Final Roundtable of the NCCN 20th Annual Conference Explores Essential Characteristics of Clinical Practice Recommendations

The third and final roundtable of the NCCN 20th Annual Conference explored essential elements of clinical practice guidelines, as well as the historical development of the NCCN Guidelines®.

FORT WASHINGTON, PA — The third and final roundtable of the National Comprehensive Cancer Network® (NCCN®) 20th Annual Conference: Advancing the Standard of Cancer Care™, What are the Characteristics of an Optimal Clinical Practice Guideline?, was held Saturday, March 14, 2015.

Moderated by F. Marc Stewart, MD, Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance, the following panelists discussed the fundamentals of optimal clinical practice guidelines, as well as lessons learned throughout two decades of development of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) and explored the optimal formula for publishing the treatment recommendations that allow for appropriate evidence-based choices in patient management: David S. Ettinger, MD, The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins; Michael Kuettel, MD, PhD, MBA, Roswell Park Cancer Institute; Jennifer Malin, MD, Wellpoint/Anthem; Joan S. McClure, MS, NCCN; Mary Lou Smith, JD, MBA, Research Advocacy Network; and Andrew D. Zelenetz, MD, PhD, Memorial Sloan Kettering Cancer Center.

Dr. Stewart commenced the roundtable discussion by asking how the NCCN Guidelines® have changed since their initial publication in 1996.

Ms. McClure, Senior Vice President for Clinical Information and Publications, NCCN, discussed that one of the major changes to the Guidelines in the past two decades is that they have become more complex for two reasons—first, they have been built out from their original, shorter format; and, second, the treatment of cancer has also increased in complexity. Indeed, noted Ms. McClure, one major advancement was the availability of the NCCN Guidelines online in real-time, as opposed to printed copies that were available originally.

Dr. Ettinger, who has chaired the NCCN Guidelines Panel for Non-Small Cell Lung Cancer (NSCLC) since its inception, noted that one constant of the NCCN Guidelines development process is that it has been funded, since day one, solely by membership dues and noted the comparable growth of the Guidelines panels to the NCCN Guidelines themselves.

"The Lung Cancer Guidelines Panel, in 1996, had seven members...now we have 35 panel members. In '96, we had 40 references. The present Guidelines have 718 references," said Dr. Ettinger.

Fellow panelists noted the considerable increase in data and evidence included in the Guidelines since they were published in 1996.

Regarding the advancements of the NCCN Guidelines panels since 1996, Ms. Smith, who was the first patient advocate to sit on an NCCN Guidelines Panel noted that, today, there are advocates representing the patient voice and patient concerns on many of the panels.

"We have come a long way," she said.
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For patients, the most important change to the NCCN Guidelines over the past 20 years was the publication of the NCCN Guidelines for Patients®, said Ms. Smith. The NCCN Guidelines for Patients take the complex information of the Guidelines and make it more understandable for the patients; it’s important to have this information, she said, as the information contained within the NCCN Guidelines gives patients a certainty about the decisions they are making about their treatment.

Dr. Malin expounded, describing how the use of the NCCN Guidelines and their patient-friendly equivalent, allow her to reassure patients that there is a consensus about the treatment they receive in her clinic and that the treatment will indeed follow best-in-class cancer care protocol.

The panel discussed the importance of clinical judgment in the development of the NCCN Guidelines, citing that this has been a deciding factor in treatment recommendations since 1996.

“We started with a rigorous methodology, but it’s evidence-based plus consensus-based,” explained Dr. Ettinger. The better the data, the better the doctor can make the decision about the best therapies to use; sometimes, however, physicians need to think outside the box and use clinical judgment on how to best apply the evidence and the Guidelines to a particular patient, he explained.

Dr. Zelenetz, who has chaired NCCN Guidelines panels for various hematologic malignancies, including Non-Hodgkin’s Lymphomas, elaborated, explaining that in many cases—especially hematologic malignancies—a multitude of diagnoses are “orphan” diseases, and there will never be enough high-level evidence to provide high-level meta-analysis. Even in the most common cancers, he added, there are points in treatment in which there is no high-level evidence.

“To ignore areas where we don’t have high-level evidence does a disservice to Guidelines users—the oncologists and patients—because it denies them access to what is expert care at these nodal points where high-level data may not exist,” said Dr. Zelenetz.

Quality of data and systematic review of evidence is crucial to the credibility of the NCCN Guidelines, said the panel.

Dr. Kuettel reviewed the Institute of Medicine (IOM) Recommendations for Developing Trustworthy Clinical Practice Guidelines, noting that the transparent development, multidisciplinary development committees, evidence levels, and review of the NCCN Guidelines indeed fall within the IOM recommended standards.

Dr. Stewart then asked the panel to discuss pathways, which have more selective treatment options among the wide range of recommendations that may be present in the NCCN Guidelines for a particular disease.

The panel discussed Guidelines versus pathways, noting key differences including the consideration of cost, which is a fundamental distinction between the two decision tools.

According to Dr. Zelenetz, pathways can potentially be helpful decision-making tools; however, he noted that this is dependent on the quality of data present, as well as their transparency.

Today, oncology pathways are mainly focused on medical oncology, explained Dr. Kuettel. He noted that an all-inclusive pathway that comprises medical, radiation, and surgical oncology would be optimal in increasing quality and decreasing cost in the treatment of people with cancer.

Considering quality and value with pathways, Ms. Smith noted the need for exceptions. Two patients can be given the same options and make different choices as a result of their preferences, experiences, and values, she explained.

Dr. Stewart and the panelists then turned to the future of NCCN Guidelines discussing how the current digitization of the library will enhance the ability to integrate the Guidelines recommendations into electronic health records (EHRs) and decision-support tools, such as IBM Watson.

Another major development in the NCCN Guidelines is the further identification and sub-typing of malignancies, based on biology and biomarkers, explained Dr. Zelenetz. He noted the importance of data within the realm of targeted therapies, explaining that when there is a strong parallel between a biomarker and biology, small data sets can be useful.
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Finally, Dr. Stewart reviewed the idea of value with the panel members, discussing the new evidence blocks that are projected to be published within the NCCN Guidelines this year, which take into account five variables for value: efficacy, safety, quality of evidence, consistency of evidence, and affordability.

These evidence blocks allow for more personalized treatment, accounting for the driving concerns for patients, said Ms. McClure. With this information at the physicians’ fingertips, she explained, they are easily able to discuss with patients the relative merits and drawbacks of therapy options.

For more information about the NCCN Guidelines, visit NCCN.org.

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About the National Comprehensive Cancer Network

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/Brighton 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 University of Utah, Salt Lake City, UT; Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance, Seattle, WA; The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL; Mayo Clinic Cancer Center, Phoenix/Scottsdale, AZ, Jacksonville, FL, and Rochester, MN; Memorial Sloan Kettering Cancer Center, New York, NY; Moffitt Cancer Center, Tampa, FL; The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute, Columbus, OH; Roswell Park Cancer Institute, Buffalo, NY; Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine, St. Louis, MO; St. Jude Children’s Research Hospital/The University of Tennessee Health Science Center, Memphis, TN; Stanford Cancer Institute, Stanford, CA; University of Alabama at Birmingham Comprehensive Cancer Center, Birmingham, AL; UC San Diego Moores Cancer Center, La Jolla, CA; UCSF Helen Diller Family Comprehensive Cancer Center, San Francisco, CA; University of Colorado Cancer Center, Aurora, CO; University of Michigan Comprehensive Cancer Center, Ann Arbor, MI; The University of Texas MD Anderson Cancer Center, Houston, TX; Vanderbilt-Ingram Cancer Center, Nashville, TN; and Yale Cancer Center/Smilow Cancer Hospital, New Haven, CT.

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