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Canadian Task Force on Preventive Health Care

Patient Preferences for Lung Cancer Screening Guideline Recommendations

Prepared by the Knowledge Translation Program

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List of Abbreviations

AGREE	Appraisal of Guidelines for Research and Evaluation
CPG	Clinical Practice Guideline
CTFPHC	Canadian Task Force on Preventive Health Care
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
IOM	Institute of Medicine
KT	Knowledge Translation
LDCT	Low-Dose Computed Tomography
PCP	Primary Care Practitioner
RAM	RAND Appropriateness Method
SMH	St. Michael's Hospital

Executive Summary

Incorporating patient priorities into clinical practice guideline (CPG) development is an important dimension of patient-centred care and can enhance the perceived legitimacy and transparency of the guideline development process. The Canadian Task Force on Preventive Health Care (CTFPHC) therefore aims to incorporate input from patients at two critical points in the guideline development process: (1) when outcomes are selected for inclusion in the systematic review protocol and (2) when the final guideline recommendations and knowledge translation (KT) tools are developed. In this project, we examined patients' values and preferences in relation to the CTFPHC's draft lung cancer screening guideline recommendations. That is, we assessed the extent to which Canadians to whom the guideline with apply perceived the recommendations to be appropriate, beneficial, and feasible to implement. We will use this information to inform the KT tools that the CTFPHC will develop to accompany the guideline. Because this is one of the first times that the CTFPHC has engaged patients in the guideline development process, we also examined participants' experiences in the project.

Method

Canadian participants to whom the CTFPHC lung cancer screening recommendations will apply completed two tasks. They first took part in a focus group during which they discussed the draft recommendations. They then completed a survey in which they rated the social acceptability and implementability of each recommendation. The survey also included closed-ended and open-ended items about participants' experiences in the project. We assessed the following outcomes across the two tasks: (a) perceptions of the recommendations, (b) experience with project tasks, (c) perceived impact of input, and d) satisfaction with the project experience.

Summary of Findings and Discussion

Perceptions of Recommendations

Participants generally agreed with the recommendations but expressed two key concerns. First, participants wondered whether the recommendations to screen for lung cancer with low-dose computed tomography (LDCT) but not with chest x-ray will be feasible to implement in remote regions. As a result, they questioned whether the recommendations will facilitate equitable access to health care across Canada. Second, participants believed that the recommendation to screen for lung cancer should apply to individuals aged less than 55 years and greater than 74 years to avoid missing a lung cancer diagnosis. These findings suggest that it may be helpful for the CTFPHC to develop KT tools aimed at explaining the harms and benefits of LDCT both in different age groups and in comparison to the harms and benefits of chest x-ray.

Participant Experience

Overall, participants indicated that they had a positive experience in the project. Specifically, they found the focus group to be informative and useful for sharing perspectives. They also both believed that the CTFPHC would value their input and enjoyed the opportunity to help address an important health care matter. Thus, participants viewed their experience in the project favourably.

Some participants provided suggestions for improving the project. Specifically, several participants noted that the CTFPHC could make the guideline topic background document easier to understand. They also mentioned that it would be helpful to receive more direction before and during the focus

group so that participants can consider the recommendations more carefully and articulate their perceptions. In addition, some participants mentioned that it would be helpful to offer evening time slots for the focus groups so that individuals who work during the day can take part. We plan to incorporate these suggestions into our process for future patient preferences projects.

Limitations

This report has the following limitations: (a) the sample was relatively small and may not be representative of the population to whom the guideline will apply; (b) the information that participants received during the project may have made them more knowledgeable than most patients about lung cancer screening; and (c) participants received information from the CTFPHC Lung Cancer Working Group chair, which may have influenced their responses.

Suggestions for Applying Findings

We provide the following suggestions for applying the findings from this project to the CTFPHC's lung cancer screening guideline:

1. **Develop KT tools that explain the balance of benefits and harms for different age groups.** The CTFPHC may be able to facilitate shared decision making among clinicians and patients by developing tools that explain why the CTFPHC recommends screening with LDCT in some age groups but not in others.

2. **Develop KT tools that explain why the CTFPHC recommends screening with LDCT rather than with chest x-ray despite the challenges of accessing LDCT in remote regions.** The CTFPHC may be able to support implementation of the lung cancer screening guideline in remote regions by developing KT tools that clarify the harms and benefits of screening with LDCT versus chest x-ray.

3. **Develop a KT tool that explains how the CTFPHC uses GRADE to create guideline recommendations.** The CTFPHC may be able to facilitate comprehension and implementation of the lung cancer screening guideline if it develops resources aimed at helping patients and clinicians understand GRADE.

Introduction

Overview

Incorporating patient priorities and perspectives into clinical practice guideline (CPG) development is an important dimension of patient-centred care.[1] Some evidence shows that patient involvement supports informed decision making, tailors recommendations to individuals, and supports decision making in instances when primary care practitioners (PCPs) perceive a conflict between patient preferences and the application of CPG recommendations.[2,3] A 2006 Cochrane review on consumer participation in health care policy and CPG development found moderate quality evidence showing a benefit of including consumers in the development of patient materials.[4] Nonetheless, guideline developers do not consistently involve patients directly in the guideline development process, even when they attempt to take patient preferences into account. Indeed, a review by the World Health Organization's Advisory Committee on Health Research revealed that only 25% of guideline developers regularly involve patients in the process of guideline development and a critical appraisal of 51 evidence-based CPGs found that only 5% of the word count and 6% of references in the guidelines referred to patient preferences.[5,6] This may be in part because there is limited data on the effectiveness of different patient engagement strategies in guideline development.[7] Indeed, research on patient preferences is not as well developed as are other areas of clinical inquiry and often involves the use of diverse methods that may or may not be effective in identifying patients' values and preferences in relation to guidelines.

Despite the limitations of past research on patient preferences, patient involvement could add important context to the rigorous methodology of CPGs by providing input on patients' diverse social circumstances, behaviours and attitudes toward risk, values, and preferences.[1-3] For guideline developers, patient involvement may also enhance the credibility, transparency, and applicability of CPGs.[8] Indeed, international organizations that appraise the quality of CPGs have set standards and introduced best practices to incorporate patient perspectives into CPGs.[5-6,9] The Institute of Medicine (IOM) and the Appraisal of Guidelines for Research and Evaluation (AGREE) Collaboration explicitly call for patient involvement in the guideline development process. The IOM recommends including a current or former patient and a patient advocate in the CPG development process.[9] Similarly, the AGREE II instrument requires guideline developers to consider integrating patient preferences through formal consultation with patients and patient groups.[10]

The Canadian Task Force on Preventive Health Care (CTFPHC) has taken steps to align its work with patient engagement standards established by the IOM and the AGREE collaboration.[11] Specifically, since its reconstitution in 2010, the CTFPHC has incorporated a contextual question on patient preferences in all evidence reviews, a process that involves a literature search on patient preferences and values specific to the analytic framework of each guideline. Although literature on patient preferences can provide some information about participants' attitudes and values related to screening, it is an indirect source that may not reflect the perspectives of the current screening population. The CTFPHC does solicit direct input from patients when refining draft versions of knowledge translation (KT) tools designed to accompany its guidelines, but this input focuses on usability of the tools rather than on content.[12] For future guidelines, therefore, the CTFPHC will take a more active approach to patient engagement by obtaining feedback directly from members of the public at earlier critical points in the guideline development process. Specifically, the CTFPHC will recruit members of the public to provide feedback at up to two stages. During Phase 1, participants will identify the screening outcomes relevant to a particular guideline topic that are most important to consider during decision making. The CTFPHC will use the results of this phase to inform the evidence review protocol for the guideline.

During Phase 2, participants will provide feedback on the social acceptability and implementability of the CTFPHC's guideline recommendations. The CTFPHC will use the findings from this phase as a basis for developing the KT tools to accompany the guideline. The CTFPHC selected two of its upcoming guidelines as opportunities to pilot its patient engagement process for guideline development: (a) hepatitis C screening and treatment and (b) lung cancer screening. This report describes the method and results of Phase 2 for the lung cancer screening guideline. Because the systematic review for the lung cancer screening guideline was already complete when the CTFPHC incorporated patient engagement into its guideline development process, we were unable to conduct Phase 1 for this guideline.

Lung cancer is a disease that occurs when cells in the lung grow in an uncontrolled way. The cancer may begin in one or both lungs and may not cause any symptoms during early stages of the disease. Over time, the cancer usually takes over parts of the lungs and spreads to other areas in the body.[13,14] Typically, the disease is at an advanced stage by the time that individuals experience symptoms (e.g., persistent cough, chest pain, shortness of breath, and unexplained weight loss).[13] Screening Canadians for lung cancer may reduce mortality, particularly among those who are at high risk for the disease. There are, however, harms associated with lung cancer screening, such as anxiety, overdiagnosis, and complications from follow-up testing.[15] Based on evidence of these harms and benefits, the CTFPHC is developing a guideline on lung cancer screening to provide primary care practitioners with recommendations on screening asymptomatic Canadians for lung cancer.

Objectives

The goal of Phase 2 in the current project was to assess perceptions of the CTFPHC's draft lung cancer screening guideline recommendations among Canadians to whom the guideline will apply. Specifically, we assessed the extent to which members of the public perceived the recommendations to be appropriate, beneficial, and feasible to implement. This process will allow the CTFPHC Lung Cancer Working Group to consider patient preferences when drafting the final guideline recommendations. It will also identify patient questions and concerns to address in the KT tools.

Methodological Approach

We used both qualitative and quantitative methods to assess patient perceptions of the CTFPHC's lung cancer screening guideline recommendations. Specifically, participants first discussed their perceptions of the guideline recommendations during a focus group. They then completed a survey in which they rated the social acceptability and implementability of each recommendation. The focus group gave participants an opportunity to clarify information about lung cancer screening, ask questions about the recommendations, and share perspectives so that they could consider a broad range of information when completing the survey.

Methods

Participants

Participants were English-speaking Canadians to whom the guideline will apply. We recruited participants by asking disease-specific organizations (e.g., COPD Canada) and community groups (e.g., Retired Teachers of Ontario) to circulate our recruitment announcement to their members. We also posted recruitment ads on public advertisement websites (e.g., Charity Village) and the CTFPHC website. In addition, we contacted members of the public who are part of the St. Michael's Hospital (SMH) KT Program's circle of contacts and have expressed interest in providing feedback on CTFPHC guidelines and tools.

We asked individuals who responded to the recruitment announcement to complete a brief online screening questionnaire to assess their eligibility to take part in the project (see Appendix A). Asymptomatic adults aged 18 years and older who had never been diagnosed with lung cancer were eligible to take part. The draft recommendations outlined different screening approaches depending on whether or not individuals had all of the following three risk factors: (a) individual aged 55–74 years old, (b) current smoker or former smoker who quit within the last 15 years, and (c) 30-pack-year smoking history (i.e., the individual had smoked the equivalent of one pack of cigarettes every day for 30 years). Thus, we recruited participants who had all three risk factors and those who had fewer than three risk factors. Participants were not eligible for the project if they indicated that they were a health care professional or had any conflicts of interest relevant to the guideline topic (e.g., owning shares in a company related to lung cancer). Participants received $35 for taking part in the project.

Procedure

Eligible participants first signed and returned a copy of the CTFPHC confidentiality agreement form. They then received a project information sheet, background document on lung cancer screening (see Appendix B), background document on the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) method[16] (see Appendix C), and copy of the CTFPHC's draft lung cancer screening recommendations (see Table 1) by email. The project information sheet outlined the purpose of the project and the role of participants in providing input from a patient perspective. The lung cancer screening background document provided participants with information on (a) lung cancer, (b) how lung cancer affects people, (c) the screening and diagnostic tests for lung cancer, and (d) the harms and benefits of lung cancer screening. We developed this document in consultation with the CTFPHC Lung Cancer Working Group. The GRADE background document provided an overview of the GRADE system, including the strength of recommendation and quality of evidence components.

Table 1. Draft lung cancer screening recommendations

Recommendations
These recommendations apply to asymptomatic adults aged 18 years and older who are not suspected of having lung cancer. These recommendations do not apply to individuals who were previously diagnosed with, or suspected of having, lung cancer.
1) We do not recommend screening for lung cancer with chest x-ray with or without sputum cytology. *Strong recommendation; low quality evidence*
2) For adults aged 55–74 years, who are current or former (i.e. quit less than 15 years ago) smokers with a 30 pack-year smoking history, we recommend three screens with low dose CT, each at one-year intervals. *Weak recommendation; low quality evidence*
3) For adults aged <55 years and >74 years, and for adult smokers of any age with less than a 30 pack-year smoking history, we do not recommend routinely screening for lung cancer with low dose CT. *Weak recommendation; low quality evidence.*

Part 1

One week after receiving the project information sheet, background documents, and draft guideline recommendations, participants took part in one of two 90-minute focus groups via teleconference. Holding the meeting via teleconference made it possible for us to recruit participants from across Canada. During the focus group, participants had the opportunity to clarify information provided in the background documents and to ask questions about the draft recommendations. They also shared their perceptions of the recommendations and the extent to which they agreed with them.

One research coordinator from the St. Michael's Hospital KT team moderated the focus group discussion using a script (see Appendix D), and a second research coordinator took notes to document the discussion. The chair of the CTFPHC Lung Cancer Working Group was also present during the focus groups to answer questions that participants had about the guideline topic or recommendations. We audio recorded all focus group discussions.

Two participants who were unable to attend either of the focus groups took part in a brief teleconference interview with both research coordinators. During the interview, participants shared their perceptions of the recommendations and asked any questions that they had about the recommendations. Because the working group chair was unable to attend the interviews, she responded to participants' questions via email following the interviews. Each interview took approximately 15–30 minutes.

Part 2

After the focus group or interview, participants completed an online survey (see Appendix E). We administered the survey using FluidSurveys. The survey included 29 scale-response items and three open-ended items aimed at assessing the social acceptability and implementability of the draft guideline recommendations (e.g., "Implementing this recommendation will lead to better health outcomes for Canadians [to whom the recommendation applies]", "I think this recommendation will be easy for primary care providers to implement in their practices across all rural settings in Canada"). They rated these items along a 9-point scale with endpoints labelled 1(*Strongly disagree*) and 9(*Strongly agree*). Participants then completed a modified version of the Rand Appropriateness Method post-survey questionnaire to assess their experience in the project.[17] Specifically, the survey included nine items to assess participants' experiences with the focus group and survey, four items to assess their perceptions of the impact that their input will have, and two items to assess participants' satisfaction with their overall experience in the project. Participants rated these items along a 9-point Likert-type scale with endpoints labelled 1(*Not at all*) and 9(*Very much*). Participants also responded to one open-ended item about the focus group, one open-ended item about the survey, and three open-ended items about their overall experience.

We will send participants a summary report of the findings and conduct a group debriefing session with them via teleconference once the project is complete. We will also send them a copy of the guideline and KT tools after the guideline is released.

Outcomes and Data Analysis

Table 2 lists the key outcomes, data sources, and data analysis methods used in the project.

Table 2. Outcomes assessed, data sources for outcomes, and data analysis methods

Outcome	Data source	Data analysis method
Perceptions of recommendations	Survey	• Descriptive statistics • Qualitative analysis
	Focus groups/interviews	• Content analysis
Experience with project tasks	Survey	• Descriptive statistics • Qualitative analysis
	Focus groups/interviews	• Content analysis
Perceived impact of input	Survey	• Descriptive statistics
Satisfaction with experience	Survey	• Descriptive statistics • Qualitative analysis

Results

Fifteen individuals took part in the project, including 3 men and 12 women aged 36–76 years old (mean age [*M*] = 62.60, standard deviation [*SD*] = 10.33). Although the majority of participants were from Ontario (*n* = 10), there were some participants from British Columbia (*n* = 3), Alberta (*n* = 1), and Manitoba (*n* = 1). Most participants lived in urban (*n* = 6) or suburban (*n* = 5) regions of Canada, but some participants lived in rural regions (*n* = 4). One participant was Aboriginal. Almost an equal number of participants did (*n* = 8) versus did not (*n* = 7) have a history of smoking. Among participants with a smoking history, only one was a current smoker; all other participants had quit within the past 15 years.

Five current or former smokers had at least a 30-pack-year smoking history and all of these participants were between the ages of 55 and 74 years. The remaining three participants with a smoking history had smoked fewer than 30 pack years.

Aside from the two participants who took part in an interview, two participants were assigned to a focus group but did not attend their session. These participants had the opportunity to submit questions about lung cancer screening and the draft guideline recommendations to the working group chair via email before completing the survey. We found a similar pattern of results when including versus excluding participants who did not attend a focus group or interview in our analyses of survey data. Thus, the survey results summarized in this report are based on data from the full sample. Survey findings related to participants' experiences during the focus group are based on data from the 11 participants who attended a focus group.

Perceptions of Recommendations

Survey Data

Recommendation 1: We do not recommend screening for lung cancer with chest x-ray with or without sputum cytology.
Strong recommendation; low quality evidence

Participants generally had positive perceptions of Recommendation 1. Specifically, participants agreed that the recommendation was appropriate, beneficial, and feasible to implement (i.e., participants' median ratings on the 9-point scale were greater than or equal to 7). They also disagreed that implementing the recommendation will lead to worse health outcomes for Canadians (i.e., median rating of 2). Two participants disagreed that implementing the recommendation will help clinicians deliver equitable health care to Canadians (i.e., they provided ratings below the midpoint of the scale). These participants noted that x-rays may be more geographically and financially accessible than low-dose computed tomography (LDCT) for Canadians who live in remote regions. They also mentioned that individuals who are claustrophobic may feel uncomfortable in an LDCT scanner and may therefore be willing to get screened only with an x-ray. See Table 3 for a summary of descriptive statistics for items assessing perceptions of Recommendation 1.

Ten participants provided open-ended responses about Recommendation 1. A few participants simply stated that they agreed with the recommendation (n = 3). Some participants reiterated their concern about the greater accessibility of x-ray versus LDCT in remote regions (n = 2). Other participants indicated that they agreed with the recommendation because screening for lung cancer with a chest x-ray can cause harms without providing any benefits (n = 2). One participant disagreed with the recommendation on the basis that chest x-rays and sputum cytology tests are less invasive and expensive than LDCT scans. The remaining participants described thoughts that did not reveal their perceptions of the recommendation (e.g., the need to educate members of the public about lung cancer screening in general; n = 2).

Table 3. Descriptive statistics for Recommendation 1 ratings (*n* = 15)

Item	Median	Q_1	Q_3
Implementing this recommendation will help support primary care providers in delivering equitable health care (i.e., no Canadian will be disadvantaged because of age, gender, income, health status, ethnicity or geographic location).	8	6	9
This recommendation adequately considers the safety and effectiveness of lung cancer screening using chest x-ray with or without sputum cytology for adults aged 18 years and older who are not suspected of having lung cancer.	8	4.5	9
Implementing this recommendation will lead to superior quality of care for Canadian adults aged 18 years and older who are not suspected of having lung cancer.	8	4.5	8.5
Implementing this recommendation will lead to better health outcomes (i.e., fewer deaths and complications from lung cancer screening) for Canadian adults aged 18 years and older who are not suspected of having lung cancer.	8	3	9
Implementing this recommendation will ultimately lead to worse health outcomes (i.e., more deaths and complications from lung cancer) for Canadian adults aged 18 years and older who are not suspected of having lung cancer.	2	1	5
I think this recommendation will be easy for primary care providers to implement in their practices across all urban settings in Canada.	8	6.5	9
I think this recommendation will be easy for primary care providers to implement in their practices across all rural settings in Canada.	7	5.5	8
Implementing this recommendation will ultimately benefit Canada's primary health care system.	8	4.5	8.5

Note: Q_1 = first quartile; Q_3 = third quartile

Recommendation 2: For adults aged 55-74 years, who are current or former (i.e. quit less than 15 years ago) smokers with a 30 pack-year smoking history, we recommend three screens with low dose CT, each at one-year intervals.
Weak recommendation; low quality evidence

Similar to the results for Recommendation 1, participants generally had favourable perceptions of Recommendation 2. That is, they agreed with most statements that described the recommendation as appropriate, beneficial, and feasible (i.e., median rating greater than or equal to 7). They also disagreed that the recommendation will lead to worse health outcomes for Canadians (i.e., median rating equal to 2). There were, however, some differences in participants' ratings of Recommendation 2 versus Recommendation 1. Specifically, in comparison to Recommendation 1, participants viewed Recommendation 2 as less feasible to implement in urban settings and less likely to facilitate access to equitable health care. In addition, whereas participants agreed that clinicians will be able to implement Recommendation 1 in most rural regions in Canada (median rating of 7), they neither agreed nor disagreed that clinicians will be able to implement Recommendation 2 in rural regions (median rating of 5). Paired *t*-tests indicated that these differences across recommendations were not statistically significant (*t*s < 1.41, *p*s > .18). We note, however, that statistical power was limited in these analyses

because of the small sample size. See Table 4 for a summary of descriptive statistics for items assessing perceptions of Recommendation 2.

Four participants disagreed with the statement that implementing the recommendation will help clinicians deliver equitable health care and five participants disagreed that all Canadians to whom the recommendation applies will be able to access the recommended LDCT scan. The majority of these participants expressed concerns about access to LDCT scans in remote regions, especially for Aboriginal populations (*n* = 7). In addition, two participants mentioned that the CTFPHC should recommend screening with LDCT for individuals aged less than 55 years and greater than 74 years.

Eight participants explained their overall perceptions of the recommendation in open-ended form. Most of these responses focused on concerns about access to LDCT scans in remote regions (*n* = 6). Participants also expressed general agreement with the recommendation (*n* = 1), referred to the benefits of early treatment (*n* = 1), and noted concerns about the potential harms of LDCT (i.e., radiation exposure; *n* = 1).

Table 4. Descriptive statistics for Recommendation 2 ratings (*n* = 15)

Item	Median	Q_1	Q_3
Implementing this recommendation will help support primary care providers in delivering equitable health care (i.e., no Canadian will be disadvantaged because of age, gender, income, health status, ethnicity or geographic location).	7	4.5	8.5
All Canadians to whom the recommendation applies will have equitable access to the low-dose CT (LDCT) described in the recommendation (i.e., no Canadian will be unable to access this test because of age, gender, income, health status, ethnicity or geographic location).	7	4	8
This recommendation adequately considers the safety and effectiveness of LDCT for adults aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	8	6	8.5
Implementing this recommendation will lead to superior quality of care for Canadians aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	8	6	9
Implementing this recommendation will lead to better health outcomes (i.e., fewer deaths and complications from lung cancer) for Canadians aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	8	6.5	8.5
Implementing this recommendation will ultimately lead to worse health outcomes (i.e., more deaths and complications from lung cancer screening) for Canadians aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	2	1.5	4
I think this recommendation will be easy for primary care providers to implement in their practices across all urban settings in Canada.	7	5	9

Item	Median	Q_1	Q_3
I think this recommendation will be easy for primary care providers to implement in their practices across all rural settings in Canada.	5	4	6.5
Implementing this recommendation will ultimately benefit Canada's primary health care system.	8	6	8.5

Note: Q_1 = first quartile; Q_3 = third quartile

Recommendation 3: For adults aged <55 years and >74 years, and for adult smokers of any age with less than a 30 pack-year smoking history, we do not recommend routinely screening for lung cancer with low dose CT.
Weak recommendation; low quality evidence.

Participants' perceptions of Recommendation 3 were generally favourable: Their median rating was greater than or equal to 6 for most items. Similar to the results for Recommendations 1 and 2, participants believed that Recommendation 3 considers the safety and effectiveness of LDCT for individuals to whom the recommendation applies. They also believed that implementing the recommendation will be feasible in urban regions and beneficial for both patients and the health care system. As was the case for Recommendation 2, however, participants neither agreed nor disagreed that it will be feasible to implement the recommendation in all rural regions across Canada. Also, in comparison to their perceptions of Recommendations 1 and 2, participants were less likely to agree that implementing the recommendation will allow clinicians to deliver equitable health care and will lead to better quality of care for individuals to whom the recommendation applies. In addition, whereas participants disagreed that implementing Recommendations 1 or 2 will lead to worse health outcomes for the intended population, they neither agreed nor disagreed that implementing Recommendation 3 will lead to worse health outcomes for the intended population. A repeated measures analysis of variance revealed that participants' median ratings of how much they agreed that implementing each recommendation will lead to worse health outcomes differed significantly across recommendations ($F(2, 28) = 3.90$, $p = .03$). Paired *t*-tests indicated that participants agreed that implementing Recommendation 3 will lead to worse health outcomes significantly more than they did for Recommendation 2 ($t(14) = 2.40$, $p = .03$), and marginally more than they did for Recommendation 1, ($t(14) = 1.97$, $p = .07$). Participants' median rating of Recommendation 1 did not differ significantly from their median rating of Recommendation 2 ($t(14) = 1.22$, $p = .24$). All other differences across the three recommendations were nonsignificant (Fs < 1.21, ps > .31). See Table 5 for a summary of descriptive statistics for items assessing perceptions of Recommendation 3.

Although participants were less likely to agree that implementing Recommendation 3 versus Recommendations 1 or 2 will allow clinicians to deliver equitable health care, only one participant provided a rating below the midpoint of the scale. This participant expressed that there is insufficient evidence to justify recommending against screening for smokers below the age of 55. In particular, this participant noted the implications of a lung cancer diagnosis for middle-aged adults, who may have children and other dependents who rely on them for financial support.

Nine participants explained their overall perceptions of the recommendation in open-ended form. Many of these participants expressed concerns that implementing the recommendation will lead clinicians to miss a lung cancer diagnosis in patients who either do not have a 30-pack-year smoking history or fall outside of the age range for Recommendation 2 ($n = 5$). This concern was greater for individuals less than 55 years than for those greater than 74 years. The remaining participants indicated agreement

with the recommendation (*n* = 1), described uncertainty about the appropriateness of the recommendation (*n* = 1), or expressed pessimism about the likelihood that clinicians will change their practice based on the recommendation (*n* = 1). One additional participant noted challenges with understanding the GRADE terminology (i.e., strength of recommendation and quality of evidence information) but did not describe any specific perceptions of the recommendation.

Table 5. Descriptive statistics for Recommendation 3 ratings (*n* = 15)

Item	Median	Q_1	Q_3
Implementing this recommendation will help support primary care providers in delivering equitable health care (i.e., no Canadian will be disadvantaged because of age, gender, income, health status, ethnicity or geographic location).	6	5	8
This recommendation adequately considers the safety and effectiveness of LDCT for adults less than 55 years, adults more than 74 years, and adult smokers of any age with less than a 30 pack-year smoking history.	8	5	8
Implementing this recommendation will lead to superior quality of care for Canadian adults less than 55 years, Canadian adults more than 74 years, and Canadian adult smokers of any age with less than a 30 pack-year smoking history.	6	5	8
Implementing this recommendation will lead to better health outcomes (i.e., fewer deaths and complications from lung cancer screening) for Canadian adults less than 55 years, Canadian adults more than 74 years, and Canadian adult smokers of any age with less than a 30 pack-year smoking history.	8	5	8
Implementing this recommendation will ultimately lead to worse health outcomes (i.e., more deaths and complications from lung cancer) for Canadian adults less than 55 years, Canadian adults more than 74 years, and Canadian adult smokers of any age with less than a 30 pack-year smoking history.	5	1.5	6.5
I think this recommendation will be easy for primary care providers to implement in their practices across all urban settings in Canada.	8	5.5	9
I think this recommendation will be easy for primary care providers to implement in their practices across all rural settings in Canada.	5	4.5	8.5
Implementing this recommendation will ultimately benefit Canada's primary health care system.	8	5	8

Note: Q_1 = first quartile; Q_3 = third quartile

Focus Group Data

Most participants agreed with the recommendations after they had a chance to ask questions about lung cancer screening and the draft recommendations. Specifically, participants believed that it is important to be selective about who to screen in order to limit the burden on the health care system and to reduce LDCT scan wait times for symptomatic adults. They also agreed that if patients are asymptomatic and a test is associated with harms, it makes sense to restrict screening to cases in which there is evidence of benefits. In addition, they indicated that they recognized the value of having

evidence-based recommendations for family physicians, who may not have the time or expertise to critically appraise research evidence.

" I started with the comment that things were kind of fuzzy and sort of apples and oranges….hard to follow and I now feel, after our discussion, that things are not only clearer to me but that I'm now much more – as a lay person, patient, or community member – much more in support and understanding of the three recommendations"

"This makes perfect sense to me – we don't want doctors to send every single patient for testing if there are no symptoms"

Some participants believed that the CTFPHC should recommend screening with LDCT for adults aged less than 55 years and adults greater than 74 years. This was because of their concern that the risk of developing lung cancer may be the same for adults of all ages. They understood that there is not enough research evidence to make recommendations for certain populations (e.g., individuals exposed to second-hand smoke or environmental chemicals and materials), but they felt that the CTFPHC should advocate for more research to be conducted with these groups. Some participants believed that a lack of evidence should not preclude the CTFPHC from developing screening recommendations for individuals with second-hand smoke or environmental exposure.

Lastly, participants discussed the importance of the patient–doctor relationship in the context of weak recommendations. Some participants believed that the CTFPHC should develop culturally accessible educational materials for patients across Canada so that they can have informed conversations with their doctors about screening and take steps to make preventive health behaviour changes (e.g., quitting smoking). Others felt that the impetus to learn and advocate for screening should also come from the patients themselves, provided that they have the educational background and skills to ask their doctor the right questions.

The majority of data from the focus groups describe questions that participants asked about lung cancer screening and the draft CTFPHC guideline recommendations. Some examples of participant questions are listed below.

Questions about the quality of evidence:

How does the CTFPHC develop recommendations when there is not enough high-quality evidence?
How does low quality evidence affect the strength of a recommendation?
What is an example of a high-quality study?
What is a randomized study?

Questions about the research underlying the recommendations:

What is the evidence supporting the age range and pack years criteria for Recommendation 2?
Was second-hand smoke or environmental exposure included in the search for evidence?
Will the guideline include recommendations for more research to be done on screening benefits in younger populations (i.e., adults less than 55 years)?
Are these studies based on Canadian or American populations?
Are these recommendations based on published studies only?
How old are the studies that were included in the systematic review?

Questions about guideline implementation:

Will these guidelines prevent doctors from ordering tests that are not recommended?
Will these guidelines eventually be linked to funding?
Will these recommendations allow doctors to refer patients to specialists?
When family doctors receive these recommendations, will they also receive details on the evidence behind them or will they simple accept the recommendations and change their practice accordingly?
The go-to test for family doctors has been the chest x-ray, so what will be the go-to test now in light of these recommendations?

Questions about the screening tests:

What is the cost of an LDCT scan?
Is it common for a 30-pack-year smoker to get referred for an LDCT scan?

Questions about the CTFPHC's guideline development process:

How frequently does the CTFPHC update its guidelines?
How does the CTFPHC select new guideline topics?

Experience with Project Tasks

Experience with Focus Group

Survey Data

Participants generally found the focus group discussion and the information provided by the working group chair to be informative. They also indicated that both the group discussion and the working group chair had a moderate influence on their responses to the survey. Although participants shared diverse perspectives during the discussions, participants did not find the discussions to be argumentative. Participants' ratings therefore suggest that the focus groups provided participants with an opportunity to learn from the perspectives of others in a non-hostile environment. See Table 6 for a summary of descriptive statistics for all focus group experience items.

Before attending the focus group, participants received a background document on lung cancer screening to prepare them for the discussion. When participants were asked to indicate how much they agreed that the information in the background document was easy to understand, their median rating was just above the midpoint of the scale (i.e., median rating of 6). Thus, participants agreed rather than disagreed that the information was easy to understand, but they did not strongly agree with the statement.

Some participants provided suggestions for ways in which we could improve the focus groups. Specifically, some participants expressed that we could better prepare participants for future focus groups by making the guideline topic background document easier to understand and ensuring that it outlines the evidence underlying the recommendations (n = 3). Participants also indicated that we could improve the focus group experience by changing how we facilitate the focus groups (e.g., inform participants in advance about the types of questions that they will discuss, ask specific questions about the recommendations to guide the discussion, explain the recommendations and their context more clearly, and provide information about each participant to give context to comments made during the

discussion; *n* = 4). The remaining participants who provided comments did not see a need for any changes (*n* = 4).

Table 6. Descriptive statistics for focus group experience items (*n* = 11)

Focus group experience item	Median	Q_1	Q_3
How easy was it to understand the information in the lung cancer background information sheet?	6	4.5	8.5
How informative was the focus group discussion that you took part in via teleconference?	9	8	9
How argumentative was the focus group discussion?	2	1	4.5
How much did the focus group discussion influence your responses in this final survey?	7	5.5	8.5
How helpful was the information provided by the content expert (i.e., the doctor on the focus group call)?	9	9	9
How much did the content expert's comments influence your responses in this final survey?	7	7	8

Note: Q_1 = first quartile; Q_3 = third quartile

Focus Group Data

During the focus group, participants noted that they appreciated the information provided by the working group chair during the discussion. They felt that the chair was clear, patient, and skilled at explaining the recommendations and GRADE method to participants.

"If we have another session, I hope you stay on!"

Although participants found the focus group sessions to be helpful, they found the lung cancer screening background document to be difficult to follow. Specifically, participants experienced challenges in understanding the statistics presented in the background document and wondered why the background document included statistics for LDCT but not for chest x-ray. They also expressed a desire to have information and statistics about harms and benefits presented separately for each test.

Experience with Survey

Participants indicated that it was generally easy to understand the survey instructions. They also indicated that they were able to complete the survey with ease. Indeed, the median rating was greater than or equal to 7 for all survey experience items. When asked to describe how we could change the survey tasks to make them easier to complete, the majority of participants indicated that they did not see a need for any changes (*n* = 7). A few participants expressed that we could improve the survey by rephrasing the recommendation statements to make them easier to understand (*n* = 3) and avoiding repetition in the survey items (*n* = 2). One participant mentioned that it would have been helpful to review a transcript of the focus group discussion before completing the survey. See Table 7 for a summary of descriptive statistics for all focus group experience items.

Table 7. Descriptive statistics for survey experience items (*n* = 15)

Item	Median	Q_1	Q_3
How clear were the survey instructions?	9	7.5	9
How well did you understand what we asked you to do in this survey?	9	8	9
How easy was it to rate the CTFPHC's recommendations in this survey?	7	6.5	8.5

Note: Q_1 = first quartile; Q_3 = third quartile

Perceived Impact of Input

Participants generally believed that the input that they provided during the project would be valued by the CTFPHC and used to inform the CTFPHC's lung cancer screening KT tools. Indeed, the median rating for these items was 7. Participants were less likely to agree that their responses would influence the CTFPHC lung cancer screening guideline (median rating of 6), but the median rating was still above the scale midpoint and did not differ significantly from the median rating of the other perceived impact items (*t*s < 1.65, *p*s > .12). See Table 8 for a summary of descriptive statistics for all perceived impact items.

Table 8. Descriptive statistics for perceived impact items (*n* = 15)

Perceived impact item	Median	Q_1	Q_3
How much do you believe that the responses provided by participants in this project can lead to a set of recommendations to assist doctors in making decisions about lung cancer screening?	7	6	8
How much do you believe that the responses provided by participants in this project will be valued by the CTFPHC?	7	6	8
How much do you believe that the responses provided by participants will influence the CTFPHC's lung cancer screening guideline?	6	6	7.5
In addition to creating clinical practice guidelines, the CTFPHC also develops knowledge translation tools to help clinicians and patients understand and implement the guidelines. How much do you believe that the responses provided by participants will influence the content of the CTFPHC's lung cancer screening knowledge translation tools?	7	6	8

Note: Q_1 = first quartile; Q_3 = third quartile

Satisfaction with Experience

Participants were generally satisfied with their experience in the project. They also indicated that their experience in the project was relatively consistent with the expectations that they had about what it would be like to take part in the project. Indeed, participants' median satisfaction rating was an 8 for both items. In particular, participants mentioned in their open-ended responses that they enjoyed the

project because they had the opportunity to help address an important health care matter (*n* = 4), hear about different perspectives (*n* = 4), learn about how guidelines are developed (*n* = 3), and improve their knowledge of lung cancer screening (*n* = 2). Also, several participants mentioned that they appreciated the way in which the project team and working group chair provided professional guidance and created a supportive environment for discussion (*n* = 4). See Table 9 for a summary of descriptive statistics for all satisfaction items.

When asked to describe aspects of the project that they did not enjoy, some participants mentioned that the lung cancer screening background document was not as helpful as it could have been because it was difficult to understand and lacked evidence to support each recommendation (*n* = 5). The remaining comments focused on logistics related to how the project was administered. Specifically, some participants noted that they were unable to attend a focus group because we did not offer any evening time slots (*n* = 2). Other participants noted that the size of the focus group made it difficult to contribute to the discussion (*n* = 1) and that they would have preferred an in-person discussion (*n* = 1). In addition, one participant noted that it would have been helpful to receive more information about the project goals and tasks beforehand.

Consistent with the general project feedback, many participants suggested that the CTFPHC could improve the project in the future by making the lung cancer screening background document and recommendation statements easier to understand (*n* = 4). For example, one participant suggested that the CTFPHC could provide hypothetical scenarios or case studies to illustrate the key information and recommendations related to the guideline topic. In addition, some participants mentioned that it would be helpful to offer evening time slots for the focus groups so that Canadians who work during the day can take part (*n* = 1). Several participants mentioned that there was nothing about the project that they disliked and that they did not see a need for any changes (*n* = 6).

Table 9. Descriptive statistics for satisfaction items (*n* = 15)

Satisfaction with experience item	Median	Q_1	Q_3
How satisfying did you find your participation in this project to be?	8	7	9
How much did your actual experience as a participant in this project match your expectations about what it would be like to take part?	8	5	9

Note: Q_1 = first quartile; Q_3 = third quartile

Discussion

International organizations that appraise guidelines have identified patient engagement as an important component of the guideline development process.[5-6,9] In this project, we used qualitative and quantitative methods to assess perceptions of the CTFPHC's draft lung cancer screening guideline recommendations among Canadians to whom the guideline will apply. Given that this is one of the first times that the CTFPHC has directly engaged members of the public in the guideline development process, we also examined participants' experiences in the project.

Perceptions of Recommendations

We assessed participants' perceptions of the recommendations by having them share their thoughts about the social acceptability and implementability of the recommendations during a focus group and in a survey. Overall, participants agreed with the recommendations. They did, however, have two key concerns about the recommendations. First, many participants wondered whether screening for lung cancer using LDCT will be a realistic option for patients who live in remote regions. Specifically, participants believed that clinicians will face challenges in referring patients for LDCT screening and that these patients will have difficult accessing a test that may not be available in their region. Second, participants believed that LDCT screening should be recommended for individuals under the age of 55 and over the age of 74. Participants expressed concern about the possibility of missing a lung cancer diagnosis in these individuals, particularly in those under the age of 55. Some participants also indicated that there is not enough evidence to justify recommending against screening in these age groups. Thus, participants generally perceived the recommended courses of action to be appropriate and beneficial. They were less certain, in comparison, that the recommendations will facilitate access to equitable care.

Participant Experience

We used closed-ended and open-ended survey items to assess participants' experiences in the project. Participants indicated that they generally had a positive experience in the project. They expressed, for example, that they believed that their input would be valued by the CTFPHC and that they enjoyed the opportunity to contribute to the guideline development process. Nonetheless, participants experienced challenges with some aspects of the project. Specifically, participants noted that the lung cancer screening background document was not as easy to understand as it could have been. This differs from the experiences of participants in the hepatitis C patient preferences project, who found the hepatitis C background document to be relatively easy to understand. One limitation of the hepatitis C background document was that it did not contain specific numerical information about the relative likelihood that individuals would experience various outcomes. The CTFPHC Lung Cancer Working Group therefore included specific numerical information in the lung cancer screening background document. It seems, however, that participants struggled to understand this information. Indeed, participants not only conveyed the difficulty of understanding the lung cancer screening background document in their survey responses, but they also spontaneously described this challenge during the focus groups. Thus, for future patient preferences projects, it will be important to identify the appropriate balance between providing participants with detailed information about the guideline topic and ensuring that the information is easy for them to understand. It will also be important to assess the literacy level of background documents that we prepare for participants.

In addition to describing the difficulty that they experienced in understanding the background document, participants noted that it would have been helpful for the focus group moderator to provide more direction before and during the focus group. In particular, participants noted that they would have liked to receive advance notice about the types of questions that they would discuss during the focus group. They also indicated that it would have been easier for them to express their thoughts about the recommendations during the focus groups if the focus group moderator had provided clearer descriptions of the recommendations and posed specific questions about the recommendations to the group. It may have been the case that because participants faced challenges in understanding the background document, they needed additional direction and guidance during the focus group to articulate their thoughts. It will therefore be important to ensure that future participants have the resources and guidance that they need to convey their preferences.

Limitations

This project has several limitations. First, the participant sample was relatively small and may not be representative of all Canadian adults to whom the CTFPHC lung cancer screening guideline will apply. Although we strived to include individuals from across Canada in the sample, we did not receive any responses to our recruitment ads from individuals living in some provinces and territories (e.g., Prince Edward Island, Yukon Territory, and Nunavut). Participants who responded to our recruitment ads may also differ from individuals who chose not to respond to our ads in ways unrelated to geographic region. Specifically, individuals who expressed interest in taking part in the project may be more interested in health care issues, engaged in patient advocacy, and/or scientifically literate. In addition, most of the participants in our sample were female. When we began to recruit participants for this project in early January 2015, we expected to be able to start the project by the end of the month. Because the CTFPHC Lung Cancer Working Group needed to revise the draft recommendations, however, we were unable to conduct the focus groups for this project until May 2015. By the time that we were ready to begin the project, some participants were no longer able to take part and we had difficulty contacting participants on our “waiting list” to fill spots. Unfortunately, out of the 20 participants who declined to participate or stopped responding to our emails during the delay, 16 were male. It may be that Canadians who are from other provinces or territories, less concerned about health care issues, and/or male would have perceptions of the draft guideline recommendations that differ from those identified in the current project. In addition, our small sample size may have limited the statistical power of our analyses and therefore made it difficult for us to detect differences in perceptions across recommendations. In future work, therefore, it will be important to assess patient preferences using a larger and more diverse sample of Canadians.

Second, the information that participants received during the project may have made them more knowledgeable than the general population about lung cancer screening. During the project, participants read a background document on lung cancer screening, discussed the draft recommendations with other participants, and received relevant information from the CTFPHC Lung Cancer Working Group chair. We gave participants this amount of information so that they would have enough knowledge about the recommendations to be able to articulate their perceptions of them. When make screening decisions, however, most Canadians may not have the same degree of relevant information as did participants in the current project. The perceptions expressed by participants in this project may therefore differ from those of Canadians who make screening decisions with more limited knowledge about the harms and benefits of lung cancer screening. We also acknowledge that some Canadians who anticipate making a decision about getting screened for lung cancer may be even more informed about lung cancer screening than were participants in the current project. These individuals

may also have perceptions of the CTFPHC's recommendations that differ from those identified in the current project. For example, these individuals may be more familiar with the potential harms of screening and may, therefore, agree with the weak recommendation against screening in adults less than 55 years, adults greater than 74 years, and adults who do not have a 30-pack-year smoking history. Thus, in future work, it will be important to examine how patients' perceptions differ as a function of knowledge about lung cancer screening.

Third, information provided by the chair of the Lung Cancer Working Group may have influenced participants' responses. The chair attended the focus groups to answer questions that participants had about lung cancer screening and the draft recommendations. Although the chair strived to provide objective and neutral responses to participants' queries, it is possible that some responses contained clues about the chair's opinions. This information may have led some participants to rate the recommendations in the survey differently than they would have had they not received any information from the chair. Participants' experience ratings in the final survey indicate that they believed that the chair had a moderate influence on their final ratings. It is not clear, however, whether this influence stemmed from neutral information that they received from the chair or from information that may have revealed the chair's opinions on the topic. To the extent that participants were influenced by the chair's opinions, their perceptions may not reflect the perspectives of individuals who are members of the general public rather than health care professionals. We note, however, that many individuals may receive some degree of information from a health care professional before making a screening decision. Given that at least some of this information is likely infused with the opinions of the health care professional, individuals may be influenced by health care professionals even in real-world decision-making contexts. Nonetheless, it may be important to examine the impact of this influence systematically in future patient preferences projects.

Suggestions for Applying Findings

We provide the following suggestions for applying the findings from this project to the CTFPHC's lung cancer screening guideline:

1. **Develop KT tools that explain the balance of benefits and harms for different age groups.** Participants in this project agreed that individuals between the ages of 55 and 74 who have a 30-pack-year smoking history should be screened for lung cancer with LDCT. They also expressed, however, that the CTFPHC should recommend screening even for individuals with a 30-pack-year history who fall outside of this age range. In particular, they believed that the benefits of screening outweigh the harms for individuals under the age of 55, who may have children and other dependents. The CTFPHC may therefore consider developing and disseminating resources that help individuals understand why screening is not recommended for individuals outside of the 55–74 age group. Specifically, the CTFPHC may produce KT tools that explain the harms and benefits of lung cancer screening with LDCT for individuals under age 55 and over age 74. These resources may help both clinicians and patients discuss and make decisions about lung cancer screening.

2. **Develop KT tools that explain why the CTFPHC recommends screening with LDCT rather than with chest x-ray despite the challenges of accessing LDCT in remote regions.** The most common concern that participants expressed about the draft guideline recommendations was that LDCT screening will be difficult to access for patients living in remote regions. Given this challenge of accessing LDCT in remote regions and the implications that it has for health care equity, some participants suggested that the CTFPHC should recommend screening for

lung cancer with chest x-ray. These participants believed that recommending for rather than against screening with chest x-ray would allow patients living in remote regions to have access to some type of screening test, even if it is not the most effective test. Because these perceptions may stem from misconceptions about the benefits of screening with chest x-ray relative to usual care, the CTFPHC may consider developing KT tools that address beliefs about the benefits and harms of screening for lung cancer with chest x-ray and LDCT. Patients and clinicians in remote regions may be less resistant to the CTFPHC's recommendations if they understand why screening with a test that is effective but less accessible may produce better outcomes than would screening with a test that is more accessible but not effective.

3. **Develop a KT tool that explains how the CTFPHC uses GRADE to create guideline recommendations.** Participants had a number of questions about the GRADE method as basis for developing guideline recommendations. For example, participants had trouble understanding how recommendations can be *strong* if they are based on low quality evidence. They also wondered why the CTFPHC recommends against rather than for screening when there is no high-quality evidence for a particular age group. Thus, the CTFPHC may be able to facilitate comprehension and implementation of its lung cancer screening guideline if it develops resources aimed at helping patients and clinicians understand GRADE.

Conclusion

In sum, we assessed how members of the public perceived a draft version of the CTFPHC's lung cancer screening guideline recommendations: Participants generally agreed with the recommendations but noted equity and implementation concerns related to age and geographic region. We also assessed participants' experience in the project and found that participants enjoyed the opportunity to share their perspectives and contribute to the guideline development process. Identifying and incorporating patient preferences into the guideline development process may therefore allow the CTFPHC to enhance its guidelines while successfully engaging Canadians in its work.

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Appendices

Appendix A – Screening Questionnaire

CTFPHC Public Perceptions Screening Questionnaire

Introduction

This survey is designed to assess your eligibility for the Canadian Task Force on Preventive Health Care (CTFPHC)'s public perceptions project. Please answer the following questions accurately and honestly. If you have any questions, concerns, or technical difficulties, please contact the project coordinator, Nadia Bashir, at bashirn@smh.ca or 416-864-6060 x77507.

Are you a practicing health care professional?

- ○ Yes
- ○ No

Please note that the information that you provide to us in this survey will be kept confidential and will not be shared with anyone outside of the CTFPHC.

Please enter your first and last name:

[ ]

Please enter your email address:

[ ]

How did you hear about this opportunity?

- ○ COPD Canada
- ○ National Asthma Patient Alliance Alert
- ○ Action Hepatitis Canada
- ○ Canadian Liver Foundation
- ○ Other, please specify... _____

What is your gender?

- ○ Male
- ○ Female
- ○ Other, please specify... _____

What is your age?

[ ]

Which province or territory do you live in?

- ○ British Columbia
- ○ Alberta
- ○ Saskatchewan
- ○ Manitoba
- ○ Ontario
- ○ Quebec
- ○ New Brunswick
- ○ Nova Scotia
- ○ Prince Edward Island
- ○ Newfoundland and Labrador
- ○ Yukon Territory
- ○ Northwest Territories
- ○ Nunavut

Which time zone do you live in?

- ○ Pacific
- ○ Mountain
- ○ Central
- ○ Eastern
- ○ Atlantic
- ○ Newfoundland

Which type of region do you live in?

- ○ Urban
- ○ Suburban
- ○ Rural

What is your ethnicity?

[ ]

Do you identify as part of one of the following Aboriginal groups?

- ○ First Nations
- ○ Métis
- ○ Inuit
- ○ No, I am not Aboriginal

Did you immigrate to Canada within the past five years?

- ○ Yes
- ○ No

Did you immigrate from one of the following parts of the world?

Central, East or South Asia Australasia and Oceania Eastern Europe Sub-Saharan Africa North Africa Middle East

- ○ Yes
- ○ No

What is the highest level of education that you have <u>completed</u>?

- ○ Less Than High School
- ○ High School
- ○ College Diploma or Bachelor's Degree
- ○ Graduate or Professional Degree

What is your annual household income?

- ○ less than $24,999
- ○ $25,000-29,999
- ○ $30,000-$39,999
- ○ $40,000-$49,999
- ○ $50,000-$59,999
- ○ $60,000-$69,999
- ○ $70,000-$99,999
- ○ $100,000 or more

How many people live in your household?

What is your occupation?

- ○ Retired
- ○ Student
- ○ Working, please specify occupation... _____
- ○ Other, please specify... _____

Are you living with any chronic health conditions?

Have you ever smoked cigarettes?

- ○ Yes, I have smoked.
- ○ No, I have not smoked

Do you <u>currently</u> smoke cigarettes?

- ○ Yes
- ○ No

Did you quit smoking within the last 15 years?

- ○ Yes
- ○ No

For how many years did you smoke?

When you were smoking, how many cigarettes did you smoke <u>each day</u>, on average?

For how many years have you smoked?

During the time that you have smoked, how many cigarettes have you smoked <u>each day</u>, on average?

Have you ever used injection drugs?

- ○ Yes
- ○ No

Have you ever been diagnosed with lung cancer?

- ○ Yes
- ○ No

Does your doctor think that you might have lung cancer?

- ○ Yes
- ○ No

Are you the caregiver of someone with lung cancer?

- ○ Yes
- ○ No

Do you have any conflicts of interest related to lung cancer?

Examples include but are not limited to the following: being a member of an organization related to lung cancer (e.g., owning a company that provides products or services related to lung cancer, owning shares in a company that provides products or services related to lung cancer, and conducting research on lung cancer.

- ○ Yes. (Please describe): _____
- ○ No

Have you ever been diagnosed with hepatitis C?

- ○ Yes, I have been diagnosed with Hepatitis C
- ○ No, I have not been diagnosed with Hepatitis C

Does your doctor think that you might have hepatitis C?

- ○ Yes
- ○ No

Are you the caregiver of someone with hepatitis C?

- ○ Yes
- ○ No

Do you have any conflicts of interest related to hepatitis C?

Examples include but are not limited to the following: being a member of an organization related to hepatitis C, owning a company that provides products or services related to hepatitis C, owning shares in a company that provides products or services related to hepatitis C, and conducting research on hepatitis C.

- ○ Yes (Please describe): _____
- ○ No

Do you have any complications of hepatitis C (e.g., cirrhosis or liver cancer)?

- ○ Yes
- ○ No

Do you have any of the following health conditions? Please select all that apply.

- ☐ HIV
- ☐ Diabetes
- ☐ Depression

Thank you for taking the time to fill out this survey.

The project coordinator will contact you by email to let you know whether or not you are eligible to take part in this project.

Take Part in Future Projects

The Knowledge Translation Program at St. Michael's Hospital conducts other projects similar to this. Even if you are not eligible to take part in this project, you may be able to participate in other current or future projects conducted by the Knowledge Translation Program. Would you be interested in joining our mailing list for project and research study recruitment?

- ○ Yes
- ○ No

You indicated that you are interested in taking part in future projects. Please provide your contact information below so that we can get in touch with you.

Please provide your contact information below

Name	
Email Address	
Phone Number	

Appendix B – Lung Cancer Screening Background Document

Canadian Task Force on Preventive Health Care
Background Information Sheet on Lung Cancer Screening

What is lung cancer?

Lung cancer is a disease that occurs when cells in the lung start to grow in an uncontrolled way. The cancer may begin in one or both lungs, and may not cause any symptoms during the early stage. Over time, the cancer usually takes over parts of the lungs and spreads to other areas in the body. Typically, by the time symptoms appear (e.g., a persistent cough, coughing up blood, chest pain, trouble breathing or unexplained weight loss), the cancer is at a later stage.

Who is at risk for getting lung cancer?
In Canada, nearly all people who get lung cancer are over the age of 50, and it gets more common as people age: more than half of new cases are among those older than 70 years.

People are more likely to develop lung cancer if they smoke, are exposed to second-hand smoke (breathing in smoke from other people's cigarettes), are exposed to certain chemicals in the environment (e.g., radon or asbestos), receive radiation exposure to the chest, or have a family history of lung cancer.
Over 80% of people diagnosed with lung cancer are either current or former smokers. Not smoking or quitting smoking is one of the most important things that people can do to lower their risk of getting lung cancer. People who quit smoking stop increasing their risk, and after some years, their risk is lower than those who continue.

How does having lung cancer affect people?

In general, lung cancer has one of the lowest survival rates among all types of cancers in Canada (one-year survival rate is 40%, five-year survival rate is 17%, based on 2006-2008 estimates). However, lung cancer doesn't affect everyone in the same way. A few people who have lung cancer won't experience serious health problems. On the other hand, most people who have lung cancer will become seriously ill and die, especially if their cancer isn't caught at an early stage. The most common type of lung cancer can be treated more successfully when doctors catch it at an early stage compared to a later stage.

How do doctors treat people for lung cancer?

Lung cancer may be treated in different ways, depending on the type of cancer that someone has and how far it has spread in the body. Doctors may use any of the following to treat lung cancer:

- Surgery: removing the portion of the lung that has cancer cells
- Chemotherapy: using medication that can shrink or kill the cancer
- Radiation therapy: using high-energy rays to kill the cancer
- Targeted therapy: using medication to stop the cancer from growing and spreading

These treatments can be successful in stopping or slowing the growth of the cancer, especially when the cancer is caught at an early stage. This may allow people to avoid serious illness and death. However, in some cases, treatments for lung cancer can also harm people. For example, some people who have surgery may get infections, some people who get chemotherapy may end up with a weakened immune system, and some people who have radiation therapy may get cancer from radiation exposure. For this reason, some people may get more harm from the treatment than help.

How do doctors screen people for lung cancer?

When doctors screen people for lung cancer, they are looking to see if people who don't show any signs of having lung cancer (e.g., a cough with blood, chest pain, or unexplained weight loss) do have early disease. The idea behind lung cancer screening is that if doctors can detect lung cancer when the disease is at an early stage (i.e., the cancer is only in a small part of one lung, and has not spread to other parts of the body), they may be able to treat the cancer and lengthen the person's life.

One new test that doctors use to screen for lung cancer is low-dose computed tomography (also known as a low-dose CT scan or LDCT). An x-ray machine scans the body and uses radiation to make a 3D image of the lungs. This is the best lung cancer screening test because it has "high sensitivity." This means that it finds most early lung cancers when they are still too small to be seen as spots on an ordinary chest x-ray. The downside is that many of the very small spots are not cancers (also called "false positives"), and would not cause trouble. However, to find out whether or not a spot is cancer is sometimes difficult, and people may need other follow-up tests, including taking samples from the lungs, to be sure what it is. These extra tests can cause harm.

The other test that doctors may order to screen for lung cancer is a chest X-ray. In this test, an x-ray machine makes an image of the chest. Doctors may use x-rays alone or in combination with a sputum cytology test. In a sputum cytology test, a doctor will have the patient cough up mucus and then send the mucus to be examined in a laboratory to see if it contains abnormal cells. The chest x-ray used with or without the sputum cytology test has a lower sensitivity than the LDCT test, meaning that many early-stage lung cancers are not visible.

How do doctors diagnose people with lung cancer?

When people get a positive lung cancer screening test result (i.e., abnormal result), their doctor will suggest follow-up testing to decide whether or not they have lung cancer. This may include a repeat CT- scan at a given interval to see if the spot grows or not; a bronchoscopy, which involves putting a tube with a camera down the throat into the lungs to examine them; or a biopsy, which involves taking a sample of cells from the lungs and examining the cells under a microscope. These additional tests can be useful because they can tell doctors whether or not something that looked like cancer on a screening test really is cancer. However, some people may get an infection, have a collapsed lung, or die after having one of these tests.

<u>What are the possible benefits of lung cancer screening with a LDCT scan?</u>

Compared to people who get screened with chest x-ray, people who get screened for lung cancer with a LDCT scan are

- more likely to get diagnosed with lung cancer when the disease is at an early stage instead of a late stage (8 more early-stage lung cancers found for every 1000 people screened)

- less likely to die from lung cancer (3 lung cancer deaths avoided for every 1000 people screened)

What are the possible harms of lung cancer screening (with either LDCT scan or chest x-ray)?

Compared to people who don't get screened, people who get screened for lung cancer may

- be more likely to have major complications (e.g., collapsed lung or severe pain) or die after having a follow-up test to find out whether or not they really do have lung cancer. It is estimated that 1 – 3 in 1000 people screened experience major complications, and 0.4 – 0.6 in 1000 people screened die from invasive follow up tests.

- be more likely to get overdiagnosed. Overdiagnosis happens when someone is diagnosed with a cancer that may never cause any health problems for them. It is estimated that 1 – 10 lung cancers are overdiagnosed for every 1000 people screened. Overdiagnosis can lead to unnecessary treatments for lung cancer, by surgery, radiotherapy, or chemotherapy. These may cause harm.

- get very worried if they are told they might have a sign of cancer and must come back for further tests in a few months. They lose sleep, cannot think clearly, and have difficulty continuing their normal work and family life.

Summary of Harms and Benefits

Research shows that for people aged 55-74 who have a history of heavy smoking* and are either current smokers or quit within the last 15 years, there are small benefits of screening for lung cancer with LDCT.

For every 1000 people who are screened with LDCT, about 400 will have a positive test, and after further testing, 40 will be diagnosed. After treatments, 3 fewer people will die of lung cancer and live longer than those screened with chest x-ray. These benefits appear to outweigh the harms of screening. For these people, screening with LDCT every year for multiple years is better than screening only every two or three years.

However, for all other people and all other lung cancer screening tests described above (e.g., chest x-ray with or without sputum cytology), research evidence does not show that the benefits of screening outweigh the harms. So for smokers with lighter smoking histories, or who quit more than 15 years ago, the benefit of screening is less, but the harms may be similar. On balance they are more likely to be hurt than helped.

*For the purpose of this project, a heavy smoker is someone who has smoked 30 pack years or more. A pack year is a unit of measurement that describes how much a person has smoked.

1 pack year = smoking one pack of cigarettes (i.e., 20 cigarettes) every single day for one year.
30 pack years = smoking one pack of cigarettes (i.e., 20 cigarettes) every single day for 30 years

For example, to smoke 30 pack years, someone may have
- Smoked one pack every day for 30 years
- Smoked two packs every day for 15 years
- Smoked three packs every day for 10 years
- Smoked one pack every day for 20 years and two packs every day for 5 years

Appendix C – GRADE Background Document

Canadian Task Force on Preventive Health Care
Background Information Sheet on GRADE System

The CTFPHC's recommendations are categorized according to the GRADE system. Based on the GRADE system, recommendations are labelled based on their **strength** and the **quality of evidence** that they are based on.

1) Recommendation Strength

The strength of the recommendation is based on a) how much certainty there is in the balance between the desirable and undesirable effects of the test or procedure, b) how much certainty or variability there is in the relevant values and preferences of patients, c) how much certainty there is about whether the test or procedure represents a wise use of resources, and d) the quality of research evidence underlying the recommendation. Based on the GRADE system, a recommendation can be either a **strong recommendation** or a **weak recommendation**.

When the CTFPHC makes a **strong recommendation**, it is confident that either

- the desirable effects of the recommended test or procedure outweigh the undesirable effects (strong recommendation for the test or procedure)

or

- the undesirable effects outweigh the desirable effects (strong recommendation against the test or procedure).

When a recommendation is **strong**, the CTFPHC believes that most people would want the recommended course of action and only a small proportion would not.

When the CTFPHC makes a **weak recommendation**, it believes that either

- the desirable effects of the recommended test or procedure probably outweigh the undesirable effects, but they are not sure (weak recommendation for the test or procedure)

or

- the undesirable effects probably outweigh the desirable effects, but they are not sure (weak recommendation against the test or procedure)

When a recommendation is **weak**, the CTFPHC believes that most people would want the recommended course of action, but many would not. Different choices are acceptable for each patient, and doctors should support patients and discuss their values and preferences to reach a decision.

2) Quality of Evidence

Based on the GRADE system, recommendations are based on scientific evidence that is **very low**, **low**, **moderate**, or **high** in quality. This information describes how much the CTFPHC believes that future research may change their understanding of the effect that a test or procedure has.

When the quality of evidence is **high**, the CTFPHC believes that future research studies probably won't change their understanding of the effect that a test or procedure has.

When the quality of evidence is **moderate**, the CTFPHC believes that future research studies may change their understanding of the effect that a test or procedure has.

When the quality of evidence is **low or very low**, the CTFPHC believes that future research studies may substantially change their understanding of the effect that a test or procedure has.

Note: GRADE = **G**rading of **R**ecommendations, **A**ssessment, **D**evelopment and **E**valuation

Appendix D – Focus Group Guide

<table>
<tr><td colspan="2">Instructions for facilitators:

• Welcome and introductions
• Reminder about consent forms & reimbursement forms
• Review process for guideline development and review CTFPHC draft guidelines</td></tr>
<tr><td colspan="2">Questions for participants

Legend:
• Questions and Instructions are indicated as such in the left hand column. Instructions are meant to be directions for the participants, given to them by the facilitator.
• Directions for the facilitator are indicated in italics in the body of the text of the second column.</td></tr>
<tr><td>Instructions</td><td>If you haven't already, please take a few minutes to review the draft guideline recommendations and information provided on the GRADE methodology.

Note: ensure that participants have had a chance to read their project information sheet and guideline topic information sheet</td></tr>
<tr><td>Question 1</td><td>Recommendation 1

What are your impressions of the recommendation?

Reminder: The guideline recommendation is _____

Probes (note: use probes if the participants do not provide enough information in their responses to the above question.)</td></tr>
<tr><td>Question 2</td><td>Recommendation 2

What are your impressions of the recommendation?

Reminder: The guideline recommendation is _____

Probes (note: use probes if the participants do not provide enough information in their responses to the above question.)</td></tr>
<tr><td>Question 3</td><td>Recommendation 3

What are your impressions of the recommendation?

Reminder: The guideline recommendation is _____

Probes (note: use probes if the participants do not provide enough information in their responses to the above question.)</td></tr>
<tr><td colspan="2">Thank participants and wrap up</td></tr>
</table>

Appendix E – Survey

CTFPHC Survey on Public Perceptions of Lung Cancer Screening

Introduction

Thank you for taking part in the focus group to discuss the CTFPHC's draft recommendations on lung cancer screening. In this survey, the CTFPHC would like to ask you a few follow-up questions about how you view the recommendations. The survey will take approximately 15–20 minutes to complete. If you have any questions, concerns, or technical difficulties, please contact the project coordinator, Nadia Bashir, at bashirn@smh.ca or 416-864-6060 x77507.

Participant ID

Please enter your participant ID in the box below. You can find your participant ID in the email that you received from the project coordinator with the link to this survey.

CTFPHC Lung Cancer Recommendations

On the following pages, you will be asked to answer questions about the CTFPHC's draft lung cancer screening guideline recommendations. Remember that these recommendations apply to asymptomatic adults (i.e., people who don't have any symptoms of lung cancer) aged 18 years and older who are not suspected of having lung cancer. These recommendations do not apply to individuals who were previously diagnosed with, or suspected of having, lung cancer.

The questions below refer to the following CTFPHC recommendation:

Recommendation 1

We do not recommend screening for lung cancer with chest x-ray with or without sputum cytology. *Strong recommendation, low quality evidence*

Please rate how much you disagree or agree with the following statements on a scale from 1 to 9 (1 = strongly disagree, 9 = strongly agree). Note that we are interested in how much YOU agree or disagree with these statements, not how much doctors or other members of the public agree or disagree with them.

Question 1

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will help support primary care providers in delivering equitable health care (i.e., no Canadian will be disadvantaged because of age, gender, income, health status, ethnicity or geographic location).	○	○	○	○	○	○	○	○	○

Question 2

If you selected “1”, “2”, “3”, or "4" as your response to Question 1, please specify why you believe this recommendation will <u>not</u> help support primary care providers in delivering equitable health care. Please select all that apply.

- ☐ Because of age. (Please explain). _____
- ☐ Because of gender. (Please explain). _____
- ☐ Because of income. (Please explain). _____
- ☐ Because of health status. (Please explain). _____
- ☐ Because of ethnicity. (Please explain). _____
- ☐ Because of geographic location. (Please explain). _____

Question 3

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
This recommendation adequately considers the safety and effectiveness of lung cancer screening using chest x-ray with or without sputum cytology for adults aged 18 years and older who are not suspected of having lung cancer.	○	○	○	○	○	○	○	○	○

Question 4

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will lead to superior quality of care for Canadian adults aged 18 years and older who are not suspected of having lung cancer.	○	○	○	○	○	○	○	○	○

Question 5

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will	○	○	○	○	○	○	○	○	○

lead to better health outcomes (i.e., fewer deaths and complications from lung cancer screening) for Canadian adults aged 18 years and older who are not suspected of having lung cancer.

Question 6

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will ultimately lead to worse health outcomes (i.e., more deaths and complications from lung cancer) for Canadian adults aged 18 years and older who are not suspected of having lung cancer.	○	○	○	○	○	○	○	○	○

Question 7

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
I think this recommendation will be easy for primary care providers to implement in their practices across all urban settings in Canada.	○	○	○	○	○	○	○	○	○

Question 8

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
I think this recommendation will be easy for primary	○	○	○	○	○	○	○	○	○

care providers to implement in their practices across all rural settings in Canada.

Question 9

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will ultimately benefit Canada's primary health care system.	○	○	○	○	○	○	○	○	○

10. Please provide any additional thoughts you may have on this recommendation (optional, 250 words maximum)

The questions below refer to the following CTFPHC recommendation:

Recommendation 2

For adults aged 55-74 years, who are current or former (i.e. quit less than 15 years ago) smokers with a 30 pack-year smoking history, we recommend three screens with low dose CT, each at one-year intervals.

Weak recommendation, low quality evidence

Please rate how much you disagree or agree with the following statements on a scale from 1 to 9 (1 = strongly disagree, 9 = strongly agree). Note that we are interested in how much YOU agree or disagree with these statements, not how much doctors or other members of the public agree or disagree with them.

Question 1

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will help support primary care providers in delivering equitable health care (i.e., no Canadian will be disadvantaged because of age,	○	○	○	○	○	○	○	○	○

gender, income, health status, ethnicity or geographic location).

Question 2

If you selected “1”, “2”, “3”, or "4" as your response to Question 1, please specify why you believe this recommendation will not help support primary care providers in delivering equitable health care. Please select all that apply.

- ☐ Because of age. (Please explain). _____
- ☐ Because of gender. (Please explain). _____
- ☐ Because of income. (Please explain). _____
- ☐ Because of health status. (Please explain). _____
- ☐ Because of ethnicity. (Please explain). _____
- ☐ Because of geographic location. (Please explain). _____

Question 3

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
All Canadians to whom the recommendation applies will have equitable access to the low dose CT (LDCT) described in the recommendation (i.e., no Canadian will be unable to access this test because of age, gender, income, health status, ethnicity or geographic location).	○	○	○	○	○	○	○	○	○

Question 4

If you selected “1”, “2”, “3”, or "4" as your response to Question 3, please specify why you believe that all Canadians will not have equitable access.

- ☐ Because of age. (Please explain). _____
- ☐ Because of gender. (Please explain). _____
- ☐ Because of income. (Please explain). _____
- ☐ Because of health status. (Please explain). _____
- ☐ Because of ethnicity. (Please explain). _____
- ☐ Because of geographic location. (Please explain). _____

Question 5

	1=Strongly	2	3	4	5=Neither	6	7	8	9=Strongly

	disagree				agree nor disagree				agree
This recommendation adequately considers the safety and effectiveness of LDCT for adults aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	○	○	○	○	○	○	○	○	○

Question 6

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will lead to superior quality of care for Canadians aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	○	○	○	○	○	○	○	○	○

Question 7

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will lead to better health outcomes (i.e., fewer deaths and complications from lung cancer) for Canadians aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	○	○	○	○	○	○	○	○	○

Question 8

	1=Strongly	2	3	4	5=Neither	6	7	8	9=Strongly

	disagree				agree nor disagree				agree
Implementing this recommendation will ultimately lead to worse health outcomes (i.e., more deaths and complications from lung cancer screening) for Canadians aged 55-74 who have smoked 30 pack-years and are either current smokers or have quit within the past 15 years.	○	○	○	○	○	○	○	○	○

Question 9

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
I think this recommendation will be easy for primary care providers to implement in their practices across all urban settings in Canada.	○	○	○	○	○	○	○	○	○

Question 10

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
I think this recommendation will be easy for primary care providers to implement in their practices across all rural settings in Canada.	○	○	○	○	○	○	○	○	○

Question 11

	1=Strongly disagree	2	3	4	5=Neither agree nor	6	7	8	9=Strongly agree

					disagree				
Implementing this recommendation will ultimately benefit Canada's primary health care system.	○	○	○	○	○	○	○	○	○

12. Please provide any additional thoughts you may have on this recommendation (optional, 250 words maximum)

The questions below refer to the following CTFPHC recommendation:

Recommendation 3
For adults aged 74 years; and for adult smokers of any age with less than a 30 pack-year smoking history, we do not recommend routinely screening for lung cancer with low dose CT.

Weak recommendation, low quality evidence.

Please rate how much you disagree or agree with the following statements on a scale from 1 to 9 (1 = strongly disagree, 9 = strongly agree). Note that we are interested in how much YOU agree or disagree with these statements, not how much doctors or other members of the public agree or disagree with them.

Question 1

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will help support primary care providers in delivering equitable health care (i.e., no Canadian will be disadvantaged because of age, gender, income, health status, ethnicity or geographic location).	○	○	○	○	○	○	○	○	○

Question 2

If you selected “1”, “2”, “3”, or "4" as your response to Question 1, please specify why you believe this recommendation will not help support primary care providers in delivering equitable health care. Please select all that apply.

- ☐ Because of age. (Please explain). _____
- ☐ Because of gender. (Please explain). _____
- ☐ Because of income. (Please explain). _____
- ☐ Because of health status. (Please explain). _____
- ☐ Because of ethnicity. (Please explain). _____
- ☐ Because of geographic location. (Please explain). _____

Question 3

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
This recommendation adequately considers the safety and effectiveness of LDCT for adults less than 55 years, adults more than 74 years, and adult smokers of any age with less than a 30 pack-year smoking history.	○	○	○	○	○	○	○	○	○

Question 4

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will lead to superior quality of care for Canadian adults less than 55 years, Canadian adults more than 74 years, and Canadian adult smokers of any age with less than a 30 pack-year smoking history.	○	○	○	○	○	○	○	○	○

Question 5

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will lead to better health outcomes (i.e., fewer deaths and complications from lung cancer screening) for Canadian adults less than 55 years, Canadian adults more than 74 years, and Canadian adult smokers of any age with less than a 30 pack-year smoking history.	○	○	○	○	○	○	○	○	○

Question 6

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will ultimately lead to worse health outcomes (i.e., more deaths and complications from lung cancer) for Canadian adults less than 55 years, Canadian adults more than 74 years, and Canadian adult smokers of any age with less than a 30 pack-year smoking history.	○	○	○	○	○	○	○	○	○

Question 7

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
I think this recommendation will be easy for primary	○	○	○	○	○	○	○	○	○

care providers to implement in their practices across all urban settings in Canada.

Question 8

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
I think this recommendation will be easy for primary care providers to implement in their practices across all rural settings in Canada.	○	○	○	○	○	○	○	○	○

Question 9

	1=Strongly disagree	2	3	4	5=Neither agree nor disagree	6	7	8	9=Strongly agree
Implementing this recommendation will ultimately benefit Canada's primary health care system.	○	○	○	○	○	○	○	○	○

10. Please provide any additional thoughts you may have on this recommendation (optional, 250 words maximum)

Please respond to each of the following statements using the scale provided. Indicate your response by selecting the number on the scale that corresponds to your response.

	1=Not at all	2	3	4	5	6	7	8	9=Very much
1. How easy was it to understand the information in the lung cancer background information sheet?	○	○	○	○	○	○	○	○	○
2. How informative was the focus group discussion that you took part in via teleconference?	○	○	○	○	○	○	○	○	○
3. How argumentative was the focus group discussion?	○	○	○	○	○	○	○	○	○

4. How much did the focus group discussion influence your responses in this final survey?

5. How helpful was the information provided by the content expert (i.e., the doctor on the focus group call)?

6. How much did the content expert's comments influence your responses in this final survey?

7. How easy was it to rate the CTFPHC's recommendations in this survey?

8. How clear were the survey instructions?

9. How well did you understand what we asked you to do in this survey?

Please describe anything that we could do to make the focus group tasks easier to complete.

Please describe anything that we could do to make the survey tasks easier to complete.

Please respond to each of the following statements using the scale provided. Indicate your response by selecting the number on the scale that corresponds to your response.

	1=Not at all	2	3	4	5	6	7	8	9=Very much
1. How well do you believe that your own survey responses reflect how acceptable the lung cancer recommendations are?	○	○	○	○	○	○	○	○	○
2. How much do you believe that the responses provided by participants in this project can lead to a set of recommendations to assist doctors in making decisions about lung cancer screening?	○	○	○	○	○	○	○	○	○
3. How much do you believe that the responses provided by participants in this project will be valued by the CTFPHC?	○	○	○	○	○	○	○	○	○

4. How much do you believe that the responses provided by participants will influence the CTFPHC's lung cancer screening guideline?	○	○	○	○	○	○	○	○	○
5. In addition to creating clinical practice guidelines, the CTFPHC also develops knowledge translation tools to help clinicians and patients understand and implement the guidelines. How much do you believe that the responses provided by participants will influence the content of the CTFPHC's lung cancer screening knowledge translation tools?	○	○	○	○	○	○	○	○	○
6. How satisfying did you find your participation in this project to be?	○	○	○	○	○	○	○	○	○
7. How much was your actual experience as a participant in this project similar to your expectations about what it would be like to take part?	○	○	○	○	○	○	○	○	○

8. Please describe what you liked about taking part in this project.

9. Please describe what you did not like about taking part in this project.

10. Please describe anything that we could change to improve this project.

What is your gender?

- ○ Male
- ○ Female

What is your age?

Which province or territory do you live in?

- ○ British Columbia
- ○ Alberta
- ○ Saskatchewan

- ○ Manitoba
- ○ Ontario
- ○ Quebec
- ○ New Brunswick
- ○ Nova Scotia
- ○ Prince Edward Island
- ○ Newfoundland and Labrador
- ○ Yukon Territory
- ○ Northwest Territories
- ○ Nunavut

Thank You

Thank you for completing this survey. If you have questions about any aspect of the project, please contact the project coordinator, Nadia Bashir, at bashirn@smh.ca or 416-864-6060 x77507.