NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

NCCS ROUNDTABLE SETS THE TONE FOR 2020 CANCER POLICY

NCCS' Fall '19 roundtable hosted key decision-makers and industry experts that helped identify 2020 policy objectives.

SESSION ONE

ACCESS TO CARE THROUGH CLINICAL TRIALS (AND STRATEGIES TO IMPROVE ACCESS AND CLINICAL TRIALS)

Dana Dornsife | Lazarex Cancer Foundation & 2019 Ellen L. Stovall Award Recipient
Glenn Ellis | Strategies for Well-Being, LLC
Sharon Rivera-Sanchez | Patient Advocate & Founder, Saving Pennies 4 a Cure
Joseph Unger, PhD, MS | Fred Hutchinson Cancer Research Center
(Moderator) John Whyte, MD, MPH | WebMD

Patients' income, suboptimal insurance coverage, and logistical challenges are barriers to participating in clinical trials, noted in research conducted by Joseph Unger, PhD, MS.

The panelists suggested potential approaches to eliminating economic barriers to clinical trial participation, including support for travel, lodging, and other incidental expenses. Panelists discussed compensating clinical trial enrollees and the need to resolve any ethical and research issues around compensating patients for participation.

The panel suggested fundamental changes to the clinical trials enterprise to address the structural issues that prevent enrollment. Suggestions included creating "competition" among clinical trials' sponsors about their achievement of enrollment diversity.

SESSION TWO

IMPROVING CANCER CARE QUALITY FOR SEXUAL AND GENDER MINORITIES

Matt Schabath, PhD, MS | Moffitt Cancer Center

Matt Schabath, PhD, MS, presented evidence that suggests at least seven specific cancer sites disproportionately affect LGBTQ populations. Dr. Schabath also cited lower rates of insurance coverage, cancer screening and early detection, and health care utilization in these populations, when compared to the U.S. population overall.

Dr. Schabath noted that the LGBTQ communiy is underserved, marginalized, and stigmatized by past experiences. Their health-seeking behaviors differ from the mainstream because they avoid or delay seeking care, avoid care due to lack of insurance and perceived discrimination, avoid care because of misconceptions or risk, do not fill prescriptions, and are more likely to receive care in emergency rooms.

Dr. Schabath outlined steps that institutions and individual providers can take to address the burden of cancer on the LGBTQ community, including provider training.

SESSION THREE

ENGAGING PATIENTS, FAMILIES, AND CAREGIVERS TO DESIGN QUALITY CANCER CARE

Harmar D. Brereton, MD | Northeast Regional Cancer Institute, 2019 Ellen L. Stovall Award Recipient
Laurie Isenberg, MBA | NCCS Board Member and Stovall Award Selection Committee Member

Dr. Harmar D. Brereton offered lessons from his practice and shared his philosopy for training young physicians. He advises them to be accessible to patients, share research results, be culturally compentent and sensitive, and invest time to talk to patients and hear their stories. By providing lessons to young physicians, Dr. Brereton shared a compelling philosophy for medical practice that includes being culturally sensivitive and fostering an environment of trust.

SESSION FOUR

QUALITY MEASUREMENT IN CANCER CARE

Karen K. Fields, MD | Moffitt Cancer Center
Kristen McNiff, MPH | KM Healthcare Consulting
Hala Durrah, MTA | Patient Family Engagement Consultant
(Moderator) Shelley Fuld Nasso, MPP | NCCS

The panel provided an overview of the current landscape for quality measurement in cancer care and efforts to foster patient-driven cancer measurement development. The panel discussed how stakeholders value different types of measures and how the health care system can and should utilize a range of measures. Dr. Karen K. Fields reviewed the types of measures currently used and their associated strengths and weaknesses. She also reviewed the types of patient-reported measures.

Hala Durrah, MTA, cautioned that patient-centered measurement is not the same as patient-reported outcomes. Instead, patient-centered measurement is driven by patients' expressed needs, not assumptions about what matters to them. It focuses on processes and outcomes that patients care about, which may or may not be patient-reported outcomes.

Kristen McNiff, MPH, described and analyzed NCCS' project, Redefining Functional Status (RFS): Patient-Led Cancer Outcome Measurement. McNiff explained NCCS flipped historic practice in measure conceptualization efforts, by naming patients as members of the committee leading development of the RFS measure and selecting a clinical/methodologist panel with experience in cancer patient-reported outcomes, functional status research, measurement methodology, and implementation/clinical workflow. The patient-driven RFS committee was charged with leading the development of the RFS measure by defining the concept and reviewing and contributing to the development of patient-centered specifications.

SESSION FIVE

STATE AND FEDERAL POLICY EFFORTS TO ADDRESS HEALTH CARE ACCESS AND COST

Katie Keith, JD, MPH | Georgetown Center on Health Insurance Reforms
Nicholas Diamond, JD, LLM, MBE | Avalare Health
(Moderator) Lindsay Houff, MPH | NCCS

Katie Keith, MD, and Nicholas Diamond, JD, MPH, reviewed the uncertainty that hangs over the Affordable Care Act (ACA) and the efforts that are being made – including in the states – to anticipate and compensate for the possibility that the ACA will be declared unconstitutional. Even if the law is not declared unconstitutional, the Trump Administration has taken steps to undermine the ACA. Although some of these actions are being challenged in the courts, the Trump Administration efforts have created chaos and resulted in declines in health insurance coverage.

Keith accurately predicted the outlines of the Fifth Court of Appeals decision. In addition to state efforts related to ACA and Medicaid, including block granting and related efforts, Diamond reviewed a list of state initiative or actions, many directed at drug access issues, including:

- State plans to import drugs from Canada
- State efforts to launch drug price transparency initiatives
- Utilization management, under consideration by as many as 30 states

Nick Diamond also reviewed his own recent article that identified cancer care developments in the states, including drug importation, step therapy, oral parity, and Medicaid work requirements. These are efforts that would likely continue, regardless of ACA developments.

SESSION SIX

HOW FDA REVIEW ACTIVITIES AND REGULATORY INITIATIVES IMPROVE CANCER CARE

Suparna Wedam, MD | U.S. Food and Drug Administration

Suparna Wedam, MD, explained the fundamental challenge that FDA faces in striking the right balance by being a consistent, thorough, and independent regulator. If the agency regulates less, it may be accused of delayed safety findings or toxic deaths. On the other hand, if the agency regulates more, it will be viewed as too cautious and stifling innovation.

Wedam reviewed a wide range of patient-centered activities that the Oncology Center of Excellence has undertaken to improve cancer drug review, including utilization of FDA Expedited Programs, piloting of the Real-Time Oncology Review program, collaboration with ASCO and Friends of Cancer Research to revise cancer clinical trial enrollment criteria, and specific patient-focused activities such as Project Patient Voice and Project Community.