

NCCN Policy Summit: Reducing the Cancer Burden Through Prevention and Early Detection

Lindsey Bandini, MPH¹; Alyssa Schatz, MSW¹; Victoria Hood, MPP¹; Nikia Clark²;
Michael J. Hall, MD, MS³; and Robert W. Carlson, MD¹

ABSTRACT

Cancer prevention, screening, and early detection play an integral role in cancer incidence and outcomes. It is estimated that 30% to 50% of cancers worldwide are preventable, and it is well established that early detection of many cancers is associated with improved treatment outcomes. A recent NCCN Policy Summit: Reducing the Cancer Burden Through Prevention and Early Detection brought together healthcare providers, payers, policymakers, patient advocates, industry representatives, and technology representatives to explore challenges, triumphs, and outstanding questions surrounding current practices. Keynotes were delivered by Dr. Lisa Richardson, Director of the Division of Cancer Prevention and Control within the CDC, and Dr. Danielle Carnival, White House Cancer Moonshot Coordinator. Dr. Richardson focused on the field of public health, translating its utility in preventing and diagnosing cancer in the United States, while Dr. Carnival discussed ambitious goals by the Cancer Moonshot in reducing the cancer burden. Panelists highlighted characteristics of high-impact prevention and early detection programs, including how genetic testing has impacted this space. Existing programs are often challenged due to limitations in data, as well as financial, structural, and social barriers to motivating individuals to act on recommendations. Despite these barriers, we can learn from highly successful programs and should apply proven attributes, such as community engagement, more broadly.

J Natl Compr Canc Netw 2023;21(9):910–914.e1
doi:10.6004/jnccn.2023.7040

Reducing the Cancer Burden Through Prevention and Early Detection

Cancer prevention, screening, and early detection play an integral role in cancer incidence and outcomes. It is estimated that 30% to 50% of cancers worldwide are preventable, and it is well established that early detection of many cancers is associated with improved treatment outcomes.¹ Cancer prevention and early detection programs are distinct from the later parts of the care continuum, as they interact with people prior to a diagnosis and rely on population-based healthcare strategies, rather than individual-level acute care characteristics of many cancer programs. A recent NCCN Policy Summit: Reducing the Cancer Burden Through Prevention and Early Detection brought together healthcare providers, payers, policymakers, patient advocates, industry representatives, and technology representatives to explore challenges, triumphs, and outstanding questions surrounding current practices. For a full list of panelists and speakers, see eAppendix 1 (available with this article at JNCCN.org).

Public Health Strategies for Cancer Control and Prevention

Our nation's investment in public health dates back more than 200 years,² with much of that time focused on the prevention and control of infectious disease. However, throughout the late 20th and early 21st centuries, with penicillin readily available, the field of public health shifted to a supporting role for all population-level health initiatives. It was during this time that areas of focus expanded to include noninfectious and chronic diseases, including cancer. In recent years, the field of public health has again been thrust into prominence due to epidemics such as SARS, MERS, and Ebola, and the COVID-19 pandemic. Therefore, the timing is opportune to highlight recent successes across the field, while acknowledging where gaps still exist. Dr. Lisa Richardson,



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¹National Comprehensive Cancer Network; ²Roswell Park Comprehensive Cancer Center; and ³Fox Chase Cancer Center.

Director of the Division of Cancer Prevention and Control within the CDC, delivered a morning keynote translating the role of public health in preventing and diagnosing cancer in the United States.

The CDC's Division of Cancer Prevention and Control is guided by the CDC's 10 Essential Public Health Services, which span assessment, policy development, and assurance, with an overarching principle of equality.³ More simply, the CDC encompasses everything from identifying a problem (surveillance) to building a response (implementation). Dr. Richardson's keynote address stressed the importance of communication, both within the context of optimizing resources through collaboration across governmental entities and through the dissemination of information external to the government. Dr. Richardson discussed 2 successful prevention and screening programs: the CDC's Colorectal Cancer Control Program (CRCCP)⁴ and the Nicotine Replacement Therapy Access project led by the organization Black People Against Tobacco (Project BAT) in Jackson, Mississippi and supported by the CDC.⁵ The CRCCP works with clinics, hospitals, and other healthcare organizations to use evidence-based interventions to increase CRC screening among people ages 45 to 75 years in clinics that serve low-income individuals and where <60% of patients are up to date on screening.⁶ From 2015 to 2020, the CRCCP reached >1.3 million patients. The initiative led by Project BAT works to identify social norms associated with tobacco use and assesses the accessibility of free or low-cost nicotine replacement therapy in their community. This initiative will help to inform future work to galvanize social change among historically underserved communities.

The CDC understands the importance of data, and therefore continues to invest in improvements to collection and dissemination. Dr. Richardson highlighted some of these advancements, including international data standardization and the fact that state-level cancer incidence and prevalence is now easily accessed through the CDC website. This important work has been actualized due to a 1992 bill that created a national program of state-based cancer registries to collect, store, and distribute data on persons with cancer.⁷ She emphasized funding as one of the most important factors in the success of public health programs, and drew attention to the many instances where public health funding had been eliminated from budgets with catastrophic consequences.⁸ Despite the continued challenges in consistent funding, the Division of Cancer Prevention and Control is working to improve their systems and workflows. These ambitious goals include a plan to decrease the turnaround time for data collection and dissemination, automating data collection from the source within the electronic health record (EHR), and implementing a cloud-based computing platform that will require fewer resources in the long term.

Investing in the Invisible: Strategies to Reduce Cancer Risk

A key question in cancer prevention, according to Dr. Richardson, is, "What are the data we have to collect to convince people to move?" A panel of experts was convened to answer key questions surrounding data and the programs they fuel, including best practices, challenges, and implications of existing evidence gaps. Dr. Michael J. Hall, Chair of the Department of Clinical Genetics at Fox Chase Cancer Center, said, "We practice so much reactive medicine in this country, and not enough proactive medicine in this country." With that sentiment in mind, panelists were able to reflect on the current situation and provide a blueprint to advance prevention efforts in the future.

Panelists highlighted how advancements in genetic testing have impacted prevention and screening programs for people with hereditary risk factors. By understanding genetic risk, individuals can be stratified accordingly, allowing resources to be appropriately focused on those at highest risk. However, several barriers exist when considering implementation of population-based genetic testing programs. In addition to practical concerns related to the cost of testing, a nationwide knowledge gap exists in understanding the importance of testing and how to properly quantify risk. Panelists also identified time and existing workflows as major limiting factors. According to Dr. Ernest Hawk, Vice President and Head of the Division of Cancer Prevention and Population Sciences at MD Anderson Cancer Center, institutions do not do a systematic job of collecting and updating an individual's risk over time, particularly for cumulative lifetime carcinogen exposures, because EHRs are not yet sophisticated enough to capture and maintain exposure data over time.

Panelists also acknowledged the limitations of the data that inform population-based screening and prevention programs. Panelists unanimously agreed that data that inform prevention efforts are not heterogeneous enough and are not reflective of the US population. Maimah Karmo, Founder and CEO of Tigerlily Foundation, experienced the devastating effects of this disconnect firsthand when she found a lump in her breast at age 31 years and was repeatedly dismissed for not fitting the mold of a "typical" patient with breast cancer. She has since dedicated her life to ensuring patient voices, particularly those of young Black women, are heard and respected. Panelists acknowledged that progress has been made regarding inclusion of the patient voice; NCCN and the US Preventive Services Task Force (USPSTF) now include the patient voice throughout their recommendation processes.

Dr. Carol M. Mangione, Chair of the USPSTF, acknowledged her organization's unique role within this space. USPSTF is an independent group of volunteers formed in 1984 to make evidence-based recommendations on clinical

preventive services for adults and children prior to symptoms of disease. In the United States, they have become an indirect gatekeeper of payment for cancer screening and preventive services, and as such are often criticized for slow turnaround. Dr. Mangione acknowledged the frustration but stressed the importance of getting things right. She also confirmed a commitment to diminishing the impact of systemic racism in the development of recommendations, as evidenced by their annual report to Congress.

Panelists were aligned on many best practices, as well as opportunities to overcome barriers. One common theme echoed throughout the session was the importance of meeting people where they are, both physically and in their understanding of cancer risk and prevention. This underscored the importance of effective communication, including how to communicate risk, how to communicate choices, and how to help people make these choices. This requires tailoring communication based on technology access and preferences. Social media can play a major role in risk communication, but panelists cautioned that it may also be considered a barrier, allowing for misinformation to be spread without safeguards. Kate Mevis, Executive Director of US Federal & State Vaccine Policy at Merck, highlighted the importance and effectiveness of community messengers in the uptake of the HPV vaccine. Ms. Mevis stated, “Yes, we saw broad national campaigns with messages that we knew to be relevant; but at the end of the day, the most meaningful impact came from local messengers on the ground—people who look like me, talk like me, I see at church, I see at the local pharmacy.” Finally, panelists applauded recent efforts to customize screening to certain communities, such as at-home cervical care screening for individuals with barriers to traditional gynecologic care. When appropriate, these programs should be constructed to distribute cancer screening equitably. All these efforts need flexible and have consistent funding, something that has historically been difficult to secure. Panelists are hopeful that legislative efforts will provide more funding to traditional prevention and screening programs as well as to complementary endeavors such as the expansion of broadband to underserved communities.

Accelerating Advancements Through the Cancer Moonshot

Cancer death rates dropped 27% over the first 20 years of this century, according to the CDC.⁹ Despite this progress, >600,000 Americans die of cancer annually.¹⁰ President Joe Biden and his wife, Dr. Jill Biden, have firsthand experience with the devastating effects of cancer, and as such have devoted time, energy, and resources to advancing cancer care in the United States. The Cancer Moonshot was launched during the final years of the Obama

administration, and was recently reignited by the Biden administration in 2022. The Cancer Moonshot emphasizes a reduction in the cancer burden through scientific advancements as well as a shift to prevention, early detection, and addressing inequities in care access and outcomes. Dr. Danielle Carnival, the White House Cancer Moonshot Coordinator, delivered an afternoon keynote highlighting the program’s successes and future goals.

The Cancer Moonshot has stimulated the growth of cancer policies and programming both by federal entities, universities, private philanthropic groups, and other nonprofit organizations. At the federal level, this was clearly demonstrated through the bipartisan passage and enactment of the 21st Century Cures Act in 2016,¹¹ and the construction of the first-ever Cancer Cabinet in 2022.¹² According to Dr. Carnival, the Cancer Cabinet has become a driving force behind cross-departmental collaborations, including many not traditionally engaged in cancer initiatives. One such example is working with the Environmental Protection Agency to accelerate cleanup in 80 previously underfunded Superfund sites, and to help states replace lead pipes and service lines. Additionally, they have worked with the United States Department of Agriculture (USDA) to study how nutrition can prevent or reduce the risk of cancer. Finally, one of the more recent successes is the bipartisan passage of the PACT Act, expanding the reach of federal funding to care for those exposed to toxic military burn pits.¹³

Dr. Carnival also highlighted the Cancer Moonshot’s aim to invest in supporting scientific discovery in cancer research. This investment in basic science is visible through the National Institutes of Health Advanced Research Projects Agency for Health (ARPA-H) program, which funds ambitious high-impact projects to accelerate advancements in the field. In a complementary effort to ensure the United States remains a leader in cancer care innovation, President Biden issued an Executive Order to launch a national biotechnology and biomanufacturing initiative to ensure that cutting-edge biotechnologies are not only invented but also manufactured in the United States. Through these efforts and others, the Cancer Moonshot has outlined the aggressive goal to decrease the death rate from cancer by at least half over the next quarter century.

Overcoming Real-World Challenges to Accelerate Effective, Accessible, and Equitable Cancer Detection Strategies

With an understanding of how risk impacts cancer screening strategies, the final panel discussion focused on early detection and efforts to improve cancer screening for Americans. Dr. Philip E. Castle, Director of the Division of Cancer Prevention at the National Cancer

Institute (NCI), clarified that screening constitutes an entire algorithm of care that includes the engagement of persons prior to their becoming patients. However, when speaking of the testing piece, it is important to acknowledge that the goal is not blanket screening for all individuals, as tests are not perfect and include some risk for false-positives and false-negatives. That said, guideline-recommended screening programs are integral to early detection and relatedly better outcomes of a cancer diagnosis.

Nikia Clark, Senior Community Outreach & Engagement Manager at Roswell Park Comprehensive Cancer Center, discussed strategies to encourage individuals to get their recommended cancer screenings, and acknowledged that “People are not as concerned about cancer screening as we are in this room. They’re not. And so, we have to acknowledge that, and we have to, again, meet people where they are.” This includes exploring existing social and structural barriers and designing programs to address these needs. Often barriers for screening are financial. Although the USPSTF issues guidance on screening, there is no national consensus on reimbursement. Policies are set by the US government for Medicare, by individual states for Medicaid, and by commercial insurers for their beneficiaries. Although there is some level of influence between groups, this level of fragmentation can lead to confusion and high out-of-pocket expenses. Dr. Chyke Doubeni, Chief Health Equity Officer at The Ohio State University Wexner Medical Center, highlighted a recent example of how reimbursement policies for colon cancer screening did not align with the clinical needs of patients. In the past, full Medicare coverage for colon cancer screening was limited to the screening and did not include the removal of polyps, which meant that if polyps were found during a screening colonoscopy, their removal (during that same procedure) was subject to coinsurance and patients often woke up with a surprise bill. Therefore, often patients were undergoing this screening without fully understanding their out-of-pocket costs. As a result of the Removing Barriers to Colorectal Cancer Screening Act passed in 2020, Medicare will now remove cost-sharing for colonoscopies even when polyps are found.

Panelists also highlighted key characteristics of other successful screening programs. All agreed that community partnership was the most important factor in designing a screening program. More specifically, community health workers and patient navigators are fundamental to advancing screening rates and, importantly, equitable screening rates. According to Clark, “We have to address that we know the message. All of us in the room know the message, but we’re not the best ones to deliver it.” According to the panel, these individuals should be representative of the communities in which they serve, and should be paid as valued members of the healthcare team. Programs should

also build bridges to advocacy organizations and Federally Qualified Health Centers (FQHCs). Expanded services via telehealth is another example of meeting people where they are. Lisa Schlager, Vice President of Public Policy for FORCE: Facing Our Risk of Cancer Empowered, notes that telehealth has also improved access. Although screening itself may not be able to be completed via telehealth visits, ancillary services such as genetic counseling, which may lead to referral of patients for risk-appropriate screening, can be.

Although many barriers exist, the panelists remained hopeful about the many opportunities to advance early detection through screening. Dr. Eric Gratias, Chief Medical Officer at eviCore healthcare, highlighted some promising pilots they are conducting around the linking of data to clinical practice in the treatment paradigm, which may ultimately translate to prevention and screening programs as well. Panelists also identified opportunities that were borne out of the pandemic, including advancements in low-cost fast diagnostic technologies. They identified screening bundles as an opportunity to remove some of the physical and social barriers to needing multiple tests from a variety of specialists over the course of a year. Finally, panelists stressed the importance of aligning on screening coverage, either through a uniform payer mechanism for cancer screening or efforts to find consensus around what should be covered across payers.

Conclusions

Risk assessment and appropriate cancer screening remain some of the most important tools in improving cancer outcomes in the United States. Existing programs are often challenged due to limitations in data, as well as financial, structural, and social barriers to motivating individuals to act on recommendations. Despite these barriers, we can learn from highly successful programs and should apply appropriate attributes, such as community engagement, more broadly. The Cancer Moonshot has set ambitious goals in reducing the cancer burden, and as such it is important that key stakeholders, particularly patients, providers, advocates, and payers remain engaged on this topic.

Submitted April 17, 2023; final revision received May 26, 2023; accepted for publication May 31, 2023.

Disclosures: M.J. Hall has disclosed serving on an advisory board for Natera, and participating in research with Caris Life Sciences, Myriad Genetics, Invitae, and Ambry Genetics. L. Bandini, A. Schatz, V. Hood, and R.W. Carlson have disclosed being employed by NCCN. N. Clark has disclosed having no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors.

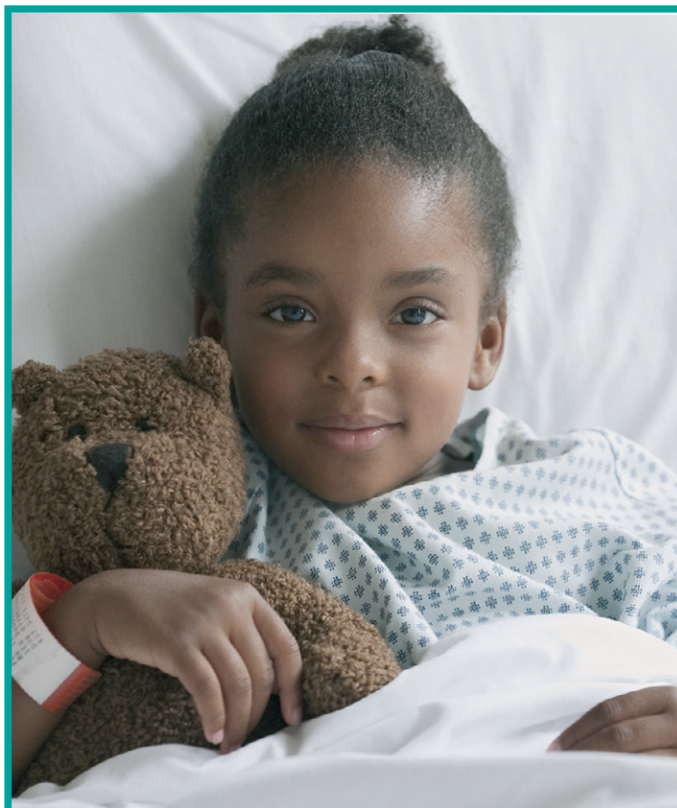
Correspondence: Lindsey Bandini, MPH, National Comprehensive Cancer Network, 3025 Chemical Road, Suite 100, Plymouth Meeting, PA 19462. Email: bandini@nccn.org

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eAppendix 1: Panel Roster

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Public Health Strategies for Cancer Control and Prevention

Lisa Richardson, MD, MPH, Director, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention

Investing in the Invisible: Strategies to Reduce Cancer Risk

Michael J. Hall, MD, MS, Chair, Department of Clinical Genetics, Fox Chase Cancer Center

Ernest Hawk, MD, MPH, Vice President and Head, Division of Cancer Prevention and Population Sciences, and Boone Pickens Distinguished Chair for Early Prevention of Cancer, MD Anderson Cancer Center

Maimah Karmo, Founder and CEO, Tigerlily Foundation

Carol M. Mangione, MD, MSPH, Chair, U.S. Preventive Services Task Force; Barbara A. Levey M.D. & Gerald S. Levey M.D. Endowed Chair, Chief of the Division of General Internal Medicine & Health Services Research, and Distinguished Professor of Medicine & Health Policy & Management, University of California, Los Angeles

Kate Mevis, Executive Director, US Federal & State Vaccine Policy, Merck

Lisa Richardson, MD, MPH, Director, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention

Moderated by **Clifford Goodman, PhD**, Consultant, Health Care Technology and Policy

Accelerating Advancements Through the Cancer Moonshot

Danielle Carnival, PhD, White House Cancer Moonshot Coordinator

Overcoming Real-World Challenges to Accelerate Effective, Accessible, and Equitable Cancer Detection Strategies

Philip E. Castle, PhD, MPH, Director, Division of Cancer Prevention; Senior Investigator, Division of Cancer Epidemiology and Genetics, National Cancer Institute

Nikia Clark, Senior Community Outreach & Engagement Manager, Roswell Park Comprehensive Cancer Center

Chyke Doubeni, MBBS, MPH, Chief Health Equity Officer, The Ohio State University Wexner Medical Center

Eric Gratias, MD, FAAP, Chief Medical Officer, eviCore healthcare

Lisa Schlager, Vice President, Public Policy, Facing Our Risk of Cancer Empowered (FORCE)

Moderated by **Clifford Goodman, PhD**, Consultant, Health Care Technology and Policy