



March 1, 2019

The Honorable Lamar Alexander
Chairman, Senate Committee on Health, Education, Labor and Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Alexander,

The Partnership to Improve Patient Care (PIPC) appreciates the opportunity to provide input on how to lower health care costs and ensure that Americans have access to affordable, quality care. PIPC members, representing a diverse, broad-based group of patients and people with disabilities, are dedicated to advancing the principles of patient-centeredness in an evolving healthcare system. We appreciate your interest in lowering healthcare spending, and by extension, making health care more affordable for patients. We believe that reducing spending is best accomplished by ensuring that patients, providers, and other stakeholders have access to high-quality, patient-centered research that is designed with them in mind. Patients and providers can then use this data to decide for themselves what treatments and services are of the highest value.

With this mission in mind, we wish to suggest several patient-centered policy approaches aimed at facilitating informed decision-making and reducing health care costs.

1. Reauthorize the Patient-Centered Outcomes Research Institute

We support reauthorization of the Patient-Centered Outcomes Research Institute (PCORI) in a manner consistent with the patient-centered principles that led to its creation. As stated by PIPC in 2010, comparative-effectiveness research can form the foundation for meeting “the critically important challenge of controlling health care costs while avoiding oversimplified rationing of patient care.” Now more than ever, we need solutions that are both evidence-based and patient-centered to improve care while addressing health care spending.

PCORI offers important infrastructure to meet this challenge. The evidence generated by PCORI provides information on the value of treatments for individuals, allowing decision-makers to understand the differential impact of treatments on subpopulations and on individual outcomes that matter to patients. We support reauthorization efforts that support patient-centered outcomes research that is timely and responsive to the needs of those making decisions about new medicines and other treatment options, as well as dissemination strategies that make information readily available to decision-makers.

Through reauthorization, PCORI's work can be realigned with the trajectory of health care over the next ten years, driving us toward a health care system in which all stakeholders, particularly patients, are armed with evidence to support high-value, personalized health care decision-making.

To ensure that PCORI's work is supporting the Committee's goal of achieving smarter and more efficient health care spending, PIPC proposes to strengthen PCORI by directing it to:

- **Establish a set of national research priorities that focus its research on high-impact disease areas and treatments.** In setting priorities, PCORI should specifically target a portion of its resources to fund research on comparative clinical effectiveness of high cost items and services, including innovative drugs, a step that has been called for by a range of stakeholders.¹ Additionally, PCORI should annually develop a Priority Therapies List of interventions with significant financial implications for the health system.
- **Conduct quick-turnaround evidence reviews for priority treatments that compare treatments' effectiveness in useful, readily applicable formats.** In determining its research agenda, PCORI should conduct a comprehensive evidence synthesis within its identified priorities. Based on gaps that are identified, PCORI should create a list of specific projects that, taken together, would fill those gaps and improve the ability of patients to make informed health decisions.
- **Improve public transparency and access to patient-centered evidence on value.** PCORI should develop a database of evidence on the comparative value of drugs and other medical products and services, as identified through its evidence synthesis, as well as a list of valid decision-support tools by priority area, to improve health decision-making.
- **Generate high-quality decision support tools to inform patient choice.** PCORI should develop tools such as: shared decision-making tools, clinical pathways, clinical practice guidelines, and value assessments. High quality tools would meet PCORI standards for methodologic rigor, transparency, and patient-centeredness. The Center for Medicare & Medicaid Innovation (CMMI) could utilize PCORI's validated tools in its demonstration projects, such as in Accountable Care Organizations and the Beneficiary Engagement demonstration on Shared Decision Making.

With key reforms included with its FY2019 reauthorization, PCORI's work can be refocused to ensure its research facilitates efficient health care spending.

2. Avoid Reliance on Quality-Adjusted-Life-Years or Similar Metrics

One of the many reasons PCORI's research is so valuable is that it does not depend on flawed, discriminatory metrics for measuring the value of a treatment to patients. Indeed, the statute creating

¹ Center for American Progress "Enough is Enough: The Time Has Come to Address Sky High Drug Prices." September 2015. Available at: <https://cdn.americanprogress.org/wp-content/uploads/2015/09/15131852/DrugPricingReforms-report1.pdf>.

PCORI explicitly prohibits the use of quality-adjusted-life-years (QALYs) or similar metrics that are well known to discriminate against seniors, chronically ill patients, and people with disabilities.² Instead, PCORI utilizes tools that enhance shared decision-making and inform patients and providers to ensure the right patient receives the right treatment at the right time. By facilitating patient-centered and personalized care, PCORI research can improve health care efficiency and avoid unnecessary or potentially harmful care, ultimately reducing health care spending.

Non patient-centered measures of value, like those that are non-transparent, disregard elements of value that are important to patients and their families. Measures that apply averages across diverse patient populations risk inappropriately reducing patients' access to important health care, resulting in poorer, and potentially more expensive, health outcomes. Of particular concern to our community are any decision-making processes that use QALY-based assessments.

The significant dangers of the QALY have been long recognized by Republicans and Democrats, alike. The Affordable Care Act specifically prohibits the development or use of a “dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual’s disability) as a threshold to establish what type of health care is cost effective or recommended.”³ Additionally, in 1992, the Administration under President George H.W. Bush established that it was a violation of the Americans with Disabilities Act for states to employ QALY-based cost-effectiveness standards in Medicaid out of concern that it would discriminate against people with disabilities.⁴ Any legislation that seeks to address health care should include language that codifies this safeguard against the use of discriminatory metrics and even expand its reach to other health care programs when possible.

3. Empowering Patients to Make Informed Health Care Decisions

We believe that substantial opportunities exist to improve health care value by equipping and empowering patients and their caregivers with the information they need to make the best decisions about their care. When patients do not have access to information that allows them to assess the best available treatment for them, our health care system bears the cost of reduced treatment adherence, increased hospitalization, and other acute care episodes.

When seeking to address costs, the Committee should make sure to consider all costs that matter to patients. There are significant societal costs associated with decreased productivity, increased disability, and lower quality of life over time. While insurers may see these costs in different buckets, patients do not. The Committee’s work could drive a more holistic view of health care centered on

² Partnership to Improve Patient Care, “Measuring Value in Medicine: Uses and Misuses of the QALY,” White Paper. Accessed December 5, 2018. [Web.](#); Haagsma JA, Polinder S, Cassini A, Colzani E, Havelaar AH. Review of disability weight studies: comparison of methodological choices and values. *Popul Health Metr.* 2014;12:20. Published 2014 Aug 23. doi:10.1186/s12963-014-0020-2

³ 42 USC Sec 1320e, 2017. Accessed December 4, 2018. [Web.](#)

⁴ See <https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>

patients and people with disabilities and promote meaningful efforts to give patients and consumers greater access and choice.

Health care stakeholders – ranging from patients, providers, and innovators – understand that a value-based health care system that truly supports advancements in personalized and individualized medicine must be built on a foundation of patient-centeredness. Patient-centered, evidence-based health care can lower overall spending by ensuring patients are able to receive timely treatment that is right for them, avoiding downstream costs, and improving patient outcomes. We look forward to engaging with the Committee as you seek approaches to reduce health care spending and improve patient outcomes in the U.S.

Please contact PIPC's Executive Director, Sara van Geertruyden (sara@pipcpatients.org), with any questions related to our shared goals of promoting accessible, affordable, and quality health care.

Sincerely,

A handwritten signature in black ink that reads "Tony Coelho". The signature is written in a cursive style with a large, stylized initial "T".

Tony Coelho
Chairman, Partnership to Improve Patient Care