



**NCCN Patient Advocacy Summit
*Value in Cancer Care – Patient Perspectives***

On Tuesday, December 1, 2015, the National Comprehensive Cancer Network® (NCCN®) convened its sixth annual NCCN Patient Advocacy Summit in Washington, DC, titled, *Value in Cancer Care – Patient Perspectives*. Moderated by Clifford Goodman, PhD, The Lewin Group, the 2015 summit brought together key stakeholders, including patients, patient advocates, academia, industry, payers, and policy makers to discuss three topics of concern to patients in 2015: value, access, and cost of cancer care.

How are Cancer Patients and Survivors Faring under the Affordable Care Act?

Following introductions and opening statements from Robert W. Carlson, MD, Chief Executive Officer, NCCN, the summit commenced with remarks from Loyce Pace, MPH, LIVESTRONG Foundation, regarding the current state of patient access to care under the Affordable Care Act (ACA).

After the initial passage of the ACA, Ms. Pace explained, LIVESTRONG was one of the groups celebrating the Act because the organization supported the access it could provide for their constituents. She explained that certain provisions of the Act had a positive impact on people with cancer, namely the end of life-time insurance caps and denials for cancer diagnosis, as well as increased access to treatment options like clinical trials. The general public benefited too, she said, from greater access to preventive screening and the extension of a dependent on one's benefits plan until age 26.

Since the passage of ACA, according to Ms. Pace, LIVESTRONG has executed polls and collaborated on studies to capture the public reaction to the act and the effect it has had on patient access to care in the United States.

LIVESTRONG partnered with the American Cancer Society (ACS) Cancer Action Network to commission a study by the Urban Institute building on their Health Reform Monitoring Survey¹. The study oversampled a group of cancer survivors in order to draw comparisons between cancer survivors and the general public regarding their health care status following ACA.

Ms. Pace highlighted results of the study, describing that 96 percent of cancer survivors reported having health care coverage, with nine percent claiming they acquired coverage in the past 12 months. The assumption, she said, is that more people came into health coverage as a result of ACA. Only 3.5 percent of respondents claimed that they had no health insurance. Moreover, the survivors reported that they were able to access routine check-ups (85.7 percent), as well as specialist visits at least once per year (72.8 percent). Comparatively, less than 37 percent of adults without cancer reported specialist visits in the past 12 months. When asked about problems accessing care, however, one in five cancer survivors reported issues.

"Affordability is where you get a little bit into the bad news, unfortunately," said Ms. Pace; according to the study, 30 percent of survivors reported unmet need for care due to cost, with 31 percent reporting that they are paying off medical bills over time. More than 39 percent of survivors, compared with 21 percent of adults without cancer, reported family out-of-pocket costs in excess of \$2,000 in the past 12 months.

The study also found that there is a particular problem among the lower-middle class who do not have the level of resources they need to offset their medical costs, but who are not caught in the safety-net programs like Medicaid, said Ms. Pace.

Ms. Pace noted that narrow networks are hindering patient access to quality care, highlighting an NCCN/Avalere joint survey that found that 25 percent of NCI-designated cancer centers surveyed reported exclusion from networks offered by their states health care exchanges.ⁱⁱ

Ms. Pace left the audience with a call to action for collaboration to ensure quality coverage, more transparency, and industry oversight. “What can we do to be sure that we’re best serving patients and survivors?” asked Ms. Pace. “We want to continue to tell the story if nothing else. We want to continue to elevate the issues and highlight the challenges that people might be having or even the success stories that we’re uncovering; but we need to be telling their stories because only then can that spur more research and more action in this space.”

Roundtable Discussion: Access to Cancer Care

Access to appropriate cancer care is of vital importance to patients with cancer and their families. The inability to obtain the right cancer care in a timely manner can have devastating results—medically, psychologically, and financially. It is therefore critical that patients have access to provider networks that include oncologists and cancer centers, and that these are located in reasonable proximity to the patient. However, to help control costs, many plans limit access to the kinds of specialists cancer patients need; this can have an adverse effect on cancer patients and their caregivers.

To further examine patient access to care, NCCN convened the following multi-stakeholder panelists for the day’s first roundtable discussion: Terry Langbaum, MAS, The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins; Bonnie Miller, RN, BSN, OCN, FAAMA, Fox Chase Cancer Center; Ms. Pace; Caroline Pearson, Avalere Health; and David Rubin, Memorial Sloan Kettering Cancer Center.

Dr. Goodman opened the panel discussion by asking Ms. Pearson to discuss the NCCN/Avalere study regarding NCI-designated cancer center participation in narrow networks. Ms. Pearson, Senior Vice President of Policy and Strategy, Avalere Health, described the 2014 studyⁱⁱⁱ, which found that five of the 20 surveyed cancer centers reported exclusion from a vast majority of or all exchanges in their state or in their region.

“If you’re a patient and want to seek cancer care at a leading cancer center [within a narrow network], there would not be a single product sold on the exchange that would cover care at that center; that’s certainly troubling when you start to think about access for specialty services,” said Ms. Pearson. She noted that one reason for the exclusion was that the rates at which the centers were being asked to sign on were unrealistic.

In a related study, Avalere also found that, when compared to typical employer-sponsored programs, the exchanges nationwide only cover about 58 percent as many oncology providers.^{iv}

Mr. Rubin, Manager of Health Outcomes and Quantitative Analytics at Memorial Sloan Kettering Cancer Center, added that his institution has sought out the insurance carriers in order to get coverage for their patients. The reaction, he noted, is that the carriers are worried that Memorial Sloan Kettering Cancer Center—and presumably other comprehensive cancer centers within the United States—will bring with them “a higher mix of cancer patients”, thus adversely affecting their bottom line. He then noted that his institution has done studies to assess whether the extra payment provided for higher-risk patients under

the ACA covers the risk for cancer, and the results shows that indeed it does, therefore not adversely affecting an insurance carrier's bottom line.

Dr. Goodman then asked Ms. Miller to discuss, from the standpoint of Fox Chase Cancer Center—if narrow network access may ultimately affect patient autonomy and patient outcomes.

Ms. Miller, who is the Administrative Director of the Women's Cancer Center at Fox Chase Cancer Center, noted that there are a number of challenges today, from the marketing of centers to patient navigation. Before people have cancer, she explained, they are choosing plans either on their exchange or through their employer that offer the lowest out-of-pocket cost and they are not necessarily concerned about access to care for a diagnosis like cancer.

As an administrator of 16 nurse navigators at Fox Chase Cancer Center, Ms. Miller sees the struggles that the patients have in garnering awareness of their coverage, she said. The nurse navigators want to focus on clinical barriers and help patients get into the system and into the right point of care; however, there are a plethora of insurance barriers, and the nurses are concerned with keeping up to date with the constantly evolving insurance landscape. To that end, Fox Chase Cancer Center has built financial counselors into their system in order to create more transparency around cost and access and allow nurse navigators to focus on clinical concerns.

Ms. Langbaum, Chief Administrative Officer at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins and Cancer Survivor, described her personal experiences as a patient with both nurse navigators and insurance-appointed financial counselors. The assigned navigators were not ideal for her, she said. Patients dealing with a new diagnosis do note the stress associated with entertaining a stranger; it should be an optional program, she said.

Ms. Miller expounded that navigation is required for several programs and cancer center designations and when Fox Chase Cancer Center formalized their nurse navigator program in 2010, many of the staff were already inherently navigating patients. Through implementation of the program, administration has torn down a number of self-imposed barriers. For example, she noted, non-clinical schedulers were the first people to contact new patients from Fox Chase and patients were unable to get answers to clinical questions they had at the onset. Now, these schedulers are connected with nurse navigators who are able to "get their hands on the right material at the right time."

Community-based navigation complements the clinical, financial, and emotional support programs offered at cancer centers, Ms. Pace added. Community-based programs are important as they can capture the "every day, practical concerns" that patients and their caregivers have about their cancer experience, she said.

Mr. Rubin described a benefit of the patient navigation at Memorial Sloan Kettering Cancer Center: patients are assigned a financial coordinator, a program that is internally funded by the cancer center. "If you reduce the load on the patient of what they have to worry about, you've done a good job. We believe that there's an inherent benefit in spending that money to help the patient," he said. Mr. Rubin added that, with emotional support from staff social workers and psychiatrists, patients are able to better cope and reenter the workforce.

Turning to individual hospital formularies, panelists agreed that specialty drug tiers are increasingly difficult to manage from both the navigator and patient standpoint.

With the combination of high deductibles and the coinsurance on the specialty tiers, most people do not actually know what the cost of their drug is going to be, explained Ms. Pearson. “Say I have a \$60 co-pay; I know what that is. You say I have to pay 30 percent of the cost of the negotiated price of my drug, and I have no idea what that is. This becomes very hard to manage,” she said.

Patients are concerned about cost, but at the end of the day, what is of most importance to them is if they will live, said Ms. Langbaum, explaining that it is of utmost importance that patients have access to the care that will lead to optimal outcomes.

When speaking to patients about the most cost-effective care, is site of care part of the discussion, asked Dr. Goodman.

Accountable Care Organizations (ACOs) and integrated delivery systems have the ability to use ownership arrangements with physicians who have outpatient facilities to direct best site of care for patients, explained Ms. Pearson. She added that payers essentially direct site of care through network design. Dr. Goodman added that such direction to reduce cost may lead to suboptimal care.

On the matter of informed decision-making with regard to site of care, Dr. Goodman asked Mr. Rubin to discuss a recent study from Memorial Sloan Kettering Cancer Center regarding outcomes of top-tier cancer centers compared with other sites of treatment.^v

Mr. Rubin discussed the study that compared five-year outcomes of more than 700,000 patients treated for cancer in the United States, which found that patients treated at top-tier hospitals have five-year survival rates of 53 percent. The same survival rate for community hospitals was 44 percent, said Mr. Rubin.

We need to create a transparent process so that patients and legislators can see that this is what’s happening, he said. “We need to provide access to their top tier facilities so that patients can get the best outcomes for them.”

Defining Value in Cancer Care – Value to Whom?

A keynote address on value in cancer care was delivered by Alan Balch, PhD, Chief Executive Officer of Patient Advocate Foundation (PAF). PAF is a not-for-profit organization dedicated to finding and providing financial resources to patients, as well as helping them navigate their insurance benefit.

Dr. Balch opened by noting the dynamic change in the oncology health care system, specifically in data and electronic health records (EHR); consolidation in the hospital market; the emergence of channel strategies around specialty pharmacy; and dramatic innovation in oncology science, specifically in precision medicine.

All these changes considered, there are four key areas, he said, that are key to defining value in cancer care—precision medicine, patient engagement, alternative payment models or payment reform, and quality measurement.

First and foremost, said Dr. Balch, we must devise a new way to track and measure outcomes, benefits, and cost longitudinally to assess value for patients. He noted that standardized treatment models based on the average patient will lead to average results. “If quality oncology becomes defined as a rigid standardization of treatment protocols, then what you’re going to get is treatment options that are limited

and average,” he said. Ideally, “the focus would be on determining the best treatment options based on the unique characteristic of the individual and also their own value preferences.”

Often, the assumption is that standardized therapy is actually a more cost-effective treatment strategy. However, he noted, precision and personalized medicine through patient engagement actually saves money because patients are administered the right treatment at the right time, avoiding costs associated with medication that may not be appropriate.

“Voluntary choices must be made in the context of voluntary cooperation and coordination,” he said.

Dr. Balch called for consideration of provider reimbursement based on treatment quality: “Physicians must have the freedom to be able to consider a range of treatment options for their patients based on guidelines and carefully weigh the risks, benefits, and costs associated with the treatment option without regard for reimbursement or incentive attached to a particular course of therapy.”

With respect to value measurement, long-term cost effectiveness models are difficult to implement in oncology because the upfront costs are so high, but the benefits of treatment may be very short term or difficult to quantify, said Dr. Balch. These benefits, however, are incredibly important to patients.

To adequately quantify value, tools must include both adverse events and ancillary treatment benefits alongside the cost effectiveness ratio and clinical benefits, including a variety of characteristic and quality-of-life issues and patient-reported outcomes, he explained.

“We have to think about quality measures that reflect outcomes that matter to patients,” he added.

“Measures need to assess care planning and shared decision-making. We have to reward providers in the health care system for delivering care and identifying treatment plans that align with their patients’ values and individual preferences.” Dr. Balch noted the importance of rewarding providers to meeting the patients’ personal needs.

“Patient groups and patients themselves need to fight for the importance of enabling value to be expressed at the individual patient level. Ultimately, the rallying cry should be patient centricity rather than value because an emphasis on the former is the way to get us to the latter,” he said.

Defining Value for Patients with Cancer

While value is often an elusive concept, it is particularly so when applied to cancer care. Most simply, value is usually understood as the outcome when benefits exceed cost. The Institute of Medicine (IOM) defines value as “best care for lower cost”; but defining benefits and costs relative to cancer are is extremely difficult. Less expensive care does not contribute to value if the quality of care is insufficient.

The following panelists discussed value in cancer care, as well as new tools for value discourse between a patient and his or her physician: Dr. Balch; Dr. Carlson; Ms. Langbaum; Shelley Fuld Nasso, MPP, National Coalition for Cancer Survivorship; Dan Ollendorf, PhD, Institute for Clinical and Economic Review (ICER); and Dana Wollins, MS, American Society of Clinical Oncology (ASCO).

Dr. Goodman opened by asking panel members to describe oncology value frameworks introduced in the past year from NCCN, ASCO, and ICER.

Dr. Ollendorf is Chief Review Officer at ICER, an organization that evaluates the evidence on the value of medical tests, treatments, and delivery system innovations; due to the high prices of new prescription drugs, ICER submits independently, publicly available analyses of the value of new drugs at the time of

their introduction.^{vi} Dr. Ellendorf described the standards that are considered in the generation of the ICER value assessment framework intended to guide payer assessment of the value of medical services.

ICER convenes independent counsels of patient advocates, clinical societies, life sciences companies, pharmaceutical benefit managers, and insurers to make evidence-based determinations of the clinical and economic value of new interventions, considering the following components: comparative clinical effectiveness; non-clinical benefits and or disadvantages; contextual considerations, such as ethical or legal issues; care value, which represents long-term perspective of benefits and the incremental costs to achieve those benefits at the individual patient level; potential Budget impact, which is the estimated net change in total health care costs over five years; provisional health system value, which considers long-term care value with an analysis of potential short-term budget impact of unmanaged utilization; and mechanisms to maximize health system value.^{vii, viii}

According to Dr. Ollendorf, the ICER framework looks carefully at all aspects of an intervention—clinical and non-clinical—in order to provide a value assessment or recommended price that ideally will lead to patient access to the most valuable treatment. To date, the ICER framework analysis has not been performed for an oncology intervention, but the organization plans to move into the oncology space in the next year.

Ms. Wollins, Senior Director of Health Policy at ASCO, described the ASCO Value Framework as a way to look at clinical benefit, toxicity, and cost as a starting point to facilitate shared decision-making and to provide transparency of information in order to address financial toxicity and clinical and emotional benefits. In looking at two treatments, the ASCO value tool considers evidence to weigh clinical benefit and toxicity to come up with a net health benefit score. Because this tool is developed using the highest level of evidence, she explained, there is still work to be done regarding the capture of data around non-clinical considerations. Looking ahead, though, once systems are in place to better capture patient-reported outcomes, the tool will be able to better integrate that information, she said.

Cost is considered separately from outcomes and toxicity, explained Ms. Wollins; ASCO believes that a patient should be able to make a treatment decision as if cost is not a hindrance, she said. If affordability is a concern, the cost portion of the framework can be consulted. Because patient payment models are very individualized, ASCO's framework refers to drug acquisition cost.

In response to multiple stakeholder requests for further information about the rationale behind NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) recommendations, NCCN developed the NCCN Evidence Blocks, explained Dr. Carlson. Released in October 2015, NCCN Evidence Blocks are visual representations of five key value measurements for system therapy recommendations: effectiveness, safety, quality and quantity of evidence, consistency of evidence, and affordability.

According to Dr. Carlson, cost has never been a consideration within the NCCN Guidelines recommendations; however, the addition of the affordability metric to the existing criteria for evaluating NCCN Guidelines recommendations allows patients, alongside their physicians, to make informed choices about their treatment based on their own personal value system.

Tabulated from surveyed data from sub-specialist NCCN Guidelines panel members, NCCN Evidence Blocks™ feature scores from “one” to “five” for each measurement, “one” being the least desirable and “five” being the most desirable. These 5x5 blocks are shaded accordingly and published beside each therapeutic recommendation within a derivative version the Guidelines. Dr. Carlson added that the affordability measurement is rated using and the panel members' knowledge of overall cost of the

regimen, including cost of drug, administration, required supportive care, identification and management of toxicity and probability of hospitalization.

Dr. Goodman asked the remaining panelists for their reaction to the launch of these three value tools.

“I basically react to them with relief,” said Ms. Langbaum. “It’s the first time that we have something concrete to look at so that a physician can sit down with a patient and have the conversation about what the patient values and what the evidence shows us... As a patient it allows me to have an intelligent conversation about the options. As an administrator, it allows me to think there’s hope that we can somehow rein in the care to something of quality.”

Individual patients are incredibly variable, she explained. However, having a tool that brings affordability to the table is important as it allows the physician to guide the patient toward proper resources should cost be a concern.

Ms. Nasso echoed the importance of tools that bring forth transparency around the issue of value and affordability and noted that, in her opinion, they can be useful providers, but, she challenged the utility of such tools for patients. Studies that assess such utility and what added value they provide for the patient population are needed, she said.

Dr. Carlson said that some stakeholders have expressed concern that the various value tools will inhibit patient access to treatment because payers will deny payment on higher-cost regimens. “Payers already know and understand what they are paying for regimens,” he said. The new value assessment tools are adding transparency around the issue of value for additional stakeholders.

A tool, in isolation, is not going to be as effective as one with a necessary support system in place, said Dr. Balch; the platform ideally would measure patient experience in shared decision-making in order to evaluate the value tool itself.

Dr. Balch added that there are definite data gaps for which patient advocacy organizations can provide information around what is truly of value to patients.

While pleased that payers and industry are collaborating on research of value in cancer care, Ms. Nasso said that a tool should be developed that would capture cost to society as a measurement. However, she said that patients themselves should not be considering cost to society when making a treatment decision. She is skeptical that one tool can be created that is both patient friendly and can reflect cost to society in a way that is useful to multiple oncology stakeholders.

In closing, Dr. Goodman asked the panel to consider what the next iterations of these value assessment tools will entail. The panel members called for collaboration and agreed that systems will need to be put in place that will evaluate the tools, as well as gather comprehensive data about patient-reported outcomes and personal value.

Addressing the Growing Financial Burden of a Cancer Diagnosis

The summit’s third session focused on the financial burden of a cancer diagnosis beginning with a keynote address from Veena Shankaran, MD, MS, Assistant Professor, Medical Oncology, University of Washington School of Medicine, and Assistant Member, Clinical Research Division, Fred Hutchinson Cancer Research Center. Dr. Shankaran began by citing studies regarding the impact rising costs are

having on patients. A recent study found that health care debt makes up 38 percent of all financial debt in the United States, ahead of student loans, credit cards, retail, utility, and mortgage debt—a problem that has been termed, “financial toxicity” in recent years, she said.^{ix}

Twenty-two percent of patients with colon cancer reported that they were in debt, found another study, with 16.5 percent forced to borrow money; even more have forgone treatment due to cost, she added.^x

People with cancer have higher financial burden than those with other chronic diseases, she said. With help from the Washington State Bankruptcy Court, Dr. Shankaran and fellow researchers compared the bankruptcy data with cancer cases from the Western Washington SEER Registry, as well as records for individuals without cancer from LexisNexis, and found that patients with cancer are 2.65 times more likely to file for bankruptcy compared with matched controls.^{xi}

“Lung, breast, prostate, colon, thyroid cancers, and leukemia and lymphoma were the most common cancers in which bankruptcy filings occurred,” she said. “And, across all these diseases, bankruptcy filings were more common in younger patients than in older patients,” she added.

Finally, patients who filed for bankruptcy were found more likely to die of the disease, she added. One theory is that individuals facing financial distress were non-adherent to prescribed treatment due to out-of-pocket costs. Additional theories include poorer access to high-quality cancer centers and lack of participation in clinical trials, she explained.^{xii}

Dr. Shankaran then outlined five strategies for decreasing financial toxicity among people with cancer:

- Measure patients’ financial health in real time while there is still opportunity to intervene. Dr. Shankaran said the potential for use of smartphones applications to help patients track expenses and help providers and clinics understand what these expenses are.
- Provide financial counseling. In a small qualitative survey of patients—primarily women with breast cancer—her team found that many of the women lost their jobs, took loans, fell into debt, and had issues with adherence. Seventy-six percent of women surveyed noted that they would have benefited from financial counseling. The greatest topics of interest to these women were money management, finding copayment assistance, and choosing and navigating an insurance plan, she explained.
- Improve transparency around the cost of treatment—not just around total cost, but out-of-pocket cost to the patients. Studies show that patients care about out-of-pocket costs, even when there is only one treatment option, explained Dr. Shankaran.
- Eliminate low-value prescribing practices where there is low evidence of improved patient outcomes as a strategy for cutting health care waste. “I think that we can all agree that questioning these practices probably has benefit from a societal standpoint in terms of decreasing waste and controlling cost,” she said.
- Restructure insurance plan cost sharing. Dr. Shankaran explained that implementing a value-based insurance design would lower cost sharing for drugs that clearly benefit patients and higher cost sharing for those without such apparent benefit.

“The rising cost of cancer care is having a negative financial impact on patients in terms of bankruptcy and various other financial outcomes,” she said. “Financial hardship may be an underappreciated driver of disparities in treatment and outcome.”

Cost of Cancer Care and the Patient Impact

The rising cost of cancer care is creating a huge burden on patients and on the U.S. health care system as a whole. Cancer care is expensive and the related expense continues to rise faster than the overall rate of healthcare expenditures in the United States. Innovation, which leads to new diagnostics and treatments in oncology and ultimately to improved outcomes, also comes at a cost. Drug prices, in particular, are escalating at an exponential pace. Some reasons cited for high drug prices are the high cost of cancer drug development, targeted therapy for smaller patient cohorts, the higher prices patients and society seem willing to pay, and the failure to take economic considerations into account in the drug approval and pricing processes.

To deliberate cost in cancer care, NCCN convened the following panelists for the summit's final roundtable: Lori Reilly, JD, PhRMA; Dan Klein, Patient Access Network Foundation; Susan Pelletier, Cancer Survivor and Advocate; Leonard Saltz, MD, Memorial Sloan Kettering Cancer Center, and Dr. Shankaran.

Dr. Goodman opened the panel discussion by asking Ms. Reilly to explain why cancer drugs cost so much.

Ms. Reilly, Executive Vice President of PhRMA, explained that, for many patients, hope and promise come through cancer medicine. Furthermore, since 1991, the United States has seen a 22 percent decrease in cancer death rates, as well as a dramatic increase in five-year survival. "We're on the cusp of even greater innovation. Some of the new immunotherapies that are coming to market are truly going to be transformational."

She added that, in her experience, the system is changing and responding to pressures about cost today, noting that there is a historically high rate of competition in the field of oncology pharmaceuticals. In addition, she said, for most medicine, a generic eventually comes to market and prices fall.

Finally, she stated that innovation can also be a part of the solution to health care cost challenges, explaining that many of the new medicines coming to market are personalized therapies.

"Do you think there is some relationship between the trends in pricing of oncology drugs and their clinical impact, outcomes, etc.?" Dr. Goodman asked Dr. Saltz.

"Unfortunately, the data would say no," Dr. Saltz, Medical Oncologist at Memorial Sloan Kettering Cancer Center replied. He cited a *JAMA Oncology* study that looked for correlation between a drug's cost and its novelty of mechanism or action of efficacy and it found none.^{xiii} "The only thing that correlated with the price of a drug that came out was the price of what came before and, essentially, what the market would bear," Dr. Saltz added.

Mr. Klein, President and Chief Executive Officer, Patient Access Network (PAN), noted that there is certainly cost sharing or shifting of more costs to patients with the movement of more drugs into multiple coinsurance tiers. PAN and agencies like PAN are an essential financial safety net for patients with cancer, he said.

If a patient enrolled in Medicare Part D, as a household of two, is at 200% of the federal poverty level that means they are making about \$30,000 a year with a \$4,700, or 15% of that patient's household income, out-of-pocket annual expense in order to get across the coverage gap, he said. That patient is badly underinsured, by definition, he explained.

Ms. Pelletier shared her personal experience paying for cancer treatment. Ms. Pelletier is a two-time breast cancer survivor and the second of three generations to be diagnosed with the disease. As a small

business owner at the time of her initial diagnosis in 1999, Ms. Pelletier and her husband had a \$20,000 deductible, and, because of the high cost of treatment, she has been on a payment plan ever since, she said.

Ms. Pelletier also said that young adult patients may have added concerns about health care cost. For example, her daughter, who is also a breast cancer survivor, chose to have her eggs harvested—a costly procedure that was not covered by insurance, she said.

Are drug prices affecting the patients you survey, Dr. Goodman asked Dr. Shankaran.

“Absolutely,” she replied. According to the patients she surveyed, Dr. Shankaran said that cost of drugs was one of the most common causes of health care debt; however, she did note that drug costs are not the only factor impacting financial toxicity—but it is a major factor. Other factors include loss of employment and diagnostic testing, she said.

The conversation turned to 340B drug pricing which, according to Dr. Goodman, was instituted in 1992, in part, to provide discounted drugs to centers that needed such discounts in order to serve low-income patients and provide more comprehensive care.^{xiv} Ms. Reilly agreed but added that the scope of use as originally intended has grown significantly. When the program was created, it was estimated that 340B would be going to less than 100 hospitals in the country, she said. Today half of all hospitals are participating. “If you’re giving more and more discounts to a larger and larger percent of customers, that has an impact in terms of how companies have to recoup,” she added.

Dr. Saltz noted that the pharmaceutical companies are publicly traded companies and that it is their responsibility to, within the letter of the law, increase their shareholder value. The market today is completely dysfunctional, he said. Medicare is “forbidden from negotiating a price, forbidden from considering the impact, forbidden from saying, ‘That’s too small a benefit. We won’t pay for it at that price,’” he added.

Mr. Klein added that patients on Medicare or Medicaid are not given access, through Inspector General and Anti-Kickback Statutes, to manufacturer-funded assistance programs. Those programs, he noted, are geared towards those with private or commercial insurance, either individual or group funded.

“If you look between 2009 and 2014, among the top six charitable assistance programs, the amount of assistance we provided went from about \$300 million to just under \$1 billion. And, that’s largely funded by contributions from drug manufacturers,” he said.

Dr. Shankaran noted that one strategy for curbing the escalating cost of care is the through value-based insurance design, although it may be easier to translate in general medicine or cancer screening, than in complex oncology care for people with advanced cancer. She also added that there may be value in performance-based payments, a model currently being tested in the United Kingdom.

She also reiterated her earlier point that providers must be more wary of ordering tests that lack evidence behind their efficacy in order to control cost.

Dr. Goodman closed the panel by asking what the next best move is in order balance cost with outcomes in cancer care. The panelists called for regulatory reform, benefit redesign, better research design, 340B reform, and increased cost transparency.

“I think there’s going to have to be an acknowledgement that we’re going to need certain minimum value for what we get, that we’re going to have to stop doing the studies that look for tiny, incremental benefits,

then approving the drugs on those time, incremental benefits, and then arguing about whether it's worth it or not," said Dr. Saltz. "We're going to have to set our standards higher. And, the only way to get away from incremental benefits is to be able to walk away from them. As an oncology community, we're going to have to do that. We're going to have to demand better therapies and the only way to get those is to walk away from the ones that aren't good enough," he said.

ⁱ Health Reform Monitoring Survey, 2014 Quarter 3 (September), including oversample of adults with a cancer diagnosis (excluding skin).

ⁱⁱ "Leading Cancer Centers May Be More Widely Included in Exchange Networks than Expected | Avalere Health." Leading Cancer Centers May Be More Widely Included in Exchange Networks than Expected | Avalere Health. Web. 17 Dec. 2015.

ⁱⁱⁱ "Leading Cancer Centers May Be More Widely Included in Exchange Networks than Expected | Avalere Health." Leading Cancer Centers May Be More Widely Included in Exchange Networks than Expected | Avalere Health. Web. 17 Dec. 2015.

^{iv} "Exchange Plans Include 34 Percent Fewer Providers than the Average for Commercial Plans | Avalere Health." Exchange Plans Include 34 Percent Fewer Providers than the Average for Commercial Plans | Avalere Health. Web. 18 Dec. 2015.

^v "MSK Study Examines Cancer-Care Outcomes among US Hospitals." MSK Study Examines Cancer-Care Outcomes among US Hospitals. Web. 17 Dec. 2015.

^{vi} "Value Assessment Project | Institute for Clinical and Economic Review." Institute for Clinical and Economic Review. Web. 18 Dec. 2015.

^{vii} "Value Assessment Project | Institute for Clinical and Economic Review." Institute for Clinical and Economic Review. Web. 18 Dec. 2015.

^{viii} "Assessing Value." ICER|Web. 18.Dec.2015

^{ix} ACA International, 2013 Survey Report: Impact of 3rd Party Debt Collection on the National and State Economies

^x Shankaran, V et al. J Clin Oncol. 30 (14): May 2012.

^{xi} Ramsey et al. Health Affairs. 32(16), 2013.

^{xii} Unger, J et al. JAMA Oncology. ePub ahead of print October 2015.

^{xiii} JAMA Oncol. 2015;1(4):539-540. doi:10.1001/jamaoncol.2015.0373.

^{xiv} "340B Drug Pricing Program." 340B Drug Pricing Program. U.S. Department of Health and Human Services. Web. 21 Dec. 2015.