1   **Lung cancer screening knowledge, perceptions and decision-making among African**

2   **Americans in Detroit, Michigan**

3

4   Yan Kwan Lau, PhD, MPH[1]

5   Harihar Bhattarai, MPH[1]

6   Tanner J. Caverly, MD, MPH[2,3]

7   Pei-Yao Hung, MS[4]

8   Evelyn Jimenez-Mendoza, MSc[1]

9   Minal R. Patel, PhD, MPH[5]

10   Michele L. Coté, PhD, MPH[6,7]

11   Douglas A. Arenberg, MD[8]

12   Rafael Meza, PhD[1*]

13

14

15   [1]Department of Epidemiology, School of Public Health, University of Michigan

16   [2]Department of Learning Health Sciences, University of Michigan

17   [3]Division of General Internal Medicine, Department of Internal Medicine, University of

18   Michigan

19   [4]School of Information, University of Michigan

20   [5]Department of Health Behavior and Health Education, School of Public Health, University of

21   Michigan

22   [6]Department of Oncology, School of Medicine, Wayne State University

23   [7]Karmanos Cancer Institute, Wayne State University

24   [8]Division of Pulmonary and Critical Medicine, Department of Internal Medicine, University of

25   Michigan

26   ***Corresponding author**: Rafael Meza

27   Address: 1415 Washington Heights, Department of Epidemiology, School of Public Health,

28   University of Michigan, Ann Arbor, MI 48109-2029, United States

29   Office: 734-763-1946

30   Fax: 734-936-2084

31   E-mail: rmeza@umich.edu

32

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

Introduction

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

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

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 study[11] estimated that the number of

106 people who did not meet the USPSTF criteria[12] 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

Methods

Recruitment

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

Intervention

A modified version of shouldiscreen.com, a web-based decision aid, was used to include the 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 study[9] 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 shouldiscreen.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

Acknowledgments

333

334   **References**

335   [1] Jensen TS, Chin J, Ashby L, Hermansen J, Hutter JD. (2015). Decision memo for screening

336   for lung cancer with low dose computed tomography (LDCT) (CAG-00439N), Feb 2015. URL:

337   https://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=274

338   [online; accessed 2019-09-17]

339   [2] National Cancer Institute. (2017). Health Information National Trends Survey (HINTS) 5,

340   Cycle 1. URL: https://hints.cancer.gov/ [Dataset online; accessed 2019-09-17]

341   [3] Haiman CA, Stram DO, Wilkens LR, Pike MC, Kolonel LN, Henderson BE, Le Marchand L.

342   (2006). Ethnic and racial differences in the smoking-related risk of lung cancer. (2006) *N Engl J*

343   *Med* 354(4):333-342.

344   [4] Aldrich MC, Mercaldo SF, Sandler KL, Blot WJ, Grogan EL, Blume JD. (2019) Evaluation

345   of USPSTF lung cancer screening guidelines among African American adult smokers. *JAMA*

346   *Oncol* 5(9):1318-1324.

347   [5] Roberts MC, Ferrer RA, Rendle KA, et al. Lay Beliefs About the Accuracy and Value of

348   Cancer Screening. *Am J Prev Med*. 2018;54(5):699-703. doi:10.1016/j.amepre.2018.02.002

349   [6] Orom H, Kiviniemi MT, Underwood W, Ross L, Shavers VL. (2010). Perceived cancer risk:

350   Why is it lower among nonwhites than whites? *Cancer Epidemiol Biomarkers Prev* 19(3):746-

351   754.

352   [7] Lau YK, Caverly TJ, Cherng ST, Cao P, West M, Arenberg DA, Meza R. (2014).

353   Development and validation of a personalized, web-based decision aid for lung cancer screening

354   using mixed methods: a study protocol. *JMIR Res Protoc* 3(4).

355   [8] Lau YK, Caverly TJ, Cao P, Cherng ST, West M, Gaber C, Arenberg DA, Meza R. (2015).

356   Evaluation of a personalized, web-based decision aid for lung cancer screening. *Am J Prev Med*

357   49(6):e125-e129.

358   [9] Hung P, Lau YK, Ackerman MS, Meza R. (2019). Designing a web-based decision aid for

359   individuals to consider lung cancer screening. In: The 13th International Conference on Pervasive

360   Computing Technologies for Healthcare (*PervasiveHealth'19*), 20-23 May 2019, Trento, Italy.

361   ACM, New York, NY, USA, 10 pages. https://doi.org/10.1145/3329189.3329210

362   [10] Jimbo M, Rana GK, Hawley S, Holmes-Rovner M, Kelly-Blake K, Nease DE Jr, Ruffin MT

363   4th. (2013). What is lacking in current decision aids on cancer screening? *CA Cancer J*

364   *Clin*, *63*(3), 193–214. doi:10.3322/caac.21180

365   [11] Richards TB, Doria-Rose VP, Soman A, Klabunde CN, Caraballo RS, Gray SC, Houston

366   KA, White MC. (2019). Lung cancer screening inconsistent with US Preventive Services Task

367   Force Recommendations. *Am J Prev Med* 56(1):66-73.

368   [12] Moyer VA. (2014). Screening for lung cancer: US Preventive Services Task Force

369   recommendation statement. *Ann Intern Med* 160(5):330-338.

370   [13] National Lung Screening Trial Team. (2013). Results of initial low-does computed

371   tomographic screening for lung cancer. *N Engl J Med* 368(21):1980:1991

372   [14] de Koning HJ, Meza R, Prevrititis SK, ten Haaf K, Munshi VN, Jeon J et al. (2014).

373   Benefits and harms of CT lung cancer screening strategies. A comparative modeling study for

374   the US Preventive Services Task Force. *Ann Intern Med* 160(5):311-320.

375   [15] Wood DE, Kazerooni EA, Baum SL, Eapen GA, Ettinger DS, Hou L et al. (2018). Lung

376   Cancer Screening, Version 3.2018, NCCN Clinical Practice Guidelines in Oncology, *J Natl*

377   *Compr Canc Netw*, *16*(4), 412-441.

378   [16] US Preventive Services Task Force (2018). Draft update summary: Lung Cancer: Screening.

379   April 2018. URL:

380   https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryDraft/lung-

381   cancer-screening1 [Document online; accessed 2019-09-30]

382   [17] Tammemägi MC, Katki HA, Hocking WG, Church TR, Caporaso N, Kvale PA, Chaturvedi

383   AK, Silvestri GA, Riley TL, Commins J, Berg CD (2013). Selection criteria for lung-cancer

384   screening. *N Engl J Med* 368(8):728-36. doi: 10.1056/NEJMoa1211776. Erratum in: N Engl J

385   Med. 2013 Jul 25;369(4):394.

386   [18] Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, Thomson R, Barratt A,

387   Barry M, Bernstein S, et al. (2006) Developing a quality criteria framework for patient decision

388   aids: Online international Delphi consensus process. *BMJ* 333(7565):417.

389   [19] Joseph-Williams N, Newcombe R, Politi M, Durand M, Sivell S, Stacey D, O'Connor A,

390   Volk RJ, Edwards A, Bennett C, et al. (2014). Towards minimum standards for certifying patient

391   decision aids: A modified Delphi consensus process. *Med Decis Making* 34(6):699-710.

392   [20] O'Connor AM, Stacey D, Boland L. (2015) Ottawa Decision Support Tutorial: Improving

393   practioners' decision support skills. Technical report, Ottawa Hospital Research Institute. URL:

394   https://decisionaid.ohri.ca/ODST/pdfs/ODST.pdf [Document online; accessed 2019-09-17]

395   [21] O'Connor AM. (2010). User Manual: Decisional Conflict Scale. Ottawa Hospital Research

396   Institute. URL:

397   https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf [Document

398   online, accessed 2019-09-17]

399   [22] Haun J, Luther S, Dodd V, Donaldson P. (2012). Measurement variation across health

400   literacy assessments: implication for assessment selection in research and practice. *J Health*

401   *Commun* 17(supp.3):141-159.

402   [23] Osborn CY, Wallston KA, Shpigel A, Cavanaugh K, Kripalani S, Rothman RL. (2013).

403   Development and validation of the General Health Numeracy Test (GHNT). *Patient Educ Couns*

404   91(3):350-356.

405   [24] R Core Team. (2018). R: A language and environment for statistical computing. R

406   Foundation for Statistical Computing, Vienna, Austria. URL: https://www.R-project.org/

407   [25] Lipkus IM, Samsa G, Rimer BK. (2001). General performance on a numeracy scale among

408   highly educated samples. *Med Decis Making* 21:37-44.

409   [26] Bakker CJ, Koffel JB, Theis-Mahon NR. (2017). Measuring the health literacy of the Upper

410   Midwest. *J Med Libr Assoc* 105(1):34-43.

411   [27] Melzer AC, Golden SE, Ono SS, Datta S, Crothers K, Slatore CG. (2020). What Exactly Is

412   Shared Decision-Making? A Qualitative Study of Shared Decision-Making in Lung Cancer

413   Screening. *J Gen Intern Med* 35, 546–553 (2020).

414   [28] Tanner NT, Banas E, Yeager D, Dai L, Hughes Halbert C, Silvestri GA. (2019). In-person

415   and telephonic shared decision-making visits for people considering lung cancer screening. *Chest*

416   155(1):236-238.

417   [29] Jemal A, Fedewa SA. (2017). Lung cancer screening with low-dose computed tomography

418   in the United States – 2010-2015. *JAMA Oncol* 3(9):1278-1281.

419   [30] Zahnd WE, Eberth JM. (2019). Lung cancer screening utilization: A Behavioral Risk Factor

420   Surveillance System Analysis. *Am J Prev Med* 57(2):250-255.

421   [31] Mazzone PJ, Tenenbaum A, Seeley M, Petersen M, Petersen H, Lyon C, Han X, Wang X.

422   (2017) Impact of a lung cancer screening counseling and shared decision-making visit. *Chest*

423   151(3):572-578.

424   [32] Crothers K, Kross EK, Reisch LM, Shahrir S, Slatore C, Zeliadt SB, Triplette M, Meza R,

425   Elmore JG. (2016). Patients' attitudes regarding lung cancer screening and decision aids. A

426   survey and focus group study. *Ann Am Thorac Soc* 13(11):1992-2001.

427   [33] Hoffman AS, Hempstead AP, Housten AJ, Richards VF, Lowenstein LM, Leal VB, Volk

428   RJ. (2018). Using a patient decision aid video to assess current and former smokers' values about

429   the harms and benefits of lung cancer screening with low-dose computed tomography. *MDM*

430   *Policy Pract* 3(1):2381468318769886.

431   [34] Reuland DS, Cubillos L, Brenner AT, Harris RP, Minish B, Pignone MP. (2018). A pre-post

432   study testing a lung cancer screening decision aid in primary care. *BMC Med Inform Decis Mak*

433   18(1):5.

434   [35] Veterans Health Administration. (2014). Screening for lung cancer. URL:

435   https://www.prevention.va.gov/docs/LungCancerScreeningHandout.pdf [Document online;

436   accessed 2019-09-17]

437   [36] Agency for Healthcare Research and Quality. (2016). Is lung cancer screening right for me?

438   URL: https://effectivehealthcare.ahrq.gov/decision-aids/lung-cancer-screening/patient.html

439   [online; accessed 2019-09-17]

440   [37] National Cancer Institute. (2019). Lung cancer screening (PDQ) – Patient version. URL:

441   https://www.cancer.gov/types/lung/patient/lung-screening-pdq [online; accessed 2019-09-17]

442

443

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)

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)

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)

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)

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)

* *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 <u>information</u> 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]