


# Is Lung Cancer Screening Knowledge Associated with Patient-Centered Outcomes? A Multi-institutional Cohort Study

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## Abstract

**Introduction.** The Centers for Medicare and Medicaid Services mandate that clinicians use a shared decision-making interaction to provide information about the harms and benefits of lung cancer screening (LCS). **Methods.** We enrolled patients from 3 geographically diverse medical centers after a decision-making interaction about undergoing LCS but before receiving a low-dose computed tomography (CT) scan. We performed the primary analysis based on the primary knowledge question, “Which of these conditions do you think that the CT scan screens for?” We used the knowledge summary score in secondary analyses. We evaluated LCS care experience by using validated instruments to measure participant-reported communication quality (Consultation Care Measure), perception of the primary LCS clinician (Consumer Assessment of Health Care Providers and Systems), and decision conflict (Decisional Conflict Scale). **Results.** Of the 409 participants, 44% correctly answered the primary LCS knowledge question. Clinician communication quality was rated positively by 93% of participants. Most (93%) participants rated their LCS clinician as good. Only 14% reported decision conflict. Correctly answering the primary LCS knowledge question was associated with higher patient-clinician communication quality scores ( $b = 0.4$ ; 95% confidence interval [CI] [0.1, 0.7];  $R^2$  change = 0.03) and higher LCS clinician ratings ( $b = 0.4$ ; 95% CI [0.0, 0.7];  $R^2$  change = 0.02) but not with decision conflict. In secondary analyses, higher total LCS knowledge score was associated with lower Decisional Conflict Scale scores ( $b = -2.2$ ; 95% CI [-3.4, -0.9];  $R^2$  change = 0.24), indicating lower decision conflict. **Conclusions.** After an LCS decision-making interaction, many patients do not retain basic knowledge about LCS but nevertheless had low levels of decision conflict. Primary LCS knowledge may be important but insufficient to ensure high-quality, patient-centered LCS care.

## Highlights

- Survey of patients with a lung cancer screening (LCS) decision-making interaction.
- Only 44% of patients correctly answered the knowledge question about LCS.
- Primary LCS knowledge was not associated with decision conflict.
- Patient knowledge about LCS may not equate to high-quality patient-centered care.

## Keywords

lung cancer screening, patient-centered communication, shared decision making

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## Introduction

Multiple organizations, including the United States Preventive Screening Task Force (USPSTF), recommend that clinicians offer lung cancer screening (LCS) using annual low-dose computed tomography (LDCT) to eligible patients.<sup>1,2</sup> Professional associations recommend<sup>1,3,4</sup> and the Centers for Medicare and Medicaid Services (CMS) mandates<sup>5</sup> a structured shared decision-making discussion with the help of a decision aid to improve patients' comprehension of LCS. The discussion requires delivery of a large amount of information regarding LCS, including 1) benefits and harms, 2) follow-up diagnostic tests, 3) false positive rates, 4) risk of overdiagnosis, 5) total radiation exposure, 6) need for annual adherence to LCS, 7) importance of smoking cessation, and 8) impact of comorbidities on additional diagnoses and treatment if concerning findings are present. In other settings, decision aids can improve patient knowledge and reduce decision conflict.<sup>6</sup> LCS decision aids often focus on providing information, but it is not clear if they improve patient-centered outcomes or change decisions.<sup>7,8</sup>

Clinicians in routine care settings are likely not regularly adhering to the CMS requirement to provide

information to their patients. Most patients who receive an LDCT for LCS do not have billing documentation of a shared decision-making interaction.<sup>9,10</sup> Clinicians often spend less than one minute in a decision-making interaction, do not engage in core tenets of shared decision making, and seldom explore the potential harms of screening.<sup>11</sup> In qualitative research, clinicians engaged in LCS supported the principles of shared decision making but perceived that patients wanted tailored rather than in-depth information based on their implicit assessment of patient values and preferences.<sup>12</sup> Patients undergoing LCS similarly reported they did not have an explicit discussion of values and preferences and recalled little information about the decision-making interaction around LCS.<sup>13,14</sup> Patients reported that discussions were brief and they did not understand the value of LCS.<sup>13,14</sup> Despite the lack of knowledge, patients expressed satisfaction and reported good communication by clinicians; many cited that basic information was sufficient.<sup>14</sup> In these studies, both patients and clinicians placed little importance on the exchange of information and instead placed importance on trust and relationships with their clinicians. Similarly, patients who felt a close relationship with a clinician who took time to explain LCS decisions reported higher readiness to engage in shared decision making.<sup>15</sup> However, high-quality shared decision making is difficult to perform with time limitations and lack of clinician knowledge of what constitutes shared decision making.<sup>12,16</sup>

We sought to describe patients' knowledge regarding LCS and quantify the association of knowledge about LCS with patient-centered outcomes, including self-reported communication quality, perception of the clinician who primarily discussed LCS, and decision conflict. The shared decision-making conversation will be referred to as a "decision-making interaction" since these interactions often took place on the phone and so cannot be labeled a "visit." Also, since we did not record and analyze each interaction, we cannot be sure they included all the recommended components of shared decision making. However, based on our prior work, it is likely that all participants had this decision-making interaction and received a decision aid (even if they did not recall this receipt in the survey; see below).<sup>13,14</sup>

## Methods

### *Setting and Recruitment*

We previously described our study design.<sup>17</sup> Briefly, we recruited patients from three medical centers with established LCS programs: VA Portland Health Care System (VAPORHCS), Portland, Oregon; Minneapolis VA

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Division of Pulmonary, Allergy, & Critical Care Medicine, Department of Medicine, Oregon Health & Science University, Portland, OR, USA (LS, SEG, DRS, CGS); Center to Improve Veteran Involvement in Care, VA Portland Health Care System, Portland, OR, USA (LS, SEG, DRS, II, CGS); School of Public Health, Oregon Health & Science University–Portland State University, Portland, OR, USA (SPMR); Center for Care Delivery and Outcomes Research, Minneapolis VA Healthcare System, Minneapolis, MN, USA (ACM); Division of Pulmonary and Critical Care, Department of Medicine, University of Minnesota, Minneapolis, USA (ACM); Health Services Research, Management and Policy, University of Florida, Gainesville, FL, USA (SD); Duke Cancer Institute, Duke University, Durham, NC, USA (JMD); Department of Medicine, Duke University School of Medicine, Durham, USA (JMD). The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: All authors declare no conflicts of interest with the work presented in this manuscript. CGS and ACM receive a portion of their regular salary based on their roles as medical directors of lung cancer screening programs at the institutions where they are employed but do not receive extra compensation for these roles. CGS receives a portion of regular salary based on a role as leader of the VA National Center for Lung Cancer Screening but does not receive extra compensation for this role. The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study is supported by an award from the American Cancer Society 128737-RSG-155-01-CPPB, Lung Cancer Screening Implementation: Evaluation of Patient-Centered Care. The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report. It was also supported by resources from the VA Portland Health Care System, Portland, Oregon; the Minneapolis VA Healthcare System, Minneapolis, Minnesota; and Duke University School of Medicine, Durham, North Carolina.

Medical Center, Minneapolis, Minnesota; and Duke University Medical Center, Durham, North Carolina. We obtained institutional review board approval at each site (VAPORHCS #3482; Minneapolis VA #4645-B; Duke #Pro00073394), and each participant completed the informed consent process prior to enrolling. Participants received \$20 for each research encounter. We restricted results to the baseline survey for the current analysis.

We prospectively recruited subjects from March 2016 to April 2019. We enrolled patients after a decision-making interaction between a clinician and patient about undergoing LDCT for LCS but before the patient received an LDCT (if the patient decided to undergo screening or within one month for those who declined screening). We contacted potential participants after documentation or confirmation from the relevant clinician that screening was discussed. VAPORHCS and Duke had centralized LCS programs that required all patients have a decision-making interaction with a dedicated screening coordinator (VAPORHCS via telephone, Duke in-person). At the Minneapolis VA, patients could have a decision-making interaction with either their primary care provider (PCP) or a dedicated screening coordinator. Each program required that patients who interacted with a screening coordinator receive a formal decision aid and strongly encouraged PCPs to provide one (Miranda et al., for the aids used).<sup>17</sup> We included patients who were eligible for LCS based on their local institution's criteria (similar to 2013 USPSTF eligibility criteria)<sup>1</sup> without reassessing those criteria. We included patients who indicated they had accepted or declined to undergo LCS.

### Data Collection

We used theoretical models of patient-centered communication and shared decision making to develop the survey.<sup>18–20</sup> Research coordinators at each site completed the survey with the participant over the phone or in person. Coordinators at each site collected all survey and electronic health record data on paper forms. These forms were then transferred to the VAPORHCS, the coordinating site.

### Primary Exposure

The primary exposure variable was knowledge about LCS. We developed seven multiple-choice knowledge questions that were adapted from previous surveys, agreed upon by expert consensus, and included core information elements of the shared decision-making visit as mandated by CMS (Supplement A). We categorized answers as “correct,” “incorrect,” “unsure,” or “missing.” Notably, during our qualitative interviews<sup>14</sup> and while

collecting quantitative data, we found that many participants felt they had no knowledge about LCS. Although we gave them the option to check “unsure,” many refused to answer the knowledge questions. We recorded data from these participants as “missing.” We excluded participants with missing data from the main analysis but included them in a sensitivity analysis. We performed the primary analysis based on the primary knowledge question, “Which of these conditions do you think that the CT scan screens for?” We used a summary score of correct answers for secondary analyses. Participants had a missing summary score only if all answers were missing (e.g., if a participant answered only one question and got it correct, then their total knowledge score would be 1).

### Outcomes

We included three patient-centered outcome measures. Participants were asked to answer communication questions regarding the clinician who spent the most time discussing LCS with them. If participants did not recall a decision-making interaction about LCS, these communication, experience, and clinician rating measures were not administered as part of the survey and were counted as missing. Despite documented decision-making interactions in the electronic health record (EHR), many participants did not recall the interaction.<sup>14</sup> This reflected similar findings from our qualitative analyses in which some participants did not feel a discussion or shared decision-making process had occurred.

First, we used the Consultation Care Measure (CCM), which is based on the patient-centered communication model and was recommended in an analysis of multiple communication instruments, to measure participant-reported communication quality.<sup>21,22</sup> The primary measure was the statement, “The overall quality of communication with your provider is excellent,” which was rated on a 7-point Likert-type scale from *very strongly disagree* = 1 to *very strongly agree* = 7. For the analysis, we dichotomized this variable as “high quality” if participants indicated they *agreed*, *strongly agreed*, or *very strongly agreed* (score 5 to 7), and “low quality” if the response was *neutral*, *disagree*, *strongly disagree*, or *very strongly disagree* (score 1 to 4).<sup>23</sup> Missing responses were coded as missing and not included in the statistical analyses.

Second, we used the Consumer Assessment of Healthcare Providers and Systems (CAHPS). We adapted one item from the CAHPS survey 3.0 to assess respondents' perception of the primary clinician who discussed LCS.<sup>24</sup> Participants were asked the question, “Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible,

what number would you use to rate this provider?" These ratings were dichotomized in our analysis, with 0 to 6 defined as poor and 7 to 10 defined as good.<sup>25</sup>

Third, we measured decision conflict with the Decisional Conflict Scale (DCS), a multidimensional scale of 16 items that is considered to be a reliable and valid measure for assessing decision conflict.<sup>26</sup> Each item was scored on a 5-point Likert scale (from 1 = *strongly agree* to 5 = *strongly disagree*). We created the total score for this analysis by calculating the sum of the scores, dividing by the number of items answered, and then multiplying by 25. Scores range from 0 to 100, with scores lower than 25 suggesting no decision conflict, scores greater than 37.5 (associated with decision delays and negative perceptions of uncertainty) classified as "decision conflict," and scores between 25 and 37.5 classified as "indeterminate decision conflict." As the DCS user manual does not specify how to deal with missing values, we excluded participants from the total score analysis who were missing seven or more items.<sup>27</sup>

### Other Variables

Self-reported demographic information included age, gender, race/ethnicity, marital status, education, employment, income, and tobacco use. We used self-report of mental and physical comorbidities. We collected self-reported details of the decision-making interaction. Participants indicated if they recalled a PCP and/or a screening coordinator had a LCS decision-making interaction them. We used the Single Item Literacy Screener<sup>28</sup> to assess health literacy, with scores greater than 2 indicating some difficulty with reading printed health-related material. Research coordinators abstracted EHR data regarding the profession of the person who conducted the decision-making interaction as well as the time from the decision-making interaction to survey administration.

### Analysis

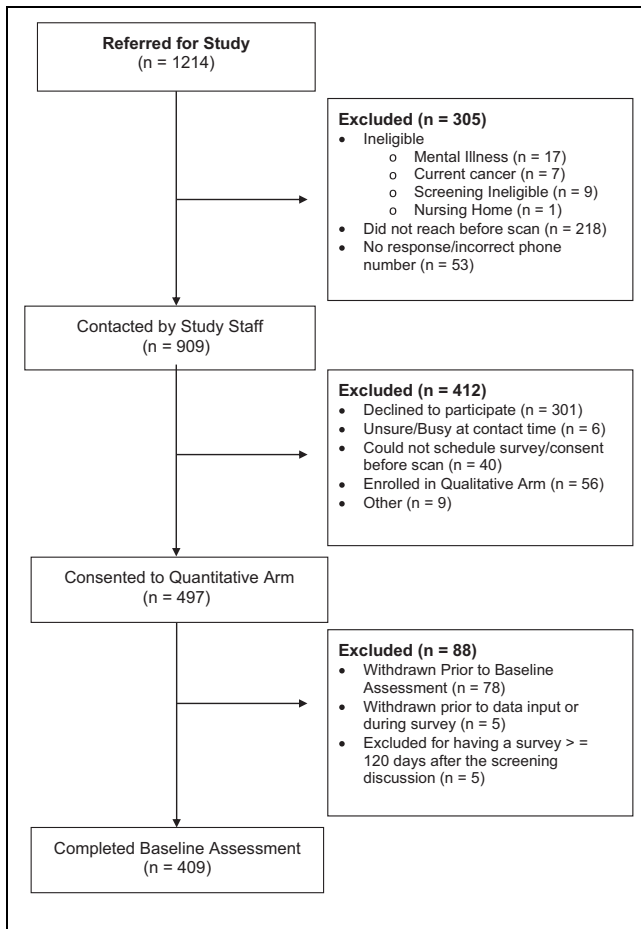
Descriptive statistics were computed for patient characteristics and main study variables. Since we did not have a priori hypotheses about differences in LCS knowledge, participant-reported communication, and decision conflict based on recall of a decision aid; the type of clinician who discussed screening; or the study site, we did not perform comparative statistics for these comparisons. Frequencies were computed excluding missing responses from the denominator. If missingness was substantial, we reported those proportions separately. In addition, we used multiple linear regression models to assess the

association between the primary knowledge question and total knowledge score with clinician communication quality, primary LCS discussion clinician perception, and DCS score. Similar to a decision aid trial, we dichotomized the primary knowledge question as "correct" versus "incorrect or unsure."<sup>29</sup> Based on previous work regarding communication quality among patients with incidental pulmonary nodules,<sup>23</sup> a priori, we adjusted for age, gender, smoking status, mental illness (defined as self-reported depression and/or posttraumatic stress disorder), education, income, self-reported chronic lung disease, and study site. We employed listwise deletion in each regression model, respectively, such that if a participant had missing data on any independent variable or the respective outcome, they were excluded from the analysis. To account for the possibility that participants skipped questions for which they did not know the answer, we ran sensitivity analyses for the regression models, such that missing data were coded as 0 (incorrect/unsure/missing) for both the primary knowledge question and summary knowledge score. Change in  $R^2$  from adding the knowledge item or summary knowledge score to the base regression models with controls was interpreted as small ( $\geq 0.02$ ), moderate ( $\geq 0.13$ ), or large ( $\geq 0.26$ ) based on Cohen's recommendations.<sup>30</sup> Analyses were conducted using SPSS version 28.0 (IBM Corp., Armonk, NY, 2021).

### Results

We included 409 participants in this study (Figure 1). The mean age of the participants was 65 years ( $s = 5.6$ ); 87% identified as male, and 86% of respondents identified as White, non-Hispanic (Table 1). Of the respondents, 35% recalled using a decision aid as part of their LCS decision-making interaction. The overall quality of communication with the clinician was rated positively by 93% of participants. Most (93%) of participants rated the perception of their LCS clinician as good. Only 14% reported decision conflict, 43% reported an indeterminate level of decision conflict, and 43% reported no decision conflict.

Figure 2 shows how participants answered the knowledge questions. Only 179 (44%) correctly answered the primary screening knowledge question and 83 (20%) were unsure. Only 141 (34%) correctly answered the knowledge question, "If further tests show that the person does have lung cancer, what would he/she be offered?" On average, participants answered two of the seven questions correctly ( $s = 1.3$ ). Only two participants answered six or more questions correctly.



**Figure 1** Study CONSORT diagram.

We stratified participants' correctly answered knowledge questions and patient-centered outcomes by 1) whether they recalled using a decision aid, 2) which self-reported clinician(s) discussed screening with them (PCP and screening coordinator v. screening coordinator only), and 3) study site (Table 2). Except for the primary knowledge question ("The LDCT screens for which condition?"), most respondents incorrectly answered the knowledge questions regardless of recalling use of a decision aid, who discussed LCS with them, or their health care institution. For example, 67 (52%) of respondents who recalled use of a decision aid correctly answered the primary knowledge question and 112 (49%) who did not recall use of a decision aid correctly answered it. Most reported high-quality communication and positive clinician rating regardless of whether they recalled receiving a decision aid, who discussed LCS with them, or their health care institution. For example, 92 (90%) of

respondents who recalled the use of a decision aid reported high-quality communication, and 169 (95%) who did not recall use of a decision aid reported high-quality communication. Of respondents who did not recall use of a decision aid, 103 (41%) reported no decision conflict, 101 (41%) reported an indeterminate level, and 45 (18%) reported decision conflict.

Correctly answering the primary screening knowledge question was associated with higher patient-clinician communication quality scores ( $b = 0.4$ ; 95% CI [0.1, 0.7];  $R^2$  change = 0.03) and more positive clinician perceptions ( $b = 0.4$ ; 95% CI [0.0, 0.7];  $R^2$  change = 0.02) but was not associated with DCS score (Table 3). In secondary analyses, higher total LCS knowledge score was associated with higher patient-clinician communication quality scores ( $b = 0.2$ ; 95% CI [0.1, 0.3];  $R^2$  change = 0.04) and lower DCS scores ( $b = -2.2$ ; 95% CI [-3.4, -0.9];  $R^2$  change = 0.24), indicating lower decision conflict. It had no association with clinician rating. We categorized missing LCS knowledge scores with unsure and incorrect scores in sensitivity analyses. Replicating the multiple regression analyses—including the same covariates—correctly answering the primary screening question was associated with higher clinician ratings ( $b = 0.5$ ; 95% CI [0.1, 0.9];  $R^2$  change = 0.03) and patient-clinician communication quality scores ( $b = 0.4$ ; 95% CI [0.1, 0.7];  $R^2$  change = 0.04) but not DCS score ( $b = -2.6$ ; 95% CI [-5.7, 0.5];  $R^2$  change = 0.01). Also matching the original regression results, higher total knowledge score (i.e., coding individuals who had missing data for all knowledge questions as 0) was associated with higher patient-clinician communication quality scores ( $b = 0.2$ ; 95% CI [0.1, 0.3];  $R^2$  change = 0.05) and lower DCS scores ( $b = -2.0$ ; 95% CI [-3.1, -0.8];  $R^2$  change = 0.03), but it was not associated with clinician perceptions.

## Discussion

In this large prospective multi-institutional study among patients considering LCS in routine care settings, we found that patients retained little accurate knowledge about LCS even though the majority had a decision-making interaction with a dedicated screening coordinator with the use of a decision aid.<sup>17,31</sup> However, most rated their experience and the quality of communication highly. Few patients reported decision conflict, although 43% reported an indeterminate level. LCS knowledge scores and measures of the decision-making interaction seemed similar regardless of whether the patient recalled using a decision aid, who discussed LCS with them, or

**Table 1** Baseline Participant Characteristics

Characteristic	<i>n</i> (%) <sup>a</sup> Or $\bar{x}$ (s)
Treatment location	
VA Portland Health Care System	207 (51%)
VA Minneapolis	133 (33%)
Duke University	69 (17%)
Time from LCS decision-making interaction to survey administration, days	25 (22.7)
Accepted/declined LCS	
Accepted	399 (98%)
Declined	10 (2%)
Age, years	65 (5.6)
Gender identity	
Male	354 (87%)
Female	55 (13%)
Racial background	
White	342 (86%)
Non-White	56 (14%)
Ethnicity	
Hispanic	3 (1%)
Non-Hispanic	395 (99%)
Marital status	
Never married	30 (8%)
Married	191 (48%)
Divorced/separated	138 (35%)
Widowed	40 (10%)
Smoking status	
Current cigarette use	231 (57%)
Past cigarette use	172 (43%)
Average cigarettes smoked per day <sup>b</sup>	
0–20	252 (66%)
21–40	118 (31%)
41 or more	14 (4%)
Pack years <sup>c</sup>	56 (24.3)
Education	
High school or less	136 (34%)
Some college or vocational work	186 (46%)
College graduate or more	79 (20%)
Employment status	
Employed (full- or part-time)	93 (24%)
Not currently working	285 (75%)
Other	3 (1%)
Income	
Less than \$40,000	202 (52%)
\$40,000 or more	188 (48%)
Health literacy <sup>d</sup>	
Some or more difficulty	55 (14%)
No difficulty	346 (86%)
Self-reported history of lung disease <sup>e</sup>	165 (46%)
Self-reported history of depression	167 (46%)
Self-reported history of PTSD	107 (30%)
Decision-making interaction	
Recalled using a decision aid	138 (35%)
Self-reported screening discussants <sup>f</sup>	
Primary care provider	296 (73%)
Unsure if primary care provider	10 (3%)
Screening coordinator	184 (46%)
Unsure if screening coordinator	33 (8%)

(continued)

**Table 1** (continued)

Characteristic	<i>n</i> (%) <sup>a</sup> Or $\bar{x}$ (s)
Electronic health record screening	
primary discussant	
Primary care provider	122 (30%)
Screening coordinator	287 (70%)
Participant report of decision-making interaction	
Overall quality of communication with clinician <sup>g</sup>	
Low quality	19 (7%)
High quality	264 (93%)
Perceptions of LCS clinician <sup>h</sup>	
Poor	19 (7%)
Good	270 (93%)
Decision conflict <sup>i</sup>	
Decision conflict	57 (14%)
Indeterminate decision conflict	170 (43%)
No decision conflict	169 (43%)

LCS, lung cancer screening; PTSD, posttraumatic stress disorder; VA, Veterans Affairs.

<sup>a</sup>Percentage are of nonmissing data.

<sup>b</sup>This is the range for both current and former cigarette users since they started smoking.

<sup>c</sup>This was calculated by first recoding usual cigarettes smoked per day into packs for both previous and current users. A range of 1 to 10 was considered 0.5 packs, 11 to 20 was considered 1 pack, and so on through 61 or more (4 packs). Participants who reported an exact number of cigarettes were recoded into packs by multiplying the number by 0.05. Next, years were calculated by subtracting smoking start age from current age for current smokers and subtracting smoking start age from smoking quit age for former smokers. Then we multiplied packs by years to compute pack years. Fifty-five participants were excluded from this computation for having missing or impossible data, including having a negative pack year (reporting a start age after a quit age) or reporting smoking start age as 0.

<sup>d</sup>This was evaluated using the Single Item Literacy Screener.<sup>30</sup>

<sup>e</sup>Chronic obstructive pulmonary disease, asbestos exposure, or other lung disease.

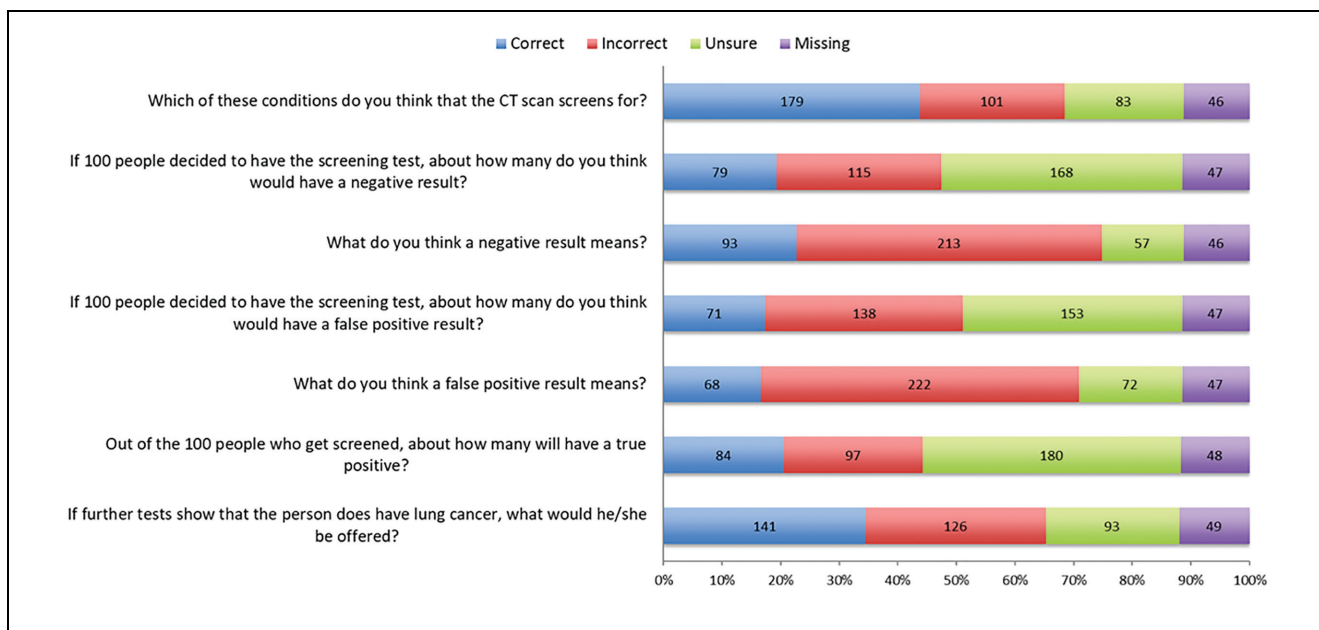
<sup>f</sup>Participants were asked separate questions regarding whether their primary care provider and a screening coordinator discussed lung cancer screening with them.

<sup>g</sup>This was evaluated using the Consultation Care Measure<sup>23,24</sup>; dichotomized scores 1 to 4 as low quality and 5 to 7 as high quality, with higher scores being better.

<sup>h</sup>This was evaluated using the Consumer Assessment of Healthcare Providers and Systems<sup>26</sup>; dichotomized scores 1 to 6 as low quality and 7 to 10 as high quality, with higher scores being better.

<sup>i</sup>This was evaluated using the Decisional Conflict Scale (DCS)<sup>28</sup>; categorized as 0 to 24 (no decision conflict), 25 to 37.5 (indeterminate decision conflict), and 37.6 to 100 (decision conflict), lower scores are better.

their health care institution. This finding suggests that while there may be other reasons to institute centralized LCS programs, such as increasing follow-up adherence,<sup>32,33</sup> the type of program may not affect other patient-centered outcomes. Finally, correctly answering



**Figure 2** Lung cancer screening knowledge question answer.

the primary LCS knowledge question regarding the purpose of LCS (i.e., screening for lung cancer) had small associations with communication quality ratings and clinician rating but not decision conflict. In secondary analyses, LCS knowledge had a moderate association with decision conflict, with each correct answer being associated with an approximately 2-point lower DCS score.

### *Clinical Implications*

Our results amplify the growing body of evidence regarding how patients experience LCS communication and decision making. It is not surprising that patients in routine care settings retained a low level of LCS knowledge as LCS decision-making interactions may be very short and have low-quality communication.<sup>11</sup> Both cancer guidelines and decision aids often underemphasize the harms of screening, which might explain our participants' low level of knowledge regarding the harms of LCS.<sup>8,34</sup> In our previous qualitative analyses, PCPs seldom provided very detailed information (although it was included in the available decision aids), and both PCPs and screening coordinators reported that patients often seemed uninterested in much of the detailed LCS information they shared.<sup>12</sup>

Experts ranked LCS knowledge sixth when asked to prioritize 18 outcome constructs to measure the

effectiveness of LCS shared decision making.<sup>35</sup> However, patients in our previous qualitative work were satisfied with the information they received and retained despite being aware that they did not know many details about the harms and benefits of screening.<sup>14</sup> We asked them if their clinician should have provided more information, and they uniformly replied they had received all the information they needed. They reported that they could obtain more information from their provider if desired. Thus, many patients may not strongly value receiving additional information about LCS. There are undoubtedly exceptions, and we suggest clinicians consider the needs of individual patients when discussing LCS. Most patients likely value that additional information is available, rather than requiring it be delivered.

It is unclear if improving LCS knowledge substantially affects patient-centered outcomes. CMS mandated a decision-making interaction that focused on information exchange based on expert opinion rather than empirical evidence.<sup>5</sup> Since the initial decision, several studies have been published to better understand the relationship between improving LCS knowledge and downstream outcomes. For instance, a randomized controlled trial reported that participants who watched a nine-minute video had a mean correct knowledge score of 44% three months afterward, only nine percentage points higher than participants receiving usual care.<sup>36</sup> About 20% more participants who saw the video felt well-prepared

**Table 2** Correct Responses to Knowledge Questions and Participant Ratings for Screening Discussion Stratified by Decision Aid Recall, Type of Clinician, and Study Site<sup>a</sup>

	Recalled Decision Aid Use, $n$ (%) or $\bar{x}$ (s)		Clinician Who Discussed Screening <sup>b</sup> $n$ (%) or $\bar{x}$ (s)		Study Site, $n$ (%) or $\bar{x}$ (s)		
	Yes	No	PCP	Screening Coordinator	Portland	Minneapolis	Duke
	Correctly answered knowledge questions	67 (52%)	112 (49%)	125 (47%)	28 (64%)	105 (58%)	38 (32%)
The LDCT scan screens for which condition?	32 (25%)	46 (20%)	50 (19%)	11 (26%)	29 (16%)	30 (25%)	20 (31%)
Of 100 people . . . how many do you think would have a negative result?	34 (26%)	58 (25%)	67 (25%)	15 (34%)	62 (34%)	18 (15%)	13 (20%)
What do you think a negative result means?	26 (20%)	44 (19%)	44 (17%)	8 (19%)	31 (17%)	20 (17%)	20 (31%)
Of 100 people . . . how many do you think would have a false-positive result?	26 (20%)	41 (18%)	55 (21%)	7 (16%)	23 (13%)	36 (31%)	9 (14%)
What do you think a false-positive result means?	32 (25%)	52 (23%)	62 (23%)	10 (23%)	38 (21%)	31 (26%)	15 (24%)
Out of the 100 people . . . how many will have a true positive?	57 (44%)	83 (36%)	101 (39%)	18 (41%)	57 (32%)	59 (50%)	25 (39%)
If further tests show . . . lung cancer, what would he/she be offered?	2 (1.2)	2 (1.4)	2 (1.2)	2 (1.3)	2 (1.2)	2 (1.4)	2 (1.4)
Knowledge Summary Score	92 (90%)	169 (95%)	198 (94%)	38 (91%)	163 (92%)	45 (96%)	56 (95%)
Participant ratings	96 (94%)	171 (93%)	203 (93%)	40 (98%)	170 (93%)	43 (90%)	57 (98%)
High-quality communication <sup>c</sup>	60 (44%)	103 (41%)	129 (44%)	18 (40%)	97 (48%)	43 (33%)	29 (44%)
Good perceptions of LCS clinician <sup>d</sup>	65 (47%)	101 (41%)	129 (44%)	20 (44%)	79 (39%)	73 (57%)	18 (27%)
Decision conflict <sup>e</sup>	12 (9%)	45 (18%)	35 (12%)	7 (16%)	25 (12%)	13 (10%)	19 (29%)

LCS, lung cancer screening; LDCT, low-dose computed tomography; PCP, primary care provider.

<sup>a</sup>For all variables except the Knowledge Summary Score and Decision Conflict Score, participants with missing responses were excluded from the calculation. Participants who answered at least knowledge question were included in the Knowledge Summary Score calculation. For the Decision Conflict Score, we excluded participants from the total score analysis who were missing seven or more items. High-quality communication included individuals who indicated they *agreed, strongly agreed, or very strongly agreed* with the statement, “The overall quality of communication with your provider is excellent.” Good perceptions of the LCS clinician included individuals who rated their provider between 7 and 10 on the item. “Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider?” No decision conflict included individuals with a score less than 25 on the Decisional Conflict Scale. Indeterminate decision conflict included individuals with a score between 25 and 37.5 on the Decisional Conflict Scale.

<sup>b</sup>PCP indicates the PCP and/or screening coordinator discussed LCS screening; screening coordinator equals only the screening coordinator discussed LCS screening.

<sup>c</sup>This was evaluated using the Consultation Care Measure.<sup>23,24</sup>

<sup>d</sup>This was evaluated using the Consumer Assessment of Healthcare Providers and Systems.<sup>26</sup>

<sup>e</sup>This was evaluated using the Decisional Conflict Scale.<sup>28</sup>



**Table 3** Association of Knowledge with Communication Quality, Clinician Rating, and Decision Conflict<sup>a</sup>

Knowledge Question <sup>b</sup>	Communication Quality with Clinician <sup>c</sup>	Perceptions of LCS Clinician <sup>d</sup>	Decision Conflict <sup>e</sup> (Lower Scores Indicate Less Conflict)
Which of these conditions do you think that the CT scan screens for?	<b>0.4 (0.1, 0.7)</b> <i>0.03</i>	<b>0.4 (0.0, 0.7)</b> <i>0.02</i>	-2.4 (-5.7, 0.9) <i>0.01</i>
Knowledge Score Total <sup>f</sup>	<b>0.2 (0.1, 0.3)</b> <i>0.04</i>	0.1 (-0.1, 0.2) <i>0.00</i>	<b>-2.2 (-3.4, -0.9)</b> <i>0.24</i>

CT, computed tomography; LCS, lung cancer screening.

<sup>a</sup>Multiple linear regression unstandardized beta coefficients and confidence intervals are shown for the primary knowledge question and the total knowledge score. Significant findings ( $P < 0.05$ ) are bolded.  $R^2$  change values are included in italics. Values outside parentheses are unstandardized betas. Values inside parentheses are 95% confidence intervals. Variables used in the linear regression model are age, gender, smoking status (current smoker or not), depression and/or posttraumatic stress disorder, chronic lung disease, education, income, and study site. The score ranges for the instruments used to measure each outcome are as follows: <sup>b</sup>primary knowledge question (0–1); <sup>c</sup>communication quality with clinician (1–7), evaluated using the Consultation Care Measure<sup>23,24</sup>; <sup>d</sup>Perceptions of LCS clinician (0–10), evaluated using the Consumer Assessment of Healthcare Providers and Systems<sup>26</sup>; <sup>e</sup>decision conflict (0–100), evaluated using the Decisional Conflict Scale (DCS)<sup>28</sup>; <sup>f</sup>Knowledge Summary Score (0–7). Listwise deletion was used in each regression model, respectively, such that if a participant had missing data on any independent variable or the respective outcome, they were excluded from the analysis.

to make an LCS decision, but the intervention did not lead to changes in screening behaviors.<sup>36</sup> In a trial that compared receipt of standard written materials to a six-minute video decision aid plus the written materials, participants had improved knowledge (70% compared with 80% correct, respectively), a small change in decision conflict score, and no change in LCS behavior.<sup>29</sup> A third trial tested a 13-minute Web-based patient- and clinician-facing decision aid compared with a 10-page Web-based guide on general cancer prevention.<sup>37,38</sup> The investigators found no difference in decisional conflict and a statistically significant, 1-point-higher knowledge score (out of 12) when measured one month after use of the decision aid and a higher number of participants in the treatment arm who received an LDCT for LCS.

Observational studies have largely echoed and supported these results. For example, investigators reported that a six-minute LCS educational video led to modest knowledge improvements immediately after its use that waned a month later.<sup>39</sup> Eberth and colleagues<sup>40</sup> reported that patients had a low level of LCS knowledge that was only weakly related to decision conflict. Lastly, a systematic review found that seven of nine studies found modestly improved LCS knowledge compared with or after using a decision aid.<sup>7</sup>

Combined with our results, these studies have several implications. First, researchers often only modestly improved LCS knowledge among selected patients using fairly lengthy interventions in experimental settings. Clinicians report they do not have the time for lengthy LCS discussions, and many patients likely would not value more time spent on LCS information that would

occur at the expense of other priorities.<sup>14,31</sup> Thus, it seems unlikely that clinicians and health care systems can deploy interventions that markedly improve LCS knowledge for patients in routine care settings. Second, even if LCS knowledge could be improved, it seems unlikely there would subsequently be large effects on decision conflict. Two of three trials found a small effect of a decision aid on decision conflict,<sup>29,36,38</sup> and our secondary analyses found that improved knowledge scores were associated with small differences in decisional conflict. Third, our study found that only 14% of participants reported decision conflict after their LCS decision-making interaction. While decision conflict was in an indeterminate range for 43%, it is not clear how important small changes in the DCS score would be for these patients. Furthermore, experts ranked decision conflict last as an outcome construct to measure the effectiveness of LCS shared decision making.<sup>35</sup> Decisional satisfaction or regret after the LDCT may be more important patient-centered outcomes. Investigators should study the association of LCS knowledge with decision regret to better understand if the resources spent to increase LCS knowledge are likely to be worthwhile for most patients in routine care settings. Overall, increasing knowledge may be challenging and at most only modestly effective at reducing decision conflict, which is not elevated for most patients and may not be an important patient-centered outcome.

Despite the potential concerns regarding LCS knowledge as a patient-centered outcome or a meaningful factor that could improve other outcomes, we do not want to minimize its importance. Knowledge is a core

component of patient-centered communication.<sup>18</sup> Many patients intrinsically value knowledge, and clinicians ideally should tailor their information exchange based on individualized and explicit patient preferences.<sup>31</sup> Finally, our study found small but significantly higher patient-clinician communication quality scores and more positive clinician perceptions, suggesting that increasing LCS knowledge may improve patients' ratings of their providers. However, we also want to emphasize that patient-centered communication also includes consideration of patients' values and preferences, which may prove to be a more important focus than information exchange.

### Limitations

Although our previous qualitative analysis suggested patients who declined to undergo LCS had similar knowledge and satisfaction with the LCS process, the current results may not be generalizable since very few participants in the current analysis declined LCS.<sup>14</sup> We did not validate our LCS knowledge questions, but several questions are similar to a validated instrument that was published after our study began.<sup>41</sup> We did not directly observe patient-clinician communication during their decision-making interaction, so we cannot be certain that CMS guidelines were followed. However, each site used standardized operating procedures for dedicated screening coordinators, and our qualitative results strongly suggest LCS coordinators adhered to CMS guidelines and PCPs provided basic information to patients.<sup>14,31</sup> There is no consensus regarding the optimal length of time a patient retains knowledge about LCS, but note that the average time from discussion to survey administration was 25 days, and we did not find any differences in knowledge over time in our qualitative work.<sup>14</sup> We did not evaluate whether additional efforts at improving knowledge would be associated with even higher-quality communication outcomes; ratings were already high, raising the possibility of a ceiling effect. We also do not know if knowledge is associated with longer-term outcomes that are important for patients undergoing LCS, such as cigarette smoking behaviors and adherence to follow-up, and plan to analyze these associations in the future.

### Conclusions

Information exchange is only one of several mechanisms for supporting patients in making health-related decisions.<sup>18–20,42,43</sup> It is recommended that decision aids include many details about LCS, but they should also help patients share their values and preferences with their


clinician.<sup>44</sup> Our study suggests that while information exchange may be important to ensure that patients understand the primary goal of LCS, exclusively focusing on this aspect of LCS decision making may lead to, at best, modest improvements in patient-centered outcomes. We suggest that CMS and other organizations reconsider the benefits and harms of their LCS decision-making mandates and recommendations that focus on information exchange.

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