



PIPC ROUNDTABLE SUMMARY: ASSESSING VALUE TO THE PATIENT

June 17, 2016

For the past several years, there has been a shift to a health care system based on value, rather than volume. Amidst this shift, “value to whom” has been a consistent question, with payers, providers, patients and other stakeholders defining “value” from different vantage points. PIPC has continuously advocated that value should first and foremost be considered through the lens of patients and people with disabilities who are the ultimate beneficiaries of health care.

PIPC convened a roundtable on May 6, 2016, because we are very concerned that payers, physicians and policymakers are increasingly using value frameworks in the private sector – and potentially in the public sector – to determine patient access. Many emerging value frameworks are driven by payers, represent the ideals of payers, and are therefore representative of their goal to reduce costs. Although labeled as “value frameworks,” many of these frameworks do not accurately capture what patients value. In fact, they often are in conflict with stakeholder efforts to move towards a more patient-centric health care system and advance access to personalized and precision medicine.

PIPC has long advocated for policies that advance the patient-centeredness movement. Beginning with the creation of the Patient-Centered Outcomes Research Institute (PCORI), PIPC has led the development of consensus recommendations from patients and other stakeholders on how to best engage patients and people with disabilities in research and in health care delivery systems. Congress indicated its support for a patient-centered health system by forbidding use of quality-adjusted life years (QALYs) and cost-effectiveness in PCORI’s work, indicating that their goal was to move toward personalized and precision medicine. This roundtable explored how patients can influence the ongoing payer-driven work to define value so that it better reflects value to the patient.

Roundtable participants included the following organizations:

*Alliance for Aging Research
American Association of People with Disabilities
Association of Community Cancer Centers
Association of University Centers on Disabilities
Asthma and Allergy Foundation of America
Avalere Health
Cancer Support Community
Familial Hypercholesterolemia (FH) Foundation*

*Faster Cures
Global Liver Institute
International Myeloma Foundation
National Alliance on Mental Illness
National Health Council
National Patient Advocate Foundation
Patient-Centered Outcomes Research Institute*

Part One

The Real Implications of Status Quo Value Frameworks and Tools

“We can’t stop the private payers from using these tools, but we can make recommendations on how to make them better. We can stop public programs from going down a path of using these tools against those of us who are patients. Ultimately, we want tools that help us understand the value of treatments for us as individuals. We’ve had many roundtables giving policymakers recommendations on patient-centered solutions, now we have to make it clear that there are real consequences for those of us who are patients if we do not assess value to patients.”

— Tony Coelho, PIPC Chairman

Roundtable participants expressed frustration that even amidst all the strides made to engage patients and people with disabilities – from the Americans with Disabilities Act (ADA) to the Patient-Focused Drug Development Program at the Food and Drug Administration (FDA) – patients are not at the table for conversations about value-based health care. The recently proposed CMS Part B Drug Payment Model was referenced by participants of the roundtable as an example of patients being excluded from the debate around value, representing a step backward in the patient-centeredness movement – evidenced by CMS’s proposed reliance on average value assessments of clinical and cost effectiveness, and the lack of engagement with patients through the development of the proposal. Their proposal followed similar proposals from the Center for American Progress and from some Democratic U.S. Senators seeking to rank drugs by their “effectiveness” under the assumption that all patients fit an average.

In light of these challenges, roundtable participants discussed the real implications for patients and people with disabilities of value frameworks and tools as they currently exist, and proposed tactics to advance more patient-centered solutions.

Shared and supported decision-making tools are early in development and not widely used, allowing for existing value frameworks and tools to become the *de facto* determinant of treatment value in the private sector. Existing frameworks include the Institute for Clinical and Economic Review’s (ICER) work to analyze effectiveness and cost of treatments, the American Society of Clinical Oncology (ASCO) framework for comparing the relative clinical benefit, toxicity, and cost of treatment in the medical oncology setting intended to standardize care, the Memorial Sloan Kettering Drug Abacus based on information available from the FDA approval process, and the NCCN Evidence Blocks providing a visual representation of five measures. Because ICER was specifically referenced in the

CMS proposed Part B Drug Payment model, there was significant attention to its implications for patients. The shortcomings of status quo value frameworks and tools and potential considerations for improving their patient-centeredness were summarized as follows:

VALUE FRAMEWORK'S FOCUS ON COST EFFECTIVENESS LIMITS THEIR USE BY PATIENTS & PROVIDERS

Participants recognized that existing value frameworks and tools are not generally intended by developers for use by patients and people with disabilities. The underlying frustration for patients is that they hinder efforts to advance best practices in shared and supported decision-making that are being developed for patients. While PCORI has provided the model for patient-centeredness and patient engagement, some value framework developers are not learning from the PCORI model because of their distinct mission to develop cost-effectiveness tools for payers. Therefore, value assessments do not accurately portray the disease and its implications for real patients and people with disabilities.

Existing value assessments and tools are often used for purposes to which they were not intended when developed. For example, clinical guidelines developed for clinicians are being increasingly used by payers to determine coverage or to validate financial incentives encouraging clinicians to use certain treatments. “Fit for use” was specifically discussed in relation to the ASCO value framework. As a clinical decision aid, it is through the clinician that information is delivered to the patient. It is not a shared or supported decision-making tool used directly by patients to determine value based on their unique characteristics and preferences, nor is it intended for use by payers to drive financial incentives.

It was discussed that clinical and policy committees at medical specialty societies, such as ASCO and NCCN, should be more informed about the misuse of value frameworks and tools by payers to promote a one-size-fits-all calculation of value. Value frameworks and clinical guidelines should be explicit about their value for clinical decision-making and their limitations so they are drafted to be uniquely suited for use by clinicians. Fit for use is an important component of transparency to ensure that developers are clear about the intended use and limitations of value frameworks and tools.

VALUE FRAMEWORKS ARE LIMITED BY FOCUS ON RANDOMIZED CLINICAL TRIALS (RTC) DATA

Representatives of patients and people with disabilities whose treatments or disease areas have been the subject of a value assessment clearly articulated the limitations of relying on RCT data which represent only a small part of the population and do not represent real-world treatment impacts. RCT data are not generalizable to a broad population because of their limited scope, significantly lacking representation from underserved populations, diverse populations, people with disabilities and elderly individuals with comorbidities. Despite not being “generalizable,” the research and academic community view RCT data as the “gold standard” for an evidence-based analysis, being considered the most scientifically rigorous. Another issue faced by organizations such as ICER and ASCO is the limitations RCT data present in their ability to compare the outcomes from different clinical trials.

Roundtable participants reinforced the importance of changing the culture of research to recognize the value of alternative patient data sources, without viewing such a change as an assault on evidence-based medicine. This cultural shift will be imperative in improving the patient-centeredness of value frameworks. Data from learning healthcare systems should be incorporated into determinations of value for patients and people with disabilities so that it can be updated regularly. Real-time data is available from large clinical electronic information and from payer claims databases that could be leveraged in a more dynamic process for assessing the value of treatments. For example, Kaiser Permanente has 10 million lives with longitudinal data, clinical electronic health information, and more cancer survivors than all of the clinical trials combined, making it real-time data. Additionally, these new sources of data can achieve relevance for populations not represented in RCT data.

We have to push back on the RCT as “The Gold Standard” data source for value assessment. While there is no doubt but that RCTs may offer the height of scientific rigor, clinical trial endpoints rarely capture—completely and robustly—the outcomes that matter most to patients.

— Cary Sennett, *Asthma and Allergy Foundation of America*

VALUE FRAMEWORKS LACK TRANSPARENCY

Participants noted that existing value frameworks and tools are not transparent about the evidence on which their assessments are based, nor the limitations presented by that data such as the limited populations and outcomes captured by the evidence. Stakeholders should understand the evidence used to develop value assessments, the quality and source of evidence, and the limitations of the evidence. By articulating the limitations of the data that informs the development of a value framework or tool, it will be clear where gaps exist. For instance, transparency about the lack of data on the impact of a treatment on patients with certain comorbidities could facilitate work to generate that information over the next 5-year period.

“I think, in as much as you think about these cost effectiveness analyses as being the meat grinder, it’s what goes into that meat grinder to get what comes out. There’s so many different ingredients that go in, and where the costs come from, where the QALYs come from, where the outcomes come from. All of those individual pieces are all subject to so many limitations that it’s one of the huge issues with these kinds of approaches and these kinds of models. And so we have to worry about the quality and source of every piece of information...So, when the outcomes are only coming from clinical trials, it means that only those populations were studied, but it also means that it’s only those outcomes that were studied.”

— Eleanor Perfetto, *National Health Council*

VALUE FRAMEWORK DEVELOPERS OFTEN FAIL TO ENGAGE PATIENTS AND PEOPLE WITH DISABILITIES

Patients and people with disabilities are not routinely engaged in the development of existing value frameworks and tools, nor are they meaningfully engaged in payer decisions related to value assessments. One participant with a disability described her experience in clinical encounters where the clinician did not acknowledge her role as the decision-maker, but instead spoke to her accompanying friend or family member. Similarly, value framework developers are not sufficiently acknowledging the role of patients in determining treatment value, nor are payers considering data or expertise from organizations representing patients and people with disabilities related to value.

Roundtable participants recounted the failure of value framework developers to reach out to patients and patient advocates for their input on value frameworks and tools, and to explain the process through which they are developed. For example, the first step in ICER's value assessment process includes releasing a scoping document, which includes a set of questions on which stakeholders have an opportunity to comment prior to finalization. The participants affected by ICER assessments were not aware that this process was happening and therefore did not have an opportunity to comment. Following the finalization of the scoping document, ICER produces a draft report that reflects answers to foundational questions outlined in the scoping document. Roundtable participants reported having had varying levels of engagement in commenting on the draft report that affected their patients. In one example, organizations representing multiple myeloma patients were not prepared to meet the two-week comment deadline for a recent draft ICER report affecting their community because there was no outreach, and the draft report was 172 pages long.

“I think if they [ICER] were interested, there were very simple, obvious things that they could have been done to contact and get the patient perspective and they just didn't.”

— *Lindsey Trischler, International Myeloma Foundation*

Participants advocated for outreach to patients from developers of value assessments and a transparent engagement process. Participants also supported increased transparency from payers on their decision-making process. It was suggested that payers be called upon to explain to patients their decision-making process and to work collaboratively to identify opportunities to interact and share data as they make coverage and benefit decisions, including accountability and follow-up from engagement activities.

“The concept ‘nothing about us without us’ means engagement of people with disabilities, both on a systematic level and on an individual level.”

— *Michael Murray, AAPD*

LACK OF CONSENSUS ON ASSUMPTIONS, DEFINITIONS AND QUESTIONS

Several participants expressed that without patient and stakeholder engagement, oftentimes the foundational question being asked by the value framework developer, or the way in which they are defining important concept is misguided or wrong, from the perspective of impacted patients and people with disabilities. One participant described a recent ICER report as defining the disease itself incorrectly by not using the worldwide consensus definition around cholesterol, instead choosing a definition that did not reflect actual patients that are candidates for treatment. Ultimately, flawed foundational questions in the ICER scoping document generated a flawed report, but triggered aggressive utilization management by payers who are denying coverage for patients. Despite the fundamental flaw in how the value question may be framed, the media and payers that report on or use the assessment of value will accept the answers as the basis for driving certain clinical decisions and public perception.

FAILURE TO REFLECT OUTCOMES THAT MATTER TO PATIENTS AND PEOPLE WITH DISABILITIES

Quantifying value in a way that is useful and meaningful to patients and people with disabilities requires a basic understanding of their values and preferences. In contrast, existing value frameworks and tools are not tailored for use in treatment decision-making by patients and people with disabilities, and therefore do not typically reflect patient-centered outcomes.

Cost effectiveness analyses are used by payers outside of the U.S. to determine whether to cover a treatment and under what circumstances to cover a treatment. The National Institute for Clinical Effectiveness (NICE) in the United Kingdom (U.K.), uses cost-effectiveness thresholds to determine what treatments patients will have access to. In one example, a patient living in the U.K. with macular degeneration was not provided treatment for one eye until the other eye was already blind. In the U.S., most individuals would find that determination to be egregious. Although the U.K. changed its policy for this disease, the example underscores the limitation of a value framework rooted in cost effectiveness, and the need for supported and shared decision-making tools that allow patients and providers to consider multiple factors related to their care.

It is critical to identify and integrate the appropriate patient-centered criteria in assessing the value of treatments for a particular condition by engaging affected patients and people with disabilities. Participants identified several specific outcomes that matter to patients and people with disabilities that are too often ignored (note these will differ based on the patient population and condition being treated):

- **Frequency of Treatment and Site of Service** – Frequency of treatments should be an additional consideration, especially for treatments that are delivered in a physician office or other facility that requires travel and potential caregiver burden.
- **Value over Time** – Long-term patient benefits including quality of life should be a consideration in determining the value of a treatment for a patient.
- **Employee Productivity** – The ability to return to work and to live independently matters both to patients and to employers who are the purchasers of health care.
- **Caregiving** – The need for caregiving is an outcome that deeply affects the value of treatments for individual patients, and varies based on the availability of a caregiver who may be forced to themselves take time off work, which could have significant consequences for the entire family.

“I think, considering the patient’s going through the journey, we should always set them as the focal point. It’s important. You can’t move forward with this without hearing the voice of the patient or even the caregiver or the family members.”

— *Brissan Guardado, ACCC*

PRODUCES A SINGLE UNIVERSAL SCORE OR VALUE

Value frameworks may result in a single universal “value score” that does not reflect the different ways that patient sub-groups, and individual patients, define value. Payers use these determinations of value to restrict access to treatments without consideration of the varying value presented by a treatment or technology for the individual patient. The CMS proposed Part B Drug Payment Model explicitly proposes to employ ICER’s framework, which arrives at a single value-based benchmark price for a treatment, that cannot possibly account for the varied definitions of value among patients with different needs, characteristics, and treatment goals. Treatments impact patients differently based on their comorbid conditions as well. Value to patients simply cannot be captured in a single number.

“It’s as if populations, however, are not made of healthier individuals.”

— *Donna Cryer, Global Liver Institute*

USE OF QUALITY ADJUSTED LIFE YEARS (QALYs) DISADVANTAGES PEOPLE WITH DISABILITIES

Roundtable participants representing people with disabilities articulated serious concerns about the use of QALYs in research and in the development of value frameworks and tools such as those produced by ICER. A “one-size-fits-all” mentality does not recognize the diversity among patients and people with disabilities, so a treatment that may work best for 90 percent leaves the remaining 10 percent behind. Additionally, the societal impact analysis based in cost-per-QALY may not account

for the value of substantially improving the life of a person with a disability. We should be dismantling the use of QALYs as a determinant of treatment value in value frameworks and tools, as opposed to promoting their use.

QALYs do not account for the costs of innovative technologies that enable people with disabilities to live full and productive lives. Technologies produced specifically for people with disabilities often have a significant impact throughout society (ex. texting technologies developed for the deaf are now widely used). To say that the cost of technology outweighs the benefit for an individual with a disability is likely not taking into consideration the broader systemic benefits that also could emanate from that technology.

People with disabilities often say “nothing about us without us” because they want a seat at the table both in individual care decision-making and in systemic decisions impacted by value frameworks and tools. Roundtable participants asserted that when people with disabilities are hidden from society, whether by institutionalization or otherwise, their lives may be defined to have less value. Alternatively, if people with disabilities are living in communities and are known by individuals in their communities, the worth and value of their individual lives will be shared by society. According to the Census, 19 percent of U.S. population has a disability, making people with disabilities the largest minority group and one that overlaps with all other subgroups as well. Although largely ignored in the value debate, their voices are increasingly united against the use of the QALYs to determine value, especially as people with disabilities gain the benefits of accessibility and increasingly live in communities.

“I wonder whether this has something to do with institutions and how people with disabilities are kept out of society...because if I’m always kept out of society, then people don’t get to know me and they don’t see that I have worth -- and if I’m always kept behind a door or a gate then they say, well, if you had cancer, it doesn’t really matter. If you have epilepsy, it doesn’t really matter. Let’s not worry about that.”

— *Liz Weintraub, AUCD*

FOCUS IS ON COST TO SOCIETY, NOT COSTS THAT MATTER TO PATIENTS

Because they are developed for use by payers, existing value frameworks and tools have a limited perspective on the economic component of value. While financial toxicity was raised as an issue for health care decision-making in the context of out-of-pocket costs, participants also recognized that there are long-term, personal and societal costs that are not being considered in assessing value. For example, there are emotional and mental health consequences for people that cannot access treatments or the right treatments for them, resulting in broad systemic costs on society when an individual stops working and/or becomes disabled and qualifies for federal disability programs. For example, a person not given access to the right treatment for a mental health condition may not

adhere to the treatment and may become homeless or suicidal. Once an individual is outside the system of health care because they are uninsured or homeless or otherwise, it is impossible to deliver valuable health care to them. A cost-effectiveness analysis does not take into consideration these broader costs, instead focusing on short-term costs that are relevant to a health insurance plan's actuarial analysis.

For example, the innovations providing cures for hepatitis C have been the subject of significant cost-effectiveness analyses that do not account for costs over the lifetime of patients no longer living with the disease. Mental health advocates provided an analogy about the implications of the U.S. response to the cure for hepatitis C, articulating what might happen if a cure were developed for a serious mental illness such as schizophrenia. The value of the curative treatment is not the cost of a single intervention, but the value over the patient's lifetime of being free of the disease and free of the onset of multiple comorbidities that emanate from that disease. Communities waiting for their "cure" do not want the hepatitis C experience of being denied access based on a flawed assessment of value.

Roundtable participants relayed that based on their personal experiences, being forced to accept the "highest value" or least costly treatment can have a negative impact on health outcomes, especially for patients with certain conditions such as epilepsy and mental health conditions.

It is critical to identify and incorporate long-term benefits into value assessment frameworks as well, recognizing that short-term benefits are not all that matter to patients. For example, providing patients with a pre-existing condition the first-line therapy early in their disease process can prevent them from requiring more aggressive and expensive treatments in the future. Additionally, there are opportunity costs associated with *not* providing certain treatments that may be expensive. Overall, providing truly patient-centered care is cost effective at the population level. That being said, roundtable participants were very sensitive to society's moral obligation to value the individual lives of patients and people with disabilities, and therefore not to allow payers to dictate the terms of the value debate solely based on a treatment's cost effectiveness.

"We get stuck in this timeframe of looking at the cost or the value of a single clinical intervention, whether it's for the average person or the individual patient, and just the cost of that clinical intervention... we should be measuring the cost of this intervention versus taking it away and how much it's going to cost the system not in the next quarter, not in the next year, but over the next 40 years."

— *Andrew Sperling, NAMI*

Part Two

Next Steps to Achieve Value for Patients and People with Disabilities

Participants discussed whether patients and people with disabilities are better served by addressing the status quo challenges of existing value frameworks and tools that are having an immediate and negative impact on patient access, or whether we should be focused on the future development of a “disruptive” alternative. Both were identified as necessary components of a thoughtful political and thought-leadership campaign that ultimately sought to achieve an assessment of value to individual patients and people with disabilities.

As value frameworks continue to evolve, patients should, and will, continue to make important contributions to their development. For example, some patient groups have valuable data about individual patients that they use to match patients with appropriate providers and treatments as well as data from patient registries and other sources. Patient groups also offer expertise on the conditions they represent, both from the perspective of patients, but also via their close collaboration with the medical community. The data, information, and perspective that patient groups bring to the conversation around value assessment, and supporting their capacity to contribute, is a critical part of driving value in health care. Yet, existing efforts to develop value frameworks and tools do not recognize this work, do not support it and do not incorporate the patient data that is available.

TACTICS TO IMPACT THE STATUS QUO DEVELOPMENT OF VALUE FRAMEWORKS AND TOOLS

I. Advocate for Use of Patient-Centered Value Model Rubric

The National Health Council’s (NHC) Patient-Centered Value Model Rubric should be used by developers of value assessments to mitigate the existing shortcomings of value assessments and tools.

Participants acknowledged that it would not be wise to ignore the status quo work to assess treatment value or to disengage from it. The NHC’s rubric already provides a guide to evaluate the patient-centeredness of value models and to guide value model developers on the meaningful incorporation of patient engagement throughout their processes. It was often referenced as addressing the challenges articulated above because of patient engagement. The rubric outlines the domains that must exist for a value framework to be patient-centered:

- **Patient Partnership.** Patients should be involved in every step of the value model development and dissemination process.
- **Transparency to Patients.** The assumptions and inputs into the value model itself – and each step in the process – should be disclosed to patients in an understandable way and in a timely fashion.

- **Inclusiveness of Patients.** The value model should reflect perspectives drawn from a broad range of stakeholders, including the patient community.
- **Diversity of Patients/Populations.** The value model should account for differences across patient subpopulations, trajectory of disease, and stage of a patient's life.
- **Outcomes Patients Care About.** The outcomes integrated into the value model should include those that patients have identified as important and consistent with their goals, aspirations, and experiences.
- **Patient-Centered Data Sources.** The value model should rely on a variety of credible data sources that allow for timely incorporation of new information and account for the diversity of patient populations and patient-centered outcomes, especially those from real-world settings and reported by patients directly. The data sources included should reflect the outcomes most important to patients and capture their experiences to the extent possible.

Roundtable participants agreed to continue pushing existing developers of value assessments to use the NHC rubric as a guide to improve their work so that private payers are responding to a broader set of patient-centered criteria when making coverage decisions. Value framework developers were perceived as being potentially receptive to improving their process to engage stakeholders and better incorporate patient data in a version 2.0 in the future.

II. Train Advocates

There is a significant need to increase the capacity of patients and people with disabilities to participate and comment on the development of value frameworks and tools.

It was also suggested to do more targeted education of patient communities that will be impacted by value assessment by sharing with them the experiences of patient communities that went before them. Organizing webinars and calls with speakers to offer their perspectives was also suggested. For example, the NHC is developing a “Get Ready Checklist” based on the experience of patient communities impacted by the development of value frameworks and tools. When a patient community recognizes that they will be the subject of the development of a value framework or tool, it would provide them with steps to prepare and to provide meaningful comments and input. It was suggested to also develop a set of consistent messages for patient organizations providing feedback to the developers of value frameworks and tools so that their concerns for patient-centeredness resonate.

“...people say they want the patient in the middle, but I used to say that I felt like ‘Flat Gwen,’ I would just be moved around as this two-dimensional character in the middle of a patient-centered discussion. So we have to make sure that we’re not just flat advocacy.”

— *Gwen Darien, NPAF*

III. Engage Providers

Providers and patients need to collaborate to ensure that value assessment frameworks do not conflict with making treatment decisions that are right for individual patients.

Participants acknowledged that a component of our work to achieve value for patients and people with disabilities requires training providers about partnering with their patients to discuss their treatment choices, their impacts and associated out-of-pocket costs so that patients have information to make their own value determinations. Physicians have a role to play in helping patients determine what is high and low value based on their unique characteristics and preferences. Providers can ensure that existing value frameworks and tools do not result in driving one-size-fits-all treatment decisions.

IV. Engage Payers

Payers should engage with patients and people with disabilities in a conversation about how value frameworks are developed and used.

Participants recognized that payers are broadly using existing value frameworks and tools to determine coverage of treatments. According to some surveys, around half of the payer community is using ICER reports in their formulary evaluation process and in preparing pharmacy and therapeutics (P&T) committee recommendations. Additionally, to the extent a payer is using existing value frameworks and tools, they are likely using them in all of the markets they serve, from private plans to Medicare Advantage and Medicaid Manage Care. Therefore, it is vital to continue to engage them and to communicate how value to patients and people with disabilities potentially drives down costs.

V. Engage Policymakers

Participants agreed that policymakers should not endorse the use of existing value frameworks and tools in public policy, whether through the proposed Part B Drug Payment Model or otherwise.

It was strongly suggested that policymakers engage with patients and people with disabilities so they are achieving value from the patient perspective and based on reliable information that accurately reflects the conditions under consideration, recognizing that efforts to achieve cost effectiveness should not be at the expense of our moral and ethical obligation to patients and people with disabilities.

VI. Engage Purchasers

It was discussed that we should approach the value issue from the broader perspective of a large employer so that these purchasers recognize the benefits of increased productivity and overall well-being, thereby increasing employee retention.

This tactic was perceived to be potentially effective in getting the attention of payers who do not perceive their client or customer to be the patient, but instead to be purchasers such as large employers.

CREATE MULTIPLE “DISRUPTIVE” ALTERNATIVES THAT CAPTURE VALUE TO PATIENTS

Participants described the need for “disruptive” frameworks and tools to assess individual value that could be used by patients and people with disabilities. Because existing value frameworks and tools are developed for a payer audience without engaging patients and people with disabilities, these “disruptive” alternatives would follow the recommendations of the NHC rubric on patient-centeredness. As described, these tools would allow patients and providers to assess value at the individual patient level, while also being useful to payers seeking to better understand value at the population level. In one example provided during the discussion, Avalere Health and FasterCures described their partnership to develop such a “disruptive framework” through a multi-stakeholder effort including patient advocates, public and private payers, and pharmaceutical and device manufacturers. Their framework will be responsive to stakeholder input, intending to build off of important foundational work that NHC has begun with the value rubric. It’s also imperative that there be a toolbox available to assess value from varying perspectives and for varying audiences, as one single tool cannot capture value to all patients, with different conditions and disabilities, alone.

“People are actually being affected right now, today, by the decisions that are being made - being denied potentially life-saving treatments. So a new value framework in the future is great but there is something happening today that we must address now.”

— *Cat Davis Ahmed, Familial Hypercholesterolemia Foundation*

Part Three

Conclusion

PIPC looks forward to supporting the implementation of the key strategies identified by our roundtable participants. While we oppose the misuse of existing value frameworks and tools in public programs, we look forward to taking steps that will potentially improve the ongoing work of entities developing value frameworks and tools. We also support efforts to advance the development of “disruptive” alternatives that empower patients and people with disabilities to determine value based on their unique characteristics and preferences. Our society has a moral and ethical obligation to take care of the most vulnerable among us. Advancing patient-centered solutions will allow the country to deliver health care in manner that both respects individuals while improving the health of populations.