

On Wednesday, November 28, 2012, the National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 21 of the world's leading cancer centers dedicated to improving the quality and effectiveness of care provided to patients with cancer, convened the [NCCN Patient Advocacy Summit: Patient Perspectives Across the Cancer Care Continuum](#). The NCCN Patient Advocacy Summit, which was held in Washington, DC, brought together oncology patient advocacy groups, patients, provider groups, policy-makers, industry, and employers to provide education on the impact of the Affordable Care Act (ACA), commonly known as health care reform, address the needs of patients across the care continuum, and discuss survivorship as a stage of the care continuum. The Summit consisted of a series of panel discussions featuring key stakeholders moderated by Clifford Goodman, PhD, The Lewin Group.

Attendees were welcomed to the Summit by Patricia J. Goldsmith, Executive Vice President and Chief Operating Officer, NCCN, and The Honorable Ellen O'Kane Tauscher. Ms. Tauscher, Strategic Advisor for Baker, Donelson, Bearman, Caldwell & Berkowitz, PC, Former Under Secretary of State for Arms Control & International Security, Former Member of Congress, Representative to the NCCN Foundation Board of Directors, and cancer survivor, provided opening remarks to frame the Summit.

Ms. Tauscher first described her own cancer care experience, which began when she was diagnosed with Stage III non-metastatic esophageal cancer in 2010. Her diagnosis came 30 years following her grandmother's death, which was a result of the same disease. Ms. Tauscher subsequently underwent eight rounds of chemotherapy, 25 rounds of radiation and, on December 3, 2010, underwent esophageal reconstruction surgery. Acknowledging that many patients with cancer struggle with making treatment decisions, Ms. Tauscher described her experience of drawing on her political career and making important decisions.

"I could use my investment banking skills and my ability to triangulate in some way, compartmentalize, and to dispassionately look at this like any problem I was going to solve," said Ms. Tauscher. "If my grandmother was still alive and she had esophageal cancer, what would I tell her to do?"

Ms. Tauscher also discussed how she envisioned her life following her treatment and the importance of a medical team that understood and shared her goals. "I wanted to return to a quality of life that approximated my previous lifestyle," she said.

Ms. Tauscher acknowledged that during her treatment she had tremendous support and access to a great team of clinicians, but even then, navigating the health care system was a challenge. When you have cancer, the American health care system is a troubling system in the worst of times, said Ms. Tauscher. The Affordable Care Act (ACA), she said, is important because people no longer need to worry about denial of coverage due to preexisting conditions, and because they are empowered by the ability to find insurance

and take care of themselves. Currently, the system is too unfriendly for success, she explained: “As an American who wants to project American power, I want to get it right for us so that we can get it right for others.”

Ms. Tauscher closed her remarks by giving the attendees a call to action: We need to find credible metrics on which to score congress that tie together investment, research and development, and technology and give people a sense of return on investment. We need guideposts by which to measure our success and we need advocates on Capitol Hill to be the “itch that needs to be scratched.”

### **Health Care Delivery – Impact of Supreme Court Ruling and How Patients Receive Care**

The [June 28, 2012 Supreme Court ruling on the ACA](#) and its effects on patient care were the key topics of the first panel, which included Arthur Beckert, MS, Executive Director, Sarcoma Alliance; Susan Dentzer, Editor-in-Chief, *Health Affairs*; Edward George, MD, practicing physician and Chairman, National Policy Board, US Oncology; Pamela Germain, MBA, Vice President of Managed Care and Outreach, [Roswell Park Cancer Institute](#); Scott Gottlieb, MD, practicing physician and Resident Fellow, American Enterprise Institute for Public Policy; and John Greene, Director of Customer Centric Engineering, Salesforce.com and cancer survivor.

Dr. Goodman opened the panel by asking Ms. Dentzer to remind the attendees what impact the Supreme Court ruling had on the ACA and its implementation. Ms. Dentzer summarized that the ACA provides a variety of provisions, including, but not limited to, the elimination of co-pays for select preventative screening, including some cancer screening, and the ability for uninsured young adults to remain on their parents’ or guardians’ insurance until the age of 26. Further, come 2014, the law prohibits the denial of coverage for patients with preexisting conditions, as well as lifetime caps on insurance coverage. While these are popular provisions, according to Ms. Dentzer, one area that remains dubious is the Medicaid expansion portion of the ACA, which gives people under 133 percent of the poverty line access to Medicaid, making 15 million Americans “newly eligible” for coverage, with the federal government picking up 100 percent of the states’ costs for expansion during the first year. The specific provision of ACA’s Medicaid expansion allowing the federal government to withhold all Medicaid dollars from states that decided not to expand their Medicaid coverage was considered “unduly punitive” and ruled unconstitutional; however, the expansion of Medicaid itself was allowed to stand, permitting the states to choose whether or not to expand their Medicaid programs. Providers, payers, and the industry are watching related developments in the states closely.

When asked by Dr. Goodman how they felt about the ruling to uphold the ACA, the panel asserted the need for immediate collaboration between providers, payers, community and academic treatment centers, government, and patients. Panel members agreed that as more groundbreaking advances are made in cancer care, cancer—in many cases—is progressing from an acute disease to a chronic condition. Subsequently, access to care for preexisting conditions is imperative and collaboration must be fostered between the payer market and treatment providers in order to truly empower consumers.

Dr. Goodman also asked the panel members to consider how providers are affected by the ACA. Dr. George noted that for providers like US Oncology, the ACA addresses their number one challenge: ensuring that all patients have access to care. He spoke to the importance of the elimination of lifetime coverage limits, as well as denial of coverage for preexisting conditions; however, he added, as states decide whether to uphold the Medicaid portion of the ACA, uncertainty still exists as to whether the uninsured or underinsured will have access to coverage and delivery.

Dr. Goodman then inquired about the “big picture effect” of the ACA. Dr. Gottlieb commented that, while access to care is seemingly improved by ACA, quality of care is a concern. Capitation and shifting risk is going to adversely affect patients, said Dr. Gottlieb, explaining that bundled payments will supersede fee-for-service models, thus pitting providers against the technology that they use for delivery. He then noted that provider productivity will suffer as physicians are subsidized and incentivized to use the least expensive treatments—not necessarily the most effective.

In response, Dr. Goodman asked Dr. George to comment on how the shift in payment models is affecting US Oncology. Dr. George responded that US Oncology, like many large oncology health care providers, uses evidence-based pathways or guidelines for treatment in order to ensure optimal patient care. Within the pathways, said Dr. George, there are ways to be more cost efficient, and by staying within the guidelines, doctors still act in the best interest of the patients. In the rare case that a physician believes that the optimal treatment falls outside of the pathways, provisions are in place to ensure that patients are able to receive treatment, said Dr. George.

To illicit further clarity, Dr. Gottlieb was asked to elaborate on the effect of the aforementioned scenarios. Dr. Gottlieb responded that as insurance exchanges come into play as a result of the ACA, standard care will be covered first, such as contraception and immunizations, but, in order to make up for those covered expenditures, co-insurance may be required for catastrophic illness such as cancer, said Dr. Gottlieb.

When asked how the ACA is affecting Roswell Park Cancer Institute, Ms. Germain explained that with the shift in site of care, high-cost academic facilities outside of major community health systems are left on the sidelines without Accountable Care Organization (ACO) affiliation. For example, patients with cancer will oftentimes see ACO-affiliated general practitioners as well as have frequent community hospital and emergency room visits during the course of their treatment—especially as they live longer with their diseases. In addition, for some of the more common tumor types, patients may be denied access to academic facilities like Roswell Park Cancer Institute because there are other more cost effective options in the community. The outcome, according to Ms. Germain, is that patients are dissuaded from seeking best-in-class care, or even second opinions.

The situation is especially risky for patients with rare cancers, Mr. Beckert concurred, “Sarcoma patients’ outcomes are better if they go to a sarcoma center.” He continued, specialty facilities are the most expensive facilities and, therefore, they may not be included in health insurance exchanges. Mr. Beckert added that the best case scenario today is that a patient is able to obtain a second opinion from a specialist

or an out-of-network referral, and trust the two providers to collaborate on best treatment to be administered at a community center.

Dr. Goodman asked Mr. Greene to describe how a patient navigates a system riddled with uncertainties. Mr. Greene described that, although he was very fortunate to have excellent employer-provided health insurance that covered his treatment, his wife and full-time caregiver was “completely overwhelmed” with the amount of administrative work that is necessary to maintain a sense of order when a loved one is going through cancer treatment. “I don’t know how people would do it if they were outside a place like San Francisco or Seattle or where some of these great treatment centers are,” he said. “I don’t know how they’d do it if they didn’t have a decent amount of money.”

As a follow up, Ms. Dentzer was asked by Dr. Goodman to describe where the American health care system is from a systems standpoint, to which she replied, “The question is, how do we achieve [better value]?” Ms. Dentzer explained that the reform demands that the industry reevaluate where dollars are being spent and where patients are seeing value. She cited that as much as one-third of money spent on cancer care is wasted on treatment such as end-of-life chemotherapy where patients experience no value. Other panelists agreed, explaining that, exclusive of ACO affiliation or payment method, electronic health record (EHR) optimization and advanced planning are essential. The earlier a patient makes a decision about hospice and the less physicians prescribe chemotherapy in the last 14 days of life, the more dramatically the cost of care will drop and quality of life of patients will increase, said the panel. In addition, noted the panel, EHR optimization is key. Health care data must be discoverable and extractable, said Ms. Germain.

Dr. Goodman closed out the first panel by asking, “What is the single greatest challenge or threat to patient access to cancer care?” The panel responded with a variety of answers, including budget allocation, transition time between payment models, and government mandates. Mr. Greene responded by challenging attendees to bring together the technology and medical fields to provide a technology platform and foundation that will change the game. “I feel like a challenge is bringing people together to do bigger things,” he said.

### **Addressing Patient Needs Across the Care Continuum**

Distress management, advanced planning, and patient empowerment were the key topics addressed during the second roundtable, Addressing Patient Needs Across the Care Continuum, which included Barbara L. Anderson, PhD, clinical psychologist and Professor of Psychology, [The Ohio State University](#); Loreen Brown, MSW, Senior Vice President of Commercial Consulting, Xcenda; Joanne Buzaglo, PhD, Vice President of Research & Training, Cancer Support Community Research and Training Institute; Bruce Gould, MD, Medical Director and President, Northwest Georgia Oncology Centers, and Chair, Medical Home Steering Committee, Community Oncology Alliance; Stephen Edge, MD, Medical Director – Breast Center and Chief of Breast Surgery, [Roswell Park Cancer Institute](#); and Thomas Smith, MD, Professor of Oncology, [The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins](#), and Harry J. Duffey Family Professor of Palliative Medicine and Director of Palliative Medicine, Johns Hopkins Medical Institutions.

Dr. Goodman opened the panel with a discussion about the initial affects of a cancer diagnosis on a patient. The panel unanimously declared that such diagnoses leave a patient overwhelmed with anxiety, followed by confusion; however, the panel members discussed distress management and planning resources that have been developed to address the needs of people with cancer including standardized testing and in-patient self-evaluation techniques.

When asked by Dr. Goodman about cognitive ability in patients after a cancer diagnosis, Dr. Anderson said that upon learning that they have cancer, many patients don't recall their initial conversations with their physicians. In the diagnosis phase, patients are in a crisis and they require comprehensive crisis management, she said.

"Patients who have cancer are hit by a tidal wave and they're under water," said Dr. Edge. "Surgery is not a treatment for fear...Our job is to somehow help them back away from the tidal wave," he said. Further, he explained the pivotal role that oncologists and oncology nurses play in not only the patient's physical treatment, but in recognizing the need for psychological support, as well.

Following up, Dr. Goodman asked what can be done to bridge the gap with patient recall being so low. To combat the uncertainty that arises with diagnosis, Dr. Gould stressed the importance of a comprehensive doctor-family meeting. During such a meeting, he said, the patient and his or her family have the necessary time to provide a good family history and to talk about treatment. He also emphasized the importance of a follow-up meeting to discuss any lingering questions just prior to commencing treatment.

Dr. Smith added that documenting such conversations is critical. All answers to such questions should be recorded, filed, and shared with all treating physicians, he said. In addition, he said that he writes the most important facts for the patient on one sheet of paper that they keep and reference throughout treatment; information included are: diagnosis, stage, where the cancer has spread, the goal of treatment (remission, cures, etc.), treatment, side effects, and when to call the oncologist or go to the emergency room. By breaking down the plan for the patient, they are more confident in their ability to manage their state, said Dr. Smith. He added that if a doctor and a patient and their family sit down to have a conversation on the prognosis, patients are three times less likely to be depressed—and so are their caregivers.<sup>1</sup> "Lowering uncertainty lowers chances of stress."

For terminal patients, according to Dr. Gould, it's better to be upfront and honest: "People would rather know bad news than no news at all. Well informed patients and their caregivers make [oncologists'] jobs easier and we can be better partners."

---

<sup>1</sup> JAMA. 2008 Oct 8;300(14):1665-73. doi: 10.1001/jama.300.14.1665.

Patient advocacy organizations are also on the forefront of patient preparation. The Cancer Support Community instituted a model in which counselors meet with patients, either in person or on the phone, following diagnosis but prior to meeting with their oncologist, during which they systematically go through all patient questions and concerns. According to Ms. Buzaglo, this straightforward discussion prior to meeting with the oncologist significantly lowers patient distress levels and boosts confidence levels, thereby empowering patients and their families to take a more active role in their initial treatment discussions.

Once treatment is initiated and initial uncertainties are addressed, according to Dr. Anderson, patients with adequate economic resources and strong familial support systems report significant decreases in distress, yet about 20 percent of patients hold significant stress levels that begin to evolve into early stages of depression.<sup>2</sup> In those cases, she added, best practices are being initiated in treatment facilities to ensure that patients are consistently monitored.

According to the panel, physicians and treatment centers use various methods to measure patients' distress level. A common tool today is the National Institute of Mental Health (NIMH) Center for Epidemiologic Studies Depression Scale (CES-D) in which patients answer 20 standardized questions about their feelings and behaviors. Another method being used in treatment facilities is the Distress Thermometer—a symbolic representation of a patients' mood on a day-to-day basis that family and caregivers are able to adjust. The physical representation of emotional state allows hospital staff and caregivers to adjust their care accordingly and offer additional support if needed.

Probing further into the economic impacts of cancer care, Dr. Goodman lamented that with the cost of chemotherapy treatments approaching 10 thousand dollars per month, how does the cost of care affect patient distress and decision about treatment? With the potential for hundreds of thousands of dollars in bills, patients feel defeated, said Dr. Edge. He explained that, like physicians at other NCCN Member Institutions, he and his colleagues work off of best-in-class oncology treatment guidelines that have been consistently reviewed and updated for 15 years; however, price is not a consideration in the guidelines. It's the oncologist's responsibility, he said, to discern if the patient is distressed about payments and lead them in the right direction. Economic counselors are on staff or, if necessary, doctors can ultimately adjust treatment accordingly, depending on prognosis.

Dr. Buzaglo added that only one-third of patients that qualify for co-pay assistance actually access it. Patients are completely unprepared to deal with the management of the financial end of cancer, she said. "We need to be equipped to give education and resources to patients who indicate that they have economic concerns."

Ms. Brown agreed, stating that, along with economic counseling, educational materials are essential for patients and their caregivers to make qualified decisions about their treatment going forward. With the technology that is available today, she said, the industry needs to determine the best way to make support materials—both for distress and financial concerns—available to patients.

---

<sup>2</sup> Maunsell, E., et al, (1992). *Cancer*, 70, 120-125.

Dr. Goodman then asked how the panelists manage caregiver stress along with patient stress. Caregiver distress is not a new area of interest in oncology; however, as Drs. Buzaglo and Anderson explained, past studies focused on the impact of caregiver stress on the patient—not the long-term effects on the caregiver. Dr. Anderson added that many studies have been conducted on long-term caregivers for patients with Alzheimer’s disease, and they show that caregivers have better outcomes when they are able to find resources to help navigate the health care system, have a plan for payment, and are able to identify sources of social support.

Panelists broached the topic of end-of-life cancer care, acknowledging that there needs to be open discussion at pivotal points of treatment to reassess the patient’s goals and, in turn, decide if the treatment is still on course to meet their needs. Dr. Smith said that palliative care conversations should involve the treating oncologist, in order to better manage pain and reduce stress and distress. He also noted that palliative care can improve outcomes for both the patient and caregiver, as opposed to patients who received treatment in the last two weeks of life: “Hospice care should be involved when the patient has three to six months to live.” Dr. Smith added that studies have shown that if hospice care is involved, patients’ spouses experience good survival rates, with spouses still living at one and two years after the patient is deceased.<sup>3</sup>

According to the panel, a key factor in improving patient care is empowering the patient and their caregiver to play an active role in their treatment. The panelists urged that patient distress must be a primary concern and the creation of new tools and resources is necessary. However, to do so, noted the panel, studies must be conducted to assess outcomes of patients with and without distress counseling and active palliative care planning.

“I would like to see a better understanding of how people gather and use information, when they gather and use information, and how we can best deliver it...medical homes are great; computers and software and iPads are great; but, I don’t think that we really know how to make things available to people at the right time,” said Dr. Edge.

### **Survivorship – What Happens After Cancer Treatment?**

Patient survivorship and the unique challenges faced by patients and their physicians as they are transitioned out of active cancer treatment were the key topics of the third panel, which included Dr. Buzaglo; Lidia Schapira, MD, Assistant Professor and medical oncologist, [Massachusetts General Hospital & Harvard Medical Center](#); Samuel Silver, MD, PhD, Assistant Dean for Research and Professor of Internal Medicine, [University of Michigan Comprehensive Cancer Center](#); Ms. Tauscher; and Susan Tofani, Director of Payer and Network Relations, Oncology Management Services.

---

<sup>3</sup> Christakis, et al, Soc Sci Med. Aug;57(3):465-75, 2003.

Dr. Goodman opened the third panel with a discussion of ‘survivorship’ as a new concept in oncology. Dr. Buzaglo reflected on the concept of survivorship and questions frequently asked: First, there is the term itself. What makes a survivor: Diagnosis? End of treatment? Five years in remission? She further indicated that some patients never consider themselves survivors.

Dr. Goodman then asked Dr. Silver when, in his career, the concept of survivorship arose. In the last 10 years, the number of survivors has increased dramatically and today there are more than 12 million survivors in the United States and about 50 percent of them have been survivors for more than five years,<sup>4</sup> said Dr. Silver. Because cancer survivors are living longer, patients and their physicians are faced with a new set of problems, including induction of disease as a result of cancer treatment and complications from onset of other comorbidities.

According to Dr. Schapira, at Massachusetts General Hospital Cancer Center the concept of survivorship is dealt with upfront during the patient’s first meeting with their oncologist. It is important to look at the patient as an equal partner and learn what they want their survivorship to look like, she said.

Survivorship means different things to different patients, according to the panelists. In most cases, patients want to return to a relatively normal life that resembles their life before cancer, they said. In some cases, however, special considerations need to be made when considering treatment, such as maintaining fertility or sexual function. The panel agreed that, no matter what a patient’s idea of “survival” looks like, it is essential that the doctor and patient be on the same page. They concluded that it’s important for the doctor to be honest about prognosis and, as discussed in the second panel, plan accordingly for palliative care if necessary.

Ms. Tauscher shared that she handled her cancer treatment as a business plan—envisioning her survivorship and planning out the steps ahead that would ultimately take her to that point. “The psycho-management of cancer is very important,” she said. “I had to form in my head what my goals were and from the very beginning, my decision was to maximize my chance to have an optimum quality of life...If you don’t have a goal, you’ll go bumping all over the place.”

Much like the goals that Ms. Tauscher created for herself, doctors and patients must work together to determine a survivorship care plan, Dr. Schapira explained. Developed as a result of pediatric cancer survivors who inevitably outgrew their pediatricians, the survivorship care plan is an outline of past diagnoses and treatment, and reactions, as well as future treatment and testing protocols and milestones that patients take with them after treatment. Transitioning back to more routine care can be challenging for patients, and these plans help the survivor receive better medical treatment, said Dr. Schapira.

---

<sup>4</sup> Chubak et al, J Oncology Practice 8:184-189, 2012.

Ms. Tofani agreed, stating that, from a medical home perspective, many primary care patients who have been treated for cancer in the past are moving into medical homes and they are very likely to follow a survivorship plan.

Despite its importance, said Dr. Silver, studies indicate that less than 15 percent of patients said that they had seen a survivorship plan—treatment records were provided, but not future plans.<sup>5</sup> According to Dr. Silver, the major challenge for oncologists is that there is still a lack of evidence: “I treat with new chemotherapy every week, and we don’t know what the long-term side effects are.”

An additional hurdle, noted by Dr. Schapira, is when patients move away from their oncologists’ practicing area. To ensure that patients continue to receive optimal treatment, oncologists must collaborate with patients and their new treating oncologists, she said. Dr. Schapira shared the example that, when patients leave her practice, she counsels them to make sure they understand their plan, and then works with them to find a new doctor. “I make sure that they have everything that they need. I transfer the care to someone who is also an expert, and I make sure that she has an appointment,” said Dr. Schapira.

As stated by Dr. Buzaglo, the oncologist must make sure that a patient, or their caregiver, is well-versed in their treatment history as well as their plan. Ms. Tauscher added that her survivorship plan was a constant conversation and she insisted that her entire care team—her oncologist, surgical oncologist, and primary care physician understood her wishes. “I felt that I had graduated to survivorship when I went back to my primary care physician,” she said.

Dr. Goodman asked the panel to describe if and how they use survivorship care plans. For Oncology Management Services, a survivorship plan is just one element of a much larger system. A patient’s doctors are involved in advanced communication regarding a patient, and when a patient calls with a question or symptom it is recorded and the physicians are able to reach into the data and learn their patient’s history, said Ms. Tofani. From there, she added, the physician can evaluate occurrence and reevaluate treatment if necessary.

As Dr. Buzaglo noted, studies are currently underway to evaluate the social and emotional implications of surviving cancer. At the Cancer Support Community, researchers are looking at patients who are five years out of treatment. We are finding that patients are interested in information on nutrition and exercise, said Dr. Buzaglo. She went on to explain that inquiries about the future show that the patient understands that they have a chronic condition and they are looking toward the future. Further, practicing proper nutrition and exercising are ways in which a patient can take responsibility for their health after experiencing lack of control during cancer.

Dr. Goodman closed the final panel by asking, what is the most important thing that physicians can do to close the gap in survivorship? The panel answered unanimously: use research and technology to make resources and information more available to patients.

---

<sup>5</sup> Merport et al, Support Care Cancer 20:1579-1583, 2012.

"Patients need to be better prepared with good questions to ask," said Dr. Schapira. "Physicians, nurse practitioners, and physician assistants need to help each other so that the problem may be national and the solution may be regional...so that in every community those who have knowledge of caring for cancer patients can educate those who don't."

### **About the NCCN Oncology Policy Program**

The NCCN Oncology Policy Program was initiated in 2009 to allow opportunities for discussion among oncology stakeholders to address relevant health policy concerns. The NCCN Oncology Policy Program has convened Policy Summits in areas such as comparative effectiveness research (CER), risk evaluation and mitigation strategies (REMS), patient advocacy, off-label drug use and compendia, biosimilars and molecular testing.

During 2012, NCCN continued this initiative with invitation-only summits focused on current policy issues. The first two summits of 2012 focused on the use of guidelines and pathways and data needs in oncology. The third summit of the year focused on patient advocacy and access to care.

### **Quick Links**

[NCCN Guidelines®](#) - [FREE NCCN Compendium®](#) [NCCN Biomarkers Compendium™](#) [NCCN Templates®](#)  
[Educational Events](#) [CME/CE Programs](#) [NCCN Guidelines for Patients®](#)