

**Testimony for the Record
Submitted to the
House Committee on Energy & Commerce
Subcommittee on Health
For the hearing
“Investing in America’s Health Care”**

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Chairwoman Eshoo, Ranking Member Burgess, and distinguished Members of the Subcommittee thank you for inviting me to participate in today’s hearing. It is a great honor to appear before you to share my experience as a PCORI-funded researcher and to discuss the work PCORI has done over the past nine years, the impact their investments in research has made, and the importance of Congress’s reauthorization of their funding through the PCOR Trust Fund. I am a professor jointly appointed at the Johns Hopkins Schools of Medicine, Nursing, and Public Health, where I have served as faculty for 25 years. The views I express in this testimony are my own, and do not necessarily reflect the views of The Johns Hopkins University.

As a board-certified general internist, I have had the experience of treating patients who struggle with a range of illnesses and health care needs. My patients live with chronic conditions such as heart disease, diabetes, kidney disease, asthma, and depression. Each patient’s health is impacted by individual predispositions and behaviors, factors within the healthcare system, and a unique constellation of factors far removed from my office, including family and social networks, exposure to stress and discrimination, and the availability and quality of housing, healthy foods, and safe, clean environments for work and recreation in their communities.

As a health services researcher, I have devoted my career to improving quality and addressing disparities in care delivered within the U.S. health care system — specifically the ways race and socioeconomic factors shape these disparities, and the ways our health systems might help eliminate them. Currently, I direct the Johns Hopkins Center for Health Equity, where my colleagues and I work to identify practical, effective solutions to achieve health equity for every person and family, across healthcare settings and communities, in partnership with governments, non-governmental organizations, and academia. We have developed programs targeting health professionals’ skills, patients’ health behaviors, and health systems’ ability to address patient’s medical needs and social determinants of health. Over the past 9 years, we have completed three NIH-funded trials improving hypertension control within African-American communities. And now, with the support of PCORI, I am leading a new trial called “RICH LIFE,” launched in fall 2016 with 30 primary care clinics in Maryland and Pennsylvania. RICH LIFE will investigate whether system improvements and team-based care models can help reduce disparities in cardiovascular risk factors including

hypertension, diabetes, and depression. This study can help health clinic directors and primary care doctors choose how to care for people who have high blood pressure and could be extremely impactful in communities that have high rates of this condition and limited access to health care.

Throughout my experience as a practicing clinician and as a researcher, one theme is clear. Too often, patients and their caregivers simply do not have enough information, or that information is inaccessible or not relevant to their unique circumstances, to make informed decisions about their care. And too often, we as clinicians are left choosing among various options and forced to make decisions about our patients without knowing which specific choice would best fit each patient's unique needs and preferences. For all the advances we have made with new, innovative clinical research, we sometimes still lack the information we need to help our patients make the best choice based on their own individual preferences and values. That is why the Patient-Centered Outcomes Research Institute – or PCORI - is so important.

PCORI's unique governance structure emphasizes patient and stakeholder engagement.

PCORI was created as a private, nonprofit research organization led by a Board of Directors, supported by advisory committees, and designed to represent the entire health care community dedicated to supporting patient-centered outcomes research. It is the leading funder of comparative effective research (CER), which is research that compares how well different treatments and care approaches work so patients and doctors have the information they need to make decisions that are right for them. PCORI's research is unique and complementary to research funded or conducted by the NIH (which focuses on discovery), AHRQ (which focuses on health services research), and FDA (which focuses on reviewing drugs, devices and other products for safety and efficacy).

Specifically, PCORI funds patient-centered outcomes research (PCOR), which is CER that focuses not only on traditional clinical outcomes but also on the needs, preferences, and outcomes most important to patients and those who care for them. This research is helping patients choose the treatments best for them given their preferences and improve their health outcomes on a wide range of issues, including many of the most pressing health concerns our country faces today, such as heart disease, cancer, diabetes, and opioid dependence.

And unique to PCORI, they are the only research funder that ensures that everyone who has a stake in improving health care has a seat at the table. Patients and other decision-makers work right alongside researchers, to shape and guide this research, ensuring it will focus on the outcomes that matter most to patients and their clinicians. As a researcher who has received funding from both the NIH and from PCORI, I have seen firsthand the values and differences of both institutions and what they bring to the table. Clearly, with their focus on discovery and development, the NIH's work is critical. Given that discoveries lead to ever more options for care, there is a great need for the real-world, patient-centered research that PCORI funds so that we can figure out how to make optimal use of all those new discoveries and developments. Indeed, PCORI's fundamental mission is to fund the research that will help patients and their caregivers navigate through their various

options and help them make the choice that is right for them. The unique perspective that PCORI has brought to the research funding scene is the expectation that any kind of research done on people has to be done with them, incorporating their views, experiences, and preferences, all the way from determining what problem to focus on to how it should be done, who the research should engage, and what should with the results once we have them.

Continued federal commitment to disseminating and implementing research findings will yield a significant return on investment.

To date, PCORI has funded more than 600 studies that address a variety of high-priority conditions and topics, such as cancer, cardiovascular disease, mental health, and opioid abuse. Their research has looked specific populations, such as veterans, older adults, minority populations, and patients with multiple chronic conditions and advanced illnesses. Their research also explores new and emerging approaches to care, such as the best ways to leverage telehealth, community health workers, transitional care and other system level interventions. PCORI-funded research also considers strategies and methods to help patients and doctors communicate with each other through approaches such as shared decision-making. And importantly, PCORI funds not just the dissemination of research findings, but also the implementation of actionable results.

For example, PCORI funded a study that found that a simple decision aid can help people who go to the ER with chest pain better understand their risk of having a heart attack and decrease unnecessary hospitalizations for testing. Hospitals can use a decision aid like the one in this study with ER patients who have chest pain but no heart attack diagnosis. The decision aid could help ER patients and doctors work together to make the best decision for each patient. Over five years, this could benefit 9.4 million Americans and save \$4.8 billion nationwide. PCORI is now working to implement this aid in five other hospitals in Alabama, California, and Minnesota.

Another example is a study that compared rates of opioid use in Washington State clinics implementing an initiative focused on more-cautious prescribing of opioid drugs with clinics that did not use such strategies. This health system-based initiative led to reductions in high-dose opioid prescribing while preserving patient pain control.

One more study showed that a behavioral health home—a patient-centered way of coordinating care resources, including using a wellness coach to coordinate mental and physical healthcare services—can help people with serious mental illnesses manage their conditions, potentially enabling them to live longer, healthier lives. The success of this behavioral health home in improving important outcomes was so compelling that the Pennsylvania Medicaid program is expanding the model to more than 40 additional providers across the state. And PCORI is supporting efforts to expand this model to focus on adult opioid treatment programs and youth residential treatment centers that treat emotional, behavioral, and substance use issues.

These are just a few examples of PCORI's research having real-world impacts on patient care. Many of these studies showed that providing more information helped patients make better decisions based on their values and preferences. And based on these examples, using a more patient-centered approach not only improves health outcomes and patient quality of life, but it also reduces the utilization of health care services.

Research is a long-term endeavor. Sustained and robust investment in PCORI is vital.

This is why I am here. To share these success stories and to demonstrate the critical work that PCORI has been doing and to urge Congress to support a reauthorization and continuation of PCORI's funding that will enable this critical work to continue. These are merely a small handful of examples, but they tell a clear story. Simply put, results from PCORI-funded research are actionable, impactful, and have the potential to improve health outcomes for patients across the country. That is why it has strong support from more than 170 health care organizations ranging from patient organizations, such as the American Heart Association and the National Multiple Sclerosis Society, to provider groups, such as the American College of Physicians and the American College of Surgeons, to major medical and health systems, such as Johns Hopkins University and Stanford University School of Medicine, to payers, such as the Association of Community Health Plans and the Better Medicare Alliance.

But as much as PCORI has already contributed to changing the culture of research by engaging patients and stakeholders as partners instead of subjects, and beyond the impactful evidence that has already come out of PCORI-funded studies, there is still much more to be done. Patients and other health care decision-makers continue to face decisions every day about their care – whether it is considering what new drug would best manage their condition or how best to implement a behavioral health home model to most effectively managing patients with serious mental illness or what system improvements and team-based care models can help reduce disparities in cardiovascular risk factors. That is why it is critical to continue to provide a long-term and consistent investment in patient-centered outcomes research.

Ensuring PCORI has that long-term and consistent funding is not only vital to their mission of funding high-impact and patient-centered research, it provides the stability researchers need to conduct the research that answers questions patients and their caregivers have about their care, while also providing training and support for the next generation of researchers.

Recommendation: Preserve PCORI's authorization and funding for at least another 10 years.

In closing, 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 to evaluate which treatment approaches work best, for which patients, taking into account the needs, preferences, and outcomes most important to patients and those who care for them. 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. In view of our shared goal of improving the health and outcomes of all patients, I urge Congress to renew its investment in patient-centered outcomes research and enact a 10-year reauthorization of its charge and funding before it expires on September 30, 2019. Attached please find a letter detailing important views from the community that was sent on May 13 to Chairman Pallone and Ranking Member Walden, along with their counterparts at the Committee on Ways and Means, from the Friends of PCORI Reauthorization. Thank you for your time and for this opportunity to share my experiences as a PCORI-funded researcher and to provide my perspectives on the importance of their current work and potential for the future. I look forward to our discussion.