



**Lunenfeld-Tanenbaum
Research Institute**

MOUNT SINAI HOSPITAL 
Joseph and Wolf Lebovic Health Complex

Ontario Familial Colorectal Cancer Registry

Supported with funds from US National Institutes of Health

Phase 4 Follow-Up Questionnaire

We last heard from you when you completed a Personal History or a Follow-Up Questionnaire. We would like to update some of the information you provided, including your family history, and ask some additional questions about your health.

**If you have questions about this questionnaire,
or would like to complete it over the phone,
please contact us at:**

(416) 586-4800 ext 2759

toll free 1-866-225-2728

email: OFCCR@lunenfeld.ca

4. a) Since your last questionnaire, have you had a sigmoidoscopy?

A sigmoidoscopy is a procedure similar to a colonoscopy but does not require extensive preparation with oral laxatives the night before the procedure or dietary modification. Preparation of the bowel is required and is done with an enema. This procedure can be done with or without sedation.

- Yes
- No → skip to question 5
- Don't know → skip to question 5

b) Since your last questionnaire, on how many separate occasions have you had a sigmoidoscopy?

Number of sigmoidoscopy tests: _____ Don't know

c) When did you have your most recent sigmoidoscopy?

Age: _____ **OR** Year: _____

OR Number of years since last sigmoidoscopy: _____

- Don't know

**d) What were the reasons for your most recent sigmoidoscopy?
(CHECK ALL THAT APPLY)**

- To investigate a new problem
- Family history of colorectal cancer
- Routine exam or check-up
- Follow-up of a previous problem
- Follow-up of FOBT result
- Other (specify): _____
- Don't know

5. a) Since your last questionnaire, have you had a colonoscopy?

In a colonoscopy, the entire large bowel is examined and medication is usually given intravenously to relax you or make you sleepy. It is done in an outpatient clinic or hospital. Preparation involves drinking fluids or taking pills to cleanse the bowel.

- Yes
- No → skip to question 6
- Don't know → skip to question 6

b) Since your last questionnaire, on how many separate occasions have you had a colonoscopy?

Number of colonoscopy tests: _____ Don't know

c) When did you have your most recent colonoscopy?

Age: _____ **OR** Year: _____ **OR** Number of years since last colonoscopy: _____

Don't know

**d) What were the reasons for your most recent colonoscopy?
(CHECK ALL THAT APPLY)**

- To investigate a new problem
- Family history of colorectal cancer
- Routine exam or check-up
- Follow-up of a previous problem
- Follow-up of FOBT result
- Other (specify): _____
- Don't know

6. a) Since your last questionnaire, have you had a CT colonography or virtual colonoscopy?

This is not a regular colonoscopy. It is a procedure done using a CT scan with you lying on a table that slides through a large circular scanner or a tunnel. Typically a tube is inserted to inflate the rectum with air. Preparation is the same as for a traditional colonoscopy. You are not given medications to relax you or make you sleep. This procedure may also be referred to as a virtual colonoscopy.

- Yes
- No → skip to question 7
- Don't know → skip to question 7

b) Since your last questionnaire, on how many separate occasions have you had a virtual colonoscopy?

Number of virtual colonoscopy tests: _____ Don't know

c) When did you have your most recent virtual colonoscopy?

Age: _____ **OR** Year: _____ **OR** Number of years since last virtual colonoscopy: _____

Don't know

**d) What were the reasons for your most recent virtual colonoscopy?
(CHECK ALL THAT APPLY)**

- To investigate a new problem
- Family history of colorectal cancer
- Routine exam or check-up
- Follow-up of a previous problem
- Follow-up of FOBT result
- Other (specify): _____
- Don't know

7. a) Since your last questionnaire, have you had a barium enema and colon X-ray?

A barium enema is an x-ray examination of your colon. X-rays of the colon are taken following a barium enema. Preparation involves fluids, laxatives, and an enema to cleanse the bowel. Barium is a special fluid introduced into the bowel before the x-ray.

- Yes
- No → skip to question 8
- Don't know → skip to question 8

b) Since your last questionnaire, on how many separate occasions have you had a barium enema?

Number of barium enema tests: _____ Don't know

c) When did you have your most recent barium enema?

Age: _____ **OR** Year: _____ **OR** Number of years since last barium enema: _____

- Don't know

**d) What were the reasons for your most recent barium enema?
(CHECK ALL THAT APPLY)**

- To investigate a new problem
- Family history of colorectal cancer
- Routine exam or check-up
- Follow-up of a previous problem
- Follow-up of FOBT result
- Other (specify): _____
- Don't know

II. POLYP REMOVAL & COLORECTAL SURGERIES

8. a) **Since your last questionnaire, has a doctor told you that you had polyps in your colon or rectum?**

Include polyps that were found during any of the procedures discussed above and not just polyps that may have been found during your most recent procedure.

- Yes
- No → skip to question 9
- Don't know → skip to question 9

- b) **Since your last questionnaire, have you had any of these polyps removed (usually done during colonoscopy)?**

- Yes
- No → skip to question 9
- Don't know → skip to question 9

- c) **Since your last questionnaire, on how many separate occasions have you had polyps removed?**

Number of times polyps removed: _____ Don't know

- d) **Since your last questionnaire, when was the first time you had polyps removed?**

Age: _____ **OR** Year: _____ **OR** Number of years since first polyps removed: _____

- Don't know

- e) **Since your last questionnaire, when was the second time you had polyps removed?**

- Not Applicable

Age: _____ **OR** Year: _____ **OR** Number of years since second polyps removed: _____

- Don't know

- f) **Since your last questionnaire, when was the third time you had polyps removed?**

- Not Applicable

Age: _____ **OR** Year: _____ **OR** Number of years since third polyps removed: _____

- Don't know

If you had more than 3 procedures to remove polyps, please state when these procedures were completed on the back cover of the questionnaire or on a separate piece of paper.

9. a) **Since your last questionnaire, have you had surgery to remove any of your colon or rectum?**

- Yes
- No → skip to question 10
- Don't know → skip to question 10

b) **Since your last questionnaire, when was the first time you had surgery on your colon or rectum?**

Age: _____ **OR** Year: _____ **OR** Number of years since surgery: _____

- Don't know

c) **How much of your colon or rectum did you have removed?**

- Partially removed
- Completely removed
- Don't know

d) **What was the reason for this surgery?**

- Benign tumor (including polyps)
- Malignant tumour (cancer)
- Diverticulitis
- Inflammatory bowel disease, such as Ulcerative colitis or Crohn's disease
- Other (specify): _____
- Don't know

*Answer the questions below if you had more than one surgery on your colon or rectum.
Otherwise, skip to **Question 10**.*

e) **Since your last questionnaire, when was the second time you had surgery on your colon or rectum?**

Age: _____ **OR** Year: _____

OR Number of years since your second surgery: _____

- Don't know

f) **How much of your colon or rectum did you have removed?**

- Partially removed
- Completely removed
- Don't know

g) What was the reason for this surgery?

- Benign (including polyps)
- Malignant tumour (cancer)
- Diverticulitis
- Inflammatory bowel disease, such as Ulcerative colitis or Crohn's disease
- Other (specify): _____
- Don't know

III. GENERAL HEALTH & MEDICATION INFORMATION

10. In general, would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor
- Don't know

11. How much do you currently weigh?

Pounds: _____ **OR** Kilograms: _____ Don't know

12. a) Since your last questionnaire, have you smoked at least one cigarette a day for 3 months or longer?

- Yes
- No → skip to question 13
- Don't know → skip to question 13

b) Do you currently smoke?

- Yes → skip to question 13
- No

c) When did you stop or quit smoking?

Age: _____ **OR** Year: _____ **OR** Number of years since you quit smoking: _____
 Don't know

13. a) Since your last questionnaire, have you taken any aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin regularly, at least 2 times a week for more than a month? This includes low doses used in association with heart conditions.

- Yes
- No → skip to question 14
- Don't know → skip to question 14

b) Since your last questionnaire, how often did you take aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin, when you were using it at least 2 times a week for more than a month?

Number of pills per day: _____ *OR* Number of pills per week: _____

- Don't know

c) Since your last questionnaire, how many months or years in total did you take aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin, when you were using it at least 2 times a week for more than a month?

Number of months: _____ *OR* Number of years: _____

- Don't know

14. a) Since your last questionnaire, have you taken a special type of NSAID known as COX-2 inhibitors such as Celebrex (generic name Celecoxib), Vioxx (generic name Rofecoxib), or Bextra (generic name Valecoxib), at least 2 times a week for more than a month?

- Yes
- No → skip to question 15
- Don't know → skip to question 15

b) Since your last questionnaire, how often did you take this type of medication Celebrex (generic name Celecoxib), Vioxx (generic name Rofecoxib), or Bextra (generic name Valecoxib), when you were using it at least 2 times a week for more than a month?

Number of pills per day: _____ *OR* Times per week: _____

- Don't know

c) Since your last questionnaire, how many months or years in total did you take this type of medication Celebrex (generic name Celecoxib), Vioxx (generic name Rofecoxib), or Bextra (generic name Valecoxib), at least 2 times a week for more than a month?

Number of months: _____ *OR* Number of years: _____

- Don't know

15. a) Since your last questionnaire, have you taken any other NSAIDs (non-steroidal anti-inflammatory drugs) such as Ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren, regularly, at least 2 times a week for more than a month?

- Yes
- No → skip to question 16
- Don't know → skip to question 16

b) Since your last questionnaire, how often did you take this type of medication (Ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren), when you were using it at least 2 times a week for more than a month?

Number of pills per day: _____ **OR** Number of pills per week: _____

- Don't know

c) Since your last questionnaire, how many months or years in total did you take this type of medication (Ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren), when you were using it at least 2 times a week for more than a month?

Number of months: _____ **OR** Number of years: _____

- Don't know

IV. REPRODUCTIVE HEALTH (WOMEN ONLY)

If you are a male, skip to Question 17

16. a) Since your last questionnaire, have you had any surgery on your uterus and/or ovaries?

- Yes
- No → skip to question 17
- Don't know → skip to question 17

b) Since your last questionnaire, when was the first time you had surgery on your uterus or ovaries?

Age: _____ **OR** Year: _____ **OR** Number of years since surgery: _____

- Don't know

c) What type of surgery did you have the first time?

- Hysterectomy (only the uterus or womb was removed)
- Hysterectomy with one ovary or part of an ovary removed
- Hysterectomy with both ovaries removed
- One ovary removed, completely or partly without hysterectomy
- Both ovaries removed, completely or partly, without hysterectomy
- Other, (specify): _____
- Don't know

*Continue to question 16d and 16e if you had more than one surgery on your uterus or ovaries. Otherwise skip to **Question 17**.*

d) Since your last questionnaire, when was the second time you had surgery on your uterus or ovaries?

Age: _____ **OR** Year: _____ **OR** Number of years since your second surgery: _____

- Don't know

e) What type of surgery did you have the second time?

- Hysterectomy (only the uterus or womb was removed)
- Hysterectomy with one ovary or part of an ovary removed
- Hysterectomy with both ovaries removed
- One ovary removed, completely or partly without hysterectomy
- Both ovaries removed, completely or partly, without hysterectomy
- Other, (specify): _____
- Don't know

V. CANCER HISTORY

17. a) Since your last questionnaire, have you had a diagnosis of any type of cancer, including skin cancer, leukaemia, lymphoma or any other malignant tumour?

- Yes
- No → skip to question 19
- Don't know → skip to question 19

b) **Cancer 1:** What type of cancer was it? _____ (type or site)

- Don't know

c) When were you diagnosed with this cancer?

Age: _____ **OR** Year: _____ **OR** Number of years since diagnosis: _____

- Don't know

d) Is this cancer diagnosis:

- New cancer
- Spread from another cancer (metastatic)
- Recurrence of a previously diagnosed cancer
- Don't know

e) Did you have radiation treatment for this cancer?

- Yes
- No → skip to question 17g
- Don't know → skip to question 17g

f) When did you start radiation treatment?

Age: _____ **OR** Year: _____ **OR** Number of years since radiation: _____

- Don't know

g) Did you have chemotherapy for this cancer?

- Yes
- No → skip to question 18
- Don't know → skip to question 18

h) When did you start chemotherapy treatment?

Age: _____ **OR** Year: _____

OR Number of years since start of chemotherapy treatment: _____

- Don't know

18. a) Since your last questionnaire, have you had more than one cancer (including skin cancer, leukemia, lymphoma or any other malignant tumour)?

- Yes
- No → skip to question 19
- Don't know → skip to question 19

b) Cancer 2: What type of cancer was it? _____ (type or site)

- Don't know

c) When were you diagnosed with this cancer?

Age: _____ **OR** Year: _____ **OR** Number of years since diagnosis: _____

- Don't know

d) Is this cancer diagnosis:

- New cancer
- Spread from another cancer (metastatic)
- Recurrence of a previously diagnosed cancer
- Don't know

e) Did you have radiation treatment for this cancer?

- Yes
- No → skip to question 18g
- Don't know → skip to question 18g

f) When did you start radiation treatment?

Age: _____ **OR** Year: _____

OR Number of years since start of radiation treatment: _____

Don't know

g) Did you have chemotherapy treatment for this cancer?

Yes

No → skip to question 19

Don't know → skip to question 19

h) When did you start chemotherapy treatment?

Age: _____ **OR** Year: _____

OR Number of years since start of chemotherapy treatment: _____

Don't know

If you had more than two cancers, please state: 1) type of cancer, 2) when you were diagnosed, and 3) if/when you had radiation treatment and/or chemotherapy treatment on the back cover of the questionnaire or on a separate piece of paper.

VI. FAMILY HISTORY

19. Since your last questionnaire, have any of your blood relatives developed cancer(s)?

We are asking about your grandparents, parents, siblings, aunts, uncles, nieces, nephews, children, grandchildren and any other more distant blood relatives you may have (for example, cousins and their children).

If some are your half-brothers or half-sisters, please write “half-brother” or “half-sister” and indicate whether they have the same mother or father as you.

Yes → complete the table on the next page

No → skip to question 20

Don't know → skip to question 20

Full Name (First/Middle/Last)	Relationship (e.g. sibling, first cousin)	Sex (M/F)	Type of cancer	Date of Diagnosis	Age at Diagnosis	Location (City & Prov/State)
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					

If you need more space, please use the back cover of the questionnaire.

20. Since your last questionnaire, have any of your blood relatives died? We are asking about your grandparents, parents, siblings, aunts, uncles, nieces, nephews, children, grandchildren and any other more distant blood relatives you may have (for example, cousins and their children).

- Yes → complete the table below.
- No → skip to question 21
- Don't know → skip to question 21

Full Name (First/Middle/Last)	Relationship (e.g. sibling, first cousin)	Sex (M/F)	Cause of Death	Date of Death (day/month/year)	Age at death	Place of Death (City & Prov/State)
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					
	<input type="checkbox"/> Maternal <input type="checkbox"/> Paternal					

If you need more space, please use the back cover of the questionnaire.

VII. GENETIC TESTING

21. a) Since your last questionnaire, have you had any genetic testing (i.e. a blood test to look for gene mutations that indicate a possible increased risk for cancer)?

Include genetic tests conducted at a clinical genetic service or family cancer clinic. Please **do not include** if you had a blood test as a part of this or another research study.

- Yes
- No → skip to question 22
- Don't know → skip to question 22

b) Have you received your gene test result?

- Yes
- No → skip to question 22
- Don't know → skip to question 22

c) What was the result of your gene test?

Please describe: _____

- Don't know

VIII. CONTACT INFORMATION

22. Your Contact Information

Since your last questionnaire, has there been any change to your name, address, phone number(s) or email?

- Yes
- No → skip to question 23

Full Name: _____

Address: _____

Town/City: _____

Province/State: _____ Postal Code/ZIP: _____

Canada USA Other, specify: _____

Tel. (Home): _____ (Work): _____ (Cell): _____

Email: _____

23. Please indicate your current marital status:

- Currently married or living as married/common law
- Separated → skip to question 25
- Divorced → skip to question 25
- Widowed → skip to question 25
- Single or never married → skip to question 25
- Prefer not to answer → skip to question 25

24. If you are married or living as married/common law, please provide the name of your spouse/partner.

First Name	Middle Name	Last Name	Maiden Name (if applicable)
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25. Alternate Contact

In case we lose contact with you in the future (e.g. change of address/name/phone number etc.) and need to contact you, could we please have the name of someone who is not living with you to whom we might write or call for your new address?

Name of relative or friend: _____

Relationship (e.g. sister, friend): _____

Address: _____

Town/City: _____

Province/State: _____ Postal Code/ZIP: _____

Canada USA Other, specify: _____

Tel. (Home): _____ (Work): _____ (Cell): _____

Email: _____

Thank you very much for your time in completing this questionnaire.

If you have questions, please contact us at:

(416) 586-4800 ext 2759 or toll free 1-866-225-2728 or email: OFCCR@lunenfeld.ca

