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Media Contact:
Katie Kiley Brown, NCCN
215.690.0238
brown@nccn.org

Disparities in Defined Value Pose Challenges to Oncology Decision-Makers, Say NCCN Panelists

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The second roundtable discussion of the NCCN 20th Annual Conference explored the concept of value in oncology decision-making, challenging the perceived definition of value and true quality for the patient.

FORT WASHINGTON, PA — On Friday, March 13, 2015, as part of its 20th Annual Conference: Advancing the Standard of Cancer Care™, the National Comprehensive Cancer Network® (NCCN®) hosted its second roundtable, *Value-Based Decision-Making at the Bedside*, which reflected on the tools available to oncology clinicians, such as clinical practice guidelines and pathways, and how the use of these tools has impacted bedside evidence-based decision-making for both physicians and patients, the criteria used to assess shared decision-making, and the relationship between outcomes and cost when determining value.

Moderated by Clifford Goodman, PhD, The Lewin Group, Friday's panelists included Peter B. Bach, MD, MAPP, Memorial Sloan Kettering Cancer Center; Stephen B. Edge, MD, Baptist Cancer Center; Linda House, RN, BSN, MSM, Cancer Support Community; Jennifer Malin, MD, Wellpoint/Anthem; and James L. Mohler, MD, Roswell Park Cancer Institute.

Dr. Goodman opened the discussion by asking Dr. Mohler, Chair of the NCCN Guidelines Panel for Prostate Cancer, to describe the intended use of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) at the bedside. Dr. Mohler explained that, at Roswell Park Cancer Institute, the NCCN Guidelines® are an integral part of a patient visit as a tool that provides all reasonable options and empowers patients to make informed choices about their care

"I believe it's my job to educate the patient and it's the patient's job to decide what treatment they want," said Dr. Mohler.

According to Dr. Edge, physicians are not typically walking into exam rooms with the Guidelines; however, faculty and staff do know the content of the NCCN Guidelines and are providing patient support through the NCCN Guidelines for Patients®. It's necessary to understand, he added, that the NCCN Guidelines are guidelines, and there are a number of patients—about 20%—who are not treated according to the NCCN Guidelines because they have refused treatment or because of comorbidities or other factors that do not make them candidates for such treatment. This is acceptable, said Dr. Edge, as long as the reasons for the decision are well documented.

Dr. Goodman asked the panel to address the subject of pathways and their role in decision-making.

Patients have a very hard time getting the information they need to make informed decisions, explained Dr. Edge. Having recently moved from an academic setting to a generally lower literacy and lower education community practice, Dr. Edge noted that there are pressures to produce more patients and more revenue and these pressures lead to less quality time with patients and less resources with which to provide this valuable information.

Ms. House noted recent Cancer Support Community research showing that, while 60% of patients are aware of the NCCN Guidelines, less are aware of pathways that may be affecting their treatment. Further, she said, more than half of patients report that they are underprepared to make informed decisions about their care; however, they are the ones that ultimately live with the collateral damages.

There is a major discrepancy between a patient's and a physician's definition of value, she noted.

This situation is an emergency, said Dr. Bach. To one extent, the biomedical community and delivery system are to be credited for trying to bring decision aids to patients. On the other hand, he said, "We don't even value the data that patients would need for these decisions the same way we do about data we care about."

"Patients can come to reasonable conclusions when given full information," said Ms. House.

The challenge with reimbursement models is that most of the incentives come from the profit margin on the drugs, explained Dr. Malin. She described a proposed plan in which physicians would be paid per-hour per-patient, rather than reimbursed on a procedural basis, the intent of which is to incentivize the physician to spend more time with patients during the decision-making process and to be accountable for education, counseling, and distress management, as well as collecting and sharing the data.

Dr. Goodman asked the panel to what extent cost further narrows or directs treatment decision making with the patient.

Dr. Mohler stated that physicians are largely ignorant to cost, which creates a challenge in treatment counseling with regard to cost and value.

"None of us were prepared [to talk about cost], but you can't ignore it," said Dr. Edge. He explained that physicians try to bring forth what the costs will be to the patient; however, with a myriad of different products and health care systems, it is very difficult to develop the models to do so.

Furthermore, according to Ms. House, patients experience tremendous guilt concerning the high cost of their cancer drugs, noting their concern that they are draining their families' finances, yet they feel that they are the only ones to benefit from it.

Dr. Bach explained that oncology is the only health care sector that claims to be innovative where there are lower returns and where value has not raised at the same level as cost.

The panel agreed that they have seen patients decline chemotherapy—even for manageable chronic disease such as chronic myelogenous leukemia (CML)—due to cost.

In determining value, we need to consider the patient's ideals of value and quality—cost may not always be a determining factor, said Ms. House. The system must take into account patients' concerns about toxicity, psychological factors, and ultimate quality of life, she added.

"We are all in this together," said Dr. Mohler. "This whole thing—you can't say it's just about cost because it's about cost *to whom*."

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The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 26 of the world's leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives. Through the leadership and expertise of clinical professionals at NCCN Member Institutions, NCCN develops resources that present valuable information to the numerous stakeholders in the health care delivery system. As the arbiter of high-quality cancer care, NCCN promotes the importance of continuous quality improvement and recognizes the significance of creating clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers.

The NCCN Member Institutions are: Fred and Pamela Buffett Cancer, Omaha, NE; Case Comprehensive Cancer Center/University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute, Cleveland, OH; City of Hope Comprehensive Cancer Center, Los Angeles, CA; Dana-Farber/Brigham and Women's Cancer Center | Massachusetts General Hospital Cancer Center, Boston, MA; Duke Cancer Institute, Durham, NC; Fox Chase Cancer Center, Philadelphia, PA; Huntsman Cancer Institute at the

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