American Cancer Society

> NATIONAL LUNG CANCER ROUNDTABLE

Overcoming Stigma as a Barrier to Equitable Lung Cancer Care

July 10, 2024

Brought to you by the ACS Comprehensive Cancer Control Initiatives Team. ACS is proud to be a training & technical assistance provider for grantee coalitions within the CDC National Comprehensive Cancer Control Program.

Housekeeping Slide



- 1. Today's seminar will be recorded. The link to view the recording will be shared with all who have registered.
- 2. If you have any issues during today's seminar or have any questions for our presenters, please use the chat.
- 3. To ensure that there are no disruptions during the presentation, all participants have been muted by the host.
- We will have a Q&A portion at the end so please put your questions in the chat.
- 5. We would like to launch a short poll before beginning our webinar...

Today's webinar is supported by the **Centers for Disease Control and Prevention** of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$750,000 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Access to Cancer Care Series





Objectives for Today



We hope you will learn more about....

- 1. The importance and rationale of a person-centered approach to lung cancer screening.
- 2. How to engage diverse community partners into the lung cancer community.
- 3. Recommendations for changing the public discourse around lung cancer to create more equitable lung cancer screening, treatment, and survivorship.

Time for a quick poll!

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1. Brief pre-survey

ACS Webinar Series for Cancer Coalitions





Overcoming Stigma as a Barrier to Equitable Lung Cancer Care **PRESENTER**



Dr. Jamie L. Studts, PhD, FSBM
Professor of Medical Oncology
Scientific Director of Behavioral Oncology
Co-Leader of Cancer Prevention and Control
Co-Director of Population Health Shared Resource
University of Colorado School of Medicine
Member, Thoracic Oncology Research Initiative

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Overcoming Stigma (and Nihilism) as a Barrier to Equitable Lung Cancer Screening

- Dr. Jamie L. Studts -

Overcoming Stigma (and Nihilism) as a Barrier to Equitable Lung Cancer Screening

Jamie L. Studts, PhD

Professor of Medical Oncology Scientific Director of Behavioral Oncology Co-Leader of Cancer Prevention and Control Co-Director of Population Health Shared Resource Member, Thoracic Oncology Research Initiative







State of Lung Cancer – Reality Check of Hope

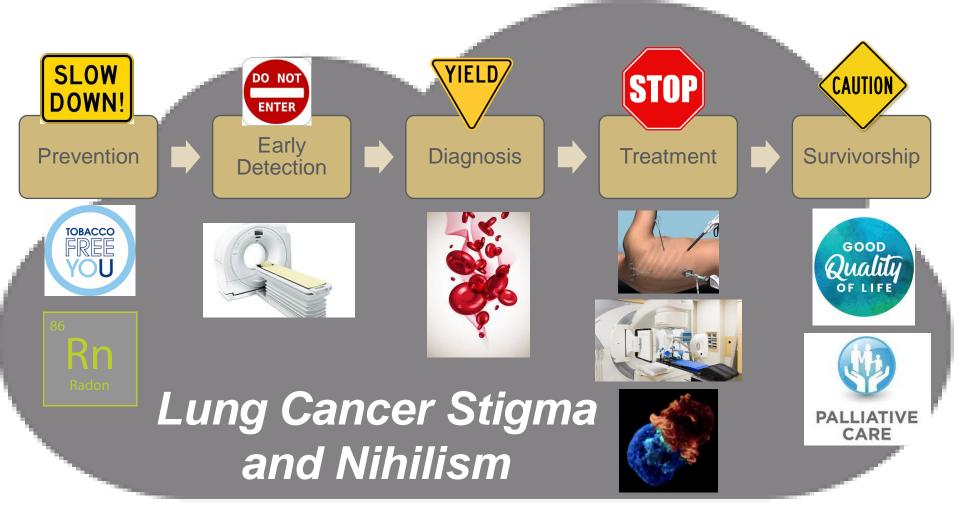
- Smoking rates are declining to the lowest levels measured
- Radon-related risk awareness is increasing.
- Lung cancer screening and early detection is accelerating.
- Late-stage lung cancer diagnosis is declining.
- Lung cancer incidence is declining.
- Lung cancer mortality is declining.
- Lung cancer 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 Control Continuum





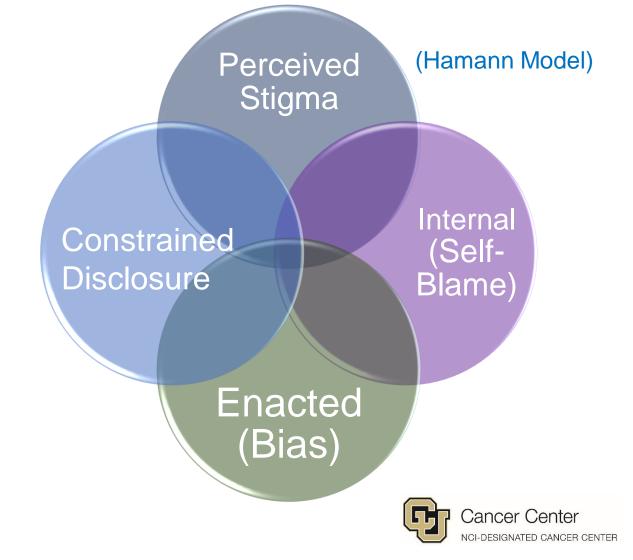


What is Lung Cancer Stigma?

...an attribute that is <u>deeply</u> <u>discrediting</u> that turns an individual from a whole and usual person to a <u>tainted</u>, <u>discounted one</u>. (Goffman, 1963)

"othering"

... a mark of shame or discredit

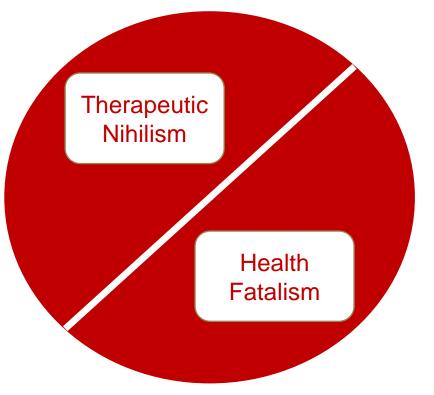




Therapeutic nihilism and fatalism also constitute cardinal threats to achieving optimal lung cancer outcomes.

Therapeutic nihilism

involves skepticism regarding the worth of therapeutic agents especially in a particular disease. (clinical side)



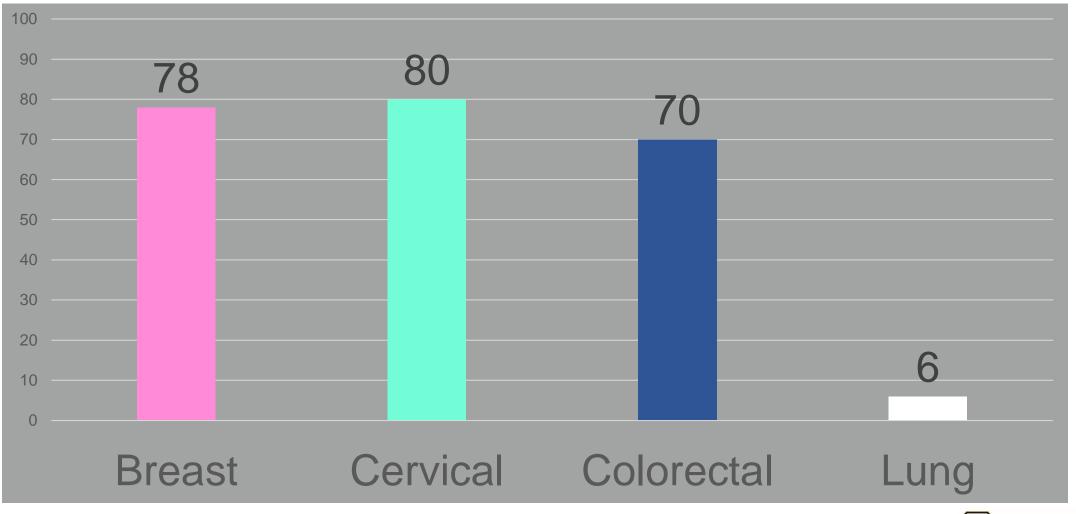
Health fatalism refers to a sense of lack of control and powerlessness over health and illness. (patient and community side)

Relative to lung cancer stigma, therapeutic nihilism and fatalism have received substantially less research attention but present a formidable challenge to lung cancer care and optimal outcomes.





The Opportunity: Cancer Screening Implementation







Lung Cancer Screening

"Lung cancer screening continues to be 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)





WHY SO LOW?

- New, translation takes time!
- Field of Dreams Fallacy:
 - "If you build it, they will come."
- Awareness: Nonexistant
 - Community
 - Organizations
 - Healthcare systems
 - Clinicians
 - Screening-Eligible Individuals!!!

Engagement Approach: Wrong

Fear Appeal

University of Colorado Anschutz Medical Campus

- Stigma Appeal
- Rational Appeal

Screening Perspective/People: New







Socioecological Model of Lung Cancer Screening



- Public/Society
- Policy Organizations
- Advocates
- Healthcare Systems
- Lung Cancer Screening Programs
- Primary Care Clinicians
- Family and Friends
- Candidates





Socioecological Perspectives on Lung Cancer Screening

- Public/Society undeserving, self-inflicted, should quit smoking
- Policy Organizations favorable policies, but apprehensive
- Advocates full speed ahead, "Why isn't this happening?"
- Healthcare Systems mixed, revenue stream? unaware?
- Lung Cancer Screening Programs full speed ahead, but...
- Primary Care Clinicians busy, not worth my time, nobody wants it
- Family and Friends largely unaware
- Candidates largely unaware, skeptical, self-blame/undeserving





Getting the **PEOPLE** Part Right

Community

LCS Program Team

LCS Candidates and Participants

Navigation

Placing LCS Candidates and **Participants** at the **CENTER** of the LCS Process



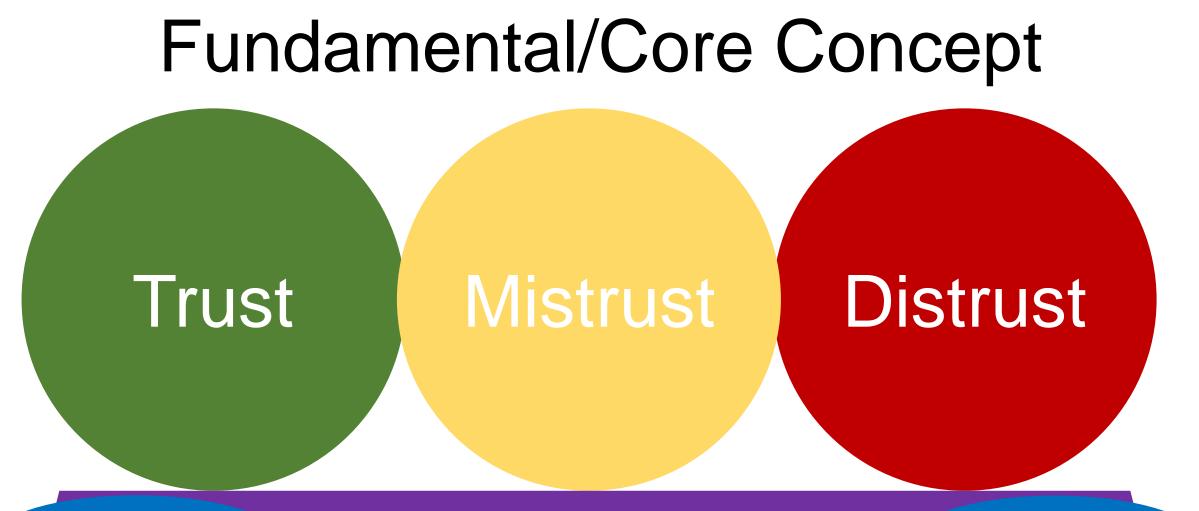


Lung cancer screening implementation must start with understanding the community of individuals who are eligible.

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.







Institutions

Trustworthiness

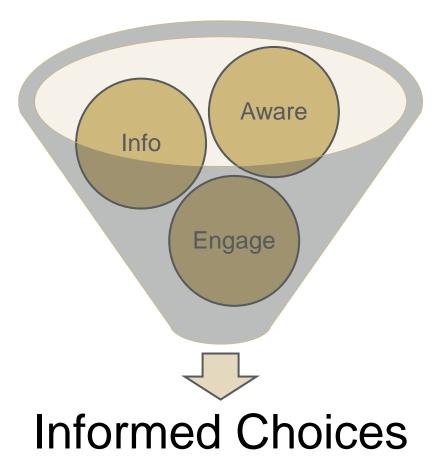
Individuals



<u>Credit to Dr. Rueben Warren, Tuskegee University</u> <u>https://www.youtube.com/watch?v=li31VPDcDds</u>



Health Communication Regarding LCS





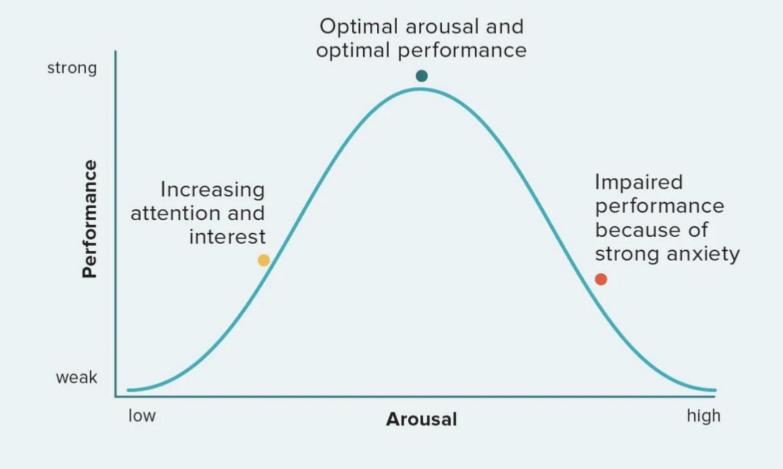




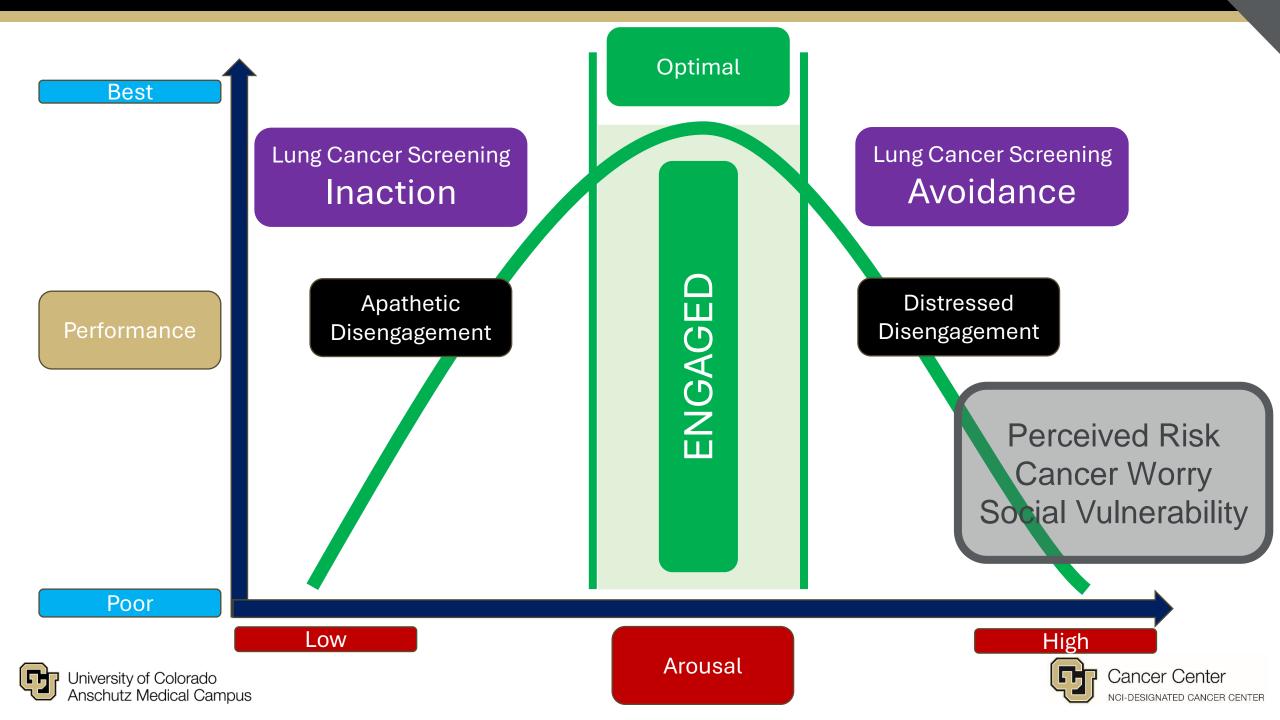
Remember back to **Psychology 101** \odot \odot \odot There is an optimal level of arousal associated with optimal performance of any task. University of Colorado

Anschutz Medical Campus

YERKES-DODSON LAW BELL CURVE







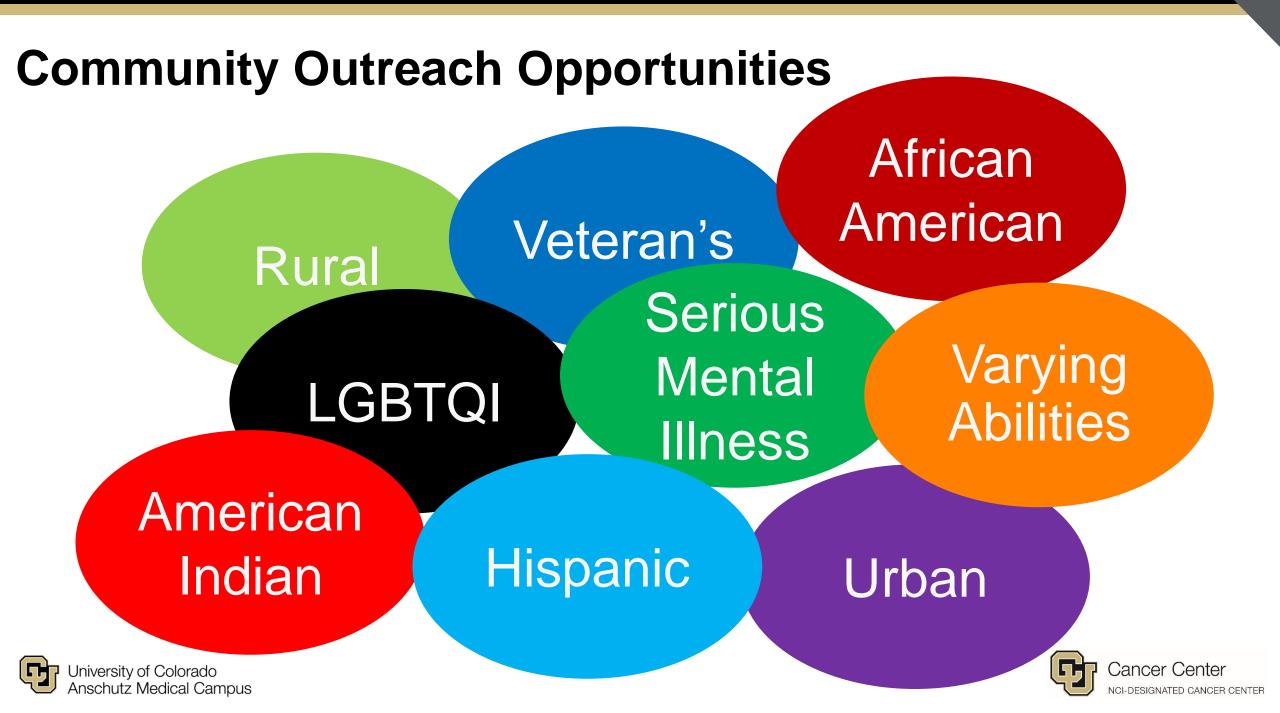
Equitable Implementation of Lung Cancer Screening

- 1) Assume stark and distressing disparities are emerging even without documentation
- 2) Consider targeted outreach and engagement opportunities to collaborate with specific communities
- 3) Explore community as well as clinician-focused efforts
- 4) Mitigate likely exacerbation of known disparities in lung cancer outcomes
- 5) Diverse communities, diverse methods, diverse levels of intervention



Bilenduke, E., Anderson, S., Brenner, A., Currier, J., Eberth, J. M., King, J., Land, S. R., Risendal, B. C., Shannon, J., Siegel, L. N., Wangen, M., Waters, A. R., Zahnd, W. E., & Studts, J. L. (2023). Equitable implementation of lung cancer screening: avoiding its potential to mirror existing inequities among people who use tobacco. *Cancer Causes & Control:* Advance online publication. https://doi.org/10.1007/s10552-023-01790-z



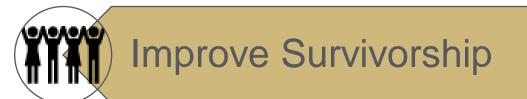












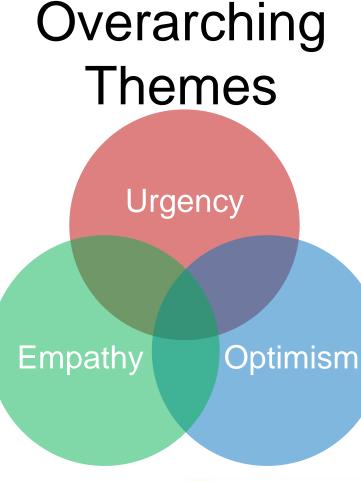


Enhance Understanding and Empathy





https://nlcrt.org/





The Engaged Approach to Lung Cancer Screening



Staff

Facing

Resources

Trainings

Toolkit/Manual

Community

A person-centered approach to supporting implementation of high quality lung cancer screening, regardless of institutional resources

Essential Elements

- 1) Places candidate at the center of process
- 2) Emphasizes relationship and engagement
- 3) Reinforces and centralizes sustained communication
- 4) Empowers LCS program staff/clinicians
- 5) Utilizes technology/digital tools to deliver resources
- 6) Builds a learning community with other LCS staff
- 7) Maintains minimal budget impact with high returns
- 8) Employs de-stigmatizing and supportive messages





Participant

Facing

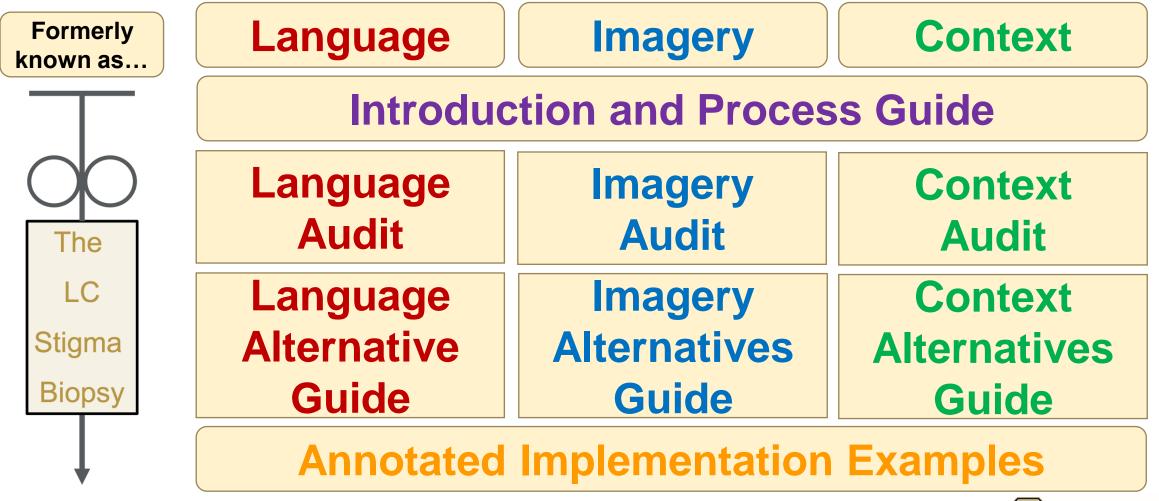
Tools

Letters

Newsletters

Guides

Lung Cancer Stigma – Communications Assessment Toolkit (LCS-CAT)



University of Colorado Anschutz Medical Campus

(Supported by the American Cancer Society National Lung Cancer Roundtable)



Health Communication and Marketing Best Practices for Lung Cancer Screening

Recommendations:

- 1) Convey accurate information about lung cancer screening (hard)
- 2) Encourage engagement with a health care clinician (call to action)
- 3) Seek unbiased presentation of LCS benefits/harms/unknowns
- 4) Avoid messages and imagery that stigmatize or induce fear



[Funded by a grant from the Bristol-Myers Squibb Foundation (501c3).]







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





Stigma, Nihilism, and Lung Cancer Screening

- 1) Lung cancer screening is currently the most significant missed opportunity in cancer prevention and control.
- 2) Lung cancer screening should be considered a health disparity area as compared to utilization of other evidence-based cancer screenings.
- 3) Lung cancer stigma and nihilism/fatalism play direct and indirect roles in dampening implementation of lung cancer screening.
- 4) Lung cancer stigma and nihilism/fatalism impact every level of the social ecology of implementing lung cancer screening.





ACS Webinar Series for Cancer Coalitions



Overcoming Stigma as a Barrier to Equitable Lung Cancer Care

Thank You

ACS Webinar Series for Cancer Coalitions





Overcoming Stigma as a Barrier to Equitable Lung Cancer Care **PRESENTER**



Dr. Lisa Carter-Bawa, PhD, MPH, APRN, ANP-C, FAAN

Director, Cancer Prevention Precision Control Institute Center for Discovery & Innovation at Hackensack Meridian Health Director, Community Outreach & Engagement, John Theurer Cancer Center Professor of Medicine, Hackensack Meridian School of Medicine Professor of Oncology, Georgetown University School of Medicine



The Pursuit of Person-Centered Lung Cancer Screening and Care How Do We Shift the Status Quo?

~ Dr. Lisa Carter-Bawa ~

The Pursuit of Person-Centered Lung Cancer Screening and Care

How Do We Shift the Status Quo?

Lisa Carter-Bawa, PhD, MPH, APRN, ANP-C, FAAN

Director, Cancer Prevention Precision Control Institute Center for Discovery & Innovation at Hackensack Meridian Health Director, Community Outreach & Engagement, John Theurer Cancer Center Professor of Medicine, Hackensack Meridian School of Medicine Professor of Oncology, Georgetown University School of Medicine



We cannot treat the lung cancer screening community as a 'one size fits all' community







3 Ways to Engage the Lung Screening Eligible Community

- 1. Leveraging Your Community
- 2. Novel Community-Based Interventions
- 3. Comprehensive Assessment of Public Facing Communication







Community Advisory Boards

- Do not underestimate the <u>power</u> of your community
- Leverage your community to create spaces to develop
 <u>trustworthiness</u> between your health system and the people
 - you are serving













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Tailored Outreach Interventions

- Consider culturally-tailored interventions specific to the community you serve
 - Potential to address medical mistrust and stigma in a vulnerable patient population head on
 - Fosters patient engagement by leveraging components of outreach that are personally relevant
 - Provides another avenue toward building trustworthiness with lung screening-eligible individuals



Tailored Outreach Intervention: Witness Project® Lung





- Comprehensive educational program
- Leverages the cancer and cancer screening experience of Black Americans through testimonials and 'witnessing' to community members in faith- or community-based settings
- Each Witness Project[®] Lung program is conducted by a Witness Role Model and supported by a Community Health Worker from the community-based health system
- Uses visual, audio and video, and text components



Designed to assist content developers:

- Reduce the prevalence of stigmatizing language and imagery in lung cancer screening and treatment information
- Reduce stigmatizing language and imagery in tobacco cessation material
- Complete a language audit of existing print and digital lung cancer and tobacco-related information to identify and remove stigmatizing language



Addresses 3 Components of Communication:

- . Language
- . Context



Imagery







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?

- 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.
- At the bottom of the form, add the total number of instances from the 4 categories to get a Total Language Audit Score.
- 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.



Imagery Audit Tool for creators of lung cancer materials



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.
- Pirst, 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.
- A 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.







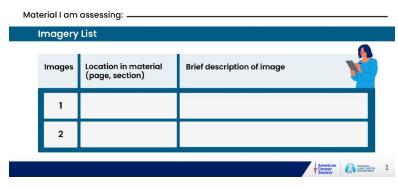
What is the Imagery Audit Tool? images that may convey lung cancer stigma. The Imagery Audit Tool

helps you inform content choices when creating new materials.

How do I use this tool?

- 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



Language Audit Tool for creators of lung cancer materials



What is the Language Audit Tool?

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- 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.





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?



- Write the name of the material you are assessing at the top of page 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

Hackensack
 Meridian Health
 KEEP GETTING BETTER

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

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?

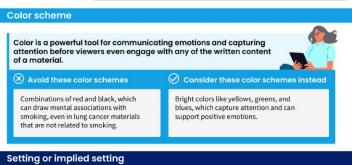
- If you are changing an existing material you assessed with the Language Audit Tool:
- See which labeling, blaming, oversimplifying, or other stigmatizing language you identified in your material. If you used a digital version, you highlighted them in your
- document. If you used a hardcopy, you circled or highlighted them.
 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

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

Imagery Alternatives

Material I am assessing:





Interactions between people



Context Alternatives

Material I am assessing:

Message alternatives

Yes-or-no questions you reflected on in the Context Audit Tool:

- Does the material use components of stigma (labeling, stereotyping, separation, status loss, and discrimination) to convey this message?
- If this material achieves its purpose, could it also lead to more public
 - stigma or self-stigma in people with lung cancer or who use tobacco?
- 3 Are fear, blame, or disgust used as tools to achieve the intended message in this material?
- Obes interpreting this message from an oppositional/antagonistic personative increase its stimulation potential?
- perspective increase its stigmatizing potential?

Guidance:

Components of stigma and purpose (for questions 1 & 2)

When considering how to avoid the components of stigma in your material, it can be helpful to look at it like this: if you're not working against stigma, you're working for it. In other words, **the best** way to avoid stigma is to actively combat it.

Your intended message does not have to be to "eliminate lung cancer stigma" for anti-stigma strategies to be helpful in your materials. See the list below, adapted from Brewis and Wutich's work on stigma, for strategies that can support an anti-stigma message:² **Reframe**: Avoid blame, focus on biological and social contributors to health

- Reeducate: Include facts that challenge common misinformation or misconceptions about stigma
- Build self-esteem: Confront and argue against contributors to self-stigma
- Advocate: Share information to build a stronger community around lung cancer

Fear, blame, or disgust (for question 3)

There are mixed findings on how well fear-arousing communication strategies work in reaching public health goals. Still, there is little doubt that the fear and disgust conveyed in lung cancer messages have contributed to lung cancer stigma.

In place of messages that incite powerful negative emotions, we suggest aiming to **convey a** message of hope, reassurance, and solidarity within the lung cancer and cancer survivorship communities. New examples include:

- Early detection and new treatments offer hope
- People who have a higher risk of lung cancer can get emotional relief from screening tests that show they don't have cancer
- Stories from people who formerly smoked and their caring healthcare clinicians who have skill in tobacco treatment offer a feeling of collaboration

Develop and test lung cancer messages not only to combat stigma but also to reflect the changing reality of lung cancer risk, diagnosis, and survivorship.











Welcome to Lung Talk!





About You...

Welcome

Introduction

Your Lungs

About You...

Please tell us if you currently smoke or have quit smoking?







Cigarette Smoke: What It Does

Welcome Lung Diseases Cigarette Smoke Lung Cancer No Symptoms Symptoms

Talk About It Summary



- Increases heart rate
- Reduces blood flow
- Lowers body temperature





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LungTalk

What I Would Like To Talk About

Welcome Lung Diseases Talk About It Summary To Talk About LungTalk Printout More Information



I would like to talk about (choose up to 3):

- My personal risk of lung cancer.
- More information about the lung scan.
- Benefits of lung screening.
- False positives, over-diagnosis, and radiation exposure.
- What my doctor recommends for me.
- How long I would have to do yearly lung scans.
- Ways to stop smoking.

Other

Please click the right arrow when you are ready.





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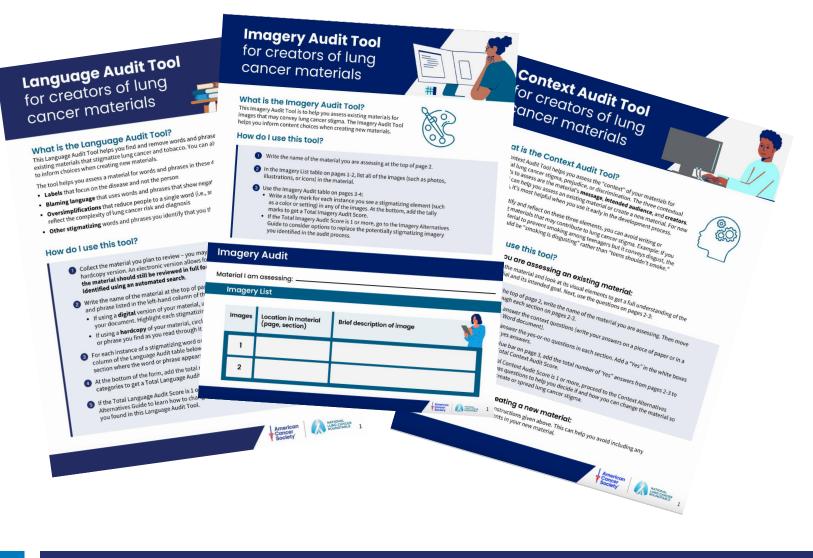




Table 1. LCS-CAT Summary of Findings

Audit Domain

Language		Imagery		Context	
Labels	9–Current smoker	Image #1	Black background, lung disease	Intentions	In some instances, the following terminology is used, "cigarette smoking is responsible for 90% of all lung cancer". Although true, the language could be softened to "exposure to cigarette smoke is responsible " and other causes of lung cancer could be included.
	9–Former smoker	Image #2	Cigarette in ashtray	Audiences	Possibility that someone who currently smokes navigates to the section meant for people who no longer smoke and feels bad about the positive tone of this messaging in contrast to the one meant for those who currently smoke. Tricky but something to consider.
Blame language	0	Image #3	Potentially off- putting stock lung photos	Values	No concerns
Oversimplification	2–Quitting	Image #4	Animation of burning cigarette in ashtray with chemicals in smoke		
	2–Do you/did you smoke?				
Other	1—Lung cancer kills				

#, number; LCS-CAT, Lung Cancer Stigma Communications Assessment Tool.



Again...We <u>cannot</u> treat the lung cancer screening community as a 'one size fits all' community







It's time to think outside the box and create a person-centered toolbox that addresses lung cancer screening with empathy, empowerment, and hope.





ACS Webinar Series for Cancer Coalitions



Overcoming Stigma as a Barrier to Equitable Lung Cancer Care

Thank You

ACS Webinar Series for Cancer Coalitions



Overcoming Stigma as a Barrier to Equitable Lung Cancer Care







ACS CCC brings you this series through a cooperative agreement with the CDC National Comprehensive Cancer Control Program. Our goal is to provide quality trainings and technical assistance to NCCCP's 66 grantee coalitions across the country.

Promoting Non-Invasive CRC Screening

American Cancer Society

August 14, 2024, 1 - 2 p.m. ET

On Aug. 14, the ACS Comprehensive Cancer Initiative team, in partnership with the ACS National Colorectal Cancer Roundtable, will examine how the promotion of non-invasive cancer screening addresses multiple challenges in CRC screening completion.



Register Today!

bit.ly/3yhwgbA



AUG 14 | 1-2 PM EST

Promoting Non-Invasive CRC Screening

National Lung Cancer Screening Day





Saturday, November 9, 2024

https://www.lungcancerscreeningday.org/

Promotional toolkits and resources are available upon registering at the website.





ACS Webinar Series for Cancer Coalitions



Overcoming Stigma as a Barrier to Equitable Lung Cancer Care

Thank You!



