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

June 11, 2015

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.

In follow-up to its development of a white paper identifying key issues in achieving patient-centeredness in alternative payment models, the Partnership to Improve Patient Care (PIPC) convened a Roundtable of leaders from the patient community. 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.

Participants in this roundtable:
- Dr. Kristin Carman, Vice President, Health Policy Research, Health and Social Development Program, American Institutes for Research (AIR)
- Ms. Sally Okun, Vice President, Advocacy, Policy & Patient Safety, PatientsLikeMe
- Ms. Caitlin Morris, Senior Policy Analyst, FamiliesUSA
- Dr. Josh Seidman, Vice President, Payment and Delivery Reform, Avalere Health
- Mr. Marc Boutin, CEO, National Health Council
- Mr. Dario Dieguez, Research Project Manager, Epilepsy Foundation
- Mr. Andrew Sperling, Director of Legislative Advocacy, National Alliance on Mental Illness
- Ms. Jennifer Bright, Partner, Momentum Health Strategies
- Dr. Clarke Ross, Public Policy Director, American Association on Health and Disability
- Ms. Cynthia Bens, Vice President, Public Policy, Alliance for Aging Research
- Ms. Sara Skubikowski, National Patient Advocate Foundation
- Ms. Donna Cryer, CEO, Global Liver Foundation
- Mr. Jose Fernandez, Men's Health Network
- Ms. Ivonne Fuller Cameron, CEO, Hepatitis Foundation International
- Dr. Eleanor Perfetto, Professor of Pharmaceutical Health Services Research, University of Maryland School of Pharmacy
- Ms. Sara van Geertruyden, Executive Director, Partnership to Improve Patient Care (PIPC)
- Mr. Tony Coelho, Chairman, Partnership to Improve Patient Care (PIPC)

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Part One
Overview of Participant Concerns and Goals

T he participants in the roundtable 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.

> ➢ *Institutionalize pathway for engagement*
> ➢ *Capacity building to improve patient readiness for engagement*
> ➢ *Build on existing models*
> ➢ *Identify patient defined outcomes in measure development*
> ➢ *Focus on assessment of patient engagement in organizations and point of care*
> ➢ *Define engagement strategies for ACOs*

Part Two
Capitalize on the Momentum to Engage Patients

Participants recognized that a unique opportunity exists to capitalize on the momentum to engage patients and beneficiaries in the health care system and to institutionalize pathways for patients and beneficiaries to be engaged and empowered. This opportunity is particularly important in view of the growing momentum behind "value-based" payment models. There is significant evidence that engaged and empowered patients are more likely to receive the right care at the right time, which contains costs and decreases unnecessary utilization. Additionally, the health system has a growing capacity to meet the needs of individual patients, as well as embrace sophisticated methods to understand subpopulations and big data.

To achieve truly "value-based" incentives in health care, it will be essential to measure and reward outcomes and value that matter to patients. Yet, there is concern that patients will simply be used as a tool by new models of care delivery to meet certain quality metrics, as opposed to having incentives for patients themselves to be actively engaged and empowered. According to Roundtable participants, a value-based model will be immensely successful if it engages patients to achieve their goals and not only to achieve the goals of a system. As such, the U.S. health care system should be working toward defining value for patients, or else find that each state-based health initiative or alternative payment model is working toward a different end goal with little consensus on what really matters to patients.

The participants referred to the Patient Trifecta from the National Health Council as a reference for patient engagement in care delivery. In this trifecta, the current health system currently focuses only on the clinical outcomes component. Perhaps more important is the journey that the patient experiences, allowing the patient to be informed firsthand what works, and what doesn't work, in the context of their own life. The journey includes all the social determinants of health, i.e. geography, literacy, health, economic status, etc. Yet, patients are seldom asked about that journey. The third component is a patient's aspirations and goals, their reasons for living, and the milestones that a patient wants to achieve to experience better or optimal health.

In order to account for all three, quality measures, financing, and the delivery system must be addressed. Participants expressed considerable concern that cost control will come to dominate other priorities after the next Presidential election cycle, and that quality and patient-centeredness will receive inadequate attention. In the interim, we must work toward a better health care system that delivers the right care based on an individual's trifecta, allowing for the appropriate care for the individual, as opposed to dictating or hapless patient care. For example, patients with chronic conditions were described as often being provided care that does not meet their trifecta – and therefore they do not necessarily adhere to it.
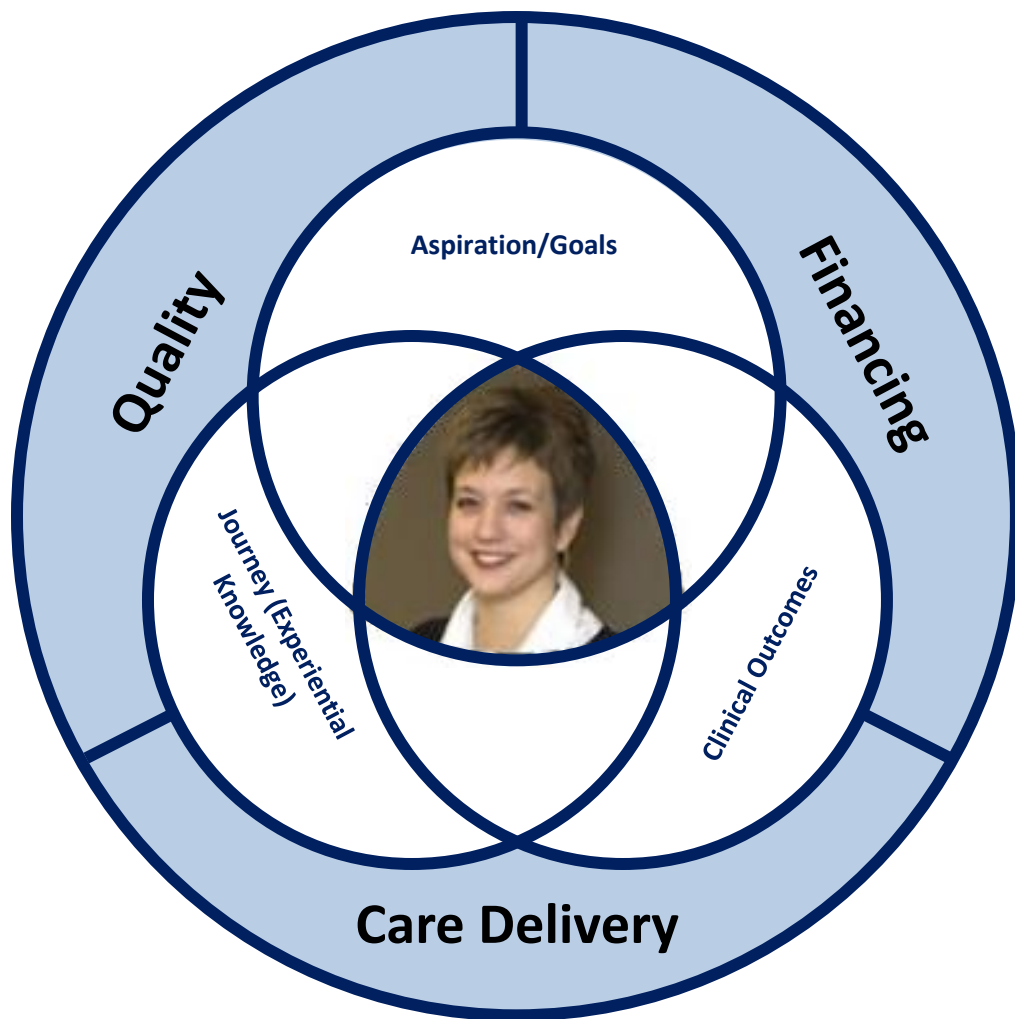
Participants referenced the [Roadmap for Patient and Family Engagement](#) developed by the American Institutes for Research, which provides a framework for being engaged in individualized care, and also in the design of the health care systems that serve patients, such as hospitals and primary care medical homes, as well as in policy making. Within this continuum, the patient moves from recipient to partner and shared leader based on their care experiences. Partnership and shared leadership could include patients being involved in the design of care delivery systems and co-creating quality measures. Health systems can impede or facilitate engagement by preparing patients and families to engage, and clinicians and leadership to value and support their engagement. Fundamentally, health systems must embrace transparency and accountability, otherwise we cannot expect people to operate in a system that they are neither informed about nor understand.

The roadmap also calls for aligning mandates and incentives to support patient engagement that can fully motivate organizations to change their behavior and culture. For example, payment policies can link performance to patient and family engagement metrics, such as reimbursing team meetings in primary care settings and reimbursing clinicians who use certified decision aids. Regulations could require patient and family engagement competencies, such as certifications and accreditation. Regulations could also call upon organizations to implement a community benefit plan to improve the community environment and more fully meet the community's health needs. Accountable care organizations and hospitals could hold a public meeting annually that solicits consumer involvement. Patients can be involved in patient-safety committees at hospitals and assist with criteria for hiring staff. These are simple examples of procedures that could help a patient become more broadly engaged.

Participants acknowledged that the concept of engagement does not just mean that patients sit on boards and committees, but also public deliberation, requiring an informed public's views. To become informed, the lay public must be convened and provided information, and subsequently given an opportunity to open a dialogue with experts and decision-makers to make them aware of the public's values. As one participant noted, "It's vital to speak to people where they are." The participant provided an analogy of an airplane where the pilot determines the destination, the food, and the seating, leaving the passenger to simply ride and hope they reach their preferred destination. That is essentially what has been done to patients in the current health care system.

Participants understood that making the case for beneficiary engagement requires a strong demonstration of the return on investment. For example, life sciences companies began to hire Chief Patient Engagement Officers when they could identify the points and purpose of engagement, as well as methods and the return on investment. Many companies are now viewing engagement as an opportunity to eliminate unwanted innovation and care.

Additionally, it is vital to articulate the value of engaging to patients. Patient satisfaction ratings often indicate that patients assume they are receiving high-quality care, which causes them not to question the care they are receiving. One strategy to improve care delivery might be to create mechanisms to engage and respond to patients that are *not* satisfied with their care.

For instance, Medicare serves primarily an aging population and people with disabilities. These individuals will want their values to be considered in the development of new payment models. Otherwise, they will likely view the changes negatively. Participants were enthusiastic that beneficiaries, including patients and people with disabilities, will want to be helpful in developing the model for beneficiary engagement plans underway at CMS. Developing the pathway for that engagement should be a priority.

It is not just patients that can benefit from this shift to valuing outcomes that matter to patients – health care systems and payers will also benefit. Effective public buy-in will foster an environment where new payment models can move forward with the support of patients, as opposed to having patients at odds with the proposed changes. An example was provided of a health plan that

experienced significant criticism for decisions affecting their patients, and responded to the criticism by reaching out to patient and beneficiary stakeholder groups for their input before making final decisions in order to better understand stakeholder perspectives. Doing so allowed the health plan to either incorporate the patient perspective in their decisions or be able to take steps in advance to mitigate the perceived negative impact.

Participants discussed that it is not sufficient to engage one patient on a panel of 20 people that otherwise represents primarily physicians. Patients have provided feedback that they do not perceive their voices as meaningful in this environment. Although a step in the right direction, it is imperative that patient engagement opportunities leave the patient feeling heard and valued, otherwise they will not participate.

In care delivery, if people are engaged in their own health and life situation, they will be healthier than they otherwise would have been. On the policy level, entities such as the Patient-Centered Outcomes Research Institute (PCORI) and the Food and Drug Administration (FDA), as well as some health care systems, are just beginning to develop the case for engaging patients in the design of research and in governance. Without the patient perspective on what is important, changes that policymakers want to achieve in the shift to a value-based system will be hindered by limited uptake and enrollment from patients. For example, a patient will not join an accountable care organization or remain within its network without a strong understanding of its benefits for patients. If the goal is to change patient behaviors, then patients must relate to the structural changes that are happening to promote a value-based system so that they feel it has value to them – not just to the system. Therefore, participants recommended a framework of measuring quality of care delivered that is not just about what health systems want patients to do, but is also about what *patients* want to do.

Engagement will also require that HHS create opportunities and invitations for people to engage. Effectively pulling patients into key decisions at HHS will be challenging. Participants called on HHS to identify for patients the value and implications of their engagement so they are motivated to participate. To be motivated to engage, patients, especially those with chronic conditions, must care passionately enough to do more than manage their condition and their lives, which may include working and raising a family. A certain level of transparency and education must exist so the patient realizes that although the scientific and clinical component of their health care may be addressed, the non-clinical factors (distance to treatment, language skills, income, religious beliefs, etc.) require their engagement in order to be addressed.

While one challenge is to identify the best levers to promote meaningful engagement, the patient community is also challenged to articulate the problem, a solution, and the saliency of that solution using more sophisticated models than in the past, such as the Roadmap for Patient and Family Engagement. Participants agreed that there is an opportunity with policymakers, particularly in the current Administration, to catalyze the patient-centeredness movement with structural changes that can institutionalize patient engagement and create that "aha" moment whereby policymakers realize the value of the patient voice in their work. For example, the Office of Science and

Technology Policy at the White House was referenced as embracing patient engagement and innovation, as well as the FDA's Patient-Focused Drug Development Program. Strategically, patients and patient organizations should be supporting the efforts of these enlightened policymakers openly and vocally to demonstrate they represent a larger body of stakeholders. It is also important to enlighten other policymakers in key decision-making positions about the value of engagement so that it spreads.

Part Three
Readiness to Engage

Participants agreed that readiness and capacity to engage should be priorities for a patient engagement strategy, including engagement of communities. Patients should be provided prominent advocacy positions that empower them in governance, such as designated slots for patient and family representatives on any committees that have oversight authority related to healthcare. Nevertheless, there were concerns about patient readiness to be engaged at that level. Participants used the analogy to readiness in the military, which utilizes specialized training to prepare for military action. Patients need resources and training to engage in this type of advocacy, including the development of detailed literacy and other skill sets so that patients can play more sophisticated roles.

For example, the Knight Foundation promotes community engagement, and provided a Challenge Award for a project called "Patients Assemble" which was intended to create this type of readiness among patients to engage. The project was intended to raise awareness of input opportunities relevant to patients published in the Federal Register, yet readiness among patients to use the prototype to submit regulatory comments posed a significant challenge.

While acknowledging strategies on the clinical side to promote patient-centered care, such as incentives for clinical team meetings, there is less effort to develop the citizen voice that will drive decisions about what it means to be patient-centered. One participant noted that there is no national communication strategy and no celebrity-fueled Ad Council campaign showing the diversity of patients and their very different health care needs. One could imagine a campaign that raises awareness of the need for patient engagement and provides clear opportunities to be trained and ready for engagement.

Participants agreed that patients are paying for their care and are responsible for their health outcomes, so they have a stakeholder interest in how health care is designed and delivered. Once patients realize that the existing health system is not meeting their needs and preferences, an opportunity arises to deliberatively work with patients, particularly those with chronic conditions, to determine how they articulate the problem and engage their participation in developing the solution.

Although there is a concerted effort among HHS agencies to identify patients to serve on technical expert panels and committees, there is less effort to make that input meaningful through education, training and other supportive activities. Both HHS and communities more broadly must not only identify patients that want to be engaged, but also support them in their participation. This includes covering expenses related to their participation, and providing resources to train patients and people with disabilities to be advocates for themselves and for the larger community of patients

that they represent. Specifically, HHS should extend resources to support patient involvement. It was suggested that HHS establish a fund to both train patient advocates to perform well in these new positions, and to provide for travel expenses, thus playing a leading role in establishing readiness.

It was also suggested that PCORI could similarly lead readiness by designating a portion of its engagement award funding to build capacity to engage more broadly, not solely in research. By taking a broader role in building capacity for engagement, PCORI could be encouraging patients to be more involved in the identification of outcomes that matter to them so that, in addition to being involved in generating research, they are also compelled to use the information in their health care decision-making, as is their stated purpose in the law.[1]

It was highlighted that PCORI's Eugene Washington Engagement Awards provide a maximum of $250,000 to awardees, and the Pipeline to Proposals provide only a range of $15,000 to $50,000. Participants commented that this amount seemed low in light of the millions being spent on research that requires patients to be actively engaged. For engagement to be meaningful, there is a clear need to build capacity for patients to engage in their health (both research and care) through education and training initiatives. Without that foundation, patients will continue to struggle to overcome feeling that their engagement is "token" in nature. PCORI could ready patients by providing resources for the delivery of education and training through its partners, thereby benefiting not only the conduct of patient-centered outcomes research, but also the uptake of the evidence it provides and the development and use of tools for shared decision-making at the point of care. Although the Agency for Health Research and Quality (AHRQ) has reorganized itself to focus on dissemination, including the development of shared decision-making tools, significant attention has not been given to building capacity among patients to be active participants in their own care or to rise to broader patient engagement in larger health system decisions, which is a component of dissemination.

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[1] See 42 U.S.C. 1320e(c), stating "The purpose of the Institute is to assist pa- tients, clinicians, purchasers, and policy-makers in making in- formed health decisions…"

Part Four
Models for Consideration

P articipants recognized that the patient-centeredness movement has led to some positive developments that could provide examples for value-based care models. Specifically, these models could be very informative as HHS seeks to establish a clear and supportive engagement plan for beneficiaries, including patients and people with disabilities, in the *Better, Smarter, Healthier* Initiative and in the Health Care Payment Learning and Action Network.

First, PCORI was referenced for its five years of experience building patient engagement programs for research and dissemination. These engagement strategies, also being evaluated for their effectiveness, will provide invaluable lessons for HHS. PCORI's work will support the shift to a patient-centered health system with research that measures outcomes that matter to patients, as well as by developing innovative strategies for disseminating and communicating evidence in a manner that effectively supports shared decision-making,

For example, participants discussed the role contractors often play in the implementation of new programs. Contractors are not typically required to compensate patients for their engagement, but if engagement is indeed a priority for HHS, providing compensation to engaged patients should be written into vendor contracts. PCORI has had to address this issue in the context of engaging patients in their contracted research to overcome "token" engagement practices. PCORI developed, in collaboration with its Patient Engagement Advisory Panel, a framework for compensating patients who are engaged in research, whether as a co-investigator or as part of an advisory panel guiding the research design and implementation. Their work could be very informative as HHS develops its own policies for compensating patients for their engagement.

Second, The Centers for Independent Living movement has a long history, and was also referenced as a model for patient centeredness by empowering people to choose their care setting and community service provider. In one example, it was highlighted that clients of the State of Maryland developmental disabilities system have a choice of community providers, and are allowed to request a change in the chosen provider every three months. This system allows the person to identify their chosen provider based on how they care, whether they listen to patient preferences, and their ability to identify a job for the individual. Translating that more person-centered model from the community to the larger medical system of care should be a priority.

Participants discussed the FDA's Patient-Focused Drug Development Program as a prime example of achieving an "aha" moment that led some governmental policymakers to value the patient voice. The FDA has combined its legislatively mandated activities, such as developing a benefit/risk framework that involves patients, emphasizing patient-reported outcomes in the drug development process, and getting the patient perspective, into what they now refer to as Patient-Focused Drug

Development. Legislation required the FDA to have 20 meetings in a five-year period with patients with different diseases. The FDA began with a Federal Register Notice to frame the questions to ask patients. The process has evolved and improved over time, allowing FDA to learn from patients about the impact of the condition on their lives, including symptoms impacting their quality of life, productivity, morbidity, and mortality. A "voice of the patient" report can then be used in the future for drug development for those conditions.

A consequence of the FDA's 20 disease meetings was to create a cultural shift about the value of patient engagement, by facilitating that "aha" moment for the FDA. FDA staff listened to patients, and realized that outcomes that matter to patients were not necessarily aligned with the outcomes that policymakers assumed to be most important. With this appreciation for the information from patients, there are efforts to determine how to more effectively acquire information from patients. Over time, it will be important to create a standardized process for engaging patients, without being overly prescriptive and hindering innovative strategies, so that demonstrating patient engagement is not a moving target. A step in the right direction would be to identify a place for patient preference data in the benefit and risk framework, which will become public and therefore will ultimately change behaviors.

The FDA has not yet standardized the Patient-Focused Drug Development process to allow for a life sciences company or patient organization to demonstrate meeting that standard for being patient-focused. There is a need to define the term "patient-focused drug development" in order to articulate what patient engagement is in patient-focused drug development, and how it is best accomplished. Additionally, the rules for a drug being approved and the rules for device approval are vastly different. Participants referenced the National Health Council's stratification tool as a positive first step to guide the collection of patient experience data.

The Substance Abuse and Mental Health Services Administration (SAMHSA) also has patient engagement activities to share, having engaged multiple community groups in their work. It was noted that SAMHSA has already begun to develop metrics for patient engagement that are being reported to the Secretary, and could be informative to the development of a dashboard, as will be discussed in more detail below.

Part Five

Coordinating Council and Accountability for Patient Engagement

The [American Recovery and Reinvestment Act of 2009](#) (ARRA) established the [Federal Coordinating Council for Comparative Effectiveness Research](#) (CER) to foster optimum coordination of CER conducted or supported by Federal departments and agencies. In under a year, this council solicited public input to inform the development of a strategic framework driving investments and activities for CER. The council's reliance on public input was continued and re-emphasized in the creation of PCORI in 2010, which was also called upon to solicit public input and focus on patient outcomes and preferences in its work on comparative clinical effectiveness research.

There are varying models within HHS for patient and beneficiary engagement. Although variation will be required for different programs with different goals, participants recommended that HHS develop a strategy for not reinventing the wheel, but instead learn from existing engagement strategies to inform overarching patient engagement policies. Participants referenced a coordinating council, such as was established under ARRA for CER, as a potential model for coordinating patient engagement among all of the HHS agencies. Significant work is being done to engage patients among the various agencies, particularly at the FDA and SAMHSA. Additionally, PCORI is researching and evaluating the most effective strategies for engaging patients in their work. Participants believe that an HHS coordinating council could facilitate shared learning among the agencies to ensure that effective strategies are translated and modeled more broadly. For example, the evolving patient engagement strategies utilized by the FDA could be very informative to the Centers for Medicare and Medicaid Services (CMS) effort to provide guidance to ACO's about beneficiary engagement and capturing patient experience data.

While there is a long list of governmental activities that should meaningfully engage patients and beneficiaries, participants questioned who the responsible party is at HHS to determine that meaningful engagement has been accomplished as new health programs are implemented. It was suggested to elevate the responsibility for patient engagement at HHS. As an example, PCORI has a designated stakeholder engagement staff member. Participants agreed that patient and beneficiary engagement should be a responsibility within the HHS Secretary's Office - not just in the office of the Secretary, but in the actual Secretary's Office.

A coordinating council could be used to report up to the Secretary on how many patients, patient advocates and patient advocacy organizations have been engaged and how that engagement is progressing against a transparent metric within their own department or agency. Coordination of efforts through a coordinating council and use of a dashboard by the Secretary were identified as strategies to ensure agencies are accountable for engagement. The Secretary could use a routinely updated patient engagement dashboard to track engagement activities, set goals, and measure

progress toward those goals. To begin the process, patient engagement could be embedded in the portfolio of the Deputy Secretary or a counselor to the Secretary. The next step would be the creation of the coordinating council to begin the dialogue among agencies, which would hopefully inspire the "aha" moment to create the patient engagement dashboard. Participants acknowledged that the answer is not to create a massive infrastructure for patient engagement, but instead to make it a meaningful, measured, and transparent responsibility for the department.

Part Six
Measuring Outcomes that Matter to Patients

P articipants acknowledged that, generally speaking, the health care system is not focused on the outcomes that matter to patients, including quality of life and dignity. Participants identified quality measurement as an arena "in chaos", and therefore a prime opportunity for action.

Quality measurement affects all aspects of the health system. Clinicians want to care for people, yet they are given less time to spend with patients to deliver the personalized care that is increasingly available, and their financial incentives are driven by quality measurements applied to their practice. At the same time, the payers are under an inordinate amount of stress financially, often causing them to incentivize providers to deliver cost effective care based on averages, potentially at the expense of personalized care and quality.

Yet, by focusing only on the science of health care, health systems are spending stretched resources on care that many patients do not want. Overuse of unwanted or ineffective therapies as part of end-of-life care is a good example of significant waste that does not meet the Patient Trifecta, as described above. Ultimately, patients benefit most when providers are accountable for asking about the patient's motivations, which includes helping patients articulate those motivations and the milestones they want to achieve and using that information to develop a care plan. Implementing quality measures for this kind of engagement in care delivery, even just process measures showing engagement happened, would be transformational.

BlueCross/BlueShield of Massachusetts was referenced as having been using patient-reported outcome measures as part of care for decades, facilitated by a voluntary effort through their alternative quality contracts. Many contract providers in Massachusetts are part of these alternative quality contracts. There is evidence that embedding patient-reported outcome measures, such as the patient health question depression screener (known as the PHQ-9), into care delivery processes results in significant changes in how care is managed. Efforts to develop quality measures that make use of patient-reported outcome data should be at the forefront of measure development.

Additionally, the entire business model of an innovator is challenged because of the significant cost of trying to innovate for narrowly targeted treatments and conditions. However, to meet a patient's trifecta, we must connect innovation and access because although some patients should receive high-cost innovative products, many will meet their trifecta without them. Quality measures that seek to achieve the outcomes preferred by patients would ensure that patients are accessing the care they need and want early in the treatment process, preventing overutilization and adverse events from receiving the wrong care.

Now is the time to harness the momentum in the patient-centeredness movement to bring patients into the determination of how we measure quality in our health system. In an effort to balance both quality and cost effectiveness, the patient voice should be primary in the quality measure development process. The opportunity is apparent at the Office of Clinical Standards and Quality; although traditionally focused on clinical measures of quality, it is now moving toward the development and use of measures that incorporate patient-reported outcome data. For example, the Medicaid Information Technology System (MITS) is currently developing an engagement e-measure. Participants also referenced an article in the Journal of the American Medical Association in June, 2013[2] in which HHS specified areas where measurement needs to change, specifically discussing patient-reported outcomes measure-based quality measures. Clearly, there is momentum at HHS to better recognize patient-reported outcomes measures in the transition to value-based health care.

The challenge is taking developed, validated, and reliable measures created for the purposes of measuring patient health status or the impact of a specific intervention on a specific population, and translating them to be useful for accountability purposes in a value-based payment system. We should be addressing the practical and logistic issues about how to operationalize those measures and integrate them into the existing health care infrastructure, such as embedding them into electronic infrastructure. The goal is to use data collected from patient-reported outcomes measurement tools and integrate it into quality measures for comparative performance reporting among providers. In the meantime, participants acknowledged this is an arduous process that will take time, and we must identify interim steps.

Unfortunately, patient outcomes are often ignored in the quality measure development and implementation process. A participant provided an example of a specific measure being used in the physician quality reporting system (PQRS) around stroke prevention and atrial fibrillation (AFIB) that exemplifies this issue. Older age is a primary contraindication to the use of anticoagulation. However, a person's risk of stroke with atrial fibrillation dramatically increases with age. Despite the availability of several treatments to safely prevent stroke with anticoagulation in older individuals, who are largely served by Medicare, a measure that discourages anticoagulant use with increased patient age was added to the PQRS. The measure produces a clinical conflict. Physicians may not be using the treatment because of fear of appearing as poor performers on the measure, thus patients may not be experiencing positive health outcomes since their risk of stroke is higher and the strokes experienced by elderly patients are the most debilitating. The result could be higher health care costs, without achieving the patient-preferred outcome of avoiding stroke.

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[2] **The Future of Quality Measurement for Improvement and Accountability.** Patrick H. Conway, MD, MSc; Farzad Mostashari, MD, MPH; Carolyn Clancy, MD. *JAMA*. 2013;309(21):2215-2216. doi:10.1001/jama.2013.4929.

Patients should not only provide input into the measure gaps, but also the review of measures over time, so that public deliberation can raise legitimate concerns about the performance of a measure to achieve outcomes that matter to patients. Measure developers, particularly those developing quality measures based on patient-reported outcome measures, should be engaging patients throughout the process. To capture the outcomes that are important to patients, patients have to be involved in articulating them. It is an additional labor-intensive process to then translate that patient-reported outcome measure and turn it into a quality measure. For more clinically oriented measures such as in the example of AFIB, the measure is not necessarily focused on the population most likely to have a stroke. The question is how to improve the measure through public deliberation so that it meets the needs of the target population.

In the past, many patient-reported outcome measures were originated by asking clinicians questions about patients - not asking patients directly. Therefore, new strategies that better engage patients on the front end are needed to develop patient-reported outcome measures so that they can be the fundamental building blocks for quality measurement. Participants referenced work from the Robert Wood Johnson Foundation to create patient-reported outcome measures from an open research exchange platform as an example of efforts to get that front-end input from patients.

Participants also referenced the National Institutes of Health (NIH) PROMIS program. Although a positive example of an effort to create a database of measures, varying methodological techniques were used in the development of those measures. It is a good starting point, but many of the items likely came from doctors and not patients as the measures are often derived from older tools. Often the measures are of limited value for patients that are at the ceiling or floor, e.g. either very sick or not sick at all. Over time, with additional questions added to the item pools, they can better reflect a variety of patients. At this stage, the measures are likely only validated for a particular population, which may or may not translate to others.

With ample resources, the National Quality Forum (NQF) was referenced as a significant player in the shift to more patient-centered measure development and implementation. The NQF's committees identify high priority measure gaps by consensus. Measures are also endorsed by the NQF and are incorporated into the Measure Application Partnership (MAP).

Participants also discussed the Consumer Assessment of Healthcare Providers and Systems (CAHPS) database. Although payers were perceived as very comfortable using the CAHPS database as an indicator of being consumer-centered, consumers and patients believe it has significant room for improvement. Therefore, work is underway to make the CAHPS' methodology more appropriate and more person-centered. For example, CMS has invested in a personal experience survey of recipients of Medicaid's home and community-based services as a CAHPS module. They are interviewing the most severely disabled and aged people who are receiving home and community-based services, and adapting the CAHPS' methodology. Further, the National Institute of Disability, and now Independent Living, Rehabilitation Research (NIDILRR), has invested in adapting the module for people with severe intellectual disabilities. It was discussed that a module is being pilot tested to show that the CAHPS can indeed be adapted.

The community of people with intellectual disabilities was referenced as performing significant work to improve the metrics applied to care in the community. NIDILRR has invested in taking the National Core Indicators for people with intellectual disability, and pilot testing it for the aged and physically disabled people in three states. It will be piloted in another 10 states this year. For people with intellectual disabilities, there are two quality measurement systems that have operated for over 20 years. First is the National Core Indicators, which is a state-based quality measure system, and second is the Council Quality Leadership Personal Outcome Measures, focused on the individual person and outcomes, quality of life, and their living situation. Clinical stakeholders, such as hospitals and physicians could learn from community-based organizations that have been driving and investing in quality and person-centeredness. These examples from NQF and NIDILRR demonstrate instruments and methodologies exist to measure quality in a person-centered manner. Now is the time to invest in their adaptation and piloting.

Participants highlighted the challenges of investment and accountability to develop pilot tests that show the validity of these person-centered measures. An additional challenge is that volunteer health organizations all want their own little grouping of measures within their disease-focused area. There are over 1,000 endorsed measures, and every year the NQF adds more measures. Some measures have potential for improving health systems, while others do not. The overwhelming number of measures available is clearly a barrier to providing quality care. Streamlining measures so that all health systems are capturing the most important measures for patients should be a priority. For example, the work of the IOM through the Vital Signs initiative is a good example of ongoing efforts to identify a core set of measures. It is also a high priority of the NQF Measure Applications Partnership to identify cross-cutting measures that apply to conditions across the board.

For providers, there continues to be frustration about the sheer volume of activities required to meet the various quality measures, which is at odds with the development and implementation of new, often very patient-centered, measures. Additionally, the lack of transparency to the patient of existing measures being used creates an environment wherein the patient does not have an expectation of that quality measure being met. As an example, the participants referenced the 30-day medication check for people with mental illness – patients and their caregivers cannot advocate for that medication check to happen if they are not aware it should be happening. There is a gap between the defined expectations that health systems impose on providers, per the work of NQF and other measure developers, and patient expectations of their providers, as patients are unaware and disengaged in measure development and implementation.

There is also a disconnect between the measures used by medical systems of care, and the existing community-based system. The medical system is accountable for meeting certain measures, often through their payment model, yet patients are often being cared for in the community. For patients to benefit from measures intended to increase care quality, they must be knowledgeable about the measures that are being applied in order to advocate for themselves.

Additionally, care coordinators and community health workers can be advocates for the patient as part of the care team and bring that advocacy into the community. The IOM's Vital Signs initiative recognized the role of the community, and included engagement of patients and communities in its core set of measures. The intent is to build their readiness to engage in the larger health system, and to hold that health system accountable to a core set of measures.

The Centers for Independent Living movement, referenced above as a model for engagement, has already sought to address the disconnect between non-clinical community based organizations and medical organizations. Engagement between patient advocates and the Administration on Community Living (ACL) led to a proposal to connect community and medical organizations through the meaningful use of health information technology. As a result, the Deputy Administrator of ACL went to the Office of the National Coordinator for Health Information Technology to create the electronic Long-Term Services and Supports (eLTSS) project.

Part Seven

Beneficiary Engagement in ACOs

The Affordable Care Act, enhanced now by recent legislation providing incentives for providers to join alternative payment models, allows for demonstrated innovations that prove to the actuary that they save money while maintaining or improving quality to be expanded and replicated. In the next few years, CMS will determine the winners and losers among demonstrated alternative payment models. Beneficiaries will have to live with the models chosen to continue and potentially expand, and therefore deserve a seat at the table for key decisions, including how these new models will be evaluated for success, and particularly whether they achieved outcomes that matter to patients.

Participants discussed whether the appropriate tactic for patient engagement in these new models of care is simply to create a seat at the table for patients, such as in the newly established CMS Health Care Payment Learning and Action Network created to guide the shift to value-based models, or to also create an additional table specifically for patients and beneficiaries so that their voices are not lost. Both strategies seemed to be necessary to ensure the shift to value-based models reflects the ultimate beneficiary.

One component of this effort should be the development and use of measures that support the beneficiary voice, as discussed above. Participants referenced the work of Dr. Karen Sepucha, who has indicated that measures of decision quality are needed in two ways. First, patients should be able to demonstrate they have knowledge, i.e. access and use of the information, to make an informed decision. Second, the values and preferences of patients should be considered in the decision-making process.

Specifically, CMS has solicited input through a Request for Information in the Federal Register from the public to define meaningful beneficiary engagement for accountable care organizations. Participants agreed that developing that model behind closed doors, with only reference to comments from the Request for Information, is insufficient. Instead, CMS should conduct a series of discussions with beneficiaries, including patients and people with disabilities, to determine the most effective guidance that ensures meaningful engagement while promoting the development and implementation of innovative engagement strategies.

Without being overly prescriptive, policymakers should articulate a standard for beneficiary engagement that reflects levels of activity, from low to high, with aligned rewards. As an example of where guidance is needed, participants referenced the Centers for Medicare and Medicaid Innovation's (CMMI) State Innovation Models Initiative (SIM) initiative, whereby states are only required to provide a list of the people that they have engaged, but there are no standards for

meaningful engagement. Participants also discussed ongoing CMS efforts to develop beneficiary engagement strategies specifically for accountable care organizations.

Measuring value to *patients* and incorporating patient-reported outcome-based quality measures were considered priorities for any beneficiary engagement plan. As discussed above, specific approaches to engaging patients and families are needed to ensure the measures are indeed meaningful to patients. Implementing those approaches will require significant resources for the development of those measures. Additionally, policymakers must consider the platform and infrastructure development needed to implement these measures effectively, such as the technological infrastructure that makes measurement possible. A step in the right direction would require accountable care organizations to collect patient-generated health data, such as patient-reported outcome measures, and to act on the data collected so it is integrated into their workflow. Effective shared decision-making will require accountable care organizations to collect patient-generated data and use it.

Accountable care organizations will need to have a sense of the information that patients are able to provide, and the information patients require from clinicians. To support this, people should have access to their health information, whether it is via a patient portal or a full view of their health records in some other manner. If patients are unable to access the information they need to make decisions at the initiation of their care, it will be impossible to demonstrate the information is being used in their decision-making. In this context, PCORI is called upon to demonstrate that its research is affecting health care decisions, which will be impossible if health systems do not make the information accessible.

Participants highlighted the work of AHRQ on dissemination and the development of shared decision-making tools as potentially supporting informed choices within alternative payment models. It was questioned whether AHRQ sufficiently incorporates the patient voice into it's the development of these tools. It was perceived that AHRQ consults with patients primarily on the back end while developing tools. It was suggested that, because AHRQ hires contractors for much of this work, they build into these contracts with their vendors certain requirements for patient engagement throughout the development and implementation of dissemination and shared decision-making tools.

Participants also commented on the need for physicians to be competent to engage patients in their care, and to understand the value of engagement. For example, CMS has been fostering team-based care strategies and the IOM has developed two papers related to team-based care. The discussion paper titled [Patients and Health Care Teams Forging Effective Partnerships](#) discusses having patients as partners on the team. A lesson from that work is that the people receiving team-based care often don't realize they have a team of providers, indicating a lack of transparency to the patient.

Bringing together the work on team-based models of care, as well as beneficiary engagement in accountable care organizations, provides an opportunity to connect the dots. Engaging beneficiaries

around the type of care they will receive will require more transparent and accessible information so beneficiaries know what kind of care to expect and can hold their team accountable.

Participants described the work of CMS to apply Lean principles of eliminating rework. CMS has described Lean principles as follows: "In the past, stakeholder input in terms of technical expert panels (TEPs) and public comment opportunities were specified as discrete events in a measure's lifecycle. However, in an increasingly connected environment and in keeping with Lean principles of eliminating rework, contractors are encouraged to solicit input early in measure development and often throughout the lifecycle. To this end, contractors can avoid wasting time and resources on measures that do not carry meaning for consumers and are unduly burdensome for providers."[3] Similarly, it was suggested that holding alternative payment models accountable in their contracts for continuous patient engagement using Lean principles could be another pathway for promoting effective patient engagement strategies.

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[3] See http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/MeasuresManagementSystemBlueprint.html

Part Eight

Recommendations

Based on the roundtable discussion summarized in this report, participants proposed a set of specific recommendations for policymakers. Broadly speaking, participants agreed that all health care policy decisions should consider a patient's trifecta: their journey, their aspirations and goals, and their clinical outcomes. CMS should align policy mandates and incentives for alternative payment models with support for patient engagement. This will more effectively drive organizations to change their behavior and culture related to engagement, similar to the change in culture for research being advanced by PCORI:

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.[4]

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.

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[4] This consensus recommendation from the roundtable was directly shared with Dr. Patrick Conway on April 15, 2015, stating, "ACO's should collect and act on patient-generated experiences and integrate those learnings into the work flow."

Strategies to Engage and Empower Patients in Care Delivery

Part Nine

Conclusion

We request the aforementioned recommendations to be embraced and implemented by HHS and PCORI. Our goals should be aligned to promote a patient-centered U.S. health care system that recognizes the patient as the ultimate beneficiary and their personal trifecta, which includes:

- The patient journey
- The patient's aspirations and goals
- The patient's optimal clinical health outcomes.

With continued dialogue and efforts to keep patients engaged at the forefront, we know that this can be accomplished with HHS and PCORI leading the way. Personalized and precision medicine will only be achieved if we get beyond "token" efforts to bring patients into health care decision-making, and instead embraces and expands upon the existing best practices to more effectively engage and empower patients.

Strategies to Engage and Empower Patients in Care Delivery