Canadian Task Force on Preventive Health Care

Patient preferences for depression screening among adults: Phase 2 data summary

Prepared for the Canadian Task Force on Preventive Health Care

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Executive Summary

Incorporating patient priorities and perspectives into clinical practice guideline (CPG) development is an important part of patient-centered care. The Canadian Task Force on Preventive Health Care (Task Force) 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 recommendation statements are developed, and (3) when knowledge translation (KT) tools are developed. In this project, we identified the outcomes that members of the screening for depression populations believe are important to consider when making screening decisions related to depression, as well as their overall preferences for screening given the risks of potential harms and benefits. We also examined participants' perceptions of their experience with the project using an engagement evaluation tool.

A total of 18 Canadians participated in the project; 13 were members of the depression screening population, and 5 had already been diagnosed with or were receiving treatment for depression. After receiving a background information sheet on depression, including the results from the systematic review, participants completed a survey to assess how important various outcomes would be to consider when making decisions about depression screening. Next, they took part in a focus group where they discussed the importance of considering the outcomes during decision making. Participants then completed a second survey that repeated the same questions as the first survey. They also answered questions about their experience with the engagement process.

Summary of Findings and Discussion

In the final survey, participants rated all screening benefits as *critical* to consider during decision making, whereas they rated all screening harms slightly lower, but still i*mportant* or *critical.* Participants typically selected screening benefits more frequently than harms when asked to prioritize outcomes. Reasons participants viewed screening as beneficial included beliefs that a) widespread and regular screening could potentially reduce the stigma surrounding mental health, b) their lived experience related to depression influenced their preferences, c) screening is important for early diagnosis, and diagnosis is the first step towards treatment and improved outcomes, and d) screening initiated by a primary care provider could reduce the barrier of fear or stigma surrounding discussion of mental health concerns with a doctor.

Participants generally believed that the benefits of screening outweighed the harms, and had a strong preference to be screened if given the opportunity. There were mixed opinions about the impact that the level of evidence for the harms and benefits had on their screening preference. Some felt the lack of evidence was concerning, while others felt that they still would prefer to be screened so they could feel informed and be proactive to diagnose depression early.

Participants felt a discussion about depression with a primary health care provider was critical, and identified types of information that would be helpful as part of a screening discussion, including: confidentiality of depression screening tests and results, framing screening as part of a normal healthcare routine, potential screening risks, including false positives, as well as treatment options and supports available. They may perceive a guideline to be more socially acceptable if it either recommends screening or encourages clinicians to make screening decisions that are consistent with patients' preferences.

Participants indicated that they had a positive experience in the project and appreciated the opportunity to provide input on what they perceived to be a very important topic. Some participants provided suggestions for improving the surveys and the focus group, such as addressing background noise from on participant's lines, having smaller number of people on focus groups to allow for more robust discussions, and moderating discussions more effectively so that one participant does not dominate the call.

Limitations

Limitations of this project include: (a) the sample was relatively small and may not be representative of the Canadian screening and treatment populations (the majority of participants had a college diploma, bachelor's, graduate, or professional degree, all participants lived in urban or suburban areas, and none of the participants identified as Indigenous);
(b) the background information that participants received may have made them more knowledgeable than most patients about screening and treatment outcomes; and (c) participants received information about screening for depression from the 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 Task Force's screening for depression guideline:

1. ***Provide resources to support a discussion of patients' preferences and shared decision making (particularly when recommendations are inconsistent with patients' preferences).*** If the Task Force recommendations differ from the patients' preferences identified in this project, the Task Force may consider developing and disseminating resources that help clinicians and patients address inconsistencies between patient preferences and guideline recommendations.

2. ***Develop KT tools that address information needs of patient participants*****.** For example, the tools could clearly describe harms and benefits of screening and the evidence (or lack of evidence) for potential outcomes, screening timeframes and process, and treatment options, risks, and availability following a diagnosis of depression.

3. ***Send participants a summary of how their feedback in the final guideline and KT tools was used.*** Participants were fairly to moderately convinced that their input would influence final decisions by the Task Force or that their values and preferences would be included in the final advice.

4. ***Emphasize the difference between 'usual care' and screening in shared decision making tools****.* Participants emphasized the importance of a discussion with their primary care provider about depression, especially considering that many participants felt they would not know what symptoms to look for, or would not feel comfortable initiating discussion on symptoms or concerns around mental health with their doctor. However, participants mentioned that it would be important to emphasize the distinction between informal discussions or 'usual care', and a formalized screening program.

Introduction

The Canadian Task Force on Preventive Health Care (Task Force) recruits members of the public to provide input during the guideline development and knowledge translation (KT) tool development process at up to three critical phases. This document presents summary data from Phase 2 of the Task Force patient preferences assessment about screening for depression among adults. We collected Phase 2 data through focus groups and surveys. We examined patients' perceptions of the harms and benefits of screening for depression among adults. Specifically, we asked how important patients believe it is for people to consider various harms and benefits, as well as the evidence for the harms and benefits, when making decisions about getting screened for depression. We also examined participants' experiences in the project. Data were collected between July 16th and August 30th, 2019.

Methods

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

Participants

Recruitment

We recruited English-speaking Canadians who would be members of the target population for depression screening in adults, as well as those who had already been diagnosed with or who were receiving treatment for, depression by posting recruitment advertisements on public advertisement websites (i.e., Craigslist and Kijiji).

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 18 years and older were eligible to take part in the project. Participants were not eligible for the project if they indicated that they were:

- less than 18 years of age;
- a health care practitioner;
- aware of any conflicts of interest relevant to the guideline topic (e.g., owning a company that provides products or services related to depression or mental health)

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 5 males and 13 females who were 22 to 56 years of age (mean age = 36 years, standard deviation = 9.94). Five participants had already been diagnosed with or were receiving treatment for depression. None of the participants self-identified as Indigenous. (i.e. First Nations, Métis, or Inuit). Participants were from Ontario (*n* = 9), British Columbia (*n* = 4), Saskatchewan (*n* = 1), Alberta (*n* = 1), Manitoba (*n* = 1), Quebec (*n* = 1), and

Prince Edward Island (*n* = 1). All participants lived in urban and suburban areas (*n* = 14; *n* = 4); no participants lived in rural areas. The majority of participants had a college diploma or bachelor's degree (*n* = 12) or a graduate or professional degree (*n* = 2); four participants had high school degrees (*n* = 4). Participants had household incomes of less than $25,000 (*n* = 4), $25,000 – $29,999 (*n* = 1) $30,000-$39,999 (*n* = 3), $40,000-$49,999 (*n* = 3), $60,000-$69,999 (*n* = 2), and $70,000-$99,999 (*n* = 5).

Outcome ratings

Below is a summary of participants' perceptions of the harms and benefits of screening for depression in adults. These data were collected using a modified RAND Appropriateness Method (RAM)[1] with surveys and focus groups. (See the Patient Engagement Protocol)

Outcome scale ratings

In the first part of the survey, participants rated the importance of potential outcomes of screening for depression in adults. All participants were provided with information on each of these potential outcomes, also referred to as harms and benefits, and were asked, "For each statement, please rate how much it would influence your decision on whether or not to be screened for depression".

Participants rated the importance of the information they were given about the outcome from 1-9, where scores indicated:

- 1-3 - not important for decision making
- 4-6 - important for decision making
- 7-9 - critical for decision making

Survey responses are summarized below, and presented in Figure 1 and Table 1. Figure 1 and the synopsis below are based on the post-focus group survey results, while Table 1 includes both pre-and post-focus group survey data for comparison purposes. Short descriptions of outcomes are used in both Figure 1 and Table 1. Full descriptions of the outcomes that participants were asked to rate are outlined in Appendix B.

Median post-survey outcome ratings for benefits ranged from 7 to 8. Median post-survey outcome ratings for harms ranged from 6 to 7. Between the pre and post surveys, median outcome ratings of benefits remained generally the same, while median outcome ratings increased slightly for several harms. The post-survey IQR of the benefit ratings indicated participants felt all benefits were *critical* for decision making, with the exception of missed work or school, which lies in the *important* to *critical* range. The post-survey IQR of the harm ratings were lower overall, ranging from *important* to *critical*. There was also generally a wider range of ratings for harms than for benefits, indicating participants had a slightly greater range of opinions on the importance of considering harms associated with screening compared with opinions on the importance of considering benefits.

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 within the box indicates the median. For instance, looking at "ectopic pregnancy" in the sample figure below, the range is 3-9, the IQR is 5-9, and the median is 7. All possible responses are whole numbers; therefore, the median will sometimes be the same value as the first or third quartile. Similarly, a quartile may be the same value as the corresponding whisker. In those cases, a line next to the quartile indicates the median or whisker is the same number

Sample

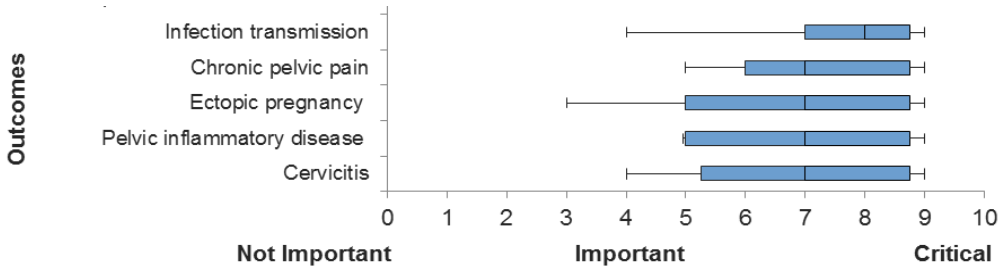

Figure 1: Post-survey outcomes scale ratings (n = 18)

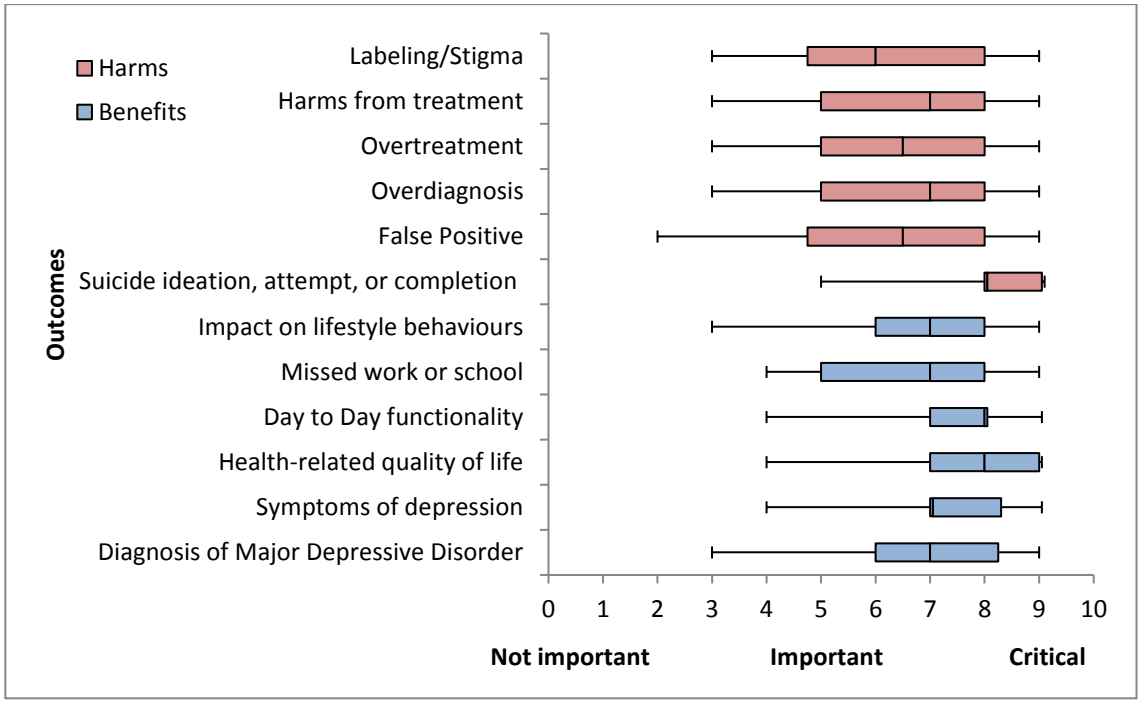

Table 1. Pre- and post-survey outcomes scale ratings (n = 18)

Outcome	Pre-survey (*n* = 22)			Post-survey (*n* = 18)		
	Median	IQR*	Range	Median	IQR	Range
Benefits						
Diagnosis of major depressive disorder	7	5-8	2-9	7	6-8.25	3-9
Symptoms of depression	7.5	6-9	3-9	7	7-8.25	4-9
Health-related quality of life	8	6-8.25	5-9	8	7-9	4-9
Day to day functionality	8	6.75-9	4-9	8	7-8	4-9
Missed work or school	6.5	5-8	4-9	7	5-8	4-9
Impact on lifestyle behaviors	7	6-8	5-9	7	6-8	3-9
Suicide ideation, attempt, or completion	8	6.75-9	4-9	8	8-9	5-9
Harms						
False positive	5	5-7.25	4-9	6.5	4.75-8	2-9
Overdiagnosis	6	4.5-7	2-9	7	5-8	3-9
Overtreatment	5.5	5-7	3-9	6.5	5-8	3-9
Harms from treatment	6.5	6-8	5-9	7	5-8	3-9
Labeling/Stigma	6	5-8	2-9	6	4.75-8	3-9

**Note: IQR = interquartile range.*

Overall preferences for screening

In the second part of the survey, participants rated their overall preference for screening. They were asked to rate the questions presented in Table 3 on a scale from 1-9 where 1 = “Not at all”; 5 = “Neutral”; and 9 =“Very much”.

There was a wide range of preferences for screening among participants. The median post-survey preference for screening considering the potential harms and benefits was 7.5, indicating that overall, most participants had a strong preference for screening. However, when considering the evidence, the median screening preference was slightly lower at 5.5, indicating participants were more neutral towards screening when considering that the risk of many of the harms and benefits of screening for depression are not well known. Table 3 presents the pre- and post-focus group survey data on overall preferences for screening.

Table 3. Pre- and post-survey overall screening preferences (n = 18)

Survey Question	Pre-survey (*n* = 22)			Post-survey (*n* = 18)		
	Median	IQR*	Range	Median	IQR	Range
Considering **the harms and benefits** of screening for depression, how much would you want to be screened?	7	5.75-9	2-9	7.5	5-9	1-9
Considering that the **risk of many of the harms and benefits** of screening for depression **are not well known**, how much would you want to be **screened**?	6	5.25-7.25	2-9	5.5	4-7.5	1-9

**Note: IQR = interquartile range.*

Participant perceptions of screening outcomes and overall screening preference

Four focus groups (*n* = 18) were used to gather qualitative data from participants about the perceived importance of the harms and benefits of screening and their overall preferences for screening for depression. Focus group recordings and notes were coded using a directed content analysis approach.[2]

Participants requested additional background information, and identified information and topics they considered important to discuss with their primary care providers in order to make an informed screening decision. They asked for more information on anxiety's role in depression, the timing and frequency of screening, and depression triggers. Participants stated that information about the confidentiality of depression screening tests and results, framing screening as part of a normal healthcare routine, and discussions around potential screening risks, including false positives, as well as treatment options and supports available, were important for primary care providers to cover in conversations with patients about screening.

Participants generally expressed an overall preference for screening, citing that the benefits of screening outweighed the harms. There were mixed opinions about the impact that the level of evidence for the harms and benefits has on their screening preference. Some felt the lack of evidence was concerning, while others felt that they still would prefer to be screened so they could feel informed and be proactive to diagnose depression early.

Tables 4, 5 and 6 present summaries of participants' screening discussion preferences, perceptions of screening outcomes, and overall values and preferences for screening respectively.

Table 4. Participants' screening discussion preferences (n = 18)

Information from family physician required to make informed screening decision	Illustrative quotes
i) depression triggers and symptoms, and the potential impact on daily life ii) information regarding possible risks *before* screening carried out iii) measures that would be taken to guard against a false positive iv) option of multiple screenings over a series of appointments v) being informed that screening is taking place (not done surreptitiously) vii discussion around confidentiality of screening results vii) framing screening as part of the normal healthcare process rather than individually targeted viii) preference for informational handout rather than screening ix) tailored questions to allow for individualized responses x) discussion regarding timelines, treatment options and supports available	*I would like the doctor to let you know that you can have these symptoms without them having a real effect on your life FG2* *I have been screened for depression several times and never been made aware that there were any risks to screening. FG1* *If you meet with a doctor one time, you might be feeling down but then another time you could be feeling better. Would the screening be over several visits or checking other symptoms? FG2* *It should be analogous to screening for high blood sugar, heart disease. FG4* *I agree that a thorough understanding of the side effects should be made clear at the time treatment is being discussed. I'm just not sure if it makes sense to me to have that conversation at the point of screening. If I'm being checked for blood pressure or heart disease, at that point they are not going into the details of the side effects of potential medications. FG4*

Table 5. Participant perceptions of potential screening outcomes (n = 18)

Outcomes	Summary	Illustrative quotes
Potential Benefit: Diagnosis of major depressive disorder	i) possible lifesaving outcome of diagnosis is a critical benefit ii) overall, potential benefits outweigh possible harms iii) possibility of a false positive should not be ignored iv) putting a name to symptoms is helpful	*I rated it critical because I probably wouldn't be alive if I hadn't been diagnosed and got treatment. FG1* *Even weighing all the pros and cons, even if I can get 1% better with my day to day routine and my life in general, that potential benefit will definitely over time outweigh the harms of screening. FG1*
Potential Benefit: Decreased missed work or school	i) considered important because of the financial and personal fulfillment consequences ii) concerns raised about the loss of work or school caused by treatment itself iii) outcomes that affect day-to-day life were considered important iv) decreased performance at work or school is as important as missing work or school v) quality time with family is also an important benefit vi) rated very important because missing work or school can lead to depression, setting up a cause and effect cycle of depression-absence-depression	*Quite important because of financial consequences of missing work which could further perpetuate certain feelings of depression. FG1* *Potentially if work is a source of satisfaction and fulfillment, reducing that would help with a sense of purpose and meaning. FG1* *Considering the prevalence of depression in the Canadian population, it could have incredible economic ramifications if we are able to sort that out before it causes people to miss work and school. FG2*
Potential Benefit: Improved Lifestyle Behaviors	i) considered of less importance than missing work or school ii) improvement in quality time with family and spouse may flow from this benefit	*It improved my ability to cope after treatment and access to supports, and things changed more quickly. FG3*

Potential Benefit: **Decreased Suicidality**	i) considered to be the most important benefit ii) the word 'suicide' elevates the entire topic of screening for depression into a critical need	*The fact that screening could lead to treatment that would prevent some suicides, that seems to have resonated with a lot of people and I think that's what ultimately this whole study is out to do, improve and possibly save lives. FG2*
Potential Harm: **False Positive**	i) more information regarding individual susceptibility to false positive diagnosis is needed ii) this raises the possibility of missing the genuine diagnosis of a physical disorder or, alternatively, ruling out depression iii) can result in a lack of trust in the healthcare system iv) concerns surrounding the implications of treating a false positive v) benefits outweigh the risks of not screening	*I have had what I would consider initially a false positive. I actually had an autoimmune disorder and depression was a symptom. Screening was critical in getting the larger illness diagnosed and treated. FG1* *There's major depressive disorder and then there's depression relating to people's circumstances. FG3* *I would rather it be something physical because with physical illness there are blood tests that prove you have it whereas with mental health it's very subjective. FG4*
Potential Harm: **Overdiagnosis**	i) overdiagnosis may mask a physical disorder or underlying condition that may not receive treatment ii) once a patient is labeled as having a history of mental illness, concern arises that healthcare professionals will automatically attribute subsequent symptoms to depression iii) overdiagnosis was considered more significant than a false positive iv) this harm detracts from those who genuinely suffer from depression v) overdiagnosis takes a functioning individual and labels them, with consequences	*It detracts from the genuinely depressed and makes it less significant for those with a valid diagnosis. FG4* *Ignorance is bliss. If someone is unaware of the problem, there is harm to making them aware and adding anxiety. FG3* *Thinking in terms of ADHD 10 to 20 years ago, I think that overdiagnosing actually makes it less significant for the people with a valid diagnosis. FG4* *You may have a label of mental illness and your other concerns may not carry the same weight as perhaps somebody who didn't have this diagnosis. FG4*
Potential Harm:	i) responses were similar to those of overdiagnosis	

Overtreatment	ii) possible harms outweigh the possible benefits	*If there's no reason to treat it, why send someone down that path and potentially cause more harm than good. FG3* *There's not that much to gain but there's a fair bit to lose. FG3*
<u>Potential Harm:</u> **Labelling/Stigma**	i) diagnosis impacts insurance eligibility ii) both internal and external stigma prevent screening iii) culture of birth country plays a role in the degree of stigma and acts as a deterrent to screening iv) communication and education are needed to offset this possible harm v) stigma arises from healthcare providers as well as the public vi) public awareness is improving, which helps decrease this harm vii) labelling is actually helpful if the diagnosis leads to treatment	*I think anxiety and stigma is a huge factor in why people don't get treatment or why people don't get diagnosed. In my experience, outside of external stigma, my internal stigma is probably the worst, and this has probably held me back. FG1* *I grew up in India and there, mental health conditions have a huge stigma relative to what Canadian society has. FG1* *For someone who is racialized, throwing an additional stigma onto them as having a psychiatric illness or being medicated can have consequences for them. FG2*

Table 6: Participant's values and preferences for screening (n = 18)

Summary: Participants' preference for screening	Illustrative quotes
In general, participants expressed a preference for screening and did not feel the group's discussion impacted their decision. <u>Reasons for choosing to be screened:</u> i) widespread screening helps improve health professionals' attitudes toward mental health ii) screening offers the opportunity to overcome hesitation about personally raising the subject iii) screening is the first step toward accessing treatment iv) lived experience influences the decision to be screened v) witnessing the experiences of others who suffer from depression encourages screening <u>Reservations regarding screening:</u> i) concern regarding risks ii) preference for screening to be optional rather than mandatory iii) would opt for screening only if there was an indication for it (e.g. family history, symptoms)	*I would hope that my doctor continues screening, even if it's a casual conversation as opposed to actual screening because I don't want to lose that time with my family again. FG1* *I have been thinking about going for screening. Now I'm not sure I want to get screened because I might get a false positive. FG1* *I have lived with undiagnosed depression for some time and now that I have been treated, I've seen both sides of it and couldn't imagine my life without having treatment. FG1* *Are we using resources appropriately if we are just blanket screening everybody unless there's kind of a reason or a suspicion? FG3* *I heard some interesting counterpoints in this discussion but it's not enough to change my opinion. FG2*
Summary: Impact of level of evidence on participants' screening preference	**Illustrative quotes**
Mixed responses as to whether level of evidence would affect the decision to screen, with individual responses skewed toward a negative impact: <u>No impact:</u>	*Knowing the risks might have discouraged me [from previous screening]. Where I'm at now, having help and getting okay with things, I would be okay with being screened without that evidence. I don't need it now.*

i) benefit of diagnosis outweighs risks ii) experiential component considered more important than statistics iii) a family history of depression would outweigh the gaps in knowledge in a decision to screen <u>Negative impact:</u> i) more information needed due to the possibility of a false positive or overtreatment ii) specific statistics and examples are needed iii) lack of concrete evidence alone is a deterrent iv) implications of a diagnosis with such vague evidence raises concern	*FG1* *Even knowing the risks, I think screening for depression is the prudent step to take. FG1* *I do think the lack of evidence does influence me. I haven't been screened yet and I'm on the cusp and debating whether I should go for it. FG1* *If you are diagnosed, you risk all these other things. It's almost better not to get a formal diagnosis. FG2* *I have a bit of suspicion regarding the screening because I feel like what are the motivations there? Because if it's tied to the pharmaceutical industrial complex, then it's pointless. FG2*

Factors influencing access to screening

Focus group (*n* = 18*)* responses revealed several barriers and facilitators to accessing and completing screening for depression. Factors identified included type and strength of relationship with PCPs (e.g. could potentially be uncomfortable bringing up or discussing sensitive topics with a walk-in clinic clinician), treatment concerns (e.g. cost and fear of potential treatment side effects), and knowledge gaps (e.g. lack of understanding of depression symptoms or what to look for). Some participants noted that including depression screening consistently as part of a regular health check-up could also help de-stigmatize mental health issues. Table 7 provides a summary of barriers and facilitators identified.

Table 7. Factors that influence participants' access to screening (n = 18)

Potential Barriers to Screening	Illustrative quotes
i) time commitment, duration and cost of treatment would be possible deterrents ii) privacy and confidentiality concerns iii) test reliability – false positive/negative results iv) concern regarding treatment side effects v) lack of rural access to mental healthcare vi) lack of a long-term relationship with family doctor (use of walk-in clinics) vii) risk of false positive impacting insurance eligibility viii) exercise prescribed as treatment is not plausible, leaving medication as the only option ix) negative influence of friends' attitudes and media portrayal of those suffering from mental health issues x) societal consequences of being diagnosed and treated xi) age gap between care providers and millennials, resulting in an uncomfortable relationship xii) personal lack of understanding of the ways in which depression manifests and attributing symptoms such as fatigue to alternative underlying causes	*If somebody is falsely identified as having depression, what is the outcome? How is it documented for insurance companies? My insurance company excluded mental health issues. FG1* *When I think about depression, my mind just jumps to treatment and side effects. FG2* *I have heard really horrible stuff about the medication. FG2* *There was a New York Times article not too long ago about people having trouble weaning off medication. FG2* *It's hard for someone diagnosed with depression to do a lot of exercise. Sometimes just getting out of bed is a major, major challenge. FG2* *Having the courage to have that conversation because it's so hard to say to someone, 'I am living with this, can you help me?' FG1*

Potential Facilitators to Screening	Illustrative quotes
i) doctor-initiated conversation about screening and depression ii) knowledge that your doctor is open to the concept of screening iii) information regarding supports available iv) ability to use an iPad or other electronic device to report symptoms v) understanding the meaning of screening, usual care, diagnosis and treatment vi) anonymous community to share information with vii) depression screening carried out in the same manner as is done for physical health, applied to all patients, which would help de-stigmatize mental health issues	*If my physician told me that we can start with changes and talking through things and not getting the drugs right from the get-go. F1* *I was lucky to have a doctor that was comfortable talking about mental health issues and life issues and she made sure I knew about some of the support she could provide. FG1* *Using an iPad to report symptoms could lead to a more passive opportunity to discuss symptoms with the doctor. FG2* *Anyone who takes the screening should know that this isn't a final diagnosis until maybe they get diagnosed by the psychiatrist or after having a couple of visits with someone, that the screening is just preliminary, not a final result. FG2*

Participant engagement and experience

In the post-focus group survey, participants were asked a series of questions (see Appendix F) about their experience in the project[3]. Participants responded using a 7-item scale, with the following response options: No extent (1), Very small extent (2), Small extent (3), Fair extent (4), Moderate extent (5), Large extent (6), or Very large extent (7). Figure 3 and Table 8 in Appendix G summarize participants' engagement ratings.

Overall, participant experience questions were highly rated, indicating a positive engagement experience. Most questions had a median response of 6 or higher. Questions with slightly lower medians of 4 and 5 were related to participants' belief that their input would influence the final decisions that underlie the engagement process as well as the belief that their values and preferences would be included in the final advice of the Task Force. However these ratings still indicate participants felt fairly to moderately positive about these engagement questions.

Next, participants were asked to rate questions about the clarity and ease of the tasks that they were requested to complete using a 9-point scale, where 1 = "Not at all" , 5 = "Neutral", and 9 = "Very Much". Figure 4 and Table 9 in Appendix H summarize participants' task clarity and comprehension ratings.

Overall, participants responded positively to all five questions, indicating a sense of clarity and ease surrounding tasks and participation. All medians fell at the high end of the response options (7.5 to 8). Participants were also asked to summarize what they had been asked to do in the survey. Of those who answered the question related to task comprehension, all participants accurately described the survey tasks they completed; nine participants chose not to answer the open-ended question.

In addition, 16 open-ended survey questions were asked to gather qualitative data from participants about their experience in the project. Table 10 in Appendix I summarizes participants' main impressions of the background information sheet, focus group, and survey.

Limitations

In addition to the limitations of the methods discussed in the Patient Engagement Protocol, there were further limitations specific to this project. Our sample was not representative of the target screening population in Canada. The majority (*n* = 14) had a college diploma, bachelor's, graduate, or professional degree. Due to the high education level of participants, these participants may have higher health literacy, different risk factors or protective factors, and/or preferences that differ from the target screening population. Furthermore, all participants lived in urban or suburban areas (*n* = 18), and only none of the participants identified as Indigenous. As such, the preferences, barriers, and facilitators facing typically underserved groups such as rural Canadians and Indigenous populations are not represented in these results.

Suggestions for applying findings

Below are our suggestions for applying the findings from this project to the Task Force's guideline regarding screening for depression among adults:

1. **Provide resources to support a discussion of patients' preferences and shared decision making (particularly when recommendations are inconsistent with patients' preferences**) Because the Task Force develops evidence-based guidelines, the Task Force may not always be able to produce guideline recommendations that are consistent with all patients' preferences. For example, if evidence indicates that harms of screening outweigh the benefits, the Task Force may develop a recommendation that is inconsistent with patients' preferences for wanting to be screened. In this case, the Task Force may consider developing and disseminating resources that help clinicians and patients address inconsistencies between patient preferences and guideline recommendations. Specifically, the Task Force may produce KT tools that assist clinicians in discussing screening in the context of a patient's preferences. In addition, the T may develop KT tools for patients that explain the balance between the harms and benefits of screening. These resources may support both clinicians and patients in shared decision-making.

2. **Develop KT tools that address information needs of participants.** Participants had additional questions about the timing and processes for screening, as well as availability, types, and timelines of treatment following a diagnosis of depression from screening, and difference between usual care and screening. Additionally, explanations for why some of the risks are unknown may assist patients' understanding of what a lack of data for outcomes means. Participants had mixed feelings around how the level of evidence of the risk for many of the screening outcomes impacted their preference to be screened. Thus, the guideline and KT tools should integrate relevant information to help address patients' concerns, and help health care

providers and patients engage in shared decision-making so patients can make an informed choice about screening for depression.

3. **Send participants a summary of how their feedback in the final guideline and KT tools was used.** Participants fairly to moderately believed that their input would influence final decisions that underlie the engagement process, and that their values and preferences would be included in the final advice of the Task Force. Upon public release of the guideline and KT tools, the Task Force may send an email to participants to explain how their feedback was integrated into the final guideline and KT tools, providing specific examples. In the case where Task Force guideline recommendations differ from participants' preferences identified in this project, the Task Force should also clearly outline the reasoning behind their recommendations to project participants. The Task Force may also request that participants complete the participant engagement measure again to explore whether participants' beliefs shifted when presented this information.

4. **Emphasize the difference between 'usual care' and screening in shared-decision making tools.** Many participants emphasized the importance of a discussion with their primary care provider about depression, and being proactive to diagnosis depression early. Participants felt the distinction between informal discussions or 'usual care', and standardized screening should be made clear in any recommendations. The Task Force may consider emphasizing the difference between a formalized screening process, and usual care when drafting recommendations and shared decision making tools.

Conclusion

Through this project we explored screening preferences for a sample of the population to whom the guideline will be relevant, as well as those already exposed to depression diagnosis or treatment. In the surveys, the benefits of screening were consistently rated as more important than harms. However, all outcomes included in the surveys were rated as *important* or *critical.* The majority of participants expressed a strong preference for screening for depression among adults, however there were mixed opinions on how screening preference is impacted by the level of evidence for each outcome. Many participants enjoyed the opportunity to participate, found the project interesting and appreciated being able to contribute to an important topic. These findings should be integrated into the screening for depression among adults guideline and KT tools, as well as into future Task Force patient engagement 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. Hseih H, Shannon SE (2005). Three Approaches to Qualitative Content Analysis. Qualtitative Health Research. 15 (9): 1277-1288.
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Appendix A: Screening questionnaire

Introduction

This survey is designed to assess your eligibility for the Canadian Task Force on Preventive Health Care (CTFPHC)'s patient preferences project on depression screening in adults. Please answer the following questions accurately and honestly.

If you have any questions, concerns, or technical difficulties, please contact Kyle Silveira, at silveirak@smh.ca.

Do you need mental health support? You can call the Mental Health Helpline at 1-866-531-2600 or find your local Canadian Mental Health Association branch.

Please note that the information provided to us through 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:

_____

Are you a practicing health care professional?

- ❍ Yes
- ❍ No

Display This Question:

If Are you a practicing health care professional? = Yes

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.

How old are you?

- ❍ 17 years old or younger
- ❍ 18-25
- ❍ 26-30
- ❍ 31-35
- ❍ 36-40
- ❍ 41-45
- ❍ 46 years old or older

End of Block: Eligibility: Age

Start of Block: Under 18

Display This Question:

If How old are you? = 17 years old or younger

Q57 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 people aged 18 years of age or older.

Q59
Have you ever been diagnosed or treated for depression by a health professional?

- ❍ Yes
- ❍ No

Q60
Are you currently receiving treatment for depression?

- ❍ Yes (4)
- ❍ No (5)

Do you have any conflict of interest related to depression or mental health?

Examples include but are not limited to the following:

- Being a member of an organization related to depression or mental health
- Owning a company that provides products or services related to depression or mental health
- Owning shares in a company that provides products or services related to depression or mental health
- Conducting research on depression or mental health

❍ Yes (please describe) : _____

❍ No

How did you hear about this opportunity?

❍ Charity Village

❍ Craiglist

❍ Kijiji

❍ 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
- ❍ I don't know

Which type of region do you live in?

- ❍ Urban
- ❍ Suburban
- ❍ Rural

What is your gender?

- ❍ Male
- ❍ Female
- ❍ Non-binary
- ❍ Prefer to self-describe : _____
- ❍ Prefer not to say

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

- ❍ First Nations
- ❍ Métis
- ❍ Inuit
- ❍ No, I am not Indigenous

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 $25,000
- ❍ $25,000-29,999
- ❍ $30,000-$39,999
- ❍ $40,000-$49,999
- ❍ $50,000-$59,999
- ❍ $60,000-$69,999
- ❍ $70,000-$79,999
- ❍ $80,000-$89,999
- ❍ $90,000-$99,999
- ❍ $100,000 or more

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

The project team will only contact you by email if you are eligible and space permits 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? If you indicate yes, we will take this as your consent for your name and email address to be added to our mailing list.

- ❍ Yes
- ❍ No

Appendix B: Descriptions for outcomes

Short description	Full description
Benefits (*n* = 7)	
Diagnosis of major depressive disorder	Screening may lead to diagnosis of major depression disorder by a health care provider
Symptoms of depression	If screening leads to treatment, it may decrease symptoms of depression
Health-related quality of life	If screening leads to treatment, it may improve health-related quality of life
Day to day functionality	If screening leads to treatment, it may improve how a person functions in their day to day life
Missed work or school	If screening leads to treatment, it may decrease the amount of missed work or school
Impact on lifestyle behaviors	If screening leads to treatment, it may improve lifestyle behaviours (for example, less alcohol and drug abuse, smoking, and gambling)
Suicide ideation, attempt, or completion	If screening leads to treatment, it may decrease thinking about, planning, attempting, or completing suicide
Harms (*n* = 5)	
False positive	Screening may result in identifying someone as having depression when they do not have depression (called a false positive result)
Overdiagnosis	Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment. This can lead to unnecessary tests, treatments, worry and concern (called overdiagnosis)
Overtreatment	Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms (called overtreatment)
Harms from treatment	If screening leads to treatment harms may include unwanted side-effects from medication or new or worsening symptoms from poorly applied psychotherapy
Labeling/stigma	Screening may result in labeling someone as having depression which can lead to anxiety or stigma

Appendix C: Background Sheet

CTFPHC Patient Background Information Sheet
Screening for Depression among Adults

What is depression?
Depression is a mental illness that affects important parts of life such as work, family, or hobbies and social activities. To be diagnosed, a person must have five or more symptoms from the list below, including at least one of the first two, **for at least two weeks**:

- Sad mood
- Loss of interest or pleasure in activities
- Major weight loss or weight gain
- A hard time falling or staying asleep
- Feeling very tired during the day or loss of energy
- Restlessness (constantly moving or unable to be still) or feeling sluggish
- Feelings of worthlessness or extreme guilt
- Difficulty thinking, concentrating, or making decisions
- Thoughts of death, suicide, or suicide attempts

How common is depression?
Depression is very common. More than 300 million people worldwide are living with depression, making it the #1 cause of disability.

- 5% of Canadians report having symptoms of depression in the past year, and about 3.2 million Canadians (11% of the population) report having symptoms of a major depressive episode at some point during their life.
- Most episodes of depression last less than 6 months, but sometimes episodes can last for more than 2 years.
- Women are more likely than men to experience depression, but as people get older, this difference between genders decreases.

How does depression affect people?
Depression decreases a person's quality of life and increases the risk of suicide. It is considered a possible life-threatening disease, with depressed men at greater risk of dying early from suicide compared to depressed women.
Depression can negatively impact a person's work or school and may also create tension or conflict in close relationships, causing more distress. Depression may increase risk-taking behaviours (e.g., taking drugs, binge-drinking, gambling, and smoking) or suicidal thoughts and behaviour (thoughts about attempting or completing suicide). Depression is more common among people with cancer, heart disease, and stroke. Having depression along with other chronic illnesses, including diabetes, also increases risk of dying.

What are some risk factors for depression?
There is no single cause of depression. In general, social (exposure to violence or neglect), psychological (low self-esteem), and biological factors (such as genetics and brain chemistry) can contribute to depression. You are more likely to experience depression if you:

- Have another mental health disorder (e.g., drug/alcohol misuse)
- Have a family history of psychiatric illness
- Have chronic illnesses (e.g., cancer or cardiovascular disease)
- Have experienced depression before
- Have traumatic childhood experiences

- Lack social support from partner, friends, or family
- Live with high stress problems like concerns over money or housing

What is depression screening?
All health care providers should watch for signs of depression. If someone discusses symptoms of depression with their health care provider, they will be checked for depression (this is called “usual care”). However, doctors, nurse practitioners, and other providers can also use a formal process to check for depression in *every* person, even if the person has *not* noticed any symptoms or has *not* reported symptoms. This is called *screening*.

Screening uses a standard set of questions asked either in-person or in a survey to help identify depression symptoms. A positive screening test does not always mean a person is depressed. It means that a heath care provider should do more tests to find out if a person has depression. Screening for depression is not the same as diagnostic testing, and does not always lead to identification and treatment of depression.

How is depression diagnosed?
If the screening test shows you may have depression, you would need to have a more detailed talk with your doctor. More time would be spent learning about your symptoms and impact on your life. You may also be referred to a mental health specialist (for example, a therapist or a psychiatrist) for more follow-up or treatment.

How is depression treated?
Depression is one of the most treatable mental disorders. The most commonly used treatments include:

- *Lifestyle changes* -Eating well, exercising, getting enough sleep, and getting support from family and friends can all help you feel better when you have symptoms of depression.
- *Supportive treatments* - Peer support and professionally-led support groups that help share and validate each other’s experiences. This works best when you’re experiencing mild symptoms of depression.
- *Psychotherapy* - A therapist helps identify problems and suggests ways to change behaviour or thoughts to help relieve symptoms. This is recommended when symptoms are more serious or when other supportive interventions are not helping enough.
- *Antidepressants* - Prescribed medication that help to relieve symptoms of depression. Medication is recommended when you are experiencing severe symptoms, or when your symptoms are not improving with other treatments.

What are the possible <u>benefits</u> of *screening for and treating* depression among adults?
If depression screening works, more people who have depression may be found, and they can be helped through treatment. If screening leads to treating depression, it may reduce symptoms of depression, improve health-related quality of life, and reduce suicidal thoughts or attempts. Other benefits might include improved day-to-day functioning, less lost time at work/school, and less risk-taking behaviour (e.g., alcohol abuse, smoking, drugs, and gambling).

What does the research say about the <u>benefits</u> of depression screening (beyond usual care)?
There is not enough research to answer this question. One study showed no differences in symptoms of depression or health-related quality of life between adults who received depression screening compared to those who did not. There is not enough evidence to know if additional screening for depression reduces the number of adults who meet the criteria for depression diagnosis, or who think about, plan or attempt suicide. There is also not enough evidence to know how additional screening for depression influences adults’ day-to-day functionality, lost time at work or school, or their lifestyle behaviours.

What are the possible <u>harms</u> of *screening* adults for depression?

Ways depression screening could harm you include:

- *False positive screening test* - when the screening test shows that you may have depression, but upon closer look by your health care provider, they determine that you do not actually have depression.
- *Overdiagnosis* of depression - when you are going through the normal ups and downs of life, but do not have depression.

    - Overdiagnosis could lead to treatment for depression that would have gone away on its own without treatment (*overtreatment*).
    - Also, being labeled as 'having depression' can sometimes lead to social stigma and may make it harder for you to cope with the illness.

Depression screening that leads to being diagnosed with depression may lead to treatment. Ways depression treatment could harm you include:

- *From psychotherapy*:
    - Sometimes symptoms can get worse or new ones can develop during therapy- even when the therapist is well trained, and there is a good fit between you and the therapist. This risk is greater when therapy is poorly applied.
- *From antidepressants*
    - More than 10% of people who take antidepressants experience these short-term side-effects: nausea and vomiting, diarrhea, dizziness, fatigue, headache, tremor, or weight gain.
    - Sexual dysfunction (for example, less desire for sex or delayed orgasms) can also occur and often last the entire time that a person is taking an antidepressant.
    - There is also a risk of higher anxiety and agitation in the short term when someone starts taking an antidepressant.
    - Antidepressants may also be linked to an increased risk of suicidal thoughts and behaviours in people less than 24 years of age.

What does the research say about the harms of depression screening?
There is not enough research to know if screening for depression increases or decreases harms related to screening such as false positives, overdiagnosis, overtreatment, labeling/stigma, and harms associated with treatment for depression.

Appendix C: Pre- and post-focus group survey

Q1 CTFPHC Survey on Public Perceptions of Screening for Depression among Adults

Q2 Introduction: The Canadian Task Force on Preventive Health Care (CTFPHC) receives funding from the Public Health Agency of Canada (PHAC) to develop evidence-based clinical practice guidelines for preventive health care in Canada. The CTFPHC has created the following survey to assess how members of the public view screening for depression in the general adult population. Getting screened for depression has both harms and benefits. In this survey, the CTFPHC would like to know how important you think it is to consider each of these harms and benefits when people make decisions about depression screening. **The survey will take approximately 10–15 minutes to complete**.

If you have any questions, concerns, or technical difficulties, please contact the research assistant, Kyle Silveria, at silveirak@smh.ca Do you need support? You can call the Mental Health Helpline at 1-866-531-2600 or find your local Canadian Mental Health Association branch.

Page Break

Q3 Confidentiality Agreement:

The individual 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 (CTFPHC) in the course of carrying out their responsibilities as an above individual, or that CFPHC may develop while performing its mandate, strictly confidential; (b) not use any Confidential Information for any purpose other than those indicated by CTFPHC; (c) Not disclose any Confidential Information to any third party without the prior written consent of the Chair of CTFPH, 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 Inhere under 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 the Agency; (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.

Q4 I acknowledge that I have read and agree to the above Confidentiality Agreement

- ❍ Yes (1)
- ❍ No (2)

Page Break

Display This Question:

If I acknowledge that I have read and agree to the above Confidentiality Agreement = No

Q33 Thank you for taking the time to fill out this survey.

Unfortunately, it appears that you are not eligible to take part in this research project.

The CTFPHC is exclusively soliciting the opinions of members of the general public who have read and agree to the CTFPHC Confidentiality Agreement.

Skip To: End of Survey If Thank you for taking the time to fill out this survey. Unfortunately, it appears that you are not...() Is Displayed

Q5 Participant ID:
Please enter your participant ID in the box below. You can find your participant ID in the email you received from Kyle Silveira with the link to the survey.

_____

Q6 Date:

_____

Page Break

End of Block: Default Question Block

Start of Block: Block 1

Q35 Before you begin the survey, please take the time to **read the Background Information Sheet below**. A PDF copy of the background information sheet can also be found attached to the email you received from Kyle Silveira with the link to the survey.

[Insert Background Information Sheet]

Q8 I have read the Background Information Sheet and am ready to proceed with the survey.

- ❍ I agree (1)

Page Break

End of Block: Block 1

Start of Block: Block 2

Q36 Screening for Depression among Adults:

The next section of this survey presents a series of statements about the potential **BENEFITS and HARMS** that adults may experience after being screened for depression. Remember: Screening for depression is a process where health care providers check for depression in every person, even if the person has not noticed any symptoms or has not disclosed symptoms to their health care provider. People who have noticed symptoms and notified their health care provider will get checked for depression (but this is called "usual care", not "screening").

Depression screening uses a standard set of questions asked either in-person or in a survey to help identify depression symptoms. A positive screening test does not always mean a person is depressed. It means that a heath care provider should do more tests to find out if a person has depression. Screening for depression is not the same as diagnostic testing, and does not always lead to identification and treatment of depression.

Q10 Potential Benefits

Please rate how important each of the following potential BENEFITS would be for you to consider, if you were making a decision on whether or not to be screened for depression.

1-3 not important for decision-making
4-6 important for decision-making
7-9 critical for decision-making

Please Note: For each of these benefits, we either had "no studies" or "we did not have enough evidence to know". This means that when we searched for studies that could answer questions about the benefits of screening, we did not find any studies or we did not find trustworthy information. More information about this is in the background information sheet.

	1 (1)	Not important for decision making 2 (2)	3 (3)	4 (4)	Important for decision making 5 (5)	6 (6)	7 (7)	Critical for decision making 8 (8)	9 (9)
Screening may lead to diagnosis of major depression disorder by a health care provider (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may decrease symptoms of depression (2)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may improve health-	❍	❍	❍	❍	❍	❍	❍	❍	❍

related quality of life (3)									
If screening leads to treatment, it may improve how a person functions in their day to day life (4)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may decrease the amount of missed work or school (5)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may improve lifestyle behaviours (for example, less alcohol and drug abuse, smoking, and gambling) (10)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may decrease thinking about,	❍	❍	❍	❍	❍	❍	❍	❍	❍

planning, attempting, or completing suicide (11)	

Q11 If you would like to provide any comments about your rating, please enter them in the space below.

_____

End of Block: Block 2

Start of Block: Block 3

Q12

Potential Harms Please rate how important each of the following potential HARMS would be for you to consider, if you were making a decision on whether or not to be screened for depression.

1-3 not important for decision-making
4-6 important for decision-making
7-9 critical for decision-making

Please Note: For each of these harms, we either had "no studies" or "we did not have enough evidence to know". This means that when we searched for studies that could answer questions about the benefits of screening, we did not find any studies or we did not find trustworthy information. More information about this is in the background information sheet.

	1 (1)	Not important for decision-making 2 (2)	3 (3)	4 (4)	Important for decision-making 5 (5)	6 (6)	7 (7)	Critical for decision-making 8 (8)	9 (9)
Screening may result in identifying someone as having depression when they do not have depression (called a false positive result) (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment. This can lead to	❍	❍	❍	❍	❍	❍	❍	❍	❍

unnecessary tests, treatments, worry and concern (called overdiagnosis) (4)									
Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms (called overtreatment) (6)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, harms may include unwanted side-effects (7)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in labelling someone as having depression which can lead to anxiety or stigma (9)	❍	❍	❍	❍	❍	❍	❍	❍	❍

Q13 If you would like to provide any comments about your rating, please enter them in the space below.

Page Break

End of Block: Block 3

Start of Block: Block 4

Q14 Screening for Depression among Adults

Below is the same list of statements about potential harms and benefits of screening for depression you just rated. Please select **five** items on this list that you think are **most critical to consider** when adults make decisions about screening for depression.

Indicate your response by clicking on the statement that you wish to select.

Please do not select more than five items.

- ❑ If screening leads to treatment, it may decrease symptoms of depression (1)
- ❑ Screening may lead to diagnosis of major depression disorder by a health care provider (2)
- ❑ If screening leads to treatment, it may improve health-related quality of life (3)
- ❑ If screening leads to treatment, it may improve how a person functions in their day to day life (4)
- ❑ If screening leads to treatment, it may decrease the amount of missed work or school (11)
- ❑ If screening leads to treatment, if may improve lifestyle behaviours (for example, less alcohol and drug abuse, smoking, and gambling) (5)
- ❑ If screening leads to treatment, it may decrease thinking about, planning, attempting, or completing suicide (6)
- ❑ Screening may result in identifying someone as having depression when they do not have depression (called a false positive result) (7)
- ❑ Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment. This can lead to unnecessary tests, treatments, worry and concern (called overdiagnosis) (8)
- ❑ Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms (called overtreatment) (17)
- ❑ If screening leads to treatment, harms may include unwanted side-effects (19)
- ❑ Screening may result in labelling someone as having depression which can lead to anxiety or stigma (22)

Q15 If you would like to provide any comments about your selections, please enter them in the space below.

_____

Q16 In the space below, please list any additional harms and benefits of screening for depression that did not appear on the rating list but that you think are critical for adults to consider when making a decision whether or not to be screened for depression.

_____

Page Break

End of Block: Block 4

Start of Block: Block 6

Q19
Screening Preference
Considering **the potential harms and benefits** of screening for depression, how much would you want to be **screened**?

	Not at all 1 (1)	2 (2)	3 (3)	4 (4)	Neutral 5 (5)	6 (6)	7 (7)	8 (8)	Very much 9 (9)
I would want to be screened for depression (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍

Q20 If you would like to provide any comments about your rating, please enter them in the space below:

Page Break

Q34
Considering that **the risk of m**any of the harms and benefits of screening adults for depression **are not well known,** how much would you want to be screened ?

	Not at all 1 (1)	2 (2)	3 (3)	4 (4)	Neutral 5 (5)	6 (6)	7 (7)	8 (8)	Very much 9 (9)
I would want to be screened for depression (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍

Q35 If you would like to provide any comments about your rating, please enter them in the space below:

_____

End of Block: Block 6

Start of Block: Block 5

Q21 **We will now ask you some questions about your experience participating in this project.**

Q17 In the space below, please briefly summarize the tasks that we asked you to perform in this survey.

_____

Q18 Please respond to each of the following statements using the scale provided.

	Not at all 1 (1)	2 (2)	3 (3)	4 (4)	Neutral 5 (5)	6 (6)	7 (7)	8 (8)	Very much 9 (9)
How easy was it to understand the information in the background information sheet? (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍
How easy was it to rate the harms and benefits using the 9-point scale? (2)	❍	❍	❍	❍	❍	❍	❍	❍	❍
How easy was it to select the top five harms and benefits from the full list? (3)	❍	❍	❍	❍	❍	❍	❍	❍	❍
How clear were the survey responses? (4)	❍	❍	❍	❍	❍	❍	❍	❍	❍
How well did you understand what we asked you to do in this survey (5)	❍	❍	❍	❍	❍	❍	❍	❍	❍

Q22 In the space provided, please describe anything we could do to make the survey tasks easier to complete:

_____

Q23 **Demographic Information**

Q24 What is your age?

_____

Q25 What is your gender?

- ❍ Male (1)
- ❍ Female (2)
- ❍ Non-binary (3)
- ❍ Prefer to self-describe (4) _____
- ❍ Prefer not to say (5)

Q26 Which province or territory do you live in?

- ❍ British Columbia (1)
- ❍ Alberta (2)
- ❍ Saskatchewan (3)
- ❍ Manitoba (4)
- ❍ Ontario (5)
- ❍ Quebec (6)
- ❍ New Brunswick (7)
- ❍ Nova Scotia (8)
- ❍ Prince Edward Island (9)
- ❍ Newfoundland and Labrador (10)
- ❍ Yukon Territory (11)
- ❍ Northwest Territories (12)
- ❍ Nunavut (13)

End of Block: Block 7

Start of Block: Block 8

Q27 The focus group dates are listed below in eastern time (EST). By dragging and dropping each focus group date, please rank the focus group dates based on your preference for attending (i.e., #1 = the focus group that works best with your schedule and #2 = the focus group that works least with your schedule).

If none of the focus group dates work with your schedule, please email Kyle Silveira at silveirak@smh.ca

_____ Tuesday, August 20th, 2019 at 3-4pm EST (1)
_____ Thursday, August 22, 2019 at 6-7pm EST (2)

Page Break

End of Block: Block 8

Start of Block: Block 9

Q28
Next Steps:
Thank you for completing this survey. Within 1 to 2 weeks we will provide you with a summary of your survey responses and the responses provided by other participants. We will also ask you to take part in a teleconference focus group discussion about the harms and benefits you rated. If you have questions about any aspect of the project, please contact Kyle Silveira at silveirak@smh.ca

Do you need support? You can call the Mental Health Helpline at 1-866-531-2600 or find your local Canadian Mental Health Association branch.

Appendix D: Sample personalized response sheet

Task Force Survey on Public Perceptions of Screening for Depression among Adults (Phase 2)

Personalized Rating Sheet

Survey 1

Prepared for Participant Number X

Introduction

A total of 22 people from across Canada completed the Task Force Survey on Public Perceptions of Screening for Depression among Adults. 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 given information about the outcome and asked to “Please rate how important each of these outcomes would be for you to consider, if you were making a decision on whether or not to be screened for depression.”

Participants could rate the importance of the information from 1-9:

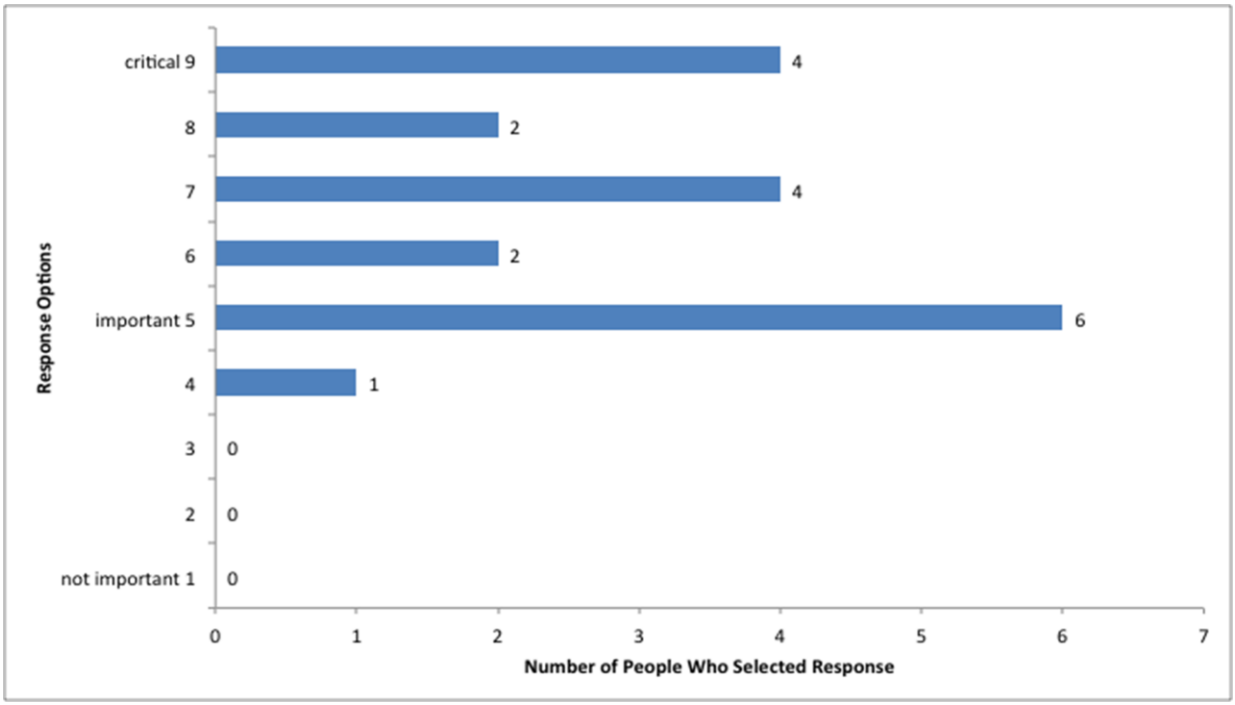
- 1-3 - not important to my decision to be screened or not for depression
- 4-6 - important to my decision to be screened or not for depression
- 7-9 - critical to my decision to be screened or not for depression

EXAMPLE: How to read the graph

Sample Outcomes Scale Rating

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

Sample Survey Outcome: *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:

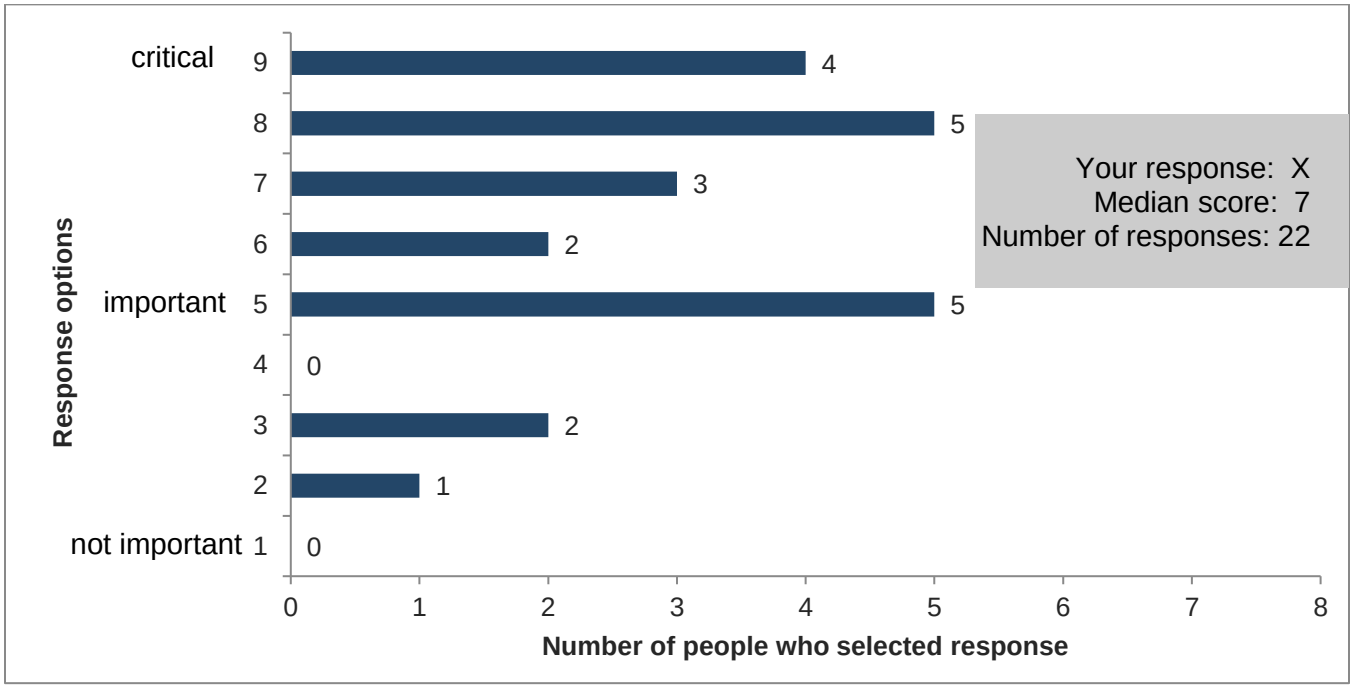
- The number on the rating scale that you selected for this outcome
- The median rating for this outcome across all participants (you can think of this like an "average" of the ratings selected by all participants)
- The total number of participants who rated this outcome

In this example, four participants rated the question with a "9", two participants rated it an "8", four participants rated it a "7", two participants rated it a "6", six participants rated it a "5", one participant rated it a "4", and no participants rated it a "3" or "2" or "1". In this example, "you" rated the outcome as

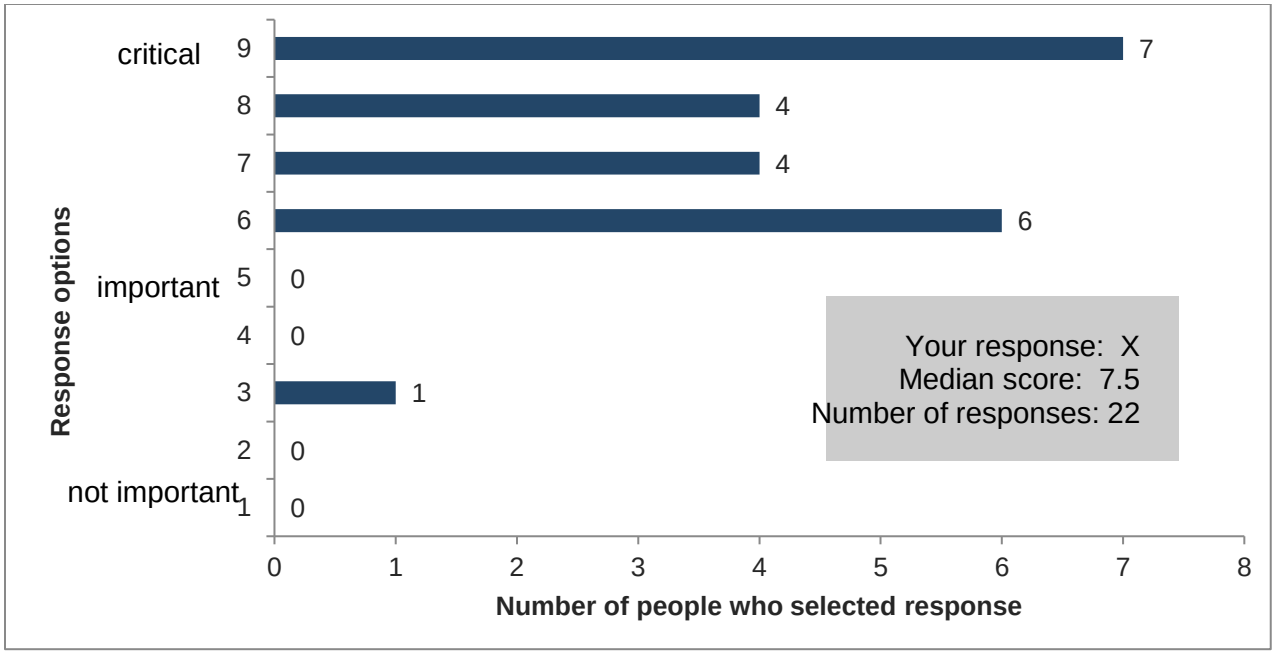
Your personalized answers are broken down by potential harms and benefits for depression screening among adults below:

Summary of Outcomes Ratings

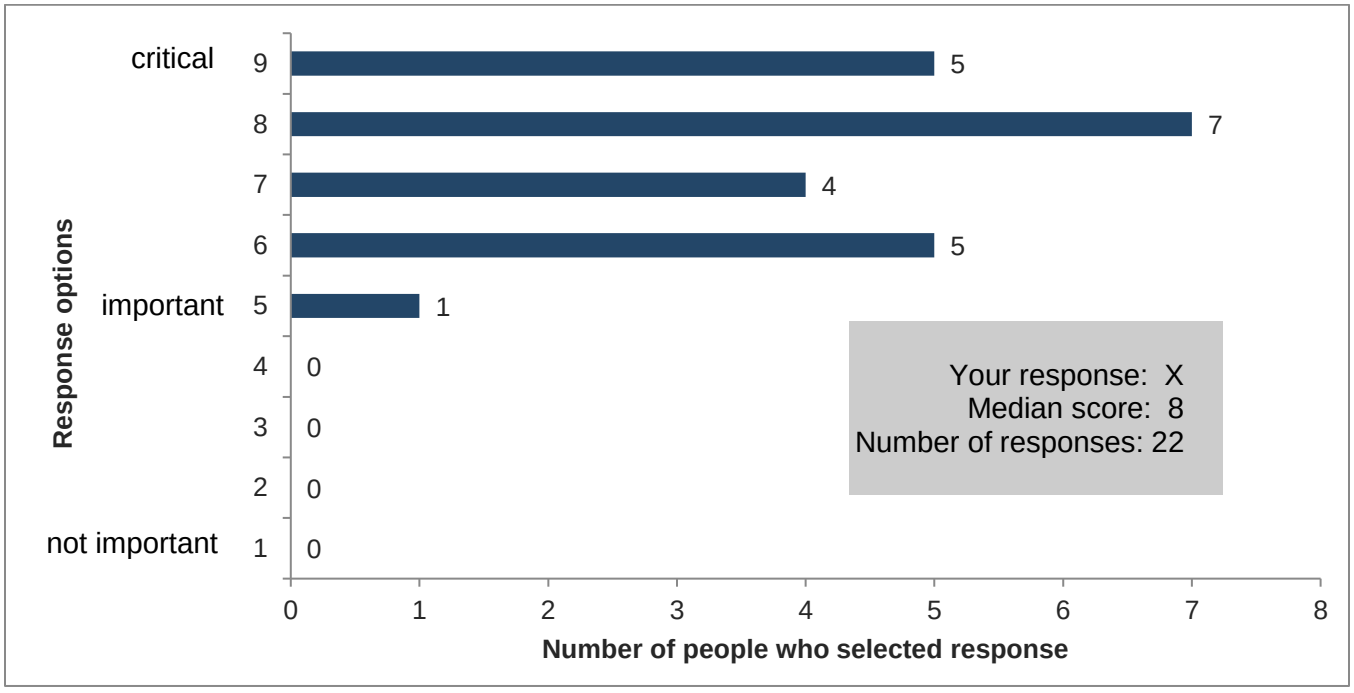
1. **Potential Benefit:** Screening may lead to diagnosis of major depression disorder by a health care provider



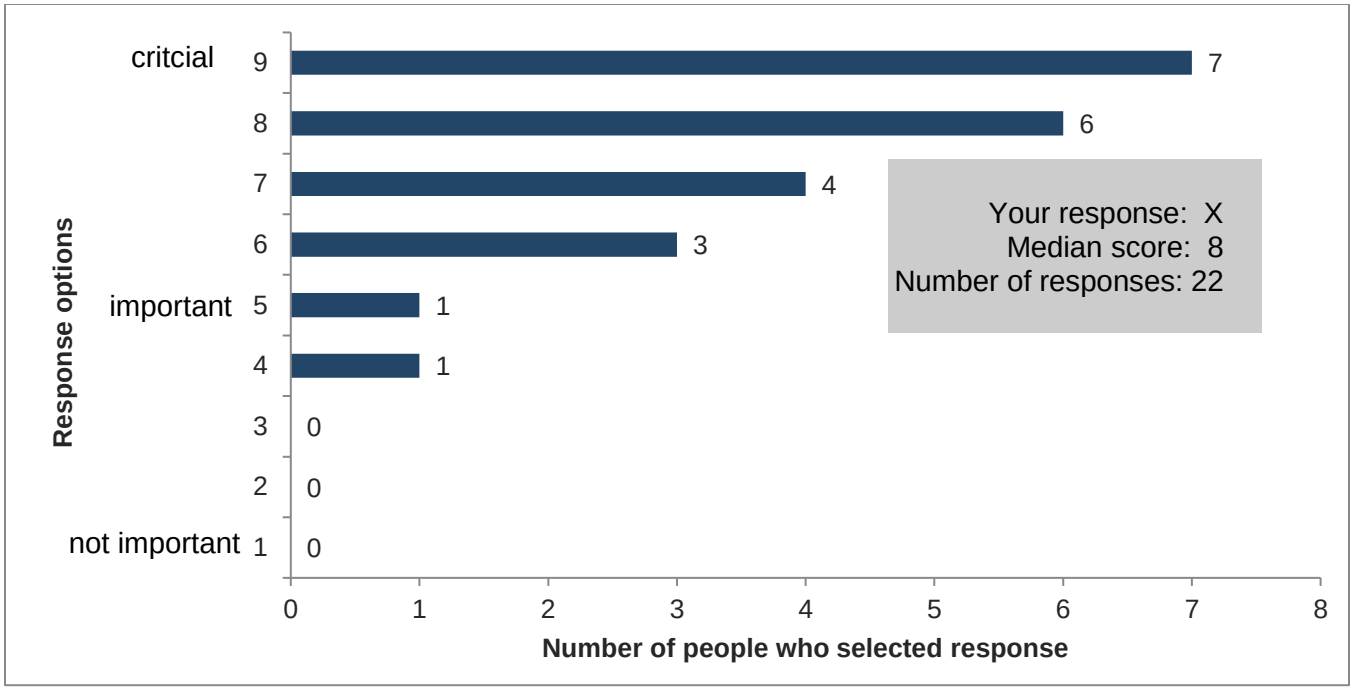
2. **Potential Benefit:** If screening leads to treatment, it may decrease symptoms of depression



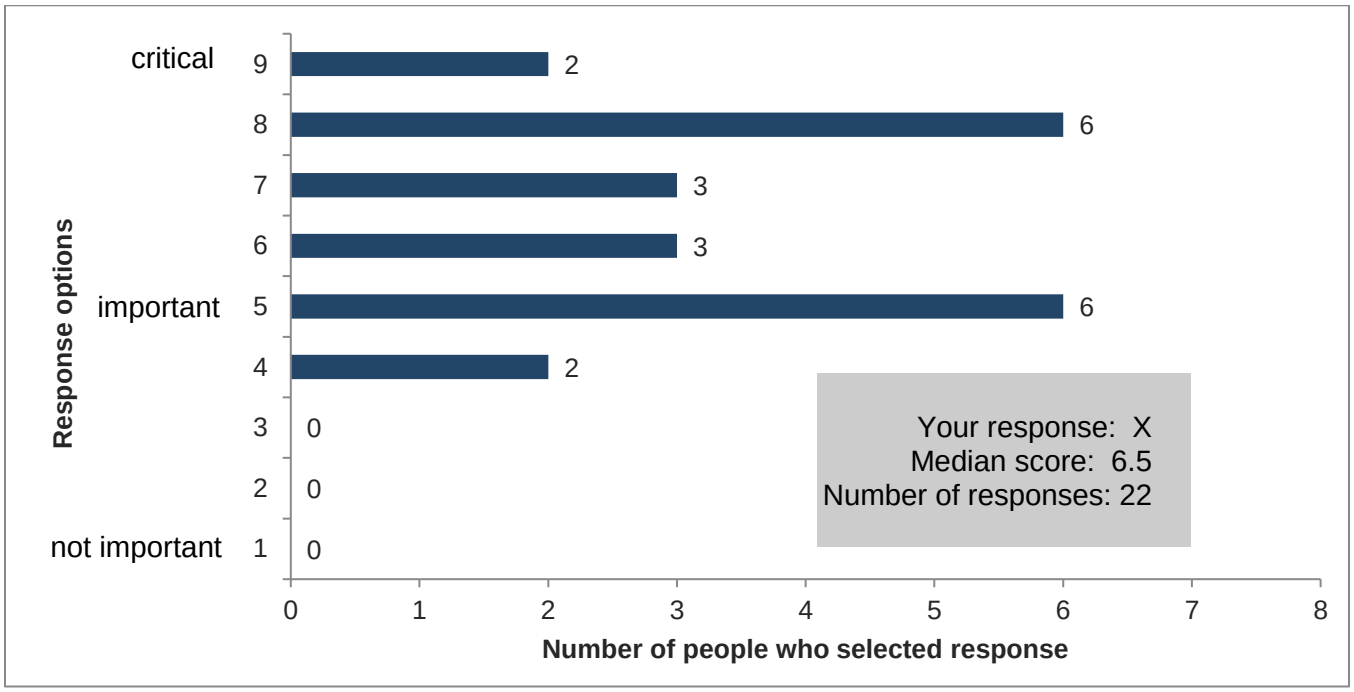
3. **Potential Benefit:** If screening leads to treatment, it may improve health-related quality of life



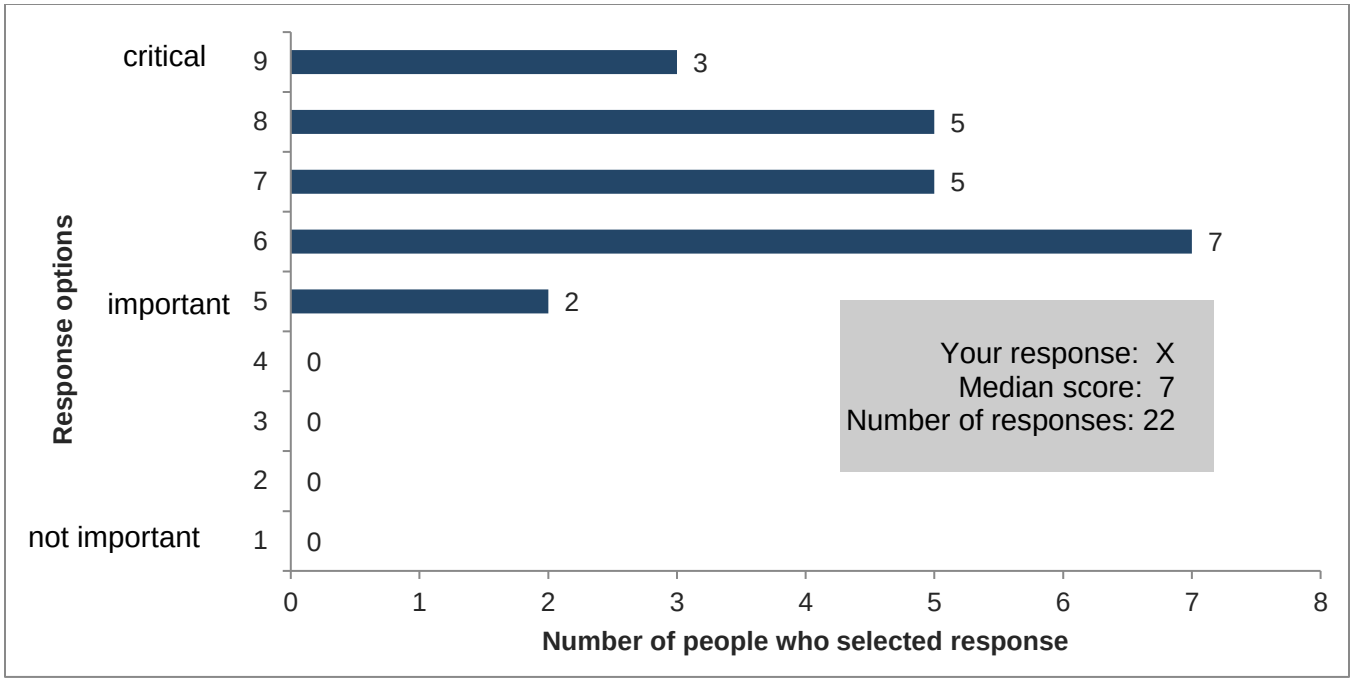
4. **Potential Benefit:** If screening leads to treatment, it may improve how a person functions in their day to day life



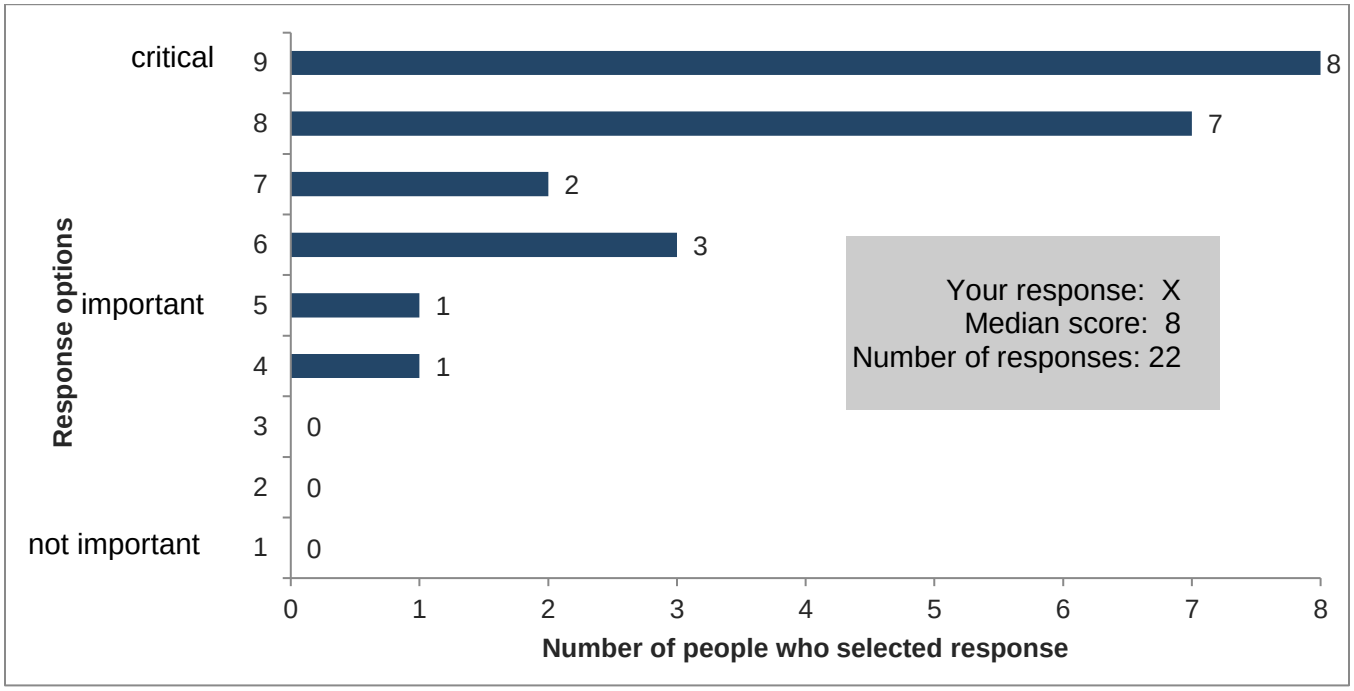
5. **Potential Benefit:** If screening leads to treatment, it may decrease the amount of missed work or school



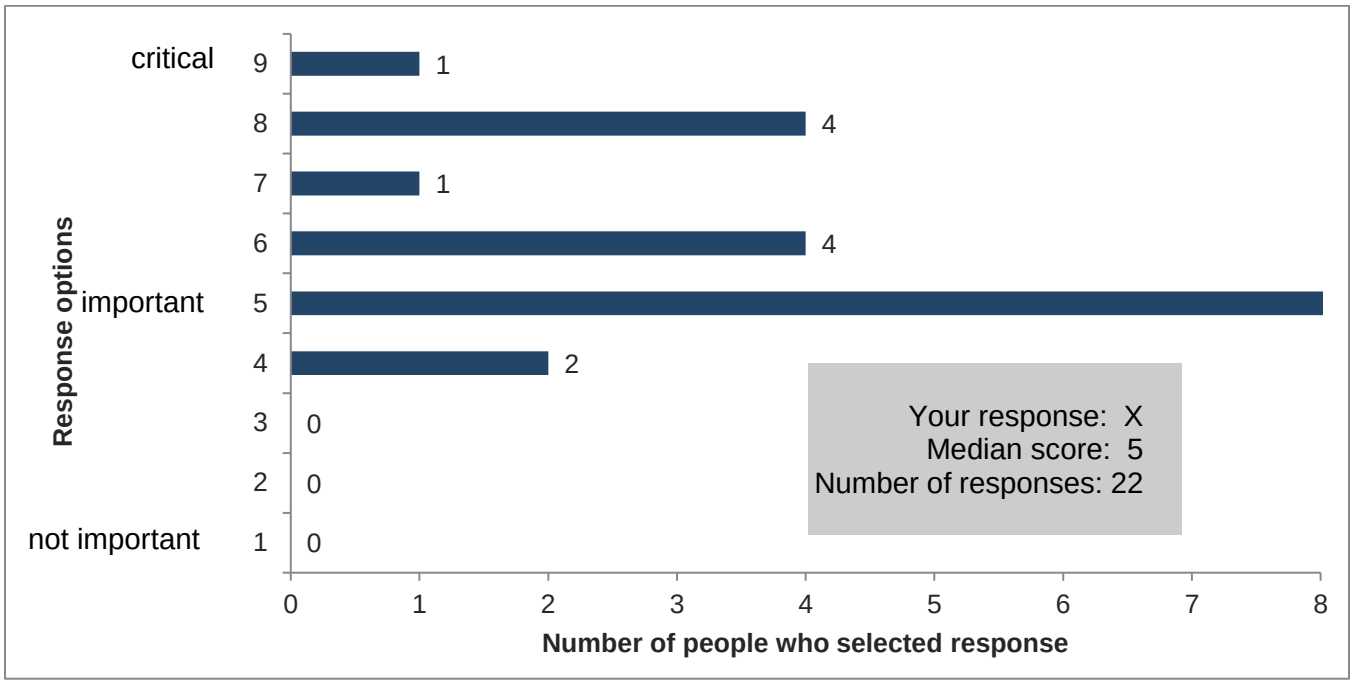
6. **Potential Benefit:** If screening leads to treatment, it may improve lifestyle behaviours (for example, less alcohol and drug abuse, smoking, and gambling)



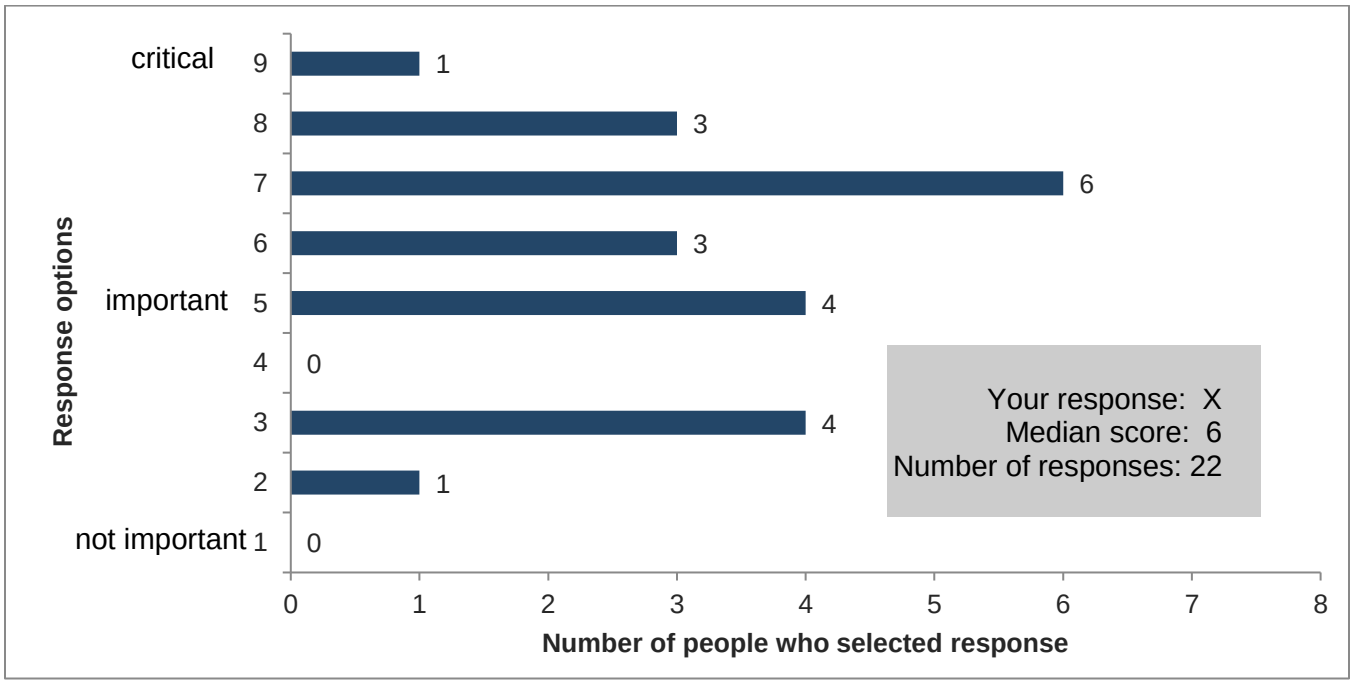
7. **Potential Benefit:** If screening leads to treatment, it may decrease thinking about, planning, attempting, or completing suicide



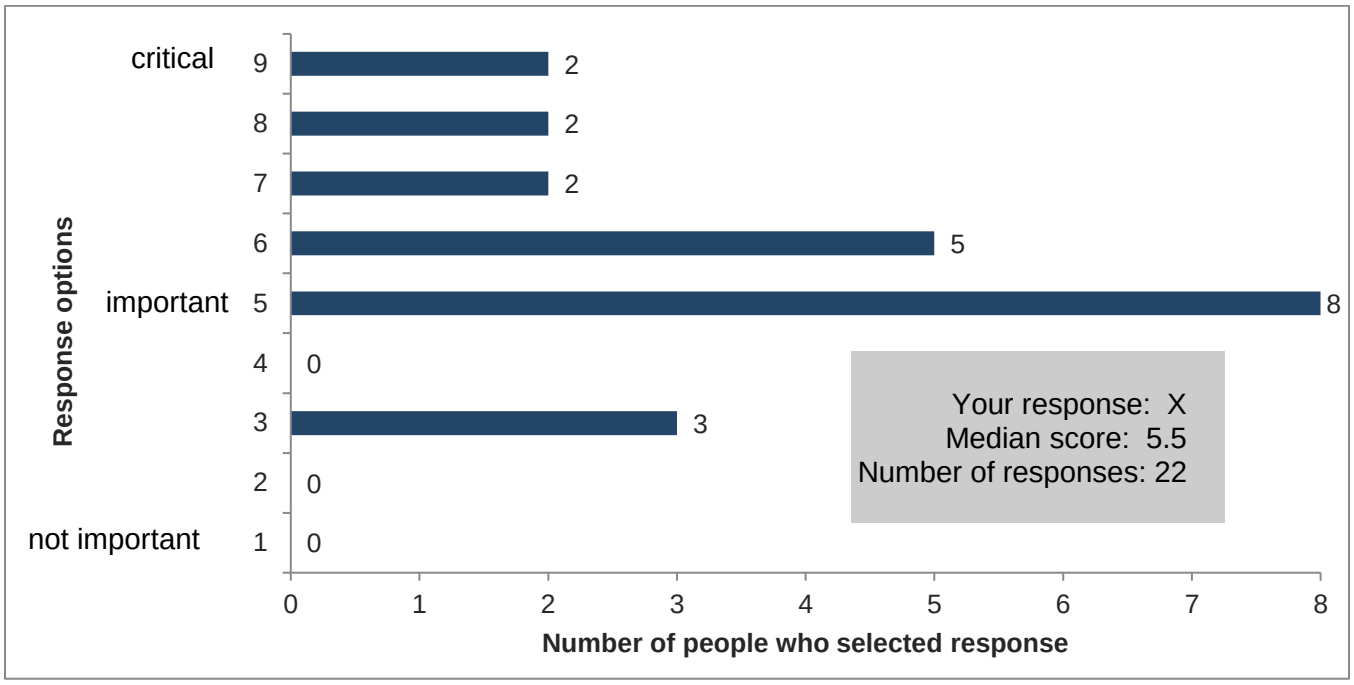
8. **Potential Harm:** Screening may result in identifying someone as having depression when they do not have depression (called a false positive result)



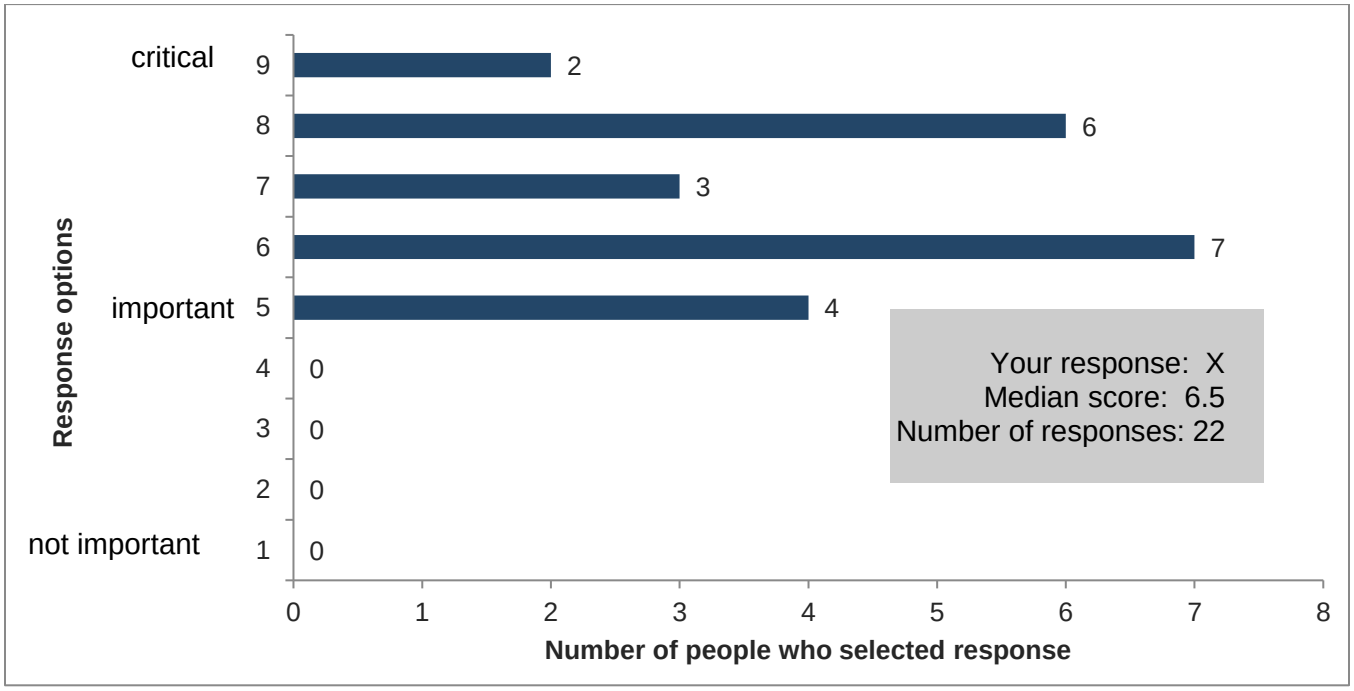
9. **Potential Harm:** Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment. This can lead to unnecessary tests, treatments, worry and concern (called overdiagnosis)



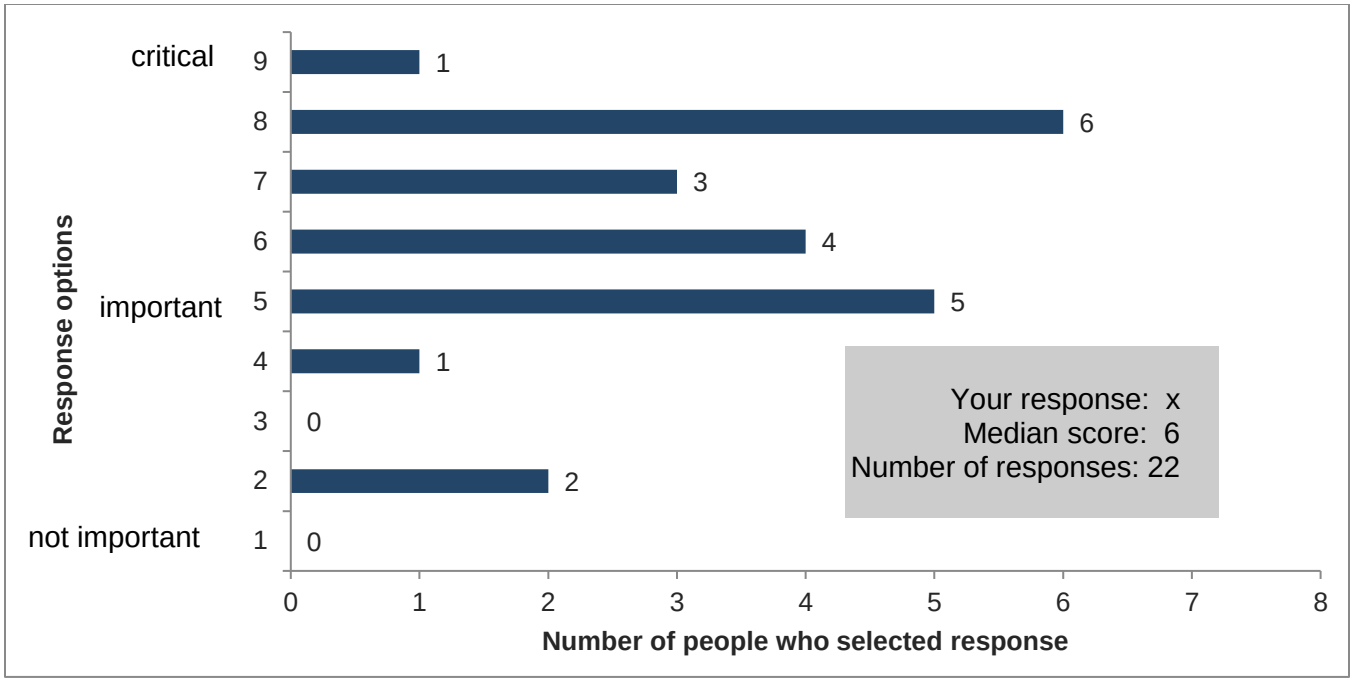
10. **Potential Harm:** Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms (called overtreatment)



11. Potential Harm: If screening leads to treatment with medication, harms may include unwanted side-effects



12. Potential Harm: Screening may result in labelling someone as having depression which can lead to anxiety or stigma


critical
important
not important
Response options
9
8
7
6
5
4
3
2
1
1
6
3
4
5
1
0
2
0
Your response: x
Median score: 6
Number of responses: 22
0
1
2
3
4
5
6
7
8
Number of people who selected response

Selection of the Top Five Potential Harms or Benefits to Consider When Making Decisions About Screening for Depression.

In the survey, we listed 14 potential harms and benefits of screening for depression and asked you to select the five items on the list that you think are most critical to consider when people may decisions about screening for depression among adults. Here are the outcomes that **you** selected as the top five items that are most important to consider (in no particular order):

- Selected Outcome 1
- Selected Outcome 2
- Selected Outcome 3
- Selected Outcome 4
- Selected Outcome 5

Below is a table that lists of **all** of the statements about harms and benefits of depression screening that were included in the survey, and the number of participants who selected each option as one of their "top five" items that were most critical to consider:

Potential Harm or Benefit:	Number of participants who selected this as a "top five" item to consider
If screening leads to treatment, it may decrease thinking about, planning, attempting, or completing suicide	17
If screening leads to treatment, it may improve health-related quality of life	17
If screening leads to treatment, it may decrease symptoms of depression	14
If screening leads to treatment with medication, harms may include unwanted side-effects	10
If screening leads to treatment, if may improve lifestyle behaviours (for example, less alcohol and drug abuse, smoking, and gambling)	10
If screening leads to treatment, it may improve how a person functions in their day to day life	10

Screening may result in identifying someone as having depression when they do not have depression (called a false positive result)	9
Screening may result in labelling someone as having depression which can lead to anxiety or stigma	6
Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment. This can lead to unnecessary tests, treatments, worry and concern (called overdiagnosis)	5
Screening may lead to diagnosis of major depression disorder by a health care provider	5
Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms (called overtreatment)	4
If screening leads to treatment, it may decrease the amount of missed work or school	3

Overall Screening Preference Scale Ratings

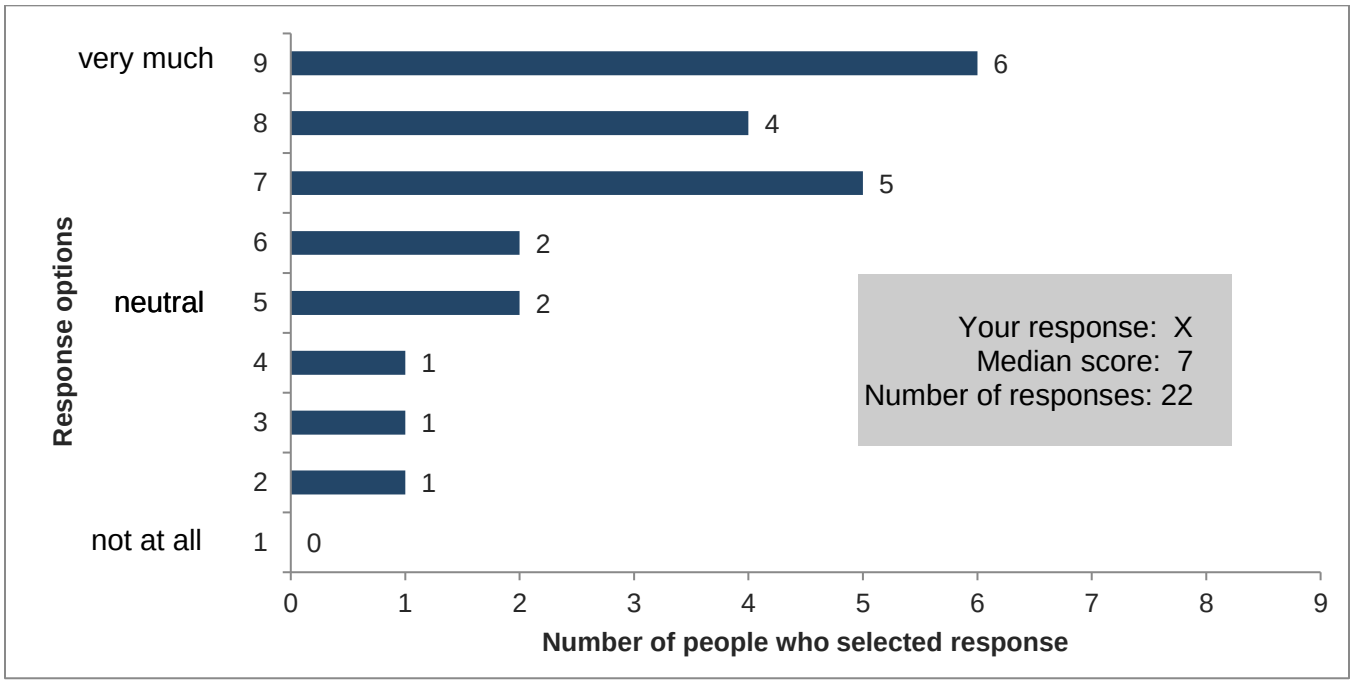
For these questions, participants were asked to rate how much they would want to be screened for depression.

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

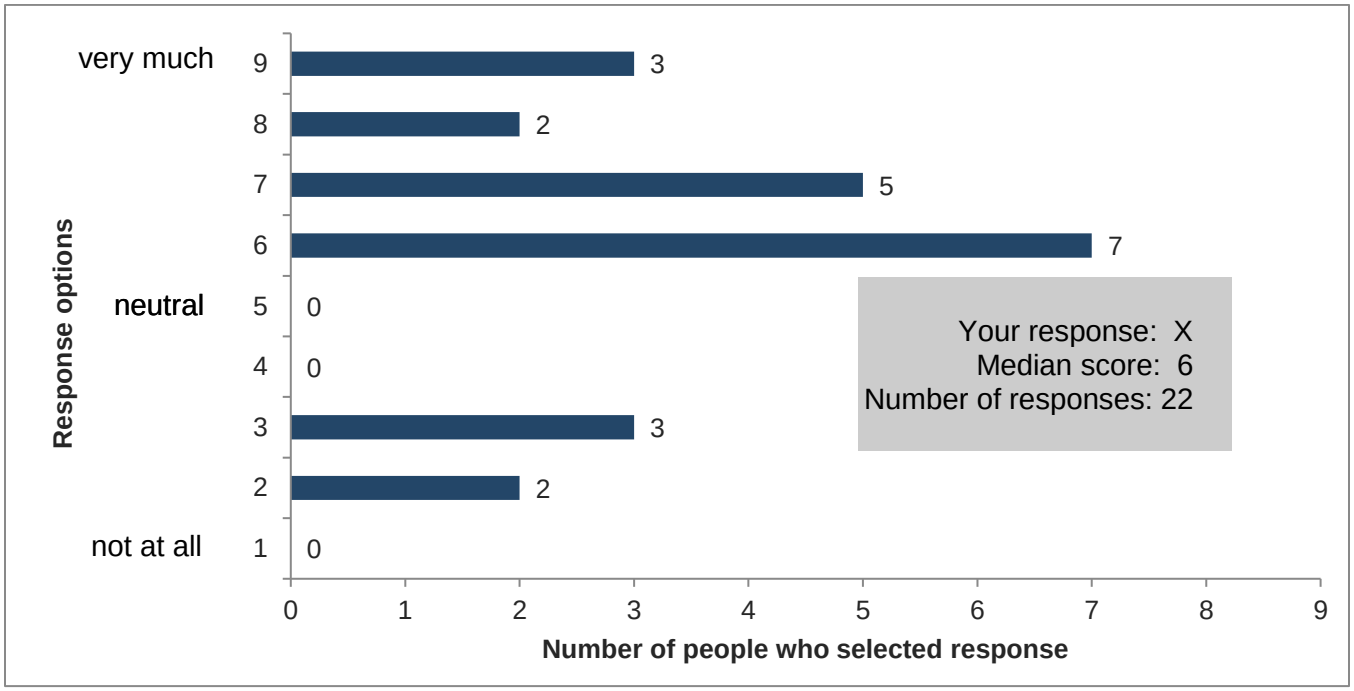
Your answer and the answers given by all participants are presented in the same graph format as the earlier questions.

Summary of Considerations for Screening Scale Ratings

1. **Screening preference question:** Considering the potential harms and benefits of screening for depression, how much would you want to be screened?



2. **Screening preference (given low evidence) question:** Considering that the risk of many of the harms and benefits of screening for depression are not well known, how much would you want to be screened?



Appendix E: Focus group guide

Welcome, introductions, and ground rules

Welcome (greet people as they join the teleconference)

Hello everyone and thank you for joining us today for the Canadian Task Force on Preventive Health Care focus group on screening for depression among adults.

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.

We are going to go through some introductions and background information for the next five minutes. I will **mute** everyone's line while I'm providing this information. I will unmute everyone once we get into the discussion.

I have two colleagues joining me today. The first is _____ (Kyle or Arthana) who will be our note taker. The second is Dr. _____ (Eddy Lang, the chair) (or Dr. John LeBlanc, the vice-chair) of the Task Force's screening for depression among adults guideline development working group, and they will be on the line to answer any questions content related questions you may have.

I will now give some background information on the project.

- This project is for the Canadian Task Force on Preventive Health Care.
- The Task Force develops guidelines for and against screening. These guidelines are for primary care providers, such as family physicians, to tell them who to screen and when to screen, as well as who not to screen and when not to screen.
- Now, the Task Force is developing a guideline on screening for depression among adults.
- The purpose of this conversation that we're having today is to get feedback from members of the public on your opinions about the potential outcomes of screening. Today, when we say outcome, we mean the effects screening for depression could have on someone's health.
- We are using what is called a Modified Delphi technique, which is a method that repeats the same questions in a survey, a focus group, and a second survey to understand your preferences.
- What this means is we provide you with some background information on depression and depression screening, including the results of the systematic review of the evidence for each potential outcome. We then ask you to rate how important the screening

outcomes are to you in a survey. That's the survey you've completed already, so thank you.

- And now, today we will discuss the outcomes you rated in the survey. And we provide you with an opportunity to ask Dr. _____ any content questions you may have about depression screening after reviewing the materials that were sent to you.
- After the focus group, we will send you another survey and ask you to re-rate the same outcomes to see if you change any of your ratings based on any new information we discuss during today's session.
- We really encourage you to ask Dr. _____ any questions you may have.
- I will **unmute** everyone momentarily. Does anyone have any questions about the purpose of today's session?
- Thanks, I'll **mute** everyone again and finish the instructions.

Reminders

- Some reminders for the call:

- Please mute yourself when you are not speaking. You can mute yourself using the mute button on your phone.
- If people do not mute themselves and we can hear a lot of background noise, we may mute you from our end. If we do this, a voice will come over your line to tell you that you have been muted. To unmute yourself, you can press **.
- Also, to allow us to capture all the information being discussed today as a group, if everyone could say their name before they speak and take turns speaking, it would help the transcriptionist when converting the audio to text. As well, I find it helps us to get to know who else is on the line since we are not doing the focus group in person.

- I want to emphasize there is no need to wait for me to call on you to speak, feel free to jump in once the other person is done talking. I may call on people if the group is very quiet or if the discussion is going very fast just to make sure everyone has a chance to speak if they wish. I also want to emphasize that 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 please let me know.

Confidentiality and consent to audio record

- Now I will talk about confidentiality: We take the issue of confidentiality seriously. No personal information about you will be shared with anyone outside of the study team. Your real name will not appear anywhere in the reports from today's session.
    - Any other information from today that could identify who you are will also be changed. So for example, if you say "in Toronto, where I live" we will replace that with something like "in the place where the participant lives".

- We strongly urge you to respect each other's privacy and not discuss what is said in the focus group with others. Also, please do not share the study materials with anyone outside of the study. The documents shared with you are not publicly available yet. Once the guideline recommendations are finalized they will be emailed to you and posted to the Task Force website.
- To respect everyone's privacy; we want to give you the option of using either your first name OR your participant ID number for the recording. I will call on each of you to state whether you would prefer to be called by your participant ID number or first name, and ask you to state that you consent to participate in today's recorded discussion.
- For example, "This is Lynsey, I consent to participate" or you could say "This is Participant 1, I consent to participate". Let's begin with _____(name or participant x).

Participant Name/No.	Email	Phone Number	Notes

- Have I missed anyone? Thank you.

- We are now ready to begin. I have unmuted everyone and we will begin audio recording. If anyone is opposed to audio recording today's session please let me know now.

  [Turn recorder on]

- The audio recorder is now on. Today's date is _____, and I am conducting the Task Force focus group number___ on screening for depression. There are _**7**_ participants present on the call today.

  We will start with some questions about the background information sheet on depression that you received prior to completing the survey.

1) Depression among adults 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) Do you believe additional information should be included in this background information sheet?

4) When having a discussion with your family physician about screening for depression, 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 depression screening?

2) Overall preference before discussion:

As a reminder from the survey and background information sheet, when we say screening, we mean the process where health care providers check for depression in every person, even if the person **has not noticed any symptoms or has not disclosed symptoms** to their health care provider. People who have noticed symptoms and notified their health care provider will get checked for depression (but this is called "usual care", not "screening").

Before we begin, does anyone have any questions for our content expert about screening, or the differences between screening for depression and usual care?

5) After reviewing the background document and completing the pre-focus group survey, what is your overall preference for depression screening? That is, if given the opportunity, would you choose to be screened or not?

6) As was described in the background information sheet, the risk of many of the potential harms and benefits of screening for depression are not well known. That means that when we searched for studies that could answer questions about the benefits and harms of screening, we did not find any studies or we did not find trustworthy information. Given this information, how much would you want to be screened?

    a. Probe: How does the level of evidence for the potential harms or benefits impact your screening preference?

3) Pre-focus group survey results – depression screening harms and benefits:

We are now going to review the pre-focus group survey results. Our discussion will focus on the harms and benefits that were rated differently (largest range in responses) across the group.

Please have your personalized data summary sheet in front of you so that you can review during the conversation.

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

Potential Benefit:

Please turn to *page 3* and refer to *question 1* located at *the top* of the page. The outcome reads '*Potential Benefit: Screening may lead to diagnosis of major depression disorder by a health care provider*'

7) . Responses for this question ranged from *2 - 9* with a median of 7.
    a. Are there any questions about this *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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Benefit:

Please turn to *page 5* and refer to *question 5* located at *the top* of the page. The outcome reads '*Potential Benefit: If screening leads to treatment, it may decrease the amount of missed work or school.'*

1. . Responses for this question ranged from *4 -9* with a median of 6.5.
    a. Are there any questions about this *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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Benefit:

Please turn to *page 5* and refer to *question 6* located at *the bottom* of the page. The outcome reads '*Potential Benefit: If screening leads to treatment, it may improve lifestyle behaviours (for example, less alcohol and drug abuse, smoking, and gambling).*

1. . Responses for this question ranged from *5-9* with a median of 7.
    a. Are there any questions about this *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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Benefit:

Please turn to *page 6* and refer to *question 7* located at *the top* of the page. The outcome reads '*Potential Benefit: If screening leads to treatment, it may decrease thinking about, planning, attempting, or completing suicide'*

1. . Responses for this question ranged from *4-9* with a median of 8.
    a. Are there any questions about this *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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Harm:

Please turn to *page 6* and refer to *question 8* located at *the bottom* of the page. The outcome reads '*Potential Harm: Screening may result in identifying someone as having depression when they do not have depression (called a false positive result).*

1. . Responses for this question ranged from *4 - 9* with a median of 5.
    a. Are there any questions about this harm 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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Harm:

Please turn to *page 7* and refer to *question 9* located at *the top* of the page. The outcome reads '*Potential Harm: Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm, or would have resolved without treatment. This can lead to unnecessary tests, treatments, worry and concern (called overdiagnosis).*

1. . Responses for this question ranged from *2-9* with a median of 6.
    a. Are there any questions about this harm, or overdiagnosis, 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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Harm:

Please turn to *page 7* and refer to *question 10* located at *the bottom* of the page. The outcome reads '*Potential Harm: Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms (called overtreatment).*

1. . Responses for this question ranged from *3-9* with a median of 5.5.
   - **a.** Are there any questions about this harm 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 (for example, while some people rated it as critical, you rated it as important or less)?

Potential Harm:

Please turn to *page 8* and refer to *question 12* located at *the bottom* of the page. The outcome reads '*Potential Harm: Screening may result in labelling someone as having depression which can lead to anxiety or stigma'*

1. . Responses for this question ranged from *2-9* with a median of 6.
   - **a.** Are there any questions about this harm 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 (for example, while some people rated it as critical, you rated it as important or less)?

Selection of the Top 5 Potential Harms and Benefits for Depression among Adults

2. Please turn to page 9 and refer to the list of 12 potential benefits and harms of screening for depression among adults. We asked you to select five items on the list that you think are <u>most critical to consider</u> when people are making decisions about screening.
   a. Take a look at your selected top five outcomes. How did you decide which outcomes were most important for you to consider as part of your screening decision?
      i. Probe: <u>Why</u> did you select the outcomes that you did? <u>Why</u> did you feel these outcomes were more important than the others listed?

   b. <u>Benefits</u> were typically selected <u>more frequently</u> than harms when participants were asked to select the outcomes they feel are most important to consider in a screening decision. Do you have any thoughts about this trend?

4) Overall preference after discussion:

****moderator note: Only ask these questions if not extensively discussed earlier in FG**

Survey Question:

1. Please turn to *page 11.* The question at the *top* of the page reads *'Considering the potential harms and benefits of screening for depression, how much would you want to be screened?*

Responses ranged from *2-9* with a median of 7.

- **a.** Take a look at how you rated this question. What was your rationale for rating the question the way you did?
  - **a.** What harm or benefit is the **most important** for you when making this decision?
  - **b.** What harm or benefit is the **least important** for you when making this decision

- **b.** Have your preferences changed from those you expressed in the first survey and earlier in today's discussion?

2. Now take a look at the question at the *bottom* of page 11. The question there reads *'Considering that the risk of many of the harms and benefits of screening for depression are not well known, how much would you want to be screened?*

Responses ranged from *2 - 9* with a median of 6.

- **c.** Take a look at how you rated this question. What was your rationale for rating the question the way you did?
  Probes:
  a. Did you rate the first question on page twelve differently than the second question?
  b. How did the level of evidence for the potential harms and benefits impact your screening preference?

4) Additional Information:

3. 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 depression?

5) Potential barriers or facilitators to screening:

4. Screening for depression is completed by a doctor or nurse practitioner who asks a short series of questions. Your answers are tallied up and a score is determined. Specific scores indicated whether it is likely or not that you have depression and if further diagnostic tests are required.
    - **a.** If you choose to get screened, what do you think 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 a baby health etc.)
        - **iii.** Probe: fear (do not want to talk about mental health with doctor/nurse practitioner because of concerns of what might happen)

    - **b.** If you choose to get screened, what would make getting the screening test easy, if anything? (probe: what would make it harder?)

6) Closing remarks:

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

Conclusion

- Thank you for taking the time to be a part of our focus group today.
- This week you will each receive a link to another online survey via email. This is the same survey you completed prior to today's discussion but with some extra questions about your experience participating in the project. The reason that the survey asks the same questions is so that you have an opportunity to change or confirm your responses from the first time you completed the survey. For example, a person may have developed new understanding or a new perspective after discussing the outcomes in greater detail during today's discussion and wants to change their rating of that outcome. Another person may feel surer about their responses and keep the ratings the same. We like to see the differences and the similarities in people's ratings before and after the teleconference discussion.
- You will have approximately one week to complete the online survey.
- We will process your reimbursement payment once we close the survey. Please note that the reimbursement payment can take up to 45 days to process, but it usually doesn't take that long.

- Once we develop a report of our findings we will create a summary to send to you. You will also be invited to attend an optional debrief session to review the results of the study and add additional comments.
- We understand that questions or additional comments may come up after today's call. This is very normal. If you have any additional questions or something that you would like to add to today's discussion, please feel free to email Kyle. We will do our best to answer your question. If we are not able to answer your question we will forward it to the working group content expert for their opinion.

  Thank you and have a great day!

Appendix F: Patient engagement survey

Please respond to each of the following statements using the scales provided. Respond to each question 1-7:

1: No extent
2: Very small extent
3: Small extent
4: Fair extent
5: Moderate extent
6: Large extent
7: Very large extent

If you select 1-4 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)?

Appendix G: Participant engagement data

Figure 3. Survey responses for participant engagement items (n = 18)

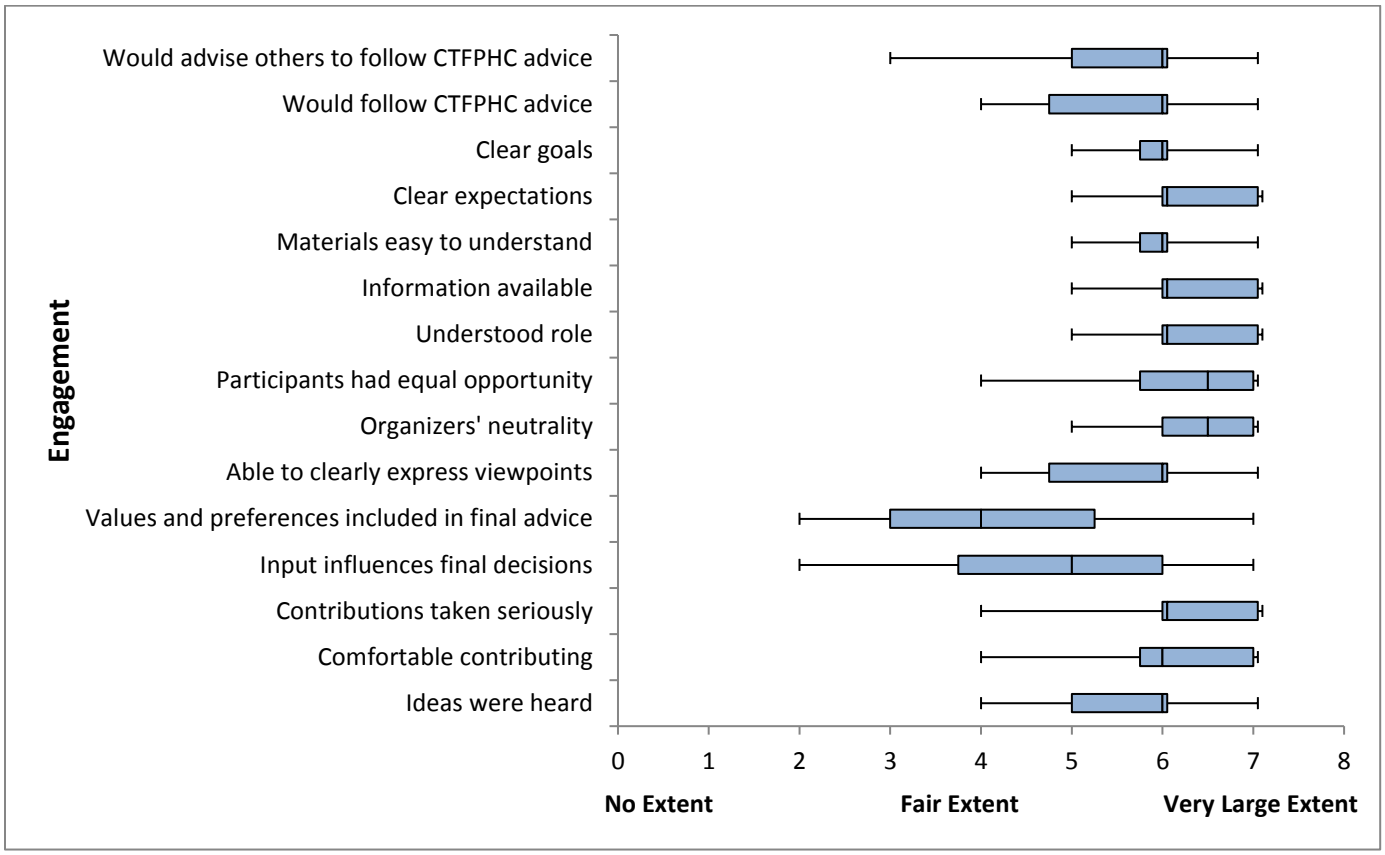


Table 8. Survey responses for participant engagement items (n = 18)

Question	Median	IQR*	Range
To what extent do you believe that your ideas were heard during the engagement process?	6	5-6	4-7
To what extent did you feel comfortable contributing your ideas to the engagement process?	6	5.75-6	4-7
Did organizers take your contributions to the engagement process seriously?	6	6-7	4-7
To what extent do you believe that your input will influence final decisions that underlie the engagement process?	5	3.75-6	2-7
To what extent do you believe that your values and preferences will be included in the final health advice from this process?	4	3-5.25	2-7
To what extent were you able to clearly express your viewpoints?	6	4.75-6	4-7
How neutral in their opinions (regarding topics) were organizers during the engagement process?	6.5	6-7	5-7
Did all participants have equal opportunity to participate in discussions?	6.5	5.75-7	4-7
How clearly did you understand your role in the process?	6	6-7	5-7

To what extent was information made available to you either prior or during the engagement process so as to participate knowledgeably in the process?	6	6-7	5-7
To what extent were the ideas contained in the information material easy to understand?	6	5.75-6	5-7
How clearly did you understand what was expected of you during the engagement process?	6	6-7	5-7
How clearly did you understand what the goals of the engagement process were?	6	5.75-6	5-7
To what extent would you follow health advice from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?	6	4.75-6	4-7
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)?	6	5-6	3-7

**Note: IQR = interquartile range*

Appendix H: Participant experience data

Figure 4. Survey responses for experience items (n = 18)

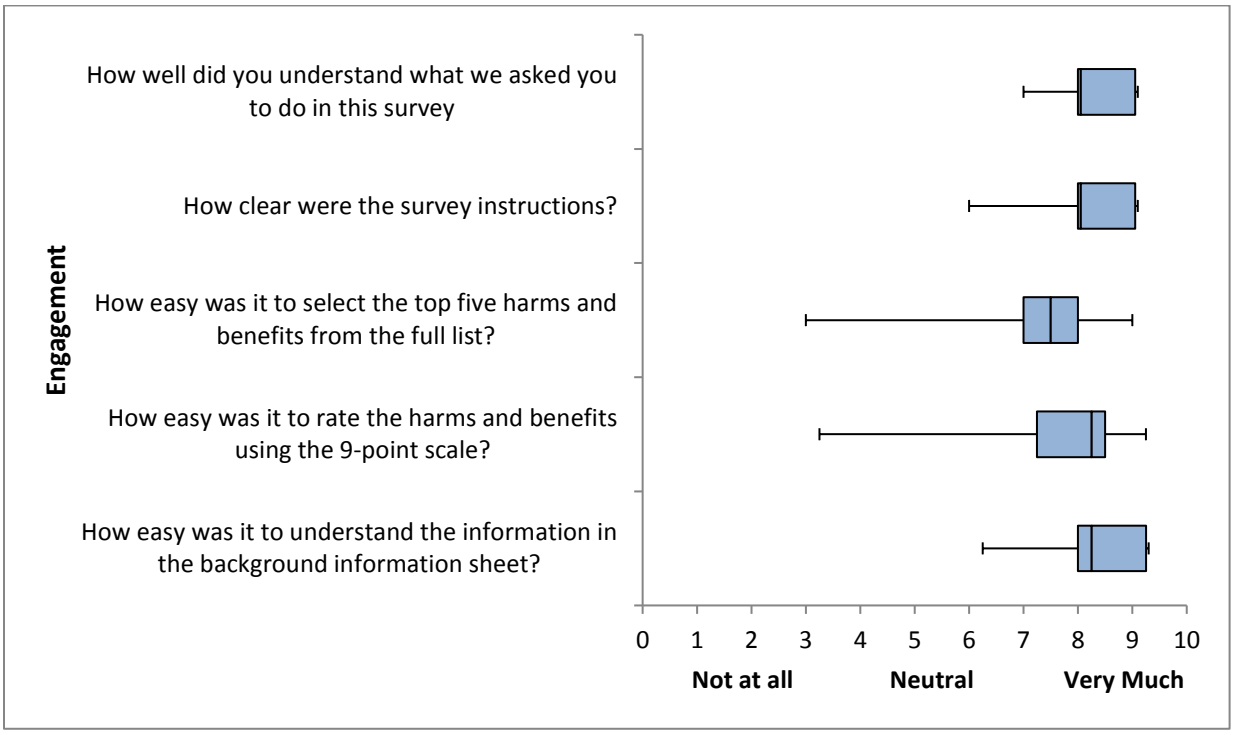


Table 9. Survey responses for experience items (n = 18)

Question	Median	IQR*	Range
How easy was it to understand the information in the background information sheet?	8	7.75-9	6-9
How easy was it to rate the harms and benefits using the 9-point scale?	8	7-8.25	3-9
How easy was it to select the top five harms and benefits from the full list?	7.5	7-8	3-9
How clear were the survey instructions?	8	8-9	6-9
How well did you understand what we asked you to do in this survey?	8	8-9	7-9

**Note: IQR = interquartile range*

Appendix I: Participant's overall experience

Table 10. Qualitative data for project experience (n = 18)

Project component	Participants' impressions	Illustrative quotes
Background information sheet	**Positive feedback** Participants considered the information to be straightforward and easy to understand. Positive attributes of the background sheet: i) amount of information presented was appropriate ii) content was respectful and compassionate iii) user-friendly terminology	*Information provided was reflective of my experience FG3* *I felt the language the document was written in was very positive and respectful for everyone, so not just understanding but being compassionate toward people who have lived experience of depression. FG1*
	Suggestions for improvement Additional information or alternative formatting that would improve the background sheet: i) highlight the difference between screening and usual care earlier in the document ii) interspersing graphics with blocks of text to improve flow iii) anxiety's role as a symptom of depression iv) additional resource links (including links to support services) v) information about access to mental health care	*I realized when reading through this that there is a big difference between being screened for depression and having the patient report their symptoms and then be tested based on that. I think it would help if that was highlighted a little bit more near the top, the real difference. FG2* *It's a lot of text to read and figuring out a way to present it so it's more visually appealing so you get the message both ways, especially considering different literacy levels. FG3* *How do I access help? FG4*

Focus groups and interviews	**Positive feedback** Participants noted that they felt understood, and appreciated the moderator's neutrality Participants in smaller focus group enjoyed the focus group size, as they felt it allowed them to contribute more and feel heard.	*"The moderator on our phone call responded to my comments in a way that made me feel heard and understood."(*Adult Dep_PH2_17) *"The moderator was encouraging of all contributions."(Adult Dep_PH2_17)* *"The focus group was smaller than expected, which made it easier to contribute and feel heard."(Adult Dep_PH2_17)*
	Suggestions for improvement Participants in larger focus group sizes felt they did not have as much opportunity to contribute, particularly when individual participants dominated the conversation. One participant felt they were not asked the right questions, and had more to contribute. One participant felt a separate group for marginalized people who may experience depression differently could be useful, to explore their different perspectives and preferences. Background noise on participants' lines can make it difficult to understand or interact with their comments. Some participants felt a video conference or in-person focus group would allow for more robust discussion, while others felt the teleconference format was ideal for confidentiality.	*"I wanted to say more but wasn't asked the right questions or given much opportunity to speak" (Adult Dep_PH2_02)* *"There was an individual who was inconsiderately speaking a little much that perhaps didn't give others a chance to say more at times" (Adult Dep_PH2_19)* . *"I feel that my experiences were unique in the group who did not have as much direct experience dealing with abusive and demeaning behaviour by health care providers as a marginalized person with long term health conditions. I feel there needs to be more focus on marginalized people who are more likely to experience stressors that affect their mentally and emotionally."* *(Adult Dep_PH2_01)* *"I think we all contributed fairly equally. Unfortunately, one participant was difficult to understand due to a poor connection/background noise. I felt like I was unable to respond to or engage with her comments as I did with the other participants."* *(Adult Dep_PH2_17)*
Overall project experience	**Positive feedback** Participants felt the engagement process was well organized and respectful. Participants enjoyed learning about depression screening and hearing others' thoughts, inputs,	*"It was a great experience. The language used was respectful. I enjoyed the teleconference" (Adult Dep_PH2_21)* *"The organizer made the process very smooth & comfortable, etc. "* *(AdultDep_PH2_06)* *"The process was very welcoming. I felt valued*

	and perspectives. Participants appreciated the opportunity to have a voice and be heard, and contribute to what they felt was an important health care topic.	*and respected in every step. Thank you for your hard work."* *(Adult Dep_PH2_21)* *"I really liked hearing the other input and stories from the other participants in the focus group. I could relate a lot and it was quite eye opening so I appreciated the opportunity."* *(Adult Dep_PH2_18)* *"I appreciated the opportunity to be heard on an important matter."* *(AdultDep_PH2_06)*
	Suggestions for improvement Online version of the survey did not allow for immediate response to questions that arose while participants completed the survey. Emailing questions and awaiting answers was considered 'cumbersome' Sending outline of Focus Group questions or themes in advance could help participants feel more prepared, given the long period of time between completing the survey and focus group Limitation of finite response options results in less accurate information collected. An open-text box option would be preferable. Combining similar questions on the survey would be helpful. The similarity caused confusion in assigning ratings, and some questions felt repetitive Having a progress bar showing percent of survey completed could be useful	*"I didn't realize during the focus group we were going to be giving ideas to improve the depression backgrounder sheet or input about that so I felt unprepared to discuss; also, I didn't realize we'd be asked our thought process around choosing the ratings we did -- especially hard to remember something that took place a month ago -- maybe if we'd been alerted to this key point ahead of time that would have helped?"* *(Adult Dep_PH2_02).*