



June 22, 2015

The Honorable Orrin G. Hatch
Chairman
Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Ron Wyden
Ranking Member
Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Chairman Hatch and Ranking Member Wyden:

The Partnership to Improve Patient Care (PIPC) applauds the Senate Finance Committee for inviting public comment in its work to address chronic diseases. PIPC would welcome the opportunity to put together a meeting of patient organizations to help the committee better understand how policy changes could advance a patient-centered health system from the perspective of the ultimate beneficiary of this work - the patient. Our comments will focus on the committee's request for policy recommendations that improve patient outcomes and options that empower Medicare patients to play a greater role in managing their health and meaningfully engaging with their health care providers.

The U.S. has made significant progress in advancing patient-centeredness in clinical and health systems research over the last several years. Recognizing the need to instill patient-centered principles into the foundation of our health care system, PIPC strongly advocated for the authorization of the Patient-Centered Outcomes Research Institute (PCORI) in 2010 to change the culture of research to better respond to patient needs, outcomes, and preferences, an objective that PCORI is embracing as it shifts away from traditional investigator-initiated research topics to targeted and patient-driven research topics. Building on PCORI's creation and an increased focus on patient-centeredness, Congress specifically allowed the Food and Drug Administration (FDA) to develop and implement strategies to solicit the views of patients during the medical product development process and consider the perspectives of patients during regulatory discussions as part of the Food and Drug Administration Safety and Innovation Act in 2012. This was a significant achievement for patient-centeredness in the drug development process. Additionally, the FDA is also increasingly focused on patient-reported outcomes in their policies and quality improvement

programs. These developments highlight the recognition by policymakers that patients should not be in the back seat, but should instead be driving research, and are capable of translating patient-centered research into health care decision-making.

Since its founding, PIPC has been at the forefront of patient-centeredness in CER – both its generation at PCORI and translation into patient care. With a focus on the front end of clinical CER, PIPC's members initially coalesced around the recognition that policymakers will find it difficult to develop a patient-centered payment and healthcare delivery system without an evidence base developed around patient-centered principles. As the concept of patient-centeredness becomes better defined in its application to research, PIPC looks forward to bringing the patient voice to the discussion of how to advance patient-centered principles in a value-based health care system, specifically in the development of new payment and delivery models.

More recently, work to shift from health care payment based on volume to “value-based” models has taken hold, in part due to broad cost-containment pressure and in part due to the expansion of value-based payment policy via the Affordable Care Act. This movement holds significant implications for patients – on the one hand, value-based payment reform can improve care quality, coordination and patient experience. At the same time, many forms of value-based payment put providers at financial risk for spending targets, which will fundamentally change the doctor-patient relationship, and create the risk of stinting on care that is best for the individual patient and, depending on how they are implemented could promote rigid “one-size-fits-all” applications of comparative effectiveness research.

This broad trend toward value-based or alternative payment models (APMs) underscores the importance of ensuring that value-based tools support patient-centeredness in health care. Failure to advance patient-centeredness in payment reform risks blunting much of the progress that has been made to date in patient-centered research. APMs are increasingly utilizing evidence standards and value-based tools that rely on comparative effectiveness research (CER) and other sources of health care data, presenting both opportunities and challenges as we instill patient-centered principles in a value-based health care system. For example, Congress is beginning to recognize the value of patient-centeredness, referencing shared decision-making as a goal for new accountable care organizations (ACOs) and directing the Centers for Medicare and Medicaid Innovation (CMMI) to embrace concepts such as shared decision-making and evidence-based medicine in its guidance to demonstration project partners. Also, the experience with Patient-Centered Medical Homes (PCMHs) hold great opportunities for engaging patients in informed treatment and health care decision-making, and therefore advancing patient-centeredness.

Health care stakeholders – ranging from patients, providers, and innovators – understand that a value-based health care system that truly supports advancements in personalized or precision medicine must be built on a foundation of patient-centeredness. By incorporating patient-centered principles throughout the building blocks of our health care system, we can provide high-quality care in a manner that is both beneficial to the individual patient and sustainable. We believe the Senate Finance Committee has an opportunity to better align provider incentives around high

quality care care for people with chronic conditions and therefore improve health outcomes and treatment adherence.

Last year, PIPC developed a white paper to highlight some of the most important opportunities and issues to address in translating principles of patient-centeredness to APMs, or value based payment models.¹ Additionally, PIPC's Chairman Tony Coelho recently convened an expert roundtable of 17 thought-leaders in the area of patient engagement and activation, all of whom shared their concerns about the existing health care infrastructure for meaningful patient and beneficiary engagement. The Roundtable focused on how patients can be more effectively engaged in U.S. health care policy development and implementation so that the country is assured of building a patient-centered healthcare system that values the outcomes that matter to patients, and empowers patients to pursue those outcomes by being actively engaged in their own health care decisions.² We are eager to share with the committee what we have learned in our work to promote policies that support a patient-centered health system, particularly from our recent work focused on care delivery.

Recommendations

We would highlight the following recommendations from our white paper and from our recent roundtable discussion that we believe to be particularly relevant for your work on chronic care:

1. Policymakers should establish formalized mechanisms that provide a meaningful voice to patients in the creation and testing of APMs.
 - a. Policymakers should create a national advisory panel on patient-centeredness in value-based payment that is comprised of representatives of patients and their caregivers, primary care and specialist physicians and other providers, and other relevant stakeholders.
 - b. Implement an open and transparent process for testing and implementing APMs., including transparency to the patient about the policies and incentives that drive their treatment choices.
 - c. Work with stakeholders to identify, and subsequently apply, clear patient-centeredness criteria in its approval and evaluation of APMs.
 - d. Support the inclusion of patients and their providers in the development of quality improvement strategies and quality measurement development and adoption.
 - e. Center value definitions on value to patients.
2. CMS, quality organizations, physician and specialty societies should catalyze the expansion of available quality measures and ensure they are appropriately incentivized in APMs.
 - a. Focus on investments in measuring clinical outcomes that are consistent with individual needs, outcomes and preferences, and use that information for quality improvement. Doing so will require that CMS engage patients throughout the

¹ <http://www.pipcpatients.org/PIPC-APM-White-Paper.pdf>

² http://www.pipcpatients.org/pipc-admin/pdf/bca6af_PIPC%20HHS%20Roundtable%20Summary%20and%20Recommendations.pdf

development and use of quality measures, including quality measures based on patient-reported outcomes measures, so that these patient-centered outcomes are driving value assessments. This includes patient input at the front end to identify gaps where measures need to be developed, and also at the back end, assessing performance of measures being used that may need to be updated or replaced.

- b. Expand support for measure development and endorsement, specifically for patient-reported outcomes measures.
 - c. Require accountable care organizations, and other alternative payment models, to collect patient-generated health data, such as through patient-reported outcome measures, and act on the data collected so that it is integrated into their workflow.
 - d. Explore clinical data registries as one potential mechanism for enabling robust, comprehensive quality measures in ways that are administratively feasible for providers.
 - e. Provide transparency to patients, particularly in alternative payment models, both in the measures being used to determine quality care and the incentives being used to drive certain types of care.
3. Foster informed choices from the range of clinical care options.
 - a. Prioritize APMs that make patient engagement and informed treatment decision-making accessible, through shared decision-making and other tools.
 - b. Allow physicians participating in APMs to tailor care to an individual patient.
 - c. Fund research dissemination activities that support the engagement of patients, patient groups, and providers in the development and implementation of dissemination and implementation tools, including shared decision-making tools.
 - d. Prioritize the development of payment models that foster patient engagement and shared decision-making and report annually on progress to advance patient-centeredness in alternative payment models.
 - e. Promote the development and use of measures that support patient engagement, and require the use of those measures by alternative payment models to hold them accountable for engagement.

Conclusion

PIPC applauds the committee's work to improve care for people with chronic conditions. We would highlight that, ultimately, improving patient care requires policies that achieve the outcomes that matter to patients. Doing so will increase adherence, providing patients with the right care at the right time, and decrease unnecessary utilization of services. The recommendations above are strategies that will propel patients into a partnership with their providers and with the broader health system.

We recognize that achieving meaningful patient engagement will require the development and application of metrics for patient engagement and shared decision-making that recognize patient preferences for clinical outcomes and quality of life. We look forward to exploring with the Senate Finance Committee where there may be opportunities for enhancing patient engagement so that we

are developing appropriate metrics that support a patient-centered health system. We also urge you to review our more in-depth reports attached to our comments.

In closing, PIPC urges the Senate Finance Committee to convene patient organizations as it moves forward with legislation. Patients are the ultimate beneficiary of this work, yet often policymakers look to other stakeholders to speak on their behalf. We would encourage the committee not to make this mistake, and instead to invite patients to the table and give them a meaningful voice in the discussion about how to realistically achieve improved outcomes for people with chronic conditions.

Thank you for this opportunity to comment and I look forward to continued collaboration on this important work.

Sincerely,

A handwritten signature in black ink, consisting of a stylized monogram on the left and the name "Coelho" in a cursive script on the right. The signature is enclosed in a thin black rectangular border.

Tony Coelho
Chairman
Partnership to Improve Patient Care