## A: PARTICIPANT INFORMATION

1. What is your age today?

\_\_\_\_ Years of age

2. What is the date of your birth?

Month: \_\_\_\_ Day: \_\_\_ Year: \_\_\_\_

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

You completed your First Questionnaire on:

Month: \_\_\_\_ Day: \_\_\_ Year: \_\_\_\_

## **B: MEDICAL HISTORY**

These questions ask about medical tests that you might have had <u>since the date</u> <u>that you completed your first questionnaire</u>. <u>Check</u> the correct answer in the first column, and <u>IF YES</u>, also answer the questions in <u>all</u> three columns to the right.

Since your first questionnaire, have you had any of the following medical tests?	Since your first questionnaire, how many separate tests have you had?	When did you have the <u>most</u> <u>recent</u> test?	What were the reasons for the <u>most recent</u> test? (check <u>all</u> that apply)
<ol> <li>Fecal Occult Blood Test         <ul> <li>(or hemocult or smear test) Done as part of a routine exam, the test uses cards to detect blood in your stool.</li> <li>1.</li></ul></li></ol>	Total number of tests since first questionnaire	Years of age:  OR Year: 	<ol> <li>1. (a) To investigate a new problem</li> <li>2. (a) Family history of colorectal cancer</li> <li>3. (a) Routine exam or check-up</li> <li>4. (a) Follow-up of a previous problem</li> <li>5. (a) Other (please specify)</li> <li>9. (a) Don't know</li> </ol>
<ul> <li>2. Sigmoidoscopy Procedure to look inside the lower bowel with a lighted tube, usually without anesthesia. Medications to empty the bowel are given beforehand. </li> <li>1.  ⑧ Yes </li> <li>2.   ⑧ No</li></ul>	Total number of tests since first questionnaire	Years of age:  OR Year: 	<ol> <li>8 To investigate a new problem</li> <li>8 Family history of colorectal cancer</li> <li>8 Routine exam or check-up</li> <li>8 Follow-up of a previous problem</li> <li>8 Other (please specify)</li> <li>8 Don't know</li> </ol>
<ul> <li>3. Colonoscopy</li> <li>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.</li> <li>1.      Yes     No   </li> </ul>	Total number of tests since first questionnaire	Years of age:  OR Year: 	<ol> <li>1. (a) To investigate a new problem</li> <li>2. (a) Family history of colorectal cancer</li> <li>3. (a) Routine exam or check-up</li> <li>4. (a) Follow-up of a previous problem</li> <li>5. (a) Other (please specify)</li> <li>9. (a) Don't know</li> </ol>

Have you <u>ever</u> (at any point in your life) had this medical test?	If yes, please answer the questions below:
<ul> <li><b>4. Barium enema</b></li> <li>An X-ray exam of the large bowel. An enema containing a barium solution is used to outline the inside of the colon and rectum.</li> <li>1.      <ul> <li>Yes</li> </ul> </li> </ul>	How many separate tests have you <u>ever</u> had?  Total number of tests
2. <sup>®</sup> No	When did you have the <u>first</u> barium enema? Years of age: OR Year: Year: What were the reasons for this <u>first</u> test? (check <u>all</u> that apply) 1. (8) To investigate a new problem 2. (8) Family history of colorectal cancer 3. (8) Routine exam or check-up 4. (8) Follow-up of a previous problem 5. (8) Other (please specify) 9. (8) Don't know

When did you have the <u>most recent</u> barium enema?
Years of age:
OR
Year:
What were the reasons for this most recent test? <i>(check <u>all</u> that apply)</i>
<ol> <li>1. (1) To investigate a new problem</li> <li>2. (2) Family history of colorectal cancer</li> <li>3. (3) Routine exam or check-up</li> <li>4. (3) Follow-up of a previous problem</li> <li>5. (3) Other (please specify)</li> </ol>
9. ® Don't know

#### Have you ever (at any point in your life) had this medical test?

#### 5. Virtual Colonoscopy

A CT scan which creates an image of the colon. Medications to empty the bowel are given beforehand. A new procedure, not widely available.

- 1. **8** Yes
- 2. ⑧ No

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

	1.   Yes (go to question 2.   No (go to question) 1.   No (go to question)		
7.	Since the date of your first questionnaire, have you had any polyps removed?	removed since d to question 9)	
		8. First polyp removal	9. Second polyp removal
		Since the date of your first questionnaire, when did you first have polyps removed?	When did you <b>next</b> have polyps removed?
		Years of age:	Years of age:
		OR	OR
		Year:	Year:
		11. Third polyp removal	12. Fourth polyp removal
		When did you <b>next</b> have polyps removed?	When did you <b>next</b> have polyps removed?
		Years of age:	Years of age:
		OR	OR
		Year:	Year: 

# 13. <u>Since the date of your first questionnaire</u>, have you had surgery to remove any part of your colon or rectum?

- 1. <sup>®</sup> Yes (go to question 14)
  - 2. 
     No (go to question 19 on the next page)

## 14. <u>Since the date of your first questionnaire</u>, how many surgeries on your colon or large bowel have you had?

\_\_\_\_ Number of surgeries since first questionnaire (go to question 15)

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

15. First Surgery	16. Second Surgery	17. Third Surgery	18. Fourth Surgery	
Since date of first questionnaire	Since date of first questionnaire	Since date of first questionnaire	Since date of first questionnaire	
When did you <b>first</b> have this surgery?	When did you <b>next</b> have this surgery?	When did you <b>next</b> have this surgery?	When did you <b>next</b> have this surgery?	
Years of age:	Years of age:	Years of age:	Years of age:	
OR	OR	OR	OR	
Year:	Year:	Year:	Year:	
During this surgery, was your colon or rectum completely or partially removed? 1. <sup>®</sup> Completely removed 2. <sup>®</sup> Partially removed 9. <sup>®</sup> Don't know	<ul> <li>was your colon or ctum completely or partially removed?</li> <li>© Completely noved</li> <li>© Partially removed</li> <li>© Mathematical Structure</li> <li>© Completely removed</li> <li>© Completely noved</li> </ul>		During this surgery, was your colon or rectum completely or partially removed? 1.	
What was the reason for this surgery? (Check all that apply)	for this surgery? for this surgery?		What was the reason for this surgery? (Check all that apply)	
<ol> <li>1. (a) Cancer</li> <li>2. (a) Diverticulitis</li> <li>3. (a) Ulcerative colitis</li> <li>4. (a) Inflammatory bowel disease (IBS)</li> <li>5. (a) Crohn's disease</li> <li>6. (a) Other: (specify)</li> <li>9. (a) Don't know</li> </ol>	<ol> <li>1. (a) Cancer</li> <li>2. (a) Diverticulitis</li> <li>3. (a) Ulcerative colitis</li> <li>4. (a) Inflammatory bowel disease (IBS)</li> <li>5. (a) Crohn's disease</li> <li>6. (a) Other: (specify)</li> <li>9. (a) Don't know</li> </ol>	<ol> <li>1. (a) Cancer</li> <li>2. (a) Diverticulitis</li> <li>3. (a) Ulcerative colitis</li> <li>4. (a) Inflammatory bowel disease (IBS)</li> <li>5. (a) Crohn's disease</li> <li>6. (a) Other: (specify)</li> <li>9. (a) Don't know</li> </ol>	<ol> <li>1. (a) Cancer</li> <li>2. (a) Diverticulitis</li> <li>3. (a) Ulcerative colitis</li> <li>4. (a) Inflammatory bowel disease (IBS)</li> <li>5. (a) Crohn's disease</li> <li>6. (a) Other: (specify)</li> <li>9. (a) Don't know</li> </ol>	

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

1. 
<sup>®</sup> Yes (go to question 20)

2. 

8 No (go to next page)

#### 20. Since your first questionnaire, how many cancer diagnoses have you had?

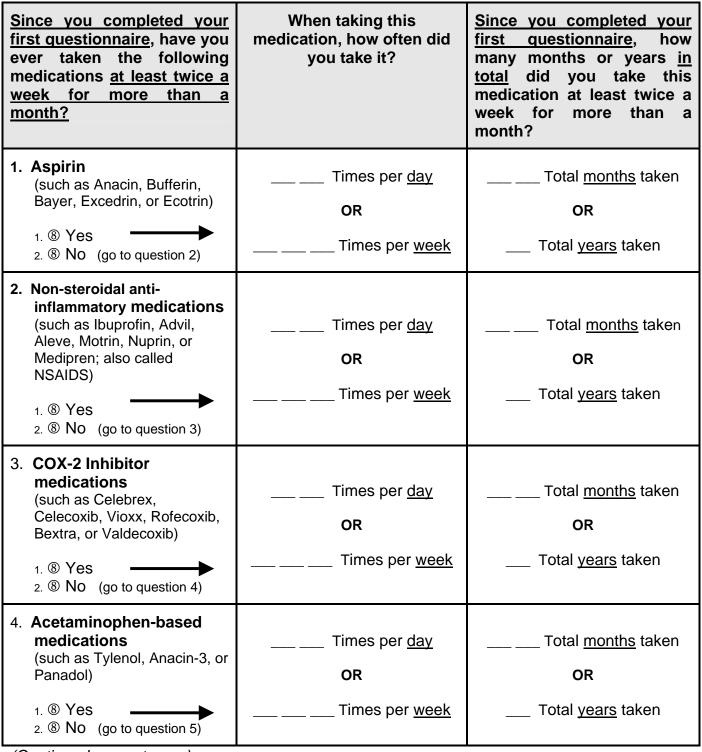
\_\_\_\_ Number of cancer diagnoses since first questionnaire (go to question 21)

Please answer questions below for each cancer diagnosis you have had since your first 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 <b>first</b> tell you that you had this type of cancer?	When did your doctor <b>first</b> tell you that you had this type of cancer?	When did your doctor <b>first</b> tell you that you had this type of cancer?	
Years of age:	Years of age:	Years of age:	
OR	OR	OR	
Year:	Year:	Year:	
24. Fourth Cancer	25. Fifth Cancer	26. Sixth Cancer	
What type of cancer was it?	What type of cancer was it?	What type of cancer was it?	
()	()	()	
When did your doctor <b>first</b> tell you that you had this type of cancer?	When did your doctor <b>first</b> tell you that you had this type of cancer?	When did your doctor <b>first</b> tell you that you had this type of cancer?	
		cancer?	
Years of age:	Years of age:	Years of age:	
Years of age: ———— OR			

## **C: MEDICATIONS**

These questions ask about medications that you may have taken since you completed your first questionnaire, beginning with common medications such as aspirin. (Check the correct answer in the left column, <u>if yes</u>, also answer the questions in the columns to the right).



(Continued on next page)

Since you completed your first questionnaire, have you ever taken the following medications <u>at least twice a</u> <u>week for more than a</u> <u>month?</u>	When taking this medication, how often did you take it?	Since you completed your first questionnaire, how many months or years <u>in</u> <u>total</u> did you take this medication?	
<ul> <li>5. Multivitamins <ul> <li>(pills or tablets, do not include individual vitamins)</li> </ul> </li> <li>1.  <ul> <li>8 Yes</li> <li>2.  <ul> <li>8 No (go to question 6)</li> </ul> </li> </ul></li></ul>	Times per <u>day</u> <b>OR</b> Times per <u>week</u>	Total <u>months</u> taken <b>OR</b> Total <u>years</u> taken	
<ul> <li>6. Folic acid or Folate (separate pills or tablets)</li> <li>1.      <ul> <li>1.          <ul> <li>Yes</li> <li>2.          <ul> <li>No (go to question 7)</li> </ul> </li> </ul> </li> </ul></li></ul>	Times per <u>day</u> <b>OR</b> Times per <u>week</u>	Total <u>months</u> taken <b>OR</b> Total <u>years</u> taken	
<ul> <li>7. Calcium (separate pills or tablets)</li> <li>1.      <ul> <li>Yes</li> <li>No (go to question 8)</li> </ul> </li> </ul>	Times per <u>day</u> <b>OR</b> Times per <u>week</u>	Total <u>months</u> taken <b>OR</b> Total <u>years</u> taken	
<ul> <li>8. Calcium-based antacids (such as Tums, Rolaids, Alka-mints, or Chooz antacid gum)</li> <li>1.      Yes     2.      No (go to question 9)</li> </ul>	Times per <u>day</u> OR Times per <u>week</u>	Total <u>months</u> taken <b>OR</b> Total <u>years</u> taken	

9. How much do you currently weigh?

\_\_\_\_ Pounds

OR

\_\_\_\_ Kilos

D: WOMEN'S HEALTH

- 1. <u>Since you completed your first questionnaire</u>, have you been prescribed an estrogen pill or patch, alone or in combination with another hormone that you used for 6 months or longer?
  - 1. 
    <sup>®</sup> Yes (go to question 2)
    - 2. <sup>®</sup> No (go to question 3)
- 2. <u>Since you completed your first questionnaire</u>, how many months or years in total have you taken estrogen (in any form)?
  - \_\_\_\_ Total <u>months</u> taken OR \_\_\_\_ Total <u>years</u> taken
- 3. <u>Since completing your first questionnaire</u>, have you had surgery on your ovaries and/or uterus (womb)?

1. (8) Yes (go to question 4)
 2. (8) No (go to next page)

Answer the questions below for each gynecological surgery that you've had since comple	əting
your first questionnaire.	

5. Second Surgery	6. Third Surgery
Since your first questionnaire, when did you <b>next</b> have this surgery?	Since your first questionnaire, when did you <b>next</b> have this surgery?
Years of age:	Years of age:
OR	OR
Year:	Year:
Which female organs were removed during this surgery? (check all that apply)	Which female organs were removed during this surgery? (check all that apply)
<ol> <li>8 One ovary (in whole or part)</li> <li>8 Both ovaries</li> <li>8 Uterus (womb)</li> <li>4 8 Other (specify)</li> </ol>	<ol> <li>8 One ovary (in whole or part)</li> <li>8 Both ovaries</li> <li>8 Uterus (womb)</li> <li>4 8 Other (specify)</li> </ol>
	Since your first questionnaire, when did you <b>next</b> have this surgery? Years of age:  OR Year:  Which female organs were removed during this surgery? (check all that apply) 1.   One ovary (in whole or part) 2.   Both ovaries 3.   Uterus (womb)

#### E: YOUR ETHNIC BACKGROUND

#### 1. Do you consider yourself to be Hispanic or Latino? (please check one box)

- Yes Hispanic or Latino (A person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. Does <u>not</u> include persons of Portuguese or Brazilian descent).
- 2. 8 No Not Hispanic or Latino
- 9. 8 Don't know

#### 2. What race do you consider yourself to be? (please check all that might apply)

- 1. <sup>(8)</sup> Caucasian/White
- 2. 8 Black or African American (does not include Africans or persons of Caribbean origin)
- 4. 
   B Japanese (includes Okinawan)
- 5. <sup>®</sup> Chinese
- 6. 8 Filipino, Malay, Indonesian
- 7. <sup>®</sup> Korean
- 8. 
   Southeast Asian (such as Vietnamese, Laotian, Thai, Hmong, Kampuchean)
- 9. 8 South Asian (such as Indian, Pakistani, Sri Lankan)
- 10. 
   Native American (such as Inuit, Aleutian, First Nations Person)
- 11. 
   Polynesian (such as Hawaiian, Maori, Samoan, Tongan, Tahitian, Cook Islander)
- 12. 
   Micronesian (such as Chamorro)
- 13. <sup>®</sup> Australian Aboriginal
- 14. <sup>®</sup> Melanesian (such as Fijian, New Guinean)
- 15. 8 Caribbean Black (such as Jamaican, Trinidadian, Tobagonian)
- 16. ® Central/South American (such as Costa Rica, Salvadorian, Colombian, Brazilian)
- 17. <sup>®</sup> Black African
- 18. 
   North African (such as Egyptian, Algerian, Moroccan)
- 19. 
   Middle Eastern (such as Iranian, Lebanese, Kuwaiti, Saudi)
- 21. 8 Other: (please specify):
- 99. 8 Don't know

#### F: YOUR HEALTH

This set of questions are about how you feel about your health. There are no wrong answers; we just want to know what you think about these issues.

- 1. (Skip if you have ever been diagnosed with colorectal cancer). Do you think your chance of getting colon (bowel) cancer is higher or lower than the average person of your age and sex?
  - 1. <sup>®</sup> Much lower
  - 2. <sup>®</sup> Somewhat lower
  - 3. <sup>®</sup> The same
  - 4. 
     Somewhat higher
  - 5. <sup>®</sup> Much higher
- 2. Have you <u>ever</u> had a blood test to look for genes for colorectal cancer as part of your health care? (Do not include tests conducted as part of this research study or other research studies).
  - 1. ⑧ Yes
  - 2. ⑧ No
  - 9. 8 Don't know
- 3. In general, would you say your health is (select one)
  - 1. <sup>®</sup> Excellent
  - 2. <sup>®</sup> Very good
  - 3. 8 Good
  - 4. <sup>®</sup> Fair
  - 5. **8** Poor

	These are a list of activities that you might do during a typical day. Does your health <u>now</u> limit you in these activities?						
4.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. (select one)	1.	2. ® Yes, limited a 3. ® No, not limited a all				
5.	Climbing several flights of stairs. (select one)	1.	2. ® Yes, limited a little	3. ⑧ No, not limited at all			

	During the last 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your <u>physical health</u> ?						
6.	Have you accomplished less than you would like? (select one)	o. ⑧ All of the time	1. ® Most of the time	2. ⑧ Some of the time	3. ® A little of the time	4. ® None of the time	
7.	Were you limited in the kind of work or other activities? (select one)	o. ⑧ All of the time	1. ® Most of the time	2. ® Some of the time	3. ® A little of the time	4. ⑧ None of the time	

ot	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any <u>emotional problems</u> (such as feeling depressed or anxious).						
8.	Have you accomplished less than you would like? (select one)	o. ⑧ All of the time	1. ® Most of the time	2. ® Some of the time	3. ® A little of the time	4. ® None of the time	
9.	Did you do work or other activities less carefully than usual (select one)	o. ⑧ All of the time	1. ® Most of the time	2. ® Some of the time	3. ® A little of the time	4. ⑧ None of the time	

10. <u>During the past 4 weeks</u>, how much did pain interfere with your normal work, including both work outside the home and housework?

- 1. <sup>®</sup> Not at all
- 2. <sup>®</sup> A little bit
- 3. <sup>®</sup> Moderately
- 4. <sup>®</sup> Quite a bit
- 5. <sup>®</sup> Extremely

These questions are about how you <u>feel</u> , and how things have been with you <u>during the past 4 weeks</u> .					
11. Have you felt calm and peaceful? (select one)	o. ⑧ All of the time	1. <sup>®</sup> Most of the time	2. ⑧ Some of the time	3. ® A little of the time	4. ⑧ None of the time
12. Did you have a lot of energy? (select one)					
	o. ® All of the time	1. <sup>®</sup> Most of the time	2. ® Some of the time	3. ® A little of the time	4. ® None of the time
13. Have you felt downhearted and depressed? (select one)	o. ⑧ All of the time	1. <sup>®</sup> Most of the time	2. ⑧ Some of the time	3. ® A little of the time	4. ⑧ None of the time
14. Has your physical health or emotional problems interfered with your social activities, like visiting friends and relatives? (select one)	o. ⑧ All of the time	1. <sup>®</sup> Most of the time	2. ⑧ Some of the time	3. ⑧ A little of the time	4. ⑧ None of the time

# 15. Have you ever participated in any other genetic or family-based cancer studies, other than this study?

1. **8** Yes

- 2. ⑧ NO
- 9. 8 Don't know

#### **G:** Contact Information

Would you prefer to have study information e-mailed to you when this is possible?

1. **8** Yes

2. ⑧ No

If yes, what is your e-mail address:

# 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?

First name:	
Last name:	
Relationship to you:	
Street Address:	
City:	
State:	
Country (if not USA):	
Zip code:	
Phone number including area code:	
E-mail address:	