# CTFPHC Patient Preferences Protocol

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**Knowledge Translation Program**
**Li Ka Shing Knowledge Institute**
**St. Michael's Hospital**

**Contact:**
Dr. Nadia Bashir

**E:** bashirn@smh.ca
**T:** 416-864-6060 ext. 77507

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For questions about this report, please contact:

Dr. Nadia Bashir
Research Coordinator
Knowledge Translation Program
Li Ka Shing Knowledge Institute
St. Michael's Hospital
Toronto, Canada
Email: bashirn@smh.ca
Phone: 416-864-6060 ext. 77507

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## BACKGROUND

Bringing patient priorities and perspectives into the process of clinical practice guideline (CPG) development is an important dimension of patient-centred care[1]. There is some evidence showing that patient involvement supports informed decision making, 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 is limited data evaluating patient engagement in the guideline development process. Indeed, research on patient preferences is not as well developed as are other areas of clinical inquiry, often using diverse methods and 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[1,1-3]. 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]. Specifically, 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. The CTFPHC has also used patient input to develop knowledge translation (KT) tools for each guideline released to date. For future guidelines, however, the CTFPHC will take a more active approach to patient engagement by obtaining feedback directly from patients at earlier critical points in the guideline development process. Specifically, the CTFPHC will recruit members of

the public to provide feedback at one or two stages of the guideline development process. The phases included for each guideline will be determined by the guideline working group. During Phase 1, participants will use the RAND Appropriateness Method to rate and select the screening outcomes relevant to a particular guideline topic that are most important to them.[10] The CTFPHC will use the results of this phase to inform the evidence review protocol for the guideline. During Phase 2, participants will take part in a focus group and survey about 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.

Given that the CTFPHC has not previously actively involved patients in the guideline development process, it is unknown whether the strategy outlined above will be an effective method for engaging patients. Specifically, it is unknown whether both patients and CTFPHC members will perceive this strategy as a method that successfully identifies patient preferences and enhances the quality of CTFPHC guidelines. Thus, it will also be important to evaluate the process that will be used to engage patients.

## OBJECTIVES

1. To engage patients during the guideline development process
2. To evaluate the process used to engage patients in the guideline development process

## METHODS

### Phase 1: Outcome Ratings

#### Participants

We will recruit approximately 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, partners or caregivers of intended targets). To optimize the extent to which our sample is representative of the Canadian population, the number of participants recruited from each province and territory will correspond to the national population distribution (i.e., six participants from British Columbia, Alberta, Saskatchewan, and Manitoba; eight participants from Ontario; four participants from Quebec; one participant from the Maritimes; and one participant from the territories). We will use the following methods to recruit a diverse sample that will allow us to address health equity issues relevant to the guideline topic:

1. Posting recruitment ads (see Appendix A) on public advertisement websites (e.g., Charity Village, Kijiji, Craigslist)
2. Posting ads on social media websites (e.g., Facebook)
3. Posting ads on the CTFPHC website

4. Emailing members of the public who are part of the St. Michael's Hospital (SMH) KT Program circle of contacts and have expressed interest in providing feedback on CTFPHC guidelines and tools.

Individuals who express interest in taking part in the project will be asked to complete a brief online survey containing demographic, health, health equity, and conflict of interest screening questions (see Appendix B). Individuals who meet the demographic, health, and health equity inclusion criteria specified by the relevant guideline working group (see Appendix C) will be invited to take part in Phase 1. Individuals who do not meet the inclusion criteria for the project will be informed that they are not eligible to take part. For all guideline topics, individuals who already have the disease, are the caregiver of someone with 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) will be excluded.

Eligible participants will receive a project information sheet (see Appendix D), guideline topic information sheet (developed by the guideline WG), and CTFPHC confidentiality agreement form by email. The project information sheet will outline the purpose of the project and the role of participants in providing input from a patient perspective. The guideline topic information sheet will provide 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 will be remunerated $35 for their participation as per KT Program policy.

## Procedure

*Part 1.* Participants will be given two weeks to complete an online survey (see Appendix F), which will be developed and administered using FluidSurveys. During the survey, participants will 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.[11] They will also have an opportunity to explain each rating in open-ended form. We will obtain the list of outcomes from the relevant CTFPHC guideline working group, who will develop the list based on the process outlined in the CTFPHC procedure manual. Next, participants will select the five outcomes on the list that they believe are most critical. They will 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 will be informed that the 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 will then briefly summarize the tasks that they were asked to perform. They will also rate items adapted from the RAND Appropriateness Method post-survey questionnaire to assess their understanding of the survey instructions and ability to complete the survey tasks with ease.[10]

*Part 2.* After completing the survey in Part 1, participants will receive a copy of (a) their own outcome ratings and the distribution of ratings provided by all participants for each outcome, (b) the top five outcomes that they selected and the frequency with which each outcome was selected as a top five outcome across participants, and (c) the additional outcomes identified by participants in Part 1 (see personalized panelist rating sheet in Appendix G). Participants will then have two weeks to complete the same survey used in Part 1. In this case, however, participants will also be able to rate and select the additional outcomes identified in Part 1. They will not have the opportunity to list outcomes that are not included in the Part 2 survey.

*Part 3.* After completing the survey in Part 2, participants will receive a copy of (a) their own Part 2 outcome ratings and the distribution of ratings provided by all participants for each outcome, and (b) the top five outcomes that they selected in Part 2 and the frequency with which each outcome was selected as a top five outcome across participants. Participants will then take part in a group discussion via teleconference. Holding the meeting via teleconference will make it possible for a diverse range of individuals from across Canada to take part. Participants will be assigned to one of three meeting groups based on the region in which they live. Specifically, one group will include the participants from British Columbia, Alberta, Saskatchewan, and Manitoba; a second focus group will include the participants from Ontario; and a third focus group will include the participants from Quebec and the Maritimes. The participant from the territories will be assigned to either the first or third focus group depending on the time zone in which he/she lives. During the meeting, participants will discuss the importance of each outcome. A research coordinator from the SMH KT team will moderate the discussion using a script (see Appendix H). A second research coordinator will take notes to document the discussion. A content expert on the guideline topic will also be present to answer questions that participants have about the guideline topic or outcomes.

*Part 4.* After the meeting, participants will have two weeks to complete the same procedure used in Part 2. In this case, the post-survey questionnaire will also include items to assess participants' overall satisfaction with their Phase 1 experience.

## Outcomes

*Patient preferences.* Our primary outcomes of interest will be the perceived appropriateness of considering each outcome when making screening decisions (calculated based on the RAND Appropriateness Method[10]) and the top five outcomes selected by participants. We will assess these using the responses from the Part 4 survey.

*Patient satisfaction.* Our primary outcomes of interest will be the extent to which participants were satisfied with the opportunity to provide input and believed that their input would enhance the guideline development process. This will be measured using the items from the Part 4 post-survey questionnaire.

### Data Analysis

We will calculate the perceived appropriateness of each outcome based on the median importance rating (and interquartile range) of each outcome and the degree of agreement across participants. See Appendix I for a description of the method that will be used to calculate appropriateness. We will also calculate the frequency with which each outcome was selected as a "top five" outcome by participants. For the patient satisfaction data, we will calculate descriptive statistics for the quantitative data and conduct a qualitative analysis of the open-ended responses.

### Dissemination

We will prepare a final report summarizing the survey results for the relevant CTFPHC guideline working group. Participants from Phase 1 may also receive a copy of the report upon request.

## Phase 2: Social Acceptability and Implementability of Guideline Recommendations

### Participants

Consistent with qualitative methods, we will recruit 12-16 participants from Phase 1 to take part in a focus group and follow-up survey. We will hold the focus group via teleconference to make it possible for a diverse range of individuals from across Canada to take part. To verify that participants still meet the inclusion criteria relevant to the guideline topic, participants will complete the same online screening questionnaire that they completed during Phase 1 (i.e., questionnaire will include the same demographic, health, health equity, and conflict of interest questions as in Phase 1). Participants who still meet the screening criteria will receive a project information sheet (see Appendix J) and guideline topic information sheet by email to remind them about the purpose of the project and to explain the format of the focus group. They will also be asked to sign a copy of the CTFPHC confidentiality agreement. Participants will be assigned to one of two focus groups based on their availability and will be remunerated $35 for their participation as per KT Program policy. Individuals who no longer meet the screening criteria for the project will be informed that they are not eligible to take part in Phase 2.

### Procedure

*Part 1.* Prior to the focus group, participants will receive instructions for taking part in the focus group via teleconference (see Appendix K), a copy of the CTFPHC draft guideline recommendations, and a GRADE information sheet (see Appendix L). During the one-hour focus group, participants will be asked to discuss the social acceptability and implementability of the recommendations from a patient perspective. A research coordinator from the SMH KT team will moderate the discussion using a semi-structured focus group script developed based on the behaviour change work of Michie and colleagues[12] (see Appendix M). Basing the script on this framework will allow us to identify the specific types of barriers that may limit patient adherence to the guidelines (e.g., gaps in knowledge about screening [knowledge-based barrier] versus erroneous beliefs about screening consequences [belief-based barrier] versus

lack of motivation to get screened [motivation-based barrier]). A second research coordinator will take notes to document the discussion. A content expert on the guideline topic will also be present to answer questions that participants have about the guideline topic or recommendations. The focus group discussion will be audio recorded.

*Part 2.* One week after the focus group, participants will be asked to complete an online survey. During this survey, they will rate the social acceptability and implementability of the guideline recommendations along Likert-type scales. They will also rate items assessing their overall satisfaction with the experience, which will be very similar to those included in the Phase I post-meeting survey (see Appendix N).

### Outcomes

*Patient preferences.* Our primary outcomes of interest will be participants' perceptions of the social acceptability and implementability of the recommendations, which will be assessed using the qualitative data from the focus groups and the social acceptability survey data. We will use these findings to identify the behaviour change dimensions that the KT tools should target. For example, if participants indicate that they would not follow a recommendation against screening because they believe that avoiding screening will be harmful, the KT tools for the guideline will be designed to address these beliefs.

*Patient satisfaction.* Our primary outcomes of interest will be the extent to which participants were satisfied with the opportunity to provide input and believed that their input will enhance the CTFPHC's guideline and KT tool development process. This will be measured using the overall satisfaction items from the survey.

### Data Analysis

We will use a content analysis approach to summarize comments from the focus group discussion.[13] Specifically, we will 1) develop a codebook of mutually exclusive categories based on the focus group script and on emergent themes 2) code the data under categories and 3) report the data by category. For the social acceptability and patient satisfaction survey data, we will calculate descriptive statistics for the quantitative data and conduct a qualitative analysis of the open-ended responses.

### Dissemination

We will prepare a final report summarizing the results for the relevant CTFPHC guideline working group and the KT Working Group. Participants from Phase 1 and Phase 2 may receive a copy of the report upon request.

## Phase 3: CTFPHC Member Satisfaction Survey

### Participants and Procedure

Members of the relevant guideline working group and KT Working Group will complete a brief online survey after the guideline and KT tools are complete. Guideline working group members

will respond to Likert-type and open-ended survey items assessing the extent to which they believe that Phase 1 had a positive impact on the guideline development process (e.g., increased knowledge of patient preferences, was a good use of resources, etc.). Guideline working group members and KT Working Group members will respond to Likert-type and open-ended survey items assessing the extent to which they believe that Phase 2 had a positive impact on the KT tool development process (see Appendix O).

### Outcomes

Our primary outcomes of interest will be the extent to which CTFPHC member participants believe that the patient engagement strategies used in this project had a positive impact on the guideline and KT tool development process.

### Data Analysis

We will calculate descriptive statistics for the quantitative data and conduct a qualitative analysis of the open-ended responses.

### Dissemination

We will prepare a final report summarizing the survey results for the CTFPHC.

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