

Advisory Panel on Patient Engagement: In-Person Meeting

April 20, 2018

8:45 AM – 1:30 PM ET



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome and Review Agenda

Kristin L. Carman, PhD

Director of Patient and Public
Engagement

Jane Perlmutter, PhD, MBA

Chair

David White, PhD

Co-chair



Housekeeping

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



Housekeeping (cont.)

- We ask that panelists stand up their tent cards when they would like to speak and use the microphones
- Please remember to state your name when you speak



Agenda – Advisory Panel on Patient Engagement, April 20

8:45 AM	Welcome
9:00 AM	Chat with Dr. Joe Selby
9:40 AM	Farewell Ceremony
10:00 AM	Working Committees Report Out
10:30 AM	PEAPs in Action: Ohio Regional Meetings
11:00 AM	Engaging Communities in Disseminating PCORI-funded Research Findings
11:30 AM	GRAB LUNCH
11:45 AM	PEAPs In Action: CMS Patient and Family Engagement Affinity Group
12:45 PM	Closing Discussion: Reflections and Future Planning
1:30 PM	Adjourn



Chat with Dr. Joe Selby

Joe Selby, MD, MPH

PCORI Executive Director

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PEAP Farewells

- **Jane Perlmutter** – 3 year term
- **Libby Hoy** – 2 year term
- **Anjum Khurshid** – 3 year term
- **Bennett Levitan** – 3 year term
- **Jimmy Lin** – 3 year term
- **Mark Mishra** – 3 year term
- **Philip Posner** – 3 year term
- **Ronnie Todaro** – 3 year term



Working Committees Report Out

- Ambassadors Program Redesign
- Engagement Rubric 2.0

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PEAPs In Action: Ohio Regional Meetings

Tom Scheid, MA
Health Advocate

Emma Kopleff, MPH
Program Officer, Public and Patient Engagement

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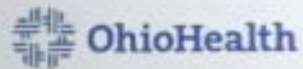
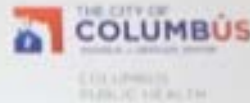
Healthcare Collaborative of Greater Columbus (HCGC)

- Regional consortium of over **100 diverse stakeholder organizations** from across central Ohio (e.g., clinicians, health systems, social service providers, payers, employers, patients, researchers)
- Collaborators include Columbus Medical Association Foundation, United Way, City of Columbus, etc.
- Regional learning sessions focus on topics of interest and aim to **support local understanding** of healthcare initiatives at national, state and regional levels

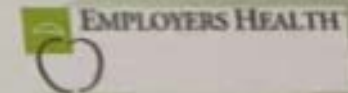
Thanks to Our HCGC Sponsors!



Columbus Medical Association



Anthem.



- 100% of our Board of Directors & Staff
- Individual & Corporate Donations



Better Health Partnership (BHP) – Cleveland, Ohio

- HCGC's sister organization
- Similar approach to regional learning sessions on topics of interest
- Over 130 attendees comprised primarily of primary care physicians, but also local health foundations, and local community health providers

Making the Connection Between HCGC and PCORI

Three key components:

- An idea and a vision
- Aligned objectives and missions
- Making the connection



Columbus: Approach and Objectives

- Provide an overview of PCORI's mission, scope of work and approach to stakeholder engagement
- Share current findings within the broader context of PCORI's research agenda
- Review and discuss PCORI's funded research on shared decision-making and why its important
- Identify shared opportunities for impactful dissemination of research results

Columbus: Lessons Learned and Key Takeaways

- High points:
 - Active participation and dialogue
 - Ideal test audience for messaging of and deep dive into timely results
 - Post presentation debrief with staff and leadership
- Challenges and opportunities:
 - Breadth vs. depth
 - Different stakeholders may interpret findings differently or have trouble applying to their setting



Cleveland: Approach and Objectives

- Provide an introduction to the Patient-Centered Outcomes Research Institute (PCORI)
- Review and discuss PCORI's funded research on shared decision-making and why its important
- Identify shared opportunities for impactful dissemination of research results

Cleveland: Lessons Learned and Key Takeaways

- High points:
 - Participation from about fifty conference attendees
 - Appropriate depth and breadth aligned well with with co-panelists from Cleveland Clinic
 - Ideal test audience for messaging of timely results to primary care provider audience
- Challenges and opportunities:
 - Time limits posed challenges to achieving all objectives

Patient-Centered Outcomes Research in Action

April 13, 2018

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

Better Health Partnership
Corporate College East, Cleveland, Ohio



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Questions?



Engaging Communities in Disseminating PCORI-funded Research Findings

Lia Hotchkiss, MPH

Director, Eugene Washington PCORI Engagement Award Program

Arielle Gorstein, MPH

Senior Program Associate, Engagement, Dissemination and Implementation

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Takeaways from the Ohio Regional Meetings



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 engagement projects and conferences -- not research
- Awarded over \$50 million since 2014, creating an expansive network of individuals, communities and organizations interested in and able to participate in PCOR



Engagement Award Funding Opportunities

- **Engagement Award: *Dissemination Initiative*** for organizations and communities to actively disseminate PCORI-funded research findings.
- **Engagement Award: *Capacity Building*** projects to build a community of individuals and organizations better able to participate in PCOR/CER, and/or develop infrastructure and partnerships to disseminate PCORI-funded research results.
- **Engagement Award: *Conference Support*** for convenings to explore issues related to PCOR/CER, or communicate PCORI-funded research results to targeted end-user audiences.

ENGAGEMENT AWARD CATEGORIES	DISSEMINATION INITIATIVE	CAPACITY BUILDING	CONFERENCE SUPPORT
	UP TO \$300,000 UP TO 2 YEARS	UP TO \$250,000 UP TO 2 YEARS	UP TO \$50,000 UP TO 1 YEAR

Upcoming Funding Cycle Deadline: June 1, 2018

Engagement Award: Dissemination Initiative

- ***New Engagement Award announced February 2, 2018***
- Funding for projects designed by organizations and communities with established relationships with end users to actively disseminate findings from PCORI-funded studies
- Dissemination strategies may be used together—in combination or in sequence—to:
 - Increase the reach of evidence
 - Increase people’s motivation to use and apply evidence
 - Increase people’s ability to use and apply evidence
- Applicants should draw on their own experience and creativity in proposing dissemination strategies most likely to be successful with their target audience
- Applicants must propose appropriate evaluation strategies for understanding the extent to which goals were accomplished

Engagement Award: Dissemination Initiative

- The following may serve as the basis for dissemination activities under this award:
 - [Primary research results](#) published in peer-reviewed journals
 - PCORI-funded [systematic reviews](#) and systematic review updates
 - PCORI [Evidence Updates](#) (*right*)
 - [PCORI continuing medical education](#) activities

The screenshot shows a PCORI Evidence Update page. At the top, it says 'Systematic Review' and 'EVIDENCE UPDATE' with the date 'MARCH 2018'. The title is 'Antipsychotics for Children with Hyperactivity or Disruptive Disorders'. Below the title, it states: 'New evidence¹ is available that can help clinicians, caretakers, and others who must weigh the benefits and harms of antipsychotic treatment in children and adolescents.'

THE FINDINGS
For children with diagnosed attention deficit hyperactivity disorder (ADHD) and/or other disorders, the benefits of antipsychotic treatment may be modest and the harms may be significant. The harms can affect children throughout their lifetimes. Children taking antipsychotics should be monitored carefully by a clinician while they are taking these medicines.

Possible Benefits of Antipsychotics

- Second generation antipsychotics (and risperidone in particular) probably reduce conduct problems (to a moderate degree) and aggression (to some extent) in children with disruptive disorders and/or ADHD with severe aggression.
- Antipsychotic treatment likely reduces hyperactivity and overall illness severity to some degree in children with disruptive disorders, with or without ADHD, although in children having only ADHD with severe aggression and who are resistant to stimulants there may be no benefit.
- There is no or very limited data on the effects of antipsychotics on symptoms in children with ADHD who do not have a comorbid disruptive disorder or severe aggression. Most findings were from short-term studies.

Possible Harms of Antipsychotics

- Studies found that some children taking antipsychotics may gain significant weight. The amount gained varied by drug, but olanzapine seems to cause the most weight gain.
- Second generation antipsychotics likely increase the occurrence of several side effects. These include drowsiness, tiredness, involuntary movements, elevated triglycerides, and increases in weight and body mass index.
- The metabolic changes that accompany treatment with antipsychotics can increase the risk of heart disease, stroke, and diabetes.
- Published studies reported side effects that occurred over relatively short treatment periods (six to 12 weeks). Data on the adverse effects of longer term treatment are more limited, but it is generally believed that the adverse events associated with antipsychotic use in children is underestimated.

Additional text on the right side of the page: 'otic medications such as) to treat hyperactivity, and young adults with rders. The Food & Drug ppsychotics for the may prescribe the drugs' and 'ing'.

Below the main content, there are two bar charts and a pie chart. The first bar chart shows '9% FOSTER CARE' and '2% NOT IN FOSTER CARE'. The pie chart shows '28%'.

Source (both graphs): Crystal, 2016. Data are from 2011.

Footnote: 1. First- and Second-Generation Antipsychotics in Children and Young Adults: Systematic Review Update. Comparative Effectiveness Review. (Prepared by the University of Alberta Evidence-Based Practice Center.) Agency for Healthcare Research and Quality. March 2017. Errata January 2018. 2. Crystal S, Mackie T, Fenton MC, et al. Rapid Growth of Antipsychotic Prescriptions for Children Who Are Publicly Insured Has Ceased, But Concerns Remain. Health Affairs. 2016;35(6):974-82.

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Engagement Award: Capacity Building*

- **Capacity Building projects will:**
 - **Support organizations with strong ties to end-user audiences to lay the groundwork for dissemination and implementation of PCOR/CER results**
 - PCORI intends for these projects to focus on strengthening the infrastructure and relationships necessary to actively disseminate and implement PCORI-funded research results or products
 - **Support organizations of patients, caregivers, clinicians, and other stakeholders to equip them to engage as partners in PCOR/CER**
 - Applicants must clearly explain how the capacity that is developed through an award will be applied to existing or planned PCOR/CER partnership opportunities
 - Applicants are encouraged to use or adapt available resources whenever possible, rather than develop new products and tools

**Original Engagement Award category with a revised name and expanded focus on dissemination and implementation.*



Engagement Award: Capacity Building Examples

- National Alliance of Healthcare Purchaser Coalitions project, ***National Alliance Disseminates PCOR/CER Findings Thru Purchaser-led Coalitions to Improve Patient-Centered Outcomes***
- COPD Foundation project, ***Considering Needs of End Users in COPD Research and Evidence Dissemination***
- University of Colorado Denver project, **Operation PCOR: Training Veterans as Partners in PTSD Research** (right)



Engagement Award: Conference Support*

- The types of meeting/conference/workshop themes eligible for support include but are not limited to:
 - Research Design and Methodology
 - Addressing methodological and technical issues of major importance in the field of PCOR/CER
 - Research Development
 - Exploring potential topics for PCOR/CER with patients, researchers, or other relevant stakeholders
 - Dissemination and Implementation
 - Communicating existing or emerging findings from PCORI-funded research to a targeted, essential end-user audience

**Previously known as Engagement Award Initiative Notice for Research Meeting and Conference Support (EAIN)*



Engagement Award: Conference Support Examples

- Center for Health Policy Development/National Academy for State Health Policy's *State-to-State Peer Learning Conference on Using PCOR and CER to Inform State Policymaking*
- East Tennessee State University College of Public Health Conference on *Developing a Research Agenda to Prevent and Control Cardiovascular Disease in Central Appalachia*
- Metastasis Research Society's PCOR/CER Conferences for *Engaging Key Stakeholders in Metastatic Cancer Research and Treatment (right)*



MRS/METAvivor

Metastatic Breast Cancer Engagement Conference & Webinar Series

Engaging Key Stakeholders in Metastatic Cancer Research and Treatment: Metastatic Breast Cancer Conference and Webinar Series

Please check for available dates
October 2017 - June 2018

[\(Click here to find out more information\)](#)

Thank You

Contact Information:

Eugene Washington PCORI Engagement Award Program
Patient-Centered Outcomes Research Institute (PCORI)
1828 L Street NW, 9th Floor
Washington, DC 20036

Telephone: 202-370-9312

Email: ea@pcori.org

Visit: <http://www.pcori.org/funding-opportunities/programmatic-funding/eugene-washington-pcori-engagement-awards>

Lunch

We will resume at 11:45 AM ET



PEAPs In Action: Patient and Family Engagement Opportunities Across CMS Programs

Libby Hoy , Founder/CEO, Patient & Family Centered Care Partners

Philip Posner, Science Advisor, ORISE.ORAU

Elizabeth Truong, Senior Advisor, Center for Clinical Standards & Quality, CMS

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Closing Discussion: Reflections and Future Planning



Thank you
and
Safe Travels!