Colon Cancer Family Registry Questions

Dear Mayo Clinic Colon Cancer Family Registry participants: Thank you for again completing a questionnaire for our studies. For most people, the last questionnaire completed for this study was about 5 years ago but we have included the actual date in the cover letter that came with this survey.

Basic Information

1. Date Today *(mm-dd-yyyy)*

2. Birth Date *(mm-dd-yyyy)*

3. Since the last survey, 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

4. What is your current contact information?
   We may contact you if clarification is required on any of the answers to this survey. No information will be sold or used for commercial use.

Phone	Type
Primary Phone	☐ Home ☐ Cell ☐ Work
Secondary Phone	☐ Home ☐ Cell ☐ Work

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

Screening Questions

5. Since the last survey, have you had a fecal occult blood test?
   This is a test to detect blood in the stool (feces) and is usually done at home using a kit. There are two types of tests (hemoccult and fecal immunochemical test or FIT). Both types of FOBTs use cards and 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 the last survey, how many separate occasions have you had a fecal occult blood test?
   Number of fecal occult blood tests over the last 5 years ___________________________
   ☐ Do Not Know/Prefer Not to Answer

   5.2 When did you have your most recent fecal occult blood test?
   Age ____________________ OR Year ____________________
   ☐ Do Not Know/Prefer Not to Answer

©2018 Mayo Foundation for Medical Education and Research

5.3 What were the reasons for the most recent fecal occult blood test (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 fecal occult blood test result
- ☐ Other: Specify ______________________________
- ☐ Do Not Know/Prefer Not to Answer

6. Since the last survey, have you had a DNA-based whole stool test (like Cologuard)?

This is a test to detect 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 either mailed or delivered back to the laboratory for analysis.

- ☐ 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 the last survey, how many separate occasions have you had a DNA-based whole stool test?

Number of tests ______________________

- ☐ Do Not Know/Prefer Not to Answer

6.2 When did you have your most recent DNA-based whole stool test?

Age ________________ OR Year ________________

- ☐ Do Not Know/Prefer Not to Answer

6.3 What were the reasons for the most recent DNA-based whole stool test (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 fecal occult blood test result
- ☐ Other: Specify ______________________________
- ☐ Do Not Know/Prefer Not to Answer

7. Since the last survey, 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 one more enemas.

- ☐ 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 the last survey, how many separate occasions have you had a sigmoidoscopy?

Number of sigmoidoscopies ______________________

- ☐ Do Not Know/Prefer Not to Answer

7.2 When did you have your most recent sigmoidoscopy?

Age ________________ OR Year ________________

- ☐ Do Not Know/Prefer Not to Answer

7.3 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 fecal occult blood test result
- ☐ Other: Specify ______________________________
- ☐ Do Not Know/Prefer Not to Answer

8. Since the last survey, 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 clinic or hospital. Preparation involves drinking fluids or taking pills to cleanse the bowel.
   ☐ 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 the last survey, how many separate occasions have you had a colonoscopy?
   Number of colonoscopies ___________________________
   ☐ Do Not Know/Prefer Not to Answer

8.2 When did you have your most recent colonoscopy?
   Age ____________________ OR Year ____________________
   ☐ Do Not Know/Prefer Not to Answer

8.3 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 fecal occult blood test result
   ☐ Other: Specify ____
   ☐ Do Not Know/Prefer Not to Answer

Polyp Removal and Colorectal Surgeries

9. Since the last survey, 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 9.1
   ☐ No Skip to Question 10
   ☐ Do Not Know/Prefer Not to Answer Skip to Question 10

9.1 Since the last survey, have you had any of these polyps removed (usually done during colonoscopy)?
   ☐ Yes Continue to Question 9.2
   ☐ No Skip to Question 10
   ☐ Do Not Know/Prefer Not to Answer Skip to Question 10

9.2 Since the last survey, how many separate occasions have you had polyps removed?
   Number of times polyps were removed ___________________________
   ☐ Do Not Know/Prefer Not to Answer

These next questions ask about the first three procedures since the last survey. If you had more than three procedures we may call for this information.

9.3 Since the last survey, when was the first time you had polyps removed?
   Age ____________________ OR Year ____________________
   ☐ Do Not Know/Prefer Not to Answer
   Doctor ____
   Hospital ____
   City/Town and State ____

9.4 Since the last survey, when was the second time you had polyps removed?
   Age ____________________ OR Year ____________________
   ☐ Do Not Know/Prefer Not to Answer
   Doctor ____
   Hospital ____
   City/Town and State ____

9.5 Since the last survey, when was the third time you had polyps removed?

Age ____________________ OR Year ____________________

☐ Do Not Know/Prefer Not to Answer

Doctor ____

Hospital ____

City/Town and State ____

10. Since the last survey, have you had surgery to remove any of your colon or rectum?

☐ 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 the last survey, when was the first time you had surgery on your colon or rectum?

Age ____________________ OR Year ____________________

☐ Do Not Know/Prefer Not to Answer

Doctor ____

Hospital ____

City/Town and State ____

10.2 How much did you have removed?

☐ Partially

☐ Completely

☐ Do Not Know/Prefer Not to Answer

10.3 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

If you've had more than one surgery on your colon or rectum in the last 5 years, please answer the questions below. Otherwise, skip to Question 11.

10.4 Since the last survey, when was the second time you had surgery on your colon or rectum?

Age ____________________ OR Year ____________________

☐ Do Not Know/Prefer Not to Answer

Doctor ____

Hospital ____

City/Town and State ____

10.5 How much did you have removed?

☐ Partially

☐ Completely

☐ Do Not Know/Prefer Not to Answer

10.6 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

General Health and Medication Information

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

11. In general, compared to others your same age, would you say your health is:
   ☐ Excellent
   ☐ Very Good
   ☐ Good
   ☐ Fair
   ☐ Poor
   ☐ Do Not Know/Prefer Not to Answer

12. How much do you currently weigh?
   ☐ Enter pounds ______________________________ OR Enter kilos ______________________________
   ☐ Do Not Know/Prefer Not to Answer

13. Since the last survey, have you smoked at least one cigarette a day for 3 months or longer?
   ☐ Yes Continue to Question 13.1
   ☐ No Skip to Question 14
   ☐ Do Not Know/Prefer Not to Answer Skip to Question 14

13.1 Do you currently smoke?
   ☐ Yes Skip to Question 14
   ☐ No Continue to Question 13.2
   ☐ Do Not Know/Prefer Not to Answer Continue to Question 13.2

13.2 When did you permanently stop smoking at least one cigarette a day?
   Age _____________________ OR Year _____________________
   ☐ Do Not Know/Prefer Not to Answer

14. Since the last questionnaire, have you had a blood test to look for genes that 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 or something you ordered yourself through the mail. Please do not include if you had a blood test as a part of this research study.
   ☐ Yes Continue to Question 14.1
   ☐ No Skip to Question 15
   ☐ Do Not Know/Prefer Not to Answer Skip to Question 15

14.1 Have you received your gene test result?
   ☐ Yes What was tested and please describe the result of your gene test? ____
   ☐ No
   ☐ Do Not Know/Prefer Not to Answer

14.2 If you had a gene test, results could 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 form. This form will need to be signed and returned to give us permission to collect 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 form which you can sign if you do decide to share your genetic test results.

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 the last questionnaire, have you ever taken aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin, at least 2 days a week for more than a month? This includes low doses used in association with heart conditions.
   ☐ Yes Continue
   ☐ No Skip to Question 16
   ☐ Do Not Know/Prefer Not to Answer Skip to Question 16

15.1 Since the last questionnaire, how often did you take aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin, when you were using it at least 2 days a week for more than a month?
   ☐ Enter times per day __________________________
   AND
   ☐ Enter times per week __________________________
   ☐ Do Not Know/Prefer Not to Answer

15.2 Since the 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 days a week for more than a month?
- ☐ Enter number of months ______________________

OR
- ☐ Enter number of years ______________________
- ☐ Do Not Know/Prefer Not to Answer

16. Since the last survey, 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 the last survey, 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 ______________________

AND
- ☐ Enter times per week ______________________
- ☐ Do Not Know/Prefer Not to Answer

16.2 Since the last survey, 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 ______________________

OR
- ☐ Enter number of years ______________________
- ☐ Do Not Know/Prefer Not to Answer

17. Since the last survey, have you ever taken a special type of NSAID such as Celebrex (generic name celecoxib), 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 Question 18; Men – Skip to Question 19
- ☐ Do Not Know/Prefer Not to Answer Women – Skip to Question 18; Men – Skip to Question 19

17.1 Since the last survey, how often did you take this type of medication [a COX-2 inhibitor such as Celebrex (celecoxib) or Bextra (valdecoxib)] at least 2 times a week for more than a month?
- ☐ Enter times per day ______________________

AND
- ☐ Enter times per week ______________________
- ☐ Do Not Know/Prefer Not to Answer

17.2 Since the last survey, how many months or years in total did you take this type of medication [a COX-2 inhibitor such as Celebrex (celecoxib) or Bextra (valdecoxib)] at least 2 times a week for more than a month?
- ☐ Enter number of months ______________________

OR
- ☐ Enter number of years ______________________
- ☐ Do Not Know/Prefer Not to Answer

Women's Health

This section asks questions that are only applicable to women. If you are male, please skip to Questions 19.

18. Since the last survey, 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 the last survey, when was the first time you had surgery on your uterus or ovary?

Age ________________ OR Year ________________
- ☐ Do Not Know/Prefer Not to Answer

18.2 What type of surgery did you have the first time?
- ☐ Hysterectomy with 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 Question 19.

18.3 Since the last survey, when was the second time you had surgery on your uterus or ovary?

Age ____________ OR Year ____________
- ☐ Do Not Know/Prefer Not to Answer

18.4 What type of surgery did you have the second time?
- ☐ Hysterectomy with 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

Cancer History

19. Since the last survey, have you 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

Cancer 1:

19.1 What type of cancer was it? ____________________
- ☐ Do Not Know/Prefer Not to Answer

19.2 Is this cancer diagnosis a...
- ☐ new cancer diagnosis
- ☐ recurrence or spread (metastases) of a cancer that was diagnosed earlier
- ☐ don’t know

Doctor ____________________

Hospital ____________________

City/Town and State ____________________

19.3 When were you diagnosed with this cancer?

Age ____________ OR Year ____________
- ☐ Do Not Know/Prefer Not to Answer

19.4 Did you have radiation treatment for this cancer?
- ☐ Yes Continue to Question 19.4
- ☐ No Skip to Question 19.5
- ☐ Do Not Know/Prefer Not to Answer Skip to Question 19.5

19.5 When did you start radiation treatment?

Age ____________ OR Year ____________
- ☐ Do Not Know/Prefer Not to Answer

19.6 Did you have chemotherapy treatment for this cancer?
- ☐ Yes Continue to Question 19.7
- ☐ No Skip to Question 19.8
- ☐ Do Not Know/Prefer Not to Answer Skip to Question 19.8

19.7 When did you start chemotherapy treatment?

Age ____________ OR Year ____________
- ☐ Do Not Know/Prefer Not to Answer

Colon Cancer Family Registry Questions

(continued)

Since the last interview, have you been diagnosed with a second 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 Question 20.

Cancer 2:

19.8 What type of cancer was it? ____________________

☐ Do Not Know/Prefer Not to Answer

19.9 When were you diagnosed with this cancer?

Age ____________ OR Year ____________

☐ Do Not Know/Prefer Not to Answer

Doctor ____________________

Hospital ____________________

City/Town and State ____________________

19.10 Did you have radiation treatment for this cancer?

☐ Yes Continue to Question 19.11

☐ No Skip to Question 19.12

☐ Do Not Know/Prefer Not to Answer Skip to Question 19.12

19.11 When did you start radiation treatment?

Age ____________ OR Year ____________

☐ Do Not Know/Prefer Not to Answer

19.12 Did you have chemotherapy treatment for this cancer?

☐ Yes Continue to Question 19.13

☐ No Skip to Question 20

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

19.13 When did you start chemotherapy treatment?

Age ____________ OR Year ____________

☐ Do Not Know/Prefer Not to Answer

Family History

20. In the past we have collected detailed family history. In the last 5 years, have any of your blood relatives had a diagnosis of any type of cancer, including leukemia, lymphoma or any other malignant tumor?

☐ 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 mother's or father's side)	Type of Cancer	Age at Diagnosis	Year at Diagnosis

21. In the last 5 years, have any of your blood relatives passed away?
- ☐ 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 mother's or father's side)	Sex (M/F)	Year of Death	Age at Death	Cause of Death	Place of Death (City, State)

Alternate Contact

22. In case we 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 22.1
- ☐ No Skip to Question 23
- ☐ Do Not Know/Prefer Not to Answer Skip to Question 23

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

Full Name ______________________________

Relationship ______________________________

22.2

Street Address	
City	
State	Country (if not USA)
Zip Code	
Phone Number	☐ Home ☐ Cell ☐ Work
Phone Number	☐ Home ☐ Cell ☐ Work

23. Thoughts? We would love to hear anything you would like to share with us about our study, such as 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 (866) 514-8452
Email: coloncfr@mayo.edu
Visit Us Online: https://www.mayo.edu/research/centers-programs/colon-cancer-family-registry