Dear Chairman Grassley and Ranking Member Wyden,

The undersigned are writing to express our strong support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI). Our health care system requires solutions that are both evidence-based and patient-centered, to improve care while also addressing health care spending. PCORI is uniquely set up to meet this challenge, as it is the only organization dedicated to funding comparative clinical effectiveness research (CER) studies comparing which treatment approaches work best, for which patients, given their needs and preferences. The goal is to help health care providers and payers better understand health care treatment options and to help patients and those who care for them make better informed health and health care decisions. Delivering care that is most clinically effective and incorporates outcomes that matter to patients is both cost effective and essential to our well-being as a nation.

As of December 2018, PCORI has awarded more than $2.4 billion in grants to more than 600 research-related projects in 44 states across the U.S. In 2014, PCORI saw the first large number of research results from its funded studies reported in major medical journals. Several of these projects generated particularly promising evidence for improving care and patient outcomes in key areas, such as cardiovascular disease, prostate cancer, opioid prescribing, and type 2 diabetes management.

PCORI-funded research also supports personalized care by discouraging ineffective and low-value care. In fact, the U.S. Government Accountability Office concluded in its March 2018 report that PCORI is fulfilling its Congressional mandate to develop and promote the application of solid methodology standards for conducting trustworthy CER.

Unless Congress acts, however, all of this work will cease at the end of September 2019. To build on the momentum to date and to enable PCORI to continue its work toward achieving smarter and more efficient health care spending, we ask you to consider the following recommendations.

Reauthorize PCORI and its current funding mechanism for at least an additional 10 years. Among PCORI’s signature achievements in its first 10 years has been the creation of a new paradigm for conducting research that better integrates patient perspectives. PCORI uniquely funds patient-centered outcomes research that engages patients throughout the research process, including in the research design, so that it captures outcomes that matter to patients to improve health care decisions. This is a
vitaly important function, and PCORI research provides a wealth of valuable data for patients and health care providers, while also informing how the health care system can be more efficient. Research is a long-term endeavor, and some high quality CER studies can take 4-5 years to complete. Even after the completion of these studies, additional time is needed to develop and implement clinical decision support and shared decision-making tools.

For the ongoing investment in PCORI-funded research to be most impactful, stability in PCORI funding is imperative to allow ample time to conclude studies, disseminate the findings, develop implementation tools, and drive implementation where appropriate. Reaffirming the commitment to PCORI for another 10 years will allow the institute to build on its success in changing the culture of research to be more patient-centered, and to enhance its work in partnership with other agencies and stakeholders to support a sustainable infrastructure for disseminating and implementing research outcomes meaningfully into practice.

**Ensure PCORI stays true to its mission of patient-centered research by maintaining its mandate to conduct comparative clinical effectiveness research.**

All stakeholders agree that high-quality, evidence-based care is crucial to reducing costs in the health care system. PCORI is the only research organization dedicated to funding studies that compare care approaches to determine what works best, for whom, and under which circumstances. By providing feedback on what care is going to provide the best result to each patient, PCORI is generating invaluable information that will save our health care system significant expenditures by empowering patients to choose treatments that work best and therefore limit adverse events such as hospitalization and multiple courses of treatment.

In creating PCORI, Congress committed to build the evidence base for improved health decisions, seeking to empower patients and drive innovation and value in health care. Reauthorization is an opportunity for Congress to ensure that PCORI continues to uphold this commitment and serve the needs of an evolving health care system.

We look forward to engaging with you throughout the reauthorization process. Thank you for your consideration of our recommendations.

Sincerely,

**Organizations**

AcademyHealth
Alliance for Aging Research
American Academy of Neurology
American Association for the Study of Liver Diseases
American Association of Neurological Surgeons, Congress of Neurological Surgeons
American Association on Health and Disability
American Heart Association
American Society for Transplantation and Cellular Therapy
American Urological Association
Arthritis Foundation
Association of American Universities
Association of Schools and Programs of Public Health
Association of University Centers on Disabilities
Better Medicare Alliance
BrightFocus Foundation
Caregiver Action Network
Celiac Disease Foundation
Children's Hospital of Philadelphia
Cincinnati Children's Hospital Medical Center
Dorney-Koppel Foundation
Duke University School of Medicine
Families USA
Fight Colorectal Cancer
Genetic Alliance
Heart Valve Voice US
Hydrocephalus Association
Infectious Diseases Society of America
International Cancer Advocacy Network
Men's Health Network
National Partnership for Women & Families
National Ataxia Foundation
National Blood Clot Alliance
National Hispanic Medical Association
National Kidney Foundation
National Psoriasis Foundation
NEC Society
New York University School of Medicine
Partnership to Improve Patient Care
Planetree International
Pulmonary Fibrosis Foundation
Society of General Internal Medicine
Stanford University School of Medicine
Sterling Health IT
Sturge-Weber Foundation
The Asthma and Allergy Foundation of America
The Crohn's & Colitis Foundation
The Society of Thoracic Surgeons
Tulane University School of Medicine
University of Alabama at Birmingham
Vanderbilt University Medical Center

**PCORI Ambassadors**
Rosie Bartel, Patient Advocate
Thomas Carton, Chief Data Officer; Principal Investigator; Louisiana Public Health Institute
Jill Harrison, Direct of Research, Planetree International
Donald A McClain, Senior Associate Dean for Clinical Research Director; Clinical and Translational Science Institute
Sandra Sufian, Associate Professor; University of Illinois; College of Medicine and Applied Health Science
Ron Wincek, PCORI Ambassador Jill Harrison, Direct of Research, Planetree International
cc: The Honorable Bill Cassidy
    The Honorable Mark Warner
    The Honorable Shelley Moore Capito
    The Honorable Chris Van Hollen