# JAMA Internal Medicine | Original Investigation | LESS IS MORE

# **Evaluating Shared Decision Making for Lung Cancer Screening**

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**IMPORTANCE** The US Preventive Services Task Force recommends that shared decision making (SDM) involving a thorough discussion of benefits and harms should occur between clinicians and patients before initiating lung cancer screening (LCS) with low-dose computed tomography. The Centers for Medicare & Medicaid Services require an SDM visit using a decision aid as a prerequisite for LCS coverage. However, little is known about how SDM about LCS occurs in practice.

**OBJECTIVE** To assess the quality of SDM about the initiation of LCS in clinical practice.

**DESIGN, SETTING, AND PARTICIPANTS** A qualitative content analysis was performed of transcribed conversations between primary care or pulmonary care physicians and 14 patients presumed to be eligible for LCS, recorded between April 1, 2014, and March 1, 2018, that were identified within a large database.

MAIN OUTCOMES AND MEASURES Independent observer ratings of communication behaviors of physicians using the OPTION (Observing Patient Involvement in Decision Making) scale, a validated 12-item measure of SDM (total score, 0-100 points, where 0 indicates no evidence of SDM and 100 indicates evidence of SDM at the highest skill level); time spent discussing LCS during visits; and evidence of decision aid use.

**RESULTS** A total of 14 conversations about initiating LCS were identified; 9 patients were women, and 5 patients were men; the mean (SD) patient age was 63.9 (5.1) years; 7 patients had Medicare, and 8 patients were current smokers. Half the conversations were conducted by primary care physicians. The mean total OPTION score for the 14 LCS conversations was 6 on a scale of 0 to 100 (range, 0-17). None of the conversations met the minimum skill criteria for 8 of the 12 SDM behaviors. Physicians universally recommended LCS. Discussion of harms (such as false positives and their sequelae or overdiagnosis) was virtually absent. The mean total visit length of a discussion was 13:07 minutes (range, 3:48-27:09 minutes). The mean time spent discussing LCS was 0:59 minute (range, 0:16-2:19 minutes), or 8% of the total visit time (range, 1%-18%). There was no evidence that decision aids or other patient education materials for LCS were used.

**CONCLUSIONS AND RELEVANCE** In this small sample of recorded encounters about initiating LCS, the observed quality of SDM was poor and explanation of potential harms of screening was virtually nonexistent. Time spent discussing LCS was minimal, and there was no evidence that decision aids were used. Although these findings are preliminary, they raise concerns that SDM for LCS in practice may be far from what is intended by guidelines.

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n 2013, the US Preventive Services Task Force (USPSTF) recommended lung cancer screening (LCS) using annual low-dose computed tomography (CT) for current and former smokers at high risk for lung cancer. More than 6 million individuals in the United States are eligible for LCS, including more than 4 million Medicare beneficiaries. However, although LCS can reduce the chances of death from lung cancer, LCS also causes harms. For example, because most lung nodules detected by screening are benign, many individuals who complete LCS then undergo follow-up procedures, some of which are invasive, that do not find cancer. A Screening can also lead to the diagnosis and treatment of cancer that would not have affected the individual during his or her lifetime (overdiagnosis), with attendant physical, psychological, and financial harms.

Although experts disagree on how well the existing evidence suggests an overall net benefit of LCS, <sup>6,7</sup> consensus has emerged on the importance of shared decision making (SDM). The USPSTF recommends that LCS should not be initiated without SDM that involves a thorough discussion of its benefits and harms. Furthermore, in 2015, the Centers for Medicare & Medicaid Services (CMS) issued requirements for an SDM visit using a decision aid prior to covering LCS. <sup>8</sup> However, how (or if) SDM occurs in clinical practice is unknown. We used content analysis to assess SDM for LCS in a sample of existing audiorecorded encounters between patients and physicians from community practice.

#### Methods

We identified conversations about initiating LCS in the Verilogue database. Detailed data collection methods are published elsewhere.<sup>9</sup> In brief, the Verilogue database contains more than 135 000 recordings from more than 2150 US health care professionals, mainly in private solo or group practices. The Verilogue analyst electronically searched the database of transcribed outpatient encounters collected between April 1, 2014, and March 1, 2018, to identify encounters that: (1) were between primary care physicians (PCPs) or pulmonologists and patients who were eligible for LCS based on age (ie, 55-80 years of age) and (2) contained key words relevant to LCS: (scan OR screen OR CT) AND (lungs OR chest OR smoke OR low-dose OR lung cancer). Two of us (A.T.B. and T.L.M.) manually reviewed transcripts to identify encounters with discussions about initiating LCS. This study was determined to not be human subjects research by the University of North Carolina Institutional Review Board. Participating patients provided written consent to be recorded, with the knowledge that all protected health information will be redacted from the recordings and transcripts.

### **Analyses**

Two of us (T.L.M. and M.M.) independently reviewed and coded transcripts using OPTION (Observing Patient Involvement in Decision Making), a validated scale designed to measure the extent to which clinicians involve patients in decisions within consultations. The scale assesses 12 SDM clinician

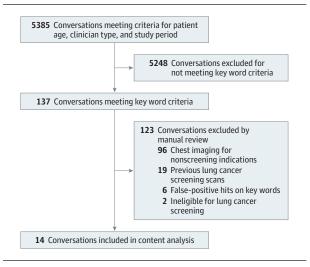
# **Key Points**

**Question** What is the quality of guideline-recommended shared decision making about lung cancer screening in clinical practice?

**Findings** In this qualitative content analysis of 14 recorded and transcribed outpatient clinical encounters, the quality of shared decision making about lung cancer screening was poor, as rated by 2 independent observers using a validated shared decision making scale. Potential harms of screening were not adequately explained, and decision aids were not used.

**Meaning** Despite recommendations, shared decision making for lung cancer screening in practice may be far from what is intended by guidelines.

Figure. Flow Diagram Describing Included and Excluded Physician-Patient Conversations



communication behaviors, such as "explains the pros and cons of options to the patient."10-12 The authors rated each behavior along the following scale, as specified in the OPTION rater manual<sup>11</sup>: 0, no attempt to perform the behavior; 1, perfunctory or unclear attempt to perform the behavior; 2, behavior performed at minimum or baseline skill level; 3, behavior performed to a good standard; and 4; behavior performed to a high standard. Coding discrepancies were resolved by group consensus. For each item, we calculated the mean item score for conversations and the proportion of conversations with a rating of 2 (minimum or baseline skill level) or better. We calculated a standard total OPTION score by summing individual item scores for each conversation and scaling to 100 points. Coders also agreed on the presence or absence of references to decision aids or other informational material and measured total visit and LCS conversation times.

#### Results

We identified 5385 conversations involving age-eligible patients occurring between April 1, 2014, and March 1, 2018 (Figure). Of these, 137 met the key word criteria. Manual

review of these transcripts yielded 14 conversations about initiation of LCS. Most conversations were excluded because they involved discussion of chest imaging conducted for nonscreening (eg, diagnostic or unclear) indications, previously completed CT scans, or other unrelated discussions that included the key words.

Patients' mean (SD) age was 63.9 (5.1) years; 9 (64.3%) were female, 7 (50.0%) had Medicare, and 8 (57.1%) were current smokers (**Table 1**). The 14 conversations involved 10 unique physicians (5 pulmonologists and 5 PCPs). All physicians were in office-based group or solo private practice.

#### **Analyses of SDM**

Mean SDM behavior item scores ranged from 0 to 0.79 on the scale of 0 to 4 (Table 2). Two conversations met baseline skill criteria (level 2) for 1 behavior each, 2 met baseline skill criteria for 2 behaviors each, and no conversations met baseline skill criteria for the remaining 8 of 12 communication behaviors, including explaining the pros and cons of LCS. No physician adequately explained false positives or their sequelae (eg, the need for additional imaging or invasive diagnostic procedures). No physician discussed overdiagnosis.

The mean total OPTION score for the 14 LCS conversations was 6 on the scale of 0 to 100 (range, 0-17). The mean score was 5 of 100 (range, 0-17) for pulmonologists and 7 of 100 (range, 0-15) for primary care physicians. The mean score was 6 of 100 (range, 0-15) for Medicare patients and 6 of 100 (range, 0-17) for patients with other payers. **Table 3** shows example conversations along with OPTION item scores. The mean total visit length was 13:07 minutes (range, 3:48-27:09 minutes). The mean time spent discussing LCS was 0:59 minute (range, 0:16-2:19 minutes), or 8% of the total visit time (range, 1%-18%). We found no reference to decision aids or other patient education materials.

#### Discussion

In a small sample of recorded clinical encounters between patients and physicians, we found that physicians' efforts to engage patients in SDM about initiating LCS were cursory at best. Despite guidelines from organizations including the USPSTF and CMS, no conversations met even basic skill criteria for explaining the pros and cons of LCS. Although the sample is small and these findings are clearly preliminary, they raise concerns that SDM in practice may be far from what is intended by guidelines.

The fact that the main drivers of harms from LCS (false positives and their sequelae, as well as overdiagnosis) were not adequately explained by physicians is troubling. However, these findings are consistent with other evidence that discussions between patients and physicians regarding preferencesensitive cancer screening decisions are imbalanced with respect to explaining the pros and cons. For example, in a national survey about prostate cancer screening, US men reported that their health care professionals emphasized the pros of screening substantially more than the cons. <sup>13</sup> More broadly, our findings are consistent with increasingly robust evidence

Table 1. Characteristics of Conversations in the Analytic Sample and Conversations Matching Search Term Key Words

<u> </u>	Patients, No. (%)		
Characterist'	Sample	Age-Eligible Key Word	
Characteristic	(n = 14)	Matches (n = 137)	
Age, mean (SD), y	63.9 (5.1)	68.7 (7.1)	
55-64	7 (50.0)	44 (32.1)	
65-80	7 (50.0)	93 (67.9)	
Sex			
Male	5 (35.7)	66 (48.2)	
Female	9 (64.3)	71 (51.8)	
Race/ethnicity			
White	14 (100)	115 (83.9)	
Black or African American	0	17 (12.4)	
Other	0	5 (3.6)	
Primary insurance			
Medicare	7 (50.0)	92 (67.2)	
Private, HMO, or PPO	6 (42.9)	37 (27.0)	
Medicaid	0	7 (5.1)	
No insurance	1 (7.1)	1 (0.7)	
Employment			
Full-time	4 (28.6)	25 (18.2)	
Part-time	0	5 (3.6)	
Retired	4 (28.6)	80 (58.4)	
Homemaker, unemployed, or do not know	6 (42.9)	27 (19.7)	
Living situation			
Lives with family or friends	8 (57.1)	105 (76.6)	
Lives alone	4 (28.6)	26 (19.0)	
Unknown	2 (14.3)	6 (4.4)	
Current smoker			
Yes	8 (57.1)	28 (20.4)	
No	6 (42.9)	109 (79.6)	
Reason for visit			
Follow-up for preexisting condition	13 (92.9)	102 (74.5)	
Acute needs, well visit, or other	1 (7.1)	35 (25.5)	
Provider seen			
Pulmonologist	8 (57.1)	58 (42.3)	
Primary care, family medicine, or internist	6 (42.9)	79 (57.7)	
	Clinicians, No. (%)		
	Sample (n = 10)	Age-Eligible Key Word Matches (n = 38)	
Sex			
Male	7 (70.0)	29 (76.3)	
Female	3 (30.0)	9 (23.7)	
No. of years in practice			
3-20	5 (50.0)	21 (55.3)	
≥21	5 (50.0)	17 (44.7)	
Specialty			
Pulmonologist	5 (50.0)	13 (34.2)	
Primary care, family medicine, or internist	5 (50.0)	25 (65.8)	
Geographical region			
Northeast	3 (30.0)	8 (21.1)	

(continued)

that patients, members of the public, and clinicians tend to overestimate the benefits and underestimate the harms of medical interventions, including treatments, tests, or screening tests. <sup>14,15</sup>

We are unaware of other studies using the OPTION scale to evaluate discussions about the initiation of LCS. However, a systematic review by Couët et al<sup>16</sup> identified 29 studies using the OPTION scale and found that clinicians generally performed poorly (mean, 23 of 100) across a variety of other decisions and clinical contexts. The review identified 2 factors associated with higher OPTION scores; 1 factor was duration of the encounter. This finding is not surprising because explaining equipoise, listing options, explaining pros and cons, checking understanding, and then integrat-

Table 1. Characteristics of Conversations in the Analytic Sample and Conversations Matching Search Term Key Words (continued)

	Patients, No. (%)		
Characteristic	Sample (n = 14)	Age-Eligible Key Word Matches (n = 137)	
Midwest	3 (30.0)	8 (21.1)	
South	2 (20.0)	15 (39.5)	
West	2 (20.0)	7 (18.4)	
Primary setting (≥50% time)			
Private practice, office-based	10 (100)	36 (94.7)	
Other	0	2 (5.3)	

Abbreviations: HMO, health maintenance organization; PPO, preferred provider organization.

ing preferences into a shared decision requires time. In our study, physicians spent less than 1 minute, on average, discussing LCS. It seems doubtful that meaningful deliberation about a decision as complex and consequential as initiating yearly CT scanning can occur as an ad hoc addition to a brief outpatient visit.

A second factor associated with higher OPTION scores in the review by Couët et al<sup>16</sup> was "SDM interventions," which were primarily decision aids and/or clinician training. This finding is consistent with a review of interventions to improve adoption of SDM, which also suggested that interventions directed at both patients and clinicians were the most promising.<sup>17</sup> Decision aids delivered before an encounter between the patient and clinician could help address physician time constraints, and several LCS decision aids have been tested.<sup>18-20</sup> However, decision aid use in practice is rare.<sup>21</sup>

The 2016 CMS coverage decision policy recognized the time and effort needed for LCS SDM by establishing reimbursement criteria for an SDM visit, which was required before covering an initial CT scan for LCS. Specifically, CMS requires that an SDM visit involve use of 1 or more decision aids and a documented discussion of the "benefits and harms of screening, follow-up diagnostic testing, overdiagnosis, false-positive rate, and total radiation exposure." None of the 7 encounters involving Medicare patients in our study met these criteria. Although we do not know whether CT scans were completed or reimbursed by Medicare, these findings raise concerns about whether practicing physicians are actually meeting these requirements.

Table 2. Presence of Shared Decision Making Communication Behaviors in Lung Cancer Screening Conversations<sup>a</sup>

Shared Decision Making Communication Behavior Item by the Clinician (Abbreviated Item Name)	Mean Item Score (of 0-4) (Range) <sup>b</sup>	Conversations Rated ≥2 (Baseline Skill Level), No. (%)
1. Draws attention to an identified problem as one that requires a decision making process (identifying problem)	0.43 (0-2)	1 (7)
<ol><li>States that there is more than one way to deal with the identified problem ("equipoise") (explaining equipoise)</li></ol>	0.79 (0-2)	3 (21)
3. Assesses patient's preferred approach to receiving information to assist decision making (eg, discussion in consultations, read printed material, assess graphical data, use videotapes or other media) (assessing preferred approach)	0	0
4. Lists options, which can include the choice of "no action" (listing options)	0.50 (0-2)	1 (7)
<ol><li>Explains the pros and cons of options to the patient (taking no action is an option) (explaining pros and cons)</li></ol>	0.14 (0-1)	0
<ol><li>Explores the patient's expectations (or ideas) about how the problem(s) are to be managed (exploring expectations)</li></ol>	0	0
7. Explores the patient's concerns (fears) about how problem(s) are to be managed (exploring concerns)	0	0
8. Checks that the patient has understood the information (checking understanding)	0.07 (0-1)	0
<ol><li>Offers the patient explicit opportunities to ask questions during the decision making process (offers opportunities for questions)</li></ol>	0.21 (0-2)	1 (7)
10. Elicits the patient's preferred level of involvement in decision making (eliciting preferred involvement)	0.43 (0-1)	0
11. Indicates the need for a decision making (or deferring) stage (indicating need for decision)	0.36 (0-1)	0
12. Indicates the need to review the decision (or deferment) (indicating need to review or defer)	0	0

<sup>&</sup>lt;sup>a</sup> For 14 patients/conversations.

Involvement in Decision Making) Rater Manual (eg, for item 5—explaining pros and cons, a score of 1 is given if "the clinician fails to provide information about more than one option"; a score of 2 is given if the clinician provides details about the pros and cons of the options"; a score of 3 is given if "requires the behavior is exhibited to a good standard"; and a score of 4 is given if "the clinician does this task to a high standard").

<sup>&</sup>lt;sup>b</sup> Individual items were scored on a magnitude scale, where 0 = no attempt to perform the behavior, 1 = perfunctory or unclear attempt to perform the behavior, 2 = behavior is performed at a baseline skill level, 3 = behavior is performed to a good standard, and 4 = behavior is performed to a high standard. Item-specific guidance is given in the OPTION (Observing Patient

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Table 3. Illustrative I	ung Cancer Screening	Conversations

Conversations	Encounter Characteristics
Lowest-Scoring Conversations	
Physician: Because of the smoking history, um, I'd like to get a CT scan of the lungs and make sure there's nothing in there. Um, this is a new benefit now. Insurance companies are paying for it.  Patient: Okay Physician: Okay? Now, I'll just get that set up and we'll move on.	Patient: Male, aged 65-69 y, former smoker Physician: Primary care Total OPTION score: 0 of 100 IIndividual OPTION scores: score = 0 for items 1-12 <sup>a</sup>
Physician: Uh, let me see when we last did a chest x-ray. That's been a while. The other thing, Medicare is now paying for uh, CT scans of the chest as a screening tool, so uh, we can work on scheduling that for you too. Um, and especially just in that for about 5 min it may take a pretty good picture, just to make sure we don't miss anything there as well. Um, and then the last thing is your, there's a second pneumonia shot we're advising for people called Prevnar.	Patient: Female, aged 70-74 y, former smoker Physician: Primary care Total OPTION score: 0 of 100 Individual OPTION scores: score = 0 for items 1-12 <sup>a</sup>
Highest-Scoring Conversations	
Physician: Okay, so, [PATIENT NAME], one of the recommendations, now I just want to discuss this with you. You can decide. Um, one of the recommendations now is that if you have smoked more than 30 pack-years, which you have, and you've quit sometime within the last 15 y, which you have. Patient: Yeah. Physician: That you have a yearly chest CT. If you want to do that, I can make it available. Patient: It's, it's a what? Physician: A chest CT scan to look for cancer, early cancer. Um, before, we never had anything we could do. If you got lung cancer, bye. Patient: Yeah. Physician: Um, now we're finding that if we find these things really early by doing about a yearly CT scan on it, that we can actually intervene and do something about it. Are you interested in getting that done? Patient: Yeah, yeah. (later) Physician: (to nurse) I need the code for the, um, smoker CT scan, please.	Patient: Male, aged 60-64 y, former smoker Physician: Primary care Total OPTION score: 15 of 100 Individual OPTION scores: score = 0 for items 3, 5-9, and 12; score = 1 for items 4, 10, and 11; score = 2 for items 1 and 2 <sup>a</sup>
Physician: There is one other sort of side issue but it is related. Um, it is becoming more and more clear that people who um, smoked uh, or quit smoking but did smoke for a length of time up until about 75 had a risk of getting lung cancer.  Patient: Uh-huh.  Physician: And there has always been this great dilemma of how can we find those people before it is too late and chest x-rays have been rather disappointing.  Patient: Oh.  Physician: Because they are just not a good enough test. They show the problem when it is big and dramatic, by which time it is generally too late. So, now the newest information suggests that a CT scan, I am sure you know what a CT scan is.  Patient: Yes.  Physician: A low-dose CT scan. So, we give you the least amount of radiation. Um, once in a lifetime. I am assuming that you have no symptoms. We are talking about a screening test.  Patient: Uh-huh.  Physician: Somewhere between 60 and 75, um, it is finding some of these people and really saving their lives, so I would like to suggest that we consider a low-dose CT scan of your chest. Again, there is no particular emergency in the next couple of months, are you agreeable to that as well?  Patient: Yeah.	Patient: Female, aged 60-64 y, current smoker Physician: Pulmonologist Total OPTION score: 17 of 100 Individual OPTION scores: score = 0 for items 3-7 and 12; score = 1 for items 1, 8, 10, and 11; score = 2 for items 2 and 9 <sup>a</sup>

Abbreviations: CT, computed tomography; OPTION, Observing Patient Involvement in Decision Making.

Although it is tempting to conclude that SDM for LCS should be conducted at dedicated referral LCS centers, such a paradigm does not fully acknowledge what is known about how and when patients actually make decisions about screening. For example, a study recently found that 50% of patients eligible for screening who received LCS decision support (a video decision aid) in a primary care practice preferred to be screened. 18 In contrast, in a recent study of patients attending a tertiary LCS program who received robust decision support (including a decision aid), 95% chose to be screened.<sup>22</sup> We suspect that patients referred to LCS programs will presume that the purpose of referral is to complete screening, rather than to decide about screening. We believe that current evidence suggests that true patient-centered solutions will require a robust and flexible primary care-based decision support infrastructure that allows meaningful decision support to be provided when and where the issue of LCS is first raised.

#### Limitations

The major limitation of this study is its small sample from private community practices and the limitations inherent in qualitative studies. Larger studies are needed to fully describe current practice and the challenges associated with SDM for LCS.

## Conclusions

We believe these preliminary findings should engender a more pressing discussion among clinical leaders, policy makers, and researchers about how to meaningfully involve patients in LCS decisions. Until more is known, we believe that guideline and policy makers should not assume that recommending SDM for cancer screening decisions with a "tenuous balance of benefits and harms," <sup>23(p971)</sup> like LCS, will protect patients who would value avoiding screening harms.

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<sup>&</sup>lt;sup>a</sup> Individual items are presented in Table 2.

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