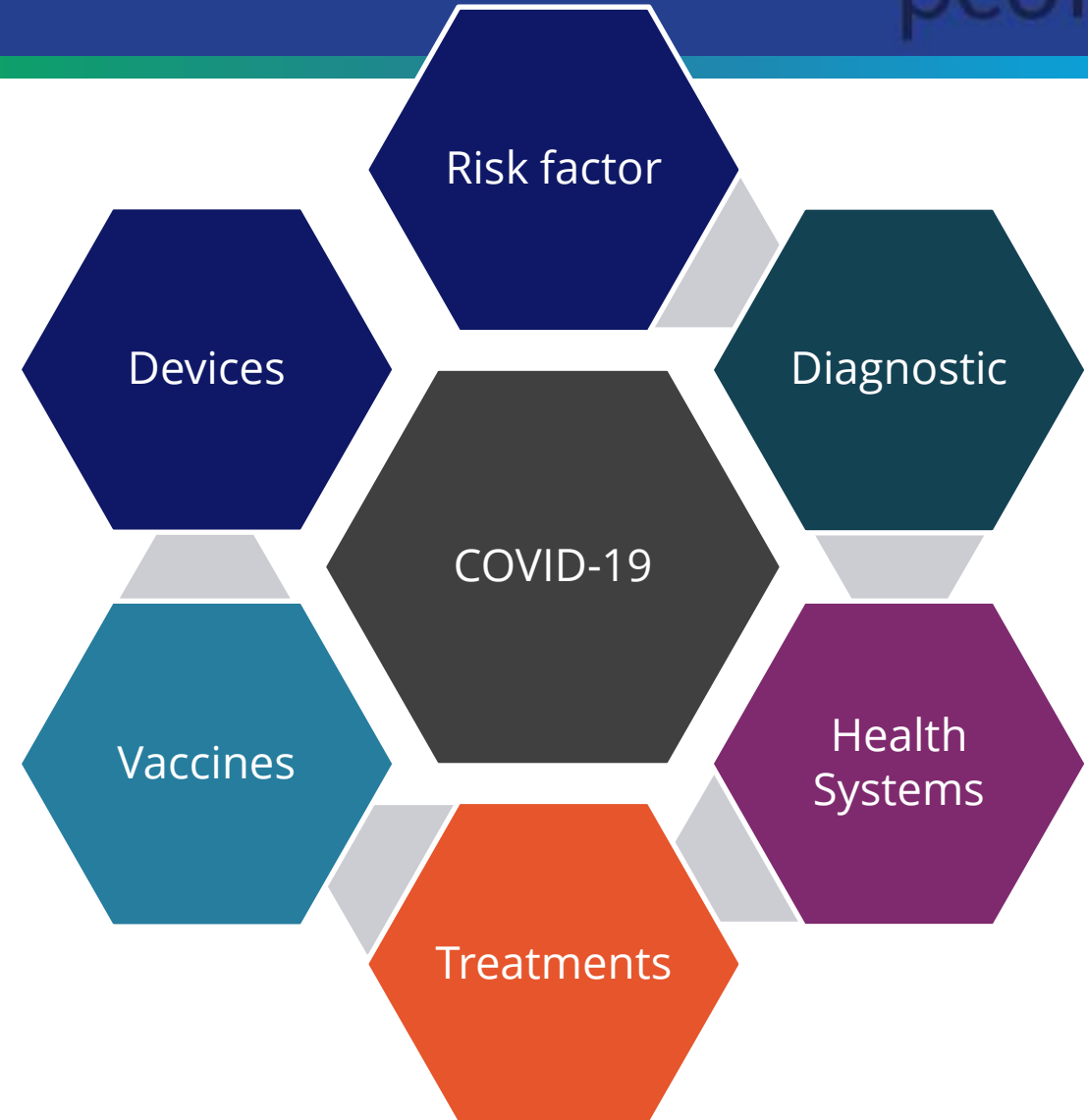
4.

PCORI Funding Announcements

PCORI Funding Opportunities

Maternal Morbidity and Mortality
- Applications under review
- Awards to be announced: March 2022

Intellectual and Developmental Disabilities
- Applications under review
- Awards to be announced: March 2022

Urinary Incontinence
- Applications under review
- Awards announced: March 2022

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PCORI Funding Opportunities

2021 Cycle 3 PLACER PFA
- Upcoming: PFA will be posted September 2021
- Awards to be announced: July 2022

2021 Cycle 3 PCS PFA
- Upcoming: PFA will be posted October 2021
- Awards to be announced: August 2022

2021 Cycle 3 Broad PFA
- Upcoming: PFA will be posted October 2021
- Awards to be announced: August 2022

Our Goals

- Elicit input from stakeholders—most with previous experience related to the PCORI application and contract lifecycle—with a focus on the Engagement Awards

- Assess challenges and other critical barriers that stakeholders may have experienced during the application and contract lifecycle

- Identify potential solutions to ensure that the PCORI Engagement Award program is equitably accessible to all, including small organizations and investigators who are new to PCOR/CER

Engagement Awards
What is Working and Barriers

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What is Working

Funding

Communication with PCORI

Engagement Award Support

Barriers

Lack of awareness of PCORI EA awards

Lack of clarity around what PCORI EA funds

Administrative burden

PCORI website

Recommendations and Final Product Ideas

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Recommendations

Mentorship

Flexible Funding Opportunities

Matchmaking

Accessibility of Materials

Additional Resources
- Step-by-step tutorials/checklists

Final Product Ideas

Replicable Work
- Toolkits, infographics, videos, training

Strategic Plan and/or research roadmap to outline the future of the organization and engaged research (e.g., 1-, 3-, 5-year plans)

Discussion

- What are your reactions to these findings?
- What resonates with you?
- In your view, what is most important for PCORI to know?

Thank You!

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- Questions?
  - Contact the Eugene Washington PCORI Engagement Awards program
    - ea@pcori.org
    - 202-370-9312

- https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards
- https://www.pcori.org/events/2021/expanding-access-engagement-awards-public-panel-discussion-challenges-and-opportunities

Appendix

Informants

- **Scott Berns,** President and CEO, National Institute for Children's Health Quality, and Co-founder, The Progeria Research Foundation

- **Jen Brown**, Co-director/Co-founder, Alliance for Research in Chicagoland Communities at Northwestern University

- **Laverne Morrow Carter**, President, Research, Education and Social Solutions, Inc.

- **Crispin Goytia-Vasquez**, Program Manager, Icahn School of Medicine at Mount Sinai and Patient/Caregiver Principal Investigator for the INSIGHT network

- **Alma McCormick,** Executive Director, Messengers for Health

- **Fatema Mirza**, Executive Director, Worry Free Community

- **Kasha Morris**, Secretary and Co-founder, Tango2 Research Foundation

- **Al Richmond,** Executive Director, Community-Campus Partnerships for Health

- **Deneen Robinson,** Policy Director, The Afiya Center

- **Brendaly Rodriguez,** Director, Chula Vista Community Collaborative

- **Regina Greer-Smith,** President, Healthcare Research Associates, LLC

Goals for Today

We want to hear your priorities and perspectives on *studying* engagement.

What can we learn by studying engagement that would make engagement easier, more inclusive and effective for study teams and partners?
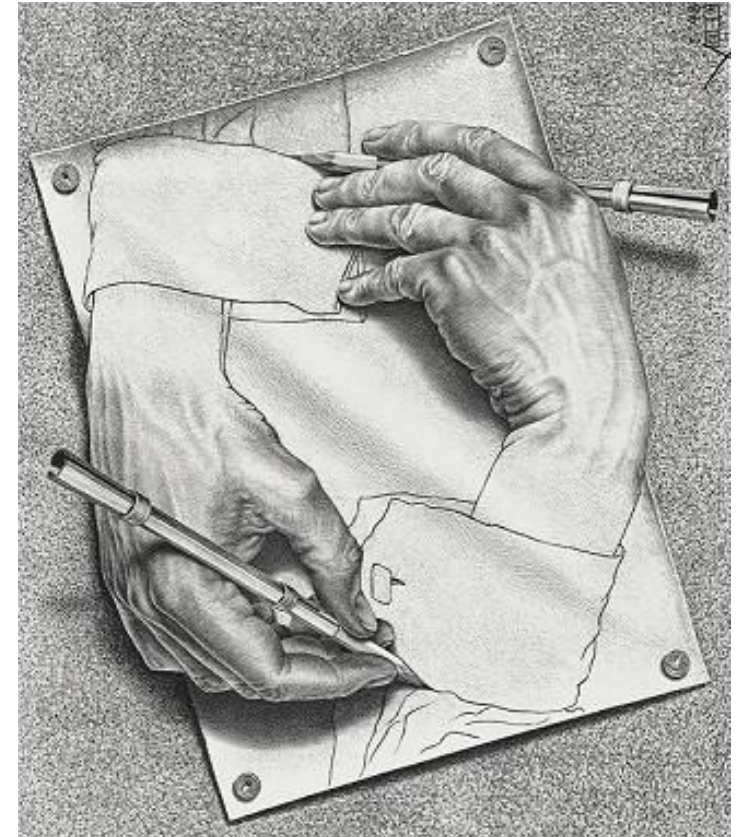
Engagement at PCORI

We have been studying our own projects, and we know some things about the nature of engagement, the ways engagement can affect study conduct, and its challenges.

But the **generation of evidence** on engagement approaches, as well as the ultimate outcomes of engagement, **has been limited...**

So, we do not yet have answers to critical questions being asked by awardees and others.

What we know about Engagement

- Engagement is **feasible in all phases of CER and PCOR** and with a variety of stakeholders;

- Engagement can **influence the design and conduct of research studies** in meaningful ways including acceptability, feasibility, quality, and relevance;

- Engagement can **benefit** the patient and stakeholder partners, communities, and researchers involved;

- PCORI's approach to engagement **influences the culture of healthcare research;**

- There are **known challenges** to address, including those related to infrastructure and resources, people and teams, organizational policies, and balancing views and priorities.

Areas for Exploration

- How to measure and define successful engagement

- Understanding the supports needed to achieve successful engagement

- When to use certain engagement strategies

- Determining whether a study is patient-centered

Using Padlet

- Padlet can be used to supplement your response to the discussion questions on the following slide (https://padlet.com/czahlis/SoE; link also in the Chat)

PEAP Discussion on the Science of Engagement
Understanding Patient and Stakeholder Priorities

Type your responses in the comment field below each question.

What are the problems or challenges that you see in engagement that research could help us overcome?

♡ 0

Add comment

Note: If you do not have a Padlet account, your response will be anonymous. You can identify yourself by writing your name, if you wish.

Questions for Discussion (on Padlet)

- What are the problems or challenges that you see in engagement that research could help us overcome?

- What are the benefits of engagement that you would like research to help us demonstrate?

- What questions do you think will provide the most actionable information for future research teams?

Stretch Break

3:10 – 3:30pm EDT

Assessing the Effectiveness of Different Approaches for Combating Institutional Racism

Hillary Bracken
Program Officer, Healthcare Delivery & Disparities

Lisa Stewart
Senior Engagement Officer, Public & Patient Engagement

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Background

- Measuring institutional racism and discrimination is needed to promote transparency and accountability in healthcare settings.

- Prior research has focused on measuring patient-reported experience of racism, discrimination, and bias
  - Several validated scales exist (e.g., Everyday Discrimination Scale and Major Experiences of Discrimination Scale)

- However, additional measures are needed to assess the impact of interventions to address institutional racism and discrimination.

What Metrics Matter?

- What outcome measures would be the most meaningful to you for assessing the comparative effectiveness of different approaches to address bias, racism, and discrimination in the health system?

Engaging Communities in the Measurement of Institutional Racism and Discrimination

What other measures are important?

- What types of *patient-reported* measures would be meaningful?
  - For example, patients' reports of clinicians' conversational pace and tone and body language or their perception of the shared decision-making process.

- What types of *resource use* measures would be meaningful?
  - For example, the amount of time clinicians spend with patients of color; or receipt of guideline-recommended preventive, curative, or promotive care to patients of different gender or sexual orientation

- What types of *organizational change* measures given the short duration (5 years) of many research studies would be meaningful?

THANK YOU

Thank you to:

- Jennifer Canvasser
- Gwen Darien
- Sarah Donelson
- Maureen Fagan
- Marilyn Geller
- James Harrison

- Jill Harrison
- Matthew Hudson
- Anita Roach
- Umair Shah
- Sandy Sufian

Celebration forthcoming!

Announcements

Upcoming Events

Mark your calendars!

- Public Comment Period *(June 28-August 27)*

- Board Meetings *(July 27, August 24, September 27-28, October 26, November 15-16, and December 1-2)*

- Farewell/Welcome event *(early October)*

- Annual Meeting *(November 17-19)*

Post-Meeting Survey

- Don't forget!
  - Post-meeting survey: https://survey.alchemer.com/s3/6424275/PEAP-Summer-2021-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

Adjourn