

NCCN Patient Advocacy Summit Summary

On Thursday, September 23, 2010, the National Comprehensive Cancer Network® (NCCN®) Patient Advocacy Summit convened in Washington, D.C. at the National Press Club. This invite-only Policy Summit was attended by patient advocates, providers, employers, clinician, and industry representatives within the oncology community. These key stakeholders gathered for a day-long session to discuss the current issues that most profoundly affect patient care. The Summit featured a series of panel discussions including representatives from each sector in attendance. Each roundtable was moderated by William T. McGivney, PhD, Chief Executive Officer of NCCN.

Implementation of Health Care Reform and the Impact on Cancer Care

The first session, focusing on the implementation of health care reform and its impact on the oncology community, featured a presentation by Scott Gottlieb, MD, fellow at the American Enterprise Institute for Public Policy. A roundtable discussion followed the presentation, where Dr. Gottlieb was joined by Al Benson III, MD, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Nancy Davenport-Ennis, Patient Advocate Foundation, Pauline Lapin, MHS, Centers for Medicare and Medicaid Services (CMS), Alan Rosenberg, MD, Wellpoint, and Cara Tenenbaum, Ovarian Cancer National Alliance.

Dr. Gottlieb's presentation started with a discussion of three questions that may have the most direct impact on oncology and the treatment patients with cancer receive. The first theme addressed was consolidation among providers where hospitals or insurers are buying up providers and practices. This is occurring for several reasons – impending formation of accountable care organizations, new payment structures, long-term employment and stability for providers, and development of narrow networks by insurers. Consolidation may affect cancer care; care may be harder to come by in more rural settings and where networks are very narrow.

Dr. Gottlieb emphasized the possible importance of the new Independent Payment Advisory Board (IPAB). IPAB is the revamped MedPac, but with the authority to implement its recommendations. IPAB will cap the rate of Medicare growth that will be tied into the Consumer Price Index. IPAB will make a set of recommendations in an effort to bring Medicare spending in line with overall inflation. These recommendations will be sent to Congress and Congress will have 30 days to either come up with a competing set of recommendations that achieves the same level of savings or codify IPAB's set into law. As IPAB is currently constituted, the main focus will be on medical products. Dr. Gottlieb predicted that they will take down existing price schedules and confer broad authorities on CMS. CMS would like these broad authorities to engage in tacit reference pricing, implement least costly alternative authority, require sponsors to demonstrate the demanded higher price for their product, and better control payment for off-label drug use.

Dr. Gottlieb touched on the point that Medicare Part B may come under fire in a deficit reduction act. Changes would include reinvigorating the Competitive Acquisition Program, moving all Part B drugs into Part D, and an SGR fix. Dr. Gottlieb also commented on how the November mid-term elections may affect implementation of health care reform.

After introductions of the panel members, discussion turned to health care reform in general. Dr. McGivney questioned the panelists on their perceived highlights and lowlights of the Accountable Care Act. The panelists agreed that the insurance reforms were beneficial to patients and are probably the most agreed-upon element

of health care reform. Ms. Lapin from CMS commented that along with the excitement and anxiety at CMS surrounding health reform, there is fear as to how they will implement all the required regulations and rules. Ms. Lapin commented that she is worried about the medical community having the capacity to serve the increasing number of people that will be entering the health care system. She also highlighted that the Center for Medicare and Medicaid Innovation was created under Section 3021 to test innovative payment and service delivery models that may reduce expenditures and improve quality of care.

Dr. Rosenberg expressed some key points on health reform. WellPoint is concerned that, without an individual mandate that is now being challenged in the courts, premiums will continue to rise and increasingly fewer employers will be able to offer health insurance to their employees. Dr. Rosenberg questioned the quality of the data used to make health care decisions in the United States – he postulated that the data is not good enough to make scientific decisions and inform patients of their appropriate choices. When questioned by Dr. McGivney as to whether WellPoint will turn to greater utilization management to control costs, Dr. Rosenberg stated that because of required medical loss ratios they will not engage in greater utilization management and, instead, will turn to the construct of accountable care organizations.

Affordability of care was also an issue discussed by participants. While no solution to this problem was offered, Scott Gottlieb made an interesting comment,

“And I don’t know where we ever constructed the argument that we can’t spend 20% GDP on healthcare, 25% GDP on healthcare. I mean I’m not saying we should be, but it’s a reasonable discussion to have. The only reason it’s unaffordable is because we said we want to everything, but we don’t want to spend more than 15% GDP. Healthcare is not a bad place to spend money. After all, we’re paying it to ourselves. It’s better than shipping off money to China. I don’t understand why we don’t want to think about health care as something that we should be spending more money on, frankly.”

While health care reform has provided some needed health insurance reform, many day-to-day issues that exist in the oncology community will only become more complex and will represent a significant conundrum for the oncology community.

Major Developments in Oncology

The second session focused on the use of biomarkers in oncology. The session started with a presentation by Mark Kris, MD, Memorial Sloan-Kettering Cancer Center, and was followed by a roundtable discussion where Dr. Kris was joined by R. Kate Kelley, MD, University of California San Francisco Helen Diller Family Comprehensive Cancer Center, Stacy Lewis, Young Survival Coalition, and Pam Moffitt, North Central Cancer Treatment Group.

Dr. Kris focused on the impact of biomarkers and how they have changed the face of treatment for patients with lung cancer. In lung cancer, researchers and physicians have been able to identify subgroups of patients and greatly improve survival rates. The basic model to identify biomarkers and incorporate them includes basic research where targets and treatments are discovered, clinical research where effectiveness is proved in humans, and implementation of the findings into clinical practice. Today there is routine use of molecular characteristics to select therapies for patients with lung adenocarcinoma. He also commented that lung cancer could be a model for other cancer types.

Dr. Kris touched on challenges he sees in regards to biomarkers and personalized medicine. Challenges identified included hospital organization, design of clinical trials, resource allocation, priority identification, and stewardship of resources. Dr. Kris was especially concerned with the design of clinical trials and the need to reform clinical trials. He also highlighted the importance of having separate clinical trials for new agent development and comparative effectiveness studies.

Several key topics were discussed during the roundtable portion of this segment of the program. Discussion points included tissue and biospecimen availability, the potential, promise, and expectations that surround biomarkers, and the interplay between pathology and oncology. Pathology and its importance in the uptake of biomarkers was highlighted with emphasis on communication, adoption, and education. It was stated that pathologists will need to take a leadership role in incorporating biomarkers into their daily routine and practice. Lastly, other key issues addressed included quality of testing, and affordability and accessibility of biomarker testing for patients.

Information Needs and Resources for Patients

Information needs and resources for patients were the main topics of discussion for the third session roundtable. Participants in the roundtable included Brian Garofalo, G Consulting Services, Joan McClure, MS, NCCN, Mary Lou Smith, Research Advocacy Network, Cara Tenenbaum, Ovarian Cancer National Alliance, and Kathryn West, Amgen Oncology.

Discussion centered on what patients need to ensure they receive the best care possible with as much assistance as they want or require. Navigating the financial and reimbursement system for many patients is difficult and they need assistance. There are a number of resources available to patients, but many patients do not know how to access them. One possible solution is to have these resources available in clinicians' offices. While this may sound like a reasonable approach, many nurses and office staff are already overloaded with work and would not be able to adequately assist patients in determining which resources are available and how to access them. Clinics and practices would require dedicated staff to fully assist patients in identifying available resources.

Mr. Garofalo commented that there are great partnership opportunities available within pharmaceutical companies, but organizations must know who to approach and have the appropriate plan. Many pharmaceutical companies already support patient advocacy organizations that arm patients and caregivers with skills and tools.

How information is communicated to patients was also discussed. Electronic communication is vital to the spread of information and how patients become aware of new developments. The point was stressed that when considering electronic communication, it is important to remember that certain groups may favor different technologies such as texting or email. An additional issue discussed was the amount of information available to patients and their understanding and comprehension of it. It is vital that physicians and nurses understand and assess what their patients understand, both through office discussions and outside reading. Provided by many different sources, there is a wide array of information available to patients. Duplication of information with discrepancies may lead to patient confusion. It was suggested that collaboration was needed in the delivery of information to ensure clear information is received by patients. Patient-to-patient discussion was also highlighted as an opportunity for patients to become more informed. Patients can feel free to ask "stupid questions" and have someone that has gone through the same process tell them what they can expect.

Providing patients with information and resources will continue to be a focus of multiple stakeholders and collaboration will be needed across the spectrum to ensure accurate information and timely assistance is available to all patients.

Working Together to Improve Access to Cancer Care

The day concluded with a roundtable discussion on improving patient access to cancer care. Roundtable participants included Ken Anderson, MD, Dana-Farber/Brigham and Women's Cancer Center, Ron Finch, EdD, National Business Group on Health, Patricia Goldsmith, NCCN, Alan Rosenberg, MD, Wellpoint, Thomas P. Sellers, MPA, National Coalition for Cancer Survivorship, Dawn Stefanik, RN, Oncology Nursing Society, and Katherine Stultz, Celgene Corporation.

The first topic of discussion was the role of oncology nurses in treating patients with cancer. Oncology nurses are currently involved in far more than direct patient care. They are asked to involve themselves in insurance and other resource issues. In the case of research nurses, they provide the direct line of contact for patients enrolled in trials and are assuming the role of the ultimate patient advocate. Nurses and other providers need to be compensated by payers for the time they spend with patients going over detailed treatment plans and what resources are available to them in the community.

It is being recognized that to deliver health care today it takes a team. A single patient can have upwards of 10 interactions in order to receive their treatment on a given day. Some medical centers are using facilitators to ensure that their patients get all of the required tests and treatments for their protocol. Other offices or centers may use navigators as a constant point of contact for patients. Navigators help patients coordinate their care. Both facilitators and navigators greatly assist patients in ensuring they receive their care in a timely fashion.

A second topic of discussion was the design of oncology health care benefits. According to Ron Finch, there is a need for a structured approach to offering benefits that eliminates the chasm between the treatment world and the payer world. NCCN and the National Business Group on Health (NBGH) will be working together to develop evidence-based benefits derived from the recommendations within the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines™). The collaboration entails developing a total plan of action that will start from identifying benefits, to contracting to have those benefits included in health plans, to ensuring that employees are aware of what their health plan includes. The collaboration will also focus on benefits employees with cancer need when returning to work, other employee assistance programs, and survivorship issues.

In regards to patients, concern was expressed that patients need to be involved in collaborations such as the NCCN/NBGH project. Patients must be taught to advocate on their own behalf and to be involved in all processes that affect their care. Concern was also expressed about the health and financial literacy of Americans. Effort must be put forward so that patients understand both the clinical and financial impact of their treatment choices.

Many issues were raised throughout the day that will require all stakeholders to collaboratively work together. By working together, patients with cancer will benefit and hopefully live happier, healthier lives.