

# PCORI ADVISORY PANEL ON PATIENT ENGAGEMENT

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*Winter 2020 Meeting*  
Day 1

January 30, 2020

8:30am-4:30pm ET

# Webinar Housekeeping



- Webinar is available to the public and is being recorded
- Members of the public are invited to listen to this teleconference and view the webinar
- Anyone may submit a comment through the webinar chat function, although 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](http://www.pcori.org/events) for more information on future activities

# Welcome

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# Panel Leadership



- Thomas Scheid, Chair, Advisory Panel on Patient Engagement
- Gwen Darien, Co-Chair, Advisory Panel on Patient Engagement
- Kristin Carman, Director, Public and Patient Engagement

# PEAP Advisory Panel Members



- **Tom Scheid – Chair**  
*Patient Advocate*
- **Gwen Darien – Co-Chair**  
*National Patient Advocate Foundation*
- **Jennifer Canvasser**  
*Necrotizing Enterocolitis Society*
- **Katherine Capperella**  
*Johnson & Johnson*
- **Anita Roach**  
*Food Allergy Research and Education*
- **Jill Harrison**  
*Brown University*
- **Beverly Rogers\***  
*Bev J Rogers Enterprises, LLC*
- **Matthew Hudson**  
*Prisma Health–Upstate*
- **Freddie White-Johnson**  
*University of Southern Mississippi*
- **Sonya Ballentine**  
*Illinois Institute of Technology College of Psychology*
- **Marilyn Geller**  
*Celiac Disease Foundation*
- **Sarah Donelson**  
*Aimmune Therapeutics*
- **Maureen Fagan**  
*University of Miami Health System*
- **Umair A. Shah**  
*Harris County Public Health*

# PEAP Advisory Panel Members



- **Brendaly Rodríguez**  
*University of Miami and FL Community Health Worker Coalition*
- **James Harrison**  
*University of California San Francisco*
- **Sandy Sufian\***  
*University of Illinois at Chicago, College of Medicine*
- **Norah Schwartz**  
*El Colegio de la Frontera Norte*
- **Beth Careyva**  
*Lehigh Valley Hospital, Inc.*
- **Tracy Carney**  
*University of Pittsburgh Medical Center*
- **Simon Mathews**  
*Johns Hopkins Medicine*
- **Danny van Leeuwen**  
*Health Hats*
- **Neely Williams**  
*Community Partners' Network, Inc.*
- **Crispin Goytia-Vasquez**  
*Icahn School of Medicine at Mount Sinai*

*\*Attending virtually*

# Ten More Years!



# Thank You!



...To the **Advisory Panel**  
on Patient Engagement  
and all PCORI  
supporters!



## Senate Champions



Mark Warner (D-VA)



Bill Cassidy (R-LA)



Diana DeGette (D-CO)



Don Beyer (D-VA)



Chris Van Hollen (D-MD)



Shelly Moore Capito (R-WV)



# Josie Briggs, MD

Interim Executive Director & Acting Chief Science Officer



- Among many things, I am:
  - A nephrologist and health sciences researcher
  - For nearly 20 years I was in leadership positions at the National Institutes of Health
  - Currently, Editor in Chief, *Journal of the American Society of Nephrology*

# Nakela Cook, MD, MPH, FACC

## PCORI's New Executive Director



**Nakela Cook, MD, MPH**  
*New PCORI Executive Director*

- Cardiologist with a long and distinguished career as a researcher and advocate for engaging patients, clinicians, and other stakeholders in key research initiatives
- We are excited to welcome her to PCORI on April 15th, 2020

# Agenda – Day One



## Morning

- 8:30 AM – Welcome & Introductions
- 9:15 AM – Reauthorization Update
- 9:45 AM – Ideas on Topic Generation Following Reauthorization
- 10:30 AM – Break
- 10:45 AM – Engagement: What We've Learned
- 11:45 AM – Eugene Washington PCORI Engagement Awards Update
- 12:15 PM – Lunch

# Agenda – Day One



## Afternoon

- 1 PM – Input on Developing a Taxonomy for Patient Driven Research Communities
- 2:15PM – Break
- 2:30PM – Communications Update: Website and Annual Meeting
- 3:30PM– Special Projects and Workgroups: Opportunities for Involvement
- 4:30PM – Closing Remarks/Adjourn

# Agenda – Day Two



- 9 AM – Welcome
- 9:15 AM – PEAP Spotlight – Brendaly Rodríguez
- 9:45 AM – Discussion: Diversity, Equity and Inclusion Principles
- 11:45 AM – Closing Remarks/Adjourn

# Introductions

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Advisory Panelists

# Reauthorization Update

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Josie Briggs

Interim Executive Director & Acting Chief Science Officer

Jean Slutsky

Chief Engagement and Dissemination Officer

# Features of PCORI's New Law



- 10-year extension
- Loss of Medicare Trust Fund transfer as a funding mechanism
- Increase of federal mandatory appropriations to compensate for the lost Medicare transfers
- Identifies intellectual and developmental disabilities and maternal mortality as research priorities
- Requires PCORI to balance long-term and short-term priorities when identifying research priorities
- Directs PCORI to collect economic data in the course of a study (i.e., burdens, economic impact, out-of-pocket costs, non-medical costs to patients, absenteeism)
- Increases private payer representation on the Board by 2 slots
- Shifts methodology committee appointment responsibility from the GAO to the Board
- Strengthens and formalizes PCORI's dissemination and implementation mandate
- Directs GAO to review any barriers to conducting research (e.g., cost of covering medical treatments) encountered by PCORI-funded researchers
- Directs GAO to analyze PCORI's dissemination program using a range of potential available data and performance metrics



# Questions?

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# Ideas on Topic Generation Following Reauthorization

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Jonathan Moore

Associate Director, Public & Patient Engagement

Greg Martin

Deputy Chief Engagement and Dissemination Officer

Kelly Dunham

Senior Manager, Strategic Initiatives, Office of the Chief Science Officer

# Discussion Outline



1. Topic Generation Prior to Reauthorization
2. Current Examination of Topic Generation
3. New Ideas on Topic Generation
4. Group Discussion

**Goal:** Hear from you all about how PCORI can evolve to better engage the stakeholders you represent following reauthorization.

# Topic Generation Prior to Reauthorization

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# Our National Priorities for Research



- 1. Assessment of Prevention, Diagnosis, and Treatment Options**
- 2. Improving Healthcare Systems**
- 3. Communication and Dissemination Research**
- 4. Addressing Disparities**
- 5. Accelerating Patient-Centered Outcomes Research and Methodological Research**

# Snapshot of Funded Projects

## Number of funded awards:

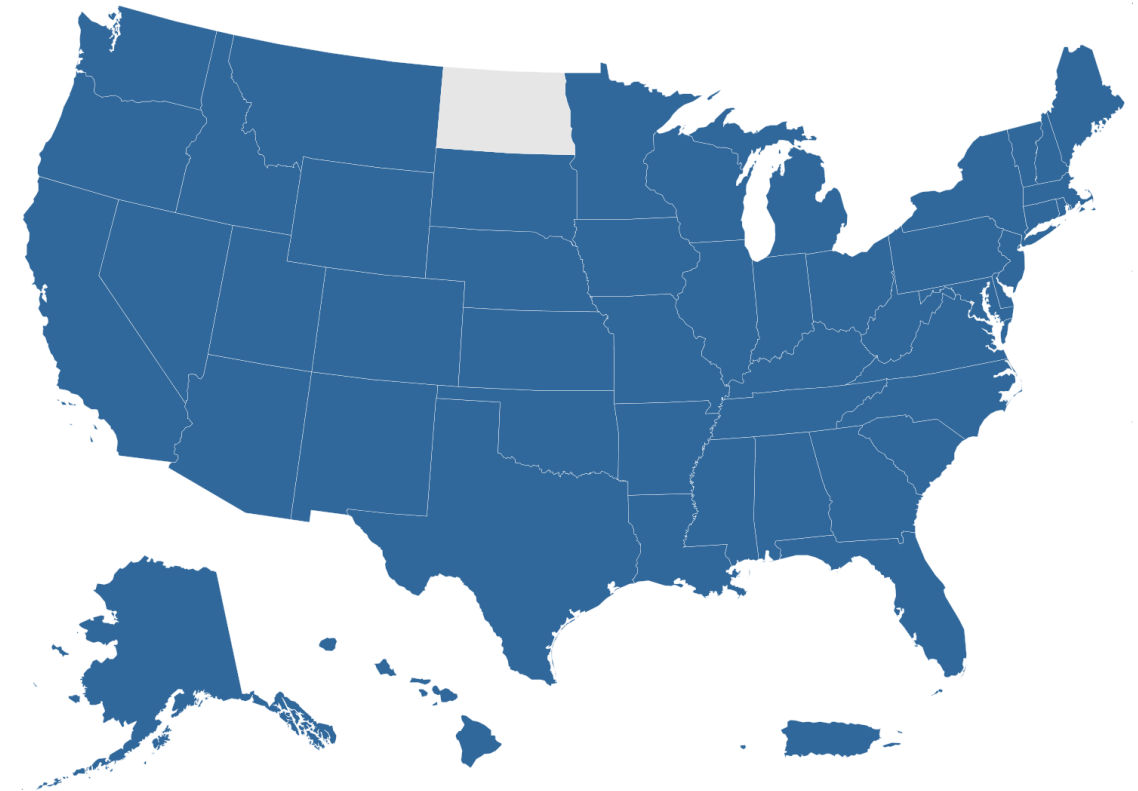
More than 1,400

## Amount awarded:

More than \$2.5 billion

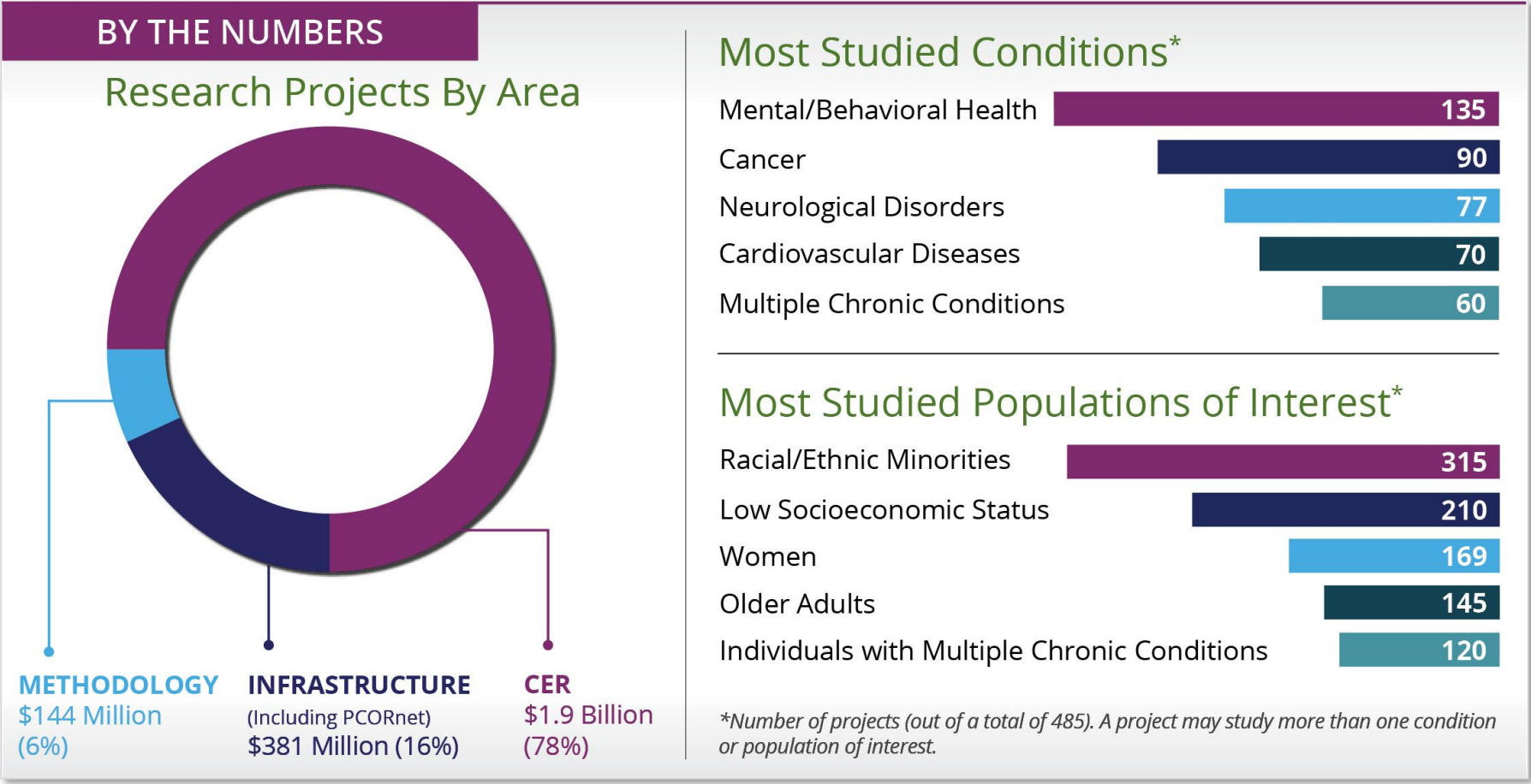
## Number of states where we are funding projects:

49 (plus the District of Columbia and  
Puerto Rico)



AS OF NOVEMBER 2019  
All awards

# About Our Research Portfolio



AS OF NOVEMBER 2019

# Examples of PCORI-funded Topics



- Age-Related Hearing Loss
- Anxiety in Children, Adolescents, & Young Adults
- Care Transitions – Service Clusters
- Chronic Low Back Pain
- Chronic Pain/Long Term Opioid Therapy
- Chronic Pain – Unsafe Opioid Prescribing
- Falls in Elderly
- Hepatitis C – New Therapies; Hard-to-Treat Patients
- Hypertension
- MAT Delivery for Pregnant Women w/Opioid Use Disorder
- Multiple Sclerosis
- NOACs for Blood Clots
- Obesity
- Office-Based Opioid Treatment for OUD
- Palliative Care
- Posttraumatic Stress Disorder in Adults
- Severe Asthma in African Americans & Hispanics
- Sickle Cell Disease
- Symptom Management for Patients with Advanced Illness
- Treatment-Resistant Depression
- Uterine Fibroids



# Current Stakeholder Engagement in Topics

Individual  
Meetings and  
Calls

Stakeholder  
Specific  
Convenings

In-Person  
Workshops

Virtual  
Workshops

Board of  
Governors

# Current Examination of Topic Generation

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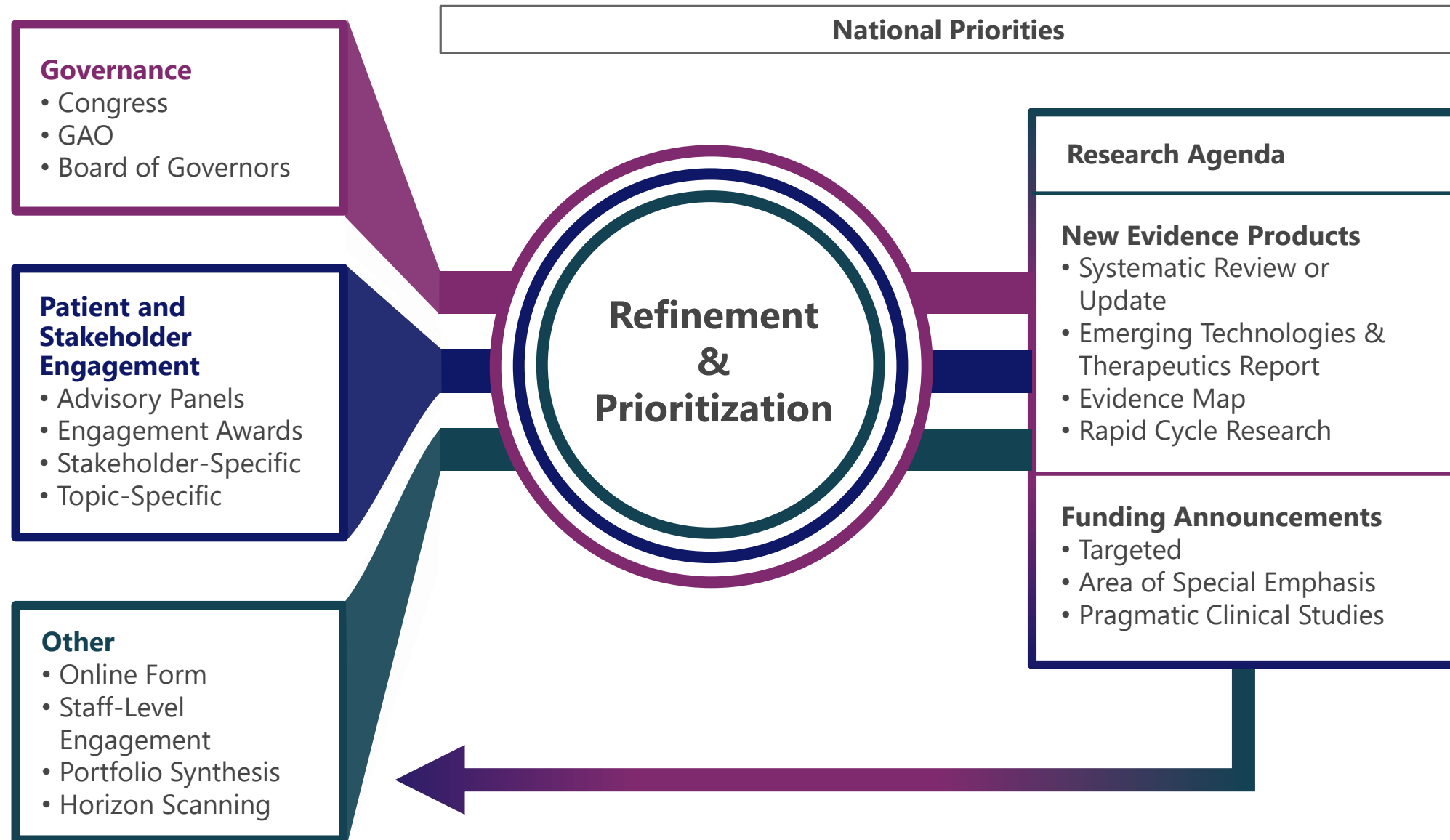


# Current Examination of Topic Generation



- Reauthorization provides a unique opportunity to reexamine how we generate topics at PCORI
- We have learned from the experience of PCORI 1.0 and are eager to put that knowledge to work
- There are new methods and sources for stakeholder engagement that were not available previously
- There are new evidentiary needs and new evidence products to help meet them for various stakeholders across health care
- PCORI has started thinking about these issues and we value your thoughts on new ways to gather priorities for communities across the health care landscape

# DRAFT Topic Generation Visualization



# New Ideas on Topic Generation

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# New Ideas on Topic Generation

## Methods

- Virtual convenings
- Deliberative convenings
- Crowdsourcing
- Regional engagement

**Other new methods?**

## Communities

- Underrepresented communities
- Racial/ethnic minorities
- Stigmatized and emerging health care issues

**Other new voices?**

# Group Discussion

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# Group Discussion



- What kinds of new and innovative methods would you recommend to PCORI as we reconsider topic generation?
- What methods would be most effective to generate topics important to the communities you live and work in?
- Where should PCORI go to seek new voices to ensure that all health care stakeholders have a seat at the table?
- What else is happening in your communities that would be informative to PCORI's work?



# BREAK

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We will return at approximately  
10:45am EDT

# Engagement: What We've Learned

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Kristin L. Carman  
Director, Public & Patient Engagement

Laura Forsythe  
Director, Evaluation & Analysis

# Discussion Outline



1. Background: PCORI's mandate and engagement as a foundation
2. What we've learned: The difference engagement has made
3. What's next: Implications for the future

# Background

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# The Patient-Centered Outcomes Research Institute: Established to Meet Stakeholders' Needs

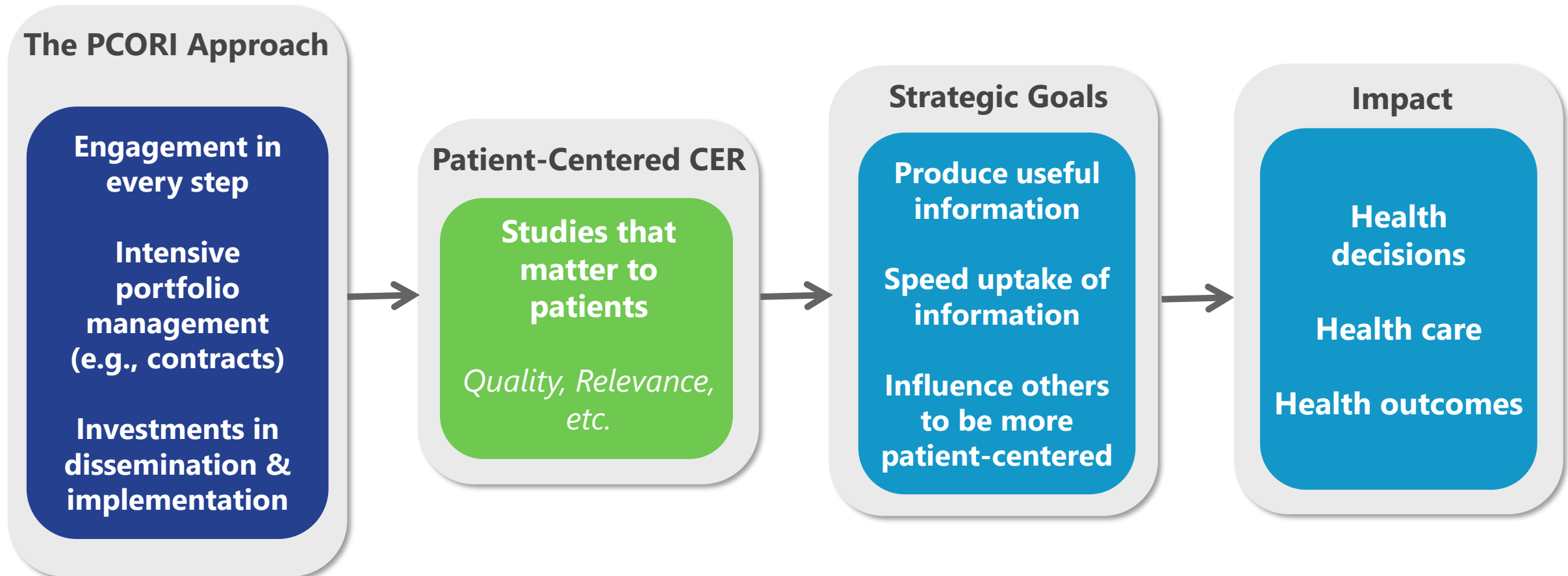


“The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence** concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be 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



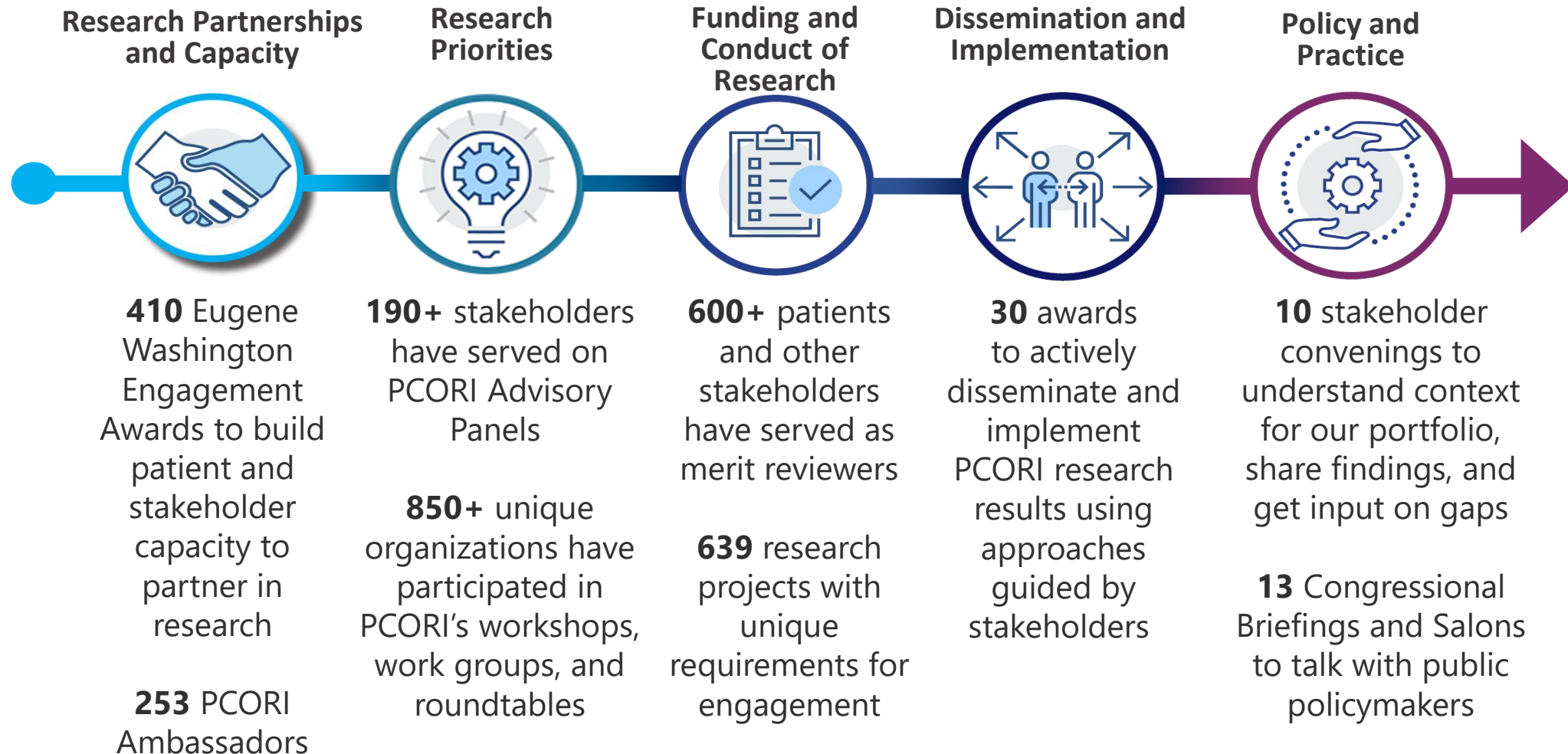
# The Path to Impact: PCORI's Conceptual Model



# Engagement: A Foundation for Everything PCORI Does

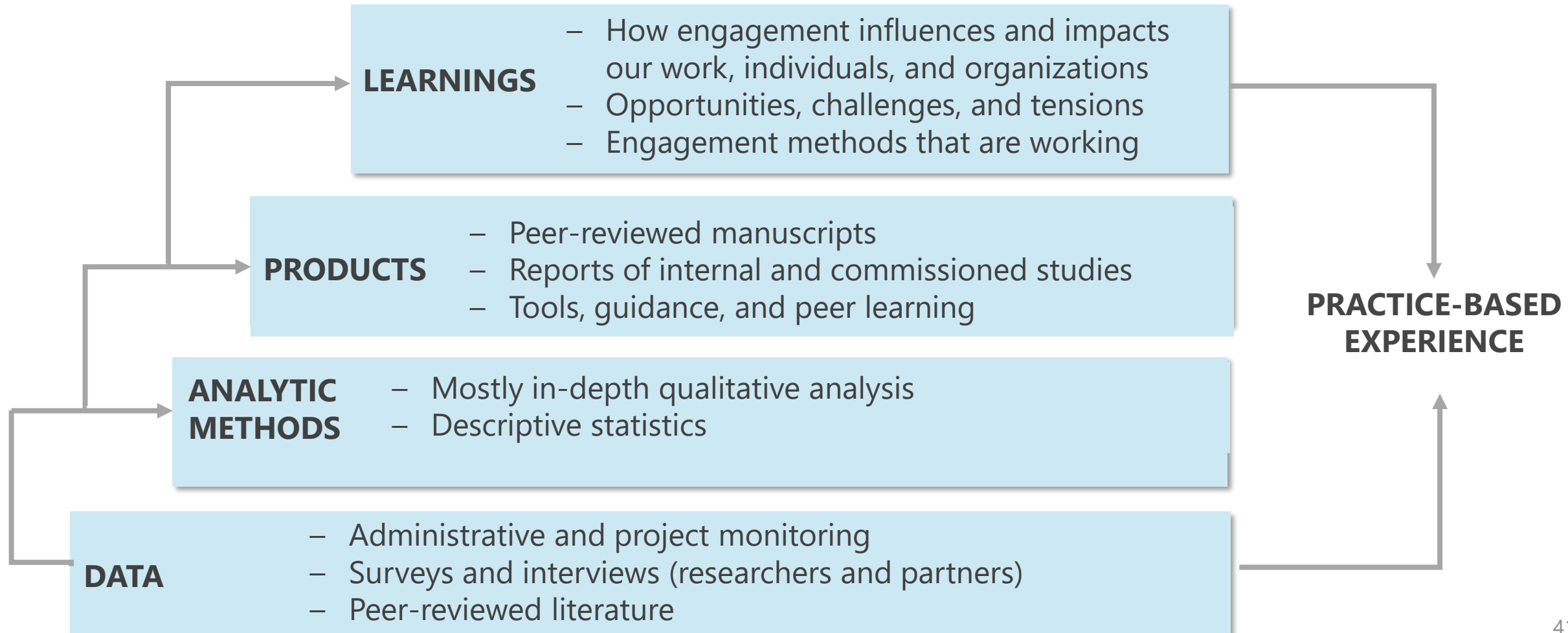


# PCORI Creates Opportunities for Engagement at Every Step of the Research Process





## *Findings synthesized across efforts to build evidence and inform practice*



# What We've Learned

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# Engagement Makes Meaningful Differences in Research Projects



*Core themes emerged across multiple studies of engagement*

## Engagement influenced...

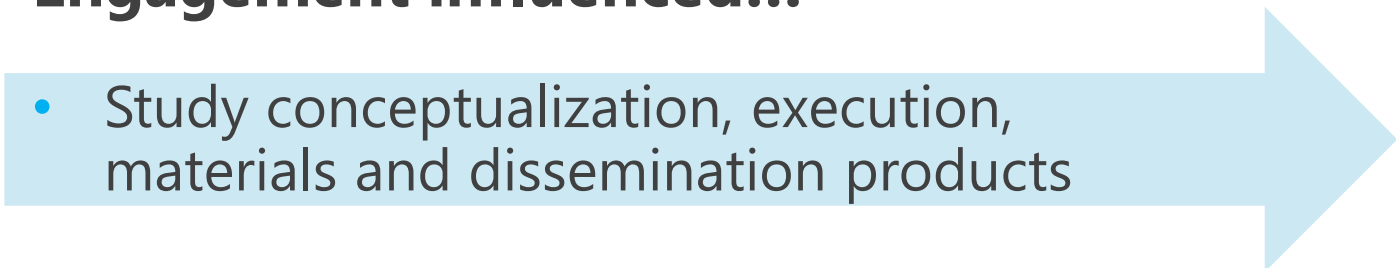
- Study conceptualization, execution, materials and dissemination products
- Carrying out study tasks
- Engagement design and practice
- Researchers' understanding of patients, clinicians, and health care organizations

For example, in one recent study about engagement in PCORI-funded research projects, nearly 400 distinct examples of engagement influence were analyzed from in-depth interviews with 60 projects

# Engagement Makes Meaningful Differences in Research Projects

## Engagement influenced...

- Study conceptualization, execution, materials and dissemination products
- Carrying out study tasks
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- Researchers' understanding of patients, clinicians, and health care organizations



Engagement influences **all aspects** of CER projects

Research focus  
Research design  
Intervention tailoring/delivery  
Recruitment/retention  
Data collection/measures  
Data analysis  
Dissemination

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Data analysis

Dissemination

# Engagement Influences Research Focus

- Identification of topic or project
- Formulation or expansion of research aims or questions
- Choice of comparator(s)
- Determination of research outcomes (primary and secondary)

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## **Comparing the Effectiveness of Nonsurgical Treatments for Lumbar Spinal Stenosis (LSS) in Reducing Pain and Increasing Walking Ability**

Included measures of physical activity and walking capacity as primary outcome measures because stakeholders and patients stressed the importance of maintaining their independence.

# Engagement Influences Research Focus

- Identification of topic or project
- Formulation or expansion of research aims or questions
- Choice of comparator(s)
- Determination of research outcomes (primary and secondary)

## Comparing Different Treatments for People Who Have Had a Stroke – The PROSPER Study

Modified primary outcomes based on patient priorities to include home time out of hospital.

*“Yes, stroke survivors were concerned about long-term survival, but they were equally concerned about the quality of that survival and the potential for recovery beyond 3 months or 1 year (i.e., the typical time points in stroke outcomes research)... So we revisited our aims, overhauled our data collection plan, and ensured that our goals were not only informed by patients but also aligned with the issues that patients cared about the most.”*

- O'Brien E., 2014, *Circ Cardiovasc Qual Outcomes*



# Engagement Influences Research Design

- Practical guidance on how to carry out the research
- Choice of design (e.g., delayed start, mixed methods)
- Study participant allocation and randomization designs
- Broader inclusion and less restrictive exclusion criteria

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## **Comparing Clinic and Home-Based Exercise Programs to Help Adults with Multiple Sclerosis (The TEAMS Study)**

Chose to randomize by clinics (cluster randomization) rather than individuals to prevent treatment crossover, based on stakeholder feedback about patients participating together in clinic-based support groups.

# Engagement Influences Recruitment and Retention

- Designing outreach and recruitment strategies (e.g., developing consent materials, setting compensation)
- Anticipating barriers (e.g., addressing factors to improve participation among hard-to-reach populations)
- Solving unanticipated problems
- Participating in recruitment, enrollment, and retention activities

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## Comparing Broad- and Narrow-Spectrum Antibiotics for Children with Ear, Sinus, and Throat Infections

Partners helped to create the consent script used to recruit parent participants.

# Engagement Influences Recruitment and Retention



- Designing outreach and recruitment strategies (e.g., developing consent materials, setting compensation)
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## Tailoring Resources to Help Children and Parents Manage Type 1 Diabetes

Stakeholders provided input that helped the study appeal to families who traditionally experience disparities in diabetes control & spoke in favor of in-person recruitment.

*"As a result, minority families were enrolled in numbers proportionate to our sites' population demographics and as good as or better than similar recently published trials."*

*- Fiallo-Scharer R., 2017, Contemp Clin Trials*

# Linking the Influence of Engagement to Effects on the Research Projects

## Influence on Study Conduct

- Discrete decisions, events, behaviors, strategies

## Effects on the Projects

- How specific influences shape the project (more intermediate)
- Generally focuses on practical aspects

# Ways that Engagement Shapes PCORI-Funded Research Projects



## **User-Orientation & Acceptability:**

studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs

# Ways that Engagement Shapes PCORI-Funded Research Projects



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## Training Doctors to Discuss Goals of Care with Patients Who Have Advanced Cancer

Patient partners ensured that survey response burden for outcome measures was minimized for people with advanced cancer, who fatigue easily

Oncologists informed understanding of the practice landscape and refined and the intervention (e.g., addressed concerns about time involved, demonstrating respect for oncologist-patient relationship)

*"Rates of physician participation and retention were higher than usual in our intervention, suggesting that involving physician stakeholders, though slower in the design phase, created a more relevant study and increased buy-in."*

- Solomon, 2017, Patient



# Ways that Engagement Shapes PCORI-Funded Research Projects



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## **Feasibility:**

interventions, enrollment, and data collection that are more doable in real-world settings

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*"To our knowledge, this is the largest telerehabilitation trial ever conducted on people with MS anywhere in the world. In fact, there are very few studies of this magnitude in any area of MS research. If we didn't have this front end, patient engagement structure, which PCORI requires in the application process, we'd probably be behind on recruitment. **This study was set up in such a way that there were built-in mechanisms for ensuring that you reach the finish line** with the appropriate sample size that will allow us to take the study to the next level."*

James Rimmer, PhD, MA, PI of The TEAMS study  
University of Alabama at Birmingham

# Ways that Engagement Shapes PCORI- Funded Research Projects



## **User-Orientation & Acceptability:**

studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs

## **Feasibility:**

interventions, enrollment, and data collection that are more doable in real-world settings

## **Quality:**

study rigor, comprehensiveness, and quality of materials and products

## **Relevance:**

results applicable and important for decision-making

## **Engagement Scope & Quality:**

engagement processes are effective, and stakeholders are well equipped

## Patients & Stakeholders

- More knowledge and enthusiasm for research
- Developed skills and professional opportunities
- Improved personal health and healthcare
- New or better relationships
- Feeling of making a difference

## Communities

- Built trust
- Increased research capacity
- Strengthened relationships among stakeholders
- Increased awareness of different stakeholder perspectives

## Researchers

- Deeper understanding of real-world experiences and concerns of their study populations
- More knowledge about engagement
- Commitment to engagement in the future



# PCORI's Approach to Engagement is Helping Achieve Our Third Strategic Goal of Influencing the Culture of Research



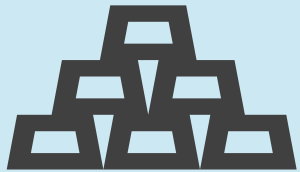
## PCORI is credited with inspiring change at other organizations and institutions

*Specific examples are described in more detail at <https://www.pcori.org/engagement/influencing-culture-research>*

- Seed funding for partnerships
- Training of students, fellows, and partners
- Patient reviewers
- Requirement to involve patients & stakeholders in strategic research planning
- Standing patient and stakeholder advisory boards
- Policies to support engagement in research
- Journal policies for person-centered language
- Adoption of patient-centered approaches by federal agencies, academic institutions, and funders

# Engagement Can Be Challenging

## Infrastructure and Resources



- Knowledge
- Skills & Experience
- Money
- Time

## People and Teams



- Access
- Ensuring Diversity & Inclusivity
- Relationships & Communication

## Organizations



- Competing Priorities
- Contracting Policies
- IRBs

## Balancing Views and Priorities



- Differing Perspectives
- Value Conflicts
- Internal vs. External Validity

# In Sum: What Has PCORI Accomplished in Engagement?

Opportunities  
for Engagement

Guidance

Portfolio of  
Projects and  
Research

Science of  
Engagement

Culture Change

In all aspects of  
the research  
process

### Meetings & Events

Type of Event  
Stakeholder Workshops ▼ Go

AUG 22


**PCORI Stakeholder Webinar on Cervical Ripening in the Outpatient Setting: A Systematic Review**  
PCORI hosted a stakeholder webinar on cervical ripening in the outpatient setting, which is the topic for a new systematic evidence review commissioned via the... [Read More](#)

AUG 20


**PCORI Stakeholder Webinar on Radiation Therapy for Brain Metastases: A Systematic Review**  
PCORI hosted a stakeholder webinar on radiation therapy for brain metastases, which is the topic for a new systematic evidence review commissioned via the Agency... [Read More](#)

JUL 09

**PCORI Stakeholder Webinar on Interventions for Dyspnea in Patients with Advanced Cancer: A Systematic Review**  
PCORI hosted a stakeholder webinar on interventions for dyspnea in patients with advanced cancer, which is the topic for a new systematic evidence review commissioned...

**PATIENT-CENTERED OUTCOMES  
RESEARCH INSTITUTE**  
1838 L STREET NW, SUITE 900  
WASHINGTON, DC 20036  
202.627.7700

## Seeking Reviewers FOR SUMMARIES OF RESEARCH



**Are you the parent of a child newly diagnosed with Duarte galactosemia (DG)?**

If yes, Patient-Centered Outcomes Research Institute, or PCORI, would like to invite you to review a short summary from a recently completed study about DG. We believe you provide a valuable perspective that can improve these materials!

**Who is PCORI?**  
PCORI is a national nonprofit, nongovernmental organization. PCORI creates easy-to-read summaries of research findings for the general public. PCORI asks patients and caregivers to review summaries to make sure they are written in a way that is easy to understand and useful.

**What Would I Need to Do?**  
If you agree to help, PCORI will send you a 1.5-page summary to read and a form with questions asking how clear or confusing you found the summary. After you have completed your review, you would send your responses back to PCORI.

<b>Time requirement</b> It usually takes about 30-40 minutes to review the summary and complete the form.	<b>Timeline</b> The abstract will be available to review mid July. You will have 2 business days to complete your review.	<b>Compensation</b> You will receive \$75 for reviewing the summary and completing and returning the form.
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# In Sum: What Has PCORI Accomplished in Engagement?

Opportunities  
for Engagement

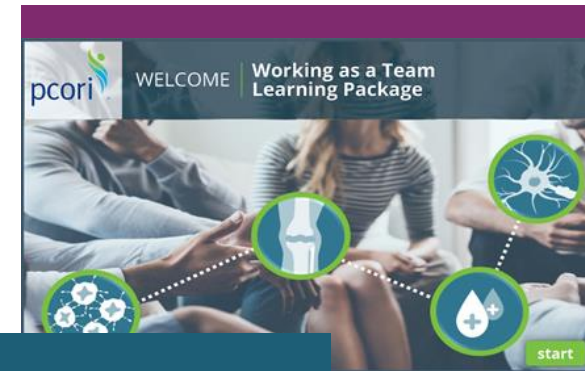
**Guidance**

Portfolio of  
Projects and  
Research

Science of  
Engagement

Culture Change

**Initially general,  
non-directive  
supports;  
increasingly more  
structured and  
tailored and based  
on developing  
evidence**





# In Sum: What Has PCORI Accomplished in Engagement?

Opportunities  
for Engagement

Guidance

**Portfolio of  
Projects and  
Research**

Science of  
Engagement

Culture Change

# In Sum: What Has PCORI Accomplished in Engagement?

Opportunities  
for Engagement

Guidance

Portfolio of  
Projects and  
Research

**Science of  
Engagement**

Culture Change

**Body of evidence  
from large-scale  
laboratory of  
innovation**

# In Sum: What Has PCORI Accomplished in Engagement?

Opportunities  
for Engagement

Guidance

Portfolio of  
Projects and  
Research

Science of  
Engagement

**Culture Change**

# What's Next

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# Future Actions to Build on PCORI's Accomplishments

## Opportunities for Engagement

Expanded approaches and mechanisms to ensure participants are diverse and representative

## Guidance

Update Rubric; explore opportunities to expand standards and criteria for engagement

## Portfolio of Projects and Research

Make engagement easier and more efficient through portfolio management and support

## Science of Engagement

Implement innovative methods, including exploring new funding opportunities

Develop and use validated measures of engagement

## Culture Change

Spread learnings about engagement

# Selected References for Further Reading



- Hemphill R, Forsythe LP, Heckert AL, Amolegbe A, Maurer M, Carman K, Mangrum R, Stewart L, Fearon N, and Esmail L. **What Motivates Patients and Caregivers to Engage in Health Research and How Engagement Affects Their Lives: Qualitative Survey Findings.** Health Expectations. 2019; 00: 1– 9. <https://doi.org/10.1111/hex.12979>
- Mauer, Maureen. **"Understanding the Influence and Impact of Engagement in PCORI-Funded Studies: A Qualitative Study."** PCORI Annual Meeting 2019, 19 September 2019, Washington D.C.. Plenary Presentation: How Engagement Is Making Research More Useful. Slides: <https://www.pcori.org/sites/default/files/PAM19-Lunch-Plenary-Engagement-Making-Research-Useful-Maurer-Presentation-Slides.pdf>.
- Forsythe LP, Carman KL, Szydlowski V, Fayish L, Davidson L, Hickam DH, Hall C, Bhat G, Neu D, Stewart L, Jalowsky M, Aronson N, Anyanwu CU. **Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute.** Health Aff (Millwood). 2019 Mar;38(3):359-367.
- Boivin A, Richards T, Forsythe L, Grégoire A, L'Espérance A, Abelson J, Carman KL. **Evaluating patient and public involvement in research.** BMJ. 2018 Dec 6;363:k5147.
- Forsythe LP, Frank LB, Tafari AT, Cohen SS, Lauer M, Clauser S, Goertz C, Schrandt S. **Unique Review Criteria and Patient and Stakeholder Reviewers: Analysis of PCORI's Approach to Research Funding.** Value Health. 2018 Oct;21(10):1152-1160.
- Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA; Advisory Panel on Patient Engagement (2013 inaugural panel). **The PCORI Engagement Rubric: Promising Practices for Partnering in Research.** Ann Fam Med. 2017 Mar;15(2):165-170.

# Group Discussion

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# Eugene Washington PCORI Engagement Award Program Updates

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Alicia Thomas

Senior Program Officer, Eugene Washington  
PCORI Engagement Awards



# Discussion Outline



- Program Overview
- Portfolio Highlights
- Planning Ahead
  - Project Funding Announcements
  - Enhancing Evaluation Efforts
- Q&A

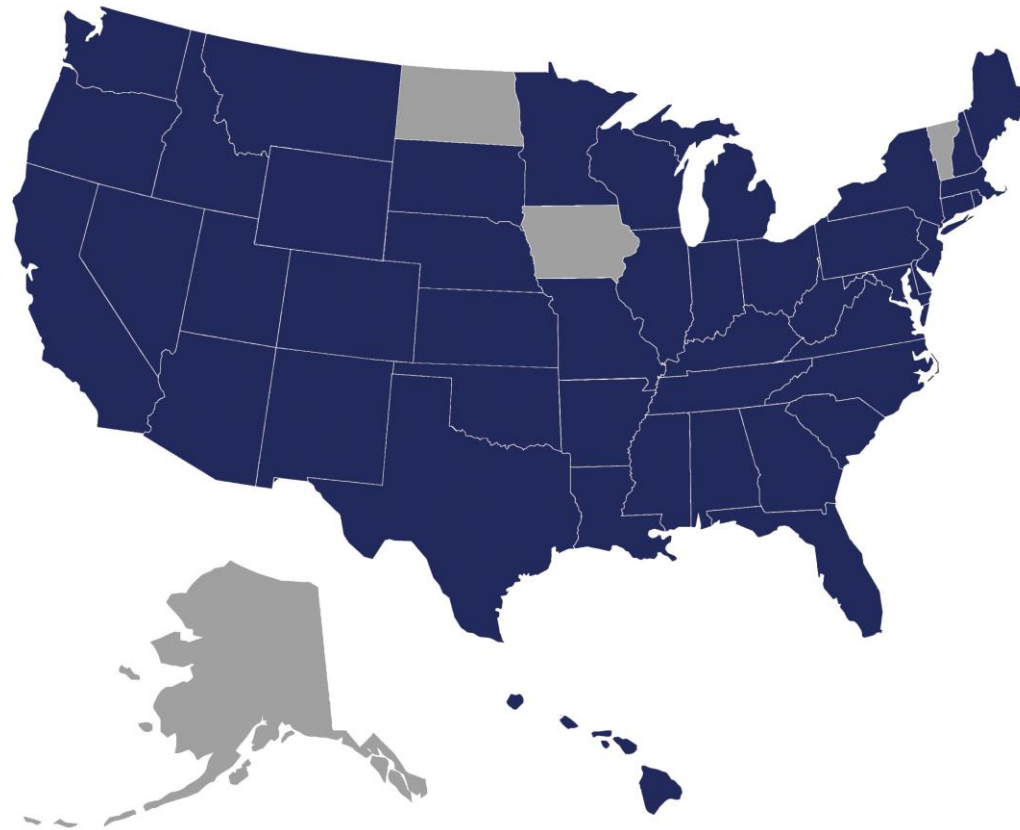
# Eugene Washington PCORI Engagement Award Program

- Support projects to build a community of patients and other stakeholders equipped to participate as partners in clinical comparative effectiveness research (CER), as well as serve as channels to disseminate PCORI-funded study results
- Funding for projects and conferences, NOT research



# Building a National Network for PCOR

- ~\$94.7 Million awarded since 2014, creating an expansive network of individuals, communities and organizations interested in and able to participate in PCOR



# Selected Project Highlights

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# Engagement Awardees in Action

Motor City School Health Collaborative / Henry Ford Health System



Alliance for Aging Research



Endometrial Cancer Action Network for African-Americans (ECANA) / University of Washington

# Awardee Collaboration



- Engagement Awardees collaborate and co-submitted an abstract to the American Society on Aging Annual Meeting in Atlanta, GA and will be presenting in March 2020 *"Collaboration for Engaging Patients and Caregivers in Dementia and Aging Research"*
  - University of Texas San Antonio (PL: Carole White)
    - *Stakeholder Alliance for Better Palliative Care for People with Dementia and their Caregivers*
  - Council for Jewish Elderly (PL: Rachel Berman)
    - *Sages in Every Setting: Enhancing an innovative model to incorporate older adult voice into research*
  - Livewell Alliance (PL: Heidi Gil and Stephani Shivers)
    - *Empowering Partners: Engaging Individuals with Dementia and Care Partners in PCOR/CER*



# Planning Ahead

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# Engagement Award Funding Announcements

## 2014-2016

- Knowledge Awards
- Training and Development Awards
- Dissemination & Implementation Awards
- Meetings and Conference Support

## June 2018-June 2019

- Capacity Building Award
- Dissemination Initiative Award
- Conference Support

## Beginning of 2020

- Dissemination Initiative
- Capacity Building
- Stakeholder Convening

## October 2017-February 2018

- Engagement Award (general)
- Meetings and Conference Support

## November 2019

- Special Project Funding Announcements:
- Community Convening
  - Accelerating the Adoption of Tools and Resources

## 2020 and onwards

Opportunities for growth and further tailoring using stakeholder input in PCORI 2.0



# Special Project Funding Announcements

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SPECIAL  
PROJECT  
FUNDING  
ANNOUNCEMENTS

**ACCELERATING THE  
ADOPTION OF TOOLS  
AND RESOURCES**



UP TO **\$100,000**  
UP TO **1 YEAR**

**COMMUNITY  
CONVENING**



UP TO **\$100,000**  
UP TO **1 YEAR**

# Engagement Award: Accelerating the Adoption of Engagement Tools and Resources



- PCORI seeks to give organizations and community groups the opportunity to **scale up or adopt meaningful engagement tools and resources** with more communities, stakeholders, and patients, **with the intent to further build capacity/skills for PCOR/CER**
- **Provides funding support to scale/adopt engagement work that has been created or developed under:**
  - Eugene Washington PCORI Engagement Award;
  - PCORI-funded Research Award; or
  - PCORI Infrastructure Funding Award

# Engagement Award: Community Convening



- PCORI seeks to fund convenings designed by **organizations and community groups** to bring diverse stakeholders together to provide an opportunity for **collaboration around an identified, unifying area or health topic of interest** such as
  - Geography (e.g., state or regional focus, etc.)
  - Health condition (e.g., mental/behavioral health, reproductive and perinatal health, etc.)
  - Population (e.g., LGBTQ+, rural, veterans, etc.)
- These convenings should **increase the involvement of communities underrepresented in PCOR/CER**, taking into account real-world circumstances or historical factors that may hinder communities typically not engaged in research

# Review Cycle

- **149** LOIs received on November 15 for this review cycle
  - Accelerating the Adoption of Tools and Resources: **38**
  - Community Convening: **111**
- **38** invited to submit full proposals
  - Accelerating the Adoption of Tools and Resources: **14**
  - Community Convening: **24**
- Full proposals under review and review meeting to be held February
- Decisions will be made in March and Awards will be sent in April
- Projects will kick off June 2020

# New Funding Announcements

ENGAGEMENT AWARD CATEGORIES	<b>DISSEMINATION INITIATIVE</b>	<b>CAPACITY BUILDING</b>	<b>STAKEHOLDER CONVENING</b>
			
	UP TO <b>\$250,000</b> UP TO <b>2 YEARS</b>	UP TO <b>\$250,000</b> UP TO <b>2 YEARS</b>	UP TO <b>\$100,000</b> UP TO <b>1 YEAR</b>

# Engagement Awards Evaluation Reporting Tool

- **Goal:** To ensure that a standard set of metrics is being reported by Engagement Awardees
- Reporting Tool was created to guide Awardees who have never shared results in this manner; allows them to see what is expected of them and what should be included in evaluation planning and reporting
- Template will allow for consistency across reports
- Will help PCORI more effectively evaluate individual Awards and the Engagement Award Program

## PCORI Engagement Awards Evaluation Reporting Tool

**Instructions:** The goal of this reporting tool is to ensure that a standard set of indicators is being reported for Engagement Awards. Given the difficulty in applying metrics and a standard set of indicators around engagement best practices, this tool provides a baseline of outcomes to report on in Engagement Award projects. At a minimum, evaluation reports should document the reach (in absolute numbers) of their acceleration/adoption of tools/resources. Not all projects will have outcomes that fit into each category. However, please address these categories as comprehensively as possible. Some projects may have multiple outcomes within each category. Once completed, please upload this document the PCORI Online portal with the Final Deliverable milestone.

Outcome Type	Measurement Examples (Quantitative or Qualitative)	Measurement	Examples of Questions to Consider	Brief Description
<b>Reach (individual level)</b> The number, proportion, description of end users	<ul style="list-style-type: none"><li>• Description of target population (# and relevant information)</li><li>• Description of how the target population is reached</li></ul>	Click or tap here to enter text.	<ul style="list-style-type: none"><li>• Who is the target population?</li><li>• How will they be reached?</li><li>• By whom?</li></ul>	Click or tap here to enter text.
<b>Engagement (researchers, stakeholders, patients, communities)</b>	<ul style="list-style-type: none"><li>• # of opportunities for patient and stakeholder partners to engage</li><li>• # of jointly identified</li></ul>	Click or tap here to enter text.	<ul style="list-style-type: none"><li>• Which partners have been involved throughout the planning and</li></ul>	Click or tap here to enter text.

# Group Discussion

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# BREAK

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We will return at approximately  
1:00pm EDT



# Input on Developing a Taxonomy for Patient Driven Research Communities

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Michelle Johnston-Fleece  
Senior Program Officer, Public & Patient  
Engagement

Claudia Grossmann  
Senior Program Officer, Research Infrastructure

Prashila Dullabh  
Senior Fellow, Health Sciences, NORC at the University  
of Chicago

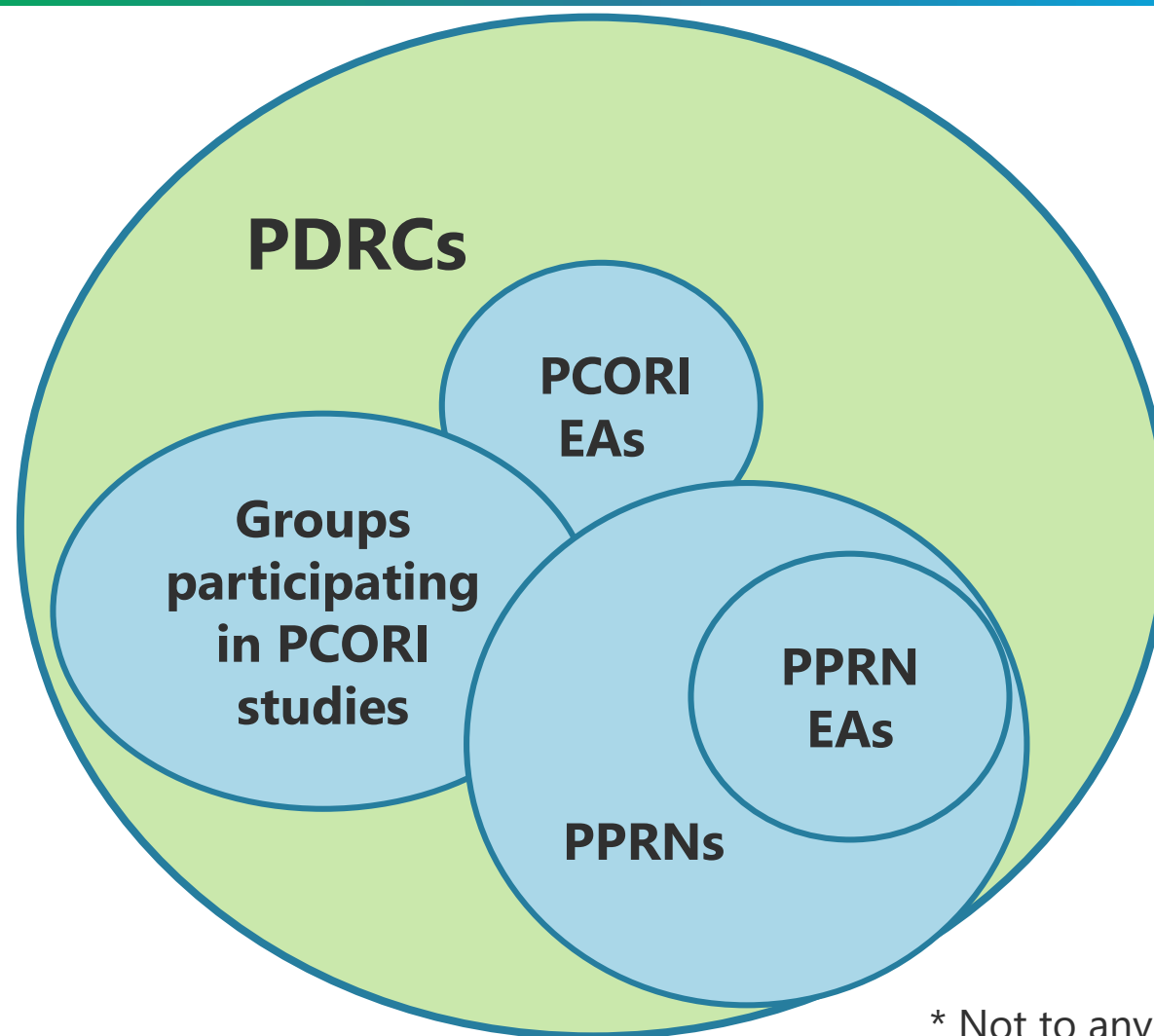
# Objectives



- Provide an update on the activities of the PDRC Learning Network
- Overview of process for developing a taxonomy
- Solicit input on:
  - Our approach for characterizing PDRCs
  - The role of PDRCs in the broader research landscape
  - Implications for PCORI

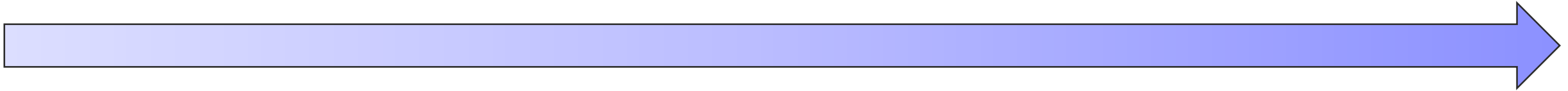
# PDRCs and PCORI

- **PDRC** = groups whose primary focus is to enable research that is a priority to their community
- **PPRNs** = PDRCs led by patients/participants and organized around the evidence needs of their communities originally funded as part of PCORnet
- **PPRN EAs** = Recipients of PPRN Limited Competition Engagement Award
- **EAs** = Engagement Awards



\* Not to any scale

# Research and Implementation Continuum



**Discovery**

*Pre-clinical*

**Safety and  
Efficacy**

*Pre-market*

**Effectiveness and  
CER**

*Post-market*

*Outcomes*

**Dissemination**

**Policy and  
Practice**

*Implementation*

*Coverage/Payment/  
Reimbursement*

# PDRC Learning Network



## Why:

- Helping catalyze a future where PDRCs play a much greater role in guiding the entire clinical and care delivery research enterprise
- Heard desire for patient-driven groups to learn and share

## How:

- Within PCORI, a collaborative partnership between Research Infrastructure and Engagement
- NORC contracted for coordination

## When:

- 2.5 years starting July 2019
- First meeting in September 2019

# PDRC Learning Network Goals

Contribute to and  
shape a national  
discussion on the  
roles of PDRCs

Generalize  
learnings in PDRC  
priority areas

Help inform PCORI  
in supporting  
PDRCs

Support learning  
between PDRCs

**PPRN EA Projects**

- 4 learning network meetings held
- 2 monthly seminars held
  - *Shifting of research cultures to embrace patient's as partners throughout the research life cycle. (Daniel Mullins, University of Maryland)*
  - *Safe data sharing and privacy consideration in engaging patients in access to their own medical records. (Cyndi Grossman, Formerly of FasterCures)*
- Development and kickoff of workgroups:
  - *Improving representativeness of PDRC membership and research participants*
  - *Elaborating on sustainable PDRC business models*
  - *Improving effectiveness of digitally based engagement efforts*
- Landscape analysis and development of PDRC taxonomy

Contribute to and shape a national discussion on the roles of PDRCs

- Conduct a landscape review of PDRCs
- Develop a conceptual model to inform the work of the network
- Create communication products to inform the work of the network
- Create products to facilitate communication of the network's progress with lay and scientific audiences



Help inform PCORI  
in supporting  
PDRCs

- Define priorities and needs based on network convening and workgroups
- Articulating priorities for multiple stakeholders (e.g. funders, research organizations)
- Make recommendations to PCORI and the field

# Group Discussion

---

# Group Discussion

- Does the working definition adequately capture the breadth of PDRCs?
- Do our criteria for the taxonomy adequately capture the field?
  - Is it more helpful to cast a wide net to include more organizations or to focus tightly?
- Do the different PDRC organization types seem comprehensive?
- What about the role of PDRCs is most impactful in the research landscape?
  - What are the implications for PCORI?



# Taxonomy of Patient/Participant-Driven Research Communities (PDRCs)

NORC at the University of Chicago

January 30, 2020

# Seeking PEAP Input on Key Topics

- Does the working definition adequately capture the breadth of PDRCs?
- Do our criteria for the taxonomy adequately capture the field?
  - Is it more helpful to cast a wide net to include more organizations or to focus tightly?
- Do the different PDRC organization types seem comprehensive?
- What about the role of PDRCs is most impactful in the research landscape?
  - What are the implications for PCORI?

# What We Have Done

*September 2019 to January 2020*

## Review of PCORI Materials



## Peer-Reviewed and Gray Literature Review



## Review of 116 Websites of Potential PDRCs



## 29 Key Informant Interviews



# Subject Matter Experts (SMEs)

## Subject Matter Experts

**Lorraine Johnson, JD, MBA**

Chief Executive Officer, LymeDisease.org

**Rebekah Angove, PhD**

Vice President of Evaluation and Patient Experience, Patient Advocate Foundation (PAF)

**Brendaly Rodriguez, MA, CPH**

Current member of PCORI Patient Engagement Advisory Panel (PEAP)

**Katherine Browne, MBA, MHA**

Independent Consultant

**Dominick L. Frosch, PhD**

Executive Director and Senior Scientist at the Palo Alto Medical Foundation Research Institute

Co-Director, Sutter Health Center for Health Systems Research

# Working Definition of Patient/Participant-Driven Research Communities (PDRCs)



# Working definition of Patient-Driven Research Community (PDRC)

An organization or group of organizations that is **led and/or governed by patients/participants and/or caregivers** and whose **primary purpose is to enable research that is a priority to those patient/participant or caregiver communities.**

A PDRC:

- has a shared sense of purpose;
- ensures that the views of patients/participants and/or caregivers are central to governance bodies and decision-making; and
- is a stable entity that engages in research or maintains established relationships past any one funding award or research project.

# Discussion Questions

- Does the working definition resonate with you or does it adequately capture what a PDRC is?
- Is there anything that should be added, emphasized or removed?

# What are we finding?

# Testing Definition of PDRC with Real World Examples

- Objective: Understand landscape of PDRCs, how they work, and how they can advance PCOR
  - Not designed to capture entire landscape but offer a sample of the range of PDRCs (n=48)
- Potential PDRCs identified through literature review and key informant suggestions
  - Reviewed publicly available information on organization websites and conducted targeted Google searches



# Testing Definition of PDRC with Real World Examples

## ■ Strengths

- First effort to identify, describe, and understand the landscape of a wide array of organizations that conduct patient-driven research, identifying opportunities to strengthen and advance patient-centered research

## ■ Limitations

- Level of detail and information available on public websites; characteristics may vary by project or over time—this is a snapshot; sample not meant to be inclusive of all PDRCs in the health care research ecosystem

# Number of PDRCs identified

- In a preliminary analysis, NORC reviewed 116 organizations and identified **48 PDRCs**

PDRC Designation	Number
PDRCs	48
Not clear whether PDRC	13
Not a PDRC	55
<b>Total Number of Organizations Reviewed</b>	<b>116</b>

# Who was included?

The organization....

- is patient/participant-led and/or governed (patient/participant membership in governance)
- states research is an objective or priority on its website
- is a stable entity that maintains relationships past any one funded award or research project

# Reasons for exclusion

- **Researcher-led** or lacks information around patient involvement in leadership
- Groups focused primarily on advocacy or other patient/participant services and supports, with **less emphasis on research program or agenda**
- Patient-driven research communities or research teams that **convened for a single project**
- Initiatives or programs where patient/participant involvement seems traditionally **patient-centered rather than patient/participant-driven**



# Reasons for exclusion

- **Funders of PDRCs**
- **Government-led entities or government/public partnerships;** patient/participant role in governance is sometimes unclear
- **University institutes or projects;** typically not patient-led; possibly accountable to university aims
- Entities that do not report designing patient/participant-driven research agendas but **make technology and other resources available to patients/participants**

# Discussion Questions

- Do our criteria for the taxonomy adequately capture the field?
  - Is it more helpful to cast a wide net to include more organizations or to focus narrowly?
- Do the different PDRC organization types seem comprehensive?

# PDRCs' Role in Research

- Within our sample, PDRCs most commonly **connect stakeholders to promote patient-driven research** and **collect, aggregate, and/or share patient/participant-generated health data**

PDRC Role (n=48)	Number of PDRCs (%)
Connects stakeholders to promote patient/participant involvement in research	37 (77%)
Collects, aggregates, and/or shares patient/participant-generated data	30 (63%)
Collaborates with outside entities or researchers to conduct patient-driven research	25 (52%)
Funds research that aligns with participant/patient-identified research priorities and agendas	23 (48%)
Provides education to patients/participants and/or other stakeholders to prepare them to conduct research or be a participant in research	21 (44%)
Coordinates and/or conducts advocacy for policies and funding that supports patient-driven research and/or PDRC research priorities	19 (40%)*
Leads, owns, and conducts patient-driven research	13 (27%)

\*34 PDRCs reported conducting advocacy efforts, though 15 conduct general advocacy rather than specifically research (e.g. raising awareness, focus on care delivery, etc.)

# Examples of PDRC role in research

**Connects stakeholders to research**



Partners with Love/Avon Army of Women to unite cancer researchers with women willing to participate in research studies on the causes and prevention of breast cancer

**Collects, aggregates, and/or shares patient-generated data**



Has biorepository to share biological samples from infants affected by NEC, as well as infants who did not experience NEC

**Collaborates with outside entities**



In addition to core research team, fosters patient-driven collaboration with growing network of researchers dedicated to KIF1A and related disease areas (e.g., collaborative research network with researchers and physicians at Columbia University Medical Center)

# Discussion Questions

- Have we characterized the full range of research activities conducted by PDRCs? If not, what are we missing?
- To what extent are these findings consistent with your experience and perspectives on the work of communities?
- Of the range of activities identified, where would PCORI be most helpful in advancing the work of PDRCs?

# Discussion Questions

- Are we missing PDRCs that might be focused on other things?
  - If so, who might these be and what are they focusing on?

# PDRC Structure and Type(s)

We identified three types of PDRC structures:

## Type 1: Independent organization

often formally incorporated as a non-profit or for-profit corporation



The Chordoma Foundation **is a nonprofit organization governed by its own Board of Directors**, which includes multiple chordoma survivors



The Cystic Fibrosis Reproductive and Sexual Health Collaborative is led by a **Governance Board that includes members from CF-Patient Task Force and Research Advisory Panel**

## Type 2: Consortium or coalition of organizations or other entities

multiple organizations/stakeholders joined by shared purpose; elected/selected leadership and/or own governance board(s)



The International Alliance of Dermatology Patient Organizations (i.e., Global Skin) **is comprised of 155 patient association members**; its Board of Directors are “skin patient leaders in their own organizations who, in many cases, are skin patients themselves.”



**Type 3: A project or initiative housed under an “umbrella” entity  
(i.e., a component or subsidiary of an organization)**

parent organization may or may not be patient/participant-led;  
accountable to the umbrella organization’s leadership and mission,  
if applicable

# PDRC Structure and Type(s)

- Within our sample:
  - Most PDRCs function as an independent organization (type 1), but some are a consortia or coalition (type 2)
  - No PDRCs are a subsidiary/component of a larger organization (type 3)
- Most PDRCs in the sample are nonprofit
  - No major trends in structure by for-profit/nonprofit status

# Discussion Questions

- Do these descriptions of PDRC structure types resonate with you? What structure types are we missing?
- Are there variations within these organizational structures that are important to distinguish and/or capture?

# Any Questions?

Prashila Dullabh  
Dullabh-Prashila@norc.org

**Thank You!**



**NORC**  
*at the UNIVERSITY of CHICAGO*

 insight for informed decisions™

# **BREAK**

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We will return at approximately  
2:30pm EDT

# Communications Update & Discussion: Tool Repository, Web Redesign, & Annual Meeting

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Bill Silberg  
Director, Communications

Ivey Wohlfeld  
Program Manager, Eugene Washington  
PCORI Engagement Awards

Alana Cole  
Program Associate, Public & Patient  
Engagement

Marla Bolotsky  
Associate Director, Communications

Amy Damsker  
Senior Operations Manager, Communications

# Engagement Tool and Resource Repository

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**Ivey Wohlfeld**

Program Manager, Eugene Washington PCORI  
Engagement Awards

**Alana Cole**

Program Associate, Public & Patient Engagement





# Website New Feature: Tool Repository



- Support researchers preparing or conducting patient-centered outcomes research (PCOR), especially investigators new to the field
- Facilitate peer learning among PCORI awardees as well as non-PCORI awardees
- Inspire and motivate creativity among PCOR investigators when creating tools and resources
- Provide and adapt resources for their project needs so teams do not need to *recreate the wheel*
- PCOR capacity building not just for researchers but for patient and stakeholder research partners

# About the Repository



- Available online as of September 2019
- Contains Engagement Tools as identified by PCORI staff from research portfolio and Engagement Award deliverables
- Staff established inclusion/exclusion criteria
- Resources are tagged with codes for resource focus, phase of research, health condition, patient and public stakeholders, and population of interest
- Each resource includes a brief description
- Users can search using filters or keywords

# How Were Tools Selected for Inclusion?

Category	Inclusion Criteria	Exclusion
Engagement Focus	<ul style="list-style-type: none"> <li>• Tool explicitly describes or facilitates engagement in the preparation, conduct, or dissemination phases of PCOR.</li> <li>• Tool describes or facilitates engagement in healthcare program or intervention planning, implementation, and/or evaluation.</li> <li>• Tool will support authentic and meaningful engagement of patients and stakeholders in the preparation, conduct, and dissemination of PCOR.</li> </ul>	<ul style="list-style-type: none"> <li>• Engagement in health research outside of PCOR</li> <li>• Engagement tool development for shared decision making</li> <li>• Engagement in patient preference studies</li> <li>• Tool primarily focuses on study objectives unrelated to engagement.</li> </ul>
Tool Type	<ul style="list-style-type: none"> <li>• Tool will support the preparation, conduct, dissemination, and/or evaluation of PCOR capacity building and engagement.</li> <li>• Tool or resource was packaged as a training, roadmap, toolkit, guide, checklist, curriculum, model/framework, survey/questionnaire, interview guide, protocol, glossary, or template.</li> </ul>	<ul style="list-style-type: none"> <li>• Peer-reviewed publication</li> </ul>
Tool Completion	<ul style="list-style-type: none"> <li>• Tool is complete and is presented as a final version.</li> </ul>	<ul style="list-style-type: none"> <li>• Tool is incomplete or in progress.</li> </ul>
Adaptability	<ul style="list-style-type: none"> <li>• Tool can inform the work of other project teams and could be applicable to different settings.</li> </ul>	<ul style="list-style-type: none"> <li>• Tool is <i>not</i> likely to inform the work of other project teams or be applicable to other settings.</li> </ul>
PCORI Funded	<ul style="list-style-type: none"> <li>• Tool and/or resource was developed through a PCORI-funded Engagement or Research Award.</li> </ul>	<ul style="list-style-type: none"> <li>• Tool and/or resource was <i>not</i> developed through a PCORI-funded Engagement or Research Award.</li> </ul>
Practice-Based Foundation	<ul style="list-style-type: none"> <li>• Tool was developed based on best practices or practice-based findings.</li> </ul>	<ul style="list-style-type: none"> <li>• Tool was <i>not</i> developed based on best practices or practice-based findings.</li> </ul>

# Examples of Tools in the Repository

Sample MOUs  
and Governance  
Documents

PCOR Training  
Toolkits

Focus Group  
Protocols

Facilitator  
Guides






Newsletters

Job Descriptions  
for Staff and  
Board Members

Social Media  
Toolkits

## Engagement Tool and Resource Repository for Patient-Centered Outcomes Research

PCORI is committed to advancing patient-centered, stakeholder-engaged research and the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process. We do this to ensure that the results of the studies we fund are relevant, trustworthy, and more likely to be used in practice. PCORI also supports the uptake of engagement practices and methodologies within the broader healthcare research community. To encourage the spread of these practices, we have assembled a repository of engagement-related tools and resources developed and used by PCORI awardees. This searchable peer-to-peer repository includes resources that can inform future work in patient-centered outcomes research (PCOR) and was developed based on a process, which you can learn more about [here](#).

Refine Results	
▼ Resource Focus	
▼ Phases of Research	
▼ Health Conditions	
▼ Patients and Public Stakeholders	
▼ Populations	

### Browse Tools and Resources

Displaying 1 - 10 of 159 results

#### MULTICARE HEALTH SYSTEM

##### "We're basically you!" Video

This video shares the experiences and concerns of adolescents and young adults ages 15 to 39 with cancer care. It was developed as part of an initiative to advance patient-centered care practices and research initiatives targeting

# Evaluating the Repository

Assess  
usefulness  
of tools

Identify  
top tools  
for deeper  
dive

Identify  
gaps where  
tools are  
needed

# Group Discussion

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# Group Discussion

- **Tool Repository**
  - What resources do you want to see more of?
  - Tell us about your experience
- **Evaluation Plan**
  - Are these the right questions?
  - Are we using the right methods?



# Website Redesign

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**Marla Bolotsky**

Associate Director, Digital Media Engagement,  
Communications

# Discussion

1. Recent website updates
2. Group discussion

# Website Enhancements

Reworked Word Choices:

**Public Abstract** ➡ **Results Summary**

**Engagement Award Project** ➡ **Engagement in Research Project**

**Profile** ➡ **People**

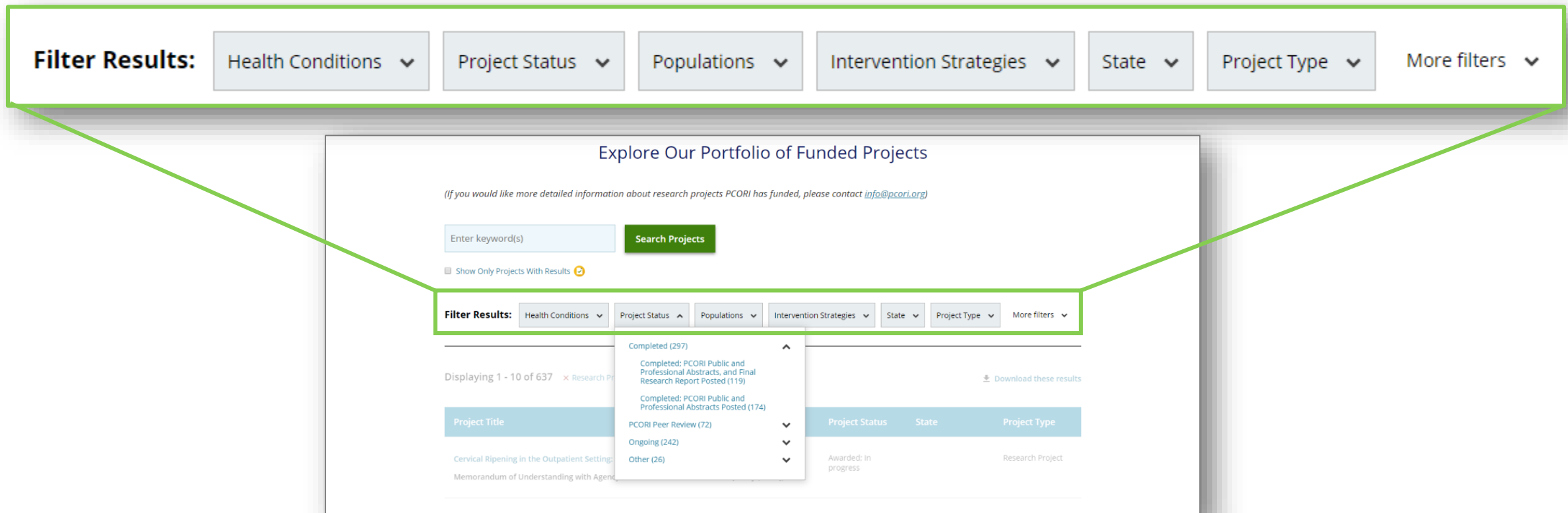
**Award** ➡ **Project**

**Conditions** ➡ **Health Conditions**

**Research in Action** ➡ **PCORI Stories**

# Website Enhancements

Redesigned our project search tool and new filters for Populations and Intervention Strategies:



The screenshot displays the PCORI project search tool interface. At the top, a green-bordered box highlights the 'Filter Results' section, which includes dropdown menus for 'Health Conditions', 'Project Status', 'Populations', 'Intervention Strategies', 'State', 'Project Type', and a 'More filters' option. Below this, the main search area is titled 'Explore Our Portfolio of Funded Projects'. It features a search bar with the placeholder 'Enter keyword(s)' and a green 'Search Projects' button. A checkbox labeled 'Show Only Projects With Results' is also present. The 'Filter Results' section is repeated below the search bar, with the 'Populations' dropdown menu open, showing a list of categories: 'Completed (297)', 'Completed: PCORI Public and Professional Abstracts, and Final Research Report Posted (119)', 'Completed: PCORI Public and Professional Abstracts Posted (174)', 'PCORI Peer Review (72)', 'Ongoing (242)', and 'Other (26)'. The main content area displays a table of project results, with columns for 'Project Title', 'Project Status', 'State', and 'Project Type'. The first row shows 'Cervical Ripening in the Outpatient Setting: Memorandum of Understanding with Agenc...' under the 'Project Title' column, 'Awarded: in progress' under 'Project Status', and 'Research Project' under 'Project Type'. A 'Download these results' link is visible on the right side of the table.

# Website Enhancements

## Changed Public Abstracts to Results Summary:

 This project has results

**For Children Discharged after Hospitalization for Serious Bacterial Infections, Are Orally Administered Antibiotics as Effective as Antibiotics Given Intravenously through a PICC?**

 Sign Up for Updates to This Study    

Results Summary

Professional Abstract

Results Summary

Download Summary [Español \(pdf\)](#) [Audio Recording \(mp3\)](#)

**What was the research about?**

Children hospitalized for a severe infection often need to continue to take antibiotics after they go home. In this study, the research team wanted to learn if antibiotics taken by mouth work as well as those given through an IV peripherally inserted central catheter, or PICC. A PICC is a thin tube put into a vein in the upper arm. The PICC reaches into a large vein near the heart. The research team also wanted to

Results Summary

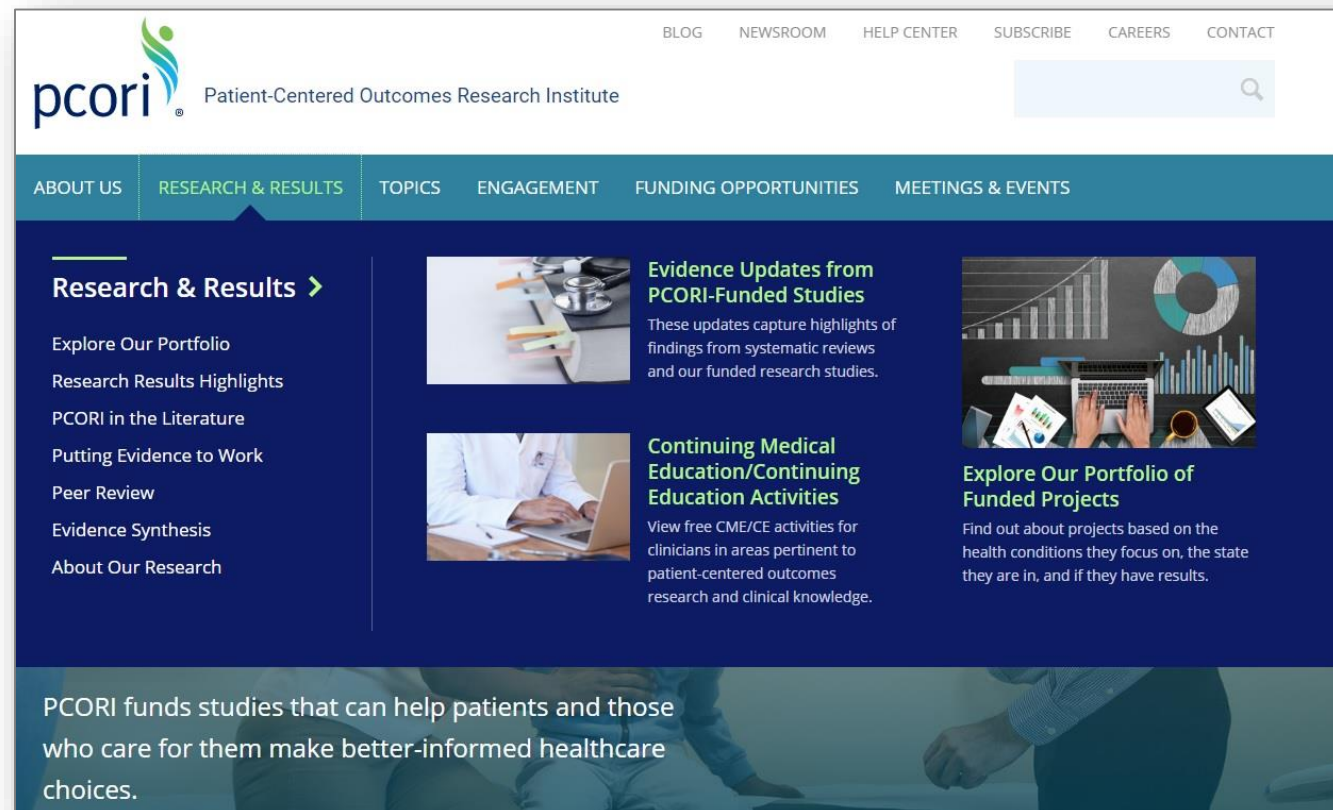
Professional Abstract

Results Summary

Download Summary [Español \(pdf\)](#) [Audio Recording \(mp3\)](#)


# Website Enhancements

Added a Mega Menu and New Topic Pages:

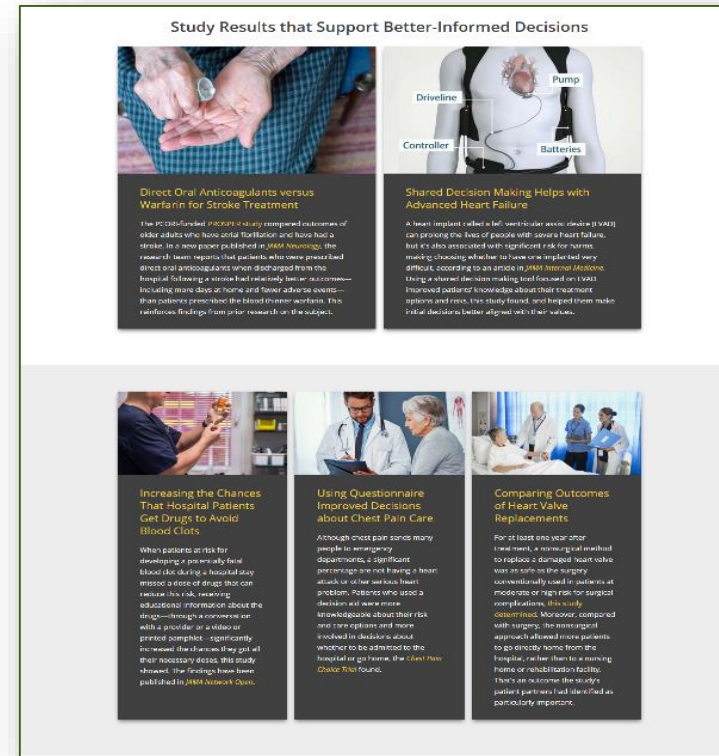


# Website Enhancements

## New Topic Pages:



The screenshot shows the PCORI website with a navigation bar at the top. The main content area is titled "Cardiovascular Disease" and features a large graphic with the following statistics: "No. 1 cause of death", "800,000 deaths each year", and "\$320 BILLION in healthcare costs and lost productivity annually". Below this, it states: "To address this problem, PCORI has funded 69 comparative clinical effectiveness research studies and related projects to help patients and those who care for them make **better-informed decisions** about their options for preventing, diagnosing, and treating **cardiovascular disease**." The page also includes a section titled "PCORI Answers Critical Questions" with three sub-sections: "Patient: I want to avoid having another deep vein blood clot. Which of the many blood-thinning drugs would be most safe and effective for me over the long term?", "Caregiver: My 85-year-old father is leaving the hospital after surviving a stroke. What drug would work best for him to avoid another hospital stay or need to go into a nursing home?", and "Clinician: How can I best help my patients in this small rural town get their blood pressure under control and avoid heart attacks and strokes?"



The screenshot shows the "Study Results that Support Better-Informed Decisions" section of the PCORI website. It features six articles arranged in a 2x3 grid, each with a title, a small image, and a brief summary of the study findings.

- Direct Oral Anticoagulants versus Warfarin for Stroke Treatment:** The PCORI-funded research compared outcomes of older adults who have atrial fibrillation and have had a stroke. In a new paper published in *JAMA Neurology*, the research team reports that patients who were prescribed direct oral anticoagulants when discharged from the hospital following a stroke had relatively better outcomes, including more days at home and fewer adverse events, than patients prescribed the blood thinner warfarin. This cautious findings from prior research on the subject.
- Shared Decision Making Helps with Advanced Heart Failure:** A heart implant called a left ventricular assist device (LVAD) can prolong the lives of people with severe heart failure, but it's also associated with significant risk for harm, making choosing whether to have one implanted very difficult, according to an article in *JAMA Internal Medicine*. Using a shared decision making tool focused on LVADs improved patients' knowledge about their treatment options and risk, the study found, and helped them make final decisions better aligned with their values.
- Increasing the Chances That Hospital Patients Get Drugs to Avoid Blood Clots:** When patients at risk for developing a potentially fatal blood clot during a hospital stay receive a dose of drugs that can reduce this risk, receiving educational information about the drug—through a brochure or with a provider or a video or printed computer—significantly increased the chances they got all their necessary doses, this study showed. The findings have been published in *JAMA Network Open*.
- Using Questionnaire Improved Decisions about Chest Pain Care:** Although chest pain sends many people to emergency departments, a significant percentage are not having a heart attack or other serious heart problem. Patients who used a decision aid were more knowledgeable about their risk and care options and more involved in decisions about whether to be admitted to the hospital or go home, the *Clinical Heart Failure* found.
- Comparing Outcomes of Heart Valve Replacements:** For at least one year after treatment, a minimally-invasive method to replace a damaged heart valve was on par with the surgery conventionally used in patients at moderate or high risk for surgical complications, research recently determined. Moreover, compared with surgery, the minimally-invasive approach allowed more patients to go directly home from the hospital, rather than to a nursing home or rehabilitation facility. There are no known downsides, patient partners had identified as particularly important.

# Group Discussion

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# Group Discussion

- What is the primary reason you visit the PCORI website?
- Which of the following site features/tools do you use and how/why do you use them?
  - Searchable list of funded studies
  - Projects with Results (Results summaries and Final Research Reports)
  - Literature Explorers
  - Evidence Updates

# Group Discussion

- How could we improve these features to make them more useful?
- What other areas of the site do you use?
- What information or resources do you think are missing from the PCORI website?

- [Explore Our Portfolio](#)
- [Results Summaries](#)
- [Results and Final Research Reports](#)
- [PCORI in the Literature](#)
- [Engagement in Health Research](#)
- [Evidence Updates for Patients, Clinicians and Families](#)

# PCORI Annual Meeting

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**Amy Damsker**

Senior Operations Manager,  
Communications

# Group Discussion

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# Group Discussion

- How do we engage the community who can't be at the Annual Meeting in person?
- What meeting session formats are most appealing?

# Special Projects & Workgroups: Opportunities for Involvement

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Krista Woodward

Senior Program Associate, Public & Patient Engagement

Michelle Johnston-Fleece

Senior Program Officer, Public & Patient Engagement

Denese Neu

Engagement Officer, Public & Patient Engagement

Laura Forsythe

Director, Evaluation & Analysis

Christine Broderick

Engagement Officer, Public & Patient Engagement

Rachel Hemphill

Program Officer, Evaluation & Analysis

# Ambassador Program Workgroup

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**Krista Woodward**

Senior Program Associate, Public & Patient  
Engagement







Thank You!

# Subcommittee Original Purpose

- The subcommittee was formed in August 2017 to address staff and Ambassador feedback
- Subcommittee charge and responsibilities:
  - Inform the redesign of the PCORI Ambassador Program by providing guidance and identifying necessary components of an efficient program
  - Ensure better alignment with current PCORI priorities and Ambassadors' interests
  - Refocus the Ambassador Program towards community-based promotion, knowledge sharing, translation, and grassroots organizing



Left to right: Meghan Berman, Freddie White-Johnson, Tom Scheid, Jimmy Lin, Sonya Ballentine, Norah Schwartz, Phil Posner, and Krista Woodward

*Note: Not all subcommittee members pictured.*



# Subcommittee Accomplishments

- Refined program mission, vision, and strategic objectives
- Advised on Ambassador Center design
- Reviewed and provided input on new e-learning training
- Informed and participated in new webinar series ("Coffee Breaks")
- Developed idea for newsletter "Call to Action" series
- Ambassador workshops at PCORI Annual Meetings
- Networking with other institutions (e.g. FDA)



# Future Directions

- Ambassador Program *Workgroup*
- Future focus areas :
  - Ambassador Workshop (Annual Meeting pre-conference) planning
  - Program Evaluation
  - Ambassador Recruitment

# Interested?

- We'll send a follow-up email/poll for you to indicate your interest
- Questions? Contact Krista Woodward ([kwoodward@pcori.org](mailto:kwoodward@pcori.org))



# Clinician Engagement Workgroup

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**Denese Neu**

Engagement Officer,  
Public & Patient Engagement



# Project Overview



- Overarching goal to **bridge the collaborative gap** between researchers and clinicians
- To advance research “done differently” we also need to **understand how to integrate real world research** into the day-to-day work of health care delivery
- This requires developing mechanisms to **reduce burden on clinicians** to participate in PCOR/CER studies
- Recommendations have been received and work is underway **to determine which provide the highest value** for PCORI, PCORI-funded researchers, and their partners



# Project Overview

## Task A. Environmental Scan and Resource Database

- Conduct environmental scan and identify sources of clinician engagement materials
- Evaluate engagement materials
- Develop database of resources
- Submit summary report
- **Oct – Dec 2018**

## Task B. Multi-Pronged Data Capture

- Conduct targeted literature scan to identify challenges and facilitators to clinician engagement
- Assess legal landscape
- Conduct key informant discussions to inform analysis
- Submit findings summaries
- **Jan – Sep 2019**

## Task C. Findings and Recommendations Report

- Create compendium of resources
- Prepare and submit a findings and recommendations report
- **Sep – Jan 2020**



# Next Steps

- PCORI cross-departmental discussions will:
  - Identify which actionable recommendations to advance
  - Prioritize the work and link to other PCORI efforts
  - Determine the type of additional thought-leadership needed to advance the recommendations
- PEAP can help PCORI:
  - Further explore the researcher  $\leftrightarrow$  clinician  $\leftrightarrow$  patient relationships within the scope of the recommendations
  - Tie this work-in-progress to other engagement undertakings
  - Provide additional insight to PCORI staff for moving recommendations to implementation

# Interested?



- We'll send a follow-up email/poll for you to indicate your interest
- Time commitment and timeframe will be shared after recommendations are vetted and prioritized

Contact Denese Neu ([dneu@pcori.org](mailto:dneu@pcori.org)) or  
Alana Cole ([acole@pcori.org](mailto:acole@pcori.org))

# Knowledge Translation & Uptake Workgroup

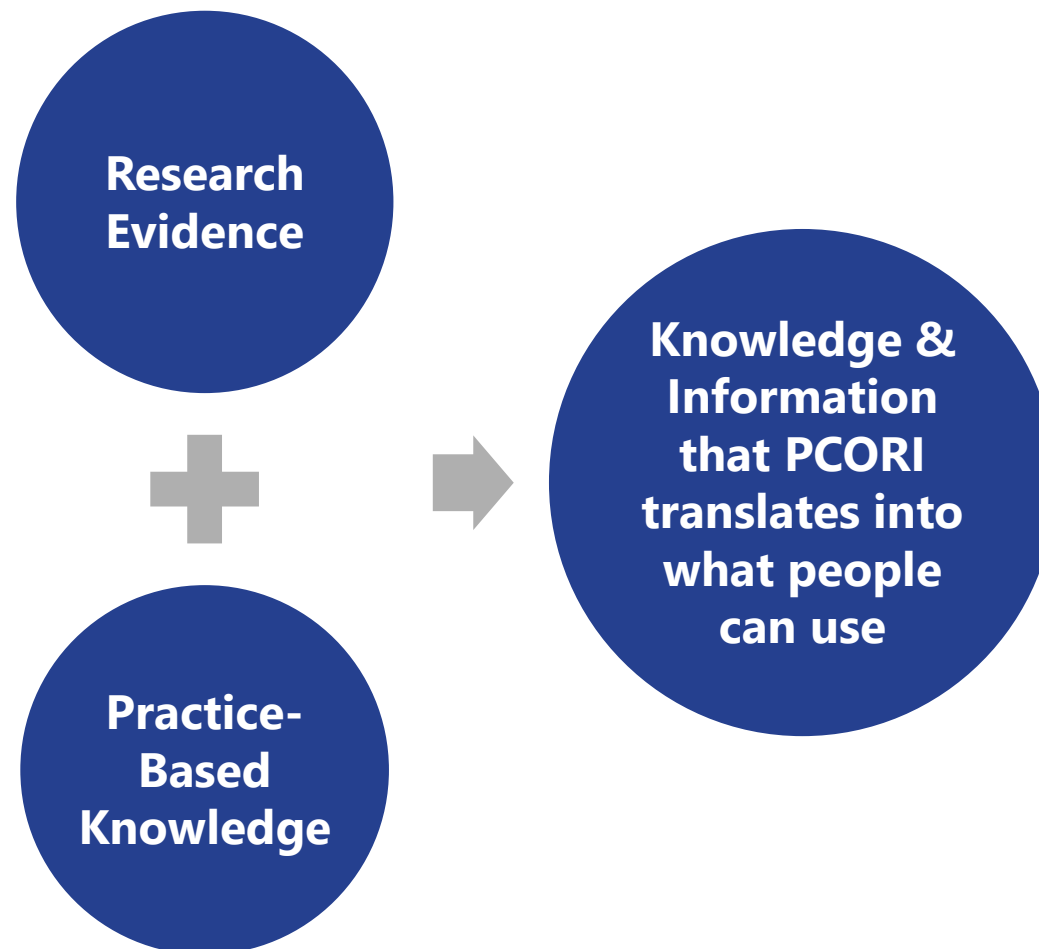
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**Christine Broderick**  
Engagement Officer,  
Public & Patient Engagement



# Sharing What We've Learned

- The difference engagement has made
- Data on influence and impacts across PCORI research portfolio
- Engagement methods that are working



# Workgroup Objectives

Advise on:

- Translating and motivating uptake of learnings/data about the influence and impacts of engagement in PCORI-funded research
- Audiences, messages, strategies and approaches
- Informing future research and practice

# Membership & Timeline



- Group will consist of up to 8 PEAP members
- Members will serve a 12-month term
- Group will meet every 1-2 months by teleconference
- Group will be facilitated by PCORI staff
  - Christine Broderick, Engagement Officer, Public and Patient Engagement

- This workgroup will assist PCORI with:
  - Identifying audiences
  - Translating content into messages and formats that resonate with different audiences
  - Identifying channels and methods for sharing content
  - Input into PCORI Engagement Rubric 2.0
  - Input into evaluating use and uptake

# How to Join



- We'll send a follow-up email/poll for you to indicate your interest
- If more than 8 people are interested in joining, PCORI staff will select members to ensure a range of perspectives

Contact Christine Broderick ([cbroderick@pcori.org](mailto:cbroderick@pcori.org))



# Studying PCORI's Patient-Centered Approach Workgroup

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**Rachel Hemphill**

Program Officer, Evaluation & Analysis

**Michelle Johnston-Fleece**

Senior Program Officer, Public & Patient  
Engagement



# New Workgroup Opportunity

- 'Studying PCORI's **P**atient-**C**entered **A**pproach' (PCA) Workgroup



# Workgroup Objectives



- To advise on:
  - PCORI's evaluation agenda
  - Projects to build evidence about promising practices for patient-centered research
  - Projects to assess the effectiveness of PCORI's approach to patient-centered research

# Membership & Structure



- Group will consist of up to 8 PEAP members
- Members will serve from February – August 2020
  - Group's agenda and membership will be revisited in conjunction with new PEAP term
- Group will be facilitated by PCORI staff
  - Rachel Hemphill, Program Officer, Evaluation and Analysis
  - Michelle Johnston-Fleece, Senior Program Officer, Public and Patient Engagement

# Activities & Time Commitment



- Group will advise on multiple projects throughout the year at key phases of project planning, conduct, and/or dissemination
- Activities will include:
  - Helping PCORI staff prioritize questions and projects to pursue
  - Providing input on specific projects
  - Generating ideas for innovative ways to answer key questions about engagement
  - Identifying which topics and questions should be brought to the full PEAP

# Activities & Time Commitment

- Members can choose which projects to advise on based on availability
- Participation will occur primarily through teleconferences
  - To be scheduled on an ad hoc basis according to project timelines and needs
  - Meetings will typically occur every 1-2 months
- Some projects may also require brief “homework” assignments
  - e.g., reviewing documents, brainstorming ideas

# Examples of Projects for Workgroup's Input



1. Review and analysis of current measures of engagement processes and outcomes
2. Synthesis of PCORI's learnings to date about engagement approaches and impact
3. Developing new ways to study engagement methods
4. Evaluation of PCORI's merit review process to inform enhancements (e.g., facilitating patient and stakeholder reviewer roles)
5. Tracking uptake and use of PCORI research results

# How to Join or Find Out More



- We'll send a follow-up email/poll for you to indicate your interest
- If more than 8 people are interested in joining, PCORI staff will select members to ensure a range of perspectives
- Group's first meeting projected for mid to late February
- Questions?
  - Contact Rachel Hemphill ([rhempfill@pcori.org](mailto:rhempfill@pcori.org)) or Michelle Johnston-Fleece ([mfleece@pcori.org](mailto:mfleece@pcori.org))



# Engagement Measures Analysis Project

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**Laura Forsythe**

Director, Evaluation & Analysis



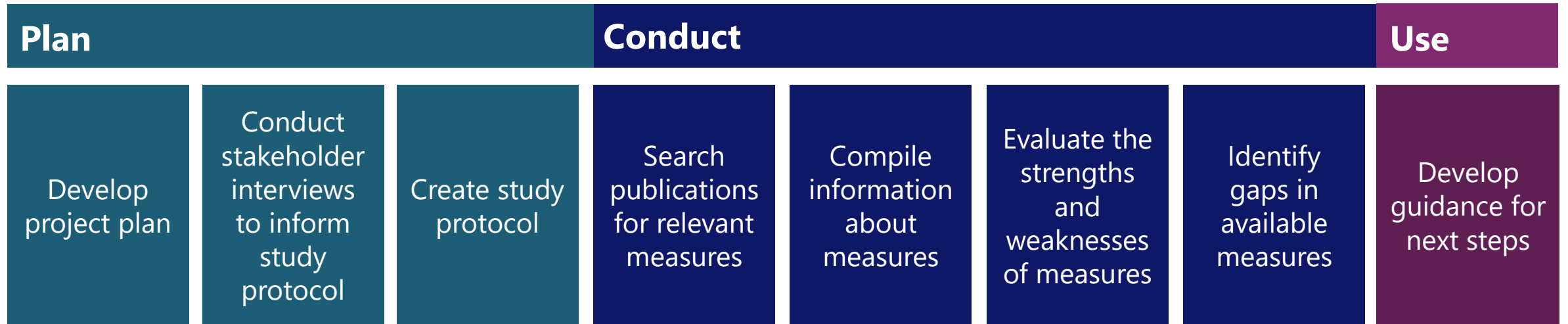
# Advancing Our Study of Engagement

- PCORI seeks to identify and facilitate the **best-practices** for engagement and to understand the **difference engagement makes** for health research
- PCORI has commissioned a landscape review and gap analysis to **identify and assess available measures of engagement** processes and outcomes
- The results of this work will help PCORI:
  - **use appropriate measures** to assess PCORI portfolios,
  - support the **development of new measures** of engagement, and
  - **develop programs and policies** to facilitate the use of measures of engagement

# Research Questions

- 1 What are current measures of engagement in health research, and what are their attributes, strengths and weaknesses?
- 2 What new or revised measures of engagement in health research are needed?
- 3 How do PCORI's programs and policies align with using existing and future measures of engagement?

# Methods



Stakeholder Engagement

# Stakeholder Engagement in This Project

- **Studying PCORI's Patient-Centered Approach Workgroup** (*PEAP work group*)
  - Provide guidance on project plan
  - Review and comment on table of findings
  - Provide periodic updates to the PEAP
- **Project Advisory Group** (*opportunity for 1-2 PEAP members*)
  - Collaborate on key informant interview guide
  - Co-produce study protocol
  - Co-produce the gap analysis
  - Provide guidance on interpretation and presentation of findings
- **Key Informants**
  - Provide input through a structured interview to inform study protocol
- **Advisory Panel on Patient Engagement** (*full PEAP*)
  - Provide guidance on interpretation and use of findings

# Next Steps



- Early February: PCORI would like to identify 1-2 PEAP members who are interested in joining the Engagement Measures Analysis **Project Advisory Group**
- Early March: The **Studying PCORI's Patient-Centered Approach Workgroup** will convene to review and provide guidance on RAND's draft project plan
- Early 2021: Findings from the landscape review and gap analysis are expected to be shared back to the full **Advisory Panel**

*Please contact Lauren Fayish ([lfayish@pcori.org](mailto:lfayish@pcori.org)) if you have project specific questions or concerns*

# Closing Remarks

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**ADJOURN**



# Dinner

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**6 PM @ Washington Marriott Georgetown**

1221 22nd St NW, Washington, DC 20037

(DAY TWO - Start time 9am ET)

