

Attachments—Additional Questions for the Record

**Subcommittee on Health
Hearing on
“Investing in America’s Health Care”
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Thank you for the opportunity to respond to these questions. My response has been prepared with assistance from staff at the Patient-Centered Outcomes Institute (PCORI).

The Honorable Nanette Barragan (D-CA)

1. During the hearing we discussed what steps PCORI taken to address racial disparities in its research agenda, and how does PCORI believe its finding can address systemic racial disparities. Would you please be able provide any additional specific information regarding PCORI’s working to address racial disparities beyond what we discussed during the hearing?

PCORI has identified the need to [address health care disparities](#) as one of its national priorities for research. Understanding that there are a number of factors that lead to disparities in care, including racial, socioeconomic and gender, PCORI has 88 comparative effectiveness research studies and related projects to help patients at risk for disparities and those who care for them make better informed decisions about their options to improve their health.

For example, one [PCORI-funded study](#) considered methods to help Latino parents learn skills to manage their children’s mental health care. These illnesses can affect a child’s physical health and overall well-being. Children with mental illnesses may also struggle to do well in school. Latino children with mental illnesses are half as likely to get mental health care as white non-Latino children. Latino families often report that they have a hard time getting care. When they do get care, they may be unhappy with it. This study showed that utilizing a tailored educational program could improve parent activation skills and their skills for working with their children’s school systems and became more involved in their children’s school lives.

Another example is a [PCORI-funded study](#) focused on helping doctors understand racial/ethnic minority patients' treatment preferences to improve their health care experiences. Patients from racial and ethnic minority groups in the United States more often report negative experiences with health care, such as discrimination from providers, than do non-Hispanic white patients. Doctors may not realize how past experiences shape their patients’ views. When doctors don’t understand what their patients want and why, patients may not get the treatment that is right for

them. In this study, the research team is developing a survey doctors can use to ask patients about their past experiences with care and treatment preferences and to plan treatment with their patients.

As a clinician and a 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. PCORI’s leadership in this field is supporting relevant and impactful research on how to address systemic racial disparities. I can attest to PCORI’s strong and consistent support of this work because my own research has benefitted from it: <https://www.pcori.org/research-results/2015/comparing-ways-reduce-high-blood-pressure-people-different-backgrounds-rich> .

The Honorable Lisa Blunt Rochester (D-DE)

1. For many reasons, communities of color are often distrustful of the medical community, and particularly of medical research and clinical trials. What steps has PCORI taken to account for these concerns and build trust with minority populations?

One important factor in PCORI’s success is their effort to build the capacity for stakeholders to actively engage in their research and to fund studies relevant to them. In PCORI-funded research, patients and other health care stakeholders are equitable partners—as opposed to research subjects—who leverage their lived experience and expertise to influence research to be more patient centered, relevant, and useful. Their early and continued involvement throughout a study can lead to greater use and uptake of research results by patients and stakeholders within the healthcare community.

For example, one [PCORI-funded project](#) seeks to engage African-American faith communities to address mental health disparities. This project is designed to increase the capacity of faith communities, youth, and stakeholders to lead, design, and conduct their own patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) studies. By directly engaging the community, PCORI is building the capacity for communities of color to proactive partners as opposed to research studies.

Another example of PCORI’s efforts to break down certain barriers is to fund research on how clinicians can best communicate with patients in minority populations or who don’t look like them. One [PCORI-funded study](#) is studying whether educational videos can help African-American patients make decisions about treatment to prevent sudden cardiac death. African-Americans have the highest rates of sudden cardiac death but are much less likely than whites to receive an ICD. Research studies also show that African-Americans are more likely than whites to refuse recommended heart procedures or surgeries. The study is also looking at whether patients who view a video featuring people of their same race have different results than patients who view a video showing people of a different race.

In my own PCORI-funded study, we explore address issues of mistrust in racial and ethnic minority communities by engaging persons from these communities in the design,

implementation, interpretation, and dissemination of findings. We also explore the degree to which trust in health professionals and healthcare organizations influences uptake of programs designed to enhance the self-managements skills of persons with hypertension. Additionally, focus on enhancing patient-centered communication skills and practices in all of the health professionals and health systems involved in our study.

The patient-centered nature of PCORI's mission, as exemplified in the studies described above, has truly changed the culture of research and has led to more meaningful and useful research.

The Honorable Susan W. Brooks

1. What does PCORI see as its role in the nation's efforts to address the opioid epidemic? What has PCORI done so far and what do you anticipate doing moving forward if reauthorized?

As the country grapples with the opioid epidemic, PCORI understands the importance of identifying evidence-based practices that can help patients, caregivers and policymakers make informed decisions about how to address this crisis. To date, PCORI has funded a [broad portfolio of research on opioids use](#) – \$169 M to fund 36 CER studies related to opioid use across the care spectrum. This includes research on:

- Prevention and preventing inappropriate opioid use from the start, including looking at non-opioid medication and alternative therapies;
- Long-term therapies looking at ways to improve pain management while reducing risk to patients; and
- Opioid Use Disorder to evaluate ways to reduce harm among opioid-dependent patients, including studies on medication-assisted treatment (which combines medications such as buprenorphine with counseling) and add-on nonmedication treatments.

One recent [PCORI-funded study](#) found alternative therapies for opioid-treated chronic lower back pain that produce better results for patients. It gives patients more control of the pain management process and lowers their risk of addiction.

With a successful reauthorization, PCORI will be able to fund larger landmark studies of innovative treatments and their health impact on patients – including focusing on addressing the opioids epidemic – that will provide answers to the most pressing questions facing patients and clinicians on what treatment interventions are best and inform health systems and payers on what interventions are of greatest value.