NCCN Policy Summit Explores How to Lower Costs for Cancer Care

On September 9, 2020, NCCN hosted a free online summit on innovative ways to lower cancer care costs. Reports from NIH estimate that cancer care costs will rise to \$173 billion by the end of 2020, prompting lawmakers to propose various approaches for curtailing costs.

The virtual summit featured addresses by Lara Strawbridge, MPH, Center for Medicare and Medicaid Innovation (CMMI); Brett Baker, Office of Senator Chuck Grassley (R-IA); Afton Cissell, JD, Office of Congressman Lloyd Doggett (D-TX); and Michelle McMurry-Heath, MD, PhD, Biotechnology Innovation Organization (BIO). The speakers joined panelists from across the oncology ecosystem to explore the impact of various regulatory and legislative approaches for improving the accessibility and affordability of high-quality, patient-centered cancer care.

"It's an exciting time in oncology," said Gena Cook, Navigating Cancer, Chair, NCCN Foundation Board of Directors. "There's a lot more work to do, but the incentives are aligning to enable the transformations that improve patient experiences and care. As the market continues to move toward value-based care, we've seen significant changes that have improved the patient experience and had an impact on reducing costs."

Many of the speakers narrowed in on technology-enabled approaches that can reduce administrative burden, lessen the duration and frequency of hospitalizations, and make treatment more convenient and comfortable for patients.

"Utilizing telehealth in an efficient manner will decrease healthcare costs by avoiding unnecessary in-person visits, while at the same time improving patient satisfaction," said Ruth O'Regan, MD, University of Wisconsin Carbone Cancer Center, Vice-Chair, NCCN Board of Directors. "The judicious use of biosimilars can offer cost savings with similar efficacy for patients, and NCCN Guidelines can be leveraged to assist physicians in making cost-effective decisions for patients with cancer."

Other panelists agreed that standardized treatment guidelines play an important role in elevating care while helping to control costs.

"The most important quality metric in cancer care is guideline adherence," said Angela Mysliwiec, MD, WellMed. "Evidence-based medicine should be the foundation of any oncology care model and results in high-quality care as well as cost containment. Deviation from guidelines is associated with poor patient outcomes and increased costs. Care Delivery Organizations are uniquely aligned to impact essential aspects of patient care and should be leveraged in collaborative relationships with oncology practices to close gaps in access to care and care management. These partnerships will ensure that efforts to provide oncology care are synergistic."

The panelists also delved into topics including drug prices, end-of-life care, academic cancer centers, pharmacy benefit managers, prior authorizations, and value-based payer models.

"Though the perception is that cancer centers are more costly, we believe that from a total cost of care perspective, we are a great clinical and financial value," said David Rubin, Memorial Sloan Kettering Cancer Center. "This is an area where payers should focus."

"We would like to see greater alignment and consistency across various payer programs," said Thomas Daly, MBA, Michigan Medicine. "Uniformity of quality and performance measures across value-based reimbursement plans would improve provider and institution performance. Clinicians could spend less time

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on administrative tasks if IT reporting capabilities for claims were more universal.”

“Patients come first, and especially providing them with the highest quality cancer care,” said Ted Okon, MBA, Community Oncology Alliance. “Unfortunately, some in our healthcare system place profits over patients, leading to patients suffering when costs run out of control.”

The NCCN Oncology Policy Program held a previous virtual summit in June on the 21st Century Cures Act, now viewable online at [NCCN.org/policy](https://www.nccn.org/policy). Additionally, the NCCN 2020 Virtual Congress: Hematologic Malignancies, a free continuing education program on blood cancers, was recently held on October 8 through 10. That will be followed by the NCCN Virtual Patient Advocacy Summit: Cancer Across the Lifespan on December 10. Visit [NCCN.org](https://www.nccn.org) for additional free webinars and downloadable guidelines for providers, patients, and caregivers. Join the conversation with the hashtag #NCCNPolicy.

New NCCN Resource for Understanding Childhood Leukemia

NCCN has announced the publication of the organization's first patient and caregiver resource focused on a childhood cancer type. The brand new NCCN Guidelines for Patients: Pediatric Acute Lymphoblastic Leukemia (ALL) shares the latest expert advice for treating infants, children, and adolescents with the most common pediatric malignancy. This guidance is intended to enable patients, their parents or guardians, and other caregivers to advocate for the best evidence-based care available. This new source of information is available for free at [NCCN.org/patients](https://www.nccn.org/patients) thanks to support from the NCCN Foundation. The book is endorsed by Alex's Lemonade Stand Foundation, National Marrow Donor Program (NMDP)/Be The Match, CancerFree Kids, The Pediatric Cancer Foundation of the Lehigh Valley, and The Leukemia & Lymphoma Society (LLS).

“My heart aches for every child, parent, and guardian who experiences an earth-shattering event like a cancer diagnosis,” said Patrick Brown, MD, Associate Professor of Oncology and Pediatrics, Director, Pediatric Leukemia Program, The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Chair, NCCN Adult and Pediatric ALL Panels. “Thankfully, advances in treating pediatric ALL represent one of the most profound successes in medical history. Nearly 90% of the kids who are diagnosed with this type of leukemia can be cured with inexpensive and widely available therapies, as explained in these guidelines. Our aim in sharing this information is to prepare people for what they're facing while also giving them reason to feel hopeful.”

NCCN Guidelines for Patients are directly based on the clinical practice versions that inform doctors all over the world of the best way to manage cancer patients. NCCN Guidelines are considered the gold standard for clinical direction and policy in cancer management and are the most thorough and frequently updated clinical practice guidelines available in any area of medicine. The evidence-based recommendations are formulated by top experts from across the 30 leading cancer centers that are part of NCCN.

The patient guidelines contain the same treatment information, but are written with easy-to-understand wording. They include charts and images, a glossary of medical terms, and suggested questions to ask during appointments. An independent study found them to be among the most trustworthy resources for people seeking online information about cancer.

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"We know firsthand how important it is for families to have accurate and trusted information about their child's treatment plan," said Liz Scott, Executive Director, Alex's Lemonade Stand Foundation. "We are honored to endorse the NCCN Guidelines for Patients: Pediatric ALL. There is so much power and hope in information!"

"We want every child around the world to receive the best-possible cancer care," said Marcie Reeder, MPH, Executive Director, NCCN Foundation. "That's why it's important for patients and caregivers to know what their doctors know. Nearly 1 million people visited our patient information website in 2019. I hope they came away with the knowledge and comfort to feel empowered against whatever they might be facing."

The library of NCCN Guidelines for Patients currently contains nearly 50 different books, including recommendations for breast, colon, lung, and prostate cancers. There are also books on supportive care topics like managing cancer-related distress, nausea and vomiting, side-effects from immune checkpoint inhibitors and CAR T-cell therapy, and special considerations for adolescents and young adults across all cancer types. The books are available for free digital download online or via the NCCN Patient Guides for Cancer app. Printed versions are available for a nominal fee at Amazon.com.

Learn more and help support these and other resources for people with cancer and their caregivers at [NCCN.org/patients](https://www.nccn.org/patients).

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New Guidelines for Maximizing Cures and Minimizing Side Effects in Children With Hodgkin Lymphoma

NCCN recently announced the publication of new NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Pediatric Hodgkin Lymphoma. Hodgkin lymphoma is one of the most curable forms of pediatric cancer, with long-term survival rates of $\geq 90\%$.¹ However, treatment can result in potentially life-threatening or life-altering long-term side effects. These new recommendations from NCCN synthesize the latest evidence and expert consensus to make sure every child receives appropriate, but not excessive, treatment.

"There has never been a more important time for these NCCN Guidelines than during this pandemic, when many patients need to be treated at their local institutions—even when a trial is available—due to travel and caregiver limitations," said Jamie Flerlage, MD, MS, St. Jude Children's Research Hospital, Chair, NCCN Pediatric Hodgkin Lymphoma Panel. "There are many treatment options to choose from for pediatric Hodgkin lymphoma; some are better than others depending on the patient's stage and risk group. These guidelines have information to help providers weigh the benefits and potential setbacks of various options for treating each individual. We'll continue to update these guidelines regularly and incorporate any important new data from ongoing clinical trials."

"With so many treatment options available, it's crucial to present all the evidence that can guide providers to the best choices for their patients," said Susan Hiniker, MD, Assistant Professor, Radiation Oncology, Stanford Cancer Institute, Vice-Chair, NCCN Pediatric Hodgkin Lymphoma Panel. "It can be a challenge for individual practitioners to follow and interpret all the clinical trial data. The NCCN multidisciplinary panel of experts deliberated and debated carefully to be sure we're sharing optimal approaches that are firmly rooted in evidence."

Hodgkin lymphoma accounts for approximately 6% of all childhood cancer diagnoses in the United States, with just over 1,000 people diagnosed under

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Our mission to improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives is never more pressing than it is with young people who have many years ahead of them.

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the age of 20 every year.² Nearly half of all people diagnosed with Hodgkin lymphoma in the United States are aged ≤ 35 years.³

"The treatment approaches for children with Hodgkin lymphoma are very different than for adults, so we really needed a separate set of guidelines for this population," said Kara Kelly, MD, Division Chief, Pediatric Hematology/Oncology, Chair of Pediatrics at Roswell Park Comprehensive Cancer Center, Chief of the Roswell Park Oishei Children's Cancer and Blood Disorders Program, and Member, NCCN Pediatric Hodgkin Lymphoma Panel. "Pediatric patients have fewer competing health concerns and may tolerate higher doses, which lowers their risk of relapse. These guidelines really focus on how to strike the right balance for disease control while reducing long-term effects from the treatment."

NCCN has been providing gold standard recommendations for clinical direction and policy in cancer management for 25 years with a proven track record for improving outcomes while reducing costs.

The organization began providing recommendations for managing childhood cancers with the NCCN Guidelines for Pediatric Acute Lymphoblastic Leukemia (ALL), which launched in May 2019. Since then, those guidelines have been translated into multiple languages, and harmonized for lower-resource settings in sub-Saharan Africa—as part of the group Allied Against Cancer working in collaboration with the African Cancer Coalition (ACC), American Cancer Society (ACS), the Clinton Health Access Initiative (CHAI), and IBM. They have also been rewritten in nonmedical terms as NCCN Guidelines for Patients: Pediatric ALL in order to empower parents and guardians as well as patients.

NCCN has subsequently published NCCN Guidelines for Pediatric Aggressive Mature B-Cell Lymphomas. Additional new guidelines for children with Wilms tumors and central nervous system cancers are coming soon.

"Our mission to improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives is never more pressing than it is with young people who have many years ahead of them," said Robert W. Carlson, MD, Chief Executive Officer, NCCN.

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Expert Breast Cancer Treatment Recommendations Based on Latest Evidence, Updated in Multiple Languages

During Breast Cancer Awareness Month in October, NCCN shared and updated evidence- and expert consensus-based management recommendations which lead to optimal outcomes for people with breast cancer.¹ Translations of the English-language NCCN Guidelines for Breast Cancer have recently been updated in Chinese, Japanese, and Spanish. The currently available Korean, French, Polish, and Portuguese versions will be updated by the end of the month. All are free at NCCN.org/global.

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Translations of the English-language NCCN Guidelines for Breast Cancer have recently been updated in Chinese, Japanese, and Spanish.

NCCN Guidelines for Breast Cancer translated into multiple languages at [NCCN.org/global](https://www.nccn.org/global)

"Breast cancer has a very high cure rate, but remains the most common cancer and the leading cause of cancer-related death for women worldwide," said Robert W. Carlson, MD, Chief Executive Officer, NCCN and Professor of Medicine (Emeritus), Stanford University Medical Center, who specialized in breast cancer. "We want health care providers everywhere to have access to the carefully vetted treatment recommendations included in the NCCN Guidelines. That's why we're always looking for ways to increase the readability and accessibility of these resources."

NCCN also adapts NCCN Guidelines into tiered and pragmatic approaches for varying resource availability in low- and middle-income countries, called the NCCN Framework for Resource Stratification of NCCN Guidelines (NCCN Framework). There are also International Adaptations of the NCCN Guidelines for Breast Cancer for the Middle East and North Africa (MENA) region and Spain, as well as NCCN Harmonized Guidelines for Sub-Saharan Africa and the Caribbean, all written in collaboration with regional oncology experts.

The NCCN Guidelines for Breast Cancer have also served as the basis for creation of 3 volumes of NCCN Guidelines for Patients, to help patients with cancer talk with their physicians about the best treatment options for ductal carcinoma in situ (DCIS), invasive breast cancer, and metastatic breast cancer.

"We are expanding our knowledge of this disease at a rapid pace," said William J. Gradishar, MD, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chair, NCCN Breast Cancer Panel. "We've made 6 updates to the main breast cancer guidelines already this year. They include multiple new treatment recommendations covering management, staging, and special circumstances such as pregnancy."

NCCN also has separate guidelines on topics such as screening, genetic/familial risk assessment, risk reduction, and supportive care.

The NCCN Guidelines for Breast Cancer were downloaded >890,000 times in 2019, making it the most-downloaded NCCN Guideline across all cancer types. At least 335,000 of those downloads came from outside the United States, including >36,000 from Spain and Mexico, 31,000 from China, and 21,000 from Brazil. The non-English versions were downloaded >4,000 times.

Visit [NCCN.org/global](https://www.nccn.org/global) to learn more about all of the available cancer resources, and join the conversation with the hashtag #NCCNGlobal.

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