

COLON CANCER FAMILY REGISTRY QUESTIONS

4. **Since the last questionnaire 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

No → Skip to Question 5

Do not know or prefer not to answer → Skip to Question 5

a. **Since the last questionnaire, how many separate occasions have you had a sigmoidoscopy?** _____times

b. **How old were you when you had your most recent sigmoidoscopy?**
_____ years of age **OR** in the year _____ (for example, 2008)

c. **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 (FOBT) result

Other (specify) _____

Do not know or prefer not to answer

5. **Since the last questionnaire, 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. Preparation involves drinking fluids or taking pills to cleanse the bowel.

Yes

No → Skip to Question 6

Do not know or prefer not to answer → Skip to Question 6

a. **Since the last questionnaire, how many separate occasions have you had a colonoscopy?** _____times

b. **How old were you when you had your most recent colonoscopy?**
_____ years of age **OR** in the year _____ (for example, 2008)

c. **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 (FOBT) result

Other (specify) _____

Do not know or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

6. **Since the last questionnaire, 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 slides 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 or make you sleep. This procedure may also be referred to as a Virtual Colonoscopy.

Yes

No → Skip to Question 7

Do not know or prefer not to answer → Skip to Question 7

a. **Since the last questionnaire, how many separate occasions have you had a CT Colonograph or Virtual Colonoscopy?** _____ times

b. **How old were you when you had your most recent CT Colonograph or Virtual Colonoscopy?**

_____ years of age **OR** in the year _____ (for example, 2008)

c. **What were the reasons for the most recent CT Colonograph or 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 FECAL OCCULT BLOOD TEST (FOBT) result

Other (specify) _____

Do not know or prefer not to answer

7. **Since the last questionnaire, 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

No → Skip to Question 8

Do not know or prefer not to answer → Skip to Question 8

a. **Since the last questionnaire, how many separate occasions have you had a barium enema?** _____ times

b. **How old were you when you had your most recent barium enema?**

_____ years of age **OR** in the year _____ (for example, 2008)

c. **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 FECAL OCCULT BLOOD TEST (FOBT) result

Other (specify) _____

Do not know or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

8. **Since the last questionnaire, 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

No → Skip to Question 9

Do not know or prefer not to answer → Skip to Question 9

a. **Since the last questionnaire, have you had any of these polyps removed (usually done during colonoscopy)?**

Yes

No

Do not know or prefer not to answer

b. **Since the last questionnaire, how many separate occasions have you had polyps removed? _____ times**

These questions ask about the first three procedures since the last questionnaire. If you had more procedures, we may need to call you.

i. **Since the last questionnaire, how old were you the first time you had polyps removed?**

_____ years of age **OR** in the year _____ (for example, 2008)

Do not know or prefer not to answer

Where did you have this procedure performed or what is the name of the doctor who has a copy of this result?

Doctor _____

Hospital/Medical Centre _____

City/Town _____ State _____

ii. **Since the last questionnaire how old were you the second time you had polyps removed?**

_____ years of age **OR** in the year _____ (for example, 2008)

Do not know or prefer not to answer

Where did you have this procedure performed or what is the name of the doctor who has a copy of this result?

Doctor _____

Hospital/Medical Centre _____

City/Town _____ State _____

iii. **Since the last questionnaire how old were you the third time you had polyps removed?**

_____ years of age **OR** in the year _____ (for example, 2008)

Do not know or prefer not to answer

Where did you have this procedure performed or what is the name of the doctor who has a copy of this result?

Doctor _____

Hospital/Medical Centre _____

City/Town _____ State _____

COLON CANCER FAMILY REGISTRY QUESTIONS

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

Yes

No → Skip to Question 10 for women, Question 11 for men

Do not know or prefer not to answer → Skip to Question 10 for women, Question 11 for men

a. **If yes, how old were you the first time you had surgery on your colon or rectum?**

_____ years of age **OR** in the year_____ (for example, 2008)

Do not know or prefer not to answer

b. **How much did you have removed?**

Partially

Completely

Do not know or prefer not to answer

c. **What was the reason for this first surgery?**

Benign or malignant tumor (including polyp)

Diverticulitis

Inflammatory bowel disease, such as ulcerative colitis or Crohn's disease

Other, specify_____

Do not know or prefer not to answer

Answer below if more than one surgery on your colon or rectum

i. **Since the last questionnaire, how old were you the second time you had surgery on your colon or rectum?**

_____ years of age **OR** in the year_____ (for example, 2008)

Do not know or prefer not to answer

ii. **How much did you have removed?**

Partially

Completely

Do not know or prefer not to answer

iii. **What was the reason for the second surgery?**

Benign or malignant tumor (including polyp)

Diverticulitis

Inflammatory bowel disease, such as ulcerative colitis or Crohn's disease

Other, specify_____

Do not know or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

FEMALES

10. Since the last questionnaire, have you had any surgery on your ovaries and/or uterus?

Yes

No → Skip to Question 11

Do not know or prefer not to answer → Skip to Question 11

a. If yes, how old were you the **first** time you had surgery on your uterus or ovary?

_____ years of age **OR** in the year_____ (for example, 2008)

Do not know or prefer not to answer

b. 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 or prefer not to answer

Answer below if more than one surgery on your uterus or ovary

i. Since the last questionnaire, how old were you the **second** time you had surgery on your uterus or ovary?

_____ years of age **OR** in the year_____ (for example, 2008)

Do not know or prefer not to answer

ii. What type of surgery did you have the second 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 or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

11. Since the last questionnaire, have you had a diagnosis of any type of cancer, including leukemia, lymphoma or any other malignant tumor?

- Yes
 No → Skip to Question 12
 Do not know or prefer not to answer → Skip to Question 12

Cancer 1

- a. What type of cancer was it? _____ type or site
- b. How old were you when this cancer was diagnosed?
_____ years of age **OR** in the year _____ (for example, 2008)
 Do not know or prefer not to answer
- c. Is this cancer diagnosis a:
- New cancer
 Spread of another cancer (metastatic)
 Recurrence of a previously diagnosed cancer
 Do not know or prefer not to answer
- d. Did you have radiation treatment for this cancer?
- Yes → _____ years of age **OR** in the year _____ (for example, 2008)
 No
 Do not know or prefer not to answer
- e. Did you have chemotherapy for this cancer?
- Yes → _____ years of age **OR** in the year _____ (for example, 2008)
 No
 Do not know or prefer not to answer

Answer below if more than one cancer diagnosed since your last interview

Cancer 2

- a. How old were you when this cancer was diagnosed?
_____ years of age **OR** in the year _____ (for example, 2008)
 Do not know or prefer not to answer
- b. What type of cancer was it? _____ type or site
- c. Is this cancer diagnosis a:
- New cancer
 Spread of another cancer (metastatic)
 Recurrence of a previously diagnosed cancer
 Do not know or prefer not to answer
- d. Did you have radiation treatment for this cancer?
- Yes → _____ years of age **OR** in the year _____ (for example, 2008)
 No
 Do not know or prefer not to answer
- e. Did you have chemotherapy for this cancer?
- Yes → _____ years of age **OR** in the year _____ (for example, 2008)
 No
 Do not know or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

Family History Update: NOTE: We are updating family history in the Mayo Colon Cancer Registry by means of a telephone call, as we have always done, from at least one member of your family so this information from you helps us know if we are collecting adequate information or if we might need to call to clarify. Some of your relatives may be part of this study and some are not. We are interested in hearing about all.

12. **Since the last questionnaire, have any of your blood relatives developed any cancer including leukemia, lymphoma or any other malignant tumor?** Please fill in these new diagnoses 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

13. **Since the last questionnaire, have any of your blood relatives died?** Please fill in these new deaths in 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)

COLON CANCER FAMILY REGISTRY QUESTIONS

14. **Since the last questionnaire, have you had a blood test to look for genes that may cause one to get colorectal/bowel 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

No → Skip to Question 15

Do not know or prefer not to answer → Skip to Question 15

a. **Have you received your gene test result?**

Yes → **What was tested and please describe the result of your gene test?** _____

No

Do not know or prefer not to answer

b. **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.

Medications: 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 acetaminophen.

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 to Letter a. (below)

No → Skip to Question 16

Do not know or prefer not to answer → Skip to Question 16

a. **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 days per week: _____

Do not know or prefer not to answer

b. **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 or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

16. Since the last questionnaire, 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 days a week for more than a month?

- Yes → Continue to Letter a. (below)
 No → Skip to Question 17
 Do not know or prefer not to answer → Skip to Question 17

a. Since the 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 days a week for more than a month?

- Enter times per day: _____ AND enter days per week: _____
 Do not know or prefer not to answer

b. Since the last questionnaire, how many months or years in total did you take this type of medication (ibuprofen, Advil, Aleve, Motrin, Nuprin, Medipren), at least 2 days a week for more than a month?

- Enter number of months: _____

OR

- Enter number of years: _____
 Do not know or prefer not to answer

17. Since the last questionnaire, 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 days a week for more than a month?

- Yes → Continue to Letter a. (below)
 No → Skip to Question 18
 Do not know or prefer not to answer → Skip to Question 18

a. Since the last questionnaire, 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 days a week for more than a month?

- Enter times per day: _____ AND enter days per week: _____
 Do not know or prefer not to answer

b. Since the 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 valdecoxib), at least 2 days a week for more than a month?

- Enter number of months: _____

OR

- Enter number of years: _____
 Do not know or prefer not to answer

COLON CANCER FAMILY REGISTRY QUESTIONS

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

- Yes → Continue to Letter a. (below)
- No → Skip to Question 19
- Do not know or prefer not to answer → Skip to Question 19

a. Do you currently smoke?

- Yes → Skip to Question 19
- No → Continue to Letter b. (below)
- Do not know or prefer not to answer → Continue to Letter b. (below)

b. When did you stop or quit smoking?

- Age: _____ **OR** Year: _____ **OR** Number of years since: _____
- Do not know or prefer not to answer

19. How much do you currently weigh?

- Enter pounds: ___ ___ **OR** Enter kilos: ___ ___
- Do not know or prefer not to answer

Thank you very much for sharing this information with the Mayo Colon Cancer Family Registry.

COLON CANCER FAMILY REGISTRY QUESTIONS

Contact Information: PLEASE provide *if* your address or phone number has changed.

Street or Mailing Address: _____

City: _____

State or Province: _____

Zip or Postal Code: _____

Country: _____

Primary phone: _____

Cell phone: _____

EMAILS: Currently, when we need to contact you about some aspect of your participation in the registry, we mail you a letter and then follow up with phone calls. We now have the option of communicating with our participants via email. We may still call or send you a letter or newsletter on occasion, but if you prefer that we try contacting you by email first, please let us know by providing your email address/addressess below.

Primary email: _____

Secondary email: _____

Alternate Contact: In case we need to contact you in the future and you have moved, could we have the name of someone who is not living with you to whom we might write or call for your new address?

Name: _____

Relationship: _____

Street or Mailing Address: _____

City: _____

State or Province: _____

Zip or Postal Code: _____

Country: _____

Phone: _____

Email: _____