

## **Leveraging Advances in Lung Cancer Care and Control to End Lung Cancer Stigma**

There have been transformative survivorship-enhancing strides in lung cancer risk reduction, early detection, diagnosis, treatment, and palliative care that are rapidly changing the lung cancer landscape. These innovations have infused opportunity and hope into the lung cancer community and provide a unique opportunity to change cultural perspectives on lung cancer that could expedite progress and facilitate the implementation of innovations in lung cancer care and control.

Individuals at high risk for lung cancer, as well as individuals diagnosed with lung cancer, face unique and disconcerting challenges linked to persistent and ubiquitous lung cancer stigma. The American Cancer Society National Lung Cancer Roundtable (NLCRT) has defined lung cancer stigma as a "...cognitive, affective, and/or social experience and internalization of real or anticipated negative appraisal, devaluation, distancing, and discrimination by others attributable to an assumed or actual history of smoking, lung cancer risk, or lung cancer diagnosis, impeding progress in lung cancer risk reduction and control." Studies have documented lung cancer stigma across all groups and domains, including individuals, social networks, clinicians, healthcare systems, and throughout society.

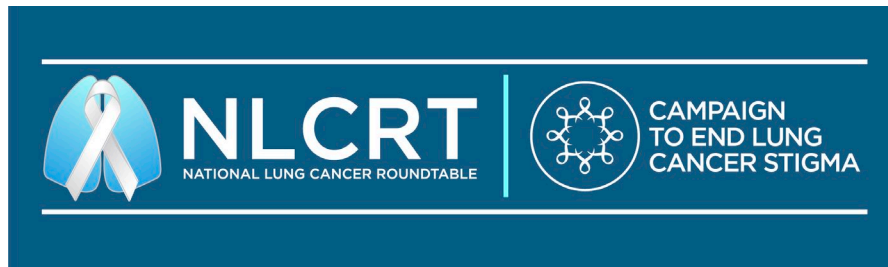
Research has consistently documented that the vast majority of individuals diagnosed with lung cancer experience stigma from peers, family members, clinicians, and society. Not only has lung cancer stigma been shown to be associated with greater psychosocial distress following diagnosis, but the element of self-blame can also reduce motivation to play an active role in care and hinders self-disclosure of a lung cancer diagnosis. This enhances the sense of isolation and separation experienced by many lung cancer survivors at some point or throughout their survivorship. The adverse effects of lung cancer stigma extend beyond those diagnosed, family members and caregivers commonly report experiencing stigma and bias, and the stigma experienced by individuals at-risk for lung cancer has proven to be a barrier to effective risk reduction and early detection.

Lung cancer stigma adversely impacts each phase of the lung cancer continuum and negatively affects all individuals and groups within the lung cancer community and beyond. Lung cancer-related stigma serves as an unnecessary and unwelcome barrier to progress to reduce the burden of lung cancer. Lung cancer stigma impedes access to and utilization of: (1) evidence-based tobacco prevention and treatment, (2) high-quality lung cancer screening, (3) optimal diagnosis and treatment, (4) survivorship support and palliative care, and (5) end-of-life and bereavement care.

Previous initiatives by prominent organizations and individuals to eliminate lung cancer stigma have raised awareness of the challenge of lung cancer stigma and identified effective approaches to reduce stigma. The NLCRT salutes these pioneering efforts and is committed to working alongside leading patient advocacy organizations, clinician groups, and scientists to build on past work and initiate and sustain new endeavors to permanently eliminate sources of lung cancer stigma as well as its detrimental effects on patients and families.

## **Formation and History of the Survivorship, Stigma, and Nihilism Task Group of the NLCRT**

Following the inaugural NLCRT meeting in 2017, the steering committee added Survivorship, Stigma, and Nihilism to the list of supported task groups in recognition of the important factors that stigma and nihilism play in achieving optimal lung cancer survivorship. Drawn from different disciplines and with ranging lung cancer experience, task group members with expertise in each area formulated plans to enhance lung cancer survivorship and address lung cancer stigma and nihilism with specific strategies based on the current science and input from task group expertise.



In formulating the initial scope of work for the new task group, it was clear that there was ample momentum and opportunity to pursue the lofty goal of ending lung cancer stigma and the adverse impact it plays in lung cancer. Building on the attention allocated to lung cancer stigma and borne of a desire to leverage the strength of the inter-organizational collaboration of the NLCRT, the Survivorship, Stigma, and Nihilism Task Group convened the first National Lung Cancer Stigma Summit in February 2020. This meeting constituted the initial milestone in establishing the Lung Cancer Stigma Initiative (LCSI), an interdisciplinary group of stakeholder organizations working to end lung cancer stigma and improve lung cancer outcomes.

### **Phase I: The NLCRT Lung Cancer Stigma Initiative**

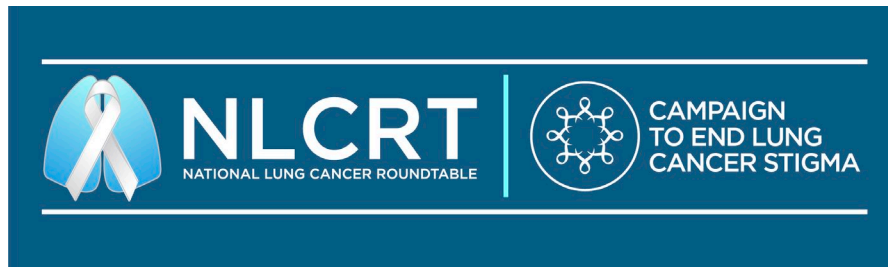
Recognizing the central importance of imagery and messaging, summit attendees developed essential themes to guide message development and imagery design. Drawing on the diverse expertise of over 70 members of the lung cancer community, the summit identified three key themes to end lung cancer stigma: (1) urgency, (2) empathy, and (3) optimism.

The first theme, **urgency**, reflects both need and opportunity. There is an immediate need to address the lung cancer stigma problem, and the innovations in lung cancer care have created a unique opportunity to alter how society thinks, feels, and acts in reference to lung cancer. The second theme, **empathy**, recognizes the power of connection, understanding, and compassion as a pathway to overcoming lung cancer stigma and addressing known gaps in support and societal understanding. Finally, **optimism** is also related to the transformations and improvements in lung cancer control that have established a more complex and accurate perspective on lung cancer and a window of hope for survival and well-being following a diagnosis. These three themes formed the foundation of a strategic plan that directly addresses the major factors that contribute to lung cancer stigma and its devastating consequences.

Summit participants also identified six key areas worthy of additional consideration: (1) improving survivorship, (2) altering the messaging, (3) educating clinicians, (4) expanding funding, (5) navigating the complex relationship with tobacco, and (6) other elements, that laid the groundwork for developing a strategic framework to guide the LCSI. Over the course of the spring, summer, and fall of 2020, the LCSI Strategic Planning Committee developed the LCSI Strategic Framework. Multiple iterations of the framework were formulated by the planning committee with review and feedback by a broad range of lung cancer community members. The final draft was officially proposed at the NLCRT Annual Meeting in December 2020. The final framework focused on three key domains (supporting survivorship, educational programs, and research prioritization that centered around the central aspects of messaging and imagery but also embedded a cross-cutting theme of addressing the complex relationship between tobacco and lung cancer across all domains.

### **The four pillars of the Strategic Framework Guiding the Campaign to End Lung Cancer Stigma include:**

- 1) **Reframing Lung Cancer** with media messages and images using core themes – urgency, empathy, optimism – to change the societal perspective on lung cancer
- 2) **Improving Survivorship** by implementing evidence-based approaches across the cancer continuum, eliminating lung cancer stigma as a barrier to optimal care
- 3) **Enhancing Understanding and Empathy** through comprehensive education and training across the lifespan to infuse accurate information and compassion in all tobacco prevention and lung cancer care and control activities



- 4) ***Amplifying and Expanding Research*** to leverage the full range of translational science to end lung cancer by expanding the scope and the fund of resources supporting comprehensive lung cancer research from the research bench to the community

The team recognizes that eliminating stigma and its adverse effects will require substantial and sustained work. One component of this work must confront the factors that led to the development and maintenance of lung cancer stigma throughout society, and a second component must work to ***mitigate*** the current negative sequelae of lung cancer stigma in the lung cancer community. Thus, while many strategies will address both prevention and mitigation, the key notion is that we must address both aspects simultaneously to achieve long-term prevention and short-term mitigation of consequences for those already carrying the weight of lung cancer stigma.

### **Phase II: The NLCRT Campaign to End Lung Cancer Stigma**

With the foundation of the strategic framework adopted and in place, the focus transitioned to phase II: intervention development. As part of that next phase, the committee, NLCRT leadership, and other stakeholders renamed the initiative “***The Campaign to End Lung Cancer Stigma***” to make the overall mission and specific goals abundantly clear.

With a broad representation of the lung cancer community (e.g., survivors, advocates, clinicians, and scientists), the Operations and Actions Committee of the Campaign to End Lung Cancer Stigma has established the operational foundation to transition to action—leveraging NLCRT resources to end lung cancer stigma and its devastating consequences on the lung cancer community and lung cancer outcomes. To date, the committee adopted guiding principles and evaluation criteria that guide decision-making, and the committee has similarly focused considerable attention on sustaining and expanding the trusted relationships among the NLCRT member organizations that will be necessary to achieve the mission and end lung cancer stigma. Based on initial decisions, the committee has identified several specific intervention development needs that align with each of the four pillars of the strategic plan, and work to develop these interventions is ongoing. Once completed, the interventions will be deployed in ***Phase III of the Campaign to End Lung Cancer Stigma*** – broad implementation!

### **Phase III: Implementing the NLCRT Campaign to End Lung Cancer Stigma**

We are anxious to share many more details regarding the implementation of the campaign interventions as they emerge as the campaign will seek opportunities to collaborate with local, regional, and national organizations to disseminate materials and work toward the end of lung cancer stigma.