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.

– Former Democratic Member of Congress, Whip, patient with epilepsy, author of the Americans with Disabilities Act
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.”
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 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 this year.
PCORI is also supported by Dr. Phil Gingrey, former Republican Congressman and founder of the Congressional Doctors Caucus

– Gingrey concludes that “to support CER is to support patient-centered care and the advancement of physician knowledge in a way that promotes good practice and allows flexibility, patient preference, and the leveraging of physician experience and instinct. That is a winning combination I would prescribe.”
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
- 177 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!
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 PCORI reauthorization efforts in Senate
  - Discussion Draft expected soon

- On July 17, Congresswoman Degette (D-CO) led committee mark-up of House E&C bill H.R. 2328, the “Community Health Investment, Modernization, and Excellence Act”
  - 3 year reauthorization

  - 7 year reauthorization;
  - minor changes to PCORI’s national research priorities to include substance use, mental health, and maternal morbidity and mortality.
KEY ISSUES

- Representation on Board of Governors
- **Length of reauthorization**
- Funding Sources
- Comparative clinical effectiveness research versus cost effectiveness analysis
- Prioritization of high cost treatments
- Dissemination and use of evidence
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.
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!
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: https://reauthorizepcori.org/resources/
LOGISTICS FOR SEPTEMBER 18

● 8:00am-10:00am Breakfast, pick up materials, ask questions
  – SVC-208 in the Capitol Visitor Center (Senate side)
    • Enter from 1st Street by Capitol
    • Head downstairs to lower level
    • Follow signs to Senate appointment desk
  – 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)
  – Please advise if you need a wheelchair accessible vehicle!

● Note that transportation is NOT provided from hotel to Capitol Hill.
  – Cab, Uber, Lyft or metro to Capitol South
Enter building this side, head to lower level!!

Register to enter room here!
WHAT TO EXPECT

● You will have a folder to hand out at each meeting, with state-specific information
● 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.
    - Comparing the effectiveness of treatments based on patient needs, outcomes and preferences
  - 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?
  - Reference state-specific fact sheets

- PCORI is changing the culture of research to value patient voices
  - Largest funder of CER with requirements for patient engagement that drive culture change

- Ask for bipartisan support for PCORI Reauthorization in 2019
  - Expires September 30, 2019
#Patients4PCORI

● 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: thayer@pipcpatients.org
