Canadian Task Force on Preventive Health Care

Patient preferences for depression screening among adults: Data summary

Prepared for the Canadian Task Force on Preventive Health Care

Submitted: September 21, 2018

Prepared By:
Lynsey Burnett, Kathleen Einarson, Alekhya Mascarenhas, Rossella Scoleri, Sherry Stein, Sharon Straus, and Ainsley Moore

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

Contact:
Lynsey Burnett

E: burnettly@smh.ca
T: 416-864-6060 ext. 77566

St. Michael's
Inspired Care.
Inspiring Science.

Table of Contents

Introduction 2
Methods 2
Participants 2
Recruitment 2
Characteristics of included participants 2
Outcome ratings 3
Outcome scale ratings 3
How to read the box plot 5
Overall preferences for screening 6
Participant perceptions of outcomes for screening 7
Participant requests for information 7
Values and preferences for screening 9
Factors influencing access to screening 11
Participant engagement and experience 12
Participant engagement ratings scale 13
Participant experience ratings scale 14
Participants' overall experience 15
Limitations 17
Suggestions for applying findings 18
Conclusion 19
References 20
Appendix A: Screening questionnaire 21
Appendix B: Background Sheet 26
Appendix C: Pre- and post-focus group survey 29
Appendix D: Sample personalized response sheet 41
Appendix E: Focus group guide 51
Appendix F: Patient engagement survey 58

Introduction

The Canadian Task Force on Preventive Health Care (CTFPHC) 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 1 of the CTFPHC patient preferences assessment about screening for depression among adults. Phase 1 data were obtained via focus groups, interviews, 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 to consider various harms and benefits of screening when making decisions about getting screened for depression. We also examined participants' experiences in the project. Data were collected between July 3rd and August 22nd, 2018.

Methods

For a detailed description of the methods used in this project, please refer to Phase 1 of the CTFPHC's Patient Engagement Protocol (http://canadiantaskforce.ca/methods/patient-preferences-protocol/)

Participants

Recruitment

Participants were English-speaking men and women in Canada 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. We recruited participants 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 3 males and 13 females who were 22 to 63 years of age (mean age = 36.5 years, standard deviation = 12.21). Two participants self-identified as Indigenous.

(i.e. First Nations, Métis, or Inuit). Participants were from Ontario (*n* = 4), Nova Scotia (*n* = 3), Saskatchewan (*n* = 2), British Columbia (*n* = 2), Manitoba (*n* = 2), Alberta (*n* = 1), Newfoundland (*n* =1), and Prince Edward Island (*n* = 1). The majority of participants lived in urban and suburban areas (*n* = 7; *n* = 5); four participants lived in a rural area. The majority of participants had a college diploma or bachelor's degree (*n* = 12) or a graduate or professional degree (*n* = 3). Participants had household incomes of less than $25,000 (*n* = 2), $25,000 – $29,999 (*n* = 3) $30,000-$39,999 (*n* = 1), $40,000-$49,999 (*n* = 2), $50,000-$59,999 (*n* = 2), $70,000-$99,999 (*n* = 4), and $100,000 or more (*n* = 2).

Outcome ratings

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

Outcome scale ratings

In the first part of the survey, participants rated the importance of 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

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

Table 1. Descriptions for outcomes

Short description	Full description
Benefits (*n* = 7)	
Decreased depression symptoms	Screening may decrease symptoms of depression
Diagnosis of major depressive disorder	Screening may result in a diagnosis of major depressive disorder by a health care provider
Improved quality of life	Screening may improve perceived physical and mental health over time, also referred to as health-related quality of life
Improved day to day function	Screening may improve how a person functions in their day-to-day life
Decreased absence	Screening may decrease the amount of time someone is absent from work or school
Improved lifestyle behaviors	Screening may improve lifestyle behaviours (for example, decreased alcohol and drug abuse, smoking, and gambling)
Decreased suicide	Screening may decrease thinking about, considering, planning, attempting, or completing suicide
Harms (*n* = 4)	
False positive – psychosocial impact	Screening may result in identifying someone as having depression when depression is not present (called a false positive result).
Overdiagnosis - psychosocial impact	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 over-diagnosis)
Overtreatment	Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms of treatment (called overtreatment)
Harms from treatment	Screening may result in harms from treatment of depression. Harms of psychotherapy can include worsening of existing symptoms or development of new ones. Harms of antidepressants can include unwanted side effects from the medication, or an increased risk of suicidal thoughts or behaviors in people under 24 years of age.

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

How to read the box plot

To show participant ratings, we used the box plot throughout this report. The box plot whiskers show the full range of responses, the box shows the interquartile range (IQR), and the line 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

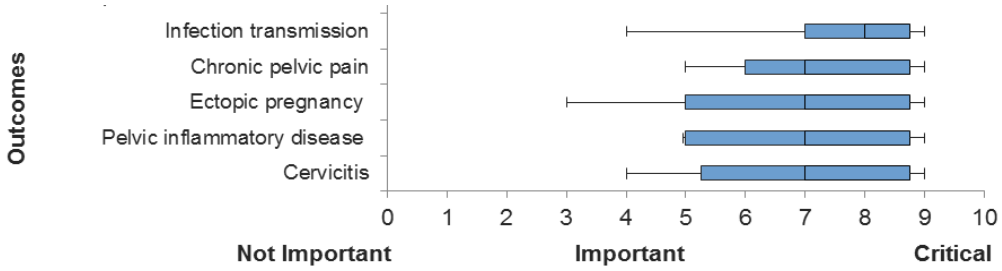


Figure 1: Post-survey outcomes scale ratings (n = 16)

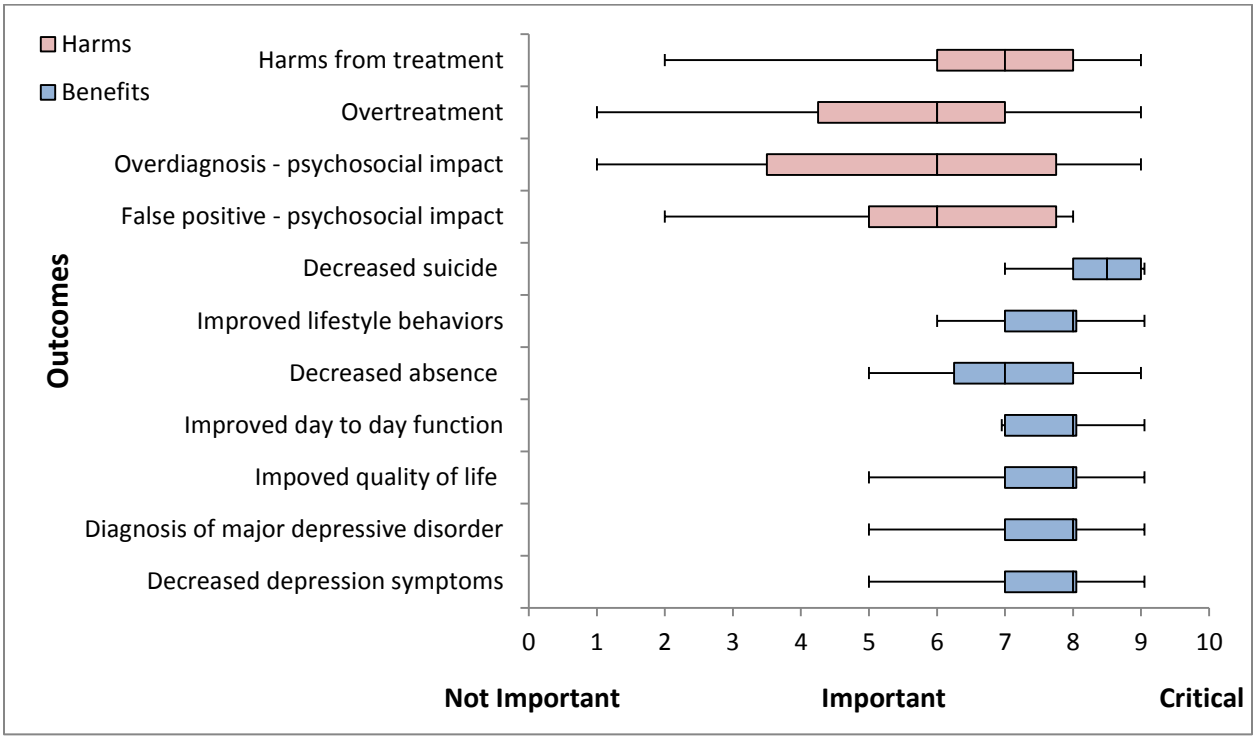


Table 2. Pre- and post-survey outcomes scale ratings (n = 16)

Outcome	Pre-survey			Post-survey		
	Median	IQR*	Range	Median	IQR	Range
Benefits						
Decreased depression symptoms	7	5-8	2-9	8	7-8	5-9
Diagnosis of major depressive disorder	7	5-8	4-8	8	7-8	5-9
Improved quality of life	7	5-8.75	5-9	8	7-8	5-9
Improved day to day function	7	6.25-8.75	4-9	8	7-8	7-9
Decreased absence	7	5-8	2-8	7	6.25-8	5-9
Improved lifestyle behaviors	8	6-8.75	3-9	8	7-8	6-9
Decreased suicide	8	7-9	5-9	8.5	8-9	7-9
Harms						
False positive – psychosocial impact	6	4-7	2-8	6	5-7.75	2-8
Overdiagnosis - psychosocial impact	6	4-8	2-8	6	3.5-7.75	1-9
Overtreatment	6	4-7.75	3-9	6	4.25-7	1-9
Harms from treatment	7.5	5-8	2-9	7	6-8	2-9

**Note: IQR = interquartile range.*

Median post-survey outcome ratings for benefits ranged from 7 to 8.5. Median post-survey outcome ratings for harms ranged from 6 to 7. Between the pre and post surveys, there was a small increase in the median outcome rating of several benefits, while median outcome ratings for harms remained generally the same. The post-survey IQR of the benefit ratings indicated participants felt all benefits were *critical* for decision making. The post-survey IQR of the harm ratings were lower overall, ranging from the low end of the *important* range up to *critical*. There was also a wider range of ratings for harms than for benefits, indicating participants had a greater range of opinions on the importance of considering harms associated with screening compared with opinions on the importance of considering benefits.

Overall preferences for screening

In the second part of the survey, participants rated their overall preference for being screened for depression. Participants were first asked to rate the statement “Considering the potential harms and benefits of screening for depression, how much would you want to be screened?” on a scale from 1-9. A score of 1 indicated “Not at all”; a score of 5 indicated “Neutral”; and a score of 9 indicated “Very much”.

A summary of survey responses is presented below as well as in Table 3. Table 3 presents overall preferences screening and includes pre- and post-focus group survey data for comparison purposes.

Table 3. Pre- and post-survey overall screening preferences (n = 16)

Outcome	Pre-survey			Post-survey		
	Median	IQR*	Range	Median	IQR	Range
Overall screening preference	7.5	5.5-8.75	1-9	8	7-9	2-9

**Note: IQR = interquartile range.*

There was a wide range of preferences for screening. However, the median post-survey preference for screening was 8, indicating that overall, most participants had a strong preference for screening.

Participant preferences for screening were further explored in the focus groups. The results of the focus group discussions are presented below.

Participant perceptions of outcomes for screening

Two focus groups (*n* = 14) and two interviews (*n* =2) were used to gather qualitative data from participants about the importance of the harms and benefits of screening and their overall preferences for screening for depression in adults. Focus group and interview transcripts were coded using a directed content analysis approach.[2]

A summary of the focus group and interview discussions, as well as survey responses, are presented in Tables 5 and 6.

Participant requests for information

Table 5. Participant requests for information (n=16)

Needs	Description	Illustrative quotes
Background information sheet	Participants generally found the background sheet to be concise, informative and easy to understand. A request was made to replace the term "problem" in the opening sentence with "condition". There was a preference for key points to be presented in list form rather than in paragraphs. Statistics were helpful but perceived to be outdated (i.e. 2012). Participants felt they would have benefited from the following supplementary	*"The sheet said how many Canadians have depression and how many have yet to be identified by a healthcare provider; it highlighted relevance of this issue."* FG1

	information in the background sheet: i) the impact of depression on family and friends ii) a statement that diagnosis of depression should be made by a healthcare professional iii) an explanation of the difference between normal short-term grief and depression iv) information about the varying degrees of severity of depression v) additional statistics regarding the percentage of suicides that occur in *untreated* individuals	
Information required to make informed screening decision	Participants felt they would need the following information to make an informed decision on screening: i) a description of mental and physical symptoms of depression ii) more information on the challenges related to self-awareness of symptoms iii) a discussion with their doctor regarding short-term vs. long-term depression iv) how to evaluate depression severity on a 1-10 scale v) the threshold at which symptoms warrant a diagnosis of depression	*"Follow-up visits with a physician would be important; if I was feeling a certain way for only a certain period of time I would want to revisit screening."* FG2

In summary, this table identifies additional background information requested by participants, as well as information and topics participants considered important to discuss with their primary care providers in order to make an informed screening decision. Participants indicated a need for more information on how depression may impact others, including friends and family, as well as additional statistics on potential harms faced by individuals living with untreated depression. Participants stated that information about mental and physical symptoms of depression, a discussion surrounding the differences in short-term depression, long-term depression and normal grief, as well as the threshold at which symptoms warrant a diagnosis of depression, were important topics for primary care providers to cover in conversation with patients.

Values and preferences for screening

The qualitative data collected through focus groups (*n* = 14) and interviews (*n* = 2) revealed the benefits and harms of screening that may influence a patient's overall preference for screening. Table 6 summarizes all unique values and preferences present in the qualitative data.

Table 6. Participants' values and preferences for screening (n = 16)

Factors	Description		Illustrative quotes
Perceived benefits of screening	1. Screening may decrease symptoms of depression	Uncertainty was expressed about the link between screening and decreasing symptoms. Diagnosis may provide reassurance and an understanding of one's symptoms. Participants felt screening may reduce suicide (although there was no discussion on the lack of evidence in support for this statement)	*"If I got a result that I was depressed, I don't think it would change my symptoms right away. I may actually be stressed."* FG2 *"[Reducing suicide] is very important because people have thoughts and talking to people about that is very important, especially at the screening age."* FG2
	2. Screening may decrease absence from school/work	Participants felt that screening may decrease absenteeism. Participants saw reduced absenteeism as beneficial to both the individual and society.	*"It is important to me as I am absent from work 1-2 days a week because of my symptoms."* FG3 *"Figure out what is going on sooner and be able to lead a more balanced and healthy lifestyle."* FG1
Perceived harms of screening	1. False Positive	Most participants considered this to be a significant harm for several reasons: i) stress is likely to result from an incorrect diagnosis ii) unnecessary treatment may be provided iii) the actual cause of any symptoms may be missed if depression is incorrectly diagnosed iv) a false positive may be challenging to remove from medical records Other participants felt this harm to be relatively insignificant	*"Might even be a mild case [that] may not have required treatment but if falsely diagnosed there can be consequences in terms of time, treatment and stigma."* FG2

		when weighed against the benefits of screening. Concerns were expressed with respect to the power differential between physician and patient. Efforts to challenge a diagnosis of depression were anticipated to be difficult.	
	2. Overtreatment	While there was an acknowledgment that no perfect method of diagnosing depression exists, participants were mixed in their opinions regarding overtreatment. Participants indicated that their attitudes regarding overtreatment would depend upon the treatment modality. Stigma was identified as a concerning harm resulting from overtreatment.	*"Everyone is into health. If they start treatment, this may even cause one to have symptoms that weren't there before."* FG2
	3. Harms arising from treatment for depression	Participants expressed several concerns regarding the adverse psychological impact of being treated: i) negative impact on self-esteem ii) adverse effects of stigma iii) a decreased sense of overall well-being Participants questioned the statistics on suicide, specifically the percentage of suicides that occurred while receiving treatment. A lack of capacity to understand and manage side effects in the targeted age group was identified as a treatment harm. While several treatment harms were identified, participants also cited the statistics that appear to indicate treatment harms are rare.	*"Being overtreated with counseling/lifestyle changes wouldn't be harmful. The only overtreatment that is harmful in my perspective is with medication."* FG3 *"People under 24 are the most fragile."* FG2

Preference to be screened	The majority of participants would prefer to be screened and stated that benefits of screening outweighed risks. Potential risks of not screening were deemed more significant than a possible false positive. Willingness to screen frequently correlated with treatment method and availability. Some participants indicated a preference for discussion with a healthcare provider over screening by checklist. Confidentiality of the screening results was cited as a deciding factor in whether to screen or not. The choice to be screened may be age-related. Participants expressed the opinion that screening would only be beneficial if treatment was accessible post-diagnosis.	*"I know it's better to be screened so one can know the result and if diagnosed seek treatment. But there is a fear of thinking I am not as healthy as I personally think."* FG2 *"Relationship with care providers is an important part of my screening decision."* FG2 *"As I grew older I would want this available as a screening tool."* FG3

This table summarizes the outcomes of screening that participants identified as most critical when making a decision about being screened for depression as an adult. It also summarizes participants' overall preferences for screening. Most participants reported that the benefits of screening outweighed the harms, with some participants considering the statistics provided appear to indicate treatment harms are rare. Participants expressed an overall preference for screening, and many participants stated that their willingness to screen may be related to the type of treatment options offered (i.e. counseling and lifestyle changes vs. medication) and treatment accessibility. Participants felt treatment harms were disproportionately associated with medications, while counseling or lifestyle changes posed less risk but are harder to implement. Generally, the potential risks associated with not screening were deemed more significant than a possible false positive, given the potential effect of undiagnosed and untreated depression.

A critical component of the focus group discussions that should be noted is that in some instances, participants used the term 'screening' during focus group discussions, however they were actually describing 'diagnostic testing' (i.e. they already were experiencing symptoms of depression or weren't feeling well). Although attempts to clarify this difference were made by the moderator, it remained difficult at times to distinguish between participants' preferences for 'screening' as opposed to 'diagnostic testing'.

Factors influencing access to screening

Focus group (*n* = 14) and interview (*n* = 2) responses revealed several barriers and facilitators to accessing screening for depression. A summary is provided in Table 7.

Table 7. Factors that influence participants' access to screening (n = 16)

Factors	Description	Illustrative quotes
Potential barriers to	Participants identified several potential barriers to screening:	

screening	i) transportation costs ii) time off work iii) timely access to a physician iv) social stigma associated with depression, especially amongst young people v) fear of diagnosis vi) lack of access to post-diagnosis treatment (e.g. limitations in the healthcare system, remote location) diminishes the importance of screening vii) literacy issues (e.g. screening languages available, general literacy) viii) lack of knowledge about depression	*"Social stigma of depression would come into play, like being ashamed to discuss your feelings with a healthcare provider and having the possibility of being diagnosed."* FG1 *"It takes courage to speak about how one is feeling."* FG4
Potential facilitators to screening	Participants identified several facilitators to screening: i) availability of screening at multiple sites (GP, walk-in clinics) ii) screening via telecommunication iii) availability of online screening iv) increasing awareness of depression and screening (e.g. Public Health awareness campaign)	*"Something over the phone so you have someone there to show empathy, attach some type of humanity to it."* FG1 *"So many services are offered that people don't even know about them."* FG2

In summary, participants described perceived barriers and facilitators to accessing and completing screening for depression among adults. Factors included concerns surrounding logistics (such as time off work and travel), potential stigma (including a fear of diagnosis and being uncomfortable discussing sensitive topics with PCPs), knowledge gaps (such as a lack of awareness of treatments and services), and treatment access (such as cost and availability).

Participant engagement and experience

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

Participant engagement ratings scale

In the post-focus group survey, participants were asked a series of questions 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). Participants were asked to explain their ratings for each engagement item. The quantitative responses to these questions are summarized in Figure 3 and Table 8. The quantitative ratings and relevant qualitative explanations are also summarized below.

Overall, participant experience questions were highly rated, indicating a positive engagement experience. Most questions had a median response of 6. Questions with the slightly lower medians of 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 CTFPHC.

A median response of 5, or moderate extent, was also recorded for questions that asked if participants felt all participants had an equal opportunity to participate in discussions, as well as the extent to which participants felt they were able to clearly express their viewpoints. Most participants who gave a lower rating for these questions attributed this to the fact that they were part of a larger focus group (n=10). These participants noted a focus group with a smaller number of people or longer length could have improved participation and engagement.

Figure 3. Survey responses for participant engagement items (n = 16)

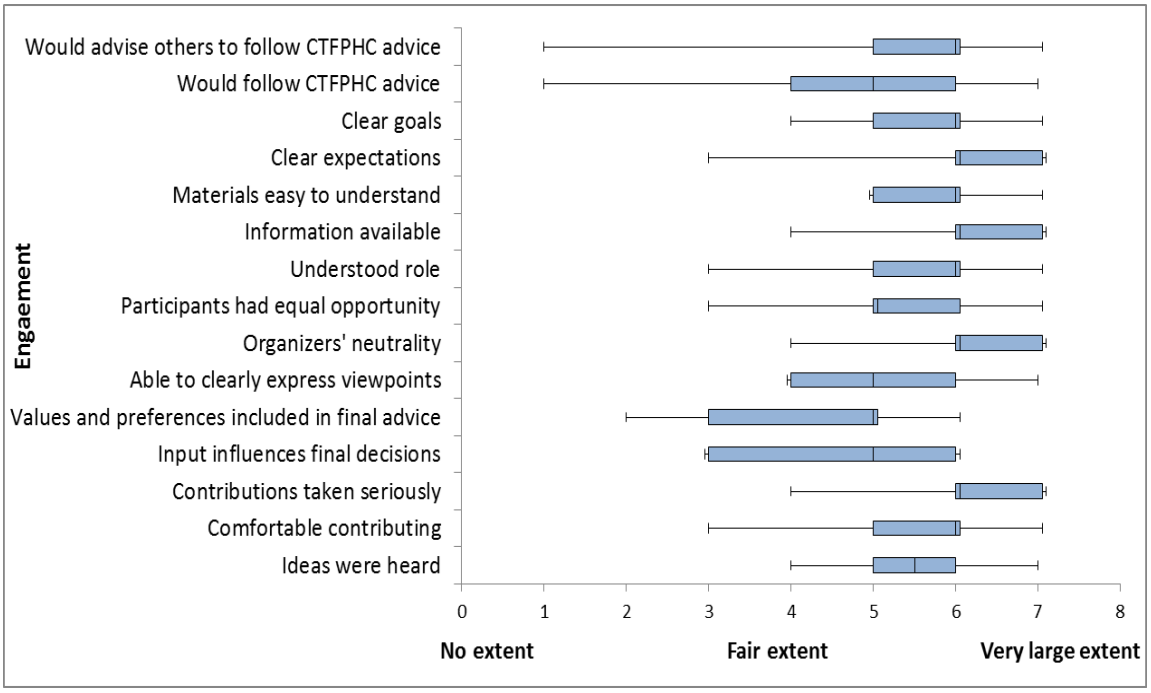


Table 8. Survey responses for participant engagement items (n = 16)

Question	Median	IQR*	Range
To what extent do you believe that your ideas were heard during the engagement process?	5.5	5-6	4-7
To what extent did you feel comfortable contributing your ideas to the engagement process?	6	5-6	3-7
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	3-6	3-6
To what extent do you believe that your values and preferences will be included in the final health advice from this process?	5	3-5	2-6
To what extent were you able to clearly express your viewpoints?	5	4-6	4-7
How neutral in their opinions (regarding topics) were organizers during the engagement process?	6	6-7	4-7
Did all participants have equal opportunity to participate in discussions?	5	5-6	3-7
How clearly did you understand your role in the process?	6	5-6	3-7
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	4-7
To what extent were the ideas contained in the information material easy to understand?	6	5-6	5-7
How clearly did you understand what was expected of you during the engagement process?	6	6-7	3-7
How clearly did you understand what the goals of the engagement process were?	6	5-6	4-7
To what extent would you follow health advice from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?	5	4-6	1-7
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	1-7

**Note: IQR = interquartile range*

Participant experience ratings scale

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

Overall, participants responded positively to all 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 to 8). Participants were also asked to summarize what they had been asked to do in the survey. The majority of participants accurately described the survey tasks they completed; four participants chose not to answer the open-ended question. Thus, there is converging evidence that participants understood the survey tasks.

Figure 4. Survey responses for experience items (n = 16)

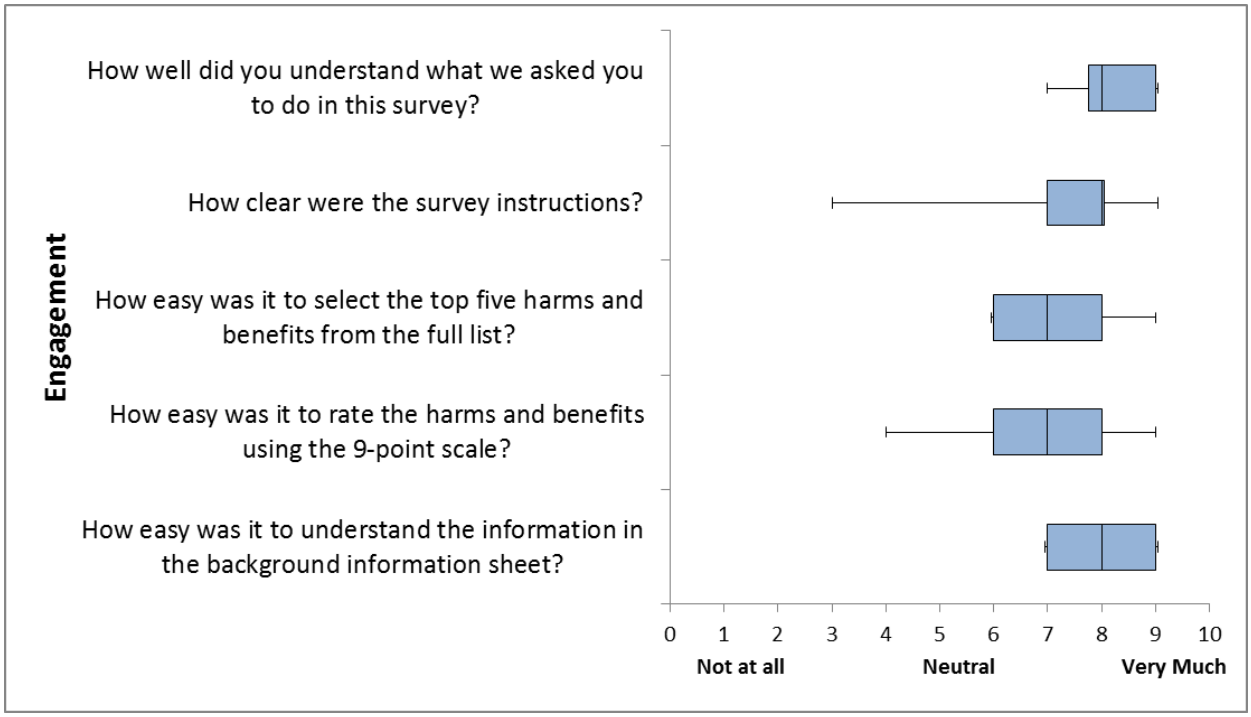


Table 9. Survey responses for experience items (n = 16)

Question	Median	IQR*	Range
How easy was it to understand the information in the background information sheet?	8	7-9	7-9
How easy was it to rate the harms and benefits using the 9-point scale?	7	6-8	4-9
How easy was it to select the top five harms and benefits from the full list?	7	6-8	6-9
How clear were the survey instructions?	8	7-8	3-9
How well did you understand what we asked you to do in this survey?	8	7.75-9	7-9

**Note: IQR = interquartile range*

Participants' overall experience

Three focus groups (*n* = 14), two interviews (*n* = 2), and 16 open-ended survey questions (*n* =16) were conducted to gather qualitative data from participants about their experience in the project. Table 10 below summarizes participants' main impressions of the background information sheet, focus group, and survey.

Table 10. Qualitative data for project experience (n = 16)

Project component	Participants' impressions	Illustrative quotes
Background information sheet	Participants reported that the sheet was easy to understand and well-organized One participant felt it should be clarified whether they should consider the screening process as they are now (with symptoms), or in a hypothetical situation where they have no symptoms (i.e. part of the screening population)	*Well written and not too much medical jargon, and the harms and benefits got equal attention. (AdultDep_PH1_09)* *Very well constructed, easy to follow. Difficult issue to tackle! (AdultDep_PH1_09)*
Focus groups and interviews	**Positive feedback** Several participants stated they enjoyed hearing, and learning from, different perspectives and opinions of other participants Several participants noted that they felt heard and were able to fully express their views Several participants stated that they appreciated the focus group moderator's respectful manner and impartiality	*I liked hearing other people's viewpoints on the subject of depression screening. It was interesting to hear different viewpoints and to learn about the taskforce (AdultDep_PH1_06)* *I felt heard and was allowed to fully express my views and rationale behind my responses. (AdultDep_PH1_07)* *I know there were some varied opinions among the group but I feel confident that all views will be considered during the process. (AdultDep_PH1_06)*
	Suggestions for improvement Several participants who took part in the larger focus group (n=10), requested a smaller number of participants in each focus group, and/or extending the length of the focus group, in order to allow more opportunity for engagement Some participants found it difficult to express their opinion due to the teleconference format or more vocal participants Some participants indicated they would have preferred a face-to-face focus group format (via video conferencing)	*Limited by time and large group format, so if someone waited to comment second or third, they may have been missed and conversation moved on (AdultDep_PH1_16)* *I felt like my opinions differed substantially from the more vocal panelists (AdultDep_PH1_11)*
Overall project experience	**Positive feedback** Participants appreciated the opportunity to	*I liked the focus group discussion as that allowed me to understand myself better in terms of how I operate while making decisions*

	provide input on what was perceived as an important and meaningful topic Participants found the overall process to be well organized, and communications to be fast and reliable	*and what all one may encounter while choosing to be screened for depression. It is a big but important and necessary decision. (AdultDep_PH1_07)* *The open forum to discuss the topic with peers was presented and completed clearly and concisely. Getting in touch with the coordinators was fast and reliable (AdultDept_PH1_22)*
	Suggestions for improvement One participant felt the participant sample size was too small, and the survey and focus group process not extensive enough to make decisions or provide policy advice One participant felt that the two month process was too long and drawn out. One participant suggested the scale for rating harms and benefits could be more granular	*20 people is a very small sample size, and the survey and focus group process was quite limited. The study does not seem anywhere near extensive enough to make decisions or provide policy advice on such a huge and life-affecting topic. (AdultDep_PH1_16)* *A 1-9 scale is too high-resolution for gut feelings about the importance of various factors. (AdultDep_PH1_08)*

Limitations

In addition to the limitations of the methods discussed in the Patient Engagement Protocol, there were additional limitations specific to this project.

1. Our sample is not representative of the target screening population in Canada. The majority (*n* = 15) 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. And, the majority of participants lived in urban or suburban areas (*n* = 12), and only two participants identified as Indigenous. As such, the preferences, barriers, and facilitators facing typically underserved groups such as rural Canadians and Indigenous populations are unlikely to be adequately represented in these results.

2. Participants consisted of members of the screening population (*n*=9), as well as those who are currently, or have previously been, diagnosed with or treated for depression (*n*=7). Focus groups therefor consisted of a mix of participants from both the screening population and individuals exposed to depression diagnosis and treatment. The opinions and preferences of those exposed to a diagnosis of, or treatment for, depression may have influenced the thoughts and preferences of unexposed individuals, and impacted focus group discussions and outcomes. Moving forward separate focus groups for exposed and unexposed members of the

population may be considered in order to differentiate the preferences of the population to whom the guideline would be relevant (i.e. the screening population) from those already exposed.

Suggestions for applying findings

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

1. **Include outcomes identified by participants as important or critical in the evidence review protocol.** Participants rated all outcomes of screening for depression in adults as either *important* or *critical*. Participants may therefore be more responsive to a guideline that is based on evidence of all outcomes included in this project. Participants also considered outcomes of screening and treatment for depression that are related to others (i.e. impact on friends and family) to be important in their screening decision. The CTFPHC may consider including patients at the stage of refining the question for evidence review, as this could lead to different outcomes being included in the review and guideline.

2. **Provide resources to support a discussion of patients' preferences and shared decision making.** Because the CTFPHC develops evidence-based guidelines, the CTFPHC may not always be able to produce guideline recommendations that are consistent with all patients' preferences. In this case, the CTFPHC may consider developing and disseminating resources that encourage a discussion about patients' preferences and to support shared decision-making between clinicians and patients. Specifically, the CTFPHC may produce KT tools that assist clinicians in discussing screening in the context of a patient's preferences. In addition, the CTFPHC may develop KT tools for patients that explain the balance between the harms and benefits of the screening intervention. The participant focus group discussions also highlighted the need to prepare materials for these focus groups on the difference between screening and diagnostic testing and case finding.

   Participants noted that people may feel uncomfortable or have difficulty discussing sensitive topics such as depression and associated symptoms with their primary care provider. Also, participants highlighted the importance of considering privacy concerns and potential societal stigma towards a diagnosis of depression when clinicians are discussing screening with patients. The CTFPHC may develop KT tools for patients that sensitively address these concerns.

   Lastly, several participants also noted the impact different types of treatment options, as well as treatment accessibility, may have on their screening preferences and decision-making. The CTFPHC may consider providing information about treatment options (including treatment-specific potential harms and effectiveness) and discussing treatment access concerns as part of KT tools to facilitate shared decision-making around screening for depression among adults.

3. **Develop KT tools that address information needs of participants.** Participants had additional questions about the outcomes of screening and treatment as it relates to others (i.e. the potential impact screening and treatment for depression may have on friends and family), and requested additional information on potential harms faced by individuals living with undiagnosed and untreated depression.

   Patients also expressed interest in further information on the mental and physical symptoms of depression, differences between normal grief, short-term depression, and long-term depression, as well as the threshold at which symptoms warrants a diagnosis of depression. Therefor the guideline and KT tools should integrate relevant information to help patients make an informed choice about screening for depression.

4. **Send participants a summary of how their feedback in the final guideline and KT tools was used.** Participants answered two engagement questions measuring the extent that they believed that their input, values, and preferences would influence and/or be included in final CTFPHC advice. These ratings were lower than most other engagement questions. Upon public release of the guideline and KT tools, the CTFPHC may send an email to participants to explain how their feedback was integrated into the final guideline and KT tools, also providing specific examples. The CTFPHC may also request that participants complete the participant engagement measure again to explore whether participants' beliefs shifted when presented this information.

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. 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 CTFPHC 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.
3. Moore, A. Development and Preliminary Evaluation of a Patient and Public Engagement Evaluation Tool. Prepared for the Canadian Task Force for Preventive Health Care, Knowledge Translation Working Group, 2016.

Appendix A: Screening questionnaire

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 Rossella Scoleri, at scolerir@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

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

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

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

Take Part in Future Projects

The Knowledge Translation Program at St. Michael's Hospital conducts other projects where we involve practicing health care professionals. 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

How old are you?

17 or younger
18-25 years of age
26-30 years of age
31-35 years of age
36-40 years of age
41 or older

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 options of people aged 18 years of age or older.

Take Part in Future Projects

The Knowledge Translation Program at St. Michael's Hospital conducts several projects over the year. 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

How old are you?

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

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.

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

- ❍ Yes
- ❍ No

Are you currently receiving treatment for depression?

- ❍ Yes
- ❍ No

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 Aboriginal groups?

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

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-$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 several projects over the year. 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: Background Sheet

CTFPHC Patient Background Information Sheet
Screening for Depression among the General Adult Population

What is depression?

Depression is a mental health problem defined by sad mood and/or loss of interest or pleasure in all or almost all activities lasting **for at least two weeks**. To be diagnosed, a person must have five or more symptoms from the list below, including at least one of the first two. Their depression must also be affecting important aspects of their life (e.g. work, home life, leisure and social activities):

- Sad mood
- Loss of interest or pleasure in all or almost all 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 physical sluggishness
- Feelings of worthlessness or extreme guilt
- Decreased ability to think, concentrate, or make decisions
- Thoughts of death, suicide, or suicide attempts

How common is depression?

Around the world, over 300 million people were living with depression in 2015, making it the #1 cause of disability globally. In 2012, 3.2 million Canadians (about 11% of the population) had reported symptoms of a major depressive episode at some point during their life. In one study, most episodes of depression lasted less than 6 months, but in about 20% of cases it lasted for more than 2 years. Slightly more females (14%) than males (9%) reported ever having a major depressive episode. Rates of depression stayed the same in Canada between 2002 and 2012, with about 5% of people reporting they had symptoms in the previous 12 months. Females were more likely than males to report depressive symptoms during the previous 12 months across those aged 15 to 24 years (9% vs. 5%) and 25 to 64 years (6% vs. 4%), but the difference was small for those 65 years and older (2% vs. 1%).

How does depression affect people?

Depression decreases a person's quality of life and increases the risk of suicide. For this reason, it is considered a possible life-threatening disease, with depressed men at greater risk of dying early compared to women. Depression increases risk for diseases such as cancer, coronary heart disease, and stroke. Having depression along with other chronic illnesses, including diabetes, also increases risk of dying.

Those who have depression often notice a negative impact on their output at work or school, due to missed work/school or problems with concentration. People who have depression may also have more tension or conflict in their close relationships, which can cause more distress. Depression may increase risk-taking behaviours (e.g., taking drugs, drinking a lot, gambling, smoking) or suicidal thoughts and behaviour (including thoughts about, attempted, or completed suicide). In Canada, suicide is the second leading cause of death among people 15 to 34 years of age. However, the greatest proportion of all suicide deaths (45%) occurs among those aged 40 to 59 years.

What are some risk factors for depression?

In general, social, psychological, and biological factors (such as genetics) contribute to depression. People with other mental health disorders (e.g., drug/alcohol misuse) or a family history of psychiatric disorders are at an increased risk of depression. Individuals with chronic illnesses, such as cancer or cardiovascular disease, are also at an increased risk of depression.

Other specific risk factors for depression include:

- Depression earlier in life
- Adverse childhood experiences
- Lack of social support from your partner, friends, or family
- Living with high stress problems like concerns over money or housing

What is depression screening?

Depression screening uses a list of questions, asked verbally by your health care provider or in a written questionnaire, to help identify if you show signs of depression. Once you answer these questions, your health care provider can check if your score is high enough to need a more detailed assessment of depression. Screening tries to identify patients who a) have not previously shared their symptoms with health care providers or b) may not recognize that their feelings could be symptoms of depression.

How is depression diagnosed?

If the results of the screening test show that 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 their impact on your life. You may also be offered a referral to a mental health specialist (for example, a therapist or a psychiatrist) for more follow-up or treatment.

How is depression treated?

- Supportive interventions
    - Peer support and professionally-led support groups can help to share and validate each other's experiences. This works best when you have mild symptoms of the illness.
- Psychotherapy
    - A therapist helps identify problems and suggests ways to change your behaviour or ways of thinking to help relieve symptoms. This is usually a recommended treatment when you have symptoms that are more serious or when other supportive interventions are not helping enough.
- Lifestyle changes
    - Eating well, getting exercise 2-5 times a week, getting adequate sleep, as well as getting support from family and friends can all help people that have depression symptoms feel better.
- Antidepressants
    - If your doctor thinks it is needed, they will prescribe medication to attempt to relieve symptoms of depression. Medication is recommended when a person is experiencing severe symptoms, or when their symptoms are not improving with other treatments.

What are the possible benefits of screening for depression among the general adult population?

If depression screening were effective, possible benefits from treating depression could include fewer symptoms of depression, better health-related quality of life, and fewer 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, gambling).

What are the possible negative effects of screening adults for depression?

Possible negative effects of screening include false positive screening test results (when the screening test shows that a person may have depression, but upon closer examination by their health care provider, they determine that the person does not actually have depression).There could also be overdiagnosis of depression (that is, when you are going through the normal ups and downs of life, but do not have depression). Overdiagnosis could result in receiving treatment for depression that would have gone away on its own without treatment (overtreatment). Harms from being labelled as having depression may include social stigma or leading you to feel less capable of coping than you truly are in day-to-day life.

There can also be undesirable consequences of depression treatment, including:

- From psychotherapy
    - Sometimes, even when the therapist is well-trained and there is a good fit between therapist and patient, symptoms can worsen and new ones can develop. This risk is greater when therapy is poorly applied.
- From antidepressants
    - There may be side effects from antidepressant medication. The following side effects occur in more than 10% of people who take antidepressants and are usually short-lived: nausea and vomiting, diarrhea, dizziness, fatigue, headache, tremor, and weight gain (usually less than 10 pounds). 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 under 24 years of age.

Appendix C: Pre- and post-focus group survey

CTFPHC Survey on Public Perceptions of Screening for Depression Among Adults

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, Rossella Scoleri, at scolerir@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.

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.

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

- ❍ Yes
- ❍ No

Participant ID:

Please enter your participant ID in the box below. You can find your participant ID in the email that you received from Rossella Scoleri with the link to the survey.

_____

Date:

_____

Before you begin the survey, please take the time to read the Background Information Sheet:

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

- ❍ I agree

Screening for Depression among Adults:

Below is a series of statements about the potential **benefits** that adults may experience after being screened for depression.

For each statement, please rate how much it would influence your decision on whether or not to be screened for depression.

Screening is using one or more tests for all patients, even if they are not seeking help with any particular symptoms, to help identify a condition or illness in some. Screening uses a specific tool to identify a condition or illness. An example of a depression screening test is a standard questionnaire that asks about potential symptoms of depression.

If you were making a decision on whether or not to be screened for depression, how important would these outcomes be for you?

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

	1	Not important for decision making 2	3	4	Important for decision making 5	6	7	Critical for decision making 8	9
Screening may decrease symptoms of depression	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in a diagnosis of major depressive disorder by a health care provider	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may improve perceived physical and mental	❍	❍	❍	❍	❍	❍	❍	❍	❍

health over time, also referred to as health-related quality of life									
Screening may improve how a person functions in their day-to-day life	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may decrease the amount of time someone is absent from work or school	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may improve lifestyle behaviours (for example, decreased alcohol and drug abuse, smoking, and gambling)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may decrease thinking about, considering, planning, attempting, or completing suicide	❍	❍	❍	❍	❍	❍	❍	❍	❍

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

_____

Screening for Depression among Adults:

Below are statements about the potential harms that adults may experience after being screened for depression.

For each statement, please rate how much it would influence your decision on whether or not to be screened for depression.

Screening is using one or more tests for all patients, even if they are not seeking help with any particular symptoms, to help identify a condition or illness in some. Screening uses a specific tool to identify a condition or illness. An example of a depression screening test is a standard questionnaire that asks about potential symptoms of depression.

If you were making a decision on whether or not to be screened for depression, how important would these outcomes be for you?

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

	1	Not important for decision-making 2	3	4	Important for decision-making 5	6	7	Critical for decision-making 8	9
Screening may result in identifying someone as having depression when depression is not present (called a false positive result)	❍	❍	❍	❍	❍	❍	❍	❍	❍
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)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms of treatment (called	❍	❍	❍	❍	❍	❍	❍	❍	❍

overtreatment) Screening may result in harms from treatment of depression. Harms of psychotherapy can include worsening of existing symptoms or development of new ones. Harms of antidepressants can include unwanted side effects from the medication, or an increased risk of suicidal thoughts or behaviours in people under 24 years of age	❍	❍	❍	❍	❍	❍	❍	❍	❍

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

_____

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.

- ❑ Screening may decrease symptoms of depression
- ❑ Screening may result in a diagnosis of major depressive disorder by a health care provider
- ❑ Screening may improve perceived physical and mental health over time, also referred to as health-related quality of life
- ❑ Screening may improve how a person functions in their day-to-day life
- ❑ Screening may decrease the amount of time someone is absent from work or school
- ❑ Screening may improve lifestyle behaviours (for example, decreased alcohol and drug abuse, smoking, and gambling)
- ❑ Screening may decrease thinking about, considering, planning, attempting, or completing suicide
- ❑ Screening may result in identifying someone as having depression when depression is not present (called a false positive result)
- ❑ Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment (called overdiagnosis)
- ❑ Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms of treatment (called overtreatment)
- ❑ Screening may result in harms from treatment of depression

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

_____

Recall: Screening is using one or more tests for all patients, even if they are not seeking help with any particular symptoms, to help identify a condition or illness in some. Depression screening uses a list of questions, asked verbally by your health care provider or in a written questionnaire, to help identify if you show signs of depression.

Screening tries to identify patients who a) have not previously shared their symptoms with health care providers or b) may not recognize that their feelings could be symptoms of depression.
Considering the potential harms and benefits of screening for depression, how much would you want to be **screened**?

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

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

_____

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

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

_____

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

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

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

Please describe what you liked about taking part in this project:

_____

Please describe what you did not like about taking part in this project:

_____

Please describe anything that we could change to improve this project:

_____

Demographic Information

What is your age?

_____

What is your gender?

_____

What is your ethnicity?

_____

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

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

- ❍ Yes
- ❍ No

Are you currently receiving treatment for depression?

- ❍ Yes
- ❍ No

Next Steps:

Thank you for completing this second survey. If you have questions about any part of the project, please contact Rossella Scoleri at scolerir@smh.ca or 416-864-6060 ext. 77337.

We will now process your honorarium payment. Please note that it may take up to 45 days for you to receive your payment by mail after we submit it for processing.

Once the data have been analyzed, you will be sent a summary report that details the findings from this project. You will then be invited to participate in an optional debrief teleconference to discuss the project findings. Once the CTFPHC publishes its guideline, you will also be sent a copy of the guideline and the accompanying knowledge translation tools.

Thank you for your participation in this project!

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

CTFPHC Survey on Public Perceptions of
Screening for Depression in Adults
Personalized Rating Sheet
Survey 1

Prepared for Participant Number: [MASTER]

Introduction

A total of 20 people from across Canada completed the CTFPHC Survey on Public Perceptions of Screening for Depression in 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 provided with information about the outcome and asked “If you were making a decision on whether or not to be screened for depression, how important would these outcomes and information be for you?”

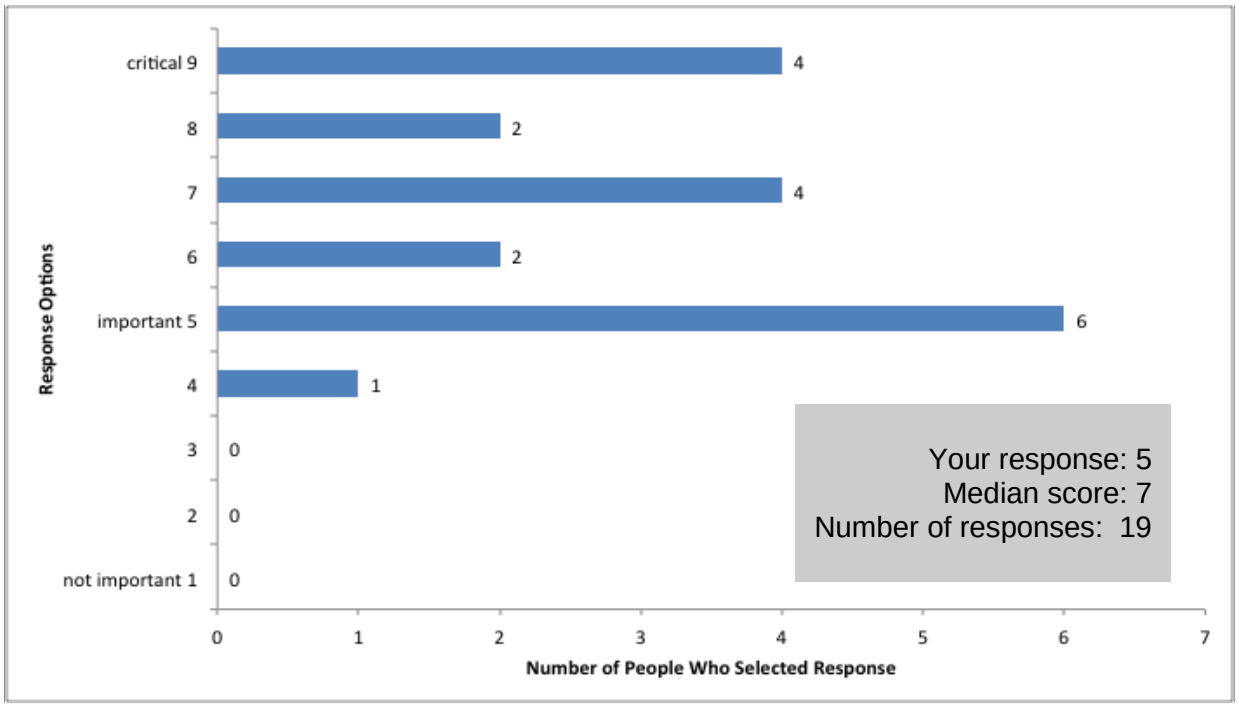
Participants could rate the importance of the information from 1-9:

- 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

Sample Harms and Benefits 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:

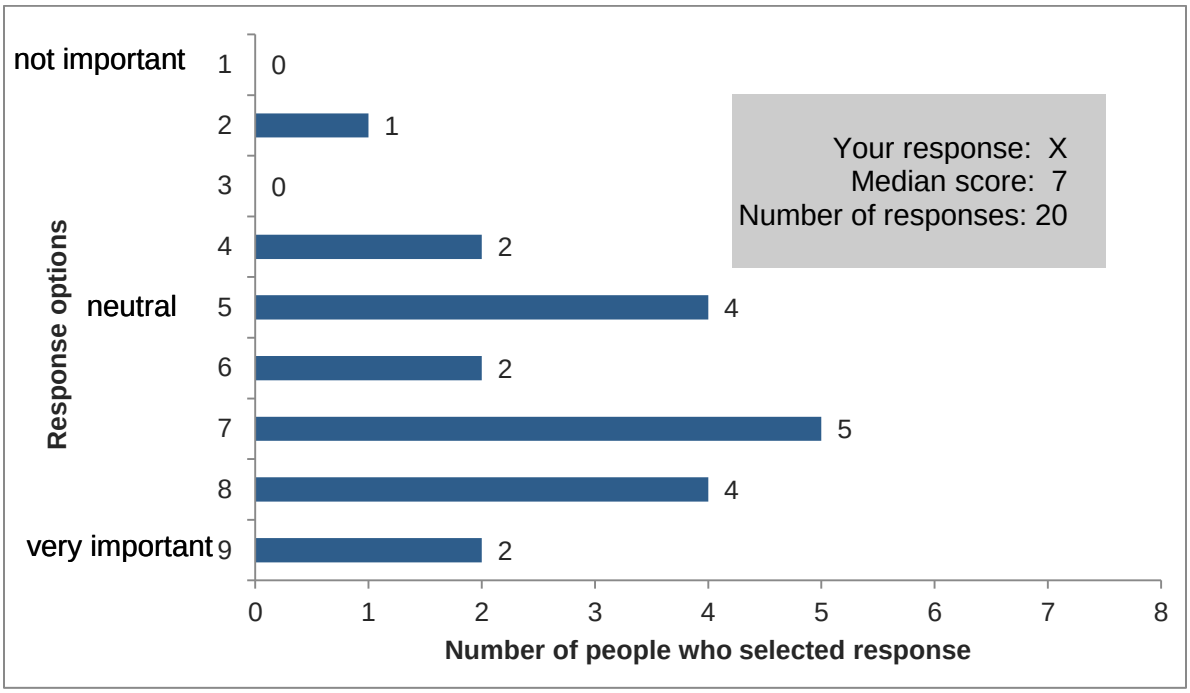
- The number on the rating scale that you selected for this outcome
- The median rating for this outcome across all participants (you can think of this like an "average" of the ratings selected by all participants)
- The total number of participants who rated this outcome

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 a "5". The median rating across all participants was "7", and there were 19 participants in total who rated this item.

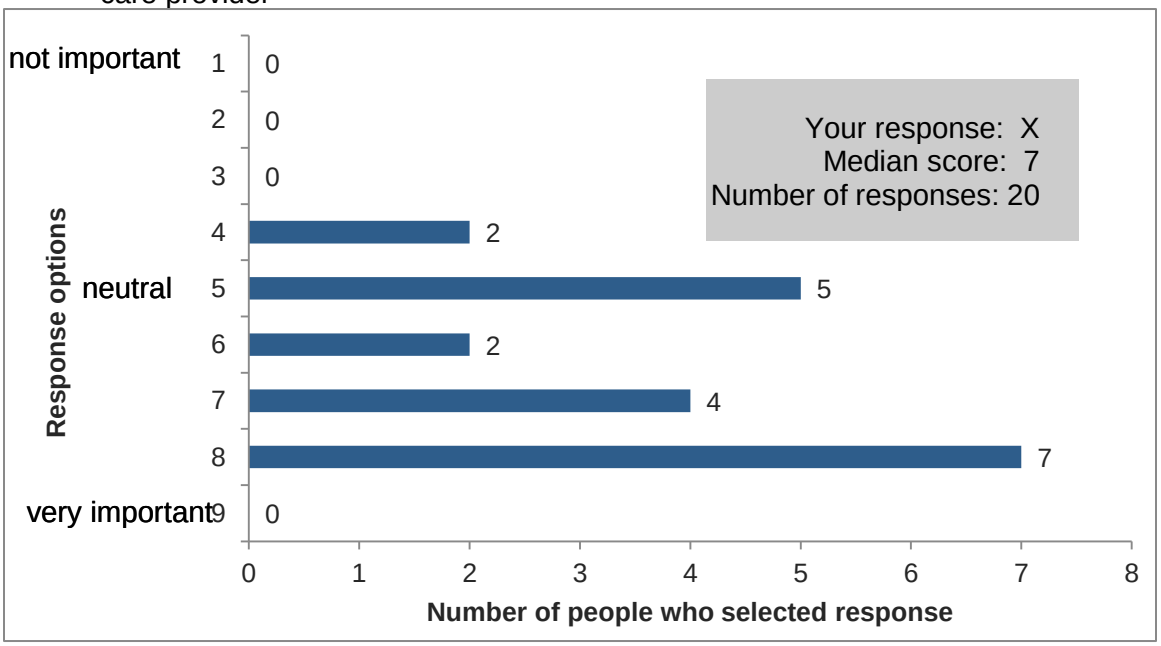
These personalized answers are broken down by potential harms and benefits for depression screening below.

Summary of Outcomes Ratings

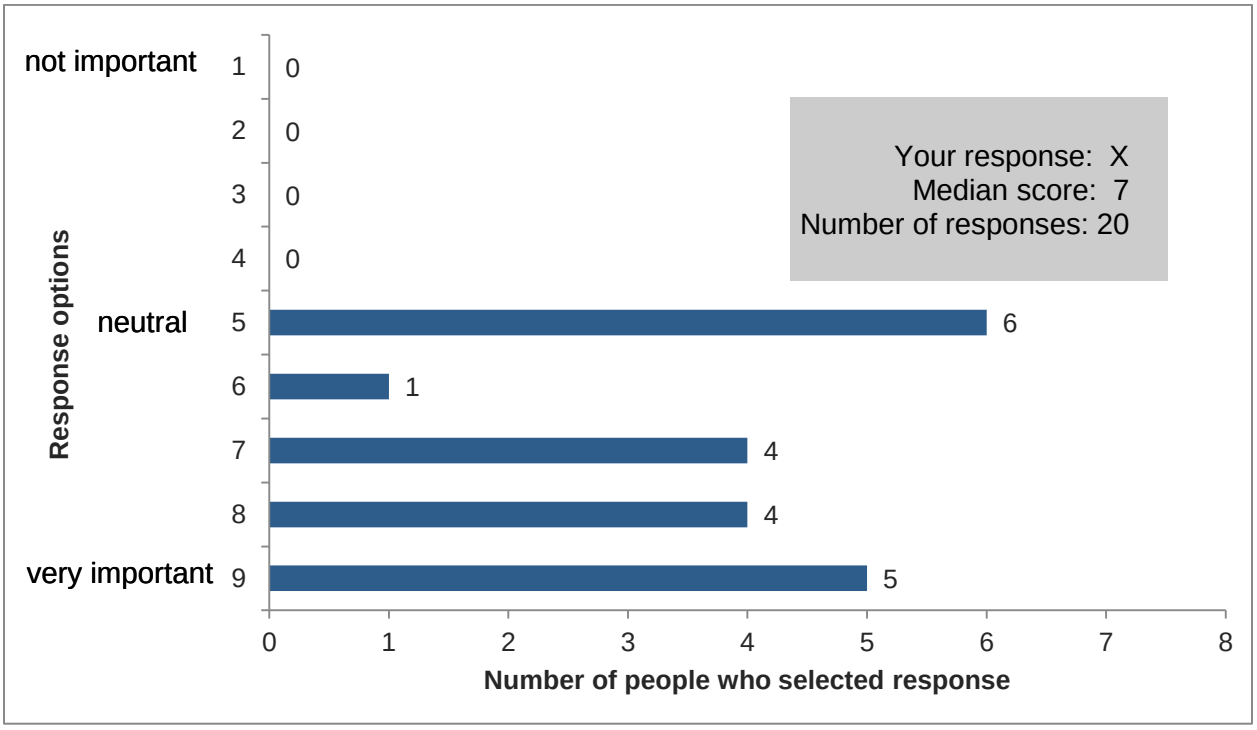
1. **Survey Benefit:** Screening may decrease symptoms of depression



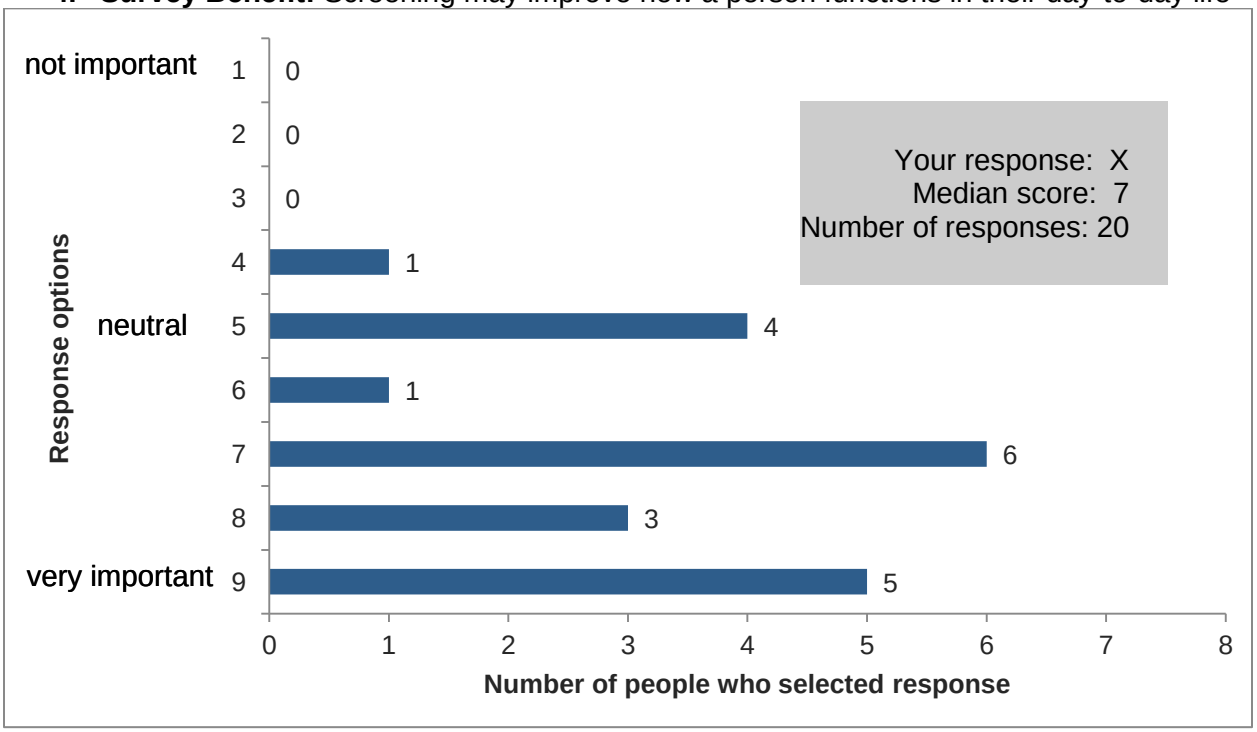
2. **Survey Benefit:** Screening may result in a diagnosis of major depressive disorder by a health care provider



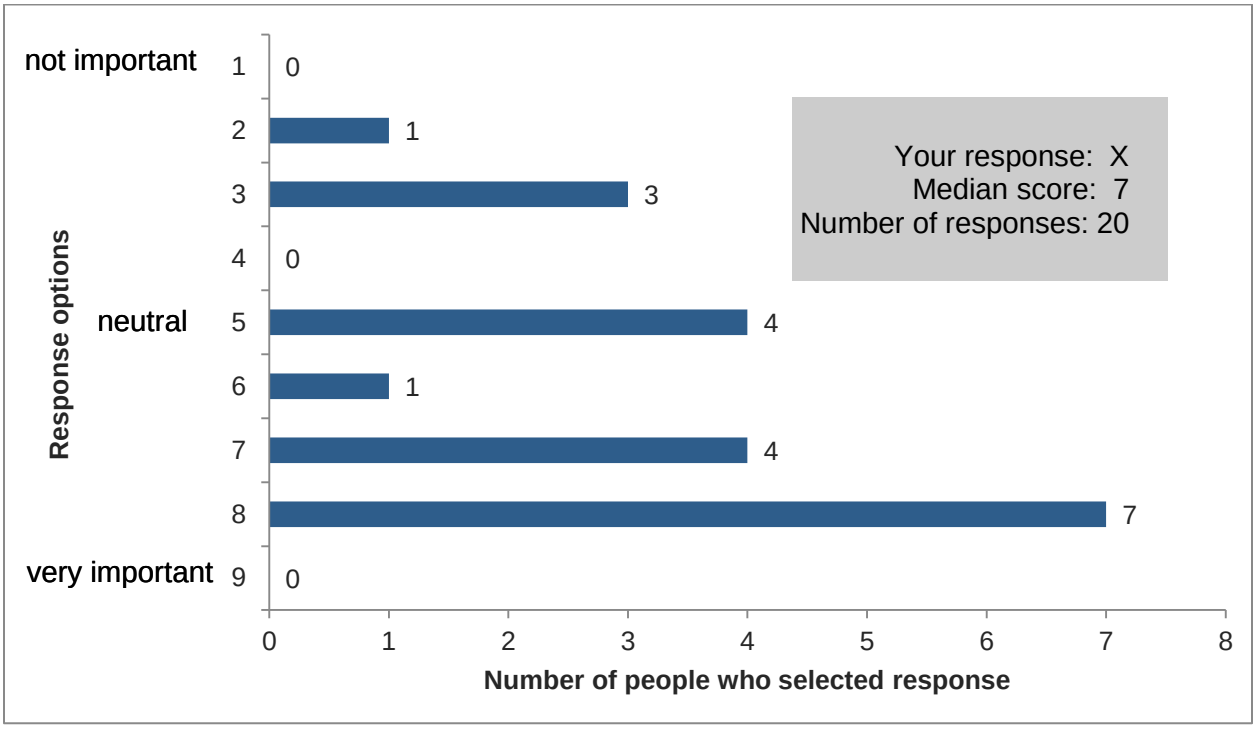
3. **Survey Benefit:** Screening may improve perceived physical and mental health over time, also referred to as health-related quality of life



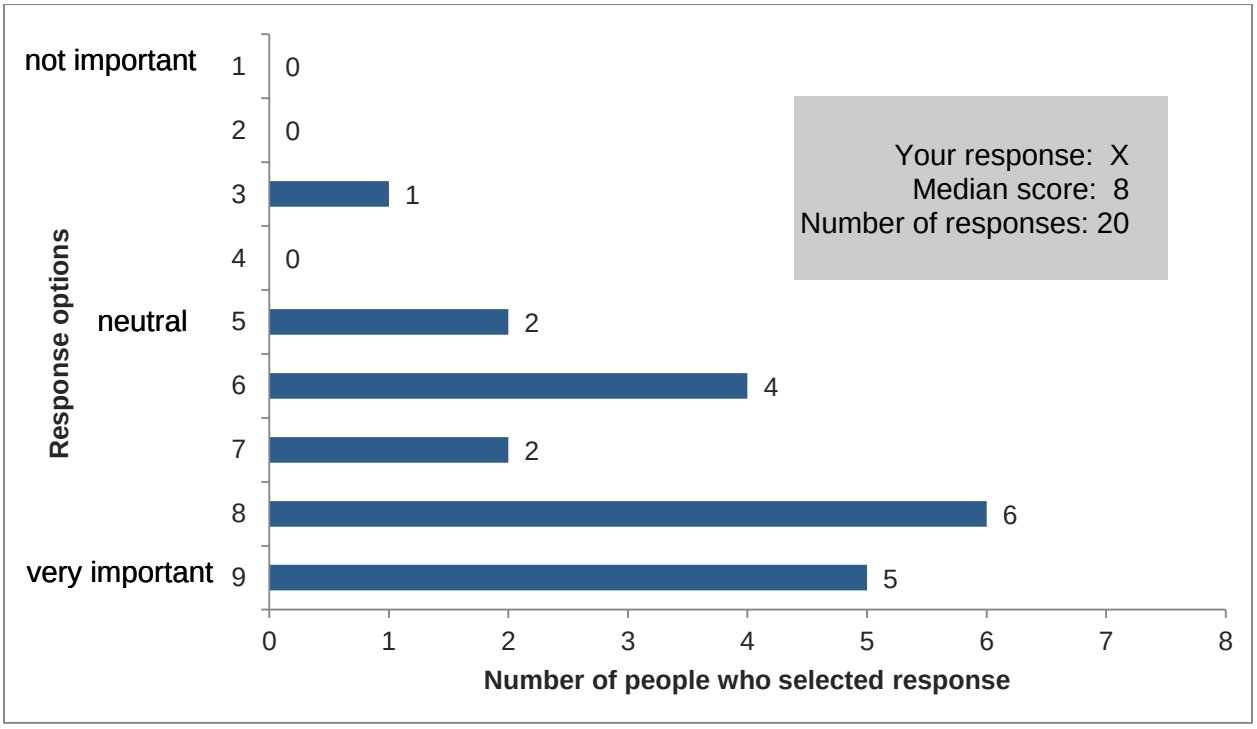
4. **Survey Benefit:** Screening may improve how a person functions in their day-to-day life



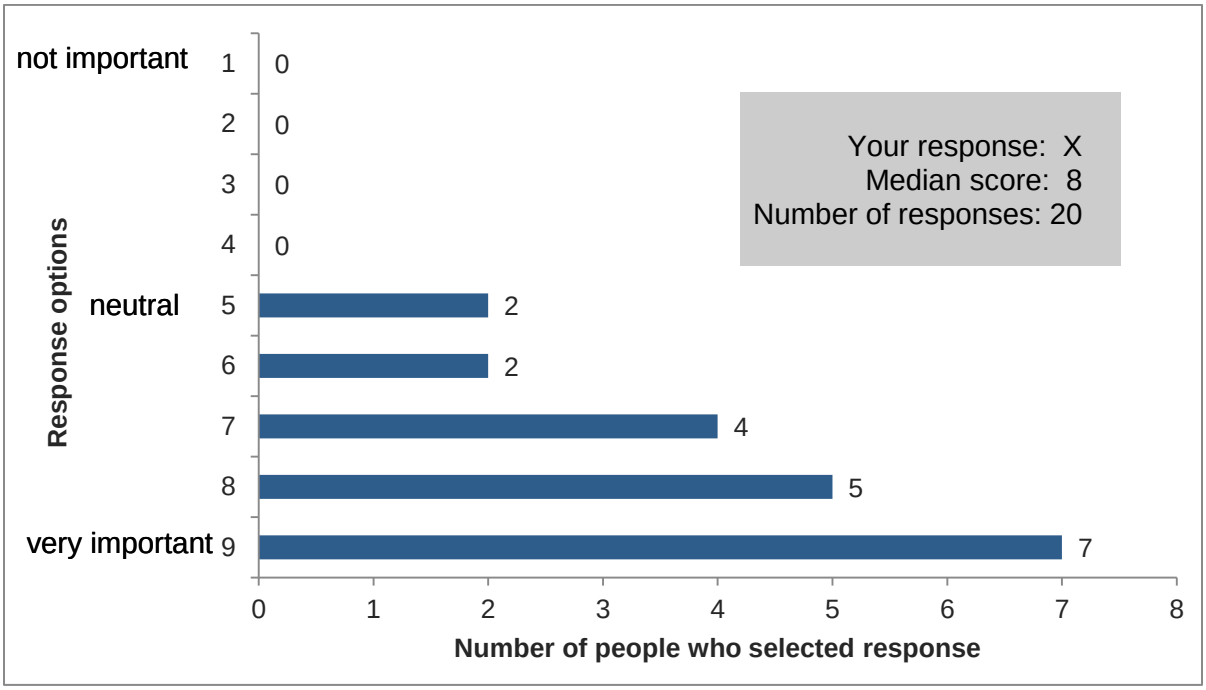
5. **Survey Benefit:** Screening may decrease the amount of time someone is absent from work or school



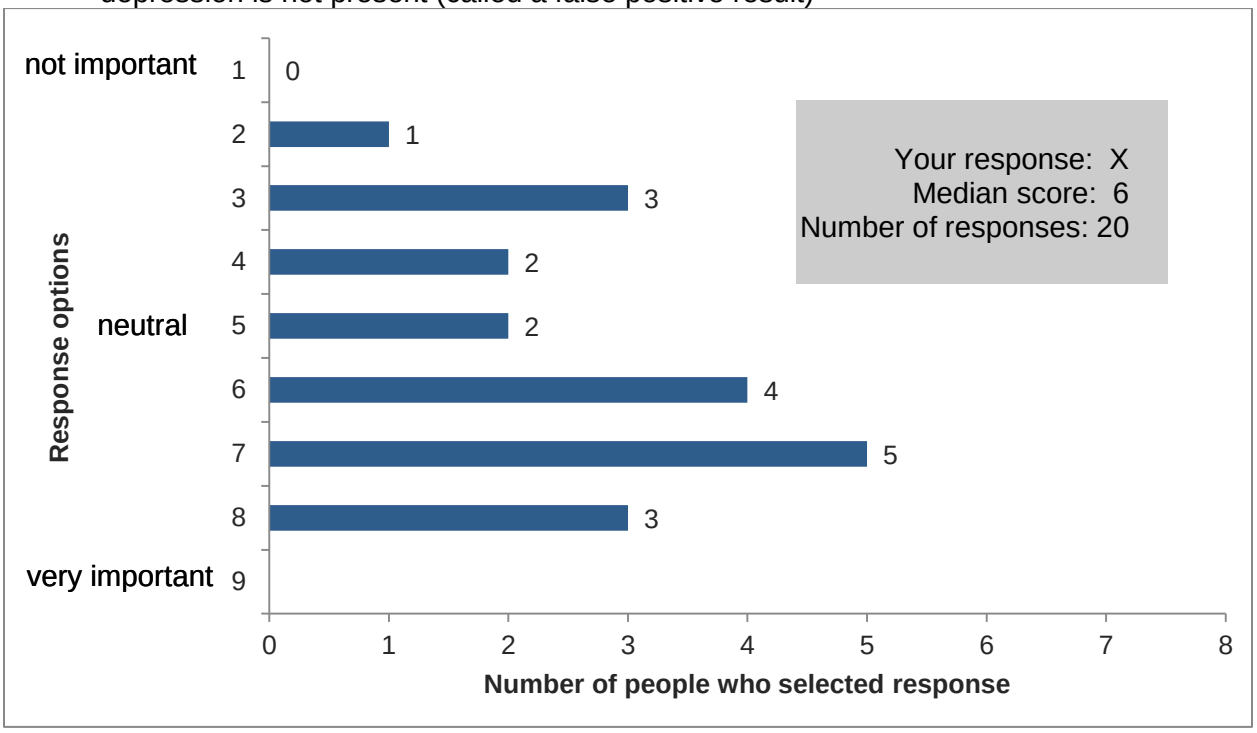
6. **Survey Benefit:** Screening may improve lifestyle behaviours (for example, decreased alcohol and drug abuse, smoking, and gambling)



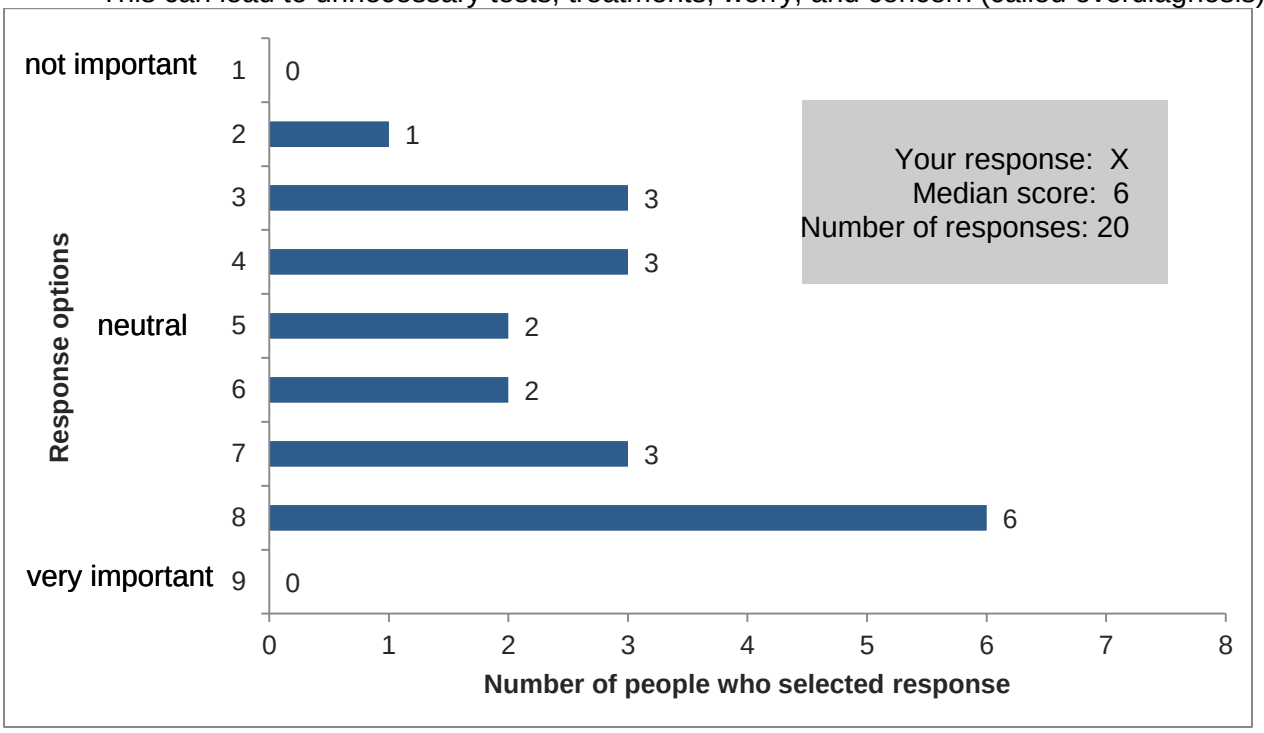
7. **Survey Benefit:** Screening may decrease thinking about, considering, planning, attempting, or completing suicide



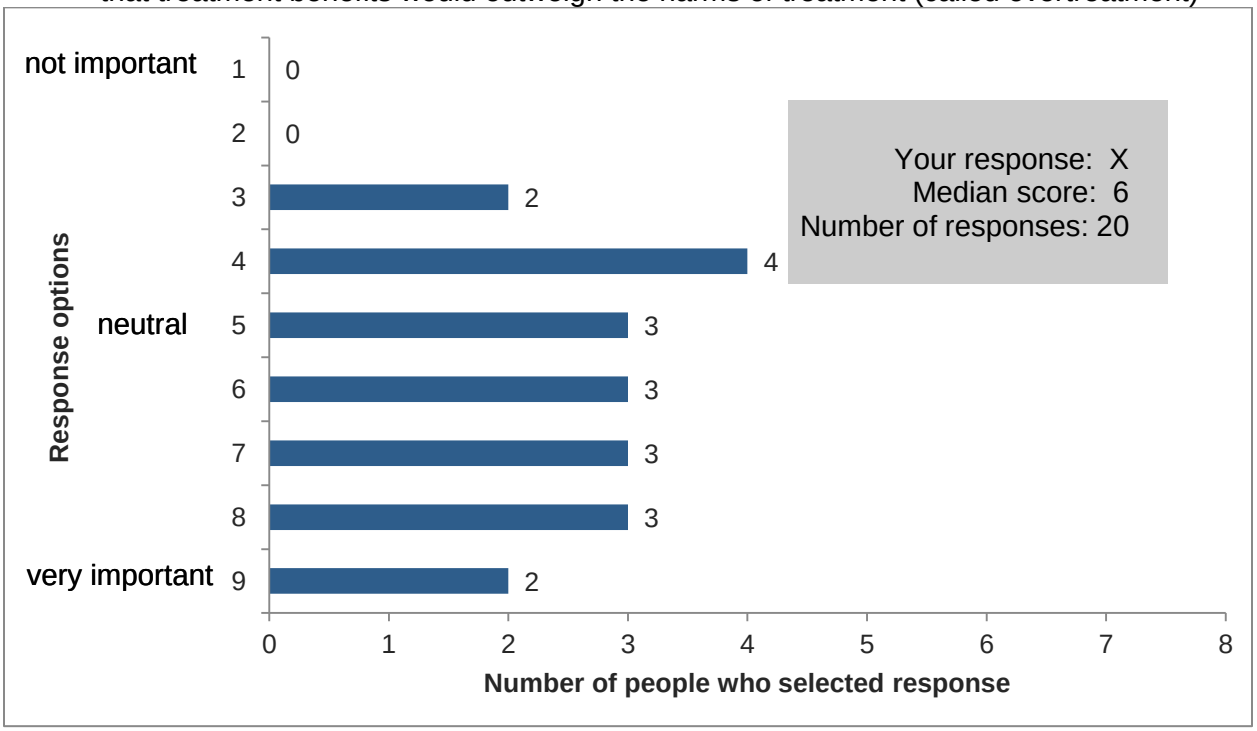
8. **Survey Harm:** Screening may result in identifying someone as having depression when depression is not present (called a false positive result)



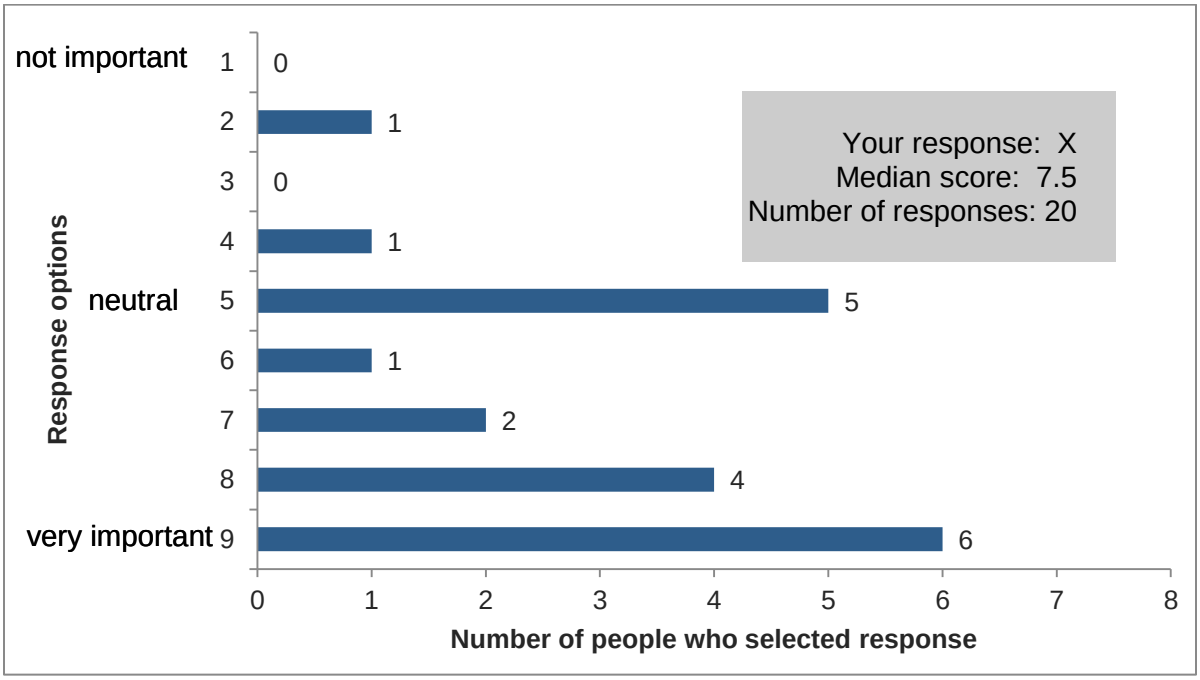
9. **Survey Harm:** Screening may result in diagnosing someone with depression when the depression wouldn't have caused them any harm or would have resolved without treatment. This can lead to unnecessary tests, treatments, worry, and concern (called overdiagnosis)



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



11. **Survey Harm:** Screening may result in harms from treatment of depression. Harms of psychotherapy can include worsening of existing symptoms or development of new ones. Harms of antidepressants can include unwanted side effects from the medication, or an increased risk of suicidal thoughts or behaviours in people under 24 years of age.



Selection of the Top Five Potential Harms or Benefits

for Depression Screening in Pregnant and Postpartum Populations

In the survey, we listed 11 potential harms and benefits of screening for depression adults 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. 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, 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:	# of participants who selected this as a "top five" item to consider
Screening may decrease symptoms of depression	8
Screening may result in a diagnosis of major depressive disorder by a health care provider	10
Screening may improve perceived physical and mental health over time, also referred to as health-related quality of life	14
Screening may improve how a person functions in their day-to-day life	14
Screening may decrease the amount of time someone is absent from work or school	4
Screening may improve lifestyle behaviours (for example, decreased alcohol and drug abuse, smoking, and gambling)	12
Screening may decrease thinking about, considering, planning, attempting, or completing suicide	14
Screening may result in identifying someone as having depression when depression is not present (called a false positive result)	5
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)	7
Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms of treatment (called overtreatment)	4
Screening may result in harms from treatment of depression. Harms of psychotherapy can include worsening of existing symptoms or development of new ones. Harms of antidepressants can include unwanted side effects from the medication, or an increased risk of suicidal thoughts or behaviours in people under 24 years of age.	6

Considerations for Screening Scale Ratings

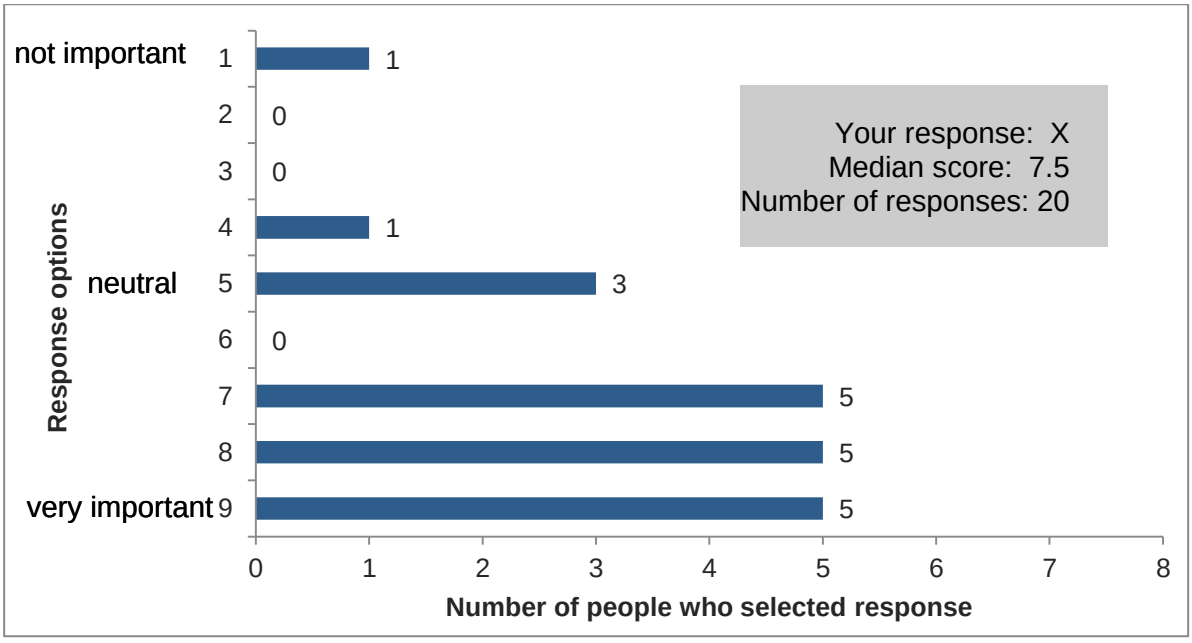
For this question, participants were asked to rate how much they would want to be screened for depression.

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. **Survey Question:** Considering the potential harms and benefits of screening for depression, how much would you want to be screened?



Appendix E: Focus group guide

CTFPHC Patient Preferences Phase 1: Adult Depression
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.

My name is _____ and I am from the Knowledge Translation Program based at the Li Ka Shing Knowledge Institute of St. Michael's Hospital. I am going to be the focus group moderator today.

We are going to go through some introductions, background information, and instructions for the next 3 to 5 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 _____ who will be our note taker. The second is Dr. Eddy Lang, who is the chair of the Task Force's depression screening guideline development working group. He will be on the line to answer any 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
- The purpose of this conversation that we are having today is to get feedback from members of the public on your opinions about the 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 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. We will also provide you with an opportunity to ask Dr. Lang 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. Lang 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

- Please have your participant data summary sheet and background information sheet in front of you 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. 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 as well as avoid speaking at the same time 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 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

- 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.
    - In addition to not using names, any other information from today that could identify who you are will 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 your participant ID number or just your first name for the recording. In a minute, I will call on each of you to state whether you would prefer to be called by your participant ID number or first name.
  First_____.....

Permission to audio record

- 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 screening for depression focus group ____. There are ____ participants present.
- We will now ask for your consent to participate. I will call on each one of you to state your name to the group and state that you consent to participate. For example, "This is Danica, I consent to participate". Let's begin with: ____.
- Have I missed anyone? Thank you.

1) Adult depression 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:

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?

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.

12. Survey Benefit: Screening may decrease symptoms of depression

6) Please turn to page 3 and refer to question 1 located at *top* of the page. The outcome reads '**Survey Benefit***: Screening may decrease symptoms of depression'* Responses 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?

13. Survey Benefit: Screening may decrease the amount of time someone is absent from work or school.

7) Please turn to page 5 and refer to question 5 located at *top* of the page. The outcome reads '**Survey Benefit:** *Screening may decrease the amount of time someone is absent from work or school.'* Responses ranged from 2-8 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?

14. Survey Harm: Screening may result in identifying someone as having depression when depression is not present (called a false positive result)

8) Please turn to page 6 and refer to question 8 located at the *bottom* of the page. The outcome reads "**Survey Harm***: Screening may result in identifying someone as having depression when depression is not present (called a false positive result)"*. Responses ranged from 2-8 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?

15. Survey 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)

9) Please turn to page 7 and refer to question 9 located at *top* of the page. The outcome reads "**Survey 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)"*. Responses ranged from 2 to 8 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, about one-third of people rated it as an 8 but you rated it as important or not important)?

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

10) Please turn to page 7 and refer to question 10 located at *bottom* of the page. The outcome reads '**Survey Harm***: Screening may result in treating depression when there is little or no evidence that treatment benefits would outweigh the harms of treatment (called overtreatment)".* Responses ranged from 3 to 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, about half of people rated it as important but you rated it as critical or not important)?

17. **Survey Harm:** Screening may result in harms from treatment of depression. Harms of psychotherapy can include worsening of existing symptoms or development of new ones. Harms of antidepressants can include unwanted side effects from the medication, or an increased risk of suicidal thoughts or behaviours in people under 24 years of age

11) Please turn to page 8 and refer to question 11 located at *the top* of the page. The outcome reads '**Survey Harm:** *Screening may result in harms from treatment of depression. Harms of psychotherapy can include worsening of existing symptoms or development of new ones. Harms of antidepressants can include unwanted side effects from the medication, or an increased risk of suicidal thoughts or behaviours in people under 24 years of age.*" Responses ranged from 2 to 9 with a median of 7.5.

- **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?

Selection of the Top 5 Potential Harms and Benefits for Depression Screening

12) Please turn to page 9 and refer to the list of 11 potential benefits and harms of screening for depression. We asked you to select five items on the list that you think were most critical to consider when people are making decisions about screening.

- a. Take a look at your selected top five outcomes. What was your rationale for selecting these outcomes?
- b. Survey harms were also selected less frequently by participants as among their top 5 outcomes to consider. Do you have any thoughts about this?

<u>4) Overall preference after discussion:</u>

2. **Survey Question:** Considering the potential harms and benefits of screening for depression, how much would you want to be screened?

13) Please turn to *page 10.* The question reads '*Considering the potential harms and benefits of screening for depression, how much would you want to be screened?'* Responses ranged from *1-9* with a median of 7.5.

- **a.** Are there any questions about screening 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?
    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
c. Have your preferences changed from those you expressed in the first survey and earlier in today's discussion?

5) Additional Information:

14) 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?

6) Potential barriers or facilitators to screening:

15) Screening for depression uses a list of questions, asked verbally by your health care provider or in a written questionnaire, to help identify if you show signs of depression. Once you answer these questions, your health care provider can check if your score is high enough to need a more detailed assessment of depression. Screening tries to identify patients who a) have not previously shared their symptoms with health care providers or b) may not recognize that their feelings could be symptoms of depression.

a. If you choose to get screened, what are potential barriers to accessing the screening test, if any?
    i. Probe: out-of-pocket expenses (e.g., transportation or taking time off)
    ii. Probe: lack of time (e.g., come in for a visit for another reason like an baby health etc.)
    iii. Probe: fear (stigma; do not want to talk about mental health with a health professional)

b. If you choose to get screened, what would make getting the screening test easy, if anything?

7) Closing remarks:

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 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 Rossella. 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)?