

On Friday, November 22, 2013, the National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 23 of the world's leading cancer centers dedicated to improving the quality, efficiency, and effectiveness of care provided to patients with cancer, convened the *NCCN Patient Advocacy Summit: Health Care Reform in 2013 and Beyond*. 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 discuss the implementation of certain aspects of the Affordable Care Act (ACA) and their effects on patients with cancer and their caregivers. The Summit consisted of a patient experience presentation, an expert overview of the current state of health care reform, and three roundtable discussions, moderated by Clifford Goodman, PhD, The Lewin Group.

Robert W. Carlson, MD, Chief Executive Officer, NCCN, welcomed attendees and introduced Tracie Cone, cancer survivor, journalist for *The Associated Press*, and author of the blog, *Tracie Fights Back: The Breast Cancer Notebook*.

Ms. Cone, a three-year breast cancer survivor described her own experience with patient advocacy beginning not with her own cancer diagnosis, but as a caregiver for her mother after she suffered a serious health issue. In her endeavor to ensure her mother's best interests and care, she learned valuable lessons that would serve her well very soon thereafter—specifically, the ability to simply ask questions of those responsible for her care.

"My experience as a journalist has shown me that experts are happy, even flattered, to be asked to share their knowledge," she said. "You just have to ask."

Not long after her mother's health crisis was resolved, Ms. Cone prepared for her annual physical, which was cut short when her physician found a lump in her breast; afraid and wanting answers as quickly as possible, Ms. Cone decided that she was not willing to wait to schedule subsequent diagnostic appointments as was protocol, and worked with her doctor to schedule imaging and a biopsy that same day.

Ms. Cone again advocated for herself when she was not pleased with her original oncologist. In journalistic fashion, after more research, Ms. Cone found Dr. Robert Carlson at [Stanford Cancer Institute](#). She reached out to schedule an appointment; originally, Ms. Cone was told that the next available was not for six weeks, but after working with the office and asking for any replacement times available, her persistence paid off and Ms. Cone had the opportunity to meet with Dr. Carlson sooner.

"For a fleeting second, I felt like I was going to be okay," she explained.

Because she asked, she said, she was able to take what could have been a six-to-eight week process of diagnosis to initiating treatment and cut it down to only three weeks.

"Instead of fitting me into a random appointment convenient for the system, people helped me out because I asked," she explained. "Fighting for one's life is no time to be timid."

Now a three-year breast cancer survivor, Ms. Cone explains that the most valuable insight she gained from her experience with cancer is that differences in care do exist and patients need to find the best care for their individual needs.

Ms. Cone culminated her remarks with advice to the audience: "Be diligent and don't take 'no' for an answer, and ask people for help. Just ask."

The Current State of Health Care Reform

Following Ms. Cone's opening remarks, Susan Dentzer, Senior Policy Advisor, The Robert Wood Johnson Foundation, delivered "The Current State of Health Care Reform."

The October 1, 2013 launch of Healthcare.gov—the online enrollment system for the new federal health care exchange—was plagued by technical issues that left enrollees unable to complete enrollment or even access the site. According to Ms. Dentzer, the media surrounding these issues drowned the overall potentially positive effect that the ACA will have on the American health care system.

"[The ACA] is not perfect, but it is taking a huge step forward," she said.

In order to ensure the success of the ACA, Ms. Dentzer explained three necessary steps: better health, better health care, and lower cost.

Better health

In America, Ms. Dentzer explained, people have access to many things that ruin their health, and, for many years, Americans have been dying at younger ages than other high-income countries.ⁱ

In fact, she explained, the World Cancer Research fund estimates that one-third to one-half of all cancer cases in the United States are related to obesity, physical inactivity, and poor nutrition.ⁱⁱ

New requirements under the ACA on tax-exempt hospitals and health systems will help ensure that these issues begin to be resolved, said Ms. Dentzer. For instance, to retain tax-exempt status, organizations must conduct community health needs assessments at least once every three years to identify the needs of the demographics they serve, as well as adopt an implementation strategy for addressing those needs. If these provisions fail to be met, hospitals will be penalized.

Another provision enacted with the ACA was the Prevention and Public Health Fund, which originally sanctioned more than \$18 billion dedicated to public health needs. However, Ms. Dentzer explained, legislation passed in 2012 cut \$6 billion from the Fund in order to offset a scheduled cut to Medicare physician payments. Since that time, she said, the budget has been cut further to support various activities, including the implementation of the Health Insurance Exchange. According to Ms. Dentzer, in order for the ACA to be successful, legislation cannot continue to reallocate the budget intended for support of public health initiatives.

At this point, said Ms. Dentzer, there is good news about overall health as child obesity rates are falling in 19 states. However, she said, adult obesity rates have not seen the same decline with 66 percent of U.S. adults overweight or obese, and, if this trend continues, 80 percent of adults will be obese by 2030.ⁱⁱⁱ

Better health care

With the implementation of the ACA, certain insurance reforms took effect almost immediately. For instance, explained Ms. Dentzer, the preexisting conditions program made those uninsured six months or more with preexisting conditions—including cancer—eligible for insurance coverage; and health insurers were barred from denying coverage when people became sick with a major illness. She also explained, the roll-out of Medicare Part D was a step forward in closing the coverage gap in the United States.

According to Ms. Dentzer, in 2014, further reform will lift restrictions for preexisting conditions for all—ensuring access to coverage for the more than 14 million cancer survivors in the United States. With the end of annual and lifetime limits, she said, people with cancer and survivors will no longer have to delay treatment once they have hit their out-of-pocket maximums.

Finally, with insurance premiums for tobacco users one-and-a-half times the cost for non-users, cessation may begin to become evident in higher-risk populations, she explained.

In order to ensure better health care, Ms. Dentzer said, the federal exchanges will cover preventative care, in many cases, with no out-of-pocket costs. These include, but are not limited to, mammography screenings for women over the age of 40 every one to two years, breast cancer genetic test counseling for women at higher risk for developing the disease, human papillomavirus (HPV) immunizations, and cervical cancer screening for sexually active teens and women.

The ACA also mandates that all health plans sold to individuals and small businesses on the federal and state exchanges and/or through Medicaid expansion must cover a minimum set of 10 areas—called Essential Health Benefits—including chronic disease management, said Ms. Dentzer.

The Essential Health Benefits, according to U.S. Health and Human Services, include ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventative and wellness services; chronic disease management; and pediatric services, including oral and vision care.

In addition, she said, plans must cover the greater of one drug in each U.S. drug class, or the same number of drugs in each category and class, as a benchmark plan. Moreover, all plans must have an exceptions process to ensure that enrollees have access to clinically important drugs, regardless of the plan's formulary.

Of particular interest to people with cancer or those at high-risk for the disease, she said, is the mandate that, on the federal and state exchanges, plans must cover routine care costs for U.S. Food and Drug Administration (FDA)-approved clinical trials for cancer or other life-threatening conditions and, moreover, plans cannot drop or limit coverage for individuals participating in clinical trials.

One must take into consideration, however, the variance in coverage that exists at the state level, Ms. Dentzer explained. A challenge to providing better health care in this country, she said, lies in the fact that the states with the highest ratio of people living at or below the poverty level are the states that have neither expanded Medicaid, nor implemented a state-based or state-partnership insurance base. Many of these states—the “stroke belt” located in the southeastern corridor of the U.S.—also show the highest incidence of obesity in the country, making their inhabitants those most in need of better access to health care and preventative measures and screening, Ms. Dentzer said.

Lower cost

Ms. Dentzer explained that, as part of the ACA, the National Quality Strategy (NQS) was established^{iv}. The six goals of the NQS are:

- Making care safer by reducing harm caused in the delivery of care,
- Ensuring that each person and family is engaged as partners in their care,
- Promoting effective communication and coordination of care,
- Promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease,
- Working with communities to promote wide use of best practices to enable healthy living, and
- Making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models.

“The least understood aspect of the ACA is the model to get more out of our health care dollars,” said Ms. Dentzer. She elucidated that the nation must give way to a new model of rewarding health care outcomes and population health, as well as lower cost while improving the patient experience.

Ms. Dentzer explained that, in oncology, health care costs are rising at a faster rate than in any other disease type, with a projected 39-percent increase from 2010 to 2020. And, she said, the fee-for-service model only encourages expensive, over-treatment with non-evidence-based medicine.

A shift toward performance-based innovations in health care is imperative, explained Ms. Dentzer, including, but limited to, patient-centered medical homes, accountable care organizations (ACOs), comprehensive primary care initiatives, and bundled payments for care initiatives, such as episode-based payment for cancer care.

Ms. Dentzer closed her overview with a statement reminding the audience of the original purpose of the ACA: “All across the country today, there are people signing people up for health coverage...All across America there are dedicated cancer providers and other trying to innovate to provide better quality of cancer care. And, all across America, in 2014, there will be people who will never have to worry again about having their insurance coverage taken away from them, about exhausting their benefits in a year, or even over a lifetime.”

Defining Essential Health Benefits

The first roundtable of the Summit focused on the design and implementation of Essential Health Benefits that are a mandatory entity of the ACA. The panelists participating in the first panel included, Dana Dzwonkowski, American Cancer Society Cancer Action Network (ACSCAN); Greg Gierer, America’s Health Insurance Plans (AHIP); Scott Gottlieb, MD, American Enterprise Institute for Public Policy; Linda House, Cancer Support Community; and Meg Jones, Washington State Office of the Insurance Commissioner, who joined via teleconference.

Dr. Goodman opened the discussion by discussing the Essential Health Benefits as defined by the ACA. These benefits are mandated as essential in order to ensure comprehensive medical care for those enrolled in both individual and small group markets, he said.

When asked why the Essential Health Benefits were important to their organizations and the patients with whom they interact, the panelists responded with both praise and concern. The Essential Health Benefits laid out by the ACA, the panel agreed, have the potential to be an important step forward in ensuring that all patients are given access to comprehensive care that, within the criteria of the ACA, will be more affordable.

Concerns, however, lie in the breadth of coverage in each area.

Dr. Gottlieb, Resident Fellow at the American Enterprise Institute for Public Policy Research and practicing physician, added that, from a policy standpoint, he is concerned about how the essential benefits will compromise the competitive structures within the insurance marketplaces; and, as a practicing physician, he awaits how these benefits will affect those patients who, today, have a very hard time accessing outpatient specialty care.

The panel agreed that instituting measures that theoretically demand comprehensive patient care is, in itself, a positive notion. For instance, according to Ms. Dzwonkowski, Health Expert, Health Care Access Issues at ACSCAN, making coverage of cancer screening and prescription drugs a mandatory element of Essential Health Benefits is a “huge win” in the prevention and treatment of cancer. However, she explained, tactical implementation of the mandate, including the medical coding, need to be enhanced. For instance, she explained, a patient who undergoes a preventative colonoscopy during which they find a polyp will, from a medical coding standpoint, undergo a diagnostic colonoscopy—not preventative. Therefore, they will experience cost-sharing that they were not expecting.

Ms. House, who is the Executive Vice President of External Affairs at Cancer Support Community, explained that the patients who contact her organization—both in person or on-line—are seeking psycho-social support for which they do not have access to otherwise. Quality and breadth of care is a legitimate concern, as coverage of psycho-social treatment under the Essential Health Benefits, implies a clinical diagnosis, she said.

“When you’re talking to people with cancer and the people that we see when we do early distress screening—and we know that there is a financial and physiological benefit to early distress screening intervention—these are the people that may not tip the scale into a clinical diagnosis of depression,” said Ms. House. However, she explained, they would still benefit from quality, psycho-social treatment.

Considering the general risk population, Dr. Goodman asked Ms. Dzwonkowski: the prevention screening protocol set by the USPSTF may be efficient, but what about those within the high-risk population?

Ms. Dzwonkowski replied, acknowledging that the USPSTF “A” and “B” recommendations are the criteria being included in the ACA guidelines for preventative medicine. And, she said, the high-risk population for colon cancer and breast cancer, for example—those who have a family history and have not had a gene mutation confirmed—will not have access to the cost-free screenings at the federal level if they are screened before the age that is specified in the recommendations.

She went on to explain that, at the state level, the networks have the authority to further regulate plans and extend the essential screening benefit to those at high risk.

“A lot of states have [extended the screening benefits] for colorectal cancer, where they’ve specified in state statute a regulation that those at high risk, meaning certain conditions, are also mandated to have coverage for colorectal screening and that no cost share could also be extended,” she said.

After discussing the quality of the Essential Health Benefits, Dr. Goodman turned to the panel to inquire about feasibility.

Ms. Jones, Public Policy and Rules Manager for the Office of Insurance Commissioner in Washington State, expanded upon the subject, noting that, in her position, she and her colleagues have consistent standards that they enforce against issuers who violate the essential benefits laws. Working in an area with mostly rural districts and one urban corridor that houses a majority of the specialty care, the state of Washington has mechanisms in place to ensure that patients have ready access to medically necessary specialty care outside of their networks—no matter how “narrow” those networks may be. She noted, however, that the standard language around such regulations is still being defined.

Networks are not given a lot of leeway, said Dr. Gottlieb, as far as how to lower their costs. Therefore, he said, networks that traditionally do not have low-cost networks are contracting with very narrow—not far-reaching—networks instead. With that, larger networks, like United Healthcare, are cutting what they reimburse because they, too, have to develop low-cost networks, and that is the only way they are permitted to manage cost, he explained. By controlling the number of medical facilities a patient can visit, the networks control cost. Whether these narrow markets will be able to maintain the essential needs of every patient is doubtful, he said.

Dr. Gottlieb then called for action from the audience, saying, “Anything that’s going to pressure the plans to point out some of the inadequacies in the law or how it disadvantages certain patients probably is going to get some reception on Capitol Hill right now across the aisle.”

“[Patients] are trying to negotiate which plan they want,” said Dr. Goodman. “They may not know their own health status...They may not know the right questions to ask. How do you help them out, and particularly cancer patients?”

Mr. Gierer, Vice President for Policy at AHIP, responded, “It’s a new marketplace and there’s going to be bumps in the road as this goes further.” He explained that the members in his network are eager to compete and it is reflected in the choice of plans available in the exchanges.

“On average, people have to choose from 50 different qualified health plans in a state exchange, offered by eight different carriers,” he said, noting that the many options for deductible levels, cost-sharing requirements and network designs is a testament to dedication that the carriers have to patients on the exchange.

“We have a shared goal of making sure that everyone who needs coverage gets it, and we feel confident that these issues will be addressed,” he said.

Ms. House added that, to help patients navigate their options, there are now innovative, easy-to-use, free tools available, such as the Cancer Insurance Checklist, developed collaboratively by 18 patient advocacy organizations, which outline important considerations when entering the exchanges and choosing the optimum plan for one’s cancer risk.

Dr. Goodman closed the discussion by asking the panel, “If you look at [the rollout] three to five years from now, what will have happened to an Essential Health Benefits package in the marketplace? Do you think these become expanded, contracted, or diversified?”

A majority of the panel agreed that, for various reasons, including political pressures and the difficulty in passing mandates at both the federal and state level, the Essential Health Benefits package will look relatively similar to how it is defined now.

Cost, noted Dr. Gottlieb, is a major concern because, as networks are forced to keep costs down, the networks will become narrower, limiting care options.

Ms. House noted, “I hope that it improves to be focused more on quality over cost.”

How Patients are Accessing Insurance

The second roundtable of the Summit focused on how patients access insurance in the new marketplace. The panel included Anna Filipic, Enroll America; Rachel Klein, Families USA; Cheryl Larson, Midwest Business Group on Health; Michael Taylor, AON Hewitt Health and Benefits; and David Woodmansee, ACSCAN.

Dr. Goodman opened the discussion by asking the panelists to explain why it is important to consider where and how patients are accessing information, as well as how Americans are going to emerge from the initial “mess” of the rollout of Healthcare.gov in October 2013.

The panelists agreed that, across the board, patient advocates, navigators, and private employers must be well-informed about the ACA, its implementation and timeline, and all ongoing updates to the programs. With the widespread, heavily opinionated media coverage of the health care reform rollout, the panel explained, patients are informed—both well-informed and ill-informed—and they are asking a lot of questions.

With the looming deadline for 2014 enrollment, explained Ms. Filipic, President, Enroll America, patients are, for the first time, learning how the ACA is going to affect them.

“We all do need to feel the fierce urgency of now,” she said. “We should feel that we have less time than we thought we would.”

Ms. Larson, Vice President of the Midwest Business Group, explained that, throughout the entire roll-out process, human relations and benefits professionals have gone a good job at leaving their political opinions at the door.

“They’ve said, ‘It is what it is;’ they’ve complied with all of the rules that they’ve had over the last several years. One of the biggest challenges that they have faced is communicating the summary of benefits coverage to employees,” said Ms. Larson.

She went on to explain that the communications challenges are evident for any self-insured employer, whether they are small, medium, or large. However, she noted—with agreement from Mr. Taylor—that many private employers are continuing to offer coverage to their employees—waiting to see what transpires in the next two or three years before they ultimately decide whether to stop offering an insurance option.

Mr. Taylor, Senior Vice President, AON Hewitt Health and Benefits, explained that there is a small population who—at this point and time—would be better off in the exchange, considering salary and the Medicaid plan and subsidy that one would receive. AON Hewitt, he said, has built models for employers to use in educating themselves and their employee population who, today, could benefit from the exchanges, rather than employer benefits.

Employers of all sizes in all markets are seriously considering the implications of the rollout and weighing their options, he continued, in order to reduce their health care volatility.

Mr. Woodmansee, Associate Director, ACSCAN, explained that there are definitely frustrations associated with the ACA, but, from a cancer perspective, it is a step in the right direction, especially concerning the elimination of preexisting conditions.

“Cancer patients have been very enthusiastic about wanting to get signed up because they’re going to get insurance for the first time, many of them, since they’ve had cancer.”

However, he noted, at the same time, there are issues that cancer patients will face in the future—especially those with rare cancers—when considering access to specialists, as well as drug coverage.

Dr. Goodman asked the panel to discuss the differences in perspective from private business and the public exchange. Mr. Taylor explained that, with the private sector, businesses know the demographics of their candidates. With the public exchange, the panelists agreed that there is no way to determine how many people will enroll, their health status, or risk factors.

Mr. Woodmansee noted that, with one million people being diagnosed with cancer each year in the United States, people who enroll today without cancer can be diagnosed with cancer next year.

“So unknown risk is in the pipeline then?” asked Dr. Goodman.

“Absolutely,” said Mr. Woodmansee. He noted that concern then lies in the ensuring that these individuals have the proper access they need after diagnosis.

Dr. Goodman asked the panel to consider the insurance terminations that were set forth in late 2013: “Is this a long-standing problem or a short-term one?”

Ms. Klein said that, without downplaying the small population who received termination notices, the media portrayed the terminations as a much larger problem than it is.

“People are getting termination notices and are confused that they’re going to be losing something that’s the known and needing to figure out the unknown,” she said. “That’s a very scary proposition for a lot of people.”

Ms. Klein explained that a vast majority of people receiving the notices are losing sub-standard plans and that they are now eligible for Medicaid or for subsidy in the marketplace; they are actually able to purchase better insurance than they had, and they will get help with that, she said. Ms. Klein and Ms. Filipic both noted that the population who will have to pay out-of-pocket to reenroll in better insurance is less than one percent of the non-elderly population.

Dr. Goodman then asked Ms. Larson and Mr. Taylor how the delay in the employer mandate is affecting employers.

Ms. Larson said that, in her experience, the employers are not changing anything with the mandate. They are using this time to evaluate the situation. With employers who have already spent between \$5 million and \$25 million just in complying with the ACA, rash decisions are not in their best interest. Even organizations that fully-fund coverage will be looking at the marketplaces, she said.

“They’ve made significant investments in time and resources, and they’re just going to use the next year to see what else they need to learn from the process,” said Ms. Larson.

Mr. Taylor concurred and added that what the private employers are planning for now is the federal excise tax slated for 2018, which will penalize employers with a 40-percent tax on the value of high-end health insurance benefits exceeding \$10,200 for an individual and \$27,500 for family coverage. What this does, he explained, is force employers to lower the quality of the coverage they offer to their employees to avoid the tax, or force their employees onto the marketplace.

In closing, Dr. Goodman asked the panel to identify one population who, when looking back in year 2016, fell through the cracks.

The panel provided a variety of suggestions, including the undocumented; those who were in need of insurance, but did not enroll because they wanted to ensure their family's financial security; those who wind up with such a high out-of-pocket cost with their employer that then enter the exchange without the prevention services they need; and younger individuals who leave themselves out by choice.

Dr. Woodmansee responded, "Taking the undocumented out of the equation, by far the biggest losers are those in states that are not expanding Medicaid that are less than 100 percent of the Federal Poverty Level."

Patient Advocate Perspectives in Health Care Reform

The final panel of the day explored the pros and cons of health care reform in the United States from a patient advocacy perspective and included Carolyn "Bo" Aldige, Prevent Cancer Foundation; Alan Balch, PhD, Patient Advocate Foundation; Linda House; Liz Thompson, Lymphoma Research Foundation; and Steve Weiss, ACSCAN.

Dr. Goodman opened the discussion by asking the panelists to touch on the issues and concerns that affect the patient population they encounter on a daily basis.

Ms. House explained that education empowers patients, and having accessible tools and counselors to assist them is key in empowering patients to make informed decisions about their health care. For instance, she mentioned tools that Cancer Support Community has assisted in creating including: the Cancer Insurance Checklist; the Cancer Experience Registry, where patients share information about their disease, treatment, and outcomes; and Open to Options, a counseling service where a Cancer Support Community liaison will walk a patient through the options open to them on the marketplace and help them make the best decisions about their health care plan. Further, she explained her concern with the sustainability of patient advocacy groups as a whole, as they rely on private funding.

"What is happening is that we are left to pick up the pieces of what's going on with the patients," she said. "The insurance companies are not providing the information that patients need to make educated decisions. I really want to talk to [the insurance companies] about their ethical responsibility to ensure that they're fully informing patients about the product that they're selling to them and what the implications could be nine months down the road."

As CEO of the Lymphoma Research Foundation, Ms. Thompson described her patient base, explaining that, although "lymphoma" is a well-known cancer type, it actually includes 72 different rare cancers. The challenge that these patients face with health care reform is access to centers of excellence—especially for pathology and proper diagnosis. In addition, she said, those diagnosed with Stage IV lymphoma can live for more than 20 years after diagnosis— in and out of remission— so access to affordable, long-term, comprehensive health care is imperative.

Ms. Aldige, President and Founder of Prevent Cancer Foundation, noted that her biggest concern with the ACA is ensuring that the Prevention and Public Health Fund does not become "the nation's piggybank." In order to successfully implement the community-based health programs—such as tobacco cessation—the United States must maintain the \$18 billion budget, she said, because, in the long run, these programs can potentially prevent cancer.

Dr. Balch, Chief Executive Officer at Patient Advocate Foundation, noted that his organization is entrenched in ensuring the success of the ACA. In the past year, he said, Patient Advocate Foundation has assisted in enrolling 11,000 uninsured into the marketplace, and, since 1996, has been providing case management support for patients. In that time, he explained, the Foundation—in collaboration with other organizations such as Live**STRONG** and Susan G. Komen Foundation—has amassed large data sets from which they can pull information to support policy positions on behalf the patient population.

"As a communicator," said Mr. Weiss, Senior Director, Communications and Media Advocacy, ACSCAN, "I think the biggest concern I have is that the political debate and the intensity of it has lasted so long and is only going to continue...you just are going to have more and more people who will never accept something called 'the Affordable Care Act' or something called 'Health Care Reform,' whether it benefits them or not."

Mr. Weiss added that, with accountability on both sides, the debate of health care reform has been filled with so many overstatements and inaccuracies that the public cannot possibly have a strong understanding of what is actually happening with the ACA.

Dr. Goodman asked Ms. Aldige to describe what she believes to be the roadblocks with the ACA.

"We're doing our best to communicate through our website and through social media to everyone that they have a right to insurance and that the need to learn about what's available and what they can sign up for and what the subsidies are," she said. That aside, Ms. Aldige explained, there is a digital divide and a vast majority of uninsured still unaware of their rights.

In the business of case management, Dr. Balch said, a roadblock for patients is affordability vs. value. At this point, he said, most patients calling in are looking for information, not to enroll; however, based on the questions they are asking, the fear is that patients will choose their coverage based on what they can afford, not what the need. With that, they will most likely not have quality coverage based on their particular needs.

Dr. Goodman then asked the panel to explain what they are hearing from patients.

Ms. Aldige and Ms. Thompson both expressed their surprise and concern that patients still are not aware that, in many cases, co-pays are eliminated for preventative testing, as well as misunderstanding of the term 'preexisting condition' and what it means to an individual.

Mr. Weiss added that, until one has the experience with a major illness—cancer, in particular—they do not know to ask the questions being discussed around the panel. Further, someone with a major diagnosis, but who has always had insurance, will not understand the risks of being denied coverage for a preexisting condition.

"People are making significant trade-offs, particularly when it comes to the cost of their care," said Ms. House.

Forty percent of the patients in the Cancer Support Community Cancer Experience Registry multiple myeloma registry report foregoing social activity to pay for treatment, she said. Further, 30 percent have decreased grocery budgets, and 23 percent have depleted their bank accounts.

"So, they're having to make these huge decisions of economic trade-off, but don't have the economic information upon which to base it," said Dr. Goodman.

"I think it's a lack of transparency on the part of the providers," said Ms. Aldige. "It's the opacity of the entire health care system when it comes to cost."

When asked by an audience member about providing information to low-literacy and disabled populations, the panel agreed that this is a major issue.

Ms. House noted that, because most of the organizations providing the content are privately funded, the resources to products such tools are just not available.

Dr. Balch added that the individual who has been uninsured is most likely—generally speaking—more low-insurance literate than the average consumer who has been insured through an employer in the past who, therefore, has a better idea of the questions to ask. Further, he said, the effort must be sustained past the point of enrollment so that patients continue to understand their coverage, changes in their coverage, and how the changes affect them.

"I think virtually every aspect of the health care system has treated consumers in a passive way," said Mr. Weiss. He added that consumers have had an entirely passive relationship with their insurance. They know they get it from their employer, but do they really know what coverage they have had, he asked.

The first way for this to change, he said, is for patients to become more active in their coverage and its value. For instance, he asked, a patient has the ability to dispute charges on a hospital bill, but how many actually do?

Dr. Goodman closed the panel by asking them to consider of how state-of-the-art advocacy will have changed in the year 2020.

“As an advocacy community, rather than have duplicate services, I think we’ll also be more sophisticated in how we collaborate together and do more handoffs and transfers into our own specific areas of expertise,” said Ms. House.

A majority of the panel agreed that, in order to deliver state-of-the-art patient advocacy, the organizations must collaborate to harness technological advances in order to deliver meaningful, customized information.

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 health care reform, use of guidelines and pathways in oncology, patient advocacy, data needs in oncology, and biosimilars and molecular testing.

During 2013, NCCN continued this initiative with invitation-only summits focused on current policy issues. The first two summits of 2013 focused on measuring quality in oncology and evolving policy issues in oncology. The third summit of the year focused on patient advocacy and health care reform.

ⁱ Institute of Medicine of the National Academies, *U.S. Health in International Perspective: Shorter Lives, Poorer Health*, January 2013.

ⁱⁱ Cancer Facts and Figures 2013, American Cancer Society.

ⁱⁱⁱ Centers for Disease Control and Prevention.

^{iv} About the National Quality Strategy (NGS), <http://www.ahrq.gov/workingforquality/about.htm>, 6 December 2013.