

*** 1. Do you consent to participate in this study?**

By selecting "Yes" and clicking "Next," you are consenting to be in this study. It tells us you understand the information about the research study. When you select "yes" and consent to be a participant in this study, you are not giving up your legal rights. Researchers or agencies involved in this research study still have their legal and professional liabilities.

- ☐ Yes
 - ☐ No
-

ELIGIBILITY

*** 2. Are you 18 years old or older?**

- ☐ Yes
- ☐ No

*** 3. Are you a resident of Canada?**

- ☐ Yes
- ☐ No

Please choose which perspective you will provide on the survey – that of the person who informed others in the family about cancer risk (the 'informer') or the person who received hereditary cancer risk information from a family member (the 'informed').

***4. I will answer survey questions from the perspective of (please choose one):**

- ☐ Informer
- ☐ Informed

SECTION 1 – BACKGROUND INFORMATION

5. What was your perception of your risk of getting cancer before you were seen by a genetic specialist?

- ☐ High ☐ Moderate ☐ Low
☐ Unknown/Insufficient information ☐ I was not seen by a genetic specialist

6. What is your genetic test result?

- ☐ BRCA1 ☐ BRCA2 ☐ Lynch syndrome
☐ I did not have genetic testing ☐ Not sure
☐ My BRCA1/2 or Lynch mutation test result was negative

Other, please describe _____

7. Have you ever been diagnosed with cancer?

- ☐ Yes ☐ No

8. How long since you were diagnosed with cancer?

Please state the number of years since the first diagnosis
_____ (drop-down menu)

9. What was your diagnosis? Select all that apply.

- ☐ Breast cancer ☐ Ovarian cancer ☐ Endometrial cancer
☐ Colon cancer
Other, please describe _____

SECTION 2 – THE FAMILY MEDIATED APPROACH – FOR INDIVIDUALS WHO SHARED THE FAMILY LETTER (i.e., the 'Informers')

10. Did you receive a family letter that explained your risk of hereditary cancer?

- ☐ Yes ☐ No

If you selected "No" and you were given other materials, please list them.

11. How many relatives were you asked to share the letter with?

12. How many relatives did you share the letter with?

13. How many first-degree relatives did you share the family letter with? First-degree relatives are children, brothers and sisters, and parents.

14. How many second-degree relatives did you share the family letter with? Second-degree relatives are aunts, uncles, nephews, nieces, grandchildren and grandparents.

15. If you were asked to share the family letter with your relatives, we are interested in your opinion about the responsibility for informing at-risk relatives about family cancer risk and your experiences.

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I do not think that I should have been the one to inform my relatives or share the information with them					
II. I do not believe it was my responsibility, but I had no problem doing it					
III. I felt responsible; however, I would have liked the assistance of someone else, i.e., another family member or a health care provider					
IV. I felt responsible for informing my children, siblings, parents and spouse					
V. I felt responsible for informing my aunts, uncles, nieces, grandchildren and grandparents					

SECTION 3 – YOUR EXPERIENCE IN COMMUNICATING CANCER RISK TO YOUR RELATIVES

If you shared the family letter with relatives, please indicate your level of agreement with the following items

16. We are interested in whether you found the family letter helpful in communicating cancer risk to your relatives.

Perceived usefulness of family letter

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I found the letter very useful in helping me to communicate the risk of hereditary cancer to my relatives					
II. The letter helped me to communicate with my relatives about hereditary cancer risk; however, some of my relatives asked questions that the letter did not address					
III. I was able to read and understand what was written in the letter, but it was hard for me to explain it to my relatives in my own words					
IV. I thought that the letter's content should have been in a more simplified form or language.					

17. How satisfied were you with using a family letter to inform your relatives about their inherited cancer risk?

Satisfaction with communication

	Disagree strongly	Disagree Somewhat	Uncertain	Agree Somewhat	Agree Strongly
I. I felt satisfied with communicating with my relatives using the family letter about the risk of genetic cancer					
II. I was satisfied with my relative's response to me communicating cancer risk and sharing the summary letter					

Self-efficacy

18. Now, we are interested in how prepared you felt to share the information with your relative. Please choose one response for each item that follows.

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. Communicating genetic information was complex for me					
II. I did not feel confident in passing on the information about cancer risk because I did not feel like I could correctly communicate the information					
III. I did not feel confident in passing on this information because of the fear of causing distress among my relatives					

Certainty

19. Were you confident that the family letter's information helped your relatives understand their increased risk of hereditary cancer?

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I felt confident that the family letter explained to my relatives what having the mutation meant					
II. I felt confident that the family letter helped my relatives to understand the importance of genetic testing					
III. I felt confident that my relatives understood the implications of the information in the family letter for their own health					

Support

20. Please share your experience with us about your relatives' reaction to hearing the news from you about your family's cancer risk

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. It was hard for me to talk to my relatives about the risk of hereditary cancer					
II. Some of my relatives relative were angry/upset					
III. Some of my relatives were uninterested when I shared the information about our family's inherited risk					
IV. In general, my relatives were grateful for the					

information about our family's inherited cancer risk
V. My relatives encouraged me to share the information with other relatives

Distress

21. Were you concerned that sharing genetic cancer risk information would cause distress within the family?

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I worried that communicating the risk of hereditary cancer would bring about conflict in the family					
II. I worried that my family would become anxious or depressed after receiving the information					

22. We would like to know if you were concerned about confidentiality

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I was concerned about sharing personal medical information with other family members (confidentiality)					
II. I worried that my relatives would not want me to know about their increased risk of cancer					

SECTION 4 – PREFERRED METHOD OF COMMUNICATING CANCER RISK INFORMATION

The following items (22-25) to be answered by the probands/carriers (i.e., the informers)

23. We would like your feedback on sharing your personal information with your relatives when communicating the risk of hereditary cancer risk to them

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. It would be acceptable to me if my name was shared with my relatives irrespective of the method that is used to communicate hereditary cancer risk information to them					
II. It would be acceptable to me if my genetic test result was shared with my relatives regardless of how they are informed of their cancer risk					
III. It would be acceptable to me if my cancer diagnosis (if applicable) was shared with my relatives when they are being informed of their hereditary cancer risk					

24. We are interested in your preferences about using a family letter to inform relatives about their hereditary cancer risk and further management. Please choose one response option for each item that follows:

	Disagree Strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I prefer to deliver the family letter in person to my relatives					
II. I prefer to deliver the letter to close relatives					

	and to mail the letter to my distant relatives
III.	I would prefer to inform my relatives using the letter in the presence of a health care professional
IV.	I believe that I should share the family letter with my relatives; however, a health care provider should call them afterwards
V.	I feel it is my responsibility to inform my relatives with a family letter; however, a health care professional should send them a follow-up email

25. We are interested in your opinions about active contact taken by a health care professional to share cancer risk information with your relatives. Please choose one response option for each of the items that follow:

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I.	I believe that my relative should be informed in person by a health care professional of the risk of hereditary cancer				
II.	I would like to disclose the information without the involvement of a health care professional				
III.	The health care professional should mail the family letter to my relatives				

IV.	The health care professional should send an email with information on hereditary cancer risk to my relatives
V.	My relatives should receive a telephone call from a health care professional informing them about the risk of hereditary cancer

26. We are interested in your opinion about the use of a mobile health application or a website for communicating the risk of hereditary cancer to your relatives

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I.	I would prefer to share the link to a secure mobile health app or a website with my relative that has all the information they need about our family's inherited cancer risk				
II.	I would prefer if my health care provider shared a link to a secure mobile health app or website with my relative that has all the relevant information they need about our family's inherited cancer risk				

27. Please share any other thoughts on any other suggestions you might have for informing relatives about inherited risk.

SECTION 5 – THE FAMILY MEDIATED APPROACH – FOR INDIVIDUALS WHO RECEIVED THE FAMILY LETTER

If you received a family letter from another relative, please indicate your level of agreement to the following items.

28. We are interested in whether the information in the family letter helped you understand your risk of hereditary cancer and the need for genetic counselling/testing.

Satisfaction with information

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. The information in the family letter was helpful					
II. The letter should have been more detailed					
III. Some of the terms used in the letter were not familiar to me; because of this, I did not find the letter useful					

Control

Cognitive control

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I understood the meaning of the letter for my family's future and me					
II. I understood what the cause of my own elevated risk was					

Behavioural control

	Disagree strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I. I understood I was eligible for genetic counselling					

II.	I understood I could undergo genetic testing to determine if I had a cancer-causing mutation that would put me at an increased risk
III.	I understood that I could manage my personal inherited cancer risk and what my options were

29. We are interested in your response to being told about your cancer risk by another relative. Please choose one response option for each item:

	Disagree Strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I.	I felt angry/upset about receiving the information				
II.	I felt sad				
III.	I felt anxious/nervous				
IV.	I was concerned				
V.	I felt a loss of control				
VI.	I was happy that my relative shared the information with me				
VII.	I did not care much about receiving the information				

SECTION 6 – PREFERRED METHOD OF RECEIVING CANCER RISK INFORMATION

The following items to be answered by the relatives (i.e., the 'informed'):

30. How would you like information about hereditary cancer risk to be shared with you?

	Disagree Strongly	Disagree somewhat	Uncertain	Agree somewhat	Agree strongly
I.	I would prefer if a family letter was provided to me by my relative				

-
- II. I would prefer if my relative contacted me directly to talk about our family's increased cancer risk
-
- III. I would prefer my relative to inform me of the risk of hereditary cancer with the help of a health care professional
-
- IV. I would prefer that a health care professional contact me directly about my risk of hereditary cancer
- V. I would prefer to use a platform such as a secure mobile health app or a website for learning about my risk of hereditary cancer
-

SECTION 7 – DEMOGRAPHIC INFORMATION

31. What is your age?

32. What is your marital status?

- ☐ Single ☐ Legally married ☐ Living Common-law ☐
- Divorced/Separated
- ☐ Widowed

33. How many children do you have? Please include stepchildren and adopted children and enter 0 if you do not have children.

34. How would you describe your gender?

- ☐ Male ☐ Female ☐ Non-binary ☐ Other, please describe

35. What is the highest level of education you have acquired?

- ☐ Less than high school
☐ High school Diploma
☐ Trade or College Diploma
☐ University, undergraduate degree
☐ University, graduate degree

36. In what income bracket would you put yourself?

- ☐ Low
☐ Middle
☐ High

37. In what province or territory do you live? Please choose one: (list out provinces)

38. Do you live in an urban or rural area? Statistics Canada defines urban areas with three sizes of population centres. All areas outside population centres are defined as rural. Please choose one of the following that best describes your residence:

- ☐ Small population centre, with a population between 1,000 and 29,999
☐ Medium population centre, with a population between 30,000 and 99,999
☐ Large urban population centre, with a population of 100,000 or more.
☐ Rural area

Please note: The survey items were separated into blocks so that questions that were relevant to each subgroup of study participants (1.the informers who were given a family letter, 2.the informers who were not given a family letter and 3.the informed) were only seen by them.