

**COLON CANCER FAMILY REGISTRY
CORE Family Studies**

3rd Follow-Up Questionnaire

Thank you for taking the time to fill out this brief follow-up questionnaire.

I. Basic Information

Let's start with questions about some basic information and your contact information.

1. **Today's Date:** _____/_____/_____

Month Date Year

2. **What is your date of birth?**

_____/_____/_____

Month Date Year

Do Not Know / Prefer Not to Answer

3. **Since "LastInterviewDate», has your name changed?**

Yes → Continue to Question 3.1

No → Skip to Question 4

3.1 **What is your name?**

First Name: _____

Middle Initial: _____

Last Name: _____

3.2 **What was your name changed from?** _____

4. **What is your current contact information?**

We may contact you if clarification is required on any of the answers to this survey. CORE Studies may also contact you about other aspects of our study. No information will be sold or used for commercial use.

Primary Phone: (_____) _____ Type: _____

Home/Cell/Work

Best times: _____ AM/PM Weekdays Weekends

Secondary Phone: (_____) _____ Type: _____

Home/Cell/Work

Best times: _____ AM/PM Weekdays Weekends

Mailing Address

Street Address: _____

City: _____

State: _____

Country (if not USA): _____

Zip Code: _____

Email:

Please note that confidentiality of email transmissions cannot be guaranteed. It might be best to provide an email address that is not a work or shared email address. Work emails are often subject to monitoring.

Primary email: _____

Secondary email: _____

II. Screening Questions

5. Since “LastInterviewDate», have you had a fecal occult blood test (FOBT)?

This is a test to detect blood in the stool (feces) and is usually done at home using a kit. One type of kit uses cards (Hemoccult) and another type requires that a small sample of stool to be placed into a container (fecal immunochemical or FIT). Both types of FOBTs are either mailed or delivered back to the laboratory for analysis.

- Yes → Continue to Question 5.1
- No → Skip to Question 6
- Do Not Know/Prefer Not to Answer → Skip to Question 6

5.1 Since “LastInterviewDate», how many separate occasions have you had an FOBT?

Number of FOBT tests: _____

Do Not Know/Prefer Not to Answer

5.2 When did you have your most recent FOBT?

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

5.3 **What were the reasons for the most recent FOBT (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 _____
- Do Not Know/Prefer Not to Answer

6. **Since “LastInterviewDate», have you had a sigmoidoscopy?**

A sigmoidoscopy is an endoscopic procedure similar to a colonoscopy but does not require extensive preparation with oral laxatives the night before the procedure or dietary modification. It is done with or without sedation after preparation of the bowel with an enema.

- Yes → Continue to Question 6.1
- No → Skip to Question 7
- Do Not Know/Prefer Not to Answer → Skip to Question 7

6.1 **Since “LastInterviewDate», how many separate occasions have you had a sigmoidoscopy?**

Number of sigmoidoscopy tests: _____

Do Not Know/Prefer Not to Answer

6.2 **When did you have your most recent sigmoidoscopy?**

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

6.3 **What were the reasons for the 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 _____
- Do Not Know/Prefer Not to Answer

7. Since “LastInterviewDate», have you had a colonoscopy?

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

- Yes → Continue to Question 7.1
 No → Skip to Question 8
 Do Not Know/Prefer Not to Answer → Skip to Question 8

7.1 Since “LastInterviewDate», how many separate occasions have you had a colonoscopy?

Number of colonoscopy tests: _____

- Do Not Know/Prefer Not to Answer

7.2 When did you have your most recent colonoscopy?

Age: _____ OR Year: _____ OR # of years since: _____

- Do Not Know/Prefer Not to Answer

7.3 What were the reasons for the 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 _____
 Do Not Know/Prefer Not to Answer

8. Since “LastInterviewDate», have you had a CT Colonograph or Virtual Colonoscopy?

This is not a regular Colonoscopy. It is a procedure done using x-rays with you lying on a table that is slide through a large circular scanner or a tunnel. Typically a tube is inserted to inflate the rectum with air. Preparation may include drinking fluid or taking laxatives to cleanse the bowel. You are not given medications to relax you or make you sleep. This procedure may also be referred to as a Virtual Colonoscopy (VC).

- Yes → Continue to Question 8.1
 No → Skip to Question 9
 Do Not Know/Prefer Not to Answer → Skip to Question 9

8.1 Since “LastInterviewDate», how many separate occasions have you had a virtual colonoscopy?

Number of virtual colonoscopy tests: _____

Do Not Know/Prefer Not to Answer

8.2 **When did you have your most recent virtual colonoscopy?**

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

8.3 **What were the reasons for the 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 _____

Do Not Know/Prefer Not to Answer

9. **Since “LastInterviewDate», have you had a barium enema?**

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 → Continue to Question 9.1

No → Skip to Question 10

Do Not Know/Prefer Not to Answer → Skip to Question 10

9.1 **Since “LastInterviewDate», how many separate occasions have you had a barium enema?**

Number of barium enema tests: _____

Do Not Know/Prefer Not to Answer

9.2 **When did you have your most recent barium enema?**

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

9.3 **What were the reasons for the 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 _____
- Do Not Know/Prefer Not to Answer

III. Polyp Removal and Colorectal Surgeries

10. Since “LastInterviewDate», has a doctor told you that you had polyps in your colon or rectum?

Be sure to include all polyps that were found during any of the procedures discussed above that you have had since your last interview and not just polyps that may have been found during your most recent procedure.

- Yes → Continue to Question 10.1
- No → Skip to Question 11
- Do Not Know/Prefer Not to Answer → Skip to Question 11

10.1 Since “LastInterviewDate», have you had any of these polyps removed (usually done during colonoscopy)?

- Yes → Continue to Question 10.2
- No → Skip to Question 11
- Do Not Know/Prefer Not to Answer → Skip to Question 11

10.2 Since “LastInterviewDate», how many separate occasions have you had polyps removed?

Number of times polyps removed: _____

- Do Not Know/Prefer Not to Answer

These next questions ask about the first three procedures since “LastInterviewDate». If you had more than three procedures, please state when these procedures were completed on a separate piece of paper and include when mailing back materials. Alternatively, we may call for this information.

10.3 Since “LastInterviewDate», when was the first time you had polyps removed?

Age: _____ OR Year: _____ OR # of years since: _____

- Do Not Know/Prefer Not to Answer

10.4 Since “LastInterviewDate», when was the second time you had polyps removed?

Age: _____ OR Year: _____ OR # of years since: _____

- Do Not Know/Prefer Not to Answer

10.5 Since “LastInterviewDate», when was the third time you had polyps removed?

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

11. Since “LastInterviewDate», have you had surgery to remove any of your colon or rectum?

Yes → Continue to Question 11.1

No → Skip to Question 12

Do Not Know/Prefer Not to Answer → Skip to Question 12

11.1 Since “LastInterviewDate», when was the first time you had surgery on your colon or rectum?

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

11.2 How much did you have removed?

Partially

Completely

Do Not Know/Prefer Not to Answer

11.3 What was the reason for this surgery?

Benign or malignant tumor (including polyp)

Diverticulitis

Inflammatory bowel disease, such as Ulcerative colitis or Crohn’s disease

Other: Specify _____

Do Not Know/Prefer Not to Answer

Answer the questions below if you had more than one surgery on your colon or rectum. Otherwise, skip to Section IV, Question 12.

11.4 Since “LastInterviewDate», when was the second time you had surgery on your colon or rectum?

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

11.5 How much did you have removed?

Partially

Completely

Do Not Know/Prefer Not to Answer

11.6 What was the reason for this surgery?

- Benign or malignant tumor (including polyp)
- Diverticulitis
- Inflammatory bowel disease, such as Ulcerative colitis or Crohn’s disease
- Other: Specify _____
- Do Not Know/Prefer Not to Answer

IV. General Health and Medication Information

The purpose of these questions is to gather some background health information from you.

12. In general would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor
- Do Not Know/Prefer Not to Answer

13. How much do you currently weigh?

- Enter pounds: _____
- Enter kilos: _____
- Do Not Know/Prefer Not to Answer

14. Since “LastInterviewDate», have you smoked at least one cigarette a day for 3 months or longer?

- Yes → Continue to Question 14.1
- No → Skip to Question 15
- Do not know/Prefer not to answer → Skip to Question 15

14.1 Do you currently smoke?

- Yes → Skip to Question 15
- No → Continue to Question 14.2
- Do not know/Prefer not to answer → Continue to Question 14.2

14.2 When did you stop or quit smoking?

- Age: _____ **OR** Year: _____ **OR** # of years since: _____
- Do Not Know/Prefer Not to Answer

These next questions ask about medications you may have taken since your last interview, beginning with a number of types of common pain relievers such as aspirin, NSAIDS and ibuprofen.

15. Since “LastInterviewDate», have you ever taken aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin, at least 2 times a week for more than a month? This includes low doses used in association with heart conditions.

- Yes → Continue to Question 15.1
 No → Skip to Question 16
 Do Not Know/Prefer Not to Answer → Skip to Question 16

- 15.1 Since “LastInterviewDate», 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?

- Enter times per day: _____
 Enter times per week: _____
 Do Not Know/Prefer Not to Answer

- 15.2 Since “LastInterviewDate», 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?

- Enter number of months: _____
 Enter number of years: _____
 Do Not Know/Prefer Not to Answer

16. Since “LastInterviewDate», have you ever taken any other non-steroidal anti-inflammatory drugs (NSAIDS) such as ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren regularly, at least 2 times a week for more than a month?

(Do not include COX-2 inhibitors. They are covered in question 17)

- Yes → Continue to Question 16.1
 No → Skip to Question 17
 Do Not Know/Prefer Not to Answer → Skip to Question 17

- 16.1 Since “LastInterviewDate», 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?

- Enter times per day: _____
 Enter times per week: _____
 Do Not Know/Prefer Not to Answer

16.2 Since “LastInterviewDate», **how many months or years in total did you take this type of medication (ibuprofen, Advil, Aleve, Motrin, Nuprin, Medipren), at least 2 times a week for more than a month?**

Enter number of months: _____

Enter number of years: _____

Do Not Know/Prefer Not to Answer

17. Since “LastInterviewDate», **have you ever taken a special type of NSAID such as Celebrex (generic name celecoxib), Vioxx (generic name rofecoxib), or Bextra (generic name valdecoxib), also known as COX-2 inhibitors, at least 2 times a week for more than a month?**

Yes → Continue to Question 17.1

No → *Women* - Skip to Section V, Question 18; *Men* – Skip to Section VI, Question 19

Do Not Know/Prefer Not to Answer → *Women* - Skip to Section V, Question 18; *Men* – Skip to Section VI, Question 19

17.1 Since “LastInterviewDate», **how often did you take this medication Celebrex (generic name celecoxib), Vioxx (generic name rofecoxib), or Bextra (generic name valdecoxib), when you were using it at least 2 times a week for more than a month?**

Enter times per day: _____

Enter times per week: _____

Do Not Know/Prefer Not to Answer

17.2 Since “LastInterviewDate», **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 valdecoxib), at least 2 times a week for more than a month?**

Enter number of months: _____

Enter number of years: _____

Do Not Know/Prefer Not to Answer

V. Reproductive Health (Women Only)

This section asks questions that are only applicable to women. If you are male, please skip to section VI (Question 19).

18. Since “LastInterviewDate», **have you had any surgery on your ovaries and/or uterus?**

Yes → Continue to Question 18.1

No → Skip to Question 19

Do Not Know/Prefer Not to Answer → Skip to Question 19

18.1 Since “LastInterviewDate», when was the first time you had surgery on your uterus or ovary?

Age: _____ OR Year: _____ OR # of years since: _____

Do Not Know/Prefer Not to Answer

18.2 What type of surgery did you have the first time?

Hysterectomy (only the uterus or womb was removed)

Hysterectomy with 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 _____

Do Not Know/Prefer Not to Answer

Answer the questions below if you had more than one surgery on your uterus or ovary, otherwise skip to Section VI, Question 19.

18.3 Since “LastInterviewDate», when was the second time you had surgery on your uterus or ovary?

Age: _____ OR Year: _____ OR # of years since: _____

Do Not Know/Prefer Not to Answer

18.4 What type of surgery did you have the first time?

Hysterectomy (only the uterus or womb was removed)

Hysterectomy with 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 _____

Do Not Know/Prefer Not to Answer

VI. Cancer History

19. Have you ever had a diagnosis of any type of cancer, including leukemia, lymphoma or any other malignant tumor?

- Yes → Continue to Question 19.1
- No → Skip to Question 20
- Do Not Know/Prefer Not to Answer → Skip to Question 20

19.1 Information related to your cancer diagnosis and treatment would be very valuable information for the registry.

Would you be willing to share this information by signing a consent form allowing us access to medical records relating to your cancer diagnosis?

If you had colorectal cancer, this consent form will include a request for "diagnostic materials" which includes samples of tissue from surgeries related to removing cancer tumors in addition to medical records.

- Yes
Thank You! We will send you a consent for release of information. This form will need to be signed and returned in order to give us permission to access these records.
- No
No problem. If you ever change your mind, feel free to contact us.
- Do not know/Maybe
Thank You! We will send you a consent for release of information which you can sign if you decide to share your medical records.

Cancer 1:

19.2 What type of cancer was it? _____

- Do Not Know/Prefer Not to Answer

19.3 When were you diagnosed with this cancer?

Age: _____ OR Year: _____ OR # of years since: _____

- Do Not Know/Prefer Not to Answer

19.4 In what state were you diagnosed with this cancer (WA, OR, etc.)?

(Location of the medical institution where you were diagnosed)

State: _____

- Do not know/Prefer not to answer

19.5 Did you have radiation treatment for this cancer?

- Yes → Continue to Question 19.6
- No → Skip to Question 19.7
- Do Not Know/Prefer Not to Answer → Skip to Question 19.7

19.6 When did you start radiation treatment?

- Age: _____ **OR** Year: _____ **OR** # of years since: _____
- Do Not Know/Prefer Not to Answer

19.7 Did you have chemotherapy treatment for this cancer?

- Yes → Continue to Question 19.8
- No → Skip to Question 19.9
- Do Not Know/Prefer Not to Answer → Skip to Question 19.9

19.8 When did you start chemotherapy treatment?

- Age: _____ **OR** Year: _____ **OR** # of years since: _____
- Do Not Know/Prefer Not to Answer

Answer the questions below if you had more than one cancer (including leukemia, lymphoma or any other malignant tumor). If you have had more than two cancers, please state: 1) type of cancer, 2) when you were diagnosed, and 3) if/when you had radiation and/or chemotherapy treatment on a separate piece of paper and include when mailing back materials. Alternatively, we may call for this information.

If you have not had any additional cancer, please skip to Section VII, Question 20.

Cancer 2:**19.9 What type of cancer was it? _____**

- Do Not Know/Prefer Not to Answer

19.10 When were you diagnosed with this cancer?

- Age: _____ **OR** Year: _____ **OR** # of years since: _____
- Do Not Know/Prefer Not to Answer

19.11 In what state were you diagnosed with this cancer (WA, OR, etc.)?

(Location of the medical institution where you were diagnosed)

State: _____

- Do not know/Prefer not to answer

19.12 Did you have radiation treatment for this cancer?

- Yes → Continue to Question 19.13
- No → Skip to Question 19.14

Do Not Know/Prefer Not to Answer → Skip to Question 19.14

19.13 When did you start radiation treatment?

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

19.14 Did you have chemotherapy treatment for this cancer?

Yes → Continue to Question 19.15

No → Skip to Question 20

Do Not Know/Prefer Not to Answer → Skip to Question 20

19.15 When did you start chemotherapy treatment?

Age: _____ **OR** Year: _____ **OR** # of years since: _____

Do Not Know/Prefer Not to Answer

VII. Family History

Over time, one may learn more about their family history of cancer and other diseases. Thus, while you may have told us about your family member's cancer history previously, we need to ask you again to ensure it is as up-to-date and complete as possible.

20. Have any of your blood relatives ever had a diagnosis of any type of cancer, including leukemia, lymphoma or any other malignant tumor?

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

Yes → Fill out the *table below*

No → Skip to Question 21

Do Not Know/Prefer Not to Answer → Skip to Question 21

If you answered "YES" to Question 20, fill out as much information as you can on the table below.

Relative Name (First/M/Last)	Relationship to You (specify side of family if applicable)	Type of Cancer	Age at Diagnosis	Year at Diagnosis	Location Diagnosed (State)

21. Since “LastInterviewDate», have you any of your blood relatives died?

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

- Yes → Fill out the *table below*
- No → Skip to Question 22
- Do Not Know/Prefer Not to Answer → Skip to Question 22

If you answered “YES” to Question 21, fill out as much information as you can on the table below.

Relative Name (First/M/Last)	Relationship to You (specify side of family if applicable)	Sex (M/F)	Year of Death	Age at Death	Place of Death (City, State)

VIII. Genetic Testing

22. Since “LastInterviewDate», have you had a blood test to look for gene mutations that indicate a possible increased risk for cancer?

Please **do not include** if you had a blood test as a part of this research study.

- Yes → Continue to Question 22.1
- No → Skip to Question 23
- Do Not Know/Prefer Not to Answer → Skip to Question 23

22.1 Have you received your gene test result?

- Yes → Continue to 22.2
- No → Skip to Question 22.3
- Do Not Know/Prefer Not to Answer → Skip to Question 22.3

22.2 What was the result of your gene test?

Please describe: _____

- Do Not Know/Prefer Not to Answer

22.3 This would be very valuable information for the registry. Would you be willing to share your test results by providing a signed consent release of information form so we can review that information in your medical records?

- Yes
Thank You! We will send you a consent for release of information. This form will need to be signed and returned in order to give us permission to access these records.
- No
No problem. If you ever change your mind feel free to contact us.
- Do Not Know/Maybe
Thank You! We will send you a consent for release of information which you can sign if you decide to share your genetic test results.

IX. Alternate Contact**23. In case are unable to contact you in the future due to a change in address, email, or phone number; may we please have the name of someone who is NOT living with you whom we might write or call for your new contact information?**

- Yes → Continue to Question 23.1
- No → Skip to Question 24
- Do Not Know/Prefer Not to Answer → Skip to Question 24

23.1 What is the name of your relative or friend who could provide updated contact information in case your information changes?

First Name: _____

Middle Initial: _____

Last Name: _____

23.2 What is his/her relationship to you?

Relationship: _____

23.3 What is his/her current address?

Street Address: _____

City: _____

State: _____ Country (if not USA): _____

Zip Code: _____

23.4 What are his/her phone numbers (home, work and/or cell)?

Phone Number: (_____) _____ Home/Work/Cell

Phone Number: (_____) _____ Home/Work/Cell

24. **Thoughts?** We would love to hear anything you would like to share with us about our study. Whether it's your thoughts on how we can improve our study or feedback on what we're doing right.

THANK YOU FOR COMPLETING THE FOLLOW UP SURVEY!

Please send the survey back in the pre-paid envelope that was provided in the packet.
If you have any questions, comments or concerns please feel free to contact us!

Phone: 1 (800) 276-0127
Email: corestudies@FredHutch.org

Visit Us Online: www.FredHutch.org/corestudies