

Advisory Panel on Patient Engagement

Winter 2019 Meeting

Day One: January 24, 2019

9:30 am - 5:00 pm ET

United States (Toll-free): 1 877 568 4108

United States: +1 (415) 930-5229

Access Code: 906-578-836

Welcome and Introductions

Kristin Carman

Director, Public & Patient Engagement

David White

Chair, Advisory Panel on Patient Engagement

Thomas Scheid

Co-chair, Advisory Panel on Patient Engagement

Agenda

Time	Title
9:00 am	Public Policy Update
9:30 am	Welcome and Introductions
9:45 am	Public & Patient Engagement: What's Ahead in 2019
10:30 am	Break
10:45 am	Dissemination and Implementation Updates
11:45 am	Group Photo
12:00 pm	Lunch

Agenda

Time	Title
12:45 pm	Kara Ayers, Board of Governors (patient representative)
1:00 pm	Communications Update
1:45 pm	Ambassador Program Workshop: Lessons Learned & Next Steps
2:00 pm	Break
2:15 pm	Breakout Session I
3:15 pm	Transition
3:25 pm	Breakout Session II
4:30 pm	Breakout Session Reports
5:00 pm	Adjourn

Housekeeping



- Reminder: Members of the public are invited to listen to PCORI Advisory Panel meetings
- If you would like to say something, place your name tent vertically on the table
- Please use the microphones and state your name before speaking

Public & Patient Engagement: What's Ahead in 2019

Kristin Carman
Director, Public & Patient Engagement

Jean Slutsky
Chief Engagement and Dissemination Officer

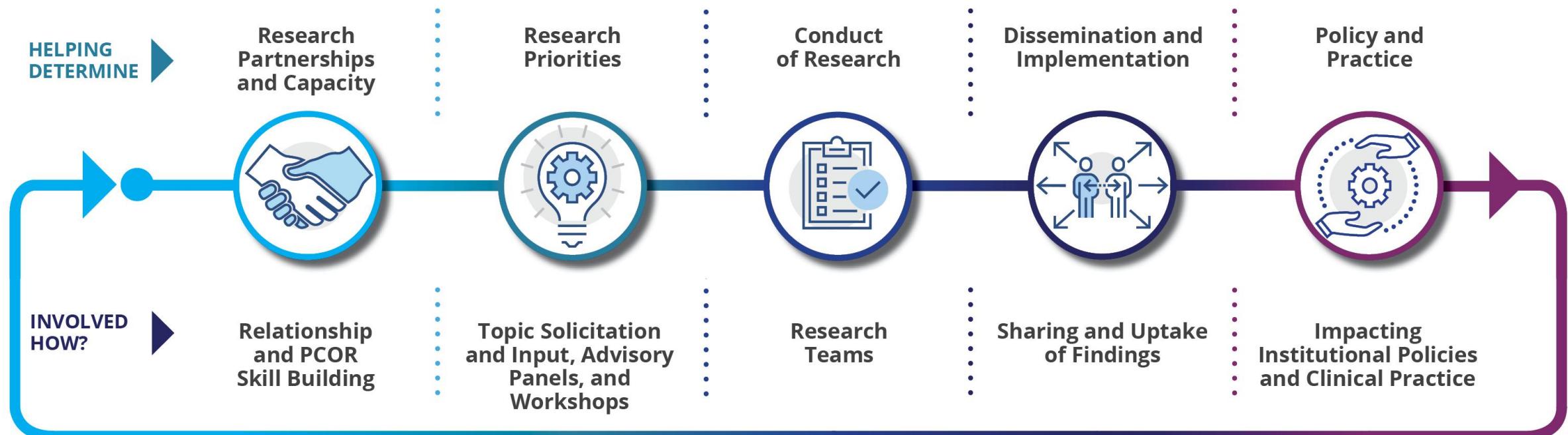
Our Discussion Today



- Provide an overview of recent and ongoing activities within the Public & Patient Engagement team
- Preview upcoming work and opportunities to engage with us
- Hear from you!

PCORI Engagement

PATIENTS AND OTHER STAKEHOLDERS ARE INVOLVED IN...



The Role of PPE: Priorities & Objectives



**Strengthen
stakeholder
relationships**

**Support and
enhance
engagement
practice**

**Build support for
dissemination**

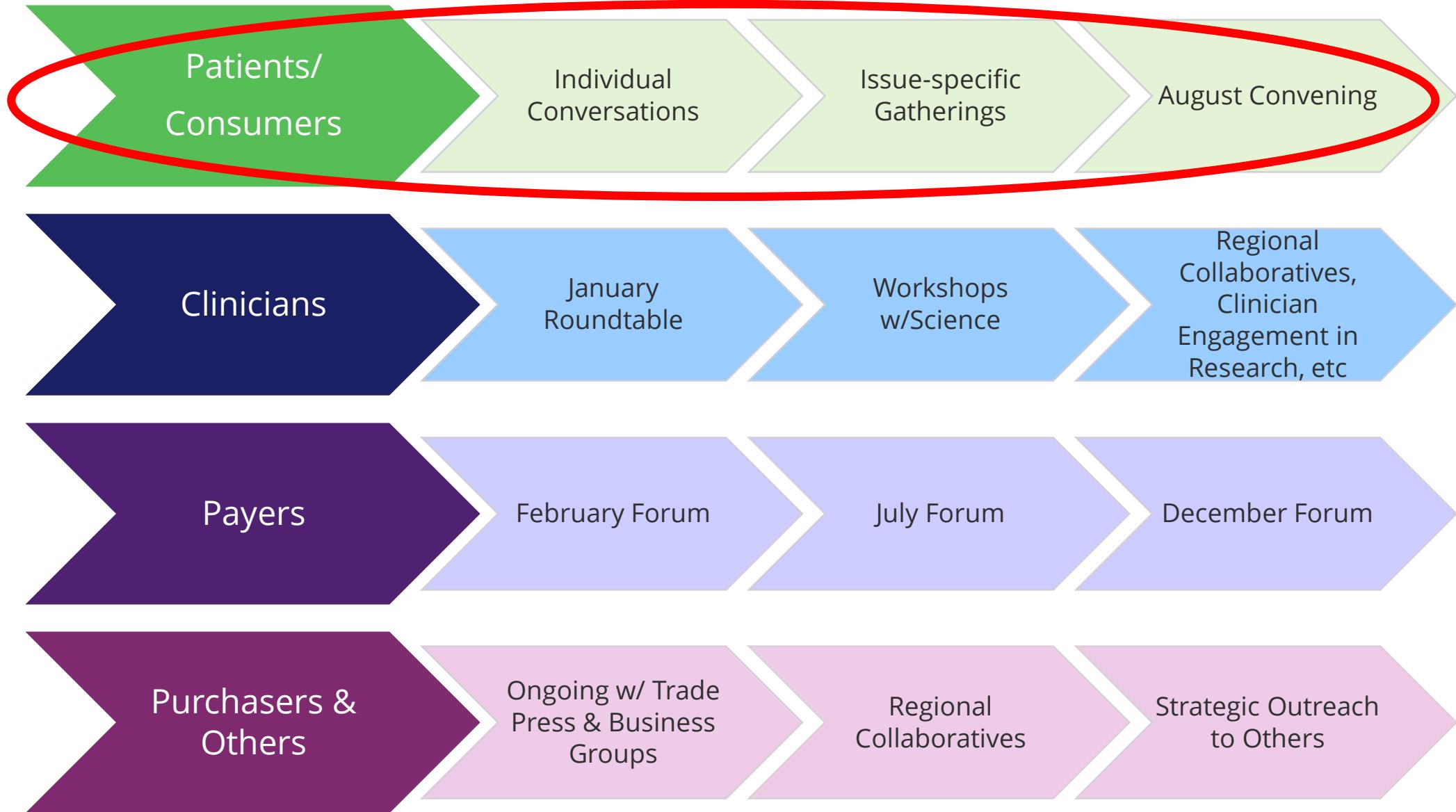
**Advance the
science of
engagement**

Strengthen Stakeholder Relationships

Roundtable forums and targeted convenings serve as primary avenues for engaging stakeholder organizations in strategic dialogue that:

- Helps to tailor PCORI's portfolio and products to stakeholder needs
- Engages stakeholders in discussions of research findings and their implications for decision making and care delivery
- Supports further dissemination of research findings
- Allows for sharing of lessons learned about the impact of engagement

Snapshot of Stakeholder Engagement in 2018



Patient, Caregiver and Consumer Engagement



- Patients, caregivers and consumers remain central to PCORI's mandate and our "true north"
- 2018 touch points provided opportunities for them to:
 - Learn about PCORI's past, current and planned activities for keeping patients at the center of our work
 - Identify ways in which PCORI can better support their organizations' priorities
 - Have their voices heard on the strategic direction on PCORI's future activities
- Touch points throughout the year culminated in a convening of over 30 patient, caregiver and consumer organizations in August, 2018

Patient, Caregiver and Consumer Engagement: Takeaways and Opportunities



Attendees at the August forum expressed strong interest in:

- Working collaboratively with each other and other stakeholders to **advance cross-cutting, "disease and population agnostic" research areas**
- Supporting PCORI's mission through the **translation of activities and research findings to lay audiences**
- Receiving updates on the development of **new training products and tools** that enable researchers and non-researchers to work together more effectively
- Continued funding opportunities that encourage **involvement and leadership from patients, caregivers and consumers**

Consumer Organizations Forum Attendees



- Alliance for Aging Research
- American Association of Kidney Patients
- American Diabetes Association
- American Heart Association
- Autism Speaks
- Black Women's Health Imperative
- Care About Fibroids
- Caregiver Action Network
- COPD Foundation
- Crohn's & Colitis Foundation
- Cystic Fibrosis Foundation
- FH Foundation
- Friends of Cancer Research
- Genetic Alliance
- Global Healthy Living Foundation
- Global Liver Institute
- Institute for Patient- and Family-Centered Care
- Lung Cancer Alliance
- LUNGevity Foundation
- Men's Health Network
- Mental Health America
- National Alliance for Caregiving
- National Alliance on Mental Illness
- National Coalition for Cancer Survivorship
- National Health Council
- National Hemophilia Foundation
- National Kidney Foundation
- National Multiple Sclerosis Society
- National Organization for Rare Disorders
- National Partnership for Women & Families
- National Patient Advocate Foundation
- Partnership to Improve Patient Care
- Society for Women's Health Research
- The Michael J. Fox Foundation
- The Veterans Health Council of Vietnam Veterans of America

Better Partnering with Payers



- Payers are historically underrepresented among engaged PCORI stakeholders
- Opportunity for PCORI to:
 - Build an ongoing relationship and communication channel with payer organizations
 - Better understand payer priorities and interests
 - Share existing and upcoming findings and new initiatives
 - Identify opportunities for future payer engagement and use of PCORI research to aid decision-making and collaboration with other related stakeholders, especially patients and caregivers
- Three forums in 2018 convened over 25 payer organizations

Upcoming Stakeholder Engagement Activity in 2019



Three additional payer forums

Leveraging strategic regional opportunities (e.g., Washington State/Bree Collaborative)

Multistakeholder convenings

- Topic specific
- Potential for additional opportunities that are impact and/or policy focused

Additional engagement with Public Policy to support reauthorization

Support additional outreach to primary care organizations and medical colleges

Support and Enhance Engagement Practice

Improving Engagement Support in Research Studies

Standardization and Greater Integration of Engagement Officers into Research Studies



Internal review to standardize engagement assessments

Workflow analysis, identifying gaps and opportunities for standardized input from EOs

Science & engagement leadership discussion and listening sessions on challenges & needs

EO integration operationalized in 2018, including standardized, updated engagement plan milestone

Updated Engagement Plan Milestone



Recognizing that many aspects of a study's engagement plan may change between the submission of the research application and the start of a study, **EOs worked with Science and Program Support colleagues** to develop an updated engagement plan template

- Awardees required to submit updated plan as a milestone document in first 6 months of project
- Opportunity for hands-on technical assistance from the Practice of Engagement in Research Program—all plans reviewed and direct feedback provided
- Introduces new level of documentation and accountability on engagement, allowing for more in-depth analysis of influence and impact on study outcomes and better insight into make-up of partners

Practice of Engagement in Research Program



- Currently, Engagement Officers actively manage 66 targeted and pragmatic clinical studies
- In fiscal year 2018 EO's provided technical assistance through:
 - Monthly project teleconferences
 - 27 site visits and ad hoc consultations
 - Review of 35 updated engagement plans
- EO's also share practice-based findings and observations by developing and delivering:
 - Webinars e.g.: Guidance for Completing PCORI's Updated Engagement Plan for New Awardees and Future Applicants
 - Blogs and Speaking engagements
 - Leading and participating in analysis of data on engagement and development of tools and publications

Advancing the Science of Engagement

Understanding The Science of Engagement

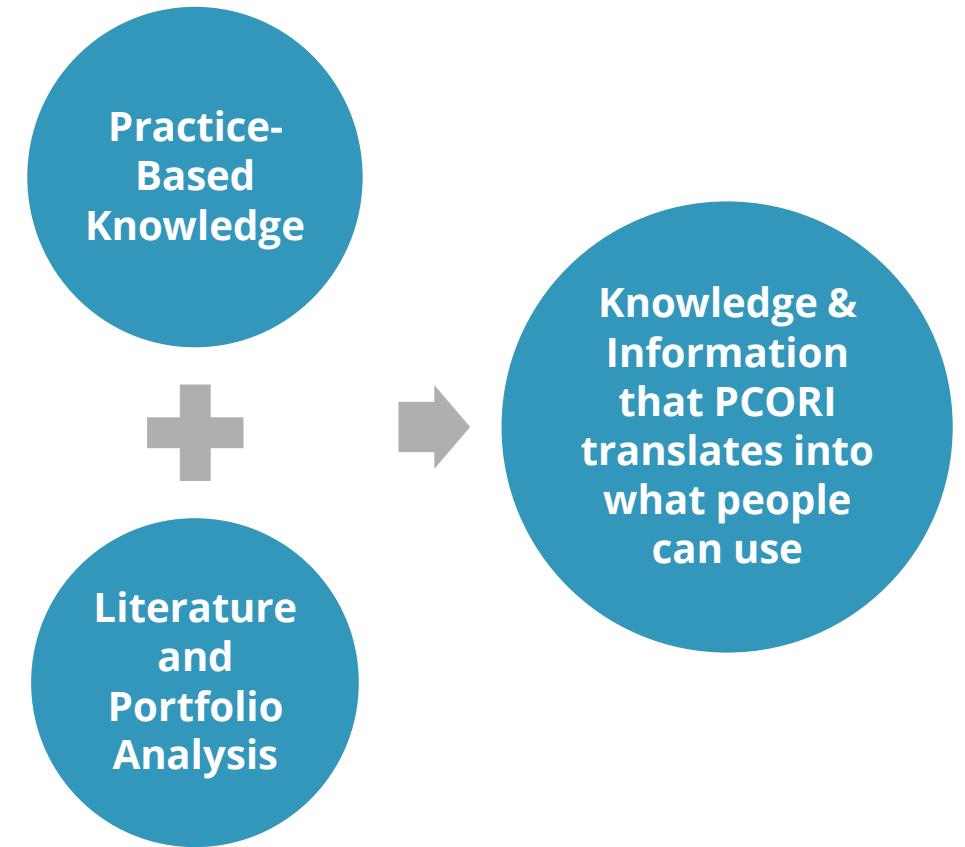


What is happening?

- 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.



Application of Findings



Generate new knowledge

- Alternative forms of input
- Translation to engagement in care delivery
- Engagement of representative populations
- Measurement

Enhance PCORI's approach to engagement

- Inform programs
- Development of guidance
- Future research/evaluation

Develop products to improve practice

- Resources
- Tools
- Trainings

Advance the field

- Identifying and describing successful practices
- Publications

Current Projects to Improve Engagement

In Partnership with and Developed for Stakeholders to Improve Engagement Practices



Project	Output	Timeframe
Research Portfolio Data Mining	Document how engagement has influenced conduct of PCORI studies and how effective engagement has been achieved to support the development of guidance and resources and the updating of the PCORI Engagement Rubric.	10/26/2017-1/30/2020
PCORI CER & Team Science Training	Online training curricula for non-scientist research partners and multistakeholder research teams	10/26/17 – 5/31/20
Talking about Data	A patient-centered guide to support researcher / stakeholder partnership in data analysis	7/1/2018-1/31/2019
Mentor Training Environmental Scan	Environmental scan and literature review that will inform targeted recommendations for the improvement of the Merit Review Mentor Training Program	7/1/2018-1/31/2019
Clinician Engagement	Environmental scan and interviews aimed at collating recommendations to helping clinicians partner with clinical researchers	10/29/2018-8/2/2019

Upcoming Projects to Improve Engagement

In Partnership with and Developed for Stakeholders to Improve Engagement Practices



Project	Purpose
Engagement Tool Identification, Creation, Expansion & Cataloging Across the Research Portfolio	Make widely available engagement resources developed by research awards teams via a searchable database
Developing and Applying Innovative Methods for Stakeholder Input into Research Topic Prioritization	Improved processes for PCORI to gather and utilize stakeholder input
State of the science and practice of engagement convening	Opportunities to learn from other organizations and innovate engagement processes
Improving Diversity in Engagement and Representativeness Among Patient Partners	Identify best practices for engaging representative populations
Landscape review on Measurement	Assess the landscape of engagement measures to inform next steps

Build Support for Dissemination

PCORI Ambassador Program



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.

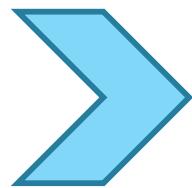
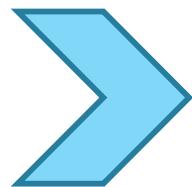
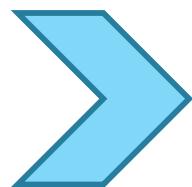
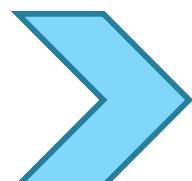
Vision

PCORI Ambassadors are knowledgeable volunteers who have elected to "spread the word" about PCORI and PCOR throughout their networks.

Ambassadors will advance PCORI's organizational mission by engaging in research, knowledge sharing, and/or conducting outreach activities or trainings in their respective communities.

Ambassador Program Strategic Objectives



-  **Build & Promote PCOR Community** by informing and empowering local communities or networks to engage with and promote PCOR research.
-  **Share & Translate Results** through community-based efforts with a focus on PCORI-funded results and products.
-  **Engage with PCORI** by acting as a diverse body of stakeholders for potential involvement in merit review, peer review, research and engagement awards, and more.
-  **Recruit & Retain PCORI Supporters** by promoting funding opportunities, sharing PCORI "story", and building Ambassador membership.

New Ambassador Center



pcori Patient-Centered Outcomes Research Institute

BLOG NEWSROOM HELP CENTER SUBSCRIBE CAREERS CONTACT

ABOUT US RESEARCH & RESULTS TOPICS ENGAGEMENT FUNDING OPPORTUNITIES MEETINGS & EVENTS

Engagement > Engage with Us > PCORI Ambassador Program > Who are PCORI's Ambassadors?



Who are PCORI's Ambassadors?



Ambassador Center

Looking for an Ambassador in your area with similar interests? Or simply looking to connect with a fellow Ambassador? If so, take a look at our new Ambassador Center.

Find Ambassadors by:

PPE Support for Cross-Departmental Engagement Efforts



Topic-specific workshops (e.g., telehealth, care transitions)

- Working closely with colleagues in Science to help shape PCORI's research portfolio and address issues relevant to dissemination and uptake
- Conceptualizing meeting topics, agendas, materials, identifying attendees and facilitation needs

Eugene Washington PCORI Engagement Awards Program

- Reviewing proposals
- Raising awareness among stakeholder communities regarding appropriate funding opportunities, particularly newer opportunities, focused on dissemination
- Ad hoc technical assistance and relationship building among awardees, colleagues, etc.

Current PCORI Efforts to Assess Potential Impact of Key Projects

Understanding the Potential of PCORI Research: Impact Analyses



- Looks at potential economic and health outcome impact of PCORI research findings, including impact on patients/caregivers, payers, and employers
- The first set of analyses are available at *impact.pcori.org* (see visual on next slide)

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Addressing Type 2 Diabetes

What would happen if people with type 2 diabetes who don't use insulin stopped daily self-monitoring of their blood sugar levels? Over five years in the United States, estimated benefits include:



BENEFITS TO PATIENTS

- **10 billion** finger sticks avoided
- **\$1,630** saved per patient in testing supplies
- **NO** negative impact on health



REDUCED COSTS AND USE OF HEALTHCARE RESOURCES

- **10 billion** test strips not used
- **\$12 billion** saved in healthcare costs
- **7 million** people in the target population

Forthcoming Impact Analyses



- Upcoming analyses include:
 - Impact of timing for surveillance testing for people treated for colorectal cancer
 - The use of TNF-inhibitors vs. steroids for Crohn's disease
 - Broad vs. narrow spectrum antibiotics
 - 2 more to be determined



**Kristin
Carman**
Director

Practice of Engagement in Research Program



Julie K. Lesch
Engagement Officer



Denese Neu
Engagement Officer



**Chinenye
Anyanwu**
Engagement Officer



Lisa Stewart
*Team Lead,
Sr. Engagement Officer*



**Meghan
Berman**
*Program
Associate*



Krista Woodward
*Sr. Program Associate, Program Associate
Ambassadors Program*



Alana Cole

Special Projects



**Michelle
Johnston-
Fleece**
*Sr. Program
Officer*

Public Engagement



Jonathan Moore
Associate Director



**Charmaine
Boone**
*Speaker Bureau
Project
Coordinator*



**Aleksandra
Modrow**
*Sr. Adminstrative
Assistant*



TBH
*Program
Associate*



Emma Kopleff
Program Officer



Whitney Brower
*Program Associate,
Merit Review*

Thank You!

Questions?

BREAK

We will return at
approximately 10:30am EST

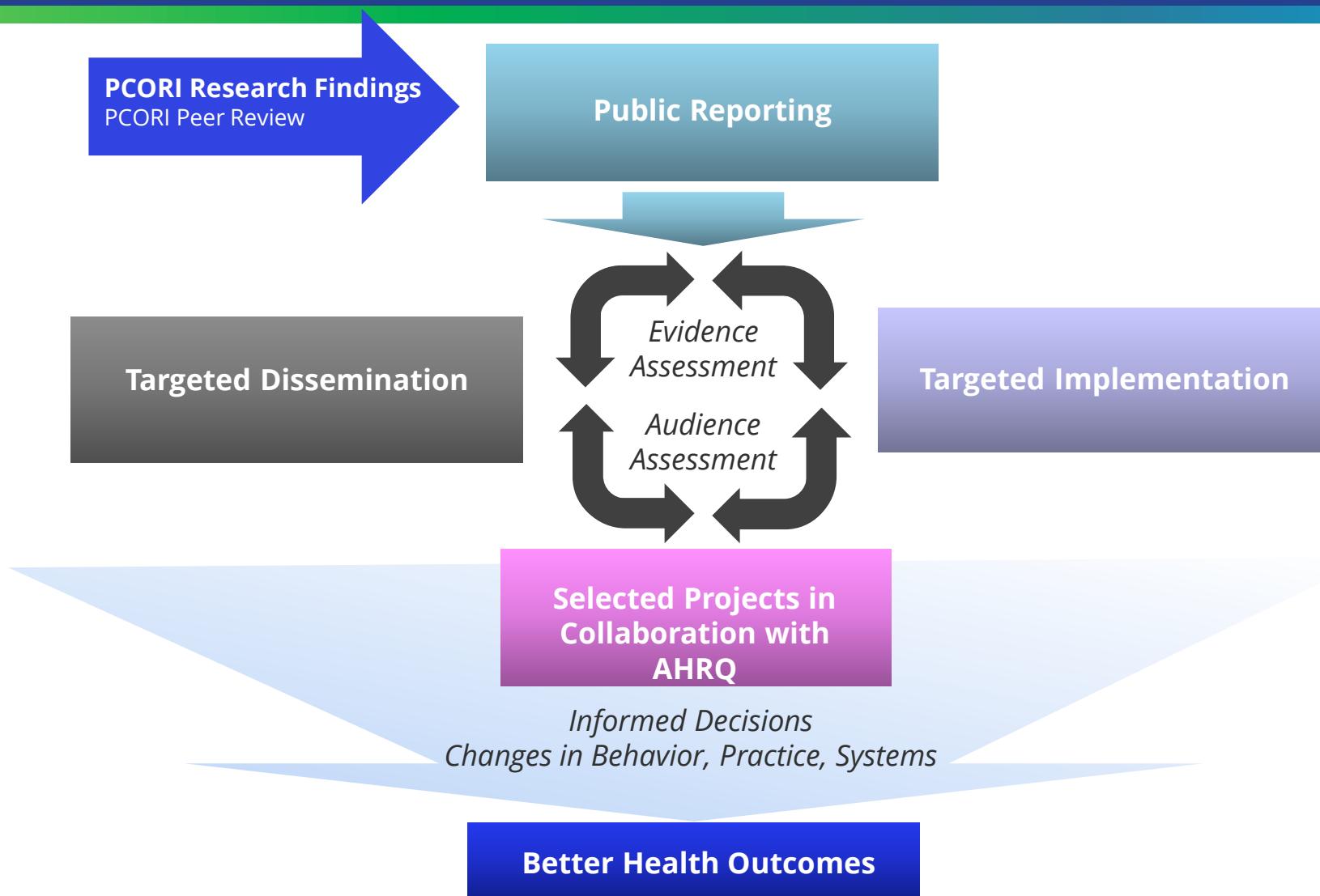


PCORI Dissemination & Implementation

Joanna Siegel
Director, Dissemination & Implementation

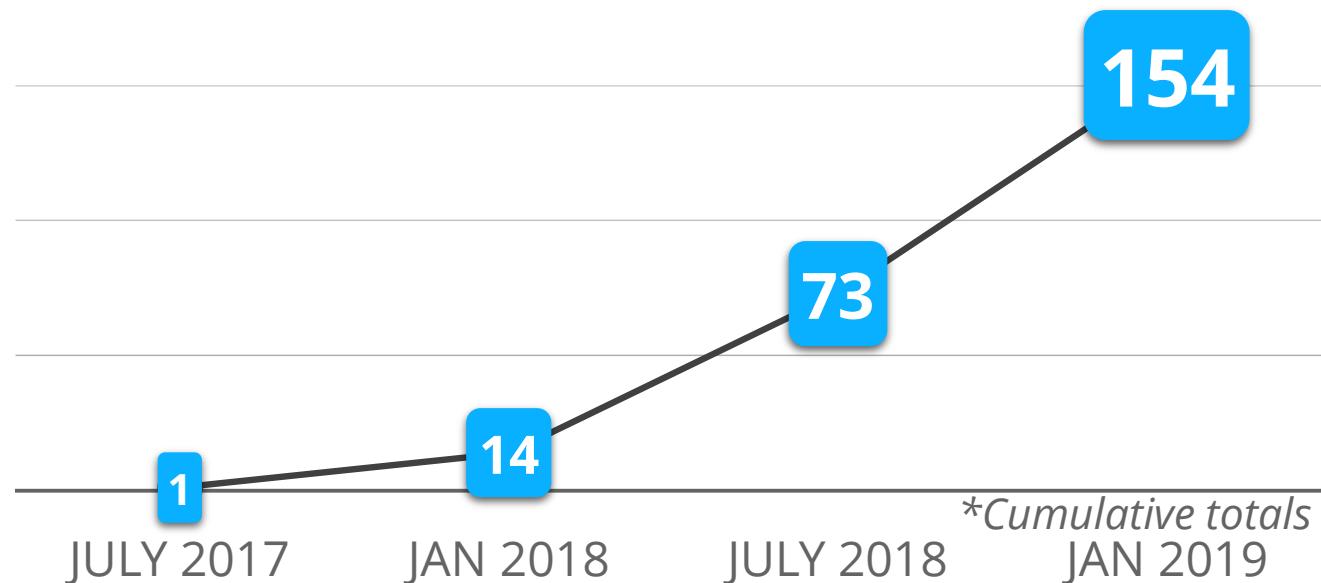
Lia Hotchkiss
Director, Eugene Washington Engagement Awards Program

PCORI Dissemination & Implementation of Research Results



Release of Findings: Completed PCORI studies

Public and professional abstracts posted to PCORI.org



Public Reporting of PCORI Research Findings following Peer Review



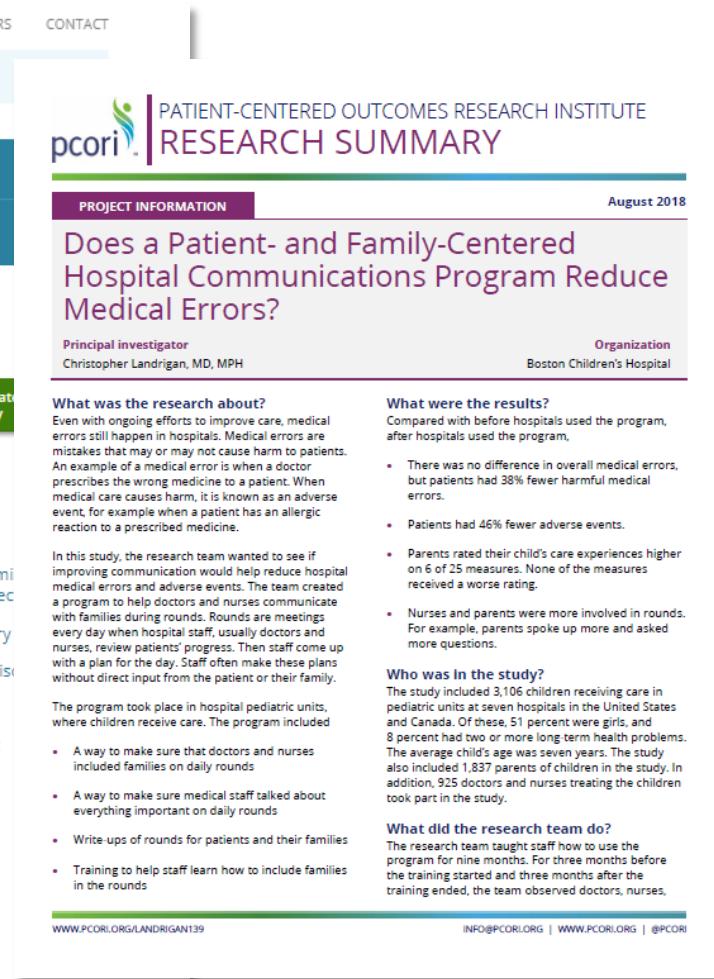
- PCORI's authorizing law and the processes adopted by the Board outline approach for releasing findings
 - To assure **accessibility and full transparency** in reporting results from PCORI studies.
- **Within 90 days** of PCORI's acceptance of the draft final research report (DFRR) following peer review, we release (post to pcori.org):
 - Public abstract -- Lay language, 6-8th grade reading level, ≈500 words
 - Professional abstract – PICOT details; ≈500-words
 - Summary of peer review process
- PCORI support for open access to findings published in peer-reviewed journals

Posted Results: The Public Abstract





The screenshot shows the PCORI website's research summary page for a study titled "Does a Patient- and Family-Centered Hospital Communications Program Reduce Medical Errors?". The page includes a navigation bar with links to About Us, Research & Results, Topics, Engagement, Funding Opportunities, and Meetings & Events. Below the navigation is a breadcrumb trail: Research & Results > Explore Our Portfolio > Does a Patient- and Family-Centered H... The main content area features the study title, a "Public Abstract" button (which is highlighted in blue), and a "Professional Abstract" button. The study summary discusses the objective of testing the effectiveness of a communication program between physicians, nurses, and families, and the study design, which is a quasi-experimental study involving 3,106 patients, 1,837 parents, 330 nurses, and 595 resident physicians across 7 pediatric hospitals. The outcomes are primary medical errors and adverse events.



The screenshot shows the "RESEARCH SUMMARY" document for the same study. The document is dated August 2018 and includes sections for "PROJECT INFORMATION", "Does a Patient- and Family-Centered Hospital Communications Program Reduce Medical Errors?", "Principal investigator" (Christopher Landrigan, MD, MPH), "Organization" (Boston Children's Hospital), "What was the research about?", "What were the results?", "What were the results?", "Who was in the study?", and "What did the research team do?". The "What was the research about?" section describes medical errors as mistakes that may or may not cause harm to patients, with an example of a doctor prescribing the wrong medicine. The "What were the results?" section highlights a 38% reduction in harmful medical errors and 46% fewer adverse events. The "Who was in the study?" section details the study population of 3,106 children across 7 hospitals. The "What did the research team do?" section describes the training of staff to include families in rounds.

Dissemination of Findings from PCORI-Funded Studies



Definitions: Dissemination



The intentional, active process of identifying target audiences and tailoring communication strategies to **increase awareness and understanding of evidence and to motivate its use** in policy, practice, and individual choices.

-- PCORI Dissemination and Implementation Framework; 2015

- Dissemination activities are designed to bring results to targeted audiences that will have a strong interest in using them.
- Key objectives: increasing **reach, motivation, and ability** to use the findings.

Dissemination generally is not enough to ensure implementation. But sometimes it's a necessary first step – and some findings may benefit from dissemination alone.



Engagement Award Funding Opportunities (Jan. 2019)



Up to
\$300,000
2 years

Engagement Award: Dissemination Initiatives

Objective: Actively disseminate PCORI-funded research findings

Up to
\$250,000
2 years

Engagement Award: Capacity Building

Objective: Develop infrastructure and partnerships for D&I of PCORI-funded research findings

Up to
\$50,000
1 year

Engagement Award: Conference Support

Objective: Convene to communicate PCORI-funded research finding to targeted end-users

Engagement Award: Dissemination Initiative



Gives organizations and communities the opportunity to propose meaningful dissemination projects aimed at spreading awareness and increasing knowledge of new evidence from PCORI-funded research.

Draws on the role of the “trusted source” to bring relevant findings to users in ways that will command their attention and interest, through organizations with **established relationships** with end-users.

Which Findings?

- Primary findings **published in peer-reviewed journals**,
- PCORI Evidence Updates, PCORI CME, findings from PCORI-funded systematic reviews.

Eligibility: All PCORI-eligible organizations; **major involvement of stakeholder** partner required

Budget: \$300k total costs, up to 2 years

Management of Mental Health Problems Among Gender Non-conforming Youth



Evidence to be Disseminated

- Goodman's study showed that mental health diagnoses were several times more common among transgender children and adolescents than among nontransgender kids of the same age.

Project Objectives

- To educate doctors and nurses, parents, and school counselors about risks facing transgender children and adolescents, and to let them know about available ways of reducing these risks.

Activities

- Create educational materials together with stakeholders and test via online focus groups.
- Final materials will be distributed to partner organizations - Mental Health Research Network, World Professional Association for Transgender Health, American School Counselor Association.

Anticipated Outcomes

- People who receive education will become more knowledgeable about health risks.
- Education will improve care offered to transgender children and adolescents.
- Long-term, this will help lower the risk of life-threatening events and thoughts about suicide.



*Michael Goodman, MD, MPH,
Emory University
Atlanta, GA*



*Addressing Disparities Research Project,
awarded 2013, completed 2018*

Translating Research Into Reality: Creating a Hub Model for Transforming Healthcare



Organization

- The Healthcare Collaborative of Greater Columbus (HCGC) is an affiliate member of the Columbus Medical Association (CMA) and member of the Network for Regional Healthcare Improvement (NRHI).

Project Objectives

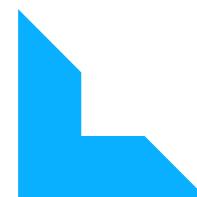
- To identify PCORI-funded research results relevant to their partners, create dissemination pathways/a HUB model for dissemination, and demonstrate and document how dissemination is maximized via a Regional Health Improvement Collaborative (RHIC).

Activities

- Engage with CMA (1000 physician members), HCGC's 38 PFACs (300 Medicare-covered patient lives), and HCGC's Quality Transparency Project (140 practice sites)
- Leverage ongoing activities to disseminate research findings including: face to face meetings; email/e-newsletters; blog posts; social media; and web connection platform.

Anticipated Outcomes

- Increase individuals' knowledge, motivation and readiness to utilize PCORI-funded research findings
- Create a replicable model for dissemination among RHICs across the country.



Carrie Baker
President and CEO
Healthcare Collaborate of Greater Columbus



PCORI Targeted Dissemination – Evidence Updates



Evidence Update for Clinicians:
Current Treatments for Localized Prostate Cancer and Symptom-Related Quality of Life

Given the evidence of high 5- and 10-year survivorship rates for localized prostate cancer, the effect of treatment on symptom-related quality of life is an important consideration for men choosing among available treatment options. Two PCORI-funded studies published in the March 21, 2017 issue of *JAMA* compare the impact of current treatments on symptom-related quality of life for men with localized prostate cancer – quality of life scores reflect symptoms men have experienced by symptoms, or a combination of symptoms. The studies looked at observed outcomes from a combined total of 3,600 men for periods of three years following treatment. This evidence offers information that can help patients:

Summary: Sexual, urinary, and bowel problems were significantly reduced at six months and at one year for men in active surveillance. These symptoms tend to improve over time.

Surgery: (open or r) was more and urina or active

- Sexual follow-up
- White entry conti three like fun (35)
- For lik tu u d

pcori | American Urological Association Education & Research, Inc. | **MHN** Men's Health Network | **ASTRO** American Society for Radiation Oncology

How Will Treating My Early-Stage Prostate Cancer Affect My Quality of Life?

Early-stage prostate cancer can be treated in different ways. Therapy (radiotherapy or brachytherapy) can cause urinary obstruction, bowel problems than surgery. No received problems in the last year, but more than those in the last year.

Two recent PCORI-funded studies compare the effects of these choices on a man's quality of life. These studies looked at three main ways to treat early-stage prostate cancer: active surveillance, surgery, and radiotherapy. Surgery would take months to make sure the cancer is not spreading. Radiotherapy uses high-energy rays to kill cancer cells in the prostate.

Here's what the new research says:

The different ways of treating early-stage prostate cancer (active surveillance, radiotherapy, or surgery) affect men differently. Men who have surgery or radiotherapy have more sexual, urinary, and bowel problems in the first year compared with men who were treated with active surveillance. After 2 to 3 years, most symptoms improve, but there may still be differences.

Surgery

Men who had surgery to remove the prostate (called a total prostatectomy) were:

- more likely to leak urine
- more likely to have problems with sex
- less of a need to rush to the bathroom to pee
- less of a feeling that their pee was unable to come out, or a

But men who had surgery had:

- less of a need to rush to the bathroom to pee
- less of a feeling that their pee was unable to come out, or a

What to expect after surgery:

- About four out of ten men who had surgery still had sexual problems 3 years after surgery. After one year, sexual problems improved. After three years, sexual problems improved for most men.
- About 2 out of every 10 men who had surgery had urinary problems caused by surgery. After one year, urinary problems improved.

Radiation

Men who had radiation to kill cancer cells in the prostate were:

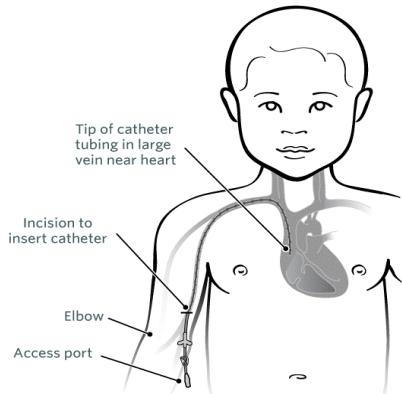
- more likely to feel burning when peeing, more likely to need to rush to the bathroom to pee
- more likely to feel burning when peeing, more likely to need to rush to the bathroom to pee
- more likely to feel burning when peeing, more likely to need to rush to the bathroom to pee

What to expect after radiation:

- Urinary problems were more likely to get better by two years after treatment. The body (external beam radiation) from outside the body (brachytherapy) from pellets placed inside the body (brachytherapy).
- About 2 out of every 10 men who had radiation had sexual problems. These problems started a few months after men had radiation.

- Current Treatments for Localized Prostate Cancer and Symptom-Related Quality of Life*
- Presents findings from PCORI-funded research (2 studies)
- Evidence Updates for **clinicians** and for **patients**
- Co-branded by American Urological Association, American Society for Radiation Oncology, and Men's Health Network

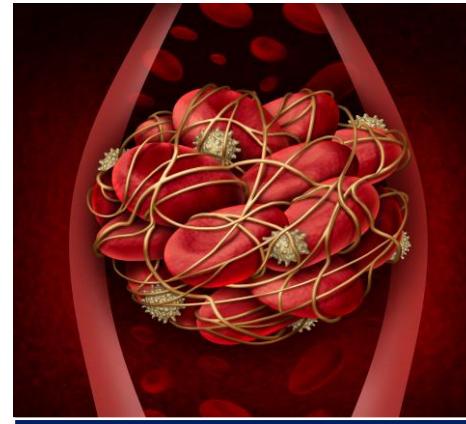
CME Programs



Osteomyelitis in Children
PI: Keren
CME Term: 5/15-6/17
Certificates Issued: 1,211



Type 2 Diabetes
PI: Donahue
CME Term: 12/18-12/19
Certificates Issued: 248



Stroke and AF
PI: Hernandez
CME Term: 9/17-1/20
Certificates Issued: 1,046

Upcoming:



Antibiotics in Children
PI: Gerber
CME Term: 4/19-4/20

New Pathways to Patients and Clinicians: Wikipedia



- Wikipedia is an open resource
- Audiences include patients and **clinicians**
- Wikipedia is editable by anyone, but has many rules for how medical and scientific data can be shared
- Wikipedia edit-a-thons are events where people experienced in working with Wikipedia teach others how to effectively edit Wikipedia pages, providing hands-on support
- PCORI held its first Wikipedia edit-a-thon on January 17th
- *Engagement Award: Integrating Patient-centered Outcomes Research into Wikipedia: An Initiative to Increase Capacity and Build Partnerships (October 2018)*

Wikipedia facts:

- Wikipedia is visited by over 500 million people a month
- More than 50% of physicians use Wikipedia
- More than 90% of medical students use Wikipedia as a resource

Heilman, J. M., & West, A. G. (2015). Wikipedia and medicine: quantifying readership, editors, and the significance of natural language. *Journal of medical Internet research*, 17(3).

Implementation Efforts

Promoting Uptake and Integration of
Findings



Definitions: Implementation



The deliberate, iterative process of **integrating evidence into policy and practice** through adapting evidence to different contexts and facilitating behavior change and decision making based on evidence, across individuals, communities, and healthcare systems.

-- PCORI Dissemination and Implementation Framework; 2015.

- Implementation activities are designed to change practice, bearing in mind the barriers as well as the opportunities in different settings.
- Key objectives: **adapting** evidence as appropriate for specific contexts, incorporating that evidence to inform decisions, and **integrating** into workflow or other processes in a sustainable way.

PCORI D&I Program Funding Initiatives



Limited Competition: Implementation of PCORI-Funded PCOR Results

- Provides PCORI investigator teams the opportunity to propose the next steps to put their findings into real world practice.
 - *Up to \$1M direct costs per project; \$9M available per year*

Implementation of Effective Shared Decision Making (SDM) Approaches

- Promotes the implementation and systematic uptake of shared decision making in practice settings. SDM approaches can be those previously studied in PCORI CER, or existing, effective SDM strategies (not PCORI-funded) that incorporate findings from PCORI research.
 - *Up to \$1.5M direct costs per project; \$6-\$8M available per year*

Implementation of Findings from PCORI's Major Research Investments

- Provides a broad application pool the opportunity to propose multicomponent strategies that will lead to uptake and integration of PCORI-funded evidence, in the context of related evidence, into real world practice.
 - *Up to \$2.5M total costs per project, \$8M available per year*

D&I Project: Advance Planning for Services to Keep Seniors at Home



Original study developed and tested a web-based tool (PlanYourLifespan) to educate seniors on health crises that often occur with age and connect them to home-based resources that can provide support. 2013; IHS \$1,9M

Findings

Use of PlanYourLifespan led to improvements in

- Planning behavior score ($p < 0.01$)
- Home services knowledge ($p < 0.05$)

Satisfaction scores were significantly higher for PlanYourLifespan users than for the control group.



- People with unmet health and home-based needs face increased rates of hospitalizations, re-hospitalizations, morbidities, and institutionalization.

*Lee Lindquist, MD, MPH, MBA,
Northwestern University at Chicago
Chicago, IL*

Implementation of PCORI Funded Patient-Centered Outcomes Research, awarded March 2017

Patient/Caregiver Advocates' Involvement in Dissemination and Implementation



D&I Project will implement PlanYourLifespan through two community organizations: FirstVitals (Hawaii) and Pastors4PCOR (Chicago), training community members who will promote access in their communities.

- PI received hundreds of emails from people asking how they could help disseminate PlanYourLifespan in their own communities
- **Lincoln Park Village**
 - Community organization working to enhance seniors' quality of life
 - Responsibilities for this project include advising on the toolkit, training a future trainer, troubleshooting protocols, and helping to interpret evaluation results.
- **Pastors4PCOR**
 - Ministry project that seeks to increase the participation of underserved communities of color in comparative effectiveness research
 - Training 3-5 community members on the PlanYourLifespan materials
 - Working with community seniors as part of this project

Questions and Discussion



BREAK

We will return at
approximately 12:45pm ET



Meet and Greet

Kara Ayers

Patient Representative,
PCORI Board of Governors



Kara Ayers



Kara Ayers, PhD, is an Assistant Professor in the Department of Pediatrics at the University of Cincinnati. Her areas of interest and research include disability policy, parenting with a disability, self-advocacy, psychosocial development with a disability, and disability in the media. Ayers is the co-founder of the Disabled Parenting Project, a peer-to-peer support network for parents with disabilities. She has served for the past five years on the boards of the Osteogenesis Imperfecta Foundation and The Association for Successful Parenting. Ayers received her PhD in clinical psychology from Nova Southeastern University.

PCORI Board of Governors

- Research Transformation Committee
- Selection Committee



Communications Update

- 2018 Annual Meeting
- Communicating for Impact

Bill Silberg
Director, Communications

Blake Whitney
Senior Editor, Communications

Marla Bolotsky
Associate Director, Digital Media, Communications

Krista Woodward
Senior Program Associate, Public & Patient Engagement

2018 Annual Meeting

What Worked, What Can Be Better

Bill Silberg

Director, Communications



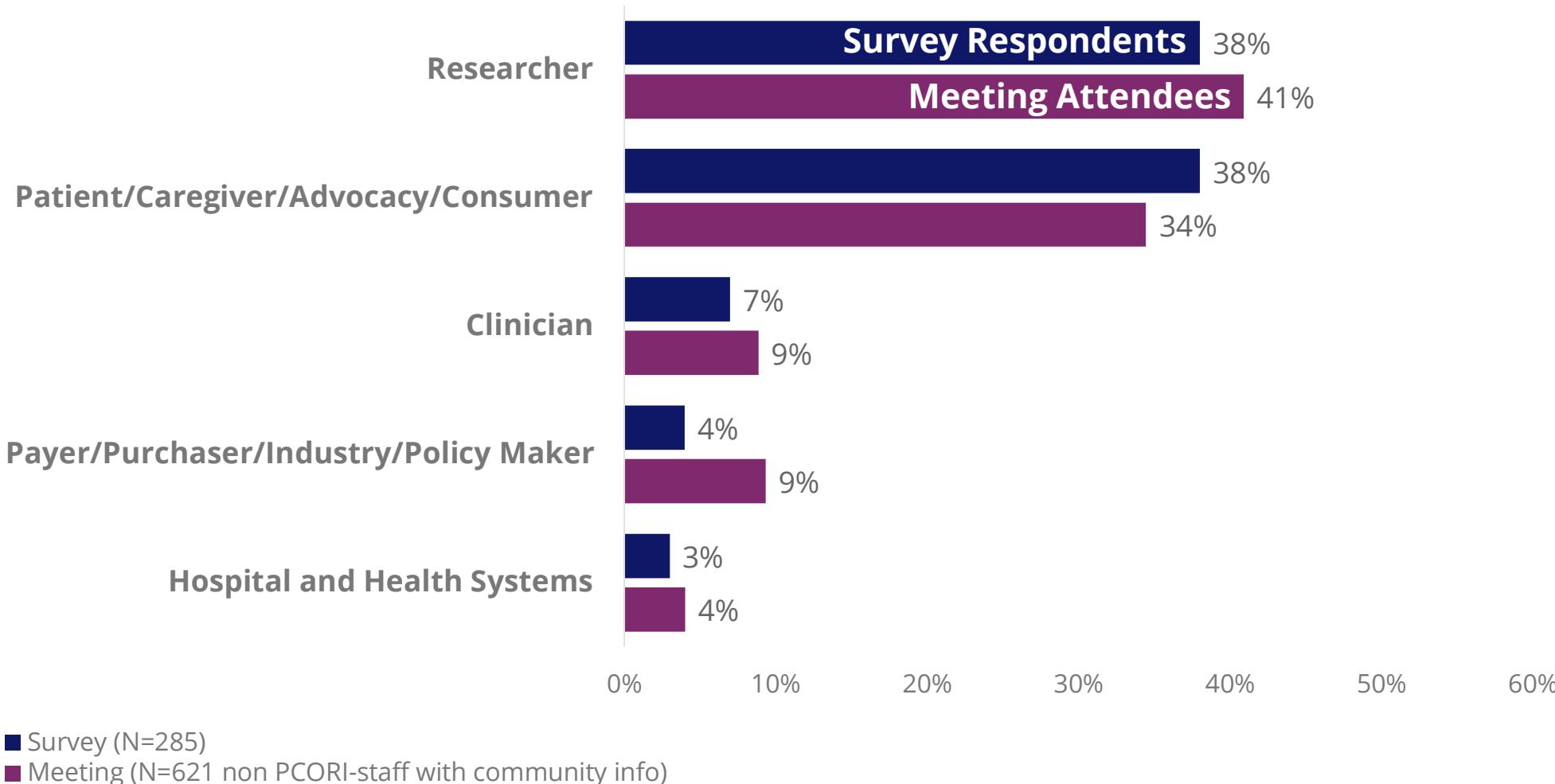


Summary



- The 2018 Annual Meeting, like previous meetings, **was well received**
- As in previous years, **networking is the top reason for attending**
 - Perceptions of networking opportunities improved from 2017
- **Sessions presented impactful research results and useful information**
 - Ratings of usefulness of sessions increased from 2017
- Respondents valued **learning about PCORI** (both the organization and specific projects)

Survey Respondents Largely Reflected Meeting Attendees



Reasons for Attending Annual Meeting



Networking is the top reason for attending the 2018 Annual Meeting

1. Networking with others (70%)
2. Learning about the results of PCORI-funded studies (63%)
3. Learning about PCORI's progress (60%)
4. Learning about PCORI's opportunities/activities in dissemination of research findings (60%)
5. Learning about stakeholder/public and patient engagement in research (56%)

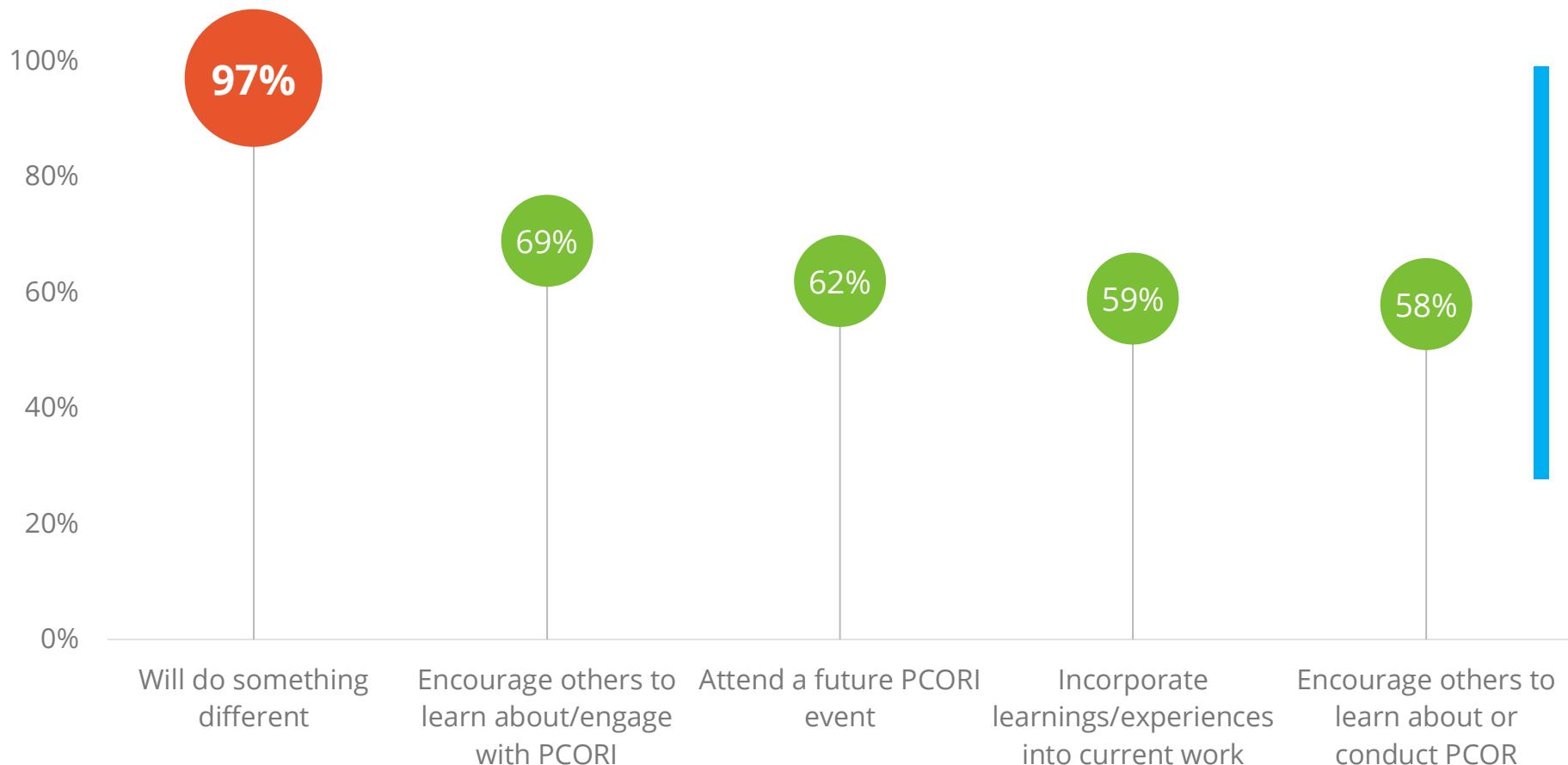
Reasons mirror qualitative feedback about **most valuable aspects** of the meeting

- Networking was most valuable in 23% of responses, followed by learning about engagement and learning about PCORI
- Both quantitative and qualitative results indicate respondents still value learning about PCORI as an organization

Meeting Will Spur Attendees To Action



- Most respondents indicated that they would do something different after the meeting*



“
I loved that the stakeholders were involved in the presentations on stakeholder engagement and now am thinking differently about engaging patient groups in my rehabilitation intervention development work. – *Researcher*

*Not mutually exclusive

Research Results Viewed as Impactful



- Respondents agreed that research results presented at the meeting were impactful

Research Results Will Impact Clinical Practice



Research Results Will Impact the Healthcare System



- 92% agreed that the meeting provided useful information that will help inform their future work or healthcare decisions
 - Up from 85% in 2017



Trends Over Time



- Compared to previous Annual Meeting surveys....
 - The proportion of patient/caregiver/advocacy respondents has increased
 - Responses were **more favorable** in 2018 compared to prior years for:
 - Usefulness of the research PCORI funds to respondents' future work or healthcare decisions
 - The value of the meeting for generating discussions about relevant topics
 - The value of the meeting for facilitating new relationships within and between researchers and stakeholders
 - Satisfaction with logistics and meeting amenities

Study Findings Presented Will Be Useful



- >90% of respondents thought results presented in the plenary and breakout sessions will help patients and those who care for them make better-informed decisions about the healthcare choices they face
 - Patients were most likely to strongly agree

Keep it
Up

“

The breakout sessions were outstanding. The speakers on each panel were outstanding. I learned how impactful peer navigators can be overall and specifically to asthma patients and to people in low-income areas. I learned about challenges of patients with Parkinson's and want to learn more. – *Patient*

“

I learned a ton about the impact projects are having on research & outcomes. It was refreshing to see science appreciated, celebrating a number of successes as result of PCORI. – *Policy Maker*

Sessions Included Diverse Stakeholders



- At least ¾ of respondents thought the plenary and breakout sessions contained diverse stakeholder groups
 - This was one of the most liked aspects of the sessions
 - Stakeholders could have larger roles during the presentations, however

“

I enjoyed the different perspectives from projects presented. Having patients in the panels was really valuable for me because [it] made me realized the importance of my work (I am new to this). – *Researcher*

“

Make sure patients are a part of every presentation. In one plenary, the moderator did not even acknowledge that the patient/researcher was on the stage! – *Patient*

Plenary/Breakout Discussions Were Useful



- Similarly, over ¾ of respondents agreed that discussions were useful additions to information shared during the presentations

“

I truly appreciated the research topics and panel discussions. The panel discussions in particular added different perspectives to the topic presented and how research and patient involvement impacts the outcomes – *Advocacy Group Representative*

- Respondents thought discussions were engaging and a good way to more thoroughly learn about the topic
- Compared to 2017, fewer respondents complained about speakers' use of jargon
- As in previous years, respondents indicated that Q&A sessions could be better structured

Comments



“

“I would like to see a workshop that deals more directly with the question of best practices in getting PCORI results in the hands of patients most affected by the focus of the research.”
—Advocacy Group Representative

“

“Make sure patients are a part of every presentation. In one plenary, the moderator did not even acknowledge that the patient/researcher was on the stage!” —Patient

“

“I enjoyed the different perspectives from projects presented. Having patients in the panels was really valuable for me because [it] made me realized the importance of my work (I am new to this).”
—Researcher

“

“I truly appreciated the research topics and panel discussions. The panel discussions in particular added different perspectives to the topic presented and how research and patient involvement impacts the outcomes.” —Advocacy Group Representative

Opportunities/Suggestions



- Stakeholders – especially patients – could have larger roles in presentations
- Respondents would like to see more sessions on Dissemination & Implementation and Engagement in 2019
- Q&A sessions could be better structured
- Selected improvements for presenting posters
- Logistical improvements

Communicating for Impact

Bill Silberg
Director, Communications

Blake Whitney
Senior Editor, Communications

Marla Bolotsky
Associate Director, Digital Media, Communications

Krista Woodward
Senior Program Associate, Public & Patient Engagement



Communications: Key to PCORI's Work



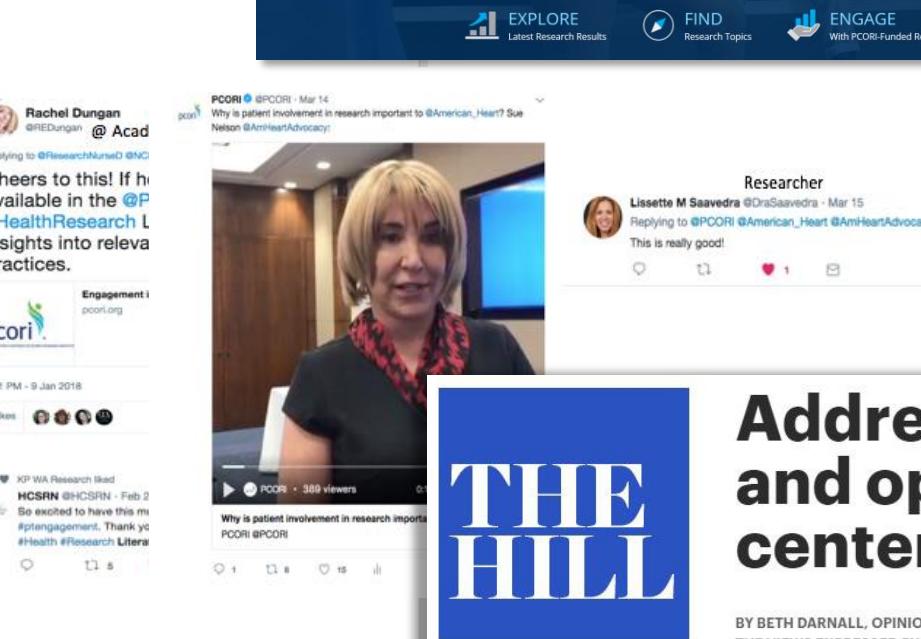
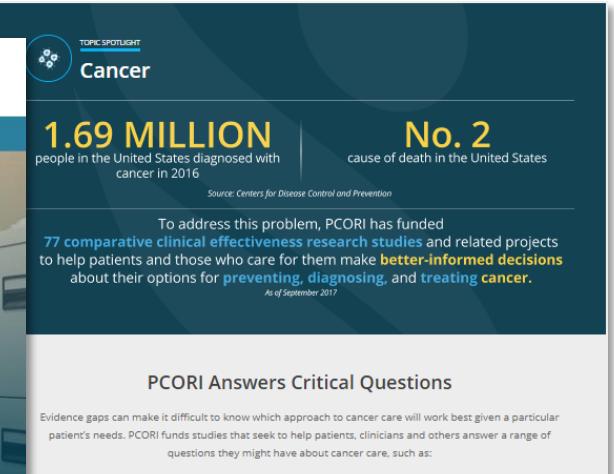
- Communications is integral to supporting PCORI's strategic goals
- As PCORI has matured, communications has become more strategic (beyond general programmatic support)
 - Less concern about general visibility and awareness
 - Advancing thought leadership on key issues
 - Illustrating the “value proposition” to support reauthorization
 - Promotion of study results with impact
 - Promoting themes and messages that speak to stakeholders

What Ties This all Together? Storytelling



- Why? Stories have power
 - They make the technical accessible
 - They make the aspirational real
 - They make the conceptual personal
- Stories show how our work is serving stakeholders and motivates them to advance our interests as aligned with their own
 - Blogs, narratives and op-eds
 - Graphics and video
 - Web content and features
 - Media and social media

How We Tell the Stories of Our Work



Addressing the dual crises of pain and opioids — a case for patient-centeredness

BY BETH DARNALL, OPINION CONTRIBUTOR — 10/31/18 06:00 PM EDT
THE VIEWS EXPRESSED BY CONTRIBUTORS ARE THEIR OWN AND NOT THE VIEW OF THE HILL

How We Tell the Stories of Our Work



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
1828 L STREET NW, SUITE 900
WASHINGTON, DC 20036
202.827.7700

RESEARCH SPOTLIGHT ON
Cardiovascular Disease

Heart disease remains one of the leading causes of death in the nation, even with many efforts to prevent, diagnose, and treat cardiovascular conditions. When heart disease and stroke are not controlled, they can lead to decreased quality of life. Heart disease and stroke cost the nation productivity in 2011, according to the US Department of Health and Human Services.

Heart disease is the **#1** cause of death in the United States.

Research Addressing Questions That Matter
PCORI funds comparative effectiveness research (CER) to determine which healthcare options work best for which patients, based on their needs and preferences. CER produces evidence that helps people make better-informed healthcare choices.

STUDY SPOTLIGHT
Older vs. Newer Drugs for Preventing Recurring Blood Clots
Patients who have a blood clot typically receive a blood thinning drug for three to six months. This study will compare two newer drugs, rivaroxaban and apixaban, to one another and to the older drug warfarin to evaluate each drug's safety and effectiveness in preventing further clots in people who are at high risk for another. *More information may be found at www.pcori.org/Orte005.*

Keep Informed
Using research to improve the health of all Americans, from the sick to the healthy, is the mission of the Patient-Centered Outcomes Research Institute (PCORI). PCORI funds comparative effectiveness research (CER) to determine which healthcare options work best for which patients, based on their needs and preferences. CER produces evidence that helps people make better-informed healthcare choices.

Project Information

Principal Investigator Ron Keren, MD, MPH
Other Principal Investigator John Smith, MD, MPH
Project Title Comparative Effectiveness of Intravenous vs. Oral Antibiotic Therapy for Serious Bacterial Infections
Project End Date April 2016

pcori | **Urology Care Foundation** | **MHN**
How Will Treating My Early-Stage Prostate Cancer Affect My Quality of Life?

Early-stage prostate cancer can be treated in different ways. The three main ways are active surveillance, surgery, and radiotherapy. Active surveillance means having your prostate checked every few years for spreading. Surgery would take out the prostate. Radiotherapy would use high-energy rays to kill cancer cells.

RESEARCH SPOTLIGHT ON
Comparing Oral to IV Antibiotics for Children With Serious Infections

For a downloadable version of the abstract, [click here](#).

What was the research about?
Researchers studied whether children who have been in the hospital with serious infections do better when they go home with antibiotics by mouth or by IV.

What did the research team learn?
Both ways of delivering antibiotics work about the same at treating infection. Some children who had antibiotics by IV had problems with the IV equipment, not the medicine. These children were more likely to come back to the emergency room or stay in the hospital again because of those problems. Children who took antibiotics by mouth had fewer problems than those who got antibiotics by IV.

How can these results help people make better choices?
When children have serious appendicitis, pneumonia, or bone infections, their families and doctors can use this information to decide which way to give antibiotics after the children leave the hospital.

Who was in the study?
Researchers looked at health records for more than 8,600 children and teens between the ages of 2 months and 18 years.

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pcori | **PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE**

RESEARCH SPOTLIGHT ON
Cancer

There are more than 100 kinds of cancer, each with a distinct pathology and a unique set of environmental triggers. People facing a cancer diagnosis often face decisions over several different ways to treat the disease. These decisions are based on individual circumstances and preferences.

1.69 MILLION
people in the United States were diagnosed with cancer in 2016

\$87.8
is estimated to be spent for cancer in the United States

Radiation
Men who had radiation to the prostate were:

- more likely to feel fatigued
- more likely to feel the need to rush to the bathroom
- more likely to feel the need to have a bowel movement
- more likely to have urinary problems or difficulty urinating

What to expect after treatment

- Urinary problems were more common by two years after treatment (radiation from outside or internal radiotherapy) than in men who had implants placed inside the prostate.
- About 2 out of every 10 men who had sexual problems after treatment had problems within 12 months after men had radiation.

Research Addressing Questions That Matter
PCORI funds comparative clinical effectiveness research (CER) to determine which healthcare options work best for which patients, based on their needs and preferences. CER produces evidence that helps people make better-informed healthcare choices.

STUDY SPOTLIGHT
Patient-Centered Information for Decision Making in Localized Prostate Cancer

This study analyzed quality of life changes over three years among prostate cancer patients who received either radical prostatectomy (surgery), external beam radiotherapy (radiation), or those who pursued active surveillance. It found that those who had either surgery or radiation reported more adverse effects. However, quality of life levels evened out among all patients after three years. *More information may be found at www.pcori.org/Chen007.*

STUDY SPOTLIGHT
North Carolina Comparative Effectiveness Study

This project examined quality of life changes over three years among prostate cancer patients who received either radical prostatectomy (surgery), external beam radiotherapy (radiation), or those who pursued active surveillance. It found that those who had either surgery or radiation reported more side effects than those who chose active surveillance. It also found that quality of life levels and adverse effects were similar after 24 months, regardless of the strategy chosen. *Further details are at www.pcori.org/Chen008.*

pcori | **PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE**
ABSTRACT

PROJECT INFORMATION
Comparing Antibiotics by Mouth or IV for Children with Serious Infections

Principal Investigator Ron Keren, MD, MPH
Organization The Children's Hospital of Philadelphia
State Pennsylvania

WHAT WAS THE RESEARCH ABOUT?
Researchers studied whether children who have been in the hospital with serious infections do better when they go home with antibiotics by mouth or by IV.

WHAT DID THE RESEARCH TEAM LEARN?
Both ways of delivering antibiotics work about the same at treating infection. Some children who had antibiotics by IV had problems with the IV equipment, not the medicine. These children were more likely to come back to the emergency room or stay in the hospital again because of those problems. Children who took antibiotics by mouth had fewer problems than those who got antibiotics by IV.

HOW CAN THESE RESULTS HELP PEOPLE MAKE BETTER CHOICES?
When children have serious appendicitis, pneumonia, or bone infections, their families and doctors can use this information to decide which way to give antibiotics after the children leave the hospital.

WHAT WERE THE LIMITS OF THE STUDY?
Patients might not have gone back to the hospital where they were treated the first time. Researchers may have missed health problems if children went back to a different hospital.

STUDY SPOTLIGHT
North Carolina Comparative Effectiveness Study

There are many types of oral and IV antibiotics. Not all hospitals use the same antibiotics to treat infections. Some antibiotics might work better than others. In the future, researchers could compare different types of antibiotics to see if one works better than others. They could find out how long children need to take antibiotics.

WHAT WAS IN THE STUDY?
Researchers looked at health records for more than 8,600 children and teens between the ages of 2 months and 18 years.

WHAT DID THE RESEARCH TEAM DO?
The researchers looked at the health records for children who had been in the hospital for serious appendicitis, pneumonia, or bone infections. The team looked at whether children got antibiotics by mouth or by IV. The team compared how often children's infections got better and how often children had to go back to the hospital because of other problems.

STUDY SPOTLIGHT
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How We Tell the Stories of Our Work

Evidence for Decisions

PCORI provides Evidence Updates to highlight some of our important research findings. Feel free to print or download these materials for personal use.

Prostate Cancer

Early-stage prostate cancer can be treated in different ways. Two recent PCORI-funded research studies provide new information on the effects of treatments and can help patients navigate their treatment decisions.

- [Prostate Cancer Evidence Update for Patients](#)
- [Prostate Cancer Evidence Update for Clinicians](#)

Check back for Evidence Updates on additional topics in the coming months.

Interested in disseminating our Evidence Updates more broadly? Contact

How Will Treating My Early-Stage Prostate Cancer Affect My Quality of Life?

Early-stage prostate cancer can be treated in different ways. The three main ways are active surveillance, surgery, and radiotherapy. Active surveillance means having your prostate checked every few months. Surgery means removing the prostate. Radiotherapy means to take out the prostate, and radiotherapy means to give rays to kill cancer cells in the prostate.

Two recent PCORI-funded studies looked at the effects of these choices on the quality of life of men with early-stage prostate cancer. These studies looked at three effects: treatment might have a man's quality of life. These are problems having sex, urinary, and bowel problems.

Sexual: What's the new research says:

The different ways of treating early-stage prostate cancer (active surveillance, radiotherapy, or surgery) affect men differently. Men who have surgery or radiotherapy have more sexual, urinary, and bowel problems in the first year compared with men who were treated with active surveillance. After 2 to 3 years, most symptoms improve, but there may still be differences.

Surgey

Men who had surgery to remove the prostate (called a prostatectomy) were:

- more likely to have problems with sex
- more likely to have bowel problems

than men who chose radiotherapy or active surveillance.

But when men had bowel problems:

- less of a bowel problem was more common to those who chose radiotherapy or active surveillance.

What to expect after surgery:

- About four out of ten men who had surgery still had problems with sex.
- About 15 percent of men who had surgery still had bowel problems.

What to expect after radiation:

- Urinary problems were much more likely to get better by two years after treatment for men who had radiotherapy than for men who had active surveillance (radiotherapy) than men who had radiation with pelvic lymph node removal.
- About 2 out of every 10 men who had radiation had sexual problems. These problems started a few months after men had radiation.

Prostate cancer grows very slowly, making it hard to know if the cancer very one.

That gives you a chance to think about quality of life issues that matter most to you.



Radiation

Men who had radiation to kill cancer cells in the prostate were:

- more likely to feel burning when peeing, or a need to urinate more often
- more likely to feel the need to rush to the bathroom for a bowel movement. This was not as common as urinary problems.

What to expect after radiation:

- Urinary problems were much more likely to get better by two years after treatment for men who had radiotherapy than for men who had active surveillance (radiotherapy) than men who had radiation with pelvic lymph node removal.
- Following initial decline, urinary function was more likely to improve for men who had radiotherapy than for men who had reduced urinary function, especially for men who had reduced urinary function at the time of treatment. For those men who had radiotherapy, urinary incontinence symptoms tended only to get worse but improve over time.
- Urinary incontinence and obstruction scores were improved in patients who had a radical prostatectomy compared to those in active surveillance.

Patient version

Clinician version

CME/CE Activities

PCORI's continuing medical education/continuing education (CME/CE) activities are designed to provide accredited professional education for clinicians in areas pertinent to patient-centered outcomes research and clinical knowledge. Any member of the healthcare community may access the activities at no cost. Find out more about the activities on our [Blog](#) or in our [Newsletter](#).

The CME/CE activities are offered by different providers. Please review each provider's requirements for earning a credit certificate or a certificate of participation.

- [Contemporary Treatment Options for Prostate Cancer \(Available soon\)](#)
- [Applying Evidence from the PCORI PROSPER Studies in Stroke Prevention & Care](#)
- [Engaging Patients and Other Stakeholders;](#)

Contemporary Treatment Opt

This CME module will be available soon.

Applying Evidence from the PC Prevention & Care

This video activity is designed to support stakeholders in applying key findings from for patients with atrial fibrillation and stroke prevention, focused discussions on specific applications, patient-centered perspectives, revealed the

This program is accredited for



 The Translation Center helps PCORI prepare clear, comprehensible summaries of PCORI's research findings so that these results will be useful to patients and providers in making healthcare decisions. PCORI posts these research summaries—one for consumer and patient audiences, and one for medical professionals—on our website within 90 days after the research results are finalized. The Translation Center also prepares audio files, Spanish translations, and other translation products to aid PCORI in the dissemination of research findings.

Putting Evidence to Work

In the past, it often has taken years for new evidence from clinical research to influence health care. And many times, these findings have failed to reach patients and families who could benefit from the information. Disseminating and promoting the uptake of research findings is part of [PCORI's legal mandate](#) to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policymakers reach better-informed health decisions.

PCORI's dissemination activities begin with the translation of all research findings into understandable summaries for posting on our website, with the help of the PCOR Translation Center.

The Patient-Centered Outcomes Research
Translation Center



PCORI's Dissemination & Implementation factsheet

Blogs and “PCORI Stories”



Improving Health in the Mississippi Delta through Powerful Engagement

A PCORI Engagement Award enables a cancer awareness and prevention program to expand its reach within rural, largely African-American communities facing high cancer rates.

Barbara Young is a survivor. The lifelong Mississippi Delta resident beat cancer four times in a place where healthcare resources are scarce. When she was first diagnosed with breast cancer, in 1987, Young and her husband were raising three small children. She was also working two jobs and running a cake-baking business from home. “I thought I was just tired from working two jobs; I didn’t know I had cancer,” she says. “I had all the warning signs, but I didn’t understand them.”

Young says a lack of information and resources in the small town where she lived made decisions about the most appropriate cancer treatment difficult. After choosing a mastectomy, Young developed cancer in her other breast. In the years following treatment of that tumor, she went on to have uterine cancer and stomach cancer. “The pain from stomach cancer was unbelievable,” she says. “I couldn’t do anything. I couldn’t even brush my own teeth.”

During her treatment, she received a call from Freddie White-Johnson, MPPA, of the local cancer outreach program, the Mississippi Network for Cancer Control and Prevention, a program of the University of Southern Mississippi. That changed her life.



To Advance Public and Patient Engagement in Research, We Must Demonstrate Its Value

Date: December 17, 2018

Blog Topics: [Engagement Blogs](#)
[Research](#)

PCORI is proud to be a leader in urging more patient and public engagement in health research. That’s why we require it in everything we do, including the studies we fund. And we’re pleased to see that others in the healthcare community are also increasingly advancing this work.

But we also know that researchers, patients, and other healthcare stakeholders want more information about how best to incorporate engagement in their work, along with tangible examples of the impact it has. We’re aware that providing such information is the best way to support those interested in engagement as well as to answer those who remain skeptical about the value of patient and public engagement in improving patient care and outcomes.



PCORI's Director of Public and Patient Engagement, Kristin L. Carman, PhD, MA, explains how

Blogs and “PCORI Stories”



Engagement Project Yields Unexpected Dividends

PCORI-funded conferences about a genetic condition were the springboard to statewide observances and launch of a clinic.

When she applied for a Eugene Washington PCORI Engagement Award, Sharron Close, PhD, of Atlanta never dreamed it would lead her all the way to the Georgia capitol and Governor Nathan Deal.

Close, a researcher at the Nell Hodgson Woodruff School of Nursing at Emory University, was leading a [PCORI-funded project](#) to involve patients and families in setting research agendas that will improve outcomes for patients with a particular sex chromosome abnormality. That abnormality, aneuploidy, occurs when a person has more or fewer than the normal number of male or female chromosomes. Also called X and Y chromosome variations, sex chromosome aneuploidy can cause developmental delays, speech and language delays, learning disabilities, psychiatric problems, and other difficulties.

The Engagement Award quickly yielded what Close calls “unexpected dividends,” including a statewide awareness day and month, a support group, and a clinic to treat patients with the condition.



Sex chromosome aneuploidy occurs when a person has more or fewer than the normal number of X (left) or Y chromosomes. (Getty)

Difficult to Diagnose

Doctors often miss diagnosing sex chromosome aneuploidy in newborns, although it's identified when parents opt for prenatal genetic testing. One of the conditions, known as Klinefelter Syndrome, affects about 1 in 400 to 500 male babies.

Engaging People Who Are Hard to Reach

Date: August 28, 2018

Blog Topics: [Engagement Blogs](#)

The Eugene Washington PCORI Engagement Awards are designed to help build a national community of patients, caregivers, clinicians, researchers, and other healthcare stakeholders who will advance patient-centered comparative clinical effectiveness research. The goal is to increase the usefulness of the evidence produced by PCORI-funded studies, while supporting the efforts of patients and others eager to see more research focused on their healthcare questions.



Some communities can become involved in research fairly easily. For others, it's far more challenging because of a variety of factors, such as education level, geography, the nature of a particular illness, age, gender, or race. As a result, researchers have to seek ways to more effectively engage these populations in research that can help to address their particular healthcare concerns.

Three Engagement Award projects highlighted below have used a variety of strategies to address the unique challenges in engaging some of these populations, such as people who live in rural areas or those with low levels of education. Strategies for overcoming these challenges include using teleconferencing and videoconferencing, building trust through relationships with community groups, accommodating cultural needs, and adapting materials to meet literacy needs. We hope the lessons these projects learned can help

- There are no MESH terms available in PubMed/MEDLINE or other literature search engines specifically designed to query “patient engagement in research”.
- The Evaluation & Analysis and Public and Patient Engagement teams collaborated on creating a new PubMed/MEDLINE search, screening criteria, and tagging schema to address this gap in the field.
 - Criteria included whether an article focused on health research, engagement in research (planning, conducting, dissemination), and explicit descriptions or analyses of engagement practices/effects.
 - To promote use of this tool, the teams worked with the Communications team to create a searchable, sortable online tool.

Engagement in Health Research Literature Explorer



- This searchable, catalogued resource for peer-reviewed literature can help identify **publications about engagement**
- It contains more than 1,000 articles that include:
 - Examples of engagement in health research
 - Evaluations of engagement in health research
 - Syntheses of engagement methods and impacts
 - Frameworks, editorials, and commentaries on engagement in health research
- Articles can be filtered by stakeholder type involvement, phase of engagement (study design, recruitment, etc.), and year.

Refine Your Results

Topic i

- Example of Engagement in Health Research (556)
- Detailed Description of Engagement in Health Research (413)
- Framework, Editorial, Commentary (347)
- Evidence for Engagement (195)

Stakeholder Involvement i

Phases of Research Engagement i

Year

Links: [Engagement in Health Research Literature Explorer](#)
[Supplemental Materials](#)

The PCORI Ambassador Center



- One of the Ambassador Program's main goals is to connect PCORI supporters to facilitate research partnerships, information sharing, and peer learning.
- Our new Ambassador Center meets this need as a searchable, sortable tool that lets both Ambassadors and external users search through the Ambassador community to foster connections and partnerships.
- The Ambassador Center lets users filter through community members based on:
 - Stakeholder Type
 - State of Residence
 - Health Condition & Populations of Interest
 - PCOR Experience

Refine Your Results

▼ Stakeholder type

▼ State i

▼ Health conditions of interest

▼ Years involved in patient-centered research

▼ Populations of interest

▼ Research phase experience

A screenshot of a search interface titled "Refine Your Results". It lists six filter categories with dropdown arrows: "Stakeholder type", "State" (with an information icon "i" to the right), "Health conditions of interest", "Years involved in patient-centered research", "Populations of interest", and "Research phase experience".

The PCORI Ambassador Center



- Users can connect with any Ambassador included in the Ambassador Center through email.
 - PCORI staff will vet all email requests and connect the two Ambassadors to guard privacy and confidentiality.
 - To date, we have received more than 20 requests from Ambassadors and external users to connect for research partnership or PCOR collaboration.
- We hope researchers and other stakeholders will use the Center when seeking patient and other stakeholder partners for research projects, PCOR initiatives, or cross-sector collaboration.

[Link: PCORI Ambassador Center](#)

Ambassador	State	Stakeholder Type	Health Conditions of Interest
Mary Ann Abiado	Ohio	Hospital/Health System	Mental/Behavioral Health, Multiple/Comorbid Chronic Conditions, Cancer, Cardiovascular Diseases, Reproductive and Perinatal Health, Trauma/Injuries
Bill Adams	Minnesota	Patient	Kidney Diseases, Multiple/Comorbid Chronic Conditions, Cardiovascular Diseases, Ear, Nose, and Throat Diseases, Gastrointestinal Disorders, Allergies and Immune Disorders, Nutritional and Metabolic Disorders, Respiratory Diseases
Valerie Adelson	Maryland	Policy Maker	Multiple/Comorbid Chronic Conditions, Neurological Disorders, Trauma/Injuries

Ambassador Program Workshop

Lessons Learned & Next Steps

Krista Woodward

Senior Program Associate, Public & Patient Engagement

Thomas Scheid

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Ambassador Workshop Objectives



- Focus on **community activation and knowledge sharing** as a means of promoting PCORI-funded research evidence;
- **Share tactics and strategies** to plan and deploy “knowledge sharing” initiatives of PCORI-funded evidence throughout diverse communities;
- Strategize ways to **prepare communities to receive and uptake PCORI-funded research evidence** into decision-making, policy, and practice; and
- Facilitate **internal and external partnerships** to build the PCORI Ambassador community.

1.

Lessons Learned: Key Themes



1. Inclusivity



- Ambassadors emphasized the importance of bringing a variety of stakeholder groups to the table for community-level engagement and knowledge transfer.
- Ambassadors emphasized the importance of understanding their communities' needs and culture in order to tailor engagement and knowledge transfer strategies appropriately.

2. Shared Goals



- Ambassadors gained insight into the process for consensus building when developing practical and targeted goals among a diverse group of stakeholders.
- Ambassadors also recognized the necessity to have realistic expectations while setting clear, explicit activities and metrics.
- The group emphasized the importance to calibrate promotional efforts to the needs and expectations of a community to ensure impact.

3. PCORI Resource Sharing



- Ambassadors are enthusiastic to share the tools and templates from this workshop with their communities.
- Ambassadors, particularly those who do not identify as researchers, clinicians, or subject matter experts, have a desire to better understand research study results to advocate for the uptake of PCORI-funded research results.

4. Preparing for Community Uptake



- Ambassadors emphasized the importance of engaging with key PCORI staff in the early stages of an initiative to prime their communities for knowledge transfer of PCORI-funded research results as they are published.
- Research project updates would be helpful for community-level dissemination, especially for projects that are not yet completed.
- Knowledge transfer plans should not be exclusively conducted using “top-down” methods.

5. Story Telling is Powerful



- Story telling can be a powerful tool for sharing research evidence, especially with a shared language that resonates with all types of healthcare stakeholders.
- Helping researchers and patients learn from each other could lead to the concept of an “Evidence-Based Story” where research evidence is packaged into a compelling storyline.
- Story telling is another way to navigate null results, lacking “clear cut” findings, or ungeneralizable conclusions due to the nature of the study.

2.

Next Steps



Next Steps



- Ambassadors and PCORI supporters need more direct guidance as to what types of products or information should be promoted through their communities.
 - Additional thought and consideration to more closely align Ambassador efforts with PCORI's organizational direction and priorities.
 - Development of resources such as a toolkit, roadmap, and "calls to action"
- Considerations for Ambassadors to form regional or condition-specific groups to strategize together to promote PCORI and PCORI-funded research evidence for increased reach.
- Recruitment of Ambassadors to increase PCORI-support as well as diversify the network by stakeholder type, geographic dispersion, and more.

Questions?

Breakout Sessions

Session I

Group A – Engagement Rubric

Group B – PCORI Research Results

Session II

Group A – PCORI Research Results

Group B – Engagement Rubric



BREAK

We will return at 4:30 pm ET



Breakout Session Report-Back

Engagement Rubric 2.0

PCORI Research Results