

1 **Lung cancer screening knowledge, perceptions and decision-making among African**
2 **Americans in Detroit, Michigan**

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33 All authors report no conflicts of interests in conducting this research.

34

35 **Words:** 2993

36 **Pages:** 21

37 **Tables:** 2

38 **Appendices:** 1

39 **Supplementary Tables:** 4

40

41 **Abstract**

42 **Background**

43 Previously, a web-based, patient-facing decision aid for lung cancer screening,
44 shouldiscreen.com, had been developed and evaluated. An initial evaluation was completed prior
45 to the Medicare coverage decision and recruited a non-diverse sample of mostly former smokers,
46 limiting the understanding of the potential effectiveness of the tool among diverse populations.

47
48 **Objectives**

49 To evaluate shouldiscreen.com among African Americans in Metro Detroit.

50
51 **Methods**

52 Using insights obtained from participatory workshops in this population, content changes to
53 shouldiscreen.com were implemented and this modified version was evaluated with a before-
54 after study. Measures included knowledge of lung cancer screening, decisional conflict, and
55 concordance between individual preference and their eligibility for screening. Surveys took place
56 between April-July 2018. Participants were contacted six months after the survey to assess
57 subsequent screening behaviors. Analysis took place in 2019.

58
59 **Results**

60 Data were collected from 74 participants aged 45-77, who were current/former smokers with no
61 history of lung cancer. Average knowledge score increased 25% from 5.7 (SD=1.94) before to
62 7.1 (SD=2.30) after (out of 13 points). Decisional conflict was halved between before and after.
63 Concordance between individual preference and eligibility for screening increased from 22%

64 (SD=41) to 35% (SD=47). Half of the participants felt uncomfortable answering surveys
65 electronically and requested paper versions.

66

67 **Conclusions**

68 Use of the tool led to small improvements in lung cancer screening knowledge and increased
69 concordance with current recommendations. Additional design modifications and modes of
70 information delivery of current decision aids should be considered to increase their efficacy in
71 helping populations with lower educational attainment and computer literacy.

72

73 **Introduction**

74 The decision to undergo low-dose computed tomography lung cancer screening (LCS) is
75 complex. An individual must weigh the potential benefit of reduced risk of dying from lung
76 cancer against the potential harms of anxiety due to false-positive and incidental findings,
77 complications from follow-up tests such as a lung biopsy, and overdiagnosis. To help patients
78 weigh the potential harms and benefits in relation to their values and preferences, the Centers for
79 Medicare and Medicaid Services (CMS) requires a shared decision-making visit with the use of
80 one or more decision aids for reimbursement.¹

81

82 While CMS did not specify a medium for delivering the decision aid, the growing trend of older
83 adults looking for health information on the Internet supports efforts to develop accessible,² web-
84 based decision tools for LCS. For these tools to be accessible and inclusive to all who might
85 benefit from learning about LCS, they need to be tested in diverse communities. This is
86 particularly important for African Americans, since African American men have higher risk of
87 lung cancer compared to other groups given equal smoking intensity.^{3,4} Knowing how to assist
88 these high-risk groups in learning about LCS is essential. Moreover, racial/ethnic minorities and
89 those with lower education have been shown to be less likely to report correct knowledge about
90 cancer screening compared to other groups with higher education.⁵ Within the US, there is
91 evidence for differences in cancer risk perception by ethnic background,⁶ requiring extra
92 attention in the design and language used in a decision aid so that it is inclusive and effective.
93 Yet, current tools have not been extensively evaluated in diverse populations.

94

95 Thus, as part of a continuous decision aid development process,⁷⁻⁹ a before-after study was
96 conducted on a widely-used decision aid that had previously been tested in a predominantly
97 white, highly educated population from Ann Arbor, Michigan: shouldiscreen.com. The website
98 focuses on preparing a person for decision-making, prior to the discussion with a provider,
99 although it is flexible enough to be used at LCS shared decision-making visits. The current study
100 focuses on recruiting African Americans from a community in Detroit, Michigan. The decision
101 aid's effect on knowledge and decisional conflict was measured. As done previously,^{7,8}
102 concordance, defined to be agreement between individual screening preferences and official
103 recommendations, was also ascertained. Analogous to patient/clinician concordance which is a
104 match between the patient's preferred option and the clinician's recommended option,¹⁰ the
105 measure of concordance here is relevant to LCS; a recent study¹¹ estimated that the number of
106 people who did not meet the USPSTF criteria¹² and reported LCS, were approximately five times
107 greater than those who did meet the criteria and received screening. This is concerning since
108 there are harms associated with LCS,¹³ thus there is a need to limit it to only those with high
109 enough risk (i.e. the screen-eligible) for it to result in a reasonable benefits-to-harm ratio at the
110 population level.^{12,14} Six months after the before-after study, study participants were contacted to
111 determine if they took steps to consult their health care providers about LCS.

112

113 **Methods**

114 *Recruitment*

115 Community-based organizations on the east side of Detroit that served the African American
116 community were engaged. In partnership with these organizations, a convenience sample of
117 study participants were recruited through various community events (March-June 2018). Study
118 participants were eligible to be a part of the study if they were current/former smokers, 45-77
119 years old, did not have a history of lung cancer, and did not participate in any prior testing of the
120 tool. Eligibility for this study included those who would *not* be recommended for LCS based on
121 USPSTF guidelines.¹² While a documented shared decision-making visit is a requirement to be
122 reimbursed for LCS for those eligible through Medicare, the essence of the decision in question
123 is both deciding to receive screening as well as *not* to, regardless of eligibility. It is important to
124 provide balanced information, so that individuals – both eligible and ineligible for LCS
125 according to the latest guidelines – can make the right decision for them using the best available
126 information. Moreover, USPSTF recommendations could change; the National Comprehensive
127 Cancer Network already recommends screening with 20 pack-years (as opposed to 30 pack-
128 years) for some groups,¹⁵ and the USPSTF is currently revising its recommendations.¹⁶
129 Therefore, this study was not limited to individuals who would be eligible by current USPSTF
130 recommendations. This study was approved by the University of Michigan Health Sciences and
131 Behavioral Sciences Institutional Review Board (# HUM00129000).

132

133 *Intervention*

134 A modified version of shouldiscreen.com, a web-based decision aid, was used to include the
135 following: basic information about LDCT screening, education about lung cancer risk factors,

136 and a lung cancer risk calculator which computes a personalized risk based on the PLCOm2012
137 model.¹⁷ This decision aid also fulfilled the relevant standards stipulated by the International
138 Patient Decision Aid instrument^{18,19} and CMS.³ Participatory design workshops that preceded the
139 before-after study⁹ prompted us to modify the tool’s content, such as adding information about
140 insurance coverage and eliminating icon arrays.

141

142 *Study design*

143 After screening for study eligibility over the phone, a participant was invited to complete a series
144 of surveys that was previously developed,^{7,8} at a meeting room in one of two community centers
145 in Detroit facilitated by 2-3 research staff. Participants had the option of choosing to complete a
146 paper survey or an online version administered by Qualtrics (an online survey platform) using a
147 laptop purchased for the study. Note that it was not an a priori aim of the study to assess the
148 mode of delivery, but options were provided based on the recommendation of community
149 partners. The “before” survey contained questions regarding socioeconomic status, smoking
150 history, knowledge of lung cancer and LCS, decisional conflict, health literacy, and numeracy.
151 At a participant’s indication of completion, a research assistant directed the participant to the
152 website where the decision aid is located. The participant was then asked by a research assistant
153 to explore the website for 5-10 minutes and report back when he/she was done reviewing the
154 website. Participants were not given any instructions on how to navigate the site, simulating how
155 it would be if the participant were to come across shouldiscreen.com on their own. When the
156 participant was done reviewing the website, the participant was asked to complete the “after”
157 survey, including: knowledge of lung cancer and LCS, decisional conflict scale, **values**
158 **clarification**, and acceptability.^{7,8} Surveys took place between April-July 2018 and each session

159 lasted approximately 60 minutes. Participants received \$20 in cash for their participation. Six
160 months after their participation, they were contacted up to 3 times and were asked about steps
161 they had taken to see a doctor about LCS, and resources they might have used for smoking
162 cessation (see Appendix 1). This took 5-10 minutes, and responses were recorded by a research
163 assistant. Participants completing this follow-up phone survey received a \$10 check for their
164 participation.

165

166 *Measures*

167 Similar to the prior study in Ann Arbor,^{7,8} outcome measures were derived from the Ottawa
168 Decision Support Framework,²⁰ and included knowledge of the risk factors of lung cancer and
169 the potential benefits and harms of LCS, decisional conflict,²¹ and acceptability. However, unlike
170 the pilot study which used the traditional decisional conflict scale, the shorter version with 10
171 items and 3 response categories was used, which reduces survey burden but retains good
172 psychometric properties.²¹ Preference for screening was determined by the first question from
173 the decisional conflict scale: “Which option do you prefer? A) I prefer to screen; B) I prefer not
174 to screen; C) Unsure.” Eligibility for LCS under USPSTF criteria was determined by self-
175 reported smoking history collected in the “before” survey. Those who chose “I prefer to screen”
176 and were eligible for screening under the USPSTF criteria, as well as those who said “I prefer
177 not to screen” and were not eligible for screening, would be classified as “concordant.” Other
178 combinations were classified as “discordant.” Items from “BRIEF: Health Literacy Screening
179 Tool”²² were further included to help determine the level of health literacy among the
180 participants (last three items on Table 1). To measure health numeracy, the General Health

181 Numeracy Test was added.²³ A summary of the values clarification responses is provided in the
182 appendix.

183

184 *Statistical analysis*

185 A sample size of at least 52 was calculated to detect a 20% improvement in knowledge assuming
186 an initial mean of 7.8, with power of 0.8. To test for the difference of means between the before
187 and after survey in the knowledge and decisional conflict score, we conducted Wilcoxon rank
188 sum test. For concordance, we used McNemar's test. All data analysis was conducted with R
189 statistical software version 3.5.2.²⁴ Analysis took place in 2019.

190

191 **Results**

192 A total of 74 participants from the African American community participated. Their
193 characteristics are summarized in Table 1. The average age of the study participants was 63 years
194 old (SD=6.84), 48.6% were women, 39.6% had a high school education or less, 68.9% were
195 current smokers, 25.0% reported a smoking history of 30 pack-years or more, and 20.5% of
196 participants were eligible for LCS according to USPSTF criteria. Although based on feedback
197 from the post survey focus groups,⁹ the 20.5% may be an underestimate as participants had
198 difficulty recalling and summarizing their smoking history given multiple quit attempts; e.g.
199 some participants only considered the most recent period they had been smoking. Of the 15
200 people who would be eligible for screening under USPSTF criteria, 12 were current smokers.

201

202 Half of the participants opted to complete the survey using paper and 48.6% reported having no
203 access to the internet at home or at work. The reasons participants gave for choosing the paper

204 survey varied: discomfort with navigating a computer device, font on the laptop was too small as
205 reading glasses were left at home, arthritis, felt it was more private to complete a paper survey as
206 opposed to an online survey, and peripheral neuropathy from their medication. Some of these
207 participants asked the research staff to help navigate the website. Navigation was done under the
208 direction of the participant to emulate as if they had a friend or family member to help click on
209 topics that were of interest to them. Regarding health literacy, 60.8% had trouble understanding
210 written health information. In terms of numeracy, we saw that the concept of “risk” as a
211 probability was not well-understood among the participants. When asked: “If 4 people out of 20
212 have a chance of getting a cold, what would be the risk of getting a cold?”, only eight
213 participants answered this correctly. Another question asked: “Your doctor tells you that you
214 have high cholesterol. He informs you that you have a 10% risk of having a heart attack in the
215 next 5 years. If you start on a cholesterol-lowering drug, you can reduce your risk by 30%. What
216 is your 5-year risk if you take the drug?” None of the responses entered were correct. We also
217 asked: “A mammogram is used to screen women for breast cancer. False positives are tests that
218 incorrectly show a positive result. 85% of positive mammograms are actually false positives. If
219 1000 women receive mammograms, and 200 are told there is an abnormal finding, how many
220 women are likely to actually have breast cancer?” For this question, 7 responses were correct.

221
222 In Table 2, we show changes in knowledge, decisional conflict, and concordance before and after
223 seeing shouldiscreen.com. Knowledge about risk factors and screening improved from an
224 average of 5.69 points (SD=1.94) before viewing the decision aid to 7.09 (SD=2.3) out of 13
225 points after, a 25% improvement. When we stratified knowledge by survey mode, there was a
226 greater improvement in knowledge among those who took the electronic survey compared to

227 those who took the paper survey (see Supplementary Table 1). Decisional conflict decreased by
228 49% from an average score of 17.46 (SD=11.44) to 8.89 (SD=9.65). Concordance between
229 individual preference and eligibility for screening increased from 21% to 33% (n=72). The
230 primary source of discordance was from those who preferred to be screened but do not meet
231 current eligibility criteria: there were 41 of these participants prior to seeing the decision aid, and
232 38 participants after. The largest improvement in concordance came from those who were
233 unsure; 16 out of 72 people were classified as “discordant” from being unsure in the *before*
234 survey, compared to 10 people in the *after* survey. Of the 6 participants who were no longer
235 unsure, 5 were classified as concordant. Lastly, we found that acceptability was high: 93% of all
236 participants said the tool helped them consider screening.

237

238 Only 15 out of 74 participants were successfully contacted six to eight months after their
239 participation. Six participants contacted their healthcare providers. According to the participants’
240 self-reported smoking history, only one out of the 15 was eligible for LCS under the USPSTF
241 criteria. Her healthcare provider gave a recommendation to be screened and the participant
242 underwent screening. Two participants were not eligible as they did not meet the pack-year
243 criterion and their health care providers did not recommend they be screened. However, two
244 participants were given screening recommendations by their healthcare providers, despite one
245 not meeting eligibility criteria (one smoked fewer than 30 pack-years, and another who was too
246 young). The one who did not have 30 pack-years reported having been screened. Finally, one
247 participant who was 61 years old with a 45 pack-year tobacco history had quit smoking 16 year
248 ago and reported that screening was not recommended by his clinician.

249

250 [Table 1 here]

251 [Table 2 here]

252

253 **Discussion**

254 We found that the use of shouldiscreen.com, when tested in a community-based African-
255 American sample, led to small improvements in LCS knowledge and increased concordance
256 (although still low) with current recommendations. The largest source of discordance was from
257 participants who were not eligible but preferred to be screened. This may be due to difficulty in
258 understanding the harms relative to the benefits, and/or that screening, a medical procedure to
259 find early signs of a disease, is generally perceived to be beneficial. Moreover, the source of
260 discordance in this study is consistent with the fact that out of the adults who reported receiving
261 lung screening in 2015, those who were not eligible under the USPSTF criteria considerably
262 outnumbered those who were eligible.¹¹ The small number of participants eligible for screening
263 under the USPSTF criteria limits the study findings from this group. Decisional conflict almost
264 halved after participants reviewed the decision aid. We also saw greater improvements among
265 those who opted for the electronic survey as opposed to the paper survey (see Supplementary
266 Table 1). Though this finding was part of an exploratory analysis, it suggests the need to further
267 examine how different kinds of media (other than a website, such as paper pamphlets), devices
268 (touchscreen tablets or cellphones), and interactions (e.g. what if the navigation were done with a
269 health counselor?) could enhance knowledge uptake.

270

271 Further, in participatory design workshops and post-survey focus groups for shouldiscreen.com,⁹
272 quantitative presentations of lung cancer risk— presented as a numerical probability or in icon

273 arrays — were poorly-received and poorly understood. Given that probabilistic information is
274 challenging for most,^{25,26} delivering *qualitative* information tailored to the individual may be
275 more desirable as a starting point for many patients.^{9,27}

276

277 This was a community-based study with convenience sampling, had a relatively small sample
278 size, and a quasi-experimental design. While this means that the findings are not necessarily
279 generalizable, they highlight important challenges in LCS implementation. In the same vein, we
280 were unable to contact most of the participants for follow-up. This limits the generalizability
281 regarding what happens after viewing the decision aid outside of a clinical setting, but hints at
282 potential challenges in delivering LCS information telephonically in low-resourced settings.²⁸
283 Nonetheless, out of the 15 participants who we did manage to follow up, the only participant
284 who was eligible went through with screening. Greater awareness about LCS in the population is
285 required to improve uptake of screening among those who are eligible, which remains low.^{29,30}
286 There were also two participants who we determined to be ineligible for screening based on their
287 survey responses, but still reported a recommendation to be screened by their providers. This
288 could indicate potential inconsistency in recording smoking history accurately. We also could
289 not establish whether the knowledge gained from having visited shouldscreen.com was retained,
290 although some degree of knowledge retention has been reported elsewhere.³¹ Finally, the value
291 clarification portion (Supplementary Tables 3.1 and 3.2) showed a high number of missing
292 responses, as well as misconceptions that remained (e.g. many participants thought that there
293 were no disadvantages to lung cancer screening); this also hints at the limitation of asking
294 someone to do this exercise on their own.

295 While additional design modifications and modes of information delivery could further improve
296 the effectiveness of current decision aids, more is needed. Many participants only had a basic
297 cellphone as their sole electronic device (shouldiscreen.com is configured to be properly
298 displayed on smartphones/tablets/computers), did not have access to internet, and/or had trouble
299 using a mouse due to poor health, and discomfort with computer devices. This has also been
300 found in another study testing shouldiscreen.com in a vulnerable population in Seattle.³² As
301 recommended in prior participatory design workshops,⁹ partnering with community
302 organizations and community leaders to foster an in-person, group-learning session to go through
303 the decision aid and discuss the pros/cons of screening could more successfully encourage
304 screening among those who might benefit most from it. Such efforts could use existing
305 community-based health promotion initiatives, such as health fairs and informational talks at
306 community town halls. Moreover, validated video decision aids for patients,^{33,34} as well as take-
307 home hand-outs,³⁵⁻³⁷ could complement the demonstration of web-based tools like
308 shouldiscreen.com.

309

310 **Conclusions**

311 Use of a web-based decision aid, shouldiscreen.com, led to small improvements in LCS
312 knowledge and improved concordance with current recommendations among African Americans
313 in an urban setting. Regardless of the medium of patient-facing decision aids, there are
314 significant structural barriers that need to be overcome to increase awareness of LCS in these
315 communities. Developers of patient-facing decision aids must be cognizant of these challenges
316 and work with community stakeholders so their tools can reach and be used by those who might
317 benefit the most.

318

319 **Acknowledgments**

320 Author contributions: YKL, TJC, MRP, MLC, DAA and RM were responsible for the
321 conception or design of the work; YKL, HB, PH and EJM were responsible for the acquisition of
322 data; YKL analyzed and interpreted the data; YKL, HB, TJC, PH, EJM, MLC, MRP, DAA and
323 RM drafted or revised the paper for important intellectual content and final approval of data; and
324 YKL and RM are accountable for all aspects of the work.

325 Other contributions: We would like to thank our community partners for their invaluable input:
326 Suzanne Cleage and Tiera Robinson at Eastside Community Network and Ms Wanda Black at
327 8330 East Jefferson.

328

329 This work was funded by the National Cancer Institute under Award No. P30CA046592 and the
330 University of Michigan Rogel Cancer Center, Cancer Control and Population Sciences Research
331 Program: Outreach and Health Disparities Grant. The content is solely the responsibility of the
332 authors and does not necessarily represent the official views of the National Institutes of Health.

333

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Table 1: Descriptive statistics (n = 74)

Variable	% (n)
Age (mean, SD)	62.7 (6.84)
Gender	
Male	51.4 (38)
Female	48.6 (36)
Smoking status	
Current smoker	68.9 (51)
Former smoker	31.1 (23)
Eligible to be screened*	20.5 (15)
Education*	
8 years of schooling or less	6.8 (5)
8-11 years of schooling	12.3 (9)
12 years or completed high school	20.5 (15)
Post high school training	11.0 (8)
Some college	28.8 (21)
College graduate or higher	19.2 (14)
Postgraduate or professional degree	1.4 (1)
Annual household income	
Less than \$15000	52.7 (39)
\$15000-\$24999	23.0 (17)
\$25000-\$34999	9.5 (7)
\$35000+	5.4 (4)
Don't know/Prefer not to answer	9.5 (7)
Survey medium	
Computer-based	50.0 (37)
Paper	50.0 (37)
Electronic devices owned*	
Basic cellphone only	30.1 (22)
Smartphone, such as iPhone, Android, Blackberry or Windows phone	34.2 (25)
Tablet like an iPad, Samsun Galaxy, Motorola Xoom or Kindle Fire	6.8 (5)
A smartphone and a tablet	20.5 (15)
I have none of these devices	8.2 (6)
Access to internet at home/work	
Yes	51.4 (38)
No	45.9 (34)
Don't know/Not sure	2.7 (2)
How often do you find numerical information to be useful?*	
Very often	13.7 (10)
Fairly often	23.3 (17)

Sometimes	37.0 (27)
Rarely	17.8 (13)
Never	8.2 (6)
<hr/>	
Trust of risk predictions of getting a disease in future*	
A lot	17.1 (12)
Quite a bit	31.4 (22)
Somewhat	32.9 (23)
A little bit	18.6 (13)
<hr/>	
How often do you have someone help you read hospital materials?	
Always	5.4 (4)
Often	2.7 (2)
Sometimes	18.9 (14)
Occasionally	23.0 (17)
Never	50.0 (37)
<hr/>	
How confident are you filling out medical forms by yourself?*	
Extremely	39.7 (29)
Quite a bit	21.9 (16)
Somewhat	21.9 (16)
A little bit	6.8 (5)
Not at all	9.6 (7)
<hr/>	
How often do you have problems learning about your medical condition because of difficulty understanding written information?	
Always	5.4 (4)
Often	5.4 (4)
Sometimes	36.5 (27)
Occasionally	13.5 (10)
Never	39.2 (29)
<hr/>	

* Does not sum to 74 due to missing data

Table 2: Changes in knowledge, decisional conflict, and concordance before and after viewing the web-based decision aid (N = 74)

	Mean (SD)		p-value	Relative change	Absolute change
	Before	After			
Knowledge (overall) [max = 13]	5.69 (1.94)	7.09 (2.3)	<0.001	+24.6%	1.4
Factors that increase the chances of getting lung cancer [max = 5]	2.66 (1.06)	3.26 (1.09)		+22.6%	0.6
Possible benefits of lung cancer screening [max = 3]	1.39 (0.84)	1.61 (0.89)		+15.8%	0.22
Possible harms of lung cancer screening [max = 3]	1.20 (0.79)	1.47 (0.95)		+22.5%	0.27
Age eligibility for lung cancer screening [max = 1]	0.41 (0.23)	0.55 (0.23)		+34.1%	0.14
Percentage of lumps found on your lung by CT that is not going to be cancer? [max = 1]	0.03 (0.16)	0.20 (0.40)		+666.7%	0.17
Decisional Conflict Scale [max = 40]	17.46 (11.44)	8.89 (9.65)	<0.001	-49.1%	8.57
Concordance*	0.21 (0.41)	0.33 (0.47)	0.016	+57.1%	0.12

*The maximum score is indicated in brackets. *N = 72 for Concordance due one participant with missing preference, and one had undetermined eligibility status for screening*

Supplementary Table 1: Changes in knowledge, decisional conflict, and concordance before and after viewing the web-based decision aid, stratified by survey medium (N = 74)

	Electronic survey (N = 37)			Paper survey (N = 37)		
	Mean (SD)		Relative change	Mean (SD)		Relative change
	Before	After		Before	After	
Knowledge (overall) [max = 13]	5.79 (2.03)	7.83 (2.29)	+35.2%	5.59 (1.86)	6.34 (2.09)	+13.4%
Decisional Conflict Scale [max = 40]	20.16 (10.96)	6.70 (7.86)	-66.8%	14.76 (11.41)	11.08 (10.82)	-24.9%
Concordance*	0.17 (0.38)	0.31 (0.47)	+82.4%	0.25 (0.44)	0.36 (0.49)	+44.0%

*N = 72 due to missing data (one had missing screening preference, one had undetermined eligibility for lung cancer screening)

Supplementary Table 2: Changes in knowledge, decisional conflict, and concordance before and after viewing the web-based decision aid, stratified by screen eligibility (N = 73)

	Screen eligible (N = 15)			Screen ineligible (N = 58)		
	Mean (SD)		Relative change	Mean (SD)		Relative change
	Before	After		Before	After	
Knowledge (overall) [max = 13]	5.67 (1.50)	7.32 (1.54)	+29.1%	5.73 (2.05)	7.04 (2.48)	+22.9%
Decisional Conflict Scale [max = 40]	15.73 (12.16)	6.00 (5.71)	-61.9%	17.59 (11.16)	9.10 (9.59)	-48.3%
Concordance*	0.87 (0.35)	0.87 (0.35)	0	0.04 (0.19)	0.19 (0.40)	+475%

*N = 72 due to missing data (one had missing screening preference, one had undetermined eligibility for lung cancer screening)

Supplementary Table 3.1: Values clarification, “pros” (What is the main advantage that you see for lung cancer screening?)

	n	%
Helps prevent lung cancer	5	6.8%
Know if you have lung cancer	19	25.7%
Early detection	16	21.6%
Saves lives	3	4.1%
Good for smokers	1	1.4%
Reduces chances of dying from lung cancer	1	1.4%
Peace of mind	1	1.4%
Live longer	2	2.7%
Missing/NA	26	35.1%

Supplementary Table 3.2: Values clarification, “cons” (What is the main disadvantage that you see for lung cancer screening?)

	n	%
Radiation	4	5.4%
No disadvantage	15	20.3%
Not detect early enough	5	6.8%
False positive	5	6.8%
Invasive follow up	1	1.4%
Death	2	2.7%
Need to stop smoking	1	1.4%
Another way for doctors to make money	1	1.4%
More harm from screening	1	1.4%
May not recover	1	1.4%
Takes time	1	1.4%
Not being able to get help	2	2.7%
Knowing there might be cancer	2	2.7%
Missing/NA	33	44.6%

Online Appendix 1: Questions for telephonic survey

1. Did you contact a healthcare provider to discuss lung cancer screening?

- 1 Yes [Skip to Q. 3]
- 2 No

2. Why did you decide against it? [Do not give options, instead, let participants speak freely. Can choose more than one response]

- 1 Did not have time / Could not miss work [end]
- 2 The clinic was too far [end]
- 3 Did not want to find out [end]
- 4 Did not think I am going to get lung cancer in my lifetime [end]
- 5 Language barrier [end]
- 6 Not eligible to be screened [end]
- 7 The harms from screening outweighed the benefits [end]
- 8 The whole process would cost too much [end]
- 7 Other, please specify: _____ [end]

3. Did your health care provider describe why lung cancer screening was important and what it involves? [Do not give options, instead, let participants speak freely. Can choose more than one response]

- 1 Yes
 - smoking history
 - eligibility
 - CT-scan
 - incidental findings
 - false positives
 - biopsy
 - early detection and better treatment options
 - other, please specify: _____
- 2 No

4. Did your health care provider give you a recommendation about whether or not to get a lung cancer screening test?

- No, the provider did not make a recommendation (Skip to Q. 5)
- Yes, recommended that I **NOT** be screened
- Yes, recommended that I be screened

4a. If you received a recommendation, how strong was the recommendation your doctor gave you?

1	2	3	4	5
Not at all strong				Very strong

4b. If you received a recommendation, did you feel like you could disagree with your doctor's recommendation.

1	2	3	4	5
Definitely felt that I could NOT disagree				Definitely felt that I could disagree

5. What were the reasons that were given to you to recommend you against screening?

- 1 Age
- 2 Other comorbidities
- 3 Not eligible to be screened
- 4 Other, please specify: _____

6. Have you been screened for lung cancer?

- 1 Yes (Skip to Q. 9)
- 2 No

7. Have you scheduled an appointment to get screened for lung cancer?

- 1 Yes (Skip to Q. 9)
- 2 No

8. Why did you decide not to get screened? [Do not give options, instead, let participants speak freely. Can choose more than one response]

- 1 Did not have time / Could not miss work
- 2 The clinic was too far
- 3 Did not want to find out
- 4 Did not think I am going to get lung cancer in my lifetime
- 5 Language barrier
- 6 Worried about having to do more procedures if they find something
- 7 Money
- 8 Not eligible to be screened
- 9 My risk was for lung cancer was too low and don't think benefits are big enough
- 99 Other, please specify: _____

9. Was it difficult or easy for you to make your decision about lung cancer screening?

1	2	3	4	5
Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult

10. How much information did you have for deciding about lung cancer screening?

1	2	3	4	5	6	7
Not Enough			Just Right			Too much

11. Which sources of information helped you come to your decision about lung cancer screening? Check all that applies.

- 1 Healthcare provider
- 2 Decision aid
- 3 My family
- 4 Friends
- 5 Other. Please specify: _____

12. Overall how would you evaluate the discussion with your provider?

0	1	2	3	4	5	6	7	8	9	10
I had a very poor experience with my discussion around lung cancer screening										I had a very good experience with my discussion around lung cancer screening

13. How much involvement did you have in the decision about lung cancer screening?

1	2	3	4	5	6	7
Not Enough			Just Right			Too much

14. There are a number of resources that people use to help them stop smoking such as telephone quitlines (e.g. 1-800-QUIT-NOW) or website (e.g. www.smokefree.gov). Before being contacted for this study, had you heard of telephone quitlines or websites for help with quitting smoking?

- 1 Yes
- 2 No (Skip to Q. 16)

15. Have you ever called a telephone quitline **or** visited a website for help with quitting smoking?

- 1 Yes
- 2 No

16. Have you ever looked for information on electronic cigarettes (also known as vape-pens, hookah pens, e-vaporizers) from any source?

- 1 Yes
- 2 No (Skip to Q. 19)

17. What kinds of information on electronic cigarettes have you ever looked for from any source? [Check all that apply]

- 1 Health effects
- 2 Using electronic cigarettes to quit or reduce smoking
- 3 List of chemicals in electronic cigarettes
- 4 Cost/Coupons
- 5 Instructions/tutorials
- 6 Where to buy
- 7 Reviews/ratings of brands
- 8 Other, please specify: _____

18. Have you used / Are you using electronic cigarettes to help you quit or reduce smoking?

- 1 Yes, I have used them in the past
- 2 Yes, I am using them right now
- 3 No
- 9 Refused

19. In general, how much would you trust information about health effects of electronic cigarettes from each of the following?

1 Health care provider	Not at all	A little	Some	A lot
2 Family / friends	Not at all	A little	Some	A lot
3 Government agencies (e.g. FDA, CDC)	Not at all	A little	Some	A lot
4 Health organizations (e.g. ACS, ALA)	Not at all	A little	Some	A lot
5 Health websites (e.g. WebMD)	Not at all	A little	Some	A lot
6 Religious organizations / leaders	Not at all	A little	Some	A lot
7 Tobacco companies	Not at all	A little	Some	A lot
8 Electronic cigarette companies	Not at all	A little	Some	A lot

20. Do you currently smoke?

- 1 Yes
- 2 No [END]

21. How likely would you be to call a quitline or visit a website for help with quitting smoking in the future?

- 1 Very likely
- 2 Somewhat likely
- 3 Somewhat unlikely
- 4 Very unlikely

[END OF SURVEY]