

Removing Stigma (and Nihilism) to Increase Lung Cancer Screening

Jamie L. Studts, PhD

Professor of Medical Oncology
Scientific Director of Behavioral Oncology
Co-Leader Cancer Prevention and Control
Co-Director Population Health Shared Resource



State of Lung Cancer – *Hope Check*

- ❖ Smoking rates are declining to the lowest levels measured
- ❖ Radon-related risk awareness is increasing.
- ❖ Lung cancer screening and early detection is accelerating.
- ❖ Late-stage lung cancer diagnosis is declining.
- ❖ Lung cancer incidence is declining.
- ❖ Lung cancer mortality is declining.
- ❖ Lung cancer survivorship is increasing.
- ❖ Palliative care and symptom management are improving.
- ❖ Lung cancer quality of life is increasing.

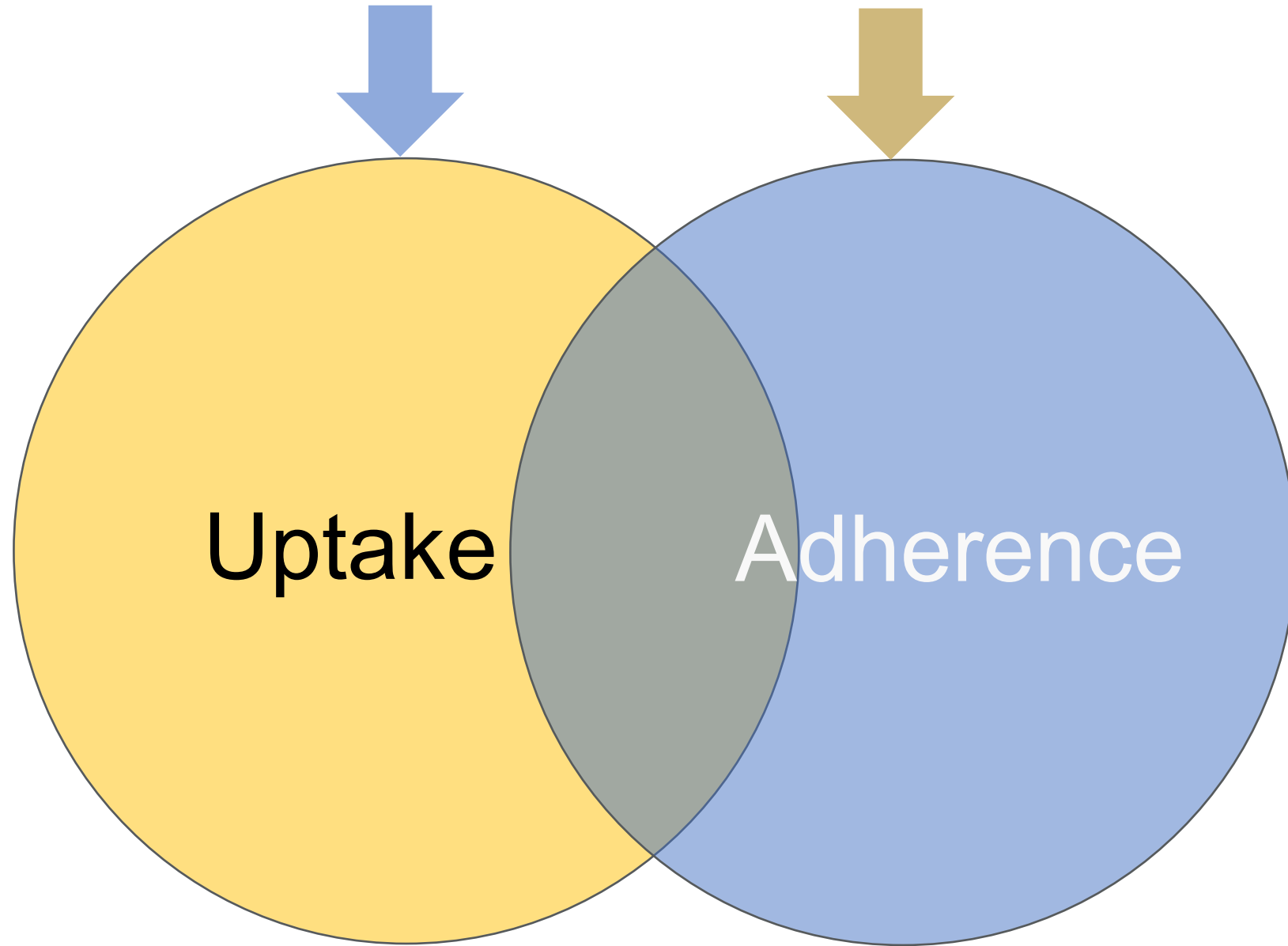
No time for “victory laps,” but these improvements must be highlighted!

Lung Cancer Screening

“Lung cancer screening is currently the greatest missed opportunity to reduce cancer mortality throughout the US—not just lung cancer mortality, but overall cancer mortality.”

-- J. L. Studts (just now and every day)

The **Twin** **Challenge** of Lung Cancer Screening



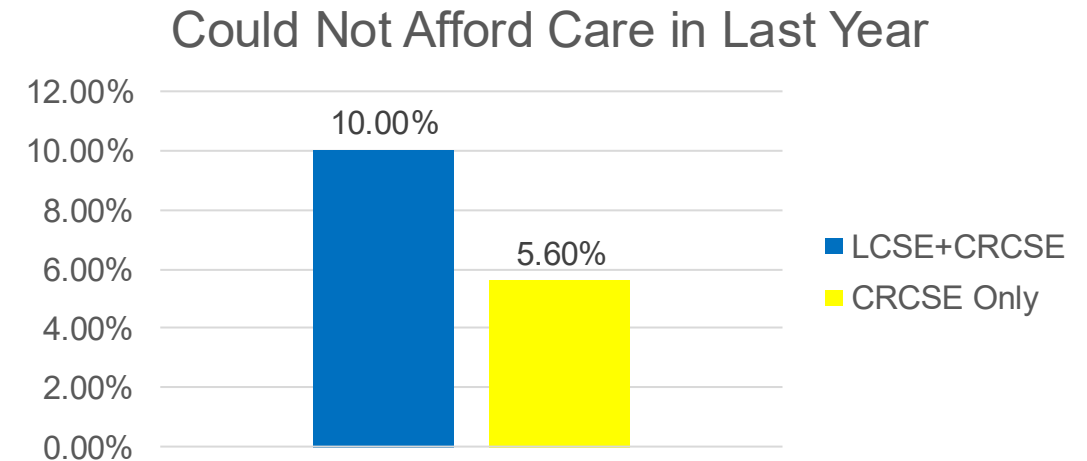
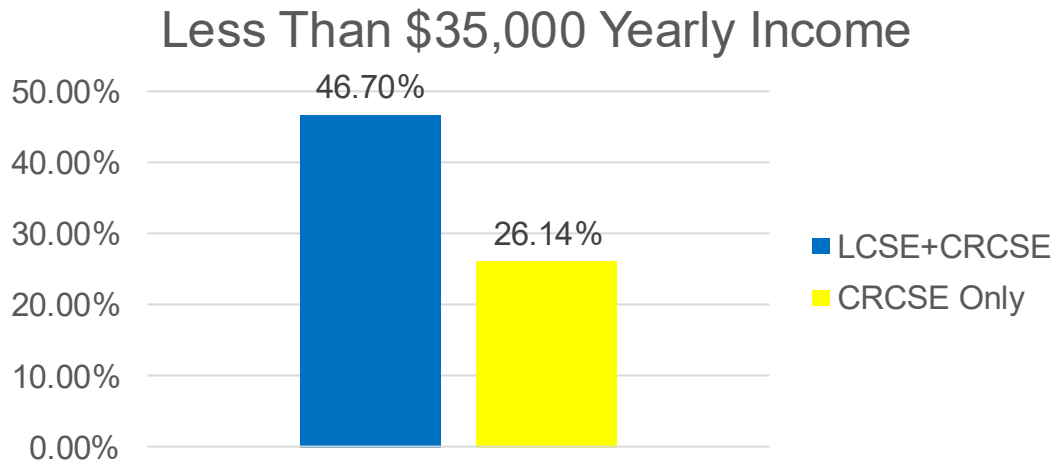
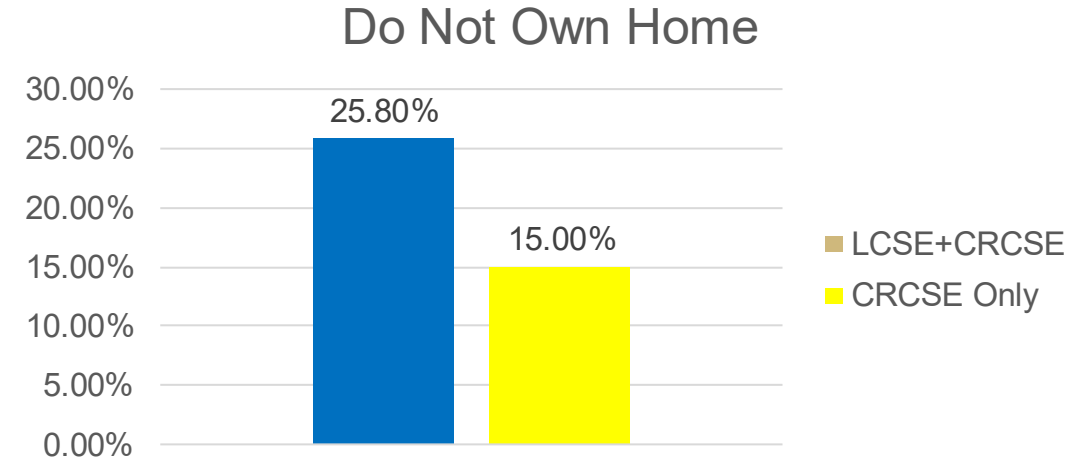
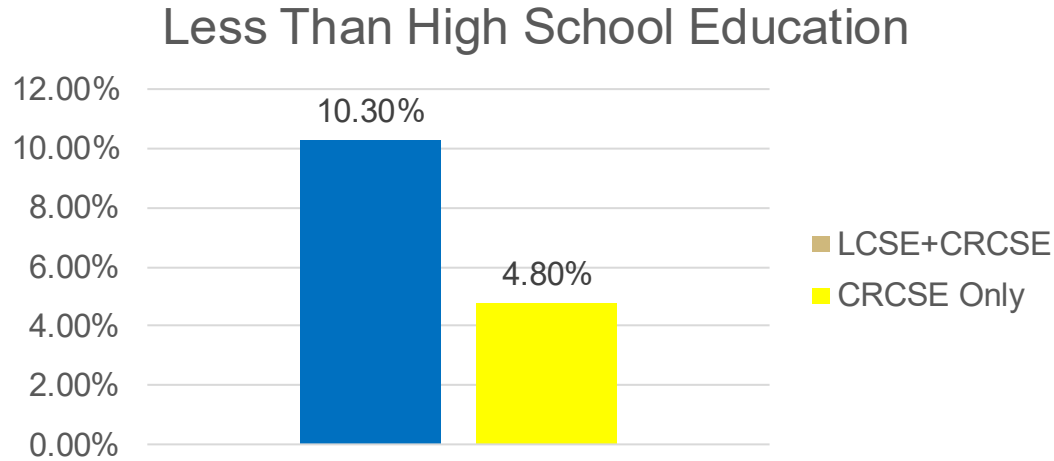
Getting
the
People
Part
Right



Placing
LCS
Candidates
and
Participants
at the
Center
of the
LCS
Process

Applying a social drivers of health lens can help us understand and reach the LCS-eligible community.

BRFSS 2022 Data



Lung cancer screening implementation must start with understanding the community of individuals who are eligible.

Without adopting stereotypes, to reach the community and achieve person-centeredness, we must understand the opportunities and challenges of the community we wish to serve.

*In the LCS context, it is vitally important to consider the difference between **persuasion** and **engagement**.*

Persuasion

- “Getting” people to screen
- Emphasis on uptake
- Built on authority
- Assumes trust
- Embraces paternalism

Engagement

- Creates opportunity to screen
- Balances uptake and adherence
- Built on respect and autonomy
- Recognizes potential lack of trust
- Embraces collaboration

What is the IASLC Language Guide?



- Many scientific organizations and clinical entities work hard to engage community members and advocates.
- However, scientific and clinical language of has not been vetted by community members.
- Efforts to bridge language were needed but not necessarily just the “jargon.”
- Guidance for language that engages and avoids stigma and disengagement.

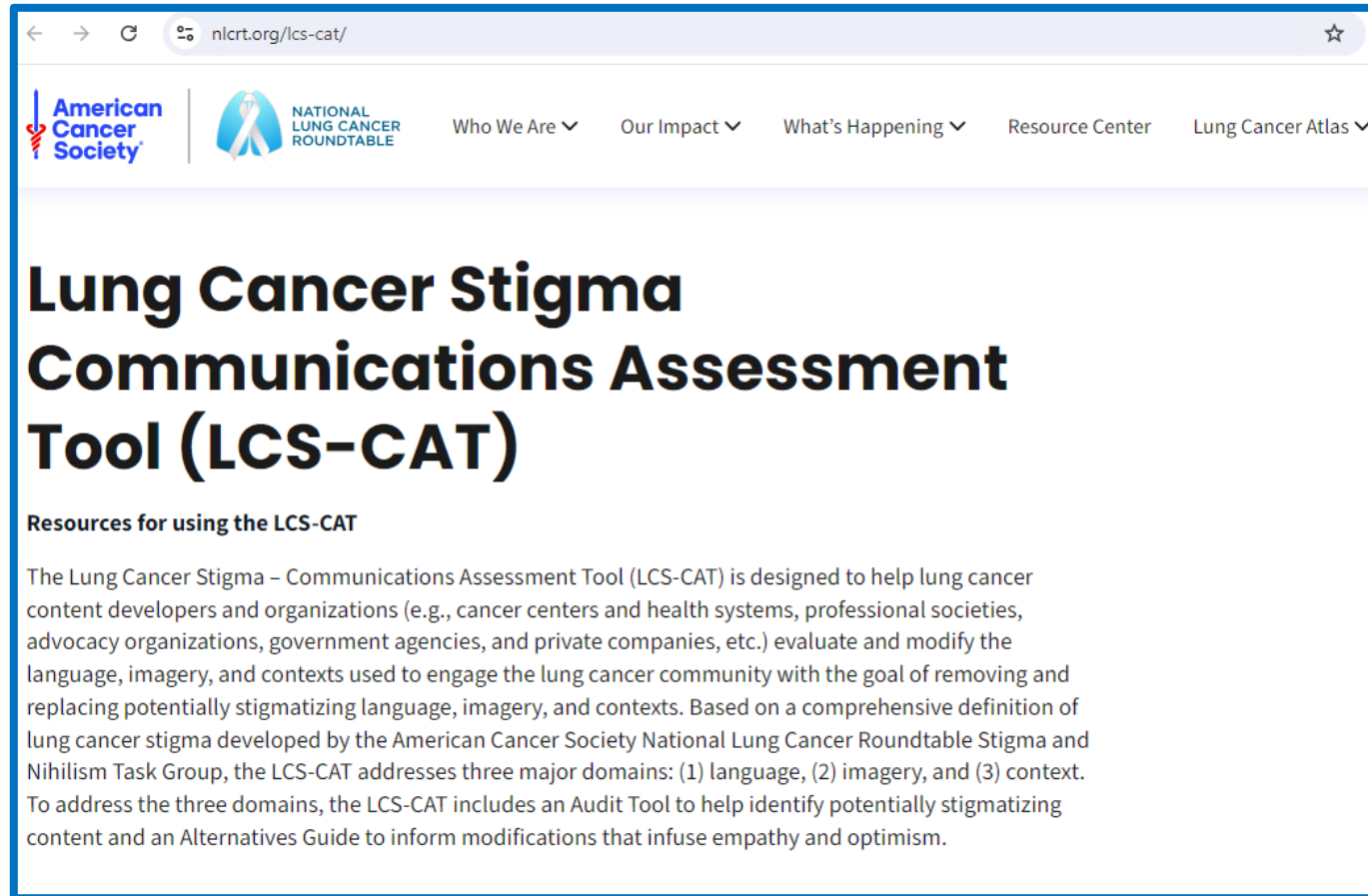


Words matter!

Images matter!

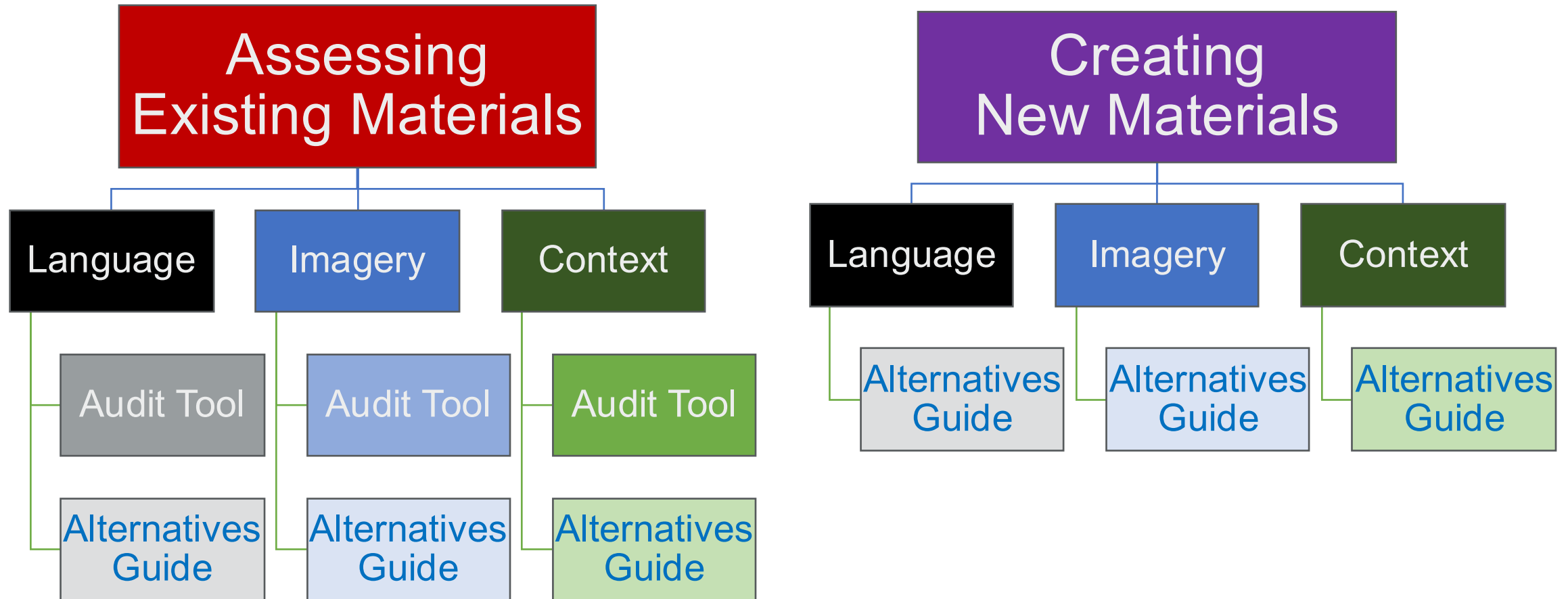
Context matters!

ACCESS: LCS-CAT Page on the NLCRT Website



- LCS-CAT page is active and available
- All materials are downloadable
- Content will continue to expand with tutorials and examples (other ideas)

The LCS-CAT can be used to revise current engagement materials or develop new materials.



LCS-CAT Language Audit Tool

- Provides a structure for identifying language in engagement materials that could contribute to lung cancer stigma.
- **Domains:**
 - Labeling language (smok**)
 - Blaming language (recalcitrant)
 - Oversimplifications (quitting)
 - Other language

Language Audit Tool for creators of lung cancer materials



What is the Language Audit Tool?

This Language Audit Tool helps you find and remove words and phrases in existing materials that stigmatize lung cancer and tobacco. You can also use it to inform choices when creating new materials.



The tool helps you assess a material for words and phrases in these 4 categories:

- **Labels** that focus on the disease and not the person
- **Blaming language** that uses words and phrases that show negativity and judgment
- **Oversimplifications** that reduce people to a single word (i.e., smoker) and do not reflect the complexity of lung cancer risk and diagnosis
- **Other stigmatizing** words and phrases you identify that you think may be stigmatizing

How do I use this tool?

- 1 Collect the material you plan to review – you may use an electronic or a hardcopy version. An electronic version allows for automated word search, but **the material should still be reviewed in full for language that may not be identified using an automated search.**
- 2 Write the name of the material at the top of page 2. Search the material for each word and phrase listed in the left-hand column of the Language Audit table below.
 - If using a **digital** version of your material, use the "Search" function in your document. Highlight each stigmatizing word or phrase in yellow.
 - If using a **hardcopy** of your material, circle or highlight each stigmatizing word or phrase you find as you read through it.
- 3 For each instance of a stigmatizing word or phrase, make a tally mark in the right-hand column of the Language Audit table below. In the middle column, write the page or section where the word or phrase appears.
- 4 At the bottom of the form, add the total number of instances from the 4 categories to get a Total Language Audit Score.
- 5 If the Total Language Audit Score is 1 or more, proceed to the Language Alternatives Guide to learn how to change the stigmatizing words and phrases you found in this Language Audit Tool.

LCS-CAT Language Alternatives Guide

- Offers alternative language for potentially stigmatizing language identified in the Language Audit Tool.

- **Domains:**

- Labeling language (person who smokes)
- Blaming language (not ready to stop)
- Oversimplifications (stopping)
- Other language

Language Alternatives Guide to help avoid lung cancer stigma



What is the Language Alternatives Guide?

The Language Alternatives Guide is to help you use language in your lung cancer materials that does not contribute to stigma, prejudice, or discrimination. It continues the process begun in the Language Audit Tool but can also be used to inform choices when creating new materials.



This guide offers specific word substitutes to consider using in your messages about lung cancer and tobacco. It is not a complete list of possible alternatives.

How do I use this guide?



If you are changing an existing material you assessed with the Language Audit Tool:

- 1 See which **labeling, blaming, oversimplifying, or other stigmatizing language** you identified in your material. If you used a digital version, you highlighted them in your document. If you used a hardcopy, you circled or highlighted them.
- 2 Check the tables below, which offer words and phrases as possible replacements for stigmatizing language you may have found in your material.



If you are creating a new material:

- 1 Consider using the words and phrases in the right column of the tables below, while avoiding those in the left column.
- 2 As you finalize your new material, consider double-checking it against the tables below for language that may contribute to stigma.

LCS-CAT Imagery Audit Tool

- Provides a process for identifying imagery that could be stigmatizing or alienating and contribute to lung cancer stigma
- **Domains:**
 - Color schemes (dark, gloomy)
 - Settings (unhealthy)
 - Interactions (social exclusion)
 - Facial expressions/body language (guilt)
 - Lung cancer tropes (fear-inducing)

Imagery Audit Tool

for creators of lung cancer materials



What is the Imagery Audit Tool?

This Imagery Audit Tool is to help you assess existing materials for images that may convey lung cancer stigma. The Imagery Audit Tool helps you inform content choices when creating new materials.



How do I use this tool?

- 1 Write the name of the material you are assessing at the top of page 2.
- 2 In the Imagery List table on pages 1-2, list all of the images (such as photos, illustrations, or icons) in the material.
- 3 Use the Imagery Audit table on pages 3-4:
 - Write a tally mark for each instance you see a stigmatizing element (such as a color or setting) in any of the images. At the bottom, add the tally marks to get a Total Imagery Audit Score.
 - If the Total Imagery Audit Score is 1 or more, go to the Imagery Alternatives Guide to consider options to replace the potentially stigmatizing imagery you identified in the audit process.

Imagery Audit

Material I am assessing: _____

Imagery List		
Images	Location in material (page, section)	Brief description of image
1		
2		



1

LCS-CAT Imagery Alternatives Guide

- Offers alternative imagery considerations for potentially stigmatizing imagery identified in the Imagery Audit Tool.
- **Domains:**
 - Color schemes (bright)
 - Settings (healthy)
 - Interactions (belonging)
 - Facial expressions/body language (hope)
 - Lung cancer tropes (hobbies)

Imagery Alternatives Guide to help avoid lung cancer stigma



What is the Imagery Alternatives Guide?

The Imagery Alternatives Guide provides suggestions for new images to replace images that may contribute to lung cancer stigma. It continues the process begun in the Imagery Audit Tool but can also be used to inform choices when creating new materials.



This guide describes non-stigmatizing visuals to help you create person-centered, empathic, and effective materials about lung cancer, smoking, and tobacco.

How do I use this guide?



If you are revising an existing material that has been assessed with the Imagery Audit tool:

- 1 Check the Imagery Audit form to see which stigmatizing **color schemes, settings, interactions between people, facial expressions or body language, or lung cancer tropes** you identified in the material.
- 2 Check the tables below, which describe imagery to avoid and alternatives.



If you are creating a new material:

- 1 Consider using the imagery characteristics listed in the right column of the tables below, while avoiding those in the left column.
- 2 As you finalize your new material, consider double-checking it against the tables below for images that may contribute to stigma.

LCS-CAT Context Audit Tool

- Provides a process for considering contextual factors that could engender potential lung cancer stigma (unintended consequences).
- **Domains:**
 - Message (theme of message)
 - Intended audience (unfavorable targeting)
 - Creators (assumptions, values)

Context Audit Tool for creators of lung cancer materials



What is the Context Audit Tool?

This Context Audit Tool helps you assess the “context” of your materials for potential lung cancer stigma, prejudice, or discrimination. The three contextual elements to assess are the material’s **message**, **intended audience**, and **creators**. This tool can help you assess an existing material or create a new material. For new materials, it’s most helpful when you use it early in the development process.



If you identify and reflect on these three elements, you can avoid writing or distributing materials that may contribute to lung cancer stigma. Example: If you develop material to prevent smoking among teenagers but it conveys disgust, the message would be “smoking is disgusting” rather than “teens shouldn’t smoke.”

How do I use this tool?



If you are assessing an existing material:

Read the material and look at its visual elements to get a full understanding of the material and its intended goal. Next, use the questions on pages 2-3:

- 1 At the top of page 2, write the name of the material you are assessing. Then move through each section on pages 2-3.
- 2 First, answer the context questions (write your answers on a piece of paper or in a blank Word document).
- 3 Then, answer the yes-or-no questions in each section. Add a “Yes” in the white boxes for any yes answers.
- 4 In the blue bar on page 3, add the total number of “Yes” answers from pages 2-3 to get the Total Context Audit Score.
- 5 If the Total Context Audit Score is 1 or more, proceed to the Context Alternatives Guide. It has questions to help you decide if and how you can change the material so it doesn’t create or spread lung cancer stigma.



If you are creating a new material:

Follow the same instructions given above. This can help you avoid including any stigmatizing elements in your new material.

LCS-CAT Context Alternatives Guide

- Offers a conceptual and reflective approach to considering contextual factors to convey person-centered, empathic, and effective engagement.
- **Domains:**
 - Reframe
 - Re-educate
 - Build self-esteem
 - Advocate
 - Facilitate empathy, hope, support

Context Alternatives Guide to help avoid lung cancer stigma



What is the Context Alternatives Guide?

The purpose of the Context Alternatives Guide is to promote reflection and suggest alternatives to contextual elements that could transmit or contribute to lung cancer stigma. It continues the process begun in the Context Audit Tool but can also be used to inform choices when creating new materials.

This guide will help you consider strategies to convey person-centered, empathic, and effective messages about lung cancer and tobacco.



How do I use this guide?



If you are changing existing material you assessed with the Context Audit Tool:

- 1 Look at the Context Audit Tool's three sections on message, intended audience, and creators to see which yes-or-no questions you marked with a "yes" in the tables.
- 2 Use the guidance below, on pages 2-5, to help you consider ways to change the stigmatizing elements you found in the Context Audit Tool. The guidance is organized into the same three sections as in the Tool.



If you are developing a new material:

Use the same instructions shown above. As you finalize your new material, consider double-checking it against the guidance below.

Lung Cancer Screening Messaging Guidebook

Recommended Messaging to Reach People Who Have Not Been Screened

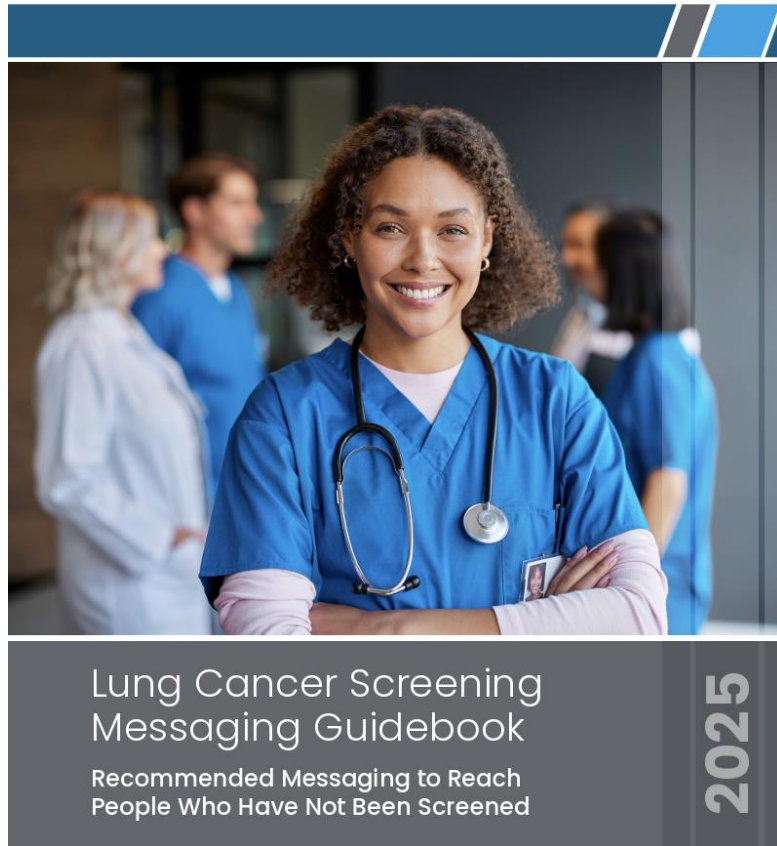
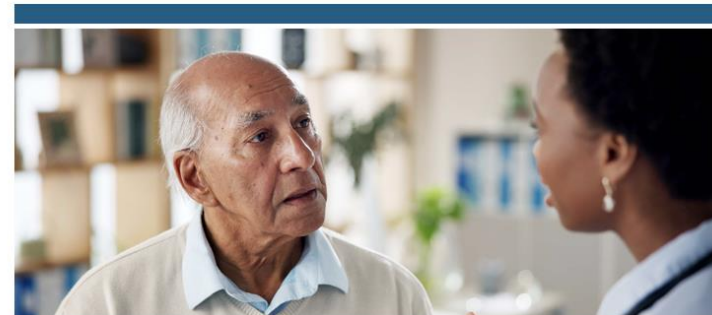


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Lung Cancer Screening – Brief Messaging Options

- 1) Lung cancer screening is covered by Medicare and by most private health insurance plans, and as of 2019, in Medicaid programs in over half of the states.
- 2) Lung cancer screening takes just a few minutes, and it is an effective way to find lung cancer early.
- 3) Anyone can get lung cancer, and screening is recommended if you are 50 or older and currently smoke or used to smoke.
- 4) Yearly lung cancer screening helps save lives by catching it early when it's easier to treat.

Some Final Thoughts

Perspective for Consideration

- For no other cancer is there a greater socioeconomic and cultural gap between the individuals who are eligible for screening and the clinicians and public health experts implementing screening.

Humility

- Working to understand and experience the perspective of others
- Replacing paternalism with empathy and support

Thank You



Kaitlyn Hoover, MS
University of Colorado
Cancer Center

Development Consultants

Lisa Carter-Bawa, PhD, MPH, APRN, FAAN
Hackensack Meridian Health

Abbie Begnaud, MD, FCCP
University of Minnesota

Jamie S. Ostroff, PhD, FSBM
Memorial Sloan Kettering Cancer Center

Jill Feldman
Lung Cancer Survivor

Elizabeth Scharnetzki, PhD
Maine Medical Center

NLCRT Team

Hannah Burson
NLCRT, ACS

Kenly Burn
NLCRT, ACS

Ella Kazerooni, MD, FACR, FACC
NLCRT, University of Michigan

Lauren Rosenthal, MPH
NLCRT, ACS

Robert Smith, PhD, FSBI
NLCRT, ACS

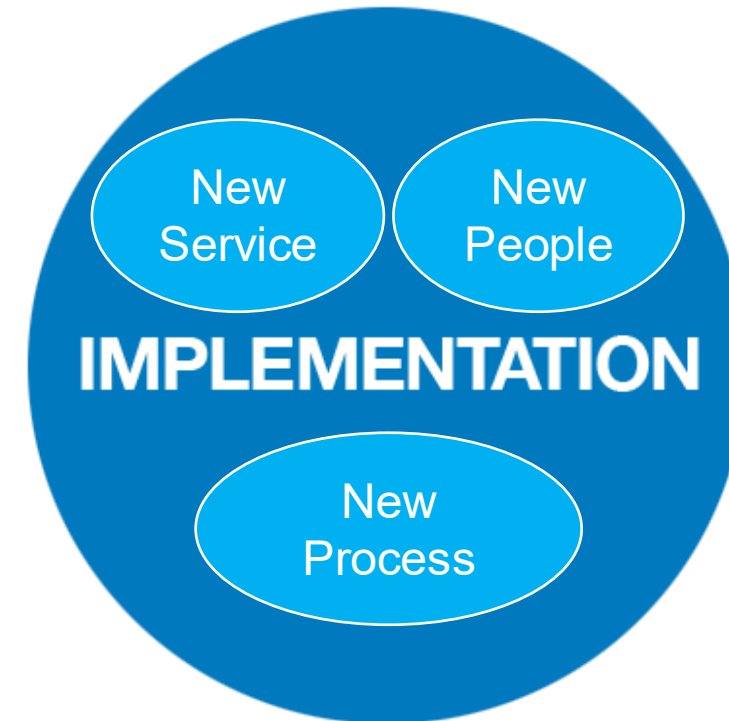


Low-dose CT for Lung Cancer Screening

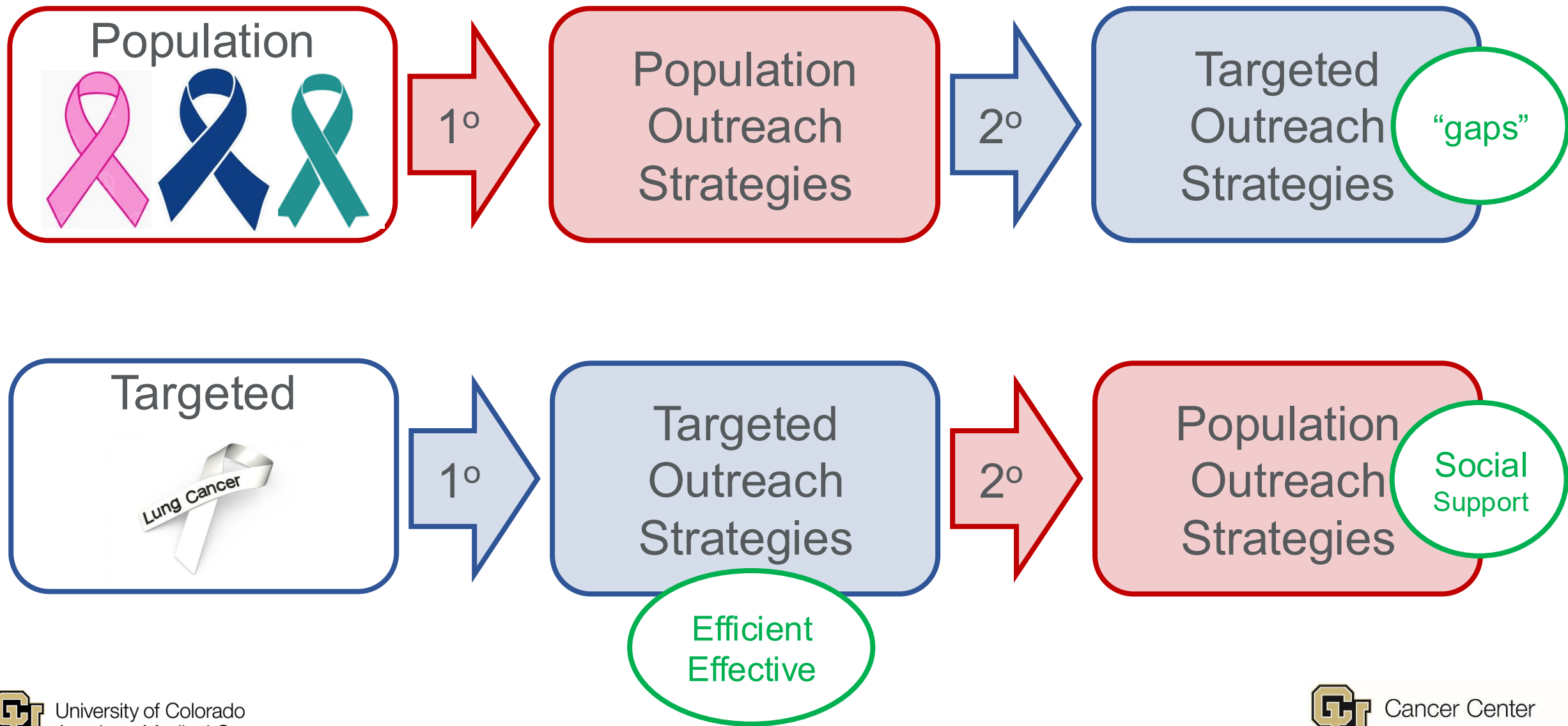
Promise



Challenge



Population vs. Targeted Cancer Screening



Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

To audit lung cancer materials and find alternatives for stigmatizing elements

Inside:

-  Context Audit and Alternatives
-  Language Audit and Alternatives
-  Imagery Audit and Alternatives



Team:

Jamie Studts, PhD and Kaitlyn Hoover, MS

Collaborators:

Abbie Begnaud, MD, FCCP
Lisa Carter-Bawa, PhD, APRN, ANP-C, FAAN
Jill Feldman
Jamie Ostroff, PhD
Lauren Rosenthal
Liz Scharnetzki, PhD
Robert Smith, PhD
Ella Kazerooni, MD, MS, FACR, FACC, FSABI

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Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

Acknowledgments

Established in 2017 the American Cancer Society National Lung Cancer Roundtable (ACS NLCRT) is a consortium of more than 225 member organizations and 220 leading experts working together to create more lung cancer survivors. Our collective power and expertise propel us to take on challenges that reduce the impact of lung cancer through risk reduction, tobacco prevention and control, early detection, improved lung cancer imaging, assurance of optimal diagnosis to position patients for appropriate therapy and care, eliminating lung cancer-related stigma, improving the quality of life for lung cancer survivors and their families, and strengthening state-based initiatives. We engage volunteer clinical, research, and public health experts, and patient and caregiver advocate representatives, in multidisciplinary collaborations that drive the national conversation, catalyze action to create, build, and strengthen innovative solutions, and develop and disseminate evidence-based interventions and best practices.

By working together and striving to avoid duplication among member organizations, we will drive progress faster than working alone to overcome lung cancer challenges, accelerate change, and address the determinants of cancer-related health disparities to advance health equity across the lung cancer continuum. This is the unique role of the ACS NLCRT.

The ACS NLCRT is thankful for the financial support from its partners, which supported the development of this resource, and the American Cancer Society. We especially wish to thank the ACS NLCRT Lung Cancer Stigma and Nihilism Task Group, the University of Colorado Cancer Center Population Health Shared Resource, Health Literacy Media, Health Decision Technologies, and Ohlander Consulting Services, Inc. for their expertise and the many hours of review and deliberation that went into developing the Lung Cancer Stigma – Communications Assessment Tool.



Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

Acknowledgments

Development Team

Jamie L. Studts, PhD, FSBM
Co-Chair, Stigma and Nihilism Task Group
University of Colorado Cancer Center

Kaitlyn Hoover, MSc
Population Health Shared Resource
University of Colorado Cancer Center

Development Consultants

Lisa Carter-Bawa, PhD, MPH,
APRN, ANP-C, FAAN
Chair, Stigma and Nihilism Task Group
Hackensack Meridian Health

Abbie Begnaud, MD, FCCP
University of Minnesota

Jill Feldman
Chair, Survivorship Task Group
Lung Cancer Survivor

Jamie S. Ostroff, PhD, FSBM
Chair, Tobacco Task Group
Memorial Sloan Kettering Cancer Center

Elizabeth Scharnetzki, PhD
Maine Medical Center

American Cancer Society National Lung Cancer Roundtable

Hannah Burson
National Lung Cancer Roundtable
American Cancer Society

Kenly Burn
National Lung Cancer Roundtable
American Cancer Society

Ella Kazerooni, MD, MS, FACR, FACC, FSABI
Chair, ACS National Lung Cancer Roundtable
University of Michigan

Lauren Rosenthal, MPH
National Lung Cancer Roundtable
American Cancer Society

Robert Smith, PhD, FSBI
ACS Chair, ACS National Lung Cancer Roundtable
American Cancer Society

We believe all people should have a fair and just opportunity to live a longer, healthier life free from cancer regardless of how much money they make, the color of their skin, their sexual orientation, gender identity, disability status, or where they live.



Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

The Lung Cancer Stigma – Communications Assessment Tool (LCS-CAT) is designed to help lung cancer content developers and organizations (e.g., cancer centers and health systems, professional societies, advocacy organizations, government agencies, and private companies, etc.) evaluate and modify the language, imagery, and contexts used to engage the lung cancer community with the goal of removing and replacing potentially stigmatizing language, imagery, and contexts. Based on a comprehensive definition of lung cancer stigma developed by the American Cancer Society National Lung Cancer Roundtable Stigma and Nihilism Task Group, the LCS-CAT addresses three major domains: (1) language, (2) imagery, and (3) context. To address the three domains, the LCS-CAT includes an Audit Tool to help identify potentially stigmatizing content and an Alternatives Guide to inform modifications that infuse empathy and optimism.

Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

■ **Mission**

- One approach to helping remove lung cancer stigma from efforts to engage community regarding lung cancer risk, risk reduction, screening, early detection, diagnosis, treatment, survivorship, palliative care, and end-of-life.

■ **Caveats**

- LCS-CAT will not “solve” the lung cancer stigma problem or guarantee that materials are optimal.
- LCS-CAT is not meant to be prescriptive—it is meant to help inform the choices being made about all types of engagement materials.
- LCS-CAT Version 1.0 will benefit from feedback and improvement with time as we learn more about engaging the broad lung cancer community.

What is Lung Cancer Stigma?



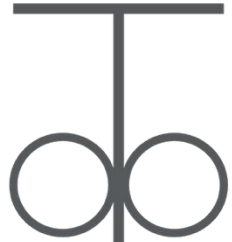
“...a cognitive, affective, and/or social experience and internalization of real or anticipated negative appraisal, devaluation, distancing, and discrimination by others attributable to an assumed or actual history of smoking, lung cancer risk, or lung cancer diagnosis, impeding progress in lung cancer prevention and control.”

“othering”

(Definition adopted by the Campaign to End Lung Cancer Stigma)

Lung Cancer Stigma Communications Assessment Tool (LCS-CAT)

Formerly
known as...



The
LC
Stigma
Biopsy



Language

Imagery

Context

Introduction and Process Guide

**Language
Audit**

**Imagery
Audit**

**Context
Audit**

**Language
Alternative
Guide**

**Imagery
Alternatives
Guide**

**Context
Alternatives
Guide**



Lung Cancer Screening Motivations