

# MEETING SUMMARY

## PRESIDENT'S CANCER PANEL

### NATIONAL CANCER PLAN STAKEHOLDER MEETING

September 7, 2023  
Virtual Meeting

The President's Cancer Panel (the Panel) brought together stakeholders from several sectors, including professional associations and nonprofit organizations. Participants provided updates on their organizations' programs, activities, and achievements related to the National Cancer Plan. The meeting was open to the public via live feed, and members of the public were invited to submit written comments and questions during and after the event. Participants and observers were encouraged to post about the event on X (formerly Twitter) and LinkedIn using the hashtags #NationalCancerPlan, #CancerMoonshot, and #Every1HasARole.

This meeting summary was prepared to satisfy requirements established by the Federal Advisory Committee Act. The summary provides an overview of presentations and discussions occurring as part of the workshop and does not necessarily reflect the views of Panel members.

#### ***President's Cancer Panel***

**Elizabeth M. Jaffee, MD, FACR, FAACP, Chair**

**Mitchel S. Berger, MD, FACS, FAANS**

**Carol A. Brown, MD, FACOG, FACS**

#### ***National Cancer Institute, National Institutes of Health***

**Maureen Johnson, PhD, Executive Secretary, President's Cancer Panel**

#### ***Participants***

**Olalekan Ajayi, PharmD, MBA, President, Association of Community Cancer Centers**

**Robert Carlson, MD, CEO, National Comprehensive Cancer Network**

**Margaret Foti, PhD, MD, CEO, American Association of Cancer Research**

**Danya Garner, PhD, RN, NPD-BC, OCN, CCRN-K, President, Oncology Nursing Society**

**Philip Greenberg, MD, FAACR, President, American Association of Cancer Research**

**Clifford Hudis, MD, FASCO, FACP, CEO, American Society of Clinical Oncology**

**Anita Kinney, PhD, RN, FAAN, FABMR, President, American Society of Preventive Oncology**

**Karen Knudsen, PhD, MBA, CEO, American Cancer Society**

**Wui-Jin Koh, MD, SVP and CMO, National Comprehensive Cancer Network**

**Yolanda Lawson, MD, FACOG, President, National Medical Association**

**William Louv, PhD, CEO, CEO Roundtable on Cancer**

**Jeff Michalski, MD, MBA, FASTRO, President, American Society for Radiation Oncology**

**Edith Mitchell, MD, MACP, FFCP, FRCP, Former President, National Medical Association**

**Brenda Nevidjon, MSN, RN, FAAN, CEO, Oncology Nursing Society**

**David Reese, MD, Chair of the Board of Directors, CEO Roundtable on Cancer**

**Elena Rios, MD, MHPH, MACP, President and CEO, National Hispanic Medical Association**

**Lynn Schuchter, MD, FASCO, President, American Society of Clinical Oncology**

**Anne Snowden, PhD, MSc**, Chief Scientific Research Officer, Health Information and Management Systems Society

## **OPENING REMARKS**

Dr. Elizabeth Jaffee welcomed invited participants and other attendees and introduced the Panel members. She read the Federal Advisory Committee requirements, and then the Panel voted on two items:

- The formation of the Working Group “Addressing Inequities in Cancer Care through Navigation” to help the Panel plan for its upcoming meeting series “Reducing Cancer Care Inequities: Leveraging Technology to Enhance Patient Navigation”
- The dates of those meetings: October 17, November 2 and 3, and December 7, 2023.

The Panel unanimously voted to approve both items.

Dr. Jaffee then reviewed the history of the President’s Cancer Panel, which was established by the National Cancer Act of 1971 and charged with monitoring the activities of the National Cancer Program and reporting to the President of the United States on barriers to progress in reducing the burden of cancer.

In April of 2023, the U.S. Department of Health and Human Services (HHS) and the National Cancer Institute (NCI) released the National Cancer Plan, a long-term initiative to meet the goals of President Biden’s Cancer Moonshot. The plan is designed to facilitate collaboration, communication, outreach, and partnerships not only in the cancer research and care community, but across all sectors of society to make faster progress in ending cancer as we know it. Its goals include:

- Prevent cancer
- Detect cancers early
- Develop effective treatments
- Eliminate inequities
- Deliver optimal care
- Engage every person
- Maximize data utility
- Optimize the workforce

Dr. Jaffee gave an overview of the meeting and its format. She invited participants and observers to submit comments via the chat feature of the virtual platform during the meeting, and on social media or via email at any time. Input received during this meeting and through public comment until September 30 will be considered and inform the Panel’s report to the President of the United States.

## **ONCOLOGY NURSING SOCIETY (ONS)**

*Danya Garner, PhD, RN, NPD-BC, OCN, CCRN-K, President, Oncology Nursing Society*  
*Brenda Nevidjon, MSN, RN, FAAN, CEO, Oncology Nursing Society*

Dr. Garner introduced ONS and gave an update on the society’s work. The society was incorporated in 1975 with a mission to advance excellence in oncology nursing and quality cancer care. Today, it has more than 35,000 members, mostly in the United States. The society provides evidence-based education and resources, guidelines for practice, nursing research and clinical trials, patient and nursing advocacy,

and connection and community for oncology nurses. Its two affiliated organizations, the Oncology Nursing Foundation and the Oncology Nursing Certification Corporation, also contribute to realizing the goals of the National Cancer Plan.

The society is guided by its strategic plan and annual clinical priorities. Current priorities include equitable and inclusive care, expansion of oncology care to non-oncology nurses, responding to the rapid growth of the oncology-drug pipeline, radiation oncology, interventional oncology, and genomics. ONS supports the National Cancer Plan by advocating for policies that propose access to quality, patient-centered care; patient navigation; and oncology nurse workforce safety and wellbeing.

While all of the society's work generally supports the aims of the National Cancer Plan, recent efforts are making contributions to three specific goals.

### **GOAL 3: PROVIDE EFFECTIVE TREATMENTS**

ONS has established a learning library that includes extensive internal and external resources, such as short videos answering questions from members, links to scientific articles, podcasts, webinars, studies, and the ONS biomarker database. The database is searchable by cancer type, biomarker, and targeted therapy. Results are immediate and provide information on implications for patient care, approved targeted therapies, and links to clinical trials.

### **GOAL 5: DELIVER OPTIMAL CARE**

Symptom management is a major part of cancer care, and the core work of the more than 60 percent of ONS members who provide direct patient care. To support this work, ONS offers evidence-based clinical resources including symptom intervention resources and guides, courses for nurses and advanced-practice providers, podcasts that deliver expert advice on symptom management, and self-paced clinical learning opportunities in the form of peer-reviewed books. These offerings also support Goal 3 of the National Cancer Plan.

### **GOAL 8: OPTIMIZE THE WORKFORCE**

The nursing workforce is facing challenges and shortages that are predicted to continue and potentially worsen over the next decade. To mitigate these losses and help create a robust workforce, ONS has strategically prioritized three cancer care roles: pre-licensure students, advanced practice nurses, and nurse scientists.

The pipeline begins with nursing students, many of whom have not been previously exposed to information about or opportunities in oncology nursing. Curricula for pre-licensure nursing students often includes little oncology content, and faculty may have limited knowledge in this area. ONS has made society membership and access to relevant courses free to pre-licensure nursing students. Some of these courses are now being offered by nursing schools for academic credit. The society also created its Learning Extension Activities Plan (LEAP) as a resource for nursing faculty who may have limited knowledge of oncology. ONS chapters participate in high school career days and connect with nursing schools to engage local students.

ONS's second pipeline focus is nurse practitioners. To meet the rising demand for care, approximately 30,200 new advanced practice nurses will be needed each year through 2031. ONS has crafted tailored resources to support nurse practitioners who may not have oncology knowledge.

There is also a great need for nursing faculty and nurse scientists, especially those with doctoral degrees. Shortages in faculty have implications for the nursing workforce at all levels, as well as for nursing

research. ONS's strategies to support early career faculty include a scholar-in-residence position and supporting nurse scientists to lead research initiatives. An oncology nurse scientists' intensive provides mock study section experience and helps participants refine their grant proposals. The society also offers training in specific research skills.

## **DISCUSSION**

Drs. Garner and Nevidjon answered questions from the Panel.

- In ONS's view, the greatest obstacle to progress toward the goals of the National Cancer Plan is the shortage of oncology nursing professionals. Additional funding to support nursing education and the pipeline would help mitigate this issue.
- ONS collaborates not only with other nursing organizations but also with individual professionals, employers, and institutions across the care continuum to support workforce development.
- Given the staffing shortages in nursing, new models of care delivery are needed. ONS is currently investigating ways to integrate professionals from other sectors, such as licensed practical nurses and advanced practice providers, to fill gaps and ensure continuity of care.
- ONS has adopted a diversity, equity, and inclusion (DEI) statement that encompasses the society's members as well as their patients and communities. The society has chapters in rural and disadvantaged areas to connect under-resourced communities with care. Telehealth access and nurturing a diverse workforce are two critical aspects of working toward more inclusive care.
- With support from industry, the society has created more than a dozen learning libraries for members and students. The libraries contain many different information delivery methods, from tip sheets and articles to videos, and are curated by staff nurses and volunteers.
- The causes of the current nursing shortage are manifold. Psychological stress and burnout from caring for vulnerable individuals through the COVID-19 pandemic, the rising rates of violence against healthcare professionals, and insufficient funding are significant contributors.

## **AMERICAN SOCIETY OF PREVENTIVE ONCOLOGY (ASPO)**

*Anita Kinney, PhD, RN, FAAN, FABMR, President, American Society of Preventive Oncology*

Dr. Kinney introduced ASPO and gave an update on the society's work. Since its inception in 1978, ASPO has worked to be a beacon of innovation and collaboration in the realm of cancer prevention and control. The society serves as a hub for the exchange and translation of cutting-edge scientific knowledge, fostering a collective drive to alleviate the cancer burden while nurturing the researchers engaged in these pursuits.

ASPO's work supports all six pillars of the cancer care continuum—etiology, prevention, detection, diagnosis, treatment, and survivorship—and is aligned with all eight goals of the National Cancer Plan. Relative to other organizations in this space, ASPO is small, with 415 members working across the

United States. The society's keystone activity is its annual meeting, which brings together cancer researchers, outreach staff, and community health advocates.

## **NATIONAL CANCER PLAN INTEGRATION**

The society has eight special interest groups, six of which directly support the goals of the National Cancer Plan.

- **Behavioral Science and Health Communication:** Uses multidisciplinary methods and theories to inform cancer prevention and control efforts and target the design and implementation, evaluation, and dissemination of behavioral interventions for risk-promoting behaviors.
- **Survivorship and Health Outcomes/Comparative Effectiveness Research:** Studies the effects of cancer on patients and families as well as the physical, psychological, social, and economic impacts of cancer.
- **Cancer Health Disparities:** Examines the causes of disparities in cancer risk factors and outcomes among population groups and develops and evaluates interventions to reduce and eliminate the unequal burden of cancer.
- **Early Career:** Facilitates collaboration between scientists at all career stages; delivers cancer-focused education through the annual meeting and regular webinars and grant writing, peer review, and building collaborations; and sponsors workshops and networking events for all career stages.
- **Early Detection and Risk Prediction:** Unites scientists investigating the overall effectiveness of population-based cancer screenings; studies optimal timing and frequency of screenings; assesses new screening technologies alongside existing methods; and analyzes overall effectiveness, coverage, and impact of cancer diagnosis and treatment.
- **Lifestyle Behaviors, Energy Balance, and Chemoprevention:** Unites scientists investigating factors in cancer, such as tobacco, nutrition, alcohol, physical activity, and energy balance; studies cancer causation, progression, and outcomes; and evaluates benefits, harms, and risks of interventions.

## **PRE-CONFERENCE WORKSHOP**

ASPO holds an annual pre-conference workshop with population science and community outreach leaders from NCI-designated cancer centers. The workshop agenda is informed by a questionnaire that asks ASPO members about current needs.

## **DIVERSITY, EQUITY, AND INCLUSION**

The society fosters DEI through travel support for early career scientists, investigators from underrepresented backgrounds, community scientists, and patient advocates who would like to attend the annual meeting. ASPO has been working for the last decade to increase the diversity of its member base.

## **RECOGNIZING EXCELLENCE**

ASPO recognizes excellence in cancer prevention research through two awards. The Joseph Cullen Memorial Award recognizes excellence in national tobacco control efforts; honors achievements in research, prevention programs, policy and advocacy; and encourages collaboration among scientists,

healthcare professionals, and advocates. The Joseph Fraumeni, Jr., Distinguished Achievement Award is presented to an outstanding scientist in preventive oncology, cancer control, or prevention; it acknowledges substantial research contributions and dedication to the field and recognizes contributions to the ASPO community. Each awardee is invited to deliver an address at the society's annual meeting.

## **DISCUSSION**

Dr. Kinney answered questions from the Panel.

- Some examples of progress toward cancer prevention for at-risk populations include advances in colorectal cancer screening that utilize healthcare system-level data and electronic health records (EHRs), as well as innovative strategies to boost lung cancer screening rates. The colorectal cancer screening efforts included mailing fecal immunochemical tests to incentivize individuals to participate in screening. This highly effective intervention was originally implemented in a health system that serves under-resourced communities and has since been implemented by other organizations.
- While the society does not track outcomes, individual researchers have data. The annual meeting includes discussion of how community outreach efforts have impacted cancer center catchment areas.
- The focus of ASPO is cancer research, but the society does evaluate strategies to disseminate members' findings to the cancer community. Individual researchers take the initiative to share their work.
- Barriers to widespread genetic testing include limited public and patient awareness and a shortage of certified genetic counselors. To address this shortage, ASPO members are researching alternative care delivery models that integrate web-based digital interventions like chatbots to provide genetic education and facilitate care delivery. Patient navigation is an essential component of the entire cancer care continuum, including connecting patients with genetic counseling resources. Cost and reimbursement are significant additional barriers to genetic testing.
- Individual ASPO members are conducting research into cultural barriers to screening and preventive care, including provider education and social determinants of health.
- The federal government should increase funding for cancer prevention and control, and health disparities research that incentivizes community engagement.
- Research by ASPO members helps drive policy. In the past, ASPO member research into telehealth counseling led to changes in reimbursement policy for that delivery model.

## **HEALTHCARE INFORMATION AND MANAGEMENT SYSTEMS SOCIETY (HIMSS)**

*Anne Snowdon, PhD, MSc, Chief Scientific Research Officer, Health Information and Management Systems Society*

Dr. Snowdon introduced HIMSS and gave an update on the society's work. The society's mission and vision are to fully realize the health potential of every human everywhere and to reform the global health system through the power of information and technology. HIMSS is based in the United States but has more than 115,000 members around the world.

## NATIONAL CANCER PLAN INTEGRATION

The society's thought leadership and digital transformation activities enable all eight goals of the National Cancer Plan.

- **Prevent Cancer:** Develop and implement proactive alerts and digital tools that support preventive health behaviors and screening strategies, personalized to every individual.
- **Detect Cancers Early:** Strengthen screening access and knowledge using digital tools that inform and encourage early detection and track outcomes.
- **Develop Effective Treatments:** Optimize real-world evidence of treatment outcomes including patient reported goals and outcomes.
- **Eliminate Inequities:** Identify disparities and underserved populations to tailor care to unique needs of each individual or population segment.
- **Deliver Optimal Care:** Personalize care optimized to fit with the unique life circumstances, goals, and values of every individual.
- **Engage Every Person:** Foster meaningful connectivity between providers and patients as partners in prevention, detection, and care delivery that is outcomes driven.
- **Maximize Data Utility:** Automate the flow of data to inform decisions of every person and every provider.
- **Optimize the Workforce:** Utilize automated work environments and digital minimalism to optimize digital work environments and retain the health workforce.

This “digital transformation” approach is informed by an extensive analysis of scientific literature and has four dimensions: person-enabled health and wellness, analytics and traceability, interoperability, and governance and workforce. In service of this approach, HIMSS has created the Digital Health Indicator scale, which measures progress toward a digital health ecosystem. With this scale, operational and care delivery processes are outcome driven and informed by data and real-world evidence to achieve exceptional and sustainable quality, safety, and performance.

Dr. Snowdon and her colleagues have a manuscript currently under review that explores the relationship between digital maturity and patient satisfaction. They found that patient experience ratings were higher for organizations with advanced digital maturity. Additionally, higher digital maturity is associated with improved quality and safety outcomes across many metrics.

## RECOMMENDATIONS

In closing, Dr. Snowdon offered the Panel three recommendations from HIMSS, all of which dovetail with the goals of the National Cancer Plan.

- Engage every person in personalized self-management of health and care, enable proactive prevention, and eliminate inequities by strengthening population health outcomes.
- Advance automated digital work environments that mobilize data across the journey of care, implement personalized digital tools, and use analytics to gather data that can better inform decisions.
- Hold organizations accountable for equity, monitor for impact, proactively prioritize population health outcomes with real-time tracking, ensure a sustainable workforce in digital

work environments, drive value for each user, and ensure that healthcare is accessible and high performing.

## **DISCUSSION**

Dr. Snowdon answered questions from the Panel.

- Barriers to achieving person-enabled health systems are multifactorial and include the disease-centered (rather than patient-centered) model of care, as well as the proliferation of health misinformation and erosion of public trust in health communications.
- Connecting patients with digital health solutions is less about technology and more about integrating those tools and transforming health systems to give patients meaningful choices.
- Effective support from the federal government would come in the form of requiring health systems to track and demonstrate outcomes on patient and community engagement, and setting targets to engage more personalized, meaningful relationships with individuals and population segments.
- An additional barrier to progress is patient access to digital devices and tools. To overcome this obstacle, health systems must tailor their care delivery models to meet the needs and realities of the communities they serve. The federal government can support this work by creating policies like meaningful use that encourage outcome-focused technology integration. One example is the German government's requirement that health systems organizations report outcomes for specific priority populations.
- Regulating health information on the internet, whether in social media or generated by artificial intelligence, will be an important step, as a large percentage of the population now seeks health information on social media.
- Interoperability issues are linked to health disparities. A federal policy might require that health systems demonstrate interoperability or concrete progress toward it in order to receive funding.

## **AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO)**

*Lynn Schuchter, MD, FASCO, President, American Society of Clinical Oncology*  
*Clifford Hudis, MD, FASCO, FACP, CEO, American Society of Clinical Oncology*

Dr. Schuchter introduced ASCO and gave an update on the society's work. ASCO is a global organization representing nearly 50,000 physicians of all oncology specialties and other healthcare professionals who care for people with cancer. The society supports and conducts research that leads to improved patient outcomes and is committed to ensuring that evidence-based practices for the prevention, diagnosis, and treatment of cancer are available to all Americans.

The society has a large portfolio of education and research initiatives that further the goals of the National Cancer Plan. Dr. Schuchter introduced three programs that, together, support six of the plan's eight goals.

### **ASCO CERTIFIED**

ASCO Certified is a new patient-centered cancer care certification program, a model that enables every clinician to deliver patient-centered care regardless of the payment model in which they operate. The certification program emerged from a collaboration with the Community Oncology Alliance to create oncology medical home standards and chemotherapy safety standards. The program is based on a



successful pilot in 12 oncology practices across the country, from small community sites to academic medical centers. Patients in the participating practices reported very positive experiences, while clinicians have reported that ASCO Certified brings value to their practice.

The program had its official launch in July of 2023 and is expanding. Commercial payers are now participating; health plans and employer health coalitions have expressed interest.

ASCO Certified supports six goals of the National Cancer Plan:

- **Develop Effective Treatments:** The program facilitates enrollment on clinical trials.
- **Eliminate Inequities:** The program uses pathways to ensure consistent delivery of evidence-based care for all patients, including addressing social determinants of health; participating sites must demonstrate their health equity efforts.
- **Deliver Optimal Care:** Optimal care is delivered through the combination of clinical pathway utilization, safety standards, and care that extends beyond treatment and includes survivorship plans.
- **Engage Every Person:** Patients are engaged through shared decision-making, requirements for patient navigation and financial counseling, and improved care coordination.
- **Maximize Data Utility:** Data on quality and cost are collected and reported to inform continuous quality improvement.
- **Optimize the Workforce:** The program emphasizes a team-based efficient care model that optimizes the oncology workforce.

## RURAL CANCER CARE ACCESS

The Rural Cancer Care Access Demonstration Project seeks to address the challenges of delivering cancer care in rural and remote areas of the United States. Challenges to care delivery in rural areas include a lack of necessary infrastructure, a lack of oncology-trained professionals, and uneven access and use of telemedicine services. These challenges create additional financial burden to patients, and there is an established relationship between the distance patients must travel to receive treatment and the likelihood that they will not complete their full treatment course.

The pilot project employed a hub-and-spoke model of care delivery and leveraged telemedicine technology to build infrastructure at remote sites. A crucial component was recruiting and training professionals to deliver care at the spoke sites. The project was a collaboration with Bozeman Health, Barrett Healthcare, Montana State University, and the Merck Foundation.

The Rural Cancer Care Access Demonstration Project supports five goals of the National Cancer Plan:

- **Eliminate Inequities:** The program addresses inequities experienced by patients in rural communities.
- **Deliver Optimal Care:** Optimal care is delivered to patients who would otherwise struggle to access it, and the program leverages important resources both at the local level and at the hub site.
- **Engage Every Person:** Patients are engaged through enhanced navigation and care coordination.
- **Maximize Data Utility:** The project relies on ASCO Certified, collecting and reporting meaningful data to track outcomes and identify barriers.

- **Optimize the Workforce:** As this program grows, it may also help address workforce challenges in urban and suburban areas.

### **MINIMUM COMMON ONCOLOGY DATA ELEMENTS (MCODE)**

The mCODE project arose from the need for data standardization to support EHR interoperability, which is crucial for delivering effective care, as well as enabling vital research. The framework has been met with enthusiastic uptake, with adoption by the Centers for Medicare & Medicaid Services (CMS) and the American Society for Radiation Oncology (ASTRO).

mCODE supports four goals of the National Cancer Plan:

- **Develop Effective Treatments:** The program will enhance the development of effective treatments by allowing important comparisons across clinical sites, health systems, and outcomes.
- **Deliver Optimal Care:** Interoperability ensures that health systems can measure quality using the same data elements and report data on a national scale.
- **Engage Every Person:** Each patient's journey will be captured.
- **Maximize Data Utility:** mCODE unlocks EHR interoperability and clinical data exchange.

### **DISCUSSION**

Drs. Schuchter and Hudis answered questions from the Panel.

- Effective support from the federal government would come in the form of reducing barriers to patient care access and facilitating access to clinical research. ASCO would like to work with the U.S. Food and Drug Administration (FDA) to reduce complexity of clinical trial design.
- Universal healthcare support for cancer care would dramatically increase access to the continuum of care, from prevention and screening to treatments and survival.
- Expanded access to telehealth is also extremely important. Federal policies to support this access would need to address the question of licensure across state lines.
- Prior authorization is another significant barrier to progress and one cited by many oncology professionals as a reason they left the cancer workforce.
- mCODE is fully HIPAA compliant. The framework provides data standards and a common language to enable interoperability. It does not create any risk to patient privacy.
- ASCO Certified guidelines have a track record of improving health systems' effectiveness and quality. Certification indicates a system's value and its dedication to ongoing improvement, as sites are audited and must meet standards on an ongoing basis. Payers like CMS respond to these concrete successes.
- To increase and support diversity in the oncology workforce, ASPO offers a summer internship program for physicians from underrepresented backgrounds. The program has been operating successfully for several years.

## **AMERICAN SOCIETY FOR RADIATION ONCOLOGY**

*Jeff Michalski, MD, MBA, FASTRO, President, American Society for Radiation Oncology*

Dr. Michalski introduced ASTRO and gave an update on the society's work. With 10,000 members around the globe, ASTRO is the leading radiation oncology society in the world. The society's vision is to improve the lives of people with cancer through radiation therapy, and its mission is to advance the field of radiation oncology through promoting equitable, high-quality care for people with cancer, cultivating and educating a diverse workforce, fostering research and innovation, and leading policy development and advocacy.

ASTRO's strategic plan is highly aligned with the National Cancer Plan, and its work directly supports four of the plan's eight goals.

### **GOAL 8: OPTIMIZE THE WORKFORCE**

One of the society's goals is to foster a diverse workplace. This includes promoting diversity, equity, and belonging in all ASTRO activities; generating a diverse radiation oncology workforce that reflects the population; fostering, mentoring, and equipping researchers from underrepresented backgrounds; and expanding the reach and accessibility of educational offerings. Mechanisms to advance this goal include medical student engagement; creation of an internal diversity, equity, and inclusion council; establishment of Key Performance Indicators on the diversity of the workforce, ASTRO committees, and awards; funding career development research, including collaborative awards and fellowships with patient advocacy groups and industry; and provision of expanded virtual learning opportunities, including the ASTRO annual meeting.

### **GOAL 7: MAXIMIZE DATA UTILITY**

ASTRO is creating informatics solutions to increase data liquidity for patients, researchers, and clinicians. Key initiatives include the publication of minimum data elements in 2018; early participation in the Common Oncology Data Elements Extension (CODEX) and founding membership of mCODE; completion of a use case to aggregate and transfer radiation treatment summary data; creation of more modern, meaningful quality measures; and the streamlining of prior authorization.

### **GOALS 4 AND 5: DELIVER OPTIMAL CARE AND ELIMINATE INEQUITIES**

To deliver optimal care and eliminate inequities, the society encourages the development of evidence-based guidelines in cancer treatment; collaborates with other specialty societies on multidisciplinary guideline development and meetings; leads quality improvement and patient safety initiatives; and established the Radiation Oncology Incident Learning System (RO-ILS) to report medical errors and near misses as well as the Accreditation Program for Excellence (APEX).

ASTRO pursues policies that move away from the current fee-for-service system. The society has recently developed a Radiation Oncology Case Rate (ROCR) legislative proposal to change payment from a per-treatment model to a per-patient model. The proposed legislation would increase patient access to care, enhance quality of cancer treatments, reduce disparities for rural and under-resourced patients, and lower Medicare spending costs. For patients, the ROCR proposal integrates transportation assistance, enhances patient-centered care by supporting shorter treatments, enables access to technologically advanced treatment closer to home, and uses a systematic approach to improve quality and protect patient safety.

## CONCLUSION

Dr. Michalski offered four commitments from ASTRO to the Panel. ASTRO will:

- Lead the radiation oncology community in pursuit of President Biden's goal to reduce cancer mortality by 50 percent over 25 years.
- Advance computational and technical areas of science.
- Lead research on precision radiation therapy that leads to better patient outcomes with reduced side effects.
- Support its network of 2,500 practices based in hospitals and communities nationwide.

Major challenges include increasing public and clinical awareness of radiation therapy, the administrative burden and care-preventing nature of prior authorization requirements. Opportunities include the development of effective treatments through innovations like artificial intelligence, radiopharmaceuticals, and FLASH radiotherapy.

## DISCUSSION

Dr. Michalski answered questions from the Panel.

- One barrier to the adoption of innovative treatments is the need for high levels of evidence in order to justify investment in costly radiation oncology equipment. Additional support for clinical research is an essential component of moving these treatments ahead and ensuring they can be implemented in community settings.
- Policies incentivizing the establishment of radiation centers in remote and rural areas, as well as vouchers for lodgings and transportation, would significantly increase care access and thus equity.
- One of ASTRO's strategic priorities is to enhance the understanding of the role of radiation in cancer care delivery. To achieve this, the society holds interdisciplinary meetings and symposia with other organizations and works through multiple channels to disseminate educational materials to primary care providers.
- Equity includes ensuring that patients receive the same standard of care, regardless of their location. Practice accreditation and board certification can support this priority by holding sites and providers to consistent standards of efficiency, technology integration, safety, and quality.
- Two concrete ways the federal government could support radiation therapy access for all patients would be (1) supporting the establishment of radiation clinics in both remote areas and under-resourced urban areas and (2) continuing to invest in cancer research.
- Results from a recent workforce survey and analysis suggest that, over the next decade, the radiation oncology workforce will have enough physicians but still lack sufficient numbers of other medical professionals. While the numbers of physicians may be sufficient, they are not evenly distributed across the country.

## **AMERICAN CANCER SOCIETY (ACS)**

*Karen Knudsen, PhD, MBA, CEO, American Cancer Society*

Dr. Knudsen introduced ACS and gave an update on the society's work. ACS is not a professional or member society but an organization that collaborates with these groups to support cancer patients, families, caregivers, and survivors. The society's mission mirrors that of the reignited Cancer Moonshot: to end cancer as we know it for everyone. Its vision is to improve the lives of people with cancer and their families through advocacy, research, and patient support to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer.

ACS is the largest nongovernment funder of cancer research and has committed around \$430 million in cancer research funding. The society has an advocacy presence at every level of government and in all 50 states, working for legislation and common-sense policies that increase access to care. It provides direct patient support in more than 20,000 communities across the country. In total, the society's work touches 55 million lives each year.

Earlier in 2023, ACS responded to the launch of the National Cancer Plan by aligning the society's policies with the plan's goals. Current activities support three of the eight goals.

### **GOAL 1: PREVENT CANCER**

ACS supports cancer prevention strategies that can be adopted by people of all ages. The society will continue to fund investigators studying novel ways to prevent cancer or cancer recurrence through mechanisms like its Clinical Trials Enabling Research Scholar program, which was launched in collaboration with the National Institutes of Health. The society will expand its partnerships with national organizations serving diverse communities to design and deliver culturally tailored outreach and cancer education programs. A new collaboration with Color Health will use clinical evidence-based research on cancer prevention to design bespoke screening strategies for workforces and individuals.

ACS will also increase its work with communities and partners to disseminate best practices related to cancer risk reduction. The society has created a series of toolkits for use by employers and employee benefit groups to demystify the prevention of colorectal, prostate, breast, lung, and skin cancer and to increase awareness of the role of nutrition and physical activity in cancer prevention. And finally, the ACS Cancer Action Network (CAN) will advocate to increase funding of critical cancer prevention programs, such as tobacco control, in all 50 states and Puerto Rico. These efforts have already met with success at the state level in Ohio.

### **GOAL 2: DETECT CANCERS EARLY**

ACS has many efforts in place to support early cancer detection. The society has updated its long-established process for developing cancer screening guidelines; the guidelines will now be updated annually rather than every five years in order to ensure that recommendations are informed by the latest scientific evidence. These living guidelines will be more nimble, more current, and more efficient.

Through mechanisms like the ACS Roundtables, information campaigns, and individual education, the society will enhance awareness of cancer prevention and early detection guidelines among patients, caregivers and healthcare professionals. ACS CAN will also continue to pursue increased access to high-quality insurance coverage through advocacy for Medicaid expansion, increased funding for critical screening programs, and reimbursement of innovative technologies. So far in 2023, six states have enacted laws to increase insurance coverage of biomarker testing.

## **GOAL 4: ELIMINATE INEQUITIES**

The society envisions a world in which disparities in cancer and mortality incidence and all people have access to cancer treatment, screening, interception, and prevention. To work toward this goal, ACS will launch a new cohort of 100,00 Black women in the VOICES study, with a goal of unraveling the etiology of cancer disparities and outcomes in this population. The society is orchestrating a “Amate a Ti Misma” (“Love Yourself”) campaign in Spanish with national partners, including Univision, to guide the public to prevention and screening resources in their communities.

ACS is a passionate supporter of patient navigation, funding navigators across the country. The CY24 CMS Medicare Physician Fee Schedule Proposal included an item on reimbursement for patient navigation; ACS CAN and ACS submitted comments in support of this proposal. The society also runs the ACS National Navigation Roundtable, which aims to catalyze work on key issues around patient navigation, disseminate best practices, and enhance the field of patient navigation.

## **DISCUSSION**

Dr. Knudsen answered questions from the Panel.

- Screening and prevention information are disseminated to the public through many channels, including cancer.org, employer toolkits, messaging campaigns, and the ECHO™ Model, which helps physicians keep apprised of the latest research and guidelines. The society also supplies data-driven toolkits to Federally Qualified Health Centers around the country.
- Raising awareness of and increasing access to cancer prevention and screening have led to concrete, quantifiable improvements in the rates of cancer, as have policy changes. ACS CAN advocacy work in Puerto Rico led to the creation of policies that outlawed smoking in public; since that time, rates of lung cancer have declined. A similar success can be seen with HPV vaccination in Puerto Rico: as vaccine uptake increased, rates of cervical cancer diagnoses declined.
- Meaningful policy action from the federal government would include reimbursement for screenings and treatment, particularly at-home screenings and blood-based detection tests, as well as patient navigation. Medicaid expansion would also significantly improve care access and thus decrease cancer cases and mortality.
- The society’s ongoing efforts include the Improving Mortality from Prostate Cancer Together (IMPACT) Initiative, which aims to improve outcomes for all and reverse disparities for Black men. Early onset colorectal cancer is an additional priority.
- For cancers that currently have no established screening methods, ACS is both supporting and conducting research through its existing cohorts.

## **NATIONAL MEDICAL ASSOCIATION (NMA)**

*Yolanda Lawson, MD, FACOG, 124th President, National Medical Association*

*Edith Mitchell, MD, MACP, FFCP, FRCP, 116th President, National Medical Association*

Dr. Lawson introduced the NMA and gave an update on the association’s work. NMA is the collective voice of African American physicians and a leading force for parity and justice in medicine. Representing more than 50,000 African American physicians and their patients, the NMA is committed to preventing disease, improving healthcare accessibility, and increasing diversity in medicine. The association has

extensive national, regional, and local infrastructure for promoting its programs. The organization comprises 26 medical specialties and more than 130 state and local affiliate societies.

The NMA's commitments include:

- Preventing the diseases, disabilities, and adverse health conditions that disproportionately or differentially affect persons of African descent and underserved populations
- Supporting efforts that improve the quality and availability of healthcare to underserved populations
- Increasing the representation, preservation, and contributions of persons of color in medicine
- Providing support to physicians of African descent and their patients

### **NMA CANCER INITIATIVE**

NMA's priorities align with those of the National Cancer Plan, particularly through the association's cancer initiative. The objectives of the initiative are to reduce cancer mortality in African American communities, increase screening in medically underserved communities, increase awareness of the importance of cancer screening, and advocate for access to affordable and comprehensive screening programs.

The association has identified numerous barriers to progress. The greatest challenge is increasing access to screenings and early detection, including the adoption of multi-cancer early detection (MCED) tests. Culturally competent outreach is another challenge. Myths and misconceptions must be addressed appropriately and respectfully in a way that engenders trust; African American physicians are well situated to do this work, as they are often trusted voices in their communities. An additional barrier is cost and administrative burden; to address this, the NMA works to promote legislation that supports reimbursement for cancer screening.

The structure of the NMA creates opportunities for a broad and tiered approach to implementation. Action at the community level is equally important to national efforts. The association collaborates with healthcare providers, community clinics, and hospitals and produces public information campaigns using various media channels, including radio. The association partners with national and local organizations on outreach programs. A pillar of the association's work is ensuring that telemedicine and technology-driven approaches address, rather than exacerbate, health disparities, including in remote areas.

Another priority area is knowledge sharing, which takes the form of annual meetings and the dissemination of best practices. This year's meeting included sessions and symposia on gynecologic oncology, reducing health disparities, and improving cancer outcomes. The association also recently launched the Consortium on Disparities of Urologic Conditions (ConDUC), within the Scientific Consortium on Prostate Cancer Education (SCOPE) registry. The registry is a database of predominantly African American patients and a resource for connecting patients to clinical trials. The consortium also provides mentoring and training for African American urologists with respect to the development of their professional skillsets and the importance of clinical trials and trial participation.

In alignment with the National Cancer Plan, the NMA's priorities include education, with a lens on disparities; workforce development, particularly for oncologists of color; modeling of best practices; collaboration with policymakers to support cancer screening legislation; and community impact.

## **WORKFORCE DISPARITIES**

Dr. Mitchell provided additional context on the history of the NMA and workforce disparities in the United States. Founded in 1895, the NMA was the first organization to explicitly work against medical disparities—those affecting patients as well as clinicians. To this day, African American providers remain underrepresented among clinicians, particularly in oncology. The NMA has several collaborative initiatives in place to increase equity and representation, including the Jane Cooke Wright, M.D. Cancer Disparities Symposium, the Cobb Scholars Program, the Multiple Myeloma Initiative, and a partnership with the National Association of Black Oncologists.

## **DISCUSSION**

Drs. Lawson and Mitchell answered questions from the Panel.

- Meaningful policy action from the federal government would prioritize increasing access to cancer care for all. Many efforts to improve access focus on uninsured Americans, but there are also many with insurance who cannot access care, particularly in rural and urban areas. Increasing access to cancer screening would have a particularly significant impact.
- There is significant distrust of medicine among communities that have experienced historical mistreatment and exploitation from providers and researchers. Creating and supporting a diverse workforce will go a long way toward increasing trust, but success will require a broad and multi-pronged approach that can meet each community and individual where they are.
- An important aspect of bolstering workforce diversity is working with local community organizations and uplifting professionals already working in the field. Providing support, education, and opportunities for professional development for professionals from underrepresented backgrounds will allow those individuals to remain and thrive in their roles.
- The 2023 Supreme Court decision to strike down affirmative action policies has already had a chilling effect on diversity in education. These deleterious effects will continue to ripple out and significantly impact the scientific and medical workforce. The pipeline depends on support for equitable education.

## **ASSOCIATION OF COMMUNITY CANCER CENTERS (ACCC)**

*Olaekan Ajayi, PharmD, MBA, President, Association of Community Cancer Centers*

Dr. Ajayi introduced the ACCC and gave an update on the association's work. Founded in 1974, ACCC brings together more than 37,000 healthcare professionals across all oncology disciplines to promote quality cancer care in all 50 states. Members rely on ACCC for education and advocacy support in adapting and responding to complex changes and challenges in the delivery of cancer care. ACCC provides resources on many topics: reimbursement issues; policy and regulatory changes at the state and national levels; trends in cancer care; operations and management for programs and practices; and integration of new technologies and therapies. ACCC members work in a diverse range of settings, from small to large and from rural to urban.

## **GOAL 8: OPTIMIZE THE WORKFORCE**

In alignment with the National Cancer Plan's eighth goal, AACR is committed to rebuilding the workforce and ensuring that professionals are adequately trained to deliver cancer care in the digital age. The association hopes to accomplish this through three pathways:



- Identify, develop, and deliver educational and advocacy resources to expand the capacity of the cancer care workforce.
- Explore innovative ways to deliver the highest quality of care.
- Collaborate with thought leaders and stakeholders across multidisciplinary organizations to identify, foster, and mentor future leaders in cancer care delivery.
- Build a coalition of oncology professionals to reflect the growing complexity of cancer care and realize more equitable cancer care delivery.

#### **GOAL 4: ELIMINATE INEQUITIES**

The association's efforts are centered around seven key priorities, the most central of which is health equity. While supportive care services are included in cancer care guidelines, gaps in implementation still exist. A 2020 survey of ACCC members identified significant barriers to the availability and delivery of comprehensive cancer care, including insufficient fee-for-service reimbursement and a lack of relevant staff and specialists to deliver supportive services. These challenges are especially pronounced in community settings of care, where organizations have less access to philanthropic and other support.

To address these issues, ACCC is creating tools, resources, and scenario-based education for providers to increase their confidence and efficacy in providing culturally competent and evidence-based care for the whole patient. Given the stark inequities in breast cancer, the association is collaborating with other stakeholders to develop a playbook for providers and cancer programs on strategies for promoting health equity in minority patients with breast cancer.

Patients with cancer have a high financial burden; some patients report that the financial costs of treatment concern them more than the possibility of dying. ACCC has developed guidelines to prevent financial toxicity for patients. The association's Financial Advocacy Network is a robust resource for cancer centers to inform and enable treatment without financial toxicity.

Cancer diagnosis and mortality rates in Appalachia are among the highest in the country, particularly for cervical, colorectal, and lung cancer. Together with six of its state societies, ACCC launched the Appalachian Community Care Alliance to address the need for improved cancer screening and care in that region. The Rural Appalachian Lung Cancer Screening Initiative seeks to increase lung cancer screening rates in targeted counties in Kentucky, Tennessee, and West Virginia by addressing operational barriers to implementation, identifying and addressing cultural barriers to care access, and partnering with local advocates to support practice sites.

#### **DISCUSSION**

Dr. Ajayi answered questions from the Panel.

- Cancer care organizations need resources and infrastructure in order to provide supportive care services on an ongoing, sustainable basis. Reimbursement for providers is a major factor, as is access to medical transportation for patients. Empowering cancer centers and cancer programs to foster community would be an effective path to sustainability.
- Workforce rebuilding will require funds for training, education, and professional development, as well as advocacy for the workforce. Connecting workers in community settings with larger cancer centers is one way to create collaborations and maximize resources.

- ACCC prioritizes collaboration. The association has many partners, including Longevity, ASCO, and government bodies.

## **NATIONAL HISPANIC MEDICAL ASSOCIATION (NHMA)**

*Elena Rios, MD, MPPH, MACP, President and CEO, National Hispanic Medical Association*

Dr. Rios introduced the NHMA and gave an update on the association's work. NHMA was established in 1994 by a group of physicians with a mission to improve the health of Hispanics and other underserved populations. The association represents 50,000 Hispanic doctors, or only about 6 percent of doctors in the United States.

Overall screening rates for cancer are lower among Black, Hispanic, Asian, and Native American populations than for non-Hispanic White Americans. Members of these populations have less insurance coverage, less access, and less representation in the healthcare workforce. Hispanic cancer survivors also report worse quality of life and unmet supportive care needs. Research indicates that institutional bias and discrimination are drivers of racial health disparities in diagnosis, prognosis, and treatment.

One of the association's primary activities has been the creation of a training organization through the NHMA Leadership Fellowship, which supports 20 physicians per year. The program offers training in executive leadership to uplift Hispanic providers as leaders at the state and national levels.

NHMA supports the efforts of the National Cancer Plan. In particular, many aspects of association's current efforts support Goal 4: Eliminate Inequities.

## **NATIONAL CANCER PLAN INTEGRATION**

Many of the association's efforts to eliminate inequities take the form of education and awareness campaigns directed at both providers and patients. Since its founding, NHMA has partnered with the U.S. Department of Health and Human Services (HHS) Office of Minority Health, CDC, and private partners to provide culturally and linguistically appropriate healthcare and prevention information. The society holds regular webinars and targeted education programs like health fairs and provides speakers for local and national media and professional events.

NHMA also created [HispanicHealth.info](http://HispanicHealth.info), a unique portal with information in English and Spanish for both providers and patients. The portal was developed with support from Congress. The National Hispanic Health Professional Leadership Network, which includes all major Hispanic health professional organizations, convenes each year at the NHMA annual conference. Creating synergy among these individuals and groups is the heart of NHMA's work.

Culturally competent and linguistically accessible prevention education, resource sharing, and information dissemination are critical. To support these goals, NHMA joined with the Association of American Indian Physicians and the National Council of Asian Pacific Islander Physicians in creating the Alliance of Multicultural Physicians.

The NHMA College Health Scholars Program is a five-year program funded by the HHS Office of Minority Health to document the efficacy of in-person and web-based mentoring for college students, beginning with students in California and Texas. The NHMA national conference also included a forum on the importance of increasing diversity through mentoring; the forum had around 2,000 participants. Through a cooperative agreement with CDC, the association has also launched a workforce development program to increase diversity in the public health sector. The NHMA is working with Advanced Research Projects Agency for Health (ARPA-H) to recruit Hispanic professionals as program managers, and with

researchers and technology organizations on a summit. The association's specialty councils support medical students and researchers in the United States and international students who want to attend medical schools here; a council of oncologists is under development.

The NHMA National Hispanic Health Foundation developed a major scholarship program for Hispanic students admitted to medical school and schools of nursing, dentistry, and public health. Its National Hispanic Pharmacists Association supports pharmacists.

The association is also building networks to support cancer research and researchers through mentorship and clinical trials and is working to increase Hispanic representation on advisory boards and councils.

Federal investment in research and data collection should focus more on access and education, as well as treatment and compliance. The lack of education and language services impedes research and clinical care. Investing more in community-based research is also important.

## **DISCUSSION**

Dr. Rios answered questions from the Panel.

- The federal government could significantly improve workforce diversity by increasing set-aside funds for nonprofit organizations and academic institutions, as these entities are closely linked to their communities. These organizations need support for recruitment, mentoring, and retention efforts.
- Another mechanism for supporting the research pipeline is subcontracts and supplements for research and training and to support community health workers. Organizations and professionals in remote areas often lack access to research funding and connection to the research enterprise.
- Cultural barriers to cancer prevention and care for Hispanics in the United States include the stigma associated with illness, the complex issue of pain management and palliative care, undocumented individuals' concerns about immigration authorities, a lack of unity or continuity in communities, bias in the healthcare system, and the heterogeneity of the Hispanic population, which comprises many different nationalities and backgrounds.
- One example of a successful cultural competency initiative is a program at Parkland Hospital in Dallas, which hired bilingual high school students to serve as translators. In exchange for their work, the students were offered nursing school tuition, which then improved the local nursing pipeline.

## **AMERICAN ASSOCIATION FOR CANCER RESEARCH (AACR)**

*Margaret Foti, PhD, MD, CEO, American Association of Cancer Research*

*Philip Greenberg, MD, FAACR, President, American Association of Cancer Research*

Drs. Foti and Greenberg introduced the AACR and gave an update on the association's work. AACR was formed in 1907 by a group of physicians and basic scientists. The association was one of the earliest supporters of the ACS and ASCO and has partnered with these organizations since their formation.

Today, AACR is the largest cancer research organization, with more than 55,000 members in 132 countries and territories around the world. The association's vision is to utilize science, technology, and policy to fundamentally change the face of cancer for all populations. Its mission is to prevent and cure all cancers through research, education, communication, and collaborations, as well as through science

policy, advocacy, and funding. Throughout its history, the association has had regular, productive interactions with government, industry, academia, professional societies, and philanthropic organizations. The association represents the spectrum of cancer research from bench to bedside, including population science, early detection, and prevention.

The association's Vision 2030 plan will integrate the goals of the National Cancer Plan. Its current work already touches nearly every area mentioned in the Plan, but current priorities connect to three specific goals.

### **GOAL 3: DEVELOP EFFECTIVE TREATMENTS**

Developing effective treatments is one of the AACR's top priorities. The association advances this work through many channels, including its 10 scientific journals, two of which are focused specifically on cancer therapeutics. Another avenue is AACR's annual meeting, which convenes professionals from all spheres of cancer research to share information, collaborate, generate new projects, and share opportunities.

AACR has numerous task forces related to targeted therapeutics. The organization also has a new oncology initiative and special conference to broaden association involvement from the immunology field and increase opportunities for interdisciplinary collaboration.

### **GOAL 4: ELIMINATE INEQUITIES**

The association has many initiatives and programs in place to support health equity. The Robert A. Winn Diversity in Clinical Trials Award Program fosters the careers of minority clinicians and increases minority patient accrual on clinical trials. The BMSF-AACR Design and Implementation of Clinical Trials Workshop is an integral part of the BMSF DCTCDP broader program to foster the careers of minority clinicians and increase minority patient accrual on clinical trials. Clinical investigators with expertise in oncology, benign hematology, cardiovascular disease, and autoimmune disorders are selected to participate as workshop faculty. The AACR Conference: The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved was launched in 2007 as a forum to provide a state-of-the-field overview of the science of cancer health disparities and discuss how to propel advances in this field. The conference has since become an important annual event for cancer and health equity researchers.

The AACR report series on health inequities in cancer highlights the serious public health challenges posed by cancer disparities and the recent progress made in addressing these inequities and includes a robust, evidence-based call to action. The goal of the report is to educate members of Congress, the public, and the scientific community about cancer disparities and the importance of medical research to the elimination of disparities; and to advocate for increased federal funding for health equity-focused research.

After a series of roundtables, AACR published its recommendations on how the research community can effectively drive diversity and inclusion in cancer drug development and trials. The association also provides significant financial support for cancer health disparities efforts.

### **GOAL 7: MAXIMIZE DATA UTILITY**

Data utility has long been a focus of the AACR's work. In 2015, the association launched AACR Project Genie, a publicly accessible cancer registry of real-world clinico-genomic data assembled through data sharing among more than 22 cancer centers worldwide. This diverse registry provides access to cancer

information and data that can drive improvements in clinical trial design and conduct as well as cancer science.

Data science will be a focus of AACR's annual meeting in 2024, with the goal of engaging data science and artificial intelligence experts and integrating them into the broader cancer science community. AACR has also partnered with Stand Up to Cancer to support clinical trials and translational science. The collaboration has supported more than 270 trials and more than 13,000 papers to date.

The association's independent grants program also continues to grow. New technologies, synthetic chemistry, combination therapies, interception, early detection, and telemedicine are all priority areas.

## **DISCUSSION**

Dr. Greenberg answered questions from the Panel.

- An essential driver of translational science is industry investment. Encouragement from the federal government for industry support of the research enterprise would be valuable.
- An important component of health equity is participation in clinical trials. Increasing diversity will require meaningful engagement with communities in rural and urban areas. Support for cancer research has long been a bipartisan issue; the next important step will be to secure bipartisan support for health equity in cancer research and care.

## **NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN)**

*Robert Carlson, MD, CEO, National Comprehensive Cancer Network*

*Wui-Jin Koh, MD, SVP and CMO, National Comprehensive Cancer Network*

Drs. Carlson and Koh introduced NCCN and gave an update on the network's work. NCCN is a nonprofit alliance of 33 leading academic cancer centers in the United States that are devoted to patient care, research, and education. The network's mission is to improve and facilitate quality, effective, equitable, and accessible cancer care so all patients can live better lives. Its vision is to define and advance high-quality, high-value patient-centered care globally.

NCCN's foundational process is the development, maintenance, and updating of an extensive library of oncology clinical practice guidelines. While the network supports the entirety of the National Cancer Plan, its current activities, particularly the NCCN Guidelines, directly address five of the Plan's goals: Prevent Cancer, Detect Cancers Early, Eliminate Inequities, Deliver Optimal Care, and Engage Every Person.

### **NCCN GUIDELINES**

The NCCN Guidelines are comprehensive, comprising 85 guidelines that apply to 97 percent of cancer cases in the United States and around the world, both adult and pediatric. The guidelines address the full continuum of care, from prevention through survivorship, as well as supportive care and management of people in special populations, such as adolescents and young adults, older adults, and cancer patients with HIV.

The guidelines are living documents, in continuous revision with input from more than 1,800 experts. Each set of guidelines is updated at least once annually or more frequently, if the science is advancing more quickly. The guidelines are multidisciplinary, with representation of numerous specialties, including patient advocacy; and they are transparent, with a strict firewall and strong transparency processes. In

2022, NCCN Guidelines were downloaded more than 13.3 million times. The site has 1.7 million registered users, nearly half of whom are from outside the United States.

A wide body of literature indicates that adherence to nationally recognized clinical practice guidelines results in superior outcomes across a variety of cancer types. Improved outcomes include increased overall survival, improved quality of life outcomes, reduced costs to both patient and health system, and increased equity in care outcomes.

In parallel with the clinical practice guidelines, NCCN now also offers more than 65 patient guidelines to help educate patients, their families, and their caregivers so that they can more effectively participate in discussion and shared decision making. These guidelines have been recognized with numerous awards for excellence in patient information and efforts to ensure inclusive representation. Where funds are available, patient guidelines are translated into other languages, including Spanish, Chinese, Korean, Ukrainian, Russian, and Polish.

## **EFFORTS TO ELIMINATE INEQUITIES**

NCCN Guidelines and other content are directly translated into 71 languages for use around the world. The guidelines are adapted in several different ways: regionally, for high-resource settings; in a resource-stratified model called the NCCN Framework; and through harmonized guidelines for use in low-to-low-middle-resource settings.

Many studies have found significant racial and ethnic disparities in rates of cancer types and outcomes. Recent research suggests that adherence to guidelines can help reduce these inequities, including through addressing social determinants of health, bias, and discrimination.

NCCN's Elevating Cancer Equity initiative aims to address racial disparities in cancer care by conducting surveys of patients, caregivers, and providers to better understand experiences and perceptions of bias in care delivery; convening a working group of national experts to understand the root causes of disparities in access to guideline-adherent care; and disseminating recommendations and advocating for their implementation.

The working group identified 17 practices to advance equitable care delivery in four different categories: community engagement, accessibility of care and social determinants of health, addressing bias in care delivery, and quality and comprehensiveness of care. These practices were incorporated into the Health Equity Report Card, which can be used to score health care systems on their progress toward diversity, equity, and inclusion, and provide a roadmap for improvement. The report card can be used by institutions themselves, by the payer community, or by the patient community to assess the equity and appropriateness of socially responsible care in different practice settings.

Patients who are members of sexual and gender minority groups often face unique challenges as they seek cancer care, including implicit bias, misgendering, and health system policies that don't recognize chosen caregiver support. Recognizing that gender specific language may be harmful to nonbinary and transgender patients, NCCN has launched an initiative to incorporate gender neutral and respectful language throughout all NCCN guidelines.

The network has also established a diversity, equity, and inclusion director's forum to identify and share best practices in DEI and to assist member institutions in responding to NCI's plan to enhance diversity in NCI-designated cancer centers. The forum is generating a series of white papers that will be made publicly available so that the identified best practices can be shared widely within the healthcare community.

## DISCUSSION

Drs. Carlson and Koh answered questions from the Panel.

- To ensure that the guidelines are representative of (and therefore meaningful for) the cancer community, NCCN has a thorough input-gathering process that seeks feedback from all member institutions. Members have the opportunity to contribute through panels and via a questionnaire; panel members share draft materials with their organizations for additional review. NCCN staff also conduct a thorough literature review to confirm that the guidelines align with the latest research, scan the proceedings of professional organization meetings for clinical trial reports, and invite input through a feedback form on the NCCN website. All submissions are carefully reviewed.
- There is evidence that care that adheres to NCCN guidelines improves outcomes. What is not yet known is why some patients continue to receive non-guideline-adherent care. NCCN continues to work to understand this complex issue.
- More than 85 percent of all adults in the United States are covered by insurance plans or payers that utilize NCCN guidelines for drugs and biologics, either in making coverage determinations or as a reference in their determinations. Usage of other guidelines is uneven; guidelines regarding newer technologies and methods like biomarker testing and certain kinds of diagnostic imaging are less frequently adopted. One way to improve quality of care would be for payers to add the NCCN biomarker compendium, appropriate-use criteria, and the radiation oncology compendium—or similar high-quality guidelines from other organizations—to their determination systems for coverage.
- In addition to reviewing NCCN guidelines to ensure that they are inclusive of sexual and gender minorities, the network has also revised guidelines to better include and support members of underrepresented groups and specific subpopulations with higher risk. This ability to provide accurate, appropriate, tailored, and inclusive guidelines sets NCCN apart from other organizations doing similar work.
- Convincing CMS and other payers to use the NCCN guidelines for coverage determination was a gradual process. The first step was introducing and encouraging uptake of the guidelines in the oncology community. Once there was demonstrated uptake of the guidelines, payers and policymakers took notice. NCCN continues to engage with legislators to encourage adoption and use of the guidelines.

## CEO ROUNDTABLE ON CANCER

*William Louv, PhD, CEO, CEO Roundtable on Cancer*

*David Reese, MD, Chair of the Board of Directors, CEO Roundtable on Cancer*

Dr. Louv introduced the CEO Roundtable on Cancer and gave an update on the organization's work. The CEO Roundtable on Cancer is a 501(c)(3) organization created to inspire leaders from private industry to play a more direct role in the effort to eradicate cancer. Its mission is to make continual progress toward the elimination of cancer as a personal disease and public health problem through initiatives that reduce the risk of cancer, enable early diagnosis, facilitate access to treatment, and hasten the discovery of effective therapies. The CEO Roundtable on Cancer was created in 2001 in response to a request from then-President George W. Bush to organize a group of corporate leaders and take action to improve cancer prevention, diagnosis, and treatment. The CEO Roundtable responded to this call to action by creating two programs: the CEO Cancer Gold Standard and Project Data Sphere.

Member organizations include large and small pharmaceutical companies, biotechnology companies, cancer centers, and healthcare organizations, while research partners include government agencies, nonprofit organizations, and independent research organizations.

## **NATIONAL CANCER PLAN INTEGRATION**

The work of the CEO Roundtable aligns with all National Cancer Plan goals, particularly Prevent Cancer, Detect Cancers Early, Eliminate Inequities, and Maximize Data Utility.

The CEO Cancer Gold Standard supports the goals of preventing and detecting cancer. This certification allows employers to document and improve their support of employees in reducing the burden of cancer. Gold Standard accreditation asks organizations to demonstrate that their health benefits and workplace culture include extensive, concrete actions in five key areas: health education and navigation; prevention and early detection; advancing treatment; survivorship; and well-being.

## **GOAL 4: ELIMINATE INEQUITIES**

To reduce inequities, the CEO Roundtable applies the Gold Standard framework to minority-serving academic institutions, allowing for greater, more meaningful reach; collaborates with Historically Black Colleges and Universities (HBCUs) and Hispanic-Serving Institutions (HSIs) to lower the burden of cancer in medically underserved communities; and partners with institutions to enhance or identify opportunities to participate in oncology research, including clinical trials. The CEO Roundtable helps HBCUs and HSIs navigate the accreditation process.

## **GOAL 7: MAXIMIZE DATA UTILITY**

To maximize data utility, the CEO Roundtable created the Collaborative Oncology Data and Analytics (CODA) Platform. The platform, part of Project Data Sphere, provides patient-level data to registered users, thus accelerating the pace of research. The platform uses tools from SAS Institute and is continually updated and improved.

## **GOALS 3 AND 5: DEVELOP EFFECTIVE TREATMENTS AND DELIVER OPTIMAL CARE**

To develop effective treatments and deliver optimal care, the CEO Roundtable has partnered with the FDA on a portfolio of data, data science, and machine learning programs and demonstration projects that use real-world data. Some projects honor patient contributions to science through thoughtful reuse of clinical trial patient data and EHRs. For example, a project exploring immune-mediated adverse reactions to checkpoint inhibitor therapy concluded that adverse event definitions must be modified to improve accuracy and safety. This work led to the publication of new definitions, which are now being embedded in standard adverse event coding.

## **DISCUSSION**

Drs. Louv and Reese answered questions from the Panel.

- The CODA Platform uses real-world patient data. Data are drawn from clinical trials and therefore, at this time, are not a representative sample, as many patients do not have access to clinical trial participation.
- Data standards are critical. The newly formed Clinical Research Data Sharing Alliance is working to improve interoperability of data systems. The CEO Roundtable also advances this work through collaborations with organizations like AACR's Project GENIE.



- A core principle of Project Data Sphere is neutrality, in order to ensure that all stakeholders feel empowered and invested. Another method of engaging partners and researchers is by offering specific use cases for platforms and data exchange in order to illustrate the potential of these tools. Allowing organizations to determine how broadly their data is shared also helps secure buy-in.
- Real-world data—and EHR data in particular—can be difficult to standardize. The CEO Roundtable is working to curate data and use automated methods to harmonize data from different sources. This issue could be addressed on the front end by standardizing data collection and ensuring that EHR platforms are interoperable.
- Meaningful policies from the federal government might focus on requirements for data sharing and interoperability, as well as incentives for the industry sector to participate in data sharing efforts.

## DISCUSSION WITH PANEL AND PUBLIC COMMENT

The Panel opened the floor to participants and the public for further discussion of the day's topics.

- Cost is a barrier to the conduct of clinical trials that include innovative technologies (e.g., proton therapy, surgical or imaging innovations). Whereas pharmaceutical companies cover the cost of experimental drugs used in trials, the costs of new technologies often fall to institutions. Because insurance companies usually will not pay for experimental treatments, this cost cannot be recovered. It would be helpful if insurance companies would commit to covering the costs of interventions delivered in the context of valid clinical trials.
- Basic research should not be overlooked as a crucial step in the cancer research pipeline. Effective support for cancer research will include preclinical science. Advocates for basic research should emphasize the translational potential of their work.
- ARPA-H is still in its infancy. Cancer research and data interoperability might be two meaningful areas of focus for the agency.
- Reducing economic barriers to cancer screening and preventive care will go a long way toward decreasing cancer diagnosis and mortality rates. The federal government could provide strategic support by incentivizing the kinds of research that industry does not fund.
- Collaboration across organizations, institutions, and agencies will be an essential element of success.
- Nearly all of the presenters identified workforce shortages as a major issue. Stakeholders agree that maintaining the pipeline must begin with equitable access to education and professional development. The recent Supreme Court decision to strike down affirmative action is already creating additional barriers and problems in this area.
  - Mitigating this harm may require new legislation or executive orders from the President, as well as significant collaboration among stakeholder groups. Presenting a united front and agreeing on messaging will strengthen the case for action from the federal government. Messaging should center on the patient, emphasizing the relationship between the workforce and patient experience.
  - Stakeholders could collaborate to create a collective map of efforts, resources, priorities, and opportunities.

- Increasing diversity in leadership positions and on advisory councils and boards within stakeholder organizations is another crucial step.
- A participant noted that the Inflation Reduction Act (IRA) may have unforeseen ripple effects on pharmaceutical research.

## **CLOSING REMARKS**

Dr. Jaffee thanked the presenters and attendees for their important presentations and discussion. She emphasized that the day's discussions were a starting point. That the Panel will continue to solicit input and engage with the cancer community on this subject. Stakeholders can send information about their progress and insights to the Panel by email using [PresCancerPanel@mail.nih.gov](mailto:PresCancerPanel@mail.nih.gov); all information received by September 30 would be considered for inclusion in the Panel's first report to the President. Additional written testimony and comments can be submitted at any time to the President's Cancer Panel via email or the Panel website (<https://prescancerpanel.cancer.gov>).

## **CERTIFICATION OF MEETING SUMMARY**

I certify that this summary of the President's Cancer Panel meeting, National Cancer Plan Stakeholder Meeting, held on September 7, 2023, is accurate and complete.

Certified by: \_\_\_\_\_ Date: November 8, 2023

Elizabeth Jaffee, MD, FACR, FAACP  
Chair  
President's Cancer Panel