ABSTRACT

US healthcare systems have been deeply impacted by significant societal shifts over the past several years. The COVID-19 pandemic has changed the way we interact with healthcare, political narratives have impacted how healthcare is perceived and engaged with by the public, and the United States has become increasingly aware of historic and ongoing racial injustices across all health and social systems. The watershed events experienced during the last several years play a critical role in shaping the future of cancer care for payers, providers, manufacturers, and, most importantly, patients and survivors. To explore these issues, in June 2021 NCCN convened a virtual policy summit: Defining the “New Normal” — 2021 and the State of Cancer Care in America Following 2020. This summit offered the opportunity for a varied group of stakeholders to begin to explore the impact of recent events on the current and future state of oncology in the United States. For a full list of panelists and speakers, see Appendix 1.

Impact of COVID-19 on Cancer Treatment and Early Detection

Throughout March and April of 2020, state and local government officials issued shelter-in-place orders to mitigate the spread of COVID-19. As a result, cancer research, prevention, treatment, and survivorship services decreased exponentially. Researchers are just beginning to quantify the impact of these mitigation efforts on cancer diagnosis and treatment. At the June 2021 Policy Summit, Murray Aitken, MBA, Executive Director of the IQVIA Institute for Human Data Science and Senior Vice President of IQVIA, presented global data from IQVIA to illustrate the significance of the disruption to our national effort to prevent and treat cancer.

COVID-19 simultaneously caused disruption in the lives of patients across the cancer care continuum, negatively impacting both physical and social health. IQVIA estimates there were 22 million fewer screening tests across 4 common screenable cancers (breast, cervical, colorectal, lung) in the United States in 2020. Compared
with 2019, colonoscopies were reduced by 90%, mammograms by 97%, Papanicolaou tests by 83%, and CT lung cancer screening by 53% at the pandemic peak.1 These numbers improved throughout 2020; however, by early 2021 these reductions in the utilization of common healthcare services were still significant, ranging from 11% (CT scans) to 23% (colonoscopies).1 The ultimate impact of the screening decline on cancer burden is unknown, but one recent study by Oakes et al2 found that although screening quickly rebounded after the initial stages of the pandemic throughout 2021, gaps in preventive cancer screening persisted. Additionally, suspended business operations led to record-setting layoffs. Patients with cancer and their families comprised a portion of the 21 million American workers laid off. With support and telehealth innovations, patients in active treatment faced additional financial barriers to treatment. Fifty-nine percent of US oncologists surveyed reported their active patient case-load was experiencing financial hardship attributable to the pandemic.1

Although these shifts in care are troubling, many oncology care providers rose to the task by quickly innovating and shifting treatment modalities as necessary. NCCN quickly released guidance on safety measures for oncology as well as modified treatment recommendations for several common cancers.3 IQVIA reports practice changes took hold quickly, with 43% of oncologists reporting changes to treatment regimens, including to oral equivalents where possible.1 Additionally, with new telehealth flexibilities announced by the US Department of Health and Human Services and many other payers, many oncologists shifted when possible to remote consultations and telehealth appointments.4 These adjustments have highlighted the commitment of stakeholders to rapidly adapt based on the best interest of patients with cancer, and have allowed for reflection on best practices moving forward.

Rebuilding Screening, Treatment, and Trial Capacity

Although screening and treatment access was dramatically reduced throughout April and May of 2020, access did begin to resume during the pandemic thanks in part to the work of many committed organizations. To explore efforts to rebuild cancer care capacity, the June NCCN Policy Summit convened a multistakeholder roundtable of leaders working to get patients back to screening, treatment, and trials. Panelists included Crystal Denlinger, MD, FACP, Senior Vice President and Chief Scientific Officer, NCCN, and practicing medical oncologist; Keysha Brooks-Coley, MA, Vice President, Federal Advocacy and Strategic Alliances, American Cancer Society Cancer Action Network (ACS CAN); Jennifer Malin, MD, PhD, Chief Medical Officer, Oncology and Genetics, UnitedHealthcare; and Christopher Lathan, MD, MS, MPH, Chief Clinical Access and Equity Officer, Dana-Farber Cancer Institute, and Associate Medical Director, Dana-Farber Network. Panelists discussed efforts to bring people back to screening, treatment, and clinical trials.

Dr. Denlinger noted she is beginning to see patients returning at rates closer to those seen prepandemic thanks to the tireless efforts of many nonprofit and governmental organizations. ACS CAN, NCCN, and the CDC partnered on the “Resume Cancer Care” campaign to raise awareness of the need to continue cancer screening and treatment throughout the pandemic through Public Service Announcements and a media tour. Dr. Malin noted that innovations in care delivery also played a significant role in improving access to care. She stated that mailing fecal immunochemical test (FIT) kits to people helped bridge the gap in access to colonoscopy screening at a time when people might feel hesitant or be unable to go to a provider’s office. It is also notable that many providers have engaged mobile screening vans to bring a variety of cancer screenings into community settings.5

Unfortunately, rates of return to screening and treatment were not equitable across communities and demographic groups. Dr. Lathan noted that people from marginalized communities are returning to screening and treatment at slower rates. For many, the pandemic further tightened necessary resources, such as time, insurance coverage, and budget, resulting in disparate return-to-screening rates. Dr. Malin concurred that data indicate the Medicaid population is not returning to screening and treatment at the same rate as the commercially insured population.

Research infrastructure also experienced significant disruption during the pandemic, resulting in decreased access to clinical trials. In response to these new challenges, research systems needed to quickly adapt to meet the needs of trial participants. Dr. Denlinger discussed this experience as an opportunity to identify adjustments to clinical trial protocols to make them work better for patients. Researchers examined protocols to identify what was absolutely necessary for patient safety and data integrity. From this, they were able to identify study requirements that were not absolutely necessary and could be removed, thus protecting patient safety and reducing study burden. Dr. Denlinger noted this has provided a better understanding of how not to “over-require” within protocols, and these learnings may help to reduce barriers and improve access for trial participants moving forward.

The COVID pandemic also shed light on the deep inequities in our health and broader social systems. Ms. Brooks-Coley noted that we must come together to use policy levers to address these disparities. Key
actions put forth by Ms. Brooks-Coley included support for national screening programs, including the National Breast and Cervical Cancer Early Detection Program through the Centers for Disease Control and Prevention as well as Medicaid expansion, which has resulted in significant improvements in access to cancer screening and treatment. Multiple studies have found that Medicaid expansion states have experienced larger increases in colorectal, breast, and cervical cancer screening and have also seen populations with higher rates of access to necessary cancer surgery compared with nonexpansion states.6–8 Ms. Brooks-Coley also noted the critical importance of patient navigation to ensure patients can access these services and navigate care systems once coverage is available.

**Innovations in Cancer Care**

The events of 2020 spurred significant innovations in the way cancer care is delivered. To explore the learnings, the summit convened a panel of experts, including Jeff Allen, PhD, President and Chief Executive Officer at Friends of Cancer Research; Timothy Kubal, MD, MBA, Senior Medical Director, Moffitt Cancer Center; Sarah Alwardt, PhD, Vice President of Operations, Ontada (now Senior Vice President of Advisory Services at Avalere Health); Jennie Crews, MD, MMM, Vice President and Medical Director, SCCA Community and Network Affiliate Programs and Clinical Professor, UW Department of Medicine; and Gwen Darien, BA, Executive Vice President for Patient Advocacy and Engagement, National Patient Advocate Foundation. Panelists discussed shifts in electronic health record (EHR) use, remote monitoring, telemedicine, and disparities in technology access.

Historically, EHRs have been used primarily as a record of a patient’s medical care. With the COVID-19 pandemic impacting patient access to in-person care, clinicians and health systems increasingly used EHRs as a tool for virtual care via patient portals and patient messaging. Panelists highlighted the utility in pushing health information to patients in real time rather than requiring a face-to-face interaction for them to access that knowledge, creating additional opportunities for partnership and patient empowerment. Telemedicine also played a significant role in improving patient access to care and protecting patient safety throughout the pandemic. Dr. Kubal noted that in the beginning of the pandemic, there was a steep decline in access to care, followed by a quick shift of patients to telemedicine due to swift practice and policy change. Dr. Kubal stated, “I’m managing people hundreds of miles away with labs through their local doctor.” The telemedicine gains made throughout the pandemic have created new pathways for academic and community oncology partnerships. Dr. Allen noted that comfort and utilization of remote monitoring also increased throughout the pandemic, offering enhanced potential for the early identification of adverse events.

Panelists, including Dr. Alwardt and Ms. Darien, continued to stress that as we invest in technology advancements, we must not do so in a way that leaves some groups of people behind. This would involve first assessing barriers that may be improved or exacerbated by technology, including broadband access in rural areas, time off from work, and availability of private space that may not be readily accessible outside of the care environment. Policymakers must understand the infrastructure that needs to be created around care systems and health technology to facilitate access. The panel concluded with a comment from Dr. Kubal on Parkinson’s law, which states, “work expands to fill the time allotted for its completion”; throughout 2020, the time allotted and urgency was “now.” Dr. Kubal noted that we must apply Parkinson’s law not only to COVID-19 but also to cancer care, and ignite an urgency that the time to advance access to optimal cancer care is now.

**Road Mapping to More Equitable Care in Medicare and Medicaid**

LaShawn McIver, MD, MPH, Director of the Office of Minority Health (OMH) at the Centers for Medicare & Medicaid Services (CMS), provided the afternoon keynote at the summit. Dr. McIver provided background on the history and core functions of OMH as well as new initiatives under the Biden administration to establish and embed equity throughout all department activities. The CMS OMH was launched more than a decade ago to lead the advancement and integration of health equity in the development, evaluation, and implementation of CMS’ policies, programs, and partnerships. OMH core functions include data analytics, program alignment, and partner engagement.

In 2021, President Biden released an Executive Order establishing equity as a defining part of the administration and directing all federal agencies to examine how they can improve equity.9 To achieve this directive at CMS, Dr. McIver noted that they are taking a comprehensive approach with multiple partner engagement and internal initiatives. Specifically, CMS has established a Health Equity Inventory, a CMS Equity Plan, a Disparities Impact Statement, a plan for engagement with community partners, and a CMS Advisory Council on Health Equity. Other notable initiatives by CMS include a Medicare Equity Plan, a Mapping Medicare Disparities Tool, and a free Health Equity Technical Assistance program by OMH for stakeholders that offers coaching and support to improve equity efforts in health systems.
Creating a More Equitable Care Delivery System

The summit concluded with the convening of an expert panel that explored opportunities to create a more equitable care delivery system. Panelists included Shonta Chambers, MSW, Executive Vice President, Health Equity and Community Engagement, Patient Advocate Foundation; Pamela Kunz, MD, Vice Chief of Diversity, Equity and Inclusion, Medical Oncology, Yale Cancer Center and Smilow Cancer Hospital; and Andrea Willis, MD, MPH, Senior Vice President and Chief Medical Officer, BlueCross BlueShield of Tennessee. Panelists discussed a range of topics relevant to disparities in cancer care including the social determinants of health, workforce representation challenges, clinical trial representation, and measuring and improving equitable care.

Disparities in cancer care exist with regard to race, ethnicity, gender, sexual orientation, disability status, and income, including across both overall survival and quality-of-life measures. Ms. Chambers noted that healthcare professionals must strive to understand not only disparities among individual groups that are discriminated against but also the impact of intersectionality. Specifically, healthcare providers should strive to understand how multiple and overlapping disenfranchised identities may impact patient experiences. It is critical for healthcare professionals to understand how this may impact an individual’s health as well as how they want to be treated by the healthcare system. Dr. Willis agreed, noting that racism “puts people in a box they have to fight to get out of every single day; and then how do they turn to a healthcare system that sometimes doesn’t even recognize the fight and sometimes doesn’t even want to acknowledge the fight…we see that in our data—we see who’s going in for care and, just as important, we see who’s not going in for care.”

Similarly, patients who identify as LGBTQ+ may feel disenfranchised by the healthcare industry. Gender-based language may be alienating, particularly in areas such as breast, ovarian, and prostate cancer. For example, language that says “women should be screened annually” may be alienating to transgender men who have ovaries and should receive screening. Dr. Kunz noted that guidelines developers can play a key role in addressing this issue by moving from gender-based screening language to organ-based screening language (ie people with prostates or people with ovaries). NCCN has recently committed to improvement in this space through an initiative to move toward more inclusive and respectful language within guidelines, including the use of gender-neutral language.

Panelists also discussed the challenges associated with homogenous clinical trial populations. Clinical trials in oncology continue to lack appropriate racial representation despite significant literature and awareness of the issue. A 2019 article published in *JAMA Oncology* found that among 230 trials leading to FDA oncology drug approvals over the past decade, race was reported in only 63%. Furthermore, just 3.1% of participants were Black and 6.1% were Hispanic in the studies reporting. Contributing factors may include challenges with covering the out-of-pocket costs associated with clinical trial participation, historic and current injustices in clinical trial practices on the part of the healthcare system, unnecessarily restrictive trial eligibility criteria, and healthcare providers failing to ask patients of color if they would be interested in a clinical trial due to biased assumptions. Several solutions were offered by Dr. Kunz and Dr. Willis, including partnering with trusted messengers and community leaders, noting that we must recognize when “we are not the best ones to have the conversation.”

Panelists also discussed the critical need to institute systems of measurement and accountability for equity within the cancer care system. Ms. Chambers noted that the Elevating Cancer Equity Working Group (ECEWG), convened by NCCN, the ACS CAN, and the National Minority Quality Forum, developed a Health Equity Report Card (HERC) to serve as a measurement and accountability tool for equity. Ms. Chambers, who cochaired the ECEWG, noted, “This comprehensive set of recommendations is like that lighthouse in the distance for me. It includes some very tangible things all of us can do no matter where we are in the ecosystem.” All panelists agreed that although moving toward measurement of equity may make some people uncomfortable, if we truly want to end disparities, we need to first be able to measure them, identify a baseline, and then strive to improve. Since the convening of this panel, CMS has proposed instituting an “equity score” for hospitals, and several health systems and ranking organizations are exploring similar initiatives. Additionally, since this summit, NCCN has begun piloting the HERC at 5 academic cancer centers, with plans to launch in the community in 2023. These programs, coupled with a broad investment across all healthcare sectors, have the opportunity to elicit meaningful change.

Conclusions

The summit highlighted key challenges and opportunities arising throughout 2020, including care and screening barriers and reductions, innovations in technology and care delivery, and new strategies to reduce inequities in care. The challenges facing the oncology care system are complex and urgent, but the oncology community has demonstrated a propensity for multidisciplinary collaboration and partnership in the face of adversity. Since the summit, stakeholders have built upon these learnings to develop new ways of delivering care and reducing
inequities. The lessons learned throughout the COVID-19 pandemic can be used to improve access to optimal cancer care for all.

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References


Appendix 1. Summit Panelists and Speakers

- Murray Aitken, MBA, Executive Director, IQVIA Institute for Human Data Science, Senior Vice President, IQVIA
- Jeff Allen, PhD, President and Chief Executive Officer, Friends of Cancer Research
- Sarah Alwardt, PhD, Vice President of Operations, Ontada
- Keysha Brooks-Coley, MA, Vice President, Federal Advocacy and Strategic Alliances, American Cancer Society Cancer Action Network
- Robert W. Carlson, MD, Chief Executive Officer, National Comprehensive Cancer Network
- Jennie R. Crews, MD, MMM, Vice President and Medical Director, SCCA Community and Network Affiliate Program; Clinical Professor, UW Department of Medicine
- Shonta Chambers, MSW, Executive Vice President, Health Equity and Community Engagement, Patient Advocate Foundation
- Gwen Darien, BA, Executive Vice President, Patient Advocacy and Engagement, National Patient Advocate Foundation
- Crystal S. Denlinger, MD, FACP, Senior Vice President, Chief Scientific Officer, National Comprehensive Cancer Network
- Clifford Goodman, PhD, The Lewin Group
- Timothy Kubal, MD, MBA, Senior Medical Director, Moffitt Cancer Center
- Pamela Kunz, MD, Vice Chief, Diversity, Equity and Inclusion, Medical Oncology, Yale Cancer Center and Smilow Cancer Hospital
- Christopher Lathan, MD, MS, MPH, Chief Clinical Access and Equity Officer, Dana-Farber Cancer Institute; Associate Medical Director, Dana-Farber Network
- Jennifer Malin, MD, PhD, Chief Medical Officer, Oncology and Genetics, UnitedHealthcare
- LaShawn McIver, MD, MPH, Director of the Office of Minority Health, Centers for Medicare & Medicaid Services
- Gary Weyhmuller, MBA, Chief Operating Officer, National Comprehensive Cancer Network
- Andrea Willis, MD, MPH, Senior Vice President and Chief Medical Officer, BlueCross BlueShield of Tennessee

*Titles and affiliations as of June 2021, the date of the summit.*