

PCORI Advocacy 101

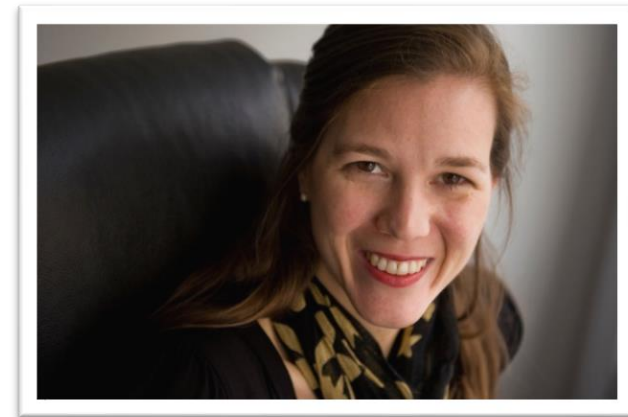
The Politics and Policy of PCORI's Creation
and Reauthorization

Preparation for 2nd Annual PCORI Advocacy
Day

October 25, 2018

Agenda

- Part One: The Creation of PCORI
- Part Two: Implementation and Building Support
- Part Three: Advocacy – Preserving PCORI



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Part One: The Creation of PCORI

Recognizing the Need for CER

Before PCORI

- Several bills funding comparative effectiveness research (CER) were introduced in 2007.
- 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.

Key Statutory Elements

- 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 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.

Part Two: Implementation and Building Support

*Improving Health Care and
Realizing PCORI's Patient-
Centered Mission*

Path to Achieving its Patient-Centeredness

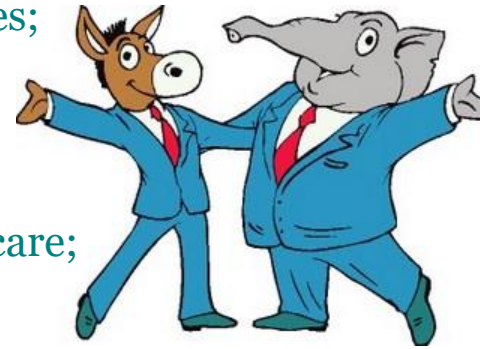
- GAO has determined that PCORI is meeting its legislative intent.
 - Advisory Panels in place
 - Including a Patient Engagement Advisory Panel
 - Shift from researcher-initiated topics to targeted funding announcements
 - Stakeholder roundtables to determine research priorities with strong patient presence
 - Enforcement of patient engagement in contracted research
 - Engagement and Pipeline awards
 - PCORnet

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 will face Congressional oversight and heightened scrutiny as part of the reauthorization process because it expires in 2019.

How PCORI Supports Improved Health Decisions

- PCORI-funded research provides subpopulation-level information that can improve individual health decisions;
- Patients view PCORI-funded research as credible, and therefore reliable;
- PCORI's Evidence Synthesis Initiative and dissemination strategies will ensure patients and providers can access information on treatment options and their value based on personal characteristics, needs and preferences;
- PCORI's work gives us information (including PCOR) to incorporate in decision aids, shared decision-making tools, value assessments, etc.;
- PCORI promotes personalized health care, not one-size-fits-all health care;
- PCORI identifies and measures outcomes that matter to patients;
- PCORI research provides information on differences in treatment outcomes by subpopulations and individual characteristics.



PCORI is a Role Model...

- For creating an infrastructure for patient engagement throughout HHS
 - CMS and CMMI
 - FDA Patient-Focused Drug Development
 - Quality measurement (identifying outcomes that matter to patients)
- For Industry
- For Congressional committees
- For Researchers



Part Three: Advocacy – Preserving PCORI

*Making Sure Your Voice is
Heard in Washington*

Patients as Advocates

- PCORI's #1 constituency is patients.
- Patients are also constituents for every Member of Congress.
- If patients see PCORI as valuable to their health care decision-making, policymakers will listen.
- Connect the dots on how PCORI's work drives care that patients value!
- More to come on efforts to convene and coalesce "Friends of PCORI" from the various supportive stakeholder groups.



Tactics to Reach Policymakers

- Coming to D.C.? Meet your Member of Congress or staff.
- Not in the Capitol? Brief your Member of Congress or staff in the local office.
- Write a letter to your Member of Congress explaining the personal value of PCORI-funded research.
- Reach out to your team to also write letters.
- Educate others about PCORI – make them ambassadors!
- Stay in touch:
<http://www.pipcpatients.org/patient-centeredness-in-research.html>.



Logistics for October 31

- 8:00am-9:00am Breakfast, pick up materials, ask questions
 - 624 Dirksen Senate Office Building
 - Meet your Friends of PCORI rep that will help you navigate Capitol Hill.
- 9:00am-12:30pm: Capitol Hill meetings!
 - You may need to cab between House and Senate (save receipts if need reimbursement)

What to Expect

- You will likely meet staff, not Members
 - Remember that staff are often young, and grow into more senior positions.
- Meetings will be around 20 minutes
 - Staff take meetings every half hour with constituents
- Arrive early when you can!
 - If meetings are tightly scheduled, arrive early, end early
- Being a few minutes late happens, albeit not preferred
 - Don't stress if you are 5-10 minutes late, but do your best to be on time
- Be succinct in telling your story to keep meetings on time

Key Messages for Advocacy Day

- Provide brief PCORI background
 - Created in 2010 as an independent research institute conducting comparative clinical effectiveness research.
 - Distinguished by requirement for patient engagement
 - Patients inform the topic
 - Patients inform the research design to measure impact of treatments on outcomes that matter to patients
 - Patients inform the dissemination to reflect how patients make decisions
- Describe your engagement with PCORI
 - How has patient engagement improved the research?
- PCORI is changing the culture of research to value patient voices
- Ask for **bipartisan** support for PCORI Reauthorization in 2019
 - Expires September 30, 2019

Drive Awareness!

- Offices on Capitol Hill are active on platforms including Twitter and Facebook, which they use to promote the issues and happenings of the Member of Congress.
- Media outlets avidly monitor social media to see what's happening on Capitol Hill, as well as what issues are being discussed.
- Sample tweet: “Great meeting with @SenatorJohnDoe to discuss the future of patient-centered research!
#Patients4PCORI
- Tweets that include photos are more likely to be noticed – take photos!

Questions and Answers

Send comments and suggestions to: shea@pipcpatients.org

Learn More: www.PIPCpatients.org.