Advisory Panel on Patient Engagement

Winter 2019 Meeting
Day Two: January 25, 2019
9am – 1pm ET

United States (Toll-free): 1 877 568 4108
United States: +1 (213) 929-4221
Access Code: 585-824-142

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome

Kristin Carman
Director, Public & Patient Engagement

David White
Chair, Advisory Panel on Patient Engagement

Thomas Scheid
Co-chair, Advisory Panel on Patient Engagement

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Agenda

Time	Title
9:00 am	Welcome
9:15 am	PCORI Research Portfolio: Data Mining to Inform the Practice of Engagement in Research
11:30 am	Break
11:45 am	2019 Strategic Planning Session
12:45 pm	Reflections and Closing
1:00 pm	Adjourn

pcori

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

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Team members

AIR Team

- Rikki Mangrum, Deputy Project Director
- Tandrea Hilliard, Task 1 Lead
- Kirsten Firminger, Task 2 Lead
- Jessica Arnold, Project Manager
- Andrew Amolegbe
- Charis Yousefian
- Tamika Cowans
- Karen Frazier
- Marla Clayman
- Tom Workman
- Emily Elstad

PCORI Team

- Kristin L Carman
- Rachel Mosbacher
- Andrea Heckert
- Julie Kennedy Lesch,
- Laura Forsythe
- Krista Woodward
- Beth Nguyen

Our Time Today

- Project purpose and overview
- Activities completed to date
- Need your input –defining successful and worthwhile engagement
- Next steps

Project Purpose and Overview

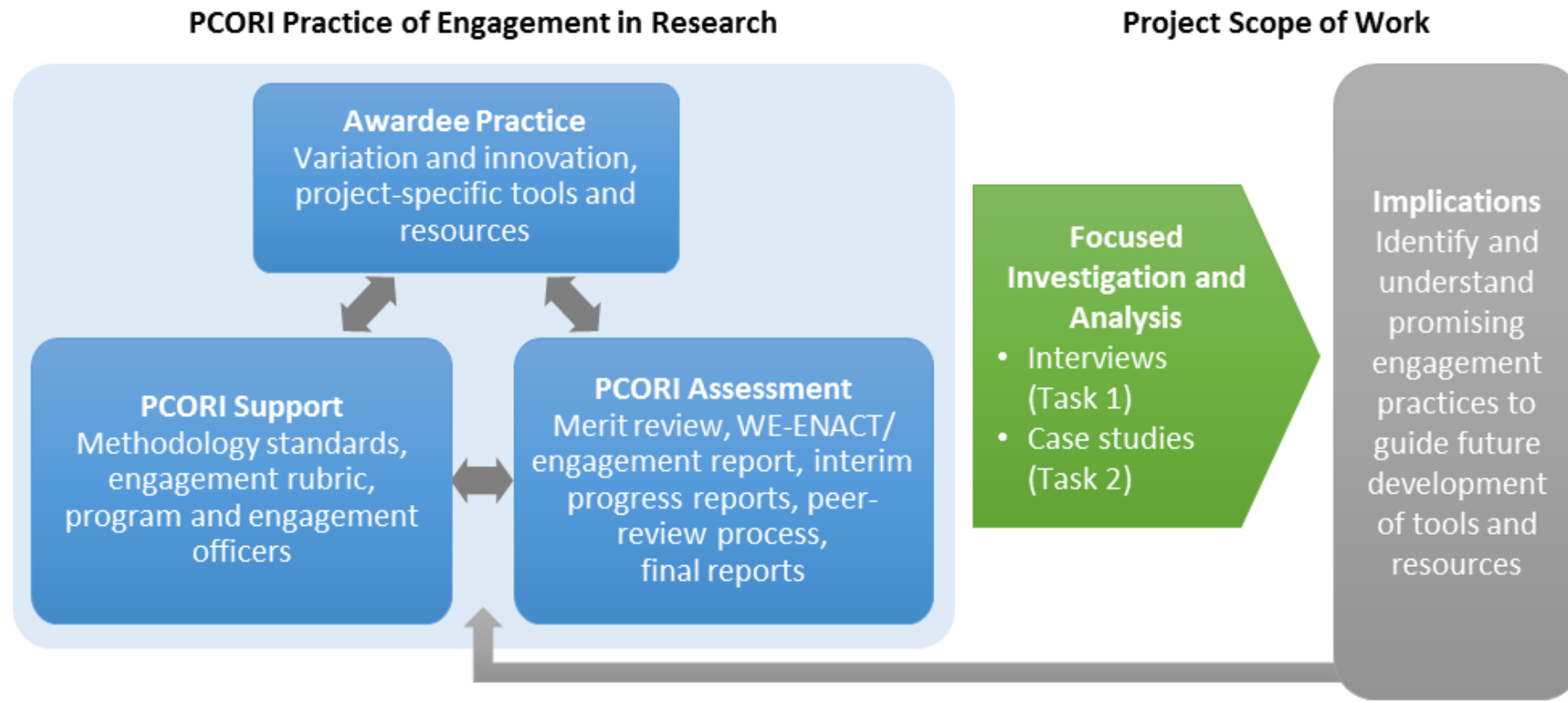# Project Rationale and Purpose

Rationale

- We need better, stronger, more robust evidence about the value of engagement in research

Purpose

- If patient and stakeholder engagement changes the course of PCORI-funded studies, how did that happen?

Project Overview

PCORI Practice of Engagement in Research

Awardee Practice
Variation and innovation, project-specific tools and resources

PCORI Support
Methodology standards, engagement rubric, program and engagement officers

PCORI Assessment
Merit review, WE-ENACT/ engagement report, interim progress reports, peer-review process, final reports

Project Scope of Work

Focused Investigation and Analysis
- Interviews (Task 1)
- Case studies (Task 2)

Implications
Identify and understand promising engagement practices to guide future development of tools and resources

Research Questions

Task 1: Interviews focus on influence (high performers)

- How has engagement influenced the planning and conduct of PCORI-funded studies and the dissemination of their results?

- What changes to the study results from that influence?

- How did PIs and partners perceive engagement as successful or unsuccessful?

Task 2: Case studies focus on practices (high & low performers)

- What are the steps needed for effective implementation of engagement practices?

- What are barriers and keys to success?

- What contextual factors influence engagement?

Currently Working On Task 1

Completed
- Drafted conceptual framework for project
- Identified criteria for sampling and finalized sample
- Revised research questions -thank you!
- Drafted interview protocols with input from PEAP- thank you!
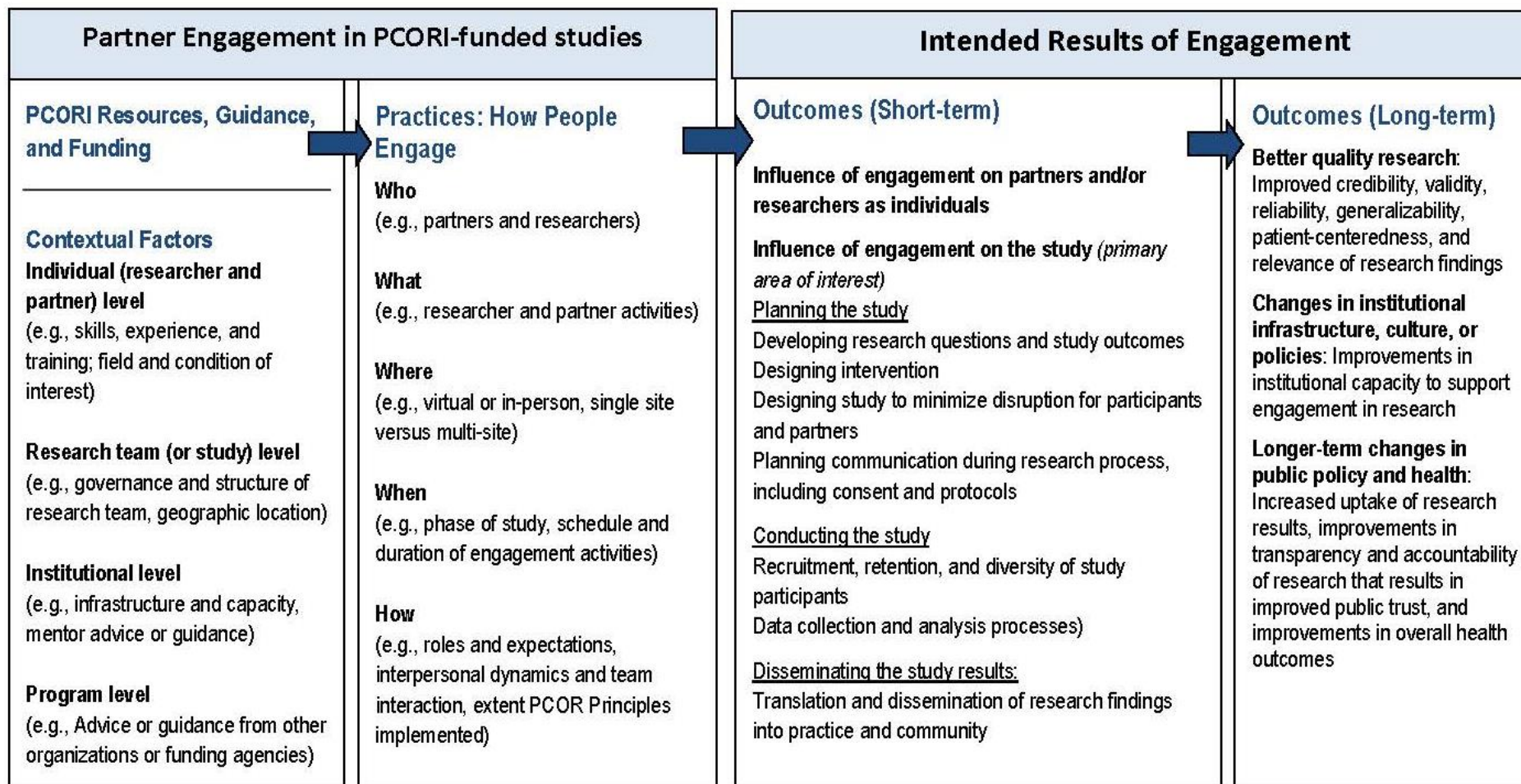- Conducted 58 interviews with PIs and 46 interviews with partners

In process
- Completing partner interviews – 5 scheduled
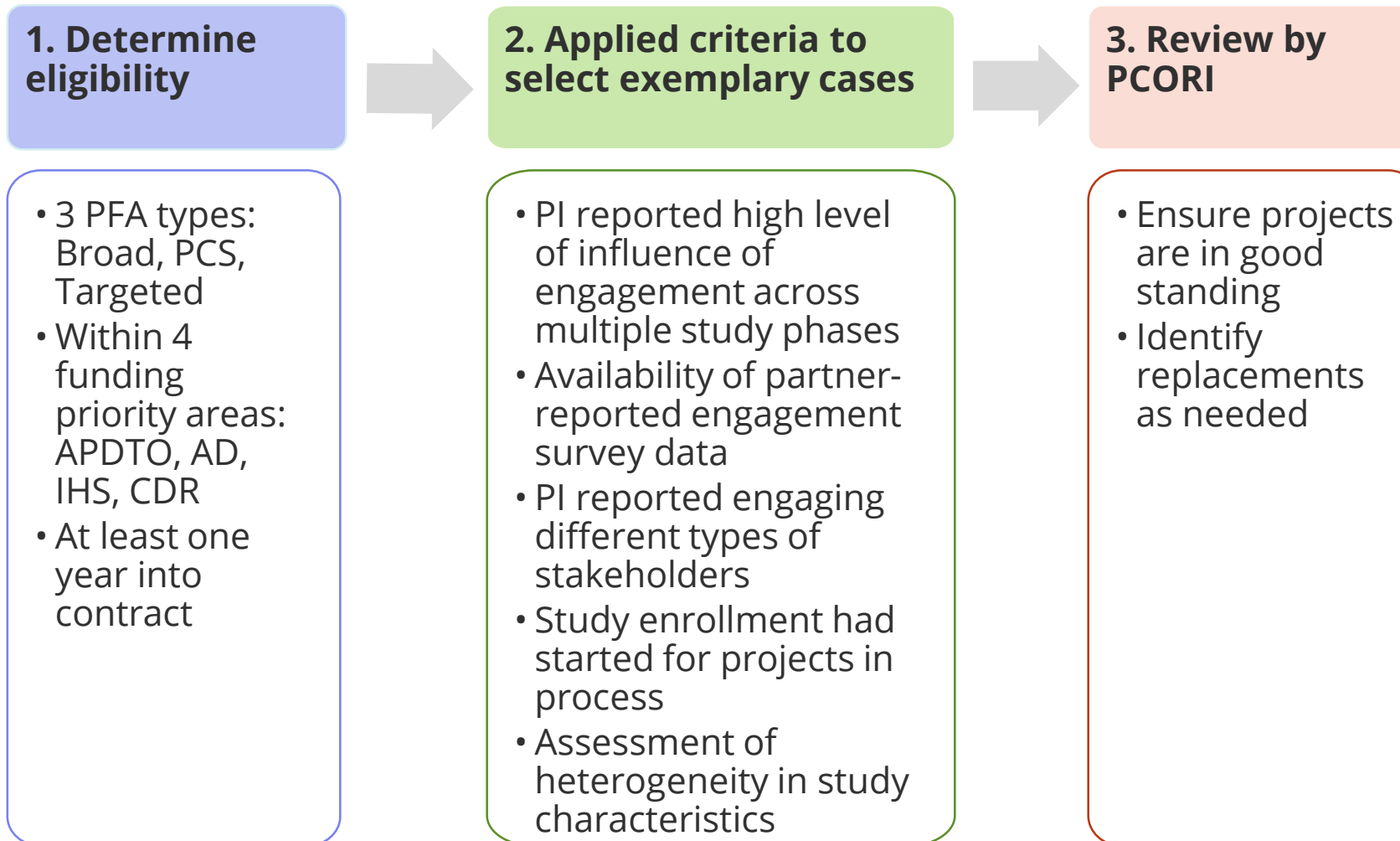- Completing coding and analysis of qualitative data – Need your input!

Next steps
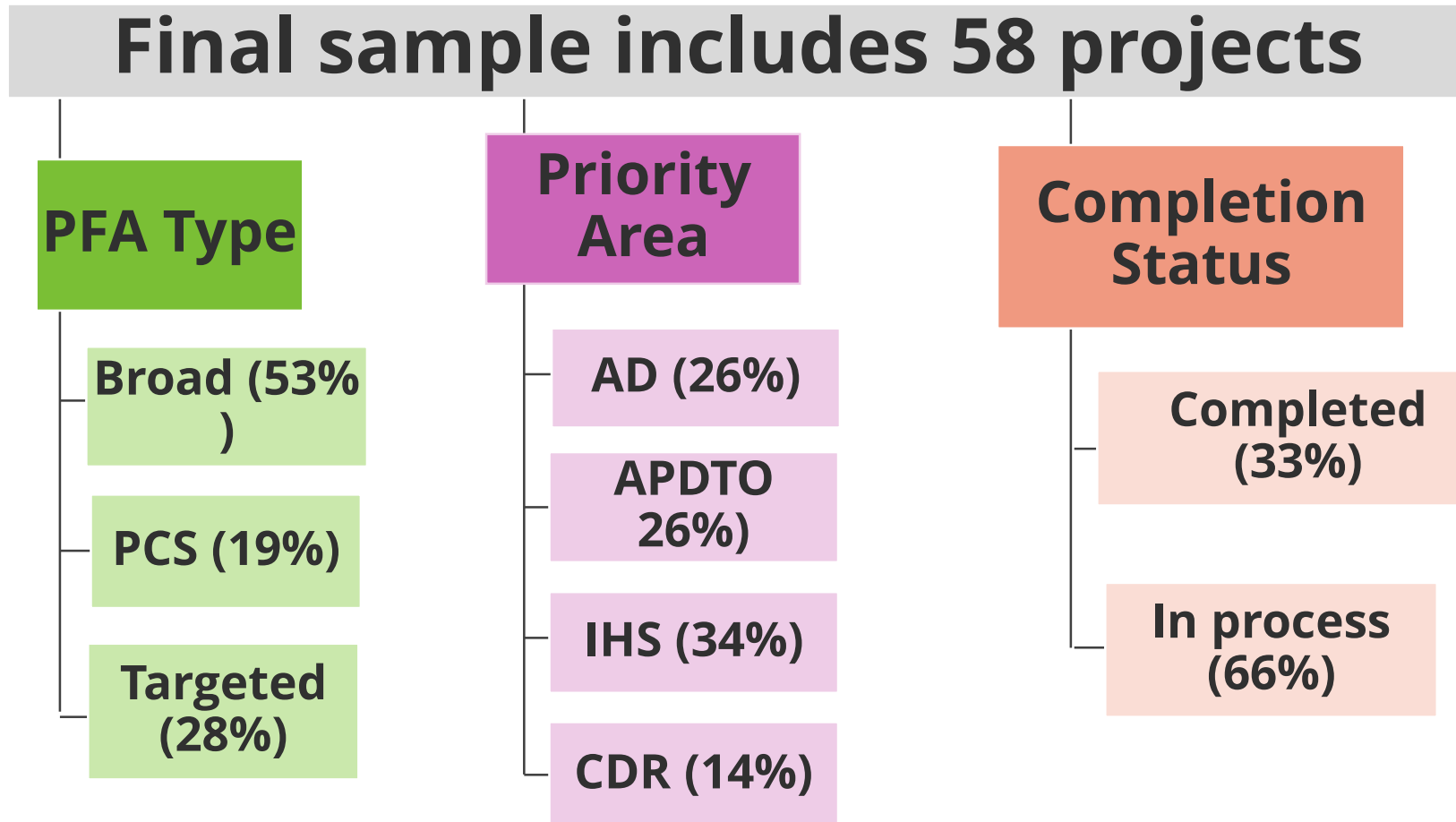- Analysis and reporting through March / April 2019

Conceptual Framework To Guide Interviews

Partner Engagement in PCORI-funded studies		Intended Results of Engagement	
PCORI Resources, Guidance, and Funding ──────────── **Contextual Factors** **Individual (researcher and partner) level** (e.g., skills, experience, and training; field and condition of interest) **Research team (or study) level** (e.g., governance and structure of research team, geographic location) **Institutional level** (e.g., infrastructure and capacity, mentor advice or guidance) **Program level** (e.g., Advice or guidance from other organizations or funding agencies)	**Practices: How People Engage** **Who** (e.g., partners and researchers) **What** (e.g., researcher and partner activities) **Where** (e.g., virtual or in-person, single site versus multi-site) **When** (e.g., phase of study, schedule and duration of engagement activities) **How** (e.g., roles and expectations, interpersonal dynamics and team interaction, extent PCOR Principles implemented)	**Outcomes (Short-term)** Influence of engagement on partners and/or researchers as individuals Influence of engagement on the study (*primary area of interest*) <u>Planning the study</u> Developing research questions and study outcomes Designing intervention Designing study to minimize disruption for participants and partners Planning communication during research process, including consent and protocols <u>Conducting the study</u> Recruitment, retention, and diversity of study participants Data collection and analysis processes) <u>Disseminating the study results:</u> Translation and dissemination of research findings into practice and community	**Outcomes (Long-term)** **Better quality research**: Improved credibility, validity, reliability, generalizability, patient-centeredness, and relevance of research findings **Changes in institutional infrastructure, culture, or policies**: Improvements in institutional capacity to support engagement in research **Longer-term changes in public policy and health**: Increased uptake of research results, improvements in transparency and accountability of research that results in improved public trust, and improvements in overall health outcomes

Sample Strategy

1. Determine eligibility

- 3 PFA types: Broad, PCS, Targeted
- Within 4 funding priority areas: APDTO, AD, IHS, CDR
- At least one year into contract

2. Applied criteria to select exemplary cases

- PI reported high level of influence of engagement across multiple study phases
- Availability of partner-reported engagement survey data
- PI reported engaging different types of stakeholders
- Study enrollment had started for projects in process
- Assessment of heterogeneity in study characteristics

3. Review by PCORI

- Ensure projects are in good standing
- Identify replacements as needed

Final Sample Description

Final sample includes 58 projects

PFA Type

- Broad (53%)
- PCS (19%)
- Targeted (28%)

Priority Area

- AD (26%)
- APDTO 26%)
- IHS (34%)
- CDR (14%)

Completion Status

- Completed (33%)
- In process (66%)

Interview Approach

- Create **project profiles** to summarize previous information collected by PCORI (e.g., final research report, progress report)
  - *Ensure we are well versed on the project's history and background and are able to take full advantage of the time with the PI/partner*
- Use **semi-structured interview protocols** for PIs and partners
  - *We know we need to go into depth on detailed information and get a richer explanation than we have gotten through prior data collection*
- Incorporate a **modified critical-incident technique approach**
  - *To better understand the work done at key points and elicit effective and ineffective behaviors and processes within an activity*
- Use an **iterative process** for conduct of interviews and analysis

Qualitative Analytic Approach

- Iterative process that includes
  - Deductive and automatic coding
  - Open and axial coding
  - Synthesizing patterns across interviews
  - Discussing findings among team members
  - Summarizing themes related to research questions and the conceptual framework

Defining Successful and Worthwhile Engagement

Need Your Input!

Defining Successful and Worthwhile Engagement

pcori

Why?

- Defining and explaining these concepts 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

- Write down any thoughts, feelings, or pictures that come to mind when you think of…
- Groups 1, 2, and 3 start with –successful engagement in a PCORI research study
- Groups 4, 5 start with –worthwhile engagement in a PCORI research study

Categorizing Types Of Influence

Category	Description	Example
Limited or no influence	No influence on plans, approaches, materials, or processes; No changes articulate	Study used existing data, stakeholders could not alter study outcomes
Confirming influence	Stakeholders review, confirm, or validate existing plans, approaches, materials, or process	Stakeholders agree with proposed study outcomes
Refining influence	Stakeholders edit or modify existing plans, approaches, materials, or processes	Stakeholders suggest tweaks to study outcomes
Redirecting influence	Stakeholders shift the direction of or create new plans, approaches, materials, or processes	Stakeholders question the study outcomes and suggest new ones
Co-producing influence	Stakeholders and researchers work together or collaborate ; Difficulty articulating changes because work evolved together	Stakeholders collaborate with researchers to select outcomes for the study

Next Steps

- Complete data collection and analysis
- Draft final report and manuscript
- 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

BREAK

We will return at approximately 11:45am EST

Reflections & Closing Remarks

Kristin Carman
Director, Public & Patient Engagement

David White
Chair, Advisory Panel on Patient Engagement

Thomas Scheid
Co-chair, Advisory Panel on Patient Engagement

Upcoming Dates

- Advisory Panel applications due: March 29th

- PEAP In-Person Meeting: June 27th & 28th

- PCORI Annual Meeting: September 18th – 20th

ADJOURN