

Board of Governors Meeting

via Teleconference/Webinar

September 27, 2021
1:00 – 3:15 PM

Welcome and Call to Order

Christine Goertz, DC, PhD

Chairperson, Board of Governors

Agenda



1:00	Welcome, Call to Order, and Consider for Approval: Minutes of the July 27, 2021, Board Meeting
1:05-1:40	Executive Director's Report
1:40-2:00	Consider for Approval: Slates of New Advisory Panelists, Chairs, and Co-Chairs • <i>Advisory Panel on Patient Engagement (PEAP)</i> • <i>Advisory Panel on Healthcare Delivery and Disparities Research (HDDR)</i> • <i>Advisory Panel on Rare Disease (RDAP)</i> • <i>Advisory Panel on Clinical Effectiveness and Decision Science (CEDS)</i> • <i>Advisory Panel on Clinical Trials (CTAP)</i>
2:00-2:45	Strategic Planning Committee Report
2:45-3:15	Public Comment
3:15	Wrap-up and Adjourn

Board Vote

Call for a Motion to:

- **Approve** the Minutes of the July 27, 2021, Board of Governors meeting

Call for the Motion to be Seconded:

- **Second** the Motion
- If further discussion, may propose an **Amendment** to the Motion or an **Alternative** Motion

Voice Vote:

- Vote to **Approve** the **Final** Motion
- Ask for votes in favor, opposed, and abstentions

Executive Director's Report

Nakela L. Cook, MD, MPH
Executive Director

PCORI *Next* Update



PCORI *Next* Vision



PCORI *Next* is our organizational transformation effort to invest in our Operational, Cultural and Professional Excellence. Our ultimate goal is to strengthen and optimize the delivery of our mission - focusing on Patient-Centered Outcomes Research that enable better-informed healthcare decisions.

Welcome Sri Mishra, MBA Chief Information Officer



Sri Mishra brings two decades of leadership experience in crafting and executing data and technology strategy at both for profit and nonprofit organizations to support and accelerate business and mission goals.

Prior to PCORI, Mishra was the Chief Data and Technology Officer at JDRF, a global nonprofit organization with a mission to find a cure for Type 1 Diabetics, and for Dentsu, one of the world's largest global media and advertising holding companies. Prior to Dentsu, Mishra led high-performing technology teams at FedEx and Equinox, enabling both organizations to develop and execute data and tech strategies, transform business processes, and upgrade IT infrastructure.

Mishra is the winner of 2020 Chief Data Officer award from Massachusetts Institute of Technology (MIT) and International Society of Chief Data Officers (isCDO). Mishra also won the prestigious Amazon-AWS Imagine award to implement AI and machine learning solutions at Nonprofits.

Mishra has a Masters (MBA Finance) from University of Alabama and Bachelor's Degree in Engineering.

Welcome Yolanda Hutchins, MA

Chief People Officer



Yolanda Hutchins is currently a Deputy Vice President and Head of Talent Acquisition, Diversity, Equity, and Inclusion, and the Employee Experience for PhRMA, a non-profit trade association for several leading biopharmaceutical research companies. Hutchins oversees key functions within the HR department and leads several internal and external working groups.

Previously, as a Senior Associate at Booz Allen Hamilton, Hutchins served as the Senior HR Manager overseeing all HR functions for several large and complex accounts, initiating and leading several high impact programs. She began her career in financial services with Citigroup.

Hutchins holds a master's from Columbia University in Organizational Psychology, a bachelor's from Indiana University in Journalism, and an Executive Certification from Georgetown University in Diversity, Equity, and Inclusion. Hutchins is on the Board of Directors for the Minds Matter DC chapter, is a member of George Washington's Advisory Council for Transformative Leadership, and a co-founding member of the DC chapter of Chief. Hutchins received Women of Color in Pharma (WOCIP) 2020 Trailblazer award and is a member of Alpha Kappa Alpha Sorority's Iota Lambda Omega chapter.

COVID-19 Portfolio Update



PCORI's COVID-19 Portfolio:

158 Awards to date



122 Enhancements Awarded, \$34.8 million

53

Engagement Award
Enhancements
\$7 million

13

D&I
Enhancements
\$5.8 million

47

Research
Enhancements
\$19.2 million

8

Methods
Enhancements
\$2.3 million

1

PCORnet®
Enhancement
\$526,020

36 New Awards in Research & Engagement, \$44.5 million

25

Engagement Award
Special Cycle
\$3.7 million

11

Targeted Research
Studies
(COVID-19 TPFAs)
\$40.8 million

As of Aug 2021

COVID-19 Enhancement Publications



Journal of Racial and Ethnic Health Disparities
<https://doi.org/10.1007/s40615-021-01125-1>



The Association Between Education and Basic Needs Insecurity for Marshallese During the COVID-19 Pandemic

Jennifer A. Andersen¹ · Don E. Willis¹ · Joseph R. Malhis¹ · Christopher R. Long¹ · Pearl A. McElfish¹

Received: 7 June 2021 / Revised: 29 July 2021 / Accepted: 29 July 2021
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[Pulmonary and Cardiovascular Original Research]



COVID-19 and Risk of VTE in Ethnically Diverse Populations

Alan S. Go, MD; Kristi Reynolds, PhD, MPH; Grace H. Tabada, MPH; Priya A. Prasad, PhD, MPH; Sue Hee Sung, MPH; Elisha Garcia, BS; Cecilia Portugal, MPH; Dongjie Fan, MSPH; Ashok P. Pai, MD; and Margaret C. Fang, MD, MPH



BRIEF COMMUNICATION

Multiple sclerosis, rituximab, and COVID-19

Annette Langer-Gould¹ , Jessica B. Smith², Bonnie H. Li², the KPSC MS Specialist Group, Brandon E Beaber, Sonu M Brara, Julie Debacker, Allen Scott Nielsen, Samira Amirova & Oluwasheyi Ayeni

¹Department of Neurology, Los Angeles Medical Center, Southern California Permanente Medical Group, Los Angeles, CA

²Department of Research & Evaluation, Southern California Permanente Medical Group, Pasadena, CA

This Issue

Views **1,830**

Citations **0**

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Comments

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Research Letter | Substance Use and Addiction



July 14, 2021

Changes in Admissions to Specialty Addiction Treatment Facilities in California During the COVID-19 Pandemic

Tami L. Mark, PhD, MBA¹; Brent Gibbons, PhD¹; Alan Barnosky, MA¹; [et al](#)

PLOS ONE

OPEN ACCESS PEER-REVIEWED

RESEARCH ARTICLE

Socioeconomic variation in characteristics, outcomes, and healthcare utilization of COVID-19 patients in New York City

Yongkang Zhang , Dhruv Khullar, Fei Wang, Peter Steel, Yiyuan Wu, Duncan Orlander, Mark Weiner, Rainu Kaushal

Published: July 29, 2021 • <https://doi.org/10.1371/journal.pone.0255171>

Supporting Families and Children with ASD/ADHD During the COVID-19 Pandemic



Enhancement Activities

- In response to COVID-19, many schools have stopped providing in-person special education services, leaving children with ASD and ADHD at risk for anxiety, changes in mood, and behavioral problems.
- This enhancement has [adapted resources from UOT](#) for parents and caregivers to [use online at home](#), including a series of [short videos](#) in English and Spanish.

Early Results from Enhancement Project

- Stakeholder organizations distributed videos using a variety of channels.
- Videos disseminated across statewide education networks in Colorado and Virginia.
- Evaluation (98 caregiver respondents) found videos to be helpful. Also indicated:
 - Modest reductions in interference and frequency of child EF problems
 - Reductions in caregiver strain



Executive Function (EF) problems are common in children with autism spectrum disorder (ASD) or attention deficit/hyperactivity disorder (ADHD) and can lead to long-term problems in academics, independent living, and quality of life.



A PCORI-funded implementation project is expanding the use of a school-based program which has been shown to improve executive functioning and classroom behaviors for students with ASD or ADHD, called Unstuck and On Target (UOT).

*Laura G. Anthony, PhD
University of Colorado Denver*

*Limited Competition Implementation Project
Awarded March 2020
Enhancement Awarded July 2020*

HERO Research Program

Clinical Trial



- Funded April 2020
- Leveraged PCORnet infrastructure
 - 1,363 HERO members randomized
 - 30 days to site activation
 - 10 days to first patient enrolled
- Results published to medRxiv for rapid dissemination
- Meta-analysis underway with other HCQ pre-exposure prophylaxis studies



[Comment on this paper](#)

Hydroxychloroquine for pre-exposure prophylaxis of COVID-19 in health care workers: a randomized, multicenter, placebo-controlled trial (HERO-HCQ)

^{ID} Susanna Naggie, Aaron Milstone, Mario Castro, Sean P. Collins, Lakshmi Seetha, Deverick J. Anderson, Lizbeth Cahuayme-Zuniga, Kisha Batey Turner, Lauren W. Cohen, Elizabeth Fraulo, Anne Friedland, Jyotsna Garg, Anoop George, Hillary Mulder, Rachel E. Olson, Emily C. O'Brien, Russell L. Rothman, Elizabeth Shenkman, Jack Shostak, Christopher W. Woods, ^{ID} Kevin J. Anstrom, Adrian F. Hernandez

doi: <https://doi.org/10.1101/2021.08.19.21262275>

This article is a preprint and has not been peer-reviewed [what does this mean?]. It reports new medical research that has yet to be evaluated and so should not be used to guide clinical practice.

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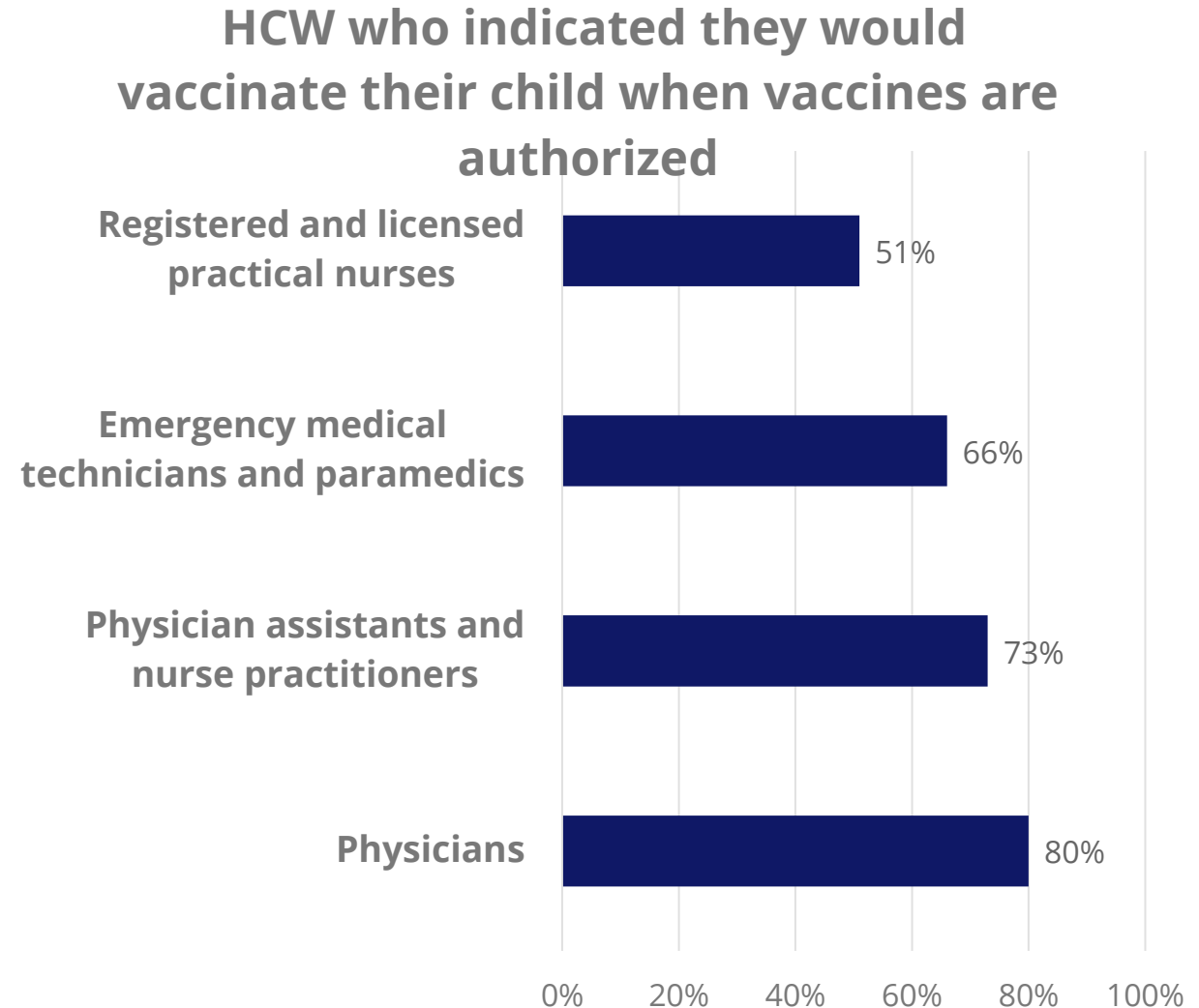
[Hydroxychloroquine for pre-exposure prophylaxis of COVID-19 in health care workers: a randomized, multicenter, placebo-controlled trial \(HERO-HCQ\) | medRxiv](#)

HERO Research Program

Registry of Healthcare Workers (HCW)



- Over 50,000 participants enrolled as of September 2021
- Addition of family members
- HERO Together
 - Pfizer-funded study on vaccine side effects
- Monthly Hot Topic polls to gauge the health care workers' perspective on evolving issues
 - Vaccine confidence
 - Financial burden

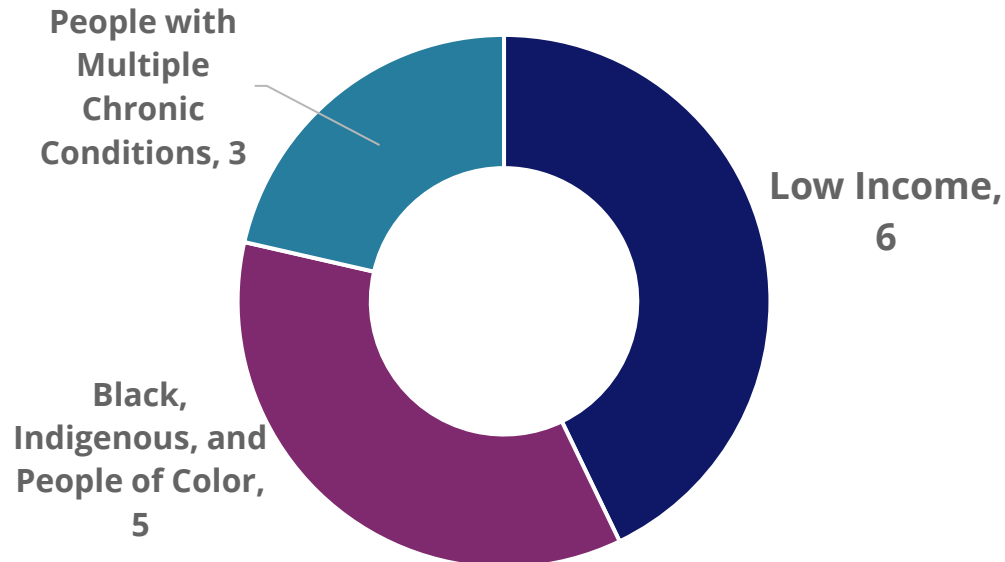


COVID-19 Targeted Funding

Research

- 9 awards made totaling \$29.8M

COVID-19 Research Award
Priority Populations

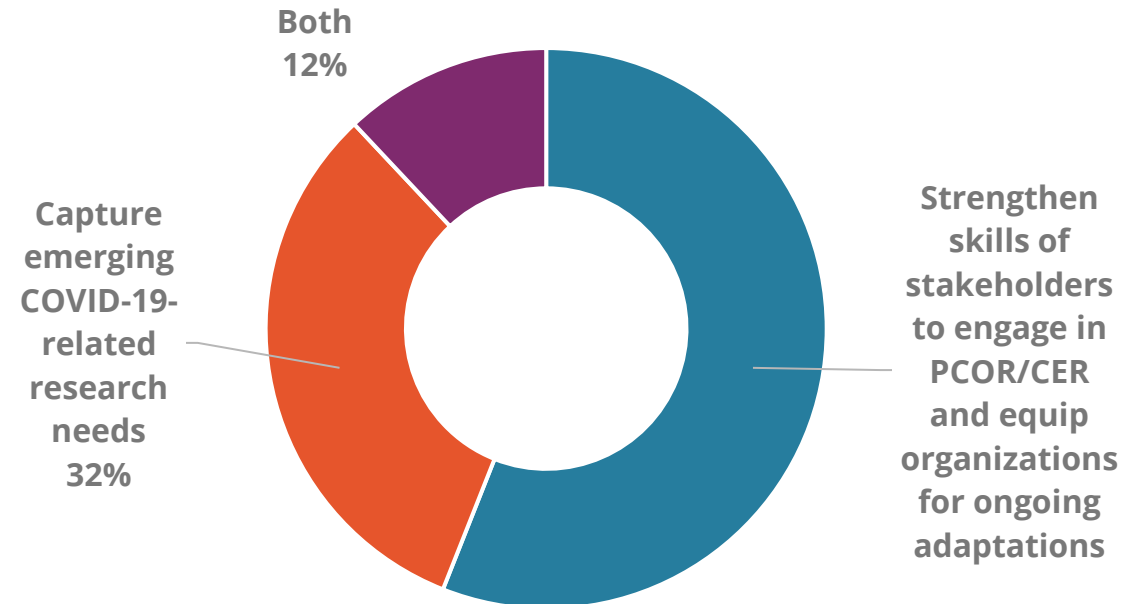


*Studies may include more than one population

Engagement

- 25 awards made totaling \$3.7M

COVID-19 Engagement Award Focus



Engagement Awards: Projects Coming to Fruition



Engaging Community Health Workers (CHW) in PCOR to Address Health Disparities in the Context of COVID-19

Culturally adapted PCOR and remote work training materials for CHWs

Disseminated training materials for researchers on the benefits of collaborating with CHWs in PCOR

Developed actionable infrastructure plan for connecting CHWs with researchers

The Impact of COVID-19 on the Mental Health of High-Risk Populations

Established a COVID-19 emotional wellness task force for understanding the mental health needs of high-risk populations due to the COVID-19 pandemic

Developed a COVID-19 emotional wellness research agenda

Disseminated project findings at the "Addressing Mental Health Needs Related to COVID-19" summit

Engaging Underserved Urban Communities in Research: Addressing Challenges in the Context of COVID-19

Developed tools and resources with strategies for engaging low-income urban communities in PCOR/CER in the context of COVID-19

Built greater capacity of Family Leaders in Boston and Washington, DC to participate in future PCOR/CER and facilitated connections between researchers and communities

Grew understanding of priorities and concerns of underserved urban communities with regards to COVID-19

Increasing Vaccine Confidence among Long-Term Care Workers PFA



- Awarded using a new expedited PFA mechanism with rapid review and award timeline
- PFA posted April 2021, 2 awards announced in July 2021
- Up to 3 years; Up to \$5,000,000
- What interventions are effective in increasing COVID-19 vaccine confidence and uptake among LTC workers?
 - ***CONFIDENT: A Randomized Trial to Increase COVID-19 Vaccine Confidence in Long-Term Care Workers***
(PI: Glyn Elwyn, Dartmouth)
 - ***ENSPIRE: Engaging Staff to Improve COVID-19 Vaccination Rates at Long-Term Care Facilities***
(PI: Clarissa Hu, Kaiser Permanente Washington Health Research Institute)

< News & Announcements



PCORI approves \$11 million for new studies to boost COVID-19 vaccination rates among long-term care workers

Results could help boost immunization rates during and beyond pandemic among key health care workers

July 12, 2021

WASHINGTON, DC—Two new studies comparing ways to boost COVID-19 vaccination rates that were approved for nearly \$11 million in new funding today by the Patient-Centered Outcomes Research Institute (PCORI) aim to

Evolving Funding Opportunities



Focus on Post-Acute COVID-19, Disproportionately Affected Populations, Social Isolation

Research:

Management and survivorship of post-acute COVID-19

**Broad Special
Area of Emphasis
(Cycle 1 2021)**

Impact of COVID-19 on disproportionately affected populations

Impact of COVID-19-related social isolation and loneliness on health outcomes

17 LOIs, 6 applications submitted

Research:

Treatment and survivorship of post-acute COVID-19

**Broad Special
Area of Emphasis
(Cycle 2 2021)**

Health system and healthcare delivery management of post-acute COVID-19

Strategies to improve outcomes of COVID-19 for disproportionately affected populations

Impact of COVID-19-related social isolation and loneliness on health outcomes

6 LOIs, 2 applications submitted

Engagement:

Long-term effects of post-acute COVID-19;

**Building Capacity
for PCOR/CER for
Topics Related to
COVID-19**

Impact of COVID-19 on disproportionately affected populations;

Impact of COVID-19 on social isolation and loneliness; and

Engaging, educating, and promoting informed decision making around COVID-19 vaccines

66 applications submitted

COVID-19 Virtual Events

Timely Delivery of Information

- March 31 - May 5, 2020
- Six-part webinar series to discuss how to deal with acute hospital disruptions early in the pandemic
- Featured frontline clinicians, operations management experts, and healthcare administrators sharing real-time learnings with the wider hospital community

Finding Hospital Capacity and Improving Patient Flow



- March 23, 2021
- Audience of over 200 attendees from across the health policy spectrum
- Featured remarks from Senator Tina Smith (D-MN) and presentations from PCORI staff and awardees

PCORI Virtual Hill Briefing: COVID-19 and the Future of Telehealth



- August 9, 2021
- Featured two awardees from Eugene Washington PCORI Engagement Awards Special Cycle focused on COVID-19.
- Projects focused on building capacity to engage in PCOR/CER of mental health needs of high-risk populations during the pandemic.

Engagement Award Lunch and Learn: Mental Health and COVID-19



PCORnet® COVID-19 Partnerships



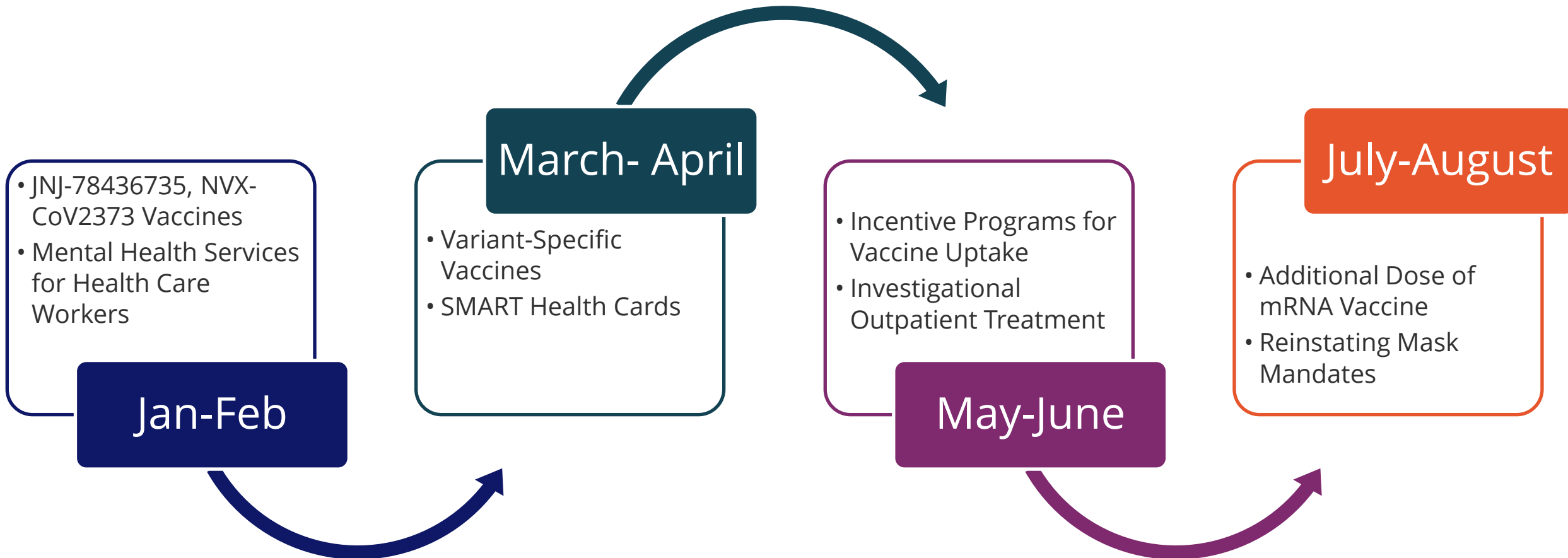
CDC and COVID-19 Surveillance

- CDC funded 43 PCORnet® sites for continued COVID-19 surveillance
- Monthly refreshes and biweekly surveillance queries of subset of PCORnet® COVID-19 Common Data Model
 - SARS-CoV-2 positive: over 1 million adults and children
 - COVID-19 vaccines: over 1.5 million adults and children
- Recent focus on myocarditis/pericarditis after COVID-19 and COVID-19 vaccines, post-acute sequelae of COVID-19 (PASC), and the effect of chronic disease control/severity on COVID-19 outcomes

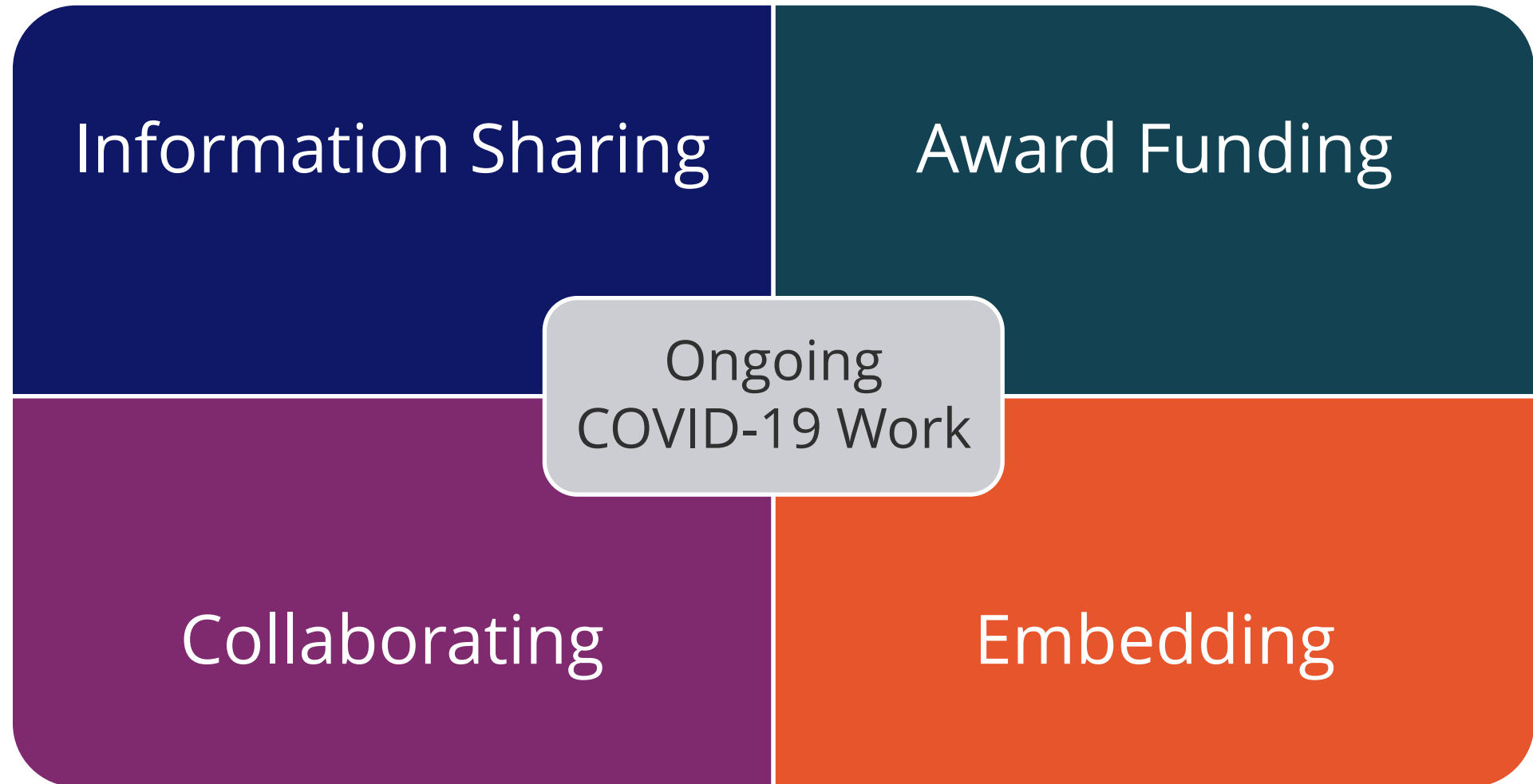
NIH and ACTIV-6

- NIH funded Phase III platform trial to test the efficacy of repurposed medications in reducing symptoms of mild to moderate COVID-19
 - 5-8 arms determined by ACTIV medication prioritization committee
- Trial utilizes PCORnet® for Clinical Coordinating Center, Data Coordinating Center, and vanguard sites
 - Award of \$155 million over approximately two years
 - Enhanced patient-centeredness, only ACTIV trial to have stakeholder engagement component

COVID-19 Biweekly Scans



Summary and Way Forward



Consideration for Approval: Slates of Advisory Panel Members, Chairs, and Co-Chairs

Michael Herndon, DO
Chair, Engagement,
Dissemination, and
Implementation Committee

Alicia Fernandez, MD
Chair, Science Oversight
Committee

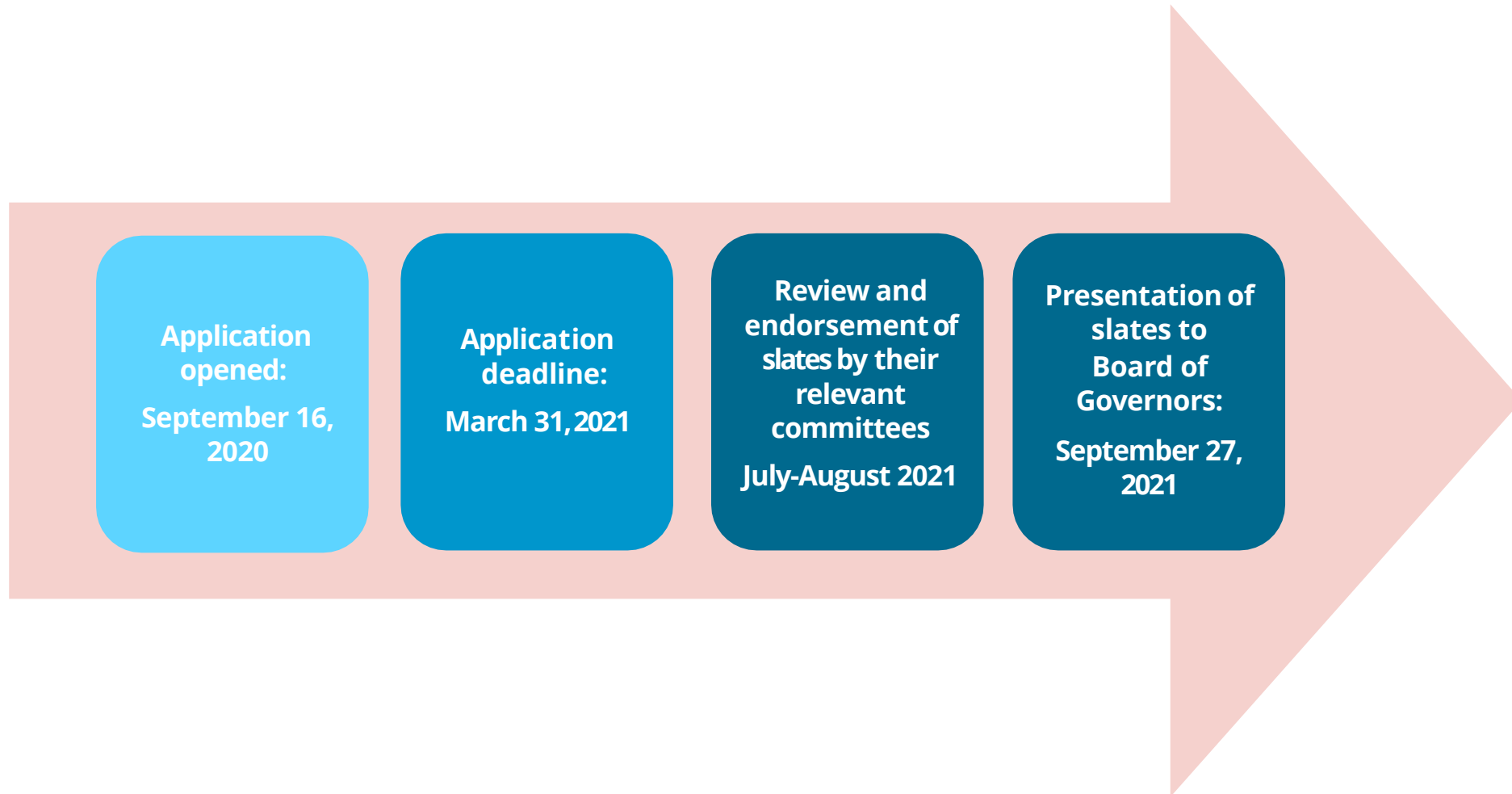
Steven Goodman, MD, MHS, PhD
Chair, Methodology Committee

Kristin Carman, PhD, MA
Director, Public and Patient
Engagement

Stanley Ip, MD
Interim Program Director,
Clinical Effectiveness and
Decision Science

Steven Clauser, PhD, MPA
Program Director,
Healthcare Delivery and
Disparities Research

Advisory Panel Selection Timeline



Slate of Panelists Proposed by the EDIC

Michael Herndon, DO
Chair, Engagement, Dissemination, and
Implementation Committee

Kristin Carman, PhD, MA
Director, Public and Patient Engagement



Advisory Panel on Patient Engagement (PEAP): Proposed Slate of Panelists



Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Donald Adams, Jr.	Patients, Caregivers, and Patient Advocates	IL	3 years
Geri Baumbblatt	Patients, Caregivers, and Patient Advocates	IL	3 years
Russell Bennett	Patients, Caregivers, and Patient Advocates	CA	3 years
Jen Brown	Patients, Caregivers, and Patient Advocates	IL	3 years
Melody Goodman	Researchers	NY	3 years
Una Lee	Clinicians	WA	3 years
Lauren Lessard	Researchers	AK	3 years
Rupa Valdez	Researchers	VA	3 years

Advisory Panel on Patient Engagement (PEAP): Proposed Chair and Co-Chair



Name	Stakeholder Group	State	Term length (or until replacements are appointed)
Proposed Chair:			
Neely Williams	Patients, Caregivers, and Patient Advocates	TN	1 year
Proposed Co-Chair:			
Karen Fortuna	Researchers	NH	1 year

Slates of Panelists Proposed by the SOC and MC

Alicia Fernandez, MD
Chair, Science Oversight Committee

Steven Goodman, MD, MHS, PhD
Chair, Methodology Committee

Steven Clauser, PhD, MPA
Program Director, Healthcare
Delivery and Disparities Research

Stanley Ip, MD
Interim Program Director, Clinical
Effectiveness and Decision Science

Advisory Panel on Healthcare Delivery & Disparities Research (HDDR AP): Proposed Slate of Panelists



Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Kelly Buckland	Patients, Caregivers, and Patient Advocates	DC	3 years
Diana Cejas	Clinicians	NC	3 years
Ashley Valentine	Patients, Caregivers, and Patient Advocates	IL	3 years

Advisory Panel on Rare Disease (RDAP): Proposed Slate of Panelists



Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Heather Adams	Researchers	NY	3 years
Natario Couser	Clinicians	VA	3 years
Giovanna Devercelli	Industry	NC	3 years
Deanna Fournier	Patients, Caregivers, and Patient Advocates	NJ	3 years
Sonia Jain	Researchers	CA	3 years
Mileva Repasky	Patients, Caregivers, and Patient Advocates	PA	3 years
Bridget Reynolds	Patients, Caregivers, and Patient Advocates	IL	3 years
Jasvinder Singh	Researchers	AL	3 years

Advisory Panel on Rare Disease (RDAP): Proposed Chair



Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Mathew Edick	Patients, Caregivers, and Patient Advocates	MI	2 years

Advisory Panel on Clinical Effectiveness and Decision Science (CEDS AP): Proposed Slate of Panelists



Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Timothy Gong	Clinicians	TX	3 years
Michael Hoerger	Clinicians	LA	3 years
Christina Nyquist	Patients, Caregivers, and Patient Advocates	VA	3 years
Jennifer Olsen	Patients, Caregivers, and Patient Advocates	GA	3 years
Sarah Wang	Patients, Caregivers, and Patient Advocates	VA	3 years

Advisory Panel on Clinical Trials (CTAP): Proposed Slate of Panelists

Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Jennifer B. Christian	Industry	NC	3 years
Angelica Geter	Researchers	GA	3 years
Janet Holbrook	Researchers	MD	3 years
Emily Largent	Researchers	PA	3 years
Elizabeth Turner	Researchers	NC	3 years

Advisory Panel on Clinical Trials (CTAP): Proposed Chair



Name	Stakeholder Group	State	Term Length (or until replacements are appointed)
Michael Jones	Researchers	MS	2 years

Board Vote

Call for a Motion to:

- **Approve** the proposed slates of members, positions, and terms for the following Advisory Panels: PEAP, HDDR AP, RDAP, CEDS AP, and CTAP

Call for the Motion to be Seconded:

- **Second** the Motion
 - If further discussion, may propose an **Amendment** to the Motion or an **Alternative** Motion

Voice Vote:

- Vote to **Approve** the **Final** Motion
 - Ask for votes in favor, opposed, and abstentions

Strategic Planning Committee Report: National Priorities Update and Research Agenda Discussion

Nakela L. Cook, MD, MPH,
Strategic Planning Committee Co-chair

Sharon Levine, MD
Strategic Planning Committee Co-chair

Strategic Planning Committee Membership



Steve Clauser



Nakela Cook
Co-chair



Jennifer DeVoe



Alicia Fernandez



Christine Goertz



Russell Howerton



Andrew Hu



Connie Hwang



Sharon Levine
Co-chair



Laura Lyman
Rodriguez



Barbara McNeil



Robin Newhouse



Michele Orza



Daniel van
Leeuwen



Robert Zwolak

Strategic Planning Committee

Purpose and Today's Report Structure

Purpose

- Update the Board on the proposed National Priorities for Health
- Begin discussions on the Research Agenda

Structure

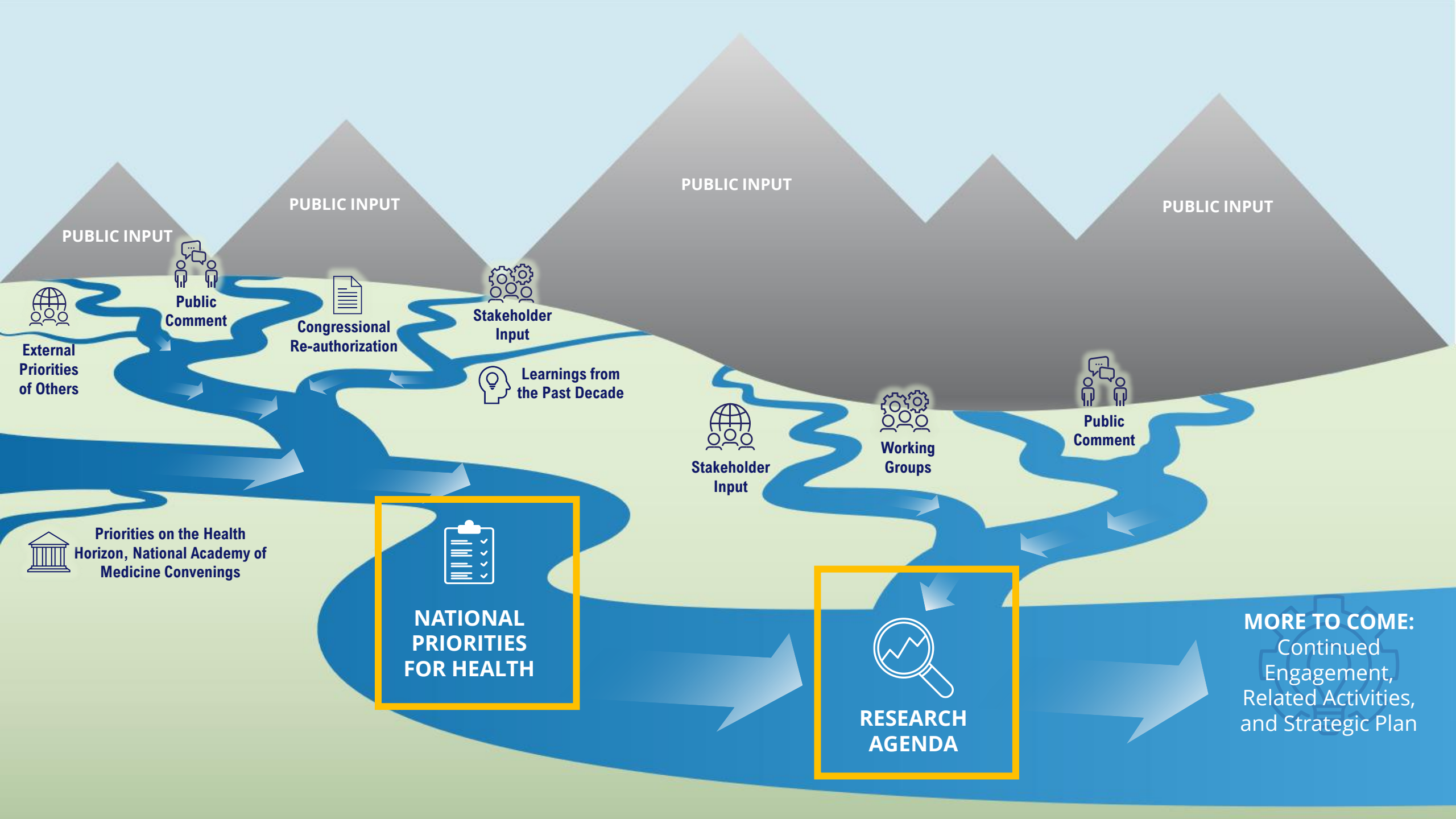
- Outline input gathering process
- Review preliminary themes from public guidance
- Consider the Research Agenda structure
- Overview of anticipated next steps

Scope of Strategic Planning Activities

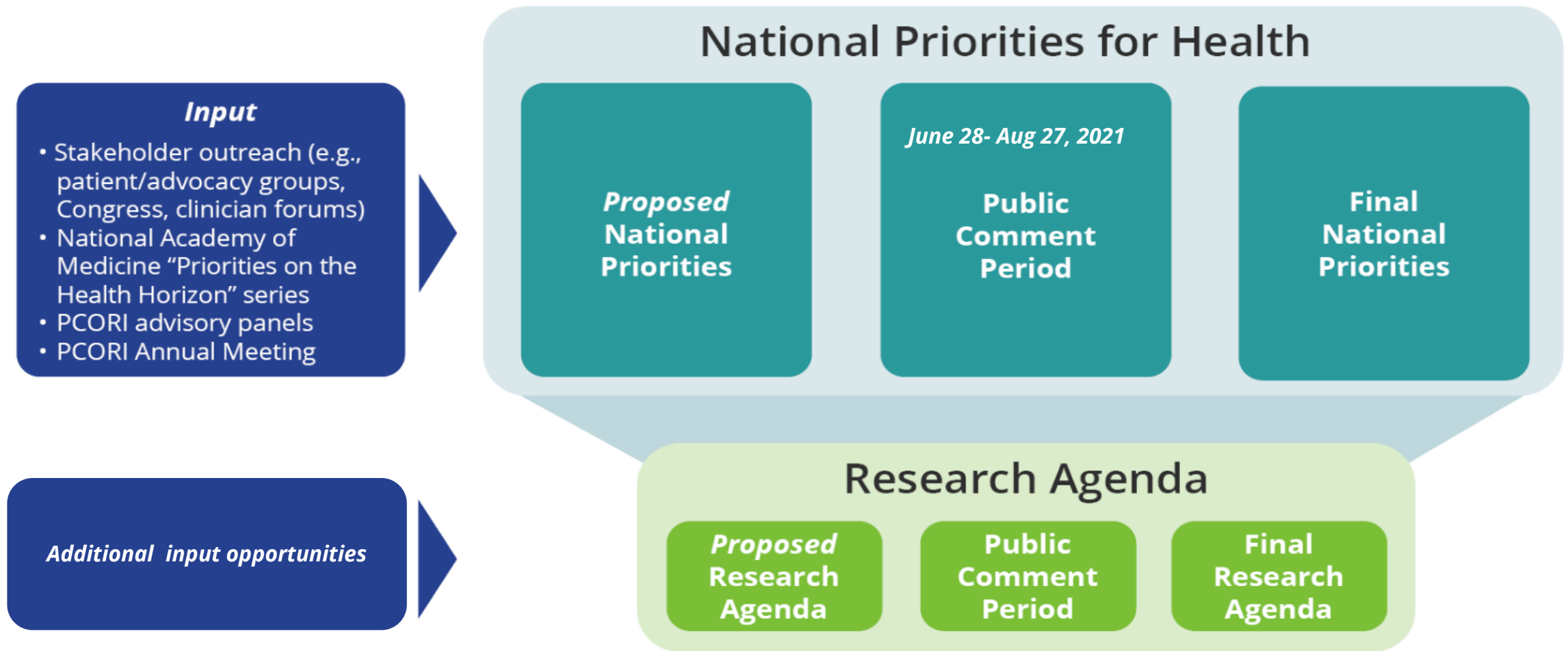


Strategic Planning

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

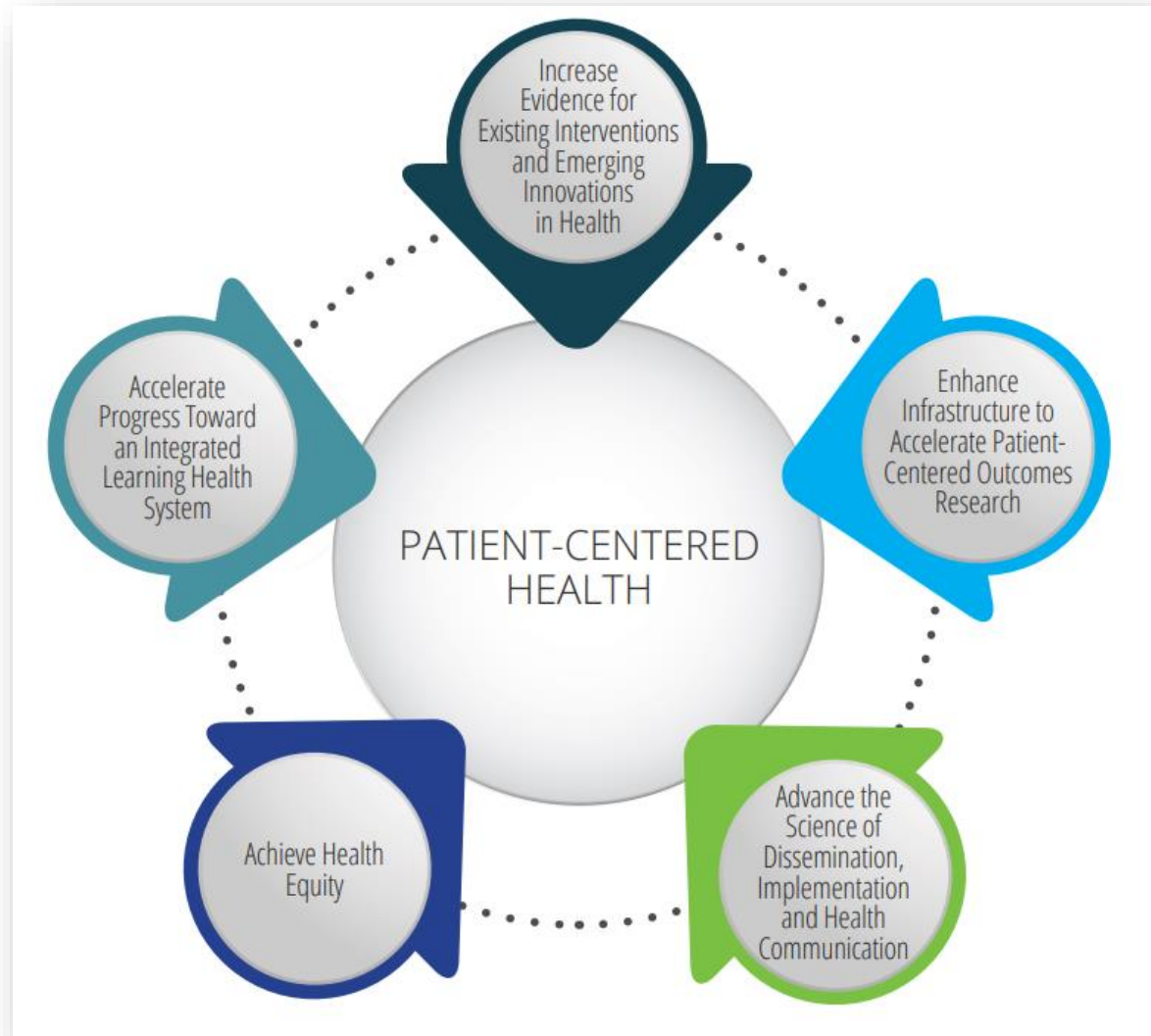


Stakeholder and Public Input and Public Comment Inform PCORI's National Priorities and Research Agenda



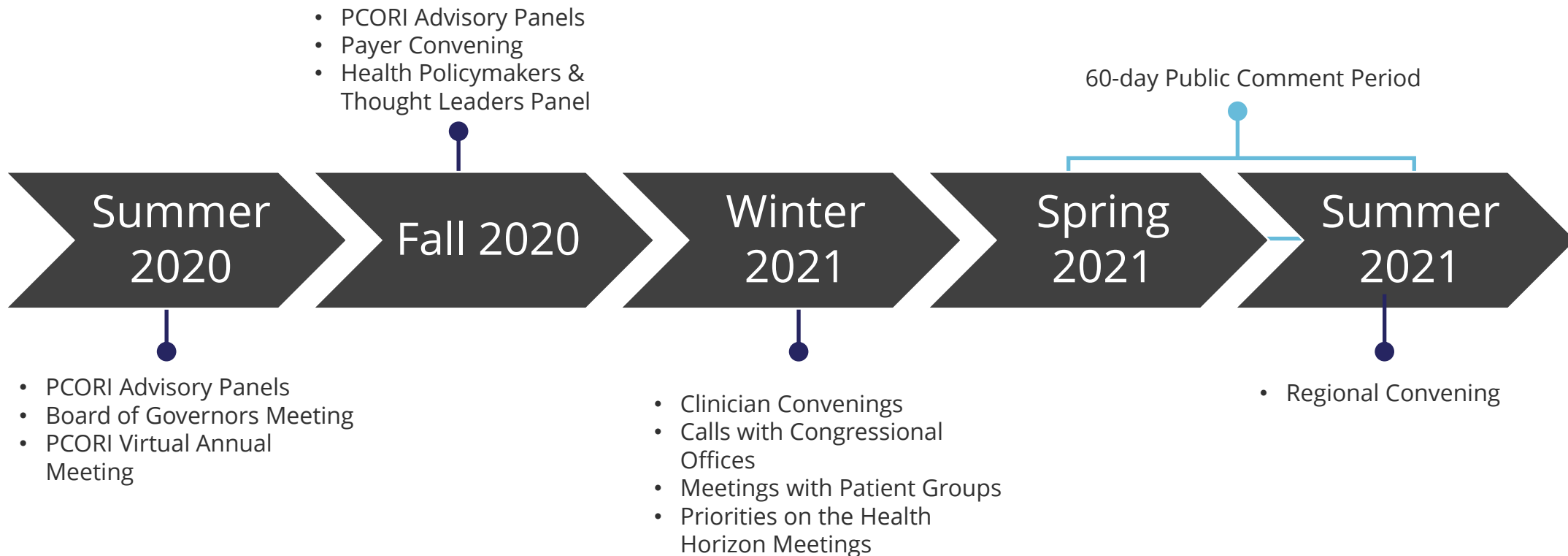
Update on Public Comment Period for National Priorities for Health

- Public comment period held from June 28- August 27, 2021
- Thank you to the public and stakeholders for submitting your comments!
- Received 113 comments from a range of stakeholders including patients, researchers, caregivers, and health systems



Input Gathering Process Reminder

PCORI received input from a range of stakeholders to identify and inform the National Priorities for Health in addition to holding discussion at Board of Governors meetings and several other activities to inform the process.

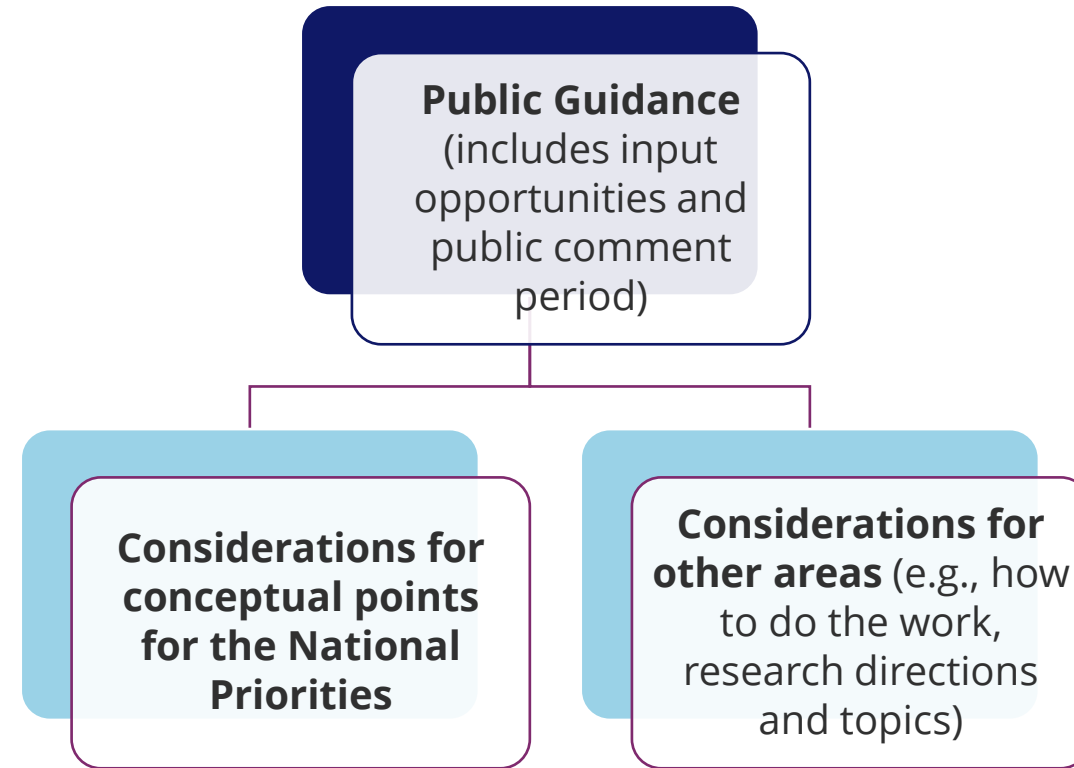


Update on Proposed National Priorities for Health

- Preliminary analysis of public comment and public input suggests strong support for the five proposed National Priorities for Health.
- Some conceptual points on the long-term goals for health were noted from the guidance with additional information for consideration on how PCORI could carry out the work.
- Final analysis is underway, but the preliminary review offers indications of positive reactions to the proposed National Priorities for Health.



Preliminary Themes from Public Guidance



Examples include:

- Distinguishing terms where relevant (e.g., health equity and disparities; telehealth and telemedicine)
- Clarifying concepts in support of the priorities (e.g., prevention)

Examples include:

- Importance of collaboration, partnerships and community involvement
- Importance of research methodologies

Process for Finalizing National Priorities for Adoption by Board

October 5th SPC Meeting

- Review public guidance synthesis
- Consider proposed responses to the synthesis (e.g., revisions to language, action plans for carrying out the work)
- Recommend National Priorities for adoption by the Board



October 26th Board Meeting

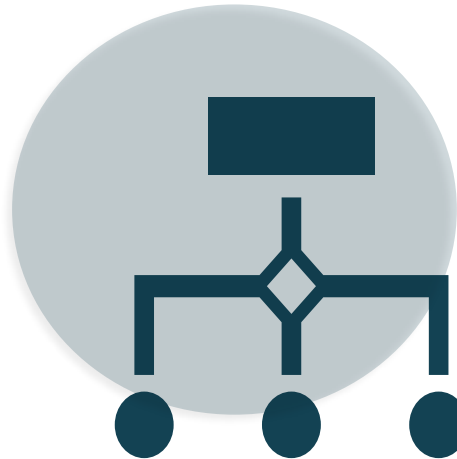
- Review public guidance synthesis and proposed responses for National Priorities
- Hear about SPC discussions and review SPC recommendations
- Consider National Priorities for adoption

Considering the Research Agenda

Why is a Research Agenda Needed?



Establishes the framework for achieving the National Priorities specifically through the strategy of funding research



Supports ability to be responsive to evidence needs of stakeholders



Fulfills authorizing law requirement

How the Research Agenda Relates to the Other Components of Our Strategic Plan



- The **strategic plan** centers on achieving the National Priorities for Health, and the Research Agenda is one major component of the plan.
- The **Research Agenda** provides a framework for achieving progress on the National Priorities specifically through the strategy of funding comparative clinical effectiveness research. It articulates parameters that guide the development of an evergreen **Research Project Agenda** via a continuous, stakeholder-engaged process.
- PCORI utilizes other strategies in addition to funding CER (for example, Dissemination & Implementation) to achieve the National Priorities, and these are described in other components of the strategic plan.

Draft Research Agenda Parameters

Based on PCORI's authorizing law, preliminary stakeholder input, desire to allow for adaptability, the following parameters serve to help shape the Research Agenda.

- **The Research Agenda should accommodate a full range of:**
 - outcomes important to patients and stakeholders
 - short- and long-term priorities
 - short- and long-term decision needs of stakeholders
 - potential individual and societal burdens and economic impacts
 - issues/topics across the lifespan
 - issues/topics across the care continuum
 - interventions
 - settings that influence health and healthcare
 - people and professionals involved in health

Draft Research Agenda Parameters

Continued



- **The Research Agenda should also be:**
 - in support of the National Priorities for Health
 - inclusive of issues affecting all groups/populations, with a focus on those experiencing disparities/inequities
 - responsive to emerging issues and new evidence
 - responsive to innovations across the care continuum

Draft Research Agenda Parameters

Continued



- **The Research Agenda should take into account:**
 - PCORI's unique role within the research ecosystem
 - PCORnet® as a unique, purpose-built resource
 - social determinants of health as factors in health outcomes
 - advances and innovations in methods, such as patient-reported data
 - state-of-the-art methods in engagement, health communication, dissemination, and implementation
 - factors of disease incidence, prevalence, and burden in the United States generally and by subpopulation (with emphasis on chronic conditions)
 - gaps in evidence in terms of clinical outcomes, practice variations and health disparities in terms of delivery and outcomes of care
 - the potential for new evidence to improve health, well-being, and the quality of care
 - the effect on national expenditures associated with a health care treatment, strategy, or health conditions

Sample of Preliminary Elements to Consider for Potential Application within the Research Agenda

Disparities

- Analyze where there are differences in health outcomes among populations
- Enhance data representativeness to support robust research
- Broaden data collected to reflect the complex influences on health outcomes (e.g., social determinants of health data)

Methods

- Maximize utilization of real-world data centered around and applicable to patients
- Leverage data linkages between disparate, large datasets (e.g., environmental, clinical, and social data)
- Advance state-of-the-art standards in methods (e.g., patient-reported outcomes)

Engagement

- Develop evidence that is useful and meaningful for patients, caregivers and the broader health community
- Leverage partnerships across sectors and incorporate multisectoral interventions
- Engage stakeholders in identifying topics for research

Patient-Centered Value

- Examine the full range of relevant outcomes to inform and increase patient-centered value of care
- Consider patient burdens (e.g., non-monetary costs) that impact value and health outcomes
- Collect and report cost data alongside health outcomes

Innovation

- Optimize impact for decision-making (e.g., earlier, more timely evidence)
- Fund topics to generate evidence relevant to the use of emerging issues (e.g., technology, drugs, devices)
- Examine unintended consequences and cost outcomes related to innovations

Health Communication

- Study approaches to best communicate research findings to the public in a trustworthy, robust, meaningful way
- Examine how to get the information to the right people, at the right time, in the right way

Research Agenda Structure

Example: Disparities

Fund research that aims to prevent and eliminate disparities in care delivery and health outcomes

Including but not limited to

- Funding research on topics where disparities in health outcomes are most pronounced
- Funding research that examines differential effects and unintended consequences for different populations
- Funding research that emphasizes inclusion and representativeness of historically understudied or excluded groups
- Funding research that incorporates the range of influences on health outcomes, starting with social determinants

Statement

What PCORI intends to do to achieve progress on the National Priorities for Health through its funded research

Research Characteristics

Describes the kind of CER PCORI would seek to fund

Research Agenda Structure

Example: Innovation

Fund research that aims to provide timely information to decision-makers about emerging innovations

Including but not limited to

- Funding research that prioritizes health innovations with high potential for impact on health outcomes
- Funding research that identifies benefits, unintended consequences, burden and economic impacts relevant to patients and that may not be traditionally or systematically measured
- Funding research on methods to more rapidly and rigorously accommodate and assess emerging health innovations

Statement

What PCORI intends to do to achieve progress on the National Priorities for Health through its funded research

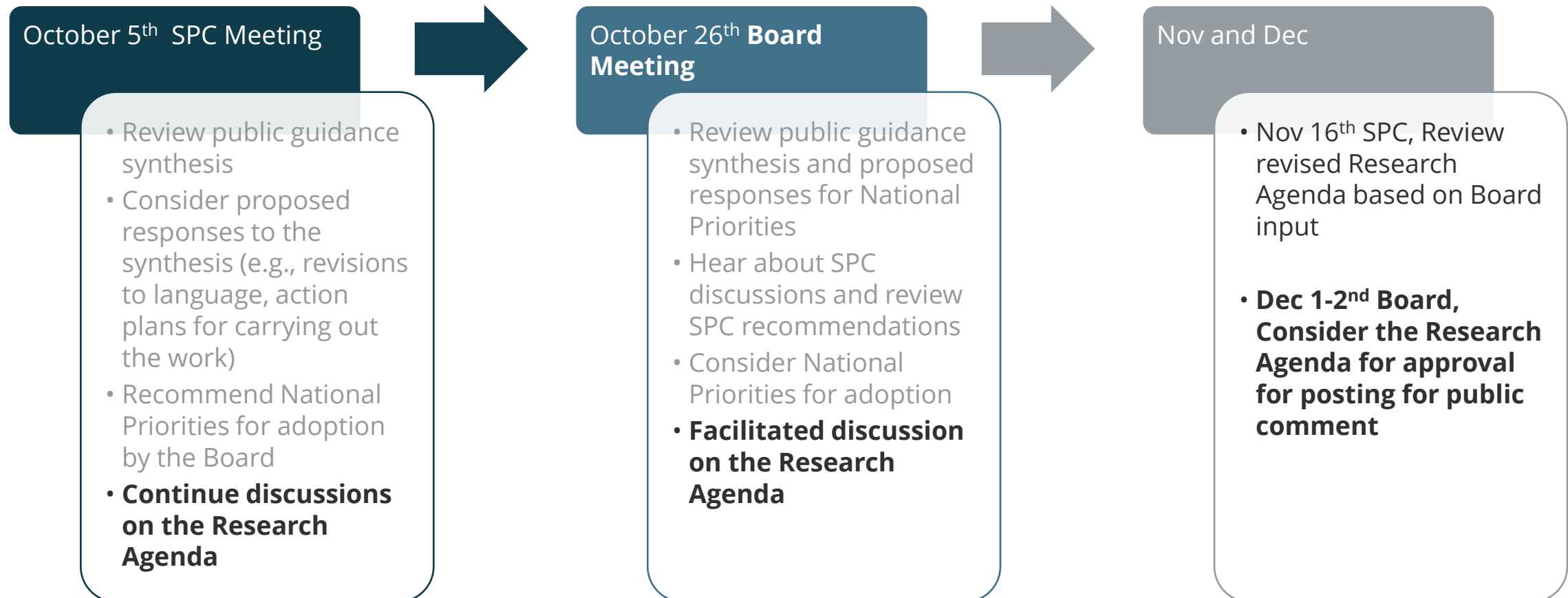
Research Characteristics

Describes the kind of CER PCORI would seek to fund

Board Discussion

- What are your reflections on the approach to the Research Agenda?
- Will the Research Agenda parameters and structure provide the envisioned path for achieving progress on the National Priorities by funding CER?

Anticipated Discussion Sequence



Questions?

Public Comment Period

Kristin L. Carman, MA, PhD
Director, Public & Patient Engagement

Closing Remarks

Wrap Up and Adjournment

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