# Legislative Outlook -What's Ahead for **Comparative Effective** Research? Webinar

Wednesday, July 24, 2019 9:30 a.m. – 10:30 a.m. ET



# JOIN THE CONVERSATION BY USING THE HASHTAG:

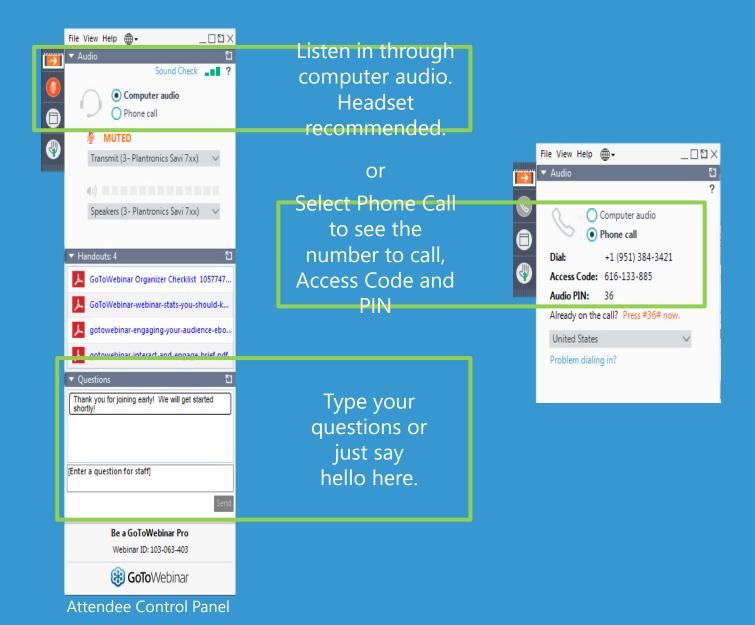
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### Participating in the Webinar



### **Materials**

### At allhealthpolicy.org

- Agenda
- Selected Resources List
- Selected Experts List
- Speaker Bios
- Webinar Slides
- Video (posted later)



### **Today's Panelists**



Tanisha Carino, Ph.D.

Milken Institute

@TanishaCarino



Anand Parekh, M.D., MPH
Bipartisan Policy Center

@AParekhBPC



Gail R. Wilensky, Ph.D.

Project HOPE

@gailwilenskycom



Moderator
Sarah J. Dash, MPH
Alliance for Health Policy
@allhealthpolicy



Sara van Geertruyden, J.D.
Partnership to Improve Care
@pipcpatients





# Agenda

9:30 a.m.-9:35 a.m. Introduction

• Sarah J. Dash, MPH, Alliance for Health Policy

9:35 a.m.-10:30 a.m.

#### Moderated Discussion with Audience Q&A

- I. Latest Congressional Activity around CER and PCORI
- II. Remaining Reauthorization Items for Congress, and Impact on Different Stakeholders
- III. Intersection with Other Health Policy Conversations (including cost reduction, the value of care and drugs, and delivery system reform)
- IV. Final Thoughts

10:30 a.m. Conclude



# Discussion Road Map

- Latest Congressional Activity
- II. Remaining Reauthorization Items
- III. Intersection with Other Health Policy Conversations
- IV. Final Thoughts

Audience members may submit questions at any time



# Sara van Geertruyden, J.D. @pipcpatients

Executive Director,
Partnership to Improve Patient Care





# Reauthorizing PCORI: Background and Status

July 24, 2019



#### **Before PCORI**

- Several bills funding comparative effectiveness research (CER) were introduced in 2007.
- The Partnership to Improve Patient Care (PIPC) was organized as a coalition led by Tony Coelho in late 2008 to support these efforts.







### Recognizing the Need for CER

- The American Recovery and Reinvestment Act of 2009 (ARRA) provided \$1.1 billion for major expansion of CER.
- ARRA called on the Institute of Medicine to recommend a list of priority topics to be the initial focus of a new national investment in CER.

"The list provides a starting point for what the report says should be a sustained effort to conduct comparative effectiveness research. As this research initiative progresses, the priorities will evolve as well."





### Overcoming the Politics: The Right

- A few Republicans warned that there's little to stop the federal government from using CER results to average which medications or treatments achieve similar results for less cost.
- When that happens, according to Sen. Pat Roberts (R-KS), it won't be long before Medicare starts rationing care.







### Overcoming the Politics: The Left

- Establish within AHRQ a Center for Comparative Effectiveness (not independent).
- Allow for cost comparisons.
- Allow for use of cost effectiveness data to be used for coverage decisions.







### How PCORI Became Patient-Centered

- Senator Max Baucus (D-MT) and Senator Kent Conrad (D-ND) introduced the Comparative Effectiveness Research Act in 2008, which evolved into the Patient-Centered Outcomes Research Act of 2009.
- Passed as part of the Affordable Care Act (ACA) as
   compromise between right and left.

  Friends of pcori reauthorization



# Key Patient Protections in PCORI Statute

- Defined CER as comparative clinical effectiveness research;
- Precluded PCORI's research as the sole source of a Medicare coverage decision;
- Banned use of QALY measures by PCORI and in Medicare;
- Made PCORI an independent institute
- Gave 2 seats to patients and 1 to consumer on Board of Governors;
- Patient "needs, outcomes and preferences" and subpopulations to be studied;
- Support for patient and consumer representatives;
- Authority for advisory panels.





### **Keeping Distance from Repeal Efforts**

- Since 2010, PCORI advocates have worked closely with Congressional allies.
  - Over the years, a House and Senate Republican have unsuccessfully introduced amendments to eliminate PCORI;
- Yet, PCORI was never included in prior reconciliation packages to repeal the ACA.
- PCORI is facing Congressional oversight and heightened scrutiny as part of the reauthorization process because it expires in 2019.
   Friends of pcori reauthorization



#### **PCORI** Reauthorization 2019

- Expected to be part of a "health extenders" package including other programs that also require reauthorization
- Senators Cassidy (R-LA), Capito (R-WV), Warner (D-VA) and Van Hollen (D-MD) are leading reauthorization efforts in Senate
  - Discussion Draft expected soon
- On July 17, Congresswoman Degette (D-CO) led committee mark-up of House E&C bill <u>H.R. 2328</u>, the "Community Health Investment, Modernization, and Excellence Act"
  - 3 year reauthorization
- On June 26, Congressman Beyer (D-VA) led mark-up of House W&M bill, H.R. 3439, <u>The Protecting Access to Information for Effective and Necessary Treatment (PATIENT) Act of 2019</u>
  - 7 year reauthorization;
  - minor changes to PCORI's national research priorities to include substance use, mental health, and maternal morbidity and mortality.





### Friends of PCORI Reauthorization

- Co-chaired by PIPC Chairman Tony Coelho (D) and former Congressman Dr. Phil Gingrey (R)
- Purpose to convene a bipartisan, large and growing group of patient/family caregiver, provider, employers/payers, industry, and research stakeholders that have an interest in supporting reauthorization of PCORI in 2019
- 172 Member Organizations
- Letter signed by nearly 170 organizations to House and Senate leaders supporting PCORI reauthorization
  - Reauthorize PCORI and its current funding mechanism for at least an additional 10 years.
  - Ensure PCORI stays true to its mission of patient-centered research by maintaining its mandate to conduct comparative clinical effectiveness research.
- Resources available online for advocates
- Learn more and join at www.reauthorizePCORI.org!





### **Key Issues**

- Representation on Board of Governors
- Length of reauthorization
- Comparative clinical effectiveness research versus cost effectiveness analysis
- Prioritization of high cost treatments
- Dissemination and use of evidence



### **Latest Congressional Activity**



Tanisha Carino, Ph.D.

Milken Institute

@TanishaCarino



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Bipartisan Policy Center

@AParekhBPC



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Sara van Geertruyden, J.D.
Partnership to Improve Care
@pipcpatients



Gail R. Wilensky, Ph.D.

Project HOPE

@gailwilenskycom





## Discussion Road Map

- I. Latest Congressional Activity
- II. REMAINING REAUTHORIZATION ITEMS
- III. Intersection with Other Health Policy Conversations
- IV. Final Thoughts

Audience members may submit questions at any time



### Remaining Reauthorization Items



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Milken Institute

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### Intersection with Other Health Policy Conversations



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- IV. FINAL THOUGHTS

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### **Final Thoughts**



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Please fill out the evaluation survey you will receive by email immediately after this presentation!



# Save the date for our next in-person event...

Congressional Briefing | "What's Next for Patient Experience Measurement?"

Monday, July 29, 2019 12:00 p.m. – 1:30 p.m. ET

Register at: <a href="http://www.allhealthpolicy.org/whats-next-for-patient-experience-measurement/">http://www.allhealthpolicy.org/whats-next-for-patient-experience-measurement/</a>



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