NLCRT Stigma Summit

Next Steps

April 27, 2020
2:00-3:15pm ET
Speakers on Today’s Web Meeting

Dusty Donaldson
Patient Advocate
LungCAN/LiveLung

Ella Kazerooni, MD, MS
Chair, NLCRT
University of Michigan

Jim Pantelas
Patient Advocate
VA Health

Robert Smith, PhD
PI, NLCRT
American Cancer Society

Ryan Soisson
Facilitator
Soisson & Associates

Jamie Studts, PhD
Chair, Survivorship, Stigma & Nihilism Task Group (NLCRT)
University of Colorado
Welcome &
Today’s Objectives
Robert Smith, PhD and Ryan Soisson
Today’s Meeting

Objectives

- Reconnect!
- Review summit conclusions
- Understand the evolving strategy
- Understand the strategic planning process

Agenda

- Introduction
- Summit Overview
- The Strategic Plan and Process
- Q&A
- Close
Questions

Please submit your question via email to: nlcrt@cancer.org
Executive Summary

Ella Kazerooni, MD, MS
Eliminating Lung Cancer Stigma: A National Initiative

Executive Summary

• Over 65 attendees representing 42 organizations

• Major initiative of NLCRT
  • Summit addressed urgent need for national strategic plan to confront lung cancer stigma and its adverse impacts on perception, self-esteem, lung cancer care, and outcomes.
  • Strategic plan will serve as an organizing framework for a sustained multi-stakeholder effort to end lung cancer stigma.

• Main objectives of the Summit
  • Understand history and current state of stigma across the care continuum
  • Identify the most important issues to address in a strategic plan
  • Recommend strategies to address the issues
  • Explore ways that individuals and organizations could help fight stigma
Eliminating Lung Cancer Stigma: A National Initiative

Goals of Day 1:
• Build a common foundation of understanding
  • Survivor/Caregiver/Provider Panel: shared personal experiences of dealing with stigma in daily life and in the healthcare environment
  • Current Data and Evidence Panel: showed adverse effects of stigma across the care continuum
• Discuss themes that would set the stage for strategic planning

Goals of Day 2:
• Start process of building strategic planning framework
• Identify key problems, strategies, and tactics for addressing stigma in small workgroups
• Create posters to characterize each component, which included a strategy, a motto/tagline, and related features and benefits of the strategy
Eliminating Lung Cancer Stigma: A National Initiative

**Strategic Plan Components:**
- How to support survivors
- How to change 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 and fundraising
- How to develop a new message

**The Planning Committee:**
- merged the components focused on changing public discourse and developing a new message because of the similar features and benefits
- added an additional component focused on addressing missed opportunities
Summit Evaluation

Jamie Studts, PhD
Summit Program Evaluation

• Overall Satisfaction & Time Worthiness (ratings)

• Helpfulness across 7 areas (ratings)
  • To what extent do you agree or disagree with the following statements?
  • The National Lung Cancer Roundtables Lung Cancer Stigma Summit helped me...

• Following the Summit (ratings)

• Five narrative queries
  • Most helpful/beneficial aspects of the summit?
  • Least impactful/beneficial aspects of the summit?
  • Recommendations for next steps?
  • What other groups, organizations should be engaged?
  • Other comments or feedbacks?
Overall Satisfaction & Time Worthiness Ratings

Overall Satisfaction with Summit (0 to 10)

Mean = 8.89 (±0.99)

Worthwhileness of Summit (0 to 10)

Respondents (N=44)
NLCRT LC Stigma Summit Helped Me...

Level of Agreement that the LC Summit helped... (N=44)

- **Completely Agree**
- **Moderately Agree**
- **Slightly Agree**
- **Slightly Disagree**
- **Moderately Disagree**
- **Completely Disagree**

<table>
<thead>
<tr>
<th>Category</th>
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<tr>
<td>Understand LC Stigma</td>
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<tr>
<td>Build Trust in NLCRT</td>
<td>68</td>
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<td>Strategic Plan Elements</td>
<td>55</td>
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<tr>
<td>Gather Ideas to End Stigma</td>
<td>59</td>
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<td>Build Commitment</td>
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<tr>
<td>Personal Contribution</td>
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<tr>
<td>Organization Contribution</td>
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Following the NLCRT LC Stigma Summit...

<table>
<thead>
<tr>
<th></th>
<th>Completely Agree</th>
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<th>Slightly Disagree</th>
<th>Moderately Disagree</th>
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<td>Deeper Understanding</td>
<td>71</td>
<td>21</td>
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<td>Strong Personal Intention</td>
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<td>Understand NLCRT Actions</td>
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<td>23</td>
<td>9</td>
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<td>Open Conversations</td>
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<td>9</td>
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</table>
What were the most impactful/beneficial aspects of the lung cancer stigma summit?

• Networking
• Collaborating
• Commitment
• Advocate stories
• Diverse groups
• Experience + evidence
• Small group discussions
• Progress toward strategic plan

• Broad expression of perspectives
• Organization & Ryan
• Broad impact/harms of LC stigma
• ACS contributions
• Interprofessional activities
• Stakeholder engagement
What were the least impactful/beneficial aspects of the lung cancer stigma summit?

- Nothing
- Some nay-saying
- Not enough time
- No clear definition of root cause
- No work product
- Conclusions too vague/hand-waving
- Some continued mistrust
- Too many small groups
- Lack of clarity for next steps
- Monopolized table discussions
- Chaos before meeting
- Too much evidence that is known
- Gallery walk – not enough time
What other groups, organizations, or individuals should be engaged in the lung cancer stigma initiative?

• Ideas
  • Formalizing stigma definition
  • Champion the meeting
  • Action/Action steps/Accountability
  • ACS-led campaign
  • Local solutions
  • Sustain communication
  • Planning committee w/ Advocates
  • Remove Great American Smoke-Out in November
  • ACA rates for tobacco users
  • Use parallel stigma knowledge and interventions
  • Share recorded content

• Groups
  • Surgeon General (Office)

• Personnel
  • Professional messaging team
  • Dedicated lung cancer media team
  • Assign program manager to organize stigma initiative
Summary

• Strong overall satisfaction and worthwhileness of time allocation for summit

• Strong agreement on benefits of summit
  • Highest for personal efforts
  • Lower for organizational efforts

• Strong support for benefits of summit on organizing future
  • A bit less clarity in personal and organizational angles for future
  • Strong support for openness and receptivity of summit discussion

• Support for benefits and some areas of concern for future
  • Supportive statements regarding networking, discussion, and team building
  • Encouragement to find measurable outcomes and sustain communication
  • Few additional groups noted, but seeking organizational structure and solutions

• Compelling support for united effort organized and championed by NLCRT
NLCRT Lung Cancer Stigma Work History

1. Founding of NLCRT & Recognition of the Importance of Lung Cancer Stigma
2. Lung Cancer Stigma Discussions and Overview at Annual NLCRT
3. Lung Cancer Stigma Discussions and Overview at Annual NLCRT
4. Lung Cancer Stigma Plan Overview at Annual NLCRT

Strategic Planning

We Are Here
NLCRT Lung Cancer Stigma Current & Near Future

We Are Here

Strategic Planning Trajectory

Monthly Updates

Stigma Summit Expanded Committee

Stigma Summit Next Steps

Strategic Plan Prep - Six Groups

Survivorship

Messaging

Funding

Tobacco

Clinicians

Other

Strategic Planning

Survivorship

Messaging

Funding

Tobacco

Clinicians

Other

Strategic Plan Draft

Strategic Plan Feedback

Strategic Plan Revisions

Announce Strategic Plan at NLCRT (2020)
## Strategic Framework Development – WORK IN PROGRESS

<table>
<thead>
<tr>
<th>Mission</th>
<th>Who you are and what you do to achieve the vision?</th>
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</thead>
<tbody>
<tr>
<td>Big Measurable Goal(s)*</td>
<td>Measurable outcomes goal(s) that define mission accomplishment</td>
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<tr>
<td>Priorities</td>
<td>Broad, long-term aims that define accomplishment of the mission</td>
</tr>
<tr>
<td>Measurable Objectives*</td>
<td>Specific measurable targets that define accomplishment of a priority.</td>
</tr>
<tr>
<td>Strategies</td>
<td>Broad activities designed to achieve a priority</td>
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<td>The NLCRT Lung Cancer Stigma Initiative is an interdisciplinary group of stakeholders working to end lung cancer stigma</td>
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Big Measurable Goal(s) – WORK IN PROGRESS

Eliminate lung cancer stigma over the course of the initiative by...

a) Developing and sustaining person-centered programs to support individuals diagnosed with lung cancer (e.g., lung cancer navigation, survivorship support & care)

b) Encouraging compassionate and empathetic media messages, images and portrayals of lung cancer risk and lung cancer diagnosis and treatment

c) Modifying tobacco education, prevention, and treatment efforts to embrace empathy and compassion and eliminate bias and fear-inducing efforts

d) Supporting efforts to train clinicians regarding awareness of lung cancer stigma and efforts to eliminate lung cancer stigma in healthcare

e) Engaging a broad coalition of individuals, stakeholder groups, professional organizations, and allies
## Priorities – WORK IN PROGRESS

<table>
<thead>
<tr>
<th>Priorities</th>
<th>Support Survivors</th>
<th>Change the Discourse</th>
<th>Address Tobacco &amp; Lung Cancer</th>
<th>Raise Provider Awareness</th>
<th>Increase Funding</th>
<th>Missed Opportunities</th>
</tr>
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<tbody>
<tr>
<td>Broad, long-term aims that define accomplishment of the mission</td>
<td>Increase evidence-based LC survivorship interventions (e.g., RTIPS)</td>
<td>Develop and disseminate empathic LC messages, images, and portrayals</td>
<td>Alter public conversation of tobacco and LC using empathic messaging</td>
<td>Raise clinical awareness &amp; end LC stigma in healthcare</td>
<td>Enhance funding and expand portfolio of LC research and care delivery</td>
<td>Discover other opportunities to end LC Stigma</td>
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</table>
| Measurable Standards | Specific measurable targets that define accomplishment of a priority | 3 RTIPS addressing LC survivorship | Increase positive messages & images of LC survivorship | Assess reach of new empathic messaging standards | # healthcare systems, organizations & providers reached & trained | Double DOD LC research budget | ????
Strategies – WORK IN PROGRESS

<table>
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# Lung Cancer Stigma Initiative Strategic Framework

## Mission

Who you are and what you do to achieve the vision:

The NCI’s Lung Cancer Stigma Initiative is an interdisciplinary group of stakeholders working to end lung cancer stigma.

## Big Measurable Goal(s)*

Measurable outcomes goal(s) that define mission accomplishment:

- Reduce lung cancer stigma by 50 percent over the course of the initiative by:
  1. Developing and sustaining person-centered programs to support individuals diagnosed with lung cancer (e.g., lung cancer navigation, survivorship support & care)
  2. Encouraging compassionate and empathetic media messages, images, and portrayals of lung cancer risk and lung cancer diagnosis and treatment
  3. Modifying tobacco education, prevention, and treatment efforts to embrace empathy and compassion and eliminate bias and fear-reducing efforts
  4. Supporting efforts to train clinicians regarding awareness of lung cancer stigma and efforts to alleviate lung cancer stigma in healthcare
  5. Engaging a broad coalition of individuals, stakeholder groups, professional organizations, and allies

## Priorities

Broad, long-term aims that define accomplishment of the mission:

- Support Survivors
- Increase evidence-based LC survivorship interventions (e.g., NCI2)
- Change the Discourse
- Develop and disseminate empathetic LC messages, images, and portrayals
- Address Tobacco & LC
- Advocate for awareness of tobacco & end LC stigma in healthcare
- Reduce Provider Awareness
- Increase funding & expand opportunities to end LC stigma
- Increase Funding
- Enhance funding and expand opportunities to end LC stigma
- Senior Opportunities
- Discover other opportunities to end LC stigma

## Measurable Standards

Specific measurable targets that define accomplishment of a priority:

- # RTMS addressing LC survivorship
- Increased positive LC survivorship messages & images of
- # Assess reach of new empathetic messaging standards
- # Healthcare systems, organizations & providers reached & trained
- # Double DOD LC research budget
- # Misled Opportunities
- Discover other opportunities to end LC stigma

## Strategies

Broad activities designed to achieve a priority:

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Specific Actions</th>
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<td>Increase evidence-based LC survivorship interventions (e.g., NCI2)</td>
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<td>Advocate for awareness of tobacco &amp; end LC stigma in healthcare</td>
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<td>4. Reduce Provider Awareness</td>
<td>Increase funding &amp; expand opportunities to end LC stigma</td>
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<tr>
<td>5. Increase Funding</td>
<td>Enhance funding and expand opportunities to end LC stigma</td>
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<tr>
<td>6. Misled Opportunities</td>
<td>Discover other opportunities to end LC stigma</td>
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Note: (Work in Progress)
Summary

Great deal of progress toward drafting a strategic plan in preparation for detailed discussions of strategy.

Sustained enthusiasm and motivation despite environmental constraints and readiness for next phase.

Readiness for and openness to your feedback and guidance based on your extensive knowledge and expertise.

Tremendous gratitude for Ryan, Lauren, Kenly, Dionne, and Kerstin for their partnership in this effort.
Strategic Framework

Committees

Dusty Donaldson

NLCRT
NATIONAL LUNG CANCER ROUNDTABLE
Selection Process

Stigma Planning Committee Members

• Lisa Carter-Harris
• Dusty Donaldson
• Ella Kazerooni
• Jim Pantelas
• Lauren Rosenthal
• Robert Smith
• Jamie Studts
Selection Process

Prerequisite: Previously engaged with lung cancer stigma

- Summit attendance not required
- To keep manageable, work groups comprise ~7 members, including lead, patient advocate, industry representative and others
- Nearly twice as many summit attendees as those assigned to committees

Brainstorm: More qualified candidates than available spots

Best Fit: Match people to most appropriate committee
Selection Process

Patient Advocates

All patient advocates who attended the Summit have been invited to join a committee.

- Each committee has at least one patient advocate
- As a patient advocate, I feel that my voice has been welcomed and respected, and that my contribution is highly valued.
Supporting Survivors

“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

Committee Members
Maureen Rigney, GO2 Foundation for Lung Cancer
Lysa Buonanno, ROS1ders
Michelle Carrillo, Amgen (TBC)
Elizabeth David, USC/Society of Thoracic Surgeons
Annette Eyer, American Lung Association
Nick Faris, IASLC
Jill Feldman, EGFR Resisters
Heidi Hamann, University of Arizona
Changing Public Discourse/Developing a New Message

Committee Members
Shonta Chambers, Patient Advocate Foundation
David Cooling, Genentech
Dusty Donaldson, LiveLung
Sara Green, AstraZeneca (TBC)
Jane Rubinstein, Stand Up To Cancer (TBC)
Keith Singer, Catch It In Time
Liz Scharnetzki, Maine Lung Cancer Coalition
Addressing the Complicated Relationship Between Lung Cancer and Tobacco

Committee Members
Jamie Ostroff, MSKCC
Marianne Gandee, Pfizer (TBC)
Jim Pantelas, Department of Veterans Affairs
Brenna VanFrank, CDC OSH (TBC)
Graham Warren, MUSC/ASCO
Renda Weiner, Boston University/ATS/CHEST
Lee Westmaas, ACS
Addressing the Lack of Health Care Provider Awareness and Understanding

Committee Members
Brendon Stiles, Weill Cornell/LCRF
Gina Hollenbeck, ALK Positive
Melissa Crouse, RET Renegades
Abby Begnaud, University of Minnesota
Tom Houston, AAFP
Joelle Fathi, University of Washington
Vickie Beckler, Medtronic
Addressing Funding for Research and Fundraising

Committee Members
Andrea Ferris, LUNGevity Foundation
Terri Conneran, KRAS Kickers
Deena Cook, GO2 Foundation for Lung Cancer
Chris Draft, Team Draft
David Hickam, PCORI
Katie McMahon, ACS CAN
Joan Schiller, Lung Cancer Research Foundation
Nancy Torrison, A Breath of Hope

“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
Addressing Missed Opportunities

**Goal**
Identify and assess missed opportunities that weren’t addressed at the summit

**Committee Members**
Paige Humble, LC Initiative of North Carolina
Andrea Borondy Kitts, Rescue Lung Rescue Life
Kimberly Buchmeier, Citizens for Radioactive Radon Reduction
Rhonda Meckstroth, ALK Positive
Elyse Park, Massachusetts General Hospital (TBC)
Jennifer Redmond Knight, KY LEADS
Elizabeth Rohan, CDC
Closing Remarks

James Pantelas
Questions

Please submit your question via email to: nlcrt@cancer.org
Questions?

NATIONAL LUNG CANCER ROUNDTABLE
Special Thanks to Our National Lung Cancer Roundtable Sponsors