University of California
San Francisco

Colon Cancer Family Registry Cohort Study

Follow-Up Questionnaire

Research with Families Today...
To Help Future Generations

FOR OFFICE USE ONLY:

[ID LABEL]

ID: __ __ __ __ — __ __ __ **Received:** __ __ - __ __ - __ __ __ __

Coded: __ __ - __ __ - __ __ __ __

Data Entered: __ __ - __ __ - __ __ __ __

University of California, San Francisco
Department of Epidemiology and Biostatistics
Colon Cancer Family Registry
Phase V

HOW TO COMPLETE THE QUESTIONNAIRE:

This follow-up questionnaire asks how your health has been since the date that you completed your last questionnaire. Although we understand that some questions may take some time to answer, it is important for us to have complete information so that we can better understand how to prevent colorectal cancer.

- Read each question and the directions carefully.
- Please use a pencil to record your answers.
- When checking boxes, be sure to put your check mark in the correct box. ☑
- Erase cleanly any answer you wish to change.
- Answer each question unless instructed to skip or go to another question. Pay close attention to the written directions and arrows that direct you to the next appropriate question.
- If you have any questions, please feel free to contact us at (415) 866--3006
- After you have completed the questionnaire, please return it to us in the postage-paid envelope provided. Our address is:

University of California, San Francisco
Department of Epidemiology and Biostatistics
ATTN: Colon Cancer Family Registry
550 16th Street, MH-2841
San Francisco, CA 94158

A: PARTICIPANT INFORMATION

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

   Month __ __ Day __ _ Year __ __ __ __

2. **How much do you currently weight?**

   __ __ __ lbs

   or

   __ __ __ kilos

Most of the questions we will be asking you in this follow-up questionnaire are about the time period since the date of your last questionnaire. Please refer to the following date when answering the questions.

You completed your <u>Last Questionnaire</u> on:

Month __ __ Day __ _ Year __ __ __ __

Today's date:

Month __ __ Day __ _ Year __ __ __ __

B: MEDICAL SCREENING HISTORY

These questions ask about medical tests that you might have had since the date you completed your last questionnaire. *(Check the correct answer in the left column. If yes, also answer the questions in all columns to the right).*

Since your last questionnaire, have you had any of the following medical tests?	**How many separate tests have you had?**	**When did you have the most recent test?**	**What were the reasons for the most recent test? *(check all that apply)***
3. Fecal Occult Blood Test (FOBT) (or hemoccult or fecal immunochemical test(FIT) or stool smear test) Usually done at home as part of a routine exam, the test requires stool smears on cards to detect blood in your stool. 1. ❑ Yes → 2. ❑ No ↴	___ ___ Total number of tests since last questionnaire	Years of age: ___ ___ **OR** Year: ___ ___ ___ ___	1. ❑ To investigate a new problem 2. ❑ Family history of colorectal cancer 3. ❑ Routine exam or check-up 4. ❑ Follow-up of a previous problem 5. ❑ Follow-up of FOBT result 6. ❑ Other (please specify) _____ 9. ❑ Don't know
4. DNA-based whole stool test (like Cologuard)? Used to detect altered DNA and/or blood in the stool 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. 1. ❑ Yes → 2. ❑ No (go to next page)	___ ___ Total number of tests since last questionnaire	Years of age: ___ ___ **OR** Year: ___ ___ ___ ___	1. ❑ To investigate a new problem 2. ❑ Family history of colorectal cancer 3. ❑ Routine exam or check-up 4. ❑ Follow-up of a previous problem 5. ❑ Follow-up of FOBT result 6. ❑ Other (please specify) _____ 9. ❑ Don't know

These questions ask about medical tests that you might have had since the date you completed your last questionnaire. *(Check the correct answer in the left column. If yes, also answer the questions in all columns to the right).*

Since your last questionnaire, have you had any of the following medical tests?	**Since your last questionnaire, how many separate tests have you had?**	**When did you have the most recent test?**	**What were the reasons for the most recent test? *(check all that apply)***
5. Sigmoidoscopy Procedure to look inside the lower bowel with a lighted tube, usually without anesthesia. Medications to empty the bowel are given beforehand. 1. ❑ Yes → 2. ❑ No ↴	___ ___ Total number of tests since last questionnaire	Years of age ___ ___ **OR** Year ___ ___ ___ ___	1. ❑ To investigate a new problem 2. ❑ Family history of colorectal cancer 3. ❑ Routine exam or check-up 4. ❑ Follow-up of a previous problem 5. ❑ Follow-up of FOBT result 6. ❑ Other (please specify) _____ 9. ❑ Don't know
6. Colonoscopy Procedure to look inside the entire bowel with a lighted tube. A medication is usually given in a vein to help relax you or make you sleepy. Medicines to empty the bowel are also given beforehand. 1. ❑ Yes → 2. ❑ No (go to next page)	_____ Total number of tests since last questionnaire	Years of age ___ ___ **OR** Year ___ ___ ___ ___	1. ❑ To investigate a new problem 2. ❑ Family history of colorectal cancer 3. ❑ Routine exam or check-up 4. ❑ Follow-up of a previous problem 5. ❑ Follow-up of FOBT result 6. ❑ Other (please specify) _____ 9. ❑ Don't know

C: POLYP REMOVAL

7. <u>Since the date of your last questionnaire</u>, has a doctor told you that you had <u>polyps</u> in your large bowel or colon or rectum*?* *Be sure to include all polyps that were found in any of the procedures you have had since your last questionnaire – not just polyps that may have been found during your most recent procedure*.

1. ❑ Yes (go to question 8)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

8. <u>Since the date of your last questionnaire</u>, have you had any polyps removed?

1. ❑ Yes (go to question 9)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

9. <u>Since the date of your last questionnaire</u>, on how many separate occasions have you had polyps removed?

___ ___ Number of separate occasions you had polyps removed since the date of your last questionnaire (go to question 10)

Please answer the questions below for each occasion that you had polyps removed.

10. First polyp removal	**11. Second polyp removal**
Since the date of your last questionnaire, when did you **first** have polyps removed? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___	When did you **next** have polyps removed? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___
12. Third polyp removal	**13. Fourth polyp removal**
When did you **next** have polyps removed? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___	When did you **next** have polyps removed? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___

D: COLORECTAL SURGERIES

14. **<u>Since the date of your last questionnaire</u>, have you had surgery to remove any part of your colon or rectum?** *Please do not include any surgeries where only polyp(s) were removed.*

1. ❑ Yes (go to question 15)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

15. <u>Since the date of your last questionnaire</u>, how many surgeries on your colon or rectum have you had?

___ ___ Number of surgeries since last questionnaire (go to question 16)

(Please respond to the questions in the column for each surgery)

16. First Surgery Since date of last questionnaire	**17. Second Surgery** Since date of last questionnaire	**18. Third Surgery** Since date of last questionnaire
When did you **first** have this surgery? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___	When did you **next** have this surgery? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___	When did you **next** have this surgery? Years of age: ___ ___ **OR** Year: ___ ___ ___ ___
How much colon or rectum did you have removed? 1. ❑ Completely removed 2. ❑ Partially removed 9. ❑ Don't know	How much colon or rectum did you have removed? 1. ❑ Completely removed 2. ❑ Partially removed 9. ❑ Don't know	How much colon or rectum did you have removed? 1. ❑ Completely removed 2. ❑ Partially removed 9. ❑ Don't know
What was the reason for this surgery? (Check all that apply) 1. ❑ Benign or malignant tumor 2. ❑ Diverticular Disease 4. ❑ Inflammatory Bowel Disease, including Ulcerative Colitis and Crohn's Disease 6. ❑ Other: (specify) _____ 9. ❑ Don't know	What was the reason for this surgery? (Check all that apply) 1. ❑ Benign or malignant tumor 2. ❑ Diverticular Disease 4. ❑ Inflammatory Bowel Disease, including Ulcerative Colitis and Crohn's Disease 6. ❑ Other: (specify) _____ 9. ❑ Don't know	What was the reason for this surgery? (Check all that apply) 1. ❑ Benign or malignant tumor 2. ❑ Diverticular Disease 4. ❑ Inflammatory Bowel Disease, including Ulcerative Colitis and Crohn's Disease 6. ❑ Other: (specify) _____ 9. ❑ Don't know

E: CANCER HISTORY

19. <u>Since the date that you completed your last questionnaire</u>, has any doctor told you that you had any type of cancer, such as leukemia, lymphoma or malignant tumor?

1. ❑ Yes (go to question 20)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

20. <u>Since your last questionnaire</u>, how many cancer diagnoses have you had?

___ ___ Number of cancer diagnoses since last questionnaire (go to question 21)

Please answer questions below for each cancer diagnosis you have had since your last questionnaire.

21. First Cancer	22. Second Cancer	23. Third Cancer
What type of cancer was it? _____ ( )	What type of cancer was it? _____ ( )	What type of cancer was it? _____ ( )
When did your doctor **first** tell you that you had this type of cancer? Years of age: ___ ___ **OR** Year: __ __ __ __	When did your doctor **first** tell you that you had this type of cancer? Years of age: ___ ___ **OR** Year: __ __ __ __	When did your doctor **first** tell you that you had this type of cancer? Years of age: ___ ___ **OR** Year: __ __ __ __
Is this cancer diagnosis a… 1. ❑ New cancer 2. ❑ Recurrence or spread (metastases) of a prior cancer 9. ❑ Don't know	Is this cancer diagnosis a… 1. ❑ New cancer 2. ❑ Recurrence or spread (metastases) of a prior cancer 9. ❑ Don't know	Is this cancer diagnosis a… 1. ❑ New cancer 2. ❑ Recurrence or spread (metastases) of a prior cancer 9. ❑ Don't know
Did you receive radiation or chemotherapy for this cancer? 1. ❑ Yes, chemotherapy 2. ❑ Yes, radiation 3. ❑ Yes, both 4. ❑ No, neither 9. ❑ Don't know	Did you receive radiation or chemotherapy for this cancer? 1. ❑ Yes, chemotherapy 2. ❑ Yes, radiation 3. ❑ Yes, both 4. ❑ No, neither 9. ❑ Don't know	Did you receive radiation or chemotherapy for this cancer? 1. ❑ Yes, chemotherapy 2. ❑ Yes, radiation 3. ❑ Yes, both 4. ❑ No, neither 9. ❑ Don't know

F: WOMEN'S HEALTH

Men, skip to next page →

24. Since completing your last questionnaire, have you had surgery on your ovaries and/or uterus (womb)?

1. ❑ Yes (go to question 25)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

Answer the questions below for each gynecological surgery that you've had since completing your last questionnaire.

25. First Surgery	26. Second Surgery	27. Third Surgery
Since your last questionnaire, when did you **first** have this surgery? Years of age: ___ ___ **OR** Year: __ __ __ __	Since your last questionnaire, when did you **next** have this surgery? Years of age: ___ ___ **OR** Year: __ __ __ __	Since your last questionnaire, when did you **next** have this surgery? Years of age: ___ ___ **OR** Year: __ __ __ __
Which female organs were removed during this surgery? (Check all that apply) 1. ❑ Hysterectomy along with one ovary or partial ovary 2. ❑ Hysterectomy along with both ovaries 3. ❑ Hysterectomy only (only uterus or womb removed) 4. ❑ One ovary was removed, in whole or part, without hysterectomy 5. ❑ Both ovaries were removed, without hysterectomy 6. ❑ Other (specify) _____ 9. ❑ Don't know	Which female organs were removed during this surgery? (Check all that apply) 1. ❑ Hysterectomy along with one ovary or partial ovary 2. ❑ Hysterectomy along with both ovaries 3. ❑ Hysterectomy only (only uterus or womb removed) 4. ❑ One ovary was removed, in whole or part, without hysterectomy 5. ❑ Both ovaries were removed, without hysterectomy 6. ❑ Other (specify) _____ 9. ❑ Don't know	Which female organs were removed during this surgery? (Check all that apply) 1. ❑ Hysterectomy along with one ovary or partial ovary 2. ❑ Hysterectomy along with both ovaries 3. ❑ Hysterectomy only (only uterus or womb removed) 4. ❑ One ovary was removed, in whole or part, without hysterectomy 5. ❑ Both ovaries were removed, without hysterectomy 6. ❑ Other (specify) _____ 9. ❑ Don't know

G: MEDICATION

These questions ask about medications that you may have taken since completing your last questionnaire. *(Check the correct answer in the left column. If yes, also answer the questions in all columns to the right).*

Since you completed your last questionnaire, have you ever taken the following medications at least 2 times a week for more than a month?	**When taking this medication, how often did you take it?**	**Since you completed your last questionnaire, how many months or years in total did you take this medication at least twice a week for more than a month?**
28. Aspirin (such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin) 1. ❑ Yes → 2. ❑ No (go to question 29)	_____ Times per day **OR** ___ ___ ___ Times per week	___ ___ Total months taken **OR** ___ Total years taken
29. Non-steroidal anti-inflammatory drugs (NSAIDS) (such as ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren. Do not include acetaminophen products such as Tylenol) 1. ❑ Yes → 2. ❑ No (go to question 30)	_____ Times per day **OR** ___ ___ ___ Times per week	___ ___ Total months taken **OR** ___ Total years taken
30. COX-2 Inhibitor medications (such as Celebrex, celecoxib, Vioxx, rofecoxib, Bextra, or valdecoxib) 1. ❑ Yes → 2. ❑ No (go to next page)	_____ Times per day **OR** ___ ___ ___ Times per week	___ ___ Total months taken **OR** ___ Total years taken

H: CIGARETTES

31. <u>Since completing your last questionnaire</u>, have you smoked at least one <u>cigarette</u> a day for 3 months or longer?

1 ☐ Yes (go to question 32) →

2 ☐ No (skip to next page)

32. Do you currently smoke cigarettes?

1 ☐ yes (skip to next page)

2 ☐ no (go to questions 33)

33. *(IF NO)* When did you permanently stop smoking at least one cigarette a day?

Age when stopped: __ __ _

OR

Year when stopped: __ __ __ __

I: YOUR HEALTH

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

1. ❑ Excellent
2. ❑ Very Good
3. ❑ Good
4. ❑ Fair
5. ❑ Poor
9. ❑ Don't know

J: NEW ADULTS

Since your last questionnaire, have there been any brothers, sisters or children that have turned 18 or older?

- ❑ Yes (go to questions below)
- ❑ No (skip to next page)

Relationship to you?	Full name?	Birth date?	May we contact them?	If yes…contact information?
_____ Relationship	_____ First _____ Middle _____ Last	____/____/_____ Date of birth OR _____ Current age	❑ Yes → ❑ No (go to next row)	_____ (Street Address) _____ (City) (State) (Zip Code) _____ (Telephone Number)
Relationship to you?	**Full name?**	**Birth date?**	**May we contact them?**	**If yes…contact information?**
_____ Relationship	_____ First _____ Middle _____ Last	____/____/_____ Date of birth OR _____ Current age	❑ Yes → ❑ No (go to next row)	_____ (Street Address) _____ (City) (State) (Zip Code) _____ (Telephone Number)

K: Family History

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

- any cancer diagnosis in your immediate and extended family
- any deaths in your immediate family

Full Name	**Relationship to You**	**Birth Date**	**Living? Y or N**	**Death Date/Age**	**Ever Had Cancer?**	**Type of Cancer?**	**Age/Year at Diagnoses ?**	**Location of Diagnoses** (State)
Sample: *John Doe*	*Cousin, father's brother's son*	*1/1/1901*	*N*	*1/1/2001 at 100*	*Y*	*Lung Prostate*	*89/1990 99/2000*	*Hawaii California*

L: GENETIC TESTING

35. <u>Since you completed your last questionnaire</u>, have you participated in any genetic or family-based cancer studies, other than this study, or had a blood test to look for genes for colorectal cancer as part of your health care?

1. ❑ Yes (go to question 36)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

36. Have you received your gene test result?

1. ❑ Yes (go to question 37)
2. ❑ No (skip to next page)
9. ❑ Don't know (skip to next page)

37. What was the result of your gene test?

Please describe:_____

_____

M: Contact Information

39. What is your current contact information?

Phone number: (Cell/Home/Work)___(_____)_____-_____

Phone number: (Cell/Home/Work)___(_____)_____-_____

Street Address: _____

City, State and Zip Code**:** _____

Country (if not USA): _____

E-mail address: _____

40. In case we need to contact you in the future, and your contact information has changed, could we have the name of <u>someone who is not living with you</u> who we might contact for your new address?

First name, Last name: _____

Relationship to you: _____

Street Address: _____

City, State and Zip Code**:** _____

Country (if not USA): _____

Phone number: (Cell/Home/Work)___(_____)_____-_____

Phone number: (Cell/Home/Work)___(_____)_____-_____

E-mail address: _____

Please check that all pages are complete. Mail the questionnaire in the postage-paid envelope provided.

We thank you again for taking the time to update your health information. No one else can take your place in this research effort.

Sincerely,

UCSF Colon Family Registry Staff

ID:_____-- __ __ __