

ADVISORY PANEL ON PATIENT ENGAGEMENT MEETING

Via GoToWebinar

Fall 2020 Meeting - Day Two
October 23, 11:30am-3:30pm EDT

Welcome

Kristin L. Carman

Director, Public and Patient Engagement

Gwen Darien

Chair, Advisory Panel on Patient Engagement



Agenda: Day Two



Part I (EDT):

- 11:30 AM – Welcome
- 11:45 AM – Director's Update, Public and Patient Engagement
- 12:15 PM – Trust and Trustworthiness of Organizations: Strategies for PCORI to Consider
- 1:10 PM – Break

Part 2 (EDT):

- 1:40 PM – Supporting DEI in Research Partnerships: Discussion of Draft Principles
- 2:50 PM – Building a Research Agenda for Studying DEI in Engagement
- 3:20 PM – Wrap-up and Announcements
- 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



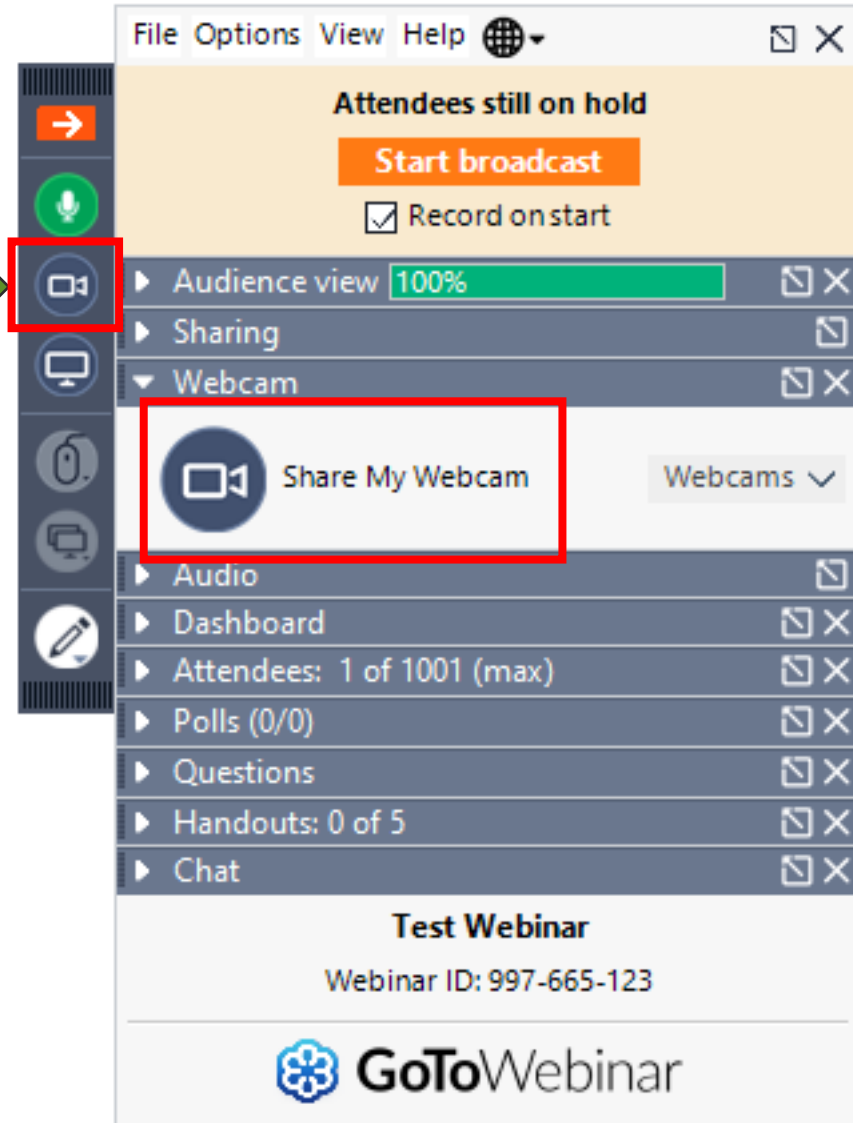
Type "I have a comment"
in the chat box



The screenshot shows the GoToWebinar interface. At the top, there's a menu bar with 'File', 'Options', 'View', and 'Help'. Below this, a status bar indicates 'Attendees still on hold' with a 'Start broadcast' button and a 'Record on start' checkbox. A list of controls is visible on the left, including 'Audience view' (100%), 'Sharing', 'Webcam', 'Audio', 'Dashboard', 'Attendees: 1 of 1001 (max)', 'Polls (0/0)', 'Questions', 'Handouts: 0 of 5', and 'Chat'. The 'Chat' section is expanded, showing a text input field with the placeholder '[Type message here]' highlighted by a red rectangle. Below the input field is a 'To:' dropdown menu set to 'All - Entire Audience' and a 'Send' button. At the bottom, the session title 'PEAP Tech Session #1' and 'Webinar ID: 149-787-971' are displayed, along with the GoToWebinar logo.

How to Turn on Your Webcam – Panelist Instructions

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



Roll Call - Advisory Panel Members



Jennifer Canvasser
*Patients, Caregivers,
and Advocacy
Organizations*



Beth Careyva
Researchers



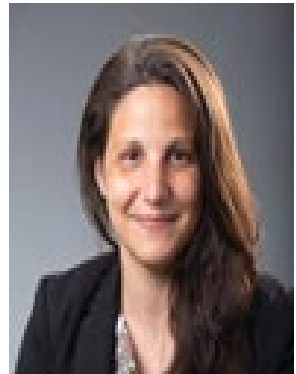
Tracy Carney
*Patients, Caregivers,
and Advocacy
Organizations*



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*

Director's Update

Public and Patient Engagement

Kristin Carman

Director, Public and Patient Engagement

Overview



1. Strategic Priorities: Public and Patient Engagement
2. Engagement Trainings Update
3. Engagement Evaluation Funding: Overview and Process
4. Openings & Opportunities

1.

Strategic Priorities

Strategic Priorities

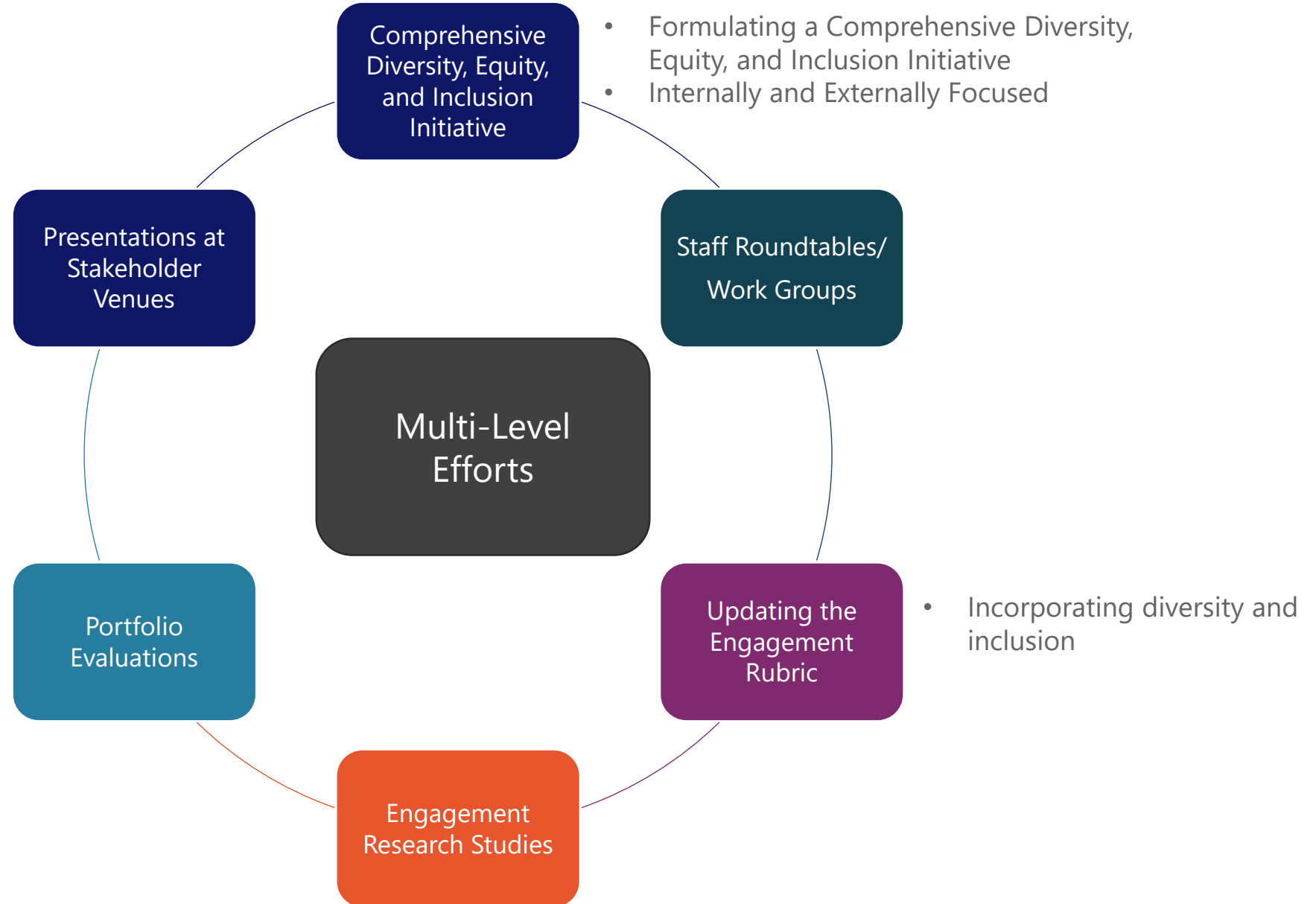
Public and Patient Engagement



- Science of Engagement
 - *Synthesizing the literature, as well as PCORI findings from qualitative studies and practice-based knowledge*
- Topic generation and National Priorities
- Update of the PCORI Engagement Rubric
 - *Integration with PEAP & organizational DEI efforts, and PCORI engagement findings*
- Developing additional trainings and resources to support engagement practice
- Facilitating broader inclusion of diverse populations
 - *Literature review and study of engagement of underrepresented populations to inform project-level and organizational engagement efforts*

PCORI Diversity, Equity, and Inclusion Activities

- PCORI Virtual Annual Meeting
- Keynote Speaker – Dr. Lisa Cooper – [Racism and Discrimination in Health Care: Raising Our Collective Consciousness](#)
 - Panel – [Standing Up to Racism, Discrimination, and Bias: A Dialogue on Health and Healthcare Equity](#)



2.

Engagement Trainings Update



Provides **foundational knowledge in PCOR/CER** to **non-scientist participants** on research and other projects.



pcori.org/research-fundamentals

Research Fundamentals: THANK YOU JENN!

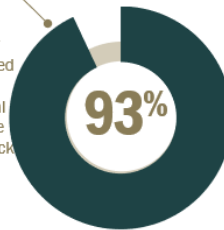


PCORI Research Fundamentals Learning Package

Completion of Evaluation Survey and Learning Package

NEC Society PCORI Research Fundamentals Learning Package: % Completion

Almost all individuals who completed the evaluation survey also indicated that they completed the Research Fundamentals Learning Package. One individual stated that they did not complete the learning package due to a lack of time/need more time to complete all the modules.

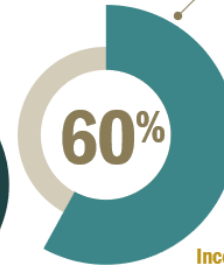


Barriers to Completion

A large number of individuals (40%) did not respond to the evaluation survey. Though one individual who did not complete the learning package participated in the evaluation survey, more information is needed from other PCOR NEC leadership who did not participate to better understand the barriers for non completion.

Evaluation Survey Response: % Completion

All NEC PCOR leadership members (N=25) were invited to complete the PCORI Research Fundamentals Learning Package. A total of 15 individuals (or 60%) completed the survey.



Incentive: % Indicating they wanted to Receive the Incentive

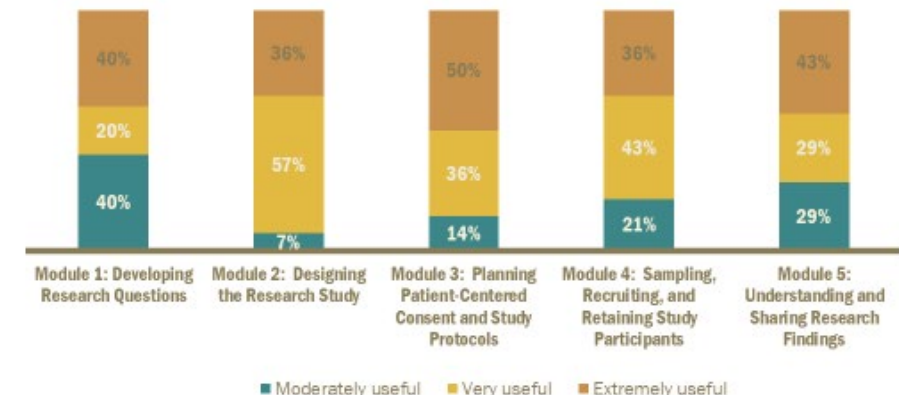
Among those eligible to receive the incentive, most (n=12) stated they wanted the incentive while a few (n=2 or 14%) indicated that they did not want to receive the incentive.



Usefulness of Module Sections of the Learning Package

"Please indicate the usefulness for each of the module sections of the learning package:"

Overall, all modules were considered useful by participants. Modules 2 & 3 had the highest levels of usefulness, while Module 1 received slightly lower levels, as compared to other modules in the learning package.



For **new and experienced researchers and stakeholder partners**, offers **practical guidance and resources to support multi-stakeholder teams** in effectively working together.



Building Effective Multi-Stakeholder Research Teams – PCORI Annual Meeting



- Featured a panel to introduce the learning package and discuss key challenges in effectively working together: **creating shared vision, establishing norms, and managing disagreement.**
- Included active engagement from 404 session viewers through the Q&A (33 questions from 27 viewers), viewer chat, and Padlet.



Many thanks to panelists Melody Goodman, Jen Lavoie, Pam Dardess, and Al Richmond, and moderator Tom Workman

3.

Engagement Evaluation Funding: Overview & Process



Engagement Evaluation Funding

Studying Engagement within Research Awards



An opportunity for **awardees to document, evaluate, and learn from** engagement practices they are employing during the COVID pandemic in terms of effects, successes, and challenges.

- The COVID-19 pandemic is having major effects on every aspect of PCORI-funded studies, including engagement
- These engagement challenges can yield effective, patient-centered solutions and strategies
- This new knowledge can fill critical gaps in the evidence about engagement and produce useful information from which others can learn
- This opportunity lets investigators & partners study engagement themselves; can hear from more people, different perspectives than through PCORI-initiated work

Engagement Evaluation Funding

Areas of Interest



Innovations in engagement approaches due to social distancing or other pandemic-specific circumstances



Successes and challenges of engagement strategies, including balancing the perspectives of different stakeholders



Effects of engagement approaches on maintaining or expanding engagement with historically underrepresented or disproportionately impacted populations



Effects of engagement on study aims and design decisions, study feasibility, acceptability to participants and the experience of the study team

4.

Openings & Opportunities



Advisory Panel Openings

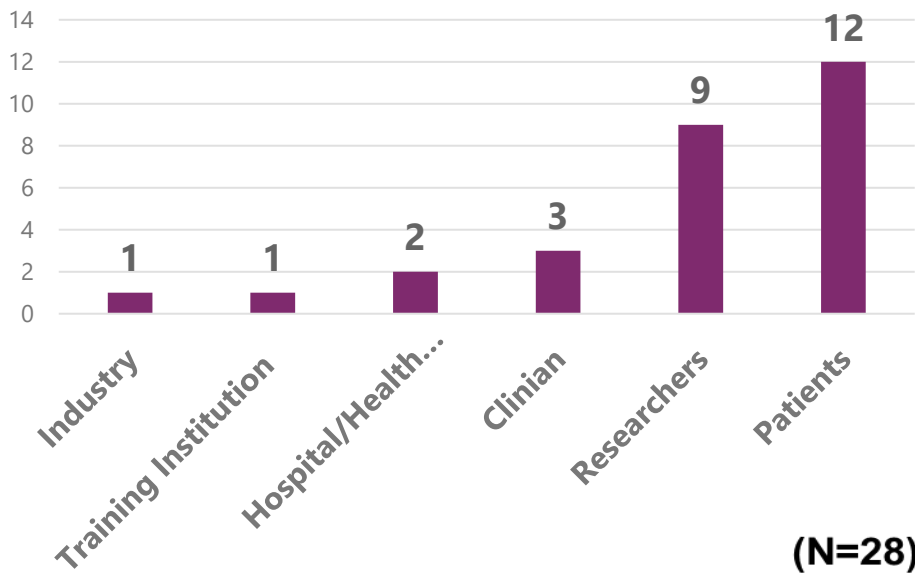
- PCORI is now accepting nominations and applications for its five advisory panels
 - Advisory Panel on Rare Disease (RDAP)
 - Advisory Panel on Clinical Trials (CTAP)
 - Advisory Panel on Patient Engagement (PEAP)
 - Advisory Panel on Clinical Effectiveness and Decision Science (CEDS)
 - Advisory Panel on Healthcare Delivery and Disparities Research (HDDR)
- Applications due March 31, 2021 by 5pm ET
 - PCORI accepts third-party nominations for its advisory panels
 - Please send a PDF of your nomination letter to the applicant
- The application, along with more information on each panel, can be found [here](#)

PCORI Ambassador Program

- The Ambassador Program will be having the annual half-day workshop on November 18th that will focus on equity and inclusion in PCOR.
- New systematic recruitment efforts will be focused on our research awardee teams and partners to enhance representativeness.

Since the last PEAP meeting . . .

Ambassador Recruitment Since June 2020



3 Coffee Breaks focused on topics like the HERO trial, COVID-19 in-patient care, and PCORnet engagement efforts.



The Ambassador Center has received **25 requests** to connect.



20 Ambassadors joined our Yammer community.



32 Ambassadors are paired in our mentor program.

There are currently **350 Ambassadors** across the country extending the reach of PCORI's research and results and spreading the importance of PCOR.

The Ambassador Program helps to facilitate connections for project collaboration. Recently, a group of **10 Ambassadors** have come together to create a funding proposal focused on addressing disparities.

Trust and Trustworthiness of Organizations

Practical Strategies for PCORI to Consider

Julie Kennedy Lesch

Senior Engagement Officer, Public and Patient Engagement

Lauren Fayish

Program Officer, Evaluation and Analysis



- Background and purpose for this session
- Group discussion to inform PCORI future directions
 - What are some traits and actions of trustworthy organizations?
 - What has PCORI as an organization done in the past to show that it is or is not a trustworthy organization?
 - What can PCORI do in the short term to be a trustworthy institution given the current climate?
 - What should PCORI do in the long term to ensure it is a trusted partner and source of information?

Majority of public thinks it's likely that vaccine will be used before safety, effectiveness fully understood

% of U.S. adults who say each of the following is ___ likely once a vaccine for COVID-19 is approved in the U.S.

■ Very ■ Somewhat ■ Not too/Not at all

A vaccine will be used before we fully understand whether it is safe, effective



Enough Americans will get vaccinated to stop the disease's spread



Everyone who wants it will have quick and easy access



Note: Respondents who did not give an answer are not shown.

Source: Survey conducted Sept. 8-13, 2020.

"U.S. Public Now Divided Over Whether To Get COVID-19 Vaccine"

PEW RESEARCH CENTER

The Washington Post

Democracy Dies in Darkness

Black doctors want to vet vaccine process, worried about mistrust from years of medical racism

By Meryl Kornfield

September 26, 2020 at 8:00 a.m. EDT

Cancer



Original Article

Bias and stereotyping among research and clinical professionals: Perspectives on minority recruitment for oncology clinical trials

Soumya J. Niranjana BPharm, MS, PhD, Michelle Y. Martin PhD, Mona N. Fouad MD, MPH, Selwyn M. Vickers MD, Jennifer A. Wenzel PhD, Elise D. Cook MD, MBA, Badrinath R. Konety MD, MS, Raegan W. Durant MD, MPH

'I Won't Be Used as a Guinea Pig for White People'

Father Paul Abernathy and his team are hoping to convince residents of Pittsburgh's historic Black neighborhoods to volunteer for vaccine trials.



What is the Role of Engagement in Building Trust among Individuals, Organizations, and Broader Communities?

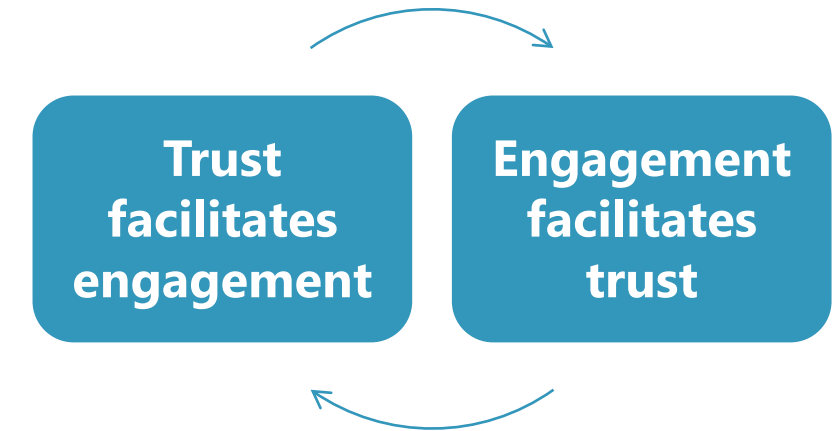


From the beginning, PCORI believed the engagement of patients and stakeholders would lead to research that:

- Better reflects the needs and values of patients, caregivers, clinicians, and other stakeholders
- Is more feasible to conduct in real-world settings
- Is more relevant, trustworthy and useful

What We've Learned Along the Way about Trust and Trustworthiness

- Must be cultivated and earned through actions
- Can be broken, and can be difficult to repair
- Perceptions of it may differ between researcher and partner
- Necessary but not sufficient for partnership
- Ongoing and dynamic: must be built and rebuilt and viewed in the context of past abuses
- Engagement and trust are mutually reinforcing



Why this Conversation? Why Now?

PCORI recognizes the value of trustworthiness and has more to learn

Research enterprise is looking for ideas and answers

You are our experts and advisors

Organizations are making bold moves to engender trust. What should PCORI be doing?

- What are some traits and actions of organizations and institutions that are trustworthy?
- What has PCORI as an organization done in the past to show that it **is** or **is not** a trustworthy organization?
- What can PCORI do in the **short term** to be a trustworthy institution given the current climate?
- What should PCORI do in the **long term** to ensure it is a trusted partner and source of information?

What are some traits and actions of organizations and institutions that are trustworthy?

Honesty

Be consistent

Show up when it matters not just when you want something

Apologize

Accountability

Concluding Thoughts and Next Steps

- ✓ Follow-up with summary of suggestions and discussion for your review and additional input
- ✓ Commitment to share final summary with PCORI leadership

Break

1:10 – 1:40pm EDT

Supporting Diversity, Equity, and Inclusion in Research Partnerships

PEAP/DEI Guiding Engagement Principles (First Draft)

Advisory Panelists:

Matt Hudson and Gwen Darien

PCORI Staff:

Lisa Stewart, Senior Engagement Officer, Public and Patient Engagement
Denese Neu, Engagement Officer, Public and Patient Engagement

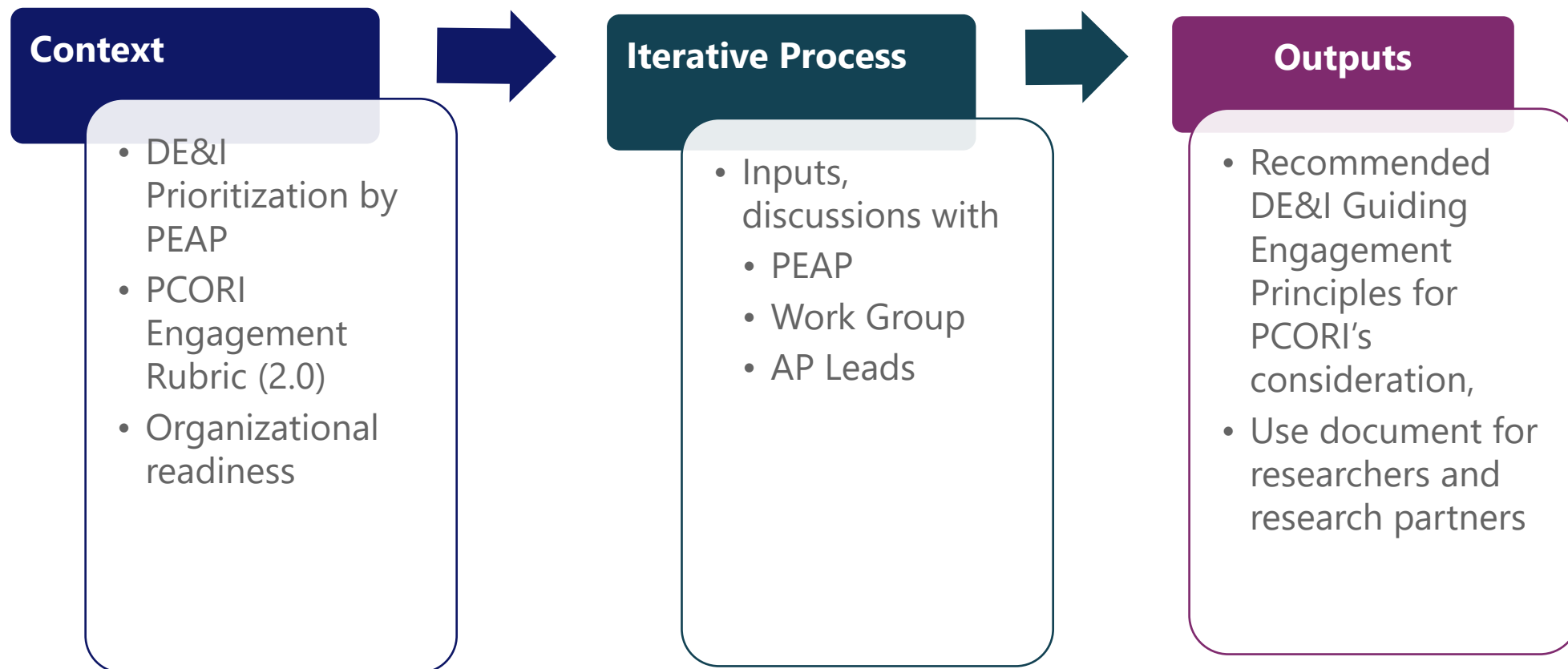
Facilitator:

Debra Joy Perez, Consultant

- Background
 - Context and Project Overview
- Discussion:
 - Group Feedback on PEAP Diversity, Equity, and Inclusion (DE&I) Engagement Principles (First Draft)
- Wrap-up and Next Steps

Project Overview

Task: To develop a set of principles, which will be submitted to PCORI as recommendations, that motivate engagement practices that embody the values of equity and inclusion



Activity Timeline

2019

PEAP set DE&I as a priority



April and June 2020

DE&I workgroup established; followed by working sessions



January 2020

PEAP exercise on DE&I integration into engagement principles



September 2020

Presentation of first draft principles



Early Feedback

PCORI's Principles Should Encourage...



Proposed PEAP DE&I Guiding Engagement Principles

What is the purpose of DEI Guiding Engagement Principles?

- A set of principles intended to guide the formation and strengthening of relationships between diverse research partners and researchers written from the perspective that centers people's lived experiences of discrimination and exclusion

Why do we need them?

- To provide high-level guidance to ensure that diversity, equity, and inclusion is an explicit goal of research partnerships, based on the belief that in order to eliminate health inequities strong partnerships with members of groups disproportionately affected are imperative

How might they be used?

- As a reference for PCORI-funded teams and the wider research community for operationalizing diversity, equity, and inclusion values into practice
- As a reference for research partners for engaging with researchers
- They should not be viewed as standards or methods

#1: Inclusion: “Inclusion of diverse groups in research partnerships goes beyond numerical representation, it requires deliberate actions, humility and use of anti-racist practices.”

#2: Equitable Partnerships: “Partnerships between researchers and non-scientists must provide mutual benefit and be anchored in a commitment to co-creation, collaborative decision-making, fairness and transparency through shared agreements that are open to renewal and change .”

#3: Trust/Trustworthiness: “Trusting relationships between researchers and research partners depend on ongoing demonstrations of trustworthiness.”

#4: Accountability: “Accountability relies upon practices, processes and people who hold research teams to standards that embody DEI values, and importantly, draw us back to our common humanity.”

Big picture questions:

- Are these the most appropriate values to focus on? Would you organize them differently?
- What important ideals are missing?

For each principle:

- Does the description associated with the principle strongly convey a DE&I value?
- What important characteristics/features are missing?
- What else should be added?

#1: Inclusion

"Inclusion of diverse groups in research partnerships goes beyond numerical representation, it requires deliberate actions, humility and use of anti-racist practices."

Core belief: Inclusion strengthens the quality, usefulness, and relevance of research.

Features:

- Strategies for input and collaboration adaptable and multiple
- Inclusion means inviting people as they are. Research teams intentionally, and continuously work to create inclusive environments
- Requires vulnerability in examining self-bias and naming discriminatory actions and/or structural racism
- Represent self and ally to others

#2: Equitable Partnerships:

"Partnerships between researchers and non-scientists must provide mutual benefit and be anchored in a commitment to co-creation, collaborative decision-making, fairness and transparency through shared agreements that are open to renewal and change."

Core belief: Equitable partnerships contribute to health equity.

Features:

- Team members are supported to fully engage in collaboration and the research process.
- Power imbalances due to social and structural differences are acknowledged.
- Co-creation is present. Roles and decision-making authority of research partners are defined collaboratively and clearly stated.
- Those most affected by the condition or circumstance are centered.
- Remuneration is equitable

#3: Trust/Trustworthiness

"Trusting relationships between researchers and research partners depend on ongoing demonstrations of trustworthiness."

.

Core belief: The best research partnerships have mutual trust and respect at the foundation.

Trusting partnerships can enhance the trustworthiness of research results.

Features:

- Trustworthiness centers the perspective of the person with the least amount of structural power
- Perceptions about the presence of trust and trustworthiness may differ widely between researchers and research partners.
- Trust is fragile and requires tending.

#4: Accountability

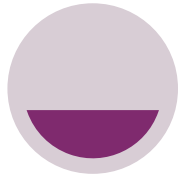
“Accountability relies upon practices, processes and people who can hold research teams to standards that embody DEI, and importantly, draw us back to our common humanity.”

Core Belief: Changing mindsets, practices and policies is hard work done against many levels of opposition.

Features:

- Diversity, equity and inclusion values should be promoted, in systems of accountability.
- Accountability begins with an awareness of past norms and must be reset and map to equity and inclusion ideals.
- A system of accountability within a research team should monitor and track, but also incentivize, support, model and celebrate DEI
- Accountability keeps the reality of power differentials within view
- Evaluation of the experience of all partners is necessary for accountability and improvement.

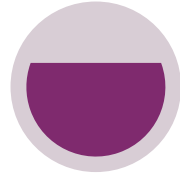
Next Steps



Second Draft

(November 2020)

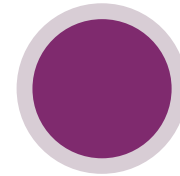
- Revise based on today's input
- Internal discussions with staff
- Workgroup review



Final Phase

(December 2020)

- PEAP review
- Draft use statement for researchers and partners



Completion

(January 2021)

- Submit recommendation of principles and use statement to PCORI for consideration

Thank You!



Building a Research Agenda for Studying Diversity, Equity, and Inclusion in Engagement

Esther Nolton
Program Officer, Evaluation and Analysis

Lisa Stewart
Senior Program Officer, Public and Patient Engagement

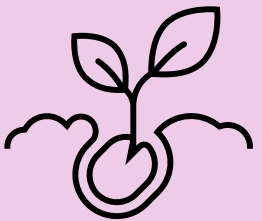
Overview

- Background and Purpose
- Diversity, Equity, and Inclusion (DE&I) Topic Ideas
- Feedback on a Developing Research Question
- Future Conversations

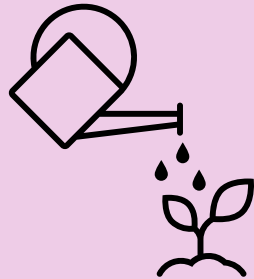
Background and Purpose

- Diverse research partnerships allow research findings to be more **translatable** and **relevant** to diverse populations

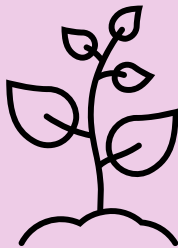
Inputs



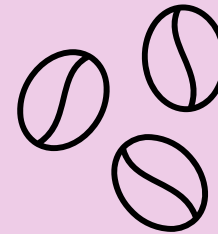
Activities



Outputs



Short-/Long-Term Outcomes



Impact



DE&I Research Topic Ideas

What Should we Study about DE&I in Engagement?



- What should PCORI study about diversity, equity and inclusion within research partnerships?
- To attract more research partners from underrepresented groups, what do you think is important to know?
- Whose perspectives about DE&I in engagement would help us understand reality?

Reactions to a Developing Research Question

What are the contexts and factors that encourage or discourage BIPOCs from engaging in research partnerships?

- Is this an important and timely question?
- Is this question actionable?
- What should we ask people in order to understand what encourages or discourages their engagement?

Future Conversations

How do we Monitor and Evaluate Current and Future Projects?



- What are key elements that we should be monitoring on PCORI-funded projects to understand the representation of partners?
- How might PCORI evaluate this in practice?

Meeting Wrap-up

1.

Advisory Panel Work Group Update

Michelle Johnston-Fleece

Senior Program Officer, Public and Patient Engagement

Denese Neu

Engagement Officer



Overview



1. Advisory Panel Work Group Update
2. Announcements
3. Closing Remarks

Studying PCORI's Patient Centered Approach (PCA) Workgroup



Purpose & Activities

- Advises on PCORI's evaluation agenda, projects that assess effectiveness of PCORI's approach, and projects that build evidence about promising practices for patient-centered research
 - Activities include advising on current projects, helping PCORI staff prioritize questions and projects to pursue, and serving as liaison to full PEAP
 - Upcoming projects include tracking uptake and use of PCORI research results, tracking PCORI's influence on other organizations, and ways of studying diversity, equity, and inclusion at PCORI

Time Commitment

- Conference calls scheduled on ad hoc basis (approximately every 2 months) at key phases of project planning, conduct, and/or dissemination
 - Workgroup members can opt into specific activities throughout the year given availability

How to Join or Find out More

- We're recruiting 4-5 new members
- We'll send a follow-up email with more information about the workgroup and how to join
- Questions?
 - Contact Rachel Hemphill (rhempfill@pcori.org) or Michelle Johnston-Fleece (mfleece@pcori.org)

DEI Guiding Principles Workgroup



Purpose & Activities

- Advises on content of PEAP's draft DEI Guiding Engagement Principles and related materials (e.g., Use Statement, operational practices)
- Potentially support other DE&I-related projects in the future

Time Commitment

- Ad hoc conference calls or other engagement method (approximately 1 every month) at key phases of content generation

How to Join or Find out More

- We're recruiting 3-4 new members
- We'll send a follow-up email with more information about the workgroup and how to join
- Questions?
 - Contact Denese Neu (dneu@pcori.org) or Lisa Stewart (lstewart@pcori.org)

2.

Announcements

Mark Your Calendars!



- Ambassador Workshop – November 18, 2020
- Winter PEAP Meeting (Virtual) – February 11-12, 2021
- Advisory Panel Application Deadline – March 31, 2021 at 5pm ET
- PCORI 2021 Annual Meeting – November 17-19, 2021

Check [pcori.org/events](https://www.pcori.org/events) for announcements of public events

3.

Closing Remarks

Thank You!

Please complete the post-meeting survey



Adjourn

