



# Effective Communication About Lung Cancer Screening Without Iatrogenic Stigma: A Brief Report Case Study Using the Lung Cancer Stigma Communications Assessment Tool of *LungTalk*

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## ABSTRACT

**Introduction:** Stigma thwarts progress in lung cancer risk reduction and control and adversely affects patients across the entire lung cancer care continuum. In developing and disseminating patient and public-facing interventions to increase lung screening, we must be cognizant of how communications have the potential for further stigmatization of at-risk populations. Creation of the Lung Cancer Stigma Communications Assessment Tool (LCS-CAT) version 1 was supported by the American Cancer Society's National Lung Cancer Roundtable to help content developers identify, remove, and replace potentially stigmatizing language and imagery from materials designed to engage individuals across the lung cancer continuum.

**Methods:** The LCS-CAT considers language, imagery, and context and was used to audit a public-facing health communication and decision support tool called *LungTalk*.

**Results:** The audit performed by two behavioral scientists revealed multiple issues in all three areas, and specific feedback and alternatives were identified.

**Conclusions:** Applying the LCS-CAT to *LungTalk* was a productive process that helped remove potentially stigmatizing language and imagery from this tool designed to engage individuals in the process of making an informed decision about lung screening. To support destigmatization of lung cancer, communication creators should consider a stigma biopsy on all public-facing campaigns for lung screening to help identify, eliminate, and replace messages that could compromise engagement with the lung cancer screening opportunity.

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**Keywords:** Stigma; Lung cancer; Communication; Lung cancer screening

## Introduction

Lung cancer stigma is an omnipresent and unfortunate phenomenon with adverse impact at multiple levels.<sup>1-3</sup> Lung cancer stigma is defined as “a cognitive, affective, and/or social experience and internalization of real or anticipated negative appraisal, devaluation, distancing, and discrimination by others attributable to

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an assumed or actual history of smoking, lung cancer risk, or lung cancer diagnosis, impeding progress in lung cancer prevention and control” (American Cancer Society National Lung Cancer Roundtable [ACS NLCRT] Stigma and Nihilism Task Group, 2021). Stigma thwarts progress in lung cancer risk reduction and control, negatively affecting the entire lung cancer care continuum. As we consider why stigma hinders progress, we must acknowledge key areas in which stigma manifests throughout the environmental milieu.

Research has revealed the presence and adverse impact of lung cancer stigma at every level across the socioecological framework<sup>4</sup> and requires a similar multilevel approach to address effectively. Traditional efforts to communicate lung cancer risks, consequences, and outcomes have frequently used stigmatizing and fear-based messaging across public health efforts related to tobacco control, treatment, and cancer care.<sup>5</sup> Although these approaches have contributed to reduced tobacco use, the unintended consequences of stigmatizing language and imagery and insensitivity to important contextual factors has contributed to a toxic and complicated messaging environment. Replacing stigmatizing and fear-based messages with efforts to engage individuals with empathy, optimism, and urgency<sup>6</sup> may be an alternative approach to messaging and imagery pertaining to the sensitive context of smoking and lung cancer. The public discourse around lung cancer has been shaped by decades of successful tobacco control messaging but has inadvertently amplified the stigma associated with lung cancer permeating the lung cancer continuum. Language, imagery, and context are critically important modifiable intervention targets that have the potential to change the landscape of this challenging phenomenon.

As we consider development and dissemination of patient and public-facing interventions to increase lung screening, we must be cognizant of how the components have the potential for further stigmatization of at-risk populations. As part of an initiative of ACS NLCRT, a group within the Campaign to End Lung Cancer Stigma created the Lung Cancer Stigma Communications Assessment Tool (LCS-CAT) version 1 to address lung cancer stigma more broadly. This newly developed tool is designed to help content developers identify, remove, and replace potentially stigmatizing language and imagery from materials designed to engage individuals with destigmatizing messages in any effort across the lung cancer continuum. Furthermore, the tool includes a section that considers contextual factors for how materials may be used that could communicate latent stigma. The LCS-CAT encompasses the following three components: (1) language, (2) imagery, and (3) context. Each component includes the following three complementary

elements: (1) background and justification, (2) audit tool, and (3) alternative guide. The tool can be used proactively to guide development of new communication tools or retrospectively to evaluate and modify established tools. The ACS NLCRT Campaign to End Lung Cancer Stigma Development Committee leveraged the pioneering work by the International Association for the Study of Lung Cancer Patient Advisory Group on developing version 1 of the International Association for the Study of Lung Cancer Language Guide,<sup>7</sup> language guides developed in other contexts,<sup>8</sup> and the developing literature regarding lung cancer stigma and its consequences,<sup>1,2,6</sup> to inform a complete draft version. The LCS-CAT was subsequently reviewed twice by experts in different aspects of lung cancer stigma, and revisions were made in alignment with both rounds of feedback. As a component of the evaluation process, the LCS-CAT development team sought applied testing with current lung cancer communication tools.

The National Cancer Institute-funded study (R01CA263662) entitled, “Leveraging social media to increase lung cancer screening awareness, knowledge and uptake among high-risk populations (INSPIRE-Lung Study)” offered this applied testing opportunity. The INSPIRE-Lung Study uses a computer-tailored health communication and decision support tool called *LungTalk* (#NCT05824273).<sup>9</sup> The overarching communication goal is to educate broadly about lung health and risk, including cancer and option to screen, and the intended audience are lung cancer screening-eligible individuals. The original version of *LungTalk* tailored on smoking status.<sup>10,11</sup> The study start-up phase updated *LungTalk* to also tailor on the top perceived lung cancer screening barriers identified in prior work.<sup>12,13</sup> Revisions were informed by results of the LCS-CAT—identifying potential stigmatizing language, imagery, or contextual factors of concern. This article discusses the method of the LCS-CAT, its outcomes, and how it informed revisions to *LungTalk*.

## Material and Methods

Two behavioral scientists conducted a language, imagery, and context audit on *LungTalk*'s master content library. The master content library is the comprehensive blueprint for this web-based program and includes all text, imagery, narration scripts, order and flow, and tailoring algorithms. The language audit included reviewing the language for the presence of seven labels (smoker, nonsmoker [never, former], admitter [of smoking], denier [of smoking], lung cancer patient, nicotine addict, subject [research]), seven terms reflective of blame (recalcitrant, noncompliant, hardcore, chief complaint, patient failed, willpower,

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		
Other	2—Do you/did you smoke? 1—Lung cancer kills ...				

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

teachable moment), four terms reflective of oversimplification (habit or lifestyle, quitting, do you/did you smoke, prevention), and a section for “other” terms identified. The imagery audit included reviewing all images and assessing for the potential to convey stigmatizing inferences, and the context audit included reviewing the entire program for effects related to intentions, audiences, and values.

## Results

The language audit revealed use of nine labels of “smoker” and nine labels of “former smoker,” two instances of the term “quitting,” and two instances of the phrase “do you or did you smoke?” including one other instance noted of using the phrase “Lung cancer kills ...”. The imagery audit revealed three areas of concern including a black background for lung disease, cigarette in ashtray, and stock lung photos and medical animation that starkly depict lung scans with a black background that may be considered off-putting or frightening to some users. The context audit revealed two areas of concern. First, in the category of intentions, the sentence “cigarette smoking is responsible for 90% of all

lung cancer” was noted. The reviewer noted while true, the language could be softened to “exposure to cigarette smoke is responsible ...” and other causes of lung cancer could also be included. Second, in the category of audience, the reviewer noted the possibility that someone who currently smokes could navigate to the section meant for people who no longer smoke and feel badly about the positive tone of this messaging in contrast to the one meant for those who currently smoke (Table 1).

## Discussion

On the basis of the LCS-CAT, *LungTalk* was revised to replace potentially stigmatizing terms and images with person-first language and updated visuals. Applying the LCS-CAT to *LungTalk* was a productive process that helped remove potentially stigmatizing language and imagery from this tool designed to engage individuals to make an informed choice about lung screening participation. Language and imagery modification may help the tool be received with lesser concerns about stigmatizing interactions with the lung screening infrastructure. Furthermore, the minimal contextual considerations

identified validate the extensive evaluation efforts that have been conducted during initial development and feasibility for *LungTalk*.

The LCS-CAT provides an explicit process and detailed instructions to evaluate any lung cancer-related communication tool. This report represents the first published use of the LCS-CAT to evaluate the potential unintended stigmatizing elements of lung cancer communication tools. As with any new tool, the LCS-CAT might also be enhanced by future modifications. Although each parameter has been identified as potentially stigmatizing in terms of language, imagery, and context, there are some terms, image parameters, and contexts that might not be universally viewed as stigma producing. Additional testing with diverse target user populations might inform development decisions about parameters to add or delete to the LCS-CAT and improve the process of achieving engagement and avoiding stigma and other biases in all tobacco, smoking, and lung cancer-related communications. In addition, depending on context and purpose, future modifications of the LCS-CAT may benefit from the inclusion of patients and clinicians in both use of, and future testing of, the LCS-CAT.

In conclusion, although lung cancer screening has great public health potential to decrease lung cancer mortality through early detection, stigma is one of the greatest obstacles at multiple levels of lung cancer prevention and control. There is strong consensus that greater dissemination and communication efforts are needed to raise awareness and promote lung cancer screening among at-risk individuals. Nevertheless, to be clear, actions taken that have the tendency to stigmatize individuals eligible for lung cancer screening are likely not intentional but rather a byproduct of the change in public discourse around lung cancer and tobacco control. Of import, global cancer stigma is increasingly being recognized as a modifiable factor for gaps in patient care and quality of life.<sup>14</sup> Until stigma is addressed at multiple levels, the public health benefit of lung cancer screening will continue to be severely challenged. As we consider ways to combat global lung cancer stigma, starting with public messaging and media image of those at risk paired with intentional outreach and education at the clinician and system levels of the importance of empathic communication have the potential to be a game changer. To realize the destigmatization of lung cancer, communication creators should consider a stigma biopsy on all public-facing campaigns for lung screening to help identify, eliminate, and replace messages that have affected public perspectives on lung cancer and thwart engagement and support for individuals facing any component of the lung cancer continuum.

## CRedit Authorship Contribution Statement

**Lisa Carter-Bawa:** Conceptualization, Writing—original draft, Writing—review and editing.

**Jamie S. Ostroff:** Conceptualization, Writing—review and editing.

**Jamie L. Studts:** Conceptualization, Methodology of tool, Writing—review and editing.

**Kaitlyn Hoover:** Writing—review and editing.

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