



NCCN 2019 PATIENT ADVOCACY SUMMIT

NCCN Patient Advocacy Summit: Value Tools for Patients in Cancer Care

December 11, 2019

Washington, DC

Overview

The [National Comprehensive Cancer Network \(NCCN\)](#) hosted its annual Patient Advocacy Summit on December 11, 2019, at the National Press Club in Washington, DC. The theme of this year's summit was "Delivering Value for Patients across the Oncology Ecosystem." Patients and advocates shared perspectives on how to define value and patient priorities in cancer treatment and noted areas that are important to patients but not adequately addressed, such as financial toxicity and treatment access. Providers and policymakers also shared their experiences and strategies to incorporate patient values in evidence-based care, including the Food and Drug Administration's (FDA) efforts to include patient-reported outcomes (PROs) in drug development.

Key themes from the panel discussions included:

- Patient values are not always in alignment with provider recommendations, so it is important for clinicians to understand priorities related to nonclinical aspects of care (e.g., transportation, financial toxicity, quality of life)
- Shared decision-making should occur during all phases of cancer treatment to understand patients' evolving values during different stages of treatment
- PROs should be collected during all phases of drug development and real-world use to drive policymaking and future drug development
- Providers should screen patients for social determinants of health that may limit access and adherence to cancer treatment

Incorporating the Patient Voice into the Evidence

Speaker: Paul Kluetz, MD, Oncology Center of Excellence, FDA

- FDA is collecting real-world evidence (RWE) directly from patients to support changes to labeling about drug product effectiveness (e.g., efficacy, symptoms benefit, and tolerability)
- RWE helps monitor postmarket safety and adverse events
- Sources used to collect PROs include mobile devices and apps

Panel Discussion 1: Untangling Perspectives: Identifying Patient-Centered Elements of Value

Moderator: Clifford Goodman, PhD, The Lewin Group

Panelists: Ilana Feuchter, MA, National Ovarian Cancer Coalition; Elizabeth Franklin, LGSW, ACSW, Cancer Support Community; Miranda Goff, LICSW, GO2 Foundation for Lung Cancer; Lillian Kreppel, HPV and Anal Cancer Foundation; Darryl Mitteldorf, LCSW, National LGBT Cancer Project; Chuck Strand, Us TOO Prostate Cancer Education & Support; Carla Tardif, Family Reach; Ronit Yarden, PhD, MHSA, Colorectal Cancer Alliance

- Panelists discussed the extent to which patient-centered value is incorporated into cancer care
 - Many panelists agreed that there has been improvement in collecting PROs and incorporating the patient voice in treatment decisions, but there is room for more patient involvement in all phases of clinical trial design and treatment decisions
 - The perception among patient advocates is that survival is an important outcome to consider in cancer treatment options, but there needs to be more emphasis on other factors that are important to patients (e.g., quality of life, financial toxicity, and psychosocial factors)
- Panelists discussed how clinical trial designs and guideline development processes can include patient preferences
 - Clinical trials can screen for patient distress to identify quality-of-life and socioeconomic factors of treatment
 - NCCN guidelines can incorporate cost of care, toxicity, and other patient values in their guideline pathways to encourage providers to discuss these factors during treatment decision-making
- Panelists discussed goals for improving patient experience and incorporating patient values over the next five years
 - Patients should be included in a discussion about their personal values at the beginning of the diagnosis and throughout each step of treatment planning, survivorship, and end-of-life care
 - Providers can gain patients' trust by engaging in shared decision-making through open, honest conversations about the patient's prognosis and risks/benefits of different treatment options
 - Screening for social determinants of health is important in ensuring that patients have resources to address challenges such as loss of work or transportation barriers to improve their access to preferred cancer treatment options

Patient-Focused Research Center (Patient FoRCe)

Speaker: Andrea Ferris, MBA, LUNGevity

- LUNGevity's Patient-Focused Research Center (Patient FoRCe) is conducting qualitative and quantitative research to understand gaps in information, misperceptions about patient attitudes, and areas of unmet need to help guide regulatory decision-making
 - To date, Patient FoRCe has surveyed 2,435 patients and 591 caregivers
 - The surveys indicate that various factors, including availability of a targeted therapy, may influence patient preferences and that values placed by patients on different attributes should be considered during clinical practice and drug discovery
 - Patient preferences and experiences should be incorporated into regulatory decision-making and protocols for drug development

Resolving Financial Toxicity Issues

Speaker: Brian Connell, The Leukemia & Lymphoma Society

- Financial toxicity is a main driver of patients' not adhering to their cancer treatment
 - 45% of patients who have spent at least \$2,000 on their treatment do not continue to fill their prescriptions
 - The Leukemia & Lymphoma Society put forward 31 policy recommendations to lower the cost of cancer care for patients, including:
 - Curb incentives that promote hospital consolidation and lead to higher payments for services
 - Promote timely generic medication approval
 - Reduce wasteful spending on common and preventable misdiagnoses
 - Enable insurers to base a drug payment on its value
 - Provide relief for patients struggling to afford their prescriptions through a monthly spending cap in Medicare Part D

Panel Discussion 2: Overcoming the Hurdles — Integrating the Patient Voice into the Care Continuum

Moderator: Clifford Goodman, PhD, The Lewin Group

Panelists: Alan Balch, PhD, National Patient Advocate Foundation; Justin E. Bekelman, MD, Abramson Cancer Center; Kimberly Bell, BSN, MBA, Cleveland Clinic Taussig Cancer Institute; Kristin L. Carman, PhD, MA, Patient-Centered Outcomes Research Institute (PCORI); Anjelica Davis, MPPA, Fight Colorectal Cancer; Edward Kim, MD, NCI Central Institutional Review Board

- Panelists discussed strategies to incorporate each patient's voice into cancer treatment care
 - It is important to use a screening tool for social determinants of health that can be implemented at the point of care and catches general hardship and distress, including financial hardship
 - The Cleveland Clinic has financial navigators that support patients with the financial aspect of care by addressing common sources of confusion about insurance and billing, coordinating with social workers and organizations that help with living expenses, and working with out-of-network providers to help avoid out-of-network charges for cancer treatment
 - Molecular tumor boards can consider financial hardship when reviewing individual cases and testing or treatment recommendations
 - PCORI is working to implement findings from its PRO research and to expand the implementation to additional sites
 - Collecting PROs in clinical trials will help ensure that the outcomes that are most valuable to patients will be included on drug labels
 - Expanding eligibility for clinical trials will also improve the representation of different subpopulations, leading to a better understanding of outcomes in subgroups
- Panelists discussed initiatives that their organizations are currently working on



- Fight Colorectal Cancer is training research advocates on key issues affecting colorectal cancer research and connecting them with opportunities to promote patient values within the research community
- NCI Central Institutional Review Board is meeting quarterly as a financial toxicity tumor board to review practice patterns that contribute to financial hardship to patients and identify potential solutions
- PCORI is matching patients with research projects and opportunities
- The National Patient Advocate Foundation is developing person-centered care pathways that include shared decision-making, patient-centered outcomes, and integration of the patient voice throughout the clinical pathway
- Cleveland Clinic is training their clinicians in shared-decision making and integrating social determinants of health and distress tools into their electronic medical record system