



Executive Summary: PIPC Roundtable on Strategies to Engage and Empower Patients in Care Delivery

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There is an abundance of evidence that indicates patients who are active in their own healthcare decisions have better outcomes at lower costs. As such, steps to increase patient engagement in their health care represent a significant opportunity for policy-makers. Yet, patients often find themselves feeling disempowered and hopeless when facing a healthcare decision because the current United States (U.S.) health care system does not provide adequate tools to be effectively engaged. The shift to so-called “value-based” or alternative payment models provides an important opportunity to improve patient engagement. However, achieving this opportunity requires understanding what patients value and structuring new payment models in ways that engage patients based on their values.

The participants in a roundtable hosted by the Partnership to Improve Patient Care (PIPC) were provided with an opportunity to articulate their concerns about the existing health care infrastructure for meaningful patient and beneficiary engagement, and to provide ideas for improvement. In discussing engagement, participants emphasized that the patient voice should be defined inclusively to include patients, patient organizations, people with disabilities, patient advocates, caregivers, and families. Participants also agreed that there is no wrong door for patient engagement. Patients, patient advocates, patient organizations, family members, and caregivers all bring a patient-focused perspective and should be given roles uniquely suited to their perspectives. For some patients, they rely on advocates such as organizations and caregivers or other supporters to be their voice due to cognitive or other challenges. During roundtable discussions, several themes emerged that led the group to a set of recommendations.

First, participants recognized that a unique opportunity exists to capitalize on the momentum to engage patients and beneficiaries in the health care system, which necessitates institutionalizing a pathway for patients and beneficiaries to be effectively engaged and empowered. There was general agreement that the implementation of alternative payment models holds significant implications for patients and will serve either to empower them and draw them towards the center of care delivery, or further disempower them and leave them at the margins of care delivery. Second, participants agreed there are opportunities to advance patient engagement both in the processes by which payment and delivery reforms are developed, and the form that they take. At both levels, recommendations included developing mechanisms to hear from and respond to patient values, and to engage patients in decision-making, which will be essential. Third, participants strongly advocated for outcomes that matter to patients to be better identified in the measure development process, and further identified opportunities for engaging patients within Accountable Care Organizations. Fourth, participants acknowledged that, as structures are established to engage patients, patients must have the capacity to engage, and therefore discussed strategies to build the capacity of patients to be engaged in policy, governance and direct care. Finally, participants acknowledged that models exist for patient engagement that would prevent “reinventing the wheel” with shared learning among U.S. Department of Health and Human Services (HHS) agencies, while leaving room for innovative strategies to be developed.

Roundtable participants recommended the following:

1. Capitalize on the momentum to engage patients:

- a. Value-based health systems should measure success by achieving outcomes that matter to patients, thereby meeting their trifecta.
- b. Align mandates and incentives to support patient engagement, driving health systems to change behavior and culture toward effective engagement.
- c. Create broader opportunities for public deliberation requiring an informed public's views. In addition to the complex public notice and comment process, HHS should create opportunities and invitations for people to more easily engage in roles uniquely suited to their experience as patients, patient advocates, patient organizations, family members, and caregivers, especially related to the development of alternative payment models at CMMI.
- d. Provide transparency to the patient about the policies and incentives that drive their treatment choices.

2. Increase readiness among patients, beneficiaries and communities to engage:

- a. Provide resources and training for patients to engage in regulatory, research and policy advocacy, including the development of detailed literacy and skill sets so that patients can play more sophisticated roles on technical advisory panels.
- b. Support patients in their participation. This includes covering expenses related to their participation, including travel. PCORI has developed a compensation framework for patient engagement in research that could provide a model for consideration.
- c. Designate increased resources from PCORI for engagement award funding to build capacity of patients and beneficiaries to engage, not only in research, but also in governance and shared decision-making.

3. Reference existing and developing models for patient engagement, including:

- a. PCORI's work to engage patients in research and build the capacity for patients to be engaged;
- b. The Centers for Independent Living movement to empower people to choose their own care setting and community service provider;
- c. The FDA's Patient-Focused Drug Development Program and its ongoing work to capture the patient experience and preferred outcomes in drug development;
- d. SAMHSA's development of metrics for patient engagement.

4. Create a Coordinating Council on Patient Engagement at HHS and increase accountability for patient engagement throughout agencies:

- a. Require a coordinating council of HHS agencies to share their experience with patient and beneficiary engagement. PCORI could also play an advisory role in this coordinating council.
- b. Make the Secretary of HHS directly accountable for patient engagement throughout the department.
- c. Create a dashboard for the Secretary that utilizes defined metrics to track engagement activities.

5. Measure outcomes that matter to patients:

- a. Engage patients throughout the 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. 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.
- c. Promote the development and use of measures that support beneficiary engagement, and require the use of those measures by alternative payment models to hold them accountable for engagement.
- d. Reference the IOM's Vital Signs initiative, as well as the Centers for Independent Living movement, in efforts to better align measures used by communities and by health systems.
- e. Establish a long-term goal of embedding patient-centered measures into the electronic infrastructure that supports health systems.

6. Increase accountability for beneficiary engagement in accountable care organizations and other alternative payment models:

- a. Conduct a series of discussions between CMS and beneficiaries, including patients and people with disabilities, to determine the most effective guidance that both ensures meaningful engagement and promotes the development and implementation of innovative engagement strategies, ultimately providing opportunities for patient input in development of new payment models at CMMI.
- b. 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.
- c. Explicitly prioritize assessing value to patients in the shift to value-based purchasing models for Medicare and Medicaid, and incorporate the use of patient-reported outcome measures.
- d. Build specific requirements into contracts between HHS and its vendors to engage patients and beneficiaries throughout their projects, particularly in the development of measures and in AHRQ's development of shared decision-making tools, using Lean principles.
- e. 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.