#### **HOW TO COMPLETE THE QUESTIONNAIRE:**

This follow-up questionnaire asks how your health has been since the date that you completed your first 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.
- ◆ After you have completed the questionnaire, put it in the postage-paid envelope provided and mail to:

Cancer Research Center of Hawai'i University of Hawai'i at Mānoa Epidemiology Program, Attention: Family Registry 1236 Lauhala Street, Room 407 Honolulu, Hawai'i 96813-2424 Thank you very much for completing this questionnaire.

If you have questions, please call (808) 586-3002

### **A: PARTICIPANT INFORMATION**

1.	What is your ag	e today?	
	Years	of age	
2.	What is the date	e of your birth	1?
	Month:	Day:	Year:
ab	oout the time pe	eriod since th	be asking you in this follow-up questionnaire are ne date of your first questionnaire. Please refer to vering the questions.
	You complete	ed your <u>Firs</u>	st Questionnaire on:
	Month:	Day:	Year:

#### **B: MEDICAL HISTORY**

These questions ask about medical tests that you might have had <u>since the date</u> that you completed your first questionnaire. <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 most recent test?	What were the reasons for the most recent test? (check all that apply)
1. Fecal Occult Blood Test  (or hemocult or smear test) Done as part of a routine exam, the test uses cards to detect blood in your stool.  1.   Yes 2.  No	———— 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>9 B Don't know</li> </ol>
2. Sigmoidoscopy Procedure to look inside the lower bowel with a lighted tube, usually without anesthesia. Medications to empty the bowel are given beforehand.  1. 8 Yes  2. 8 No	———— Total number of tests since first 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. ® Other (please specify)  9. ® Don't know
3. 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	——— Total number of tests since first 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. ® Other (please specify)  9. ® Don't know

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.  1. ② Yes 2. ③ No  When did y  What were (check all to the check all t	estigate a new problem history of colorectal cancer e exam or check-up -up of a previous problem please specify)

When did you have the most recent barium enema?
Years of age:
———— OR
Year:
<del></del>
What were the reasons for this most recent test? (check <u>all</u> that apply)
<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> </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

your large to found in an polyps that	bowel or colon or rec by of the procedures may have been four	stionnaire, has a doctor told yetum? Be sure to think about you had since your first quested during your most recent property.  On 7)  In 13 on the next page)	all polyps that were stionnaire not just		
	ate of your first ire, have you had removed?	8. Since the date of your firmany separate occasions removed?			
2. ® No (9	go to question 8) go to question 13 on next page)	removed since d to question 9)	er of occasions you had polyps late of first questionnaire (go		
		you had polyps removed.			
		9. First polyp removal	10. 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: ————		
		Years of age: ———— OR	Years of age: ——— OR		
		———— OR	— — OR		
		— — <b>OR</b> Year: ————	— — OR OR Year: — — — —		
		OR Year: 11.Third polyp removal When did you next have	OR Year: 12. Fourth polyp removal When did you next have		
		OR Year: ———  11.Third polyp removal  When did you next have polyps removed?	OR Year: ———  12. Fourth polyp removal  When did you next have polyps removed?		

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

	_	1.	8	Yes (go to question 14)
1	:	2.	8	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)

(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?	During this surgery, was your colon or rectum completely or partially removed?	During this surgery, was your colon or rectum completely or partially removed?	During this surgery, was your colon or rectum completely or partially removed?		
1. ® Completely removed 2. ® Partially removed 9. ® Don't know	1. ® Completely removed 2. ® Partially removed 9. ® Don't know	8 Completely removed     9 Partially removed     9 Don't know	<ol> <li>8 Completely removed</li> <li>8 Partially removed</li> <li>9 Don't know</li> </ol>		
What was the reason for this surgery? (Check all that apply)	What was the reason for this surgery? (Check all that apply)	What was the reason for this surgery? (Check all that apply)	What was the reason for this surgery? (Check all that apply)		
<ol> <li>8 Cancer</li> <li>8 Diverticulitis</li> <li>8 Ulcerative colitis</li> <li>8 Inflammatory bowel disease (IBD)</li> <li>Crohn's disease</li> <li>0ther: (specify)</li> </ol>	1. ® Cancer 2. ® Diverticulitis 3. ® Ulcerative colitis 4. ® Inflammatory bowel disease (IBD) 5. ® Crohn's disease 6. ® Other: (specify)	1. ® Cancer 2. ® Diverticulitis 3. ® Ulcerative colitis 4. ® Inflammatory bowel disease (IBD) 5. ® Crohn's disease 6. ® Other: (specify)	<ol> <li>8 Cancer</li> <li>9 Diverticulitis</li> <li>8 Ulcerative colitis</li> <li>9 Inflammatory bowel disease (IBD)</li> <li>9 Crohn's disease</li> <li>9 Other: (specify)</li> </ol>		
9. ® Don't know	9. ® Don't know	9. ® Don't know	9. ® Don't know		

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

	1.	Yes	(go to question 20
$\downarrow$	2. ⑧	No	(go to next page)

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

Γ	 Number of ca	ncer diagno	ses since fi	rst questionna	aire (go to	question	21)
Ť							

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?  Years of age:  When did your doctor <b>first</b> you that you had this type of cancer?  Years of age:		When did your doctor <b>first</b> tell you that you had this type of cancer?  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?	
That type of carloof was it:	- What type of carloof 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?	
When did your doctor <b>first</b> tell you that you had this type of	When did your doctor <b>first</b> tell you that you had this type of	When did your doctor <b>first</b> tell you that you had this type of	
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?	

#### **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, if yes, also answer the questions in the columns to the right).

Since you completed your first questionnaire, have you ever taken the following medications at least twice a week for more than a month?	When taking this medication, how often did you take it?	Since you completed your first questionnaire, how many months or years in total did you take this medication at least twice a week for more than a month?
1. Aspirin (such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin)  1. ® Yes 2. ® No (go to question 2)	Times per <u>day</u> OR Times per <u>week</u>	Total <u>months</u> taken  OR  Total <u>years</u> taken
2. Non-steroidal anti- inflammatory medications (such as Ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren; also called NSAIDS)  1. ® Yes 2. ® No (go to question 3)	Times per <u>day</u> OR Times per <u>week</u>	Total <u>months</u> taken  OR Total <u>years</u> taken
3. COX-2 Inhibitor medications (such as Celebrex, Celecoxib, Vioxx, Rofecoxib, Bextra, or Valdecoxib)  1. ® Yes 2. ® No (go to question 4)	Times per <u>day</u> OR Times per <u>week</u>	Total <u>months</u> taken  OR Total <u>years</u> taken
4. Acetaminophen-based medications (such as Tylenol, Anacin-3, or Panadol)  1. ® Yes 2. ® No (go to question 5)	Times per <u>day</u> OR Times per <u>week</u>	Total <u>months</u> taken  OR  Total <u>years</u> taken

(Continued on next page)

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

9.	How much do you currently weigh?
	Pounds
	OR
	Kilos

#### D: WOMEN'S HEALTH

Men, go to Section E

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		
7		

- 1. ® Yes (go to question 2)
  - 2. 8 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	months	taken
	<u>OR</u>	
 Total	years ta	aken

3. <u>Since completing your first questionnaire</u>, have you had surgery on your ovaries and/or uterus (womb)?



- 1. 

   Yes (go to question 4)
- 2. ® No (go to next page)

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

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

#### **E: YOUR ETHNIC BACKGROUND**

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

- 1. 8 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. 8 Caucasian/White
- 2. 8 Black or African American (does not include Africans or persons of Caribbean origin)
- 4. 8 Japanese (includes Okinawan)
- 5. 8 Chinese
- 6. 8 Filipino, Malay, Indonesian
- 7. 8 Korean
- 8. Southeast Asian (such as Vietnamese, Laotian, Thai, Hmong, Kampuchean)
- 9. 8 South Asian (such as Indian, Pakistani, Sri Lankan)
- 10. 8 Native American (such as Inuit, Aleutian, First Nations Person)
- 11. 8 Polynesian (such as Hawaiian, Maori, Samoan, Tongan, Tahitian, Cook Islander)
- 12. 8 Micronesian (such as Chamorro)
- 13. 8 Australian Aboriginal
- 14. 

  Melanesian (such as Fijian, New Guinean)
- 15. ® Caribbean Black (such as Jamaican, Trinidadian, Tobagonian)
- 16. 8 Central/South American (such as Costa Rica, Salvadorian, Colombian, Brazilian)
- 17. 8 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. 8 Much lower
  - 2. 8 Somewhat lower
  - 3. ® The same
  - 4. 8 Somewhat higher
  - 5. 8 Much higher
- 2. Have you ever 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. **®** No
  - 9. 8 Don't know
- 3. In general, would you say your health is (select one).
  - 1. 8 Excellent
  - 2. ® Very good
  - 3. **®** Good
  - 4. ® Fair
  - 5. ® 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. ® Yes, limited a lot	2. ® Yes, limited a little	з. ® No, not limited at all		
5.	Climbing several flights of stairs. (select one)	1. ® Yes, limited a lot	2. ® Yes, limited a little	з. ® No, not limited at all		

	<u>During the last 4 weeks</u> , 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. ® 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
7.	Were you limited in the kind of work or other activities? (select one)	o. ® 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

ot	<u>During the past 4 weeks</u> , 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. ® 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. ® All of the time	1. ® Most of the time	2. ® Some of the time	з. ® A little of the time	4. ® 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?

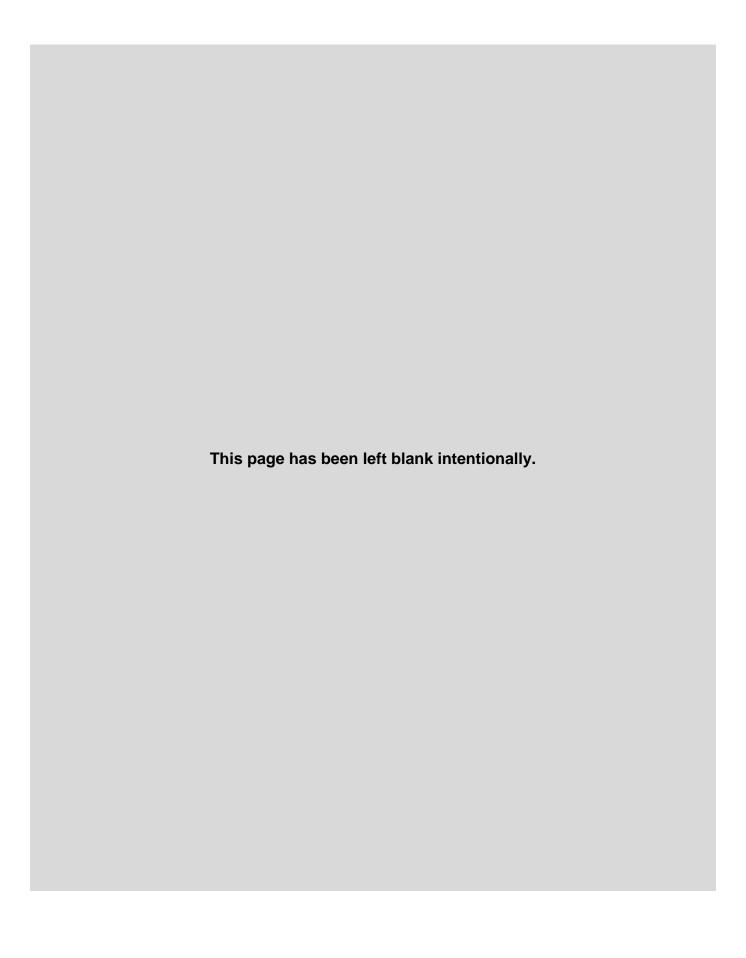
- 1. 

  Not at all
- 2. ® A little bit
- з. ® Moderately
- 4. ® Quite a bit
- 5. ® 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. ® 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
12.Did you have a lot of energy? (select one)				@ A P.	@ N
<b></b>	o. ® 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
13. Have you felt downhearted and depressed? (select one)	o. ® 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
14. Has your physical health or emotional problems interfered with your social activities, like visiting friends and relatives? (select one)	o. ® 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

# 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. ® Don't know



### **G:** Contact Information

Would you prefer to have study information possible in the future?	or newsletters e-mailed to you should this become
1. ® Yes	
2. <b>®</b> No	
If yes, what is your e-mail address:	
	ure, and you have moved, could we have the you to whom we might write or call for your new
First name:	
Last name:	
Relationship to you:	
Street Address:	
City:	
State:	
Country (if not USA):	
Zip code:	<del></del>
Phone number including area code:	
E-mail address:	

Please check that <u>all</u> pages are comple in the postage-paid envel	<del>-</del>
We thank you again for taking	the time to update your
health information. No one else carresearch effort.	-
S	incerely,
Н	awaii Family Registry Staff