



**NLCRT**  
NATIONAL LUNG CANCER ROUNDTABLE



**STIGMA  
SUMMIT**

# Executive Summary

First National Stigma Summit  
February 26-27, 2020

## Wednesday, February 26, 2020

*The National Lung Cancer Roundtable (NLCRT)* held its first national summit on **Eliminating Lung Cancer Stigma: A National Initiative** on February 26-27, 2020, in Atlanta, Georgia. Over 65 attendees representing 42 organizations from across the country participated in this catalyzing summit, including people who have experienced lung cancer, lung cancer advocates, caregivers, clinicians, researchers, public health practitioners, policy experts, and those who work on treatments.

Eliminating the stigma associated with lung cancer is a major initiative of the NLCRT. The stigma associated with lung cancer risk or a lung cancer diagnosis adversely affects the entire lung cancer control and care spectrum and compromises efforts to reduce the burden of lung cancer. The experience of lung cancer stigma among lung cancer survivors is well-documented, and the deleterious effects of lung cancer stigma span from risk reduction, early detection, diagnosis, treatment, survivorship, palliative care, to end-of-life care. Only recently has greater attention been focused on efforts to identify the development and impact of lung cancer stigma. Building on a growing understanding of lung cancer stigma, efforts are acutely needed to develop interventions to prevent the development of lung cancer stigma and mitigate its effects on achieving optimal lung cancer control.

The inaugural summit addressed the urgent need for a national strategic plan to confront lung cancer stigma and its adverse impacts on perception, self-esteem, lung cancer care, and outcomes. The strategic plan will serve as an organizing framework for a sustained multi-stakeholder effort to end lung cancer stigma.

The main objectives of the stigma summit were:

- To understand the history and current state of stigma across the care continuum
- To determine the most important issues to address in a strategic plan
- To make initial recommendations for strategies to address the issues
- To explore ways that individuals and organizations could help to fight stigma

On the first day, the participants began to build a common foundation of understanding by listening to a panel of two survivors, one caregiver, and two providers who shared their personal experiences in dealing with stigma in daily life and in the healthcare environment. These presentations highlighted the detrimental psychological, social, and physical effects of lung cancer stigma.

Next, participants added to their understanding of lung cancer stigma by learning about the current data and evidence. Current evidence shows the adverse effects of stigma across the lung cancer care continuum. By the end of the second session, participants had developed a common foundation of knowledge about stigma on which they could build a strategic plan.

The day ended with a discussion of themes that would set the stage for the second day of strategic planning.

## Thursday, February 27, 2020

On the second day of the summit, participants reconvened to start the process of building a strategic planning framework around the issues that were identified on the previous day.

Working from their understanding of patient needs and the evidence-base, participants formed workgroups to identify key problems, strategies, and tactics for addressing lung cancer stigma issues. Participant workgroups generated over 50 ideas and then grouped them into six primary components for the strategic plan.

The following six components were chosen because of their importance and potential ability to reduce stigma and change the way patients are treated. The six components were:

- How to support survivors
- How to change the public discourse
- How to address the complicated relationship between lung cancer and tobacco
- How to address the lack of health care provider awareness and understanding
- How to address inadequate funding for research
- How to develop a new message

Participants created posters to characterize each component. Each poster included a strategy, a motto or tagline, and related features and benefits of the strategy. The posters are shown below, and participants were challenged to draw icons that represented the strategies.

In the final session of the day, participants discussed the next-step activities that would move the proposed strategic plan forward into the future. Participants discussed how individuals and organizations could take action to address stigma. Immediate steps include exploring biases related to lung cancer, sharing what was learned during the summit, and supporting continued strategic planning efforts.

A detailed strategic plan to address lung cancer stigma will be presented at the 4<sup>th</sup> annual *National Lung Cancer Roundtable* meeting on December 7-8, 2020, in Washington, DC.

## How to Support Survivors

**Strategy 1: Build a Welcoming Community of Patients and Families** focuses on connecting and protecting the lung cancer community.

The umbrella icon represents a protective element for patients and their families regarding stigma.

The benefits of such protection would be to reduce patient isolation, improve the quality of their health care, and connect patients and their families to encourage mutual support, information sharing, and communication.

This strategy would engage all lung cancer survivors and target relevant organizations to recognize and overcome implicit bias, and to use more inclusive language, messaging, and positive stories in their lung cancer programs.

**Strategy 2: Develop Services and Resources for People to Feel Well-Cared For** focuses on how to make people with lung cancer feel as they would if they had never been diagnosed.

The scroll icon represents a Bill of Rights for people with lung cancer; each type of cancer is different, but patients should be treated equally.

The scenario that motivated this strategy was a person with lung cancer who entered a clinic and saw multiple posters and pamphlets about breast cancer, colorectal cancer, and healthy eating, but not any materials for lung cancer.

A more equitable strategy would be to provide resources for people with lung cancer that are as positive and equitable as the resources that are available for patients with other types of cancer.



**“Come in out of the rain”**

### Build Welcoming Community of Patients and Families

#### Benefits

- Reduce isolation
- Build community
- Connect patients and families together

#### Features

- Create new networks of connection
- Reach lung cancer survivors where they are
- Organizations use more inclusive language, messaging, and stories



**“All cancers are created equal”**

### Develop Services and Resources for People to Feel Well-Cared For

#### Benefits

- Inclusion and representation
- Empathy and equity
- Greater sense of well-being

#### Features

- Equal access to services
- Accessible to everyone
- Comprehensive, targeted, and tailored resources for lung cancer patients

## How to Change the Public Discourse

**Strategy 1: Engage and Activate the Public** focuses on how to engage the public by using targeted and tested messages designed specifically for various audience groups.

The antenna icon represents the idea of broadcasting targeted and influential messages to public audiences in the same way that radio stations deliver content to targeted audiences.

New and different target audiences for tailored messages would be identified with market stratifications outside of the simple tobacco use category.

Targeted messages would be disseminated to the audience using social and traditional media channels. Media engagement statistics would be collected to evaluate the effectiveness and reach of each message.

**Strategy 2: Develop and Test Messages, Lung Cancer Awareness Campaign** focuses on a process for creating new and unified messages for targeted audiences to create positive awareness.

The icon of the sun emerging from behind a cloud represents the ideas of hope and compassion that could be delivered by new messages to reduce stigma and increase understanding about lung cancer.

Once the audiences were identified, targeted messages would be developed for each separate audience. While each audience may have shared issues and behaviors, some will have unique challenges to overcome.

Expert communications talent would be utilized in all stages of the message creation process to address stigma using a professional marketing campaign.



**"Anyone can get lung cancer"**

**Engage and Activate the Public**

**Benefits**

- Change perceptions
- Change awareness
- Change behaviors

**Features**

- Market segmentation and targeted messages
- Social and traditional media
- Evaluation, assess, develop



**"Anyone can get lung cancer"**

**Develop and Test Messages, Lung Cancer Awareness Campaign**

**Benefits**

- Create new awareness
- Effective and unified messages

**Features**

- Identify the problem
- Engage experts
- Test with target groups



## The Complicated Relationship Between Lung Cancer and Tobacco

**Strategy 1: Multi-Level, Multi-Generational Education** recognizes that tobacco is a chronic disease that can begin very early in life.

The table icon represents an educational platform that would deliver education at multiple levels and through multiple generations.

Focusing education at a younger age would enable tobacco use and stigma to be addressed outside of the narrow context of lung cancer.

Educational programs would be designed to be appropriate for age levels of preschool, elementary school, middle school, and high school. Educational programs would be culturally and linguistically tailored.

**Strategy 2: Education without Fear or Blame** focuses on decoupling tobacco messages and images from lung cancer messages and images. Separation would result in lung cancer becoming similar to other cancers, i.e., an independent part of the conversation.

The lung icon represents that lung cancer can affect anyone who has lungs, regardless of tobacco use.

Treating tobacco use in the community as a chronic disease would help to reduce the stigma that is unique to tobacco use.

Also, raising awareness and the importance of other lung cancer risk factors would help to decouple tobacco use as the sole risk factor for lung cancer. Some risk factors are not associated with stigma, and we need to elevate tobacco to be regarded in the same way – risk without blame.



### “Education for All”

#### Multi-Level, Multi-Generational Education

##### Benefits

- Engages all stakeholders
- Increases knowledge, hope and opportunities
- Lifelong individual/integrated education

##### Features

- From preschool throughout life; lifelong
- Tailored for each audience or stakeholder



### “Empathy Not Judgement”

#### Education without Fear or Blame

##### Benefits

- Increase awareness; Decrease stigma
- Increase patient-clinician communication

##### Features

- Empathetic communication
- Positive messages and images
- Decouple tobacco images from lung cancer



## How to Address the Lack of Provider Awareness and Understanding

### Strategy 1: Threading into Multiple Contexts

recognizes that the idea that single-occasion CME trainings on stigma are not as effective as multiple message exposures over time.

The needle-and-thread icon represents the idea of threading stigma awareness and education into the fabric of all discussions around lung cancer to provide multiple message exposures to target audiences.

A repeated-exposure approach would help people to see how stigma can occur in many different contexts. Regular feedback is key.

Another goal is to gain attention to stigma using larger opportunities rather than individual presentations. Stigma could be a dedicated track at a conference or be included in research presentations.



#### “Stopping Stigma Superheroes”

#### Threading into Multiple Contexts

##### Benefits

- Reach, Reliability, Inclusivity, Availability
- Promotes ownership

##### Features

- Advocates and prepared keynotes
- Open-access slide deck for presenters
- Integrate stigma into existing programs
- ECHO-style support for stigma information

**Strategy 2: Professional Education** focuses on building the interest of professionals to address stigma in their clinical settings.

The Olympic rings icon represents the idea of an “Olympic marathon” effort that would be sustained over a long period of time.

Continuing education programming is vital.

Professional organizations would commit to educating their membership on how lung cancer stigma compromises their delivery of care. The use of role models to deliver web-based continuing education trainings would reach many practitioners.

Professionals who wanted to present on the topic could use a preconstructed, heavily annotated slide deck or recorded video as a start for their branded presentations.



#### “See it, solve it”

#### Professional Education

##### Benefits

- Role model; Reach
- Increase knowledge; Change attitudes
- Accountability insight; Improve outcomes

##### Features

- CME credit
- Health systems
- Curricula; Professional organizations



## How to Develop a New Message

**Strategy 1: Develop and Disseminate Unified Messages** focuses on developing new messages that would be disseminated to diverse audiences.

The megaphone icon represents the idea of widely broadcasting messages to diverse audiences.

The messages would be customizable so that stakeholders could adapt and brand them to fit their program and communication needs.

Ideally, the messages would be developed collaboratively by all stakeholders in the lung cancer community to represent a unified purpose and vision that all could support. The messages could also be produced by a communications agency to increase their professional appearance and effectiveness.

## Strategy 2: Get People to Care by Personifying Lung Cancer and Realigning the Message with Hope

focuses on increasing engagement by personalizing messages and aligning them with positive messages of obligation, compassion, and hope.

The handshake icon represents the idea of personalized, compassionate, and human engagement between the message sender and receiver, like two people who greet one another with a firm handshake.

The new messages would promote hope and compassion, change public and patient perceptions about lung cancer, and improve patient outcomes and the quality of life of people with lung cancer, their families, and the community.



“One voice of hope. Lung cancer...Let’s get together.”

### Develop and Disseminate Unified Messages

#### Benefits

- Realign to hope; Change public perception
- Improve patient outcomes

#### Features

- Collaboration; reach diverse audiences
- Customizable for stakeholders
- Professional marketing agency



“One voice of hope”

### Get People to Care by Personifying Lung Cancer and Realigning the Message with Hope

#### Benefits

- Increase impact; Increase engagement
- Improve physical and emotional health

#### Features

- Compassion; Humanizing
- Optimizing; Risk reduction

## How to Address Inadequate Funding

**Strategy 1: A United Voice for Funding** focuses on creating a streamlined, unified message for public and private funders at the state and national levels.

Unified messages are important because stigma is believed to be a major barrier to increasing the number of funding sources and the amount of funding for lung cancer research.

The megaphone/\$ icon represents the idea of sending targeted messages about funding to legislative audiences.

Consolidating the existing mixed messages about lung cancer funding into a streamlined, unified message would provide legislators with the information they need to carry the funding requests forward.



**“We are louder together”**

**A United Voice for Funding**

**Benefits**

- Decrease confusion
- Create a sense of urgency
- Increase the clout and pressure

**Features**

- Streamline the narrative
- Consolidate efforts and the ask
- Focus the audience

## About the National Lung Cancer Roundtable

The American Cancer Society established the NLCRT as a national coalition of public, private, and voluntary organizations and invited individuals, dedicated to reducing the incidence of and mortality from lung cancer in the United States, through coordinated leadership, strategic planning, advocacy, and action. For additional information about the NLCRT, please see [nlcrt.org](http://nlcrt.org).

The ACS and the NLCRT’s Lung Cancer Stigma Summit Planning Committee would like to thank Amgen, AstraZeneca, Bristol Myers Squibb, and Genentech for their support.