Canadian Task Force on Preventive Health Care

Patient Preferences for Visual Acuity Screening in Adults Aged 65 Years and Older: Data Summary

Prepared for the Canadian Task Force on Preventive Health Care

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Introduction

The Canadian Task Force on Preventive Health Care (CTFPHC) recruits members of the public, at up to three critical phases, to provide input during the guideline and knowledge translation (KT) tool development process. This document presents summary data from Phase 2 of the CTFPHC visual acuity patient preferences focus groups, interview, and surveys. We examined patients' perceptions of the harms and benefits of screening for visual acuity. Specifically, we asked how important patients believe it is for people to consider various harms and benefits when making decisions about getting screened for visual acuity. We also examined participants' experiences in the project. Data were collected between March 27, 2017 and May 29, 2017.

Methods

For a detailed description of the methods used in this project, please refer to Phase 2 of the CTFPHC's Patient Engagement Protocol (http://canadiantaskforce.ca/methods/patient-preferences-protocol/).

Participants

Recruitment

Participants were English-speaking men and women who would be members of the target population for visual acuity screening in Canada. We recruited participants by posting recruitment advertisements on public advertisement websites (e.g., Craigslist and Kijiji). In addition, we contacted members of the public who have previously expressed interest in providing feedback on CTFPHC guidelines and KT tools to the St. Michael's Hospital (SMH) KT Program.

We asked individuals who responded to the recruitment announcement to complete a brief online screening questionnaire to assess their eligibility to take part in the project (see Appendix A). People aged 65 years and older were eligible to take part in the project. Participants were not eligible for the project if they indicated that they were:

- a health care practitioner;
- not currently living in the community (i.e., hospitalized);
- diagnosed with a visual impairment other than a refractive impairment;
- they or their doctor are concerned about their visual acuity; or
- aware of any conflicts of interest relevant to the guideline topic (e.g., owning shares in a company related to visual acuity).

Participants were compensated $50 for participating in the project as per the SMH KT Program internal reimbursement policy.

Characteristics of included participants

The final sample consisted of 10 male and 10 female participants aged 65-74 years of age (mean age = 69 years, standard deviation = 2.6). None of the participants had immigrated to Canada within the previous five years. None of the participants self-identified as Aboriginal (i.e., First Nations, Métis, or Inuit). The majority of participants were from Ontario (*n* = 13). There were also participants from New Brunswick (*n* = 3), British Columbia (*n* = 2), and Alberta (*n* = 2). Most of the participants lived in urban areas (*n* = 11), with a few participants in suburban areas (*n* = 3), and several participants in rural areas (*n* = 6). The majority of participants had a college diploma or bachelor's degree (*n* = 10) or a graduate or professional degree (*n* = 8). The remaining participants' highest level of education was high school (*n* = 2).

Outcome ratings

Below is a summary of participants' perceptions of the harms and benefits of screening for visual acuity. As explained in the Patient Engagement Protocol, these data were collected using a modified RAND Appropriateness Method (RAM)[1] using surveys and focus groups.

Harms and benefits scale ratings

In the first part of the survey, participants rated the importance of harms and benefits of screening for visual acuity. For each of these potential harms and benefits, also called an "outcome", all participants were provided with information and asked "How important would this information be for you if you were making a decision on whether or not to be screened for visual acuity?"

Participants rated the importance of the information they were given about the outcome from 1-9: a score of 1 indicated "This isn't important for my decision at all"; a score of 5 indicated "This is neither important nor not important for my decision"; and a score of 9 indicated "This is very important for my decision".

There was limited evidence on the frequency of harms and benefits and so the likelihood of many of the potential outcomes was undefined. However, participants were asked to rate the importance of the outcomes with the undefined likelihood. This caused some participant confusion as well as a range of interpretations of the questions, which was explored in the focus groups and is discussed in the Factors that influence outcome ratings and Limitations sections below.

Table 1 provides the full description of the harms and benefits that participants were asked to rate. The short descriptions are used in Figure 1 and Table 2.

Table 1. Descriptions for harms and benefits

Short description	Full description
Benefits	
Improve visual acuity	Screening may possibly improve some measures of visual acuity when tested using charts in a physician's office
Not improve vision problems	Screening probably does not improve vision problems as reported by patients (e.g., difficulties reading the newspaper or seeing in the dark)
Reduces loss of independence	We do not know if screening reduces loss of independence
Reduces risk of falls, fractures, death	We do not know if screening reduces the risk for falls, fractures, or death
Improves functioning or quality of life	We do not know if screening improves vision-related functioning or quality of life
Harms	
Increases serious adverse effects from treatment	We do not know if screening increases serious adverse effects from treatment (e.g., infection, swelling, bleeding, double vision, eye-pain, etc.)
Increases anxiety or stress	We do not know if screening increases anxiety or stress from lack of access to treatment or having a diagnosis in the face of ineffective treatments (e.g., when other health conditions prevents safe treatment)

A summary of survey responses is presented below as well as in Figure 1 and Table 2. Figure 1 and Table 2 present the participant ratings of each of the seven outcomes. Figure 1 and the synopsis below are based on the post-focus group survey results. However, in Table 2 both pre- and post-focus group survey data are included, for comparison purposes.

How to read the box plot

To show participant ratings, we used the box plot throughout this report. The box plot whiskers show the full range of responses, the box shows the interquartile range (IQR), and the line in the box shows the median. For instance, looking at “improve visual acuity” in the sample figure below, the range is 1-9, the interquartile range is 7-9, and the median is 8. All possible responses are whole numbers; therefore the median will sometimes be the same as the first or third quartile. In those cases, a line next to the quartile indicates the median is the same number. For instance, looking at “reduce loss of independence” in the sample figure below, the range is 1-9, the interquartile range is 5-7.5, and the median is 5.

Sample figure. Box plot

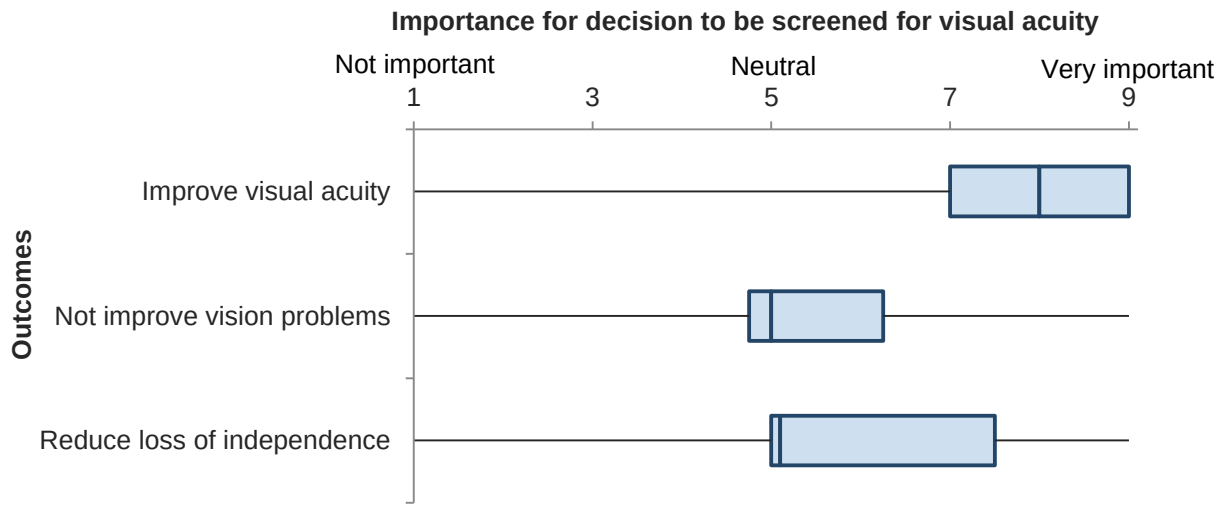


Figure 1. Post-survey harms and benefits scale ratings (n = 20)

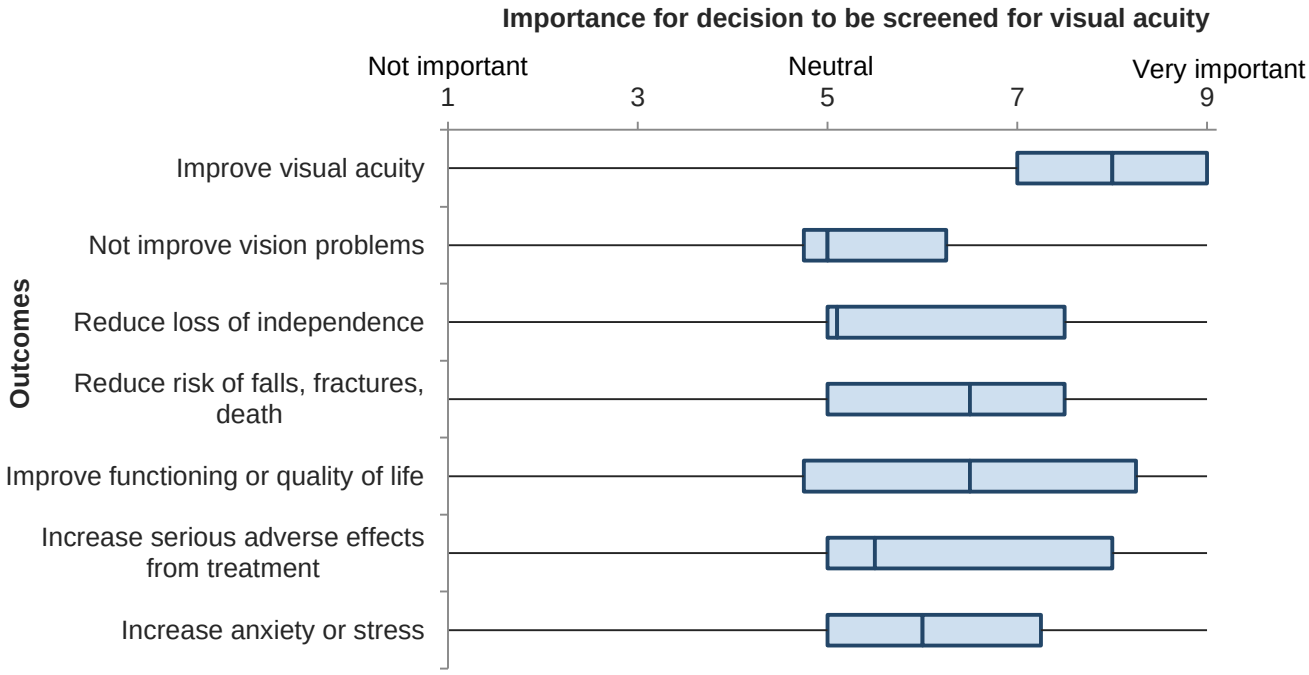


Table 2. Pre- and post-survey harms and benefits scale ratings (n = 20)

Outcome	Pre-survey			Post-survey		
	Median	IQR*	Range	Median	IQR	Range
Benefits						
Improve visual acuity	9	8-9	5-9	8	7-9	1-9
Not improve vision problems	5	5-7	1-9	5	4.75-6.25	1-9
Reduce loss of independence	5	5-7.5	1-9	5	5-7.5	1-9
Reduce risk of falls, fractures, death	5	5-7.25	1-9	6.5	5-7.5	1-9
Improve functioning or quality of life	5.5	5-8.25	1-9	6.5	4.75-8.25	1-9
Harms						
Increase serious adverse effects from treatment	7	5-8.25	1-9	5.5	5-8	1-9
Increase anxiety or stress	7	5-8	2-9	6	5-7.25	1-9

**Note: IQR = interquartile range.*

There were a wide range of ratings for each outcome. All outcome rating medians fell between 5 and 8. Every outcome included ratings at both ends of the scale, 1 and 9. The observation that ratings spanned the full range of possible responses was explored further in the focus groups and was partly attributed to the different interpretations of the lack of data available to define the likelihood of each outcome. The interpretations of the undefined outcomes were explored in greater depth during the focus groups and are described further in the Factors that influence outcome ratings and Limitations sections.

Overall preferences for screening

In the second part of the survey, participants rated their overall preferences for screening for visual acuity. For each of these questions, participants were provided with information to consider and then asked to rate, considering this information, their preference for being screened for visual acuity. Participants could rate the phrase “I would want to be screened for visual acuity” from 1-9: A score of 1 indicated “Not at all”; a score of 5 indicated “Neutral”; and a score of 9 indicated “Very much”.

Table 3 provides the short descriptions and full questions that participants were asked. The short descriptions are used in Figures 2 and 3 and Table 4.

Table 3. Descriptions for overall screening preferences

Short description	Full questions
Screening preference	
40% of older adults without regular eye care	Considering that approximately 40% of older adults do not have regular eye care from an optometrist, how much would you want your family doctor to do a screening test for impaired visual acuity?
Unknown vision problems	Considering that some older adults don't recognize that they have vision problems, how much would you want to be screened for impaired visual acuity by your family doctor?
Don't seek advice from their doctor	Considering that some older adults don't seek advice about their eyesight from their family physician, how much would you want to be screened for impaired visual acuity by your family doctor?
Potential harms and benefits	Considering the potential harms and benefits of screening for impaired visual acuity for adults aged 65 years or older, how much would you want to be screened for impaired visual acuity by your family doctor?
Unknown risk of harms and benefits	Considering that the risk of many of the harms and benefits of impaired visual acuity screening for adults aged 65 years or older are not well known, how much would you want to be screened for impaired visual acuity by your family doctor?

A summary of survey responses is presented below as well as in Figure 2 and Table 4. Figure 2 and Table 4 present overall preferences for screening. Figures 2 and the synopsis below are based on the post-focus group survey results. However, in Table 4 both pre- and post-focus group survey data are included, for comparison purposes.

Figure 2. Post-survey overall screening preferences (n = 20)

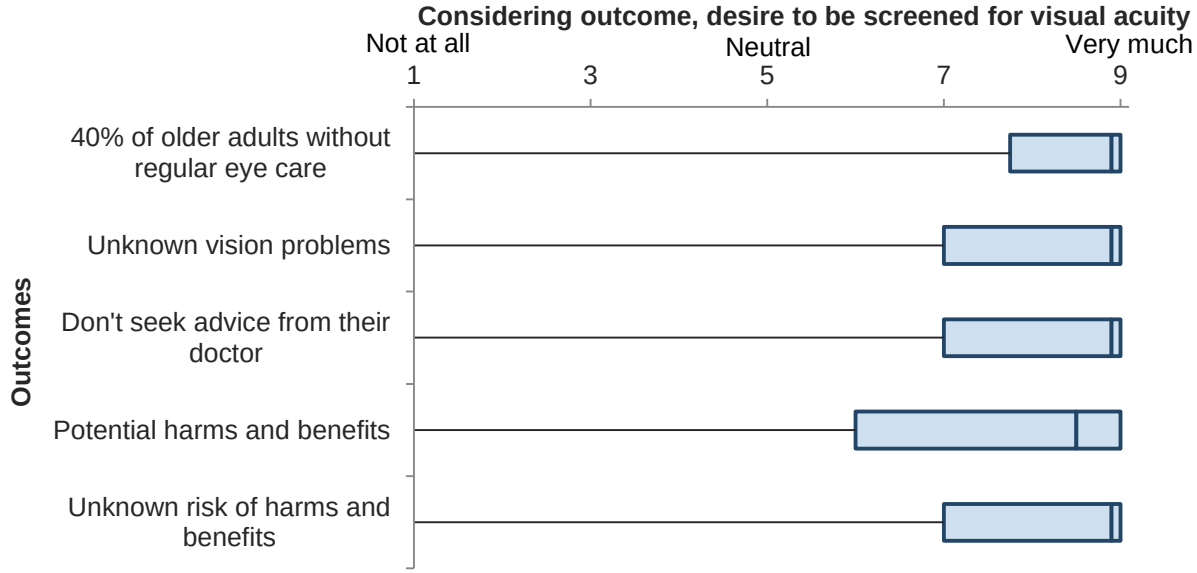


Table 4. Pre- and post-survey overall screening preferences (n = 20)

Outcome	Pre-survey			Post-survey		
	Median	IQR*	Range	Median	IQR	Range
Screening preferences						
40% of older adults without regular eye care	9	7.75-9	1-9	9	7.75-9	1-9
Unknown vision problems	9	7-9	1-9	9	7-9	1-9
Don't seek advice from their doctor	9	7-9	1-9	9	7-9	1-9
Potential harms and benefits	8.5	6.75-9	1-9	8.5	6-8.5	1-9
Unknown risk of harms and benefits	8	6.75-9	1-9	9	7-9	1-9

**Note: IQR = interquartile range.*

There were a wide range of preferences for screening. Each outcome included ratings at both ends of the scale, 1 and 9. The preferences for screening ranged from 8.5 to 9. The strong preference for screening was further explored in the focus groups. The results of the focus groups are presented below.

Participant perceptions of outcomes for screening

Three focus groups (*n* = 19), one interview (*n* = 1), and 14 open-ended survey questions (*n* = 20) were used to gather qualitative data from participants about the importance of the harms and benefits and their overall preferences for screening for visual acuity. Focus group and interview transcripts as well as open-ended survey responses were coded thematically. A summary of the focus group discussions and survey responses are presented in Tables 5 and 6.

Factors that influence outcome ratings

The qualitative data collected through the modified version of RAM identified two main areas of misconceptions or alternative understandings of study materials. These factors may contribute to outlier survey ratings and are summarized in Table 5.

Table 5. Factors that influence participants' outcome ratings (n=20)

Factors	Description	Illustrative quotes
Information needs	Overall, participants were satisfied with the information presented in the background information sheet. However, participants requested additional information when rating outcomes for screening. Common questions directed to the content expert included: **Visual acuity research** I. What kinds of studies are available for visual acuity? II. Did the studies look at quality of life factors (e.g., being able to continue regular activities)? III. More evidence is needed for visual acuity outcomes. If population wide screening is recommended, will you be able to collect data to measure efficacy of visual acuity screening? **Visual acuity screening test** I. What are current visual acuity screening practices in Canada? II. Is the visual acuity screening test invasive? III. Is the visual acuity screening test covered under provincial health care plans? IV. Do all provinces provide vision coverage for individuals over 65 years of age?	*"I think that some of the explanations provided in the conference call by the doctor should have been provided in the original information which might have led to different outcomes [ratings]. We heard some comments to this effect during the conference call" – VA009* *"If you are a senior and you are used to sewing, doing crafts, or reading… And that's been a huge part of your life. When they did the studies, did they look to see what you had done before? No way can you do that if your eyes are damaged." – VA012* *"If the screening does go country wide, will there be research in place so that in the future we will know if it really is worthwhile and if it really does help people?" – VA014* *"Are all provinces similar in their coverage of optometrists?" – VA008*

	V. If you regularly get your eyes checked by an optometrist or ophthalmologist do you still fit into the screening population? **Administering the visual acuity screening test** I. Are primary care providers the most appropriate health care professionals to administer visual acuity screening? II. Do primary care providers have the knowledge to do eye tests? III. How do the tests performed at a primary care provider's office differ from tests performed at an optometrist's or ophthalmologist's office? IV. Do primary care providers have the capacity and time for another screening test during appointments? V. Can visual acuity screening be performed by nurse practitioners or nurses? **Health system** I. What is the feasibility of rolling out population wide screening programs (e.g., do primary care providers have time)? II. Would a population wide screening program save the health system money? III. Are the CTFPHC recommendations distributed to federal or provincial health authorities?	*"I'm wondering how much training doctors have in this area. In our system here we've separated testing of eyes from the doctor to the optometrist." – VA015* *"When I was answering the questions, I was wondering […] if we did this, would screening save the medical system money?" – VA021*
Interpretation of lack of data for outcomes	Five of the seven visual acuity outcomes did not have sufficient available data in the literature to make a conclusive statement on the likelihood of the outcome. The lack of data statements that accompanied the outcomes were interpreted in various ways. Participants' interpretations either influenced the way they rated outcomes overall, or the way they understood outcomes (see below for examples). Generally, participants described one viewpoint; however, their perspective sometimes changed based on the outcome or if they were thinking of screening overall.	

	Rating process The lack of data statements influenced the way participants rated outcome statements overall, meaning participants would generally rate all statements in a similar way (i.e., higher importance, neutral importance, or lower importance). Examples included:	
	i) <u>Higher importance (rating 7-9): Regardless of evidence, visual acuity screening is important:</u> Participants stated that even though likelihood of outcomes is unknown they still believed visual acuity screening is important.	*"I believe screening is important whether or not the risks listed are known." – VA020* *"I would just as soon not know this information. I would like my doctor to recommend screening anyway". – VA015*
	ii) <u>Higher importance (rating 7-9): Some research available, but certain harms and benefits not studied:</u> Participants stated that the content expert's explanation helped in understanding the lack of data. They understood that many of these outcomes were not a part of the parameters of current studies, but that did not necessarily mean the harms were less or more likely to occur. These individuals were pro-screening.	*"Now that you've explained that the reason we don't have data is because nobody ever set up their studies to track that, there's a whole different impression of these questions for me." –VA003*
	iii) <u>Higher importance (rating 7-9): More research needed, pro-screening:</u> The lack of evidence about the impact of screening meant more screening should be done in order to collect more data about the efficacy of the screening.	*"I rated it as 8. I thought it was very important. It says reduce falls and they don't know that yet, but if they do more screening maybe they'll find out." – VA007*
	iv) <u>Higher importance (rating 7-9): Uncertainty, but possibility of benefits</u>: Even though there is not a lot of evidence behind screening; the screening process is seen as beneficial because it can lead to identifying a problem, which may reduce stress or lead to identifying treatment options.	*"I rated it a 9. Because I felt that [screening] was important. When your vision is checked and found to have a problem. It always helps you individually…The knowledge that you have a vision problem quite often is enough to get you acting." – VA018* *I gave it a 9. Very important because, to me, I think a lot of stress, anxiety, and problems with not knowing what's wrong there. And it's very important. – VA002*

	v) <u>Neutral importance (rating 4-6): Not enough information, does not influence decision making:</u> Participants explained that the lack of data made the statement inconclusive and therefore this information does not factor into their screening decision. Participants could be pro-screening overall, but rate the outcomes statements as neutral.	*"I rated it neutral because we didn't have the evidence one way or the other. In the information we were told. Intuitively, it seems like the screening is going to make a difference. But without evidence, we don't know. I couldn't really rate it without evidence." –VA021*
	vi) <u>Lower importance (rating 1-3): Evidence doesn't factor into decision, visual acuity screening is important.</u> Participants explained that lack of evidence should not affect their decision to be screened. Vision health is particularly important for seniors, therefore they believed that individuals should partake in preventive measures and be screened for visual acuity. These individuals rated outcomes as low, even though they were in favour of screening.	*"I think the lack of evidence shouldn't even enter into it. But that's just my opinion. The point is we want people who are getting into their advanced years tested at least to make sure they do have good visual acuity because a lot of people, like my wife, half the time won't wear her glasses when she needs to. She needs them all the time but she doesn't think she needs them as much as she does." – VA018*
	vii) <u>Lower importance (rating 1-3): Inconclusive evidence, not convinced that VA screening is an important health system investment.</u> Participants explained that they were not opposed to visual acuity screening; however they had concerns about investing health care dollars in screening that is not evidence-based. Others were concerned about the feasibility of busy primary care physicians following these recommendations in practice.	*"I was much more negative in my survey results, than the norm, because I just don't see compelling evidence that this is vital to do. And I think of the hour and a half I wait, two hours I wait to see my family doctor for one thing. If we're adding this on top when we're not sure if it's going to benefit people, then is it worth the expenditure of their time. So certainly the nurse or nurse practitioner before we get to the doctor is probably the way to go. Anyway, I just had a lot of questions about it, without the research to back up the necessity." – VA014*
	Outcome understanding The lack of data statements influenced the way participants' interpreted outcomes for ratings, meaning their ratings generally differed by outcome. Examples included:	
	<u>i) Neutral or lower importance (rating 4-6 or 1-3): No correlation, between visual acuity screening and outcomes:</u> Participants described how they did not think certain outcomes would be influenced by visual acuity screening. This resulted in some participants assigning a	*"Don't find these outcomes to be related to screening that is why they are not important." – VA016* *"These are irrelevant unless the types of screening are mentioned. None of these conditions would be caused by a simple*

	neutral rating and others assigning a lower importance rating for these outcomes. ii) Lower importance (rating 1-3): No evidence, increased stress due to potential harms: Participants described that the lack of evidence increased stress and anxiety because they were fearful of potential harms that could happen or inability to access treatments with proven efficacy.	*eye exam" – VA009* *"Stress is increased if a person is suffering from a health issue but cannot access appropriate care either due to their location or fear of losing their independence. Family members are also under stress if they know their parents have problems in visual acuity and ... have a driver's license" – VA012* *"Lack of access to effective treatments would increase my anxiety. In that circumstance, I don't know if I would choose screening or not." – VA021*

In summary, this table explains factors outside of participants' values and preferences that may have influenced the way they rated outcomes and thus possibly contributed to outlier responses. Factors included questions participants had about visual acuity (i.e., information needs) and participants' varied interpretations of the lack of data surrounding outcomes. These factors influenced participants' overall rating process or how they interpreted outcomes (i.e., interpretation of lack of data for outcomes).

Values and preferences for screening

The qualitative data collected through focus groups (*n* = 19), interviews (*n* = 1), and open-ended survey questions (*n* = 20) revealed four main values and preferences that may influence a patient's decision to be screened for visual acuity. Table 6 summarizes all unique values and preferences present in the qualitative data.

Table 6. Participants' values and preferences for screening (n = 20)

Factors	Description	Illustrative quotes
Personal experience	Participants explained how their personal experiences influenced their belief in screening as a preventive measure and that they were more inclined to support policies that recommend screening.	*"As a senior and most of my earlier life I've had a lot of surgeries and stuff. And I'm the first one to say I believe in screening. I believe in screening for everything, not just vision. As a senior now, a lot of my life I've had illness and I wish they had done a lot of screening back years ago when I was a very sick guy. This is very important to me and very exciting to me." – VA002* *"From my own personal experiences, I get screened more often and if I'd been screened sooner, it probably would have been better." – VA007*

Who should provide screening	The group was divided on the subject of who should provide screening. There were three distinct viewpoints: I. Eye specialists – Participants who typically received their vision care from an optometrist or ophthalmologist thought eye care specialists were the most qualified and appropriate individuals to provide visual acuity screening. II. Primary care physicians – Other participants explained how they viewed visual acuity screening to be part of a primary care physician's role. They stated it would be convenient to add to an annual checkup and that you would be more likely to reach people who do not regularly go to an eye care specialist for vision care. III. Other health professionals – Other participants stated it may not be feasible or cost effective for primary care physicians to provide screening for an additional health issue and wanted to know if other health professionals (e.g., nurses) are able to perform the screening.	*"I don't feel my family doctor has the skill or time to do this. I realize they would probably hire someone to be part of the office team but I don't see much of an advantage in that" – VA011* *"I would prefer to be screened by an ophthalmologist." – VA016* *"I go for regular checkups at my doctor's, so I would like this to be a part of my regular checkup." – VA010* *"I think it is part of the family doctor's role." – VA015* *"I do have regular screening but considering the high percentage of seniors who do not, I feel a screening by a family doctor is important" – VA020* *"I would suggest that it might be more practical and cost effective to have health professionals other than doctors do the exams" – VA005*
Feasibility for health system	Overall, participants were concerned about the feasibility of the health care system supporting a population wide screening program. Specifically, participants were concerned that: I. A high number of older adults do not have regular eye care. They wanted screening programs to target these individuals to ensure that resources were not wasted on individuals that already had regular vision care. II. Adding an additional screening test at the primary care level would increase wait times in the system. Further, as the benefits of the screening test are currently	*"Maybe the first question on any screening should be: 'Do you have regular checkups for vision problems from a professional?' and if Yes - do nothing but if No then begin a screen" – VA007* *"I might want to know how long it would take and if it would increase the wait time in my doctor's office if many patients were being screened. Unless you can assure me of some benefits beyond "may possibly", I*

	undetermined, these participants were less likely to be in favour of the screening. **III.** Allocating health care dollars to a screening test for which the efficacy is currently unknown.	*would not be inclined to spend the time." – VA014* *"I don't believe that we should be going ahead with something this massive until we have some evidence that the expenditure of time and resources provides reliable information." – VA018*
In favour of screening	Overall, the group was in favour of visual acuity screening. Specifically: I. The screening test is noninvasive and is therefore without risks or harms. Potential harms would be associated with treatment and should not influence a decision to be screened. II. Screening is viewed as a preventive measure that could save money for the health care system. III. Screening is viewed as potentially having benefits and therefore should be offered. IV. Regardless of evidence, many participants are convinced that screening is beneficial. V. Eye sight influences quality of life and therefore screening should be offered. There was a small group of participants who were not opposed to visual acuity screening, but were more hesitant to invest health care dollars for a screening test that is not evidence-based or would prefer to be screened by an eye care specialist rather than a primary care provider.	*"I would not be concerned about adverse effects from treatment at the time of screening. This is something I would consider once treatment was recommended." – VA020* *"Screening to me is very important as prevention is the most important item to save health care dollars and to help seniors live long lives' – VA002* *"I would still like to be screened on the chance that it will help me avoid the stated problems". – VA015* *"I feel screening is important whether or not you know the results." –VA020* *"Screening is important. We should look at it as a tool to protect our quality of life. Early diagnosis can make all the difference when seeking to correct or stop an issue with your sight". – VA004* *"Until we are sure that the benefits outweigh the harms for older adults, then I don't think we should be adding this to the list of already over-worked family physicians. If we do go ahead with it then there should be ways of collecting data to prove effectiveness one way or another." – VA014*

This table summarizes the four different values and preferences that influenced participants' decision to be screened for visual acuity. Factors included participants' personal experience, their opinion on who they viewed as most appropriate to administer the screening, the feasibility of having a population-wide screening program, and an attitude in favour of screening.

Factors influencing access to screening

Focus group (*n* = 19) and interview (*n* = 1) discussions and open-ended survey responses (*n* = 20) revealed three factors that may influence patients' access to visual acuity screening. A summary is provided in Table 7.

Table 7. Factors that influence participants' access to screening (n = 20)

Factors	Description	Illustrative quotes
Cost	Cost of screening was seen as a barrier for participants who lived in provinces where vision care is not funded. However, in this scenario, participants viewed screening that occurs in a primary care setting to be beneficial since there are no fees associated with primary care provider visits.	*"For me, on a pension, if it's not paid, then I wouldn't get screened because I don't have enough money. But if it's a province where you do get paid, then yes, I would like to get my eyes done when it's supposed to be." – VA007*
		"We're talking about a test performed by a family doctor, and in [province], there's no additional cost for that. So I can't see any barriers. I don't really have barriers to access my family doctor. There's no cost involved." – VA001
	Participants viewed cost to be a potential barrier if referred for additional testing or to purchase treatment options (e.g., eye glasses, surgery) is required.	*"Related to cost, if a doctor were to do an initial test and make a referral to an optometrist, if cost is a very serious concern and optometry is not covered in your province or glasses are not covered, the cost may still be a force that keeps you from going forward." – VA005*
Awareness	Majority of participants viewed visual acuity as an important health issue for senior citizens. However, they expressed that any screening recommendation must first be accompanied by a dissemination plan to increase awareness among this population. Participants had many ideas on how to raise awareness (e.g., developing a mobile app, increasing awareness through social media, and using condominium/apartment building associations to advertise screening programs).	*"However, it also seems to me that the knowledge that one should get a test may have to be disseminated first. That this is something that is important for older people. I too am over 70 but I'm very active on the Internet and there could be some way to reach people on social media or through their children on social media." – VA015*
Access to medical care	Some participants stated that it was difficult to get access to primary care in their province due to long wait times.	*"I live in [province] and people are waiting 8 years to get a family doctor." – VA019*
	Other participants stated that even if they have access to a primary care physician, their physicians have restrictive policies (e.g., one health issue per visit), which could create a time conflict if they have competing health priorities.	*"It's very difficult to get a family doctor. When you do have one, sometimes the doctor can only deal with one issue per visit." –VA002*

In summary, participants described three factors that would influence their ability to access the visual acuity screening test: cost of the screening test if vision care was not free in their province and the potential cost of treatment (e.g., diagnostic testing, glasses, and surgery); awareness of visual acuity as a relevant health issue for the senior population; and overall access to primary care providers, including long wait times in the health care system.

Participant engagement

At the end of the focus group and in the post-focus group survey, participants were asked to provide feedback on their experience in the project. The focus group and survey questions are available in Appendix E: Focus group guide and Appendix F: Participant engagement and experience items. For the full data collection method, see the Patient Engagement Protocol. A summary of the responses is presented below.

Participant experience ratings scales

In the post-focus group survey, participants were asked a series of questions about their experience in the project.[2] Participants responded using a 5-item scale, with the following response options: Not at all (1), Small extent (2), Fair extent (3), Moderate extent (4), or Large extent (5). Participants were prompted to explain their rating if they selected a rating of 1, 2, or 3. The quantitative responses to these questions are summarized in Figure 3 and Table 8. The quantitative ratings and relevant qualitative explanations are also summarized below.

All participant experience questions were highly rated, indicating a positive engagement experience. The two questions that were rated “large extent” least often asked if participants believed their input would influence the final decisions that underlie the engagement process and to what extent they found the ideas in the information material easy to understand. Three participants explained that their low rating for their beliefs that their input would be included in the final decisions was influenced by their perception that the final decision would be based on many influences, including all participants’ input. As one participant said, “Everyone’s input is important.” Other explanations included: the sample of participants was too small to be meaningful, the process would take several years, and that they did not agree with screening by a family doctor. Three participants explained their low rating of their understanding of informational material by stating that they found the survey questions difficult to understand and answer. For example, one participant stated, “I had to read the survey question a few times to understand that I was considering more than just problems seniors have with visual acuity but also the likelihood of seniors considering or approving of screening.”

Figure 3. Survey responses for participant engagement items (n = 20)

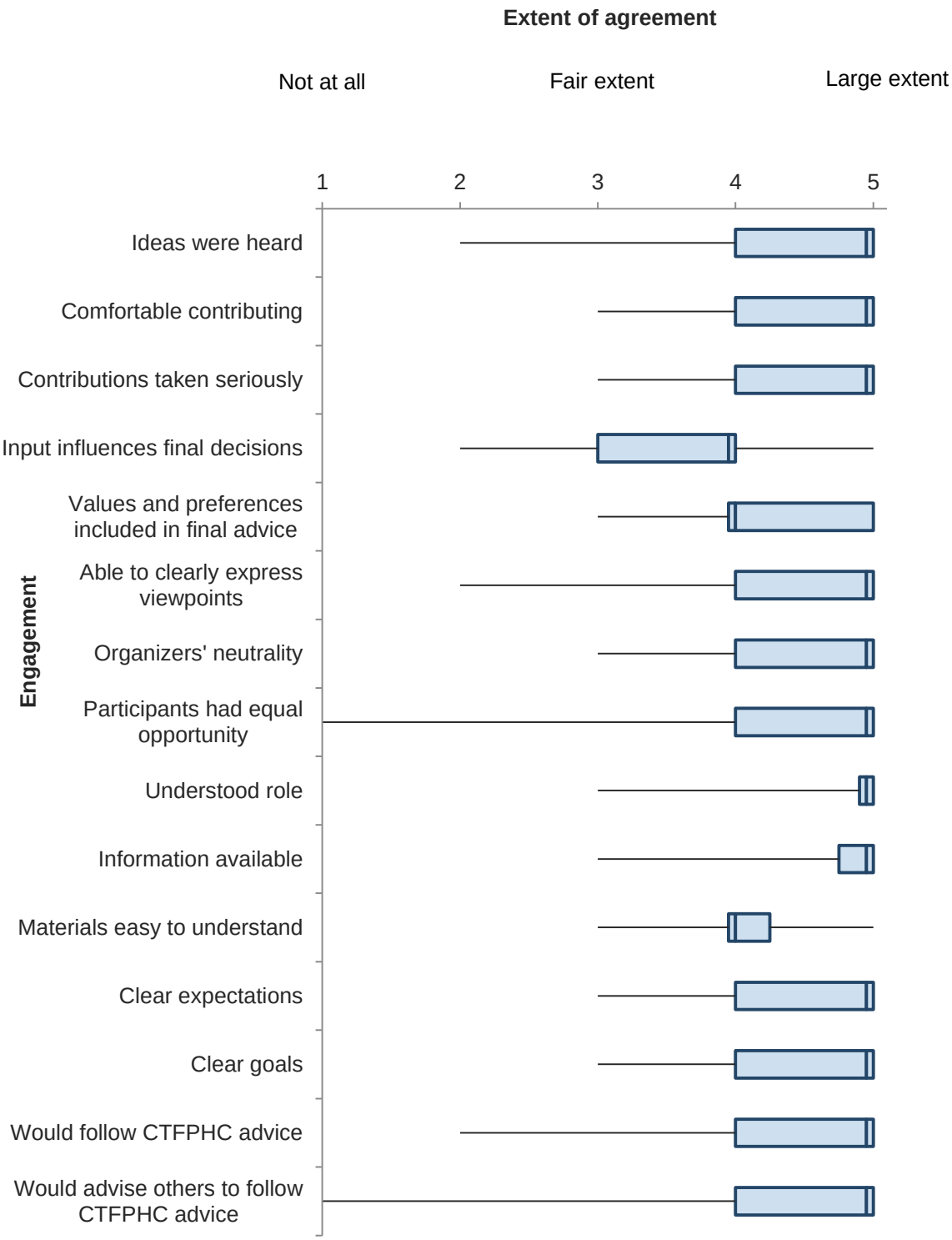


Table 8. Survey responses for participant engagement items (n = 20)

Question	Median	IQR*	Range
To what extent do you believe that your ideas were heard during the engagement process?	5	4-5	2-5
To what extent did you feel comfortable contributing your ideas to the engagement process?	5	4-5	3-5
Did organizers take your contributions to the engagement process seriously?	5	4-5	3-5
To what extent do you believe that your input will influence final decisions that underlie the engagement process?	4	3-4	2-5
To what extent do you believe that your values and preferences will be included in the final health advice from this process?	4	4-5	3-5
To what extent were you able to clearly express your viewpoints?	5	4-5	2-5
How neutral in their opinions (regarding topics) were organizers during the engagement process?	5	4-5	3-5
Did all participants have equal opportunity to participate in discussions?	5	4-5	1-5
How clearly did you understand your role in the process?	5	5	3-5
To what extent was information made available to you either prior or during the engagement process so as to participate knowledgeably in the process?	5	4.75-5	3-5
To what extent were the ideas contained in the information material easy to understand?	4	4-4.25	3-5
How clearly did you understand what was expected of you during the engagement process?	5	4-5	3-5
How clearly did you understand what the goals of the engagement process were?	5	4-5	3-5
To what extent would you follow health advice from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?	5	4-5	2-5
To what extent would you advise others to follow health advice from the Canadian Task Force on Preventive Health Care (if it related to their health condition)?	5	4-5	1-5

**Note: IQR = interquartile range*

After participants responded to questions about their engagement, they responded to questions about the clarity and ease of the tasks that they were requested to complete. Again, participants were asked to rate questions using a 9-point scale: a score of 1 indicated “Not at all”; a score of 5 indicated “Neutral”; and a score of 9 indicated “Very much”. A summary of the responses is presented in Figure 4 and Table 9.

Overall, participants responded positively to all four questions, indicating clarity and ease of participating. The lowest rated question was “How easy was it to rate the harms and benefits using the 9-point scale?” This overall rating supports the patient engagement results presented Figure 3 and Table 8, indicating that some people found the survey questions difficult to answer. Participants were also asked to summarize what they had been asked to do in the survey. Participants accurately described the survey tasks they completed. Thus, there is converging evidence that participants understood the survey tasks.

Figure 4. Survey responses for experience items (n = 20)

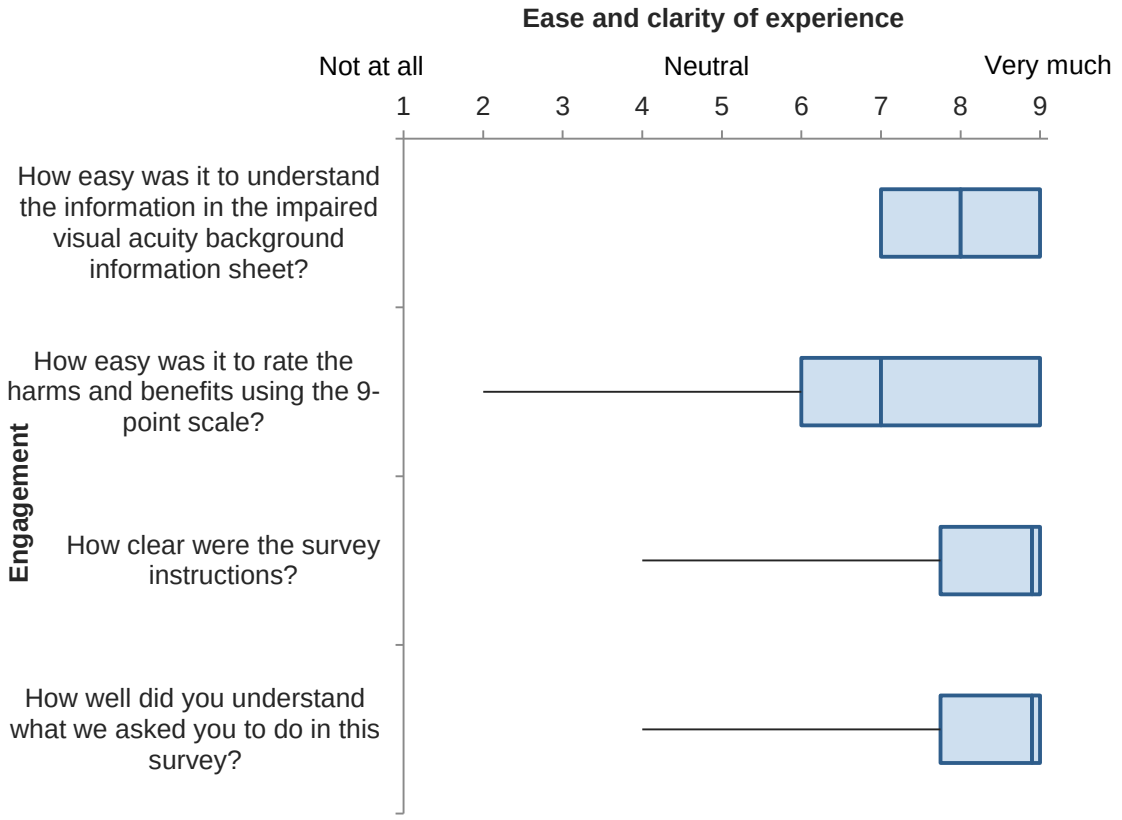


Table 9. Survey responses for experience items (n = 20)

Question	Median	IQR*	Range
How easy was it to understand the information in the visual acuity background information sheet?	8	7-9	7-9
How easy was it to rate the harms and benefits using the 9-point scale?	7	6-9	2-9
How clear were the survey instructions?	9	7.75-9	4-9
How well did you understand what we asked you to do in this survey?	9	7.75-9	4-9

**Note: IQR = interquartile range*

Participants' overall experience

Three focus groups (*n* = 19), one interview (*n* = 1), and 18 open-ended survey questions (*n* =20) were conducted to gather qualitative data from participants about their experience in the project. Table 10 below summarizes participants' main impressions of the background information sheet, focus group, and survey.

Table 10. Qualitative data for project experience (n = 20)

Project component	Participants' impressions	Illustrative quotes
Background information sheet	**Positive feedback** Most participants found the background information sheet to be straightforward, clear, and concise.	*"I found it helpful that when you made a statement you gave examples afterward to clarify and expand". – VA008* *"Very easy to read. It's important to read it. I found it very informative actually." –VA004*
	Suggestions for improvement Some participants stated that they would find it helpful if additional information were included in the background information sheet (e.g., type of research studies, vision coverage). For more details see the Factors that influence outcome ratings section above.	*"I feel the true extent of previous studies (and their narrow parameters) should have been disclosed initially. That lack of disclosure influenced my initial responses." – VA001*
Pre- and post-focus group surveys	**Positive feedback** Few participants commented on the surveys, but a couple people stated that they found the surveys easy to complete and effective. Participants also noted that they enjoyed the subject matter.	*"I liked the subject of the survey as it shows the importance of being tested for visual acuity." – VA016* *"I did a lot of surveys and this one was fairly easy to do. There wasn't a lot of ambiguity to it." – VA002*
	Suggestions for improvement Suggestions for improvement included increasing the clarity of question wording and more explicitly stating the intent of survey questions.	*"I had trouble with the survey questions as I was not sure if I comprehended the intent of the question. Maybe next time I will call someone before I submit my answers." – VA012* *"Found some of the questions with double negatives a little difficult to comprehend." – VA019*

Focus groups and interviews	**Positive feedback** Some participants stated that the focus group was their favourite part of the project. They described how the discussion was well-organized, easy to understand, interesting, and helped clarify questions from the survey. Participants appreciated that everyone had an equal opportunity to discuss their viewpoints during the focus groups. Participants stated that the content expert did a good job of answering questions and providing project context.	*"I found the process very easy and the moderators were very fair and allowed everyone a chance to speak. It also has given me more insight into my own health and what I should be looking for." – VA018* *"The doctor on the call was very willing to explain, what she felt were the shortcomings of the research to date unlike one of the other conference calls I participated in where the doctor wasn't willing to listen to suggestions for improvements in the wording and delivery of the topic from participants." – VA009* *"The exact meaning of the written questions was a bit difficult to understand clearly. I felt that the conference discussion was excellent with great participation and with your staff's responses to the participants' many questions and comments." – VA005*
	Suggestions for improvement Suggestions for improvement included improving sound quality, limiting feedback on the teleconference line, and increasing time allotted for discussion.	*"Tech problems for phone seminar." – VA003* *"More time devoted during the discussion portion would have helped… as we were rich on ideas and poor for time." – VA018*
Overall project experience	**Positive feedback** Many participants found the guideline topic interesting and were glad to have the opportunity to learn more about visual acuity. Participants enjoyed having the opportunity for their opinions to be heard and to contribute to the Canadian health care system. Participants also shared that they found the process for participation to be well-organized and accommodating.	*"It is always good to know what is proposed to improve the health and well-being of Canadians and to feel a part of the process". – VA014* *"I like participating in the discussion and hearing viewpoints of other seniors." – VA020* *"Being involved with others and experts to improve health care in Ontario and ultimately Canada." – VA019*
	Suggestions for improvement The main areas for improvement is to clarify the language and ideas presented to participants. This area of concern aligns to issues discussed in the Factors that influence outcome ratings regarding how the risks were undefined. This is discussed further in the Limitations section below.	*"Some of the information provided was quite vague, for example, the lack of research in this area. It was difficult to give a true opinion when there was very little to base it on." – VA015*

Limitations

In addition to the limitations of the methods discussed in the Patient Engagement Protocol, there were additional limitations specific to this project. The lack of data regarding the likelihood of outcomes affected the way that participants interpreted the possible outcomes of screening. As described in the Factors that influence outcome ratings section above, some participants' interpretations of the lack of data influenced how they rated outcomes overall (e.g., all unknown outcomes were rated as neutral importance), while others' interpretations influenced how they understood outcomes (e.g., all unknown outcomes were rated based on perceived correlation between screening test and outcome). Some participants emphasized the "lack of evidence" component of the question and others emphasized the outcome component of the question when selecting their rating. Further, during the focus groups, participants discussed their own experiences of visual acuity. For instance, participants discussed their need for regular eye care because of previous experience with cataracts (i.e., cataracts that have been surgically corrected) or prescription changes. In the future, we recommend being more specific and exhaustive with criteria and conditions in the screening process. These limitations should be considered for future patient engagement projects, especially when working with a lack of high quality research evidence.

Suggestions for applying findings

Below are our suggestions for applying the findings from this project to the CTFPHC's visual acuity screening guideline:

1. **Provide resources to support a discussion of patients' preferences and shared decision making.** Because the CTFPHC develops evidence-based guidelines, the CTFPHC may not always be able to produce guideline recommendations that are consistent with all patients' preferences. In this case, the CTFPHC may consider developing and disseminating resources that encourage a discussion about patients' preferences and to support shared decision-making between clinicians and patients. Specifically, the CTFPHC may produce KT tools that assist clinicians in discussing screening in the context of a patient's preferences. In addition, the CTFPHC may develop KT tools for patients that explain the balance between the harms and benefits of the screening intervention.

2. **Develop KT tools that address information needs of participants.** Participants had questions about how the screening might affect individuals as well as how it might impact the health care system and the population of Canadians over 65 years of age. Participants requested additional information about the invasiveness of screening, the opportunity costs of screening, how general access to primary care physicians would affect the efficacy of this screening, the expertise of primary care physicians in screening for visual acuity, and costs related to treatment for visual acuity. Thus, the guideline and

KT tools should integrate relevant information to help patients make an informed choice about screening for visual acuity.

3. **Consider how a lack of evidence for outcomes will affect future patient preferences projects.** Providing participants with more information on how to interpret the lack of evidence may help participants understand the purpose of participating in this project. Providing context on why information is not available will also assist participants when rating the outcomes and can provide the CTFPHC with more meaningful quantitative data.

Conclusion

Through this project we explored visual acuity screening preferences for a sample of the screening population to whom the guideline will be relevant. Participants were mostly in favour of being screened for visual acuity. However, some participants expressed concerns about the availability of screening at a population level. Participants expressed worries that a country-wide screening program might waste health care resources. Participants also indicated concerns about limited time for additional screening tests to be completed during primary care physician appointments, especially if they already access regular vision care from a vision care specialist. Many participants enjoyed the opportunity to participate and found the project interesting. However, several participants stated that the lack of evidence for outcomes made some of the survey questions challenging to answer. These findings should be integrated into the visual acuity screening guideline and KT tools, as well as into future CTFPHC patient preferences projects.

References

1. Fitch K, Bernstein SJ, Aguilar AD, Burnand, B, LaCalle JR, et al. The RAND/UCLA Appropriateness Method user's manual. RAND. 2001.
2. Moore, A. Development and Preliminary Evaluation of a Patient and Public Engagement Evaluation Tool. Prepared for the Canadian Task Force for Preventive Health Care, Knowledge Translation Working Group, 2016.

Appendix A: Screening questionnaire

Are you a practicing health care professional?

- ❍ Yes
- ❍ No

How old are you?

- ❍ Less than 65 years of age
- ❍ 65-70 years of age
- ❍ 70-75 years of age
- ❍ 75-80 years of age
- ❍ 80-85 years of age
- ❍ More than 85 years of age

Do you currently wear glasses or contact lenses?

- ❍ Yes
- ❍ No

Have you been diagnosed with any severe visual impairments (i.e. low vision, legal blindness, blindness)?

- ❍ Yes
- ❍ No

Does your doctor have any concerns related to your visual acuity (clarity of vision)?

- ❍ Yes
- ❍ No

Do you have any concerns related to your visual acuity (clarity of vision)?

- ❍ Yes
- ❍ No

Do you have any conflict of interest related to visual acuity? Examples include but are not limited to the following: being a member of an organization related to visual acuity; owning a company that provides products or services related to visual acuity; owning shares in a company that provides products or services related to visual acuity; and conducting research on visual acuity.

- ❍ Yes (please describe) _____
- ❍ No

How did you hear about this opportunity?

- ❍ Charity Village
- ❍ Craiglist
- ❍ Kijiji
- ❍ Lung Cancer Canada
- ❍ The Society of Obstetricians and Gynaecologists of Canada (SOGC)
- ❍ Locanto
- ❍ Other, please specify... _____

What is your gender?

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

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
- ❍ Some collegeCollege 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?

- ❍ Yes
- ❍ No

Please indicate which of the following chronic health conditions you are living with:

- ❑ Diabetes
- ❑ Asthma
- ❑ Heart disease
- ❑ Arthritis
- ❑ Other _____

Appendix B: Background sheet

What is impaired visual acuity?
When somebody has impaired vision it often means that their ***visual acuity*** is reduced, meaning that they have vision problems and may not be able to see very well or that things look blurry. Impaired visual acuity can make it difficult to do things like reading or watching television, and it can lead to a loss of independence if someone can't see well enough to get around.

Who is at risk for impaired visual acuity?
All older adults will experience changes to their visual acuity because of natural aging processes. Impaired visual acuity is most common in adults over 65 years of age. People who smoke, consume excessive alcohol, spent many hours under the sun during their life, or have diabetes, are more likely to develop impaired visual acuity due to age-related deterioration of the macula (the small central area of the retina), cataracts, or diabetic retinopathy (the most common cause of vision loss among diabetics caused by changes to the blood vessels in the retina).

How can impaired visual acuity affect people?
Changes in visual acuity or other visual function can be very gradual or quite sudden and may result in difficulty reading small print or seeing things at a distance; blurred, fuzzy or cloudy vision; reduced ability to see details or shapes; difficulty focusing or needing to blink frequently to focus; sensitivity to bright light or glare; difficulty seeing at night or in dim lighting; or frequent squinting, feelings of eyestrain, or 'tired' eyes.

If not corrected, impaired visual acuity can increase the risk of falling. Impaired visual acuity can also contribute to a loss of the ability to carry out tasks necessary to live independently in the community, such as driving, food preparation, and paying the bills. It can lead to less involvement in physical activity because of fear of falling and can lead to feelings of frustration, embarrassment, fear, or depressed mood.

What is screening?
Screening is the examination of a people who do not show symptoms for a condition or illness. Screening uses a specific tool to identify a condition or illness. Some examples of screening tools are urine testing, blood testing or ultrasound.

How might doctors or nurses screen for impaired visual acuity?
There are two main ways that a family doctor or other primary care provider could screen for impaired visual acuity. They might ask a patient questions, or have them fill out a questionnaire about whether they have any problems with their vision (visual acuity) or tasks related to vision such as reading the newspaper. They might also use an eye chart to test a patient's visual acuity.

If the vision screening test suggested a problem, the patient might be referred to an eye care specialist, such as an optometrist or ophthalmologist, for a full-eye examination. Decisions could then be made about treatment, such as new glasses or surgery for cataracts.

What are the possible benefits of screening for impaired visual acuity?
People who visit an optometrist regularly or who recognize for themselves that they have a vision problem – and act on it - will not benefit from screening. The people who might benefit most directly from screening would be older adults who don't have regular eye care (40% of

older adults), don't recognize they have a problem, or don't seek advice about their eyesight from their family physician. Screening this group could help find unrecognized or unreported problems and help further examination and care.

It is possible that screening could help some people get help to correct problems with vision by getting glasses or surgery or at least slowing the progression of vision loss. If visual acuity problems are treated, people could have a lower risk for falling, better day-to-day functioning and social interactions, and an improved quality of life.

What are the possible harms of screening for impaired visual acuity?
For some people who are not bothered or affected much by a little impaired visual acuity, or for whom some treatments such as new glasses may be too expensive, screening may not offer any benefit and may cause burden, such as time spent in appointments or financial cost.

Health care providers screen for visual acuity issues so they *can be treated*, but there are also possible harms from treatments. Some treatments may have side-effects that may limit the benefit of better vision. Some *possible harms* of treatment for vision problems might include:

- For laser surgery, a common approach to correcting refractive errors: over- or under-correction of sight, infection, swelling, bleeding, glare or halos around lights, or chronic dry eyes.
- For the treatments of the most common type of age-related macular degeneration: eye pain, swelling, blind spots, increased eye pressure, and (rarely) increase in the risk of stroke.
- For cataract surgery: infection, swelling, bleeding, double vision, and retinal detachment.

It is also possible that some people may receive an ineffective treatment, and some people may receive treatment for a condition that would never have caused them serious problems if left alone.

What does the research tell us?
We found 15 research studies that compared people who were screened for impaired visual acuity with those who were not screened. Referral for further testing and treatment was usually provided, if needed, to the people screened if they didn't already have a regular eye care provider. There was very little evidence on most of the outcomes that patients told us were important.

Benefits

We do not have enough evidence to know whether screening:
- *reduces loss of independence*
- *reduces the risk of falls, fractures, or death*
- *improves vision-related functioning or quality of life*

Screening *may possibly* improve some measures of visual acuity when tested using charts in a physician's office, but *probably does not* improve vision problems as reported by patients.

Harms

We do not have enough evidence to know whether screening:

- *increases serious side- effects from treatment*
- *increases anxiety or stress from lack of access to treatment or having a diagnosis in the face of ineffective treatments (such as with one form of age-related macular degeneration or when other health conditions prevent safe treatment)*

Appendix C: Pre- and post-focus group survey

1. How important would this information be for you if you were making a decision on whether or not to be screened for impaired visual acuity? *Rate the importance from 1-9:1: This isn't important for my decision at all; 5: This is neither important nor not important for my decision; 9: This is very important for my decision.*

    - Screening may possibly improve some measures of visual acuity when tested using charts in a physician's office
    - Screening probably does not improve vision problems as reported by patients (for example, difficulties reading the newspaper or seeing in the dark)
    - We do not know if screening reduces loss of independence
    - We do not know if screening reduces the risk for falls, fractures, or death
    - We do not know if screening improves vision-related functioning or quality of life

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

3. How important would this information be for you if you were making a decision on whether or not to be screened for impaired visual acuity? *Rate the importance from 1-9:1: This isn't important for my decision at all; 5: This is neither important nor not important for my decision; 9: This is very important for my decision.*
    - We do not know if screening increases serious adverse effects from treatment (for example, infection, swelling, bleeding, double vision, eye-pain, etc.)
    - We do not know if screening increases anxiety or stress from lack of access to treatment or having a diagnosis in the face of ineffective treatments (for example, when other health conditions prevents safe treatment)

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

5. Considering that approximately 40% of older adults do not have regular eye care from an optometrist, how much would you want your family doctor to do a screening test for impaired visual acuity? *Rate "I would want to be screened for impaired visual acuity" from 1-9:1: Not at all; 5: Neutral; 9: Very much.*

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

7. Considering that some older adults don't recognize that they have vision problems, how much would you want to be screened for impaired visual acuity by your family doctor? *Rate "I would want to be screened for impaired visual acuity" from 1-9:1: Not at all; 5: Neutral; 9: Very much.*

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

9. Considering that some older adults don't seek advice about their eyesight from their family doctor, how much would you want to be screened for impaired visual acuity by your family doctor? *Rate "I would want to be screened for impaired visual acuity" from 1-9:1: Not at all; 5: Neutral; 9: Very much.*

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

11. Considering the potential harms and benefits of screening for impaired visual acuity for adults aged 65 years or older, how much would you want to be screened for impaired visual acuity by your family doctor? *Rate "I would want to be screened for impaired visual acuity" from 1-9:1: Not at all; 5: Neutral; 9: Very much.*

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

13. Considering that the risk of many of the harms and benefits of impaired visual acuity screening for adults aged 65 years or older are not well known, how much would you want to be screened for impaired visual acuity by your family doctor?

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

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

Appendix D: Sample personalized response sheet

Introduction

A total of 20 people from across Canada completed the CTFPHC Survey on Public Perceptions of Screening for Impaired Visual Acuity in Adults Aged 65 or Older. This sheet provides a summary of the survey responses.

For each survey question you answered, you will see a separate bar graph. We have shown your individual answer along with a summary of the answers from all of the participants. This way you can have a record of your responses and can also see what your peers answered for each question.

Harms and Benefits Scale Ratings

This section provides information about how to read the ratings that participants provided in the survey.

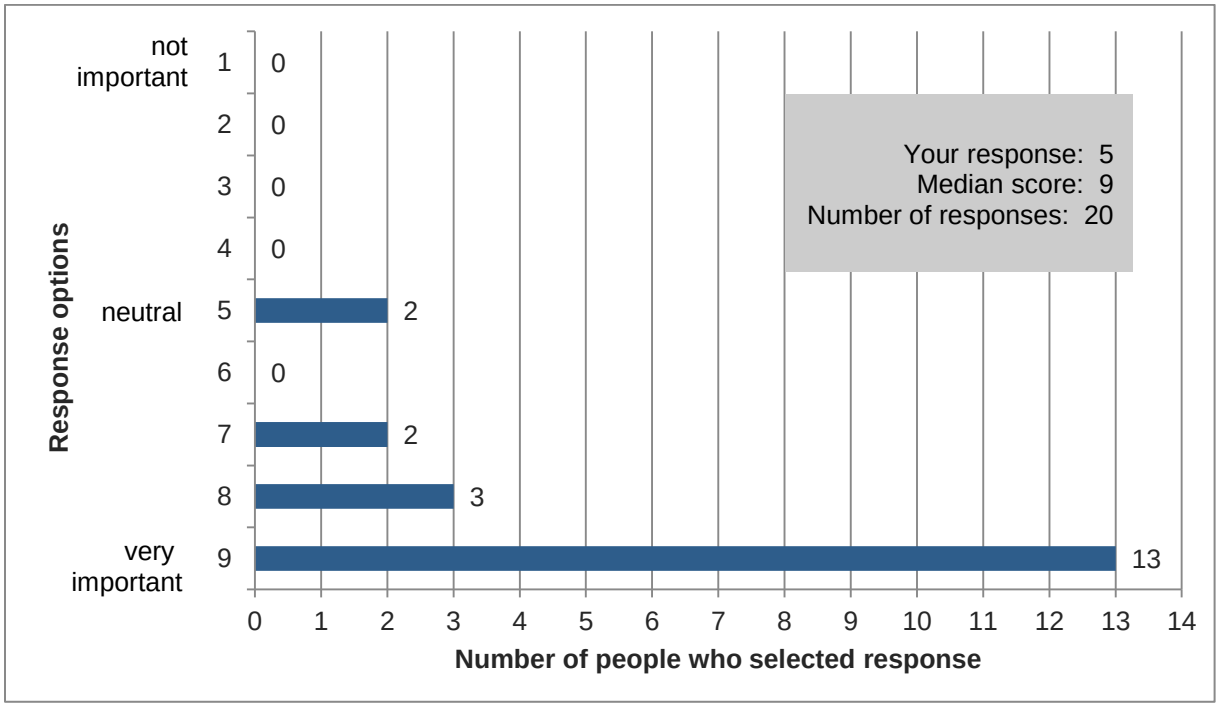
For each of these potential harms and benefits, also called an “outcome”, all participants were provided with information about the outcome and asked “How important would this information be for you if you were making a decision on whether or not to be screened for impaired visual acuity?”

Participants could rate the importance of the information from 1-9: 1 being “This isn’t important for my decision at all”; 5 being “This is neither important nor not important for my decision”; and 9 being “This is very important for my decision”.

Sample Harms and Benefits Scale Rating

Here is a sample of a graph and what the different parts mean:

Sample Survey Outcome X: Description of the potential harm or benefit



At the top of the graph you will see which potential harm or benefit this graph is about.

Along the *y*-axis of the graph (the vertical axis, running top to bottom), you will see all possible numbers on the rating scale that participants could use to rate the outcome.

Along the *x*-axis of the graph (the horizontal axis, running left to right), you will see numbers which show how many participants chose each number on the rating scale.

The box in the upper-right corner contains three pieces of information:

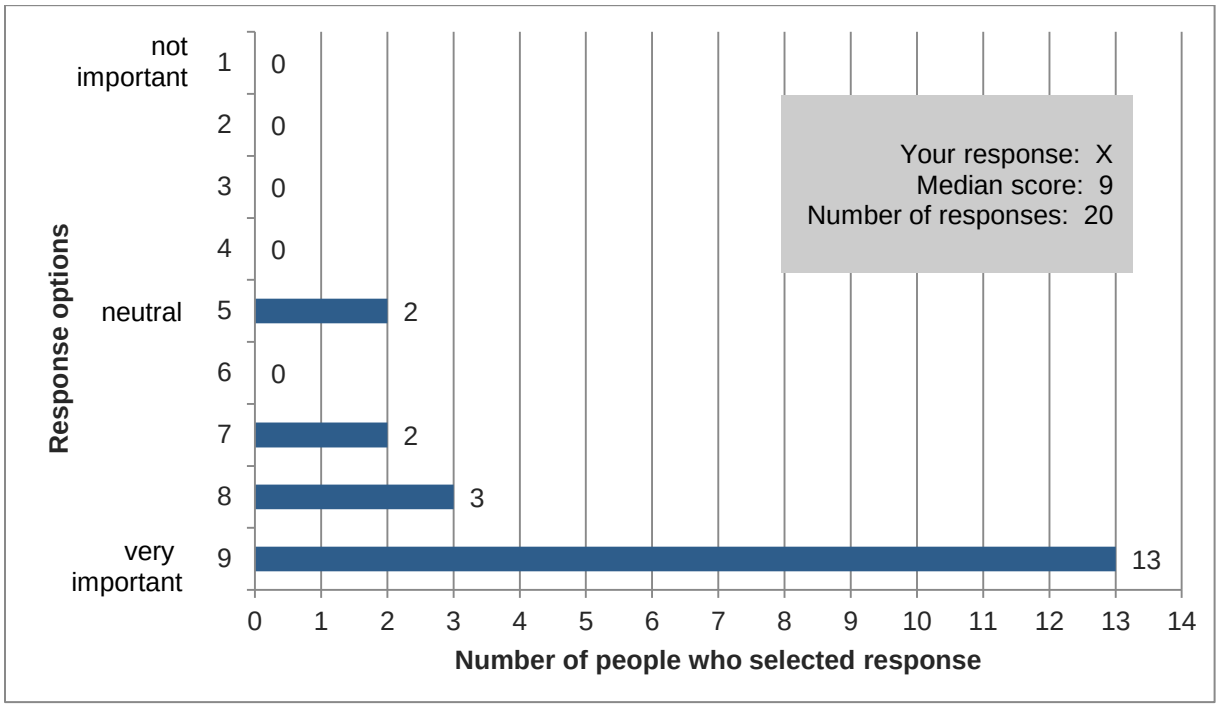
- The number on the rating scale that you selected for this outcome
- The median rating for this outcome across all participants (you can think of this like an "average" of the ratings selected by all participants)
- The total number of participants who rated this outcome

In this example, 13 participants rated the question with a "9", three participants rated it an "8", two participants rated it a "7", two participants rated it a "5", and no participants rated it a "6", "4", "3", "2", or "1". In this example, "you" rated the outcome as a "5". The median rating across all participants was "9", and there were 20 participants in total who rated this item.

These personalized answers are broken down by potential harms and benefits for visual acuity screening for adults aged 65 or older, below.

Summary of Outcomes for Adults Aged 65 or Older Scale Ratings

Survey Outcome 1: Screening may possibly improve some measures of visual acuity when tested using charts in a physician's office



Considerations for Screening Scale Ratings

This section provides information about how to read the ratings that participants provided in the survey.

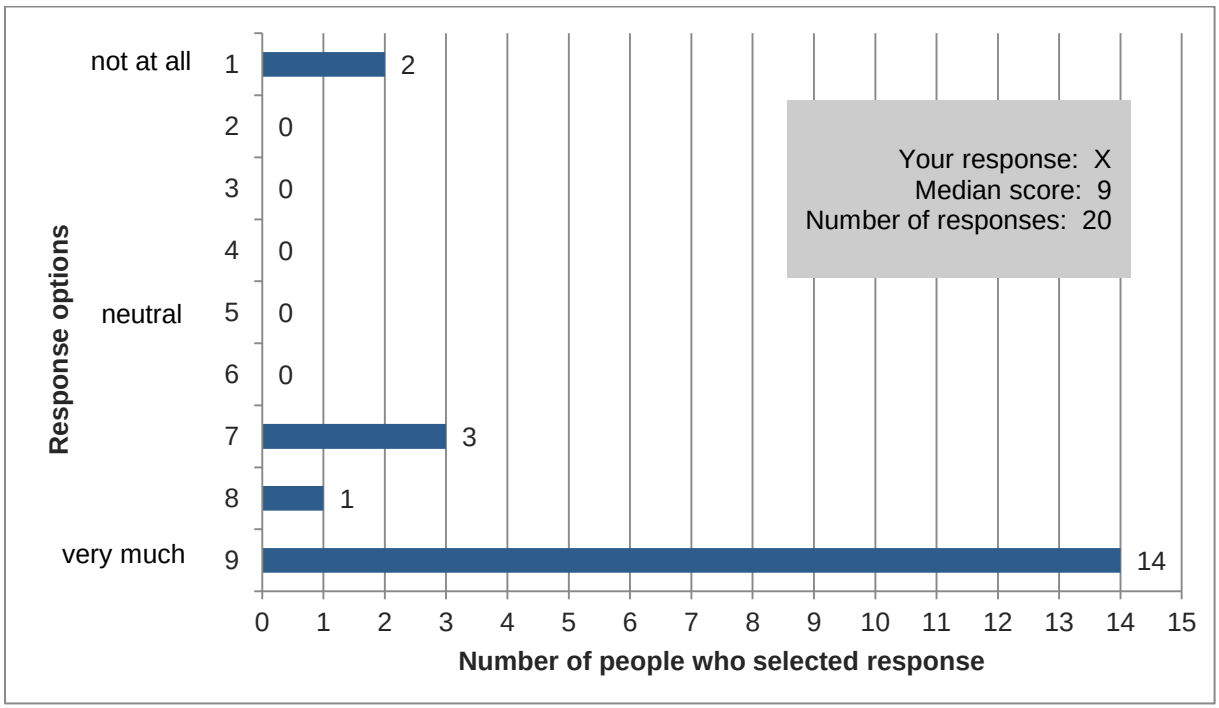
For each of these questions, participants were provided with information to consider and then asked to rate, considering this information, how much they would want their family doctor to do a screening test for impaired visual acuity.

Participants could rate the phrase “I would want to be screened for visual acuity” from 1-9: 1 being “Not at all”; 5 being “Neutral”; and 9 being “Very much”.

Your answers and the answers given by all participants are presented in the same graph format as the earlier questions.

Summary of Considerations for Screening and Treatment Scale Ratings

Survey Question 1: Considering that approximately 40% of older adults do not have regular eye care from an optometrist, how much would you want your family doctor to do a screening test for impaired visual acuity?



Appendix E: Focus group guide

1. Visual Acuity background sheet:

1) While reviewing this document, did you have any questions or general thoughts about the document?
2) How easy was the information to understand?
3) Primary care screening for visual acuity refers to the examination of individuals who do not show symptoms for impaired visual acuity. With this purpose in mind, do believe additional information should be included in this background information sheet?
4) When having a discussion with your family physician about impaired visual acuity what types of information would you like him/her to bring up?
    a. How much information do you feel you need before you can make a decision about impaired visual acuity screening?

2. Overall preference before discussion:

5) After reviewing the background document and completing the pre-focus group survey, what is your overall preference for visual acuity screening? That is, if given the opportunity, would you choose to be screened or not?
6) What impact did the lack of evidence for certain outcomes have on your overall screening preferences? For example, we do not know if screening reduces loss of independence or we do not know if screening reduces the risk for falls, fractures, or death.

3. Pre-focus group survey results – Visual Acuity screening harms and benefits:

Note: facilitator will discreetly call upon participants who responded differently from the group (outliers) and probe why.

7) Please turn to [*insert page #*] and refer to *[insert question #]* located at *[insert top or bottom]* of the page. The outcome reads '*insert outcome*'. Responses ranged from *[insert range]* with a median of [*insert median*].
    a. Are there any questions about this *[insert harm or benefit*] for our content expert?
    b. Take a look at how you rated this question. What was your rationale for rating the question the way you did?
        i. Did anyone rate differently than group?

Note: this question will be repeated for questions that were rated differently across the group [i.e., questions that were outliers].

8) What outcome is the most important to you when considering whether or not you would likely decide to be screened for visual acuity?
9) What outcome is the least important to you when considering whether or not you would likely decide to be screened for visual acuity?

4. Overall preference after discussion:

10) Reflecting on today's discussion, what is your overall preference for visual acuity screening. That is, if given the opportunity, would you choose to be screened or not?
11) Reflecting on today's discussion, what impact did the lack of evidence for certain outcomes have on your overall screening preferences? For example, we do not know if screening reduces loss of independence or we do not know if screening reduces the risk for falls, fractures, or death.
12) Have your preferences changed from those you expressed in the first survey and earlier in today's discussion?
13) [Optional if time permits] Reflecting on today's discussion is there any other information you would like to know that would help you to make a decision if you had the opportunity to decide to be screened or not for visual acuity?

5. Potential barriers or facilitators to screening:

14) VA screening is included in some provincial health plans, but not all.
Note: *Not all provinces provide eye exams for seniors over 65 as part of the health coverage. It would seem that Saskatchewan, Newfoundland and New Brunswick, Northwest Territories and Nunavut do not. There are gaps in coverage for routine eye care preventive screenings."*
    a. If you choose to get screened, what are potential barriers to accessing the screening test, if any?
        i. Probe: out-of-pocket expenses (e.g., transportation or taking time off)
        ii. Probe: lack of time (e.g., come in for a visit for another reason like an annual check-up etc.)
        iii. Probe: do you typically go to primary care for vision care or an optometrist/ does your primary care physician ask about eye care
    b. If you choose to get screened, what are potential facilitators to accessing the screening test, if any?
    c. What are potential barriers to accessing vision care in general for you, if any?
    d. What are potential facilitators to accessing vision care in general for you, if any?

15) If you were to be screened and receive a positive screen for impaired visual acuity at your doctor's office and be referred to an eye-care specialist for further diagnostic testing, there could be out-of-pocket costs (e.g., new glasses, medications, and/or eye surgery). If you were to choose to be screened, do you believe that these costs related to receiving specialist care would be a barrier?

    a. For those who would choose not to be screened, do these potential costs factors into your decision?

16) If you were to wish to get screened, do you foresee any other barriers to accessing or receiving a vision screening test?

17) For those who would choose not to get screened, would any other barriers to accessing or receiving a vision screening test factor into this decision?

6. Closing remarks:

18) Does anyone have any final comments or questions before we end today's discussion?

Appendix F: Patient engagement survey

1. Please respond to each of the following statements using the scales provided. Respond to each question 1-5: 1: Not at all, 2: Small extent, 3: Fair extent, 4: Moderate extent, 5: Large extent. If you select 1-3 for any question, please explain your rating in the space below the question.
    - To what extent do you believe that your ideas were heard during the engagement process?
    - To what extent did you feel comfortable contributing your ideas to the engagement process?
    - Did organizers take your contributions to the engagement process seriously?
    - To what extent do you believe that your input will influence final decisions that underlie the engagement process?
    - To what extent do you believe that your values and preferences will be included in the final health advice from this process?
    - To what extent were you able to clearly express your viewpoints?
    - How neutral in their opinions (regarding topics) were organizers during the engagement process?
    - Did all participants have equal opportunity to participate in discussions?
    - How clearly did you understand your role in the process?
    - To what extent was information made available to you either prior or during the engagement process so as to participate knowledgeably in the process?
    - To what extent were the ideas contained in the information material easy to understand?
    - How clearly did you understand what was expected of you during the engagement process?
    - How clearly did you understand what the goals of the engagement process were?
    - To what extent would you follow health advice from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?
    - To what extent would you advise others to follow health advice from the Canadian Task Force on Preventive Health Care (if it related to their health condition)?
2. Please respond to each of the following statements using the scale provided. Respond to each question from 1-9:1: Not at all; 5: Neutral; 9: Very much.
    - How easy was it to understand the information in the asymptomatic bacteriuria background information sheet?
    - How easy was it to rate the harms and benefits using the 9-point scale?
    - How clear were the survey instructions?
    - How well did you understand what we asked you to do in this survey?
3. In the space provided, please describe anything we could do to make the survey tasks easier to complete.