ADVISORY PANEL ON PATIENT ENGAGEMENT MEETING

Via GoToWebinar

Fall 2020 Meeting - Day One
October 22, 11:30am-3:30pm EDT

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome

Kristin L. Carman
Director, Public and Patient Engagement

Gwen Darien
Chair, Advisory Panel on Patient Engagement

Agenda: Day One

Part I (EDT):

- 11:30 AM – Welcome and Roll Call
- 11:50 AM – PCORI Strategic Updates
    - Strategic Planning, Identifying National Priorities
    - PCORI's Mandated Research Priorities
- 12:50 AM – 2020 PCORI Virtual Annual Meeting: Post-Meeting Report
- 1:20 PM – Break

Part 2 (EDT):

- 1:50 PM – Principles for the Consideration of the Full Range of Outcomes Data
- 2:20 PM – Engagement Awards Update: Bringing New Organizations to the Table
- 2:50 PM – Sustaining Engagement during the Pandemic: Sharing Novel Approaches
- 3:30 PM – Meeting Adjourned

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

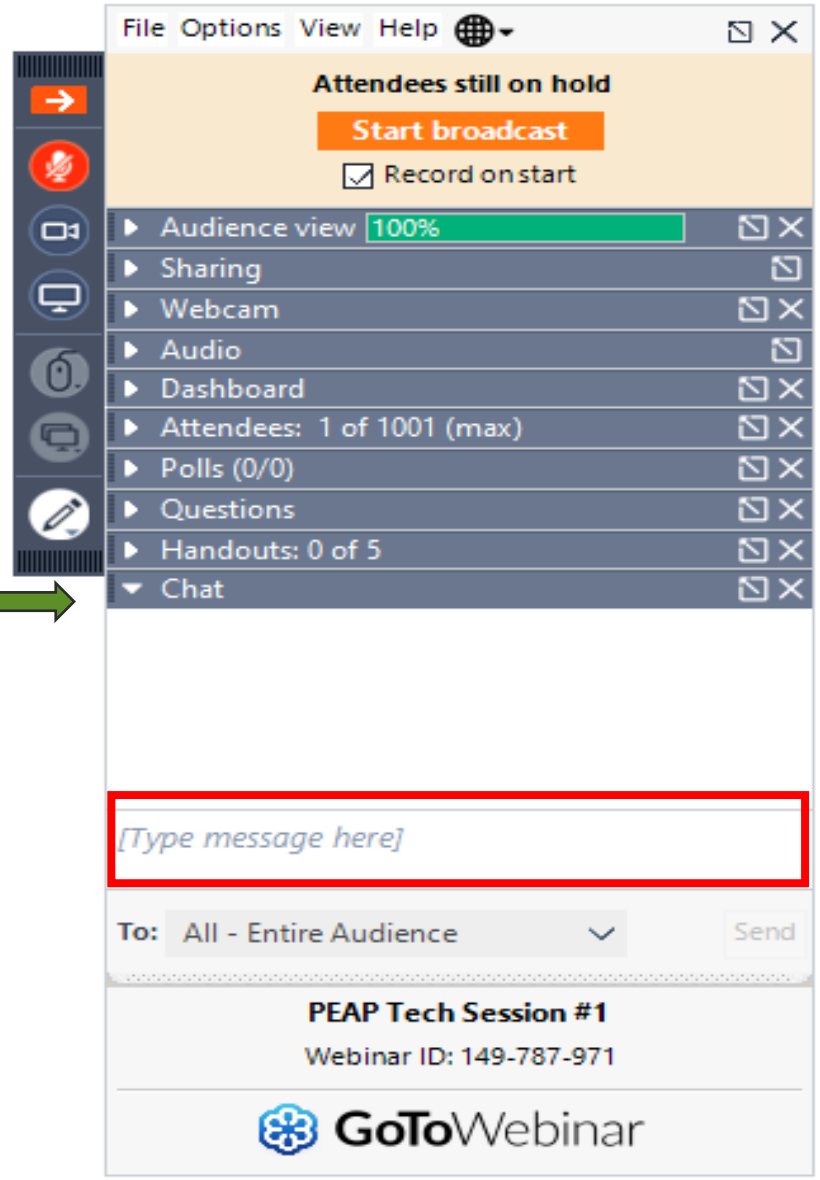
GoToWebinar Housekeeping

- 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

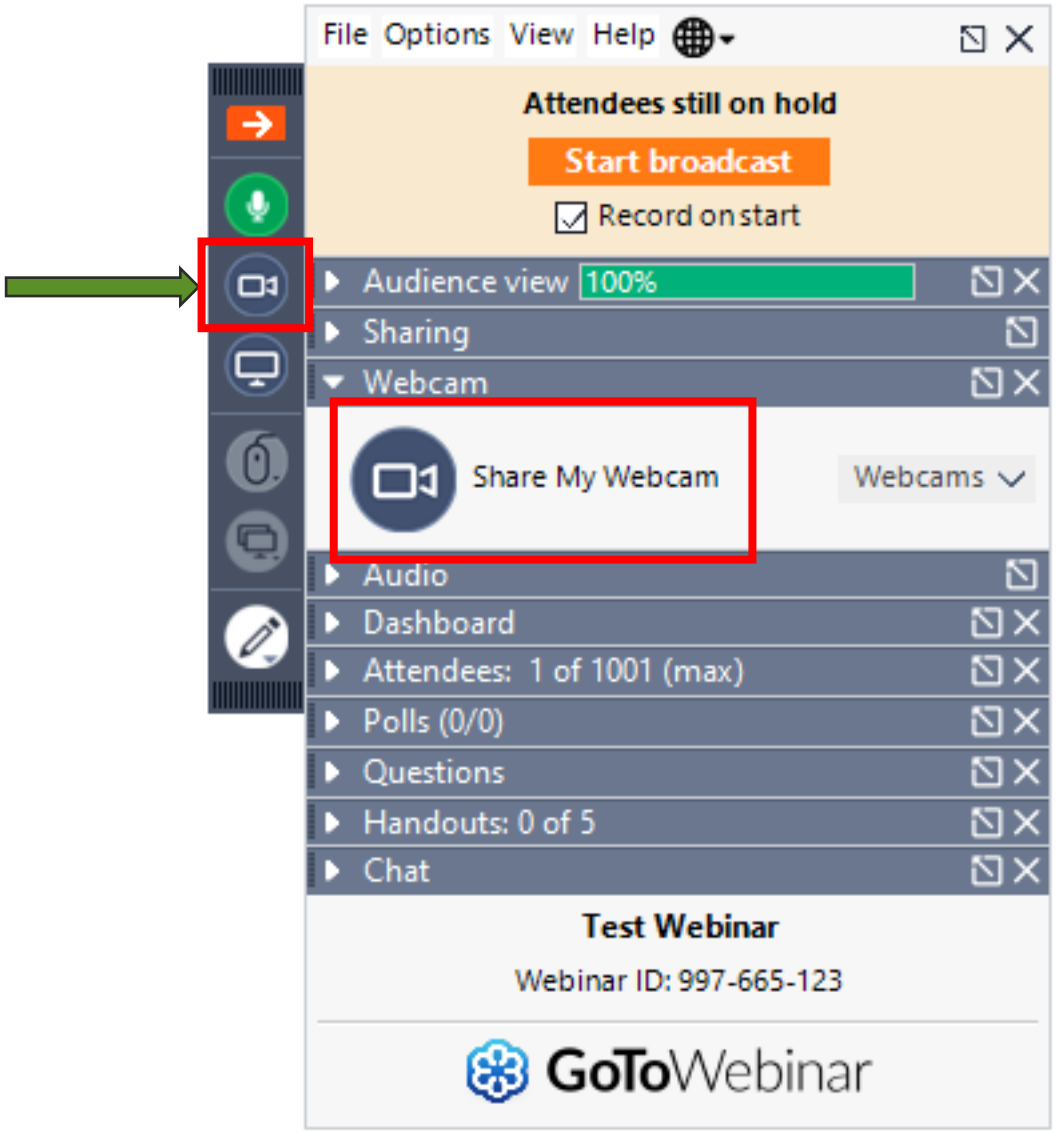
You are muted

Type "I have a comment" in the chat box



How to Turn on Your Webcam – Panelist Instructions

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



The PCORI PEAP Team

Kristin Carman
Director,
Public and Patient
Engagement

Lisa Stewart
Senior Engagement Officer,
Public and Patient
Engagement

Meghan Berman
Program Associate,
Public and Patient
Engagement

Aleksandra Modrow
Senior Administrative
Assistant,
Public and Patient
Engagement

PEAP Chair and Co-chair

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

Thank you, Danny!

Danny van Leeuwen
Representing: Patients/Consumers

Welcome new and reappointed board members!

GAO announces seven new appointments to PCORI Board of Governors

- **Kate Berry**
- **Tanisha Carino**
- **James Huffman**
- **Connie Hwang**
- **Barbara McNeil** *(Reappointed)*
- **Eboni Price-Haywood**
- **James Schuster**
- **Danny van Leeuwen**

Welcome New Members!

Karen Fortuna

Assistant Professor of Psychiatry, Geisel School of Medicine, Dartmouth University

Representing: Researchers

Nashua, NH

Margarita Holguin

Founder and CEO, Consulting Solutions Team, LLC

Representing: Patients, Caregivers, and Patient Advocates

Bonita, CA

Alma McCormick

Executive Director, Messengers for Health

Representing: Patients, Caregivers, and Patient Advocates

Hardin, MT

Al Richmond

Executive Director, Community Campus Partnerships for Health

Representing: Patients, Caregivers, and Patient Advocates

Raleigh, NC

Roll Call - Advisory Panel Members

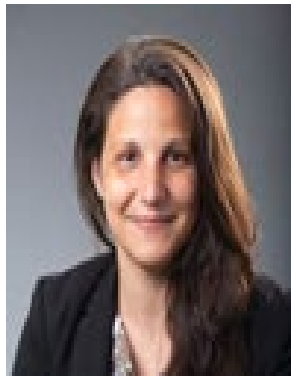
Jennifer Canvasser
Patients, Caregivers, and Advocacy Organizations

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

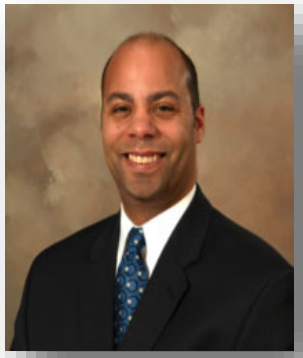
Crispin Goytia
Patients, Caregivers, and Advocacy Organizations

James Harrison
Researchers

Roll Call - Advisory Panel Members

Jill Harrison
Patients, Caregivers, and Advocacy Organizations

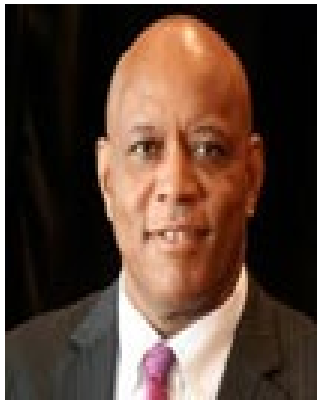
Margarita Holguin
Patients, Caregivers, and Advocacy Organizations



Matthew Hudson
Patients, Caregivers, and Advocacy Organizations

Simon Mathews
Clinicians

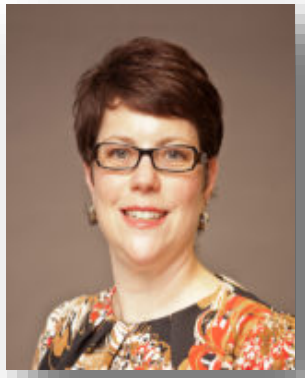
Alma McCormick
Patients, Caregivers, and Advocacy Organizations



Al Richmond
Patients, Caregivers, and Advocacy Organizations

Anita Roach
Patients, Caregivers, and Advocacy Organizations

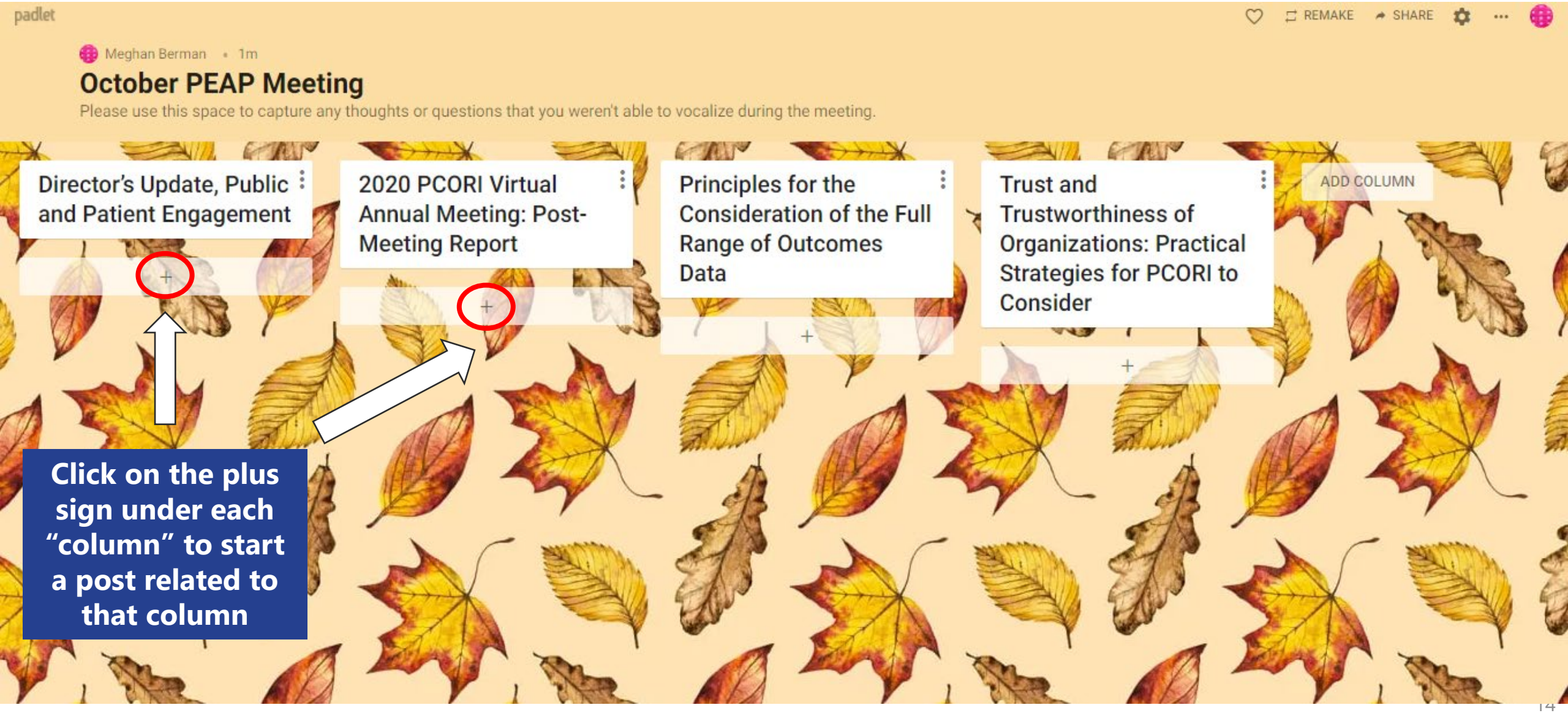
Umair Shah
Policy Makers



Sandy Sufian
Patients, Caregivers, and Advocacy Organizations

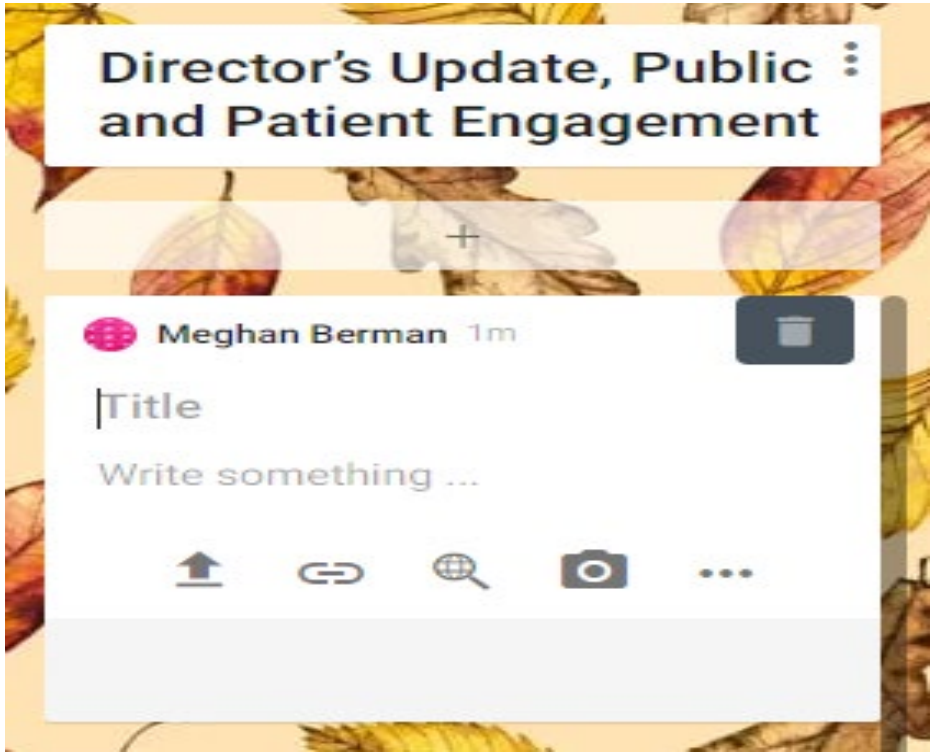
Neely Williams
Patients, Caregivers, and Advocacy Organizations

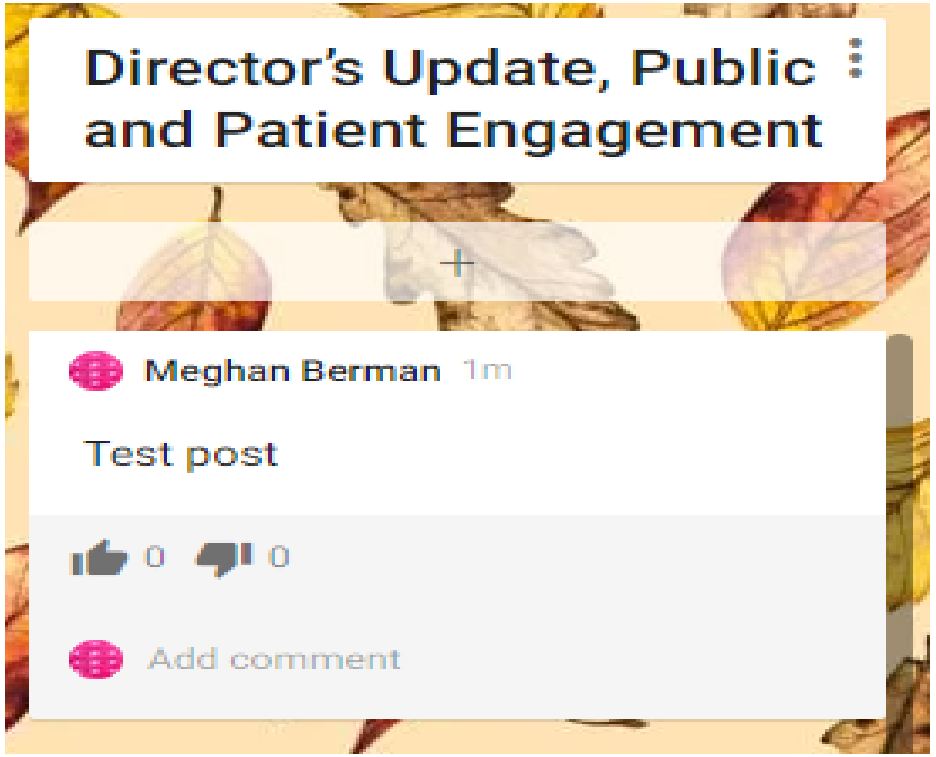
How to Use Padlet



How to Use Padlet

- When writing a post, please make the title your first name, then write your comment in the space below. You can also upload files, links, and photographs.
- You can like posts by clicking on the thumb.
- Navigate here for additional support: https://padlet.com/support





PCORI Strategic Updates

Strategic Planning: Identifying National Priorities

Jean Slutsky, Chief Engagement and Dissemination Officer

PCORI's Mandated Research Priorities

Emma Kopleff, Program Officer, Public and Patient Engagement

Caitlin McCormick, Associate Director, Public Policy

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1.

Strategic Planning: Identifying National Priorities

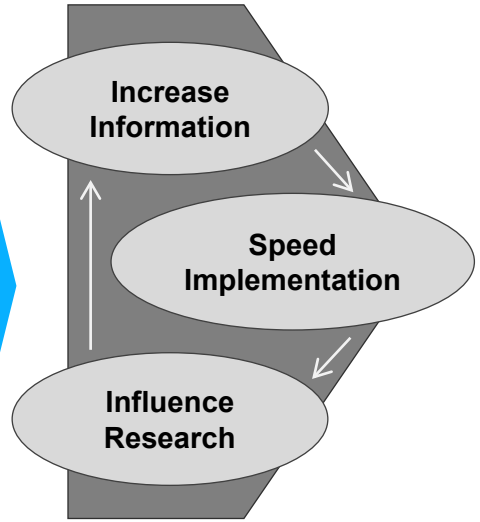
Jean Slutsky
Chief Engagement and Dissemination Officer

Original Strategic Framework (2013)

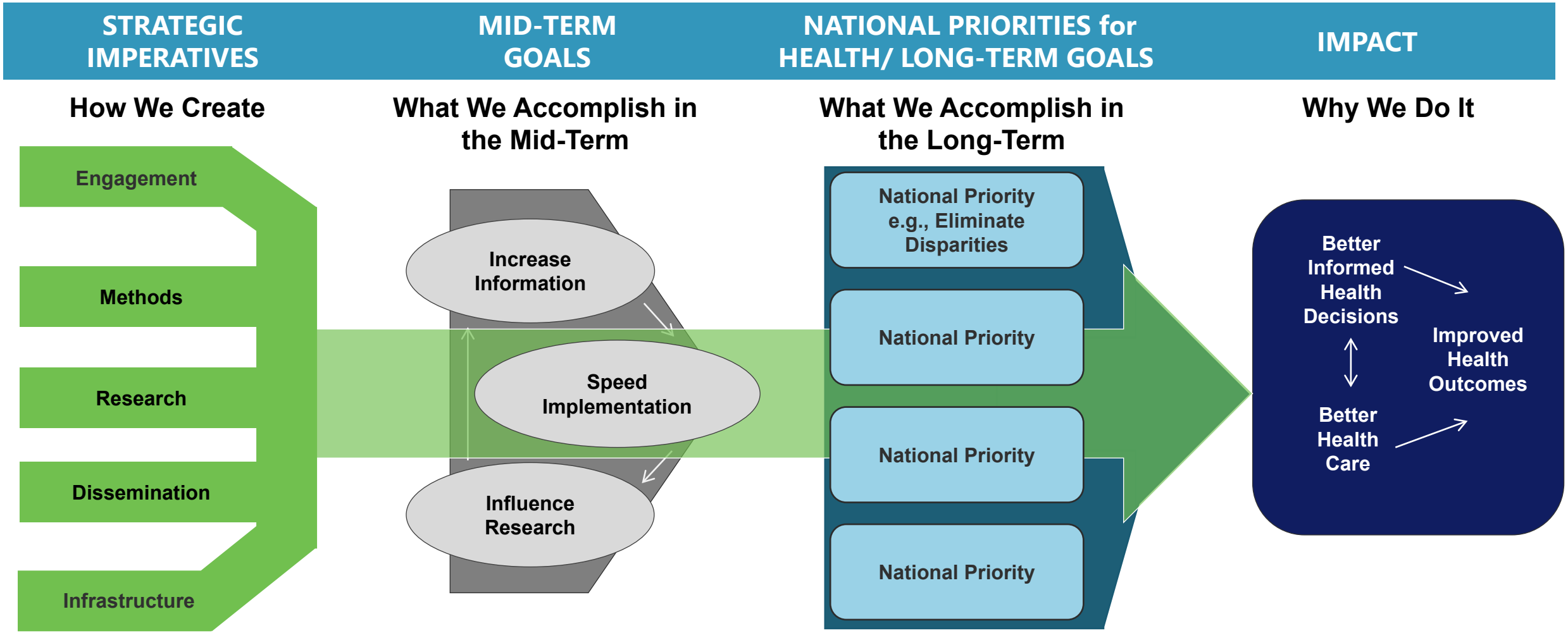
NATIONAL PRIORITIES for RESEARCH	STRATEGIC IMPERATIVES	OUTPUTS	GOALS	IMPACT
Priorities that Guide Our Research	How We Create	What We Create	What We Accomplish	Why We Do It

- Addressing Disparities
- Assessment of Prevention, Diagnosis, and Treatment Options
- Communication and Dissemination Research
- Improving Healthcare Systems
- Accelerating PCOR and Methodological Research

- Engagement → Skilled Patient-Centered Outcomes Research Community
- Methods → Patient-Centered Outcomes Research Methods
- Research → Portfolio of Patient-Centered Outcomes Research Studies
- Dissemination → Communication and Dissemination Activities
- Infrastructure → Patient-Centered Research Networks



Revised Strategic Framework



Legislatively-Mandated Priority Topics Cut Across Our National Priorities

	National Priority	National Priority	National Priority
Intellectual and Developmental Disabilities	A1	B1	C1
Maternal Morbidity and Mortality	A2	B2	C2

Intellectual and developmental disabilities and maternal morbidity and mortality:
Priority topics for the next 10 years

Existing National Priorities
Adopted in 2012

Addressing Disparities

Identifying potential differences in prevention, diagnosis, or treatment effectiveness, or preferred clinical outcomes across patient populations and the healthcare required to achieve best outcomes in each population.

Assessment of Prevention, Diagnosis, and Treatment Options

Comparing the effectiveness and safety of alternative prevention, diagnosis, and treatment options to see which ones work best for different people with a particular health problem.

Communication and Dissemination Research

Comparing approaches to providing comparative effectiveness research information, empowering people to ask for and use the information, and supporting shared decision making between patients and their providers.

Improving Healthcare Systems

Comparing health system–level approaches to improving access, supporting patient self-care, innovative use of health information technology, coordinating care for complex conditions, and deploying workforce effectively.

Accelerating PCOR and Methodological Research

Improving the nation's capacity to conduct patient-centered outcomes research, by building data infrastructure, improving analytic methods, and training researchers, patients, and other stakeholders to participate in this research.

Where Do We Go From Here
Addressing Disparities (AD)

Description

Identifying potential differences in prevention, diagnosis, or treatment effectiveness, or preferred clinical outcomes across patient populations and the healthcare required to achieve best outcomes in each population.

What we've been hearing about this Priority

- Remains more important than ever
- Needs to be strengthened (e.g., eliminate disparities rather than addressing)

We want to hear from you

- What does the reframing of the National Priorities from categories of research to goals for health mean for the AD priority?

Where Do We Go From Here

Assessment of Prevention, Diagnosis, and Treatment Options (APDTO)

Description

Comparing the effectiveness and safety of alternative prevention, diagnosis, and treatment options to see which ones work best for different people with a particular health problem.

What we've been hearing about this Priority

- Importance of prevention and its link to broader public health
- Incorporate the relationships between how individuals live, work, and play and the public health system with priority

We want to hear from you

- What does the reframing of the National Priorities from categories of research to goals for health mean for the APDTO priority?

Where Do We Go From Here
Communication and Dissemination Research (CDR)

Description

Comparing approaches to providing comparative effectiveness research information, empowering people to ask for and use the information, and supporting shared decision making between patients and their providers.

What we've been hearing about this Priority

- Importance of doing communication and dissemination, not just the research of it
- Community engagement can facilitate strong dissemination

We want to hear from you

- What does the reframing of the National Priorities from categories of research to goals for health mean for the CDR priority?

Where Do We Go From Here
Improving Healthcare Systems (IHS)

Description

Comparing health system–level approaches to improving access, supporting patient self-care, innovative use of health information technology, coordinating care for complex conditions, and deploying workforce effectively.

What we've been hearing about this Priority

- Reflect intersection of priority with broader public health ecosystem (e.g., social determinants of health)

We want to hear from you

- What does the reframing of the National Priorities from categories of research to goals for health mean for the IHS priority?

Where Do We Go From Here
Accelerating PCOR and Methodological Research (Methods)

Description

Improving the nation's capacity to conduct patient-centered outcomes research, by building data infrastructure, improving analytic methods, and training researchers, patients, and other stakeholders to participate in this research.

What we've been hearing about this Priority

- Consider infrastructure needed to support the other priorities
- Data infrastructure ecosystem could lead to efforts that complement PCORI's work
- Emphasize human component of infrastructure
  - Capacity building to include diverse participants in research
  - Development of a research pipeline for PCOR

We want to hear from you

- What does the reframing of the National Priorities from categories of research to goals for health mean for the Methods priority?

Is Anything Missing?

Looking at all the existing National Priorities and considering the revised framework,

- Is there an important goal for health that is not reflected in the National Priorities?

2.

An Update on PCORI's Mandated Research Priorities

Emma Kopleff
Program Officer, Public and Patient Engagement

Caitlin McCormick
Associate Director, Public Policy

Putting our Mandate into Action

- Reauthorization language identified two research priorities:
  - Maternal morbidity and mortality (MMM)
  - Intellectual and/or developmental disabilities (IDD)

- Implementation of mandate will include:
  - Long-term priority areas of investment
  - Ongoing opportunities for engagement

Hear from Dr. Nakela Cook in her recent blog

Formulating Our Approach to New Priority Research Areas

Date: September 8, 2020

Blog Topics: Executive Director's Blogs, Funding Awards, Research

As part of last winter's legislation that reauthorized PCORI's funding for 10 years, Congress included two new research priority areas for PCORI to address: strategies for improving maternal mortality, and improving health for individuals with intellectual and/or developmental disabilities (IDD).

These areas are of critical importance for PCORI given the long-standing health challenges faced by those affected and the opportunities that PCORI's approach to *research done differently* can contribute to meaningful health improvements. We are committed to a multipronged approach to funding research to address a variety of issues related to these two topics over the next decade.

Addressing Maternal Morbidity and Mortality

The United States consistently ranks near the bottom among high-income

Current and Near-Term Activities

Stakeholder Engagement: *Landscape review and information gathering (e.g., advisory panels, PCORI Board of Governors, preliminary key informant discussions, stakeholder surveys)*

CURRENT FUNDING OPPORTUNITIES

- *Investigator-initiated proposals for CER with areas of special emphasis**
- *Identified research priority for:*
  - *Phased Large Awards for CER*
  - *Engagement Awards areas of interest*

NEAR-TERM OPPORTUNITIES FOR EVIDENCE SYNTHESIS

- *Systematic reviews*
- *Evidence maps and/or visualizations*

ONGOING STRATEGIC PLANNING

- *Refreshing national priorities*
- *Developing topic pipeline and longer-term research agendas*
- *Engaging representative and diverse stakeholders*

*Indicates dedicated funds specific to research priorities

PCORI's Current Special Areas of Emphasis

Up to $30 million set aside for **each** of these topics, with available funding emphasizing:

- Care and care transitions for individuals with intellectual and/or developmental disabilities growing into adulthood
- Person-centered maternal care for populations likely to experience the most significant disparities in care and/or outcomes

Please find additional details on the PCORI website and within the handout provided.

Key Considerations Moving Forward

Facilitating Engagement

- Building trust and promoting transparency
- Supporting diversity, equity and inclusion
- Adapting to a pandemic context
- Learning from and providing inputs to other PCORI activities (e.g., Engagement Rubric, principles for DEI)

Refining Research Priorities

- Driven by stakeholders
- Aligning with new National Priorities
- Demonstrating PCORI's unique impact amidst other established activities in the field

- **How would PEAP like to be kept up to date and/or engaged in these activities around MMM and/or IDD?** (e.g., standing PEAP agenda item, periodic updates to subset of advisory panelists, representation at broader stakeholder convenings, etc)

- **Do you have ideas for mechanisms and/or venues for execution of these considerations?** (e.g., stakeholder surveys, small and interactive convenings, larger webinars, more "passive" communication channels, etc)

Thank You!

2020 PCORI Virtual Annual Meeting

Post Meeting Report

Tasha Parker
Director, Communications

Amy Damsker-Wright
Associate Director, Communications

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Who Attended?

2019

887

- Researcher (44%)
- Patients, Caregivers, Caregiver/Patient Advocacy Orgs (30%)
- Clinician, Hospital/ Health Systems, Training Insts. (16%)
- Industry, Payer, Policy Maker, Purchaser (10%)

2020

2,306

- Researcher (47%)
- Patients, Caregivers, Caregiver/Patient Advocacy Orgs (21%)
- Clinician, Hospital/ Health Systems, Training Insts. (23%)
- Industry, Payer, Policy Maker, Purchaser (8%)

Other (1%)

Virtual Meeting Space

Average amount of time attendees were in the virtual space: 7 hours

Engagement Opportunities

- Networking Lounge general chat and 8 topic-driven chats
- Padlet to provide input on PCORI's National priorities
- Attendee one-on-one chat between attendees
- Chat with poster presenters (44 posters)

Engagement Opportunities

4 PCORI booths visited over 1,600 times with opportunity to talk with a representative

Top Breakout Sessions

1. Disseminating & Implementing PCOR Evidence into Primary Care Practice Building on AHRQ's Experience
2. System Challenges to Inclusion of Vulnerable Populations in Pragmatic Trials
3. Patient-Centered Telehealth under the Coronavirus Pandemic
4. Building Effective Multi-Stakeholder Research Teams
5. Evidence for Dissemination Findings People Want to Know About

Preliminary Attendee Survey Results

- 525 responses (23% response rate)
- > 85% of respondents agree that the Annual Meeting:
  - Provided information that will help make health care more effective and patient-centered
  - Promoted the use of research results
  - Demonstrated how engagement impacts research
- 95% of respondents indicated they were excited for PCORI's future
- Attrition survey respondents cited schedule conflict as the main reason for registering but not attending

Discussion

- Patient inclusion and engagement
  - How did we do this year?
  - How can we improve next year?

- Do you have ideas on more engaging session formats?

- What are your thoughts on programming tracks?
  - Is there specific programming that would be of interest to the patient community?

Questions

Break

1:20 – 1:50pm EDT

Update on PCORI's Proposed Principles for the Consideration of the Full Range of Outcomes

Andrew Hu
Director, Public Policy

Joanna Siegel
Director, Dissemination and Implementation

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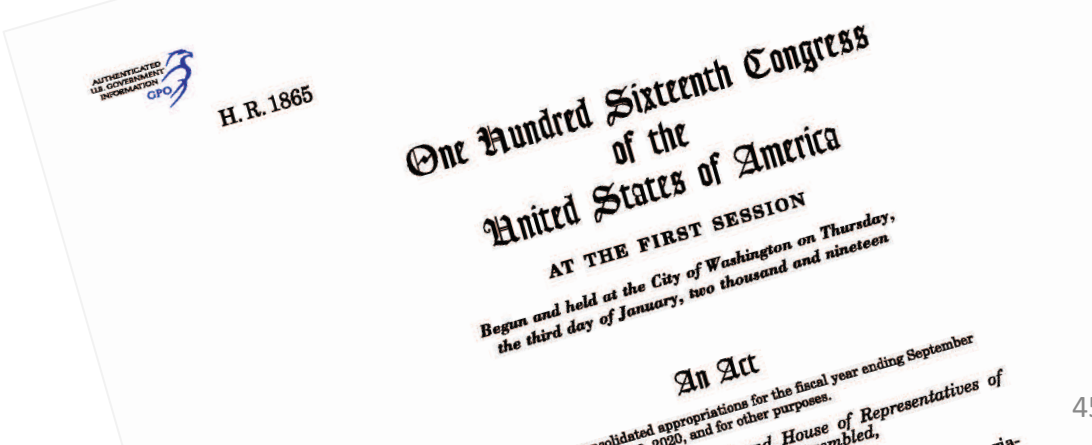
Overview of New Statutory Authority

PCORI's reauthorizing legislation directs PCORI to capture, **as appropriate**, the full range of outcomes data in the course of our research studies.

This includes economic and cost data related to the utilization of health care services, but also outcomes and measures of cost and burden **important to patients**.

Potential Burdens and Economic Impacts Include:

- Medical out-of-pocket costs, including health plan benefit and formulary design
- Non-medical costs to the patient and family, including caregiving
- Effects on future costs of care
- Workplace productivity and absenteeism
- Healthcare utilization


H.R. 1865

One Hundred Sixteenth Congress
of the
United States of America

AT THE FIRST SESSION

Begun and held at the City of Washington on Thursday, the third day of January, two thousand and nineteen

An Act

Social Security Act. Section 1181 [42 U.S.C. 1320e] (d)(2)(F)

Overview of PCORI's Cost Data Implementation Proposal

Pillar 1

- Providing guidance to Principal Investigators in future PFAs on how they should interpret this policy and incorporate it into their research proposals.
- **Timeline:** Final Principles and Guidance for Applicants by **February or March 2021**

Pillar 2

- Establishing methodology standards to further inform how PCORI-funded studies should capture relevant data.
- **Timeline:** Approximately **12 months** from the initiation of this process

Pillar 3

- Convening discussions on how this information can/should be used.
- **Timeline:** Ongoing Discussion

Progress Report
Pillar One

Proposed "Principles"

- PCORI Board of Governors approved the release of the proposed "Principles" for Public Comment on **September 14, 2020**

Seeking Public Input

- 60-Day Public Comment Period
- Webinar Series
- Advisory Panels

Revising Principles & Guidance

- Revise "Principles" based on public input
- Final approval of "Principles" in February or March 2021
- Guidance to applicants in PCORI funding announcements in Spring 2021

WE ARE HERE

Proposed Principles for the Consideration of the Full Range of Outcomes Data

What are the Principles?

- These principles are a **high-level framework** to describe PCORI's interpretation of the new mandate to collect cost burden and economic impact data

Why do we need them?

- To provide the public and potential applicants with an understanding of how PCORI interprets the mandate

How will they be used?

- These principles will serve as a point of reference for PCORI as a basis for developing guidance to potential applicants and updating PCORI's Methodology Standards
- These principles should not be viewed as standards and methods

Proposed Principles

Identifying Outcomes Important to Patients

- **Principle #1:** PCORI-funded research may consider the full range of outcomes *important to patients and caregivers*, including burdens and economic impacts.

Identifying Outcomes Important to Stakeholders

- **Principle #2:** PCORI-funded research may consider the full range of outcomes *relevant to other stakeholders*, when these outcomes have a near-term or longer-term impact on patients.

Criteria Regarding the Collection of Data

- **Principle #3:** The collection of data on burdens and economic impacts of treatment options must be appropriate and relevant to the clinical aims of the study.

Consideration of Economic Analysis

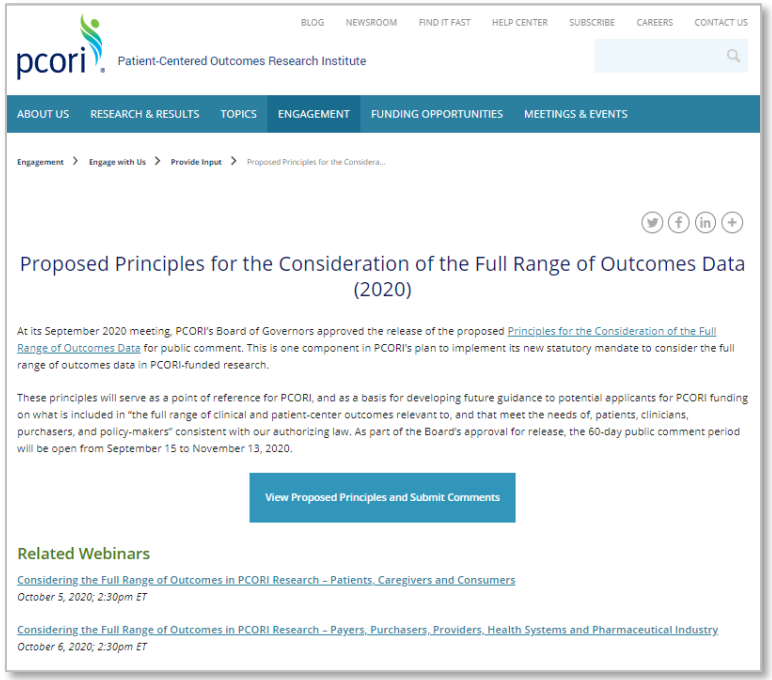
- **Principle #4:** Beyond the collection of burden and economic impact data, PCORI may support the conduct of certain types of economic analyses as part of a funded research study, to enhance the relevance and value of this information to health care decision-makers.

Themes of Input Received

- Broad **support** for the consideration of costs and economic impact data in PCORI research
- Ensure a **patient-centered and holistic** approach to the consideration of costs
- Consider the cost burdens and impacts from a **societal and community** level
- Helpful to capture **implementation or program costs**
- Having patient-centered cost/impact data can help in **value-based payment** models

References & Resources

- Proposed Principles for the Consideration of the Full Range of Outcomes Data ***(Landing Page)***



- Webinar 1 Recording **(Patients, Caregivers, and Consumers)**

- Webinar 2 Recording **(Payers, Purchasers, Providers, Health Systems and Pharmaceutical Industry)**

- Proposed Principles for the Consideration of the Full Range of Outcomes Data ***(Public Comment Webform)***

Discussion

Engagement Awards Update

Bringing New Organizations to the Table

Karen Martin
Program Director, Eugene Washington PCORI Engagement Awards

Alicia Thomas
Associate Director, Eugene Washington PCORI Engagement Awards

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Eugene Washington PCORI Engagement Award Program

- Support projects to build a community of patients and other stakeholders equipped to participate as partners in PCOR/CER, as well as serve as channels to disseminate PCORI-funded study results
- Funding to support engagement in, and with, research, not to conduct research

Engagement Award Funding Opportunities

$250,000
Up to 2 years

Engagement Award: Capacity Building

Objective: Prepare patients and stakeholders to participate as partners in PCOR/CER and/or develop partnerships and infrastructure to disseminate and implement PCORI-funded research findings

$250,000
Up to 2 years

Engagement Award: Dissemination Initiative

Objective: Support communities and organizations to actively disseminate PCORI-funded research findings

$100,000
Up to 1 year

Engagement Award: Stakeholder Convening Support

Objective: Convene stakeholders to explore critical issues related to PCOR/CER and/or communicate PCORI-funded research findings to targeted end-users

Evolution of Funding Priorities

2014-2016

- Knowledge Awards
- Training and Development Awards
- Dissemination & Implementation Awards
- Meetings and Conferences Support

October 2017-February 2018

- Engagement Award (general)
- Meetings and Conference Support

June 2018-June 2019

- Capacity Building
- Dissemination Initiative
- Conference Support

November 2019

Special Project Funding Announcements:

- Community Convening
- Accelerating the Adoption of Tools and Resources

May 2020

- Capacity Building
- Dissemination Initiative
- Stakeholder Convening
- COVID-19 Enhancements and Special Cycle

October 2020

- Capacity Building
- Dissemination Initiative
- Stakeholder Convening
- *Next Steps: Opportunities for growth under PCORI 2.0*

Discussion Questions

- What are the needs of smaller organizations (e.g., community-based organizations, patient/caregiver/advocacy organizations, associations, etc.) with regards to building capacity for stakeholder engagement in PCOR/CER?
- How can we promote the Engagement Awards to a wider range of organizations?
- What forums or networks might be interested in learning more about the program?

Funded Projects on PCORI's Website

Explore Our Portfolio of Funded Projects

(If you would like more detailed information about research projects PCORI has funded, please contact info@pcori.org)

Enter keyword(s) | Search Projects

Show Only Projects With Results

Filter Results: Project Status | State | Project Type | More filters

Displaying 1 - 10 of 846 × Engagement in Research Project **Reset All Filters** Download these results

Project Title	Project Status	State	Project Type
Accelerating Adoption of Research Ready Tools to Engage the Clinical Workforce as Champions of PCOR Louisiana Public Health Institute Daniele Farrisi, MPH	Awarded; In progress	Louisiana	Engagement Award Project
VIrtual Patient Engagement (VIP) Studio: Using Technology to Engage Hard-to-Reach Patients	Awarded; In progress	South Carolina	Engagement Award Project

Sustaining Engagement During the Pandemic

Sharing Novel Approaches

Advisory Panelists:
Gwen Darien, Jennifer Canvasser, Marilyn Geller, Crispin Goytia-Vasquez

PCORI Staff:
Kate Boyd, Program Officer, Eugene Washington PCORI Engagement Awards

Christine Broderick, Engagement Officer, Public and Patient Engagement

Courtney Clyatt, Senior Program Officer, Eugene Washington PCORI Engagement Awards

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Overview

- The Changing Landscape
  - Some of what we are seeing

- PEAPs in Action: Adapting to the Pandemic
  - Jennifer Canvasser, NEC Society
  - Marilyn Geller, Celiac Disease Foundation
  - Crispin Goytia, Patient Engagement Consultant

- Open Discussion
  - What adjustments are you making to your engagement approaches due to the pandemic?

1.

The Changing Landscape

Kate Boyd

Program Officer, Eugene Washington PCORI Engagement Awards

Christine Broderick

Engagement Officer, Public and Patient Engagement

Courtney Clyatt

Senior Program Officer, Eugene Washington PCORI Engagement Awards

Some of What we are Seeing

Contextual Factors	• Health systems focused on direct care • Research suspended • Individuals/families health affected; loss of income • Community and personal trauma
Engagement Adaptations	• Virtuality, the new normal • More intense front-end support • Community organizations are pivoting to respond to immediate personal needs of stakeholder partners • Use of intermediaries to assess and support engagement
Opportunities	• Flexible, just-in-time methods that widen participation • Involvement of stakeholder partners in study adaptation • Patient-generated data collection

2.

PEAPs in Action: Adapting to the Pandemic

Jennifer Canvasser, Founder, NEC Society

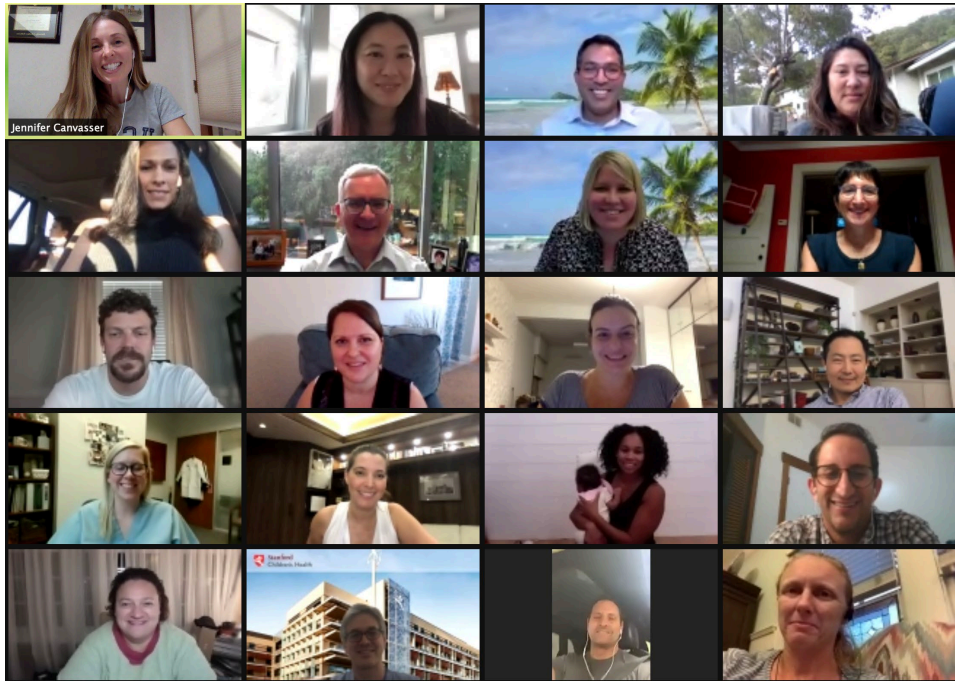
Marilyn Geller, Chief Executive Officer, Celiac Disease Foundation

Crispin Goytia-Vasquez, Patient Engagement Consultant

PEAPs in Action
Adapting to the Pandemic

- Jennifer Canvasser, NEC Society
- Marilyn Geller, Celiac Disease Foundation
- Crispin Goytia-Vasquez, Patient Engagement Consultant

Necrotizing Enterocolitis (NEC) Society



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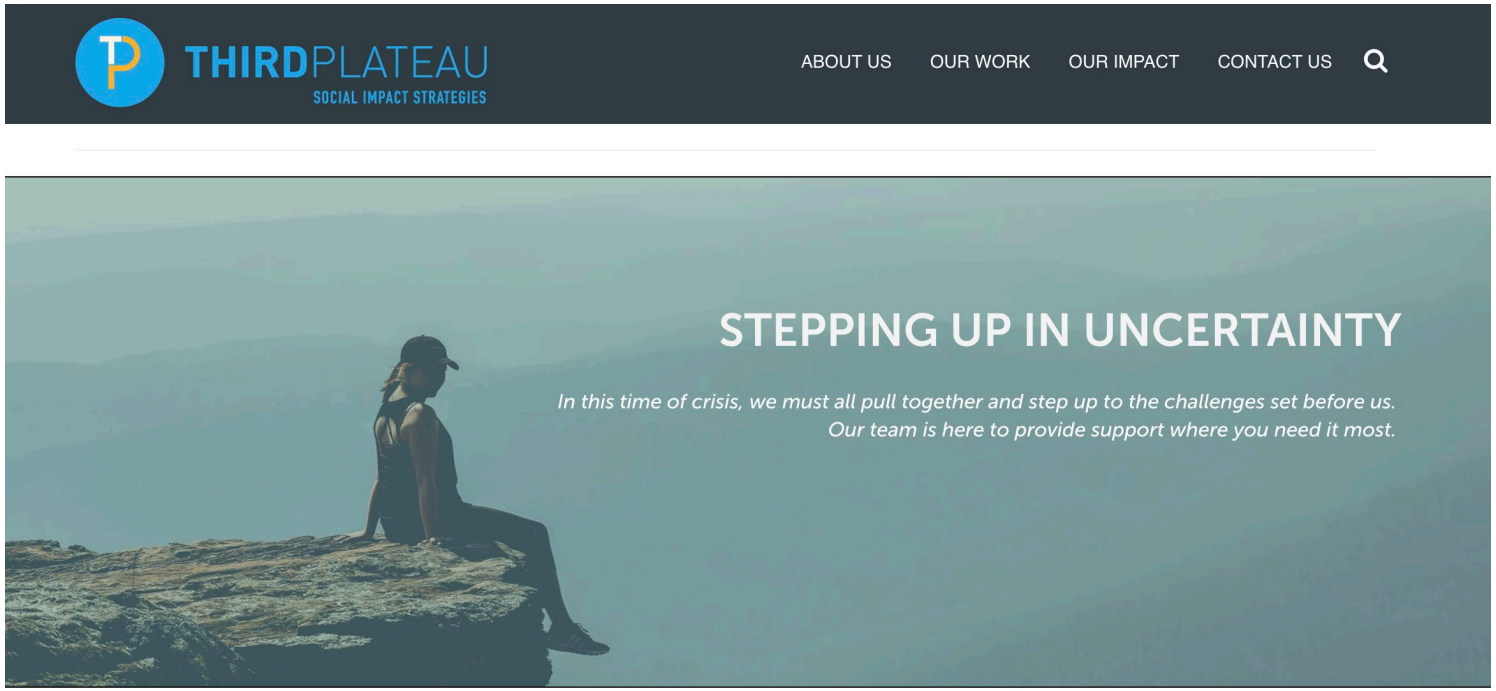


In the spirit of our core value Step Up, we've identified a number of ways below to support all of you amazing leaders and organizations in this strange time. We've pulled together a list of offerings we think might help you as you navigate this crisis. If you were hoping to see something different here, please reach out and let us know how we can help!

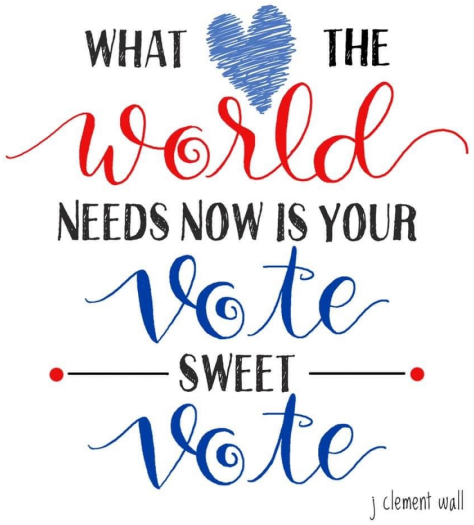
Necrotizing Enterocolitis (NEC) Society

Insights

See All

Last 28 days : Sep 17 - Oct 14

People Reached	39,435 ▲20%
Post Engagements	17,072 ▲43%
Page Likes	150 ▲15%



Fundraisers

See All

Kristen's Birthday Fundraiser for NEC Society

Fundraiser for NEC Society by Kristen Tallon

$190 raised of $200

You wrote thank you. **See Post**

Kaitlyn's Birthday Fundraiser for NEC Society

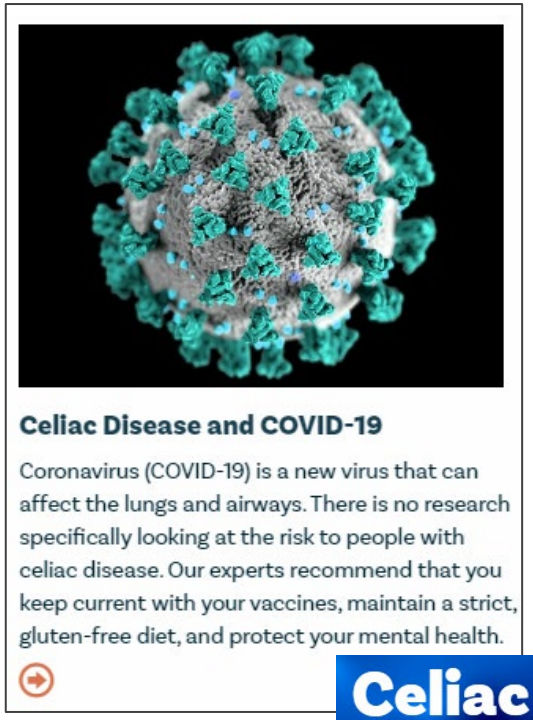
Fundraiser for NEC Society by Kaitlyn Outland

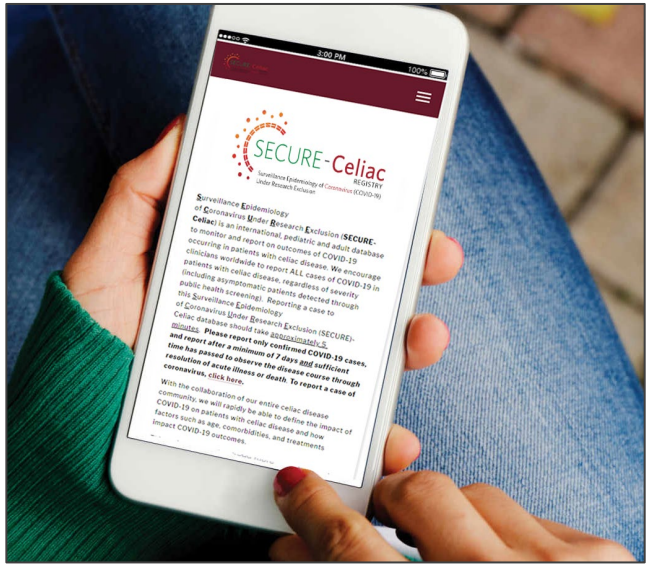
$300 raised of $300

Say Thanks

Celiac Disease Foundation

Leading the fight to increase the rate of diagnosis, to improve treatment, and to find a cure for celiac disease.





Join iAdvocate

Complete the State Advocacy Ambassador training program

Celiac Disease and Coronavirus (COVID-19) Resource Center

Lessons Learned for Virtual Engagement

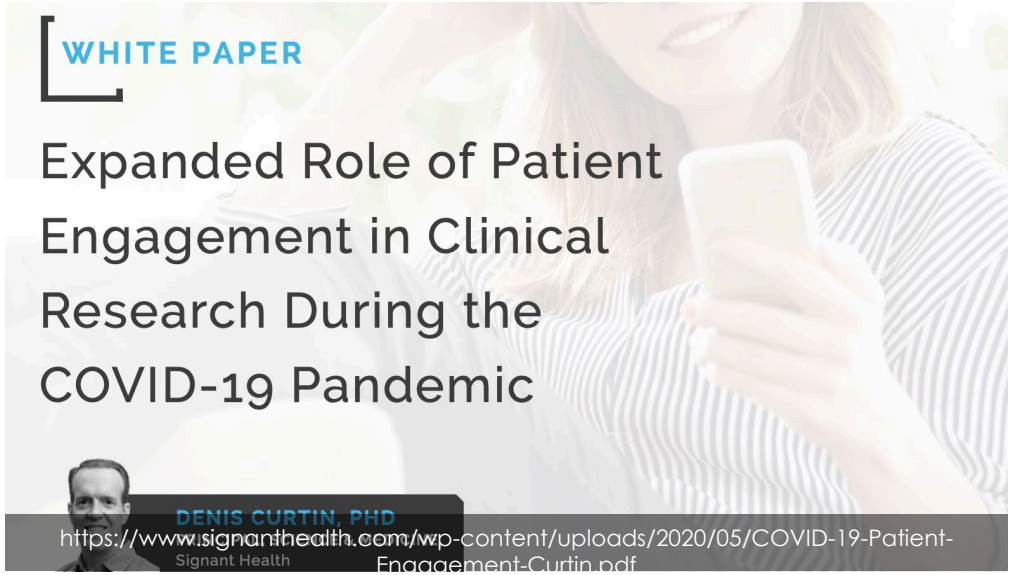
- We had to "pivot" engagement with our stakeholders across projects
  - In our Patient Dashboard Project, focus groups moved from in-person to completely virtual (Zoom, Webex, Microsoft teams)
- Recognizing stakeholders are juggling competing priorities
  - Jumping from meeting to meeting, overlapping meeting times, "zoom fatigue"
  - Deciding what projects are worth your time and energy
  - How to fit in with your family obligations
- Understanding gaps and adapting virtual technologies
  - Learned about gaps in how people use technology to connect with others (professionally & personally)
  - As a result, we created a step-by step guide on how to use zoom that were provided to stakeholders in advance of virtual personal interviews
- Check-ins (still important!)
  - Don't forget to have regular check-ins with your patient partners & stakeholders to make sure they are **NOT** left out or feeling left behind!

How to Join a Zoom Meeting

Before joining a Zoom meeting on a computer or smartphone device, you can download the Zoom app from the Zoom Download Center. Otherwise, you will be prompted to download and install Zoom when you click a join link. You can also join by phone and all instructions are below:

What you need to know about Zoom Meeting

Each meeting has a unique 9, 10, or 11-digit number called a **meeting ID** that will be required to **join** a Zoom meeting. If you are joining by telephone, you will need the teleconferencing number that should have been provided in the invite.



https://www.signanthealth.com/wp-content/uploads/2020/05/COVID-19-Patient-Engagement-Curtin.pdf

3.

Panel Discussion

What's Happening in your Communities?

Discussion Questions

- How are you changing your engagement approaches as a result of the pandemic, beyond moving to virtual?
- Is anything working better now that it did before? Have there been unanticipated gains from changes that you've made?
- What's been the downside? What's getting lost?

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