CTFPHC Patient Engagement Protocol

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Table of Contents

INTRODUCTION

Background

Incorporating patient priorities and perspectives into the process of clinical practice guideline (CPG) and patient materials development is an important dimension of patient-centred care[1]. There is some evidence that patient involvement in CPG development informs the development of guidelines which are more likely to address patient preferences, better tailors recommendations to individuals, and supports clinical 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,[5] 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[6]. This may be in part because guideline developers focus primarily on evidence of practice effectiveness rather than on evidence of patient preferences. In addition, there are limited data evaluating patient engagement in the guideline development process. Indeed, research on patient preferences is not as well developed as areas of clinical inquiry and often uses methods as well as small samples that may not be representative of the range of patients' perspectives.

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 the diverse social circumstances of patients, their behaviours and attitudes towards risk, as well as their values and preferences[1-3]. For guideline developers, patient involvement may enhance the credibility, transparency, and applicability of CPGs. International organizations that appraise the quality of CPGs have set standards and introduced best practices to incorporate patient perspectives and choices into CPGs[5-7]. 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[5,7]. The IOM recommends including a current or former patient and a patient advocate in the CPG development process[7]. Likewise, the AGREE II instrument requires guideline developers to consider integrating patient views and preferences through formal consultation with patients and patient groups[8].

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[9]. For example, since its reconstitution in April 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. Beginning in 2015, the CTFPHC also started recruiting members of the public to provide feedback at up to three critical stages of guideline development. In collaboration with the

CTFPHC and the Public Health Agency of Canada (PHAC) Global Health and Guidelines Division (GHGD), the St. Michael's Hospital (SMH) Knowledge Translation (KT) Program is responsible for coordinating all three phases of CTFPHC patient engagement.

During Phase 1, participants use the RAND Appropriateness Method (RAM) to rate the screening outcomes relevant to a particular guideline topic that are most important to consider during decision making.[10] The CTFPHC uses the results of this phase to inform the evidence review that serves as the foundation for the guideline. In Phase 2, participants again use the RAM to provide their perspectives on the screening outcomes for a particular guideline topic. In this case, however, participants also receive information from the systematic review about the relative likelihood of each outcome. The CTFPHC uses the findings from this phase to develop the final guideline recommendations and knowledge translation (KT) tools. Finally, in Phase 3, participants are engaged in usability testing of patient KT tools.

Objective

To engage patients during the guideline and patient KT tool development process

METHODS

Phase 1

Methodological Approach

When drafting the evidence review protocol for a guideline, the CTFPHC guideline working group identifies relevant outcomes of preventive health care interventions based on a process outlined in the CTFPHC procedure manual.[10] They then use the Grading Recommendations Assessment, Development and Evaluation (GRADE) 9-point scale to rate each outcome as *not important* (rating 1-3), *important* (rating 4-6), or *critical* (rating 7-9) to consider when individuals make decisions about receiving the interventions. Only outcomes that are identified as *important* or *critical* are included in the evidence profile for the guideline. In addition, only outcomes identified as *critical* are primary factors influencing a recommendation.[11]

During Phase 1, the SMH KT Program uses a modified version of the RAM to identify patient preferences in considering screening outcomes.[10] Based on this approach, participants first review background material on the topic of interest and then independently rate the same outcomes as the CTFPHC guideline working group using the GRADE 9-point scale. Next, the participants receive a summary of their own GRADE outcome ratings and the distribution of ratings provided by the entire sample of participants. They then meet as a group to discuss the outcomes and general preferences for screening with a focus group moderator and content expert. At the end of the meeting, participants rate the same outcomes again using the GRADE 9-point scale. The goal of the RAM is not to force consensus among participants. Instead, the purpose of the group discussion and the second set of ratings is to increase the likelihood that differences in ratings among participants are due to actual differences in opinion rather than to differences in knowledge about the topic. Thus, the RAM provides the opportunity for rich discussions that may allow participants to consider a broader range of information when making their final GRADE ratings. This process allows the CTFPHC guideline working group to consider

evidence on outcomes that are perceived to be important by clinicians, researchers, and members of the screening populations.

Participants

For Phase 1, the SMH KT Program recruits approximately 16-20 English-speaking members of the Canadian public (i.e., individuals who are not practicing health care professionals) for whom the guideline will be relevant (e.g., intended targets of the guideline and partners or caregivers of intended targets). To optimize the extent to which the sample is representative of the Canadian population, the SMH KT Program seeks to recruit participants from each province and territory. The following methods are used to recruit a diverse sample that will allow the CTFPHC guideline working group to address health equity issues relevant to the guideline topic:

1. Posting recruitment ads on public advertisement websites (e.g., Kijiji and Craigslist)
2. Posting ads on the CTFPHC website; and
3. Emailing members of the public who are part of the circle of contacts of the SMH KT Program in Toronto and have expressed interest in providing feedback on CTFPHC guidelines and tools.

Individuals who express interest in taking part in the project are asked to complete a brief online survey containing demographic, health, health equity, and conflict of interest screening questions (see Appendix A). Individuals who meet the demographic, health, and health equity inclusion criteria specified by the relevant CTFPHC guideline working group are invited to take part in the project. Individuals who do not meet the inclusion criteria for the project are informed that they are not eligible to take part. For all guideline topics, individuals who already have the disease and/or have conflicts of interest relevant to the guideline topic (e.g., membership in a relevant disease-specific organization or owning shares in a disease-relevant company) are excluded. Participants are reimbursed $20.64 per hour for their participation as per SMH KT Program policy.

Procedure

Part A. Eligible participants receive a project information sheet when they are informed of their eligibility to participate in the project. The project information sheet outlines the purpose of the project and the role of participants in providing input from a patient perspective. Interested participants are then sent an online survey by email that includes a copy of the CTFPHC confidentiality agreement form and a guideline topic information sheet (developed by the CTFPHC guideline working group). The guideline topic information sheet provides background information on (a) the relevant disease, (b) how the disease affects people, (c) the screening and diagnostic tests for the disease, (c) treatments for the disease, and (d) and the implications of screening, further testing, and treatment for the disease.

Participants are asked to complete an online survey within one week of receiving an online link (see Appendix B). The SMH KT program administers the survey using Qualtrics. Participants first use the GRADE outcome rating method to rate the extent to which a series of predefined screening outcomes are *not important* (rating 1–3), *important* (rating 4–6), or *critical* (rating 7–9) to consider when making decisions relevant to the guideline topic.[12] They also have an opportunity to explain each rating in open-ended form. Next, participants select the five

outcomes on the list that they believe are most critical. They then list any additional outcomes that are not on the predefined list but that are important to consider when making decisions relevant to the guideline topic. Participants are informed that a project coordinator may contact them after they complete the survey to clarify any of the additional outcomes that they listed and to determine whether these outcomes can be combined with existing outcomes on the predefined list.

To gauge participants' understanding of the survey tasks, participants are asked to briefly summarize the tasks that they were asked to perform. They also complete six closed-ended items and one open-ended item adapted from the RAM post-survey questionnaire to assess their understanding of the survey instructions and their ability to complete the survey tasks with ease.[10] Participants rate the closed-ended items along a 9-point Likert-type scale with endpoints labelled 1(*Not at all*) and 9(*Very much*).

Part B. After completing the survey in Part A, participants receive a copy of their own outcome ratings and the distribution of ratings provided by all participants for each outcome. Participants are also provided with the top five outcomes that they selected and the frequency with which each outcome was selected as a top five outcome across participants, and the additional outcomes identified by participants in Part A. Participants are then assigned to take part in one of three 60-minute focus groups via teleconference. During the focus group, participants are asked to share their rationale for their ratings and discuss factors that affect the perceived importance of various outcomes. One research assistant from the SMH KT Program moderates the focus group discussion using a script and a research coordinator takes notes to document the discussion. The chair of the CTFPHC guideline working group is also present during the focus groups to answer questions that participants have about the guideline topic or outcomes. All focus group discussions are audio-recorded.

Part C. After the focus group, participants are given approximately one week to complete the same survey used in Part A (see Appendix A). Participants receive a reminder to complete the survey within one week. In this case, however, the survey includes an expanded set of items to assess participants' engagement and experience with the project. Specifically, the survey includes 15 items to measure six meta-criteria that are considered critical for successful stakeholder engagement activities[13]. These meta-criteria include respect, trust, legitimacy, fairness, competence and accountability[13]. Participants rate these items along a 5-point Likert-type scale (e.g., 1[*Not at all*] and 5[*Large extent*]). Lastly, participants complete five closed-ended items adapted from the RAM post-survey questionnaire to assess their understanding of the survey instructions and their ability to complete the survey tasks with ease.[10] Participants also respond to three open-ended items about their overall experience.

Outcomes

Patient preferences. Primary outcomes of interest are the importance of considering each outcome when making screening decisions and the top five outcomes selected by participants. Participants' overall preferences for screening are also assessed. All outcomes are assessed using the responses from the Part B focus group discussion and the Part C survey.

Experience with project tasks. Participants' experience with the surveys and the focus group is assessed using the survey and focus group experience items included in the Part A and C surveys.

Engagement experience. Participants' experience with the engagement process is assessed using the engagement survey items included in the Part C survey.

Data Analysis

Outcome Ratings

Participants' outcome ratings are analyzed by calculating the median, interquartile range (IQR), and range for each outcome.

Top-Five Outcome Selection

The outcomes that participants select as the top five most important outcomes to consider are analyzed by calculating the frequency with which each outcome is selected as a top-five outcome by participants.

Preferences for Screening

Participants' screening preferences are analyzed by calculating descriptive statistics for quantitative data and conducting a qualitative analysis of the open-ended responses.

Focus Group Data

Focus group data is analyzed by performing a thematic analysis on the notes and audio from all focus group discussions[14].

Experience with Project Tasks

Project task experience data is analyzed by calculating descriptive statistics for the quantitative data and conducting a qualitative analysis of the open-ended responses.

Engagement Experience

Participant engagement data is analyzed by calculating descriptive statistics for the quantitative data and conducting a qualitative analysis of the open-ended responses.

Table 1. Outcomes, Data Source, and Data Analysis

Outcome	Data source	Data Analysis
Preferences in considering outcomes	• Part A Survey • Part B Focus groups • Part C Survey	• Calculate median, IQR, and range for each outcome • Calculate frequency of selected top-five outcomes • Thematic analysis of qualitative data
Overall preferences for screening	• Part B Focus groups • Part C Survey	• Calculate descriptive statistics • Thematic analysis of

		qualitative data
Experience with project tasks	• Part A Survey • Part C Survey	• Calculate descriptive statistics of quantitative data • Qualitative analysis of open-ended responses
Engagement experience	• Part C Survey	• Calculate descriptive statistics of quantitative data • Qualitative analysis of open-ended responses

Dissemination

The SMH KT Program prepares a final data summary report on the survey and focus group results for the relevant CTFPHC guideline working group. Participants are emailed a lay version of the data summary report and are invited to participate in an optional teleconference debrief session to discuss the project findings. The SMH KT Program also sends participants a copy of the guideline and KT tools after the guideline is released.

Phase 2

Methodological Approach

During Phase 2, the SMH KT Program uses a modified version of the RAM to identify patient preferences when making decisions about whether or not to be screened for a specific health condition based on the information from the systematic review.[10] Based on this approach, participants first review background material on the topic of interest and then independently use a 9-point scale to rate the extent to which each outcome would influence their decision to be screened or not be screened for the health condition. Next, they receive a summary of their own ratings and the distribution of ratings provided by the entire sample of participants. They then meet as a group to discuss the outcomes and general preferences for screening with a focus group moderator and content expert. At the end of the meeting, participants rate the same outcomes again using the 9-point scale.

Participants

For Phase 2, the SMH KT Program recruits approximately 16-20 English-speaking members of the Canadian public (i.e., individuals who are not practicing health care professionals) for whom the guideline will be relevant (e.g., intended targets of the guideline and partners or caregivers of intended targets). The same recruitment methods are used for Phase 2 as used in Phase 1.

Procedure

Part A. In Phase 2, eligible participants receive a project information sheet when they are informed of their eligibility to participate in the project. The project information sheet outlines the purpose of the project and the role of participants in providing input from a patient perspective. Interested participants are then sent an online survey by email that includes a copy of the CTFPHC confidentiality agreement form and a guideline topic information sheet (developed by the CTFPHC guideline working group). The guideline topic information sheet provides

background information on (a) the relevant disease, (b) how the disease affects people, (c) the screening and diagnostic tests for the disease, (c) treatments for the disease, and (d) and the implications of screening, further testing, and treatment for the disease. In comparison to the topic information sheet in Phase 1, the Phase 2 information sheet also includes information from the systematic review on the relative likelihood of each screening outcome.

Participants are asked to complete an online survey within one week of receiving an online link (see Appendix C). The SMH KT Program administers the survey using Qualtrics. Participants use a 9-point rating scale to rate the extent to which the likelihood of experiencing each outcome would influence their decision to be screened with endpoints labelled 1(*This isn't important for my decision at all*) to 9(*This is very important for my decision*). They also have an opportunity to explain the ratings in open-ended form. The list of outcomes and associated data is from the completed systematic review and provided by the CTFPHC guideline working group. Next, participants are asked to rate their overall preferences for screening based on prevalence data and the likelihood of experiencing each screening outcome using a 9-point rating scale (e.g., 1[*Not at all*] and 9 [*Very much*]).

To gauge participants' understanding of the survey tasks, participants are asked to briefly summarize the tasks that they were asked to perform. They also complete four closed-ended items and one open-ended item adapted from the RAM post-survey questionnaire to assess their understanding of the survey instructions and their ability to complete the survey tasks with ease.[10] Participants rate the closed-ended items along a 9-point Likert-type scale with endpoints labelled 1(*Not at all*) and 9(*Very much*).

Part B. After completing the survey in Part A, participants receive a copy of their own outcome ratings and the distribution of ratings provided by all participants for each outcome. Participants are also provided with their own ratings and the distribution of ratings provided by all participants for overall screening preferences. Participants are then assigned to take part in one of three 60-minute focus groups via teleconference. During the focus group, participants are asked to share their rationale for their ratings and discuss factors that affect the perceived importance of various outcomes. Participants are also asked to share their overall preferences to be screened based on the available evidence and if they anticipate any barriers to screening. One research assistant from the SMH KT Program moderates the focus group discussion using a script and a research coordinator takes notes to document the discussion. The chair of the CTFPHC guideline working group is also present during the focus groups to answer questions that participants have about the guideline topic or outcomes (e.g., questions about the evidence for specific outcomes). All focus group discussions are audio-recorded.

Part C. After the focus group, participants are given approximately one week to complete the same survey used in Part A (see Appendix C). Participants receive a reminder to complete the survey within one week. The survey includes items to assess participants' engagement and experience with the project. Specifically, the survey includes 15 items to measure six meta-criteria that are considered critical for successful stakeholder engagement activities[13]. These meta-criteria include respect, trust, legitimacy, fairness, competence and accountability[13]. Participants rate these items along a 5-point Likert-type scale (e.g., 1[*Not at all*] and 5[*Large extent*]). Lastly, participants complete four closed-ended items and one open-ended item adapted from the RAM post-survey questionnaire to assess their understanding of the survey instructions and their ability to complete the survey tasks with ease.[10] Participants also respond to three open-ended items about their overall experience.

Outcomes

Patient preferences. Primary outcomes of interest are the importance of considering each outcome when making screening decisions. Participants' overall preferences and anticipated barriers for screening are also assessed. All outcomes are assessed using the responses from the focus group discussion and the Part C survey.

Experience with project tasks. Participants' experience with the surveys and the focus group is assessed using the survey and focus group experience items included in the Part A and C surveys.

Engagement experience. Participants' experience with the engagement process is assessed using the engagement survey items included in the Part C survey.

Data Analysis

Outcome Ratings

Participants' outcome ratings are analyzed by calculating the median, interquartile range (IQR), and range for each outcome.

Preferences for Screening

Participant's screening preferences data is analyzed by calculating descriptive statistics for quantitative data and conducting a qualitative analysis of the open-ended responses.

Focus Group Data

Focus group data is analyzed by performing a thematic analysis on the notes and audio from all focus group discussions[14].

Experience with Project Tasks

Project task experience data is analyzed by calculating descriptive statistics for the quantitative data and conducting a qualitative analysis of the open-ended responses.

Engagement Experience

Participant engagement data is analyzed by calculating descriptive statistics for the quantitative data and conducting a qualitative analysis of the open-ended responses.

Table 2. Outcomes, Data Source, and Data Analysis

Outcome	Data source	Data Analysis
Preferences in considering outcomes	• Part A Survey • Part B Focus groups • Part C Survey	• Calculate median, IQR, and range for each outcome • Thematic analysis of qualitative data
Overall preferences for screening	• Part B Focus groups • Part C Survey	• Calculate descriptive statistics • Thematic analysis of qualitative data
Anticipated barriers for screening	• Part B Focus groups	• Thematic analysis of qualitative data
Experience with project tasks	• Part A Survey • Part B Survey	• Calculate descriptive statistics of quantitative data • Qualitative analysis of open-ended responses
Engagement experience	• Part C Survey	• Calculate descriptive statistics of quantitative data • Qualitative analysis of open-ended responses

Dissemination

The SMH KT Program prepares a final data summary report on the survey and focus group results for the relevant CTFPHC guideline working group. Participants are emailed a lay version of the data summary report and are invited to participate in an optional teleconference debrief session to discuss the project findings. The SMH KT Program also sends participants a copy of the guideline and KT tools after the guideline is released.

Phase 3

Methodological Approach

During Phase 3, the SMH KT Program uses focus groups or interviews to obtain feedback on the content, format, aesthetics, and usefulness of patient KT tools developed to accompany the CTFPHC guideline.

Participants

The SMH KT Program recruits approximately 6-8 English-speaking members of the Canadian public (i.e., individuals who are not practicing health care professionals) for whom the guideline and patient KT tools will be relevant (e.g., intended targets of the guideline and partners or caregivers of intended targets). The same methods for recruitment are used in Phase 3 as used in Phase 1 and 2.

Procedure

The SMH KT Program tool development specialist creates a preliminary version of the patient KT tools following completion of the draft CTFPHC guideline recommendations and by incorporating participant feedback from Phase 1 and 2. Once the draft patient KT tools are approved by the CTFPHC guideline working group, participants from the target patient population are recruited for usability testing.

Eligible participants are asked to complete a copy of the CTFPHC confidentiality agreement form and submit via email. Once the SMH KT Program receives a signed copy of the CTFPHC confidentiality form, participants are sent a copy of the patient KT tools and are assigned to take part in one of three 60-minute focus groups or a one-on-one interview via teleconference. Participants are provided one week to review the patient KT tools prior to attending the focus group or interview. During the focus group or interview, participants are asked to evaluate the patient KT tools for organization, content, layout, appearance, and usability. One research assistant from the SMH KT Program moderates the focus group or interview discussion using a script. The research assistant also takes notes to document the discussion. All focus group and interview discussions are audio-recorded.

Outcomes

Patient Preferences. Primary outcomes of interest are participants' preferences for the content, format, and aesthetics of the patient KT tools. Participants perceptions of the patient KT tools' utility in practice, including whether the tools would facilitate patient engagement in shared decision-making about screening or if the tools would cause any concerns when making decisions about screening, are also assessed.

Data Analysis

Focus group and interview data is analyzed by performing a thematic analysis on the notes and audio from the focus group discussions[14]. Qualitative data is synthesized from the focus groups and interviews to develop a summary of participants' preferences for the final report.

Table 3. Outcomes, Data Source, and Data Analysis

Outcome	Data Source	Data Analysis
Participant preferences	Focus groups	Thematic analysis of qualitative data

Dissemination

A SMH KT Program research assistant prepares a final report on the focus group and interview results for the SMH KT Program tool development specialist and the CTFPHC guideline working group. The final report is used to inform the final versions of the patient KT tools. The SMH KT Program also sends participants a copy of the guideline and KT tools after the guideline is released.

LIMITATIONS

This approach has several limitations. First, participant samples are relatively small and may not be representative of members of populations to be screened in Canada. Although the SMH KT Program strives to include individuals from across Canada in each sample, responses to the recruitment ads from individuals living in some provinces and territories may not be received. In addition, participants who respond to the recruitment ads may differ from individuals who chose not to respond to the ads in several ways. Specifically, individuals who express interest in taking part in the project may be more interested in health care issues, engaged in patient advocacy, and/or more likely to have a university degree.

Second, for Phase 1 and 2, participants in the project read a background document on a screening topic, discuss screening outcomes with other participants, and receive relevant information from the CTFPHC guideline working group chair before indicating their preferences in the final survey. Participants are given this amount of information so that they have enough knowledge about the screening outcomes to be able to rate each one. When Canadians make screening decisions, however, they are not necessarily required to consider and understand each relevant outcome. Thus, some Canadians may make decisions about screening without having the same level of relevant information as participants in this project. The preferences identified by participants in this project may, therefore, differ from those of other Canadians who make screening decisions with more limited knowledge about outcomes.

Further, some Canadians who anticipate making a decision about getting screened for a health condition may be more informed about screening than are participants in this project. These individuals may also have preferences that differ from those identified in the current project. In future work, therefore, it will be important to examine how patient preferences differ as a function of knowledge about screening.

Third, the chair of the CTFPHC guideline working group attends the focus groups in Phase 1 and 2 to answer questions that participants have about screening outcomes. Although the chair strives to provide objective and neutral responses to participants' queries, it is possible that some responses contain clues about the chair's opinions. This may influence participants' ratings. However, individuals usually receive some information from a health care professional before making a screening decision and this information may also be influenced by the health care professional's opinions.

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APPENDICES

Appendix A: Screening Questionnaire Template

Canadian Task Force on Preventive Health Care:

Screening Questionnaire

1) Please indicate your gender:
   a. Male
   b. Female
   c. Other_____

2) Please indicate your age:
   a. Less than 20 years
   b. 20 to 29 years
   c. 30 to 39 years
   d. 40 to 49 years
   e. 50 to 59 years
   f. 60 to 69 years
   g. 70 to 79 years
   h. 80+ years

3) Which province or territory do you live in? _____

4) Please indicate your time zone:

   a. Pacific
   b. Mountain
   c. Central
   d. Eastern
   e. Atlantic
   f. Newfoundland

5) Please indicate the type of region that you live in:
   a. Urban
   b. Suburban
   c. Rural

6) What is your ethnicity? _____

7) Are you a practicing health care professional?
   a. Yes
   b. No

8) Have you ever been diagnosed with <guideline topic>?
   a. Yes
   b. No

9) Are you the caregiver of someone who has ever been diagnosed with <guideline topic>?
   a. Yes
   b. No

10) Do you have any conflicts of interest related to <guideline topic>?
Examples include but are not limited to the following: being a member of a group related to <guideline topic>; owning a company that provides products or services related to <guideline topic>; owning shares in a company that provides products or services related to <guideline topic>; conducting research on <guideline topic>.

   a. Yes
   b. No

If yes, please describe these conflicts of interest below.

11) Do you have a romantic partner?
   a. Yes
   b. No

   If you do not have a partner, skip to Question 12

   i. If yes, Please indicate **your partner's** gender:
      1. Male
      2. Female
      3. Other_____

   ii. Please indicate **your partner's** age:
      1. Less than 20 years
      2. 20 to 29 years
      3. 30 to 39 years
      4. 40 to 49 years
      5. 50 to 59 years
      6. 60 to 69 years
      7. 70 to 79 years
      8. 80+ years

   iii. Has **your partner** ever been diagnosed with <guideline topic>?
      1. Yes
      2. No

   iv. Does **your partner** have any conflicts of interest related to <guideline topic>?

   Examples include but are not limited to the following: being a member of a group related to <guideline topic>; owning a company that provides products or services related to <guideline topic>; owning shares in a company that provides products or services related to <guideline topic>; conducting research on <guideline topic>.

      1. Yes

2. No

If yes, please describe these conflicts of interest below.

12) 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?

13) If so, what is your preferred method for us to contact you?
   a. Email
   b. Telephone

Appendix B: Phase 1 Online Survey Template

Page 1

Canadian Task Force on Preventive Health Care:

Survey on Public Perceptions of <Guideline Topic> Screening

The Canadian Task Force on Preventive Health Care (CTFPHC) receives funding from the Public Health Agency of Canada (PHAC) to develop evidence-based clinical practice guidelines for preventive health care in Canada. The CTFPHC has created the following survey to assess how members of the public view <guideline topic> screening. Getting screened for <guideline topic> has both harms and benefits. In this survey, the CTFPHC would like to know how important you think it is to consider each of these harms and benefits when people make decisions about <guideline topic> screening. The survey will take approximately 10–15 minutes to complete.

If you have any questions, concerns, or technical difficulties, please contact the project coordinator, <research assistant name>, at <name>@smh.ca or 416-864-6060 x XXXXX.

Page 2

<Insert "CTFPHC Confidentiality Agreement">

[ ] I acknowledge that I have read and agree to the above Confidentiality Agreement

Page 3

Please enter your participant ID:

Date:

Page 4

Before you begin the survey, please make sure that you have read the "Background Information Sheet on <guideline topic> Screening". You can find a copy of the background information sheet below.

<Insert "Background Information Sheet" content>

[ ] I have read the "Background Information Sheet on <guideline topic> Screening" and am ready to proceed with the survey

Page 5

Below is a list of harms and benefits that people may experience after getting screened for <guideline topic>. For each harm or benefit, please rate how critical YOU think it is to consider this harm or benefit when people decide whether or not to be screened for <guideline topic>. Use the scale below each harm or benefit to indicate whether the harm or benefit is not important, important, or critical to consider when making decisions about <guideline topic> screening. Indicate your response by selecting the number on the scale that corresponds to your response.

Note that we are interested in how critical YOU think these harms and benefits are to consider, not how critical doctors or other members of the public think these harms or benefits are.

<Outcome 1>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 2>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 3>

1	2	3	4	5	6	7	8	9

Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 4>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 5>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 6>

1	2	3	4	5	6	7	8	9

Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 7>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 8>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 9>

1	2	3	4	5	6	7	8	9

Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 10>

1	2	3	4	5	6	7	8	9
Not important				Important				Critical

If you would like to provide any comments about your rating, please enter them in the space provided below.

Page 6

Below is the same list of harms and benefits that you just rated. Please select the **five** items on this list that you think are **most critical** to consider when people make decisions about <guideline topic> screening.

Please do not select more than five items.

- ☐ Outcome 1
- ☐ Outcome 2
- ☐ Outcome 3
- ☐ Outcome 4
- ☐ Outcome 5
- ☐ Outcome 6
- ☐ Outcome 7
- ☐ Outcome 8
- ☐ Outcome 9
- ☐ Outcome 10

Page 7 ***(Part A Survey only)***

In the space provided below, please list any additional harms or benefits that did not appear on the rating list but that you think are critical for people to consider when making <guideline topic> screening decisions. The original list is provided below for your reference.

Please note that the project coordinator may contact you after you complete the survey to better understand the additional harms and/or benefits that you list here.

Existing List:
Outcome 1
Outcome 2
Outcome 3
Outcome 4
Outcome 5
Outcome 6
Outcome 7
Outcome 8
Outcome 9
Outcome 10

Page 8

In the space provided below, please briefly summarize the tasks that we asked you to perform in this survey.

Page 9 ***(Part C Survey only)***

We will now ask you some questions about your experience participating in this project. Please respond to each of the following statements using the scales provided.

Question 1: To what extent do you believe that your ideas were heard during the engagement process?

Not at all Small Extent Fair Extent Moderate Extent Large Extent

○ ○ ○ ○ ○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 1, please explain your rating in the space below.

Question 2: To what extent did you feel comfortable contributing your ideas to the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 2, please explain your rating in the space below.

Question 3: Did organizers take your contributions to the engagement process seriously?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 3, please explain your rating in the space below.

Question 4: To what extent do you believe that your input will influence final decisions that underlie the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 4, please explain your rating in the space below.

Question 5: To what extent do you believe that your values and preferences will be included in the final health advice from this process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 5, please explain your rating in the space below.

Question 6: To what extent were you able to clearly express your viewpoints?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 6, please explain your rating in the space below.

Question 7: How neutral in their opinions (regarding topics) were organizers during the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 7, please explain your rating in the space below.

Question 8: Did all participants have equal opportunity to participate in discussions?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent

○ ○ ○ ○ ○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 8, please explain your rating in the space below.

Question 9: How clearly did you understand your role in the process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 9, please explain your rating in the space below.

Question 10: To what extent was information made available to you either prior or during the engagement process so as to participate knowledgeably in the process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 10, please explain your rating in the space below.

Question 11: To what extent were the ideas contained in the information material easy to understand?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 11, please explain your rating in the space below.

Question 12: How clearly did you understand what was expected of you during the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 12, please explain your rating in the space below.

Question 13: How clearly did you understand what the goals of the engagement process were?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 13, please explain your rating in the space below.

Question 14: To what extent would you follow health advice from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 14, please explain your rating in the space below.

Question 15: To what extent would you advise others to follow health advice from the Canadian Task Force on Preventive Health Care (if it related to their health condition)?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 15, please explain your rating in the space below.

Page 10

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.

How easy was it to understand the information in the <guideline topic> information sheet?

1	2	3	4	5	6	7	8	9
Not at all								Very much

How easy was it to rate the harms and benefits using the 9-point scale?

1	2	3	4	5	6	7	8	9
Not at all								Very much

How easy was it to select the top five harms and benefits from the full list?

1	2	3	4	5	6	7	8	9
Not at all								Very much

How easy was it to identify additional harms and/or benefits that weren't already included in the survey? *(Part A Survey only)*

1	2	3	4	5	6	7	8	9

Not at all								Very much

How clear were the survey instructions?

1	2	3	4	5	6	7	8	9
Not at all								Very much

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

1	2	3	4	5	6	7	8	9
Not at all								Very much

Please describe anything that we could do to make the survey tasks easier to complete. *(Part A Survey only)*

Please describe what you liked about taking part in this project *(Part C Survey only)*

Please describe what you did not like about taking part in this project *(Part C Survey only)*

Please describe anything that we could change to improve this project *(Part C Survey only)*

Page 11

Please indicate your gender:

a. Male
b. Female
c. Other_____

Please indicate your age:

a. Less than 20 years
b. 20 to 29 years
c. 30 to 39 years
d. 40 to 49 years
e. 50 to 59 years
f. 60 to 69 years
g. 70 to 79 years
h. 80+ years

Which province or territory do you live in? _____

Page 12

Part A Survey:

Thank you for completing this survey. Within the next 1-2 weeks, we will provide you with a summary of your survey responses and the responses provided by other participants. We will then ask you to take part in a teleconference discussion about the outcomes you rated. We will then ask you to complete this survey again. If you have questions about any aspect of the project, please contact the research assistant, <research assistant name>, at <name>@smh.ca or 416-864-6060 x XXXXX.

Part B Survey:

Thank you for completing this survey. We will now process your reimbursement payment. Please note that it may take up to 45 days for you to receive your payment by postal mail after we submit it for processing. Within the next month we will also provide you with a summary of project findings. We will then invite you to take part in an optional debrief session to discuss the results. If you have questions about any aspect of the project, please contact the research assistant, <research assistant name>, at <name>@smh.ca or 416-864-6060 x XXXXX.

Appendix C: Phase 2 Online Survey Template

Page 1

Canadian Task Force on Preventive Health Care:

Survey on Public Perceptions of <Guideline Topic> Screening

The Canadian Task Force on Preventive Health Care (CTFPHC) receives funding from the Public Health Agency of Canada (PHAC) to develop evidence-based clinical practice guidelines for preventive health care in Canada. The CTFPHC has created the following survey to assess how members of the public view <guideline topic> screening. Getting screened for <guideline topic> has both harms and benefits. In this survey, the CTFPHC would like to know how important you think it is to consider each of these harms and benefits when people make decisions about <guideline topic> screening. The survey will take approximately 10–15 minutes to complete.

If you have any questions, concerns, or technical difficulties, please contact the project coordinator, <research assistant name>, at <name>@smh.ca or 416-864-6060 x XXXXX.

Page 2

<Insert "CTFPHC Confidentiality Agreement">

[ ] I acknowledge that I have read and agree to the above Confidentiality Agreement

Page 3

Please enter your participant ID:

Date:

Page 4

Before you begin the survey, please make sure that you have read the "Background Information Sheet on <guideline topic> Screening". You can find a copy of the background information sheet below.

<Insert "Background Information Sheet" content>

[ ] I have read the "Background Information Sheet on <guideline topic> Screening" and am ready to proceed with the survey

Page 5

On this page, you will see a list of harms and benefits that people may experience from screening for <guideline topic>. For each statement, please rate how much it would influence your decision to be screened or not be screened for <guideline topic>. For statements where we do not have enough data to know the potential effects on <guideline population>, we are interested in knowing how important this lack of information would be if you were making a decision on whether or not to be screened for <guideline topic>.

How important would this information be for you if you were making a decision on whether or not to be screened for <guideline topic>?

<Outcome 1>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 2>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 3>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 4>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 5>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 6>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 7>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 8>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 9>

1	2	3	4	5	6	7	8	9
This isn't important for my decision				This is neither important nor not				This is very important for my

at all				important for my decision				decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

<Outcome 10>

1	2	3	4	5	6	7	8	9
This isn't important for my decision at all				This is neither important nor not important for my decision				This is very important for my decision

If you would like to provide any comments about your rating, please enter them in the space provided below.

Page 6

Considering that approximately <prevalence data> of <guideline population> have <guideline topic> how much would you want to be screened for <guideline topic>?

1	2	3	4	5	6	7	8	9
Not at all				Neutral				Very much

Considering the potential harms and benefits of <guideline topic>, how much would you want to be screened for <guideline topic>?

1	2	3	4	5	6	7	8	9
Not at all				Neutral				Very much

(If applicable) Considering that the risk of many of the harms and benefits of <guideline topic> are not well known, how much would you want to be screened for <guideline topic>?

1	2	3	4	5	6	7	8	9
Not at all				Neutral				Very much

If you would like to provide any comments about your rating, please enter them in the space provided below.

Page 7

In the space provided below, please briefly summarize the tasks that we asked you to perform in this survey.

Page 8 *(Part C Survey only)*

We will now ask you some questions about your experience participating in this project. Please respond to each of the following statements using the scales provided.

Question 1: To what extent do you believe that your ideas were heard during the engagement process?

Not at all Small Extent Fair Extent Moderate Extent Large Extent

○ ○ ○ ○ ○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 1, please explain your rating in the space below.

Question 2: To what extent did you feel comfortable contributing your ideas to the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 2, please explain your rating in the space below.

Question 3: Did organizers take your contributions to the engagement process seriously?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 3, please explain your rating in the space below.

Question 4: To what extent do you believe that your input will influence final decisions that underlie the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 4, please explain your rating in the space below.

Question 5: To what extent do you believe that your values and preferences will be included in the final health advice from this process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 5, please explain your rating in the space below.

Question 6: To what extent were you able to clearly express your viewpoints?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 6, please explain your rating in the space below.

Question 7: How neutral in their opinions (regarding topics) were organizers during the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 7, please explain your rating in the space below.

Question 8: Did all participants have equal opportunity to participate in discussions?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent

○ ○ ○ ○ ○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 8, please explain your rating in the space below.

Question 9: How clearly did you understand your role in the process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 9, please explain your rating in the space below.

Question 10: To what extent was information made available to you either prior or during the engagement process so as to participate knowledgeably in the process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 10, please explain your rating in the space below.

Question 11: To what extent were the ideas contained in the information material easy to understand?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 11, please explain your rating in the space below.

Question 12: How clearly did you understand what was expected of you during the engagement process?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 12, please explain your rating in the space below.

Question 13: How clearly did you understand what the goals of the engagement process were?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 13, please explain your rating in the space below.

Question 14: To what extent would you follow health advice from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 14, please explain your rating in the space below.

Question 15: To what extent would you advise others to follow health advice from the Canadian Task Force on Preventive Health Care (if it related to their health condition)?

Not at all	Small Extent	Fair Extent	Moderate Extent	Large Extent
○	○	○	○	○

If you selected "Not at all", "Small Extent", or "Fair Extent" for Question 15, please explain your rating in the space below.

Page 9

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.

How easy was it to understand the information in the <guideline topic> information sheet?

1	2	3	4	5	6	7	8	9
Not at all								Very much

How easy was it to rate the harms and benefits using the 9-point scale?

1	2	3	4	5	6	7	8	9
Not at all								Very much

How clear were the survey instructions?

1	2	3	4	5	6	7	8	9
Not at all								Very much

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

1	2	3	4	5	6	7	8	9

Not at all								Very much

Please describe anything that we could do to make the survey tasks easier to complete. *(Part A Survey only)*

Please describe what you liked about taking part in this project *(Part C Survey only)*

Please describe what you did not like about taking part in this project *(Part C Survey only)*

Please describe anything that we could change to improve this project *(Part C Survey only)*

Page 10

14) Please indicate your gender:
   a. Male
   b. Female
   c. Other_____

15) Please indicate your age:
   a. Less than 20 years
   b. 20 to 29 years
   c. 30 to 39 years
   d. 40 to 49 years
   e. 50 to 59 years
   f. 60 to 69 years
   g. 70 to 79 years
   h. 80+ years

16) Which province or territory do you live in? _____

Page 11

Survey A:

Thank you for completing this survey. Within the next 1-2 weeks, we will provide you with a summary of your survey responses and the responses provided by other participants. We will then ask you to take part in a teleconference discussion about the harms and benefits you rated. We will then ask you to complete this survey again. If you have questions about any aspect of the project, please contact the research assistant, <research assistant name>, at <name>@smh.ca or 416-864-6060 x XXXXX.

Survey B:

Thank you for completing this survey. We will now process your reimbursement payment. Please note that it may take up to 45 days for you to receive your payment by postal mail after we submit it for processing. Within the next month we will also provide you with a summary of project findings. We will then invite you to take part in an optional debrief session to discuss the results. Once the CTFPHC publishes its guideline on screening for <guideline topic> you will be sent a copy of the guideline and accompanying knowledge translation tools. If you have questions about any aspect of the project, please contact the research assistant, <research assistant name>, at <name>@smh.ca or 416-864-6060 x XXXXX.