



# PIPC/CSC Oncology Roundtable Summary

## *Patient-Driven Health Care and Evidence in Oncology: Setting an Agenda*

*November 2, 2015*

The [Partnership to Improve Patient Care \(PIPC\)](#) and the [Cancer Support Community \(CSC\)](#) convened a roundtable on July 8, 2015 on “Patient-Driven Health Care and Evidence in Oncology: Setting an Agenda.” The roundtable participants represented patient organizations serving cancer patients, as well as a representative from the Patient-Centered Outcomes Research Institute (PCORI). Roundtable participants discussed the outcomes that matter to oncology patients and policies that would support high-quality, patient-driven cancer care.

Roundtable participants included representatives from the following organizations:

- Partnership to Improve Patient Care
- Cancer Support Community
- Bladder Cancer Advocacy Network
- National Patient Advocate Foundation
- CancerCare
- Fight Colorectal Cancer
- National Coalition for Cancer Survivorship
- Lung Cancer Alliance
- Friends of Cancer Research
- Cutaneous Lymphoma Foundation
- Patient-Centered Outcomes Research Institute

As a result of the roundtable, the group developed consensus around a series of recommendations for policymakers, researchers and payers. The summary below refers to *policymakers* in the context of those working in federal government to influence health care policies, Members of Congress and their staff, agencies within the Department of Health and Human Services (HHS), particularly the Centers for Medicare and Medicaid Services (CMS), entities acting in an advisory capacity such as the National Quality Forum (NQF), and contractors hired to implement health care programs, particularly payers contracting with CMS as alternative payment models (APMs).

The roundtable served as a call to action for patient organizations to determine a guiding set of principles for the cancer patient communities that they represent, reflecting their priorities for public policy as the healthcare system shifts away from a fee-for-service (FFS) model to APMs that reward providers based on their ability to achieve “value.” It was agreed that the calculus used by some organizations to define “value” does not necessarily represent value to a patient. Therefore, it

is vital for patients to come together around a core set of policy recommendations that will better achieve outcomes that matter to patients.

The final recommendations from the roundtable included:

- **Achieve Outcomes that Matter to Patients** – Outcomes that matter to patients should be an explicit goal of efforts to improve the health system.
- **Engage Patients** – Patient engagement should be prioritized by policymakers and payers. Engagement should begin early in the process of developing new policies and programs, particularly as they relate to new payment models, and should be measured to determine the use of patient input in the development of the final policy or product.
- **Promote Care Planning that Identifies Patient Preferences** – Care planning should capture the preferences of patients and should be required for implementation in alternative payment models.
- **Support Effective Shared Decision-Making** – Shared decision-making should be required in public programs and promoted by all payers and insurers. Decision aids should be developed in consultation with patient organizations to capture outcomes that matter to patients.
- **Improve Electronic Health Records** – Electronic health records should support care planning and shared decision-making.
- **Promote Patient-Driven Care Through Alternative Payment Models** – Alternative payment models should be developed and implemented in consultation with patients. Developers of these APMs should be accountable for incorporating the patient voice into the final developed policies. These policies should be continuously reviewed and updated to remain consistent with innovation and the collective patient perspective.
- **Increase Transparency to Patients and Beneficiaries** – Alternative payment models should be subject to transparency requirements to ensure that patients, throughout their disease journey whether it be short-term or chronic in nature, understand their treatment options, the out-of-pocket costs associated with their treatment options, and incentives for physicians to adhere to care protocols or pathways that could limit their treatment options.
- **Support Credible Use of Evidence** – Alternative payment models should clearly communicate the evidence supporting treatment options and the evidence that is the basis for incentivized treatment options. Patients should be made aware of the use of evidence, including its validity and credibility to drive certain treatment incentives, as part of their clinical consultations prior to treatment.
- **Use Quality Measures Reflecting Outcomes that Matter to Patients** – It must be a priority to develop and use measures of quality driven by outcomes that matter to patients. These measures should be identified as part of the process of patient engagement.
- **Develop a New Patient Satisfaction Survey and Score** – Policymakers should create a process of engaging patient organizations in the development of a patient satisfaction survey and score for use in the oncology care model, focused on achieving outcomes that matter to patients.

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# Part One

## *Outcomes That Matter to Patients*

Participants discussed the controversial nature of the term “value” often used by policymakers to indicate care that is deemed high quality and cost effective. Although there is an increasing recognition of patient-centeredness factors such as patient satisfaction and the patient experience in value discussions, the algorithms used to determine value do not typically consider patient preferences or patient differences. The term “value” conjures up the concept of a silver bullet or algorithm that would achieve value, which patients often find to be inconsistent with the objective of achieving outcomes that matter to the patient through the process of shared decision-making.

Therefore, the roundtable participants agreed to focus the roundtable discussion on outcomes that matter to patients, recognizing that patients with the same disease may look very similar on paper but have very different preferences and opinions. Rare diseases are at a particular disadvantage in value discussions, because of small sample sizes and the challenge of gathering generalizable evidence to support an “average” view of the rare disease patient. Ultimately, no patient is average.

### *Patient-Centered Outcomes Research*

Patient-centered outcomes research provides a possible evidentiary basis for advancing personalized and precision medicine that achieves outcomes that matter to patients. There has been significant progress in the prioritization of research questions that are most meaningful to patients and in measuring the outcomes that matter to patients as part of research design through the work of the [Patient-Centered Outcomes Research Institute \(PCORI\)](#). PCORI provides an example of how to identify outcomes that matter to patients in their work to include patients in the prioritization of research questions and the design of research projects. Additionally, PCORI is bound by its authorizing statute to make the resulting evidence interpretable and actionable for patients and their providers. Every study, regardless of positive, negative, uncertain results, will produce two 500-word abstracts for the patient and medical communities that are cognitively tested by patients and clinicians.

Participants agreed that the findings of one individual study are meaningless without the larger context of information on the studied issue, including the patient experience. Real patient feedback is what allows the data to be interpreted in a manner usable to patients, not just understandable to a researcher. Therefore, PCORI has committed to vetting its research results through targeted expert stakeholders, including patients, to learn what the findings mean for health care decision-making.

Participants discussed challenges for patient engagement in research, and the progress made to change the culture of research to value patient engagement, as indicators of the barriers to be

expected for the larger health care system. For example, patient organizations are challenged to educate the patient community on how to achieve a voice in research. Additionally, it is important for patient organizations to communicate study findings to patients in the larger context of research so that individual patients can interpret them in the context of their own unique characteristics and preferences. Effective communication of patient-centered outcomes research will require PCORI to establish mechanisms for educating the patient community on the outcomes of PCORI-funded research, and to get their input based on their personal experience. This process is still developing, but is viewed as promising for supporting a patient-driven health system.

Participants recognized that some clinical trials are now being designed to answer questions that are meaningful to patients. Patients want to know their participation is meaningful toward improving health care, and many clinical trials are incorporating patient-reported outcomes in order to better capture outcomes that matter to patients. Participants shared their experiences educating researchers about significant challenges that patients face in clinical trials, such as finding transportation, the cost of transportation, and the burden on caregivers as examples of how important patient engagement is to an effective research process.

Changing the culture of research to engage patients is a top priority for PCORI. From the outset, it is important that patients play a role in determining the research that is funded so that it is responsive to patient needs and supports their decision-making. Therefore, participants strongly recommended that the [National Institute of Health \(NIH\)](#) also apply patient-centeredness criteria, similar to the criteria applied by PCORI, as part of its merit review process for funding research. NIH-funded research should also measure outcomes that matter to patients. It was also suggested that payers conducting observational research on large sets of data also measure outcomes that matter to patients.

### *Care Delivery*

Increasingly, personalized medicine is an opportunity for the health care delivery system to better meet the unique outcomes that matter to an individual patient. Participants acknowledged that, for some cancer patients, survival is very different from living. When a person survives in constant pain, disfigurement or sickness, then a person may not be living out their personal goals and dreams. It could be that a provider is not giving the patient realistic expectations, leading to a patient feeling dissatisfied with their experience. A consensus emerged that by identifying outcomes that matter to patients and driving treatment to address those outcomes, patients would be more satisfied. Yet, doing so may also be contrary to the measures used to determine high quality care (e.g., five year or overall survival metrics) and thereby the outcomes that a clinician prioritizes for that patient, may be driving treatments intended to be more aggressive than truly desired by the patient. Nevertheless, outcomes that matter to patients should be key considerations identified through care coordination, care planning, and shared decision-making.

The National Cancer Institute's publication on [Last Days of Life—for health professionals \(PDQ®\)](#) highlights data showing that across the United States, 29% of patients died in a hospital, with 61.3% hospitalized at least once in the last month of life. In addition, 24% of patients were admitted to an intensive care unit at least once. Approximately 6% of patients nationwide received chemotherapy in the last month of life. Conversely, about 55% of patients who died used hospice service; however, the average length of stay was only 8.7 days, and 8.3% of patients were enrolled in the last 3 days of life.

Additionally, the patient perspective changes over time, from early diagnosis to the later stages of disease, requiring providers to meet patients where they are in their journey with a disease such as cancer. A newly diagnosed patient may have different goals than a patient that has undergone first-line, second-line, and third-line treatments and clinical trials. The challenge is to operationalize a front-end tracking system that captures the changes in a patient's goals for treatment over time. Additionally, each patient may have different goals even at the same stage of treatment. Participants therefore prioritized the development of a universal method for assessing patient treatment goals and preferences as they evolve from experience with disease, understanding that there will be differences among patients.

# Part Two

## *Patient Engagement*

It is a goal of the patient advocacy community to get patients more involved and engaged in the health care system, from policy development for APMs and innovation, down to the individual clinical decision-making level, thereby capturing the patient experience at all levels of the health care system. Unfortunately, the patient perspective is not always effectively integrated into the development of new policies that would support a patient-driven health system. For example, it was agreed that current efforts to define value, particularly for oncology care, often have very little focus on the outcomes that matter to patients, exacerbated by little opportunity for patients to engage in the valuation process and provide meaningful input. Because patients are not meaningfully engaged, the term “value” in the context of health care is often perceived by patients as working against them.

### *Engagement in Treatment Decisions*

The facilitation of patient engagement at the treatment level needs to focus on ensuring there is a full understanding of the patient goals for therapy and their risk/benefit tolerance, such their preferences related to treatment effects on neuropathy, disability, ability to engage in work and family obligations or activities, financial impact, and psychological impacts. Patients who have access to all information about potential treatment options are in a better position to be active participants in their own health care, thus allowing treatments to be tailored to their individual and unique needs and preferences. Furthermore, access to a full range of options offers flexibility based on disease severity, progression and changes in preference or quality of life as treatment evolves.

To achieve this type of patient-driven care, participants recognized the need to overcome the paternalistic attitudes of other health care stakeholders who believe they are acting in the patient’s best interest, though often without engaging the patient and/or their caregivers. Policymakers and providers often take action *for* patients, and not *with* patients, potentially causing their work to be at odds with what patients really want. Ultimately, policymakers must recognize that patients are aligned with the broader systematic goals of high quality affordable care. Although patients may drive different decisions about their own treatment than that which is deemed to be the most effective treatment for the “average” patient, a treatment that reflects individual patient preferences will also drive higher levels of adherence and less utilization of ineffective care. Therefore, patients must advocate for their perspective to be heard.

Engagement must start early to be effective. For example, when patients are engaged early in research, studies are designed to capture data on outcomes that matter to patients. Patients described how research improves when researchers are educated on barriers to participation such as transportation and caregiver burden, which can then be addressed. Similarly, a patient engaged early in treatment to identify the outcomes that matter most to them are able to design their

treatment in the early stages to meet those goals, thereby eliminating care that may be wasteful. Minimizing the time spent in a chair during treatment may be an outcome that matters to a patient who has many responsibilities at home—whether for work or family—that a provider may not immediately recognize.

### *Engagement in Governance and Policy*

Without patient engagement, efforts to reform the health system are unlikely to be successful. For example, participants referenced the evolution of the health maintenance organization (HMO), and the backlash of providers and patients to pre-authorization requirements and narrow provider networks that were perceived to hinder access to care. That backlash led to the creation of state laws on any willing provider and PPO plans. At that stage of our health system, patients had access to information and demanded access to care. HMOs could not be successfully implemented without engaging patients in their development, or considering the impact on their preferred health outcomes.

Participants strongly advocated for patient engagement throughout the governance of health systems and in the development of new payment reforms. In many ways, there are indications that the culture of medicine is shifting to value patient engagement. For example, some physician specialty societies are beginning to place patients in key advisory positions such as on their Board of Directors. Policymakers are seeking out patient perspectives for quality improvement programs in health care.

The [Health Care Payment and Learning Action Network \(LAN\)](#) was recognized as driving the metrics for value within APMs and throughout Medicare and Medicaid. Participants were pleased to learn that the [National Patient Advocate Foundation \(NPAF\)](#) is on the LAN Guiding Committee, yet there were concerns that the larger participation of patient organizations has not been directly solicited, despite the initial focus on oncology. It was recommended that the LAN include a targeted workgroup on measuring outcomes that matter to patients as a metric of value, and that all of the workgroups actively recruit and include patient representatives.

### *Capacity for Engagement*

Meaningful patient engagement will require some effort to build the capacity of patients to be engaged through education and matching patients to appropriate engagement opportunities. PCORI was recognized as potentially playing a significant role in this work to raise awareness among patients of the value of their participation in research and policy development, and potentially leveraging successful existing training programs intended to build the capacity of patients to be engaged in health care. PCORI provides an example of these efforts to build capacity for patient engagement through Engagement Awards and its Pipeline to Proposals awards intended to build the infrastructure for patient-centered outcomes research. The Pipeline to Proposal awards are an opportunity to bring together patients and clinicians to identify the questions that matter most to patients. Additionally, PCORI facilitates patient engagement in all of the phases of research,



from the conduct of the project through dissemination, communication and implementation. PCORI has also created an Ambassador program to build advocacy for patient-centered outcomes research that includes a training module about patient-centered outcomes research. This infrastructure is needed to support the changing culture of research so that patients are ready to be engaged.

Patient organizations are in a strong position to help build capacity to engage patients because they have significant national and often international patient networks, but they often lack resources and staff to do so. They would welcome opportunities to leverage the programs they have created to build a base of patients ready to engage in health care, both from a public policy and individual treatment perspective. For example, the [Research, Advocacy, Training, and Support \(RATS\)](#) program was described as creating a pipeline of educated patients that can speak for the greater patient community. It includes a curriculum of three webinars, participation in the major medical conferences, and on-site training. By developing that informed patient advocate workforce, those patients are ready to engage. There are many similar curriculums that have been developed, but patient organizations are challenged to find the resources to leverage and implement them.

Because training patients to be engaged and activated requires significant resources, organizations providing that training recognize the need to maximize that investment by matching trained patients with engagement opportunities. It is a challenge to funnel individual patients into advocacy areas that they most care about, whether it is policy or research. Often, organizations lose the trained patient to disease, or the patient goes into remission, and therefore ceases to engage. This poses a significant challenge for growing a larger network of engaged patients. Patient organizations also recognize the need to engage patients beyond those in their own databases, recognizing it is hard to reach patients that are unknown. Therefore, participants agreed that caregivers and survivors should also be considered as representatives for patient engagement.

Participants also questioned how to effectively measure that a trained patient was more engaged in their own care, and suggested a measure of the patient's ability to ask better questions at an office visit, or otherwise have a more effective interaction with their provider. Similarly, participants supported the development of measures for more effective engagement in the context of public policy and within health systems after training.

Smaller organizations also questioned how to plug into the programs of larger organizations to train patients for engagement. This would give smaller patient populations, particularly with rare forms of cancer, an opportunity to add to the database upon which outcome measures are applied. This was described as an effective way to leverage existing training programs through collaboration.

# Part Three

## *Care Planning*

In the discussion, roundtable participants immediately recognized that care planning is a key component of a patient-driven health system. The current system typically identifies patient outcomes on the back-end of care delivery as patient-reported data. Therefore, participants advocated for building patient-centered outcomes into the front-end of the health system. For instance, an electronic health record or other technology could be built to enable a front-end conversation between the patient and the physician about the outcomes that matter most to the patient, capturing whether the patient prefers an aggressive therapy, or whether the patient wants to live for a significant upcoming life event, and building the treatment plan around those preferences. Ultimately, the patient's goals for treatment, whatever they may be, should be factored into the treatment decision making.

Participants agreed that patient satisfaction surveys are also important tools, working currently as proxies for measures that do not exist. Yet, participants agreed on the need for a standardized care planning process to capture patient preferences in order to achieve care that is directed by patients. By only capturing anecdotal information on the back end, policymakers and others will consistently state that there is little that can be done with such information to improve patient care. The roundtable recommended researchers create a more sophisticated patient satisfaction survey and score that captures the existence of care planning, described in more detail below.

It was a clear priority for participants that, to be effective, care planning should begin at diagnosis and be continuously updated because patient goals change over time. Care planning should also evolve into a standardized approach that is clearly reimbursed. Care planning for oncology patients should begin at diagnosis with the identification of patients' needs and preferences through elements such as distress screening and palliative care planning. Although a standardized tool exists for distress screening and other care planning tools are being used effectively in limited settings ([Journey Forward](#), [LiveSTRONG's tool](#), [Navigating Cancer](#)), there are not standardized fields or attributes of care planning, nor do these tools capture care planning upon diagnosis. Over the patient journey, aspects of care planning may evolve to other elements such as a survivorship care plan. A challenge with survivorship care planning is that the comparative effectiveness of existing tools is not fully understood, posing challenges to making the case for implementation - although PCORI is doing a study to compare them now.

In one example of the potential value of care planning, a woman diagnosed with Stage 4 cancer was not made fully aware of her treatment options upon diagnosis. She chose to go to hospice and not undergo treatment because she had witnessed the negative impacts of chemotherapy on friends. A month later, her physician advised her that she was identified by genetic testing as a candidate for a specific oral treatment, though he had not advised her of this possibility up front. This treatment would have given her the quality of life she desired, however, because this particular treatment was not discussed with her ahead of time, she missed out on an option that would have best aligned with her treatment goals.

Policymakers are beginning to recognize the value of care planning, but should take additional steps to identify its essential elements. For APMs, care planning may be a self-reported activity that is part of a payment bundle. In Medicare FFS, CMS has released [Advanced Care Planning codes](#), which are part of the physician fee schedule and cover a small reimbursement for the physician and a few key members of the healthcare team.

It was discussed that these care planning codes could be expanded to also cover the work of other care team members, including a licensed mental health professional. Additionally, the codes should explicitly recognize that care planning includes the identification of patient preferences. Ultimately, participants strongly advocated a process of engaging patient organizations to identify the elements of a care plan that could be universally tested and standardized, and subsequently reimbursed.

### *Care Team Participation in Care Planning*

Participants recognized the potential role of members of the care team other than the physician for care planning. For example, a patient navigator could play a role in identifying the outcomes that matter to patients, including goals, costs, and physical considerations. Data was referenced that suggests many patients are more comfortable talking to an advanced practitioner or a nurse about their symptoms, concerns, and issues. It was agreed that professionals other than the physician who are part of the care team could play a role in capturing the patient's goals for treatment so that the physician is not solely burdened with that responsibility. Clinicians have increasingly less time with an individual patient, and the system is facing workforce shortages that add stress to physician workloads. Therefore, the tools that are created to support care planning and subsequently shared decision-making should allow individuals on the care team to practice to the highest level of their license.

Participants discussed the role of primary care physicians as part of the care team and care planning. It was agreed that though primary care physicians do not directly treat cancer, they should be considered part of the care team in order to better manage the patient after treatment and over time. Participants also discussed, as a long-term goal, the possibility of identifying patient preferences and goals even before diagnosis, such as patient risk tolerance, led by their primary care physician.

The care team may also include specialists that consult the patient's attending physician because there are geographies, often rural, and large health systems with narrow networks in which certain types of specialists do not practice. Though a specialist may work with local and community practitioners, the advising specialist is not necessarily reimbursed for that work, often because the specialist is not licensed in that state, perhaps living across a state border. It was not clear how to effectively leverage the expertise of specialists to better serve patients and participate in care planning without a mechanism for payment across state lines or across insurance for their consultation with other practitioners.

## *End of Life*

Care planning should also include end-of-life care planning. As a culture, Americans are hesitant to discuss their quality of life preferences at the end of life, which may impact their decisions whether or not to pursue the most aggressive forms of treatment. The participants suggested that researchers not only focus on quality of life preferences at the end of life, which tends to scare people, and instead discuss quality of life at all stages through care planning. In this way, we are advocating for behaviors and health care to consistently maximize quality of life based on the individual patient's preferences. By incorporating end-of-life care planning into care planning generally, it becomes simply one component of a longitudinal care planning process.

As an example of care planning at the end of life, one participant described their [Grief and Understanding in Death and End-of-Life Support \(GUIDES\)](#) program. Caregiver volunteers who have lost a loved one to lung cancer are connected to another caregiver with a loved one that has either recently passed away or is in hospice to give them support. A program evaluation demonstrates that the program works for families and caregivers seeking support to make end-of-life decisions that are in the best interest of the patient.

Another participant described their [Dying Well module](#), which is a part of the Cancer Survival Toolbox, and is designed to teach patients more about their choices and resources, as well as what to expect during the last stage of survival. It is the module used most frequently. Participants also referenced the work of the [Patient Quality of Life Coalition](#), which promotes public policy that will improve and expand access to high-quality palliative care. These programs are evidence that there are models with measurable and demonstrated effectiveness to feed into a process of standardizing how end-of-life care fits into the larger care planning process.

# Part Four

## *Shared Decision-Making*

To achieve patient-directed care, the patient and provider should decide together how to proceed with treatment in a process called shared decision-making. While recognizing that patients need to rely on the expertise of clinicians, clinicians should also rely on the patient to communicate their preferences so they can tailor treatment accordingly. It is often perceived that clinicians are uncomfortable with the concept of patient-directed care, yet understanding patient preferences could alleviate some of the clinician burden by giving them a clear indication of what the patient's goals may be. The next generation of shared-decision making will require the development of tools that provide patients, their caregivers and their health care teams the specificity to discuss their condition, their preferences for treatment, and their treatment options, including out-of-pocket cost and the benefits and risks associated with each. Such information is needed to support the patient's determination of the outcomes that matter most, and a positive shared decision-making experience with their providers.

Recognizing the importance of shared decision-making, the Affordable Care Act provided for the establishment of independent standards for certification of patient decision aids; for the development, update, and production of patient decision aids to assist providers in educating patients; and grants to support implementation. It also called for the development of a quality measure that includes the use of shared decision-making and preference sensitive care. Unfortunately, there has not been funding directed by Congress to these activities. Nevertheless, some states have taken steps to implement shared decision-making through a variety of strategies, providing the foundation for determining what tools work in practice to support patient-directed care.

Shared decision-making was described as including care planning that identifies patient preferences. Initially, this type of care planning would be a proxy indicator for shared decision-making indicating that, at a minimum, care planning occurred that included the solicitation of patient preferences. The decisions made at the office visit would presumably be informed by the patient preferences indicated by care planning. A later stage proxy measure of effective shared decision-making could be a survey after the office visit indicating that the patient felt heard. Ultimately, a measure could be developed to capture whether those identified preferences were appropriately sought or even achieved by the prescribed treatment.

If shared decision-making were to happen at each visit, it would create an expectation to share decisions, allowing patients to advocate for themselves. Yet, the concept of shared decision-making is largely undefined, making it difficult to measure when it has happened. As with care planning, participants advocated for the core components of a shared decision-making process to be defined in a stakeholder process including significant patient representation. There should be a core standard of demonstrable patient engagement in the development and testing of shared decision-

making tools before payers and policymakers allow for their use as such. It was suggested that either CMS could directly consult with patients on the components of shared decision-making that become part of the conditions of participation for hospitals, or the Joint Commission could directly consult with patients to include the components of shared decision-making in its accreditation standards for hospitals.

A [U.S. News and World Report article](#) shared examples related to the importance of care planning and shared decision-making from Linda House, president of the Cancer Support Community. She recalled working with a pianist who had terminal cancer and was intent on playing piano until the end of her life. For that reason, the pianist decided against taking a potentially life-extending treatment that can cause neuropathy, or numbness, in the fingertips. That same thinking caused another patient, a veterinarian, to forego that treatment because he wanted to continue to work with animals, and the way he examines them is by touching them.

Participants acknowledged that patients vary greatly in health literacy, which impacts effective shared decision-making. Yet, it was also acknowledged that over time with a disease, patients grow in their health literacy allowing their questions to providers to become more sophisticated. This growth in health literacy is facilitated by the use of effective shared decision-making tools.

It has been a perceived challenge to reconcile the identified individualized preferences that should drive patient care with the common good of policies that drive cost containment to protect public resources. Yet, outcomes that matter to patients are often aligned with the goals of policymakers seeking to strike the balance of quality and cost, as they lead to more effective treatments from the outset and less waste and overutilization. In fact, some studies indicate that decision aids do not have an impact on the length of the office visit and do not have a significant impact on the cost of care, yet they improve the quality of care provided. It was suggested that the clinical trials process does not routinely incorporate validated, patient-reported outcomes, which ultimately translates into decision-making data that does not capture outcomes that matter to patients and further complicates the development of decision aids that are useful to patients.

Despite not being widely used by providers, many decision aids have been developed. To effectively implement decision aids, patients will need to be educated about how to use them and their value for shared decision-making and patient-driven care. To change the culture of medicine to embrace the concept of shared decision-making, medical school curriculums should be updated to ensure newly trained clinicians understand its value. Another challenge is that there is no financial incentive to use shared decision-making tools, which could be addressed through payment reforms. For example, the use of decision aids could be one component of a bundle of activities demonstrating patient engagement in APMs, with the potential to be tied to an outcome measure demonstrating that care planning and shared decision-making led to treatments addressing the outcomes that mattered to the patient. Significant work needs to be done to change the culture and attitude toward patient engagement and shared decision-making, and will likely need to be driven by health care payment reforms.

Participants recommended the development of a benefit and risk calculator in consultation with patient organizations that patients can access directly to determine treatment impacts based on their individual preferences, which could also include a transparent assessment of out-of-pocket costs, as described in more detail below. As a model, participants referred to the Cancer Insurance Checklist, an interactive tool designed to assist patients with cancer shop for health insurance. Similar tools assist patients with chronic diseases. Participants recognized that family members and caregivers often play a role in pushing for more aggressive treatment when a patient may prefer a different quality of life outcome. A benefit and risk calculator developed in consultation with patient organizations would capture outcomes that really matter to patients. In this way, it could help patients understand their treatment options and their impacts, both clinical and for quality of life, and could also be used to help family members and caregivers better understand the preferences of the patient.

In one potential model and example, RTI International published a report on [A Brief Introduction to the Use of Stated-Choice Methods to Measure Preferences for Treatment Benefits and Risks](#). The report indicated that stated-choice methods, which measure stated preferences and are sometimes called discrete-choice experiments or conjoint analysis. These are often the most valid and reliable techniques available for quantifying patient preferences because data on actual choices are limited. The report indicated that work has been done to adapt and apply stated-choice methods to quantitative benefit-risk analysis.

### *Long-Term Effects of Treatment*

Shared decision-making must consider both the short- and long-term treatment effects. Quality assessments are often based on short-term effects of treatment, such as reducing specific symptoms, with little consideration of the long-term effects. It is important for a patient to know the potential implications of treatment for its impact on quality of life such as long-term neuropathy, disability, ability to engage in work and family obligations or activities, financial impact, and psychological impacts. It was suggested that care planning and shared decision-making tools allow for a patient to input their preferences, including physical outcomes, psychological and mental outcomes, and ability to engage in work and family obligations or activities, so that the impact of various treatments are communicated to the patient reflecting those preferences both in the short and long term, enabling the patient to then make an informed decision. Documentation of the impact of treatments based on these types of preferences, perhaps through electronic medical records or PCORnet, would allow for a feedback loop that allows patients to learn from their experience and perhaps the experience of others through observational research.

Research exists on long-term impacts of cancer treatments, yet this evidence is often not utilized or communicated to the patient. If given the opportunity, patients will make health care decisions based on more than the immediate clinical impact. Patients want to assess impact over time,

including cognition and the impact on their ability to engage in work and family obligations or activities.

Understanding the long-term effects of treatment could also impact the broader societal cost of cancer. For example, a patient that becomes disabled and therefore must acquire Social Security Disability Insurance (SSDI) due to their treatment presents a societal cost, yet the risk of disability may not have ever been communicated to the patient at the time of treatment. Participants agreed that impacts associated with ability to engage in work and family obligations or activities should be studied as proxies for long-term quality-of-life impacts of various treatment options. Additionally, participants recognized that in some cases, it is not clear if a long-term impact such as neuropathy is induced by the treatment or by the disease, which should also be a focus of research. Smaller patient organizations also have a strong interest in capturing data on long-term impacts of treatments such as ability to engage in work and family life and need for a caregiver, that could be fed into larger databases that may not capture those intimate details. Understanding these long-term effects would be very useful to patients in the decision-making process.

It was discussed whether a decision aid could be developed and marketed effectively to patients and providers, regardless of the payer, that could be used to tailor care to an individual. If provided in the form of an electronic tool, this was perceived as more effectively integrating into the workflow of a provider. It was acknowledged that there is currently not a commercial market for such a tool, though a market will develop if policymakers create requirements or incentives for their use.



# Part Five

## *Electronic Health Records*

**E**lectronic health records and other online tools were thought to play a significant role in research, care planning, and shared decision-making. Because patients perceive their symptoms differently, it was discussed that an online tool could capture differences in patient input to better and more objectively measure the impact of treatment on symptoms. One participant described a new platform to communicate with the electronic health record that would possibly allow for the symptoms experienced by the patient to be self-reported. It currently integrates with EPIC and a few other major electronic health records. It is hoped to integrate this type of technology in a more standardized manner in the future.

Today, patient portals tend to be one-way communications, allowing the clinical practice to share laboratory results or other health information with the patient. Some portals do not allow patients to input information related to their symptoms and preferences. Electronic health records should include a field to capture the preferences of patients, which will require a patient portal that allows for two-way communications both from the care team to the patient and from the patient to the care team. It was suggested that a two-way portal would be more reliable than simply having the provider check a box that they communicated with the patient, because the patient may not have necessarily understood what was being said in the moment of the office visit. A two-way patient portal would allow the patient to input whether they were asked their goals for treatment, felt heard, and were given options based on those goals. It would also invite the patient to provide quality of life information that may help the provider better address the patient's preferred outcomes and goals for treatment. Having this information before the office visit, especially considering the increasing time limitations that physicians have with individual patients, could be of great value, and allow physicians to engage patients at the level that they prefer.

Workflow also presents a challenge for operationalizing patient-driven health care. As one example, an organization and/or physicians practice may be trying to comply with different process measures for multiple accreditation requirements which may not fit neatly into one workflow. This creates workflow challenges, which should be addressed so that all the requirements are met and also reflected in the care plan that is capturing patient preferences.

# Part Six

## *Alternative Payment Models*

Participants discussed current efforts among policymakers to promote AMPs and value-based purchasing. Concerns were expressed that, in some cases, APMs are being developed with controlling costs as a primary objective, utilizing quality measures that are consistent with cost containment goals and not necessarily the goal of achieving outcomes that matter to patients. It was agreed that if patients had better tools to understand their treatment options, their individualized impact, and their associated out-of-pocket costs, then patients could advocate for treatment outside of those that are incentivized in the payment system to better meet their personalized needs and preferences.

It was disputed that giving patients an active and informed role in their treatment decisions would increase costs. Although in rare cases a patient may be motivated to extend life at all costs, it is more likely that patients do not want to over-utilize health care without regard to cost and physical consequences, both short and long-term. Empowering patients to have their treatment reflect their values and standards is often aligned with the goals of cost containment, preventing over-utilization and increasing adherence. Just as PCORI has changed the culture of research from viewing patient engagement as an impediment to rigorous research, patients are now faced with the challenge of changing the culture of health delivery from viewing activated and engaged patients as costly and time consuming.

The [Oncology Care Model](#) was described as having a significant impact on the evolution of oncology care. One positive element is its incorporation of psychosocial care. Yet it is a challenge that the model does not prescribe many of the elements that must be included to support patient-directed care. It was suggested that there be a process of patient engagement for identifying those elements, such as care planning that includes the identification of patient preferences and shared decision-making using tools developed in consultation with patients. Participants acknowledged that it is a step in the right direction for care coordination to be recognized and reimbursed in some APMs. For example, the Oncology Care Model provides for a monthly per-beneficiary care management payment for Medicare FFS beneficiaries and a performance-based payment for Oncology Care Model episodes. Yet, participants recognized that in some cases insurers are providing reimbursement for care planning and care coordination, while maintaining a clear incentive to provide the lowest cost treatment that is effective for an average patient that undermines meaningful shared decision-making.

It was strongly recommended that policymakers seek out patient organizations to be engaged in the development and approval of Oncology Care Models and other APMs. Currently, CMMI does not undertake a notice and comment process to solicit input into the development in APMs. A notice and comment process would be an important first step in engaging the broader patient community. However, the notice and comment process in the Federal Register is not a process that alone

meaningfully engages patients. Instead, organizations hoped for a more regular and interactive dialogue with policymakers to grapple with policies that are new and evolving so that patient-centeredness criteria are applied in the evaluation and approval of APMs, similar to the process of engaging physicians through the Physician-Focused Payment Model Technical Advisory Committee. A formal patient advisory committee could also provide counsel on the development of policies for APMs related to patient and beneficiary engagement, clinical episodes payment, population-based payments, shared decision-making, and quality measurement, among other topics. Otherwise, it is very difficult to backtrack on a policy that has been developed without continuous patient feedback. Although policymakers reach out to some patient organizations regularly, participants advocated for a process of engagement that was accountable for incorporating the patient voice into the final developed policies so as to avoid the perception of just “checking the box” that engagement happened.

# Part Seven

## *Transparency*

**T**he issue of transparency was a clear priority for roundtable participants. For most patients, there is little transparency of their treatment options outside of what is covered by insurance despite that, upon diagnosis, a patient is confined to the health insurance plan that they have until the next enrollment period. The patient's plan was likely not chosen in anticipation of having cancer. Care planning that captures patient preferences over time and effective shared decision-making would obviously increase the level of transparency to the patient about their treatment options and impacts.

The lack of transparency associated with new payment models was a key concern. Participants agreed that patients should have a role in the development of new payment models that may create financial incentives to use certain treatments. Models must also encourage meaningful shared decision-making between providers and patients. In order for shared decision-making to be truly meaningful, patients should be aware of incentives for their physicians to adhere to care protocols or pathways that could limit their treatment options. It was strongly recommended that providers in these models be encouraged to communicate to patients the full range of their treatment options, the risks and benefits of each as they relate to their individual preferences, and the associated out-of-pocket costs beginning upon cancer diagnosis. This could be a standard disclosure similar to the disclosures required for Medicare Advantage organizations, or the privacy (HIPAA) disclosures requiring acknowledgement by the patient.

### *Transparency of Clinical Pathways in Oncology*

Participants expressed significant concerns about the lack of transparency around the development and use of clinical pathways in oncology. Related to the use of clinical pathways, it was discussed that patients have a right to know they are on a clinical pathway. While the proliferation of clinical pathways was referenced as having a significant impact on patient care in oncology, patients typically are unaware when they are subject to one. How that information is communicated to a patient will have a huge impact on their decision-making, allowing them to either agree to the clinical pathway of treatment, or seek out and choose an alternative treatment. As a policy, clinical pathways allow for a certain percentage of patients to deviate to another treatment, thereby allowing an informed and activated patient to request a different treatment. While in some cases, payers and insurers that have developed and utilize clinical pathways also provide a care management fee to providers that should cover some aspects of care planning, it was questioned whether the financial incentive driving the clinical pathway would be a disincentive for meaningful shared decision-making. It was also suggested that providers that adhere to clinical pathways may be advantaged through a star rating or a better network tier, creating an even stronger incentive for clinical pathway adherence as opposed to meaningful shared decision-making.

Regarding the process for developing clinical pathways, it was agreed that if insurers or other organizations are incentivizing providers to comply with a certain clinical pathway, there should be a high level of transparency in its development. Participants discussed at length the responsible party for providing this information, and it was agreed that the payer or insurer should be disclosing the information to patients. Insurers are required to disclose co-pays, annual deductibles, and provider networks. Similarly, they could be required to disclose their development and use of clinical pathways.

A [survey](#) was completed in July, 2015 of 1300+ [CancerCare](#) clients who had been diagnosed with breast, colon, lung or prostate cancer within the past 5 years. The vast majority of respondents had not heard the term “clinical pathway” and less than a quarter said their doctor had recommended treatment that was based on one. Even when the term was defined, fewer than half acknowledged being familiar with it.

Participants discussed the elements of clinical pathway development that should be transparent to the beneficiary and the public. For example, elements should include a disclosure of the evidence that is the basis for the clinical pathway, the individuals and organizations involved in the pathway development and their conflicts of interest, and other financial incentives or potential conflicts that may play a role in pathway development. This information should be provided in a notice to the patient that the provider or practice is incentivized to use the clinical pathway and the background information for how it was developed.

Additionally, policymakers should require patient engagement in the development of clinical pathways utilized in public programs. Standards for meaningful patient engagement must go beyond “token” engagement efforts, and instead substantially demonstrate that the patient voice is accounted for in the final product. It is also vital to recognize that patients should not be given a false sense of security related to the effectiveness of any clinical pathway, as a clinical pathway may be deemed effective for a large percentage of the population, but there will always be patients for whom it is not effective. Additionally, there must be requirements in place for routinely updating clinical pathways to account for innovation.

#### *Out-of-Pocket Cost Transparency*

It was also a priority to incorporate transparency of the out-of-pocket costs associated with a patient’s treatment options. In one example, a Medicare FFS beneficiary was unable to determine the coverage and cost of a certain treatment upon calling the Medicare hotline. The beneficiary was provided a disclaimer that Medicare does not guarantee coverage based on the information provided on the call. Only after being billed will Medicare make a formal determination of coverage in writing. In another example, a patient had not received prior authorization for a treatment, and needed the treatment immediately, so the physician asked the patient to sign a financial release from the physician’s liability for covering the treatment cost if insurance denied its coverage. The patient was left in a very difficult position not knowing the personal financial implications of that

treatment decision. This lack of transparency is a significant challenge to patients and beneficiaries seeking to make informed decisions about their health care.

Policymakers should require that patients have access to their out-of-pocket costs for each of their treatment options through an online tool. Although there may be options that patients cannot afford, it was agreed that patients have a right to the information. It was also agreed that it is technologically possible for patients to know their treatment costs and coverage in real time. Participants reflected on the existence of technologies such as Uber, which knows the corner where an individual is standing and the cost of their car ride in advance, as well as travel websites that communicate all your travel options in a quick search.

The challenge for this technological solution to provide transparency of out-of-pocket costs is the data input from payers. Participants recognized that there are many intermediaries in addition to the health insurer that would need to input into a tool providing transparency on out-of-pocket costs. It would have to be routinely updated in a central repository with a host of intermediaries feeding into it. Nevertheless, participants acknowledged that policymakers already require reporting on average sales prices, and therefore argued that intermediaries could similarly report the actual out-of-pocket cost to beneficiaries for treatments. Patients could then pull their out-of-pocket costs from that repository based on their health plan,

Another participant reflected on the [Insight into Patient Access to Care in Cancer Project](#), a survey released in March indicating that patients are also very concerned about future out-of-pocket costs, such as lab tests, biopsy, imaging, etc. Often, patients are faced with tough choices when they cannot afford the proper follow-up care associated with a treatment option. In order for future out-of-pocket costs to be part of the shared decision-making process, predictable future treatment needs associated with treatment options should also be incorporated into shared decision-making tools.

# Part Eight

## *Evidentiary Standards*

Participants also advocated for transparency of the evidence that is the basis for treatment options incentivized by APMs. In this age of personalized and precision medicine, the impact of a treatment is often different for certain biomarkers, i.e. certain tumors respond differently to treatments. Therefore, it is vital to match the treatment to the patient whose tumor has the biomarker to be responsive, which requires certain evidentiary standards to be met.

Participants suggested creating a clearinghouse for evidence that would allow patients to be presented credible information that is relevant to their individual characteristics and preferences. For example, ClinicalTrials.gov was positively referenced as aspiring to post results regardless of outcome. In many cases, researchers do not publish negative results, despite that it may provide useful information. Additionally, ClinicalTrials.gov is a tool for researchers, and is not considered a tool for patients. To the contrary, PCORI's repository of research findings will be intended for patient use and may provide for a model or platform for a more patient-centered clearinghouse of evidence.

It was suggested that policymakers could foster an environment where developers of alternate payment models are called upon to consult with patients about their use of evidence, and its validity and credibility to drive certain treatments. Although patients and patient organizations are not necessarily scientists—and should not be expected to weigh in from a scientific perspective—they could raise important perspectives related to outcomes that matter to patients and therefore usability of the evidence to drive treatment decisions. As patients become more engaged in prioritizing and designing research to measure outcomes that matter to patients, they will be in a position to better consult on the potential use of that evidence for decision-making.

# Part Nine

## *Quality Measures*

To achieve patient-directed care, participants prioritized the development and use of measures of quality that are driven by outcomes that matter to patients. The [National Committee for Quality Assurance \(NCQA\)](#) and NQF identify gaps where new measures need to be developed. Currently, clinical quality improvement is measured around safety and equitability across care settings, so that a person is receiving comparable care from every institution. Quality improvement around patient-centeredness is more personalized, and tougher to measure. Therefore, patients need to be engaged in identifying the outcomes that matter and that are the basis for the development and use of better measures in the healthcare system.

It was agreed that today's standard outcomes such as survival are not the "Holy Grail," as they may be outweighed by other quality-of-life considerations for the patient. Yet outcomes such as survival are often the outcomes measured to determine the quality of care. For example, five-year survival outcomes are reported to the [Commission on Cancer](#) database. In fact, treatment response rates may have a greater value to the patient. Patients are often also concerned about the quality of life implications of the time spent in a chair during treatment. For other patients, living with stable disease may be the preferred outcome.

Ultimately, standardized measures on the impact of a treatment on outcomes that matter to patients should be developed, including symptoms associated with the disease, treatment side effects, and impact on function. It was suggested to use these standardized measures reflecting outcomes that matter to patients in clinical trials, which would make the information from those trials more useful. Unfortunately, researchers and health systems often lack clarity on validated patient-reported and patient-centered outcome measures, indicating a continued need to shift the culture of research to value patient engagement.

### *Measures to Capture Care Planning and Shared Decision-Making*

As discussed earlier, participants strongly advocated that there be a measure capturing the existence of care planning and shared decision-making to achieve a patient's preferred outcomes. Although some measures for shared decision-making have been developed, they are seldom integrated into health systems. Additionally, to be valid, patients must have opportunities to provide input on the development and ultimate value of those measures of shared decision-making. Without effective measures of shared decision-making, existing patient satisfaction surveys remain the proxies for measuring patient engagement.

Quality measures are often focused on process and not patient-centered outcomes. Yet, in some cases, a process is the best existing proxy for a patient-centered outcome. For example, participants argued that the occurrence of care planning could be a first step in indicating that patient



preferences were considered in the treatment plan. Ultimately, participants strived to systematically identify the existence of a care planning process capturing patient preferences, with a measure for whether the outcome that mattered to the patient was sought and achieved by treatment.

### *Patient Satisfaction Survey for Oncology*

In addition to the development of measures supporting care planning and shared decision-making, it was suggested that use of decision aid technologies may be incentivized by evolved patient satisfaction surveys that measure the extent to which care was directed by patients. A few existing health systems are getting feedback through patient portals and mobile apps allowing a patient to input information prior to their office visit. Participants questioned how to make this practice more widespread, and how to expand the use of these electronic tools beyond a set of pre-determined symptoms and family history so that they are used more effectively. Although PCORI is studying many of these tools to demonstrate their effectiveness, there is little incentive for health systems to adopt them. Organizations representing oncology patients could be engaged in a process to create a patient satisfaction score for use in the oncology care model, focused on achieving outcomes that matter to patients. Participants suggested that a more sophisticated patient satisfaction survey not provide one overall score, but instead be divided into sub-topics—such as the administration experience—or into segments of the patient’s journey and continuum of care, such as diagnosis, treatment, clinical trial, relapse, and survivorship planning.

The process of shared decision-making was described as a possible proxy for a patient satisfaction score. At each appointment or interaction, the patient would identify whether their preferences were solicited and identified, whether their treatment options were discussed, and whether they were satisfied with the treatment decision. Although the survey may not be a reliable assessment of whether the outcomes were improved, it would capture the value of the interaction to the patient.

It was discussed that several entities may be interested in leading the development of a more patient-centered patient satisfaction survey tool. The National Patient Advocate Foundation (NPAF) and the American Institutes of Research (AIR) have developed a [Consumer-Based Cancer Care Value Index](#), which was perceived as a strong first step to measuring value to the patient. The group also suggested that the Joint Commission, which accredits health care organizations and hospitals and already mandates a patient satisfaction survey for its accredited hospitals, could be interested in participating in the development of a more sophisticated patient satisfaction survey tool. It was also suggested that the American College of Surgeons could also be interested in this tool as part of an accreditation process.

It was suggested that the newly developed survey be implemented online and that it not be delivered directly by clinicians because a patient will be hesitant to critique their own doctor upon whom they rely for personalized attention. It should be completed by beneficiaries seeing physicians and clinical practices that participate in APMs. APMs should be required to collect that

survey information and the output from survey questions, allowing them to systematically demonstrate whether those practices or models are providing value to the patient. In the end, the physician would get a report card indicating the extent to which patients felt engaged and that the physician sought to achieve their goals. The group recognized the need to address the risk of an online survey to skew results due to the likelihood of responses from the most positive and most negative experiences.

# Part Ten

## *Recommendations*

As a result of the dialogue fostered by the roundtable, participants agreed to the following set of recommendations to better achieve outcomes that matter to patients:

- **Achieve Outcomes that Matter to Patients** – Outcomes that matter to patients should be an explicit goal of efforts to improve the health system.
  - The NIH should apply patient-centeredness criteria, similar to the criteria applied by PCORI, as part of its merit review process for funding research. NIH-funded research should also be required to measure outcomes that matter to patients.
  - Payers conducting observational research on large sets of data should identify and measure outcomes that matter to patients.
  - Outcomes that matter to patients should be key considerations identified through care coordination, care planning and shared decision-making.
  - Patient portals and other documentation of patient experience should include collection of preferred outcomes or expectations of care from the patient.
- **Engage Patients** – Patient engagement should be prioritized by policymakers and payers. Engagement should begin early in the process of developing new policies and programs, particularly as they relate to new payment models, and should be measured to determine the use of patient input in the development of the final policy or product.
  - LAN workgroups should include individual patient and/or patient group representatives. The LAN should seek input from patients on specific project activities. For example, the LAN should include a targeted workgroup on measuring outcomes that matter to patients. All LAN workgroups should include individual patient and/or patient group representatives.
  - Caregivers and survivors should also be considered as representatives for patient engagement.
  - Measures should be developed and applied to determine the effectiveness of engagement activities in public policy, clearly identifying how the engagement made a difference in policy development.
  - Training curriculums to build the capacity for patient engagement should be leveraged by PCORI and by policymakers.
  - Impact of training activities on the patient’s engagement should be measured to determine its effectiveness.
- **Promote Care Planning that Identifies Patient Preferences** – Care planning should capture the preferences of patients and should be required for implementation in alternative payment models.

- Policymakers should initiate a patient engagement process, perhaps as part of the LAN or the development of the oncology care model, to identify the elements of a care plan that could be universally tested and standardized, and subsequently reimbursed.
  - Palliative care planning, survivorship planning, and end-of-life care planning, should be elements of care planning and included in reimbursement for such planning activities.
  - Care plans should be continuously and routinely updated in a process that captures changes in patient goals over time.
  - The tools that are created to support care planning and subsequently shared decision-making should allow individuals on the care team to practice to the highest level of their license, including licensed mental healthcare professionals.
  - Reimbursement codes utilized in public programs for care planning should explicitly recognize that care planning begins with the identification of patient preferences.
- **Support Effective Shared Decision-Making** – Shared decision-making should be required in public programs and promoted by all payers and insurers. Decision aids should be developed in consultation with patient organizations to capture outcomes that matter to patients.
    - Policymakers should initiate a patient engagement process to identify the core components of a shared decision-making process required for alternative payment models, including the use of tools that allow patients to understand their condition, their preferences for treatment, and their treatment options, the benefits and risks associated with each treatment option, and their associated out-of-pocket costs.
    - Shared decision-making should include care planning that identifies patient preferences as a necessary first step to be effective.
    - Progress toward effective shared decision-making should occur in a series of steps.
      - First, policymakers should require the identification of patient preferences and a care plan aligned with those preferences as a proxy indicator for shared decision-making.
      - Next, a proxy measure of effective shared decision-making should be a new patient satisfaction survey occurring after the office visit indicating elements of shared decision-making (see recommendation below).
      - Ultimately, a measure could be developed to capture whether the identified preferences in care planning were appropriately sought or even achieved by the prescribed treatment.
    - Policymakers should require a core standard of demonstrable patient engagement in the development and testing of shared decision-making tools utilized in alternative payment models.
    - Medical school curriculums should be updated to ensure newly trained clinicians understand the value of shared decision-making.

- A benefit and risk calculator should be developed in consultation with patient organizations to capture outcomes that really matter to patients and to communicate to patients their treatment options and their impacts based on their individual preferences, including long-term impacts associated with ability to engage in work and family obligations or activities, neuropathy, disability, etc.
- **Improve Electronic Health Records** – Electronic health records should support care planning and shared decision-making.
  - Electronic health records should allow for two-way communications between patients and their care team and for annotation by the patient to capture symptoms, preferences and goals.
  - Electronic health records should include fields that capture the preferences of patients.
- **Promote Patient-Driven Care Through Alternative Payment Models** – Alternative payment models should be developed and implemented in consultation with patients. Developers of these APMs should be accountable for incorporating the patient voice into the final developed policies. These policies should be continuously reviewed and updated to remain consistent with innovation and the collective patient perspective.
  - Alternative payment models should be informed by patients through a regular and interactive dialogue applying patient-centeredness criteria to their development and implementation, similar to the process of engaging physicians through the Physician-focused Payment Model Technical Advisory Committee.
  - Models tested by the Center for Medicare and Medicaid Innovation should follow a public comment process to provide opportunities for patients and advocates to inform the development of these models.
  - Alternative payment models should undergo a process for routine review that allows their success to be measured based on the most current innovations.
- **Increase Transparency to Patients and Beneficiaries** – Alternative payment models should be subject to transparency requirements to ensure that patients, throughout their disease journey whether it be short-term or chronic in nature, understand their treatment options, the out-of-pocket costs associated with their treatment options, and incentives for physicians to adhere to care protocols or pathways that could limit their treatment options.
  - Clinical pathway development should be transparent to the beneficiary and the public, including a disclosure from the payer or insurer on the evidence that is the basis for the clinical pathway, the individuals and organizations involved in the pathway development and their conflicts of interest, and other financial incentives or potential conflicts that may have played a role in pathway development.
  - Policymakers should require patient engagement in the development of clinical pathways utilized in public programs, with standards for meaningful patient input.
  - Payers should make available to patients and beneficiaries their actual out-of-pocket cost for their treatment options through an online tool in real time, routinely

updated in a central repository with a host of intermediaries feeding data into it, and including future out-of-pocket costs associated with follow-up care.

- **Support Credible Use of Evidence** – Alternative payment models should clearly communicate the evidence supporting treatment options and the evidence that is the basis for incentivized treatment options. Patients should be made aware of the use of evidence, including its validity and credibility to drive certain treatment incentives, as part of their clinical consultations prior to treatment.
  - Policymakers should create a clearinghouse for evidence that would allow patients to be presented credible information that is relevant to their individual characteristics and preferences. PCORI’s repository of research findings may provide for a model or platform for a patient-centered clearinghouse of evidence.
  
- **Use Quality Measures Reflecting Outcomes that Matter to Patients** – It must be a priority to develop and use measures of quality driven by outcomes that matter to patients. These measures should be identified as part of the process of patient engagement.
  - APMs like the Oncology Care Model should reward providers for performing well on patient-centered quality measures.
  - Standardized measures of the impact of treatments on outcomes that matter to patients should be reflected in publicly-funded clinical trials.
  - Measure developers should prioritize the development and use of measures that demonstrate the use of care planning that includes identification of patient preferences and shared decision-making to achieve outcomes that matter to patients.
  - Patients should provide input on the development and ultimate value of measures of shared decision-making.
  - Over time, measures should be developed and used that identify whether the outcome that mattered to the patient, identified through care planning, was sought and achieved by treatment.
  
- **Develop a New Patient Satisfaction Survey and Score** – Policymakers should create a process of engaging patient organizations in the development of a patient satisfaction survey and score for use in CMMI’s Oncology Care Model, focused on achieving outcomes that matter to patients.
  - A patient satisfaction score should not provide one overall score, but instead be divided into sub-topics such as the administration experience or into segments of the patient’s journey and continuum of care such as diagnosis, treatment, clinical trial, relapse, and survivorship planning.
  - A patient satisfaction score could capture from the patient whether they were engaged in a process of shared decision-making until other more meaningful measures of shared decision-making are validated and used. At each appointment or interaction, the patient would identify whether their preferences were solicited

and identified, whether their treatment options were discussed, and whether they were satisfied with the treatment decision.

- A patient satisfaction survey should be implemented online, to be completed by beneficiaries whose physicians and clinical practices participate in alternative payment models. The collection of that survey information would be required and the output from survey questions would systematically demonstrate whether those practices or models are providing value to the patient. In the end, the physician would get a report card indicating the extent to which patients felt engaged and that the physician sought to achieve their goals.

In closing, roundtable participants urged strong consideration of these recommendations by policymakers and other health care stakeholders. We look forward to engaging in discussions related to the implementation of these recommendations. We understand that it is a policy priority for CMS to develop metrics for its *Better Smarter Healthier* Initiative through the work of the LAN, and to develop policies supporting patient engagement. We believe that the recommendations provided above will directly inform that work. The roundtable discussion and recommendations are also useful for other health care stakeholders, including provider organizations, payers and insurers, who are directly involved in the development of new models of health care. We stand ready to participate in efforts to improve the health care system to achieve our aligned goals of improving the quality and affordability of healthcare.