



National Comprehensive
Cancer Network®

Patient Advocacy Summit

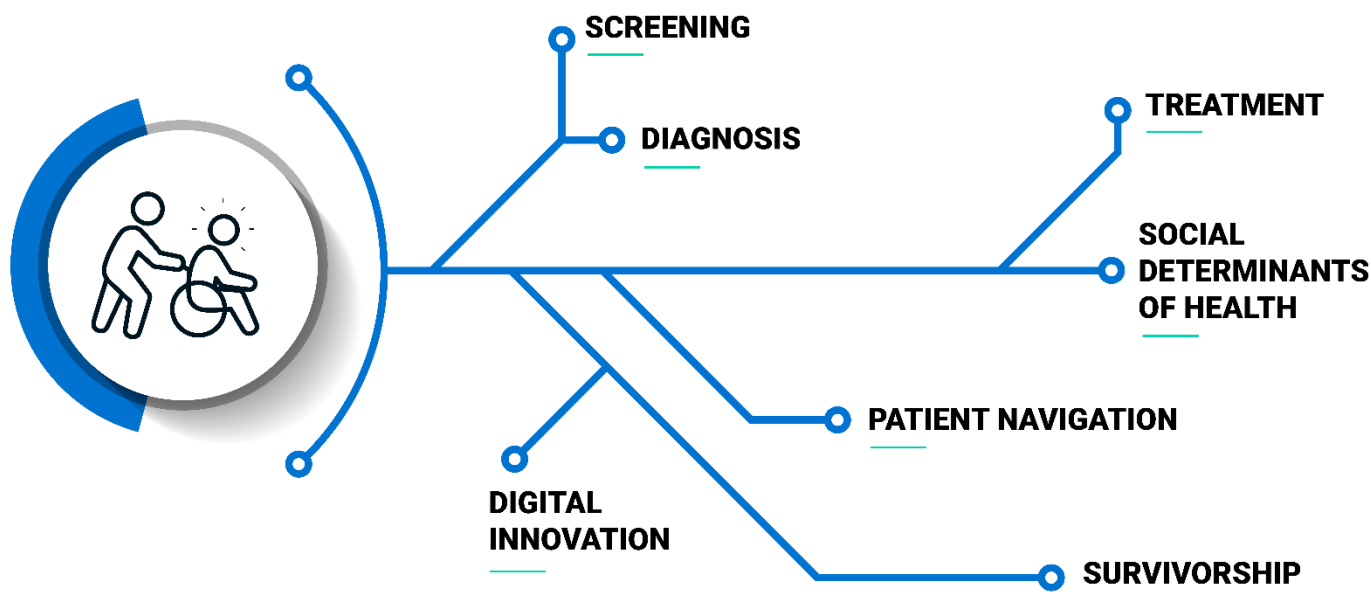
Navigating the Care Continuum from Screening through Survivorship

Summary Report

Tuesday, December 5, 2023

8:30 AM – 3:30 PM

Presented at The National Press Club in Washington, DC and Virtually



Purpose of the Summit

Patients navigating the cancer care continuum often encounter a variety of complex systems and needs, and may experience confusion and frustration when attempting to coordinate across care and social systems. Both policy and practice level challenges persist across care coordination, patient navigation, and patient education. The National Comprehensive Cancer Network[®]'s (NCCN[®]) Patient Advocacy Summit provided an opportunity for a varied group of stakeholders including patients, providers, payers, patient advocacy organizations, and industry to thoughtfully discuss issues associated with care transitions, including from screening to diagnosis and from treatment to survivorship, disparities according to health coverage and social determinants of health, and best practices to assist patients including care coordination, patient navigation, digital innovations, and programs offered by patient advocacy organizations. The summit also highlighted practice and policy solutions needed to improve seamless care access and mitigate the financial burden on patients to ultimately improve care outcomes for patients.

Where/Attended by Whom

The NCCN Patient Advocacy Summit was held Tuesday, December 5, 2023, at The National Press Club in Washington, DC. This summit was attended both virtually and in person by 350 people. Attendees included patients, providers, payers, patient advocacy organizations, caregivers, community-based organizations, and industry representatives.



Francesca M. Gany, MD, MS, of Memorial Sloan Kettering Cancer Center, gave a Keynote Address during the December 2023 Patient Advocacy Summit.

Learning Highlights

What are the Common Care Challenges Experienced by Patients?

Speakers discussed common challenges faced by patients navigating the cancer care continuum and their resulting impact. These issues include difficulty coordinating care across providers, SDOH related barriers to care, difficulty understanding their options, and more. These challenges/ barriers are reflective of complex systems and how they impact the patient's experience.

- Difficulty understanding treatment options and available services:
 1. Delayed or inadequate treatment,
 2. Increased anxiety and stress,
 3. Limited involvement in shared decision-making,
 4. Informed consent challenges,
 5. Poor treatment adherence.
- SDOH Related Barriers to Care:
 1. Limited access to healthcare,
 2. Health disparities and unequal treatment,
 3. Limited health literacy,
 4. Lack of social support
- Lack of Streamlined Care Coordination:
 1. Delayed diagnosis and treatment,
 2. Fragmented care,
 3. Inefficient care transitions.

Challenges Experienced by Different Demographic Groups

Speakers discussed some of the unique and ultimately heightened challenges faced by people from diverse backgrounds and how these challenges can impact the patient's journey navigating the cancer care continuum.

- Racial/Ethnic disparities:
 1. Access to care,
 2. Quality of care,
 3. Patient-provider communication and trust
- Accessibility issues for people with disabilities:
 1. Physical barriers,
 2. Communication barriers,
 3. Attitudinal barriers
- Patients with little/no systemic and social support:
 1. Emotional and psychological impact,
 2. Financial Burden,
 3. Limited access to resources and information
- Language Barriers:
 1. Miscommunication, misinformation, and misunderstandings,
 2. Limited access to information,
 3. Reduced trust in patient-provider relationship.
- Age-related Challenges:
 1. Limited understanding and information processing,
 2. Physical limitations and functional decline,
 3. Comorbidities and polypharmacy
- LGBTQ+ Disparities:
 1. Stigma and discrimination,
 2. Lack of inclusive healthcare services,
 3. Disparities in access to care

Impact of Financial Toxicity on Patient Experience

Speakers reported SDOH-related factors such as limited income, lack of insurance coverage, or high out-of-pocket costs can create significant financial burdens for patients. Cancer treatment often involves expensive medications, therapies, and procedures, and the inability to afford these costs may impact treatment decisions and adherence. Patients may forgo or delay necessary treatments due to financial constraints, compromising their overall cancer care journey. Speakers stated that financial burden and treatment affordability may impact the following:

- Treatment decision-making
- Treatment adherence
- Quality of life
- Time to diagnosis/Delayed diagnosis
- Survival-related outcomes/
Increased mortality



The December 2023 Patient Advocacy Summit featured an afternoon panel discussion about strategies to mitigate the economic burden on people facing cancer.

Strategies to Mitigate Financial Burden on Patients

Speakers discussed several options to mitigate the financial burden on patients, noting its importance for their well-being, treatment outcomes, and overall quality of life. Speakers noted that reducing financial worries allows patients to focus on their health, reduces stress and anxiety, and promotes equitable access to necessary cancer care. Some ideas discussed were:

- Health insurance- encourage patients to review their health insurance coverage thoroughly to understand what services and treatments are covered and what out-of-pocket expenses they will incur. They may need to explore plans with more comprehensive coverage.
- Clinical trials- Trials can offer cutting-edge treatments at low excess out of pocket costs. Patients should talk to their provider about trial options. (Note: Trials can also pose additional costs. Patients should get as much information as possible.)
- Financial assistance programs- Some organizations offer financial assistance programs specifically for cancer patients that can help cover costs of treatment, medications, transportation, and other related expenses. Patients should research and apply for these programs.
- Support from non-profit organizations- There are many non-profit organizations that provide financial assistance, counseling, and support services for cancer patients. They can help patients navigate financial challenges and provide resources for financial aid.
- Community resources- Local community resources such as community support groups and community-based organizations may offer financial resources to help alleviate the financial burden.
- Seek help from social workers- Hospital social workers can provide valuable assistance in navigating the financial aspects of cancer care. They, along with the care team, can help patients identify resources, apply for financial assistance programs, and provide guidance on managing medical bills and insurance claims.

Impact of Patient Navigation on Care

Speakers discussed the impact of patient navigation on care, and how it can mitigate many challenges of navigating the care continuum, including improved care coordination, which can lead to better patient experience, improved care delivery, and better patient outcomes. Speakers noted that patient navigation services impacts the following:

- Facilitating early detection and diagnosis
- Enhancing treatment adherence
- Improving patient-provider communication
- Providing psychosocial support
- Streamlining care transitions
- Reducing healthcare costs

2024 Summit Series

Sexual and Reproductive Health and its Impact on the Cancer Care Experience

Monday, May 6, 2024

Advancing Diversity, Equity, and Inclusion in the Cancer Workforce

Tuesday, September 10, 2024

Better Information for Better Outcomes: Policy and Practice Strategies for Patient Education

Friday, December 6, 2024

For More Information: <https://www.NCCN.org/summits>

Appendix 1.

NCCN Patient Advocacy Summit: Navigating the Care Continuum from Screening through Survivorship

Summit Speakers

- **Jennifer Bires, MSW, LCSW, OSW-C**, Inova Schar Cancer Institute
- **Karen Costello, MSS, LSW, OSW-C**, Cancer Support Community
- **Patrick Delaney**, NCCN Foundation
- **Francesca M. Gany, MD, MS**, Memorial Sloan Kettering Cancer Center
- **Tina Gerovac-Lavasseur, DNP, RN**, American Indian Cancer Foundation
- **Carmen Guerra, MD, MSCE, FACP**, Abramson Cancer Center at University of Pennsylvania
- **Jackie Herigodt**, Imerman Angels
- **Ronald Kline, MD**, Center for Medicare and Medicaid Services
- **Rifeta Kajdic-Hodzic**, Association of Cancer Care Centers (ACCC)
- **Alti Rahman, MHA/MBA, CSSBB**, American Oncology Network
- **Jamil Rivers**, The Chrysalis Initiative
- **Deric Savior, MD, FCPP**, Main Line Health
- **Lisa Schlager**, Facing Our Risk of Cancer Empowered (FORCE)
- **Rodney Tucker, MD, MMM**, O'Neal Comprehensive Cancer Center at UAB

Environmental Scan Participants

- **Alan Balch**, Patient Advocate Foundation
- **Shonta Chambers**, Patient Advocate Foundation
- **Karen Costello**, Cancer Support Community
- **Karen Demairo**, Leukemia & Lymphoma Society
- **Tina Gerovac-Lavasseur**, American Indian Cancer Foundation
- **Jackie Herigodt**, Imerman Angels
- **Ronald Kline**, CMS
- **Knoll Larkin**, National LGBT Cancer Network
- **Yamile Leon**, AONN+
- **Shawn Reilly**, National LGBT Cancer Network
- **Kristen Santiago**, LUNgevity
- **Lisa Schlager**, FORCE