CAMPAIGN TO END LUNG CANCER STIGMA

NATIONAL
LUNG CANCER
ROUNDTABLE

2023 Stigma Summit
EXECUTIVE SUMMARY

April 13-14, 2023
Loews O'Hare Hotel
Chicago, Illinois

Introduction

The *American Cancer Society National Lung Cancer Roundtable (ACS NLCRT)* held its third Stigma Summit for the *Campaign to End Lung Cancer Stigma* on April 13 and 14, 2023, in Chicago, Illinois. Sixty-five attendees representing 40 organizations from across the country participated in this catalyzing summit, including lung cancer advocates, clinicians, researchers, and industry partners. The summit focused specifically on the role of messaging in eliminating the stigma experienced by members of the lung cancer community. Summit participants were tasked with developing and refining core messages that could be leveraged for the mitigation of stigma and ultimately support the highest quality of care for individuals affected by lung cancer.

The work of the ACS NLCRT centers on three key strategic priorities: 1) promoting initiatives to eliminate lung cancer-related stigma and nihilism, 2) accelerating implementation and uptake of and adherence to early detection (lung cancer screening and nodule detection and management), and 3) improving guideline-concordant lung cancer staging and optimizing the use of biomarkers in practice. These three strategies address quality across the lung cancer care continuum and ultimately support the ACS NLCRT's mission of creating lung cancer survivors.

The second *Campaign to End Lung Cancer Stigma* virtual meeting was held in October 2021, and the first was an in-person meeting in Atlanta, Georgia, in February 2020. In the third meeting, summit attendees developed guiding themes around messaging and imagery, with the three priority themes being urgency, empathy, and optimism. These themes were the focus of this summit.

Over the course of two days, attendees engaged with presentations on the topics of stigma frameworks, ACS NLCRT activities, messaging campaigns, and more. On Day 1, the breakout groups identified opportunities to explore messaging from different perspectives. On Day 2, the breakout groups developed tangible strategies for the opportunities identified on Day 1. The structure of the two-day summit was as follows:

Day 1

- Welcome and Overview
- Opening Panel: Insights into the Lived Experience of Lung Cancer Stigma
- Keynote #1 – The Health Stigma and Discrimination Framework: Overview and Applications to Lung Cancer Stigma
- NCI Global Stigma Workshop: Federal Partners & Future Opportunities
- Breakout Groups #1: Lung Cancer Messaging Across the Socioecological Spectrum

Day 2

- Opening Comments – Launching Day #2: The Messaging Summit
- Breakout Groups #1 Report Out
- ACS NLCRT and Campaign to End Lung Cancer Stigma Updates
- Keynote #2 – The Wrong Question Campaign
- Lung Cancer-Related Media Campaigns: Language, Imagery, and Contexts
- Breakout Groups #2: Exploring Potential Messaging Across the Lung Cancer Continuum
- Breakout Groups #2 Report Out

- Wrap-Up and Next Steps

This document provides an overview of the summit and the presentations and gives links to videos of the presentation slides and audio tracks.

Summit Overview

Day 1

The summit began with a *Welcome and Overview* by Jamie Studts, PhD, Chair of the *Campaign to End Lung Cancer Stigma*. He welcomed the attendees and emphasized the role of messaging in the overarching mission. He provided a brief overview of the ACS NLCRT *Campaign to End Lung Cancer Stigma* and some examples of progress made in the field. He thanked the ACS NLCRT sponsors and the ACS NLCRT leadership and staff for making the event possible.

Session 1 of the summit, *Opening Panel: Insights into the Lived Experience of Lung Cancer Stigma,* highlighted the diverse perspectives of individuals affected by lung cancer and lung cancer stigma. Panelists emphasized that stigma around smoking is pervasive and harmful, regardless of an individual's smoking history.

Session 2 contained *Keynote #1 – The Health Stigma and Discrimination Framework: Overview and Applications to Lung Cancer Stigma by Anne Stangl, PhD, MPH.* The presentation provided a historical perspective on stigma and its impact on health outcomes. Further, the presentation highlighted an overview of the *Health Stigma & Discrimination Framework*, a global framework that can support amplified and coordinated interventions to address intersectional stigmas across diseases.

Session 3 contained one presentation on the *NCI Global Stigma Workshop: Federal Partners, Future Opportunities by Vidya Vedham, PhD*. The presentation centered on health disparities in lung cancer globally and the need to balance the short-term gain of fear-based tobacco messaging with the long-term effects of lung cancer stigma. The presentation provided an overview of the *Global Cancer Stigma Research Workshop*, which took place virtually on September 28 and 29, 2022. The workshop inspired future research into cancer inequities, the evolution of stigma over time, stigma reduction interventions, intersectionality, and new research opportunities in the field of stigma.

Session 4 contained the first breakout group session, entitled *Breakout Groups #1: Lung Cancer Messaging Across the Socioecological Spectrum*. Participants were divided into four breakout groups on the topics of community/advocacy opportunities, global opportunities, clinical opportunities, and research opportunities. The groups were tasked with exploring lung cancer messaging from different perspectives.

Day 2

Day 2 of the summit began with *Opening Comments – Launching Day #2: The Messaging Summit*, presented by the Co-Chair of the *Campaign to End Lung Cancer Stigma*, Lisa Carter-Bawa, PhD. She summarized the Day 1 presentations, including the panel, types of stigma reduction interventions, and the need for global perspectives. To set the tone for Day 2, she encouraged summit attendees to continue the momentum, passion, ideas, and challenges to the status quo.

Session 1, *Breakout Groups #1 Report Out*, contained four presentations in which a representative from each Day 1 breakout session shared key opportunities identified by the group. The first breakout group, *Community/Advocacy Opportunities*, identified opportunities around a language audit, an anti-stigma mass media campaign, education for the public and medical community, and allyship. The second breakout group, *Research Opportunities*, identified opportunities in the normalization of lung cancer images, positive messaging around tobacco use, dialogues around stigma, collaboration, and an emphasis on community, compassion, and survivability. The third breakout group, *Clinical Opportunities*, identified a variety of positive images and messages to use in messaging campaigns. They also presented negative messages to avoid, such as death, negativity around tobacco use, pervasive personal responsibility, and the message that lung cancer is preventable. The fourth group, *Global Opportunities*, identified opportunities in a purpose-driven messaging campaign highlighting diversity in the lung cancer community, the need to combine patient stories with concrete asks, and advising providers on stigmatizing language and bias.

Session 2, entitled *ACS NLCRT and Campaign to End Lung Cancer Stigma Updates*, contained three presentations on projects in the field of lung cancer stigma. The first presentation touched on ACS NLCRT priorities, initiatives, and projects. The presentation contained a review of the ACS Roundtable model and purpose, strategic aims, actions, and impacts. Finally, the presentation highlighted priorities and projects for 2023, as well as current publications to date. The second presentation discussed empathic communication skills training. The provider-level intervention was adapted in Nigeria in February 2023 to mitigate lung cancer stigma. A preliminary analysis of the training suggested improved empathic communication by providers. The next steps include abstract submissions, manuscript preparation, and planned grant submissions. The third presentation provided an update on the *Lung Cancer Stigma Biopsy*, which helps content developers to reduce the prevalence of stigmatizing content in lung cancer and tobacco language, imagery, and context. The project has been well-received, and the next steps include finalizing the toolkit, integrating implementation examples, and developing a web microsite. To enhance usability, researchers hope to pursue pilot testing and evaluation processes.

Session 3, entitled *Keynote #2 – The Wrong Question Campaign* by Dr. Jamie Studts on behalf of *Lung Cancer Canada* and the *Lung Health Foundation*, contained one presentation on *The Wrong Question Campaign*, which originated in Australia and was adapted by Canada. The campaign addresses the

lack of empathy experienced by the lung cancer community to increase awareness of the urgent need for funding, treatment, and research in the lung cancer field. The campaign had positive social and political implications in Canada and inspired the follow-up campaign, *Start Asking the Right Questions*.

Session 4 contained three presentations on the topic of *Lung Cancer-Related Media Campaigns: Language, Imagery, and Contexts*. The first presentation summarized the *Saved by the Scan* campaign conducted by the *American Lung Association* in 2017. The campaign increased awareness of low-dose CT scans among persons with a smoking history and encouraged more conversations with healthcare providers about screening. The second presentation centered on the *Screen Your Lungs* campaign conducted by *Genentech* in collaboration with the *ACS NLCRT*, the *American Lung Association*, *GO2 For Lung Cancer*, and the LUNGevity Foundation, which used nostalgia to communicate the importance of screening in a positive manner. Along with the national PSA, *Genentech* developed a website with a screening eligibility quiz, patient-facing materials, and provider-facing materials. The third presentation focused on engaging diverse communities in developing and implementing language guidelines. Person-first, identity-first, and active language were described to contextualize the discussion around the *International Association for the Study of Lung Cancer (IASLC) Language Guide*. An opportunity for members of marginalized and minoritized communities to provide feedback on the language guide would support a greater understanding of public perception and help assess the acceptability of a revised guide.

Session 5 was the second breakout group session, *Breakout Groups #2: Exploring Potential Messaging Across the Lung Cancer Continuum*. Participants were divided into four breakout groups on the topics of risk reduction, early detection, diagnostics and treatment, and survivorship and palliative care. The groups were tasked with identifying tangible strategies based on the opportunities identified in the breakout sessions of Day 1.

Session 6, *Breakout Groups #2 Report Out*, contained four presentations in which a representative from each Day 2 breakout session shared the strategies discussed in their group. The first breakout group, *Risk Reduction*, shared strategies around messaging, specifically for overall health, risk factors other than tobacco, and uncertainty or anxiety around risk factors. The group also discussed empathy in messaging and the ongoing benefit of healthy behavioral changes. The second breakout group, *Early Detection*, highlighted strategies around stigma as a public health crisis with an audience of the public. The group emphasized intersectionality and community partnerships as key components of this work. The third breakout group, *Diagnosis and Treatment*, proposed a pledge like the CDC HIV stigma pledge, education for medical assistants and other staff, peer-to-peer referrals, a new diagnosis toolkit, and a lung cancer campaign with a well-known celebrity. The fourth breakout group, *Survivorship and Palliative Care*, conceived of lung cancer survivorship care plans, personalized video responses for newly diagnosed individuals, video responses to provider questions, a script for providers, an FAQ project, and standardized questions on tobacco use.

Session 7 contained closing remarks from Lisa Carter-Bawa, Ella Kazerooni, Lauren Rosenthal, and Jamie Studts. Presenters thanked participants for attending the summit, reiterated their gratitude for the sponsors, and emphasized the value of collaborative work around lung cancer stigma.

Overview of Panel Presentations with Video Links

Day 1
Welcome and Overview
• **Welcome: Campaign to End Lung Cancer Stigma Summit #3: Messaging** Jamie Studts, PhD, Chair, ACS NLCRT Campaign to End Lung Cancer Stigma, Professor, Division of Medical Oncology, Department of Medicine, University of Colorado School of Medicine
Opening Panel: Insights into the Lived Experience of Lung Cancer Stigma
• **Opening Panel: Insights into the Lived Experience of Lung Cancer Stigma** Eugene Manley, Jr, PhD, Moderator, LUNGevity Foundation Elizabeth Scharnetzki, PhD, Moderator, Maine Health Institute for Research Natalie Brown, Patient Advocate, LUNGevity Foundation James Pantelas, Patient Advocate, Department of Veterans Affairs Teresa Conneran, Patient Advocate, KRAS Kickers Juanita Segura, Patient Advocate, Lung Cancer Foundation of America
Keynote #1 – The Health Stigma and Discrimination Framework: Overview and Applications to Lung Cancer Stigma
• **Keynote #1: The Health Stigma and Discrimination Framework: Overview and Applications to Lung Cancer Stigma** Anne Stangl, PhD, MPH, Senior Advisor, Elimination of Stigma and Discrimination, Division of Global HIV and Tuberculosis, Centers for Disease Control and Prevention
NCI Global Stigma Workshop: Federal Partners & Future Opportunities
• **NCI Global Stigma Workshop: Federal Partners, Future Opportunities** Vidya Vedham, PhD, Program Director, Centre for Global Health, National Cancer Institute
Breakout Groups #1: Lung Cancer Messaging Across the Socioecological Spectrum

Day 2
Opening Comments – Launching Day #2: The Messaging Summit
• **Reflections from Day 1 + Looking Forward** Lisa Carter-Bawa, PhD, APRN, ANP-C, FAAN, Co-Chair, Campaign to End Lung Cancer Stigma, Director, Cancer Prevention Precision Control Institute, Center for Discovery & Innovation, Hackensack Meridian Health
Breakout Groups #1 Report Out – Lung Cancer Messaging
• **Community/Advocacy Opportunities** Dusty Donaldson, LungCAN, Dusty Joy Foundation Eugene Manley, Jr, PhD, LUNGevity Foundation Elizabeth Scharnetzki, PhD, Maine Health Institute for Research • **Research Opportunities** Jill Feldman, EGFR Resisters Jamie Studts, PhD, University of Colorado • **Clinical Opportunities** Lisa Carter-Bawa, PhD, APRN, ANP-C, FAAN, Hackensack Meridian Health Abbie Begaud, MD, University of Minnesota • **Global Opportunities** Jamie Ostroff, PhD, University of Colorado Maureen Rigney, LICSW, GO2 For Lung Cancer Vidya Vedham, PhD, National Cancer Institute
ACS NLCRT and Campaign to End Lung Cancer Stigma Updates
• **ACS NLCRT Priorities, Initiatives & Projects Overview** Ella Kazerooni, MD, MS, Chair, ACS National Lung Cancer Roundtable, Professor, Department of Radiology, University of Michigan • **Empathic Communication Skills Training: A Provider-Facing Strategy to Reduce Lung Cancer Stigma** Jamie Ostroff, PhD, Chief, Behavioral Sciences Service & Director, Tobacco Treatment Program, Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center • **Campaign Update – Lung Cancer Stigma Biopsy** Jamie Studts, PhD, Chair, ACS NLCRT Campaign to End Lung Cancer Stigma, Professor, Division of Medical Oncology, Department of Medicine, University of Colorado School of Medicine
Keynote #2 – The Wrong Question Campaign

- **Keynote 2: "The Wrong Question" Campaign in Canada**
  Jamie Studts, PhD, Chair, ACS NLCRT Campaign to End Lung Cancer Stigma, Professor, Division of Medical Oncology, Department of Medicine, University of Colorado School of Medicine

Lung Cancer-Related Media Campaigns: Language, Imagery, and Contexts

- **Saved by the Scan**
  Deborah Brown, MS, CHES, Chief Mission Office, American Lung Association
- **Screen Your Lungs**
  Julie Reynolds, MBA, Marketing Manager, Targeted Therapies, Genentech
- **Engaging Diverse Communities in Developing and Implementing Language Guidelines**
  Eugene Manley, Jr, PhD, Director, STEM Workforce Initiatives, LUNGevity Foundation
  Elizabeth Scharnetzki, PhD, Staff Scientist, Maine Health Institute for Research

Breakout Groups #2: Exploring Potential Messaging Across the Lung Cancer Continuum

Breakout Groups #2 Report Out

- **Risk Reduction**
  Joelle Fathi, DNP, RN, ARNP, GO2 For Lung Cancer
  Elyse Park, PhD, MPH, Massachusetts General Hospital
- **Early Detection**
  M. Patricia Rivera, MD, University of Rochester
  Jamie Studts, PhD, University of Colorado
- **Diagnosis and Treatment**
  Abbie Begnaud, MD, University of Minnesota
  Ella Kazerooni, MD, MS, University of Michigan
- **Survivorship and Palliative Care**
  James Pantelas, Department of Veterans Affairs
  Lisa Carter-Bawa, PhD, APRN, ANP-C, FAAN, Hackensack Meridian Health

Wrap-Up and Next Steps

- **Wrap-Up and Next Steps**
  Ella Kazerooni, MD, MS, Chair, ACS National Lung Cancer Roundtable, Professor, Department of Radiology, University of Michigan
  Jamie Studts, PhD, Chair, ACS NLCRT Campaign to End Lung Cancer Stigma, Professor, Division of Medical Oncology, Department of Medicine, University of Colorado School of Medicine

Presentation Highlights: Day 1

Welcome and Overview

Jamie Studts, PhD, Chair of the *Campaign to End Lung Cancer Stigma*, welcomed the attendees to Chicago, Illinois, for the third Stigma Summit. He explained that the purpose of the summit is to convene advocates, clinicians, organizations, industry, and researchers to move forward with the possibility of a unified national campaign to mitigate the effects of lung cancer stigma. He shared a brief history of the *Campaign to End Lung Cancer Stigma*, which seeks to eliminate lung cancer stigma through coordinated leadership, strategic planning, advocacy, action, and collaboration. Then he shared various examples of progress made in this field, including the *International Association for the Study of Lung Cancer (IASLC) Language Guide*, organizational outreach efforts, and publications. He closed the presentation by thanking the ACS NLCRT sponsors and the ACS NLCRT leadership and staff for making the event possible.

Opening Panel: Insights into the Lived Experience of Lung Cancer Stigma

In the panel discussion, lung cancer survivors and advocates discussed how the stigma surrounding lung cancer affects care and treatment and how the stigma could be overcome. Panel members included lung cancer survivors Natalie Brown, Terri Conneran, Juanita Segura, and Jim Pantelas. They answered questions and shared their experiences regarding the topic of lung cancer stigma.

Ms. Natalie Brown, an advocate from Atlanta, Georgia, was diagnosed with stage IV lung cancer in July 2020 and is currently undergoing treatment and organizing a nonprofit. **Ms. Terri Conneran,** from Charlotte, North Carolina, is a six-year lung cancer survivor with the KRAS biomarker. Three years into her survival, she started the KRAS Kickers and currently works with the Dusty Joy Foundation. **Ms. Juanita Segura**, from outside of Chicago, Illinois, was diagnosed in 2014 at stage IIIB and is now stage IV with an ALK-positive diagnosis. She is passionate about advocacy and adding her voice to end the stigma surrounding lung cancer. **Mr. Jim Pantelas**, a 17-year late-stage lung cancer survivor, has dedicated his time to advocate for ending the stigma around lung cancer.

Mr. Pantelas defined nihilism as the result of stigma because it is the direct result of feeling as if you caused the disease to happen in your own body. Ms. Segura added that smoking is a common risk factor associated with lung cancer and that the public often stigmatizes the disease due to this association. The panel then discussed the stigma and nihilism surrounding lung cancer, including how people often self-blame and do not seek first-line therapy.

The panelists then discussed ways to overcome the stigma and nihilism associated with lung cancer. Ms. Conneran stated that we must first acknowledge that a problem exists and that lung cancer affects everyone with lungs. The stigma often comes from the public and stems from the association with smoking. Ms. Segura emphasized the importance of education and starting with ourselves to

break the cycle of stigmatization. Mr. Pantelas added that communication and creating safe spaces are important for overcoming the stigma, and the next generation of medical professionals should be taught to talk to cancer patients in a better way. Ms. Brown reiterated that advocacy is crucial and that anyone with lungs can get lung cancer.

The panelists also discussed how the stigma surrounding smoking can impact care, including how people are continuously asked about their smoking history, which is a question that can create feelings of guilt and discomfort. In addition, individuals who formerly smoked often feel alienated in lung cancer community settings. Mr. Pantelas emphasized that there is a need for safe spaces for lung cancer patients and that research funding should focus on cures, not just cessation. However, he stated that sometimes funding is denied because lung cancer is viewed as a preventable disease.

The panelists ended with a discussion of what they would like people to focus on in the future. MR. Pantelas suggested that organizations need to get out of their silos and work together to create a larger voice. He added that advocacy and raising awareness are important to end the stigma and secure additional funding for research. Ms. Conneran emphasized the need to look deeper than just smoking history and to break down the stigmatizing views surrounding lung cancer. Ms. Segura reiterated the importance of education and breaking the cycle of stigmatization, and Ms. Brown emphasized that anyone with lungs can get lung cancer and that advocacy is crucial.

Overall, the panelists highlighted the need to end the stigma surrounding lung cancer because it can impact care and treatment. They discussed various ways to overcome stigma and nihilism, including education, communication, and advocacy. They suggested that organizations need to work together to create a larger voice to get funding for lung cancer research.

Keynote #1 – The Health Stigma and Discrimination Framework: Overview and Applications to Lung Cancer Stigma

Anne Stangl, PhD, gave the first keynote presentation on the health stigma discrimination framework. She began the keynote with a historical overview of health-related stigma, beginning with the biblical stigma surrounding leprosy. She emphasized that stigma exists around both non-communicable and infectious diseases and highlighted HIV-related and anti-smoking campaigns that have historically worsened stigma. After drawing upon Goffman's 1996 definition of stigma, she then discussed the role of intersectional stigma and access to healthcare services. This discussion provided context for *The Health Stigma and Discrimination Framework*, published by Dr. Stangl and colleagues in 2019. The framework is unique because it does not distinguish between the stigmatizer and the stigmatized and understands that health stigma is a societal issue that negatively impacts everybody. The framework separates manifestations into practices and experiences and differentiates outcomes for affected populations from those for organizations and institutions. Dr. Stangl concluded that this framework could be utilized for the mitigation of intersectional stigma at

multiple socioecological levels for lung cancer. Finally, the adoption of a common framework can support the collective ability to respond to and reduce health-related stigma.

NCI Global Stigma Workshop: Federal Partners & Future Opportunities

Vidya Vedham, PhD, of the National Cancer Institute (NCI), presented on the NCI Global Stigma Workshop. She opened her presentation with a discussion of the global cancer burden and data on the global prevalence of lung cancer. She emphasized that there are various risk factors for lung cancer, including radon, asbestos, and genetics, among other things. Further, societal, environmental, and personal factors contribute to health disparities. She distinguished between public, systemic, and self-stigma, as well as the need to balance the short-term gain of fear-based tobacco messaging with the long-term effects of lung cancer stigma. This discussion contextualized the virtual *Global Cancer Stigma Research Workshop*, which took place on September 28 and 29, 2022. The workshop's objectives were to highlight the impact of stigma on global cancer control, showcase relevant research by the NCI and NIH grantees, and identify research gaps through conversation. Various themes emerged from this work, including misconceptions around cancer, difficulties with measuring stigma and intersectionality, the impact of stigma, resilience and strength, community voices, and the need for multi-level interventions. Future research will focus on stigma as it relates to cancer inequities, time continuums, challenges within dynamic contexts, intersectionality, and new areas of research.

Presentation Highlights: Day 2

Opening Comments – Launching Day #2: The Messaging Summit

Lisa Carter-Bawa, PhD, and Co-Chair of the *Campaign to End Lung Cancer Stigma,* reflected on the first day of the summit and set the tone for the day ahead. She emphasized the value of hearing personal experiences during the panel presentation and shared key takeaways from the presentations by Dr. Stangl and Dr. Vedham. These takeaways included types of stigma reduction opportunities and the need to think globally within this work. Next, she noted the robust discussions in the Day 1 breakout group sessions. For Day 2, she encouraged attendees to continue the momentum, passion, ideas, and challenges to the status quo.

Breakout Groups #1 Report Out

Elizabeth Scharnetzki, PhD, presented an overview of the *Community/Advocacy Opportunities* breakout group discussion from Day 1. The group identified the need to develop representative messaging for various communities with the objective of mitigating stigma. They recognized stigma as a public health concern and emphasized the value of shared understanding and awareness as they relate to messaging. They proposed creating shared template slide decks or toolkits, as well as

developing media in different formats. The breakout group discussed meeting people at community hubs and developing an understanding of how various communities want to receive information. The messaging should be optimistic and hopeful and should convey innovations in the field. Additionally, they suggested messaging that encourages overall lung health. Within these messaging campaigns, key considerations include health literacy levels and accessibility. Finally, the breakout group stressed the importance of approaching this work with humility, addressing intersectionality, and finding opportunities for allyship in the stigma field.

Jill Feldman of EGFR Resisters presented an overview of the *Research Opportunities* breakout group discussion from Day 1. The breakout group discussed destigmatizing lung cancer through the recognition that tobacco use was normal in previous generations. They emphasized that smoking is a risk factor for many other diseases and cancers. They stressed the power of imagery and how normalizing the image of lung cancer and tobacco use as an opportunity to open a dialogue about stigma. The group also identified the need for cultural humility, sensitivity, and diversity in storytelling. By understanding the humanity of the lung cancer community, messaging can be targeted and adapted for distinct groups. Finally, collaborative messaging is a key for provoking change.

Abbie Begnaud, MD, gave an overview of the *Clinical Opportunities* breakout group discussion from Day 1. The group shared positive messages, such as focusing on better outcomes through early detection and treatment options. They identified the importance of inclusivity and used HIV stigma campaigns as models. The breakout group discussed the harm of self-blame after a cancer diagnosis, as well as the role clinicians play in mitigating patient self-blame. Within the clinical setting, it is also necessary for clinicians to explain why they need to take a smoking history. Additionally, bringing awareness to other risk factors can lower the emphasis on stigma. The group suggested encouraging and low-pressure/less aggressive messaging around smoking cessation. Negative messages to avoid include those associated with sickness and death, graphic images targeting people because of their smoking history, and messaging about lung cancer as preventable.

Maureen Rigney, LICSW, presented an overview of the *Global Opportunities* breakout group discussion from Day 1. The group proposed the creation of a *Many Faces of Lung Cancer* campaign to share positive images and recognize the diversity of the lung cancer community. They emphasized that messaging campaigns need to have a clear ask and discussed the importance of sensitivity in taking a smoking history. Finally, the group recognized that the conversation about lung cancer stigma is a relatively new one and that there are many inconsistencies in the research.

ACS NLCRT Priorities, Initiatives, & Projects Overview

Ella Kazerooni, MD, Chair of the ACS NLCRT, presented on the ACS NLCRT priorities, initiatives, and projects. Since its formal launch in 2017, the ACS NLCRT has engaged more than 210 organizational members, over 225 leading experts, and other key stakeholders in the lung cancer field to support

the work of comprehensive care across the lung cancer continuum. The strategic aims of the ACS NLCRT include catalyzing action, building capacity, aligning activities, and centering equity. She highlighted the *President's Cancer Panel Lung Cancer Companion Brief* that stated its support for the ACS NLCRT. Through a multidisciplinary approach, the ACS NLCRT continues to draw upon strategic priorities for 2023. These priorities include 1) accelerating the implementation and uptake of, and adherence to, early detection of lung cancer (lung cancer screening and nodule detection and management), 2) improving guideline-concordant lung cancer staging and optimizing the use of lung cancer biomarkers in practice, and 3) promoting initiatives to eliminate lung cancer-related stigma and nihilism. Under these three strategic priorities, the ACS NLCRT has developed a variety of projects and focused task groups. Dr. Kazerooni closed the presentation by sharing the strategic plan and some ACS NLCRT publications to date. She thanked the *American Cancer Society*, the ACS NLCRT, and the industry sponsors who support our collaborative work.

Empathic Communication Skills Training: A Provider-Facing Strategy to Reduce Lung Cancer Stigma

Jamie Ostroff, PhD, presented on *Empathic Communication Skills Training*. She highlighted that around 95% of people with lung cancer report stigma from family, friends, and medical providers. This has negative consequences for psychological and clinical care outcomes. In response to these findings, researchers developed the research question: "Given the strong association between patient-provider communication and lung cancer stigma, can we target empathic communication as a mechanism to reduce patients' experience of lung cancer stigma?" A national, multisite trial of the *Empathic Communication Skills Training* was developed to promote destigmatizing interactions among oncology care providers in the lung cancer field. Dr. Ostroff shared some key recommendations and tools to facilitate the adoption of the *Empathic Communication Skills Training* practices, including a patient introductory video, a provider demonstration video, provider smart phrases, and modifying clinical scenarios with attention to patient diversity and national representativeness. In Nigeria, a preliminary analysis of the training suggested significant improvement in empathic communication with patients. The next steps include abstract submissions, manuscript preparation, and planned grant submissions. The presentation concluded with the key takeaways that clinicians play a critical role in reducing lung cancer stigma, that training around this topic is feasible, acceptable, and promising, and that taking a smoking history does not have to be a painful medical procedure.

Campaign Update: Lung Cancer Stigma Biopsy

Jamie Studts, PhD, presented on the *Lung Cancer Stigma Biopsy* and emphasized the importance of language, imagery, and contexts in the formation of societal perspectives on lung cancer. The *Lung Cancer Stigma Biopsy* toolkit is designed to support content developers in identifying and modifying stigmatizing language in their materials that address lung cancer and tobacco. This project was

developed by the ACS NLCRT *Stigma and Nihilism Task Group*. It consisted of background research, structure development, two rounds of feedback from expert reviewers, external review and pilot testing, and finally, dissemination through the Lung Cancer Stigma Portal. The next steps include finalizing the full toolkit, integrating implementation examples, and developing a website. The group will also pursue pilot testing and evaluation to enhance usability and impact. Dr. Studts thanked those who provided feedback and guidance throughout the project and the *ACS NLCRT Roundtable* for its support.

Keynote #2 – The Wrong Question Campaign

Jamie Studts, PhD, gave the second keynote on *The Wrong Question* campaign that was conducted in Canada. The campaign was launched in 2019 by *Lung Foundation Australia* and then replicated in 2020 and 2022 by *Lung Cancer Canada* and the *Lung Health Foundation* in Canada. The Australian campaign focused on the awareness of the barriers caused by the lung cancer stigma, represented by the “Did you smoke?” question. Instead of showing empathy and compassion, this question caused delayed diagnosis, lack of research funding, and a reluctance to seek help. Through social media campaigns, the initiative provided alternative questions and conversations, which resulted in a 30% decrease in individuals considering asking the wrong question. They also raised $1 million per year of federal funding to address lung cancer stigma directly.

Inspired by the Australian campaign, the first and second phases of the Canadian campaign aimed to increase public understanding of lung cancer stigma and how deadly it is and raise awareness of the urgent need for funding early diagnosis, treatment, and research. For the campaign, they used the survivor, family, and caregiver witness approach while taking care to consider equity, diversity, and inclusion principles. The evaluation of the campaign revealed high audience engagement, with about 200 million overall impressions.

The third phase of the Canadian campaign was expanded to give more emphasis on healthcare clinicians as stigma witnesses, leaning into compelling storytelling using real Canadian stories. Furthermore, this phase aimed not only to win the attention of the community but also of their policy leaders and legislators. The goals of this phase are to reduce stigma, support patients, increase lung cancer funding, and improve timely access to screening, diagnosis, and treatment.

Dr. Studts concluded that the data collected by the Australian and Canadian campaigns would be valuable for designing, implementing, and evaluating the process for messaging campaigns in the United States.

Saved by the Scan

Deborah Brown, MS, from the *American Lung Association,* opened the session by sharing an overview of the *Saved by the Scan* campaign, which is a national lung cancer screening program in

partnership with the Ad Council launched in 2017. The campaign aims to raise awareness of the benefits of early lung cancer detection and drive high-risk individuals to a quiz to determine their eligibility for screening. Although there are currently 14.2 million Americans at high risk for lung cancer, whose age range is 50-80, and who have a smoking history, only 6% of those eligible get screened. Hence, the purpose of the program is to identify the people at risk and encourage them to talk to their doctors about lung scans. To ensure that people get screened, they have an implementation guide with best practices to help people to overcome challenges, such as accessible screening locations. The evaluation of the campaign impact shows that 41% of persons with a smoking history are now aware of the low-dose CT scan and that 30% have talked to their doctors and are getting screened for lung cancer. The campaign was designed to engage and inspire people through eye-catching graphical materials and hopeful stories. Dr. Brown described what they learned from the focus groups about the barriers that people with a smoking history must get screened for. Most of these barriers are driven by anxiety and could be relieved by making the screening feel like a quick routine study for early detection. Then, she showed some of the metrics from the *Saved by the Scan* campaign, including that they had $98 million in donated campaign media, almost 900,000 completed quizzes, 26% of which correspond to high-risk individuals, and a 70% increase in awareness of low-dose CT scan among persons with a smoking history. Finally, the speaker highlighted that more than 120 people shared their stories of how the campaign saved their lives.

Screen Your Lungs

Julie Reynolds, MBA, from *Genentech,* shared an overview of the *Screen Your Lungs* campaign from the marketing point of view. She explained that the campaign aimed to reduce lung cancer stigma. She played a video showing people smoking in different everyday situations in the 1970s and 1980s because they wanted to catch the attention of people in the 55-and-older crowd who belong to the current high-risk population. The video ends with the slogan, "*If that was you, then, get your lungs screened now.*" They wanted to point out that smoking was considered an acceptable part of the culture at that time, trying to destigmatize people that used to smoke then. With the messaging framework of "No judgment, just knowing," they focused on different target audiences: people who used to smoke, people currently smoking, underserved at-risk, friends and family, and healthcare providers. For each of these groups, they identified attitudes, barriers that the attitudes created, messages that would help to break the barriers, and benefits that could come afterward (early diagnosis saves lives). They aimed to approach people with empathy, without judgment, and with a sense of hope and optimism. Ms. Reynolds said they had over $100 million of donated media in different formats. Finally, she showed some of the material that they developed for health care providers and the website to which all their public service announcements and search marketing drive. On that site, people can take the quiz to find out if they are eligible for screening and find other resources.

Engaging Diverse Communities in Developing and Implementing Language Guidelines

Eugene Manley, Jr., PhD, and **Elizabeth Scharnetzki, PhD**, presented the last talk entitled *Engaging Diverse Communities in Developing and Implementing Language Guidelines*. They developed a language guideline in collaboration with Dr. Carter-Bawa, which is an ongoing work meant to be responsive to different contexts and different cultures. Dr. Scharnetzki highlighted that language shapes people's thoughts, and words are a powerful tool to decrease bias and stigma, promote equity, and reduce shame and blame. The language used to describe individuals who may have a socially stigmatized condition can either compound feelings of social devaluation or promote empathy and equity. And language preferences may vary depending on the context, cultural norms, and social identities of the audience. *Person-first language* emphasizes the person and their experiences rather than a condition or quality. *Identity-first language* describes individuals in terms of a characteristic, which is usually felt to be an inseparable part of the identity by people who prefer this language. *Active language* underscores the role of systems as being the driving forces of repression (something that can be changed) instead of the people who may be subject to that oppression. Dr. Scharnetzki concluded that the three types of language could reduce stigma, but it is important to choose the one that is going to be responsive for a particular community. Hence, to be culturally and socially responsive, it is necessary to create opportunities for diverse community members to provide feedback on the *IASLC Language Guide* and express how they perceive their affiliated institutions. To this end, they will organize focus groups with members from diverse and underserved groups. Dr. Manley closed by saying that they also aimed to assess the acceptability of the revised language guide for communicating information about lung cancer and smoking among a diverse set of community members.

Breakout Groups #2 Report Out

Joelle Fathi, DNP, shared key takeaways from the *Risk Reduction* breakout group discussion earlier in the day. The group discussed the various risk factors for lung cancer other than tobacco. They identified a need to develop messaging that removes the emphasis, shame, and blame around tobacco use. Additionally, the *Risk Reduction* group noted that there is not always a clear cause for someone's cancer, and this can be difficult for patients to internalize. The group continued circling back to the issue of empathy and the need to incorporate this into tobacco cessation messaging. They emphasized that it is always beneficial to stop using tobacco products and make healthy behavioral changes. Finally, they shared strategies around enhancing and increasing the volume of prevention messaging in high-risk communities.

Jamie Studts, PhD, spoke on behalf of the *Early Detection* breakout group. This group compared wide-scope public health strategies and co-created regional messaging activities. They concluded that both approaches are critically important, but wide-scope public health strategies are better

suited to general campaigns, and regional messaging activities are better suited to campaigns with a clear ask. Following this model, a general messaging campaign around stigma could be conducted at the population level. Stigma reduction is difficult because it requires people to change the way they think. The group questioned the possibility of representing intersectional stigma considerations at the population level. It also considered whether it is better to utilize explicit or implicit messaging around stigma, with the option to conduct testing to compare the two approaches.

Abbie Begnaud, MD, reported highlights from the *Diagnosis and Treatment* breakout group. The group discussed adapting the CDC HIV stigma pledge for clinicians to lung cancer to encourage the use of destigmatizing language. Additionally, they felt that educating the medical staff was important because they are the first to interact with incoming patients. A peer-to-peer referral, mentoring, or navigating program would be useful for connecting people with similar experiences via telephone line or app and providing support and bringing hope to people who are newly diagnosed. A resource toolkit to provide reliable information about the disease would also be helpful for newly diagnosed individuals. Finally, the group proposed a messaging campaign led by a recognizable celebrity.

Lisa Carter-Bawa, PhD, represented the *Survivorship and Palliative Care* breakout group. She emphasized the importance of lung cancer survivorship care plans and that there are more lung cancer survivors now than ever before. The group proposed the creation of video clips or toolkits to help individuals respond to questions about their smoking history. Videos could be compiled into a library that provided guidance on language and tone for answering provider questions. The group also proposed the creation of a provider script across the cancer care continuum, similar to the *Empathic Communication Skills Training*. Education must extend to all providers that interact with patients. Finally, the group suggested standard questions around tobacco use to normalize the conversation for all patients, not just those in the lung cancer setting.

Wrap-Up and Next Steps

Ella Kazerooni, MD, MS, Chair of the ACS NLCRT, wrapped up the summit. She began by thanking Dr. Lisa Carter-Bawa and Dr. Jamie Studts for organizing the third *Lung Cancer Stigma Summit*. She went on to thank the ACS staff, the ACS NLCRT leadership, and the ACS NLCRT sponsors. She highlighted that the ACS NLCRT sponsors allow for this work to move forward and for organizations to make a difference in the lung cancer space. She thanked patient advocates for their willingness to share personal experiences to shape a better future. She emphasized that changing the public perception of lung cancer stigma is not easy, but it is necessary.

Jamie Studts, PhD, thanked the funding partners, collaborators, advocates, and others for sharing their time and ideas at the summit. He also thanked the ACS NLCRT leadership for supporting this work with tangible strategies and tactics. He shared that the ACS NLCRT leadership will likely follow up with summit attendees so that this work can continue.

This Executive Summary was thoughtfully prepared by the ACS NLCRT Executive Leadership Team:

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