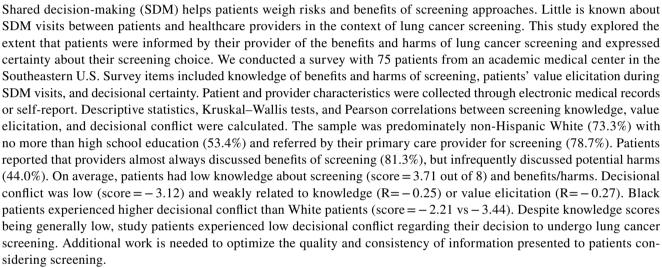
# Outcomes of Shared Decision-Making for Low-Dose Screening for Lung Cancer in an Academic Medical Center

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### Abstract



**Keywords** Computed tomography  $\cdot$  Lung cancer screening  $\cdot$  Shared decision-making  $\cdot$  Patient-provider communication  $\cdot$  Survey  $\cdot$  Early detection of cancer

### Introduction

Lung cancer screening with low-dose Computed Tomography (LDCT) has been proven through rigorously conducted randomized clinical trials [1, 2] to reduce lung cancer mortality when conducted in high-risk populations

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annually. The U.S. Preventive Services Task Force (USP-STF) updated their guidance for lung cancer screening in March 2021, expanding eligibility to include individuals aged 50–80 years who have a 20 + pack-year smoking history and currently smoke or have quit within the past 15 years [3]. This change expands the population eligible for lung cancer screening by 86% and has the opportunity to reduce known sex and racial disparities in eligibility for lung cancer screening [4].

Although screening can reduce lung cancer mortality through detection of lung cancers at earlier, more treatable stages, potential harms include overdiagnosis, false positive test results, and risk of invasive diagnostic procedures and related complications. Given this risk-benefit profile of screening, it is recommended that individual screening decisions be based upon informed and value-based discussions with one's healthcare provider. This discussion, often



referred to as shared decision-making (SDM), is a critical element of the screening process and is mandated by the Centers for Medicare and Medicaid Services (CMS) for reimbursement [5].

Prior research has shown that patients are not always informed, nor certain about whether lung cancer screening is right for them [6]. In a pragmatic trial where patients watched an online informational video about LDCT screening delivered via a patient portal, Dharod et al. found that about 30% of eligible patients [7] wanted lung cancer screening, 44% were unsure, and 25% declined screening. Through independent observation of SDM visit transcripts, Brenner et al. [8] also found that screening discussions with patients were less than 1 min in length on average, did not use decision aids or other education materials, and rarely included a discussion of harms. Shen et al. found that smoking cessation resources and/or referrals were also low in SDM visits, despite being one of many components required by CMS [9].

Given the stated concerns about the potential quality of SDM discussions and providers' time constraints and competing demands [10-15], some have argued that SDM is a barrier to LDCT screening and/or may not be worth the costs [16]. Others advocate that SDM visits and associated reimbursement requirements should continue, albeit with more consistent and balanced messaging about screening from providers [17]. More information is needed to understand how well patients are currently being educated of the risks and benefits of lung cancer screening to inform development of future provider and patient interventions. Therefore, the purpose of this study was to explore how patients who have been referred for LDCT screening by their healthcare provider describe the SDM visit, including what information they learned about screening and their level of certainty about their screening decision.

### **Material and Methods**

### **Patient Eligibility**

We conducted the study in a large academic health system located in central North Carolina, U.S. The health system has more than 2 million outpatient visits yearly. We queried the medical center's electronic health record (EHR) to identify patients who were referred for LDCT screening. We excluded patients who were flagged in the EHR as needing an interpreter. Patients were excluded if they were referred for a *diagnostic* chest CT, had a prior history of lung cancer, or had completed an LDCT screening in the past. We contacted potentially eligible patients within 10 business days after their LDCT was ordered.

### Questionnaire

Patients were asked to complete a 59-item questionnaire over the telephone to assess their knowledge of the benefits and potential harms of LDCT screening, experience discussing LDCT screening with their healthcare provider, and preparedness to undergo LDCT screening. In this analysis, we leveraged specific questionnaire sections, including the eligibility confirmation section, the demographics section, and items taken or adapted from the *Brief Knowledge Measure* scale [18], the values elicitation OPTION scale [19], and the Decisional Conflict Sure Tool scale [20]. Items were typically on a 5-point Likert scale, except for knowledgerelated items, which had 3 categorical response options (i.e., true, false, and "I don't know"). The complete questionnaire with remaining sections is provided in the Appendix A.

### **Survey Protocol**

Study surveys were programmed in the Research Electronic Data Capture system (REDCap) and conducted by telephone. REDCap is a secure web application for managing surveys and associated databases. For patients who consented to participate, we collected additional clinical and demographic data from the EHR including age, gender, asthma diagnosis, COPD diagnosis, race/ethnicity, health insurance type, smoking status, and whether the patient completed LDCT screening within 90 days of their shared decision-making visit.

Participants required 12–20 min to answer all survey questions. The Flesch-Kincaid grade level of the questionnaire was 7.6. Interviews were conducted between May 1st, 2020, and September 30th, 2020. The research team made attempts to contact 344 eligible patients, of which 147 were reached by phone within 3 call attempts. A total of 81 patients consented to participate, and from those, 75 completed the questionnaire and comprised the final analytic sample.

The study was approved under expedited review (45 CFR 46 — categories #5 and #7) by the Institutional Review Boards of the University of South Carolina and Wake Forest University.

#### **Data Transformations and Analysis**

To calculate the decisional conflict and knowledge scores, we followed procedures outlined by Elwyn et al. and Lowenstein et al., respectively [18, 19]. For the decisional conflict items, Elwyn et al. used Disagree-Neutral-Agree response options while we used 5-point Likert scale for consistency with other survey items [19]. To mirror the decisional conflict score calculation of Elwyn et al., we assigned a value of 1 to "Strongly Disagree" and "Disagree" answers, a value of 0 for "Neutral" answers, and a value of -1 to "Strongly Agree" and "Agree" answers. We then summed the values for each participant to obtain their final decisional conflict score, ranging from -4 (least decisional conflict) to 4 (most decisional conflict).

For the knowledge-related items, we tabulated the counts and proportions of participants answering correctly or answering incorrectly/"I don't know" for each question. We also created a knowledge score for each study participant by summing the number of knowledge questions they answered correctly, for a maximum score of 8 [19].

As previously established [19], we created a value elicitation score from the questions in the values elicitation section. We assigned a value of 0 to "Strongly Disagree," 1 to "Disagree," 2 to "Neutral," 3 to "Agree," and 4 to "Strongly Agree" answers, for each patient. We then summed the values and scaled them to 100 for each participant to obtain their value elicitation score.

For the value elicitation, knowledge, and decisional conflict scores, we calculated the mean and standard deviation for the study sample, overall and stratified by referring provider type (i.e., primary care provider vs. specialist) and sociodemographic characteristics. We used the Kruskal–Wallis (KW) test (a non-parametric one-way ANOVA) to evaluate significant differences in each outcome ( $\alpha$  level=0.05) across sociodemographic groups. We calculated the Pearson correlation coefficient between decisional conflict and value elicitation quality as well as with knowledge. We also calculated correlation between value elicitation quality and knowledge.

### Results

Our final sample of patients who completed the survey corresponded to an overall response rate of 21.5%. Table 1 shows the characteristics of study participants. The average age was 63.6 years old. Most participants (59/75, 79%) were referred for screening by their primary care provider Table 1 Characteristics of survey respondents referred for LDCT screening

Characteristic	n(%)
Highest education level	
Less than high school	11 (14.67)
High school graduate	29 (38.67)
Some college or associate's degree	22 (29.33)
Bachelor's degree or higher	13 (17.33)
Employment status	
Employed	20 (26.67)
Retired	25 (33.33)
Unemployed/unable to work	30 (40.00)
Gender	
Female	38 (50.67)
Male	37 (49.33)
Insurance coverage	
Medicare	35 (46.67)
Medicaid	7 (9.33)
Private insurance	28 (37.33)
Other	4 (5.33)
Race/ethnicity <sup>a</sup>	
Non-Hispanic White	55 (73.33)
Non-Hispanic Black	19 (25.33)
Smoking status <sup>b</sup>	
Current smoker	46 (61.33)
Former smoker	28 (37.33)
COPD	
Yes	25 (33.33)
No	50 (66.67)
Asthma	
Yes	7 (9.33)
No	68 (90.67)
Referring provider <sup>c</sup>	
Primary care provider	59 (78.67)
Pulmonologist/other	16 (21.33)
Completed LDCT screening within 90 days	
Yes	49 (65.33)
No	26 (34.67)
Characteristic	Mean
	(standard deviation)
Age	63.61 (6.20)

Items may not sum to 75 due to some minimal missingness

<sup>a</sup>One participant was of another race and is excluded for this item

<sup>b</sup>One participant was not assessed by their provider for smoking status and is excluded for this item

<sup>c</sup>Pulmonologists were the most frequent referring provider type, other than primary care providers; however, two participants had other provider types

Table 2	SDM	visit and	patient-	provider	value	elicitation	quality
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Statement	Strongly disagree <i>n</i> (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree <i>n</i> (%)
My health care provider explained why he or she was recommending lung cancer screening for me	0 (0)	3 (4.00)	2 (2.67)	36 (48.00)	34 (45.33)
My health care provider explained to me all my options for screening, including delaying getting screened	5 (6.67)	20 (26.67)	5 (6.67)	34 (45.33)	11 (14.67)
My health care provider told me it is an option to take no action and not get screened	6 (8.00)	25 (33.33)	5 (6.67)	23 (30.67)	15 (20.00)
My health care provider explained the risks of screening	5 (6.67)	32 (42.67)	5 (6.67)	21 (28.00)	12 (16.00)
My health care provider explained the benefits of screening	0 (0)	11 (14.67)	3 (4.00)	31 (41.33)	30 (40.00)
My health care provider inquired about my concerns, fears, and worries regarding screening	1 (1.33)	18 (24.00)	9 (12.00)	35 (46.67)	12 (16.00)
My health care provider checked my understanding of the pros and cons for screening	2 (2.67)	16 (21.33)	9 (12.00)	37 (49.33)	11 (14.67)
My health care provider gave me opportunities to ask questions	1 (1.33)	1 (1.33)	1 (1.33)	44 (58.67)	28 (37.33)
My health care provider discussed my preferred level of involvement in the decision-making process	1 (1.33)	14 (18.67)	6 (8.00)	38 (50.67)	16 (21.33)

Items may not sum to 75 due to some minimal missingness

compared to 19% (14/75) referred by their pulmonologist. One participant was referred by their cardiologist and another by a different type of provider. Men and women were nearly identically represented. Participants' most common educational attainment level was high school or GED (38.7%) and they were often unemployed or unable to work (40%). Private insurance (37.3%) and Medicare (46.7%) were the insurance types most frequently held by study subjects. Almost three-quarters (73.3%) of participants identified as non-Hispanic White. Our sample characteristics were similar to eligible patients who did not participate in the study: average age 63.6, 48.3% women, 30.1% with private insurance, 53.5% with Medicare coverage, 77.0% non-Hispanic White, and 65.8% current smokers.

Table 2 shows that participants had varied responses to statements describing the quality of their value elicitation with their provider. Participants reported that providers most commonly neglected to explain the risks of screening (49.3%), followed by failing to explain that choosing not being screened is an option (41.9%) and failing to explain all the options for screening (33.3%). Agreement was highest for reporting that one's healthcare provider gave opportunities to ask questions (96%) and explaining why the screening was being recommended to the participant (93.3%). The average value elicitation score was 66.8 out of 100 (standard deviation [SD]: 18.1).

#### Table 3 Lung cancer screening knowledge

Statement	Correct answer <i>n</i> (%)	Don't know n (%)
Without screening, lung cancer is often found at a later stage when a cure is less likely	64 (85.33)	9 (12.00)
A CT scan can find lung disease that is not cancer	59 (78.67)	16 (21.33)
A CT scan can find heart disease	33 (44.00)	31 (41.33)
A CT scan can miss a tumor in your lungs	32 (42.67)	29 (38.67)
All tumors found in the lungs will grow to be life threatening	31 (41.33)	18 (24.00)
Radiation exposure is one of the harms of lung cancer screening	30 (40.00)	28 (37.33)
A CT scan can suggest that you have lung cancer when you do not	25 (33.33)	40 (53.33)
How much does screening for lung cancer with a CT scan lower your chances of dying from lung cancer?	4 (5.33)	34 (45.33)

The proportion of correct answers was based on the full sample of 75 participants

### Table 4 Lung cancer screening decisional conflict

Statement	Strongly disagree <i>n</i> (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree <i>n</i> (%)
I feel sure about the best choice for me	0 (0)	0 (0)	3 (4.00)	47 (62.67)	25 (33.33)
I know the benefits and risks of lung cancer screening	2 (2.67)	10 (13.33)	6 (8.00)	39 (52.00)	18 (24.00)
I am clear about which benefits and risks matter most to me	2 (2.67)	4 (5.33)	5 (6.67)	44 (58.67)	20 (26.67)
I have enough support and advice to make a choice	0 (0)	5 (6.67)	5 (6.67)	42 (56.00)	22 (29.33)

Items may not sum to 75 due to some minimal missingness

Overall, the mean percentage of correct answers for knowledge questions was 46% (3.71 correct answers out of 8 total questions, SD: 1.52). Table 3 shows that only two questions were answered correctly by over half of the participants ("Without screening, lung cancer is often found at a later stage when a cure is less likely" and "A CT scan can find lung disease that is not cancer").

### Table 5 Lung cancer screening knowledge score descriptive statistics

Subgroup	Knowle	edge sc	ore <sup>a</sup>	Decisional conflict score <sup>b</sup>			Value elicitation score <sup>c</sup>		
	Mean	SD	Kruskal–Wallis <i>P</i> -value <sup>d</sup>	Mean	SD	Kruskal–Wallis <i>P</i> -value <sup>d</sup>	Mean	SD	Kruskal–Wallis P-value <sup>d</sup>
Overall	3.71	1.52	N/A	-3.12	1.53	N/A	66.8	18.1	N/A
Referring provider									
PCP	3.64	1.46	0.25	-3.05	1.58	0.76	64.8	18.2	0.10
Pulmonologist	3.93	1.73		-3.29	1.44		72.0	15.4	
Gender									
Women	3.89	1.72	0.17	-3.34	1.38	0.23	68.1	20.0	0.78
Men	3.51	1.28		-2.89	1.66		65.6	16.0	
Age group									
55–64	3.69	1.61	0.99	-3.10	1.63	0.90	69.0	17.9	0.32
65–69	3.74	1.38		-3.15	1.38		63.1	18.0	
Employment status									
Employed	3.7	1.69		-2.75	1.94		69.3	19.0	
Retired	3.48	1.26	0.52	- 3.44	1.19	0.43	67.0	15.2	0.73
Unemployed/unable to work	3.9	1.63		-3.1	1.47		65.1	20.0	
Education level									
Less than high school	2.91	1.97		-2.73	1.42		55.1	18.2	
High school graduate	3.66	1.20		-3.24	1.43		64.7	16.9	
Some college or associate's degree	3.73	1.67	0.13	-2.86	1.78	0.13	70.5	18.6	0.07
Bachelor's degree or higher	4.46	1.27		-3.62	1.39		75.6	14.9	
Race/ethnicity									
Non-Hispanic White	3.67	1.43		-3.44	1.18		67.2	17.9	
Non-Hispanic Black	3.95	1.72	0.20	-2.21	2.07	0.02	65.6	19.3	0.79

<sup>a</sup>The knowledge score for each participant is the number of knowledge questions they answered correctly, for a maximum score of 8

<sup>b</sup>The decisional conflict score is calculated by assigning a value of 1 to "Strongly Disagree" and "Disagree" answers, a value of 0 for "Neutral" answers, a value of -1 to "Strongly Agree" and "Agree" answers, and summing the values for each participant to obtain their final decisional conflict score, ranging from -4 (least decisional conflict) to 4 (most decisional conflict)

<sup>c</sup>The value elicitation score is calculated by assigning a value of 0 to "Strongly Disagree," 1 to "Disagree," 2 to "Neutral," 3 to "Agree," 4 to "Strongly Agree" answers, and summing the values. Scores were then scaled to 100 for each participant, ranging from 0 (least value elicitation) to 100 (most value elicitation)

<sup>d</sup>Significance testing from the Kruskal–Wallis test where bolded values represent *p*-values  $\leq 0.05$ 

Although mean knowledge scores were low, participants generally displayed low decisional conflict, as shown in Table 4. In the four items of the decisional conflict scale, most participants either agreed or strongly agreed that they were making the best choice for themselves, knew about the risks/benefits of screening, and had support to make their decision. The average decisional conflict score was - 3.12 (SD: 1.53, Table 5).

Decisional conflict was weakly correlated with value elicitation quality (R=-0.27, p=0.02), as well as with knowledge (R=-0.25, p=0.03). There was no significant correlation between knowledge and value elicitation quality (R=0.19, p=0.10).

In Table 5, the KW test revealed no statistically significant differences in knowledge score across demographic characteristics or referring provider. The KW test revealed a significant difference in decisional conflict between non-Hispanic Black and White participants (p = 0.02). Black participants experienced more decisional conflict (score = -2.21) than White participants (score = -3.44). The difference in mean decisional conflict score between the two groups was 1.23. While not significant, we observed that mean knowledge and value elicitation scores increased with education levels (p = 0.13 and p = 0.05, respectively). Specifically, the value elicitation score went from 55.1 for patients without a high school diploma to 75.6 for those with a college degree or higher. The average knowledge score increased from 2.91 for patients without a high school diploma to 4.46 for those with a college degree or higher.

### Discussion

Shared decision-making can help patients make more informed, engaged, and preference-sensitive decisions about their healthcare through bidirectional information exchange and deliberation with their clinical providers. Despite several intervention studies showing positive outcomes when patients and providers engage in shared decision-making, often including decision aids [20, 21], little is known about how shared decision-making for LDCT screening is conducted in real-world settings [8]. In our study, patients reported that while providers almost always discussed the benefits of screening, they infrequently discussed potential harms or explained that not being screened was also an option. On average, patients had low knowledge about lung cancer screening and its benefits and potential harms. Despite this, their decisional conflict was low and only weakly related to knowledge or value elicitation (i.e., a proxy for engagement).

Prior research shows that healthcare providers need to be better informed about lung cancer screening guidelines, its potential risks and benefits, and costs [11, 22-28]. Although studies indicate clinicians' knowledge of lung cancer screening has improved over time [29], this improvement has not necessarily translated to more informed and balanced counseling with high-risk patients. In a content analysis of conversations between patients and their healthcare providers at a different institution, Brenner et al. found that the mean time discussing lung cancer screening was only 59 s (8% of total visit time), with no evidence that decision aids or other educational guides were utilized in a primary care setting [8]. In a study by Eberth et al., most physicians reported they would be unlikely to engage in shared decision-making if the discussion took more than 5 min [10]. These findings reflect the time constraints providers commonly report as a barrier to engaging in shared decision-making and referring patients for screening [11, 14, 30, 31], as well as the (mis)perception that patients would be confused by or prefer not to have an in-depth discussion about lung cancer screening that included numerical data [12, 14]. Related to the quality of shared decision-making discussions, numerous studies including ours [6, 32, 33] have found that patients referred for lung cancer screening have limited understanding of any its potential harms. Similar to our study, Nishi et al. found harms were less likely to be addressed by the patients' healthcare provider than the benefits of lung cancer screening (20.8% vs. 68.3%, respectively) [6]. Raju et al. also found most of the patients surveyed within their institution were not aware of any screening harms [32]. A limited understanding of the harms of screening may contribute to patients' motivation to be screened, but it may also bias their decision-making [33]. An overemphasis on the positive aspects of screening was confirmed in our study and suggests a need for better patient education. Notably, we found that 81.33% of study participants agreed or strongly agreed that their provider explained benefits of screening, compared to 44% for risks of screening.

Better strategies for educating patients about the potential benefits and harms of lung cancer screening are needed. Given the highly variable and incomplete nature of shared decision-making, opportunities to develop and integrate decision aids into routine clinical practice should be explored. Conveying both the benefits and potential harms to patients is imperative, since not all patients will benefit equally from screening depending on their age, smoking history, comorbidities, family history, and other unique characteristics [34, 35]. Brief clinic-based decision aids can reduce both provider and patient knowledge gaps and streamline the shared decision-making process, particularly in primary care settings where providers are handling many competing health priorities [30]. Decision coaching has also been effectively used to help patients make informed screening choices without significantly increasing visit time [36].

Given concerns about patient-provider communication and time constraints on healthcare teams, opportunities to leverage technology and educational tools are warranted. One such program utilized an online-administered conjoint valuation survey followed by a brief educational narrative to help patients consider their lung cancer screening options and make the best choice for them [37]. This intervention reduced decisional conflict, suggesting that such tools can help individuals make the best choice for them without (or in addition to) traditional patient-provider deliberation. Similarly, tools like shouldiscreen.com [38] have been shown to improve patients' knowledge about screening, reduce decisional conflict, and increase the concordance between individuals' preferences and their screening eligibility [39]. Despite the broad appeal and use of shouldiscreen.com, Lau et al. have argued for more diverse delivery modes to support patients with varied educational attainment, as well as health and computer literacy [39]. Caverly and Hayward also argue for simplifying the shared decision-making process; rather than go over all the risks and benefits with every patient in the office, patients receive an individualized recommendation based on their risk profile, with much of the data gathered before the visit electronically [40].

Dubbing their patient-centric approach "everyday SDM," Caverly and Hayward suggest this approach is more feasible for time-constrained providers [40]. In support of this approach, the team developed a tool (*screenLC.com*) that can be used by providers to determine whether the patient's decision to get lung cancer screening is likely to be "preference-sensitive" given individuals' varied risk-benefit profiles [41].

Although our study is among a handful that have explored shared decision-making quality and outcomes in a real-world clinical setting, limitations are present. First, the sample included only English-speaking patients from one academic medical center in the Southeastern U.S. Second, due to the pilot nature of the study, we limited our sample size to only 75 individuals. A strength of our study is the non-parametric statistical approach to handle the small sample size, as well as the use of validated scales to measure knowledge, decisional conflict, and value elicitation.

### Conclusions

Additional work is needed to optimize the quality and consistency of information presented to patients when educating them about lung cancer screening. In this study, patients infrequently reported having a balanced discussion of the risks and benefits of lung cancer screening with their healthcare provider, reflected in their low average knowledge scores. Despite this, most patients (particularly those who are non-Hispanic White) felt certain about their screening choice. To help ensure patients make a well-informed choice about screening, where their values are taken into consideration, healthcare providers and their teams need continued education about the nuances of lung cancer screening and how to best conduct shared decision-making. In addition, policies or practice changes that facilitate these best practices are needed including but not limited to using decision aids, leveraging risk prediction models/tools, and increasing reimbursement for and/or allotted provider time to conduct shared decisionmaking with patients.

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### Appendix

### Confidential

### **ASPIRE Study Questionnaire**

IMPLEMENTATION OF SHARED DECISION-MAKING FOR LUNG CANCER SCREENING: A PILOT STUDY

As we said earlier, we are conducting a study about how patients like yourself feel about lung cancer screening. We recently learned that you had a lung cancer screening scan ordered by your healthcare provider, and we want to learn more about the conversation you had with your provider about this topic. This study will evaluate the extent to which healthcare providers engage in shared decision-making with their patients considering lung cancer screening. As a reminder, your participation in this study is completely voluntary. If you are ready, we will proceed with the survey questions.

Did you discuss lung cancer screening with your primary care provider?	<ul> <li>○ Yes</li> <li>○ No</li> <li>○ I don't know</li> </ul>
Has any other healthcare provider (for example, a specialist or pulmonologist or a provider at a lung screening clinic) discussed lung cancer screening with you?	<ul> <li>Yes</li> <li>No</li> <li>I don't know</li> </ul>
Who was the provider who discussed lung cancer screening with you?	<ul> <li>Pulmonologist</li> <li>Oncologist</li> <li>Internal medicine doctor</li> <li>Provider at a lung cancer clinic</li> <li>Cardiologist</li> <li>Someone else</li> </ul>
Have you completed a low dose CT scan?	○ Yes ○ No

These were all the questions I had for you at this time. I want to thank you for your time and for going through the eligibility part of the survey. Unfortunately, you do not meet eligibility criteria to complete our survey,

PART I. LUNG CANCER SCREENING EXPLANATION, CONCERNS, AND VALUES

In this section of the survey, we are interested in your opinions and experiences when discussing lung cancer screening with your health care provider. If you discussed screening with more than one provider, please answer the following items for the provider who gave you the MOST information before you had the screening CT done. We will focus on how lung cancer screening was explained to you by this health care provider.

Who first brought up the topic of lung cancer screening at your clinic visit?

○ I brought it up to my provider

- O My provider mentioned it to me first
- One of the other care team members (e.g., medical assistant or receptionist) brought it up
- I can't recall who mentioned it first

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Which of the following team members brought up the topic of lung cancer screening at your clinic visit?	<ul> <li>Physician Assistant</li> <li>Nurse</li> <li>Nurse Practitioner</li> <li>Radiology Technician</li> <li>Lab Technician</li> <li>Office Staff, including receptionist</li> <li>Office Manager</li> <li>Medical Assistant</li> <li>Medical Billing Staff</li> <li>Medical interpreter</li> <li>Other</li> </ul>
Has your healthcare provider explained that lung cancer screening is done with a CT scan?	<ul> <li>○ Yes</li> <li>○ No</li> <li>○ I don't know</li> </ul>
Has your healthcare provider talked to you about getting lung cancer screening with a test other than low-dose CT scan? (e.g., chest x-ray)	<ul> <li>○ Yes</li> <li>○ No</li> <li>○ I don't know</li> </ul>
What type of test did your provider talk with you about?	

### For each statement that I will read to you, please rate the strength of your agreement with the statement from strongly disagree, disagree, neutral, agree to strongly agree

the statement from strongly	/ alsagree, al	isagree, neutr	al, agree, to s	crongly agre	e.
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My health care provider explained why he or she was recommending lung cancer screening for me	0	0	0	0	0
My health care provider explained to me all my options for screening, including delaying getting screened	0	0	0	0	0
My health care provider told me it is an option to take no action and not get screened	0	0	0	0	0
My health care provider explained the risks of screening	0	0	0	0	0
My health care provider explained the benefits of screening	0	0	0	0	0
My health care provider inquired about my concerns, fears, and worries regarding screening	0	0	0	0	0

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My health care provider checked my understanding of the pros and cons for screening	0	0	0	0	0
My health care provider gave me opportunities to ask questions	0	0	0	0	0
My health care provider discussed my preferred level of involvement in the decision-making process	0	0	0	0	0

### PART II. LUNG CANCER SCREENING COMMUNICATION

In this section of the survey, we are interested in learning more about how you feel about your communication with your health care provider. We will focus on aspects of the lung cancer screening discussion itself, like respect, open-mindedness, listening, cooperation, and comfort.

For each statement that I will read to you, please rate the strength of your agreement with the statement from strongly disagree, disagree, neutral, agree, to strongly agree. As a reminder, this is in reference to the provider who talked to you about lung cancer screening or ordered the screening for you. I will now proceed with the statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My health care provider seemed interested in talking to me about lung cancer screening	0	0	0	0	0
My health care provider was sincere	0	0	0	0	0
My health care provider seemed willing to listen to me	0	0	0	0	0
My health care provider seemed interested in cooperating with me for shared decision-making	0	0	0	0	0
My health care provider was honest in communicating with	0	0	$\bigcirc$	0	0
me My health care provider was open to my ideas and questions	0	0	0	0	0

### PART III. LUNG CANCER SCREENING KNOWLEDGE

In this section of the survey, we are interested in what you may have learned about lung cancer screening from your discussions with your health care providers or others.

For each statement that I will read to you, please tell me whether you think it is true or false, or you don't know.

True

I don't know

False

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A CT scan can suggest that you have lung cancer when you do not	0	0	0
A CT scan can miss a tumor in your lungs	0	0	0
All tumors found in the lungs will grow to be life threatening	0	0	0
Without screening, lung cancer is often found at a later stage when a cure is less likely	0	0	0
A CT scan can find lung disease that is not cancer	0	0	0
A CT scan can find heart disease	0	0	0
Radiation exposure is one of the harms of lung cancer screening	0	0	0

How much does screening for lung cancer with a CT scan lower your chances of dying from lung cancer?	<ul> <li>Screening lowers the chance of dying from lung cancer by about 95%</li> <li>Screening lowers the chance of dying from lung cancer by about 50%</li> <li>Screening lowers the chance of dying from lung cancer by about 20%</li> <li>I don't know</li> </ul>
Does your insurance cover the cost of lung cancer screening with no cost sharing like deductibles or co-pays?	<ul> <li>○ Yes</li> <li>○ No</li> <li>○ I don't have health insurance</li> <li>○ Not sure</li> </ul>

### PART IV. LUNG CANCER SCREENING BARRIERS

In this section of the survey, we are interested in hearing about the experiences and barriers you feel might make you put off getting lung cancer screening.

## For each statement that I will read to you, please rate the strength of your agreement with the statement from strongly disagree, disagree, neutral, agree, to strongly agree.

j.	,		,		
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
l might put off having a lung scan because l worry about finding something wrong	0	0	0	$\bigcirc$	0
l might put off having a lung scan because l don't have the time	0	0	0	0	0



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l might put off having a lung scan because I don't have a regular healthcare provider	0	0	0	0	0
l might put off having a lung scan because no one in my family had lung cancer	0	0	0	0	0
l might put off having a lung scan because the cost would be a problem	0	0	0	0	0
l might put off having a lung scan because l don't have any lung problems or symptoms	0	0	0	0	0
l might put off having a lung scan because transportation would be a problem	0	0	0	0	0
l might put off having a lung scan because I am afraid the lung scan will damage my lungs	0	0	0	0	0
I might put off having a lung scan because I have had a bad experience with a hospital or healthcare provider	0	0	0	0	0
l might put off having a lung scan because I don't know enough about the test	0	0	0	0	0
l might put off having a lung scan because l think l am too old to benefit from screening for lung cancer	0	0	0	0	0
l might put off having a lung scan because l am a smoker	0	0	0	0	0
l might put off having a lung scan because l would rather not know if l have any lung problems	0	0	0	0	0
l might put off having a lung scan because I worry about feeling like a social outcast for smoking	0	0	0	0	0
l might put off having a lung scan because l worry about being blamed for having smoked	0	0	0	0	0
l might put off having a lung scan because it is not worth the effort	0	0	0	0	0



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l might put off having a lung scan because l do not trust the healthcare system	0	0	0	0	0

### PART V. LUNG CANCER SCREENING DECISION CERTAINTY

In this section of the survey, we are interested in how certain you feel about your decision to get screened for lung cancer or not. We will focus on how sure or confident you felt throughout the shared decision-making process you went through when deciding whether to get lung cancer screening.

## For each statement that I will read to you, please rate the strength of your agreement with the statement from strongly disagree, disagree, neutral, agree, to strongly agree.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
l feel sure about the best choice for me	0	0	0	0	0
I know the benefits and risks of lung cancer screening	0	0	0	0	0
l am clear about which benefits and risks matter most to me	0	0	0	0	0
I have enough support and advice to make a choice	0	0	0	0	0

### PART VI. LUNG CANCER SCREENING INTENTION

In this section of the survey, we are interested in your intention to do lung cancer screening. We will focus on your decision to undergo screening or not.

Have you undergone lung cancer screening yet?	<ul> <li>○ Yes</li> <li>○ No</li> <li>○ I don't know</li> </ul>
What is your intention with respect to undergoing lung cancer screening?	<ul> <li>I intend to undergo lung cancer screening in the next three months</li> <li>I do not intend to undergo lung cancer screening in the next three months but possibly intend to undergo screening in the long term future</li> <li>I do not intend to undergo lung cancer screening in the next three months and do not intend to undergo screening in the long term future either</li> </ul>

### PART VII. DEMOGRAPHIC INFORMATION

In this section of the survey, we are interested in learning more about your demographic information. We will focus on aspects such as education and employment.

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What is the highest grade or year of school you completed?	<ul> <li>Never attended school or only attended kindergarter</li> <li>Completed Elementary school, meaning Grades 1 through 8</li> <li>Completed Some high school, meaning Grades 9 through 11</li> <li>Completed High school, meaning Grade 12 or GED</li> <li>Completed Some college or technical school, meaning 1 to 3 years of college</li> <li>Completed College, meaning 4 years or more of college</li> <li>Completed graduate school, meaning completed a graduate-level program of study such as a master's, PhD, law school, medical school, or other similar program</li> </ul>
How would you describe your employment status?	<ul> <li>Employed for wages</li> <li>Self-employed</li> <li>Unemployed</li> <li>Retired</li> <li>Unable to work</li> <li>Homemaker</li> <li>Student</li> <li>Other</li> </ul>

We have reached the end of the survey. Thank you again for taking the time to talk to me today and completing this survey. As a reminder you will receive a \$25 gift card as a thank you for your participation. We will mail the gift card to you. Can you please provide your mailing address?

Abbreviations EHR: Electronic health record; CMS: Centers for Medicare and Medicaid Services; KW: Kruskal–Wallis; LDCT: Lowdose computed tomography; REDCap: Research Electronic Data Capture system; SD: Standard deviation; SDM: Shared decision-making; USPSTF: US Preventive Services Task Force

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**Data Availability** All data and materials as well as software application or custom code support published claims and comply with field standards.

Code Availability Available upon request to the corresponding author.

### Declarations

**Ethics Approval** The study was approved under expedited review (45 CFR 46 — categories #5 and #7) by the Institutional Review Boards of the University of South Carolina and of Wake Forest University.

**Consent to Participate** Informed consent was obtained from all individual participants included in the study.

Conflict of Interest The authors declare no competing interests.

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