

## HEALTH POLICY: PART II

# THE PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE: REAUTHORIZATION NEEDED IN 2019

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The Patient-Centered Outcomes Research Institute (PCORI) is an independent nonprofit, nongovernmental organization authorized by Congress in 2010 as part of the Affordable Care Act (ACA) legislation. The authors of the ACA sought to fund research that can help patients and their caregivers make better informed decisions about the healthcare choices they make. PCORI must be reauthorized this year to continue its important work, and SGIM will work with other organizations to support this reauthorization.

PCORI's mission is to improve healthcare delivery and outcomes by producing and promoting evidence-based information from stakeholder-guided research.<sup>1</sup> PCORI seeks to fund useful research likely to change practice and improve patient outcomes. A key priority is sharing research results with the public. The organization has also sought to influence research funded by others to become more useful to patients and other healthcare decision makers.

Since 2012, PCORI has funded hundreds of studies, including many to SGIM members, that compare healthcare options to identify, which option(s) work best, particularly in light of patients' individual circumstances and preferences. In a unique funding model, PCORI works closely with healthcare stakeholders—including patients and caregivers, clinicians, researchers, purchasers, payers, industry, hospitals and health systems, policy makers, and training institutions—to identify comparative effectiveness studies that address high-priority clinical questions and focus on outcomes that are important to patients.

PCORI has transformed patient centered research in a variety of ways that are highly aligned with the priorities of SGIM researchers, educators, and clinicians. A principal innovation has been the engagement of patients and caregivers in research throughout the research process. In PCORI-funded research, patients are partners—rather than research subjects—who leverage

their experiences and expertise to make research more patient-centered, relevant, and useful. Patients and caregivers are engaged throughout the research process, including study planning, implementation, and dissemination of study findings.<sup>2</sup> In addition to the critical role of stakeholders in PCORI projects, PCORI has engaged stakeholders in identifying important topics for funding announcements, in the peer-review process, and in dissemination strategies to assure that the research they fund is relevant to the needs of all potential users and to assure that potential users learn about findings. Another area where PCORI, as a funder, has been innovative is in its emphasis on developing rigorous methodology standards. These standards maximize the likelihood that research conducted with PCORI funding is of high-quality and that research findings are valid and generalizable.

PCORI is funded through the Patient-Centered Outcomes Research Trust Fund (PCOR Trust Fund) that was established by the ACA. The PCOR Trust Fund receives income from the following three sources:

1. a statutory appropriation from the general fund of the Treasury;
2. transfers from the Centers for Medicare and Medicaid Part A trust fund; and
3. a fee assessed on private insurance and self-insured health plans (the PCOR fee).<sup>3</sup>

Importantly, the funding does not come from annual congressional appropriations in the federal budget. In addition to funding PCORI staff and research projects, approximately 16% of the PCOR Trust Funds are directed through the Agency for Healthcare Research and Quality (AHRQ) to work with PCORI in disseminating patient centered outcomes research and evidence.<sup>4</sup> AHRQ seeks to produce evidence to make health care safer, high-

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er quality, more accessible, equitable, and affordable and also to work with partners to make sure that the evidence is understood and used.

The initial authorization of PCORI from the ACA will expire on September 30, 2019. If Congress does not pass new authorizing legislation, the organization will cease to exist (the organization has reserved funds to close out ongoing work if it is not reauthorized).

What is needed for reauthorization? The key requirement is legislation from Congress to reauthorize PCORI and assure its funding. Recently, a group calling themselves “Friends of PCORI Reauthorization” has been established. Key leaders from this group

are working with Republican and Democratic leaders in the House and Senate to identify individuals interested in filing legislation and promoting it in Congress. Because of the important role that PCORI has played in promoting and funding patient-centered research that is important to our members and patients, SGIM is participating in Friends of PCORI Reauthorization meetings and hopes that this process will lead to successful reauthorization.

**References**

1. Patient-Centered Outcomes Research Institute. About us. [www.pcori.org/about-us](http://www.pcori.org/about-us). Accessed January 1, 2019.
2. Patient-Centered Outcomes Research Institute. The value of engagement. <https://www.pcori.org/about-us/our-programs/engagement/value-engagement>. Accessed January 1, 2019.
3. Patient-Centered Outcomes Research Institute. Our funding. <https://www.pcori.org/about-us/financials-and-reports/our-funding>. Accessed January 1, 2019.
4. Agency for Healthcare Research and Quality. Patient-Centered Outcomes Research (PCOR) Trust Fund Allocation. <http://www.ahrq.gov/pcor/potential-of-the-pcortf/allocation.html>. Content last reviewed October 2018. Accessed January 1, 2019.

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