

Developing a Conceptual Framework for a Person-Centered Approach to Improving Adherence and Outcomes in Lung Cancer Screening: The Engaged Approach to Lung Cancer Screening: A Brief Report



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ABSTRACT

Introduction: Translating outcomes from randomized trials of lung cancer screening into community practice settings has been challenging. We developed a framework—the Engaged Approach to Lung Cancer Screening (EA-LCS)—for improving adherence and individual and population health outcomes in LCS.

Methods: Employing community-engaged research, we conducted semistructured interviews with LCS program staff (N = 15) and participants (N = 7) and administered brief surveys to understand LCS adherence. We combined our knowledge of LCS implementation with data to formulate the EA-LCS framework, including principles and strategies instrumental for LCS adherence.

Results: Program staff identified four factors that facilitated adherence: (1) the use of specialized tracking software, (2) the importance of personal connection and a reliable touchpoint, (3) centralized program operations, and (4) standardization and streamlining of reports to participants and clinicians. Participant data identified four factors supporting adherence: (1) a single contact point and information availability, (2) tailored communications, (3) personalized results delivery, and (4) increased scan accessibility. Combined analyses identified three overarching themes in the EA-LCS framework: (1) respect, (2) trust, and (3) engagement.

Conclusions: The EA-LCS conceptual model integrates three foundational principles (person-centeredness, trustworthy relationships, and sustained communications)

to enhance LCS adherence. Efforts are underway to translate the EA-LCS framework into materials to support adherence.

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Keywords: Lung cancer screening; LCS; Person-centered care; Adherence; Low-dose computed tomography; LDCT

Introduction

United States-based guideline-developing organizations have formulated recommendations favoring low-dose computed tomography (LDCT)-based lung cancer

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screening (LCS) among high-risk individuals. LCS implementation has received similar support from health insurance coverage-linked organizations, including the United States Preventive Services Task Force¹ and the Centers for Medicare & Medicaid Services.² Nevertheless, translating LCS into community practice has been complicated. A National Cancer Policy Forum meeting highlighted potential implementation challenges,³ and subsequent research revealed suboptimal translation⁴ regarding shared decision making,⁵ eligibility criteria,⁶ tobacco cessation treatment,⁷ and screening adherence.⁸

LCS algorithm adherence is vital to achieving individual and population health LCS benefits. Data from the National Lung Screening Trial and the Dutch-Belgium Randomized Lung Cancer Screening Trial (i.e., NELSON) trials revealed phenomenal LDCT adherence to multiple rounds of screening: 95% and 90%,¹⁰ respectively. Nevertheless, early community reports have raised adherence concerns.^{8,11,12} Lopez-Olivo et al. 12 meta-analysis reported a pooled adherence rate of 55% with substantial variability across studies (range: 12%-91%). In the most robust exploration, Silvestri et al. 13 analyzed registry data to reveal an annual adherence rate of 22%. Overall, LCS adherence rates remain starkly lower than in the landmark trials, demanding efforts to facilitate adherence and optimize investments in LCS research and policy.

To address this critical need, we used communityengaged research to identify barriers and facilitators of LCS adherence and then used these data to develop the framework for the person-centered Engaged Approach to LCS (EA-LCS).

Materials and Methods

This IRB-approved study collected qualitative and quantitative data from (1) LCS Program Staff and (2) Screening Program Participants recruited from two diverse regions.

Procedure

Screening Program Staff. Known LCS program directors and coordinators/navigators received email study invitations. Detailed characteristics are in Table 1.

Screening Program Participants. Participants were recruited through flyers posted in the Moffitt Cancer Center Clinic and through electronic health records identifying LCS adherent and nonadherent individuals. Participants were defined as nonadherent if they missed at least one annual LCS.

Table 1. Demographic Characteristics of Lung Cancer Screening Center Staff and Participants (Frequencies and Percentages)

Screening Center Staff ($N = 15$)	n	%
Demographics		
Age		
Mean (range)	44 (26-58)	
Sex		
Female	10	66.7
Male	1	6.7
Not reported	4	26.7
Race		
White	13	86.7
Asian	1	6.7
Mixed (NH/PI and Black/AA)	1	6.7
Ethnicity		
Not Hispanic or Latino	13	86.7
Hispanic or Latino	1	6.7
Not reported	1	6.7
Role in program ^a		
Director/medical director	1	6.7
Program member	1	6.7
Program manager	1	6.7
Program coordinator	5	33.3
Screening navigator	5	33.3
Other	4	26.7
Carponing Contar Participants		
Screening Center Participants (N = 7)	n	%
(N=7)	n 	/0
Demographics		
Age (y)		
Mean (Range)	66 (56-69)	
Sex		
	_	
Female	5	71.4
Female Male	1	14.3
Female		
Female Male Not reported Race	1	14.3 14.3
Female Male Not reported Race White	1 1 4	14.3 14.3 57.1
Female Male Not reported Race	1	14.3 14.3
Female Male Not reported Race White Not reported Ethnicity	1 1 4	14.3 14.3 57.1
Female Male Not reported Race White Not reported	1 1 4	14.3 14.3 57.1
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status	1 1 4 3	14.3 14.3 57.1 42.9
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino	1 1 4 3	14.3 14.3 57.1 42.9
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status	1 1 4 3	14.3 14.3 57.1 42.9 85.7
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced	1 1 4 3 6	14.3 14.3 57.1 42.9 85.7 71.4
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income	1 1 4 3 6 5	14.3 14.3 57.1 42.9 85.7 71.4 14.3
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income \$50,001-\$75,000	1 1 4 3 6 5	14.3 14.3 57.1 42.9 85.7 71.4 14.3
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income	1 1 4 3 6 5 1	14.3 14.3 57.1 42.9 85.7 71.4 14.3 14.3
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income \$50,001-\$75,000	1 1 4 3 6 5 1 1	14.3 14.3 57.1 42.9 85.7 71.4 14.3 14.3
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income \$50,001-\$75,000 Over \$75,000	1 1 4 3 6 5 1 1	14.3 14.3 57.1 42.9 85.7 71.4 14.3 14.3
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income \$50,001-\$75,000 Over \$75,000 Employment	1 1 4 3 6 5 1 1	14.3 14.3 57.1 42.9 85.7 71.4 14.3 14.3 85.7
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income \$50,001-\$75,000 Over \$75,000 Employment Retired	1 1 4 3 6 5 1 1 1 6	14.3 14.3 57.1 42.9 85.7 71.4 14.3 14.3 85.7 71.4
Female Male Not reported Race White Not reported Ethnicity Not Hispanic or Latino Marital Status Married/living with partner Single, never married Single, separated/divorced Income \$50,001-\$75,000 Over \$75,000 Employment Retired Work outside the home, full-time	1 1 4 3 6 5 1 1 1 6	14.3 14.3 57.1 42.9 85.7 71.4 14.3 14.3 85.7 71.4

 $^{{}^}a\!\mathit{Multiple}$ responses allowed.

After providing consent, both staff and participants completed a survey and an audio-recorded semi-structured interview before receiving \$75.

 $[\]ensuremath{\mathsf{HMO}},$ health maintenance organization; PPO, preferred provider organization.

Measures

Program Staff. The surveys measured (1) LCS program history and characteristics, and (2) demographics and training history. The interview posed questions regarding (1) program history, (2) current program operations, (3) perspectives on retention and adherence, and (4) areas for program improvement.

Program Participant. The surveys measured (1) demographics and health history, (2) tobacco use, (3) LCS-related perspectives and experiences, and (4) perspectives about messaging and engagement. Interview questions addressed (1) LCS experiences, (2) perspectives regarding follow-up testing, and (3) communication preferences, adherence-improvement strategies, and building participant engagement.

Data Analysis

Analyses included descriptive statistics for survey data and a qualitative description approach for interview data.

Results

Drivers of LCS Engagement

Program Staff (N = 15). Staff data revealed four factors supporting LCS adherence: (1) specialized tracking software, (2) personal connection with the program staff and a reliable touchpoint with the program, (3) centralized program operations, and (4) standardization and streamlining of reports. Representative quotes associated with identified factors are in Table 2. Regarding tracking software, most program operations initially used a spreadsheet, but this became increasingly untenable with program growth. A second factor involved developing a personal connection and reliable touchpoint. This theme represented a program navigator recognizing the importance of relationships and facilitating trustworthiness. Staff also noted that centralized program operations facilitated adherence. Centralized LCS programs adopt responsibility for most LCS-related healthcare, including eligibility, shared decision-making, delivering results, supporting referrals, and importantly, supporting adherence. The final factor involved streamlining and standardizing reporting (e.g., Lung Imaging Reporting and Data System [Lung-RADS]). Staff suggested that there should be consistency in results reporting for referring clinicians using the Lung-RADS system that clearly streamlines follow-up recommendations.

Program Participants (N = 7). Participant narratives identified four primary factors: (1) single point of contact and information availability, (2) tailored communications, (3) personalized results delivery, and (4)

increased accessibility to scans. Participants reported a strong desire for simple procedures to contact the LCS program—often specifically mentioning the importance of a known program navigator/coordinator who could help address challenges. The second and complementary factor involved the desire for accessible LCS information through a trusted source. Having trusted sources allows participants to independently explore information about important LCS processes. Program participants expressed a desire for communications tailored to their preferences for receiving information as this would increase the likelihood of reading and responding. Communication preferences were heterogeneous. A fourth factor indicated a strong preference for results delivery to be personalized with many preferring to be contacted by phone for a two-way dialogue. Finally, respondents also noted the need for expanded LCS program accessibility (location and expanded hours beyond nine to five on weekdays) as a logistical consideration that impacts adherence.

Development of the Framework for EA-LCS

The team adopted a socioecological perspective and embraced Lung-RADS to provide a structured and predictable algorithm to inform adherence. The *EA-LCS* framework incorporated three themes (e.g., respect, trust, and engagement) guiding the adoption of three foundational principles, two cross-cutting considerations, and 11 key strategies (Fig. 1).

Foundational Principles. First and foremost, the EALCS embraces a person-centered approach to LCS implementation, linking to the *respect* theme. Facilitating optimal adherence requires a thorough understanding of the community of individuals eligible for LCS. Individuals at high risk of lung cancer encounter barriers to LCS uptake and adherence, including stigma, fatalism, and medical distrust, ¹⁴ and may have less access owing to geography or socioeconomic resources.

The second EA-LCS principle highlights the *trust* theme and recognizes the importance of building trusted relationships between candidates/participants and LCS programs. LCS implementation remains in its infancy and lacks a favorable social environment. Staff may need to recognize and embrace the importance of integrating relationship development efforts to facilitate LCS adherence.

The third EA-LCS principle connects with the *engagement* theme and emphasizes sustained communication, including the idea that every participant contact is an opportunity to build engagement and affiliation, using clear and empathic communication and employing supportive and encouraging imagery.¹⁵

Group	Theme	Representative quotes
LCS program staff	Use of specialized tracking software	"Well, there's a report that comes out twice a week and that'll show patients that are scheduled for their CT lung screening, but it's not just for one month it's for all of those scheduled for the next couple months. So like tomorrow again a report, and it could be like five pages long and it'll have, you know, July, August, September of a whole bunch of patients that are scheduled for CT lung screenings, but they don't all show up So, I just go in daily and just look at who I need to call and check it"
	Developing a personal connection and reliable touchpoint for program participants	"I feel like I develop a relationship with a lot of the patients, so that they trust me, and they come back, and they want to see me every year and check in. I feel like that's a really good way to not only enhance the program and the experience but also to help with adherence when they know that I am their go-to person for lung cancer screening, they're going to see me again next year. I'm not going anywhere, and that I expect them to come back every year." Another respondent highlighted the importance of connection and identifying with a program, "I think like feeling connected to something Sort of something that has a structure around it or it gets a "screening program." It's not like it's just a test, but part of that preventive or early detection approach. And probably the contact with the navigator helps because it identifies, identifies it with an actual person."
	Centralized program operations	"We worked really, really hard to get out there to our providers to show them that we are not making more work for anyone that we really want to in the most positive sense of the word own these patients and that we take full responsibility for making sure that we schedule the appropriate follow up and we communicate results to them and to their referrers."
	Streamlining and standardizing reporting of results	"One of my goals is constantly being a good communicator to our referring doctors, referring nurse practitioners, whatever they are, because I think that communication is crucial, you know, and again, building that relationship with them and I try really hard to communicate in every way that I can." In addition to a systematic reporting, staff also noted the importance of clear written and verbal communication with participants, favoring plain language over more detailed medical terminology.
LCS participants	Importance of a single point of contact Communications tailored to their preferences for receiving	"It would be better if everybody calls from the same number. Which I know technically isn't that hard to do even if it's not the same phone." "So, I think a combination of things, a text, an email, and a phone call. think they could have called on my cell phone if I didn't respond to a
	information Personalized delivery of results	mailing." "It's a good system when you actually get to talk to someone in case you have questions. I don't like it when people leave messages because you may forget your question by the time you actually get to speak with someone."
	Expanded accessibility to LCS programs	"I do have to go a distance. Not far. It's not hundreds of miles. It's maybe 20 miles. The hours are, well I don't want to go early in the morning because then I'm stuck in traffic going to work. I always schedule at 3:30 because that's their last appointment. If I get stuck in traffic, the CT tech calls me and is like are you getting close, its Friday afternoon. Are you coming? and I'm like yeah. I'm in traffic. I am coming. Later hours would be very good or even Saturday."

Fundamental Considerations of the EA-LCS. In addition to the three *EA-LCS* Foundational Principles, two cross-cutting considerations have been adopted, a *Communications Audit* and the *Tripartite Framework of Behavioral Adherence Elements.*

Communications Audit. Communication preferences vary across individuals, and many perceive benefits from

receiving multiple notices across platforms. A *Communications Audit* involves identifying primary and secondary contact information and communication preferences from each participant and providing opportunities to update preferences.

Tripartite Framework of Behavioral Adherence Elements. The EA-LCS considers three different behavioral

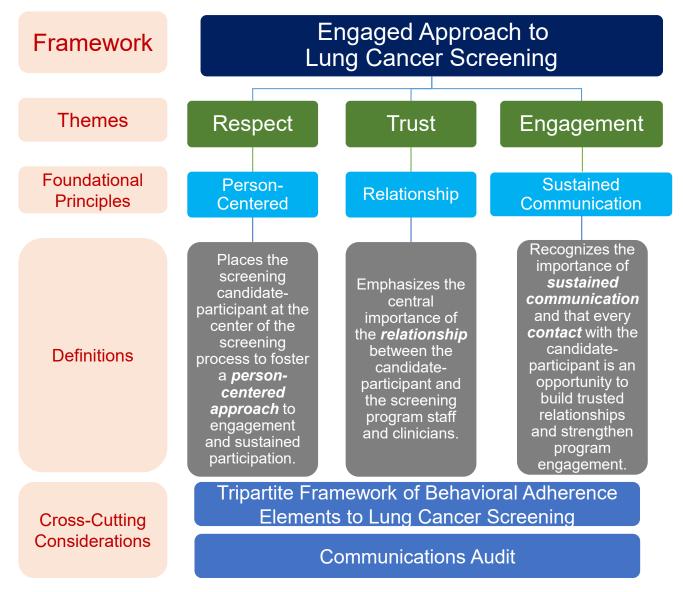


Figure 1. The EA-LCS. EA-LCS, Engaged Approach to Lung Cancer Screening

adherence elements. Figure 2 shows the first behavioral adherence element (baseline adherence), conducting the baseline LDCT as scheduled (the show-no-show rate). The second element (interval adherence) involves recommended follow-up, interval scans, or diagnostic

procedures recommended by Lung-RADS (usually 3 or 4) or the clinical team. Adherence to interval recommendations likely constitutes the most vital element given the identification of a suspicious finding. *Annual adherence* is the third and most challenging behavioral

The Tripartite Framework of Behavioral Adherence Elements to Lung Cancer Screening					
Awareness	Eligibility/Choice	Baseline Scan	Interval Scan	Annual Scan	
Pre-Screening Phase		Baseline Adherence	Interval Adherence	Annual Adherence	
		Within three months of scheduled initial scan	Within one month (+/-) of the planned diagnostic test or procedure	Within 11 – 15 month window of baseline scan	

Figure 2. The tripartite framework of behavioral adherence elements to lung cancer screening.

Table 3. Strategies Within the EA-LCS Key Strategies (We recommend/encourage) Recommended Strategy Rationale The EA-LCS adopts a socioecological framework that places Placing the candidate at the center of the LCS program instead of the program coordinator or navigators helps understand the candidate's the candidate or participant at the center of the screening process and fosters a person-centered individual context and perspective on screening participation and engagement approach. work with candidates to build engagement and trust to sustain involvement with the program. The EA-LCS favors the centralization of screening program Centralized program operations streamline candidate management operations and responsibility for candidate/participant from the initial appointment schedule to communications with the management across the LCS cascade. referring physician and specialty care if needed. The EA-LCS strongly encourages initial and ongoing There is a lack of public awareness and trust in LCS that impacts relationship development efforts between the candidate/ individual decisions to participate and sustain engagement with the participant and the screening program staff and LCS algorithm. During the initial phases of launching clinicians. implementation, there is an acute need to act in trustworthy ways with candidates/participants until such time that there is a greater social endorsement of LCS and a social norm of considering LCS if eligible. The EA-LCS acknowledges the importance of an available, A single and recognizable source of reliable contact is a key component single, and primary point of contact for all program of program engagement and feeling connected to a program. communications, questions, or issues. Empathic communication by program staff facilitates the connection with the program and leads to adherence. The EA-LCS recognizes that every contact with the Given the novelty of LCS and the fact that most individuals will only candidate/participant in the context of LCS is an need annual screening, frequent touchpoints and consequently, opportunity to act in a trustworthy manner to build rapport building is constrained. Each point of communication, be it relationships and strengthen program engagement. digital, email, telephone, or face-to-face is an opportunity to form relationships and build engagement or a missed opportunity to achieve the same. The EA-LCS centralizes and encourages sustained Programs should create additional contact points by using newsletters communication and engagement between the LCS or other means to communicate content to candidates or candidate/participant and staff and clinicians (and participants and build familiarity with the program and LCS referring clinicians). procedures. For the individuals who have established primary care clinicians, communicating effectively with referring clinicians builds trust and the program can benefit as an extension of that trust. The EA-LCS embraces a foundation of communication Screen-eligible individuals report that lung cancer and smokingconstructed on the basis of principles of plain language related stigma impede them from pursuing LCS and that the novelty and stigma-free, person-centered messaging and imagery. and unfamiliarity of LCS breed skepticism and distrust. The EA-LCS recommends that extensive consideration be given to the content, imagery, and overall design of all communication materials regarding LCS programs. Attention to plain language content that also works to communicate with a low literacy burden is important to facilitating engagement. The design and imagery used in all communications, including the avoidance of tobacco-related images or fear-based appeals, matters. The EA-LCS wishes to empower ALL LCS staff and clinicians Every staff member and clinician impacts the connection between the in the mission of engaging candidates and participants to candidate/ participant and the program. For example, radiology achieve adherence to the LCS process. techs that administer LDCTs may not always be considered part of an LCS program, yet they play a vital role and have an opportunity to spend time interacting with LCS program participants. This time can be partially used to reinforce program goals, support participants in their efforts to screen, calm concerns and fears about screening, and deliver poignant messages about the importance of returning annually. It provides a clinical opportunity to address the importance of adherence if a participant did not recall that annual screening was a key element of the screening process.

The EA-LCS leverages available and expanding technology

candidates/participants.

and digital tools to build and sustain engagement with

(continued)

The emergence of high-quality LCS program management software

accordance with those preferences.

integrates opportunities to facilitate reliable communication and

person-centered approaches. Many platforms offer the opportunity to automate communications that can be delivered across platforms, including email, mail, and text messaging. This automation creates opportunities to assess participant communication preferences and tailor delivery and content in

Table 3. Continued			
Recommended Strategy	Rationale		
The EA-LCS encourages formation of a learning community among LCS programs to construct, test, and disseminate best practices.	Few programs achieve desirable, let alone optimal adherence rates. It is reasonable to think that some solutions may be tied to local or regional challenges and opportunities. Convening with regional or institutionally linked programs to explore best practices or ideas for building engagement may help optimize service delivery and outcomes.		
The EA-LCS seeks cost-efficient interventions that support engagement but minimize costs and adverse program budget impact.	LCS is not considered a lucrative operation and some programs operate on very modest budgets, particularly programs with a lower volume and in rural or underserved areas (despite the disproportionate burden of risk in these areas). Thus, it is important to consider the costs associated with efforts to support engagement and adherence.		

EA-LCS, engaged approach to lung cancer screening; LCS, lung cancer screening.

adherence element – completion of the annual LDCT scan for individuals who received Lung-RADS 1 or 2. This conceptualization recognizes that different interventions may be necessary to support adherence to each element. In addition, some approaches that support one element might hinder adherence to another.

Discussion

Studies of community-based LCS programs have highlighted multiple implementation challenges that must be addressed to achieve the individual and population health potential of LCS. 12,13 Specifically, LCS implementation currently faces the twin challenges of both uptake and adherence to the screening algorithm. Efforts to address only one component of the twin challenge are unlikely to render optimal outcomes. Our research indicated that three behavioral elements of LCS will play a vital role in determining the utility of LCS and whether community-based implementation will achieve the promise engendered by the National Lung Screening Trial results. Although translational divergences are expected, the stark adherence gap should serve as a call to action for intervention development.

The EA-LCS framework was developed by triangulating data from LCS staff and participants/candidates and expert knowledge. Driven by the foundational principles and cross-cutting considerations, this framework provides 11 key implementation strategies that should be considered when developing interventions to improve adherence and patient outcomes (Table 3).

Strengths and Limitations

Strengths. Participants were drawn from two diverse regions with high rates of LCS eligibility and included perspectives from adherent and nonadherent individuals. LCS staff represented a broad cross-section of LCS program directors and coordinators/navigators. Second, the study was driven by a socioecological perspective that

considered the social and environmental contexts across multiple strata. Finally, this study completed the essential first steps in the process of developing and evaluating a person-centered framework constructed in collaboration with community partners.

Limitations. The small sample size is reasonable for our predominantly qualitative and developmental efforts but may constrain the generalizability of findings and conclusions.

Conclusions and Future Directions

This research formulated the EA-LCS framework, which provides a foundation of principles and considerations aimed at supporting LCS implementation and building engagement to facilitate LCS adherence. The next phases of research will develop an LCS program intervention on the basis of the EA-LCS framework, and then undertake usability testing in preparation for a feasibility and acceptability trial before pursuing an efficacy trial to evaluate the impact of the EA-LCS intervention on LCS engagement and adherence.

CRediT Authorship Contribution Statement

Margaret Byrne: Conceptualization, Funding acquisition, Project administration, Methodology, Writing - review & editing

Erin A. Hirsch: Methodology, Writing - review & editing

Kaitlyn Hoover: Methodology, Writing - review & editing

Jessica H. McCoy: Data curation, Formal analysis, Visualization, Writing - original draft, Writing - review & editing

Courtney R. Blair: Data curation, Formal analysis, Visualization, Writing - original draft, Writing - review & editing

Michelle Futrell: Methodology, Writing - review & editing

Upal Basu Roy: Conceptualization, Project administration, Methodology, Data curation, Writing - review & editing

Jamie L. Studts: Conceptualization, Funding acquisition, Project administration, Methodology, Writing - review & editing

Disclosure

Dr. Studts has provided consulting to Genentech and J&J to support efforts facilitate lung cancer screening. The remaining authors declare no conflict of interest.

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