Canadian Task Force on Preventive Health Care

Patient Preferences for Abdominal Aortic Aneurysm Screening: Data Summary

Prepared for the Canadian Task Force on Preventive Health Care

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Summary

This document presents summary data from Phase 2 of the Canadian Task Force on Preventive Health Care (CTFPHC) abdominal aortic aneurysm (AAA) patient preferences focus groups (*n* = 19) and survey (*n* = 19). In this project, we examined patients' perceptions of the harms and benefits of screening and treatment for AAA in asymptomatic adults aged 65-80 years at average or increased risk for AAA. Specifically, we inquired about how important patients believe it is for people to consider various harms and benefits when making decisions about getting screened for AAA. We also examined participants' experiences in the project. Data was collected between August 23 and September 9, 2016.

Please note that this document contains a summary of data only. We will provide a full report in mid-October.

Data Summary

Perceptions of Harms and Benefits and Overall Preferences for Screening

Table 1. Descriptive statistics for possible benefits of screening (*n* = 19)

Question: If you are a man, how important would this information be for you if you were making a decision on whether or not to be screened for AAA? If you are a woman, how important would this information be for you in relation to a decision on whether or not to have a male family member or friend screened for AAA? Responses were provided on a 9-point scale with endpoints labelled 1(*This doesn't factor into my decision at all*) and 9(*This factors into my decision a lot*).

Item	Median	Q_1	Q_3
Out of 1,000 men who don't get screened, 3.5 men aged 65-80 years will have a ruptured AAA (3-5 years after screening). This is compared to 1.9 out of 1,000 men who do get screened	7	4	8
Out of 1,000 men who don't get screened, 2.9 men aged 65-80 years will die as a result of an AAA rupture or related complications (3-5 years after screening). This is compared to 1.6 out of 1,000 men who do get screened.	8	5	9
Out of 1,000 men who don't get screened, 1.4 men aged 65-80 years will have to undergo emergency surgery for a ruptured AAA (3-5 years after screening). This is compared to 0.7 out of 1,000 men who do get screened.	7	6	8
Out of 1,000 men who don't get screened, 0.5 men aged 65-80 years will die 30 days post emergency surgery for a ruptured AAA (3-5 years after screening). This is compared to 0.2 out of	7	4	8

Item	Median	Q_1	Q_3
1,000 men who do get screened			

Note: Q_1 = first quartile; Q_3 = third quartile.

Table 2. Descriptive statistics for possible harms of screening (*n* = 19)

Question: If you are a man, how important would this information be for you if you were making a decision on whether or not to be screened for AAA? If you are a woman, how important would this information be for you in relation to a decision on whether or not to have a male family member or friend screened for AAA? Responses were provided on a 9-point scale with endpoints labelled 1(*This doesn't factor into my decision at all*) and 9(*This factors into my decision a lot*).

Item	Median	Q_1	Q_3
For every 1,000 men screened, 8.1 will undergo elective surgery for AAA. This is compared to 2.6 men that are not screened (3-5 years after screening)	6	5	7
For every 1,000 screen-detected men that undergo elective surgery for AAA, 0.3 will die within the first 30 days following the surgery (3-5 years after screening)	5	5	7
For every 1,000 men with non-screen-detected AAA (an AAA found not by screening) that undergo elective surgery, 0.2 will die within the following 30 days following the surgery (3-5 years after screening)	5	3	7
Approximately 45% of men over 65 years of age that are screened positive for an AAA will be over-diagnosed (that is, their AAA would never grow in size; would never lead to any symptoms such as pain, discomfort or rupture; and would never otherwise be identified)	7	5	9

Note: Q_1 = first quartile; Q_3 = third quartile.

Table 3. Descriptive statistics for overall preferences about getting screened (*n* = 19)

Item: I would want to get screened for an AAA (or want a male/female family member or friend to get screened for an AAA). Responses were provided on a 9-point scale with endpoints labelled 1(*Not at all*) and 9(*Very much*).

Item	Median	Q_1	Q_3
If you are a man over 65 years of age, considering that up to 7.6% of men of this age have an AAA, how much would you	8	5	8

Item	Median	Q_1	Q_3
want to get screened for an AAA? If you are woman, considering that up to 7.6% of men over 65 years of age have an AAA, how much would you want a male family member or friend of this age to be screened for an AAA?			
If you are a man, considering the harms and benefits of AAA screening in men aged 65-80 years, how much would you want to get screened for an AAA between the ages of 65-80 years? If you are a woman, how much would you want a male family member or friend aged 65-80 years to be screened for an AAA considering the harms and benefits of AAA screening in men of this age?	8	5	8
If you are a man, considering that there is no evidence which shows it is effective to screen men under 65 years of age, how much would you want to get screened for an AAA before the age of 65? If you are a woman, how much would you want a male family member or friend under the age of 65 to be screened for an AAA considering that there is no evidence which shows it is effective to screen men of this age?	3	1	6
If you are a man, considering that there is no evidence which shows it is beneficial to screen men over 80 years of age, how much would you want to get screened for an AAA after the age of 80? If you are a woman, how much would you want a male family member or friend over the age of 80 be screened for an AAA considering that there is no evidence which shows it is beneficial to screen men of this age?	3	1	6
If you are woman, considering that few women have an AAA - approximately 6 times less than men - how much would you want to get screened for an AAA? If you are a man, how much would you want a female family member or friend to get screened for an AAA considering that few women have an AAA?	4	2	6
If you are woman, considering that research shows that women do not benefit from screening for AAA, how much would you want to get screened for an AAA? If you are a man, how much would you want a female family member or friend to get screened for an AAA considering that research shows that women do not benefit from screening for AAA?	2	1	6

Item	Median	Q_1	Q_3
If you are a man who has smoked in the past, or is smoking now, and research shows smokers are much more likely to have an AAA than non-smokers, how much would you want to get screened for an AAA? If you are a woman, how much would you want a male family member or friend who has smoked in the past, or is smoking now, to get screened for an AAA considering that research shows smokers are much more likely to have an AAA than non-smokers?	8	6	9
If you are a man who never smoked and considering that research shows non-smokers are far less likely to have an AAA than someone who has smoked, how much would you want to get screened for an AAA? If you are a woman, how much would you want a male family member or friend who has never smoked to get screened for an AAA considering that research shows non-smokers are far less likely to have an AAA?	5	3	6

Note: Q_1 = first quartile; Q_3 = third quartile.

Table 4. Qualitative data for factors that influence patients' decision to be screened for AAA (*n* = 19)

Factors	Influence on screening behaviour	Recommendation
Understanding of preventive health care	- Some participants had difficulty understanding why healthy people would be screened - Patients' beliefs about preventive health care influenced their screening preferences (i.e., whether resources should be used to help current patients or future patients)	- Provide more information about the purpose of screening
Previous screening behaviour	- Participants who indicated they had been screened for other health conditions were more likely to indicate they also wanted to be screened for AAA	- Compare AAA screening to screening for other health conditions (e.g. breast cancer) that participants are familiar with
General information on AAA (pg. 1-2 of the backgrounder)	- Participants indicated they were in favour of screening after reading general information on AAA - Many believed "knowledge is power" and would rather know if they have an AAA - Participants indicated that because an ultrasound is used for screening, there are no risks involved. For this reason, they would get screened	- Provide more information around potential harms of screening as opposed to only the harms of treatment
Risk factors for AAA	- Participants indicated that if risk factors applied to them, they would get screened	- Provide more information about risk factors
Benefits of screening	- Some participants were not persuaded by small differences in outcomes when people are screened versus are not screened - Other participants felt that screening is beneficial if even one life is saved	- Use whole numbers as opposed to decimals; this makes it easier for individuals to think of the numbers as people
Risks associated with surgery	- Many participants started to question their decision to be screened once they saw the risks associated with surgery	- Indicate which risks are associated with surgery in general versus for AAA surgery specifically
Limited resources	- Participants perceived the prevalence of AAA to be low and health care resources to be limited; therefore, participants	- Provide information on the prevalence of AAA in Canada,

	did not believe that population-based screening is appropriate	accessibility of ultrasound machines across Canada, and the cost of screening

Most participants would choose to be screened if they felt the risk factors applied to them or if they typically get screened for other health conditions. However, the majority of participants would not recommend population-based screening. They were instead in favour of targeted screening based on risk factors.

Participant Engagement

Table 5. Descriptive statistics for participant engagement items (*n* = 19)

Responses were provided on a 5-item scale with variable endpoints. Responses were converted to numerical values by assigning “1” to the lowest response option and “5” to the highest response option.

Participant engagement item	Median	Q_1	Q_3
To what extent do you believe that your ideas were heard during the engagement process?	5	4	5
To what extent did you feel comfortable contributing your ideas to the engagement process?	5	4	5
Did organizers take your contributions to the engagement process seriously	5	4	5
To what extent do you believe that your input will influence final decisions that underlie the engagement process?	4	3	4
To what extent do you believe that your values and preferences will be included in the final health advice from this process?	4	3	4
To what extent were you able to clearly express your viewpoints?	5	4	5
How neutral in their opinions (regarding topics) were organizers during the engagement process?	4	4	5
Did all participants have equal opportunity to participate in discussions?	5	4	5
How clearly did you understand your role in the process?	5	4	5
To what extent was information made available to you either prior to or during the engagement process so as to participate knowledgeably in the process?	5	4	5
To what extent were the ideas contained in the information material easy to understand?	4	3	5
How clearly did you understand what was expected of you during the engagement process?	5	4	5
How clearly did you understand what the goals of the	5	3	5

engagement process were?			
To what extent would you follow health advice generated from the Canadian Task Force on Preventive Health Care (if it related to your health condition)?	4.5	4	5
To what extent would you advise others to follow health advice from the Canadian Task Force on Preventive Health Care (if it related to their health condition)?	4	4	5

Note: Q_1 = first quartile; Q_3 = third quartile

Table 6. Descriptive statistics for survey experience items (*n* = 19)

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

Survey experience item	Median	Q_1	Q_3
How easy was it to understand the information in the AAA background information sheet?	8	7	9
How easy was it to rate the harms and benefits using the 9-point scale?	7	5.25	7.5
How clear were the survey instructions?	8	7	9
How well did you understand what we asked you to do in this survey?	9	7.25	9

Note: Q_1 = first quartile; Q_3 = third quartile

Table 7. Qualitative data for experience with AAA backgrounder (*n* = 19)

		Comments	Suggestions for improvement
Overall document		- Easy to understand for someone without a medical background - Quantity of information was good	- Consider displaying statistical information in another format (e.g., a graph or visual) - Consider bolding main messages in the document - A patient decision aid could be a useful KT tool
Page 1	**What is AAA?**	- Found the visual representation of which organs are affected by an AAA to be helpful - Easy to understand (i.e., no medical jargon)	- Provide information on how prevalent AAA is in the population and in comparison to other health conditions
	Who is at risk for AAA?	- Dissatisfied with risk factor information: -Difficulty understanding why women are not typically screened and evidence behind that recommendation (e.g., would female heavy smokers also fall in the not screening category?) - Hard to comprehend risk factor information in paragraph form	- Correct typo: 10.3% should be 13% - Display risk factors together in a list as opposed to paragraphs - Rank risk factors in order of importance - Provide more information about why women are not typically screened for an AAA and the quality of evidence behind statements about it
	How does having AAA affect people?	- Provide more information about signs and symptoms of an AAA - Better emphasize information on AAA ruptures	- Provide more information on signs and symptoms of an AAA and guidance on when to seek medical attention - Summarize AAA rupture information in one section as opposed to across Pages 1 and 2
Page 2	**How do PCPs screen people for AAA?**	- Dissatisfied with ultrasound information: -Concerned that population-wide screening is not feasible with current ultrasound resources and	- Provide information on prevalence of AAA screening in primary care - Provide information on resource capacity and accessibility of ultrasounds across Canada

		specialists -Concerned ultrasound wait times would increase and negatively affect screening of other health conditions	- Clarify whether AAA screening can be combined with screening for other conditions in the abdominal area
	How do PCPs treat people for AAAs?	- Provide more guidance around the chance of rupture and screening (e.g., if most AAAs do not rupture, why should patients get screened)	- Provide specific information about the size of an AAA and its relationship to treatment
Page 3	**What are the benefits of AAA screening?**	- Table with statistical information was difficult to interpret - Some people interpreted the numbers as percentages instead of as the number of people - Found the table to be repetitive and wordy - Confused by placement of "3-5 years after screening"; did not understand how the statement applied to individuals who did not get screened - Difficult to understand how the numbers in the table related to each other - Unclear how the size of an AAA factored into numbers presented	- Consider using a visual or graph as opposed to a table - Reduce repetition by moving "(3-5 years after screening)" from the rows and placing it under the title of the third column "Out of 1, 000 men who get screened (3-5 years after screening)" - Explicitly state assumptions for the table (e.g., whether numbers are mutually exclusive, what population the numbers apply to, and whether the numbers refer to all AAAs or large AAAs only) - Compare AAA screening statistics to screening statistics for other conditions to put numbers in perspective

Page 4	**What are the possible harms of AAA screening?**	- Risks associated with surgery were overwhelming - Table with statistical information was hard to interpret - Some people interpreted the numbers as percentages instead of as number of people - Found the table to be repetitive and wordy - Confused by placement of “3-5 years after screening”; did not understand how the statement applied to individuals who didn’t get screened -	- Categorize risks of surgery by those associated with surgery in general versus those for AAA surgery - First statement in the table was confusing; clarify how individuals who do not get screened can still get elective surgery - Use whole numbers or percentages instead of decimals - Reduce repetition by moving “(3-5 years after screening)” from the rows and placing it under the title of the third column “Out of 1, 000 men who get screened (3-5 years after screening)” - Consider using a visual or graph as opposed to a table