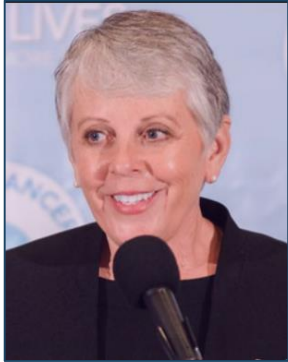


NLCRT Strategic Plan and Stigma Initiative



Dusty Donaldson



**Lisa Carter-Harris, PhD,
APRN, ANP-C**



Jamie Studts, PhD

5. Implementation of Lung Cancer Screening and Follow-up.
Thomson C, Fathi J, et al. ✓
6. Advanced Lung Cancer Imaging. Sullivan D, McNitt-Gray M, et al. ✓
7. Nodule Management. Gould M, Silvestri G et al.
8. Promoting Guideline Adherent Lung Cancer Staging.
Farhood F, Silvestri GA, et al. ✓
9. Comprehensive Biomarker Testing. Rivera MP, Johnson G, Silvestri G, et al.



NATIONAL LUNG CANCER ROUNDTABLE



NLCRT
NATIONAL LUNG CANCER ROUNDTABLE



**STIGMA
INITIATIVE**

Dusty Donaldson, Lisa Carter-Harris, Jamie L. Studts
Survivorship, Stigma, and Nihilism Task Group

NLCRT Lung Cancer Stigma Initiative

Strategic Plan Development

- Eliminating lung cancer stigma is essential across the continuum of care to achieve the NLCRT goal of *“lowering the impact of lung cancer through prevention, early detection, and the assurance of optimal diagnosis & therapy”*
- We will accomplish our goal through coordinated leadership, strategic planning, advocacy, action & collaboration



Stigma Summit

February 27-27, 2020

Atlanta

<https://vimeo.com/395837313>



NATIONAL LUNG CANCER ROUNDTABLE

MY EXPERIENCE ON THE NLCRT STIGMA INITIATIVE STEERING COMMITTEE

Dusty Donaldson

Dusty Joy Foundation, LungCAN

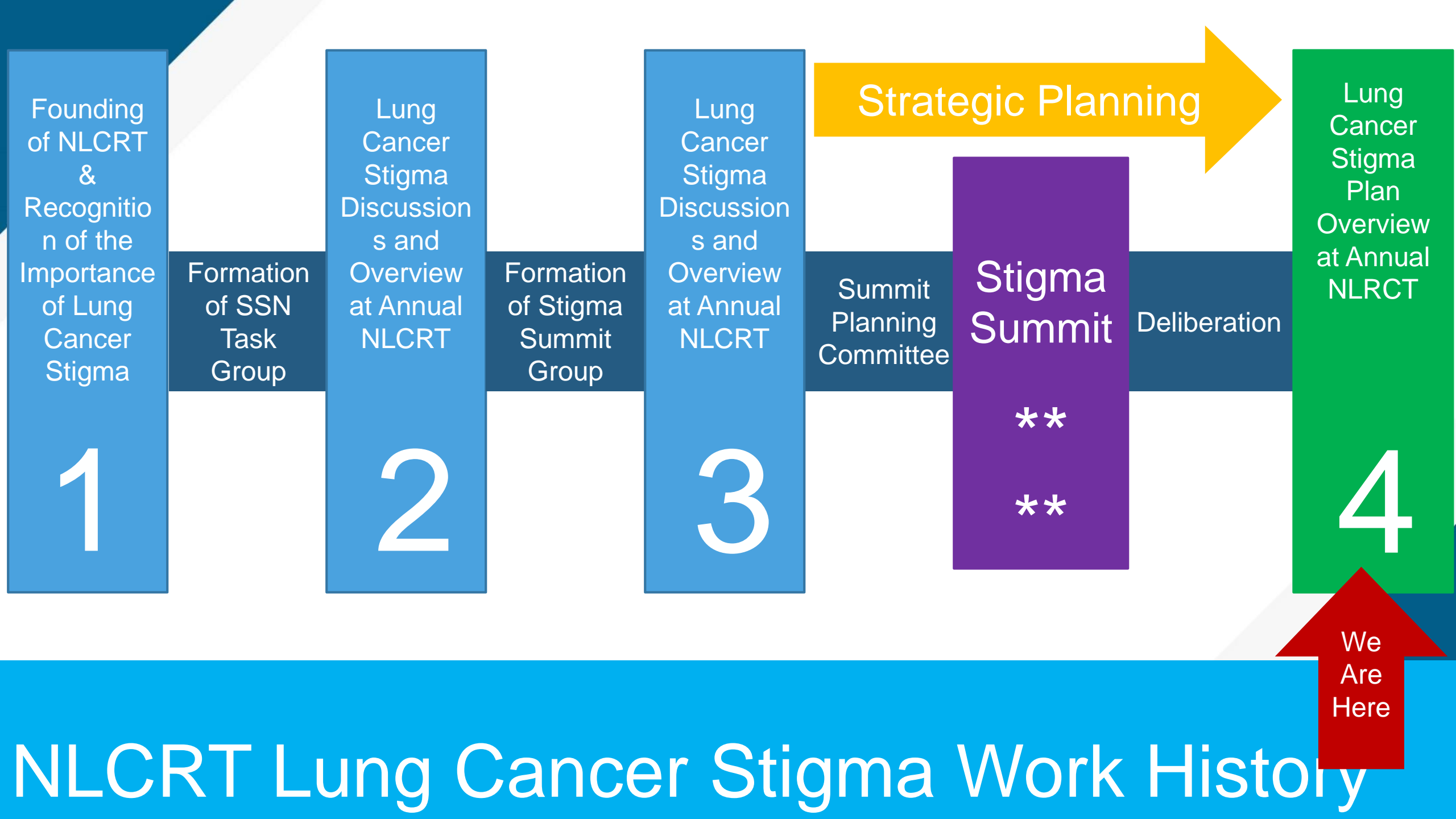


NATIONAL LUNG CANCER ROUNDTABLE

HISTORY OF THE NLCRT LUNG CANCER STIGMA INITIATIVE

Lisa Carter-Harris

Vice-Chair, Survivorship, Stigma, Nihilism Task Group



Founding of NLCRT & Recognition of the Importance of Lung Cancer Stigma

1

Formation of SSN Task Group

Lung Cancer Stigma Discussions and Overview at Annual NLCRT

2

Formation of Stigma Summit Group

Lung Cancer Stigma Discussions and Overview at Annual NLCRT

3

Summit Planning Committee

Strategic Planning

Stigma Summit

**

**

Deliberation

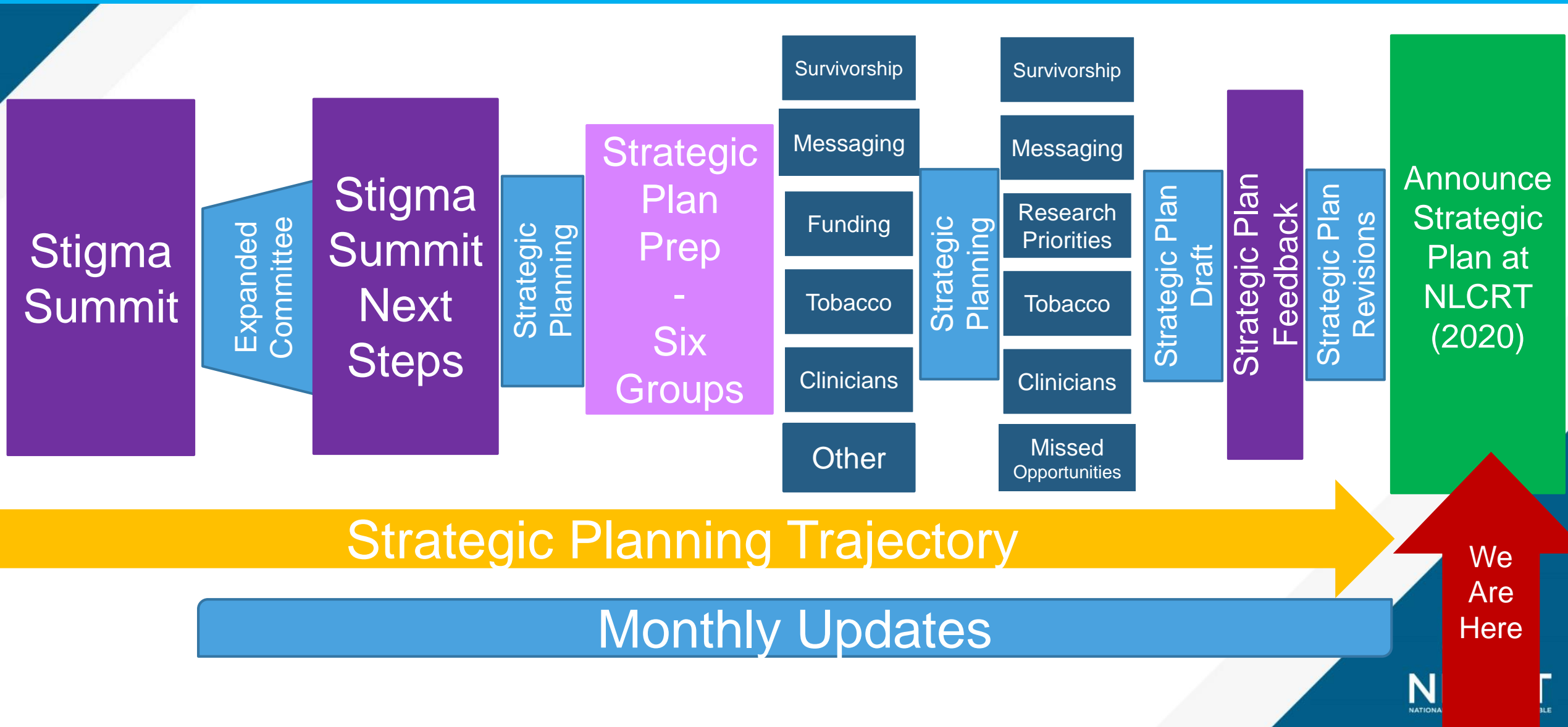
Lung Cancer Stigma Plan Overview at Annual NLCRT

4

We Are Here

NLCRT Lung Cancer Stigma Work History

NLCRT Lung Cancer Stigma Current & Near Future

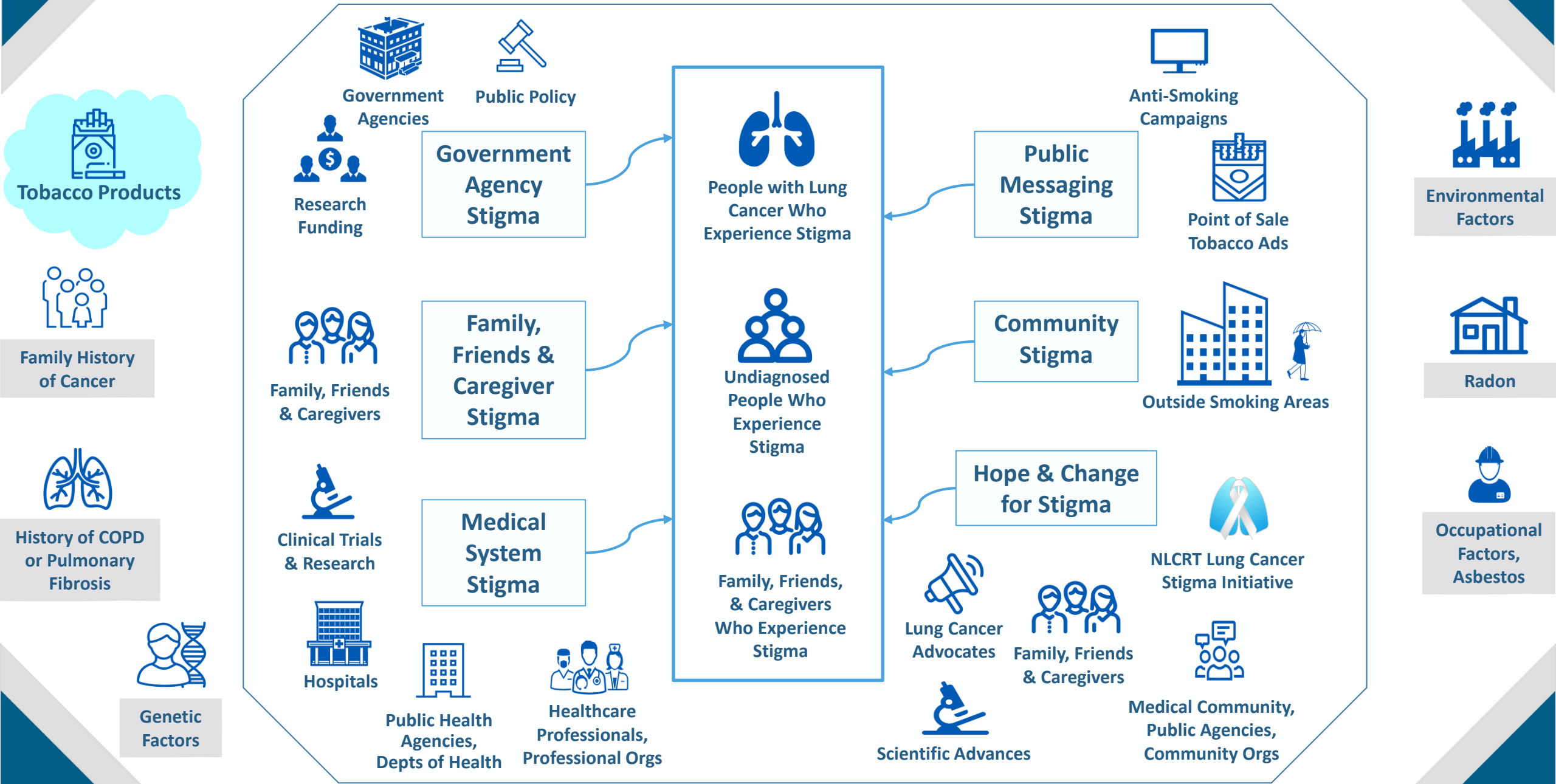


NLCRT Lung Cancer Stigma Initiative

- Develop tools and strategies for individuals, groups, and organizations to prevent, confront, mitigate, and extinguish the causes and consequences of lung cancer stigma.
- A combination of efforts to prevent emergence while also mitigating the consequences of lung cancer stigma
- Central component of messaging and imagery
 - Messaging themes
 - Imagery and stories



Lung Cancer Stigma





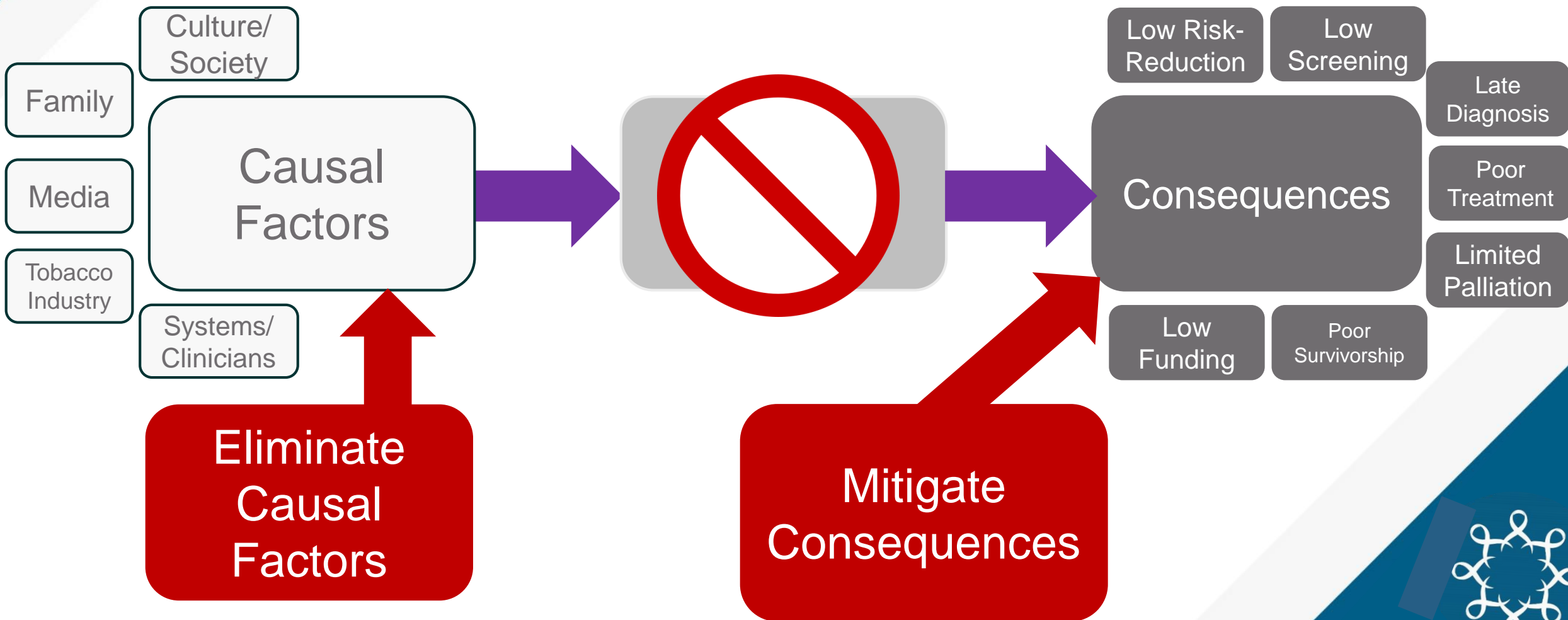
NATIONAL LUNG CANCER ROUNDTABLE

NLCRT LUNG CANCER STIGMA INITIATIVE STRATEGIC FRAMEWORK VERSION 1.0

Jamie L. Studts

Chair, Survivorship, Stigma, Nihilism Task Group

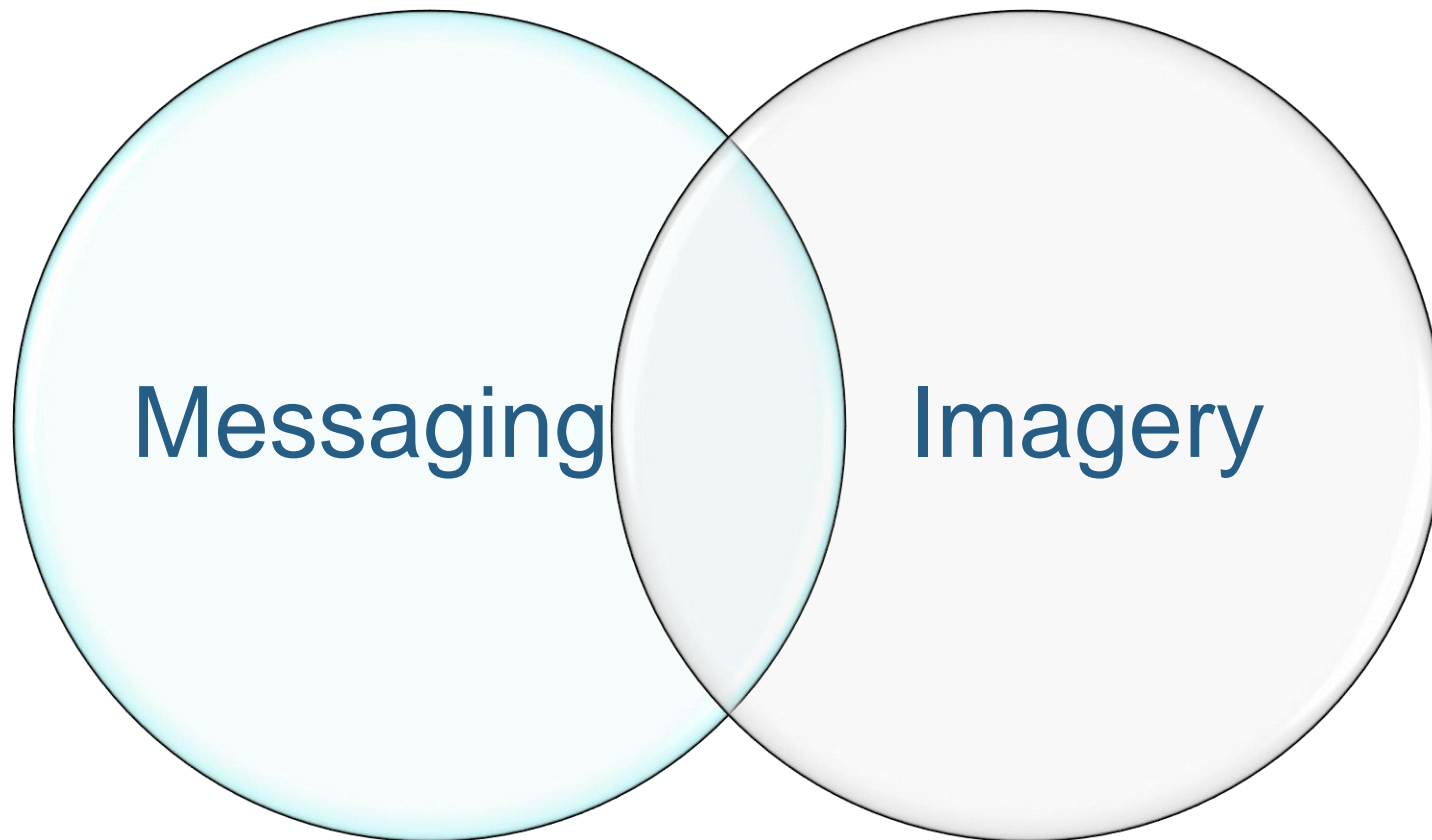
The Fundamental Lung Cancer Stigma Pathway



NLCRT Lung Cancer Stigma Initiative Framework



Messaging → Messaging and Imagery



The complex
new story that
we want people
to understand
and embrace.



Messaging and Imagery Themes

Overarching Themes

Urgency

The time is now!

Empathy

Socio-emotional
(support and
compassion)

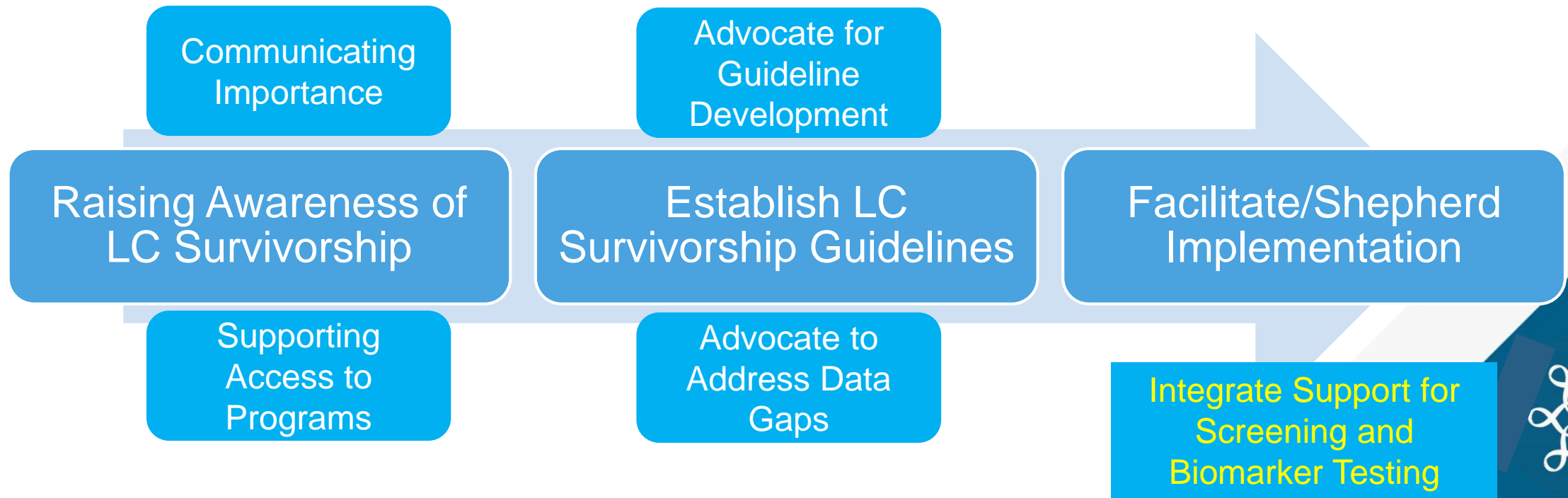
Optimism

Outcomes
(anti-nihilism/fatalism)



Lung Cancer Stigma Supporting Survivorship

- 1) Messaging to help people know they are not alone
- 2) Support survivorship education
- 3) Create expectations around survivorship (optimism, hope)
- 4) *Supporting LDCT implementation (normalizing informed screening)*
- 5) *Supporting biomarker testing implementation (normalizing testing)*



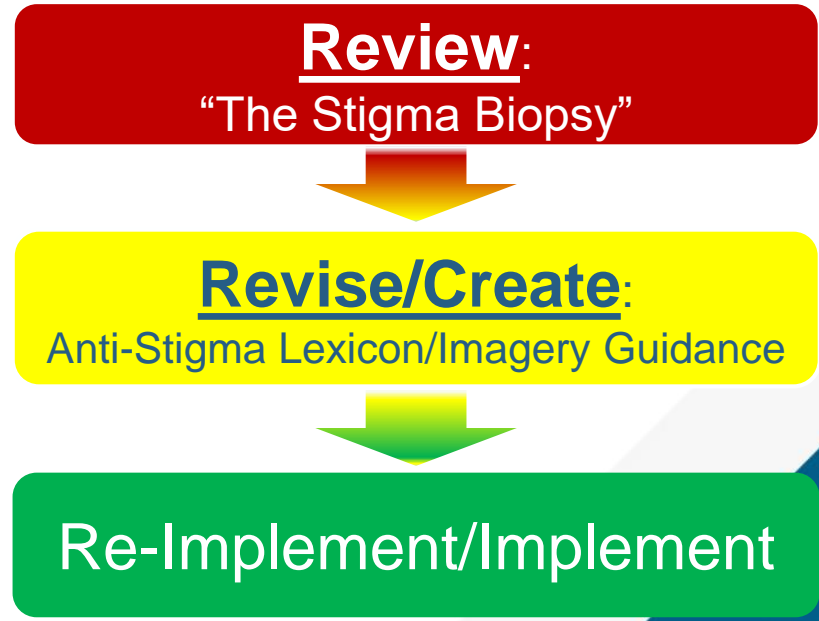
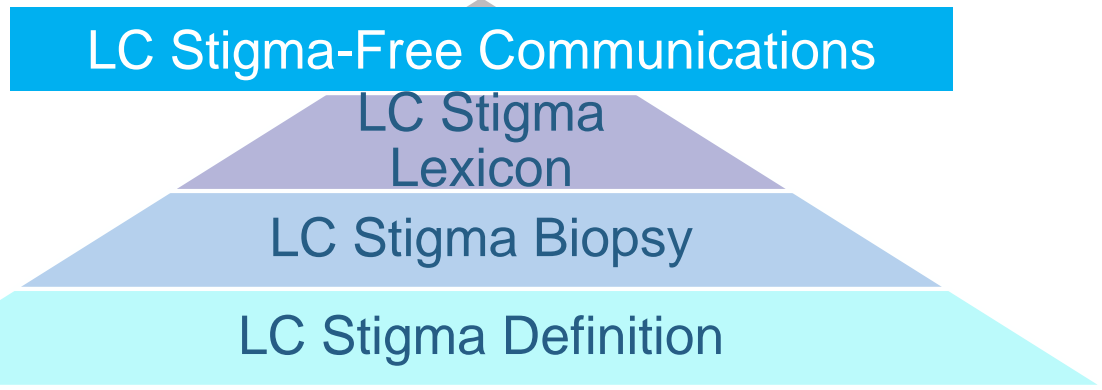
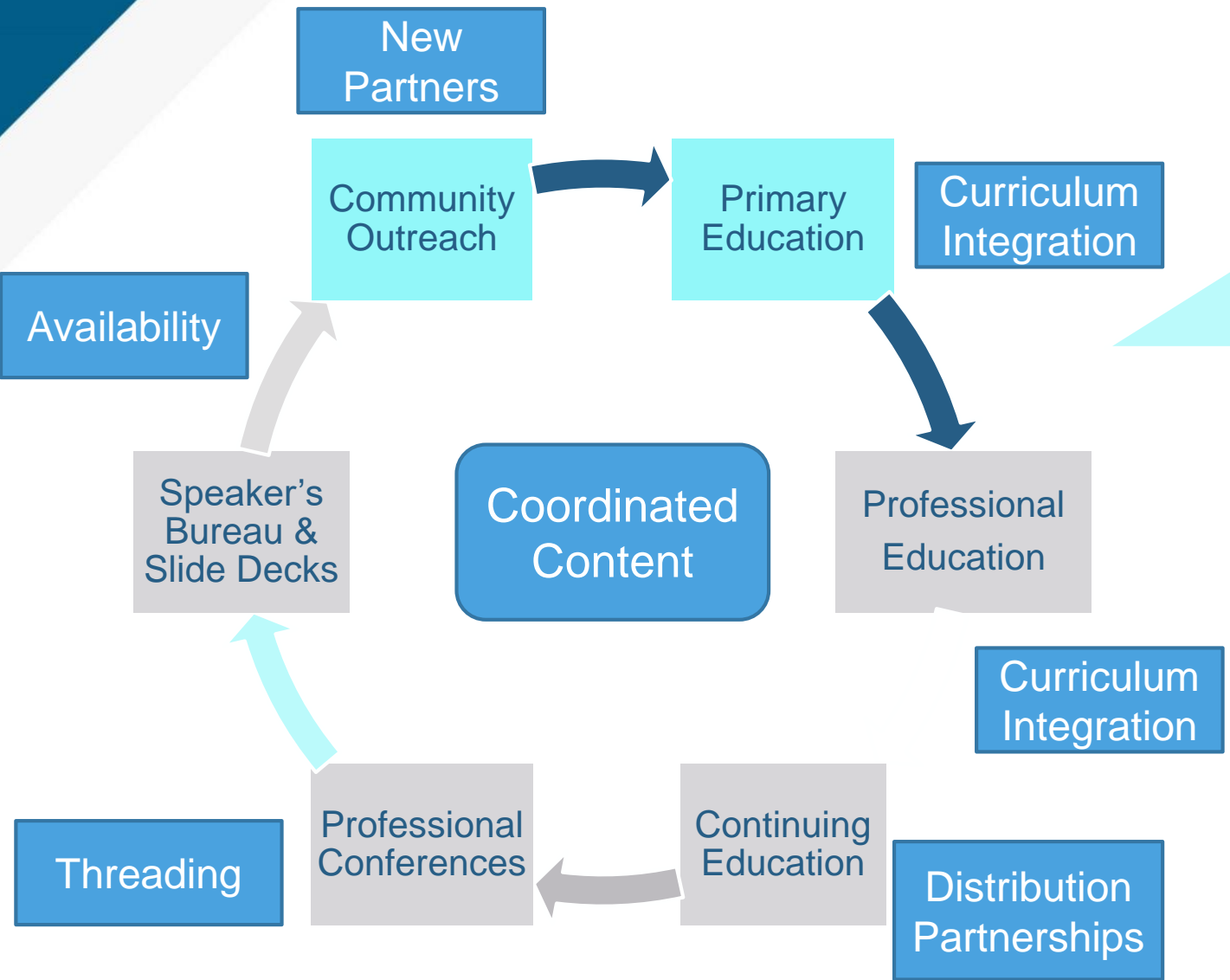
Lung Cancer Stigma and Tobacco Complexity

Education about
Addiction and
Eliminating Blame

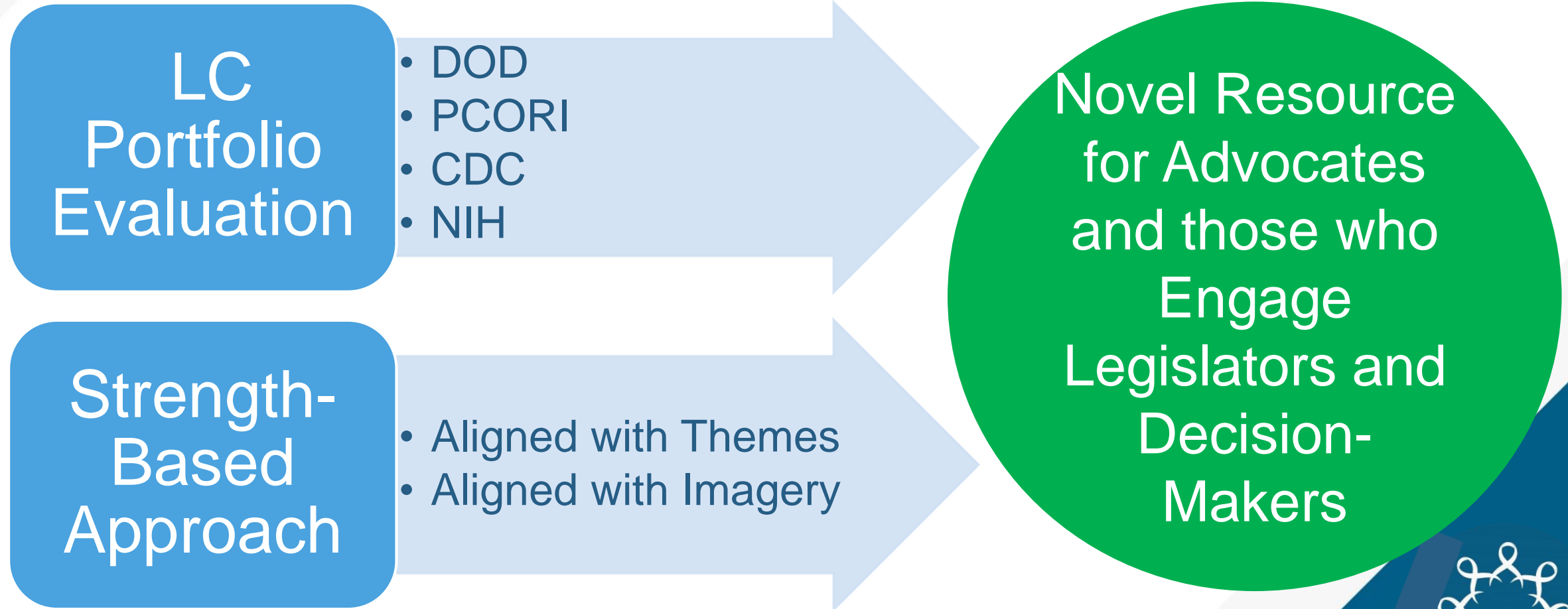
Education infused with
Messaging Components



Lung Cancer Stigma Educational Effort

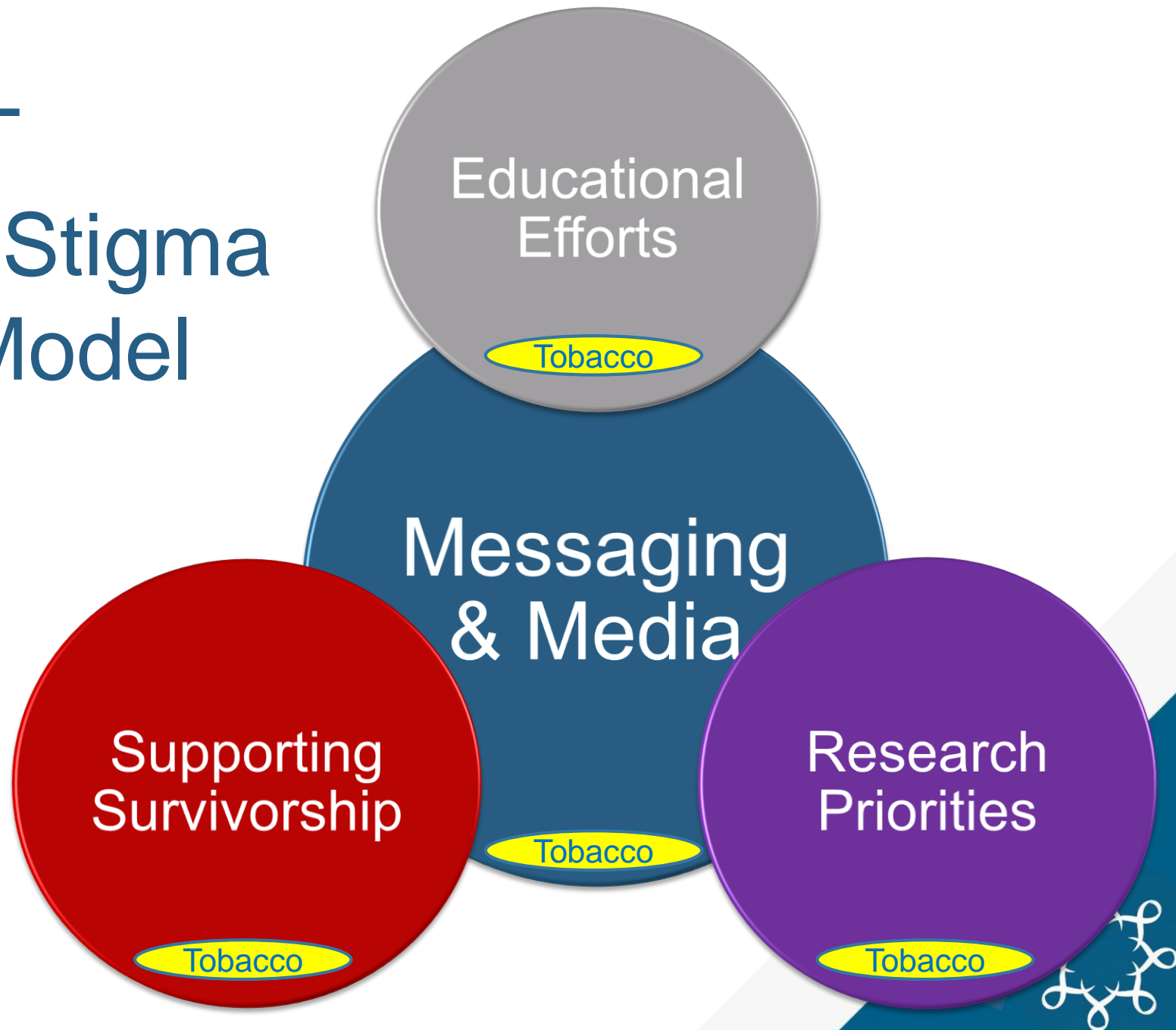


Lung Cancer Stigma Research Priorities



NLCRT Lung Cancer Stigma Summary Model

Messaging/media is the central component, but considering tobacco is a cross-cutting theme.



Transition to Strategic Plan Version 1.0





Big Measurable Goal

Nationally-representative, population-based estimate of lung cancer stigma (survey).

Mission

The NLCRT Lung Cancer Stigma Initiative is an interdisciplinary group of stakeholder organizations working to end lung cancer stigma and improve lung cancer outcomes.

Core Beliefs and Themes

Lung cancer stigma adversely impacts each component of the lung cancer control continuum across all groups within the lung cancer community and beyond. Lung cancer stigma impedes access to and utilization of...

1. evidence-based tobacco prevention and treatment.
2. high quality lung cancer screening
3. optimal diagnostic and treatment
4. survivorship support and palliative care
5. end-of-life and bereavement care

Efforts to end lung cancer stigma will be based on themes of urgency, empathy, and optimism.

Goal 1



Reframe Lung Cancer new message/engage media (cross-cutting)

Measurable Objectives

- # of messaging materials developed
- # of messaging materials delivered
- Measurable impact of specific materials

Strategies

- 1. Create and implement a national campaign addressing lung cancer stigma using identified themes in partnership with national media experts.
- 2. Infuse themes (urgency, empathy, optimism) and imagery throughout all strategies and promote to NLCRT member orgs.
- 3. Provide media training for advocates incorporating new messaging.

Goal 2



Improve Survivorship


Measurable Objectives

- # of resources developed
- # of resources delivered
- Measurable impact of resources

Strategies

- 1. Create a culture of survivorship by raising awareness, establishing empathic, person-centered LC survivorship care guidelines (e.g., surveillance, screening, distress, behavior change, risk reduction), and facilitating implementation of guidelines.
- 2. Support low-dose CT implementation (normalizing informed screening).
- 3. Increase comprehensive biomarker testing for lung cancer patients.
- 4. Promote access to and awareness of clinical trials.

Goal 3



Enhance Understanding and Empathy

Measurable Objectives

- # of education and training materials developed
- # of education and training materials delivered
- Measurable impact of education and training materials

Strategies

- 1. Create and promote a stigma biopsy toolkit and process to eliminate stigma from LC and tobacco-related education, training, and outreach.
- 2. Create and implement an anti-stigma core curriculum for health professions, prof education, continuing ed, professional conferences.
- 3. Develop a speaker's bureau and slide decks to help organizations reflect on and address LC stigma.
- 4. Partner with other organizations that address stigma issues for best practice exchange and mutually beneficial collaboration (intersectional).

Goal 4



Amplify and Expand Research

Measurable Objectives

- # of resources materials developed
- # of resources and materials delivered
- Measurable impact of resources and materials

Strategies

- 1. Conduct a LC research portfolio evaluation regarding breadth and depth of LC research by federal funding organizations.
- 2. Adopt a strengths-based approach to amplify and expand research.
- 3. Create a novel resource and additional messages for advocates and those who engage legislators and decision makers.



Big Measurable Goal & Mission

- **Big Measurable Goal**
 - Nationally-representative, population-based estimate of lung cancer stigma (survey).
- **Mission**
 - The NLCRT Lung Cancer Stigma Initiative is an interdisciplinary group of stakeholder organizations working to end lung cancer stigma and improve lung cancer outcomes.



Core Beliefs and Themes

- Lung cancer *stigma adversely impacts each component of the lung cancer control continuum* across all groups within the lung cancer community and beyond. Lung cancer stigma impedes access to and utilization of...
 - evidence-based tobacco prevention and treatment,
 - high quality lung cancer screening,
 - optimal diagnostic and treatment,
 - survivorship support and palliative care,
 - end-of-life and bereavement care.
- Efforts to end lung cancer stigma will be based on themes of *urgency*, *empathy*, and *optimism*.



Goals



Reframe Lung Cancer



Improve Survivorship



Enhance Understanding and Empathy



Amplify and Expand Research



Reframe Lung Cancer

- 1) Create and implement a national campaign addressing lung cancer stigma using identified themes in partnership with national media experts.
- 2) Infuse themes (*urgency*, *empathy*, *optimism*) and imagery throughout all strategies and promote to NLCRT member organizations and beyond.
- 3) Provide media training for advocates incorporating new messaging.



Enhance Understanding and Empathy

- 1) Create and promote a stigma biopsy toolkit and process to eliminate stigma from LC and tobacco-related education, training, and outreach.
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Amplify and Expand Research

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NLCRT Measurement Model

Societal Change
in Stigma

Culture-Level
LC Stigma
Change

Cultural Beliefs
National Survey

Change in
Stigma with
Program

Immediate
Outcomes of
Specific Elements

Impact of
Tools

Number of
Tools
Delivered

Tool Delivery –
within Framework Elements

Number of
Tools
Delivered

Proximal
Productivity

Tool Development –
Addressing Framework Elements

Number of
Tools
Designed

Institutional and Organizational Buy-In/Sign-On





Big Measurable Goal

Nationally-representative, population-based estimate of lung cancer stigma (survey).

Mission





The NLCRT Lung Cancer Stigma Initiative is an interdisciplinary group of stakeholder organizations working to end lung cancer stigma and improve lung cancer outcomes.

Core Beliefs and Themes

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Efforts to end lung cancer stigma will be based on themes of urgency, empathy, and optimism.

Goal 1	Measurable Objectives	Strategies
 Reframe Lung Cancer new message/engage media (cross-cutting)	# of messaging materials developed	<ol style="list-style-type: none"> Create and implement a national campaign addressing lung cancer stigma using identified themes in partnership with national media experts. Infuse themes (urgency, empathy, optimism) and imagery throughout all strategies and promote to NLCRT member orgs. Provide media training for advocates incorporating new messaging.
	# of messaging materials delivered	
	Measurable impact of specific materials	
Goal 2	Measurable Objectives	Strategies
 Improve Survivorship	# of resources developed	<ol style="list-style-type: none"> Create a culture of survivorship by raising awareness, establishing empathic, person-centered LC survivorship care guidelines (e.g., surveillance, screening, distress, behavior change, risk reduction), and facilitating implementation of guidelines. Support low-dose CT implementation (normalizing informed screening). Increase comprehensive biomarker testing for lung cancer patients. Promote access to and awareness of clinical trials.
	# of resources delivered	
	Measurable impact of resources	
Goal 3	Measurable Objectives	Strategies
 Enhance Understanding and Empathy	# of education and training materials developed	<ol style="list-style-type: none"> Create and promote a stigma biopsy toolkit and process to eliminate stigma from LC and tobacco-related education, training, and outreach. Create and implement an anti-stigma core curriculum for health professions, prof education, continuing ed, professional conferences. Develop a speaker's bureau and slide decks to help organizations reflect on and address LC stigma. Partner with other organizations that address stigma issues for best practice exchange and mutually beneficial collaboration (intersectional).
	# of education and training materials delivered	
	Measurable impact of education and training materials	
Goal 4	Measurable Objectives	Strategies
 Amplify and Expand Research	# of resources materials developed	<ol style="list-style-type: none"> Conduct a LC research portfolio evaluation regarding breadth and depth of LC research by federal funding organizations. Adopt a strengths-based approach to amplify and expand research. Create a novel resource and additional messages for advocates and those who engage legislators and decision makers.
	# of resources and materials delivered	
	Measurable impact of resources and materials	



Known Questions & Next Steps

- Attention to the complexity of LC and tobacco
- Finalizing the measurement model/specifics
- Prioritization process (early wins, long gains)
- Eliciting and managing partnerships/ownership
- All the additional questions in your head 😊



Ending Stigma in Lung Cancer



Together We Can !!!

Thank You

