

ADVISORY PANEL ON PATIENT ENGAGEMENT MEETING

Via GoToWebinar

Winter 2021 Meeting - Day One

February 11, 11:30am-3:00pm EST

Welcome

Kristin L. Carman

Director, Public and Patient Engagement

Gwen Darien

Chair, Advisory Panel on Patient Engagement

Neely Williams

Co-chair, Advisory Panel on Patient Engagement



Agenda: Day One



Part I (EST):

- 11:30 AM – Opening Remarks and Roll Call
- 11:40 AM – Advisory Panel Perspectives: Community Reactions in A Climate of Change, Hope, Scarcity, and Mistrust
- 12:30 PM – Stretch Break
- 12:35 AM – PCORI Updates
- 12:50 PM – Engagement Rubric Update
- 1:20 PM – Lunch Break

Part II (EST):

- 1:50 PM – How to Understand Diversity, Equity, and Inclusion (DE&I) in Engagement: Input for Upcoming Projects
- 2:30 PM – Use Recommendations for PEAP DE&I Engagement Principles
- 3:00 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
- Mentimeter – Live Polling Tool
 - Participation limited to PEAP
- 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



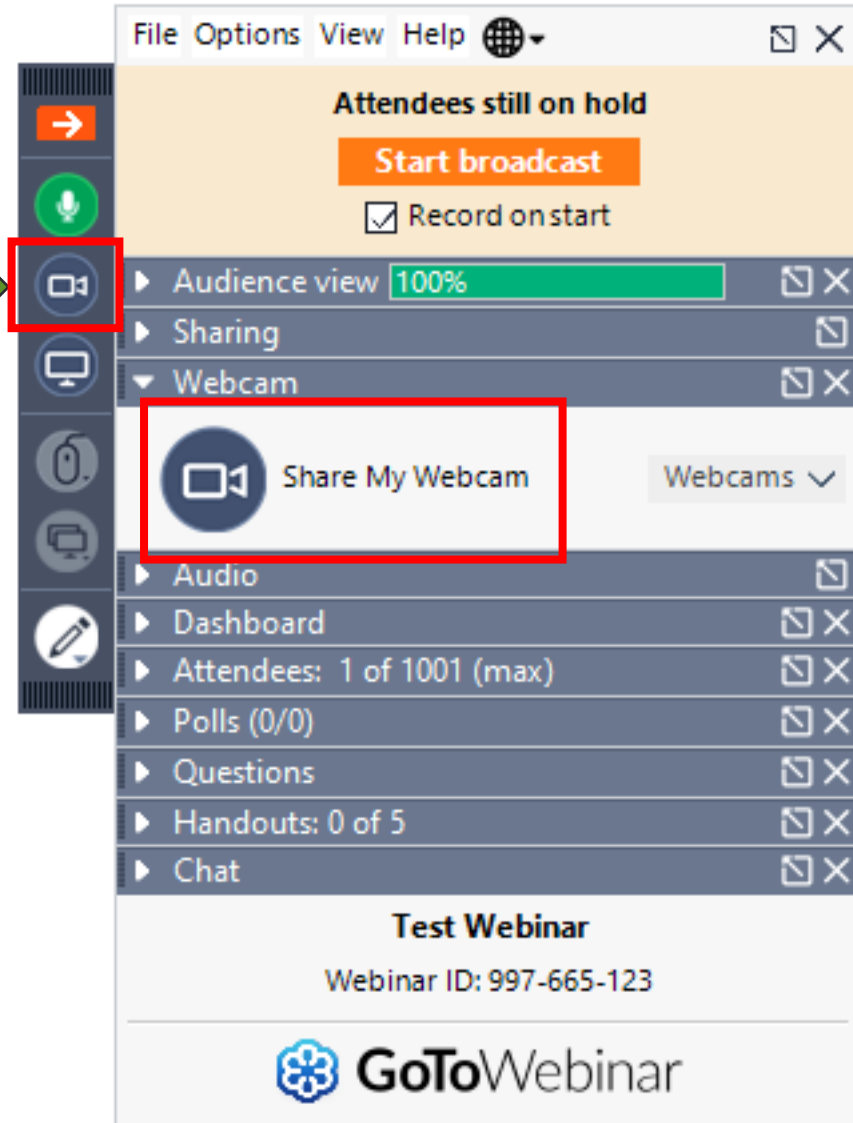
Type "I have a comment"
in the chat box



The screenshot displays the GoToWebinar interface. At the top, a menu bar includes 'File', 'Options', 'View', and 'Help'. Below this, a status bar indicates 'Attendees still on hold' with a 'Start broadcast' button and a checked 'Record on start' option. A sidebar on the left contains icons for navigation and controls. The main panel lists various session elements: Audience view (100%), Sharing, Webcam, Audio, Dashboard, Attendees (1 of 1001), 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

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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



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



Jennifer Canvasser
*Patients, Caregivers,
and Advocacy
Organizations*



Beth Careyva
Researchers



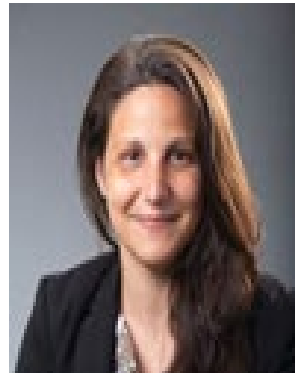
Tracy Carney
*Patients, Caregivers,
and Advocacy
Organizations*



Gwen Darien
*Patients, Caregivers,
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Organizations*



Sarah Donelson
Industry



Karen L. Fortuna
Researchers



Maureen Fagan
Clinicians



Marilyn Geller
*Patients, Caregivers,
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Organizations*



Crispin Goytia
*Patients, Caregivers,
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Organizations*



James Harrison
Researchers

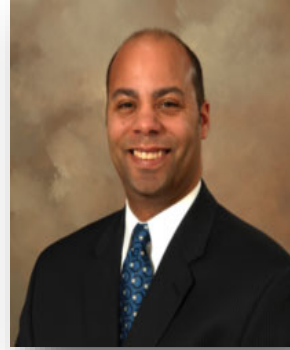
Roll Call - Advisory Panel Members



Jill Harrison
*Patients, Caregivers,
and Advocacy
Organizations*



Margarita Holguin
*Patients, Caregivers,
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Organizations*



Matthew Hudson
*Patients, Caregivers,
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*Patients, Caregivers,
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Organizations*



Neely Williams
*Patients, Caregivers,
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Organizations*

Advisory Panel Perspectives

Community Reactions in A Climate of Change, Hope, Scarcity, and Mistrust

Stretch Break

12:30 – 12:35pm EDT



PCORI Updates

Kristin Carman
Director, Public & Patient Engagement

William Lawrence
Senior Clinical Advisor, Engagement

Meghan Berman
Program Associate II, Public & Patient Engagement

Strategic Planning: Focus on National Priorities for Health



We continue to garner input from a variety of stakeholders. Emerging themes from input received include the following:

- Potentially evolving Addressing Disparities to Eliminating Disparities, achieving Health Equity, or similar strengthening of work in this area
- Consider reflecting or embedding a public health and social ecosystem perspective within the National Priorities



Overview of PCORI's Cost Data Implementation Proposal



Pillar 1

- Providing guidance to Principal Investigators in future PFAs on how to interpret this policy and incorporate into research proposals
- **Timeline:** Final Principles and Initial Guidance for Applicants by **March 2021**

Pillar 2

- Establishing methodology standards to inform the 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



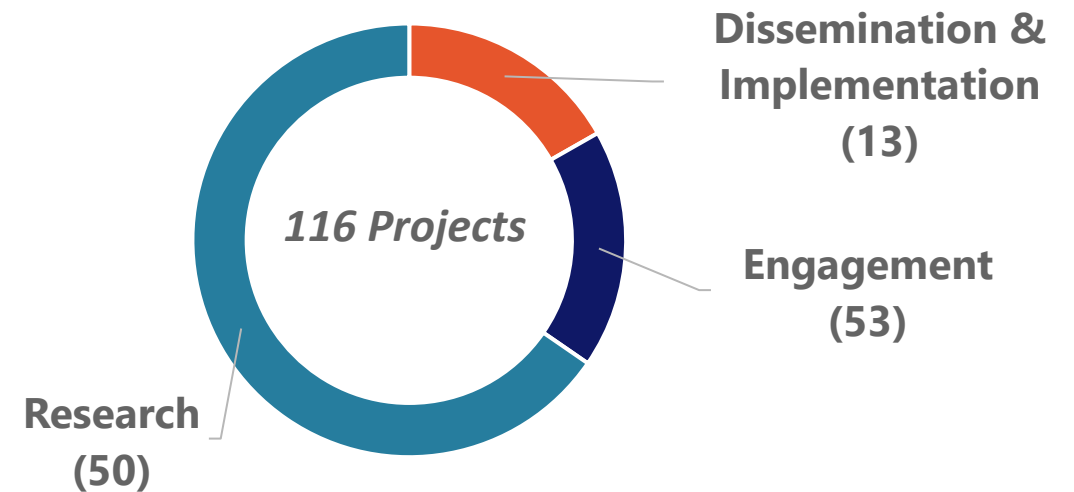
www.heroesresearch.org

COVID-19 Targeted Funding

- Adaptations to healthcare delivery
- Impact on vulnerable populations
- Healthcare workforce well-being, management and training



COVID-19 Enhancement Projects



As of January 5th, 2021

Update: Balancing Short- and Long-term Evidentiary Needs



Horizon scanning reports
Emerging technology reports
Evidence maps



Systematic reviews
Focused observational research



Phased trials (up to \$22M)
Large pragmatic studies (up to \$10M)
Broad research studies (up to \$5M)

Time to
Complete

Up to 1 year






1-2 years

3-7 years

D&I and engagement activities occur throughout timeline
Stakeholders provide input for report and research topics

Making Results Accessible

- For certain studies or evidence synthesis products, PCORI creates Evidence Updates:
 - Summaries of PCORI-funded studies in accessible language
 - Written for healthcare providers, patients and caregivers for clinical decision-making

MAY 2020

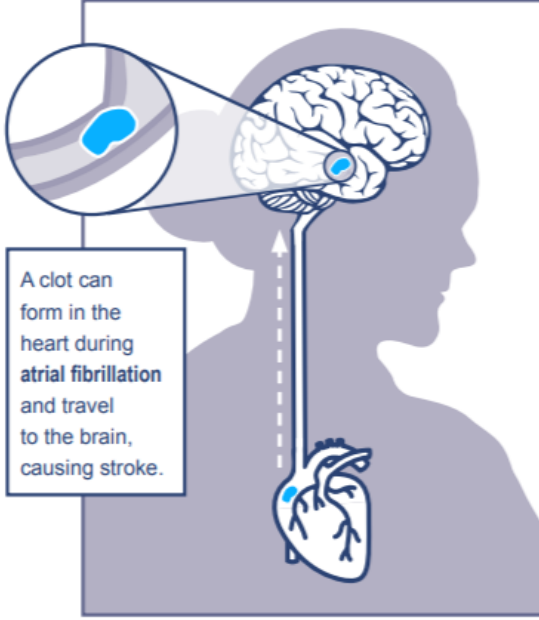
Reducing Risk of Stroke When You Have Atrial Fibrillation

People with atrial fibrillation (AFib) or atrial flutter are five times more likely to experience a stroke compared with people who have a normal heart rhythm. The risk of stroke increases with age.

Medicines that keep the blood from clotting, called anti-coagulants, lower the risk of stroke but can also cause serious bleeding.

What Causes AFib-Related Stroke?

When a person has AFib or flutter, the atria—the two upper chambers of the heart—beat very fast or abnormally. Because of this, blood in the atria is not pushed out completely with each heartbeat. Blood may pool in the atria and form clots that can flow into the brain, causing a stroke.



Types of Anticoagulant Medications

New: Strengthening Support for Returning Research Results



Exciting work from the Dissemination and Implementation Program...

PCORI ask that awardees make **every reasonable effort** to return aggregate research results to study participants. (PCORI's **500-word lay language public results abstract** (posted to [pcori.org](https://www.pcori.org)) is one way to fulfill this obligation.)

NEW! PCORI Awardees can now receive up to \$2500 for results return activities.

- Funds intended to cover nominal costs for postage, mailing supplies, limited staff time and/or email blast services. Studies with over 5000 participants may request additional funds.
 - **Existing awardees may request** these funds at any time during the project period
 - **New Applicants are now asked to budget** up to \$2500 for results return activities in the application

Why is this Significant?

- Returning aggregate research results to trial participants fulfills an ethical responsibility

“The principle of respect for persons ... encompass[es] a moral obligation to offer research results to research participants upon the completion of a study. This practice avoids treating people as merely a means to an end, acknowledges that the person made an important contribution to the research project, and may have direct implications for the health of the participants.” (Rigby & Fernandez 2005)
- Most investigators support the idea of returning aggregate research results their study participants however results return is not widespread:
 - 40% of clinical trial authors in a recent survey planned to return aggregate study results to their participants; (*Schroter et al., 2019*)
 - Researchers reported barriers including cost, logistics, and IRB policies
- Current trends: Interest in results return is steadily increasing within health care in the U.S and Europe

New RFP: Analytic and Operational Support for the Engagement of the Public and Patients



Request for Proposals (RFP)

- Released February 8th, period of performance: 3 years
- Covers a range of projects:
 - Support Services for the Engagement in Health Research Literature Explorer
 - Uptake of PCORI-Funded Research Results in Medicare Policy and Coverage
 - Update of the PCORI Engagement Rubric
 - Studying the Factors and Contexts for Engaging Diverse Research Partners
 - Resource Center to Support PCORI Activities Related to the Capture of Patient-Centered Cost and Economic Impact Data
- Awards expected: late May 2021
- Projected TO award dates: On a rolling basis, following IDIQ awards
- Projected IDIQ start date: August 16, 2021

[RFP Available on PCORI website](#)

Analytic and Operational Support for the Engagement of the Public and Patients

Diversity, Equity, and Inclusion



- Offerors must demonstrate a thorough understanding of diversity, equity, and inclusion with regard to the objectives and requirements of the RFP
- Offerors must demonstrate how their team, partners, and subcontractors will complete tasks in a way that is reflective of a commitment to diversity, equity, and inclusion. Therefore:
 - PCORI welcomes consortia proposals
 - Primary applicants are encouraged to demonstrate partnership among diverse organizations
 - PCORI is especially interested in responses that demonstrate meaningful leadership or engagement of organizations led by and/or serving communities traditionally underrepresented in research

Upcoming Deadline

Advisory Panel Applications



- 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](#)

Engagement Rubric Update

Kristin Carman

Director, Public & Patient Engagement

Michelle Johnston-Fleece

Senior Program Officer, Public & Patient Engagement

Corinne Zahlis

Program Associate, Public & Patient Engagement



Goals for Today

- Provide background on why the Rubric must be updated
- Discussion of key considerations and inputs
- Next steps, including timing

Background

PCORI's Approach to Engagement
and Development of the
Engagement Rubric



PCORI's Initial Establishment To Meet Stakeholders' Needs



"The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence** concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis... and the **dissemination** of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services..."

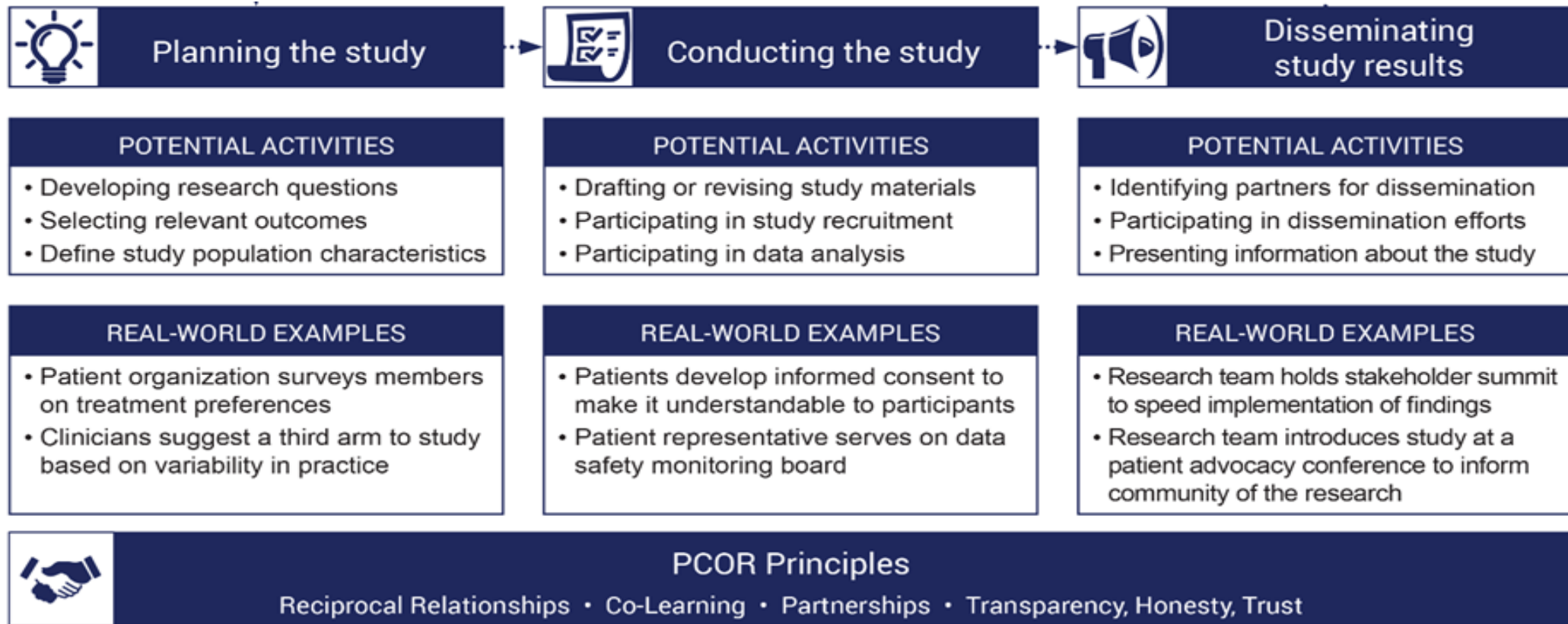
—from PCORI's authorizing legislation



Background: Rubric Development

- PCORI set out a mandate to our research awardees to engage stakeholders
- While Engagement was required, the standard was very broad; prospective awardees and others were uncertain about how to meet it
- In response to the need, the [Engagement Rubric](#) was released in **2014**
 - developed in collaboration with PEAP
 - building on fields of Community Based Participatory Research, health care engagement, and others
- Included 2 critical concepts as a starting point:
 - Engagement can – and should – occur throughout the project lifecycle
 - Recognition of the need for underlying values to support meaningful engagement
- The Rubric was ***intentionally nonprescriptive***

Engagement Rubric



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

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

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

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

Influence of the Rubric

In the intervening years since the Rubric's development, it has:

- Been cited 96 times*⁺
- Been utilized by over 500 PCORI-funded projects
- Influenced the field more broadly
- Been used to guide engagement beyond PCORI-funded projects

The PCORI Engagement Rubric: Promising Practices for Partnering in Research

Susan Sheridan, MBA, MIM, DHL¹

Suzanne Schrandt, JD^{1,2}

Laura Forsythe, PhD, MPH³

Advisory Panel on Patient Engagement (2013 inaugural panel):

Tandrea S. Hilliard, PhD, MPH⁴

Kathryn A. Paez, PhD, RN⁵

¹Patient Engagement, Patient-Centered Outcomes Research Institute (PCORI), Washington, DC

²Patient Engagement, Arthritis Foundation, Atlanta, Georgia

³Evaluation & Analysis, Patient-Centered Outcomes Research Institute (PCORI), Washington, DC

⁴American Institutes for Research, Washington, DC

ABSTRACT

PURPOSE Engaging patients, caregivers, and other health care stakeholders as partners in planning, conducting, and disseminating research is a promising way to improve clinical decision making and outcomes. Many researchers, patients, and other stakeholders, however, lack clarity about when and how to engage as partners within the clinical research process. To address the need for guidance on creating meaningful stakeholder partnerships in patient-centered clinical comparative effectiveness research, the Patient-Centered Outcomes Research Institute (PCORI) developed the PCORI Engagement Rubric (Rubric).

METHODS PCORI developed the Rubric drawing from a synthesis of the literature, a qualitative study with patients, a targeted review of engagement plans from PCORI-funded project applications, and a moderated discussion and review with PCORI's Advisory Panel on Patient Engagement.

RESULTS The Rubric provides a framework for operationalizing engagement to incorporate patients and other stakeholders in all phases of research. It includes: principles of engagement; definitions of stakeholder types; key considerations for planning, conducting, and disseminating engaged research; potential engagement activities; and examples of promising practices from PCORI-funded projects.

CONCLUSIONS PCORI designed the Rubric to illustrate opportunities for engagement to researchers interested in applying for PCORI funding and to patients and other stakeholders interested in greater involvement in research. By encouraging PCORI applicants, awardees, and others to apply the rubric, PCORI hopes to shift the research paradigm from one of conducting research on patients as subjects to a pursuit carried out in collaboration with patients and other stakeholders to better reflect the values, preferences, and outcomes that matter to the patient community.

Ann Fam Med 2017;15:165-170. <https://doi.org/10.1370/afm.2042>.

*Sheridan, Schrandt, Forsythe; Advisory Panel on Patient Engagement (2013 inaugural panel), Hilliard and Paez. *The PCORI Engagement Rubric: Promising Practices for Partnering in Research*. *Ann Fam Med*. March 2017, 15(2) 165-170.

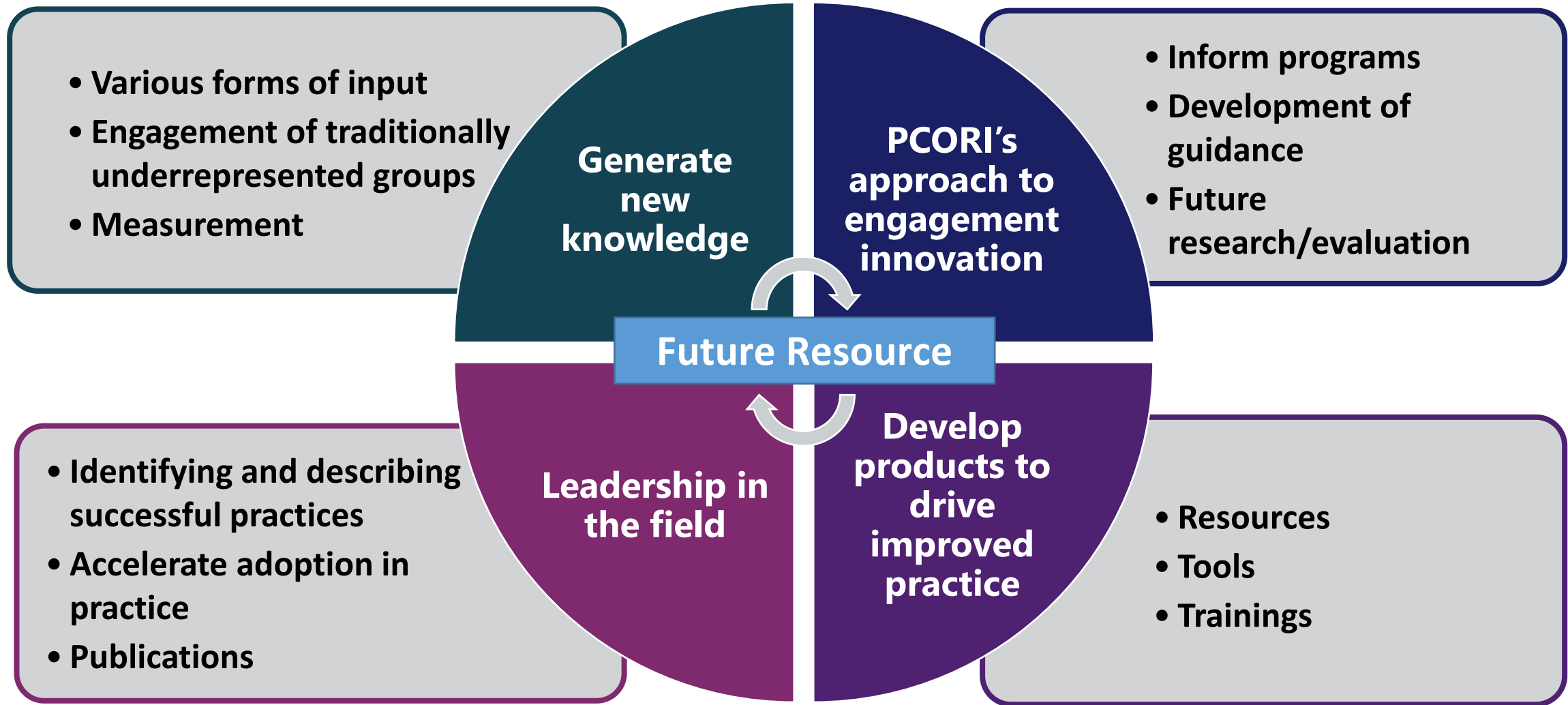
⁺As of 1/22/21; This is an undercount of citations in that we cannot track citations of the Rubric on PCORI's website

Rubric Update

Project Objectives
& Next Steps



The Rubric → A Multi-Purpose Resource



Engagement Rubric Update – Objectives

- To use knowledge developed in the natural laboratory created during PCORI's first ten years in order to **address facilitators and barriers to engagement** and to maintain PCORI's leadership in the field by providing **guidance and tools to support engagement**.
- To reflect PCORI's key priorities for advancing engagement both within PCORI and in the field:
 - Support the use of appropriate, effective engagement practices
 - Encourage stronger collaborations and sustainable partnerships
 - Make engagement more accessible, easier, and more efficient
 - Improve diversity, equity, and inclusion in engagement
 - Diffuse learnings about engagement

The 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.

Project Inputs: Existing and Developing

PCORI Research and Analyses

- Research on Influence and Impact of Engagement
- P2P and EA portfolio analyses
- PCORI synthesis work
- Upcoming:
 - Engagement Measures Landscape Review and Gap Analysis
 - Literature review on engagement of underrepresented communities
 - Study of Engagement of Underrepresented Communities
 - Synthesis of Health Lit Explorer

Translational Activities

- Updated Engagement Plans
- AHRQ Learning Health System Practical Guidance

Resources & Products for Engagement Practice

- Research Fundamentals
- Building Effective Multi-Stakeholder Research Teams
- Engagement in Data Analysis Guidebook
- Clinician engagement

DE&I Efforts

- PEAP DE&I Principles
- PCORI DE&I efforts

Others?

- Recommendation of “early engagement” as a stage of the research process
- Recommendation of DE&I principles



Discussion Question:

- **Are there other inputs we should be considering?**

Outstanding Questions for Rubric Update

- **What are PCORI's additional objectives for the Rubric?**
 - *Guidance for awardees on engagement practice?*
 - *Provide real-world examples?*
 - *Link to resources, tools, trainings?*
 - *Drive PCORI policies and programs?*
 - *Set engagement standards?*
 - *Influence the field?*
- **Who are the key audiences for the Rubric?**
 - *How to address the needs of various audiences?*
- **What will final Rubric format be?**
 - *Static document?*
 - *Interactive web product?*
 - *Any multimedia components?*



Discussion Questions:

- **What are the most important audiences to reach with the Rubric?**
- **What do they need from it?**

Immediate next steps:

- Internal strategic planning activities
- Procure vendor for key activities, e.g., support content development, convening meeting

Governance & Advisory Panel Input (*exact dates TBD*):

- At key junctures with EDIC and Advisory Panels (PEAP, HDDR, CEDS, RDAP, and CTAP)

Final Rubric content: by August 2022

Opportunities for PEAP Engagement

- Sharing other organizational policies, frameworks
- Key informant interviews/focus groups
- Stakeholder Convening
- Input at meetings of PEAP and Work Groups
- Ad hoc consultation

Venues:

- Studying the PCORI Patient-Centered Approach (PCA) Work Group
- DE&I Work Group
- PEAP meetings
- Individual consultation

Questions & Discussion



Questions & Discussion



Thoughts or reactions?



How do you use the current Rubric?

- *What are its assets and shortfalls?*
- *What would you like it to become?*

Lunch Break

1:20 – 1:50pm EDT



How to Understand Diversity, Equity, and Inclusion (DE&I) in Engagement

Input for Upcoming Projects

Esther Nolton
Program Officer, Evaluation & Analysis

Lisa Stewart
Senior Program Officer, Public & Patient Engagement



Roadmap



1. Recap Fall PEAP Meeting Discussion
2. Upcoming DE&I Research Projects at PCORI
3. Discuss Considerations And Implications
4. Monitoring to Support PCORI-funded Projects



Placeholder for Mentimeter Question

How often do you provide demographic information about yourself on questionnaires?

- a. Almost Always*
- b. Frequently*
- c. Often*
- d. Rarely*
- e. Never*



Placeholder for Mentimeter Question

Of the different types of demographic questions that could be asked, which ones are you least comfortable with answering? Select all that apply.

- | | |
|------------------------------|------------------------------------|
| <i>a. Race/Ethnicity</i> | <i>g. Income</i> |
| <i>b. Gender Identity</i> | <i>h. Geographic Location</i> |
| <i>c. Sexual Orientation</i> | <i>i. Job Title/Employer</i> |
| <i>d. Age</i> | <i>j. Insurance Coverage</i> |
| <i>e. Disability Status</i> | <i>k. Marital Status</i> |
| <i>f. Educational Level</i> | <i>l. Professional Credentials</i> |



Placeholder for Mentimeter Question

What are the reasons why you have chosen not to share demographic information in the past?



Recap of Fall PEAP Meeting Discussion

- **Timely** and **important** for PCORI to be studying diversity, equity, and inclusivity of research partnerships
- We must be **culturally responsive** to unreached communities
- Utilize social sciences and frameworks focused on understanding **historical**, **social**, and **cultural** contexts
- Not just understand, also create **sustainable** systems and practices to maintain diverse research partnerships



Upcoming DE&I Research Projects at PCORI



**DE&I in
Research Partners**



**DE&I in
Applicants**



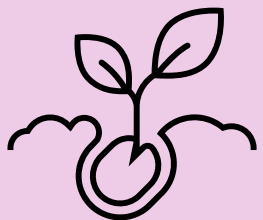
**DE&I in
Study Samples**



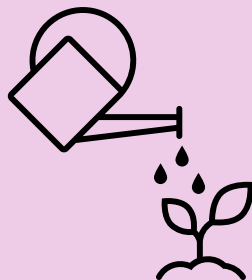
Research Study: Background and Purpose

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

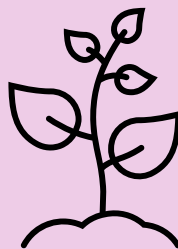
Inputs



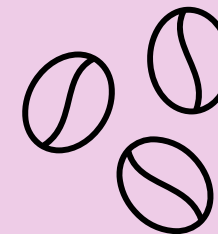
Activities



Outputs



Short-/Long-Term Outcomes



Impact





Upcoming Project on DE&I in Engagement for Research Design and Conduct

Initial Research Questions:

- What are the individual-, organizational-, or system-level **contexts** and **factors** that influence the involvement (or non-involvement) of individuals from underrepresented racial and ethnic groups in research partnerships?
- What are the **experiences, levels of involvement**, and **perceived inclusiveness** of individuals from underrepresented racial and ethnic groups in research partnerships?
- What **tools, resources**, or **approaches** and **specific practices** effectively build diverse, equitable, and inclusive (patient-centered outcomes) research partnerships? How well do they align with the needs identified and what are the gaps in known practices or available tools, resources, or approaches?



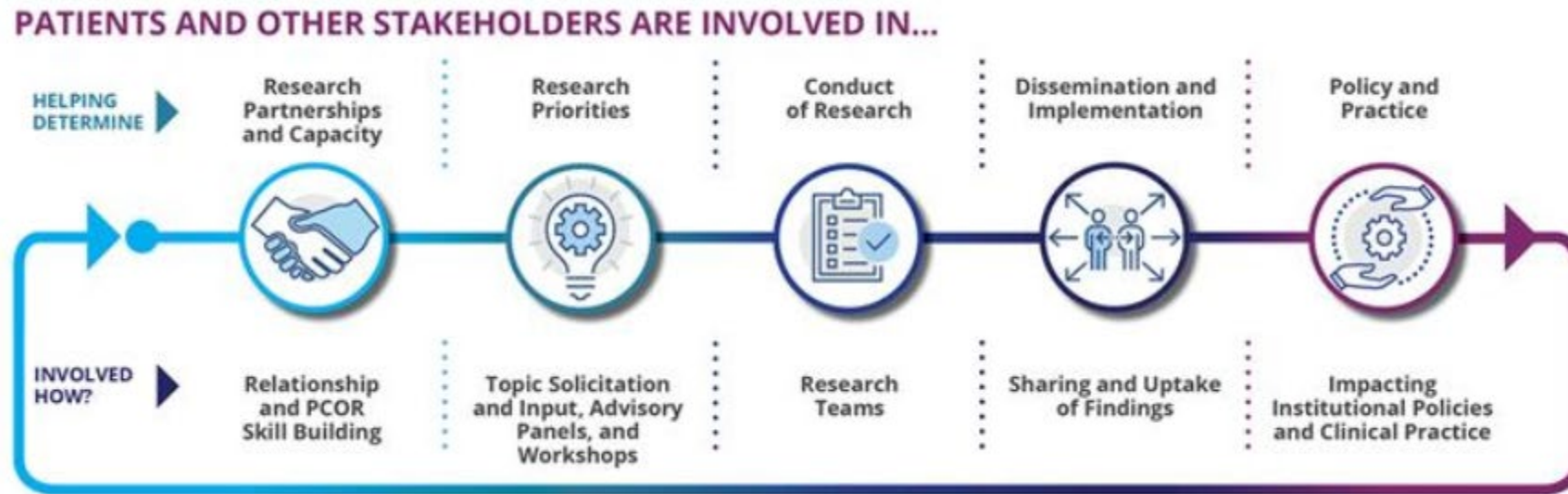
Considerations and Implications

How should we study DE&I in engagement?

- What are the potential **unintended consequences** associated with studying DE&I in engagement?
- What are some things that are critical for us to do or think about so that our **process** is trustworthy, and **findings** are meaningful?



Please go to www.menti.com
Enter code: **XX XX XX**



What are other questions PCORI should study about DE&I in engagement to help inform better practice?



Learning for Use

Who benefits from this work?



**Contributions to the
Body of Knowledge**



**Supporting PCORI-
Funded Projects**



What should PCORI know about DE&I in projects?

- What should PCORI ask project teams to **routinely report** on to understand DE&I in their projects?
- What might be the **challenges** in collecting and reporting these data?



Future Conversations

- More **questions will emerge** – your input helps us keep asking timely and relevant research questions
- We will incorporate what we learned to the **design** and **conduct** of upcoming research
- Feedback from PEAP will continue to be **pivotal to developing research** on DE&I in engagement

Review of Use Statement for Recommended DE&I Guiding Engagement Principles

Presenters: Matt Hudson and Debra Joy Perez

Advisory Panel DE&I Co-Chairs: Gwen Darien and
Matt Hudson

PCORI Staff: Lisa Stewart and Denese Neu,
Engagement Officer



Providing Perspectives

“

The Advisory Panel on Patient Engagement will advise and provide recommendations to PCORI's Board of Governors, Methodology Committee, and staff to help plan, develop, implement, improve, and refine efforts toward meaningful patient-centered research. The PE Panel will not serve in an official decision--making capacity, but its recommendations and advice will be taken into consideration by the Institute's Board of Governors, Methodology Committee, and staff.

Source: Charter of the Advisory Panel on Patient Engagement

The Journey

January 2020

PEAP exercise on DE&I
integration into engagement
principles

April and June 2020

DE&I workgroup established;
followed by working sessions

September 2020 – January 2021

Iterative process and drafting
final recommendation to PCORI

February 2021

Finalized Recommended DE&I
Guiding Principles and Use
Statement

Recommended DE&I Guiding Engagement Principles

What is the purpose of the recommended DE&I 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 DE&I 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 perspectives and groups in research partnerships goes beyond achieving categorical representation; it requires explicit invitations, clearly stated intentions, culturally appropriate actions, humility, and the deliberate creation of welcoming environments that foster a sense of belonging”.

#2: Equitable Partnerships: “Partnerships between researchers and other diverse stakeholders must provide mutual benefit and be anchored in respect and 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 among research team members depend upon building confidence and a sense of mutual reliance among participants as they work toward achieving a shared goal. Ongoing demonstrations of trustworthiness among the research team depend upon transparent and authentic communication and a shared commitment to goals and processes. All members of the research team must commit to genuinely working to earn the trust of others”.

#4: Accountability: “Accountability demands practices, processes, and people that can hold research teams to standards that embody DEI and importantly, help the team stay committed and focused on the common goal through their actions”.

Recommended DE&I Guiding Engagement Principles

***Recommended
DE&I Guiding
Engagement Principles
“Use Statement”***

Content outline:

- Who developed the principles
- Why were they developed
- Who would find them useful
- How they can be applied

❖ Self-Assessment Worksheet

❖ Tactics

Placeholder for Mentimeter Question

- What resonates with you in the Use Statement?
- Are there any critical self-assessment questions missing?
- Based on your experience, are there any effective strategies missing from the tactics list? (If so, what?)

Thank You!



- To all PEAP members from 2019-present for walking together and fully engaging in every session!
- To the PEAP DE&I workgroup for providing guidance at critical points in the work!
- To members of the Public and Patient Engagement Team for their important insights
- To Debra Joy Perez for facilitating and providing subject matter expertise!

And...

- To Gwen Darien and Matt Hudson for co-chairing this effort!

A vibrant blue and white fireworks display against a dark night sky. The fireworks are in various stages of explosion, with long, thin streaks of light radiating outwards. In the foreground, the silhouettes of palm trees are visible, their fronds reaching upwards. The overall scene is festive and celebratory.

Now, let's celebrate!

Adjourn

