Ontario Familial Colorectal Cancer Registry

Supported with funds from US National Institutes of Health

Phase 5 Follow-Up Questionnaire

Please refer to the date of your last questionnaire when answering the questions

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

416-586-8810

toll free: 1-866-225-2728

email: OFCCR@lunenfeld.ca

Version: Aug 2018

Today's date _________/________/_________
YYYY MMM DD

Your date of birth _________/________/_________
YYYY MMM DD

CONTACT INFORMATION

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

☐ Yes ☐ No

↓

Name: ____

Address: ____

____

Primary phone: ________________________________ home / cell / work (please circle one)

Secondary phone: ______________________________ home / cell / work (please circle one)

Email: ____

MARITAL STATUS

Please indicate your current marital status:

☐ Married or common law, please provide the name of your spouse/partner:

____

☐ Separated

☐ Divorced

☐ Widowed

☐ Single

☐ Prefer not to answer

BOWEL SCREENING

***Since your last questionnaire*, have you had a <u>Fecal Occult Blood Test (FOBT)</u>?**

This test detects traces of blood in the stool (feces) and is usually done at home using a kit.
<u>There are two types of tests (hemoccult and fecal immunochemical test or FIT).</u>
Both types of FOBTs use cards and are sent to the laboratory for analysis.

☐ Yes ☐ No ☐ Don't know

Number of FOBT tests	When was your most recent test?	Reasons for the most recent test? *(check all that apply)*
Number of FOBT tests since last questionnaire ___________ ☐ Don't know	Age _______ *or* Year ______ *or* ___years ago ☐ Don't know	☐ 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

***Since your last questionnaire*, have you had a <u>DNA-based whole stool test (like Cologuard)</u>?**

This test detects altered DNA and/or blood in the stool (feces) and is usually done at home using a kit. This kit requires a whole stool sample which is sent to the laboratory for analysis.

☐ Yes ☐ No ☐ Don't know

Number of DNA-based stool tests	When was your most recent test?	Reasons for the most recent test? *(check all that apply)*
Number of DNA-based stool tests since last questionnaire ___________ ☐ Don't know	Age _______ *or* Year ______ *or* ___years ago ☐ Don't know	☐ 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

***Since your last questionnaire*, have you had a Colonoscopy?**

Procedure to look inside the entire bowel with a lighted tube. Preparation involves oral laxatives to empty the bowel the day before. Medication is usually given to relax or make you sleepy.

☐ Yes ☐ No ☐ Don't know

Number of Colonoscopy tests	When was your most recent colonoscopy?	Reasons for your most recent colonoscopy? *(check all that apply)*
Number of Colonoscopy tests since last questionnaire ____________ ☐ Don't know	Age _______ *or* Year ______ *or* ___years ago ☐ Don't know	☐ 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

***Since your last questionnaire*, have you had a Sigmoidoscopy?**

Similar to a colonoscopy but there is no preparation with oral laxatives the day before the procedure. Preparation of the bowel is done with an enema. This procedure can be done with or without sedation.

☐ Yes ☐ No ☐ Don't know

Number of Sigmoidoscopy tests	When was your most sigmoidoscopy?	Reasons for the most recent sigmoidoscopy? *(check all that apply)*
Number of Sigmoidoscopy tests since last questionnaire ____________ ☐ Don't know	Age _______ *or* Year ______ *or* ___years ago ☐ Don't know	☐ 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

POLYP REMOVAL

***Since your last questionnaire*, has a doctor told you that you had <u>polyps</u> in your colon or rectum?**

Include polyps found during any of the procedures discussed in previous questions and not just polyps that were found during your most recent procedure.

☐ Yes ☐ No ☐ Don't know

↓

Have you had any polyps removed?

☐ Yes ☐ No ☐ Don't know

↓

On how many different occasions have you had polyps removed?

Number of times polyps removed: ________________ ☐ Don't know

First occasion polyps removed	Age ______ *or* Year ________ *or* _____ years ago ☐ Don't know	Hospital/Clinic ______________________ Doctor (if known) ______________________ ***Please see consent form on page 15.***
Second occasion polyps removed	Age ______ *or* Year ________ *or* _____ years ago ☐ Don't know	Hospital/Clinic ______________________ Doctor (if known) ______________________ ***Please see consent form on page 15.***
Third occasion polyps removed	Age ______ *or* Year ________ *or* _____ years ago ☐ Don't know	Hospital/Clinic ______________________ Doctor (if known) ______________________ ***Please see consent form on page 15.***

If you had more than 3 procedures to remove polyps, please use the back page of the questionnaire to record when these procedures were completed.

COLORECTAL SURGERIES

***Since your last questionnaire*, have you had <u>surgery to remove any part of your colon or rectum</u>?**

☐ Yes ☐ No ☐ Don't know

<u>First</u> surgery on your colon or rectum	**<u>Second</u> surgery on your colon or rectum**
Age _____ *or* Year ______ *or* ____ years ago ☐ Don't know	Age _____ *or* Year ______ *or* ____ years ago ☐ Don't know
How much of your colon or rectum was removed? ☐ Completely removed ☐ Partially removed ☐ Don't know	**How much of your colon or rectum was removed?** ☐ Completely removed ☐ Partially removed ☐ Don't know
What was the reason(s) for this surgery? *(check all that apply)* ☐ Benign tumor (including polyps) ☐ Malignant tumour (cancer) ☐ Diverticulitis ☐ Inflammatory bowel disease, such as Ulcerative Colitis or Crohn's disease ☐ Other (specify): _______________________________ ☐ Don't know	**What was the reason(s) for this surgery?** *(check all that apply)* ☐ Benign tumor (including polyps) ☐ Malignant tumour (cancer) ☐ Diverticulitis ☐ Inflammatory bowel disease, such as Ulcerative Colitis or Crohn's disease ☐ Other (specify): _______________________________ ☐ Don't know

GENERAL HEALTH

In general, compared to others your same age, would you say your health is:

☐ Excellent

☐ Very Good

☐ Good

☐ Fair

☐ Poor

☐ Not sure

How much do you currently weigh?

Pounds: ____________ *or* Kilograms: _____________

☐ Don't know

SMOKING

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

☐ Yes → Do you currently smoke?

- ☐ Yes
- ☐ No → When did you stop or quit smoking?
  - Age _____ *or* Year _______
  - ☐ Don't know

☐ No

☐ Don't know

MEDICATIONS

***Since your last questionnaire*, have you taken any of these medications regularly (at least twice a week for more than a month)?**

<u>Aspirin</u>
such as Anacin, Bufferin, Bayer, Excedrin or Ecotrin. This includes low doses used in association with heart conditions.

☐ Yes ☐ No ☐ Don't know

How often did you take aspirin since your last questionnaire?	How long have you taken aspirin since your last questionnaire?
_____ per day *or* _____ per week	_____ months *or* _____ years
☐ Don't know	☐ Don't know

<u>Non-steroidal anti-inflammatory drugs (NSAIDS)</u>
such as Ibuprofen, Advil, Aleve, Motrin, Naproxen, Nuprin or Medipren

☐ Yes ☐ No ☐ Don't know

How often did you take NSAIDS since your last questionnaire?	How long have you taken NSAIDS since your last questionnaire?
_____ per day *or* _____ per week	_____ months *or* _____ years
☐ Don't know	☐ Don't know

<u>Other non-steroidal anti-inflammatory drugs (NSAIDS) known as COX-2 inhibitors</u>
such as Celebrex (Celecoxib) or Vioxx (Rofecoxib)

☐ Yes ☐ No ☐ Don't know

How often did you take COX-2 inhibitors since your last questionnaire?	How long have you taken COX-2 inhibitors since your last questionnaire?
_____ per day *or* _____ per week	_____ months *or* _____ years
☐ Don't know	☐ Don't know

REPRODUCTIVE HEALTH (WOMEN ONLY)

Men, please go to the next page.

***Since your last questionnaire*, have you had surgery on your uterus and/or ovaries?**

☐ Yes ☐ No ☐ Don't know

First surgery on your uterus or ovaries.	**Second surgery on your uterus or ovaries.**
Age _____ *or* Year ______ *or* ____ years ago ☐ Don't know	Age _____ *or* Year ______ *or* ____ years ago ☐ Don't know
What type of surgery did you have? ☐ Hysterectomy (only the uterus 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	**What type of surgery did you have?** ☐ Hysterectomy (only the uterus 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

CANCER HISTORY

***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 ☐ Don't know

Cancer 1	Cancer 2
Type ______________________ ☐ Don't know	**Type** ______________________ ☐ Don't know
Age _____ *or* Year ______ *or* _____ years ago ☐ Don't know	Age _____ *or* Year ______ *or* _____ years ago ☐ Don't know
Is this cancer diagnosis: ☐ New cancer ☐ Spread from another cancer (metastatic) ☐ Recurrence of a previous cancer ☐ Don't know	**Is this cancer diagnosis:** ☐ New cancer ☐ Spread from another cancer (metastatic) ☐ Recurrence of a previous cancer ☐ Don't know
Did you receive radiation or chemotherapy for this cancer? ☐ Yes, chemotherapy ☐ Yes, radiation ☐ Yes, both ☐ No, neither ☐ Don't know	**Did you receive radiation or chemotherapy for this cancer?** ☐ Yes, chemotherapy ☐ Yes, radiation ☐ Yes, both ☐ No, neither ☐ Don't know
Hospital/clinic where your cancer was diagnosed: ______________________ Doctor (if known) ______________________ ***Please see consent form on page 15.***	**Hospital/clinic where your cancer was diagnosed:** ______________________ Doctor (if known) ______________________ ***Please see consent form on page 15.***

If you had more than two cancers, please use the back page of the questionnaire to record:
1) type of cancer, 2) when you were diagnosed, and 3) if/when you had radiation and/or chemotherapy.

FAMILY HISTORY

1. ***Since your last questionnaire*, have any of your blood relatives developed cancer?**

We are asking about your grandparents, parents, siblings, children, grandchildren, aunts, uncles, nieces, nephews and cousins. For half-brother or half-sister, please indicate whether they have the same mother or father as you.

☐ Yes ☐ No ☐ Don't Know

Full Name	Relationship (e.g. sibling, first cousin)		Type of cancer(s)	Year of Diagnosis	Age at Diagnosis	Hospital (City/Prov or State)
		☐ Mother's side ☐ Father's side				
		☐ Mother's side ☐ Father's side				
		☐ Mother's side ☐ Father's side				
		☐ Mother's side ☐ Father's side				
		☐ Mother's side ☐ Father's side				

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

2. ***Since your last questionnaire*, have any of your blood relatives died?**

We are asking about your grandparents, parents, siblings, children, grandchildren, aunts, uncles, nieces, nephews and cousins.
For half-brother or half-sister, please indicate whether they have the same mother or father as you.

☐ Yes ☐ No ☐ Don’t Know

Full Name	Relationship (e.g. sibling, first cousin)		Cause of Death	Year of Death	Age at Death	Place of Death (City/Prov or State)
		☐ Mother’s side ☐ Father’s side				
		☐ Mother’s side ☐ Father’s side				
		☐ Mother’s side ☐ Father’s side				
		☐ Mother’s side ☐ Father’s side				
		☐ Mother’s side ☐ Father’s side				

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

GENETIC TESTING

***Since your last questionnaire*, have you had any <u>genetic testing</u> (a blood test to look for gene mutations that indicate a possible increased risk for cancer)?** Only include genetic tests ordered by a clinical genetic service or family cancer clinic.

☐ Yes ☐ No ☐ Don't know

Have you received your gene test result?

☐ Yes, Result: ______________________________

☐ No

☐ Don't Know

ALTERNATE CONTACT INFORMATION

Alternate Contact

In case we are not able to reach you in the future, please provide the name of someone <u>who is not</u> living with you whom we might call or write for your new address?

Name of relative or friend: ______________________________

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

Address: ______________________________

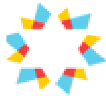
____

Home: ____________Work:____________Cell:____________

Email: ______________________________

Thank you very much for taking the time to complete this questionnaire.

If you reported colon polyps removed or a diagnosis of cancer, please provide permission to access your medical records by signing the consent form on the next page.



Lunenfeld-Tanenbaum Research Institute
Sinai Health System

Authorization to Release of Medical Information/Tissue For Research Purposes

I hereby authorize the Ontario Cancer Registry or the Medical Record and/or Pathology Department and/or treating or family physician to release information/tissue for my cancer diagnosis or colon polyp(s) to: Dr. Steven Gallinger, Principal Investigator, Ontario Familial Colorectal Cancer Registry, 60 Murray Street, Box 31, Toronto, ON M5T 3L9.

***Please list any hospital/clinic where polyp(s) were removed and/or cancer surgery was performed or cancer treatment was provided*:**

1. ____

2. ____

3. ____

______________________________ ______________________________
Surname of patient ***Given Names***

____
Date of Birth (yyyy mm dd)

I am the (please check): ____ Patient ____ Legal Representative

If legal representative, please state family relationship:

Signature: ______________________________ **Date:** ____________________

Witness (if available): ______________________________ Date: ____________________

☐ **Optional Consent :** I give permission to the OFCCR to access medical records and available tissue related to my cancer/polyp diagnoses periodically, without a time limit.
Please initial box if you are in agreement.

ONTARIO FAMILIAL COLORECTAL CANCER REGISTRY (OFCCR)
416-586-8810 or Toll Free 1-866-225-2728
Fax: 416-586-8335

OFCCR File #: ______________