



Canadian Task Force on Preventive Health Care

Patient Preferences in Considering Hepatitis C Screening and Treatment Outcomes: Phase Two

Prepared for The Canadian Task Force on Preventive Health Care

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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
IOM	Institute of Medicine
KT	Knowledge Translation
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 three critical points in the guideline development process: (1) when outcomes are selected for inclusion in the systematic review protocol; (2) when the final guideline recommendations are developed; and (3) when knowledge translation (KT) tools are developed and tested for usability with patients and health practitioners. In this project, we examined patients' perceptions of the harms and benefits of screening and treatment for hepatitis C in asymptomatic adults aged 18 years or older who are at average or increased risk for hepatitis C. Specifically, we inquired about how important patients believe it is for people to consider harms, benefits, and treatment costs when making decisions about getting screened for hepatitis C. We will use this information to inform the final guideline recommendations and KT tools. We also examined participants' experiences in the project.

Method

Asymptomatic adults aged 18 years or older to whom the CTFPHC hepatitis C screening recommendations will apply completed two tasks. In a focus group, they discussed how important it is for people to consider harms and benefits when making decisions about getting screened for hepatitis C. They then completed a follow-up survey in which they rated how much the likelihood of experiencing each harm or benefit would factor into their decision to get screened for hepatitis C. 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 harms and benefits of screening, (b) experience with project tasks, (c) perceived impact of input, and (d) satisfaction with the project experience.

Summary of Findings and Discussion

Perceptions of Harms, Benefits, and Costs of Screening and Treatment

Participants perceived the majority of screening benefits to be relatively important to consider when making decisions about hepatitis C screening. The one exception was reduced mortality, which participants perceived as a particularly important screening benefit. Similarly, participants perceived all harms related to treatment to be relatively important to consider when making decisions about hepatitis C screening. Overall, the majority of participants stated that they would want to get screened for hepatitis C; however, many noted concerns about the high cost of treatment.

Participant Experience

Overall, participants reported that they had a positive experience in the project. Results indicate that participants completed the tasks with relative ease, believed that their preferences would have an impact on the CTFPHC's guideline, and enjoyed the opportunity to take part in the project. To improve the focus group and survey experience, several participants recommended that the background information sheet present data in a visual format for comprehensibility. We plan to incorporate this suggestion into our process for future patient preferences projects.

Limitations

This report has the following limitations: (a) although our sample included participants from Ontario, British Columbia, Quebec and Nova Scotia, 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 people about hepatitis C screening and treatment; (c) the hepatitis C background document contained one factual error; and (d) participants received information from the CTFPHC Hepatitis C 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 hepatitis C screening guideline:

- 1. Ensure patient KT tools present statistical harms and benefits data in visual format**
- 2. Create KT tools that include information on the cost of treatment**

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 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 As such, 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 methods used to develop CPGs by providing input on patients' diverse social circumstances, behaviours, attitudes, 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} For example, 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 preventive health care, it is an indirect source that may not reflect the perspectives of the current patient population. For several years, the CTFPHC has solicited 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 The CTFPHC is therefore now taking 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.

The CTFPHC recruits members of the public to provide feedback at up to two stages. During Phase 1, participants identify the screening outcomes relevant to a particular guideline topic that are most important to consider during decision making. The CTFPHC uses the results of this phase to inform the evidence review protocol for the guideline. In a new approach for Phase 2 that is currently being piloted, participants provide their perspectives on the harms and benefits of screening and treatment for a particular guideline topic. Specifically, we inquire about how important patients believe it is for people to consider specific harms and benefits when making decisions about getting screened. The CTFPHC uses the findings from this phase to develop the final guideline recommendations and KT tools. This report describes the method and results of Phase 2 for the CTFPHC's guideline on hepatitis C screening.

Hepatitis C is a disease caused by the hepatitis C virus. This virus enters the body through the blood, but may eventually damage the liver.¹³ Many individuals who have hepatitis C will develop only mild liver damage, even if they have been infected with the virus for several decades. Some individuals will, however, develop liver cancer or cirrhosis (i.e., permanent scarring of the liver), which can lead to death.^{14,15} The CTFPHC aims to develop a guideline on to provide primary care practitioners with recommendations on screening individuals for hepatitis C. That is, the CTFPHC will outline recommended approaches for testing asymptomatic members of the population for the disease. Screening approaches for hepatitis C are associated with both harms and benefits.^{15,16} The CTFPHC will consider evidence on these harms and benefits when developing its recommendations on hepatitis C screening.

Objectives

The goal of Phase 2 in the current project was to assess perceptions of the importance of considering harms and benefits of screening among asymptomatic adults aged 18 years to whom the guideline will apply. Specifically, we inquired about how important patients believe it is for people to consider harms, benefits, and costs when making decisions about getting screened for hepatitis C. This process will allow the CTFPHC Hepatitis C 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 parents' perceptions of how the harms and benefits of screening and treatment would factor into their decisions about being screened for hepatitis C. The focus group gave participants an opportunity to clarify information about hepatitis C screening, ask questions about the harms, benefits, and costs of screening and treatment, and share perspectives so that they could consider a broad range of information when completing the survey.

METHODS

Participants

Participants were English-speaking asymptomatic adults aged 18 years or older at average or increased risk for hepatitis C. We recruited participants by posting recruitment ads on public advertisement websites (e.g., Craigslist and Kijiji) and contacting participants from previous CTFPHC patient preferences projects.

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 1). Male and female adults aged 18 years and older were eligible to take part if they were asymptomatic otherwise healthy adults at average risk for hepatitis C and asymptomatic otherwise healthy adults at risk for hepatitis C (e.g., injection drug users; recent immigrants who have arrived in Canada within the last five years from countries where hepatitis C is common, including from Central Asia, East Asia, South Asia, Australasia and Oceania, Eastern Europe, Sub-Saharan Africa, North Africa, or the Middle East; adults born between 1950 and 1970 not suspected of having hepatitis C; and men who have sex with men). Participants were not eligible for the project if they had been diagnosed with hepatitis C or HIV; had received treatment for hepatitis C; were a hemodialysis patient; were a health care professional or had another occupational exposure risk; or had any conflicts of interest relevant to the guideline topic (e.g., owning shares in a company related to hepatitis C). Participants received \$35 for taking part in the project.

Procedure

Eligible participants first signed and returned a copy of the CTFPHC confidentiality agreement form (see Appendix 2). They then received a project information sheet (see Appendix 3) and a background document on hepatitis C screening, treatment, and treatment costs (see Appendix 4). The project information sheet outlined the purpose of the project and the role of participants in providing input from a patient perspective. The hepatitis C screening and treatment background document provided participants with information on (a) hepatitis C, (b) who is at risk of hepatitis C, (c) how hepatitis C affects people, (d) how doctors screen people for hepatitis C, (e) the benefits and harms of hepatitis C screening; (f) how doctors treat people for hepatitis C, (g) the benefits and harms of hepatitis C treatment, and (g) who pays for hepatitis C treatment. This document was developed by the CTFPHC Hepatitis C Working Group.

Part 1

One week after receiving the project information sheet and background documents, participants took part in one of three 60-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 ask questions. They also shared their perceptions of the harms and benefits of hepatitis C screening and treatment and of the costs associated with treatment.

One research assistant from the St. Michael's Hospital KT team moderated the focus group discussion using a script (see Appendix 5), and a research coordinator took notes to document

the discussion. The Chair of the CTFPHC Hepatitis C Working Group was also present during the focus groups to answer questions that participants had about the guideline topic. We audio recorded all focus group discussions.

Part 2

After attending the focus group, participants completed an online follow-up survey (see Appendix 6). We administered the survey using FluidSurveys. The survey included ten scale-response items aimed at assessing how the benefits of screening and the harms of treatment will influence a person's decision to get screened for hepatitis C (e.g. "For every 10,000 people screened, 37 will receive drug treatment for hepatitis C and 7 people will experience flu-like symptoms"). They rated these items along a 9-point scale with endpoints labeled 1 (*This doesn't factor into my decision at all*) and 9 (*This factors into my decision a lot*). Participants then completed a modified version of the Rand Appropriateness Method (RAM) 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 labeled 1 (*Not at all*) and 9 (*Very much*). Participants also responded to 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 1 lists the key outcomes, data sources, and data analysis methods used in the project.

Table 1. Outcomes assessed, data sources for outcomes, and data analysis methods

Outcome	Data source	Data analysis method
Perceptions of benefits and harms related to screening and treatment	Survey	• Descriptive statistics
	Focus groups	• Content analysis
Experience with project tasks	Survey	• Descriptive statistics
		• Qualitative analysis
Perceived impact of input	Survey	• Descriptive statistics
Satisfaction with experience	Survey	• Descriptive statistics
		• Qualitative analysis

RESULTS

In total, fifteen individuals took part in the project, including 8 men and 7 women aged 25-66 years old (mean age [M] = 50, standard deviation [SD] = 14.71). Participants lived in Ontario (n = 9), British Columbia (n = 3), Quebec (n = 2), and Nova Scotia (n = 1). Most participants (n = 12) reported having a college diploma education or higher. One participant self-identified as an injection drug user. No participants identified as Aboriginal or as an immigrant to Canada.

One participant who completed the survey did not attend a focus group. We found a similar pattern of results when including versus excluding this participant 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 14 participants who attended a focus group.

Perceptions of Harms and Benefits

Survey Data

The median importance rating was equal to 6 for three screening benefits. Thus, participants perceived the majority of screening benefits to be relatively important (i.e., 6 out of 9) to consider when making decisions about hepatitis C screening. The one exception was reduced mortality, which participants perceived as a slightly more important (i.e., 7 out of 9) screening benefit. See Table 2 for a summary of descriptive statistics for possible benefits of screening.

Table 2. Descriptive statistics for possible benefits of screening (n = 15)

Question: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

Item	Median	Q ₁	Q ₃
Out of 10,000 people who don't get screened, 24 people aged 25-64 will become seriously ill from the hepatitis C virus and may develop liver scarring, which can prevent the liver from functioning properly. This is compared to 18 out of 10,000 people who do get screened.	6	5	7
Out of 10,000 people who don't get screened, 35 people aged 25-64 will die from hepatitis C. This is compared to 26 out of 10,000 people who do get screened.	6	5	7.5
Out of 10,000 people who don't get screened, 15 people aged 25-64 will develop liver cancer. This is compared to 12 out of 10,000 people who do get screened.	6	5	8
Out of 10,000 people who don't get screened, 0 (zero) hepatitis C related deaths among people aged 25-64 are prevented. This	7	5	7.5

Question: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

Item	Median	Q ₁	Q ₃
is compared to 9 prevented deaths out of 10,000 people who do get screened.			

Note: Q₁ = first quartile; Q₃ = third quartile.

Participants' median ratings were either 5 or 6 for all treatment harms in the survey. Thus, participants perceived all harms related to treatment to be relatively important to consider when making decisions about hepatitis C screening. See Table 3 for a summary of descriptive statistics for harms related to treatment.

Table 3. Descriptive statistics for harms of treatment (n = 15)

Question: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

Item	Median	Q ₁	Q ₃
For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 8 will experience weakness and feel tired because they have low levels of red blood cells (anemia).	6	3	8
For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 7 will experience flu-like symptoms.	5	3.5	7
For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 6 will become more vulnerable to other types of infections because they have low levels of cells that help to fight infections.	6	5	8
For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 3 will experience unpleasant psychological side effects, such as depression.	6	5	9
For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 8 will experience skin rashes.	5	3	8

Note: Q₁ = first quartile; Q₃ = third quartile.

Overall, there was no difference between participants' ratings of screening benefits and treatment harms, $t(14) = 0.50$, $p = 0.62$.

Overall Preference for Screening

In considering the benefits of screening and harms of treatment, participants reported a strong preference to screened for hepatitis C (median rating of 8 [IQR 6-9] on a 9-point scale).

Focus Group Data

Focus group data provided information on the factors that influence participants' decision to be screened for hepatitis C. See Tables 4 and 5 for a summary of focus group data.

Table 4. Focus group participants' perceptions of screening harms and benefits (n = 14)

	Hepatitis C screening benefits	Hepatitis C screening harms
General perceptions	<ul style="list-style-type: none">- Identifying and being treated early is beneficial- Identifying that someone has a condition may motivate healthy lifestyle changes- Screening is beneficial because it will decrease hepatitis C virus (HCV) transmission- Screening program will benefit not only infected individuals but also community at large- Differences in benefits between being screened or not are minimal- Targeted screening for high-risk groups may be more appropriate	<ul style="list-style-type: none">- Concerned about mental health and the stigma associated with a positive test result and lack of immediate treatment- There needs to be an awareness piece with screening to combat stigma associated with HCV
Influence on screening behaviour	<ul style="list-style-type: none">- Most participants would <u>opt to be</u> screened even though they did not find the harms and benefits statistics persuasive because they would rather know if they were HCV positive and take precautions not to infect others- A few participants would <u>opt not to be</u> screened because if they couldn't be treated immediately, they would rather not know. Other participants did not feel that they belonged to the high-risk population groups	

Table 5. Focus group participants' perceptions of treatment harms, benefits, and cost (n = 14)

	Hepatitis C treatment benefits	Hepatitis C treatment harms	Cost of hepatitis C treatment
General perceptions	<ul style="list-style-type: none">- The most persuasive points included better quality of life, improved liver health, and potential to clear virus from body	<ul style="list-style-type: none">- Side effect duration after treatment commences is long	<ul style="list-style-type: none">- Do not want to take funds from other health conditions to fund HCV treatment- Save money by improving screening techniques or perform targeted screening and redirect savings to provide more treatment coverage

	Hepatitis C treatment benefits	Hepatitis C treatment harms	Cost of hepatitis C treatment
			<ul style="list-style-type: none"> - People may try to relocate to get cheaper treatment - Mixed messages: promoting screening but not providing treatment coverage - Some participants thought not providing immediate treatment was unjust
Influence on treatment-seeking behaviour	<ul style="list-style-type: none"> - The cost of treatment was a driving factor in participants' decision to be screened and treated - Many participants indicated they would wait to get treatment due to the high cost - Most participants indicated they would tolerate side effects because of potential health benefits. Side effects may include feeling weak or tired, experiencing flu-like symptoms, being more vulnerable to other types of infections, experiencing unpleasant psychological side effects, and skin rashes. However, a few indicated the potential duration of side effects and quality of life while on medication would deter them from seeking treatment. 		

Factors that influence participants' decision to be screened for hepatitis C

Participants reported that their decision to be screened and treated for hepatitis C was not static throughout their review of the background document. While reviewing the screening benefits and harms section of the background document, participants were primarily in favour of screening because a) they believed it would provide preventive health benefits at a population level, and b) they would prefer to know their hepatitis C viral status. Similarly, while reviewing the treatment benefits and harms section of the background, most participants were in favour of treatment because they believed that the potential benefits of treatment (e.g., better quality of life and improved liver function) outweighed the potential harms (e.g., depression and flu-like symptoms).

In comparison, after reviewing information about the cost of treatment, many participants questioned their decision to be screened and/or treated. Many participants reported feeling shocked by the high cost of treatment and expressed that they would be forced to wait for treatment because paying out of pocket would not be feasible. However, participants also stated that they would not want health funds redirected from other health conditions to hepatitis C because the prevalence of hepatitis C is not high enough in Canada. Overall, participants were in favour of screening and treatment; however, the cost of treatment had a substantial influence on their preferences:

“If people could get screened I think there could be a benefit to that, however, I must say that reading further on in the document [cost of treatment section] my viewpoint changed immediately and I swung from one side to the other.” – Focus group participant

“The next thing you learned about this process is it [the treatment] could cost you over \$100 000 so that knowledge is certainly going to hamper the opinion of being screened”
 – Focus group participant

Experience with Project Tasks

Survey Data

Experience with Focus Group

Participants generally found the focus group discussion and information provided by the working group chair to be informative. They indicated that both the group discussion and the working group chair had a moderate influence on their responses to the final survey. Although participants shared diverse perspectives during the discussions, participants did not find the discussions to be argumentative. See Table 6 for a summary of descriptive statistics for all focus group experience items.

Table 6. Descriptive statistics for focus group experience items ($n = 14$)

Focus group experience item	Median	Q ₁	Q ₃
How informative was the focus group discussion that you took part in via teleconference?	7	7	8.75
How argumentative was the focus group discussion?	2	1	4
How much did the focus group discussion influence your responses in this final survey?	6	2.5	7
How helpful was the information provided by the content expert (i.e., the CTFPHC member on the focus group call)?	8	7	8.75
How much did the content expert's comments influence your responses in this final survey?	5	3	7

Note: Q₁ = first quartile; Q₃ = third quartile

Experience with Survey

Participants indicated that it was generally easy to understand the hepatitis C background information sheet and task instructions that they received before completing the survey. Indeed, the median rating was greater than or equal to 7 for all survey experience items. See Table 7 for a summary of descriptive statistics for all focus group experience items.

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

Survey experience item	Median	Q ₁	Q ₃
How easy was it to understand the information in the hepatitis C background information sheet?	7	6	9
How easy was it to rate the harms and benefits using the 9-point scale?	7	7	9
How clear were the survey instructions?	9	7	9
How well did you understand what we asked you to do in this survey?	9	7.5	9

Note: Q₁ = first quartile; Q₃ = third quartile

When asked to describe how we could change the survey tasks to make them easier to complete, several participants stated that the survey was straightforward. However, several participants would have liked to receive visual representations of background data to make it easier to understand. This survey data mirrors participant responses provided during the focus group sessions.

Perceived Impact of Input

Participants believed that the input they provided during the project would be valued by the CTFPHC and used to inform the CTFPHC's guideline on hepatitis C screening and treatment. Specifically, the median rating for all perceived impact items was 7. Thus, participants were relatively optimistic that the CTFPHC would consider their perspectives when developing the guideline. See Table 8 for a summary of descriptive statistics for all perceived impact items.

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

Responses were provided on a 9-point scale with endpoints labelled 1 (*Not at all*) and 9 (*Very much*).

Perceived impact item	Median	Q ₁	Q ₃
How well do you believe that your own survey responses reflect the importance of considering various harms and benefits when making decisions about hepatitis C screening and/or treatment?	7	6	9
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 hepatitis C screening and/or treatment?	7	6	8.5

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 hepatitis C guideline?	7	5	8.5

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 ratings were both equal to 7. In particular, participants noted in their open-ended responses that they enjoyed the project because they had the opportunity to learn about hepatitis C, share their own perspectives, hear the opinions of others, ask questions, and contribute to health care policy.

When asked to describe aspects of the project that they did not enjoy, several participants wrote that the presentation of the data in the background information sheet could have been improved, noting that the information was general and that they would have preferred visual representations of statistics. Others expressed that they did not enjoy elements of the focus group. Specifically, one participant stated that it was challenging to be the only female participant in the focus group. Another participant reported feeling that some members did not contribute to the discussion equally. In addition, one participant noted that the focus group was not long enough. Lastly, one participant reported that the project was too time-consuming.

Consistent with this feedback, some participants indicated that the CTFPHC could improve the project by providing additional statistical information in the background information sheet and visual representations of data. Although participants were provided with instructions to review the background information sheet and have the sheet available during the focus group, a few participants also suggested to clarify the instructions so that participants can contribute to the discussion. Others recommended having more participants attend the focus group, using teleconference equipment with better audio transmission, and inviting a person with lived experience of hepatitis C to attend the focus group. Despite these suggestions, several participants noted within their comments that they were satisfied with the project. See Table 9 for a summary of descriptive statistics for all satisfaction items.

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?	7	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?	7	6.5	7.5
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Focus Group Data

Perceptions about the overall readability of the background document

Generally, participants found the document to be straightforward and easy to understand; however, participants identified three main areas to improve readability. First, participants recommended making the document less text heavy by converting paragraphs to bullet points where possible. Second, they recommended improving the readability of the statistics by providing a visual (e.g., a graph, infographic), changing the format the statistics are presented in (e.g., in percentage form), clearly stating any relevant assumptions (e.g., the extent to which the people who experience one treatment harm are the same people who experience other treatment harms), and removing repetitive wording (e.g. “for every 10 000 people screened”). Third, participants suggested that we provide more information about overdiagnosis, hepatitis C virus transmission, the cost of screening, and the cost of treatment. Overall, participants found that the document was straightforward, but they noted we could make it easier to read by reducing the amount of text in it, simplifying the statistical information, and providing cost information for screening and treatment. See Tables 10 and 11 for a summary of focus group data on the overall readability of the background document.

Table 10. Focus group participants’ perceptions about readability of hepatitis C screening section (*n* = 14)

	Hepatitis C screening benefits	Hepatitis C screening harms
Readability of content Readability of content	<ul style="list-style-type: none"> - Some found the statistical information confusing - Statistics were presented out of 10, 000; would prefer out of 100 or percentage form - Visual aid (e.g., graph, diagram, or infographic) to present statistics would be helpful 	<ul style="list-style-type: none"> - Easy to understand - Liked bullet-point format
Request for additional information	<ul style="list-style-type: none"> - Explain whether statistics are mutually exclusive - Provide rates of infection by gender, age, and risk group - Provide information about how HCV is transmitted - Provide definition of screening (including age range info) 	<ul style="list-style-type: none"> - Provide information about how HCV is transmitted - Provide lay language definition of overdiagnosis - Provide information on cost of screening

Table 11. Focus group participants' perceptions about readability of hepatitis C treatment section ($n = 14$)

	Hepatitis C treatment benefits	Hepatitis C treatment harms	Cost of hepatitis C treatment
Readability of content	<ul style="list-style-type: none"> - Easy to understand - Liked bullet-point format 	<ul style="list-style-type: none"> - Found paragraphs wordy - Content was repetitive; suggest not repeating the statement "For every 10 000 people screened, 37 people..." 	<ul style="list-style-type: none"> - Easy to understand - Found paragraphs wordy; suggested using bullets
Request for additional information	<ul style="list-style-type: none"> - Provide information on treatment effectiveness and survival rates 	<ul style="list-style-type: none"> - Explain whether statistics are mutually exclusive - Describe side effect management (e.g., with other medication) - Indicate duration of side effects versus treatment time period - Note available forms of medication (e.g., tablets, intravenous) - Provide statistics for those who opt not to be treated (i.e., like screening section) 	<ul style="list-style-type: none"> - Provide cost-benefit analysis data for treatment coverage versus hospital end-of-life care - Provide breakdown of \$105,000 (e.g. drug costs, physician costs, lab costs, length of treatment) - Provide funding coverage information for private insurance and public coverage across Canada and abroad - Describe disease management while waiting for treatment - Identify prevalence of HCV in comparison to other health conditions

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 harms and benefits of screening and treatment among Canadian patients to whom the CTFPHC hepatitis C screening guideline will apply. We also examined participants' experiences in the project.

Perceptions of Harms, Benefits, and Costs of Screening and Treatment

We assessed participants' perceptions of the harms and benefits of screening and treatment by having them share their thoughts about the importance of considering harms and benefits of screening and treatment when making a screening decision. Specifically, we inquired about how important patients believe it is for people to consider harms, benefits, and treatment costs when making decisions about getting screened for hepatitis C during a focus group and in a survey.

As indicated in the survey, participants perceived the majority of screening benefits to be relatively important to consider when making decisions about hepatitis C screening. The one exception was reduced mortality, which participants perceived as a very important screening benefit. Moreover, participants perceived all harms related to treatment to be relatively important to consider when making decisions about hepatitis C screening. During the focus group, participants discussed how a population-level screening program for hepatitis C could provide preventive health benefits. In addition, many participants stated that they would want to know their own hepatitis C status but would be required to wait for treatment due to high costs. Overall, the majority of participants indicated that they would want to get screened for hepatitis C but many noted concerns about the high cost of treatment.

Participant Experience

Participants indicated that they found it relatively easy to understand the hepatitis C background information sheet and to complete the survey tasks but many noted that additional visual representations of data would be beneficial. In addition, they believed that their input would be valued by the CTFPHC and used to inform the CTFPHC's guideline on hepatitis C screening and treatment. Moreover, they indicated that they were satisfied with their overall experience in the project. Our findings therefore indicate that participants found the project tasks to be relatively accessible and viewed their overall experience to be positive.

Some participants provided suggestions for improving the focus group. Specifically, a few participants noted that we could improve the focus group experience by using teleconference equipment with better audio transmission, ensuring gender parity among focus group participants, and encouraging equal contributions to the discussion by all participants. Participants' suggestions therefore focused primarily on improving logistics related to the project tasks rather than on altering the nature or goals of the tasks. Thus, we may be able to improve participants' experiences in future patient preferences projects by making relatively minor changes to the ways in which we administer and facilitate project tasks with participants.

Limitations

This project has several limitations. First, the participant sample was relatively small and, therefore, may not be representative of all Canadian adults to whom the CTFPHC hepatitis C screening guideline will apply. Although our sample included participants from four provinces, we did not receive any responses to our recruitment ads from individuals living in Alberta, Saskatchewan, Manitoba, New Brunswick, Newfoundland and Labrador, Prince Edward Island, Yukon Territory, Northwest Territories, or Nunavut Territory. In addition, 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 than those who did not. It may be that Canadians who are from other provinces or territories or less interested in health care issues would have perceptions of the harms and benefits of screening that differ from those identified in the current project.

Second, the information that participants received during the project may have made them more knowledgeable than the general population about hepatitis C screening, treatment, and associated costs. During the project, participants read a background document on hepatitis C screening and treatment, discussed the harms and benefits of screening with other participants, and received relevant information from the CTFPHC Hepatitis C Working Group chair. We gave participants this amount of information so that they would have enough knowledge about the harms and benefits of screening to be able to articulate their perceptions of them. When making screening or treatment decisions, however, Canadian adults 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 Canadian adults who make screening and treatment decisions with more limited knowledge about the harms and benefits of hepatitis C screening and treatment.

Third, the hepatitis C background information document contained one factual error. The chair of the Hepatitis C Working Group noted that the statement "In comparison to people who don't get treated, people who get treated for hepatitis C may be less likely to die from causes other than liver disease" is incorrect. This information may have influenced participant responses when discussing the benefits of hepatitis C treatment during the focus group.

Fourth, information provided by the chair of the Hepatitis C Working Group may have influenced participants' responses. The chair attended the focus groups to answer questions about the content in the background information document. Based on the survey ratings, participants believed that the chair had a moderate influence on their responses in the follow-up survey. Thus, 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 harms and benefits information in the survey differently than they would have had they not received any information from the chair.

Suggestions for Applying Findings

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

1. Ensure KT tools present information about harms and benefits in a visual format.

A consistent theme in both survey and focus group data was participants' desire for statistics about the harms and benefits of hepatitis C screening and treatment to be presented in a visual format. We therefore recommend that the CTFPHC produce patient KT tools that include graphics of the harms and benefits of hepatitis C screening and treatment. These resources may facilitate patient understanding of guideline recommendations and support both clinicians and patients in decision making.

2. Create KT tools that include information on the cost of treatment.

Overall, participants were largely in favour of hepatitis C screening and treatment; however, the cost of treatment had a substantial influence on their preferences. We therefore recommend that the CTFPHC incorporate evidence on the cost of hepatitis C treatment into the systematic reviews and final guideline. This evidence will support the creation of patient KT tools that include information about the cost of hepatitis C treatment and help clinicians discuss hepatitis C screening in the context of patient concerns about treatment costs. These resources may support both clinicians and patients in making decisions about hepatitis C screening that are consistent with guideline recommendations.

CONCLUSION

In sum, we assessed how members of the public perceived the importance of considering the harms and benefits of screening and treatment and treatment costs when making decisions about getting screened for hepatitis C. Participants weighted screening benefits and treatment harms as equally important in influencing their decision to get screened for hepatitis C. The majority of participants stated that they would want to get screened for hepatitis C but many noted concerns about the high cost of treatment. We also assessed participants' experience in the project and found that participants completed the tasks with relative ease, believed that their preferences would have an impact on the CTFPHC's guideline, and enjoyed the opportunity to take part in the project. 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 1 – Screening Questionnaire

CTFPHC Public Perceptions Screening Survey

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 assistant, Sabrina Jassemi, at jassemisa@smh.ca or 416-864-6060 x76217.

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?

- ☐ Charity Village
 - ☐ Craigslist
 - ☐ Kijiji
 - ☐ Lung Cancer Canada
 - ☐ 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 completed?

- ☐ 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?

Are you the parent or guardian of at least one child aged 5 to 18 years old?

- ☐ Yes
 - ☐ No
-

Are you the parent or guardian of at least one child aged 5 to 12 years old?

- ☐ Yes
 - ☐ No
-

Have any of these 5 to 12 year old children ever smoked?

- ☐ Yes
 - ☐ No
-

Have any of these 5 to 12 year old children smoked in the last 30 days?

- ☐ Yes
 - ☐ No
-

Are you the parent or guardian of at least one child aged 13 to 18 years old?

- ☐ Yes
 - ☐ No
-

Have any of these 13 to 18 year old children ever smoked?

- ☐ Yes
 - ☐ No
-

Have any of these 13 to 18 year old children smoked in the last 30 days?

- ☐ Yes
 - ☐ No
-

Have you ever smoked cigarettes?

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

Do you currently smoke cigarettes?

- ☐ Yes
- ☐ No

How many cigarettes have you smoked in total over the course of your life?

Do you have any conflicts of interest related to smoking tobacco?

Examples include but are not limited to the following: being a member of an organization related to tobacco or nicotine<guideline topic=""; owning a company that provides products or services related to tobacco or nicotine<guideline topic=""; owning shares in a company that provides products or services related to <guideline topic=""; tobacco or nicotine; and conducting research on tobacco or nicotine<guideline topic="".</guideline></guideline></guideline></guideline>

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

Have you ever used injection drugs?

- ☐ Yes
- ☐ 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<guideline topic=""; owning a company that provides products or services related to hepatitis C<guideline topic=""; owning shares in a company that provides products or services related to <guideline topic=""; hepatitis C; and conducting research on hepatitis C<guideline topic="".</guideline></guideline></guideline></guideline>

- ☐ 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 assistant 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

Thank you for taking the time to fill out this survey. Unfortunately, it appears that you are not eligible to take part in this initiative.

The CTFPHC is exclusively soliciting the opinions of members of the general public who are not practicing health care professionals.

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 2 - Confidentiality Form

Canadian Task Force on Preventive Health Care
University of Calgary; 7th Floor, TRW Building
3280 Hospital Drive NW; Calgary, Alberta T2N 4Z6
Email: info@canadiantaskforce.ca

Canadian Task Force on Preventive Health Care Confidentiality Agreement

Name: _____

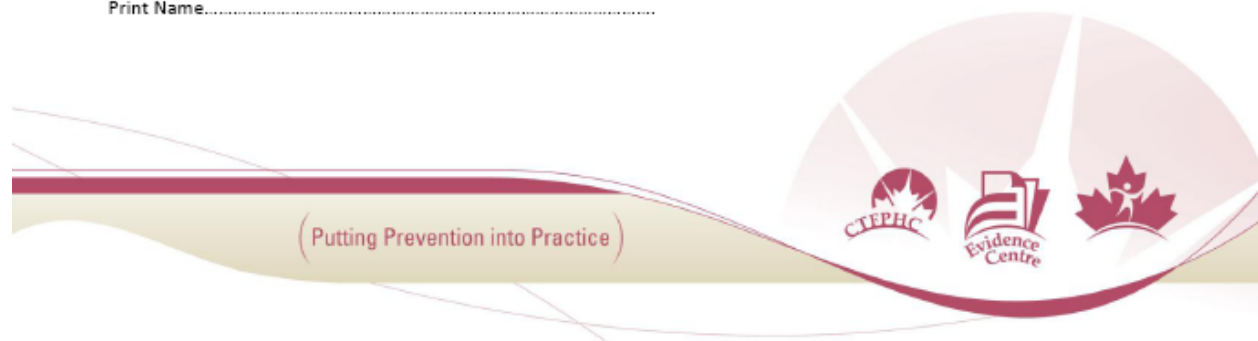
Organization (if applicable) _____

The signed individual (above) acknowledges that information that is considered confidential and/or commercially sensitive ("Confidential Information") that may be disclosed to them, must remain confidential under all circumstances.

1. The aforementioned individual acknowledges that they will ensure that all persons associated with them, including but not limited to directors, employees or contracted workers, will:
 - (a) keep all documents and information that the above individual may receive from the Public Health Agency of Canada (PHAC) on behalf of the Canadian Task Force on Preventive Health Care (CTFPHC) in the course of carrying out their responsibilities as an above individual, or that the CTFPHC may develop while performing its mandate, strictly confidential;
 - (b) not use any Confidential Information for any purpose other than those indicated by the CTFPHC;
 - (c) Not disclose any Confidential Information to any third party without the prior written consent of the Chair of the CTFPHC, and in the event that such disclosure is permitted, the above individual shall procure that said third party is fully aware of and agrees to be bound by these undertakings.
2. No Waiver of Privilege – The above individual acknowledges that the Confidential Information is the property of the CTFPHC (and as some cases may allow, a third party), and that none of the latter intend to and do not waive, any rights, title or privilege they may have in respect of any of the Confidential Information.
3. Specific Exclusions – The above individual's obligation to protect Confidential Information hereunder does not apply to Confidential Information which, even if it may be marked "confidential", in the following circumstances:
 - (a) IN PUBLIC DOMAIN – the information was legally and legitimately published, or otherwise part of the public domain (unless due to the disclosure or other violation of this Confidentiality Agreement by the above individual);
 - (b) ALREADY KNOWN TO THE above individual – the information was already in the possession of the above individual at the time of its disclosure to the above individual and was not acquired by the above individual, directly or indirectly, from the CTFPHC, the ERSC nor PHAC;
 - (c) THIRD PARTY DISCLOSES – the information becomes available from an outside source who has a lawful and legitimate right to disclose the information to others;
 - (d) INDEPENDENTLY DEVELOPED – the information was independently developed by the above individual without any of the Confidential Information being reviewed or accessed by the above individual.
4. The above individual acknowledges that there are no conflicts of interest or if there are, that they are indicated on the attached CONFLICT DISCLOSURE form.

Signature..... Date.....

Print Name.....



Appendix 3 - Project Information Sheet

Canadian Task Force on Preventive Health Care (CTFPHC): Public Perceptions of Hepatitis C Screening and Treatment

Part 2 Project Information Sheet

Background & Purpose of Project:

The Canadian Task Force on Preventive Health Care (CTFPHC) was established by the Public Health Agency of Canada to develop evidence-based guidelines for preventive health care in Canada. The CTFPHC has developed guidelines on a variety of topics, including breast cancer screening, prostate cancer screening, and type 2 diabetes screening. The CTFPHC would now like to get your input on one of its upcoming guideline topics: **hepatitis C screening**. You were invited to participate in this project because you are a resident of Canada who may be involved in making decisions about hepatitis C screening in the future.

Description of the Project:

This project consists of two parts. This information sheet explains **Part 2** of the project.

Part 2 of this project consists of two sessions.

Session 1:

Before the session, we will provide you with an information sheet on hepatitis C screening. This information sheet will contain a list of harms and benefits that people may experience after getting screened for hepatitis C. **Please read the information sheet before completing Session 1.**

During session 1, we will ask you to take part in a 60-minute group discussion about the harms and benefits of hepatitis C screening with other participants. Specifically, we will ask you to discuss how important you think it is for people to consider each of these harms and benefits when making decisions about getting screened for hepatitis C. This discussion will take place via teleconference, so there will be no travel required.

Session 2:

After you complete Session 1, we will give you one week to complete a brief online survey. You will receive a link to the survey via email. In this survey, we will provide you with a list of harms and benefits that people may experience after getting screened or treated for hepatitis C. We will ask you to indicate how important you think it is for people to consider each of these harms and benefits when making decisions about hepatitis C screening.

Potential Benefits:

You will be compensated \$35 for completing both sessions in Part 2 of this project. You will also have an important opportunity to shape new guidelines for health care in Canada.

Project Results:

You may receive a copy of the project report to review upon request.

Participation and Withdrawal

Participation in this project is voluntary and you may withdraw at any time. If you withdraw early from the project, any data collected up to that point will be used in the analysis portion of this project.

Project Contact:

If you have any questions about the project, please contact Dr. Nadia Bashir, Research Coordinator, at bashirn@smh.ca or 416-864-6060 ext. 77507 (Monday to Friday 8:00 am – 4:00 pm Eastern Time).

Appendix 4 – Hepatitis C Screening and Treatment Background Document

Canadian Task Force on Preventive Health Care

Background Information Sheet on Screening and Treatment for Hepatitis C

What is hepatitis C?

Hepatitis C is a disease caused by the hepatitis C virus. This virus enters the body through the blood, but can eventually damage the liver. Hepatitis C can be either an “acute” infection or a “chronic” infection. Acute hepatitis C is a short-term infection that the body is able to fight off. When the body is unable to fight off the infection, hepatitis C becomes a long-term, chronic infection. In most cases, hepatitis C becomes chronic.

Who is at risk?

People get hepatitis C by being exposed to the blood of someone who is infected with the virus. The people who are most likely to get hepatitis C are those who have used recreational injection drugs, received blood transfusions before 1992, or have come into contact with infected blood or needles at work.

How does having Hepatitis C affect people?

Hepatitis C doesn’t affect everyone in the same way. Many people who have hepatitis C will develop only mild liver damage, even if they have been infected with the virus for several decades. However, some people will develop liver cancer or cirrhosis (permanent scarring of the liver), which can lead to death. People who develop cirrhosis are more likely to need a liver transplant.

How do doctors screen people for hepatitis C?

When doctors screen for hepatitis C, they are looking to see if people who don’t show any signs of illness do in fact have the hepatitis C virus. According to the people who promote it, the idea behind hepatitis C screening is that if doctors detect hepatitis C when the infection is at an early stage, they may be able to treat it before it has a chance to cause serious liver damage.

Doctors use a blood test to screen people for hepatitis C. The blood sample is tested to see if it contains antibodies for the hepatitis C virus. Antibodies are molecules that the body produces in response to infection with a virus.

What are the possible benefits of hepatitis C screening?

Compared to people who don’t get screened, people who get screened for hepatitis C may

- be less likely to die from hepatitis C
- be less likely to become seriously ill from the virus and develop cirrhosis (permanent liver scarring)
- be less likely to develop liver cancer
- be less likely to need a liver transplant

- have a better quality of life
- be more likely to get successfully treated for the virus so that the virus is cleared from the body. Although this isn't a "cure", people are less likely to develop liver cancer or die when the virus has been cleared from their body
- be more likely to experience an improvement in the health of their liver
- be more likely to change their behaviour in ways that can improve their health (e.g., they may be less likely to drink alcohol and use recreational injection drugs, which can cause liver damage)
- be less likely to infect another person with hepatitis C

What are the possible harms of hepatitis C screening?

Compared to people who don't get screened, people who get screened for hepatitis C may

- get overdiagnosed. Overdiagnosis happens when someone is diagnosed with a disease that may never cause any health problems for them. Because most people with hepatitis C will never develop end-stage liver disease, people may receive unnecessary treatments for hepatitis C that can harm them (see below for more information about these harms).
- feel anxious about getting a positive test result (i.e., a test result that says that they have hepatitis C)
- be viewed negatively by others if they end up getting diagnosed with hepatitis C. This is because people may believe that only those individuals who lead unhealthy lifestyles or use recreational drugs get hepatitis C. People may also avoid contact with someone who has hepatitis C because they may be worried that they will easily catch the virus from this individual.
- have more problems in their relationship with their romantic partner if they end up getting diagnosed with hepatitis C. These problems can range from having minor disagreements to being a victim of violence or abuse.

How do doctors treat people for hepatitis C?

Chronic hepatitis C is treated with medication that attacks the hepatitis C virus. These medications either stop the virus from damaging the liver or slow down how quickly it damages the liver. People who receive treatment for hepatitis C may take medication for several months.

What are the benefits of hepatitis C treatments?

In comparison to people who don't get treated, people who get treated for hepatitis C may

- be less likely to die from liver disease
- be less likely to die from causes other than liver disease

- be less likely to develop cirrhosis (permanent liver scarring)
- be less likely to develop liver damage that is so severe that they will not survive without a liver transplant
- be less likely to develop liver cancer
- be less likely to need a liver transplant
- have a better quality of life
- be more likely to get successfully treated for the virus to the point where the virus is cleared from the body. Although this isn't a "cure", people are less likely to develop liver cancer or die when the virus has been cleared from their body.
- be more likely to experience an improvement in the health of their liver
- be less likely to infect another person with hepatitis C

What are the harms of hepatitis C treatments?

In comparison to people who don't get treated, people who get treated for hepatitis C may

- experience unpleasant side effects that lead them to stop taking their medication. This can reduce the chance that the treatment will work
- be more vulnerable to infections because they have low levels of neutrophils in their body. Neutrophils are cells that help to fight infections.
- feel weak and tired, because they have low levels of red blood cells. Red blood cells carry oxygen to cells in the body.
- experience unpleasant psychological side effects (e.g., depression)
- experience flu-like symptoms
- develop skin rashes

Appendix 5 – Focus Group Guide

Focus group guide for hepatitis C screening and treatment

Instructions for facilitators:

- Welcome (greet people as they join the teleconference)
- Introductions
 - Hello everyone and thank you for joining us today for the Canadian Task Force on Preventive Health Care Public Perceptions Focus Group on hepatitis C screening and treatment.
 - My name is _____ and I am from the Knowledge Translation Program based at the Li Ka Shing Knowledge Institute of St. Michael's Hospital and I am going to be the focus group moderator today.
 - Joining me is _____ who is the project coordinator and will momentarily be telling you more about the purpose of today's focus group and we also have _____ joining us tonight and he is a content expert and will be on the line to answer any content related questions.
 - I would just like to confirm with everyone who is on the call tonight...so I have (list names)
 - Have I missed anyone?
 - Okay I'm going to pass it off to _____ now to let her tell you more about the project and the purpose of today's focus group
- Reminder about confidentiality agreement forms & reimbursement forms
 - Thank you _____ for providing some context for today's focus group.
 - I would now like to open the floor if anyone has questions for _____ before we review the terms of consent and confidentiality.
 - Prior to this interview you had filled out a study reimbursement form and a confidentiality form. Do you have any questions about the forms you filled in? [Address any questions or concerns]If you haven't had a chance to send them to Kavitha, please do so after the focus group.
 - We take the issue of confidentiality seriously. No personal information about you will be shared with anyone outside the study team. Your real name will not appear anywhere in the written transcripts of, or reports concerning today's session. Any information from today that can identify who you are will be changed in any reports coming from this study. What this means is for example, if you say your workplace name we will replace that with a vague identifier such as 'participant's workplace' so the information cannot be linked to you. We will be audio taping this interview so that we do not lose any details of our discussion. So I request that focus group participants will only know and refer to each other on a first name basis. We strongly urge you to respect each other's privacy and not discuss what is said in the focus group with others. In order to be able to capture all the information being discussed today as a group, if everyone could say their first name before they speak and take turns speaking as well as avoid speaking at the same time it would help the transcriptionist when transcribing the audio tape. Also, just a reminder to mute

yourself when you are not speaking so everyone can better hear the current speaker.

- *As mentioned, the purpose of today's session is to hear about your perceptions of the recommendation about Hepatitis C screening and treatment. There are no right or wrong answers. Please feel free to ask any questions at any point during the focus group or if you want me to repeat any questions just let me know.*

Do I have everyone's permission to audio tape this interview?

When I turn on the audio recorder I am going to ask everyone to state their first name to the group and state that you consent to participate so I can capture it on the audio.

[Turn recorder on]

The audio recorder is now on and today's date is Juneth and I'm conducting the CTFPHC Hepatitis C screening and treatment Patient Preferences FG00 . There are insert # participants present.

[Start group introductions]

For the purpose of recording your consent to participate I will ask everyone to state their first name to the group and state that you consent to participate so I can capture it on the audio. Let's begin with insert first participant name

Thank you.

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.

Instructions

We will be discussing the background information sheet that was sent to you via email.

This sheet contains information about the following:

	<p>(a) what hepatitis C is, who is at risk, and how does having hepatitis c affect people</p> <p>(b) the benefits and harms of hepatitis C screening</p> <p>(c) the benefits and harms of hepatitis C treatment</p> <p>(d) cost of hepatitis C treatment</p> <p><i>Note: ensure that participants have had a chance to read this information and have their questions answered (if any)</i></p> <p>Out of curiosity:</p> <p>How many people have access to this document right now?</p> <p>How many people reviewed the document prior to tonight?</p> <p>Okay excellent for those of you who do not, no worries, please take a few moment to review the sheet now.</p> <p>Okay great, so how today is going to work. We have prepared a series of questions to better understand your perceptions about the information presented in the background. We are going to review the documents in sections and you will have an opportunity to ask _____questions about each section.</p>
Background on Hepatitis C	<p>Okay I am now going to pass it over to _____ to answer any questions you may have about the background sheet sections: what is hepatitis C? Who is at risk? How does having hepatitis C affect people?</p> <p>Thank you _____.</p> <p>1) In your opinion, do feel any other background information should be provided about Hepatitis C?</p>
Screening Benefits	<p><i>Direct participants to the section of the hep C backgrounder that describes the screening benefits</i></p>

	<p>I am going to pass it over to _____ again to answer any questions you may have about the possible benefits of hepatitis C screening section.</p> <p>Thank you _____.</p> <ol style="list-style-type: none"> 2) What were your initial thoughts on the possible benefits of Hep C screening? 3) How important is it for people to consider the benefits of hep C screening when making decisions about getting screened for hep C? 4) Which benefit(s) would influence your decision to be screened or not the most?
Screening Harms	<p><i>Direct participants to the section of the hep C backgrounder that describes the screening harms</i></p> <p>I am going to pass it over to _____ again to answer any questions you may have about the possible harms of hepatitis C screening section.</p> <p>Thank you _____.</p> <ol style="list-style-type: none"> 5) What were your initial thoughts on the possible harms of Hep C screening? 6) How important is it for people to consider the harms of hep C screening when making decisions about getting screened for hep C? 7) Which harms(s) would influence your decision to be screened or not the most? 8) When you make decision to be screened or not, what influences your decisions more – the benefits or harms of screening?

Treatment Benefits	<p><i>Direct participants to the section of the hep C backgrounder that describes the treatment benefits</i></p> <p>I am going to pass it over to _____ again to answer any questions you may have about the possible benefits of hepatitis C treatment section.</p> <p>Thank you _____.</p> <p>9) What were your initial thoughts on the possible benefits of Hep C treatment?</p> <p>10) How important is it for people to consider the harms of hep C treatment when making decisions about getting treated for hep C?</p> <p>11) Which benefits(s) would influence your decision to be treated or not the most?</p>
Treatment Harms	<p><i>Direct participants to the section of the hep C backgrounder that describes the treatment harms</i></p> <p>I am going to pass it over to _____ again to answer any questions you may have about the possible harms of hepatitis C treatment section.</p> <p>Thank you _____.</p> <p>12) What were your initial thoughts on the possible harms of Hep C treatment?</p> <p>13) How important is it for people to consider the harms of hep C treatment when making decisions about getting treated for hep C?</p>

	<p>14) Which harms(s) would influence your decision to be treated or not the most?</p> <p>15) When you make decision to be treated or not, what influences your decisions more – the benefits or harms of treatment?</p>
Cost of treatment	<p><i>Direct participants to the section of the hep C backgrounder that describes who pays for hepatitis C section.</i></p> <p>Our expert panel estimated that 90% of HCV+ persons who are screen-detected in primary care will be told to wait for treatment, for an unknown time period, as a consequence of policies presently in place.</p> <p>16) What are you initial thoughts about this statement?</p> <p>I am going to pass it over to _____ now to answer any questions you may have about who pays for hepatitis C treatment section.</p> <p>Thank you _____.</p> <p>17) What were your initial thoughts on the financial coverage of Hepatitis C treatment?</p> <p>18) How does the cost of treatment and coverage affect your decision to be treated the Hepatitis C?</p> <p>Probe: If you were diagnosed with hepatitis C following screening and you had no symptoms, would you be willing to wait to get treatment until you developed symptom of liver disease so that you didn't have to pay for treatment?</p>
Overall Preferences	<p>19) Considering the harms and benefits we've talked about today, would you want to get screened for hep C? Why?</p>

	<p>20) Thinking back to everything we spoke about today, overall how easy was it to understand the background sheet on hepatitis C?</p> <p>21) What type of information would like to see in patient decision aid on hepatitis c screening and treatment?</p>
Closing Remarks	<p>22) Does anyone have any additional comments on the harms and benefits we discussed today?</p>
<p>Thank participants and wrap up.</p>	

Appendix 6 – Follow-up Survey

Patient Preferences Survey: Phase 2

Page 1

Introduction

Thank you for taking part in the focus group to discuss the possible benefits and possible harms of hepatitis C screening. In this survey, the CTFPHC would like to ask you a few follow-up questions about how you view these possible benefits and harms. The survey will take approximately 15–20 minutes to complete. If you have any questions, concerns, or technical difficulties, please contact the project assistant, Radha Sayal, at sayalr@smh.ca or 416-864-6060 x77531.

Page 2

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.

Page 3

Possible Benefits of Screening (lifelong benefits)

On the following pages, you will see a list of the benefits and harms that people may experience if they are screened for hepatitis C. For each possible benefit and harm in the list below, please rate how much it would influence your decision to get screened or to not get screened.

When answering the questions below, keep in mind the following: out of 10,000 people who get screened, approximately 63 cases of hepatitis C will be discovered.

Question 1: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

Out of 10,000 people who don't get screened, 24 people aged 25-64 will become seriously ill from the hepatitis C virus and may develop liver scarring, which can prevent the liver from functioning properly. This is compared to 18 out of 10,000 people who do get screened.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Question 2: How important is the following information when you are making a decision on

whether or not to be screened for Hepatitis C?

Out of 10,000 people who don't get screened, 35 people aged 25-64 will die from hepatitis C. This is compared to 26 out of 10,000 people who do get screened.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Question 3: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

Out of 10,000 people who don't get screened, 15 people aged 25-64 will develop liver cancer. This is compared to 12 out of 10,000 people who do get screened.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Question 4: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

Out of 10,000 people who don't get screened, 0 (zero) hepatitis C related deaths among people 25-64 are prevented. This is compared to 9 prevented deaths out of 10,000 people who do get screened.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Page 4

Harms Related to Treatment (These side effects usually stop after 12-72 weeks, when treatment is finished)

When answering the questions below, keep in mind the following: out of every 10,000 people who get screened for hepatitis C, approximately 37 people will receive drug treatment.

Question 5: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 8 will experience weakness and feel tired because they have low levels of red blood cells (anemia)

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Question 6: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 7 will experience flu-like symptoms.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Question 7: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 6 will become more vulnerable to other types of infections because they have low levels of cells that help to fight infections.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Question 8: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 3 will experience unpleasant psychological side effects, such as depression.

1 = This doesn't factor into my	2	3	4	5	6	7	8	9 = This factors into my decision
--	---	---	---	---	---	---	---	--

decision at all	a lot
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Question 9: How important is the following information when you are making a decision on whether or not to be screened for Hepatitis C?

For every 10,000 people screened, 37 will receive drug treatment for hepatitis C. Out of the 37 people, 8 will experience skin rashes.

1 = This doesn't factor into my decision at all	2	3	4	5	6	7	8	9 = This factors into my decision a lot
--	---	---	---	---	---	---	---	---

Page 5

Considering the harms and benefits of hepatitis C screening, how much would you want to get screened for hepatitis C?

I would want to get screened for hepatitis C	1=Not at all	2	3	4	5	6	7	8	9=Very much
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page 6

Please respond to each of the following statements using the scale provided. Indicate your response by selecting the number from 1(Not at all) to 9 (Very much) 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 hepatitis C background information sheet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How easy was it to rate the harms and benefits using the 9-point scale?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How clear were the survey instructions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How well did you understand what we asked you to do in this survey?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

Page 7

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 informative was the group discussion that you took part in via teleconference?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How argumentative was the group discussion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How much did the group discussion influence your responses in this final survey?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How helpful was the information provided by the content expert (i.e., the CTFPHC member on the focus group call)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How much did the content expert's comments influence your responses in this survey?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page 8

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 the importance of considering various harms and benefits when making decisions about hepatitis C screening and/or treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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 hepatitis C screening for their patients?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 hepatitis C guideline? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
5. How satisfying did you find your participation in this project to be? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
6. How much did your actual experience as a participant in this project match your expectations about what it would be like to take part? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Page 9

- 1. Please describe what you liked about taking part in this project.**

- 2. Please describe what you did not like about taking part in this project.**

- 3. Please describe anything that we could change to improve this project.**

Page 10

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

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Next steps

Thank you for completing this survey. If you have questions about any aspect of the project, please contact the project assistant, Radha Sayal, at sayalr@smh.ca or 416-864-6060 x77531. 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.