Advisory Panel on Patient Engagement: In-Person Meeting

April 19, 2018
8:45 AM – 5:00 PM ET

April 20, 2018
8:00 AM – 2:30 PM ET

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Welcome, Introductions, and Review Agenda

Jean Slutsky, PA, MSPH

Chief Engagement and
Dissemination Officer

Kristin L. Carman, PhD

Director of Patient and Public
Engagement

Jane Perlmutter, PhD, MBA

Chair

David White, PhD

Co-chair

Housekeeping

- Today's meeting is open to the public and will be recorded
- Members of the public are invited to listen to the teleconference and view the webinar
- Meeting materials can be found on the PCORI website after the meeting
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled
- Visit www.pcori.org/events for more information

Housekeeping (cont.)

- We ask that panelists stand up their tent cards when they would like to speak and use the microphones

- Please remember to state your name when you speak

Agenda – Advisory Panel on Patient Engagement, April 19

9:30 AM	Welcome and Introductions
9:45 AM	Public and Patient Engagement: Key Initiatives
10:30 AM	BREAK
10:45 AM	Peer Review: Innovations and Opportunities
11:30 AM	Literature Review of Engagement in PCORI-Funded CER
12:00 PM	LUNCH
12:45 PM	Research Portfolio Data Mining Project
2:45 PM	Overview of Working Committees
3:00 PM	BREAK/Transition to Working Committees' Breakout Sessions
3:15 PM	Breakout Sessions
5:00 PM	Day 1 Adjourn

Introductions

- Please quickly state the following:
  - Name
  - Position title and organization
  - Stakeholder affiliation/group you represent

Introductions

Jane Perlmutter, PhD, MBA

Chair

Long-Term Cancer Survivor and Volunteer Research Advocate

President and Founder of sole proprietor consultancy, self-employed (Gemini Group)

Representing: Patients, Caregivers, and Patient Advocates

Introductions

David White

Co-Chair

National Committee for Quality Assurance, Health Care Consultant

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Sonya Ballentine

Peer Navigator, Illinois Institute of Technology College of Psychology

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Katherine Capperella

Global Patient Engagement Leader, Janssen Pharmaceuticals, Johnson & Johnson

Representing: Industry

Introductions

John Chernesky

Lead, Consumer Engagement, Rick Hansen Institute

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Emily Creek, MBA

Senior Director, Help & Support, Arthritis Foundation

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Libby Hoy

Founder/CEO, Patient & Family Centered Care Partners

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Gail Hunt

Board Member, PCORI Board of Governors

Member, Engagement, Dissemination and Implementation Committee

Founder, National Alliance for Caregiving

Introductions

Anjum Khurshid, MD, PhD

Director Data Integration and Assistant Professor Population Health, Dell Medical School's Department of Public Health, The University of Texas at Austin

Representing: Researchers

Introductions

Bennett Levitan, MD, PhD

Senior Director, Epidemiology, Janssen R&D, Johnson & Johnson

Representing: Industry

Introductions

Megan Lewis, PhD

Program Director, RTI International

Representing: Researchers

Introductions

Jimmy Lin, MD, PhD, MHS

Chief Scientific Officer, Oncology, Natera

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Suzanne Madison, MPH, MPA, PhD

Research, Evaluation & Grants Manager, The Sanneh Foundation

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Mark Mishra, MD

Assistant Professor, Radiation Oncology, University of Maryland

Representing: Clinicians

Introductions

Philip Posner, PhD

Science Advisor, ORISE/ORAU

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Ting Pun, PhD

Patient Stakeholder, PCORI funded Opioid Reduction study

Member, Stanford Neuroscience Patient and Family Advisory Council

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Brendaly Rodriguez, MA

Manager, University of Miami

Board Member, FL Community Health Worker Coalition

President & CEO, OPNIA Health

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Beverly Rogers

Founder, Bev J Rogers Enterprises, LLC

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Thomas Scheid, MA

Health Advocate

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Norah Schwartz, MPA, PhD

Medical Anthropologist, El Colegio de la Frontera Norte

Representing: Researchers

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Introductions

Veronica (Ronnie) Todaro, MPH

Senior Vice President and Chief Operating Officer,
Parkinson's Foundation

Representing: Patients, Caregivers, and Patient Advocates

Introductions

Jack Westfall, MD, MPH

Chair Family Medicine and Medical Director Whole Person Care,
Santa Clara Valley Medical Center Health and Hospitals

Representing: Clinicians

Introductions

Freddie White-Johnson, MPA, MS

Program Director, University of Southern Mississippi

Representing: Patients, Caregivers, and Patient Advocates

Public & Patient Engagement: Key Initiatives

Kristin L. Carman, PhD, MA

Director of Public and Patient Engagement

Advisory Panel on Patient Engagement Spring 2018 Meeting

April 19-20, 2018

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Welcome!

Kristin L. Carman

Director, Public and Patient Engagement

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Our Discussion Today

- Locate and share our work in Public & Patient Engagement (PPE) in the Engagement Department at PCORI
- Recent activities updates
  - The Science of Engagement
  - Stakeholder Engagement
  - Special Initiatives

Locate & Share PPE Work

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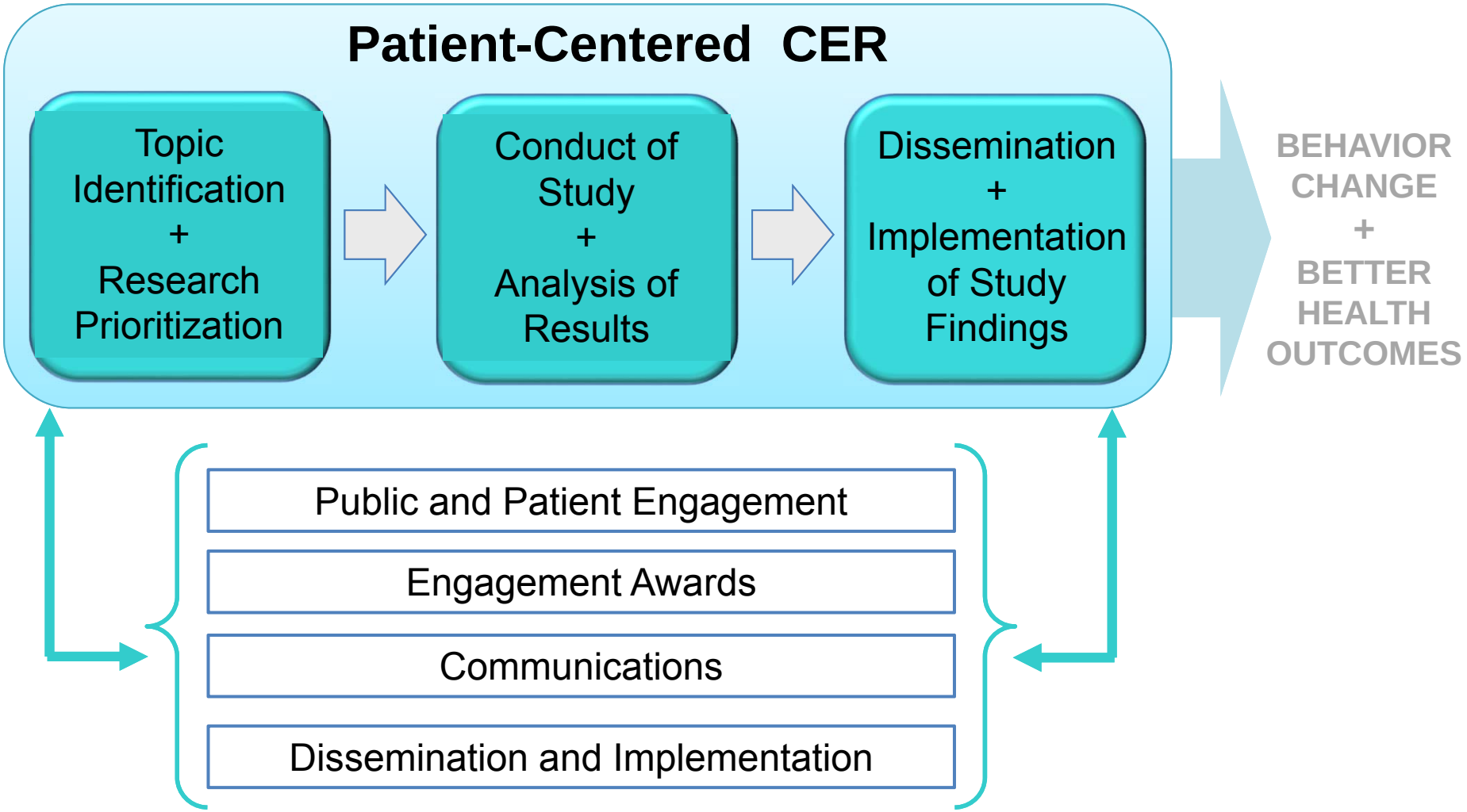
Engagement Department: Support for PCOR and Achievement of Improved Health Outcomes



The Role of PPE: Priorities & Objectives

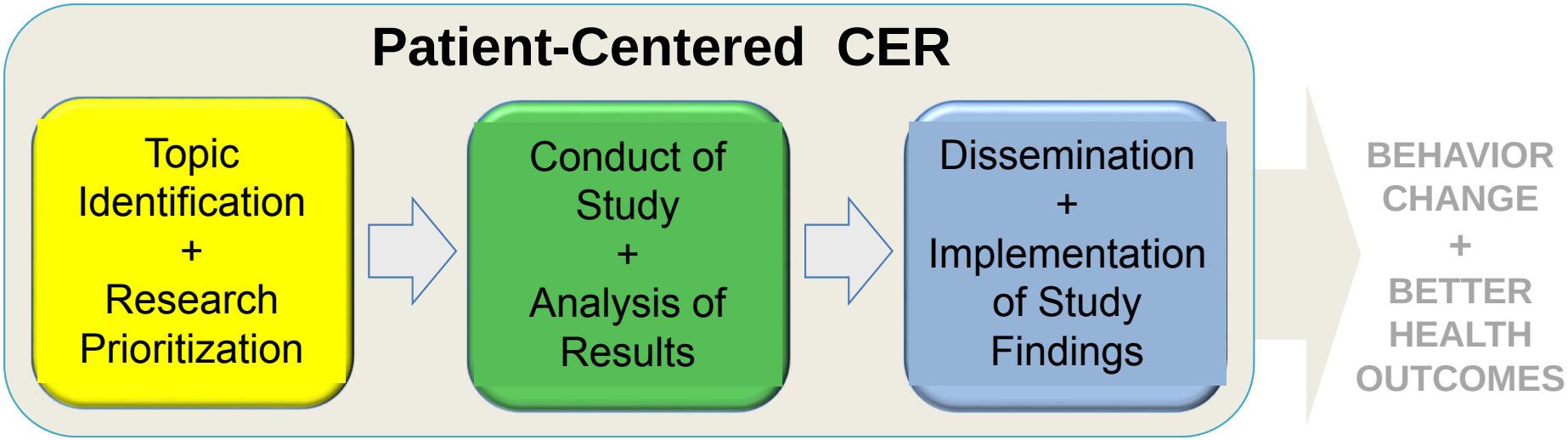
Strengthen stakeholder relationships

Advance the Science of Engagement

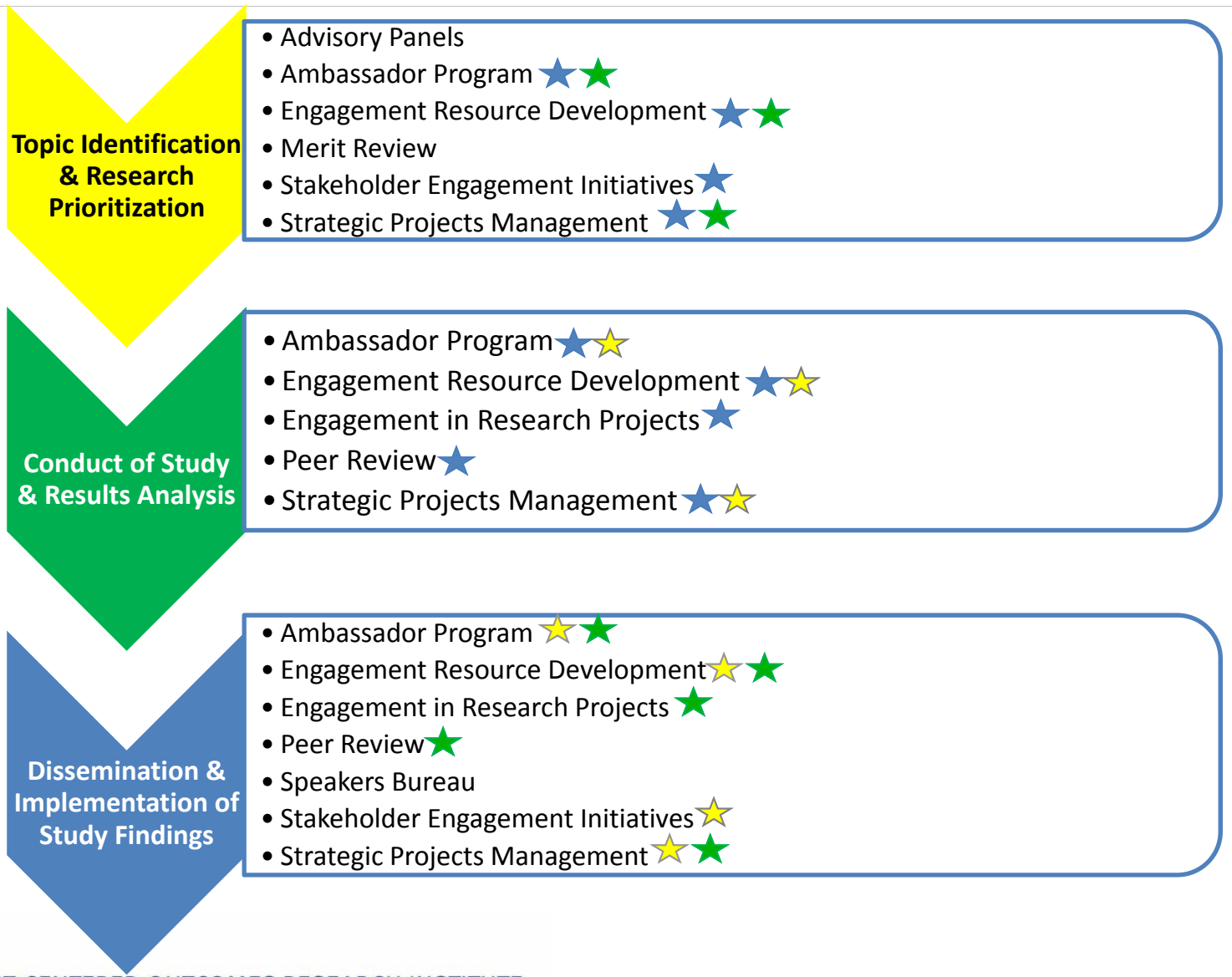
Translate and share findings with the field

Promote dissemination and uptake

Engagement Department: Support for PCOR and Achievement of Improved Health Outcomes



PPE Program Activities Aligned with Research Phases



The Science of Engagement

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Engagement in Research Support

Lisa Stewart
Engagement Officer
Team Lead

Chinenye Anyanwu
Engagement Officer

Julie K. Lesch
Engagement Officer

Denese Neu
Engagement Officer

Krista Woodward
Sr. Program Associate

Julia Anderson
Program Associate

Charmaine Boone
Sr. Admin Assistant

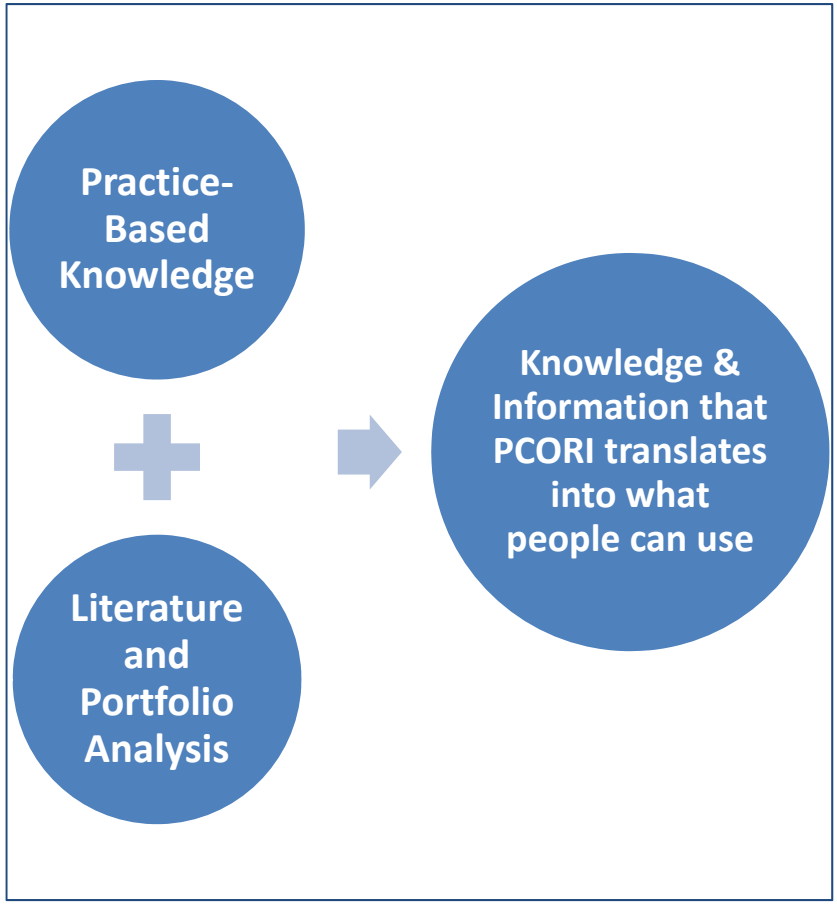
Understanding The Science of Engagement

What is happening?

- Build on existing sources of data to describe engagement in PCORI projects more deeply, including how partnerships are initiated and fostered
- Further explore the influence and impact of engagement on research – what are we learning about it and what is happening *because of it*.

How is it happening & how is it influencing results?

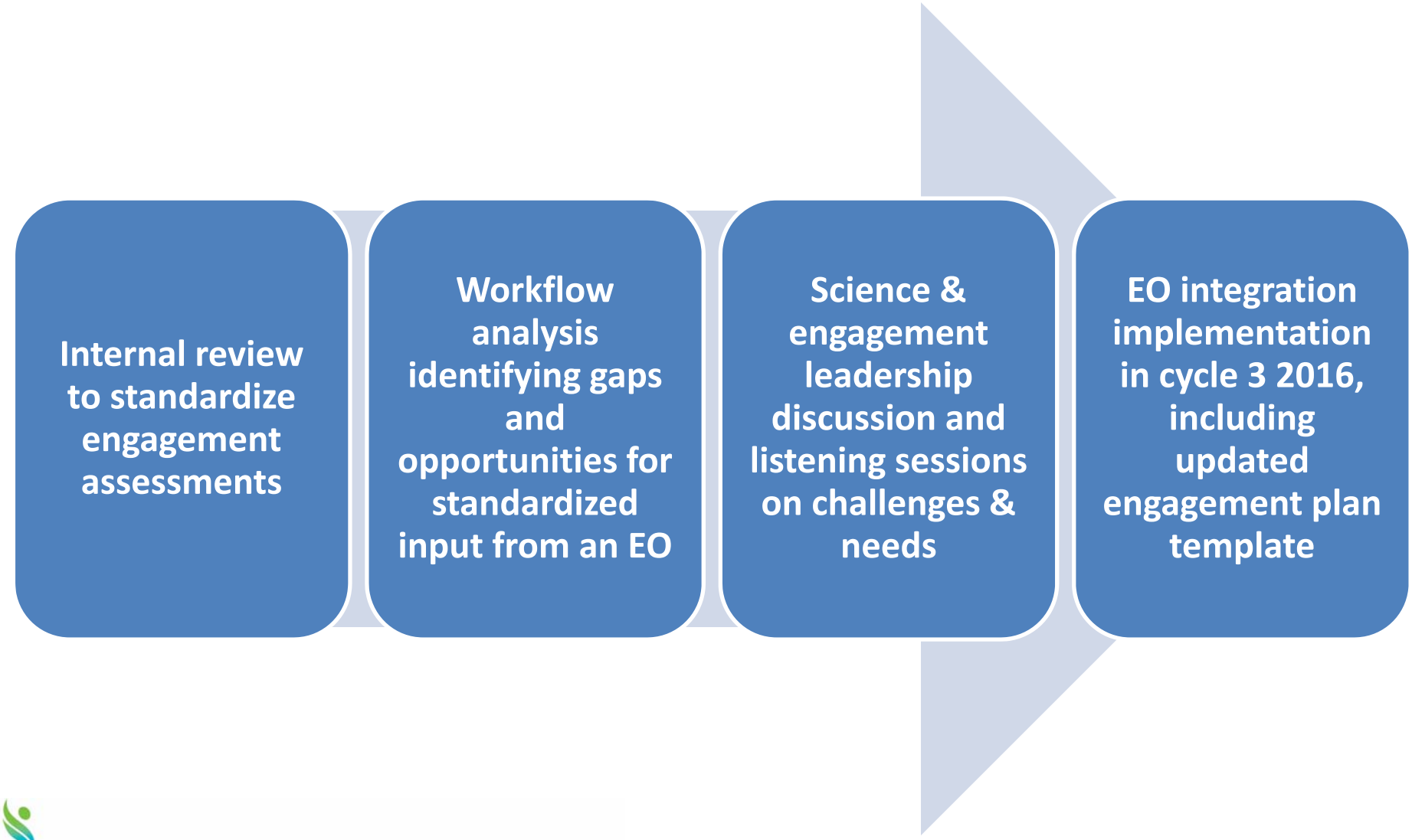
- Explore how the influence is occurring, test associations between different types of engagement and specific impacts of engagement, better understand *how* people are making engagement happen.



Translate & Share Findings with The Field

- Leverage accumulated knowledge & connect learnings across like projects
- Innovate and evolve practice-based knowledge
- Interpret practice-based knowledge & speak to the field via webinars/tools
- Translate patterns into recommendations, tools & guidance
- Bring groups together to identify cross cutting resources
- Cultivate receptor sites in groups and organizations

Standardization of EO Role and Integration



Stakeholder Engagement

Stakeholder Engagement Team

Jonathan Moore
Associate Director

Emma Kopleff
Program Officer

Anna Swanson
Program Associate

Charmaine Boone
Sr. Admin Assistant

Jourdan Davis
Program Associate

Whitney McInvale
Program Associate

Meghan Berman
Program Assistant

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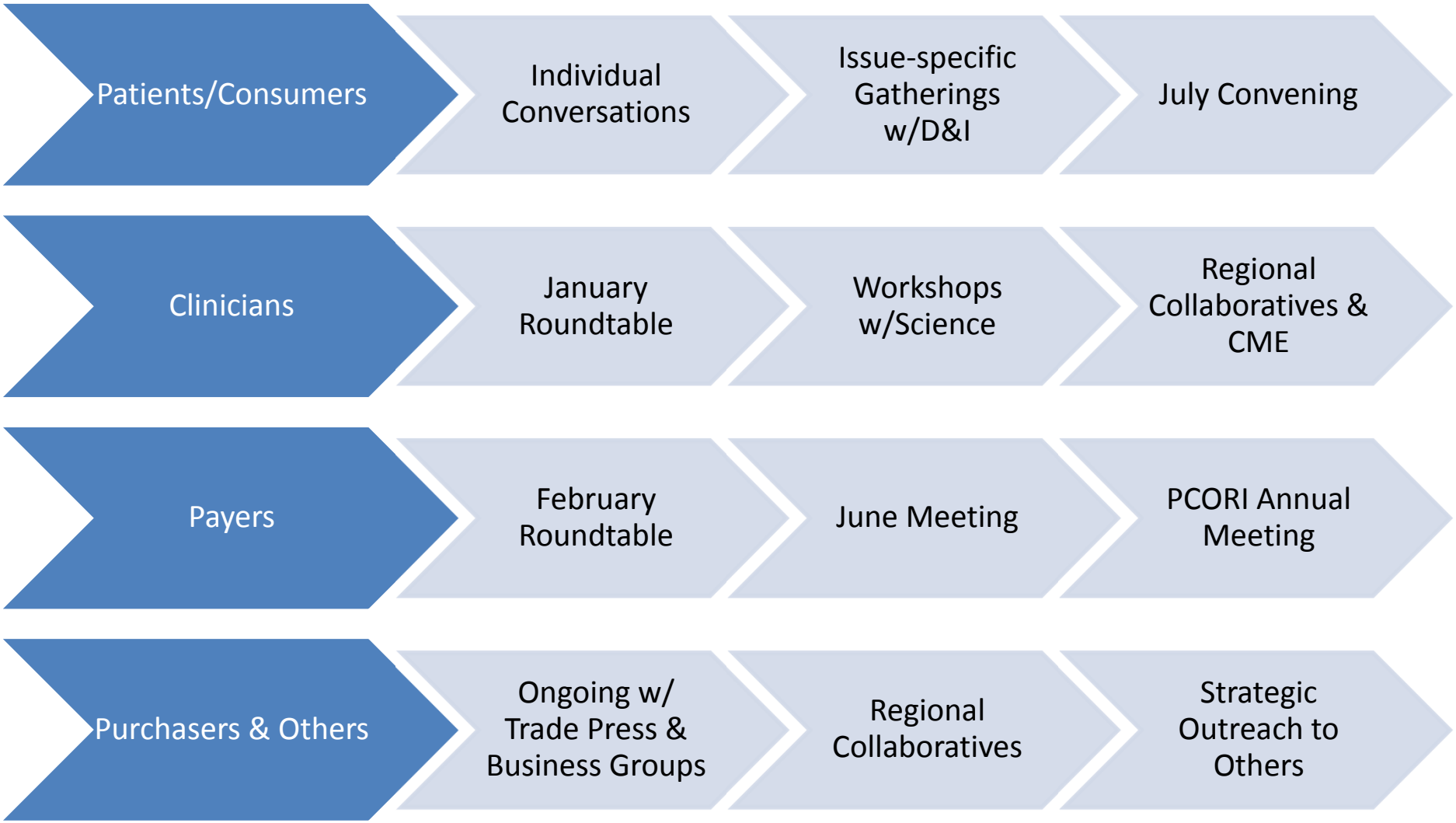
Background

Roundtable forums and targeted convenings serve as a primary strategy for addressing key priorities for public and patient engagement:

1. Strengthen stakeholder relationships
2. Advance the science of engagement
3. Translate and share findings with the field
4. Promote dissemination and implementation

Engagement Strategies by Stakeholder Group



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Update on Recent Activity

- January 25, 2018: Third roundtable for over forty **physician specialty societies**
- February 13, 2018: Kick-off for inaugural series of roundtable discussions for approximately 20 **payer organizations**

Achieved objectives:

- Shared overview of PCORI portfolio, emphasizing timely and impactful findings and interim stakeholder resources
- Solicited feedback on stakeholder priorities, what they need from PCORI, and potential opportunities for ongoing collaboration and dialogue

Physician and Payer Forum Key Takeaways

- ***Opportunities for improved communication***
  - PCORI is a trusted source of information
  - Bidirectional and more frequent communication is desired to help reduce extraneous "noise"
- ***Multipronged approaches are needed to translate research into readily available information for stakeholder decision making and practice***
  - Interim "products" from PCORI (e.g., evidence maps, impact analyses), can support immediate stakeholder needs
  - Some physician groups are willing partners in the dissemination of impactful results
  - Decision makers and executives, not just CMOs, are an important audience within payer organizations

Upcoming Activity

- May 24, 2018: Telehealth multistakeholder workshops
- June 2018: Second in series of payer roundtable forums this year
- July 2018: Consumer roundtable
- January/February 2019: Transitions in care multistakeholder workshop
- Continued regional forums as available

Special Initiatives: Current & Upcoming

Special Projects Work

Rachel Mosbacher
Program Officer, Special Projects

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Current Projects

Project	Vendor	Timeframe	PCORI Staff Lead(s)
Care Coordination Programs Portfolio Analysis	Insight Policy Research (IPR)	11/15/17 – 3/30/18	Josh Krantz
Disease Management or Case Management Portfolio Analysis	Insight Policy Research (IPR)	11/15/17 – 3/30/18	Josh Krantz
Research Portfolio Data Mining, Engagement Rubric Evaluation & Adaption	American Institutes for Research (AIR)	10/26/17 – 1/30/20	Kristin Carman
PCOR/CER Research Fundamentals and Training & Resources for Multi-stakeholder Research Teams	American Institutes for Research (AIR)	10/26/17 – 5/31/20	Erica Sarnes & Kristin Carman
Meeting Facilitation and Support for Dissemination & Implementation Workshop	NORC/AHRQ	2/20/18 – 5/31/18	Michelle Henton

Upcoming Projects

- **Four projects initiating in April:**
  - Pipeline to Proposal Awards Program Analysis
  - Gene-Therapy-Based Interventions Review
  - Engagement Awards Interim & Final Progress Report Analysis
  - Engagement Awards Deliverable Cataloging
- **Three projects initiating in May/June:**
  - Clinician Engagement Tool & Technical Support for Trials, Dissemination and Implementation of Evidence
  - Merit Review Mentor Training
  - Talking about Data: A Patient-Centered Guide to Engaging Partners in Data Analysis and Interpretation
- **At least three projects initiating by September:**
  - Engagement Tool Identification, Creation, Expansion & Cataloging Across the Research Portfolio
  - Developing and Applying Innovative Methods for Stakeholder Input into Research Topic Prioritization and Establishing Decisional Dilemmas
  - Convening on Evidence for Engagement
- **Ongoing projects, initiated as needed:**
  - Literature Reviews on Portfolio Areas, Conditions, and Burden of Disease
  - Assessment of Economic Impact of PCORI-Funded Evidence
  - Multi-Stakeholder Capacity Building, Outreach and Input, and Dissemination-Focused Workshops

Found on PCORI website here: https://www.pcori.org/sites/default/files/PCORI-AOSEPP-IDIQ-Anticipated-Tasks-March-2018.pdf

Questions?

PPE Program Activities Aligned with Research Phases

	Advisory Panels	Ambassadors Program	Engagement in Research Projects	Engagement Resource Development	Merit Review	Peer Review	Speakers Bureau	Stakeholder Engagement Initiative	Strategic Projects Management
Topic Identification & Research Prioritization	X	X		X	X			X	X
Conduct of Study & Analysis of Results		X	X	X		X		X	X
Dissemination & Implementation of Study Findings		X	X	X		X	X	X	X

Break

We will resume the meeting at 10:45 AM ET

Peer Review:
Innovations and Opportunities

Marina Broitman, PhD

Senior Program Officer, Peer Review

Office of the Chief Science Officer

Advisory Panel on Patient Engagement Spring 2018 Meeting

April 19, 2018

How PCORI Peer Review Works

PCORI's Obligations Under its Authorizing Law

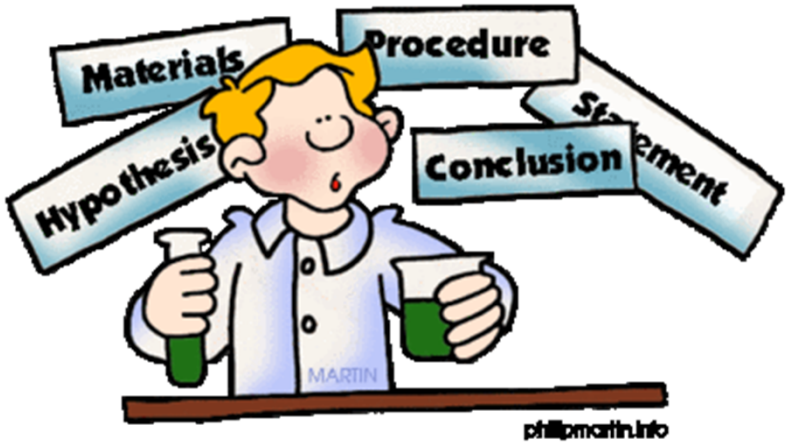
- Conduct peer review of primary research to assess:
  - **Scientific integrity**

    Do the results support the Conclusions?
  - **Adherence to PCORI's Methodology Standards**
- PCORI's Board of Governors added that the peer-review process should also:
  - *"..address issues of **relevance** and **usefulness** for multiple audiences, including patients and caregivers"*
- To meet these obligations, PCORI requires a Final Research Report, which goes through external peer review

What Makes a Final Research Report?

Draft final research report (DFRR) includes…

- ✓ Structured abstract
- ✓ Coverage of all study aims
- ✓ Description of patient & stakeholder engagement
- ✓ Detailed methods and results
- ✓ Study limitations
- ✓ Subpopulation considerations
- ✓ Checklist of adherence to PCORI's Methodology Standards
- ✓ Copy of study protocol



How The Process Works

External Peer Reviewers

Subject matter experts	• Clinical scientists with expertise in a specific research area
Methodologists	• Includes biostatisticians and other methodologists
Patients, caregivers, or patient advocates	• Personal Knowledge and/or work in the report's topic area
Stakeholders	• Clinicians, health systems, purchasers, payers, industry, policy makers

Elements of Reviewer Forms

Subject Matter Expert	Patient/Stakeholder	Methodologist
Compelling case for significance of the research	Compelling case for significance of the research	Compelling case for significance of the research
Clear and complete methods description	Are study aims/research questions meaningful	Detailed critique of methods description
Detailed description of interventions	Adequate description of patient/stakeholder engagement	Appropriateness of analytic techniques
Clear and complete study results	Are interventions meaningful to patients/stakeholders	Clear and complete study results
Do conclusions match the results	Does report inform decision-making	Do conclusions match the results

The Synthesis Letter

- Associate Editors provide a synthesis of reviewer comments, as well as their own review of the report.
- The synthesis letter includes a section specifically devoted to the patient perspective.
- In addition, authors are asked to address all reviewer comments in a disposition of comments table.

More About Patient Peer Reviewers

Patient Peer Reviewers in Our Reviewer Pool

- As of April 2018, PCORI has invited **240** patient reviewers to review
- Some people decline, some do not respond, and others have agreed but not yet completed a review

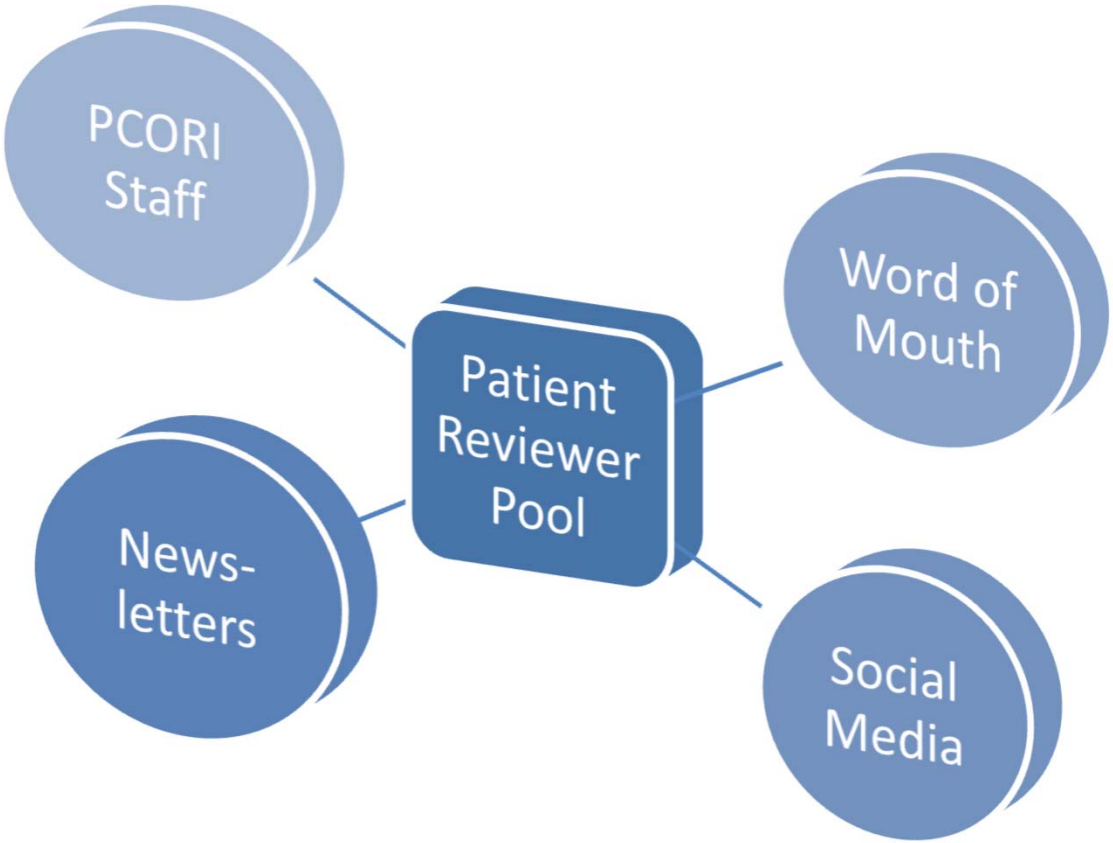
135 Complete Patient Peer Reviews from 115 Reviewers

Slide courtesy of Rebekah Webb & Kira Lesley, OHSU

Peer Reviewer Database

Community	Patient	Stakeholder	Scientist
Patient	251		
Unpaid Caregiver	55		
Patient Advocate	144		
Clinician		65	
Hospital/Health System		39	
Purchaser		2	
Payer		5	
Industry		32	
Policy Maker		12	
Training Institution		28	
Methodologist			258
Clinical Researcher			448

Main Recruitment Channels for Patient Peer Reviewers



Slide courtesy of Rebekah Webb & Kira Lesley, OHSU

Where We are Actively Recruiting

- Family
- Friends
- Facebook
- www.inspire.com
- @pcori
- @OHSUnews
- Caregiver Action Network
- Komen Advocates in Science
- Cancer Research Institute
- Native American Rehabilitation Association
- PCORI website
- Participants on PCORI panels and advisory boards, also merit reviewers
- MedicineX
- Department of Defense, Congressionally Directed Medical Research Programs, CDMRP
- Consumers United for Evidence Based Healthcare (CUE) Summit
- American Association of Nurse Practitioners
- OCHIN
- Family Caregiver Alliance
- Facing Our Risk of Cancer Empowered (FORCE)
- Transgender American Veterans Association (TAVA)
- National Breast Cancer Coalition
- Accelerating Anticancer Agent Development and Validation
- American Lung Association
- Institute for Patient and Family-Centered Care

Slide courtesy of Rebekah Webb & Kira Lesley, OHSU

Personal Demographics of Patient Reviewers (n=115)

Gender (Self-Identified)	
Women	88
Men	22
Left Blank	5

Hispanic/ Latin X= 8

Race (Self-Identified)	
White	82
Black/African American	16
American Indian/ Alaskan Native	1
Native Hawaiian or Other Pacific Islander	0
Asian	5
Other race	3
Did Not Respond	8

Health Conditions Represented by Our Patient Reviewer Database

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Slide courtesy of Rebekah Webb & Kira Lesley, OHSU

Healthcare Topics Represented by Our Patient Reviewer Database

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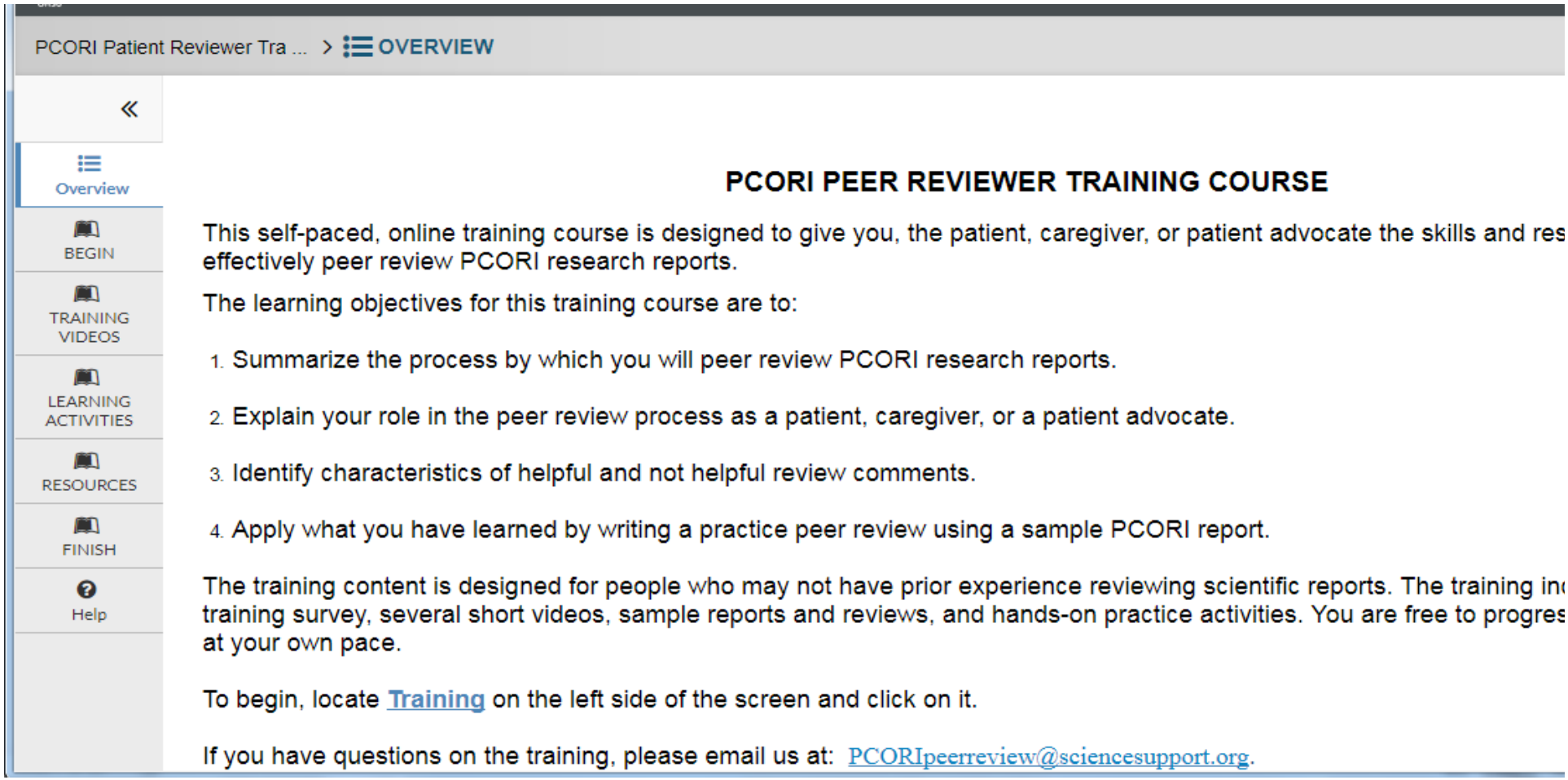
Slide courtesy of Rebekah Webb & Kira Lesley, OHSU

Preparing our Patient Peer Reviewers

Training for Patient & Stakeholder Reviewers



Training for Patient & Stakeholder Reviewers

- Specific to patients or stakeholders
- Self-paced
- Includes knowledge checks
- Sample report to review
- Practice with the reviewer form
- Examples of “more helpful” and “less helpful” comments
- Resources reviewers may access repeatedly

PEER REVIEW COMMUNICATIONS
TOOLKIT

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PEER REVIEW COMMUNICATIONS **TOOLKIT**

- ✓ Social media best practices
- ✓ Sample language for communications
- ✓ Sample shareable graphics
- ✓ Best practices for how to speak about peer review at different events
- ✓ Glossaries on social media & peer review

How Patient Reviewer Feedback has been Incorporated

How Patient Reviewer Comments Affect the Synthesis Letter

Example: Patient Registries for Comparative Effectiveness

- In the background section, the patient reviewer pointed out a disconnect between the stated outcomes in the abstract and the body. Further, the reviewer said that two of the aims stated throughout did not appear to be what was actually studied.

→ The Associate Editor incorporated a direct quote from the reviewer in their synthesis letter and asked the authors to clearly state the research questions.

Slide courtesy of Kelly Vander Ley, OHSU

How Patient Reviewer Comments Affect the Synthesis Letter

Example: Self Care Management of Cancer Symptoms

- Commenting on the intervention, the patient reviewer said the report needed to take into account the reduced learning capacity of patients undergoing moderate to advanced cancer treatment.

→ The Associate Editor directed the author to note this comment, saying: "[The reviewer] also raises the salient point that [they were] unable to retain information while actively receiving treatment and being overwhelmed with numerous bio-psycho-social issues."

Slide courtesy of Kelly Vander Ley, OHSU

Impact of Patient Review on the Final Report

Example: Skills Latina Mothers use to get healthcare for their children

- The Reviewer noted that the background section lacked a definition of "mental health needs."

→ In response, the authors amended the background section to explain this term could mean a variety of things, including "perceived need, screened and diagnosed conditions"

Slide courtesy of Kelly Vander Ley, OHSU

Impact of Patient Review on Final Report

Example D: Family Navigator Services for Children Treated with Antipsychotic Medication

- The reviewer thought it was important to include examples of how Family Navigators could affect overall health of patients.

→ In response, the authors included more case examples relating to the Family Navigator in their final report.

Slide courtesy of Kelly Vander Ley, OHSU

Seeing Like a Patient

Patient reviewers

- ✓ Shift the focus of the reports toward information that patients care about, making the final reports more patient-centered.
- ✓ Help the reports become more accessible by using language that is more understandable and meaningful to patients.

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Slide courtesy of Kelly Vander Ley, OHSU

Thank You!

Peer Review Website:
https://www.pcori.org/research-results/peer-review-our-studies
Peer Reviewer Application:
http://www.sciencesupport.org/PCORIpeer/

Literature Review of Engagement in PCORI-Funded CER

Laura Forsythe, PhD, MPH
Director, Evaluation & Analysis

Denese Neu, PhD, MS
Engagement Officer

Advisory Panel on Patient Engagement Spring 2018 Meeting
April 19, 2018

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Agenda for Today

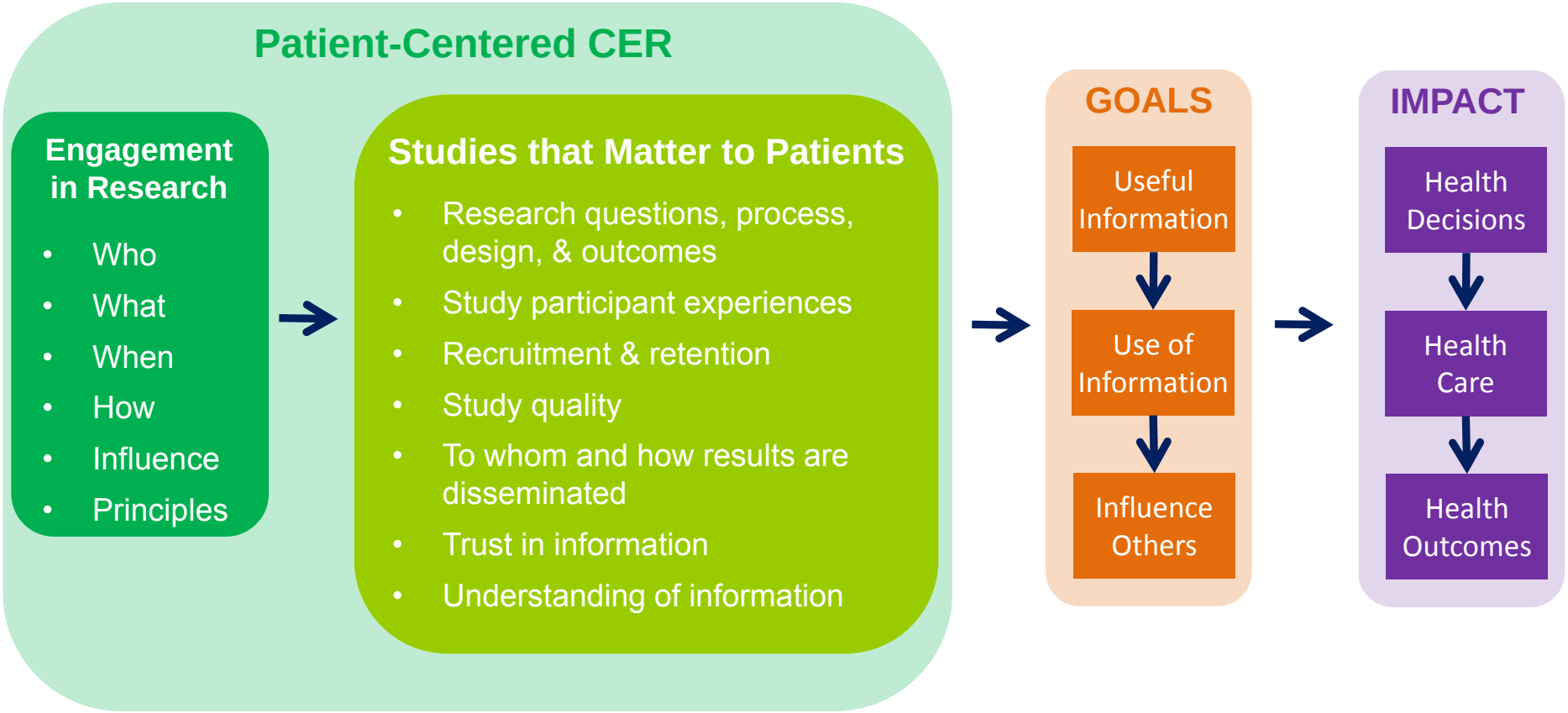
- **Welcome, Introduction**

- **Targeted Literature Review on the Contributions of Engagement in PCORI-Funded CER**
  - Background & rationale
  - Proposed approach
  - *Discussion*

Project Goals

- Conduct a review of the peer-reviewed literature associated with PCORI-funded CER to:
  - Identify and summarize the **contributions of engagement**
  - Compare the contributions of engagement identified in the literature against **PCORI's evaluation framework**
  - **Identify case examples** of the contributions of engagement in clinical CER

What Does Engagement in Research Lead to?



Predictors ***Intermediate Outcomes*** ***Long-term Outcomes***

Reviews Reveal Evidence Gaps for Impact of Engagement, Best Practices, and Measurement Tools

Patient engagement in research: a systematic review

Juan Pablo Domecq[1,2,5], Gabriela Prutsky[1,2,5], Tarig Elraiyah[1,5], Zhen Wang[1,5,6], Mohammed Nabhan[1,5], Nathan Shippee[1,5,6], Juan Pablo Brito[1,4,5], Kasey Boehmer[1,5], Rim Hasan[1,5,8], Belal Firwana[1,5,8], Patricia Erwin[1,7], David Eton[1,5,6], Jeff Sloan[1,5,6], Victor Montori[1,2,4,5,6], Noor Asi[1,5], Abd Moain Abu Dabrh[1,5] and Mohammad Hassan Murad[1,3,5,6*]

A Systematic Review of Stakeholder Engagement in Comparative Effectiveness and Patient-Centered Outcomes Research

Thomas W. Concannon, Ph.D[1,2,3], Melissa Fuster, PhD[4], Tully Saunders, BS[5], Kamal Patel, M.P.H., M.B.A.[5], John B. Wong, M.D[2,3,5], Laurel K. Leslie, M.D, M.P.H[2,3,5], and Joseph Lau, M.D[6]

A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities

Jo Brett · Sophie Staniszewska · Carole Mockford · Sandra Herron-Marx · John Hughes · Colin Tysall · Rashida Suleman

A Systematic Review of Approaches for Engaging Patients for Research on Rare Diseases

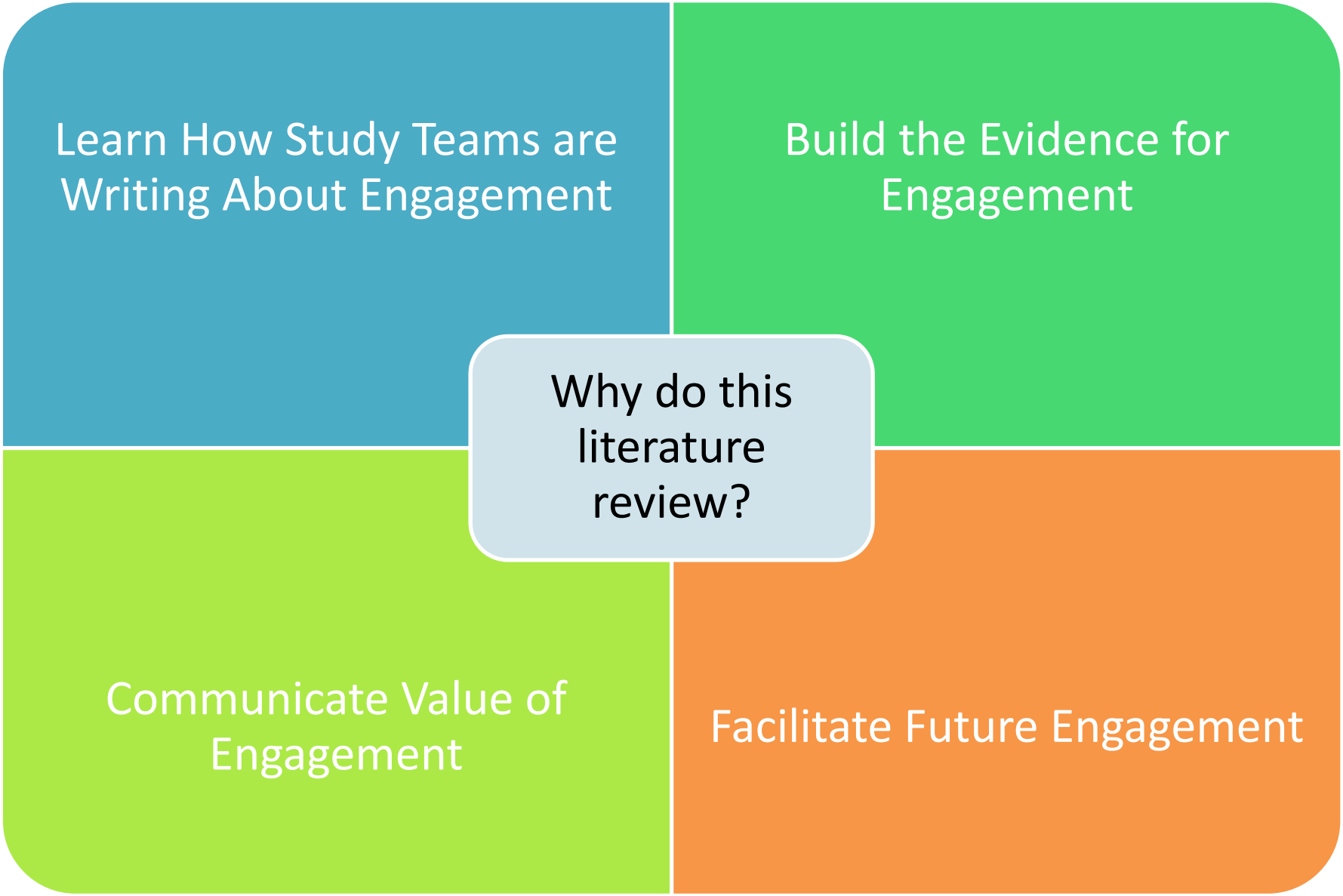
Laura P. Forsythe, PhD, MPH[1], Victoria Szydlowski, BS[1], Mohammad Hassan Murad, MD, MPH[2,3], Stanley Ip, MD[1], Zhen Wang, PhD[2], Tarig A. Elraiyah, MBBS[2], Rachael Fleurence, PhD[1], and David H. Hickam, MD, MPH[1]

Overarching Question of the Literature Review

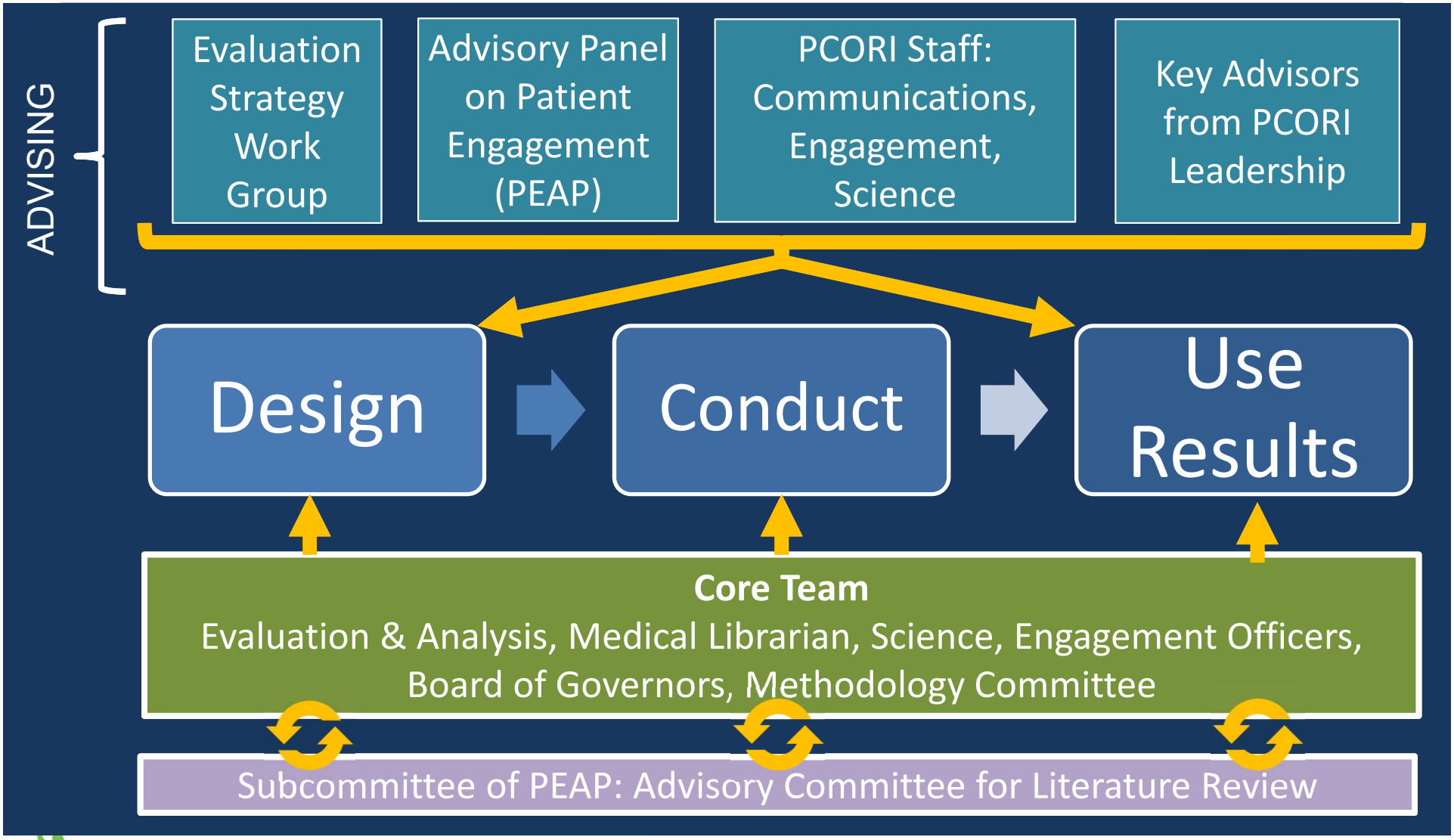
What are the contributions of engagement in PCORI-Funded CER?

What We Seek to Know

Primary	1. Contributions of engagement in PCORI-funded clinical CER studies to the: a) design & conduct of a clinical CER study b) influence on institutions, investigators, & partners to be more patient-centered c) usefulness & uptake of clinical CER findings
Secondary	2. Approaches to engagement that PCORI CER study teams use to achieve those contributions 3. Context (e.g., study design, PFA type, etc.) in which the contributions of engagement were achieved 4. How PCORI CER study teams assess the contributions of engagement


Learn How Study Teams are Writing About Engagement
Build the Evidence for Engagement
Why do this literature review?
Communicate Value of Engagement
Facilitate Future Engagement

Who is doing this project?



PEAP Advisory Committee Members

- John Chernesky
- Emily Creek
- Libby Hoy
- Anjum Khurshid
- Jane Perlmutter
- Phil Posner
- Ting Pun
- Brendaly Rodriguez
- Beverly Rogers
- Tom Scheid
- Ronnie Todaro

Plans for Collaboration

Four Teleconferences

1. Discuss and revise the research questions, methods, and analysis plans
2. Provide feedback on patterns in important information from the articles
3. Interpret the results of the literature review and determine what they mean for PCORI and those interested in PCOR
4. Identify and contribute to opportunities to share the findings

How will we pick the papers for this project?

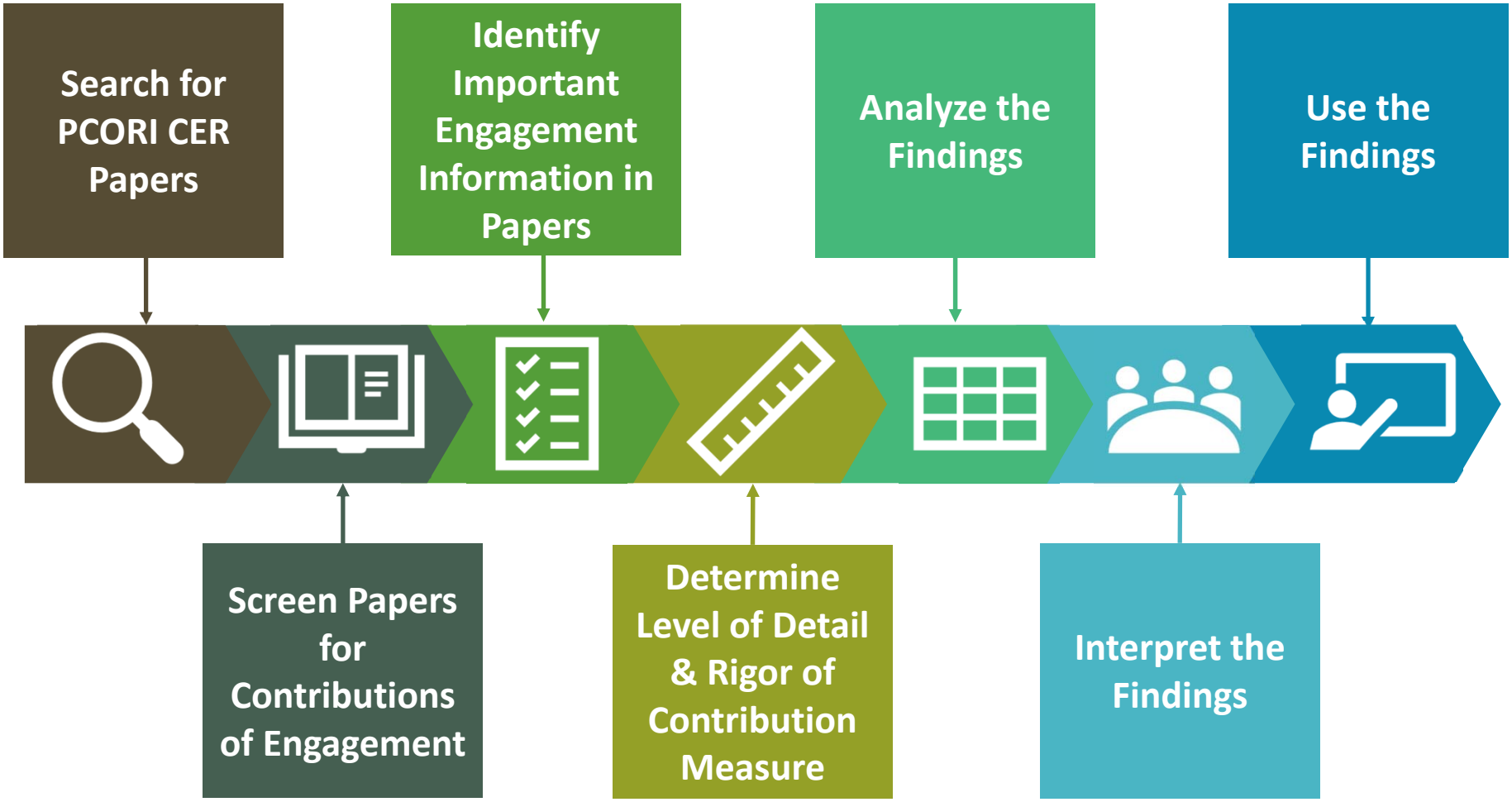
- Peer-reviewed publications
- Related to any PCORI project funded through the four CER national priorities (AD, APDTO, CDR, IHS)
- Must include information about the contributions of engagement
  - Not just descriptions of the approaches and/or the challenges of engagement and how they were overcome

Example

Engagement Approach	Engagement Contribution
"At yearly in-person meetings and monthly conference calls, community partners with direct experience as caregivers or providing services to Latino caregivers and care recipients, participated in brainstorming about intervention components. […] During study planning, team discussions addressed practical considerations of the intervention's frequency, length, and participant eligibility. "	"As a result, the intervention was reduced from 14 sessions to 8, frequency was increased to twice a month, and participant eligibility was broadened to include any Latina breast cancer survivors between the ages of 18–80, regardless of the time since diagnosis."

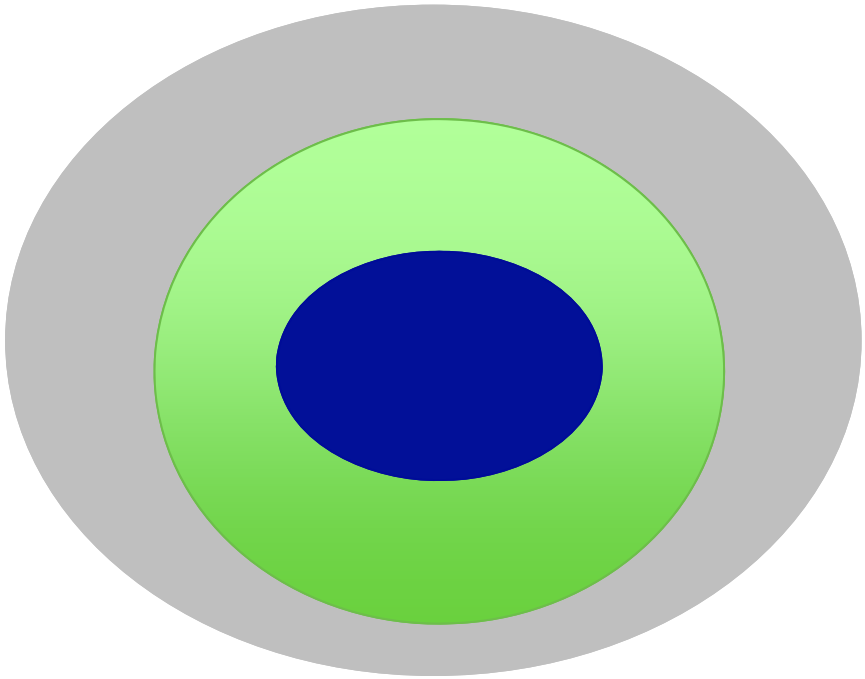
Quotations From:
Rush CL, Darling M, Elliott MG, et al. Engaging Latina Cancer Survivors, their Caregivers, and Community Partners in a Randomized Controlled Trial: Nueva Vida Intervention. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2015;24(5):1107-1118. doi:10.1007/s11136-014-0847-9.

Approach to Conducting the Literature Review



Looking Forward

All PCORI projects will have Final Research Reports



PCORI projects with publications reporting on contribution of engagement

Entire landscape publishing the contribution of engagement in research

Engaging Our PEAP

Discussion Questions:

- What can we capture in addition to answering the immediate question?
- What can we mark/time stamp to inform future comparative lit reviews?
- What new questions should we consider answering?

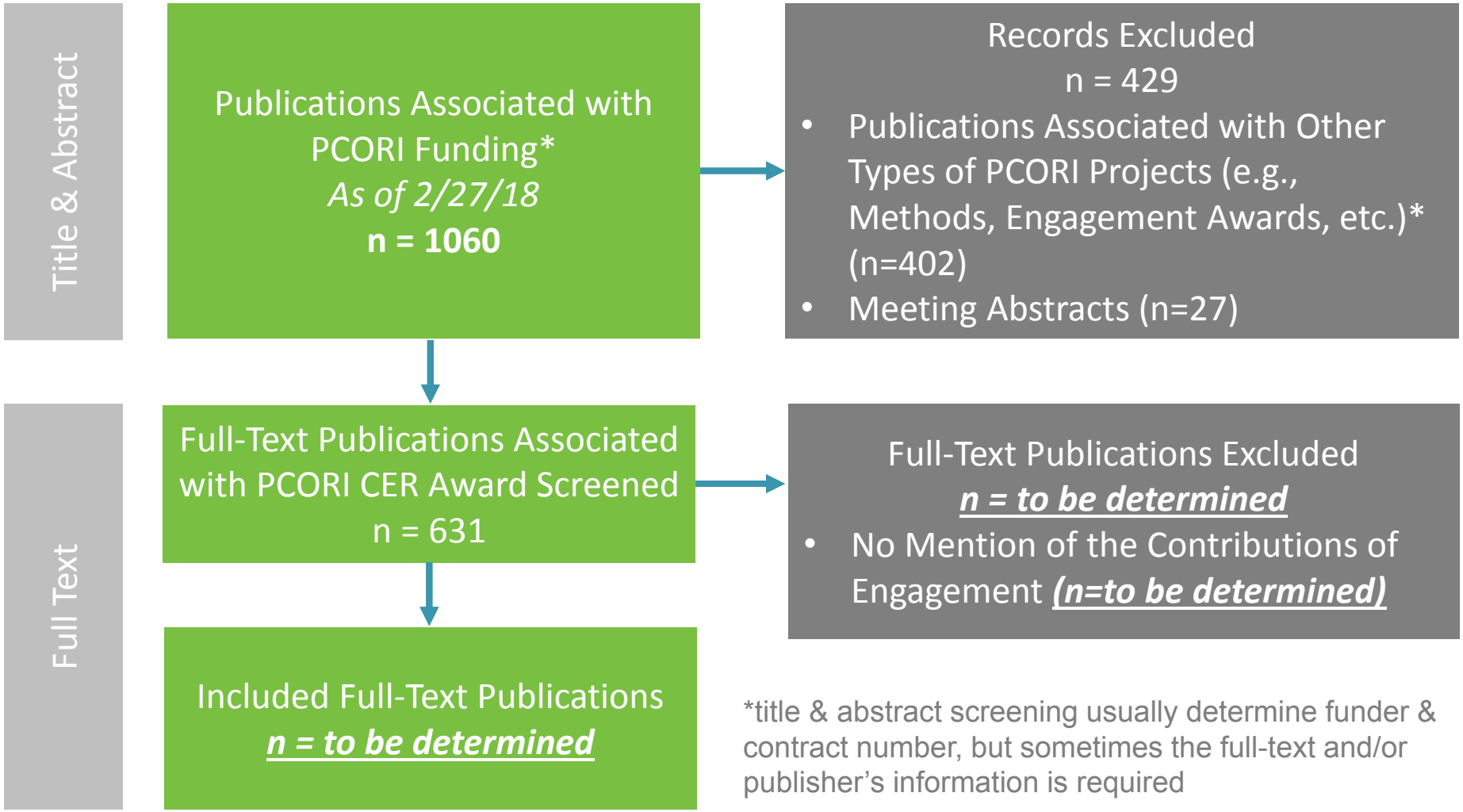
Appendix – Proposed Methods

Literature Searching

PCORI's Medical Librarian developed and maintains a search to identify all publications associated with PCORI-funding

Sources
• **Databases**: PubMed, EBSCO, Web of Science • **Hand-searching**: SalesForce publication submissions, Interim Progress Reports, Email, Google alerts, Google scholar • **Citation Lists**: Publications citing PCORI Methodology Standards

Study Selection Flow Diagram



*title & abstract screening usually determine funder & contract number, but sometimes the full-text and/or publisher's information is required

Screening – an Iterative Approach

- Our inclusion criteria require full-text screenings of publications associated with PCORI CER awards (n=631 papers)

- 50 papers will be screened in duplicate
  - Discuss screening results & experience, differences will be reconciled & 3rd person will be consulted for difficult decisions

- Remining papers (581) screened in duplicate
  - Differences will be reconciled & 3rd person will be consulted for difficult decisions

Extraction- an Iterative Approach

- Develop extraction fields from research question, reporting guidelines for engagement (GRIPP2), and other PCORI engagement data collection efforts

- Phase I ("exploratory")
  - 25% of included publications will be extracted in duplicate
  - Discuss extraction results & experience
  - Develop protocol for phase II

- Phase II
  - Pending phase II protocol, potential revisions to phase I extraction
  - Remining publications (75%) will be extracted

Quality Assessment

- Components of quality & risk of bias in included publications:
  - Level of detail about engagement
  - Robustness of how author knows the relationship between approach and contribution of engagement

Analysis

- Apply qualitative analysis techniques to answer our research questions
- Descriptive findings
- Will develop analytic plan after:
  - finalizing research questions
  - consultation with experts
  - seeing the type of extracted information

Appendix –
Proposed Extraction Fields

Informed by GRIPP2-LF, Research Questions, and Other PCORI Efforts to Evaluate Engagement in Research

Extraction: CONTEXT

RQ3. What is the context (i.e., study design, study population, etc.) in which the contributions of engagement were achieved?

Context of Engagement	
Definition	Extract the definition of engagement used in the study and how it links to comparable studies
Aim	Extract the aim of the publication
CER Study Design	Extract the CER study design, ex: RCT, observational, etc.
CER Study Condition	Extract the CER study condition, ex: cancer, depression, etc.
CER Study Population	Extract the CER study population, ex: older adult, pediatric, etc.
CER Study Sites	Extract how many CER study sites there are: single, multi, etc.
Reflection/ Critical Perspective	Extract any critical commentary on the engagement in the study that reflects on the things that went well and those that did not, so that others can learn

Extraction: Contributions

RQ1. What are the contributions of engagement in PCORI-funded clinical CER studies to the: a.) design & conduct of a clinical CER study?, b.) influence on institutions, investigators, & partners to be more patient-centered?, and c.) usefulness & uptake of clinical CER findings?

Contributions of Engagement	
Contributions of Engagement on Study Design and Conduct	Extract the positive and negative contributions that engagement has had on the design & conduct of research, specifically: • research topic and research questions • Etc.
Contributions of Engagement on Institutions, Investigators, & Partners to be more Patient-Centered	Extract the influence of engagement on others: • influence on investigators • influence on partners • influence on awardee institutions
Contributions of Engagement on Usefulness & Uptake of CER findings	Extract the positive and negative contributions that engagement has had on the usefulness & uptake of CER findings, specifically: • credibility of study findings • usefulness of information • Etc.

Extraction: APPROACHES

RQ2. What approaches to engagement do PCORI CER study teams use to achieve those contributions?

Approaches of Engagement	
When	Extract the stages at which the engagement occurred (research topic/agenda, study comparators/content, etc.)
Who	Extract the types of partners engaged (patient, caregiver, clinician, etc.)
Number	Extract the number of engaged partners
Mechanism	Extract the mechanism for engagement (co-investigator, advisory panel, survey, focus group, etc.)
Schedule & Logistics	Extract the schedule and logistics used for the engagement, specifically: • schedule & duration • location (virtual, in-person, single v multi site)
PCOR Principles	What/ how were the PCOR Principles used? • How were roles & expectations established? • What were the interpersonal dynamics?
Partner activities	Extract partner activities (generate, confirm, share, do, lead, etc.)
Researcher activities	Extract researcher activities (implementing, re-framing, etc.)

Extraction: Measure of Contributions

RQ4. How do PCORI CER study teams assess the contributions of engagement?

Measurement of Contributions	
Qualitative, quantitative, or other type of evidence of contribution	Extract methods used to qualitatively explore, quantitatively measure, or some other type of effort to assess the contribution of engagement. Examples include: • Self-reflection by researcher and/or engaged partner • Direct implementation of partner recommendations • Researcher belief that direct implementation of partner recommendations has an additional distal effect • Systematic measurement
Robustness of measure	Assess the rigor of the method used to capture or measure the contribution of engagement.

Lunch

We will resume at 12:45 PM ET

PCORI Research Portfolio Data Mining to Inform the Practice of Engagement in Research

Maureen Maurer, MPH

Principal Researcher, American Institutes for Research

mmaurer@air.org

Advisory Panel on Patient Engagement Spring 2018 Meeting

April 19, 2018

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Our time today

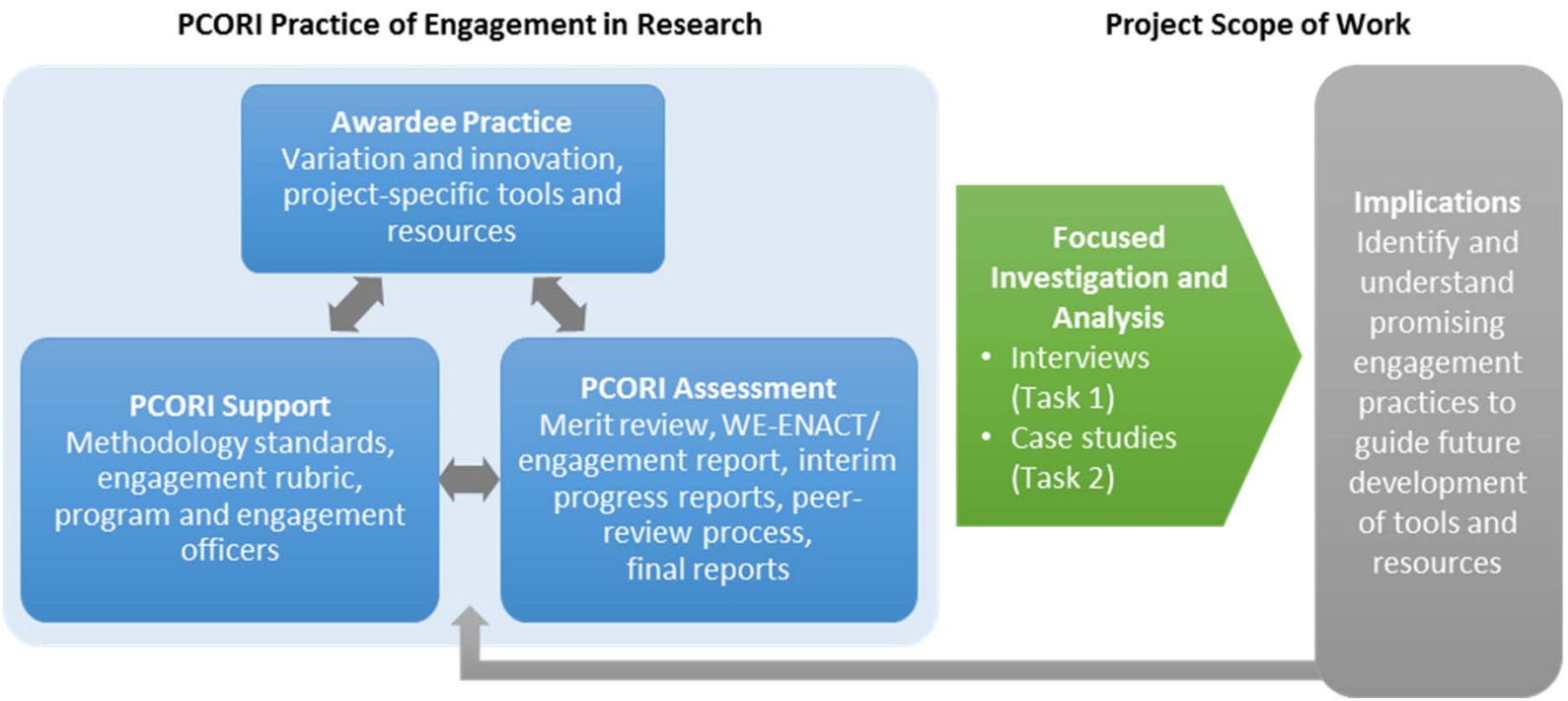
- Project purpose and overview
- Need your input
- Next steps

Project Purpose and Overview

Background

- Evidence about the value of engagement in research needs to grow
- Engagement in research = meaningful involvement of patients, caregivers, clinicians, and other stakeholders throughout the research process
- Need to understand
  - What strategies work best and for whom at different stages of research
  - Conditions affecting implementation
  - Impact of different strategies on quality of the study

Project Overview



Project Purpose

- To explore how engagement changes the course of PCORI-funded studies and the perceived influence of those changes
- To understand how successful engagement has been achieved in PCORI-funded studies

Task 1: Interviews with Principal Investigator (PIs) and Partners

- Sample 60 projects
- Conduct up to 120 interviews: Up to 1 interview with PI/research team member and 1 interview with partner
- Purpose = Understand the influence of engagement
- Results = Summary of findings along with recommendations for ongoing evaluation efforts

Task 2: Case Studies of 30 Projects

- 3-4 interviews with key team members, including PIs and partners, for 30 projects
- Purpose = Explore how and context in which successful engagement is achieved
- Results will inform
  - Guidance for awardees and prospective awardees
  - Guidance for program and engagement officers
  - Updates to PCORI engagement rubric
  - Updates to PCORI engagement assessment tools

Currently Working on Task 1

Completed

- Drafted conceptual framework for project
- Identified criteria for sampling

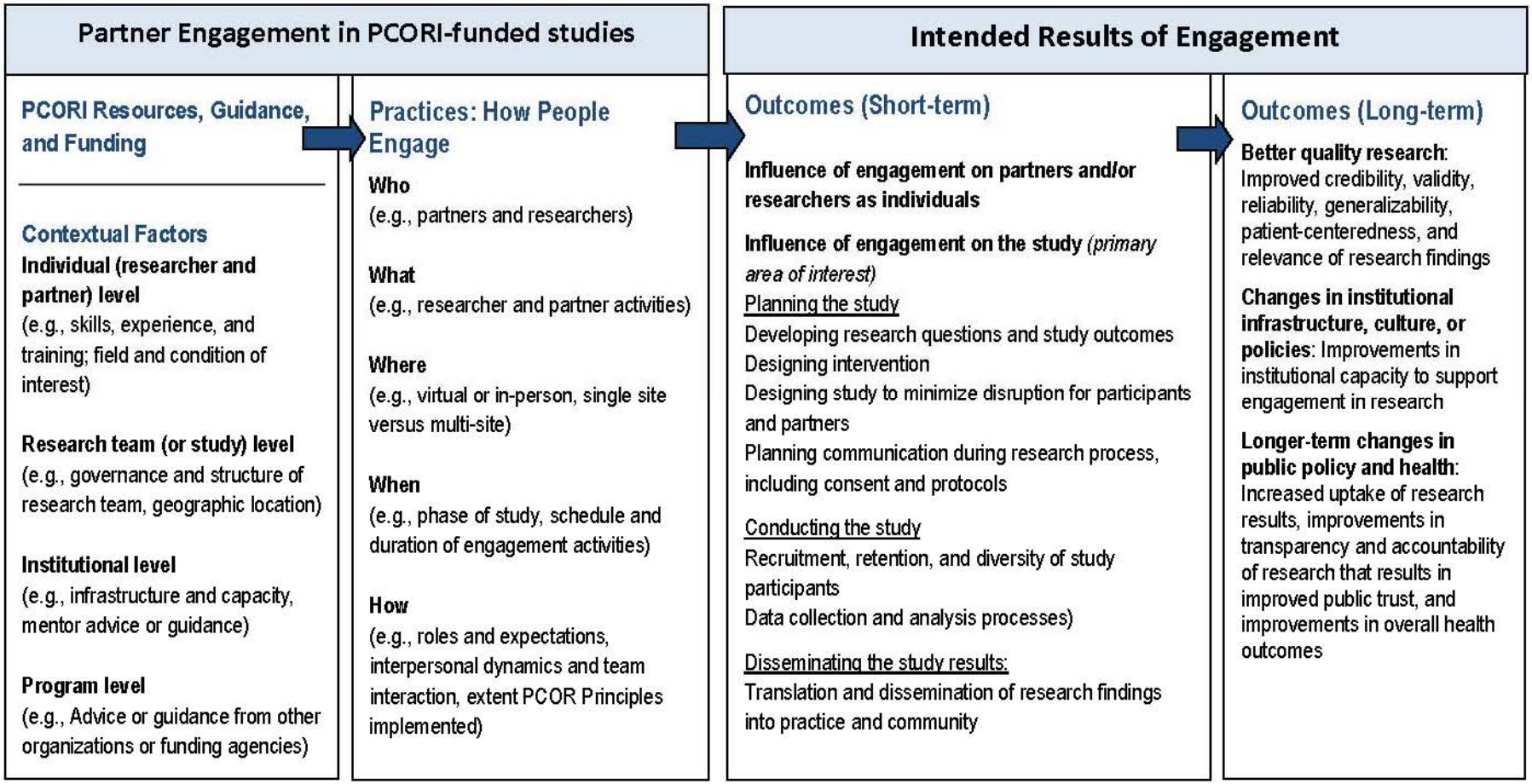
In process

- Finalizing sample
- Reviewing previous data collected by PCORI to create project profiles for projects in the sample
- Drafting interview protocols for the PI and partner interviews – talk about today

Next steps

- Interviews to start in June 2018, analysis to end in early 2019

Working Conceptual Framework



Finalizing Sample of 60 Projects

- Eligibility criteria
  - Funding announcement: broad, pragmatic, targeted
  - Priority areas: 4, not advancing methods
  - Started on or prior to December 31, 2016, could be completed or in progress
- Selected projects
  - Engagement had influence, indicated by PI reports and presence of partner data
  - Mix of health condition, population, study design

Need Your Input

Interview Protocols

Feedback on PI Interview Protocol

- What reactions do you have? If you were being asked these questions, would you be able to respond?
- Will the information elicited from the interview protocol help us answer the task's research questions?
- Are there any concepts missing from the guide that would be important to include? Any concepts that could be deleted?
- Which questions, if any, should be asked of all participants?
- What should interviewers keep in mind as they conduct the interviews?
- What can we do to make PIs feel comfortable sharing honest views on engagement?
- Anything else that is important for us to know?

Input for the Partner Interview Protocol Under Development

- Considering the PI interview protocol, which topics are most important to ask partners about? Are there other topics that we should consider for the partner interview protocol?
- Are there any topics that we should not include in the partner interview protocol? If so, why not?
- What suggestions do you have for asking partners about the PCOR engagement principles (i.e., reciprocal relationships, co-learning, partnership, and trust, transparency, and honesty)?
- What can we do to make partners feel comfortable sharing negative views on engagement?
- Are there particular things that we should consider when reaching out to partners for participation in interviews?
- Anything else that is important for us to know?

Need Your Input

Defining Successful Engagement

Defining Successful Engagement

Why?

- Defining and explaining successful engagement is a key part of the study
- Use input from interviews and PEAP to inform analysis of interviews and to select cases for the second task

Mind map activity

- **How would you describe successful engagement?**
- Write down any thoughts, feelings, or pictures that come to mind when you think of successful patient and other stakeholder engagement in research

Next Steps

- Finalize protocols
- Conduct and analyze interviews for Task 1
- Determine sampling approach for Task 2 case studies, including how to identify successful and unsuccessful cases

Thank You!

Maureen Maurer

Principal Researcher, American Institutes for Research

mmaurer@air.org

Overview of Working Committees

- Merit Review Mentor Program
- Ambassadors Program Redesign
- Engagement Rubric 2.0

Advisory Panel on Patient Engagement Spring 2018 Meeting
April 19, 2018

Merit Review Mentor Program Working Committee Update

Whitney McInvale, MPH – PCORI Working Committee Co-chair
Jane Perlmutter, PhD, MBA – Working Committee Co-Chair
Phil Posner, PhD – Working Committee Member

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April 19, 2018

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Goals

- Help identify the necessary components of a successful Mentor Program
- Provide guidance on a well-conceived program structure
- Inform the development of Mentor training support
- Identify effective evaluation methods of Mentor Performance

Results

Recommendations:

- Mentor training structure and support
- Evaluation for Mentor performance each Merit Review cycle.

Outcomes:

- Mentor Program structure successfully serves new reviewers and meets the needs of Merit Review Officers as outlined in the Scope of Work.
- Contractor support in process for a comprehensive environmental scan and lit review on peer-to-peer mentoring training in a research reviewing body.
- Preliminary meeting to begin Mentor Onboarding Toolkit design.
- Reviewer evaluation of Mentor Program successfully launched after Cycle 2 2017 Merit Review In-Person Meeting.

Questions?

Ambassador Working Committee

Krista Woodward, MPH, MSW (PCORI Co-Chair)
Senior Program Associate

Chinenye Anyanwu, PharmD, MPH (PCORI Co-Chair)
Engagement Officer

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April 19, 2018

Where We've Been...

- Working Committee formation and tasks:
  - Inform the re-design of the PCORI Ambassador program by providing guidance as well as identifying necessary components of an efficient program
  - Ensure better alignment with current PCORI priorities and Ambassadors' interests
  - Clearly define the role of an Ambassador and enhance tools/resources for Ambassadors

- Sonya Ballentine
- Jimmy Lin, MD, PhD, MA
- Philip Posner, PhD
- Ting Pun, PhD
- Thomas Scheid, MA
- Norah Schwartz, MPA, PhD
- Sara van Geertruyden, JD
- Jack Westfall, MD, PhD
- David White

Always looking for new members...

Where We Are Now…

- **Mission:** To engage health care stakeholders in strengthening the patient-centered outcomes research (PCOR) community while increasing the reach and influence of PCORI-funded research.

- **Vision:** Ambassadors would be knowledgeable and activated agents responsible for "spreading the word" about PCORI and PCOR through their networks. Ambassadors would advance PCORI's mission and vision by engaging in PCOR as research partners, supporting dissemination, and conducting outreach activities in their respective communities.

- **Objectives for Ambassadors:**
  - Community-based promotion and sharing of PCOR "promising practices", PCORI-funded research results, and products within their networks,
  - Activate local communities or networks to engage with and promote PCORI research,
  - Act as a diverse body of stakeholders for potential partnership in research activities, including but not limited to, merit review, peer review, or research and/or engagement awards (e.g. planning, conducting, disseminating)
  - Recruit and retain PCORI supporters across the health care landscape for Ambassador Program.

Where We're Going...

- Ambassador 2.0 prioritized activities:
  - Quarterly E-Newsletter Series ("The Ambassador")
  - Improved Ambassador Microsite for PCORI website
  - Enhanced Orientation Video and "Exam"
  - "Coffee Break" Ambassador Webinar Series
  - Community-Based Promotion & Knowledge Sharing Toolkit
  - Ambassador Speaker's Bureau
  - Annual Meeting Workshop: Community-based Promotion & Local Capacity Building Focus
  - Bimonthly program evaluation efforts

Questions?

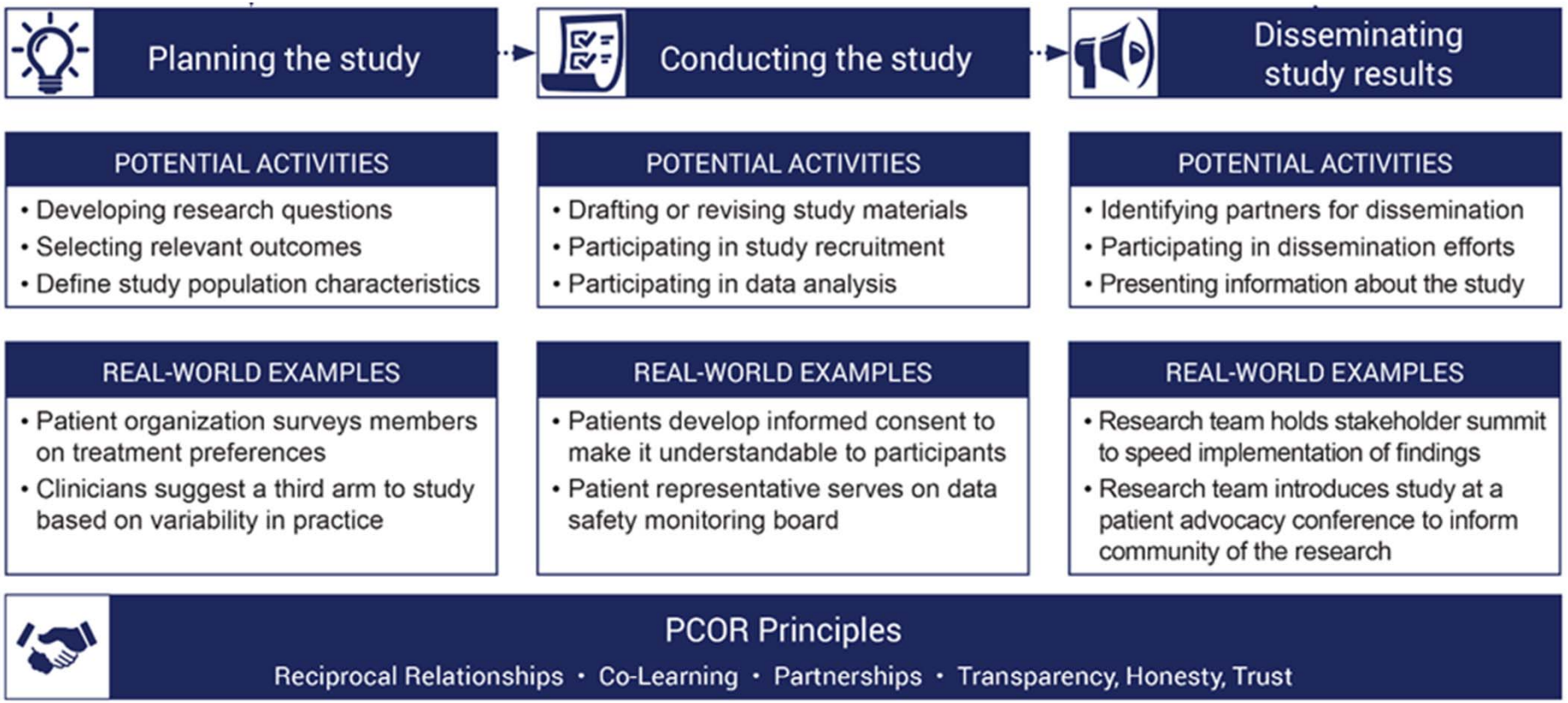
Engagement Rubric 2.0
Working Committee

Megan Lewis, PhD – Working Committee Co-chair

Lisa Stewart, MA – PCORI Working Committee Co-chair

Advisory Panel on Patient Engagement Spring 2018 Meeting
April 19, 2018

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

Where we've been...

- Working Committee role:

  To provide PCORI staff with recommendations that will inform the future revision of the Engagement Rubric. Recommendations will draw from practice-based experiences, learnings from PCORI's portfolio, and external sources

- Megan Lewis
- John Chernesky
- Emily Creek
- Suzanne Madison
- Mark Mishra
- Jane Perlmutter
- Ting Pun
- Brendaly Rodriquez
- Beverly Rogers
- Ronnie Todaro
- Jack Westfall
- David White

…and a host of staff contributors

CA4

Where we are now...

- Repository of articles on engagement and partnership building
- Access to data from the Pipeline to Proposal program and PCORI Pre-Engagement Workshop (Annual Meeting, 2016)
- Synthesis of our reactions to the literature and our own experiences with partnership building

Slide 145

CA4 all good!

Chinenye Anyanwu, 4/12/2018

Where we're going today...

- Today's activities:
  - Discuss our working definition of "pre-engagement"
  - Get reactions to a "straw" conceptual model
  - Identify activities that support relationship building

Next step – Prepare a set of recommendations to submit to PCORI staff

Questions?

Break/Transition to Breakout Sessions

Day 1 Meeting Adjourned

The Working Committees will meet from 3:30 – 5:00 PM