



November 1, 2019

The Honorable Mark Warner
United States Senate
703 Hart Senate Office Building
Washington, DC 20510

The Honorable Bill Cassidy, MD
United States Senate
520 Hart Senate Office Building
Washington, DC 20510

The Honorable Chris Van Hollen
United States Senate
110 Hart Senate Office Building
Washington, DC 20510

The Honorable Shelley Moore Capito
United States Senate
172 Russell Senate Office Building
Washington, DC 20510

Dear Senators Warner, Cassidy, Van Hollen, and Capito,

AcademyHealth, the professional society for health services research and health policy, is writing to thank you for your efforts to reauthorize the Patient-Centered Outcomes Research Institute (PCORI) and provide comment on the recently released discussion draft of the "Patient Centered Outcomes research Institute Reauthorization Act of 2019."

AcademyHealth's 4,000 members produce and use health services research and are highly engaged with PCORI and its work. Our members informed the creation of PCORI, have served in its leadership, and have received funding support. Our members also have extensive experience in the federal health research ecosystem and value PCORI's unique contributions to the evidence to improve patient outcomes. We therefore recognize how important it is for Congress to act now to reauthorize PCORI. It must have stable, predictable funding to ensure that the important patient-centered outcomes research and comparative effectiveness research it supports will continue without interruption. AcademyHealth strongly supports the discussion draft, including the modifications to PCORI's authorizing statute that reflect many of our reauthorization principles, and offers the following comments:

Support for a 10-Year Reauthorization of PCORI and Its Current Funding Mechanism

PCORI and its Trust Fund were established to provide, stable, predictable funding for patient-centered outcomes research and comparative effectiveness research, as well as the dissemination of that research. Currently, eighty percent of the Trust Fund supports PCORI, while 20 percent supports essential and complimentary activities such as data development, analysis and coordination, dissemination research, and training at the Agency for Healthcare Research and Quality (AHRQ) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE).

AcademyHealth is pleased the discussion draft preserves the Trust Fund—the level of funding, the diverse funding streams, and the duration of funding—as it is essential to PCORI and the broader research enterprise, including AHRQ. This will provide PCORI the time necessary to both conduct high quality patient-centered outcomes research and comparative effectiveness research as well as develop the accompanying clinical decision support and shared decision-making tools required to implement the research findings. AcademyHealth is pleased you have



recognized that a long-term reauthorization is necessary for PCORI-sponsored comparative effectiveness research to have its intended impact.

Consideration of a Full Range of Outcomes Data:

AcademyHealth feels strongly that scientific exploration should not be hindered by legislative restrictions on the topics pursued or how findings are used by patients and other stakeholders, and therefore, was extremely pleased the discussion draft would expand PCORI's authorization to allow for the consideration of the full range of outcomes data in its sponsored research. Limiting studies to the clinical effectiveness dimensions of the practice of medicine inadvertently limits our country's need to better understand how many other factors affect patients' and clinicians' ability to deliver the best possible care. We believe that patients and providers need to understand the potential burdens and economic impacts of the treatments they choose. To allow PCORI-sponsored research to truly improve outcomes that matter to patients at a time when healthcare costs are hurting so many American families, we urge you to ensure this provision is included in the legislation when it is introduced.

AcademyHealth thanks you for your leadership to reauthorize PCORI and urges you act swiftly to enact a long-term, fully-funded reauthorization. We welcome the opportunity to work with you to achieve this goal and hope you will consider our comments as you finalize this draft. If you have any questions, please contact our Washington Representative, Erika Miller at 202-484-1100 or emiller@dc-crd.com.

Sincerely,

A handwritten signature in black ink, appearing to read "Lisa Simpson". The signature is fluid and cursive, with a large initial "L" and "S".

Lisa Simpson MB, BCh, MPH, FAAP
President and Chief Executive Officer