Canadian Task Force on Preventive Health Care

Patient preferences for depression screening during pregnancy and the postpartum period: Phase 2 Data summary

Prepared for the Canadian Task Force on Preventive Health Care

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Executive Summary

Incorporating patient priorities and perspectives into clinical practice guideline (CPG) development is an important part of patient-centred care. The Canadian Task Force on Preventive Health Care (CTFPHC) therefore aims to incorporate input from patients at three critical points in the guideline development process: (1) when outcomes are selected for inclusion in the systematic review protocol, (2) when the final guideline recommendation statements are developed, and (3) when knowledge translation (KT) tools are developed. In this project, we identified the outcomes that members of the screening for depression in pregnancy and postpartum depression populations believe are important to consider when making screening decisions related to depression, as well as their overall preferences for screening given the risks of potential harms and benefits. We also examined participants' perceptions of their experience with the project using an engagement evaluation tool.

A total of 14 Canadians who were members of the pregnancy and postpartum depression screening population participated in the project. After receiving a background information sheet on depression in pregnant and post-partum populations, participants completed a survey to assess how important various outcomes would be to consider when making decisions about depression screening. Next, they took part in a focus group or interview where they discussed the importance of considering the outcomes during decision making. Participants then completed a second survey that repeated the same questions as the first survey. They also answered questions about their experience with the engagement process.

Summary of Findings and Discussion

In the final survey, participants rated almost all screening benefits as *critical* to consider during decision making, whereas they rated all screening harms slightly lower, but still i*mportant*. Participants typically selected screening benefits more frequently than harms when asked to prioritize outcomes. Reasons participants viewed screening as beneficial included beliefs that a) it provides the opportunity for early detection and treatment, b) undiagnosed depression could impact the baby's development, and c) they did not feel confident they would be able to recognize symptoms and seek help from a primary care provider without screening. Many participants prioritized infant well-being, and placed more importance on outcomes that impacted infant health and development than maternal outcomes. Participants also mentioned that they would place greater value on screening during the post-partum period than during pregnancy; they felt that since they have many opportunities to talk with a primary care provider during regular pre-natal check-ups, screening during the post-partum period could be more beneficial (i.e. less appointments occur during this period, and therefore fewer opportunities to catch symptoms early). Participants also emphasized that midwives were a key point of contact during the pregnancy and post-partum period and should be considered in the development of recommendations.

Participants generally believed that the benefits of screening outweighed the harms, and had a strong preference to be screened if given the opportunity. They felt a discussion about depression with a primary health care provider during the pregnancy and post-partum period is critical, and identified types of information that would be helpful as part of a screening discussion, including: differentiating between depression and the "baby blues", providing information on the prevalence of depression in the pregnancy and post-partum period, describing symptoms to be aware of, and describing potential next steps following a diagnosis (e.g. duration and availability of treatment). They may perceive a guideline to be more socially

acceptable if it either recommends screening or encourages clinicians to make screening decisions that are consistent with patients' preferences.

Participants generally understood the engagement process instructions. They indicated that they had a positive experience in the project and appreciated the opportunity to provide input on what they perceived to be a very important topic. Some participants provided suggestions for improving the surveys and the focus group, such as having longer focus group sessions or limiting the number of participants to three or four people on focus groups to allow for more robust discussions.

Limitations

Limitations of this project include: (a) the sample was relatively small and may not be representative of the Canadian screening and treatment populations; (b) the background information that participants received may have made them more knowledgeable than most patients about screening and treatment outcomes; and (c) participants received information from the screening for depression during the pregnancy and post-partum periods from the working group chair, which may have influenced their responses.

Suggestions for Applying Findings

We provide the following suggestions for applying the findings from this project to the CTFPHC's screening for depression during the pregnancy and postpartum period guideline:

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

2. ***Develop KT tools that address information needs of participants*.** (e.g. clearly describing harms and benefits of screening and the evidence (or lack of evidence) for potential outcomes, the differences between 'baby blues' and depression, screening timeframes, prevalence of depression among pregnant or postpartum Canadians, and typical duration and availability of treatment following a diagnosis of depression)

3. ***Send participants a summary of how their feedback in the final guideline and KT tools was used.*** Participants were not convinced that their input would influence final decisions or that their values and preferences would be included in the final advice.

4. ***Emphasize the difference between 'usual care' and screening in shared decision making tools****.* Participants emphasized the importance of a discussion with their primary care provider about depression during the pregnancy and post-partum period. However participants may not have clearly understood the distinction between informal discussions or 'usual care', and a formalized screening program.

Introduction

The Canadian Task Force on Preventive Health Care recruits members of the public at up to three critical phases, to provide input during the guideline and knowledge translation tool development process. This document presents summary data from Phase 2 of the CTFPHC screening for depression during pregnancy and the postpartum period patient preferences focus groups, interviews, and surveys. We examined patients' perceptions of the harms and benefits of screening for depression during pregnancy and the postpartum period. Specifically, we asked how important patients believe it is for people to consider various harms and benefits, as well as the evidence for the harms and benefits, when making decisions about getting screened for depression during pregnancy and the postpartum period. We also examined participants' experiences in the project. Data were collected between May14th, 2019 and July 3rd 2019.

Methods

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

Participants

Recruitment

We recruited English-speaking Canadians who would be members of the target population for depression screening during pregnancy or the postpartum period by posting recruitment advertisements on public advertisement websites (e.g., Craigslist and Kijiji). In addition, we contacted members of the public who previously expressed interest in providing feedback on CTFPHC guidelines and KT tools to the St. Michael's Hospital (SMH) KT Program.

We asked individuals who responded to the recruitment announcement to complete a brief online screening questionnaire to assess their eligibility to take part in the project (see Appendix A). People aged 18 years and older who were pregnant or had given birth within the last year were eligible to take part in the project. Participants were also asked if they had ever been diagnosed or treated for depression by a health professional and if they were currently diagnosed with or receiving treatment for depression. Participants were not eligible for the project if they indicated that they were:

- less than 18 years of age
- not pregnant or had not given birth in the past year
- a health care practitioner;
- aware of any conflicts of interest relevant to the guideline topic (e.g., owning shares in a company related to depression).

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 14 female participants aged 25-42 years of age (mean age = 33.6 years, standard deviation = 5.21). Over two-thirds of participants reported giving birth on or after March 1, 2018 (*n* = 10); the remaining participants were currently pregnant (*n* = 4). One participant gave birth between completing the first and second surveys. About one-quarter of participants reported that they had either been previously diagnosed with or treated for depression by a health professional, or were currently diagnosed or receiving treatment for depression (*n* = 3). One participant self-identified as Indigenous (i.e., First Nations, Métis, or Inuit). Participants were from Ontario (*n* = 7), British Columbia (*n* = 4), Quebec (*n* = 1), Prince Edward County (*n* = 1), and New Brunswick (*n* = 1). Most participants lived in urban and suburban areas (*n* = 10; *n* = 3), and one participant lived in a rural area (*n* = 1). The majority of participants had a college diploma or bachelor's degree (*n* = 8) or a graduate or professional degree (*n* = 5); One participant reported high school as their highest level of education (*n* = 1). Participants had household incomes of less than $25,000 (*n* = 3), $50,000-$59,999 (*n* = 1), $60,000 - $69,999 (*n* = 2), $70,000-$79,999 (*n* = 4), and $100,000 or more (*n* = 4).

Outcome ratings

Below is a summary of participants' perceptions of the harms and benefits of screening for depression during pregnancy and the postpartum period. We collected data using a modified RAND Appropriateness Method (RAM)[1] using surveys and focus groups (as outlined in the Patient Engagement Protocol).

Harms and benefits scale ratings

In the first part of the survey, participants rated the importance of potential harms and benefits of screening for depression during pregnancy or the postpartum period. For each of these potential harms and benefits, also called an "outcome", all participants were provided with information and asked, "If you were making a decision on whether or not to be screened for depression during pregnancy or the postpartum period, how important would these outcomes and information be for you?"

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

Table 1. Descriptions for harms and benefits

Short description	Full description
Benefits	
Health-related quality of life	If screening leads to treatment, it may improve health-related quality of life
Symptoms or diagnosis of depression	If screening leads to treatment, it may reduce symptoms or diagnosis of depression
Suicide ideation, attempt, or completion	If screening leads to treatment, it may reduce thinking about, considering, planning, attempting, or contemplating suicide
Relationship with partner or other supports	If screening leads to treatment, it may improve relationships with partners and other supports
Reported/observed capacity to parent	If screening leads to treatment, it may improve capacity to parent (for example attachment, responsiveness, and positive regard for infant)
Mother-child interactions	If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech
Infant health and development	If screening leads to treatment, it may improve infant health and development
Infant responsiveness	If screening leads to treatment, it may improve infant responsiveness
Harms	
False positive	Screening tests may identify depression when it is not really present (called false positive result)
Overdiagnosis	Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis)
Overtreatment	Screening may result in starting treatment for depression in people who would not benefit (over-treatment)
Labelling/stigma	Screening may result in labelling someone as having depression which can lead to anxiety or stigma
Harms from psychotherapy	If screening leads to treatment with psychotherapy, harms may include worsening of existing symptoms or development of new ones
Harms from antidepressants	If screening leads to treatment with antidepressants, harms may include unwanted side effects from the medication

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

How to read the box plot

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

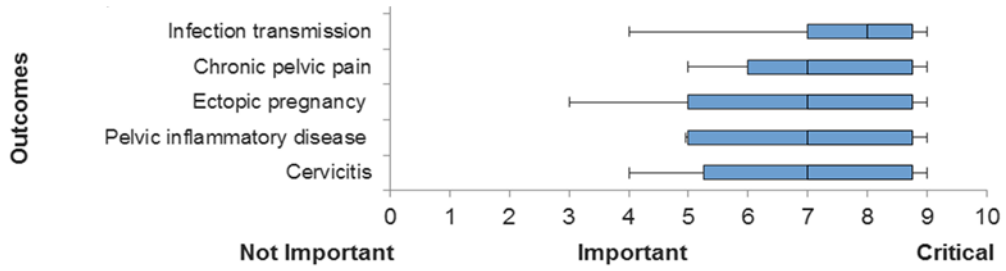


Figure 1. Post-survey harms and benefits scale ratings (n = 14)

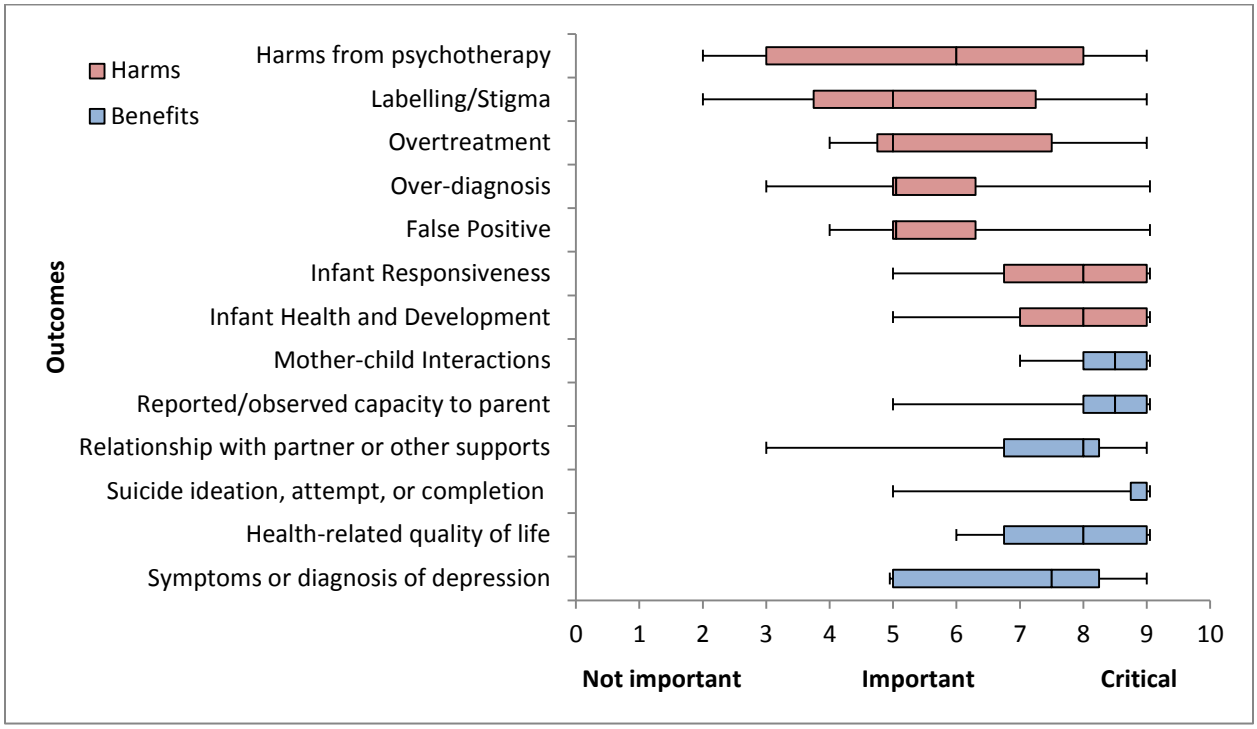


Table 2. Pre- and post-survey harms and benefits scale ratings (n = 14)

Outcome	Pre-survey (*n* = 17)			Post-survey (*n* = 14)		
	Median	IQR*	Range	Median	IQR	Range
Benefits						
Symptoms or diagnosis of depression	8	7-9	4-9	7.5	5-8.25	5-9
Health-related quality of life	8	6.5-8.5	5-9	8	6.75-9	6-9
Suicide ideation, attempt, or completion	8	7-9	5-9	9	8.75-9	5-9
Relationship with partner or other supports	7	6-8	5-9	8	6.75-8.25	3-9
Reported/observed capacity to parent	8	7-9	5-9	8.5	8-9	5-9
Mother-child interactions	8	6.5-9	3-9	8.5	8-9	7-9
Infant health and development	8	7-9	5-9	8	7-9	5-9
Infant responsiveness	8	6 -8	3-9	8	6.75-9	5-9
Harms						
False positive	6	4-8	3-9	5	5-6.25	4-9
Overdiagnosis	5	4.5-8	2-9	5	5-6.25	3-9
Overtreatment	6	4.5-7	2-8	5	4.75-7.5	4-9
Labelling/Stigma	6	4.5-8	2-9	5	3.75-7.25	2-9
Harms from psychotherapy	7	5.5-8.5	2-9	6	3-8	2-9
Harms from Antidepressants	8	5.5-8	2-9	7	5-8	1-9

**Note: IQR = interquartile range.*

Post-survey medians of benefit ratings fell between 7.5 and 9 (*critical* for decision-making). Post-survey medians of harm ratings were 5 or 6 (*important* for decision-making). The post-survey IQR of the benefit ratings were *important* or *critical.* The post-survey IQR of the harm ratings were lower, and ranged from *not important* to *critical.*

Overall preferences for screening

In the second part of the survey, participants rated their overall preferences for screening for depression during pregnancy and the postpartum period. We asked them to rate their preference for being screened given the potential harms and benefits. We also asked them to rate their preference for being screened given that the likelihood of many of the harms and benefits are not well known. Participants could rate the phrases "Considering the harms and benefits of screening for depression, how much would you want to be screened during pregnancy or the postpartum period" and "Considering that the risk of many of the harms and benefits of screening for depression during the pregnancy and postpartum period are not well known, how much would you want to be screened" 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 4. Table 4 presents overall preferences for screening and includes pre- and post-focus group survey data for comparison purposes.

Table 3. Description of 'Overall Screening Preference' Questions

Short Description	Full Survey Question
Overall screening preference (given potential **harms and benefits**)	Considering the harms and benefits of screening for depression, how much would you want to be screened during pregnancy or the postpartum period
Overall screening preference (given **available evidence** for outcomes)	Considering that the **risk of many of the harms and benefits** of screening for depression during the pregnancy and postpartum period **are not well known**, how much would you want to be **screened**?

Table 4. Pre- and post-survey overall screening preferences (n = 14)

Outcome	Pre-survey (*n* = 17)			Post-survey (*n* = 14)		
	Median	IQR*	Range	Median	IQR	Range
Overall screening preference (given potential **outcomes**)	7	5.5-8.5	5-9	8	7-9	5-9
Overall screening preference (given **available evidence** for outcomes)	7	5-8.5	3-9	7.5	7-9	3-9

**Note: IQR = interquartile range.*

There were a wide range of preferences for screening. However, the median preference for screening when considering the potential harms and benefits was 8. The median preference for screening when considering the lack of reliable evidence for potential outcomes was 7.5.

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

We conducted four focus groups (*n* = 12) and two interviews (*n* = 2) to gather qualitative data from participants about the importance of the harms and benefits of screening and their overall preferences for screening for depression during pregnancy and the postpartum period. We conducted a thematic analysis of focus group and interview transcripts.

A summary of the focus group discussions and survey responses is presented in Tables 6 and 7.

Information needs of participants

Table 6. Information needs of participants (n=14)

Information Needs	Description	Illustrative Quotes
Background sheet information	Participants found the information contained in the background sheet to be straightforward and easy to understand. Specifics as to what made the background sheet user-friendly included: - use of bullet points - minimal medical jargon - direct and clear content - headings and underlining, which provided clarity around section divisions - readily available information regarding treatment options for depression Some participants felt the addition of further information would be helpful: a) side effects of *both* appropriate and inappropriate depression treatments b) supplemental examples illustrating the distinction between "baby blues" and depression, as well as ways to determine the difference c) timeline for the occurrence of depression	*"When you're sleep deprived, anything that can make things look easier is great, so I found it really easy to consume the document."* FG1 *"I don't know what I don't know, so when there is some clarity about what this [depression] looks like and feels like, then that really helps to contextualize it."* FG5 *"I was wondering if there could be more examples about the distinction between what they call baby blues vs. depression and sort of what the timeline is for baby blues vs. depression. How different are they? How similar are they?"* FG3 *"One of my biggest*

	and/or “baby blues” d) follow-up steps in the event that depression is diagnosed through screening e) contact information for supports available to answer questions regarding depression and its diagnosis f) links to additional online resources	*questions before reading the sheet was, how would depression be treated if I were diagnosed with it and you guys answered that.”* FG1
Information provided by a family physician that would be useful as part of a shared decision making conversation about screening.	Participants agreed that a conversation with their primary care provider about post-partum depression and screening is critical. Participants identified several types of information that would be helpful as part of a discussion with their primary care provider about screening for depression during the pregnancy or postpartum period, including: a) next steps upon depression diagnosis , including typical duration and availability of treatment (both medical and non-medical therapies such as diet, exercise, support groups and other self-management strategies) b) whether previous post-partum depression increases the risk of recurrence in subsequent pregnancies c) the need for testing in the absence of symptoms d) pros and cons of screening (i.e. harms of untreated depression vs. potential risks of screening) e) information concerning the prevalence and severity of depression related to pregnancy (e.g. how common is it) f) symptoms to be aware of that might necessitate further testing (to be self-identified or noted by partner) g) timeline for individual/serial screenings (i.e. how often would screening happen) h) differences between baby blues and depression (i.e. when normal hormonal emotions cross a threshold into depression)	*“For me, I have two boys, I find that this topic never really came up. My doctor never said, ‘Do you have any concerns about potentially maybe going into a depression during the pregnancy?” Are they waiting for us to discuss the topic with them?”* FG2 *“You always want to see the light at the end of the tunnel so I would want to know how long I would be expected to need treatment before I was better again.”* FG1 *“I remember kind of feeling gee, I hope I don’t have depression symptoms, there would be something wrong with me if I did. Just to be reassured more that if you were experiencing symptoms that it is ok.”* FG2 *“It might be helpful to situate post-partum depression. How many people are impacted by it? If the number is low, perhaps what I’m feeling is just a normal bit of adapting to motherhood or is it very common?”* FG3 *“I sort of feel that depression while you’re pregnant is sort of swept under the rug. It’s important to create that awareness. That way we can look out for the symptoms.”* FG2

	i) how privacy of information is maintained j) incidence of false positive/negative results and possible consequences for both mother and baby k) potential impact of depression on other aspects of life beyond mother-infant relationship (e.g. work, relationships, etc.)	

In summary, this table identified information participants would request when learning about screening for depression during pregnancy and the postpartum period, as part of a conversation with their primary care providers. Participants emphasized the importance of having a discussion with their primary care provider about depression during the pregnancy and post-partum period, and the pros and cons of screening. Participants stated that differentiating between depression and the "baby blues", providing information on the prevalence of depression in the pregnancy and post-partum period, describing symptoms to be aware of, and describing potential next steps following a diagnosis, including duration and availability of treatment, are important conversations for primary care providers to have with patients.

Values and preferences for screening

The qualitative data collected through focus groups (*n* = 12) and interviews (*n* = 2) revealed the benefits and harms of screening that may influence a patient's overall preference for screening. Table 7 summarizes all unique values and preferences present in the qualitative data.

Table 7. Participants' values and preferences for screening (n = 14)

Factors	Description	Illustrative quotes
Preference for Screening	All participants would choose to be screened with the exception of one participant who would agree to screening only if prompted to do so by her physician. Participants provided the following information regarding the various factors that influenced their willingness to screen: a) risks associated with the assumption that depression is a normal part of the pre-postpartum process b) lack of confidence in the ability to self-identify symptoms of depression c) access to information around preventive measures such as exercise, diet and spousal relationship d) supports screening availability but	*"I feel like it's a responsibility I have to my child to take care of myself."* FG4 *"If the doctor suggested it, I would go for it. If he didn't, I don't think it would be a big deal."* FG4 *"If you're not asked those questions, there's not an opportunity for you to even realize that there may be something wrong. You may just think it's normal, all part of the postpartum process."* FG1 *"Thinking back, I am not sure if I was and it may have been very informal. The doctor had asked me just generally how*

	rejects the concept of mandatory screening e) belief that screening is an element of the mother's responsibility to her child f) although willing to screen, uncertainty around side effects provoked discomfort in some participants when deciding whether or not to screen	*are you feeling, how are you coping with the stresses of being a new mother and are you having any suicidal thoughts. Just questions like that so I feel that it may just have been an informal screening which I think is less intimidating than if she had have said 'okay I'm going to screen you for depression now'. So, informal screening for everyone would be great and then a secondary assessment after that if the doctor felt there was some risk."* FG2
Perceived Benefits of Screening		
Symptom reduction	a) screening provides information regarding symptoms to be aware of, allowing for early diagnosis and treatment b) reduction of symptoms that may negatively impact mother/baby is considered a significant priority c) one participant rated this benefit lower in the first survey (when they were pregnant), compared to rating given postpartum	*"If you are aware you have depression, you can look for alternative ways to work on it."* FG2 *"Depression is not anywhere in my family or friends' groups. I am very ignorant about it so I don't know if I would be able to recognize symptoms of it myself or just think I'm having a bad day or a bad week".* FG1
Improvement in mother-child interactions	a) this was considered a major benefit as an infant's development could be compromised if depression remains untreated b) depression impacts more than simply the mother; it also affects the baby. Outcomes that affected baby were generally considered more important than outcomes that affected just the mother c) bonding between mother and child is critical and depression can negatively impact this crucial relationship d) prior to birth, several participants felt that the mother-child relationship would not be impacted by untreated depression; this viewpoint reversed post-partum	*"I rated this quite highly. There are potential outcomes for two people, the mother and the infant and having positive attachment with babies is generally pretty well accepted that it leads to positive outcomes later in life."* FG3 *"If I didn't go for the screening, then I would perhaps not be diagnosed and not receive any treatment and perhaps feel very disconnected and alone in having to figure out what am I feeling and going through and how is this going to affect how I parent as well."* FG5
Improvement in infant responsiveness	a) the possibility of depression's negative influence on an infant's ability to interact with others was considered a key motivator for screening b) some confusion existed amongst participants regarding the definition of 'infant responsiveness' and how depression in a parent could impact this trait	*"I found this important because it affects the baby's ability to interact with their mom and potentially other people, which may cause issues further down the line."* FG1

	c) one participant stated she felt infant responsiveness and depression in the mother were unrelated and that infants develop at their own rate, independent of their mother's mental health	
Perceived Harms of Screening		
Unknown or undesirable treatment side effects	In general, potential risks associated with untreated depression were deemed to be more significant than the possibility of treatment side effects. However, several factors that could impact whether this perceived harm might influence the decision to screen were identified: a) a correlation between screening and possible treatment side effects was generally dismissed as unimportant given that the choice of treatment would be a personal one b) being provided with information about possible side effects would be critical in the decision-making process as it would impact risk/benefit ratio considerations c) previous negative experience with medication side effects would act as a deterrent	*"I think personally I find that while it is a process to go through to be screened, it is a way for me to find out more about myself and mentally prepare for what might be to come or what I might experience."* FG5 *"I can't imagine any real significant risk to being screened, even in the event of a false positive and diagnosis of depression that wasn't really there. Treatment options are still up to me as the patient so I think regardless, screening would be something that I would want."* FG3 *"Hopefully before being prescribed, the medical professional or healthcare provider will have discussed the potential side effects and benefits to trying out the antidepressant."* FG5
Overdiagnosis and unnecessary treatment	a) risks of overdiagnosis or its resulting treatment were not considered critical in comparison with failure to diagnose depression b) being screened and flagged does not necessarily mean you will receive treatment for depression c) in the event of a false positive, treatment likely would be quickly discontinued d) information concerning the harms that accompany overdiagnosis and unnecessary treatment would be needed to determine whether this risk outweighed the benefit	*"I figure it wouldn't take long to figure out that it was a false diagnosis."* FG2 *"There's more to it than screening alone. Screening is just step one. You would have to get through two hoops to get to treatment."* FG2
Anxiety or stigma resulting from being identified as having depression	a) this possible harm created a challenge for many of the participants who determined the harm/benefit ratio to be equal b) although the point was raised that screening resulting in timely treatment would offset this possible harm, the physician-moderator pointed out that	*"When you're pregnant, no one wants to find there's something wrong with them, whether it's with yourself or the baby."* FG2

	there may be a considerable delay between screening and diagnosis c) one participant indicated she would be more concerned about anxiety associated with the diagnosis than stigma d) attitudes of stigma around mental health conditions held by families of origin was a major concern e) a depression diagnosis would be shocking and would likely cause anxiety f) being stigmatized in the workplace or other settings was also raised as a concern g) there is considerable anxiety inherent in being a new mom and labelling a person as having depression may increase this	*"Mental health conditions in my family of origin have a lot of stigma".* [FG4] *"Receiving the diagnosis undoubtedly can be a bit of a shock and something people have to digest so the initial response might cause anxiety and in the worst-case scenario perhaps coming across situations where others perceive a person to be different and to label them or stigmatize them. It's both a personal and interpersonal implication that could result."* [FG5]
Rationale for highest ranked harms and benefits of screening	1) ability to intervene proactively in the event of depression 2) suicide prevention 3) improved capacity for parenting 4) in general, benefits prevailed over harms as the potential benefits were deemed to outweigh the impact of possible harms 5) outcomes that affect the baby general ranked higher (as opposed to just the mother)	*"I feel these are the core of what makes a new mom and a newborn first of all safe, and also it helps improve the health of both the mother and newborn and the development of the baby which would in turn feed back to the mother feeling less depressed."* [FG6]

This table summarizes the harms and benefits of screening depression during pregnancy and the postpartum period that participants discussed. It also summarizes participants' overall preferences for screening.

Overall, participants prioritized infant wellbeing, and felt outcomes that impacted the infant were among the most important to consider. Participants also emphasized that they felt a responsibility to themselves and their baby to be screened. Participants felt that reducing symptoms of depression, as well as impacts on the child-mother bond, are critical benefits of screening for depression during pregnancy and the postpartum period. Participants expressed concerns that without screening, they may not be capable of identifying symptoms of depression, or may not take initiative to seek input from a primary care provider, especially considering all of the stresses and changes one goes through as a new parent. Generally, participants were not overly concerned with false positives, overdiagnosis or overtreatment, as they felt treatment decisions would be separate from screening decisions, and any impacts from false positives or overdiagnosis would be resolved quickly.

Factors influencing access to screening

Focus group (*n* = 12*)* and interview (*n* = 2) responses revealed several barriers and facilitators to accessing screening for depression during pregnancy and the postpartum period. A summary is provided in Table 8.

Table 8. Factors that influence participants' access to screening (n = 14)

Factors	Description	Illustrative quotes
Potential barriers to screening	Participants identified potential barriers to screening: a) access, time commitment, duration and cost of screening and/or treatment b) privacy and confidentiality concerns c) test reliability – false positive/negative results d) concern regarding treatment side effects e) discomfort or embarrassment discussing the topic with family doctor f) presence of family members during medical appointments g) language barriers h) screening offered exclusively by physicians or nurse practitioners (to the exclusion of midwives or other healthcare professionals) i) physician ambivalence toward screening j) fear, stigma and cultural expectations around mental health issues k) being provided with 'too much' information may deter some from being screened l) more barriers to screening exist in the post-partum period than during pregnancy	*"With the midwife I went to you always saw the mother and father at all the appointments and maybe the mom wouldn't be as comfortable being as open if her spouse or the father was present."* FG1 *"I did not see an obstetrician. I saw a midwife. It would be a barrier if they were not included as a screening practitioner."* FG3 *"A language barrier that prevented someone from correctly understanding the questions, that could affect the answers."* FG2 *"I have a lot of friends who are a bit newer to Canada and I guess I'm always quite concerned about how culturally safe different kinds of screening or treatment they may need is."* FG5 *"Too much information might scare someone."* FG6 *"There is so much going on in the first few weeks that a lot of mothers might just put off going and getting help if they needed to."* FG6
Potential facilitators to screening	Participants identified potential facilitators to screening: a) wide screening availability, including birthing classes and other pre-post pregnancy, non-medical environments b) topic initiated by a supportive physician	*"Access to a healthcare provider you trust and feel comfortable discussing information with."* FG1 *"Some people don't want to have that discussion. Some people are very private so if you were just to have simple stuff like*

	c) pamphlets, posters and other materials available in waiting rooms to provide information and act as a starting point for discussion around screening d) screening offered both pre and postpartum e) informal approach to screening, which would make it less intimidating f) screening carried out at regular appointments rather than necessitating an additional visit g) understanding the screening process and next steps in the event depression is identified h) a screening form that distinguishes between depression, hormones and general emotions surrounding pregnancy and birth i) multiple screening formats, including in-person, online and by phone to increase accessibility j) culturally sensitive, multi-lingual screening k) incentive offered to screening participants	*brochures and flyers that are given to people who are pregnant, that would be very helpful."* [FG2] *"It would be great if it would provide the service of checking up on me to see if I am alright."* [FG6] *"As a new mom, after you give birth, you are quite in a passive state and it could be a person calling or a follow-up email just to remind you. I think that proactive approach for a new mom is sometimes very important. Sometimes you just kind of get lost when you are trying to take care of a newborn."* [FG6]

In summary, participants described perceived barriers and facilitators to accessing and completing depression screening during pregnancy and the postpartum period. Participants noted that screening may be more beneficial during the post-partum period compared with the pregnancy period, as there are more significant barriers during this period (e.g. lack of automatically scheduled prenatal doctor's visits, busier schedules and stress associated with caring for a newborn). Participants also emphasized that midwives were a key point of contact during pregnancy and post-partum period, and could be facilitators for screening and shared-decision making conversations. Additional factors identified that could impact access to screening included language barriers, combining screening with regularly scheduled visits with health care providers (e.g. prenatal visits), offering a variety of screening formats to increase accessibility (e.g. online, over telephone), privacy and confidentiality concerns, and fear, stigma, or cultural expectations around mental health issues.

Participant engagement

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

Participant experience ratings scales

In the post-focus group survey, participants were asked a series of questions about their experience in the project.[2] Participants responded using a 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 9. The quantitative ratings and relevant qualitative explanations are also summarized below.

Overall, the participant experience questions were highly rated, indicating a positive engagement experience. The majority of questions had a median response of 6 or higher. The two questions with lower median ratings of 5 asked if participants believed their input would influence the final decisions that underlie the engagement process and if participants believed their values and preferences would be included in the final advice of the CTFPHC. When expanding on the rationale behind their ratings for these questions, some participants stated it was difficult to gauge at this point in the study whether and how their feedback would be incorporated and influence decisions:

"I am hopeful but am aware how research evidence and politics also influence policy decisions." (P/PP Dep_PH2_ 35)

"I really have no idea, but will base on the professional nature of survey that everyone's feedback will be considered and included." (P/PP Dep_PH2_05)

Additionally, the questions with the highest medians of 7 asked if participants believed that the organizers were neutral in their opinions during the engagement process, if they felt that organizers took their contributions to the engagement process seriously, and if the ideas and materials provided were easy to understand.

Figure 3. Survey responses for participant engagement items (n = 14)

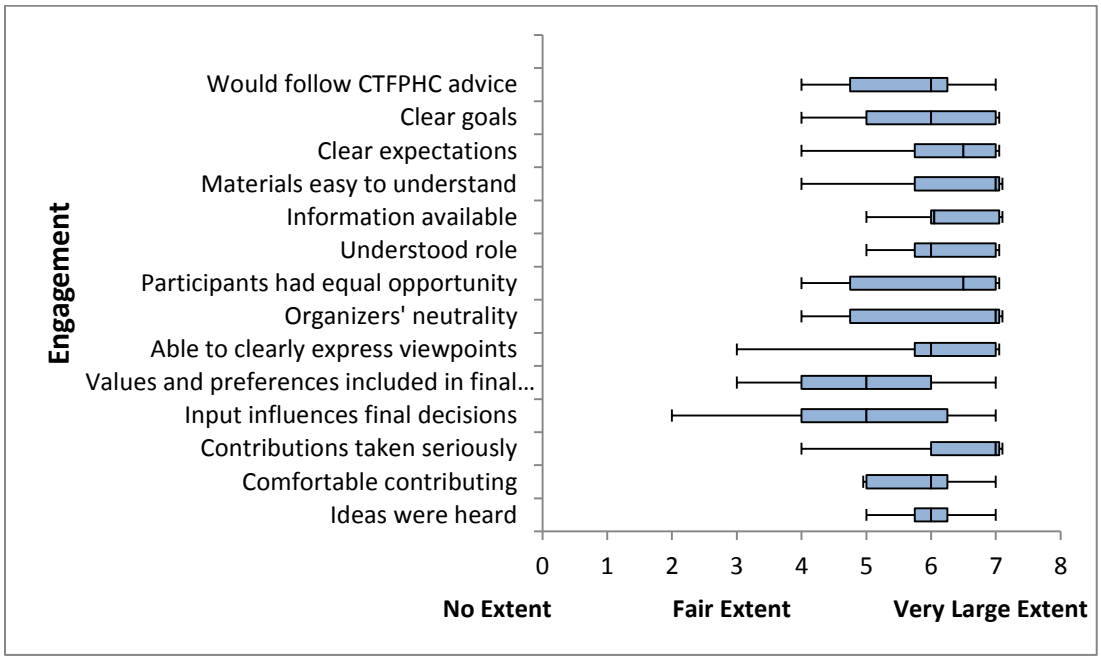


Table 9. Survey responses for participant engagement items (n = 14)

Question	Median	IQR*	Range
To what extent do you believe that your ideas were heard during the engagement process?	6	5.75-6.25	5-7
To what extent did you feel comfortable contributing your ideas to the engagement process?	6	5-6.25	5-7
Did organizers take your contributions to the engagement process seriously?	7	6-7	4-7
To what extent do you believe that your input will influence final decisions that underlie the engagement process?	5	4-6.25	2-7
To what extent do you believe that your values and preferences will be included in the final health advice from this process?	5	4-6	3-7
To what extent were you able to clearly express your viewpoints?	6	5.75-7	3-7
How neutral in their opinions (regarding topics) were organizers during the engagement process?	7	4.75-7	4-7
Did all participants have equal opportunity to participate in discussions?	6.5	4.75-7	4-7
How clearly did you understand your role in the process?	6	5.75-7	5-7
To what extent was information made available to you either prior or during the engagement process so as to participate knowledgeably in the process?	6	6-7	5-7
To what extent were the ideas contained in the information material easy to understand?	7	5.75-7	4-7
How clearly did you understand what was expected of you during the engagement process?	6.5	5.75-7	4-7
How clearly did you understand what the goals of the engagement process were?	6	5-7	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)?	6	4.75-6.25	4-7

**Note: IQR = interquartile range*

After participants responded to questions about their engagement, they responded to questions about the clarity and ease of the tasks that they were asked 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 10.

Overall, participants responded positively to all five questions, indicating clarity and ease of participating. All medians fell at the high end of the response options (8 or above). Participants were also asked to summarize what they had been asked to do in the survey. The majority of participants also accurately described the survey tasks they completed. Thus, there is converging evidence that participants understood the survey tasks.

Figure 4. Survey responses for experience items (n = 14)

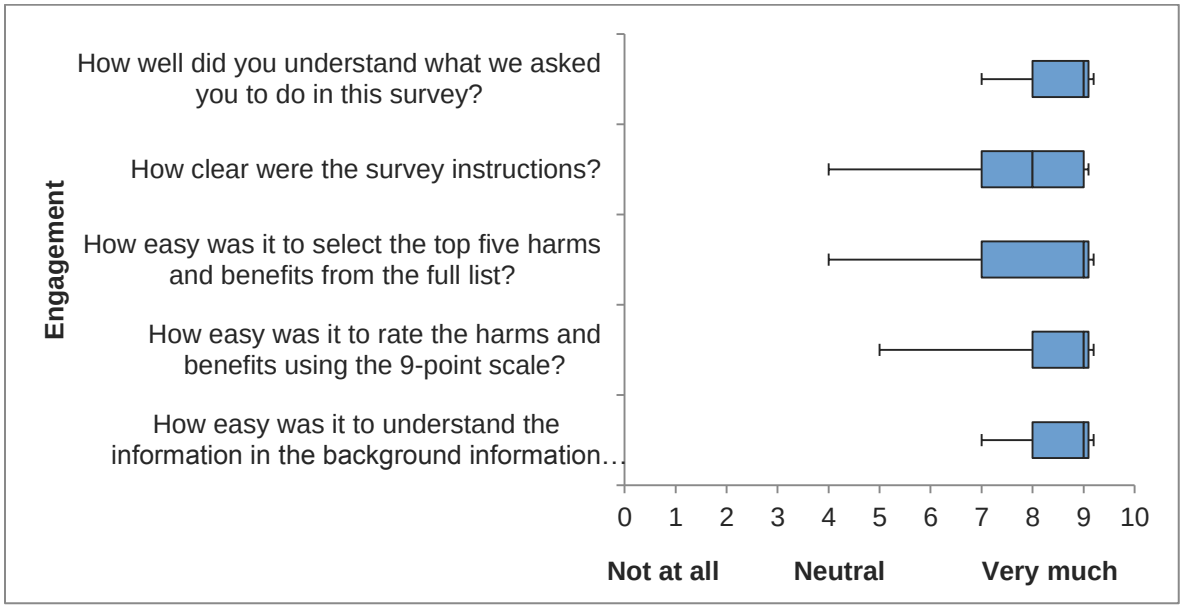


Table 10. Survey responses for experience items (n = 14)

Question	Median	IQR*	Range
How easy was it to understand the information in the background information sheet?	9	7.75-9	5-9
How easy was it to rate the harms and benefits using the 9-point scale?	8	7-9	6-9
How easy was it to select the top five harms and benefits from the full list?	8	7.75-9	5-9
How clear were the survey instructions?	8.5	6.75-9	5-9
How well did you understand what we asked you to do in this survey?	9	8-9	3-9

**Note: IQR = interquartile range*

Participants' overall experience

Four focus groups (*n* = 12), two interviews (*n* = 2), and 19 open-ended survey questions (*n* =14) were conducted to gather qualitative data from participants about their experience in the project. Table 11 below summarizes participants' main impressions of the engagement process.

Table 11. Qualitative data for project experience (n = 14)

Project component	Participants' impressions	Illustrative quotes
Focus groups and interviews	**Positive feedback** Several participants found the focus group discussion open, honest, and neutral, and felt the moderator understood and valued their feedback and perspectives. Participants stated that appreciated the opportunity to provide input, and felt their voices as members of the target population were particularly valuable to hear. Some participants found the teleconference format convenient and accessible.	*"During the focus group call, the moderator made a point of summarizing my comments which showed me she understood the points I was trying to make. At the end of the call, I was also told my feedback was very helpful, which was great to hear. " (P/PP Dep_PH2_27)* *"My opinion was asked for nearly every question, which made me feel like my opinion was valued and taken seriously" (P/PP Dep_PH2_27)* *"As a new mother who is going through the postpartum period, I'm the ideal candidate for researchers to understand what level of pre and postpartum support is important and critical for new mothers" (P/PP Dep_PH2_27)*
	Suggestions for improvement Suggestions for improvement included increasing the length of the focus group, limiting number of participants on the call and encouraging less engaged participants to contribute more, to allow for more robust discussion. One participant felt the content expert was slightly biased against screening One participant felt a teleconference was not an appropriate format for effective discussion.	*"I was a bit disappointed by the lack of engagement by other participants during the focus group." (P/PP Dep_PH2_05)* *"More time would have enabled more robust participation." (P/PP Dep_PH2_35)* *"At times it felt that the subject matter expert was slightly biased against screening."(P/PP Dep_PH2_35)* *"The focus group felt rushed and while I understand teleconference was necessary to enable broad Canada-wide participation, this format does impact effectiveness of communication." (P/PP Dep_PH2_35)*
Overall project experience	**Positive feedback**	

	Participants noted that project communication was particularly clear and helpful	*"All material and emails were very well documented and explained" (P/PP Dep _PH2_27)* *"Instructions and expectations were clear so that participants are able to contribute easily." (P/PP Dep_PH2_06)*
	Participants appreciated the opportunity to have their opinion heard, and contribute to health care.	*"If I can contribute even a tiny part in the postpartum health of any mom going forward, then any time to this project was very well spent! "(P/PP Dep_PH2_27)*
	Participants enjoyed learning about depression screening during pregnancy and the postpartum period.	*"It was interesting learning that there aren't any conclusive studies supporting the benefits of screening."(P/PP Dep_PH2_05)*
	Suggestions for improvement In addition to the focus group suggestions above, one participant requested more clarity surrounding some questions in the survey, and explicitly including midwives in any recommendations or guideline materials. One participant felt that since values and preferences change, especially before and after giving birth and becoming a new mother, that additional survey timepoints could be useful. One participant suggested offering a different focus group format than a teleconference.	*"Tracker on survey to give a sense of length/where you are in process. Include midwives as part of health care team in general." (P/PP Dep_PH2_05)* *"Maybe a yearly survey on this topic to see if the viewpoint of pregnant women has changed" (P/PP Dep_PH2_02)* *"Have mentioned some items that could use clarification. Teleconference format focus group not ideal but understandable."(P/PP Dep_PH2_35)*

Limitations

In addition to the limitations of the methods discussed in the Patient Engagement Protocol, there were further limitations specific to this project. Our sample was not representative of the target screening population in Canada. The majority (*n* = 13) had a college diploma, bachelor's, graduate, or professional degree. Due to the high education level of participants, these participants may have higher health literacy, different risk factors or protective factors, and/or preferences that differ from the target screening population. Furthermore, the majority of participants lived in urban or suburban areas (*n* = 13), and only one participant 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.

Suggestions for applying findings

Below are our suggestions for applying the findings from this project to the CTFPHC's screening for depression during pregnancy and the postpartum period guideline:

1. **Provide resources to support a discussion of patients' preferences and shared decision making (particularly when recommendations are inconsistent with patients' preferences**) 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. For example, if evidence indicates that harms of screening outweigh the benefits, the CTFPHC may develop a recommendation that is inconsistent with patients' preferences for wanting to be screened. In this case, the CTFPHC may consider developing and disseminating resources that help clinicians and patients address inconsistencies between patient preferences and guideline recommendations. 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 screening. These resources may support both clinicians and patients in shared decision-making.

   Lastly, many participants noted a need for expanded screening beyond family doctors and obstetricians, specifically mentioning midwives as key points of contact during the pregnancy and post-partum periods. The CTFPHC may consider developing and disseminating KT tools that target interdisciplinary maternal and child health care providers.

2. **Develop KT tools that address information needs of participants.** Participants had additional questions about screening timeframes, availability and timelines of treatment following a diagnosis of depression from screening, and the prevalence of depression among pregnant and post-partum populations in Canada. Participants generally prioritized infant wellbeing when determining outcomes that were important to their screening decision, and generally placed more importance on benefits rather than harms when considering a screening decision. Additionally, explanations for why some of the risks are unknown may assist patients'

understanding of what a lack of data for outcomes means. Many participants felt that the lack of evidence for many of the screening outcomes did not mean these outcomes would not occur, and would not change their preference to be screened. Thus, the guideline and KT tools should integrate relevant information to help address patients' concerns, and help health care providers and patients engage in shared decision-making so patients can make an informed choice about screening for depression during the pregnancy and post-partum period.

3. **Send participants a summary of how their feedback in the final guideline and KT tools was used.** The lowest rated engagement questions related to the extent participants believed that their input would influence final decisions that underlie the engagement process, and that their values and preferences would be included in the final advice of the CTFPHC. 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, providing specific examples. In the case where CTFPHC guideline recommendations differ from participants' preferences identified in this project, the CTFPHC should also clearly outline the reasoning behind their recommendations to project participants. The CTFPHC may also request that participants complete the participant engagement measure again to explore whether participants' beliefs shifted when presented this information.

4. **Emphasize the difference between 'usual care' and screening in shared-decision making tools.** Many participants emphasized the importance of a discussion with their primary care provider about depression during the pregnancy and post-partum period. However participants may not have clearly understood the distinction between informal discussions or 'usual care', and standardized screening. The CTFPHC may consider emphasizing the difference between a formalized screening process, and usual care when drafting recommendations and shared decision making tools.

Conclusion

Through this project we explored screening preferences for a sample of the screening population to whom the guideline will be relevant. 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 indicated a strong desire to be screened for depression during pregnancy or the postpartum period, even considering that the likelihood of many of the outcomes are not well known. They noted screening during the post-partum period by different health professionals would be particularly valuable. Many participants enjoyed the opportunity to participate and appreciated the opportunity to contribute to what was perceived as a very important and relevant topic. These findings should be integrated into the screening for depression during pregnancy and the postpartum period 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. 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 during pregnancy and postpartum. Please answer the following questions accurately and honestly.

If you have any questions, concerns, or technical difficulties, please contact Kyle Silveira, at silveirak@smh.ca or 416-864-6060 x76218.

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 (1)
- ❍ No (2)

End of Block: Eligibility: HCP

Start of Block: Yes, HCP

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 (1)
- ❍ No (2)

How old are you?

- ❍ 17 years old or younger (1)
- ❍ 18-25 (2)
- ❍ 26-30 (3)
- ❍ 31-35 (4)
- ❍ 36-40 (5)
- ❍ 41-45 (6)
- ❍ 46 years old or older (7)

Q57 Thank you for taking the time to fill out this survey.
Unfortunately, it appears that you are not eligible to take part in this initiative.

The CTFPHC is exclusively soliciting the opinions of people aged 18 years of age or older.

Q42 Did you give birth on or after February 1, 2018?

- ❍ Yes (1)
- ❍ No (2)

Are you currently pregnant?

- ❍ Yes (1)
- ❍ No (2)

Q55 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 pregnant or have given birth since February 1, 2018.

Q56 **Take Part in Future Projects**
The Knowledge Translation Program at St. Michael's Hospital conducts other projects where we ask for public input. 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 (1)
- ❍ No (2)

End of Block: Ineligible

Start of Block: Depression

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

- ❍ Yes (4)
- ❍ No (5)

Q60
Are you currently receiving treatment for depression?

- ❍ Yes (4)
- ❍ No (5)

End of Block: Depression

Start of Block: Eligibility: Conflict of interest

Do you have any conflict of interest related to depression or mental health in pregnancy, birth, or postpartum? 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) (1) _____
- ❍ No (2)

End of Block: Eligibility: Conflict of interest

Start of Block: Demographic Questions

How did you hear about this opportunity?

- ❍ Charity Village (1)
- ❍ Craiglist (2)
- ❍ Kijiji (3)
- ❍ Other, please specify... (6) _____

Which province or territory do you live in?

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

Which time zone do you live in?

- ❍ Pacific (1)
- ❍ Mountain (2)
- ❍ Central (3)
- ❍ Eastern (4)
- ❍ Atlantic (5)
- ❍ Newfoundland (6)
- ❍ I don't know (7)

Which type of region do you live in?

- ❍ Urban (1)
- ❍ Suburban (2)
- ❍ Rural (3)

What is your gender?

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

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

- ❍ First Nations (1)
- ❍ Métis (2)
- ❍ Inuit (3)
- ❍ No, I am not Aboriginal (4)

What is the highest level of education that you have completed?

- ❍ Less than high school (1)
- ❍ High school (2)
- ❍ College diploma or bachelor's degree (3)
- ❍ Graduate or professional degree (4)

What is your annual household income?

- ❍ less than $25,000 (1)
- ❍ $25,000-29,999 (2)
- ❍ $30,000-$39,999 (3)
- ❍ $40,000-$49,999 (4)
- ❍ $50,000-$59,999 (5)
- ❍ $60,000-$69,999 (6)
- ❍ $70,000-$99,999 (7)
- ❍ $100,000 or more (8)

Thank you for taking the time to fill out this survey.
The project team will only contact you by email if you are eligible and space permits to take part in this project.

Take Part in Future Projects

The Knowledge Translation Program at St. Michael's Hospital conducts other projects similar to this. Even if you are not eligible to take part in this project, you may be able to participate in other current or future projects conducted by the Knowledge Translation Program.

Would you be interested in joining our mailing list for project and research study recruitment? If you indicate yes, we will take this as your consent for your name and email address to be added to our mailing list.

- ❍ Yes (1)
- ❍ No (2)

Appendix B: Background sheet

CTFPHC Patient and Public Engagement: Background Information
Screening for Depression in Pregnant and Postpartum Populations

What is depression during pregnancy and the postpartum period?

Depression is an illness that can happen at any time, including during pregnancy or during the postpartum period (the first year after having a baby). Depression is different than short-term feelings of sadness after childbirth, sometimes called the 'baby blues'. The 'baby blues' are common and usually fade within a couple of weeks. Depression **lasts longer** and **symptoms are more severe.** Symptoms happen nearly every day for **at least 2 weeks**, and may include:

- Sad mood most of the day
- Loss of interest or pleasure in most or all activities
- Gaining or losing a lot of weight
- A hard time falling or staying asleep
- Feeling very tired during the day or having little or no energy (beyond the normal tiredness of caring for a new baby)
- Being restless (constantly moving or unable to be still) or sluggish (slow, tired)
- Feeling guilty, or like you don't have any worth or value
- Trouble thinking, concentrating, or making decisions
- Thoughts of death, thoughts of suicide, or suicide attempts

How common is depression? What are the effects of having depression during pregnancy or within one year after having a baby?

Depression is just as common for women who are not pregnant as it is for women the same age who are pregnant or have recently had a baby. However, having depression either while pregnant or as a new parent can have a negative impact on partner relationships and the ability to parent, decrease quality of life, or increase suicidal thoughts and actions. If postpartum depression is not treated, it can also become chronic and last beyond the first year after childbirth, affect mother-child interactions (less touching, smiling, and speech), or have a negative impact on the baby's physical, mental, and emotional development.

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

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

depression is not the same as diagnostic testing, and does not always lead to identification and treatment of depression.

How is depression diagnosed?

When someone feels symptoms of depression, diagnostic tests are used to decide whether the person has depression. This is *diagnosis*. If screening shows that a person may have depression, a health care provider will spend time talking about how the symptoms affect day-to-day life and may conduct diagnostic tests. The person might also be sent to a mental health specialist for more in-depth diagnostic testing or for treatment.

How is depression treated during pregnancy or within one year after childbirth?

- **Lifestyle changes** - Eating well, getting some exercise every day, sleeping as much as possible, mainly at night, and help from family and friends can all help a person feel better.
- **Support** - Peer support groups and expert-led support groups can help with sharing and understanding experiences. This works best for mild symptoms of depression.
- **Talk therapy** - A therapist can help spot problems and suggest changes behaviour or ways of thinking. This may help relieve symptoms. This treatment is usually recommended when symptoms are more serious or when other interventions are not helping enough.
- **Medications (Antidepressants)** - Medication may help relieve symptoms of depression during pregnancy or postpartum. Antidepressants may be used when medications have been successful in the past, other treatments are not helping, or when symptoms are severe and have a big impact on day-to-day life.

What are the possible benefits of depression screening and treatment?

Possible ***benefits*** *for the mother* of screening that leads to identifying and treating depression could be:

- Better mental health, which may include reduced symptoms of depression, better health-related quality of life, and/or reduced suicidal thoughts or attempts
- Better relationship with a partner
- Better capacity to parent a child
- Better interaction between mother and baby

Possible ***benefits*** *for the baby* of screening that leads to identifying and treating maternal depression could be:

- Better infant health and development
- Better infant responsiveness

What does the research say about the benefits of depression screening?

Benefits for the mother: There is very little conclusive research about this question. One study showed that depression screening during the postpartum period may improve women's scores on one of the two depression questionnaires at 6 months (the scores on the other questionnaire did not differ between the groups screened or not screened). That study found no difference in women's capacity to parent, interactions with their child, or relationship with their partner. There is not enough

evidence to know if screening for depression changes the number of women who think about, plan, or attempt suicide.

Benefits for the baby: There is also not enough research to know if screening for depression during pregnancy or the postpartum period improves a baby's development. One study found no big differences in the wellbeing (for example, doctor visits) of infants whose mothers were screened for depression compared to those whose mothers were not.

What are the possible harms of depression screening and treatment?

Possible ***harms*** *for the mother* as a result of screening for depression could include:

- *False positive* screening result: when the questions on a screening test say a person might have depression, but then the next tests shows that they do not have depression after all
    - False positives may cause unnecessary stress while waiting for additional tests
- *Overdiagnosis* of depression: when the normal ups and downs of pregnancy or the postpartum period are diagnosed as depression
    - This could result in receiving treatment for depressive symptoms that would have gone away on their own without treatment (*overtreatment*)
- *Labelling*: Being labelled with depression as a result of a screening test could result in stigma, feelings of inadequacy or failure, and/or feeling less able to cope

Possible ***harms*** *for the mother* as a result of identifying and treating depression could include:

- Harms of psychotherapy: Poorly applied psychotherapy could cause symptoms to worsen or new ones to develop
- Medication side effects: more than 10% of people on antidepressant medications report side effects like nausea and vomiting; diarrhea, dizziness, fatigue, headache, sexual dysfunction, tremor, and weight gain (usually less than 10 pounds).
    - For people who are pregnant, possible harms of antidepressants include a small risk of major vaginal bleeding after giving birth and high blood pressure

Possible ***harms*** *for the baby* as a result of identifying and treating maternal depression could include:

- Medication side-effects: using certain antidepressants during pregnancy may include a small risk of infant heart problems, premature birth, and problems with infant growth.

What does the research say about the harms of depression screening?

Harms for the mother or baby : There is not enough research to know if screening for depression increases or decreases harms for the mother or baby related to screening (such as false positives, overdiagnosis, overtreatment, labeling/stigma, or harms from medication side-effects on the baby).

Post-survey (unexposed) P/PP Dep Phase 2

Start of Block: Default Question Block

Q1 CTFPHC Survey on Public Perceptions of Screening for Depression in Pregnant and Postpartum Populations

Q2 Introduction: The Canadian Task Force on Preventive Health Care (CTFPHC) receives funding from the Public Health Agency of Canada (PHAC) to develop evidence-based clinical practice guidelines for preventive health care in Canada.The CTFPHC has created the following survey to assess how members of the public view screening for depression during pregnancy or the postpartum period (i.e., one year after giving birth). 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 in pregnancy or the postpartum period. The survey will take **approximately 10–15 minutes to complete**.

If you have any questions, concerns, or technical difficulties, please contact the research assistant, Kyle Silveira, at SilveiraK@smh.ca or 416-864-6060 x 76218.

Page Break

Q3 Confidentiality Agreement:

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

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

- ❍ Yes (1)
- ❍ No (2)

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

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

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

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

_____

Q6 Date:

_____

Q39 Before you begin the survey, please take the time to read the Screening for Depression Background Information Sheet :

[insert Background Information Sheet (See Appendix B)]

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

- ❍ I agree (1)

Q10 Below is a series of statements about the POTENTIAL BENEFITS that pregnant and postpartum populations may experience after getting screened for depression.
Screening for depression is a process where health care providers check for depression in every

person, even if the person has not noticed any symptoms or has not disclosed symptoms to their health care provider. People who have noticed symptoms and notified their health care provider will get checked for depression (but this is called "usual care", not "screening"). Please rate how important each of these potential benefits would be for you to consider, if you were making a decision on whether or not to be screened for depression during pregnancy or postpartum.

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

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

	1 (1)	Not important for decision making 2 (2)	3 (3)	4 (4)	Important for decision making 5 (5)	6 (6)	7 (7)	Critical for decision making 8 (8)	9 (9)
If screening leads to treatment, it may reduce symptoms or diagnosis of depression (2)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may improve health-related quality of life (3)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may reduce thinking about, considering, planning, attempting, or contemplating suicide (4)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it	❍	❍	❍	❍	❍	❍	❍	❍	❍

may improve relationships with partners and other supports (5)									
If screening leads to treatment, it may improve capacity to parent (for example attachment, responsiveness, and positive regard for infant) (6)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech (7)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may improve infant health and development (8)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment, it may improve infant responsiveness (9)	❍	❍	❍	❍	❍	❍	❍	❍	❍

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

Q12 Below is a series of statements about the POTENTIAL HARMS that pregnant and postpartum populations may experience after getting screened for depression.
Screening for depression is a process where health care providers check for depression in every person, even if the person has not noticed any symptoms or has not disclosed symptoms to their health care provider. People who have noticed symptoms and notified their health care provider will get checked for depression (but this is called "usual care", not "screening"). Please rate how important each of these potential harms would be for you to consider, if you were making a decision on whether or not to be screened for depression during pregnancy or postpartum.

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

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

	1 (1)	Not important for decision-making 2 (2)	3 (3)	4 (4)	Important for decision-making 5 (5)	6 (6)	7 (7)	Critical for decision-making 8 (8)	9 (9)
Screening tests may identify depression when it is not really present (called false positive result) (1)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis) (3)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in starting treatment for depression in people who would not benefit (over-treatment) (4)	❍	❍	❍	❍	❍	❍	❍	❍	❍
Screening may result in labelling someone as having depression which can lead to anxiety or stigma (2)	❍	❍	❍	❍	❍	❍	❍	❍	❍
If screening leads to treatment with pyschotherapy, harms may include worsening of existing symptoms or	❍	❍	❍	❍	❍	❍	❍	❍	❍

development of new ones (5)									
If screening leads to treatment with antidepressants, harms may include unwanted side effects from the medication (6)	❍	❍	❍	❍	❍	❍	❍	❍	❍

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

Q14

Below is the same list of statements about potential harms and benefits you just rated. Please select **FIVE** items on this list that you think are **most critical to consider** when people make decisions about screening for depression during pregnancy or the postpartum period.

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

Please do not select more than five items.

- ❑ If screening leads to treatment, it may reduce symptoms or diagnosis of depression (1)
- ❑ If screening leads to treatment, it may improve health-related quality of life (2)
- ❑ If screening leads to treatment, it may reduce thinking about, considering, planning, attempting, or contemplating suicide (3)
- ❑ If screening leads to treatment, it may improve relationships with partners and other supports (4)
- ❑ If screening leads to treatment, it may improve capacity to parent (for example attachment, responsiveness, and positive regard for infant) (5)
- ❑ If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech (6)
- ❑ If screening leads to treatment, it may improve infant health and development (7)
- ❑ If screening leads to treatment, it may improve infant responsiveness (8)
- ❑ Screening tests may identify depression when it is not really present (called false positive result) (9)
- ❑ Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis) (10)
- ❑ Screening may result in starting treatment for depression in people who would not benefit (over-treatment) (11)
- ❑ Screening may result in labelling someone as having depression which can lead to anxiety or stigma (12)
- ❑ If screening leads to treatment with pyschotherapy, harms may include worsening of existing symptoms or development of new ones (14)
- ❑ If screening leads to treatment with antidepressants, harms may include unwanted side effects from the medication (15)

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

_____

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

_____

Q19 Considering the **potential harms and benefits** of screening for depression, how much would you want to be **screened** during pregnancy or the postpartum period?

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

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

_____

Q36 Considering that the **risk of many of the harms and benefits** of screening for depression during the pregnancy and postpartum period **are not well known**, how much would you want to be **screened** ?

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

Q37 If you would like to provide any comments about your rating, please enter them in the space below:

_____

Q46 **We will now ask you some questions about your experience participating in this project.**

Q47 In the space below, please briefly summarize the tasks that we asked you to perform in this survey.

_____

Q48 Please respond to each of the following statements using the scale provided.

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

Q49 In the space provided, please describe anything we could do to make the survey tasks easier to complete:

_____

Q80 Please describe anything that we could change to improve this project:

_____

Q81 Please describe what you liked about taking part in this project:

_____

Q82 Please describe what you did not like about taking part in this project:

_____

Q23 **Demographic Information**

Q24 What is your age?

_____

Q25 What is your gender?

_____

Q29 Are you pregnant?

- ❍ Yes (1)
- ❍ No (2)

Q30 Did you give birth on or after February 1, 2018?

- ❍ Yes (1)
- ❍ No (2)

Q42 Were you acting as a surrogate during that pregnancy?

- ❍ Yes (1)
- ❍ No (2)

Q38 Is your current pregnancy a surrogacy?

- ❍ Yes (1)
- ❍ No (2)

Q41 How many children have you given birth to in the past?

- ❍ This will be my first child (1)
- ❍ 1 (2)
- ❍ 2 (3)
- ❍ 3 or more (4)

Q31 Have you ever been diagnosed or treated for depression by a health professional?

- ❍ Yes (1)
- ❍ No (2)

Q32 Are you currently receiving treatment for depression?

- ❍ Yes (1)
- ❍ No (2)

Q26 Which province or territory do you live in?

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

End of Block: Block 7

Start of Block: Block 9

Q28
Next Steps:

Thank you for completing this survey. If you have questions about any part of the project, please contact Kyle Silveira at silveirak@smh.ca or 416-864-6060 ext. 76218

We will now process your reimbursement 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 our data is 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!!

Appendix D: Sample personalized response sheet

Task Force Survey on Public Perceptions of Screening for Depression in Pregnant and Postpartum Populations (Phase 2)

Personalized Rating Sheet

Survey 1

Prepared for Participant Number X

Introduction

A total of 17 people from across Canada completed the Task Force Survey on Public Perceptions of Screening for Depression in Pregnant and Postpartum Populations. 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 in pregnancy or the postpartum period, how important would these outcomes and information be for you?”

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

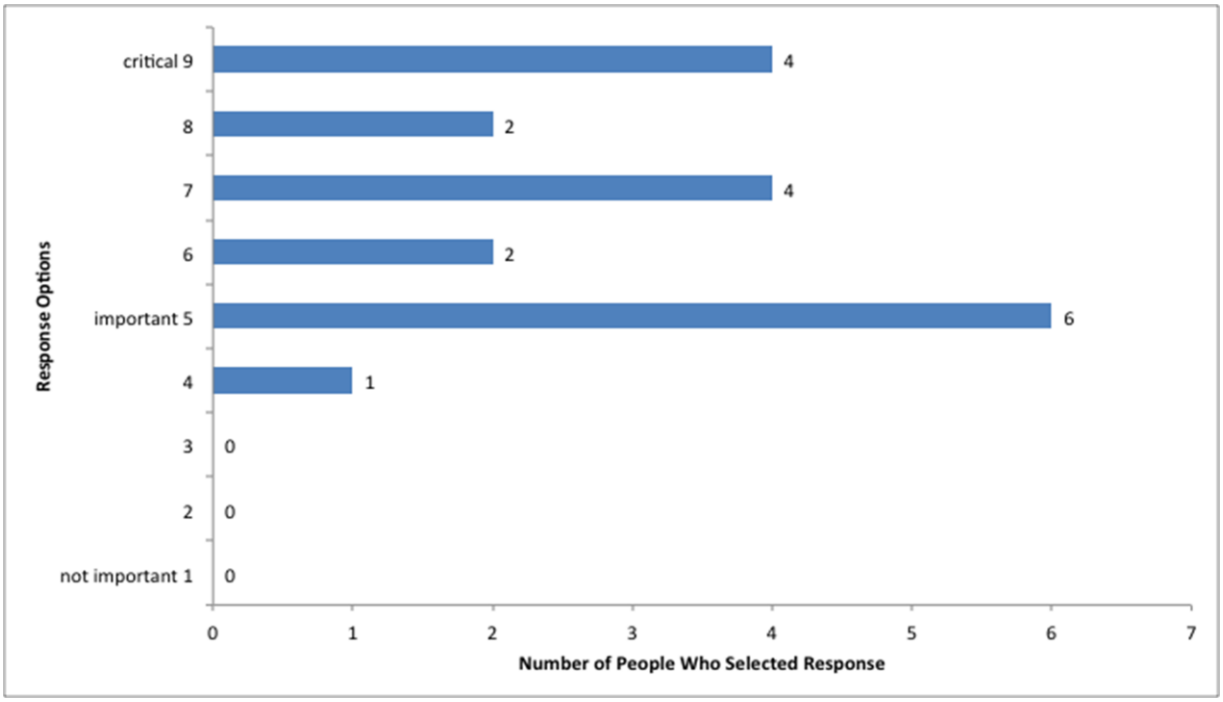
- 1-3 - not important to my decision to be screened or not for depression
- 4-6 - important to my decision to be screened or not for depression
- 7-9 - critical to my decision to be screened or not for depression

EXAMPLE: How to read the graph

Sample Outcomes Scale Rating

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

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



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

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

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

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

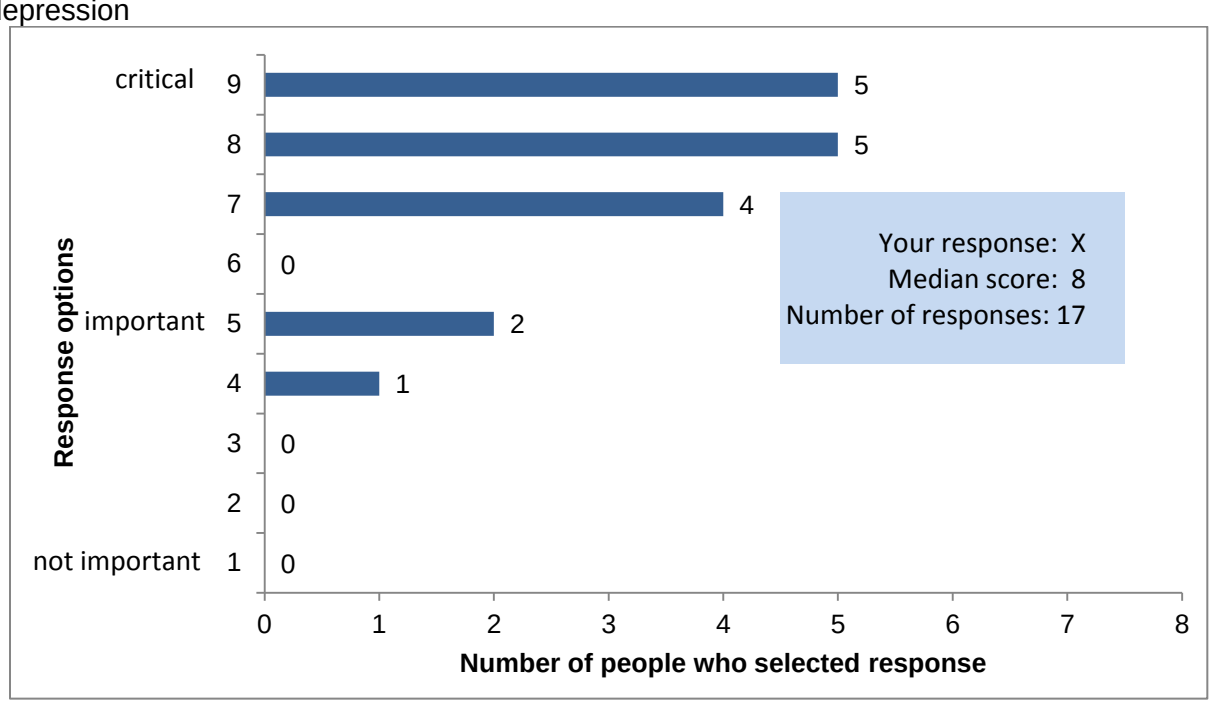
- The number on the rating scale that you selected for this outcome
- The median rating for this outcome across all participants (you can think of this like an "average" of the ratings selected by all participants)
- The total number of participants who rated this outcome

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

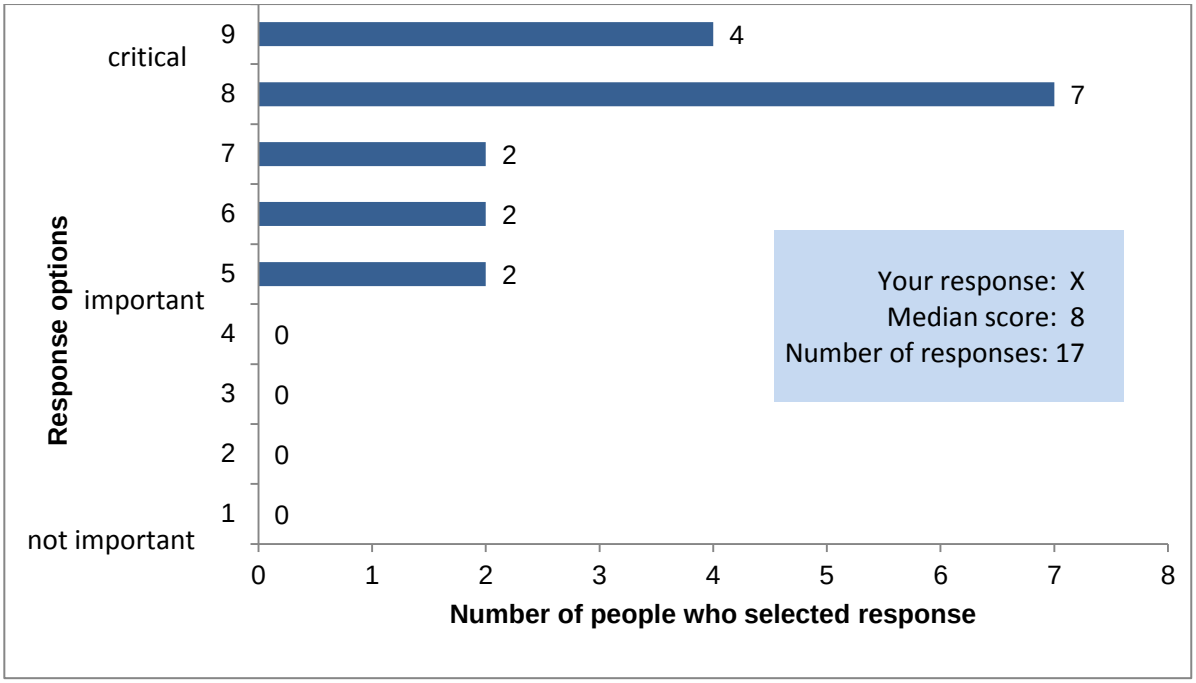
Your personalized answers are broken down by potential harms and benefits for depression screening in pregnancy or the postpartum period below:

Summary of Outcomes Ratings

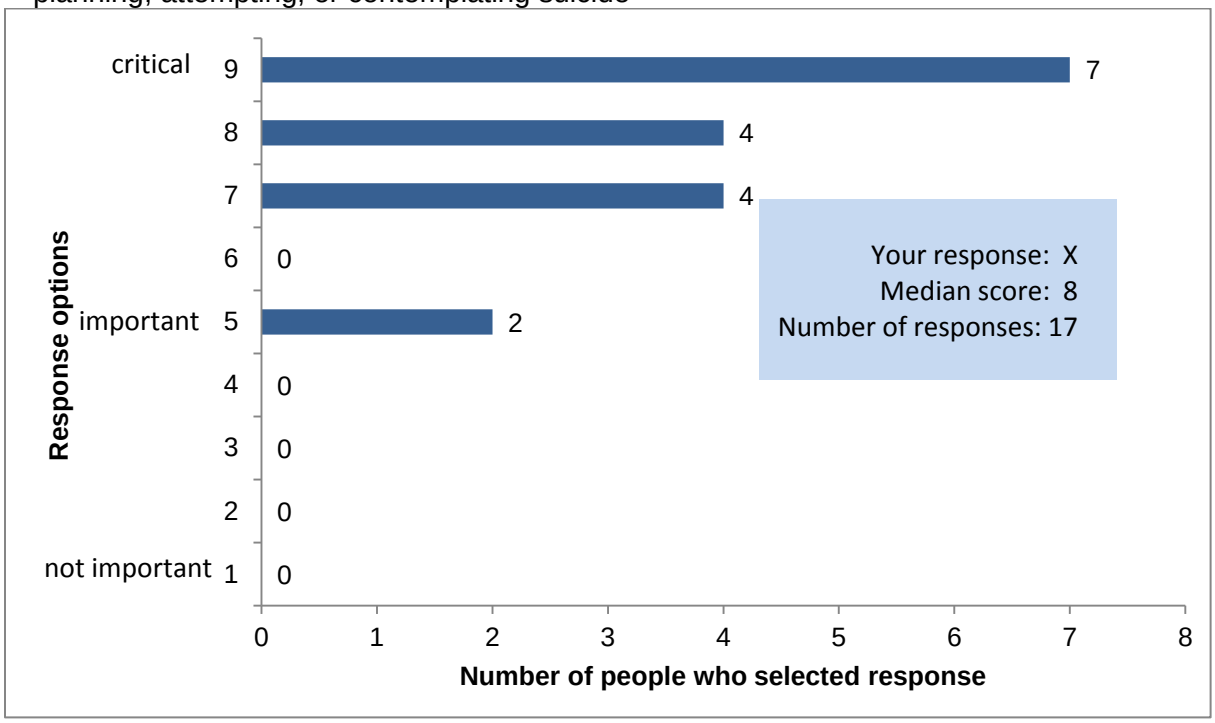
1. **Potential Benefit:** If screening leads to treatment, it may reduce symptoms or diagnosis of depression



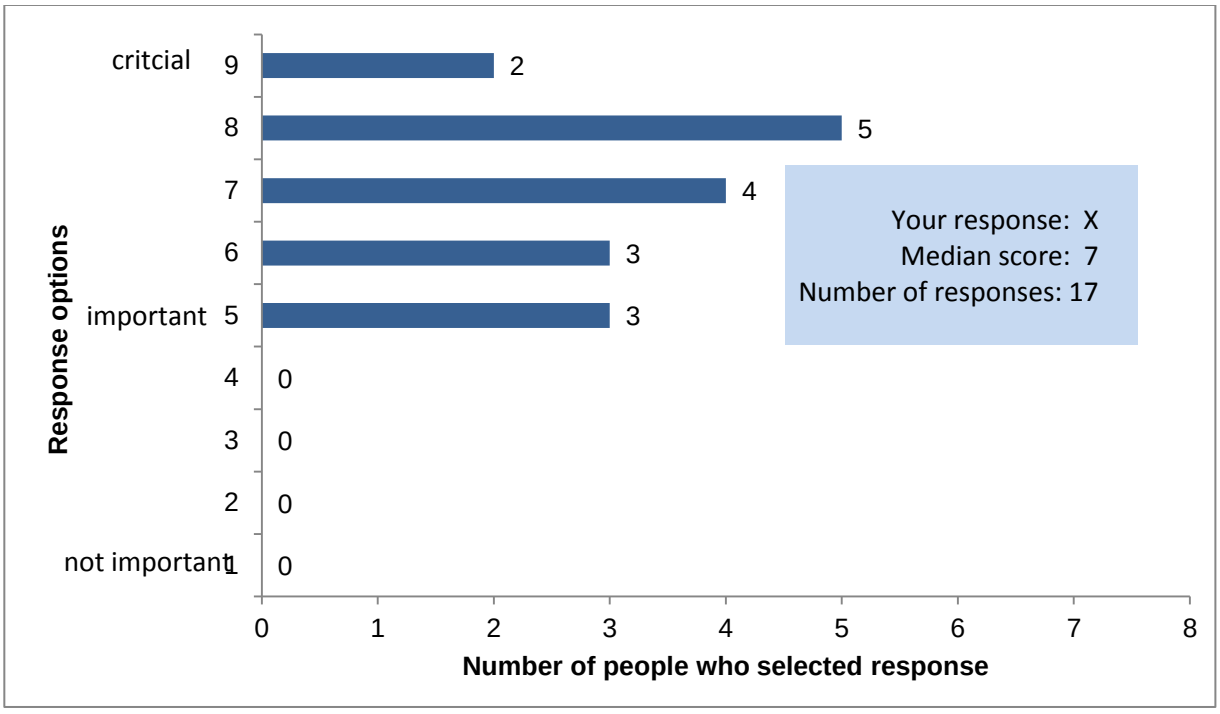
2. **Potential Benefit:** If screening leads to treatment, it may improve health-related quality of life



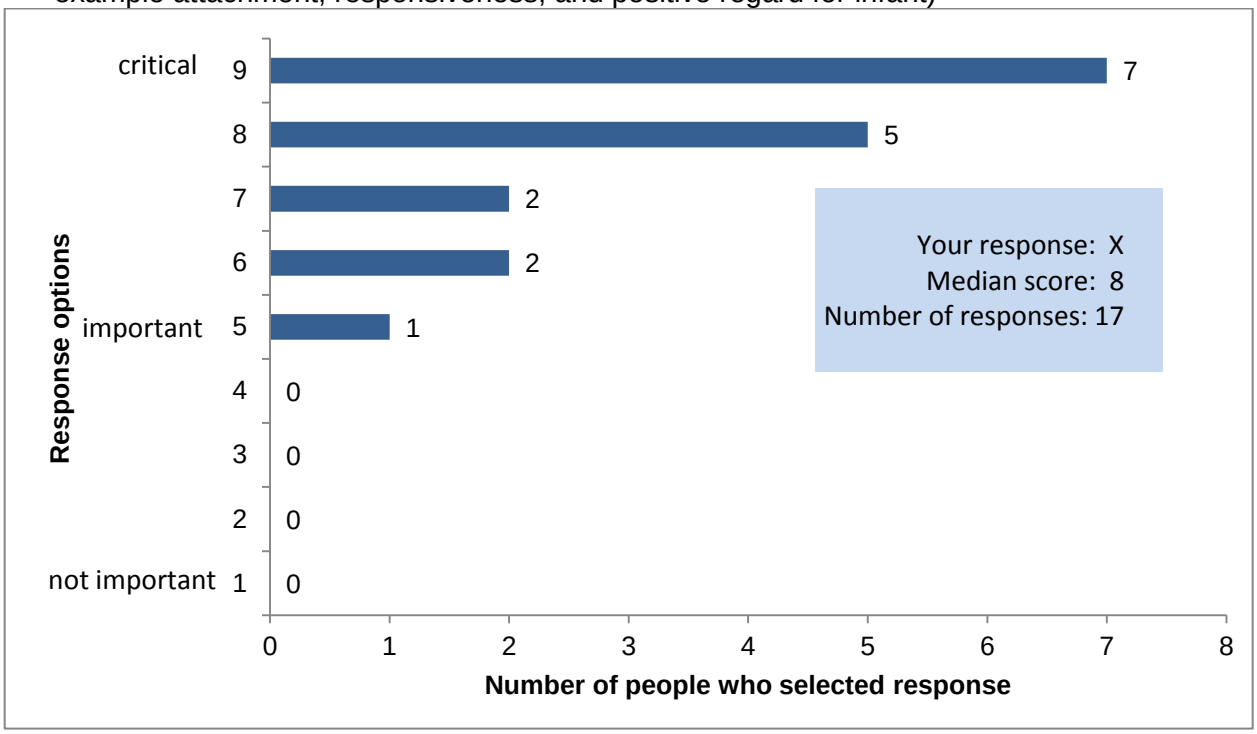
3. **Potential Benefit:** If screening leads to treatment, it may reduce thinking about, considering, planning, attempting, or contemplating suicide



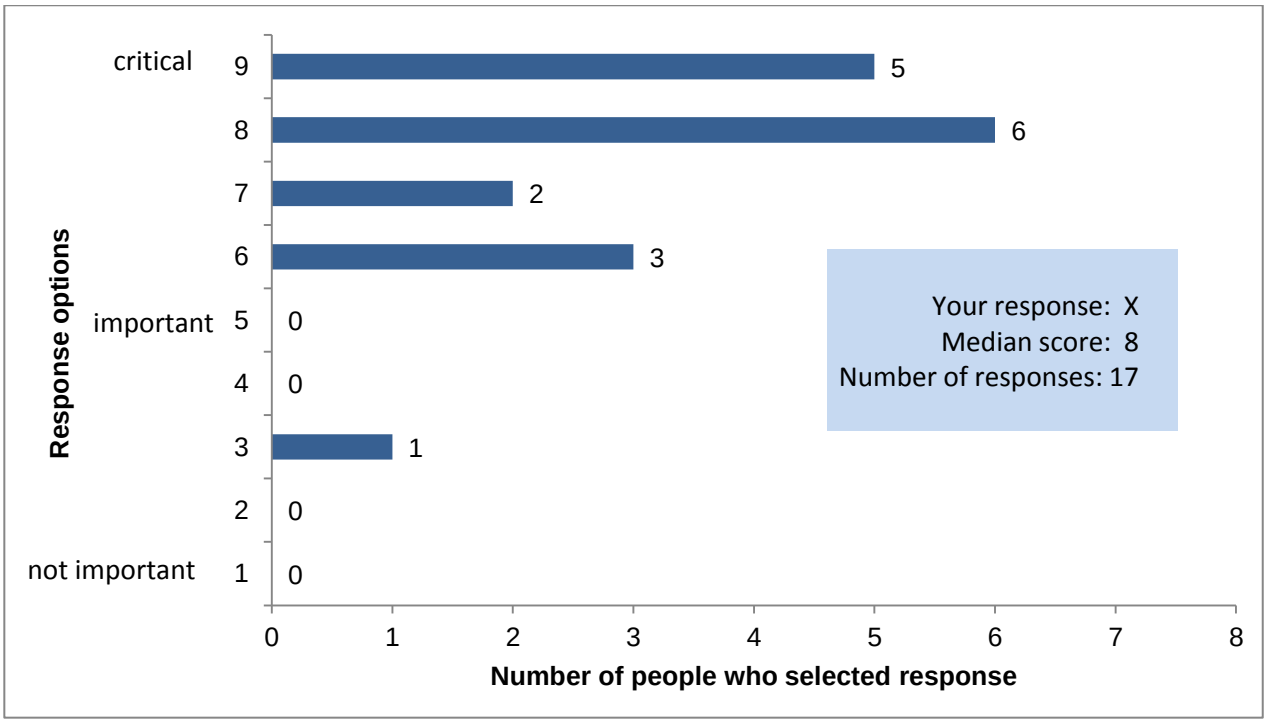
4. **Potential Benefit:** If screening leads to treatment, it may improve relationships with partners and other supports



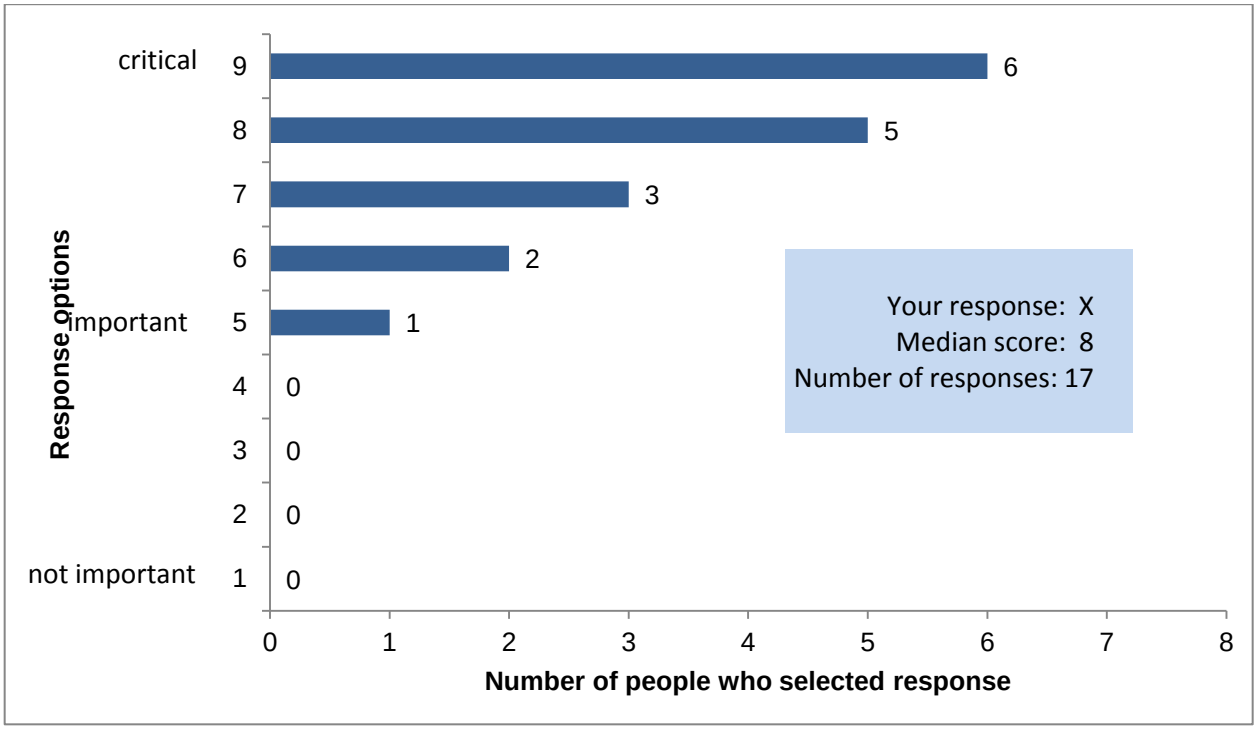
5. **Potential Benefit:** If screening leads to treatment, it may improve capacity to parent (for example attachment, responsiveness, and positive regard for infant)



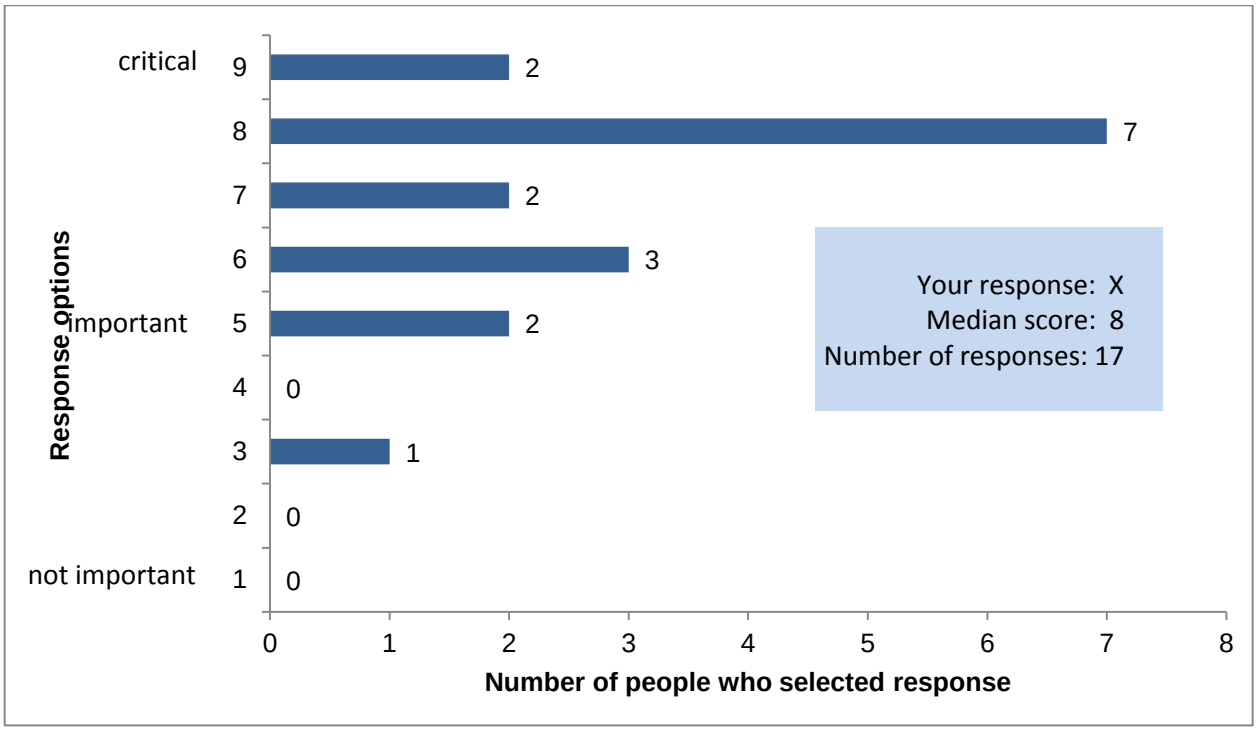
6. **Potential Benefit:** If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech



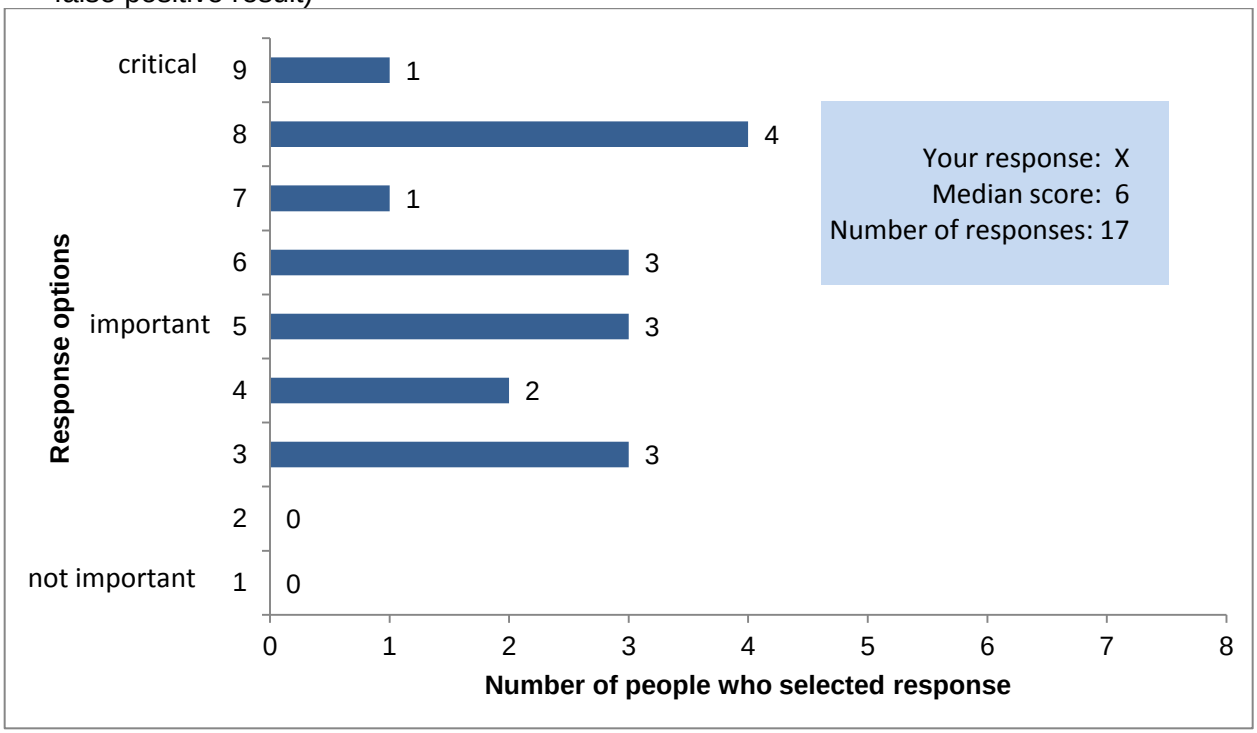
7. Potential Benefit: If screening leads to treatment, it may improve infant health and development



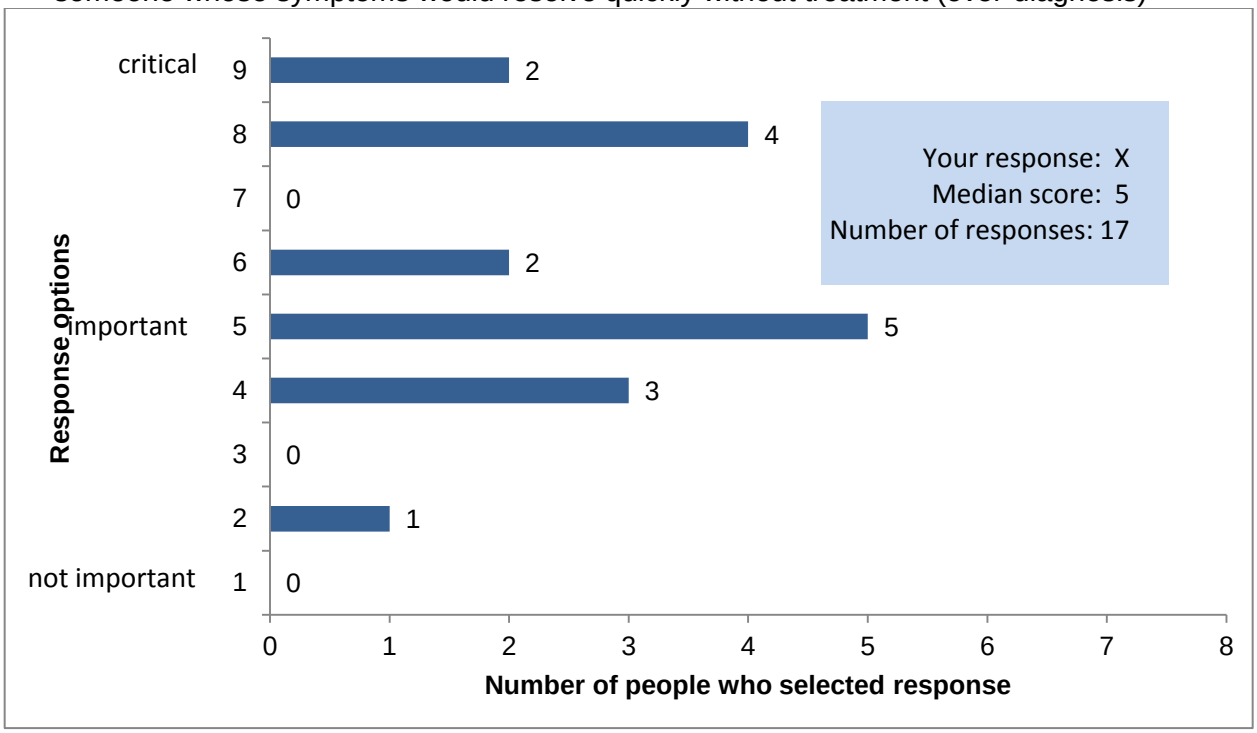
8. Potential Benefit: If screening leads to treatment, it may improve infant responsiveness



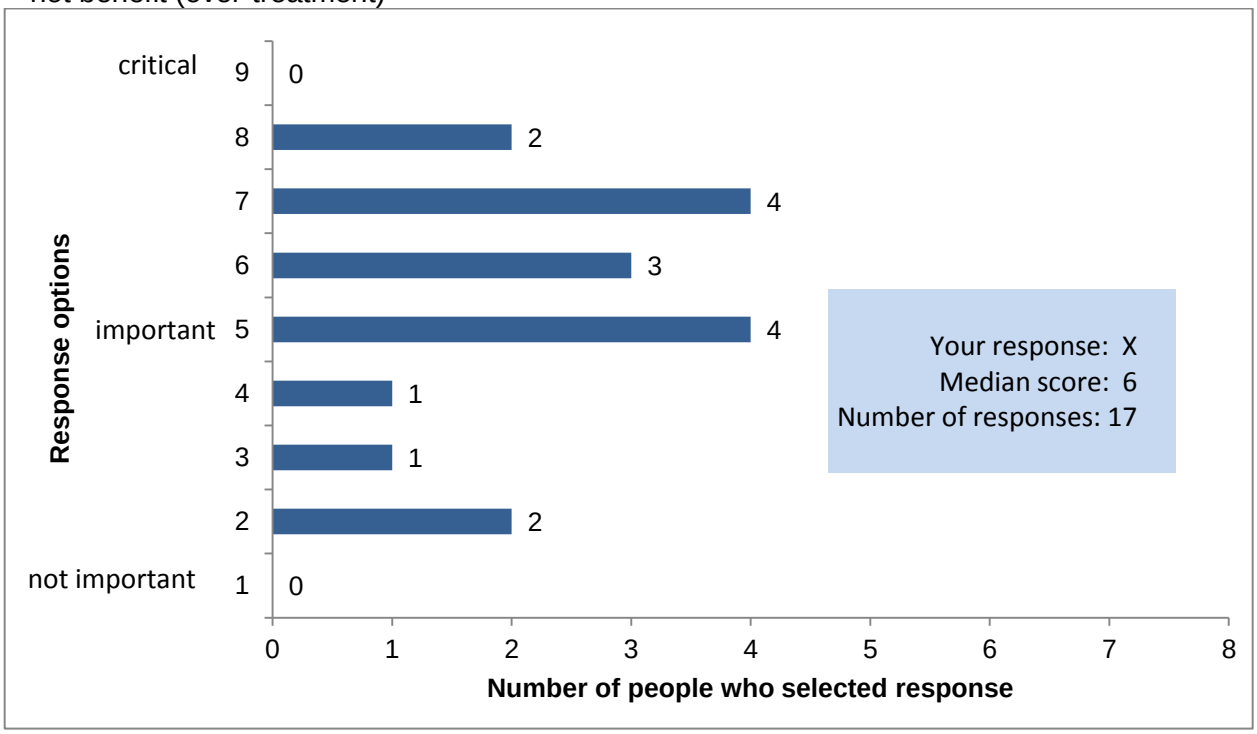
9. Potential Harm: Screening tests may identify depression when it is not really present (called false positive result)



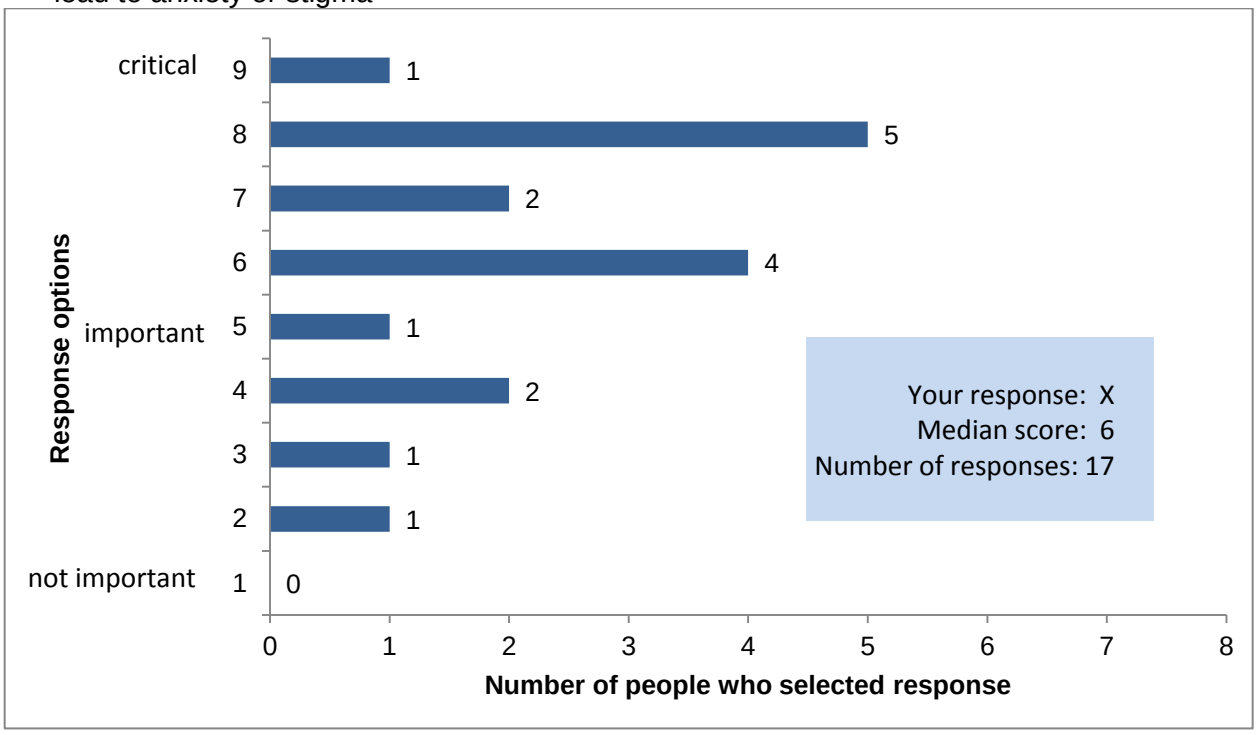
10. Potential Harm: Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis)



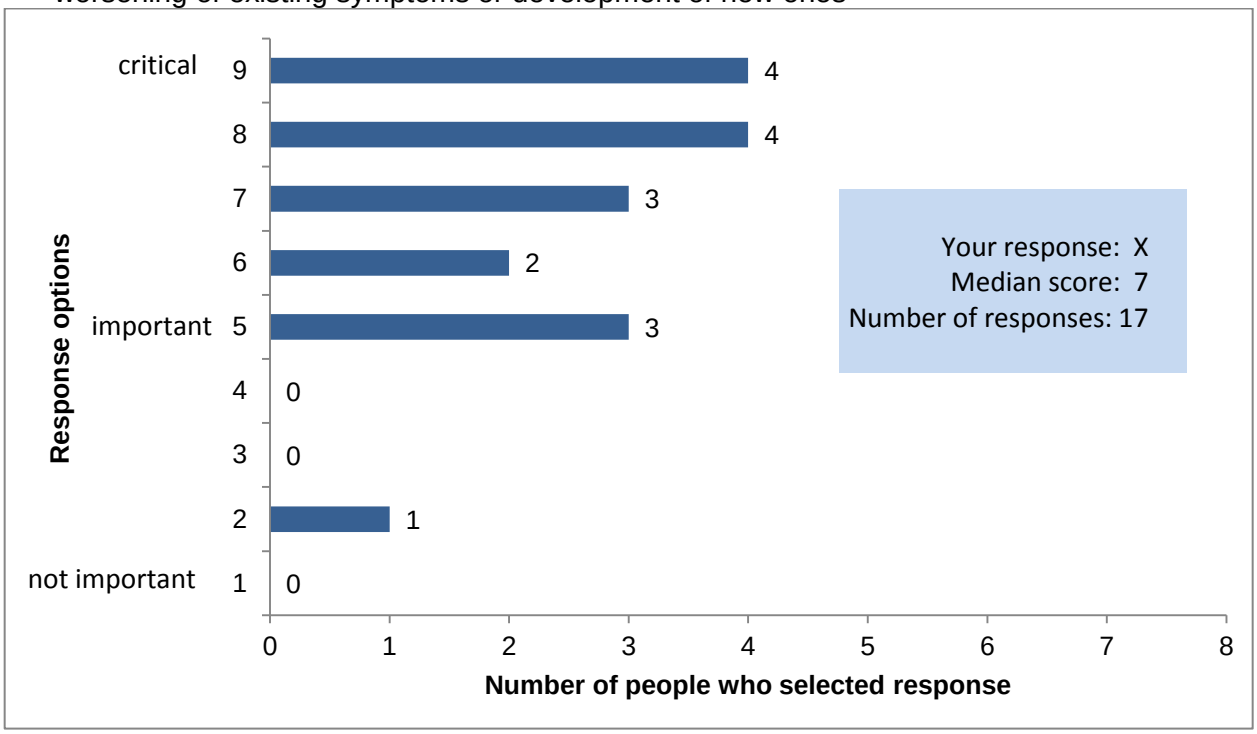
11. Potential Harm: Screening may result in starting treatment for depression in people who would not benefit (over-treatment)



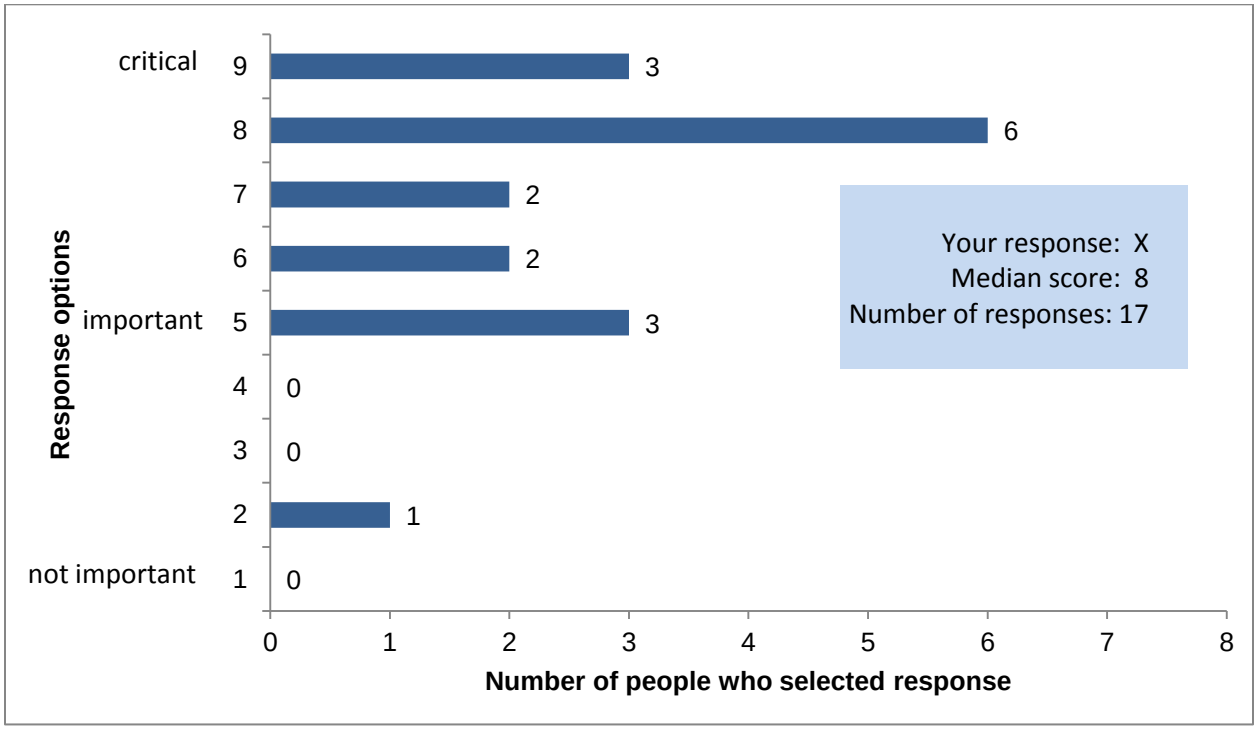
12. Potential Harm: Screening may result in labelling someone as having depression which can lead to anxiety or stigma



13. Potential Harm: If screening leads to treatment with pyschotherapy, harms may include worsening of existing symptoms or development of new ones



14. Potential Harm: If screening leads to treatment with antidepressants, harms may include unwanted side effects from the medication



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

In the survey, we listed 14 potential harms and benefits of screening for depression in pregnant and postpartum populations 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 during pregnancy or the postpartum period. 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 in pregnant and postpartum populations that were included in the survey, and the number of participants who selected each option as one of their "top five" items that were most critical to consider:

Potential Harm or Benefit:	**Number of participants who selected this as a "top five" item to consider**
If screening leads to treatment, it may reduce symptoms or diagnosis of depression	11
If screening leads to treatment, it may reduce thinking about, considering, planning, attempting, or contemplating suicide	11
If screening leads to treatment, it may improve infant health and development	11
If screening leads to treatment, it may improve capacity to parent (for example attachment, responsiveness, and positive regard for infant	11
If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech	7
If screening leads to treatment, it may improve health-related quality of life	7

If screening leads to treatment with pyschotherapy, harms may include worsening of existing symptoms or development of new ones	5
Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis)	5
Screening tests may identify depression when it is not really present (called false positive result)	4
If screening leads to treatment with antidepressants, harms may include unwanted side effects from the medication	3
Screening may result in labelling someone as having depression which can lead to anxiety or stigma	3
If screening leads to treatment, it may improve infant responsiveness	3
If screening leads to treatment, it may improve relationships with partners and other supports	2
Screening may result in starting treatment for depression in people who would not benefit (over-treatment)	0

Overall Screening Preference Scale Ratings

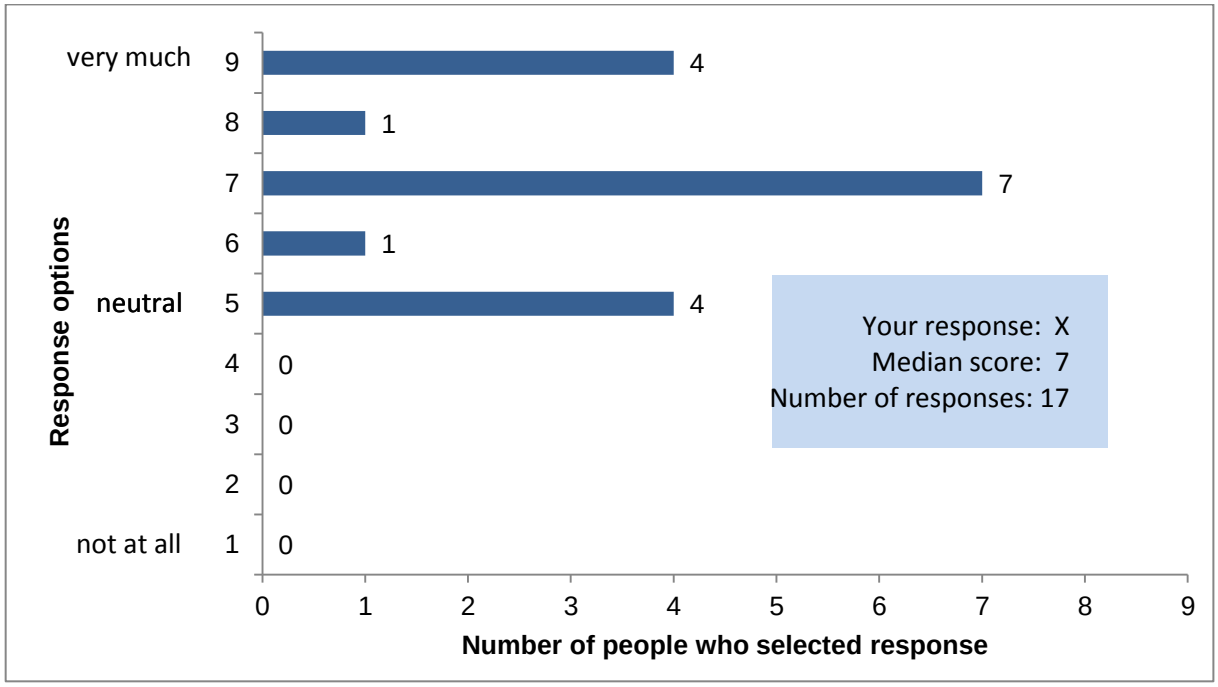
For these questions, participants were asked to rate how much they would want to be screened for depression during pregnancy or the postpartum period.

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

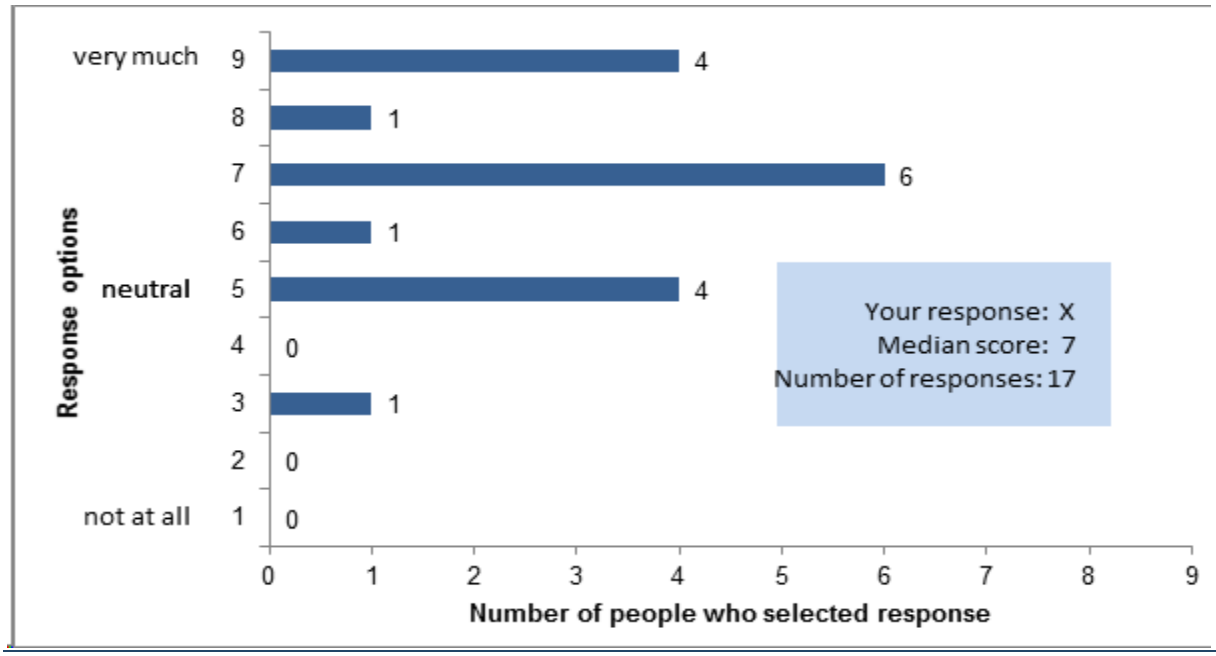
Your answer and the answers given by all participants are presented in the same graph format as the earlier questions.

Summary of Considerations for Screening Scale Ratings

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



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



Appendix E: Focus group guide

Welcome, introductions, and ground rules

Welcome (greet people as they join the teleconference)

Hello everyone and thank you for joining us today for the Canadian Task Force on Preventive Health Care focus group on screening for depression in pregnant and postpartum populations, which I will now call 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 and I am going to be the focus group moderator today.

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

I have two colleagues joining me today. The first is _____ who will be our note taker. The second is Dr. _____ the chair (or vice-chair) of the Task Force's depression in pregnant and postpartum populations screening guideline development working group and they will be on the line to answer any questions content related questions you may have.

I will now give some background information on the project.

- This project is for the Canadian Task Force on Preventive Health Care.
- The Task Force develops guidelines for and against screening. These guidelines are for primary care providers, such as family physicians, to tell them who to screen and when to screen, as well as who not to screen and when not to screen.
- Now, the Task Force is developing a guideline on screening for depression in pregnant and postpartum populations.
- The purpose of this conversation that we're having today is to get feedback from members of the public on your opinions about the potential outcomes of screening. Today, when we say outcome, we mean the effects screening for depression during pregnancy or the postpartum period 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 during pregnancy and the postpartum period 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. And we provide you with an opportunity to ask Dr. _____ any content questions you may have about depression screening after reviewing the materials that were sent to you.
- After the focus group, we will send you another survey and ask you to re-rate the same outcomes to see if you change any of your ratings based on any new information we discuss during today's session.
- We really encourage you to ask Dr. _____ any questions you may have.
- I will **unmute** everyone momentarily. Does anyone have any questions about the purpose of today's session? Thanks, I'll **mute** everyone again and finish the instructions.

Reminders

- 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.

Confidentially

- Now I will talk about confidentially.
- 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. I will now **unmute** everyone and call on each of you to state whether you would prefer to be called by your participant ID number or first name. First…..
- Have I missed anyone?

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 and today's date is _____ and I'm conducting the Task Force screening for depression in pregnant and postpartum populations 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 (or participant ID) 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.

Participant Name	Email	Phone Number	Notes

<u>1) Depression in pregnancy and the postpartum period background sheet:</u>

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 during pregnancy or the postpartum period what types of information would you like him/her to bring up?

    a. How much information do you feel you need before you can make a decision about depression screening?

2) Overall preference before discussion:

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

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

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

6) Considering that the risk of many of the harms and benefits of screening for depression during the pregnancy and post-partum period are not well known, how much did you want to be screened?

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

We are now going to review the pre-focus group survey results. Our discussion will focus on the harms and benefits that were rated differently (largest range in responses) across the group. Please have your personalized data summary sheet in front of you so that you can review during the conversation.

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

Potential Benefit: If screening leads to treatment, it may reduce symptoms or diagnosis of depression

Please turn to *page 3* and refer to *question 1* located at *top* of the page. The outcome reads '*3: Potential Benefit:* ***If screening leads to treatment, it may reduce symptoms or diagnosis of depression***

7) . Responses for this question ranged from *4-9* with a median of 8
    a. Are there any questions about this *benefit* for our content expert?
    b. Take a look at how you rated this question. What was your rationale for rating the question the way you did?
        i. Did anyone rate differently than group (for example, while some people rated it as critical, you rated it as important or less)?

Survey Benefit: If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech.

Please turn to *page 5* and refer to *question 6* located at the *bottom* of the page. The outcome reads ' *Potential Benefit: If screening leads to treatment, it may improve mother-child interactions like mutual touching, smiling, and speech.*

8) Responses ranged from 3-9 with a median of 8.
    - **a.** Are there any questions about this *benefit* for our content expert?
    - **b.** Take a look at how you rated this question. What was your rationale for rating the question the way you did?
        i. Did anyone rate differently than group (for example, while some people rated it as critical, you may have rated it as important or less)?

Survey Harm: If screening leads to treatment, it may improve infant responsiveness

9) Please turn to *page 6* and refer to *question 8* located at *bottom* of the page. The outcome reads '*Potential Benefit: If screening leads to treatment, it may improve infant responsiveness'*. Responses ranged from 3 to 9 with a median of 8.
    - **a.** Are there any questions about this *benefit* for our content expert?
    - **b.** Take a look at how you rated this question. What was your rationale for rating the question the way you did?
        i. Did anyone rate differently than group (for example, about two-thirds of people rated it as critical but you rated it as critical or not important)?

Potential Harm: Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis)

10) Please turn to page 7 and refer to question 10 located at *the bottom* of the page. The outcome reads '*Potential Harm: Screening may result in diagnosing and possibly treating depression in someone whose symptoms would resolve quickly without treatment (over-diagnosis)* Responses ranged from 2 to 9 with a median of 5.
    - **a.** Are there any questions about this *harm* for our content expert?
    - **b.** Take a look at how you rated this question. What was your rationale for rating the question the way you did?
        i. Did anyone rate differently than group (for example, about two thirds of people rated it as important but you rated it as critical or not important)?

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

11) Please turn to page 8 and refer to question 12 located at *the bottom* of the page. The outcome reads '*Potential Harm: Screening may result in labelling someone as having*

depression which can lead to anxiety or stigma Responses ranged from 2 to 9 with a median of 6.

c. Are there any questions about this *harm* for our content expert?

d. 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 important but you rated it as critical or not important)?

Potential Harm: If screening leads to treatment with anti-depressants, harms may include unwanted side effects from the medication

12) Please turn to page 9 and refer to question 14 located at *the bottom* of the page. The outcome reads '*Potential Harm: If screening leads to treatment with anti-depressants, harms may include unwanted side effects from the medication* Responses ranged from 2 to 9 with a median of 8.

e. Are there any questions about this *harm* for our content expert?

f. 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, over one half of people rated it as critical, but you rated it as important or not important)?-

Selection of the Top 5 Potential Harms and Benefits for Depression Screening in Pregnant and Postpartum Populations

13) Please turn to page 10 and refer to the list of 14 potential benefits and harms of screening for depression in pregnant and postpartum populations. We asked you to select five items on the list that you think are 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? (why did you select the outcomes that you did? Why did you feel these outcomes were more important than the others listed?)

b. Harms were typically selected less frequently than benefits as being among people's top 5 potential outcomes that are most critical to consider when people make decisions about screening. Do you have any thoughts about this?

4) Overall preference after discussion:

Survey Question: Considering the potential harms and benefits of screening for depression during pregnancy and the postpartum period, how much would you want to be screened?

1. Please turn to *page 12.* The question at the top of the page reads 'Considering the potential harms and benefits of screening for depression, how much would you want to be screened during pregnancy or the post-partum period?
2. Responses ranged from *5-9* with a median of 7.

a. Take a look at how you rated this question. What was your rationale for rating the question the way you did?
    a. What harm or benefit is the most important for you when making this decision?
    b. What harm or benefit is the least important for you when making this decision
b. Have your preferences changed from those you expressed in the first survey and earlier in today's discussion?-

3. Now take a look at the question at the bottom of page 12. The question there reads 'Considering that the risk of many of the harms and benefits of screening for depression during the pregnancy and post-partum period are not well known, how much did you want to be screened?
4. Responses ranged from *3-9* with a median of 7.
    c. Take a look at how you rated this question. What was your rationale for rating the question the way you did?
        a. How did the fact that the evidence review did not find enough conclusive evidence to know the likelihood of many of the potential harms and benefits of screening impact your screening preference? (Did you rate the first question on page twelve differently than the second question?)

4) Additional Information:

5. 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 during pregnancy or the postpartum period?

5) Potential barriers or facilitators to screening:

6. Screening for depression during pregnancy or the postpartum period is completed by a doctor or nurse practitioner who asks a short series of questions. Your answers are tallied up and a score is determined. Specific scores indicated whether it is likely or not that you have depression and if further diagnostic tests are required.
    a. If you choose to get screened, what do you think are potential barriers to accessing the screening test, if any?
        i. Probe: out-of-pocket expenses (e.g., transportation or taking time off)
        ii. Probe: lack of time (e.g., come in for a visit for another reason like a baby health etc.)
        iii. Probe: fear (do not want to talk about mental health with doctor/nurse practitioner because of concerns of what might happen)

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

6) Closing remarks:

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

Conclusion

- Thank you for taking the time to be a part of our focus group today.
- This week you will each receive a link to another online survey via email. This is the same survey you completed prior to today's discussion but with some extra questions about your experience participating in the project. The reason that the survey asks the same questions is so that you have an opportunity to change or confirm your responses from the first time you completed the survey. For example, a person may have developed new understanding or a new perspective after discussing the outcomes in greater detail during today's discussion and wants to change their rating of that outcome. Another person may feel surer about their responses and keep the ratings the same. We like to see the differences and the similarities in people's ratings before and after the teleconference discussion.
- You will have approximately one week to complete the online survey.
- We will process your reimbursement payment once we close the survey. Please note that the reimbursement payment can take up to 45 days to process, but it usually doesn't take that long.
- Once we develop a report of our findings we will create a summary to send to you. You will also be invited to attend an optional debrief session to review the results of the study and add additional comments.
- We understand that questions or additional comments may come up after today's call. This is very normal. If you have any additional questions or something that you would like to add to today's discussion, please feel free to email Kyle. We will do our best to answer your question. If we are not able to answer your question we will forward it to the working group content expert for their opinion.

  Thank you and have a great day!

Appendix F: Patient engagement survey

Please respond to each of the following statements using the scales provided. Respond to each question 1-7: 1: No extent, 2: Very small extent, 3: Small extent, 4: Fair extent, 5: Moderate extent, 6: Large extent, 7: Very large extent. If you select 1-4 for any question, please explain your rating in the space below the question.

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