

2023 Annual Meeting American Cancer Society National Lung Cancer Roundtable



December 4–5
Washington, D.C.

Pathways of Care: Focusing on the Patient Experience
Across the Lung Cancer Continuum



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Meeting Overview

On December 4-5, 2023, the American Cancer Society National Lung Cancer Roundtable (ACS NLCRT) convened its seventh Annual Meeting at the Grand Hyatt Hotel in Washington, DC. The theme of the in-person event was ***Pathways of Care: Focusing on the Patient Experience Across the Lung Cancer Continuum***.

The ACS NLCRT was created by the American Cancer Society in 2017. It works throughout the lung cancer continuum and has launched several successful initiatives around its strategic priorities. Its strategic priorities include 1) accelerating the implementation, uptake, and adherence to early detection through lung cancer screening and nodule detection and management; 2) improving guideline-concordant lung cancer staging and optimizing the use of biomarkers in practice; and 3) promoting initiatives to eliminate lung cancer-related stigma and nihilism. Additional priorities are to support and strengthen state and local initiatives, reduce disparities, and advance health equity in lung cancer care and outcomes.

The 2023 Annual Meeting hosted 350 participants and consisted of keynote presentations, moderated panel discussions, and twelve concurrent breakout sessions over two days to allow maximum attendee participation. Over the course of the two-day meeting, presentations were delivered on patient advocate perspectives, ACS NLCRT initiatives, ACS NLCRT organizational member projects, health equity, and the regionalization of lung cancer screening (LCS). Participants viewed 30 posters by ACS NLCRT members and volunteers, engaged in collaborative conversations with other attendees, and learned more about partner and sponsor efforts.

The theme of the meeting was to recognize the value of the patient experience in patient-centered care to improve health outcomes across the lung cancer care continuum.

Day 1 began with Session 1, titled *Welcome and Patient Advocate Story*. Session 2 featured the Day 1 keynote presentation and a panel discussion on lung cancer policy. Session 3 was a patient advocate panel. Participants then moved into concurrent sessions A-F for the afternoon. Session 4 contained *Updates on Select ACS NLCRT Initiatives*. Session 5 provided *Updates on Select ACS NLCRT Member Organization Initiatives*. Day 1 was adjourned with a closing presentation.

Day 2 began with Session 6, a *Welcome, Recap of Day 1, and Patient Advocate Story*. Participants then moved into concurrent sessions G-L and then reconvened for Session 7, a *Health Equity and Lung Cancer Keynote & Panel Discussion*. Session 8 featured a debate on centralized versus decentralized lung cancer screening. The two-day meeting concluded with Session 9, *Close Out: Final Thoughts on the 7th ACS NLCRT Annual Meeting*.

This document highlights the diverse and impactful presentations given by partners in the lung cancer field during the two-day national meeting. It also includes information about the valuable sponsors and member organizations that make this work possible.

Table of Speakers with Presentation Links – Day 1

Monday, December 4, 2023	
General Session 1: Welcome and Patient Advocate Story	
<ul style="list-style-type: none"> • Welcome & Overview of ACS NLCRT Ella A. Kazerooni, MD, MS, FACR, FACC, FSABI, Chair, ACS NLCRT, University of Michigan • ACS Lung Cancer Screening Guidelines (Robert Smith, PhD slides) Ella A. Kazerooni, MD, MS, FACR, FACC, FSABI, Chair, ACS NLCRT, University of Michigan • Patient Advocate Story John Stewart 	
General Session 2: Lung Cancer Policy Keynote & Panel Discussion	
<ul style="list-style-type: none"> • Keynote: Lung Cancer Policy - Anatomy of a Movement Laurie Fenton Ambrose, GO2 for Lung Cancer • Moderator Gregory Kane, MD, MACP, Thomas Jefferson University • Eliminating Financial Barriers to Lung Cancer Screening—When Free Is Not Really Free A. Mark Fendrick, MD, University of Michigan • ACS CAN Policy Perspective Marissa Brown, ACS Cancer Action Network • Recent Policy Wins Timothy Merchant, RadNet • Screening as an Episode of Care Ruth Carlos, MD, MS, FACR, University of Michigan • NCQA Quality Measure Development: Lung Cancer Screening and Follow-up Ella A. Kazerooni, MD, MS, FACR, FACC, FSABI, Chair, ACS NLCRT 	
General Session 3:	
Patient Advocate Panel: Learning from Patients' Lived Experiences	
<ul style="list-style-type: none"> • Moderators Jill Feldman, EGFR Resisters Laura Petrillo, MD, Massachusetts General Hospital • Donnita Butler • Ameish Govindarajan, MD, MSKCC • Montessa Lee • Aurora Lucas • Daniel West 	

Table of Speakers – Day 1 (Continued)

General Session 4: Updates on Select ACS NLCRT Initiatives	
• Moderator	Ella A. Kazerooni, MD, MS, FACR, FACC, FSABI, Chair, ACS NLCRT, University of Michigan
• Accelerating Uptake and Implementation of Early Detection	Carey C. Thomson, MD, MPH, FCCP, Mount Auburn Hospital/Beth Israel Lahey Health, Harvard Medical School
• Development of A Best Practice Guide for Building an Early Detection Program	Debra S. Dyer, MD, FACR, National Jewish Health
• Campaign to End Lung Cancer Stigma	Jamie L. Studts, PhD, University of Colorado Lisa Carter-Bawa, PhD, APRN, ANP-C, FAAN, Hackensack Meridian Health
• Improving Guideline-Concordant Staging	Farhood Farjah, MD, MPH, FACS, University of Washington
• Lung Cancer Staging Education Tool	Jeffrey B. Velotta, MD, FACS, Kaiser Permanente Oakland Keith Singer, Catch It In Time
General Session 5: Updates on Select ACS NLCRT Member Organization Initiatives	
• Moderator	Pierre De Delva, MD, FACS, University of Mississippi Medical Center
• National Lung Cancer Screening Day Partnership	Jane Kim, MD, MPH, U.S. Dept. of Veterans Affairs Christopher Slatore, MD, MS, Oregon Health & Science University Portland, VA Medical Center
• American Lung Cancer Screening Initiative	Priyanka Senthil Shreya Papneja Mitchell Anderson
• Partnership with the American Academy of Family Physicians	Robert J. Volk, PhD, MD Anderson Cancer Center
• Addressing Lung Cancer Biomarker Testing Through Project ECHO	Adam H. Fox, MD, Medical University of South Carolina
• ACS National Navigation Roundtable	Linda Fleisher, PhD, MPH, Fox Chase Cancer Center
Closing of Day 1	
• Closing of Day 1	Ella A. Kazerooni, MD, MS, FACR, FACC, FSABI, Chair, ACS NLCRT, University of Michigan

Table of Speakers with Presentation Links – Day 2

Tuesday, December 5, 2023	
General Session 6: Welcome, Recap of Day 1 & Patient Advocate Story	
<ul style="list-style-type: none"> Welcome & Recap Douglas Wood, MD, FACS, FRCSEd, Vice Chair, ACS NLCRT, University of Washington Patient Advocate Story Daniel Cadigan, MD 	
General Session 7: Health Equity and Lung Cancer Keynote & Panel Discussion	
<ul style="list-style-type: none"> Moderators M. Patricia Rivera, MD, ATSF, FCCP, University of Rochester Lori Sakoda, PhD, Kaiser Permanente of Northern CA Keynote: Research and Clinical Science Gaps in Diverse Populations Eliseo J. Pérez-Stable, MD, National Institutes of Health 	
<p>Panelists</p> <p>Morhaf Al Achkar, MD, PhD, MSCR, FAAFP, Karmanos Cancer Institute Leah Backhus, MD, MPH, FACS, Stanford University Efrén Flores, MD, Harvard Medical School Scout, MA, PhD, National LGBT Cancer Network</p>	
General Session 8: PRO/PRO Debate: Regionalization of Lung Cancer Screening (Centralized vs Decentralized)	
<ul style="list-style-type: none"> Moderator Douglas Wood, MD, FACS, FRCSEd, Vice Chair, ACS NLCRT, University of Washington 	
<p>Panelists</p> <p>Jane Kim, MD, MPH, U.S. Department of Veterans Affairs Peter J. Mazzone, MD, MPH, FCCP, Cleveland Clinic Richard Wender, MD, Penn Medicine</p>	
General Session 9: Close Out: Final Thoughts on the 7th ACS NLCRT Annual Meeting	
<ul style="list-style-type: none"> Welcome & Overview of ACS NLCRT Ella A. Kazerooni, MD, MS, FACR, FACC, FSABI, Chair, ACS NLCRT, University of Michigan 	

Presentation Highlights – Day 1

Session 1 – Welcome, Overview & Patient Advocate Story

Dr. Ella Kazerooni, Chair of the ACS NLCRT, welcomed attendees to the seventh annual ACS NLCRT Annual Meeting. She spoke about the Roundtable's growth and highlighted the collective dedication to increasing lung cancer survivors and thrivers. Dr. Kazerooni emphasized the NLCRT's comprehensive approach, covering areas from early detection to advanced therapy and addressing pervasive issues like stigma and nihilism surrounding lung cancer. She highlighted the importance of health equity and survivorship and acknowledged the limited knowledge surrounding survivors' needs. She recognized the contributions of the NLCRT members and supporting organizations and then praised the ACS for its pivotal role in the fight against lung cancer. She also recognized the efforts of the NLCRT task group members and the uniqueness of the NLCRT's coverage across the entire cancer continuum. Finally, Dr. Kazerooni introduced Mr. Keith Singer, who was invited to introduce the patient advocate speaker, Mr. John Stewart. Dr. Kazerooni emphasized the significance of starting each day with a patient story to ground everyone in the primary purpose of this work: the patients themselves.

Mr. Keith Singer introduced patient advocate Mr. John Stewart. Mr. Singer, associated with Catch It In Time and the ACS NLCRT, shared his connection with Mr. Stewart, whom he met through Dr. Drew Moghanaki earlier in the year. Mr. Singer emphasized their shared commitment to lung cancer advocacy and screening, particularly praising Mr. Stewart's remarkable advocacy efforts. Mr. Stewart, who smoked for most of his life, was saved by lung cancer screening (LCS). Mr. Singer highlighted the persistent challenges of smoking in the entertainment industry and strategies used to circumvent smoking restrictions. In closing, Mr. Singer reintroduced Mr. Stewart, emphasizing their strong bond before inviting him to address the audience.

Mr. John Stewart, a patient advocate, was the third speaker of the session. He began by expressing gratitude for being invited to the meeting. His journey with lung cancer began with a PET scan at age 60 that revealed a spot in his left lung, leading to surgery to remove two-thirds of the lung. Reflecting on his family's history of smoking-related deaths, he recounted his own smoking habits from a young age and how perceptions of smoking have changed over time. Mr. Stewart discussed the pain and discomfort he experienced during medical procedures, highlighting the importance of surgeons being mindful of patients' comfort, especially during tube removal. He detailed subsequent surgeries for cancer in his right lung and the recurrence in his left lung, which led to a pivotal moment where Dr. Drew Moghanaki offered a lifesaving option involving five radiation treatments at UCLA. Having undergone surgeries on both lungs

and radiation treatment, John expressed his willingness to share his extensive knowledge and experiences with people who were interested in his story. He expressed immense gratitude to Dr. Kazerooni and the audience for the opportunity to speak.

Dr. Ella Kazerooni presented the ***American Cancer Society Lung Cancer Screening Guideline*** on behalf of Dr. Robert Smith. She emphasized that the screening guideline update was the result of an extensive evidence-based review and that it was recently published with several companion papers supporting some of the evidence. Dr. Kazerooni discussed the crucial elements of the guideline, focusing on lung cancer diagnosis and mortality beyond 15 years after quitting smoking. She compared the primary differences between the 2021 United States Preventive Service Task Force (USPSTF) recommendation and the 2023 ACS guideline.

The USPSTF guideline recommends annual lung cancer screening through low-dose computed tomography (LDCT) for individuals aged 50 to 80 with a smoking history of 20 pack-years who currently smoke or who quit within the last 15 years. The main difference found in the ACS guideline is the removal of the 15-year quit criterion. This was based on evidence that emerged from a systematic review conducted by the ACS Cancer Related Evidence Synthesis Team (CrEST). Their review showed that the elevated risk of lung cancer persists for 2 or 3 decades compared with individuals who never smoked. Sorting data by the age of smoking cessation suggested that the increased risk of lung cancer beyond 15 years of quitting stems from the effect of aging and counteracts the beneficial influence of smoking cessation.

However, the data also emphasized the benefits of quitting smoking because quitting reduces the risk of lung cancer relative to the risk that rises over time while continuing to smoke. The removal of the <15 years after quitting criterion allows many people with a smoking history to stay eligible for screening beyond that period as their risk continues to increase.

She also analyzed the potential positive impact of the new guideline on screening outcomes, with an estimated increase of 21% in lives saved and an increase of 19% in life-years gained by removing the <15 years quitting criterion.

She underscored the importance of shared decision-making and health status assessment for eligibility, which are included in both guidelines. In this regard, the ACS guideline places greater emphasis on specifying a life expectancy of at least five years, aiming to offer clearer parameters. To conclude, Dr. Kazerooni urged the audience to familiarize themselves with the updated guidelines and emphasized the need for advocacy to facilitate policy changes for broader coverage of lung cancer screening.

Session 2 – Lung Cancer Policy Keynote & Panel Discussion

Ms. Laurie Fenton Ambrose, President, Founder, and CEO of the GO2 for Lung Cancer Foundation, gave the keynote presentation ***Lung Cancer Policy - Anatomy of a Movement***. Her presentation chronicled her journey of advocating for lung cancer policy over two decades. She began by sharing personal reflections on her commitment to public service and traced the evolution of the lung cancer advocacy movement. Highlighting key milestones and challenges faced by the lung cancer community, Ms. Fenton Ambrose emphasized the pivotal role of policy in transforming survivorship. She articulated the intertwined nature of science and policy, portraying how they were essential in driving medical advancements and ensuring their effective implementation for the benefit of individuals. She underscored the complexity of healthcare policy, its impact on people's lives, and the allocation of federal research funding.

Ms. Fenton Ambrose outlined a strategic approach to policy impact that included activating a group of unified advocacy voices, educating elected leaders by sharing data, legislating through collaboration with identified champions to devise strategies and lead internal efforts, and validating the implementation of laws by monitoring how they are executed.

The timeline of advocacy efforts began in 1995 with the foundation of the Alliance for Lung Cancer Advocacy, Support and Education (ALCASE), which was an organization founded by patients and survivors and solely dedicated to the lung cancer community. This organization became the Lung Cancer Alliance and moved to Washington, DC, to initiate public policy dialogues aimed at promoting prevention, early detection, and treatment research.

In 2004, the lung cancer community came together for the first National Lung Cancer Advocacy Summit to inform Congress members and staff about the public health impact of lung cancer. That year, they filed an amicus brief in a federal case against the tobacco industry, urging funding for independent research and a national early detection program as recompense for their criminal actions.

In 2006, lung cancer was designated as a national public health priority, solidifying the initial legislative steps. That year, the International Early Lung Cancer Action Program (I-ELCAP) study was published in the *New England Journal of Medicine*. In 2007, the Lung Cancer Alliance produced the first white paper that revealed a lack of comprehensive state plans when assessing state comprehensive cancer control plans and their strategies to improve outcomes.

In 2008, Ms. Fenton Ambrose organized a meeting with the House Defense Appropriation Chairman, John Murtha, to advocate for the creation of a pipeline dedicated to supporting veterans who were at increased risk of lung cancer because of their occupational exposures.

They also created a coalition of eight cancer groups whose survival rates remained below 50% to increase funding. In 2009, they introduced the first bi-partisan, bicameral legislation to establish a comprehensive interagency response by the Health and Human Services, Defense, and Veterans Affairs departments to reduce lung cancer mortality.

In 2010, a seminal report was developed that documented the unique and devastating impact of lung cancer on women. Between 2011 and 2012, the National Lung Screening Trial confirmed that LDCT scans reduced mortality, which accelerated policy efforts for an implementation plan to bring high-quality screening and care into community settings.

In 2013, the USPSTF gave a B recommendation for screening 55-80-year-old at-risk people. This recommendation, together with reports indicating that LCS was a cost-effective health benefit, triggered the formal request to CMS to open a national coverage determination for screening at-risk seniors, which was announced in 2015. In 2016, Congress introduced the *Women & Lung Cancer Research & Preventive Services Act* to evaluate research on women and lung cancer, improve access to preventive services, and conduct public awareness campaigns on the disease.

Other achievements mentioned by Ms. Ambrose were the creation of the [Deadliest Cancers Coalition](#), increased collaboration efforts around early detection and survivorship care in Kentucky, the creation of the [Lung Cancer Caucus](#) for congressional education, advocacy activities during the COVID-19 pandemic, and recent legislative initiatives for increased access to lung cancer screening, expansion of Medicaid coverage, and protection of preventive services.

Ms. Ambrose stressed the growth of the advocacy movement over 18 years, which contributed to funding, research, legislative, and health achievements, including an increase in survival rates from about 15% in 1995 to 27% in 2023. Finally, she highlighted the need to expand the army of advocates, increase research funding, secure the passage of new legislation, and enhance collaboration among stakeholders. The keynote underlined the value of a persistent, unified, and data-informed approach to influence policy for lifesaving changes in the field of lung cancer.

Dr. Mark Fendrick is a general internist and economist who focuses on health policy. He presented on ***Eliminating Financial Barriers to Lung Cancer Screening—When Free Is Not Really Free***. He emphasized the importance of equity, access, and affordability of services for extending and improving the quality of life of individuals and underserved populations. Based upon his previous work on preventive services provisions in the Affordable Care Act (ACA), he highlighted the critical issue of free cancer screenings, including free screenings for lung cancer. Despite the ACA mandate that lung cancer screening must be at no cost for eligible people, many individuals fail to complete the full screening process due to financial barriers and lack of follow-up. He stressed that while the initial lung cancer screening test might be free, subsequent steps and

follow-up procedures are often not covered or have high out-of-pocket costs that disproportionately affect underserved populations.

Dr. Fendrick has advocated for policies that remove financial barriers for the entire continuum of care in cancer screenings. He shared published data showing that people most likely to benefit from screening, such as Black and male individuals and those who currently smoke, are the ones facing the highest out-of-pocket costs for follow-up procedures. Referencing guidelines and initiatives, he urged for a shift in perception and emphasized that cancer screening is a continuous process, not just a single test. He asserted that the position of the ACS is that *"follow-up tests are integral to the screening process, and patients should not face cost sharing for any follow-up procedure associated with a positive LCS test."* To conclude, Dr. Fendrick called for collective efforts and policy changes to address the financial barriers that hinder individuals from receiving comprehensive and affordable care throughout the entire cancer screening journey.

Mr. Timothy Merchant spoke next about **RadNet**, an organization that operates outpatient imaging centers and performs about 5% of all lung cancer screening across the United States. The advocacy efforts and successful legislative initiatives of RadNet have focused on removing the financial barriers for follow-up care after breast and lung cancer screenings. RadNet is committed to diverse patient care and employee representation.

Mr. Merchant shared RadNet's recent success in Maryland, where legislation was passed to eliminate deductibles, co-shares, and coinsurance requirements for follow-up care after breast cancer and lung cancer screenings, all the way to biopsy in lung cancer. Given that the lung cancer mortality rate among women is higher than the breast cancer mortality rate, Mr. Merchant encouraged others to explore comparable legislative actions in their states.

He also emphasized the importance of community education around cancer screenings. Mr. Merchant expressed his commitment to replicate the success of Maryland in other states, such as Florida, where only 3% of the eligible screening population gets screened for lung cancer. In this regard, Mr. Merchant spoke about the Florida Lung Health Coalition, which involves various stakeholders to support increased screening access, particularly for veterans, firefighters, and those facing financial barriers. Finally, he highlighted the ongoing efforts to advocate for LDCT screenings as part of the benefits program for firefighters in California due to their exposure to harmful environments during service.

Ms. Marissa Brown presented on the **American Cancer Society Cancer Action Network (ACS CAN) Policy Perspective**. The ACS CAN mission is to advocate for evidence-based public policies to reduce the cancer burden for all individuals. She began by acknowledging the collaborative efforts and partnerships that focus on expanding coverage for biomarker testing. This initiative

aims to increase access to biomarker testing while reducing disparities in coverage, especially for those who would benefit most.

She highlighted the successful enactment of model legislation in 13 states and the plans to expand campaigns in 12 more states in 2024. She noted the challenges faced in this advocacy, particularly resistance from the opposition. Ms. Brown emphasized the importance of comprehensive screening as a continuum and the ACS CAN commitment to eliminating barriers, particularly related to cost, in various states.

She underscored the significance of patient navigation in cancer care and discussed efforts to address the lack of structured reimbursement for patient navigation services. The ACS CAN initiatives engage policymakers at federal and state levels to advocate for coverage expansion, especially for patient navigation during screening phases.

Finally, she explained the implications of a proposed rule by the Centers for Medicare & Medicaid Services (CMS) related to reimbursement for patient navigation services. She outlined the rule coverage from diagnosis through treatment and highlighted the need for the inclusion of screening services in Medicare payments. She expressed optimism about the progress made, but she also emphasized the need for continued work on expanding coverage for screening services and Medicaid coverage for screening at the state level.

Dr. Ruth Carlos, a professor of radiology, presented on ***Policies Eliminating OOP Costs After a Positive LDCT: Intended and Unintended Consequences***. Dr. Carlos addressed the potential unintended consequences of eliminating out-of-pocket costs for lung cancer screening, focusing on Maryland's policy case. She began by sharing a personal story about her father's battle with metastatic lung cancer and the impact of eligibility criteria on access to screening. Dr. Carlos stressed the importance of supportive policies for equitable access and outcomes in cancer care.

She highlighted the positive aspect of Maryland's law, which eliminated costs for downstream diagnostic tests resulting from lung cancer screening. However, she raised concerns that while the law prohibits insurers from imposing additional costs on patients, it does not require increased reimbursement to cover these costs. Claims data from insured patients showed significant total costs and out-of-pocket expenses for additional diagnostic procedures, and the lack of increased reimbursement identified a potential loss of revenue for healthcare providers.

Dr. Carlos explored ways to mitigate these issues and proposed the hiring of community health workers to improve screening rates, particularly among minority populations. She also investigated the potential increased revenue from increased cancer detection and emphasized the need for policy changes to ensure adequate reimbursement for healthcare providers.

She advocated for leveraging payer investments in health equity initiatives such as affordable housing and medication adherence and suggested that lung cancer screening should be included in the health equity metrics of quality contracts.

She stressed the importance of increased state and national mandates to improve health equity around lung cancer screening and suggested that future payment models will likely include metrics related to equitable screening rates and outcomes. In conclusion, Dr. Carlos highlighted the opportunity to align beneficial actions with financial gains in healthcare to promote equitable lung cancer screening and outcomes.

Dr. Ella Kazerooni gave a presentation on behalf of the National Committee for Quality Assurance (NCQA) titled ***NCQA Quality Measure Development: Lung Cancer Screening and Follow-Up***. The Healthcare Effectiveness Data and Information Set (HEDIS) measures are widely used by health systems and insurers to drive adherence to preventive services and inform practice improvements. The HEDIS measures enable the comparison of health plans across the dimensions of care and services, including preventative services.

Dr. Kazerooni explained that adopting a HEDIS measure for lung cancer screening will be instrumental in implementing strategies to raise screening rates within healthcare facilities. This initiative aligns with NCQA's goal to improve quality metrics across various healthcare services and integrate them into electronic health records (EHRs) for easier data extraction and reporting. She underscored the significance of lung cancer screening because of its impact as a leading cause of cancer death.

The proposed HEDIS measure aims to establish an evidence-based, reliable, and valid measure of lung cancer screening and encourage accurate recording of smoking and tobacco use data in EHR systems. The measure's objectives include enhancing lung cancer screening among eligible individuals and improving the information structure in electronic health records to facilitate the identification of eligible patients. The NCQA's HEDIS measure development for lung cancer screening is supported by partnerships with the ACS NLCRT and the American Lung Association (ALA).

The measure focuses on individuals aged 50-80 who currently smoke or who previously smoked, who are eligible for LDCT lung cancer screening, and who received follow-ups based on scan results. Dr. Kazerooni emphasized the collaboration with technical expert panels to guide the measure's development and testing. The measure aims 1) to collect quantitative and qualitative data to assess smoking data completeness, availability, and standardization, 2) to investigate measure design decisions and the feasibility of reporting, and 3) to learn how health systems can utilize the measure to enhance tobacco use cessation and lung cancer screening rates.

Testing for this measure is expected to begin in spring 2024, followed by a public comment period and finalization in early 2025. Dr. Kazerooni concluded by sharing that the HEDIS measure development seeks to improve the uptake of screening and data collection related to smoking and tobacco use and to provide a comprehensive approach to enhancing patient outcomes.

Session 3 – Patient Advocate Panel: Learning from Patients' Lived Experiences

Ms. Jill Feldman from the EGFR Resisters and **Dr. Laura Petrillo** from the Massachusetts General Hospital were moderators for the panel discussion in which lung cancer survivors and advocates discussed how lung cancer diagnosis and treatment affected their lives and the lives of their loved ones. The panel members included lung cancer survivors **Ms. Donnita Butler**, **Ms. Montessa Lee**, **Mr. Daniel West**, **Dr. Ameish Govindarajan**, and **Ms. Aurora Lucas**. They answered questions and shared the challenges they experienced in their journeys since receiving lung cancer diagnoses.

Ms. Jill Feldman, a lung cancer survivor, opened the session by talking about the importance of the quality of life for survivors who are sometimes on prolonged treatments. She emphasized that survivors and their families not only live with uncertainty and fear but also face physical, emotional, and economic burdens around challenging treatment decisions. She offered to help healthcare workers develop the necessary skills to support the needs of lung cancer survivors because "*medicine isn't just about eradicating cancer - it's about restoring lives.*" Ms. Feldman reminded the audience that 80% of people diagnosed with lung cancer do not have access to quality care. She concluded by recognizing all the people who have contributed to the rapidly evolving landscape of lung cancer research, treatment, and care.

Dr. Laura Petrillo, a co-moderator, invited the audience to listen to the survivors with gratitude and compassion. She emphasized that their survivor stories revealed barriers and challenges that are opportunities for improvement.

Ms. Donnita Butler, a Navy veteran residing in northern Virginia, was recently diagnosed and treated for stage 1A2 lung adenocarcinoma. She had multiple risk factors, including a smoking history, a family history of lung cancer, and environmental exposures to carcinogens that justified her getting a lung cancer screening scan. She is focused on her recovery and advocates for lung cancer awareness. She sees opportunities to develop more inclusive lung cancer screening guidelines, reduce stigma perceptions, and build mental health support services.

Mr. Daniel West, an advocate from Houston, Texas, was diagnosed with EGFR positive, stage 2B, non-small cell adenocarcinoma in December 2022. His nodules were found incidentally through

a CT scan that he received as part of a cardiovascular screening. He was surprised by the diagnosis because he had quit smoking in 2006. After undergoing surgery, chemotherapy, and targeted therapy for his gene mutation, he has no evidence of active disease. Mr. West expressed his gratitude to his doctors and his husband, who has been his caregiver.

Ms. Montessa Lee was diagnosed with small-cell lung cancer at the age of 28 in 2006. She was suffering from chest pain and dyspnea, but because of her age, she received two misdiagnoses. The first chest image revealed a mass that covered three-fourths of her left lung. Ms. Lee said she decided to channel her anger about the delayed diagnosis into advocacy efforts.

Dr. Ameish Govindarajan, a physician trained in Internal Medicine, was diagnosed with AKT-positive, stage 4 non-small cell lung cancer during medical school. Like Ms. Lee's experience, his young age delayed his diagnosis. He is interested in research on the intersection of supportive care and oncology.

Ms. Aurora Lucas was diagnosed with stage 3A non-small cell lung cancer with an EGFR mutation at the age of 28 in 2021. She was working as a special education teacher at that time. Because she was young and she was covered by a Health Maintenance Organization, her diagnosis was delayed. She emphasized that she had had to advocate for herself to get the screening.

Ms. Butler had to advocate for her care by insisting her primary care provider do the LDCT screening. She knew about the test and that it was covered because she read a brochure in 2018. She also had to ask for a second screening in 2023, which revealed she had cancer. She highlighted that nobody followed up with her between the two screenings. She expressed discomfort in receiving negative comments about her access to her own medical records.

Ms. Lee discussed the stigma of being a young and healthy person without a smoking history. Not being considered part of the high-risk group for lung cancer led to a medical bias that caused a delay in her diagnosis. She received support from her family to switch from a smaller hospital to a larger institute and to get an oncologist to manage her case.

Dr. Govindarajan, apart from not being considered for lung cancer because of his age, suffered from being treated like a medical student rather than receiving support as an average person with lung cancer. He felt bad about the way doctors communicated the diagnosis, the treatment, and the potential prognoses. Now, as a physician, he is focused on how doctors give information and how effectively they communicate with patients. He invited the audience to focus more on personhood and to understand the effort that patients make to go to the doctor.

Next, the panel members talked about biomarker testing. When doctors told Ms. Lucas that she had to do biomarker testing, she first thought that she might have the mutation in her body, with

all the associated hereditary consequences. Mr. West said that the group of doctors who participated in his diagnosis did not tell him that his tumor had been sent for biomarker testing. He was surprised when a second-opinion oncologist told him that the biomarker testing performed in the first hospital revealed he had an EGFR-positive tumor.

The panelists then shared how doctors explained staging to them, especially to those who were in stage 3. Ms. Lucas was concerned when doctors told her to do a brain MRI. She was shocked when she found out she had more than one nodule, and doctors sent her to see an oncologist. Mr. West knew he had positive lymph nodes and that he would need chemotherapy when talking to a nurse by phone. He would have preferred to hear it directly from a doctor, in person, and with his husband present, allowing them to ask any follow-up questions.

Ms. Feldman described that the treatment affected her life as well as that of her family. Given that she had a family history of lung cancer, she was an advocate before being diagnosed, which meant that she knew a lot of information about lung cancer. However, she had not imagined the impact that being diagnosed would have on her life. Being an active mother was important and meaningful to her. Doctors told her that she did not need pulmonary rehabilitation, but after the lobectomy, she could not play soccer or basketball with her kids.

Ms. Lucas discussed how cancer affected her plans for her future. She expressed relief that her oncologist talked to her about making fertility plans and felt lucky to find a doctor whose specialty was fertility treatment for patients with lung cancer. She said that participating in Facebook groups gave her peace of mind.

Next, the panelists talked about support for lung cancer patients. Ms. Lee explained how important building a support network was for her because her immediate family lived far away from her home. She created a team of caregivers composed of family and church members who made a schedule to drive her to appointments for chemotherapy and radiation. She said, "*It took me swallowing my pride to go ask for help, even for a ride.*" Ms. Butler talked about mental support. She grew up in a dysfunctional family, which contributed to her depression and anxiety throughout her life. She was happy that she had different types of mental and emotional therapies before being diagnosed with lung cancer. However, she experienced fear and anxiety about recurrence. It was difficult to find resources for mental support until she found organizations such as the GO2 for Lung Cancer Foundation. She still sees the need to increase the availability of mental health support initiatives. Mr. West found emotional support by joining a group at LUNGeivity when he started chemotherapy. He said, "*I really needed to be around people who were having the same experiences as I was.*" Ms. Lucas, who participated in the same group, said that she looked for support as a way of relieving the burden on her family.

Next, the panel members discussed doctor-patient communication. Mr. West said he would have preferred more education about treatment options for multiple nodules. Dr. Govindarajan described his experience as a patient with shared decision-making. He recalled how his doctor asked him about his career plans before discussing the treatment he would receive. In contrast, Ms. Feldman highlighted that she had to insist that her doctor talk about plans before considering the best treatment for her.

Finally, the panelists outlined the improvements they believed should be implemented in the healthcare system to enhance patient-centered care and support. They advocated for reduced disparities in lung cancer screening, increased mental support for patients and caregivers, recognition of the human aspect behind scientific developments, heightened awareness about LCS for both patients and doctors, inclusive screening guidelines, comprehensive support post-diagnosis, and a reduction in lung cancer stigma.

Session 4 – Updates on Select ACS NLCRT Initiatives

Dr. Carey C. Thomson presented on ***Accelerating Uptake and Implementation of Early Detection: Harnessing IT/EHR Workshop***. Dr. Thomson discussed the major outcomes of different initiatives aimed at accelerating the uptake and implementation of early detection of lung cancer using information technology (IT) and EHR systems. She emphasized the need for technology to streamline processes without adding burden to the already complex workflows faced by healthcare professionals. Dr. Thomson contextualized the work of the NLCRT's Early Detection Task Group, highlighting the collaboration with EHR developers and software engineers around the necessity of lung cancer screening in the IT domain.

Next, she described LUNGplan, an economic tool that helps healthcare centers to identify necessary resources for comprehensive programs in LCS and for managing incidental pulmonary nodules (IPNs). The tool is downloadable from the ACS NLCRT website (<https://nlcrt.org/lungplan-overview/>).

Dr. Thomson also described an initiative from the President's Cancer Panel called *Closing the Gaps in Cancer Screening Document*, which focused on the use of IT to promote appropriate cancer risk assessment and screening. This document was a seminal work for the IT and EHR Systems task group in the Accelerating Uptake of Lung Cancer Screening Workshop.

Dr. Thomson described the barriers and challenges they found to accelerate lung cancer screening using IT and EHR systems. Challenges included misclassifying current and former smoking tobacco use status, suboptimal use of the available data, and the need for validated prediction models integrated into EHR systems to determine eligibility and to track the

provider's patient population. Other challenges included information overload for providers and patients and the poor ability of EHR systems to support adherence to screening.

The most popular strategy among those proposed by the task group was to establish a national consensus on developing core EHR elements and standards across the whole care continuum for screening patients, both for lung cancer screening and IPNs.

Finally, she described an ACS NLCRT standalone workshop on accelerating the uptake of screening, harnessing IT and EHR systems to improve individual eligibility for screening, patient tracking after screening, communication between patients, providers, and health care staff (including navigation), and workflow optimization within primary care settings. After reviewing the barriers, challenges, and strategies with software vendors and industry experts, they created actionable tactics and chose those with the highest feasibility and impact.

Dr. Thomson emphasized that the common goal of the most popular strategies was the identification of tobacco use history. Other strategies targeted quality measures, the creation of centralized programs for tracking patients, and the elimination of the prior authorization requirement for screening.

She concluded by highlighting the ongoing work within the NLCRT that focused on operationalizing the identified tactics from the IT and EHR workshop. Dr. Thomson emphasized the importance of collaborative efforts and partnerships to advance technology-driven solutions for patient navigation and the early detection of lung cancer.

Dr. Debra Dyer presented on the *Development of A Best Practice Guide for Building an Early Detection Program*. Dr. Dyer and her colleagues are members of the Early Detection Implementation Strategies Task Group. They developed a playbook aimed at guiding the creation and improvement of lung cancer screening programs. Initially focusing on screening, the document expanded to encompass incidental pulmonary nodule management. The playbook was designed as a flexible electronic resource that evolves over time. It guides the user through three phases: 1) assessing needs and making the case, 2) program planning, and 3) implementation and sustainability.

She highlighted the importance of engaging leadership, identifying physician champions, defining the program model (centralized, decentralized, or hybrid), designing the workflow logistics, building technological infrastructure, and planning the engagement of referring providers. Their recommendation is to start with a pilot phase, make necessary modifications as required, and adapt the program gradually as it progresses.

Dr. Dyer also emphasized the importance of monitoring adherence. The group collaborated with the U.S. Lung Ambition Alliance and the Academy of Oncology Nurses and Navigators to develop

a useful model that could be easily disseminated. She talked about funding opportunities for IPN programs offered by Astra Zeneca and the Lung Ambition Alliance. She described a case study from National Jewish Health and presented their phrase tracker system based on the Fleischner Society guidelines for IPNs. The system helps calculate and monitor patient follow-ups and sends automated reminders. The system also refers suspicious nodules to their weekly nodule conference. The system implementation led to a 41% increase in timely IPN follow-ups and a significant stage shift towards early cancer detection. The playbook, currently at version 8, is expected to be finalized and released in January.

Dr. Jamie Studts presented on the *Campaign to End Lung Cancer Stigma*. He shared about the Survivorship and Stigma Nihilism Committee, which focuses on societal factors impacting lung cancer outcomes. The committee aimed to shift societal perspectives on lung cancer, emphasizing empathy, optimism, and urgency to combat stigma and nihilism. They outlined four themes, including societal change around the perception of lung cancer, survivorship enhancement, clinician education around empathic communication and stigma, and broadening the funding and support for lung cancer research.

He highlighted the committee's efforts, including multiple summits focusing on messaging featuring lived experiences and global successes in destigmatizing lung cancer. He also stressed the need for a cultural change to reduce stigma and nihilism around lung cancer because it is a societal problem. After working hard on themes and messages, the committee is ready to collaborate with content developers and work with industry partners and any interested party for a national media campaign to reshape societal perceptions of lung cancer.

Furthermore, the committee introduced the *Lung Cancer Stigma Communications Assessment Tool*, which aims to assess and remove potentially stigmatizing language, imagery, and scenarios in lung cancer communications. Dr. Studts discussed the tool's structure, audit process, and its use in identifying and replacing stigmatizing elements in communication materials. His team published the data obtained by testing the tool on the LungTalk website, which helps support informed and shared decision-making around LCS. Dr. Studts emphasized ongoing efforts to enhance empathic communication, develop clinician resources, and combat lung cancer stigma through initiatives like the assessment tool and summits focused on changing societal perspectives.

Dr. Farhood Farjah presented on *Improving Guideline-Concordant Lung Cancer Nodal Staging*. He addressed the significance of accurate staging for optimal treatment selection and improved patient outcomes. He also highlighted the conclusions of the March 2023 ACS NLCRT Staging Summit that focused on gaps in pre-treatment and intraoperative nodal staging.

For pre-treatment nodal staging, Dr. Farjah said that while guidelines recommend a specific procedure for lymph node biopsy that applies to 75% of patients with suspected lung cancer, the actual execution of this guideline is about 25-40%. Similar limitations apply to intraoperative nodal staging. The goal of the staging summit was to bridge these gaps through clinician education, patient education, guideline reconciliation, and performance feedback.

Regarding clinician education, efforts will be made to develop educational videos aimed at clinicians across specialties to enhance the understanding of nodal staging, guidelines, and decision-making. Patient education was recognized as a crucial aspect. Education efforts should focus on creating patient-friendly educational tools led by patient partners to facilitate informed conversations with healthcare providers.

The third tactic focused on reconciling differences between the two prominent North American guidelines to minimize disparities in nodal staging. Performance feedback was identified as a key aspect, aiming to provide surgeons and hospitals with feedback on their performance in nodal staging. However, limitations in databases and expenses hindered this effort. The group proposed to pilot performance feedback among participating surgeons, positioning for national scaling if financial support becomes available. Regarding intraoperative nodal staging, the National Cancer Database is already providing performance feedback to hospitals. Hence, the group proposed to disseminate this capability to help surgeons and pathologists comply with standards.

Dr. Jeffery Velotta and **Mr. Keith Singer** presented a ***Lung Cancer Nodal Staging Project: Patient Education Tool Kit***. They emphasized the origin of the project from discussions at the nodal staging concordant guideline meeting in March 2023 and its development in response to concerns raised during breakout sessions. The goal was to create an interactive and user-friendly educational toolkit to explain lung cancer nodal staging for patients, caregivers, and families.

They intended to develop a high-quality, equitable, and easily understandable tool that accommodated diverse learning styles, including interactive animations, videos, glossaries, and note-taking capabilities. Recognizing the impact on patients' well-being, they aimed for a concise yet informative approach, acknowledging the short average attention span of individuals and the need for quick, informative content.

The presentation showcased a prototype, revealing an interactive program that allowed users to explore information at their own pace and in their preferred format. They highlighted the potential for multilingual support and emphasized the tool's value in facilitating meaningful conversations between patients and providers. Dr. Velotta and Mr. Singer expressed excitement about the project's potential, aiming for a live launch in the summer of 2024. They acknowledged funding support from the ACS NLCRT and welcomed feedback for further improvement. Finally,

they discussed plans to create educational tools for clinicians to enhance their understanding of nodal staging procedures and indications. Mr. Phil Bowman, the project's lead developer, was also introduced, offering live access to the prototype for feedback and suggestions.

Session 5 – Updates on Select ACS NLCRT Member Organization Initiatives

Dr. Jane Kim and **Dr. Christopher Slatore** spoke about the ***National Lung Cancer Screening Day Partnership***. The Department of Veterans Affairs (VA) wanted to encourage lung cancer screening among veterans, with specific efforts aligned to coincide with Veterans Day. Accordingly, they collaborated with NASA, and the partnership produced a poignant video featuring a lung cancer survivor veteran and a NASA astronaut who was also a veteran. Dr. Kim detailed the steps leading to the VA's involvement, which began with an invitation from the ACS, the ACS NLCRT, and the American College of Radiology. Following an enthusiastic response from VA leadership, preparations commenced, and a national team of experts in radiology, primary care, pulmonary medicine, and prevention was formed.

The VA's engagement included a National Lung Cancer Screening Week celebrated by 113 VA medical centers, a significant increase from the previous year's participation of only five centers. Dr. Kim attributed this success to effective communication strategies, extensive resources provided to participating sites, and regular engagement with site coordinators. Various activities were highlighted, such as the NASA-VA collaboration, which received 5,000 views in the week after launch, the distribution of articles to 3 million subscribers, and a Satellite Media Tour with widespread coverage reaching 860,000 impressions across all media.

Dr. Kim emphasized leadership engagement as a critical factor in their success and acknowledged the valuable contributions of volunteers who assisted in gathering essential materials for frontline coordinators. Lessons learned included the importance of early and consistent communication along with the need for earlier coordination of news and social media campaigns in future initiatives. The presentation concluded with a discussion on forthcoming steps, aiming to assess the impact of their efforts through increased screenings among veterans and gathering feedback from facilities to improve future engagements.

Mr. Mitchell Anderson, **Ms. Priyanka Senthil**, and **Ms. Shreya Papneja** spoke about the ***American Lung Cancer Screening Initiative (ALCSI)***. The ALCSI is an organization led by young advocates focused on comprehensive community outreach, public policy, and support for lung cancer screening research. They began by highlighting the ALCSI's extensive community outreach efforts, spanning over 450 lung cancer screening events, including community presentations, health fairs, farmer's markets, and educational initiatives across various states

like Massachusetts, Illinois, Washington DC, and California. Their focus was on educating communities about lung cancer screening and assisting qualifying individuals. They encountered substantial receptiveness from communities previously unaware of this vital health measure.

They then detailed their National White Ribbon Relay, which symbolizes unity and love within the lung cancer community. The relay, led by ALCSI members, spread across their 48 college chapters, culminating in Denver, Colorado, with a ribbon bearing team signatures. Additionally, the ALCSI *Not Just A Statistic* project created a platform for those impacted by lung cancer to share their experiences in community centers and libraries nationwide.

Their podcast series, the ALCSI Podcast, aims to disseminate patient and caregiver stories, along with professional insights, enhancing awareness. Their advocacy efforts were substantial, involving collaborations with governors, mayors, and legislators to issue proclamations recognizing November as National Lung Cancer Awareness Month. This advocacy created public service announcements (PSAs) featuring mayors and members of Congress, encouraged screenings, and highlighted personal connections to lung cancer.

The ALCSI's involvement in public policy was highlighted by their contribution to passing Senate resolutions that emphasized the importance of early detection and recognized National Lung Cancer Awareness Month. The ALCSI's advocacy efforts for increasing access to lung cancer screening included meetings with congressional representatives and gaining co-sponsorship for the *Increased Access to Lung Cancer Screening Act*.

The speakers also spotlighted ALCSI support for lung cancer screening research. The ALCSI promoted studies that evaluated screening among high-risk groups and raised awareness at community events to encourage participation in research initiatives. The ALCSI team expressed gratitude for the support they received from various stakeholders and invited participation in their year-end update meeting that will showcase their efforts.

Dr. Robert Volk presented on the ***American Academy of Family Physicians Partnership***. He discussed two major initiatives regarding lung cancer screening in collaboration with the American Academy of Family Physicians (AAFP). He provided an update on the ongoing membership survey and key interviews aimed at understanding the attitudes of family physicians and real-world implementations of lung cancer screening in primary care.

The membership survey, launching soon, will encompass a stratified sample of about one thousand AAFP members across the United States, including various geographic divisions and diverse practice settings. Dr. Volk highlighted the survey's scope, covering awareness of guidelines and recommendations, including CMS policy, assessment of eligibility, shared decision-making practices, smoking cessation strategies, delivery model preferences, and willingness to use risk-based models and biomarkers in screening. He emphasized the

significance of understanding the perspectives of family physicians due to their crucial role in enhancing lung cancer screening uptake.

Additionally, Dr. Volk outlined the demographics of AAFP members and showcased their diverse backgrounds. This context underscores the importance of obtaining insights from this sizable primary care research group. He emphasized that 70% of family physicians are doing telemedicine. They work 60 hours a week, spending half of that time on administrative tasks, which is one of their major concerns.

Dr. Volk also discussed the development of a shared decision-making toolkit for AAFP members that will be publicly available in diverse languages. The toolkit, led by experienced clinicians nominated by the AAFP, aims to facilitate feasible and practical tools for family physicians to streamline shared decision-making around lung cancer screening. Concerns such as reducing the burden for clinicians leveraging clinical team members, low reimbursement, lack of quality metrics, and eligibility assessment were identified as key areas for tool development. The toolkit comprises components such as a clinician summary with guidelines, a one-page decision support tool, a pack-year assessment tool, a video depicting the LDCT experience to reduce patient concerns, and traditional decision aids for patient education.

Dr. Volk concluded by expressing excitement about the forthcoming tool rollout and the valuable insights expected from surveys and interviews. He highlighted the collaborative effort and dedication of his team in bringing these resources to fruition.

Dr. Adam Fox presented *Addressing Lung Cancer Biomarker Testing Through the ECHO Model*. Dr. Fox began by explaining the Extension For Community Healthcare Outcomes (ECHO) model, an evidence-based framework for promoting knowledge dissemination and learning through a virtual network of participants and specialists. This model encourages non-hierarchical, bidirectional learning and case-based discussions.

The goals of Project ECHO are 1) to enhance knowledge and confidence for overcoming institutional barriers and strengthening biomarker testing programs within each institution and 2) to foster connections by conducting state-specific ECHO sessions to address common barriers and create advocacy opportunities at the state level.

Dr. Fox highlighted the project's growth from a three-state pilot in 2022 to 11 states in 2023. He provided an overview of last year's sessions, indicating state-based and combined sessions focusing on addressing biomarker testing barriers for lung cancer treatment. In an ECHO session, participants introduce themselves, share a didactic presentation, and focus on a case-based discussion that allows sharing of challenges and learning points in a bidirectional learning experience. Dr. Fox mentioned the involvement of subject matter experts, facilitator partners, and participating sites in 33 discussion sessions with a total of 140 attendees.

Post-project survey results demonstrated high satisfaction levels and increased confidence, knowledge, and self-efficacy among respondents. They reported improvements in practice and addressed barriers to biomarker testing. The strategies to enhance biomarker testing primarily centered on interdisciplinary communication, policy establishment within teams, and the collection of quality specimens. Looking to the next year, Dr. Fox discussed the upcoming expansion to seven more states, totaling 18 states participating in ECHO sessions.

He credited the success of the project to the collaborative efforts of participating sites, leadership support, faculty members, the ECHO office team, the ACS NLCRT, state ECHO coordinators, and sponsors.

Dr. Linda Fleisher presented on *the ACS National Navigation Roundtable (NNRT)*. She emphasized the significance of navigation, which has been evolving for nearly 30 years. Navigation is helpful across the continuum of care, from outreach to survivorship.

The ACS NNRT was established in 2017 and is comprised of more than 100 organizations that focus on health equity and collaborate to advance navigation as part of care. She highlighted the leadership within the ACS NNRT and participating organizations and emphasized the collective effort and synergy among these groups to drive navigation forward.

The ACS NNRT's work includes researching, developing professional standards and metrics, acting as a thought leader, conducting educational webinars, ensuring sustainability, and advocating for policies supporting navigation. Dr. Fleisher spoke about evidence-based practices in patient navigation and highlighted the development of consensus standards that define roles (e.g., patient manager, nurse navigator) and the skills and training required for these roles.

Additionally, she discussed the importance of utilizing metrics for measuring the impact of navigation programs and implementing frameworks to guide navigation initiatives. The ACS NNRT has been conducting webinars and focusing on the CMS physician rule as a significant milestone, allowing potential reimbursement for navigation. Dr. Fleisher invited participation in upcoming webinars to delve deeper into understanding the new CMS rule and its implications for navigation programs.

Looking forward, the ACS NNRT aims to address gaps in evidence through implementation science research and to focus on consistent implementation of navigation practices. They also aim to push for national and federal level policies that support funding and reimbursement for navigation, aiming for increased adoption across various states and health plans. Dr. Fleisher emphasized the availability of resources and information on the ACS NNRT website, inviting individuals to explore the website, access resources, and connect with organizations involved in patient navigation. Overall, Dr. Fleisher expressed enthusiasm about collaboration between the ACS NNRT and the ACS NLCRT and for potential joint efforts in advancing patient navigation.

Closing of Day 1

Dr. Ella Kazerooni closed Day 1 by expressing gratitude to the speakers, panelists, and attendees. She acknowledged the emotional impact of the ALSCI's work in raising awareness and making a difference in lung cancer early detection and screening. She highlighted the generational shift in perceptions about lung cancer and recognized that the efforts of youth and their passion for lung cancer screening are altering the narrative and shifting the stages at which lung cancer is detected.

Dr. Kazerooni praised the collective efforts of the lung cancer community in advancing science, implementing screening programs, aiding tobacco cessation, and improving survivorship. She commended Dr. Chi-Fu Jeffery Yang, the founder of the ALSCI, for his dedication, and she emphasized the transformative impact of the ALSCI's existence. Dr. Kazerooni encouraged attendees to engage with Dr. Yang to learn about the organization's inception and growth. She also thanked John Stewart, who led the patient advocacy story of the day.

Dr. Kazerooni mentioned the agenda for Day 2, including Dr. Douglas Wood's review of the Day 1 breakout sessions and a patient story to set the tone for Day 2. She highlighted the smaller breakout sessions aimed at enhancing interaction and encouraged attendees to explore the posters showcasing the work of individuals and organizations in the field of lung cancer.

In conclusion, she thanked everyone for their presence, expressed anticipation for the upcoming Day 2 of the meeting, and invited attendees to enjoy the networking reception.

Presentation Highlights – Day 2

Session 6 – Welcome, Recap of Day 1, and Patient Advocate Story

Dr. Douglas Wood opened Day 2 of the meeting with a recap of the previous day's events. He acknowledged Dr. Ella Kazerooni's presentation, on behalf of Dr. Robert Smith, that described the updated ACS guidelines for lung cancer screening and praised it as a thorough, evidence-based resource that everyone in the field should read. He emphasized that the most important change was the elimination of the <15 years after quitting criterion.

However, he expressed some disappointment about the maintained upper age limit for screening, which has been removed from the National Comprehensive Cancer Network (NCCN) guideline. He highlighted Mr. John Stewart's inspiring personal lung cancer story, Ms. Laurie Fenton Ambrose's Lung Cancer Policy Keynote speech summarizing 30 years of advocacy, and the subsequent panel discussion led by Dr. Gregory Kane. Dr. Wood summarized the panel's focus on ensuring access to screening, enhancing equity, managing financial impacts, and elevating lung cancer screening as a quality measure in primary care.

He emphasized the significance of the patient advocacy panel, which showcased the diverse stories of patients and provided valuable insights into their lived experiences and a better understanding of patient perspectives. The testimonies are valuable inputs to enhance doctor-patient communications. Finally, Dr. Wood commented on the strong engagement of Concurrent Session participants and invited the concurrent session leaders to provide brief summaries of their sessions.

Dr. Peter J. Mazzone, on behalf of Dr. Robert Smith, presented an overview of **Concurrent Session A: Population vs Individual Risk Assessment for Lung Cancer Screening Eligibility**. The session aimed to explore various methods of determining eligibility to maximize screening impact and benefits at both individual and population levels. The discussion was framed around the advantages and disadvantages of risk-based categorical guidelines and the potential for personalized risk-based strategies. Four speakers contributed to the session summary.

First, Dr. Rich Hoffman discussed implementing lung cancer screening from a primary care perspective. He highlighted the limitations of the current blunt categorical risk-based screening model and emphasized the inefficiencies of smoking history for the identification of a group with heterogeneous overall risk. He believed that primary care could embrace risk models to optimize screening benefits and reduce disparities, although they need feasibility improvements. He

stressed the importance of using risk models for shared decision-making and emphasized that high-quality screening is crucial for impactful outcomes.

Second, Ms. Jill Feldman shared her personal experience and emphasized the need for a holistic approach to risk assessment that considers family risk and other individual factors beyond tobacco history. Her case, distinct from traditional risk factors, highlighted the importance of developing risk tools that incorporate diverse risk factors and biomarkers.

Third, Dr. Hormuzd Katki discussed risk and benefit models to identify high-benefit individuals for screening. He explained that while current risk models identify at-risk individuals, it would be important to calculate their benefits, given that some risk factors also lead to low net benefit situations. Dr. Katki introduced a benefit tool, which had been built into an EHR system that incorporated lung cancer risk and comorbidities to assess screening eligibility. He described a proposed trial to test its implementation through clinical decision support systems.

Fourth, Dr. Lecia Sequist explored the potential of artificial intelligence tools in lung cancer risk prediction. She highlighted gaps in risk understanding and introduced Civil, an AI-based risk prediction tool using whole CT imaging to estimate lung cancer risk from one to six years. Dr. Sequist proposed using such tools for broader inclusion in screening recommendations, similar to approaches in colorectal and cervical screenings.

Dr. Gerard Silvestri summarized the key highlights from ***Concurrent Session C: Optimizing the Use of Lung Cancer Biomarkers in Practice***. Five speakers contributed to the session summaries.

First, Ms. Cori Chandler from the American Cancer Society focused on legislative action to eliminate barriers to biomarker testing. She illustrated maps that showcased states that are introducing legislation for biomarker testing coverage. The initiative has reached 24 states. She emphasized the efforts across states to ensure broader coverage and highlighted the role of the ACS in softening the ground for such legislation. Ms. Chandler encouraged the audience to join their states in the cause.

Second, Ms. Terri Conneran shared her inspiring story about self-advocacy for biomarker testing and her initiative called KRAS Kickers. She gathered a large following on Facebook, uniting people globally around biomarker testing issues, particularly for KRAS mutations.

Third, Dr. Bruce Johnson described the patient's journey, highlighting the critical time lapses and challenges encountered in obtaining biomarker test results. He emphasized the importance of reflecting on failures and challenges to accelerate diagnostics and ensure that patients receive timely and effective treatment.

Fourth, Dr. Adam Fox discussed the Triage for Appropriate Treatment Task Group's project, which examines data on lung cancer treatment and biomarker testing in a population of more than 200,000 patients. He highlighted that within 60 days, 30% of patients with stage 4 lung cancer in their Medicare group of people 65 years or older passed away. These data emphasize the need for expedited testing to ensure more patients benefit from biomarker-directed therapies.

Fifth, Dr. Ignacio I. Wistuba, a pathologist, discussed turnaround time issues in biomarker testing, highlighting various bottlenecks in the process, such as ordering delays, specimen wastage, and logistical challenges in sample processing. His insights shed light on the complexity of the diagnostic journey and the need for streamlining these processes.

Finally, Dr. Silvestri celebrated the diverse audience present in the meeting, including clinicians, advocates, and people from the industry.

Summaries for Concurrent Sessions D, E, and F were not presented because of lack of time. Instead, short summaries of the concurrent presentations follow.

Dr. Daniel Cadigan, a primary care physician and an 11-year survivor of stage 4 lung cancer with an EGFR exon 19 deletion, was the final speaker of the Welcome Session 6 on Day 2. Initially, he was skeptical of his own diagnosis at the age of 46 due to his lack of a smoking history. Mr. Cadigan experienced a persistent cough with unusual sputum and fever that led to an unforeseen diagnosis of adenocarcinoma. Unprepared for stage 3 confirmation during a surgery that had been expected to reveal stage 1, he underwent chemotherapy and discovered one year later in 2014, that he had stage 4 adenocarcinoma.

Since then, he has struggled with various treatments, including Avastin and Osimertinib. He retired from clinical practice in June 2023 because of the compounded toxicities of his medications. Despite resistance from local radiologists and colleagues in his medical community, Dr. Cadigan became a staunch advocate for early screening within his practice. His efforts proved fruitful, leading to the identification of early-stage cancers in several of his patients, underscoring the importance of proactive detection measures.

Despite his intricate lung cancer journey, he expressed profound gratitude for surviving and witnessing his children's pivotal life events. Dr. Cadigan underscored the significance of empathy in healthcare, citing a disheartening encounter with an unsympathetic oncologist. He concluded his talk with a heartfelt appreciation for the medical community, particularly researchers, recognizing their invaluable contributions to lung cancer treatment.

Concurrent Session D: Turning Away from Lung Cancer Stigma and Nihilism to Improve Care and Outcomes: New Data & Perspectives

Session D was a panel with four speakers. Dr. Smita Banerjee, Ms. Dannel Boatman, Ms. Dusty Donaldson, and Dr. Anne Stangl presented. The moderators were Dr. Lisa Carter-Bawa and Dr. Jamie Studts.

First, Dr. Smita Banerjee spoke on the perception of negative appraisal and devaluation reported by 95% of lung cancer patients. Stigma and nihilism are important because they affect both the quality of life and the quality of care given to patients. Decreases in quality of care include delays in seeking or receiving tobacco treatments, screening, diagnostic workups, biomarker testing, enrollment in clinical trials, and palliative care. Clinical empathy training to help clinicians understand and appreciate the patient experiences and communicating that understanding back to patients in a supportive way is helpful.

Second, Ms. Danelle Boatman spoke on *Messaging to Encourage LCS Action in Appalachia*. West Virginia has the highest cancer mortality rates, where most diagnosed cases of lung cancer are found at a late stage. A key research question is to identify which messages best motivate Appalachians with a smoking history to seek screening. Themes that resonate include hope, family, and prolonged life. Among people with a smoking history, psychological factors such as mistrust of the system and inertia to take action are barriers to screening.

Third, Ms. Dusty Donaldson from LungCAN spoke on *Dawn of Hope: A Patient Advocate's Perspective*. She gave eight examples of patient quotes that illustrated stigmatizing words, phrases, and thoughts. Institutional and governmental stigma are part of the problem. Funding for lung cancer research is very low compared to other types of cancer research, even though lung cancer mortality is much higher for lung cancer than for other types of cancer. Instead of messages that use fear tactics, it is better to use positive, lifesaving messages to motivate patients to seek lung cancer screening.

Fourth, Dr. Anne Stangl spoke on *Stopping the Stigmatization of People Living With and At Risk of HIV: How the Public Health Community Turned Away from Fear-Based Messaging*. Messaging related to smoking and lung cancer had a different history than HIV messaging. In the 1960s and 1970s, industry advertising for cigarettes was strong. Initial public service announcements were based on increasing awareness of possible negative effects in the hope that people would 'make the right choice' for themselves. Then, beginning in 1980, fear-based messages began to replace information-based messages. Given the existing evidence in favor of fear-based messaging and the deeply ingrained biases and stigma toward people who smoke, it may be difficult to shift the messaging toward empathy and compassion.

Concurrent Session E: Patients as Advocates and Partners in Research

Session E was a panel with four speakers. Ms. Kristen Kimball, Dr. Manali Patel, Dr. Upal Basu Roy, and Mr. James Pantelas presented. The moderator was Dr. Michelle Mollica.

First, Dr. Michelle Mollica spoke on *Patients as Advocates and Partners in Research*. The presentation emphasized the importance of engaging with advocates as partners in lung cancer research and discussed key considerations for meaningful engagement, including barriers and facilitators. The NCI Office of Cancer Survivorship supports research on the effects of all cancers among cancer survivors and their families. The NCI Office of Advocacy Relations helps to ensure that the collective patient perspective is included in NCI efforts to advance cancer research and improve patient outcomes.

Second, Ms. Kristen Kimball spoke on *Adding Care Partners to the Research Advocate Table*. She gave a short history of her family and her 59-year-old husband Dave's diagnosis in May 2012. Dave undertook several research advocacy projects, including three clinical trials, articles, an NPR interview, teaching, and the Boston March for Science. She emphasized that including a care partner in research is helpful because it enables both observed (care partner) and experienced (patient) perspectives. Engaging patient advocates can be facilitated by inclusive behaviors, making them feel safe, teaching them why and how, and leveraging their strengths. Research advocate training is also helpful.

Third, Dr. Manali Patel spoke by video on *Partnering with Patients and Communities to Improve Lung Cancer Care*. This presentation highlighted several gaps in lung cancer care despite many recent advances in clinical care. Her research group works with patients and communities to help mitigate those gaps, which include unawareness of treatment goals among 70% of patients, undertreated symptoms in 90% of patients, and persistent disparities. Patients and communities have lived experiences that can suggest solutions to many of the problems. Levels of community engagement include informing, consulting, involving, collaborating, and sharing leadership in partnerships.

Fourth, Dr. Upal Basu Roy from LUNGeivity spoke on *Patient Partnerships: Lessons from the Nonprofit World*. He made the business case for engaging patients and caregivers in research and showed that clinical period costs (phases 1, 2, and 3) as measured by Expected Net Present Value (ENPV) and Net Present Value (NPV) could be improved by several hundred times (349x/ENPV, 619x/NPV in Pre-Phase 2 and by 750X, 649x in Pre-Phase 3). Patient partnerships are key drivers of success in research partnerships and should be intentional, community-based, participatory, free from hierarchy, customized to the type of project, evaluated systematically, and should span the entire continuum of projects.

Fifth, Mr. James Pantelas spoke as a *Patient and Research Advocate*. He highlighted that patients contribute lived experience to projects, can guide patient communications and interactions, can contribute to the design of studies, support recruitment and retention efforts, help with community outreach, create trust within the patient community, and help disseminate information and findings. Research professionals can help by treating patients with respect,

allowing them to contribute, recognizing their time and effort, compensating them fairly, and including them from the start and not just as an afterthought.

Concurrent Session F: Promoting State-Based Initiatives and Partnerships

Session F was a panel with five speakers. Dr. Pierre De Delva, Ms. Nikki Hayes, Ms. Lisa Mei, Dr. Ronald Myers / Dr. Grant Greenberg, and Dr. Jennifer Redmond Knight presented. The moderator was Dr. Jessica Olson.

First, Dr. Pierre De Delva spoke on the *Mississippi Lung Cancer Roundtable (MSLCRT)*. The mission of the Roundtable is to reduce the incidence, impact, and mortality of lung cancer in Mississippi. The Roundtable approach is to create a collaboration of patients, caregivers, cancer centers, and partners to work toward the mission. The MSLCRT roadmap includes focusing on the patient, mitigating healthcare disparities, working on tobacco control and early detection programs, and improving the treatment of early and late-stage disease through clinical surgery, radiotherapy, biomarker care, and multidisciplinary team care.

Second, Ms. Nikki Hayes presented on *State-Based Initiatives and Partnerships to Increase Lung Cancer Screening: Approaches and Lessons Learned from National Comprehensive Cancer Control Program Cancer Coalitions*. The NCCCP supports cancer coalitions in all 50 states, the District of Columbia, 8 U.S. Territories and Pacific Island Jurisdictions, and seven tribes or tribal organizations. The support helps participants to create and implement cancer control programs that focus on risk reduction, early detection, better treatment, improved quality of life for survivors, and advancing equity in cancer health outcomes. Almost all control plans include tobacco cessation strategies, and more than 50% also include radon mitigation strategies. About 65% include lung cancer screening strategies, and almost all include strategies for improving the quality of life of cancer survivors.

Third, Ms. Lisa Mei spoke on *Lung Cancer Screening Activities in Michigan*. Michigan set a goal for its 2017 Lung Cancer Early Detection Program (LCEDP) of increasing lung cancer screening and tobacco cessation referrals in alignment with the state cancer plan for 2021-2030. In 2023, the LCEDP developed partnerships with two large health systems, a nonprofit representing 12 tribes, and a healthcare quality improvement organization. The LCEDP focused on education for 150 providers and health equity, tobacco cessation training, and referrals for tribal health clinics. They also identified barriers such as stigma, implicit bias, racial discrimination, and potential costs from follow-up procedures and treatments.

Fourth, Dr. Ronald Myers and Dr. Grant Greenberg spoke on *Preparing to Have a Conversation About Lung Cancer Screening: A Pilot Project*. This presentation described a project to increase knowledge and awareness about lung cancer screening among members of the Pennsylvania Academy of Family Physicians (PAFP). The project was based on the free online course for CME

credits titled *Shared Decision-Making in Lung Cancer*. Dissemination methods included a notice in the PAFP newsletter, a 1500-word article in the Keystone Physician magazine, linking to the CHEST course on the PAFP website, sending an email invitation, messaging from the PA Department of Health, health system and cancer center leaders, and presentations at two conferences. Results will be evaluated based on course completion statistics and participant surveys about knowledge gained and intention to change practices.

Fifth, Dr. Jennifer Redmond Knight spoke on *Kentucky's Lung Cancer Screening Policy Work*. This presentation was about the success of the Kentucky collaboration in 2013-2022 to create policy changes that created a screening program with the state DOH, created a screening fund, and an advisory committee to manage the project. The presentation gave highlights of the implementation process and lessons learned. Results from the project showed a 19% decline in late-stage lung cancer incidence in Kentucky between 2014 and 2019, which was two times faster than the decline in the national incidence average.

Session 7 – Health Equity and Lung Cancer Keynote & Panel Discussion

Dr. Patricia Rivera gave an introduction about the ***Health Equity Task Group: Interests, Priorities, and Plans for 2024***. She and Dr. Lori Sakoda are the co-chairs of this newly created group at the NLCRT. She emphasized how advancements in lung cancer care have significantly improved patient outcomes. However, these developments have also exacerbated disparities, especially among historically marginalized communities that do not always receive guideline-concordant care. The task group aims to alleviate the disproportionate impact of lung cancer, especially within these communities. Their objective is to work collaboratively with community stakeholders and various partners to develop, implement, and evaluate inclusive, sustainable, and community programs. These initiatives prioritize patient-centered and evidence-based care, aspiring to be both inclusive and sustainable.

Dr. Eliseo J. Pérez-Stable delivered the keynote presentation for Day 2, ***Research and Clinical Science Gaps in Diverse Populations***. He underscored the need for strategies to address disparities, emphasizing the importance of diversity in the scientific and clinical workforce. He stressed the need for community engagement, standardized measurement of social and demographic factors influencing health, big data, and data scientists.

Dr. Pérez-Stable is the Director of the National Institute on Minority Health and Health Disparities at the National Institutes of Health. His research focuses on race, ethnicity, and socioeconomic status as the fundamental pillars of health disparity science. He called for re-evaluating the reference population, which has historically used White demographics. He shared that the

economic burden of health disparities is estimated at over \$420 billion annually. The burden is primarily due to an excess of premature deaths but is also due to excess medical care costs and lost labor market productivity.

He then addressed disparities in smoking rates. He noted that American Indian/Alaskan Native populations have the highest smoking rates, approximately 21%, which parallel the smoking rates seen in the general population of 10-20 years ago. Dr. Pérez-Stable highlighted the significant impact of the educational gradient on smoking rates. Then, he described the persistent gap in smoking disparities by race, even among more educated Black and African Americans, who have higher smoking rates compared to Whites. Regional variations in smoking rates, particularly in the Midwest and South, also illustrated the presence of disparities.

Dr. Pérez-Stable stressed the necessity of addressing disparities in smoking cessation interventions for people who smoke fewer than ten cigarettes per day. He also cited the lack of evidence-based approaches. He celebrated the notable decrease in both lung cancer incidence and mortality for all groups, especially Black and African American males since they were the group with the most improvement.

However, he emphasized disparities in lung cancer mortality and incidence rates across diverse racial and ethnic groups. Latin and Asian Americans had lower mortality and incidence rates. He also talked about disparities in access to screening and emphasized that despite the evidence of benefits, lung cancer screening uptake has been very slow.

He explored the complex interplay of race, ethnicity, smoking intensity, and lung cancer risk and showed that among groups with similar smoking habits, Black and African Americans face the highest risk of developing lung cancer. These findings encourage further investigation into biological and social factors affecting nicotine metabolism and genetic markers. Dr. Pérez-Stable emphasized the importance of defining specific somatic mutations that are crucial for optimal treatment. However, accessibility to tests and subsequent therapies remains a challenge, especially within underserved communities, and warrants attention and resolution.

He also addressed the role of racism in health care and research and emphasized its impact on health outcomes. He highlighted that structural racism influences total cancer mortality, particularly in racially and economically segregated areas. Dr. Pérez-Stable described the impact of racial and ethnic differences in patient-clinician communication and trust-building and the importance of cultural competence in health care. Finally, he stressed the need to promote health equity in healthcare systems, expand access, implement patient-centered care, and engage community resources for better health outcomes.

Dr. Morhaf Al Achkar, Dr. Efren Flores, Dr. Estelamari Rodriguez, and Dr. Scout participated in the **Panel Discussion**. Dr. Rivera opened the discussion and invited the panel to focus on what

has worked and what has not worked for mitigating the negative impact that social determinants of health have on lung cancer.

Dr. Achkar stressed that multilevel initiatives involving health systems, such as the Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) project, have shown success. These initiatives explicitly address racism, directly engage with patients, provide feedback on benchmarking disparities, and employ health navigators for effective communication. Dr. Achkar shared essential strategies, such as providing evidence-based education, implementing accountability measures, and centering on equity by acknowledging and addressing medical racism. Initiatives aimed at diversifying the workforce, like the NIH Continuing Umbrella for Research Experiences (CURE), have made an impact, although the progress is still below expectations. Furthermore, studies have demonstrated that primary care significantly reduces medical costs and improves outcomes, including less likelihood of being diagnosed with metastatic cancer and having cancer-specific mortality.

Dr. Rodriguez discussed her experience at the University of Miami, which involved the use of EMR systems for patient outreach, specifically employing a "wellness check" system to gather patient-reported outcomes before visits. This strategy helped them identify social determinants like transportation or language barriers. They also have promoted lung cancer screening through various campaigns in Spanish. Although it has been challenging to quantify the impact of this approach, Dr. Rodriguez believes they have built community trust and engagement, which are two ways of addressing disparities.

Dr. Flores emphasized the evolving nature of both the role of healthcare providers and the community and highlighted the importance of adapting to meet changing needs. He reminded the audience that health care affects only 20% of patient outcomes, whereas the other 80% is shaped by external factors. Hence, addressing the social needs of patients will improve both their health and their lives. He cited the example of his institution employing digital asset coordinators to aid patients with the patient portal so they could interact with healthcare staff. Finally, Dr. Flores emphasized the need for continuous community outreach for lasting impact.

Dr. Scout highlighted the lack of research on LGBTQIA populations in health care, expressing concerns about legislative attacks on the community in various states, resulting in migration from hostile regions. He noted disparities in healthcare access and challenges like misgendering protection in hospitals. Scout emphasized the need for tailored outreach and the importance of collecting data on LGBTQIA populations. He also pointed out that despite higher tobacco usage rates in the LGBTQIA community, several NCI-designated cancer centers lack nondiscrimination statements.

The panel discussed the most pressing priorities in research to reduce inequities across the lung cancer continuum.

Dr. Achkar highlighted lung cancer molecular testing and screening. He shared the story of an African American friend who passed away, stressing the importance of ensuring equitable access to timely biomarker testing. Concerning lung cancer screening, his research shows that only 5% of lung cancer cases are diagnosed by screening, and he proposed to do more research on the relevance of primary care on lung cancer.

Dr. Rodriguez proposed making molecular testing a standard of care for all patients diagnosed with lung cancer to eradicate disparities. She shared that Medicaid expansion has improved lung cancer outcomes, suggesting that changing insurance policies is another way of reducing disparities.

Dr. Flores proposed creating more safe spaces and opportunities for dialogues with patients and among the healthcare community. He highlighted the need for supporting patients throughout the lung cancer care continuum, especially addressing their social needs by covering as many services as possible. Dr. Flores concluded that "*health equity requires a healthcare delivery transformation.*"

Scout stressed that data collection about sexual orientation and gender identity (SOGI) in the HCR should be a priority to reduce disparities affecting the LGBTQIA community. Without this data, research cannot reach accurate conclusions, hindering tailored solutions for this population. Scout has been providing technical assistance to some cancer centers to improve data collection.

Next, the panel and audience members explored the challenges of funding research around transgender community data. The challenges are primarily due to the limited size of the transgender population. To address these disparities, they proposed several strategies, like combining the efforts of multiple institutions, applying for minority grants, and training reviewers on SOGI perspectives. Dr. Achkar highlighted the importance of encouraging minority community members to lead health diversity advocacy groups and to participate on grant review boards.

Dr. Rodriguez proposed reducing the logistical burdens for patients to reduce inequities in clinical trials. One example of a logistical burden is an unnecessary in-person visit. Dr. Flores suggested that data science could be leveraged to predict and minimize disparity gaps in advance. Audience members and panelists agreed that inequity around lung cancer is a political problem, not a science problem. They also discussed the necessity of having institutional programs for cultural humility training to help turn the workforce into advocates and allies. Dr. Rodriguez pointed out that institutions that have successfully fostered a cultural change have

created dedicated equity and inclusion offices that have conducted surveys for data collection and engaged in top-down conversations.

Session 8 – PRO/PRO Debate: Regionalization of Lung Cancer Screening (Centralized vs Decentralized)

Dr. Jane Kim presented on *Lung Cancer Screening in the Veterans Health Administration (VHA)*. Dr. Kim shared the VHA journey in implementing lung cancer screening across the largest US-integrated health system. They combined centralized and decentralized programs, starting in 2013 with a demonstration pilot project to assess the implementation needs and initial results in their health system.

The pilot project included eight academic medical centers with centralized, comprehensive programs, including pulmonary, primary care, radiology, a multidisciplinary lung cancer program, tobacco cessation support, and a screening coordinator. Findings revealed that a quarter of patients met screening criteria, and two-thirds of the patients who had undergone low-dose CT scans required follow-up. Their projections for the entire VA population estimated that nearly 900,000 were eligible for LCS, representing a yearly cost of \$750 million to \$1 billion.

Then, they moved to the *guidance and implementation* phase, for which they developed a National LCS toolkit with pilot materials to guide other sites wishing to start their screening programs. In 2016, the VHA National Leadership Council approved recommendations for LCS with LDCT. One year later, they developed the VHA Clinical Preventive Services Guidance statement, which was aligned with USPSTF guidelines, and an implementation memo for facilities that were starting screening programs.

In the following years, the VHA National Lung Precision Oncology Program and the National Center for Lung Cancer Screening (NCLCS) were developed to offer a centralized set of tools and resources to be disseminated to sites starting cancer screening programs. The first initiative was a nationally coordinated network of sites with experts that offer support to other facilities or clinics interested in starting up LCS programs in their region.

The NCLCS functions as a support center for the lung cancer screening platform, an EHR-embedded suite of decision support tools alongside a tracking system. Dr. Kim emphasized that the programs have notably accelerated lung cancer screening and witnessed an 80% rise in screenings over three years while assessing 250,000 veterans.

Next, she described their decentralized models and enumerated their challenges, underscoring care coordination issues and delayed results from community providers. Dr. Kim highlighted the

advantages of centralized programs in enhancing adherence while recognizing the importance of decentralized models in providing accessibility. However, there are some concerns about effectively assessing eligible patients in decentralized models.

To conclude, Dr. Kim underscored the VA's commitment to supporting frontline clinicians with tools and advocating staff training for patient discussions to ensure informed decision-making in time-limited settings. The VA endeavors to streamline and enhance lung cancer screening programs within its healthcare system.

Dr. Peter Mazzone presented on the *Centralized Approach to Lung Cancer Screening*. Dr. Mazzone outlined the three approaches to lung cancer screening: centralized, decentralized, and hybrid. He clarified that centralized programs do not necessarily limit access to a single center, citing an example of a large program across multiple geographical sites. In centralized programs, anyone in the health system can spot eligible individuals for screening and refer them to the program, and then the program handles the rest, including shared decision-making, LDCT ordering, interpretation, and findings management.

The core question he addressed was whether the structure of the screening program increased its overall benefit or reduced its harm at both population and individual levels. He explored five key questions to evaluate the impact of program structure, analyzing existing literature and their program's experience.

Dr. Mazzone presented different levels of evidence showing that the implementation of centralized programs increases uptake, demonstrates better-shared decision-making processes, shows better test performance in terms of radiation dose, manages findings more effectively, exhibits higher adherence rates, and reduces disparities between Whites and Blacks.

Finally, Dr. Mazzone highlighted that centralized programs tend to offer better structures for quality improvement and incorporate important elements like registries, steering committees, and screening coordinators. He concluded that centralized screening programs have exhibited favorable impacts across multiple facets of lung cancer screening, supporting their value in enhancing screening efficacy.

Dr. Richard Wender spoke on how *Decentralized Lung Cancer Screening Is A Vital Part Of Our National Screening Program*. Dr. Wender responded to arguments favoring centralized lung cancer screening by highlighting the need for a decentralized approach alongside centralized methods. He emphasized the critical role of primary care in cancer screening despite the decentralized system in the United States. While recognizing the success of centralized screening, he underscored the critical role of primary care to ensure broader access to screening.

Discussing the significance of primary care, Dr. Wender cited a National Academy's report emphasizing its role in improving health outcomes and life expectancy. He stressed that all preventive care is associated with having a trusted source of primary care. Dr. Wender highlighted the decentralized nature of primary care in the United States, with over 500,000 clinicians in diverse practices, many operating independently, especially in rural areas.

Examining cancer screening rates, he noted achievements in breast, cervical, and colorectal cancer screenings despite decentralized approaches. Dr. Wender pointed out that even though awareness and support for lung cancer screening in primary care settings is very high, the rates of lung cancer screening are low, probably because of barriers within the decentralized model.

He stressed the importance of the endorsement of primary care clinicians and highlighted the implementation challenges they face in increasing LCS rates. He emphasized the need for quality measures, simplified eligibility criteria, and precise pack-year quantification. He also discussed decision-making, noting its significance but suggesting that linking it to coverage might hinder discussions and potentially limit screening indications.

In conclusion, Dr. Wender stressed the importance of both centralized and decentralized approaches, recognizing that the only way to keep up to date for an annual test is to have some component of centralized population management. He advocated for collaborative strategies involving primary care, hospitals, and innovative methods like value-based payments to ensure effective lung cancer screening across diverse healthcare settings.

Session 9 – Close Out: Final Thoughts on the 7th ACS NLCRT Annual Meeting

Dr. Ella Kazerooni closed the meeting by expressing gratitude to all attendees for their commitment to enhancing lung cancer survivorship. She emphasized the importance of patient engagement, especially for underserved populations. She highlighted the significance of proactive approaches that encouraged the use of inclusive and non-stigmatizing language in patient interactions to create a culture change in health care.

Dr. Kazerooni expressed appreciation to the American Cancer Society and the ACS NLCRT for organizing the meeting. Finally, she acknowledged Dr. Gerard Silvestri's tribute to Lauren Rosenthal, Director of the ACS NLCRT.

NLCRT Member Organizations

A Breath of Hope Lung Foundation
 AbbVie
 Academy of Oncology Nurse & Patient Navigators
 Advocate Aurora Lutheran General Hospital
 Aetna
 ALK Fusion
 ALK Positive
 American Academy of Family Physicians
 American Association for Thoracic Surgery
 American Association for Women in Radiology
 American Association of Nurse Practitioners
 American Association of Physicists in Medicine
 American Cancer Society
 American Cancer Society Cancer Action Network
 American College of Chest Physicians (CHEST)
 American College of Preventive Medicine
 American College of Radiology
 American College of Surgeons Commission on Cancer
 American Indian Cancer Foundation
 American Lung Association
 American Lung Cancer Screening Initiative
 American Medical Women's Association
 American Public Health Association
 American Society for Radiation Oncology
 American Society of Clinical Oncology
 American Society of Preventive Oncology
 American Telehealth Association
 American Thoracic Society
 Amgen
 Anne Arundel Medical Center
 Ascension Sacred Heart Cancer Center (FL)
 Association for the Treatment of Tobacco Use and Dependence
 Association of Community Cancer Centers
 Association of State & Territorial Health Officials
 AstraZeneca
 AvMed
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 Bronson Oncology
 Cancer Support Community
 CancerCare
 Caring Ambassadors
 Catch It In Time
 CDC Division of Cancer Prevention and Control
 CDC Office on Smoking and Health
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 Chris Draft Family Foundation
 ChristianaCare Health System
 Citizens for Radioactive Radon Reduction
 Cleveland Clinic
 Commoner Center, City University of New York
 Daiichi-Sankyo
 Dana-Farber Cancer Institute
 Delfi Diagnostics, Inc.
 Dusty Joy Foundation (LiveLung)
 EGFR Resisters
 Elevance
 Eli Lilly and Company
 EMD Serono, Inc.
 Essentia Health Cancer Center (ND)
 Exact Sciences
 Fleischner Society
 Foundation Medicine
 Fred Hutchinson Cancer Center
 Free ME From Lung Cancer
 Genentech
 Georgetown University Lombardi Cancer Center
 Georgia Lung Cancer Roundtable
 Gilead Sciences
 GO2 Foundation for Lung Cancer
 GRAIL
 Grandview Cancer Center
 Guardant Health
 Health First Cancer Institute (Florida)
 Hillsdale Hospital (Michigan)
 Houston Methodist
 Humana
 Huntsman Cancer Institute at the University of Utah
 Illinois Lung Cancer Roundtable
 Incyte
 Indian Health Service
 Inspira Health
 Intercultural Cancer Council
 International Association for the Study of Lung Cancer
 International Cancer Action Network
 International Early Lung Cancer Action Program
 Intuitive
 Janssen Pharmaceuticals
 Jefferson Health

The NLCRT, member organizations, and partners are committed to the adoption of language, phrasing, and imagery that is person-first, judgment-free, and non-stigmatizing. This shift in language takes time and dedicated effort, and slips happen, but it is an important part of creating a more supportive and empathic environment to reduce the burden of lung cancer. We appreciate your effort!

Johnson & Johnson Lung Cancer Initiative
 Kaiser Permanente Northern California
 Kentucky Cancer Consortium
 Kentucky LEADS Collaborative
 KRas Kickers
 Lee Health Regional Cancer Center
 Lehigh Valley Health Network
 LGBT HealthLink
 Life and Breath
 LuCa National Training Network
 Lung Cancer Awareness Month (LCAM) Coalition
 Lung Cancer Foundation of America
 Lung Cancer Initiative of North Carolina
 Lung Cancer Research Foundation
 Lung Health Services, Inc.
 LungCAN
 LUNgevity Foundation
 Maimonides Medical Center
 Maine Lung Cancer Coalition
 Maryland Department of Health
 Median Technologies
 Medical Imaging & Technology Alliance
 Medical University of South Carolina
 MedMyne
 Medtronic
 Memorial Sloan Kettering Cancer Center
 Merck
 MeVis Medical Solutions
 Michigan Department of Health and Human Services
 Mississippi Lung Cancer Roundtable
 Missouri Lung Cancer Coalition
 Moffitt Cancer Center
 Mount Sinai Health System
 National Alliance for Hispanic Health
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 National Cancer Institute
 National Comprehensive Cancer Network
 National Minority Quality Forum
 New York City Health & Hospital
 North American Association of Central Cancer Registries
 North American Quitline Consortium
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 Radiology Health Equity Coalition
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 Sanford Health
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 Sarasota Memorial Health Care System
 Seidman Cancer Center
 Silver Cross Hospital (IL)
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 Society for Behavioral Medicine
 Society for Public Health Education
 Society for Research on Nicotine and Tobacco
 Society of General Internal Medicine
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 University of Kansas Cancer Center
 University of Maryland School of Medicine
 University of Michigan Rogel Cancer Center
 University of Mississippi Cancer Center and Research Institute
 University of Texas Southwestern Moncrief Cancer Institute
 University of Virginia Cancer Center
 University of Washington
 University of Wisconsin Carbone Comprehensive Cancer Center
 Upstage Lung Cancer
 Vanderbilt-Ingram Cancer Center
 VA-PALS (Partnership to Increase Access to Lung Screening)
 Veterans Health Administration
 VisionGate
 Wake Forest Comprehensive Cancer Center
 XACT Robotics
 Yale Cancer Center