

FINAL, Version 3
SEATTLE COLON CFR
Major (4-Year) Follow-up Questionnaire
March 17, 2003

NOTE: This version is formatted for telephone administration and to follow up where both family history and other data were collected together. It will be modified as necessary for sites that utilize in-person and self-administered (mailed) data collection method or had different times of administration of different parts of the data collection.

QUESTION NAMING CONVENTIONS:

Q_ - QUESTION
M_ - MOTHER
F_ - FATHER
S_ - SIBLING
_S[#] - SIBLING NUMBER (1ST, 2ND, ETC.)
C_ - CHILD
_C[#] - CHILD NUMBER (1ST, 2ND, ETC.)
REL_ - RELATIVE
NEW - NEW SIBLING OR CHILD (NOT REPORTED AT BASELINE)
VS - VITAL STATUS
CA - CANCER
CA[#] - CANCER NUMBER FOR INDIVIDUAL (1ST, 2ND, ETC.)
_E - EVER
_SB - SINCE BASELINE
_F - FREQUENCY
_D - DURATION
_N - NUMBER OF [ITEMS OF INTEREST—SURGERIES, POLYPECTOMIES, ETC.)
_A - AGE (AT OUTCOME)
_W - WHEN [OUTCOME OF INTEREST—SURGERY, CANCER DX, ETC.)
_T - TYPE (OF OUTCOME—SURGERY, CANCER)
_R - REASON (FOR OUTCOME)

Font Definitions

Bold with Italics – Actual script interviewer should speak to the respondent.

[➔ **BOLD CAPS IN SQUARE BRACKETS IN COURIER FONT**] – Indicates the appropriate skip pattern for the chosen response.

(BOLD, ITALICIZED, CAPS IN PARENTHESES) – Relative name, mentioned previously in interview, that is inserted into the script by the computer.

CAPS – Response choices the interviewer can enter into the computer or additional information the interviewer can use to clarify the question for the respondent.

[CAPS IN SQUARE BRACKETS] – Instructions for interviewer.

CAPS IN COURIER FONT TYPE – Variable name.

(CAPS IN COURIER FONT TYPE IN PARENTHESIS ABOVE VARIABLE NAME) – DD NAME_FU

(CAPS IN COURIER FONT TYPE IN PARENTHESIS UNDERLINED VARIABLE NAME) – CDS Gold Version Name

[CAPS UNDERLINED IN TIMES NEW ROMAN IN SQUARE BRACKETS] - Internal note

Edits made to December 20, 2002 version:

- All “age at [x]” fields were standardized to 3-digits.
- All “number of [procedures] since b/l” were standardized to 2 digit (standardizing to 1 digit would possibly result in problems with “9” being reported, which would be used to indicate “don’t know/refused” responses (over a 4-year period).
- All “number of years since [x] (since b/l)” were standardized to 1 digit (should be ≤ 4)
- All “medications times per day” fields were standardized to 2-digits (standardizing to 1 digit would possibly result in problems with “9” being reported, which would be used to indicate “don’t know/refused” responses.
- All “medications times per month” fields were standardized to 3-digits.
- To Q_WEIGHT, number of digits for reporting weight in kilos was changed from 2 to 3.
- To Q_RACE1_FU, 3, “LATINO, HISPANIC, MEXICAN AMERICAN, MEXICAN, CUBAN, PUERTO RICAN” was removed from response categories.

JULY 2003 REVISIONS

- List of cancers updated, and changed.

SECTION 1: IDENTIFICATION, INTRODUCTION

Q_FU_IV_DT [INTERVIEW DATE]
[ENTER MONTH] ___ __
[ENTER DAY] ___ __
[ENTER YEAR] ___ __ __ __

(BL_IV_DT)

Q_BL_IV_DT *You completed the first questionnaire/health survey for us in (MONTH, YEAR). The questions we will be asking you today are about the time period since that interview.*

(AGE_EPI_FU)

Q_AGE **What is your age today?**
[FILL IN AGE] ___ __ __ [DON'T KNOW/REFUSED, ENTER 999]

(DOB_FU)

Q_BIRTH **What is your date of birth?**
[ENTER MONTH] ___ __ [DON'T KNOW/REFUSED MONTH, ENTER 99]
[ENTER DAY] ___ __ [DON'T KNOW/REFUSED DAY, ENTER 99]
[ENTER YEAR] ___ __ __ __ [DON'T KNOW/REFUSED YEAR, ENTER 9999]

SECTION 2: PERSONAL MEDICAL HISTORY, MEDICATIONS, SCREENING

The next questions ask about medical tests you might have had since you completed the last interview in (MM/YY).

Q_FOBT *A fecal occult blood test (FOBT) is a test using specially treated cards to detect the presence of blood in the stool. It is also called a stool smear test or a hemoccult test. This test may be done as part of a routine physical exam, or at home using a kit that contains 3 cards.*

(HEMOCCULT_FU)

Q_FOBT_SB *Since the date of your last interview (MM/YY), have you had a fecal occult blood test (FOBT)?*
1 YES
2 NO [➔ GO TO Q_SIG]
9 DON'T KNOW/REFUSED [➔ GO TO Q_SIG]

(HEMOCCULT_NO_FU)

Q_FOBT_N [IF YES] *Since the date of your last interview (MM/YY), how many separate tests have you had?*
[ENTER NUMBER OF TESTS SINCE LAST INTERVIEW] ___ __
[DON'T KNOW/REFUSED, ENTER 99]

(HEMOCCULT_LST_AGE_FU)

Q_FOBT_W **When did you have the most recent test [SINCE YOUR LAST INTERVIEW]?**
1 [ENTER AGE AT MOST RECENT FOBT] ___ __ __ *or*
2 [ENTER YEAR OF MOST RECENT FOBT] ___ __ __ __ *or*
3 [ENTER NUMBER OF YEARS SINCE MOST RECENT FOBT] ___
9 DON'T KNOW/REFUSED
[\[TRANSMITTED TO IC AS AGE @ X\]](#)

Q_FOBT_R **What were the reasons for the most recent test?** [SELECT ALL THAT APPLY]

- 1 **TO INVESTIGATE A NEW PROBLEM** (H_LST_PROBLEM_FU)
- 2 **FAMILY HISTORY OF COLORECTAL CANCER** (H_LST_FAMHX_FU)
- 3 **ROUTINE EXAM OR CHECK-UP** (H_LST_ROUTINE_FU)
- 4 **FOLLOW-UP OF A PREVIOUS PROBLEM** (H_LST_FU_PROB_FU)
- 5 **OTHER, SPECIFY:** _____ (H_LST_OTHER_FU, H_LST_OTH_TEXT_FU)
- 9 DON'T KNOW/REFUSED

(SIGSCOPE_FU)

Q_SIG_SB **There are two procedures that look inside the bowel using a lighted tube.**

In a sigmoidoscopy, the examination is limited to the lower colon [bowel] and rectum and is usually done in a doctor's office without anesthesia.

In a colonoscopy, the entire large colon [bowel] is examined and a medication in a vein is usually given to relax you or make you sleepy. In preparing for the colonoscopy, you may have had an enema suppository or solution inserted into the rectum, or you would have taken between ¼ and 1 gallon of liquid preparation, such as Golytely or Oral Fleets, the day before the procedure to empty your bowels. You may also have been on a liquid diet.

Since the date of your last interview (MM/YY), have you had a sigmoidoscopy?

- 1 YES
- 2 NO [➔ GO TO Q_COL_SB]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_COL_SB]

(SIGSCOPE_NO_FU)

Q_SIG_N **[IF YES] Since the date of your last interview, how many separate sigmoidoscopies have you had?**

[ENTER NUMBER OF SIGMOIDOSCOPIES SINCE LAST INTERVIEW] ___
[DON'T KNOW/REFUSED, ENTER 99]

(SIGSCOPE_LST_AGE_FU)

Q_SIG_W **When did you have the most recent sigmoidoscopy [SINCE YOUR LAST INTERVIEW]?**

- 1 [ENTER AGE AT MOST RECENT SIGMOIDOSCOPY] ___ or
- 2 [ENTER YEAR OF MOST RECENT SIGMOIDOSCOPY] ___ or
- 3 [ENTER NUMBER OF YEARS SINCE MOST RECENT SIGMOIDOSCOPY] ___
- 9 DON'T KNOW/REFUSED

[\[TRANSMITTED TO IC AS AGE @ X\]](#)

Q_SIG_R **What were the reasons for the most recent sigmoidoscopy? [SELECT ALL THAT APPLY]**

- 1 **TO INVESTIGATE A NEW PROBLEM** (SIG_LST_PROBLEM_FU)
- 2 **FAMILY HISTORY OF COLORECTAL CANCER** (SIG_LST_FAMHX_FU)
- 3 **ROUTINE EXAM OR CHECK-UP** (SIG_LST_ROUTINE_FU)
- 4 **FOLLOW-UP OF A PREVIOUS PROBLEM** (SIG_LST_FU_PROB_FU)
- 5 **OTHER:** _____ (SIG_LST_OTHER_FU, SIG_LST_OTHER_TEXT_FU)
- 9 DON'T KNOW/REFUSED

(COLSCOPE_FU)

Q_COL_SB **Since the date of your last interview (MM/YY), have you had a colonoscopy?**

- 1 YES
- 2 NO [➔ GO TO Q_BARIUM]
- 9 DON'T KNOW [➔ GO TO Q_BARIUM]

(COLSCOPE_NO_FU)

Q_COL_N **[IF YES] Since the date of your last interview, how many separate colonoscopies have you had?**

[ENTER NUMBER OF COLONOSCOPIES SINCE LAST INTERVIEW] ___
[DON'T KNOW/REFUSED, ENTER 99]

(COLSCOPE_LST_AGE_FU)

Q_COL_W **When did you have the most recent colonoscopy [SINCE YOUR LAST INTERVIEW]??**

- 1 [ENTER AGE AT MOST RECENT COLONOSCOPY] ___ or
- 2 [ENTER YEAR OF MOST RECENT COLONOSCOPY] ___ or
- 3 [ENTER NUMBER OF YEARS SINCE MOST RECENT COLONOSCOPY] ___
- 9 DON'T KNOW/REFUSED

[\[TRANSMITTED TO IC AS AGE @ X\]](#)

Q_COL_R **What were the reasons for the most recent colonoscopy?** [SELECT ALL THAT APPLY]
1 **TO INVESTIGATE A NEW PROBLEM** (C_LST_PROBLEM_FU)
2 **FAMILY HISTORY OF COLORECTAL CANCER** (C_LST_FAMHX_FU)
3 **ROUTINE EXAM OR CHECK-UP** (C_LST_ROUTINE_FU)
4 **FOLLOW-UP OF A PREVIOUS PROBLEM** (C_LST_FU_PROB_FU)
5 **OTHER:** _____ (C_LST_OTHER_FU, C_LST_OTHER_TEXT_FU)
9 DON'T KNOW/REFUSED

(BARIUM_EVER_FU)

Q_BAR_E **A barium enema (BE) is an x-ray examination of your colon. In this procedure, a barium solution, and usually air, is infused into the colon [bowel] through the rectum, allowing the organs to be seen on x-ray. Have you ever had a barium enema/x-ray test?**
1 YES
2 NO [➔ GO TO Q_VIRTUAL]
9 DON'T KNOW/REFUSED [➔ GO TO Q_VIRTUAL]

(BARIUM_NO_FU)

Q_BAR_N **[IF YES] How many separate barium enemas have you had?**
[ENTER TOTAL NUMBER OF BARIUM ENEMAS] ___ __
[DON'T KNOW/REFUSED, ENTER 99]

(BARIUM_1ST_AGE_FU)

Q_BAR_F_W **When did you have the first barium enema?**
1 [ENTER AGE AT FIRST BARIUM ENEMA] _____ or
2 [ENTER YEAR OF FIRST BARIUM ENEMA] _____ or
3 [ENTER NUMBER OF YEARS SINCE FIRST BARIUM ENEMA] ___ __
9 DON'T KNOW/REFUSED

Q_BAR_F_R **What were the reasons for the first barium enema?** [SELECT ALL THAT APPLY]
1 **TO INVESTIGATE A NEW PROBLEM** (B_1ST_PROBLEM_FU)
2 **FAMILY HISTORY OF COLORECTAL CANCER** (B_1ST_FAMHX_FU)
3 **ROUTINE EXAM OR CHECK-UP** (B_1ST_ROUTINE_FU)
4 **FOLLOW-UP OF A PREVIOUS PROBLEM** (B_1ST_FU_PROB_FU)
5 **OTHER, SPECIFY:** _____ (B_1ST_OTHER_FU) (B_1ST_OTH_TEXT_FU)
9 DON'T KNOW/REFUSED

(BARIUM_LST_AGE_FU)

Q_BAR_L_W **[IF Q_BAR_N >1] When did you have the most recent barium enema?**
1 [ENTER AGE AT MOST RECENT BARIUM ENEMA] _____ or
2 [ENTER YEAR OF MOST RECENT BARIUM ENEMA] _____ or
3 [ENTER NUMBER OF YEARS SINCE MOST RECENT BARIUM ENEMA] ___ __
9 DON'T KNOW/REFUSED
[\[TRANSMITTED TO IC AS AGE @ X\]](#)

Q_BAR_L_R **What were the reasons for the most recent barium enema?** [SELECT ALL THAT APPLY]
1 **TO INVESTIGATE A NEW PROBLEM** (B_LST_PROBLEM_FU)
2 **FAMILY HISTORY OF COLORECTAL CANCER** (B_LST_FAMHX_FU)
3 **ROUTINE EXAM OR CHECK-UP** (B_LST_ROUTINE_FU)
4 **FOLLOW-UP OF A PREVIOUS PROBLEM** (B_LST_FU_PROB_FU)
5 **OTHER:** _____ (B_LST_OTHER_FU, B_LST_OTH_TEXT_FU)
9 DON'T KNOW/REFUSED

(VIRTUAL_C_EVER_FU)

Q_VIRTUAL **Have you ever had a colonograph, also known as a virtual colonoscopy? In preparing for the virtual colonoscopy, you may have had an enema or taken a liquid preparation, such as Golytely or Oral Fleets, the day before the procedure to empty your bowels.** THIS IS A PROCEDURE THAT USES A CT SCAN TO CREATE AN IMAGE OF THE COLON. THIS PROCEDURE IS NOT WIDELY AVAILABLE AT THIS TIME. DO NOT INCLUDE WHOLE BODY SCAN.
1 YES
2 NO
9 DON'T KNOW/REFUSED

(POLYPS_FU)

Q_POLYP **Since the date of your last interview (MM/YY), has a doctor told you that you had polyps 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 last interview—not just ones that may have been found during your most recent procedure.**
1 YES
2 NO [➔ GO TO Q_CRSRG_SB]
9 DON'T KNOW/REFUSED [➔ GO TO Q_CRSRG_SB]

(POLYP_REM_FU)

Q_POLYP_R [IF YES] **Since the date of your last interview (MM/YY) have you had any polyps removed?**
1 YES
2 NO [➔ GO TO Q_CRSRG_SB]
9 DON'T KNOW/REFUSED [➔ GO TO Q_CRSRG_SB]

(POLYP_REM_NO_FU)

Q_POLYP_R_N **Since the date of your last interview, on how many separate occasions have you had polyps removed?**
[ENTER NUMBER OF POLYPECTOMIES SINCE LAST INTERVIEW] ___
[DON'T KNOW/REFUSED, ENTER 99]

| 1 st POLYPECTOMY | 2 nd POLYPECTOMY | 3 rd POLYPECTOMY |
|--|---|---|
| (POLYP_REM1_AGE_FU) Q_POLYP_R1_W Since the date of your last interview, when did you first have polyps removed? 1 [AGE AT] ___ or 2 [YEAR OF] ___ or 3 [YEARS SINCE] ___ 9 DON'T KNOW/REFUSED | (POLYP_REM2_AGE_FU) Q_POLYP_R2_W Since the date of your last interview, when did you next have polyps removed? 1 [AGE AT] ___ or 2 [YEAR OF] ___ or 3 [YEARS SINCE] ___ 9 DON'T KNOW/REFUSED | (POLYP_REM3_AGE_FU) Q_POLYP_R3_W Since the date of your last interview, when did you next have polyps removed? 1 [AGE AT] ___ or 2 [YEAR OF] ___ or 3 [YEARS SINCE] ___ 9 DON'T KNOW/REFUSED |
| [IF POLYPECTOMIES =1 ➔ Q_CRSRG_SB] [IF POLYPECTOMIES >1 ➔ Q_POLYP_R2_W] | [IF POLYPECTOMIES =2 ➔ Q_CRSRG_SB] [IF POLYPECTOMIES >2 ➔ Q_POLYP_R3_W] | |

(CRSRG_FU)

Q_CRSRG_SB *Since the date of your last interview (MM/YY), have you had surgery to remove any of your colon or large bowel?*

- 1 YES
- 2 NO [➔ GO TO Q_CANCER1]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_CANCER1]

(CRSRG_NO_FU)

Q_CRSRG_N [IF YES] *Since your last interview, how many surgeries on your colon have you had?*

[ENTER NUMBER OF SURGERIES SINCE LAST INTERVIEW] ____
 [DON'T KNOW/REFUSED, ENTER 99]

| 1st CR SURGERY | 2nd CR SURGERY | 3rd CR SURGERY |
|---|---|---|
| (CRSRG1_AGE_FU) Q_CRSRG1_W <i>Since the date of your last interview, when did you first have this surgery?</i> 1 [AGE AT S] ____ or 2 [YEAR OF S] ____ or 3 [YEARS SINCE S] ____ 9 DON'T KNOW/REFUSED [TRANSMITTED TO IC AS AGE @ X] | (CRSRG2_AGE_FU) Q_CRSRG2_W <i>Since the date of your last interview, when did you next have this surgery?</i> 1 [AGE AT S] ____ or 2 [YEAR OF S] ____ or 3 [YEARS SINCE S] ____ 9 DON'T KNOW/REFUSED [TRANSMITTED TO IC AS AGE @ X] | (CRSRG3_AGE_FU) Q_CRSRG3_W <i>Since the date of your last interview, when did you next have this surgery?</i> 1 [AGE AT S] ____ or 2 [YEAR OF S] ____ or 3 [YEARS SINCE S] ____ 9 DON'T KNOW/REFUSED [TRANSMITTED TO IC AS AGE @ X] |
| (CRSRG1_T_FU) Q_CRSRG1_T <i>During that surgery, was your colon completely or only partially removed?</i> 1 COMPLETELY 2 PARTIALLY 9 DON'T KNOW/REFUSED | (CRSRG2_T_FU) Q_CRSRG2_T <i>During that surgery, was your colon completely or only partially removed?</i> 1 COMPLETELY 2 PARTIALLY 9 DON'T KNOW/REFUSED | (CRSRG3_T_FU) Q_CRSRG3_T <i>During that surgery, was your colon completely or only partially removed?</i> 1 COMPLETELY 2 PARTIALLY 9 DON'T KNOW/REFUSED |
| Q_CRSRG1_R <i>What were the reasons for that surgery?</i> [SELECT ALL THAT APPLY] 1 CANCER (CRSRG1_R_CAN_FU) 2 DIVERTICULAR DISEASE (CRSRG1_R_DIV_FU) 3 ULCERATIVE COLITIS (CRSRG1_R_COLITIS_FU) 4 INFLAMMATORY BOWEL DISEASE (CRSRG1_R_IBS_FU) 5 CROHN'S DISEASE (CRSRG1_R_CROHN_FU) 6 OTHER, SPECIFY: (CRSRG1_R_OTHER_FU) (CRSRG1_R_OTH_TEXT_FU) 9 DON'T KNOW/REFUSED | Q_CRSRG2_R <i>What were the reasons for that surgery?</i> [SELECT ALL THAT APPLY] 1 CANCER (CRSRG2_R_CAN_FU) 2 DIVERTICULAR DISEASE (CRSRG2_R_DIV_FU) 3 ULCERATIVE COLITIS (CRSRG2_R_COLITIS_FU) 4 INFLAMMATORY BOWEL DISEASE (CRSRG2_R_IBS_FU) 5 CROHN'S DISEASE (CRSRG2_R_CROHN_FU) 6 OTHER, SPECIFY: (CRSRG2_R_OTHER_FU) (CRSRG2_R_OTH_TEXT_FU) 9 DON'T KNOW/REFUSED | Q_CRSRG3_R <i>What were the reasons for that surgery?</i> [SELECT ALL THAT APPLY] 1 CANCER (CRSRG3_R_CAN_FU) 2 DIVERTICULAR DISEASE (CRSRG3_R_DIV_FU) 3 ULCERATIVE COLITIS (CRSRG3_R_COLITIS_FU) 4 INFLAMMATORY BOWEL DISEASE (CRSRG3_R_IBS_FU) 5 CROHN'S DISEASE (CRSRG3_R_CROHN_FU) 6 OTHER, SPECIFY: (CRSRG3_R_OTHER_FU) (CRSRG3_R_OTH_TEXT_FU) 9 DON'T KNOW/REFUSED |
| [IF # SURGERIES =1 ➔ GO TO Q_CANCER1] [IF # SURGERIES >1 ➔ GO TO Q_CRSRG2_W] | [IF # SURGERIES =2 ➔ GO TO Q_CANCER1] [IF # SURGERIES >2 ➔ GO TO Q_CRSRG3_W] | |

CANCER HISTORY

(CANCER_TOLD1_FU)

Q_CANCER1 *Since the date of your last interview (MM/YY), has a doctor told you that you had any type of cancer, leukemia or malignant tumor?*

- 1 YES
- 2 NO [➔ GO TO Q_MEDS]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_MEDS]

| 1 ST CANCER | 2 ND CANCER | 3 RD CANCER |
|---|---|---|
| (SITE1_FU) Q_CANCER_1T [IF YES] <i>What type of cancer was it?</i> [ENTER CODE] _____ | (SITE2_FU) Q_CANCER_2T [IF YES] <i>What type of cancer was it?</i> [ENTER CODE] _____ | (SITE3_FU) Q_CANCER_3T [IF YES] <i>What type of cancer was it?</i> [ENTER CODE] _____ |
| (AGEDX1_FU) Q_CANCER_1W <i>When did your doctor first tell you that you had this type of cancer?</i> 1 [ENTER AGE @ DX] _____ or 2 [ENTER YR @ DX] _____ or 3 [ENTER YRS SINCE DX] _____ 9 DON'T KNOW/REFUSED [TRANSMITTED TO IC AS AGE @ X] | (AGEDX2_FU) Q_CANCER_2W <i>When did your doctor first tell you that you had this type of cancer?</i> 1 [ENTER AGE @ DX] _____ or 2 [ENTER YR @ DX] _____ or 3 [ENTER YRS SINCE DX] _____ 9 DON'T KNOW/REFUSED [TRANSMITTED TO IC AS AGE @ X] | (AGEDX3_FU) Q_CANCER_3W <i>When did your doctor first tell you that you had this type of cancer?</i> 1 [ENTER AGE @ DX] _____ or 2 [ENTER YR @ DX] _____ or 3 [ENTER YRS SINCE DX] _____ 9 DON'T KNOW/REFUSED [TRANSMITTED TO IC AS AGE @ X] |
| (CANCER_TOLD2_FU) Q_CANCER_2 <i>Were you diagnosed with another kind of cancer since your last interview?</i> 1 YES [➔Q_CANCER_2T] 2 NO [➔Q_MEDS] 9 DK/REF [➔Q_MEDS] | (CANCER_TOLD3_FU) Q_CANCER_3 <i>Were you diagnosed with another kind of cancer since your last interview?</i> 1 YES [➔Q_CANCER_3T] 2 NO [➔Q_MEDS] 9 DK/REF [➔Q_MEDS] | |

[INTERNAL NOTE: REQUEST CONSENT TO COLLECT PATHOLOGY RPT FOR CRC]

| CANCER TYPES | | |
|-----------------------------------|--|---|
| 10 <u>ABDOMINAL</u> | 46 <u>GALL BLADDER</u> | 33 <u>RECTAL</u> |
| 11 <u>[RETIRED CODE]</u> | 47 <u>GASTROESOPHAGEAL</u> | 34 <u>SKIN-BASAL OR SQUAMOUS CELL CARCINOMA</u> |
| 44 <u>APPENDIX</u> | 48 <u>HEPATO-BILIARY</u> | 49 <u>SMALL INTESTINE (BOWEL)</u> |
| 45 <u>BILIARY DUCT</u> | 22 <u>INTESTINAL, NOS</u> | 35 <u>SPINAL</u> |
| 12 <u>BLADDER</u> | 23 <u>KIDNEY</u> | 36 <u>[RETIRED CODE]</u> |
| 13 <u>BLOOD</u> | 24 <u>LEUKEMIA (ACUTE, CHRONIC, OTHER)</u> | 37 <u>STOMACH (GASTRIC)</u> |
| 14 <u>BONE</u> | 25 <u>LIVER</u> | 38 <u>TESTICULAR</u> |
| 15 <u>BRAIN</u> | 26 <u>LUNG</u> | 39 <u>THROAT</u> |
| 16 <u>BREAST</u> | 27 <u>LYMPHOMA, HODGKINS</u> | 40 <u>THYROID</u> |
| 17 <u>CERVICAL</u> | 28 <u>MELANOMA</u> | 50 <u>URETER</u> |
| 18 <u>COLON (LARGE INTESTINE)</u> | 29 <u>NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC)</u> | 41 <u>UTERINE</u> |
| 19 <u>COLORECTAL</u> | 30 <u>OVARIAN</u> | 42 <u>OTHER (SPECIFY):</u> |
| 20 <u>ENDOMETRIAL</u> | 31 <u>PANCREATIC</u> | _____ |
| 21 <u>ESOPHAGEAL</u> | 32 <u>PROSTATE</u> | 43 <u>[RETIRED CODE]</u> |
| | | 99 <u>DON'T KNOW/REFUSED</u> |

MEDICATIONS

Q_MEDS *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.*

(ASPIRIN_FU)

Q_ASPRN_SB *Since the date of your last interview (MM/YY), have you ever taken aspirin, such as Anacin, Bufferin, Bayer, Excedrin, or Ecotrin, at least 2 times a week for more than a month?*

- 1 YES
- 2 NO [➔ GO TO Q_NSAID_SB]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_NSAID_SB]

(ASPIRIN_FRQ_FU); (ASPIRIN_INT_FU)

Q_ASPRN_F [IF YES] *Since the date of your last interview, how often did you take aspirin, when you were using it at least 2 times a week for more than a month?*

- 1 [ENTER TIMES PER DAY] ___ or
- 2 [ENTER TIMES PER WEEK] ____
- 9 DON'T KNOW/REFUSED

(ASPIRIN_LEN_FU); (ASPIRIN_TIME_FU)

Q_ASPRN_D *Since your last interview, how many months or years in total did you take aspirin at least 2 times a week for more than a month?*

- 1 [ENTER NUMBER OF MONTHS] ___ or
- 2 [ENTER NUMBER OF YEARS] ___
- 9 DON'T KNOW/REFUSED

(IBUPROFEN_FU)

Q_NSAID_SB *Since the date of your last interview (MM/YY), have you ever taken any other non-steroidal anti-inflammatory drugs such as ibuprofen, Advil, Aleve, Motrin, Nuprin, or Medipren, at least 2 times a week for more than a month? [DO NOT INCLUDE COX-2 INHIBITORS]*

- 1 YES
- 2 NO [➔ GO TO Q_COX2_SB]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_COX2_SB]

(IB_FRQ_FU); (IB_INT_FU)

Q_NSAID_F [IF YES] *Since the date of your last interview, how often did you take 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?*

- 1 [ENTER TIMES PER DAY] ___ or
- 2 [ENTER TIMES PER WEEK] ____
- 9 DON'T KNOW/REFUSED

(IB_LEN_FU); (IB_TIME_FU)

Q_NSAID_D *Since your last interview, 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?*

- 1 [ENTER NUMBER OF MONTHS] ___ or
- 2 [ENTER NUMBER OF YEARS] ___
- 9 DON'T KNOW/REFUSED

(COX2_FU)

Q_COX2_SB *Since the date of your last interview, have you ever taken Celebrex, Celecoxib, Vioxx, Rofecoxib, Bextra, or Valdecoxib, also known as COX-2 Inhibitors, at least 2 times a week for more than a month?*

- 1 YES
- 2 NO [➔ GO TO Q_ACETM_SB]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_ACETM_SB]

(COX2_FRQ_FU); (?? COX2_INT_FU)

Q_COX2_F [IF YES] *Since the date of your last interview, how often did you take this medication [CELEBREX, CELECOXIB, VIOXX, ROFECOXIB], when you were using it at least 2 times a week for more than a month?*

- 1 [ENTER TIMES PER DAY] ___ or
- 2 [ENTER TIMES PER WEEK] ____
- 9 DON'T KNOW/REFUSED

(COX2_LEN_FU); (COX2_TIME_FU)

Q_COX2_D **Since your last interview, how many months or years in total did you take type of medication [CELEBREX, CELECOXIB, VIOXX, ROFECOXIB], at least 2 times a week for more than a month?**
1 [ENTER NUMBER OF MONTHS] ___ or
2 [ENTER NUMBER OF YEARS] ___
9 DON'T KNOW/REFUSED

(ACETAMIN_FU)

Q_ACETM_SB **Since the date of your last interview (MM/YY), have you ever taken acetaminophen-based medications, such as Tylenol, Anacin-3, or Panadol, at least 2 times a week for more than a month?**
1 YES
2 NO [➔ GO TO Q_MULTI_SB]
9 DON'T KNOW/REFUSED [➔ GO TO Q_MULTI_SB]

(ACET_FRQ_FU); (ACET_INT_FU)

Q_ACETM_F **[IF YES] Since the date of your last interview (MM/YY), how often did you take type of medication [ACETAMINOPHEN-BASED MEDICATIONS], when you were using it at least 2 times a week for more than a month?**
1 [ENTER TIMES PER DAY] ___ or
2 [ENTER TIMES PER WEEK] ___
9 DON'T KNOW/REFUSED

(ACET_LEN_FU); (ACET_TIME_FU)

Q_ACETM_D **Since your last interview, how many months or years in total did you take type of medication [ACETAMINOPHEN-BASED MEDICATIONS] at least 2 times a week for more than a month?**
1 [ENTER NUMBER OF MONTHS] ___ or
2 [ENTER NUMBER OF YEARS] ___
9 DON'T KNOW/REFUSED

(MULTIVITAMIN_FU)

Q_MULTI_SB **Since the date of your last interview (MM/YY), have you taken multivitamin pills or tablets, not individual vitamins, at least 2 times a week for more than a month?**
1 YES
2 NO [➔ GO TO Q_FOLIC_SB]
9 DON'T KNOW/REFUSED [➔ GO TO Q_FOLIC_SB]

(MV_FRQ_FU); (MV_INT_FU)

Q_MULTI_F **[IF YES] Since the date of your last interview (MM/YY), how often did you take multivitamin pills or tablets, when you were using it at least 2 times a week for more than a month?**
1 [ENTER TIMES PER DAY] ___ or
2 [ENTER TIMES PER WEEK] ___
9 DON'T KNOW/REFUSED

(MV_LEN_FU); (MV_TIME_FU)

Q_MULTI_D **Since the date of your last interview (MM/YY), how many months or years in total did you take multivitamins at least 2 times a week for more than a month?**
1 [ENTER NUMBER OF MONTHS] ___ or
2 [ENTER NUMBER OF YEARS] ___
9 DON'T KNOW/REFUSED

(FOLATE_FU)

Q_FOLIC_SB **Since the date of your last interview (MM/YY), have you taken folic acid or folate pills or tablets at least 2 times a week for more than a month?**
1 YES
2 NO [➔ GO TO Q_CALC_SB]
9 DON'T KNOW/REFUSED [➔ GO TO Q_CALC_SB]

(FA_FRQ_FU); (FA_INT_FU)

Q_FOLIC_F [IF YES] *Since the date of your last interview, how often did you take folate or folic acid, when you were using it at least 2 times a week for more than a month?*

- 1 [ENTER TIMES PER DAY] ___ or
- 2 [ENTER TIMES PER WEEK] ____
- 9 DON'T KNOW/REFUSED

(FA_LEN_FU); (FA_TIME_FU)

Q_FOLIC_D *Since your last interview, how many months or years in total did you take folate or folic acid at least 2 times a week for more than a month?*

- 1 [ENTER NUMBER OF MONTHS] ___ or
- 2 [ENTER NUMBER OF YEARS] __
- 9 DON'T KNOW/REFUSED

(CALCIUM_FU)

Q_CALC_SB *Since the date of your last interview (MM/YY), have you taken calcium pills or tablets [NOT INCLUDING ANTACIDS] at least 2 times a week for more than a month?*

- 1 YES
- 2 NO [➔ GO TO Q_ANTAC_SB]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_ANTAC_SB]

(CALCIUM_FRQ_FU); (CALCIUM_INT_FU)

Q_CALC_F [IF YES] *Since the date of your last interview, how often did you take calcium pills, when you were using it at least 2 times a week for more than a month?*

- 1 [ENTER TIMES PER DAY] ___ or
- 2 [ENTER TIMES PER WEEK] ____
- 9 DON'T KNOW/REFUSED

(CALCIUM_LEN_FU); (CALCIUM_TIME_FU)

Q_CALC_D *Since your last interview, how many months or years in total did you take calcium at least 2 times a week for more than a month?*

- 1 [ENTER NUMBER OF MONTHS] ___ or
- 2 [ENTER NUMBER OF YEARS] __
- 9 DON'T KNOW/REFUSED

(ANTACIDS_FU)

Q_ANTAC_SB *Since the date of your last interview (MM/YY), have you taken calcium-based antacids [SUCH AS TUMS, ROLAIDS, EXTRA-STRENGTH ROLAIDS, ALKA-MINTS, CHOOZ ANTACID GUM] at least 2 times a week for more than a month?*

- 1 YES
- 2 NO [➔ GO TO Q_WEIGHT]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_WEIGHT]

(ANTACID_FRQ_FU); (ANTACID_INT_FU)

Q_ANTAC_F [IF YES] *Since the date of your last interview, how often did you take calcium-based antacids, when you were using it at least 2 times a week for more than a month?*

- 1 [ENTER TIMES PER DAY] ___ or
- 2 [ENTER TIMES PER WEEK] ____
- 9 DON'T KNOW/REFUSED

(ANTACID_LEN_FU); (ANTACID_TIME_FU)

Q_ANTAC_D *Since your last interview, how many months or years in total did you take calcium-based antacids at least 2 times a week for more than a month?*

- 1 [ENTER NUMBER OF MONTHS] ___ or
- 2 [ENTER NUMBER OF YEARS] __
- 9 DON'T KNOW/REFUSED

WEIGHT

(WEIGHT_FU)

Q_WEIGHT **How much do you currently weigh?**
 [ENTER POUNDS] ___ ___ [DON'T KNOW/REFUSED, ENTER 999]
or
 [ENTER KILOS] ___ ___ [DON'T KNOW/REFUSED, ENTER 99]

ETHNICITY

(ETHNIC_FU)

Q_ETHNIC **Do you consider yourself to be Hispanic or Latino?** [SELECT ONE.]
 1 YES [HISPANIC OR LATINO. A PERSON OF MEXICAN, PUERTO RICAN, CUBAN, SOUTH OR
 CENTRAL AMERICAN, OR OTHER SPANISH CULTURE OR ORIGIN, REGARDLESS OF RACE.
 [THE TERM, "SPANISH ORIGIN," CAN BE USED IN ADDITION TO "HISPANIC OR LATINO."
 [DOES NOT INCLUDE PERSONS OF PORTUGUESE OR BRAZILIAN DESCENT]
 2 NO [NOT HISPANIC OR LATINO]
 9 DON'T KNOW/REFUSED

(S_RACE1_FU; S_RACE2-4_FU)

Q_RACE1_FU **What is your race ?** [SELECT ALL THAT APPLY]
 1 CAUCASIAN/WHITE
 2 AFRICAN AMERICAN/BLACK (EXCEPT AFRICAN; EXCEPT CARIBBEAN)
 4 JAPANESE (INCLUDES OKINAWAN)
 5 CHINESE
 6 FILIPINO, MALAY, INDONESIAN
 7 KOREAN
 8 SOUTHEAST ASIAN (EXCEPT CHINESE) (SUCH AS VIETNAMESE, LAOTIAN, THAI, HMONG,
 KAMPUCHEAN)
 9 SOUTH ASIAN (SUCH AS INDIAN, PAKISTANI, SRI LANKAN)
 10 NATIVE AMERICAN, INUIT, ALEUTIAN, FIRST NATIONS PERSON
 11 POLYNESIAN (SUCH AS HAWAIIAN, MAORI, SAMOAN, TONGAN, TAHITIAN, COOK
 ISLANDER)
 12 MICRONESIAN (SUCH AS CHAMORRAN)
 13 AUSTRALIAN ABORIGINAL
 14 MELANESIAN (SUCH AS FIJIAN, NEW GUINEAN)
 15 CARIBBEAN BLACK (SUCH AS JAMAICAN, TRINIDADIAN, TOBAGONIAN)
 16 CENTRAL/SOUTH AMERICAN (SUCH AS COSTA RICA, SALVADORIAN, COLOMBIAN,
 BRAZILIAN)
 17 BLACK AFRICAN
 18 NORTH AFRICAN (SUCH AS EGYPTIAN, ALGERIAN, MOROCCAN)
 19 MIDDLE EASTERN (SUCH AS IRANIAN, LEBANESE, KUWAITI, SAUDI)
 21 OTHER (S_RACE1-4_OTH_FU) _____
 99 UNKNOWN/DON'T KNOW/REFUSED

SECTION 3: REPRODUCTIVE HISTORY, HRT [ONLY IF FEMALE]; IF MALE → GO TO SECTION 4]

(HTR_FU)

Q_HRT_SB **Since the date of your last interview (MM/YY), 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 YES
 2 NO [→ GO TO Q_ENDOM_E]
 9 DON'T KNOW/REFUSED [→ GO TO Q_ENDOM_E]

(HRT_LEN_FU) ; (HRT_TIME_FU)

Q_HRT_D [IF YES] In total, how many months or years did you take estrogen (in any form)?

- 1 [ENTER NUMBER OF MONTHS] ___ or
- 2 [ENTER NUMBER OF YEARS] ___
- 9 DON'T KNOW/REFUSED

(HYST_E_FU)

Q_HYST1_SB Since the date of your last interview (MM/YY), have you had any surgeries on your ovaries and/or uterus?

- 1 YES
- 2 NO [➔ GO TO Q_HRT_SB]
- 9 DON'T KNOW/REFUSED [➔ GO TO Q_HRT_SB]

| 1st GYNECOLOGICAL SURGERY | 2nd GYNECOLOGICAL SURGERY |
|---|--|
| (? IC DATA DICTIONARY NAMES) Q_HYSTY1_T [IF YES] <i>What type of gynecologic surgery did you have?</i> 1 HYSTERECTOMY ALONG WITH ONE OVARY OR PARTIAL OVARY 2 HYSTERECTOMY ALONG WITH BOTH OVARIES 3 HYSTERECTOMY ONLY [PROMPT: ONLY THE UTERUS OR WOMB WAS 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/REFUSED | (? IC DATA DICTIONARY NAMES) Q_HYSTY2_T [IF YES] <i>What type of surgery did you have?</i> 1 HYSTERECTOMY ALONG WITH ONE OVARY OR PARTIAL OVARY 2 HYSTERECTOMY ALONG WITH BOTH OVARIES 3 HYSTERECTOMY ONLY [PROMPT: ONLY THE UTERUS OR WOMB WAS 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/REFUSED |
| (HYSTY1_AGE_FU) Q_HYSTY1_W <i>When did you (since your last interview) first have this surgery?</i> 1 [AGE AT SURGERY] _____ or 2 [YEAR OF SURGERY] _____ or 3 [YEARS SINCE SURGERY] ___ 9 DON'T KNOW/REFUSED | (HYST2_AGE_FU) Q_HYSTY2_W <i>When did you (since your last interview) have this next surgery?</i> 1 [AGE AT SURGERY] _____ or 2 [YEAR OF SURGERY] _____ or 3 [YEARS SINCE SURGERY] ___ 9 DON'T KNOW/REFUSED |
| (HYST_2_FU) Q_HYST2_SB <i>Since that surgery, have you had any other surgeries on your ovaries and/or uterus?</i> 1 YES 2 NO [➔ Q_HRT_SB] 9 DON'T KNOW/REFUSED [➔ Q_HRT_SB] | |

SEATTLE'S SECTION 4: FAMILY HISTORY—PROBAND VERSION

These next questions ask about the health history of the family members we discussed during your initial interview. Specifically, brothers and sisters, and children who are related to you by blood. This does not include adopted relatives, or relatives by marriage asked you these questions before, but family history changes over time, including what you know about it. HALF SIBLINGS ARE EITHER THE SAME MOTHER OR THE SAME FATHER, BUT DO NOT SHARE BOTH PARENTS WITH YOU.

MOTHER VITAL STATUS

Q_M_VS [IF MOTHER WAS NOT LIVING AT BASELINE → GO TO Q_M_CA1]
[IF LIVING AT BASELINE] *Is your mother still living?*
1 YES [→ GO TO Q_M_CA1]
2 NO
9 DON'T KNOW/REFUSED [→ GO TO Q_M_CA1]

Q_M_DEC_W [IF NO] *When did she die?*
1 [[ENTER YEAR OF DEATH] ___ __ __ or
2 [ENTER AGE AT DEATH] ___ __ or
3 [ENTER YEARS SINCE DEATH] ___ __
9 DON'T KNOW/REFUSED

Q_M_DEC_L *In what city and state (and country if outside US) did she die?*
[ENTER CITY] _____
[ENTER STATE] _____
[ENTER COUNTRY IF NOT USA] _____
[DON'T KNOW/REFUSED = BLANK]

MOTHER CANCER HISTORY

Q_M_CA1 *[Has/had] [she/your mother] ever diagnosed with cancer?*
1 YES
2 NO [→ GO TO Q_F_VS]
9 DON'T KNOW/REFUSED [→ GO TO Q_F_VS]

| 1 ST CANCER | 2 ND CANCER | 3 RD CANCER | 4 TH CANCER | |
|---|--|--|--|--|
| Q_M_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] _____ | Q_M_CA2_T | Q_M_CA3_T | Q_M_CA4_T | |
| Q_M_CA1_A What was her age when she was diagnosed? [ENTER AGE @ DX _____] [DON'T KNOW/REFUSED = 999] | Q_M_CA2_A | Q_M_CA3_A | Q_M_CA4_A | |
| Q_M_CA1_W In what year was she diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ 9 DON'T KNOW/REFUSED | Q_M_CA2_W | Q_M_CA3_W | Q_M_CA4_W | |
| Q_M_CA2 [Has/had] your mother been diagnosed with another kind of cancer? 1 YES → Q_M_CA2_T 2 NO → GO TO FATHER 9 DON'T KNOW/REF → GO TO FATHER | Q_M_CA3 1 YES → Q_M_CA3_T 2 NO → FATHER 9 DK/REF → FATHER | Q_M_CA4 1 YES → Q_M_CA3_T 2 NO → FATHER 9 DK/REF → FATHER | Q_M_CA5 1 YES → Q_M_CA3_T 2 NO → FATHER 9 DK/REF → FATHER | |

| CANCER TYPES | | |
|----------------------------|---|---------------------|
| 10 ABDOMINAL | 21 ESOPHAGEAL | 33 RECTAL |
| 11 [RETIRED CODE] | 46 GALL BLADDER | 34 SKIN-BASAL OR SC |
| 44 APPENDIX | 47 GASTROESOPHAGEAL | 49 SMALL INTESTINE |
| 45 BILIARY DUCT | 48 HEPATO-BILIARY | 35 SPINAL |
| 12 BLADDER | 22 INTESTINAL, NOS | 36 [RETIRED CODE] |
| 13 BLOOD | 23 KIDNEY | 37 STOMACH (GASTR) |
| 14 BONE | 24 LEUKEMIA (ACUTE, CHRONIC, OTHER) | 38 TESTICULAR |
| 15 BRAIN | 25 LIVER | 39 THROAT |
| 16 BREAST | 26 LUNG | 40 THYROID |
| 17 CERVICAL | 27 LYMPHOMA, HODGKINS | 50 URETER |
| 18 COLON (LARGE INTESTINE) | 28 MELANOMA | 41 UTERINE |
| 19 COLORECTAL | 29 NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC) | 42 OTHER (SPECIFY): |
| 20 ENDOMETRIAL | 30 OVARIAN | 43 [RETIRED CODE] |
| | 31 PANCREATIC | 99 DON'T KNOW/REF |
| | 32 PROSTATE | |

FATHER VITAL STATUS

Q_F_VS [IF FATHER WAS NOT LIVING AT BASELINE → GO TO Q_F_CA]
[IF LIVING AT BASELINE] *Is your father still living?*
1 YES [→ GO TO Q_F_CA]
2 NO
9 DON'T KNOW/REFUSED [→ GO TO Q_FA_CA]

Q_F_DEC_W [IF NO] *When did he die?*
1 [ENTER YEAR OF DEATH] ___ ___ ___ *or*
2 [ENTER AGE AT DEATH] ___ ___ *or*
3 [ENTER YEARS SINCE DEATH] ___ ___
9 DON'T KNOW/REFUSED

Q_F_DEC_L *In what city and state (and country if outside US) did (S/HE) die?*
[ENTER CITY] _____
[ENTER STATE] _____
[ENTER COUNTRY IF NOT USA] _____
[DON'T KNOW/REFUSED = BLANK]

FATHER CANCER HISTORY

Q_F_CA1 *[Has/had] [he/your father] ever diagnosed with cancer?*
1 YES
2 NO/NOT THAT I'M AWARE OF [→ GO TO Q_S_VS]
9 DON'T KNOW/REFUSED [→ GO TO Q_S_VS]

| 1ST CANCER | 2ND CANCER | 3RD CANCER | 4TH CANCER | |
|---|--|--|--|--|
| Q_F_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] _____ | Q_F_CA2_T | Q_F_CA3_T | Q_F_CA4_T | |
| Q_F_CA1_A What was his age when he was diagnosed? [ENTER AGE @ DX _____] [DON'T KNOW/REFUSED = 999] | Q_F_CA2_A | Q_F_CA3_A | Q_F_CA4_A | |
| Q_F_CA1_W What year was he diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ 9 DON'T KNOW/REFUSED | Q_F_CA2_W | Q_F_CA3_W | Q_F_CA4_W | |
| Q_F_CA2 [Has/had] your father been diagnosed with another kind of cancer? 1 YES → Q_F_CA2_T 2 NO → GO TO SIBLING 9 DON'T KNOW/REF → SIBLING | Q_F_CA3 1 YES → Q_F_CA3_T 2 NO → SIBLING 9 DK/REF → SIBLING | Q_F_CA4 1 YES → Q_F_CA4_T 2 NO → SIBLING 9 DK/REF → SIBLING | Q_F_CA5 1 YES → Q_F_CA5 2 NO → SIBLING 9 DK/REF → SIBLING | |

| CANCER TYPES | | |
|----------------------------|---|---------------------|
| 10 ABDOMINAL | 21 ESOPHAGEAL | 33 RECTAL |
| 11 [RETIRED CODE] | 46 GALL BLADDER | 34 SKIN-BASAL OR SC |
| 44 APPENDIX | 47 GASTROESOPHAGEAL | 49 SMALL INTESTINI |
| 45 BILIARY DUCT | 48 HEPATO-BILIARY | 35 SPINAL |
| 12 BLADDER | 22 INTESTINAL, NOS | 36 [RETIRED CODE] |
| 13 BLOOD | 23 KIDNEY | 37 STOMACH (GASTR) |
| 14 BONE | 24 LEUKEMIA (ACUTE, CHRONIC, OTHER) | 38 TESTICULAR |
| 15 BRAIN | 25 LIVER | 39 THROAT |
| 16 BREAST | 26 LUNG | 40 THYROID |
| 17 CERVICAL | 27 LYMPHOMA, HODGKINS | 50 URETER |
| 18 COLON (LARGE INTESTINE) | 28 MELANOMA | 41 UTERINE |
| 19 COLORECTAL | 29 NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC) | 42 OTHER (SPECIFY): |
| 20 ENDOMETRIAL | 30 OVARIAN | 43 [RETIRED CODE] |
| | 31 PANCREATIC | 99 DON'T KNOW/REF |
| | 32 PROSTATE | |

SIBLINGS

Q_SIBS

At the time of your first interview, you reported having:

- [NO BROTHERS OR SISTERS SO WE WILL CONTINUE WITH CHILDREN] [➔CHILDREN]; [IF REPORTS SIBS,
 [___ LIVING FULL BROTHERS (LIST NAMES) AND]
 [___ LIVING FULL SISTERS (LIST NAMES) AND]
 [___ LIVING HALF BROTHERS (LIST NAMES) AND]
 [___ LIVING HALF SISTERS (LIST NAMES) AND]
 [___ FULL BROTHERS NOT LIVING AT THE TIME OF YOUR FIRST INTERVIEW (LIST NAMES) AND]
 [___ FULL SISTERS NOT LIVING AT THE TIME OF YOUR FIRST INTERVIEW (LIST NAMES) AND]
 [___ HALF BROTHERS NOT LIVING AT THE TIME OF YOUR FIRST INTERVIEW (LIST NAMES) AND]
 [___ HALF SISTERS NOT LIVING AT THE TIME OF YOUR FIRST INTERVIEW (LIST NAMES)]

| 1 ST SIBLING | 2 ND SIBLING | |
|--|---|---|
| Q_S1_VS [IF LIVING SIBS @ B/L = 0 [➔ GO TO Q_S1_CA1] [IF LIVING SIBS @ B/L = 1] <i>Is your brother/sister (NAME) still living?</i> [IF LIVING SIBS @ B/L > 1] <i>Starting with your oldest [BROTHER/SISTER], (NAME), is (S/HE) still living?</i> 1 YES [➔Q_S_CA1] 2 NO 9 DON'T KNOW/REFUSED [➔Q_S_CA1] | Q_S2_VS [IF SUBSEQUENT SIBLS LIVING @ B/L] <i>Continuing with your next oldest [BROTHER/SISTER], (NAME), is (S/HE) still living?</i> 1 YES [➔Q_S_CA1] 2 NO 9 DK/REF [➔Q_S_CA1] | Q_S3 1 YES 2 NO 9 DK/ |
| Q_S1_DEC_W [IF NO] When did (S/HE) die? 1 [ENTER YEAR OF DEATH] ___ ___ ___ or 2 [ENTER AGE AT DEATH] ___ ___ or 3 [ENTER YEARS SINCE DEATH] ___ ___ 9 DON'T KNOW/REFUSED | Q_S2_DEC_W | Q_S3 |
| Q_S1_DEC_L In what city and state (and country if outside US) did (S/HE) die? [ENTER CITY] _____ [ENTER STATE] _____ [ENTER COUNTRY IF NOT USA] _____ [DON'T KNOW/REFUSED = BLANK] | Q_S2_DEC_L | Q_S3 |
| Q_S1_CA1 [Has/had] (S/HE) ever diagnosed with cancer? 1 YES 2 NO/NOT THAT I'M AWARE OF [➔ GO TO NEXT SIB]; IF NO MORE SIBLINGS [➔ GO TO Q_S_NEW1] 9 DON'T KNOW/REFUSED [➔ GO TO NEXT SIB]; IF NO MORE SIBLINGS [➔ GO TO Q_S_NEW1] | Q_S2_CA1 1 YES 2 NO ➔NEXT SIB IF NO MORE SIBS ➔Q_S_NEW1 9 DK/REF ➔ NEXT SIB; IF NO MORE SIBS ➔Q_S_NEW1 | Q_S3 1 YES 2 NO IF NO 9 DK/F IF NO |

| 1ST CANCER | 2ND CANCER | 3RD CANCER | 4TH CANCER |
|--|--|--|--|
| Q_S1_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] _____ | Q_S1_CA2_T | Q_S1_CA3_T | Q_S1_CA4_T |
| Q_S1_CA1_A What was [HIS/HER] age when (S/HE) was diagnosed? [ENTER AGE @ DX _____] [DON'T KNOW/REFUSED = 999] | Q_S1_CA2_A | Q_S1_CA3_A | Q_S1_CA4_A |
| Q_S1_CA1_W What year was (S/HE) diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ 9 DON'T KNOW/REFUSED | Q_S1_CA2_W | Q_S1_CA3_W | Q_S1_CA4_W |
| Q_S1_CA2 [Has/had] this sibling been diagnosed with another kind of cancer? 1 YES → Q_S1_CA2_T 2 NO → Q_S2_VS 9 DON'T KNOW/REF → Q_S2_VS | Q_S1_CA3 1 YES → Q_S1_CA3_T 2 NO → Q_S2_VS 9 DK/REF → Q_S2_VS | Q_S1_CA4 1 YES → Q_S1_CA4_T 2 NO → Q_S2_VS 9 DK/REF → Q_S2_VS | Q_S1_CA5 1 YES → Q_S1_CA5_T 2 NO → Q_S2_VS 9 DK/REF → Q_S2_VS |

| CANCER TYPES | | |
|----------------------------|---|---------------------|
| 10 ABDOMINAL | 21 ESOPHAGEAL | 33 RECTAL |
| 11 [RETIRED CODE] | 46 GALL BLADDER | 34 SKIN-BASAL OR SC |
| 44 APPENDIX | 47 GASTROESOPHAGEAL | 49 SMALL INTESTINI |
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| 13 BLOOD | 23 KIDNEY | 37 STOMACH (GASTR |
| 14 BONE | 24 LEUKEMIA (ACUTE, CHRONIC, OTHER) | 38 TESTICULAR |
| 15 BRAIN | 25 LIVER | 39 THROAT |
| 16 BREAST | 26 LUNG | 40 THYROID |
| 17 CERVICAL | 27 LYMPHOMA, HODGKINS | 50 URETER |
| 18 COLON (LARGE INTESTINE) | 28 MELANOMA | 41 UTERINE |
| 19 COLORECTAL | 29 NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC) | 42 OTHER (SPECIFY): |
| 20 ENDOMETRIAL | 30 OVARIAN | 43 [RETIRED CODE] |
| | 31 PANCREATIC | 99 DON'T KNOW/REF |
| | 32 PROSTATE | |

Q_NEWS **Do you have any other biological siblings, either full or half, that we have not covered?**
1 YES
2 NO [→ GO TO Q_C_VS]
9 DON'T KNOW/REFUSED [→ GO TO Q_C_VS]

Q_NEWS_N **[IF YES] How many brothers and sisters?**
[ENTER NUMBER OF BROTHERS] ___ ___
[ENTER NUMBER OF SISTERS] ___ ___
[DON'T KNOW/REFUSED, ENTER 99]

| 1ST NEW SIBLING | 2ND NEW SIBLING | |
|--|---|--------------------------|
| Q_NEWS1 [FOR FIRST SIBLING] <i>Starting with your oldest sibling, is this a full [brother/ sister] or a half [brother/sister]?</i> 1 FULL BROTHER 2 FULL SISTER 3 HALF BROTHER 4 HALF SISTER 9 DON'T KNOW/REFUSED | Q_NEWS2 [IF SUBSEQUENT SIBS @ B/L] <i>Continuing with your next oldest sibling, is this a full brother/sister or a half brother/sister?</i> | Q 1 - Q 1 |
| Q_NEWS1_NM What is [his/her] name? [TRY TO OBTAIN FIRST AND LAST NAME] [FILL IN NAME] _____ DON'T KNOW/REFUSED = BLANK | Q_NEWS2_NM | Q 1 |
| Q_NEWS1_BD When was (S/HE) born? 1 [ENTER MONTH] ____ [DON'T KNOW/REF MONTH= 99] [ENTER DAY] ____ [DON'T KNOW/REF DAY= 99] [ENTER YEAR] ____ [DON'T KNOW/REF YR= 9999] <i>or</i> 2 [ENTER CURRENT AGE] ____ 9 DON'T KNOW/REFUSED | Q_NEWS2_BD | Q 1 |
| Q_NEWS1_VS Is (S/HE) still living? 1 YES [→ GO TO Q_S_CA1] 2 NO 9 DON'T KNOW/REFUSED [→ GO TO Q_S_CA1] | Q_NEWS2_VS 1 YES → Q_S_CA1 2 NO 9 DK/REF → Q_S_CA1 | Q 1 1 } 2 } 9 I |
| Q_NEWS1_D_W [IF NO] When did (S/HE) die? 1 [ENTER YEAR OF DEATH] ____ <i>or</i> 2 [ENTER AGE AT DEATH] ____ <i>or</i> 3 [ENTER YEARS SINCE DEATH] ____ 9 DON'T KNOW/REFUSED | Q_NEWS2_D_W | Q 1 |
| Q_NEWS1_D_L In what city and state (and country if outside US) did (S/HE) die? [ENTER CITY] _____ [ENTER STATE] ____ [ENTER COUNTRY IF NOT USA] _____ [DON'T KNOW/REFUSED = BLANK] | Q_NEWS2_D_L | Q 1 |
| Q_NEWS1_CA1 Was (S/HE) ever diagnosed with cancer? 1 YES 2 NO/NOT THAT I'M AWARE OF → SIBLINGS 9 DON'T KNOW/REFUSED → SIBLINGS | Q_NEWS2_CA1 1 YES 2 NO → SIBLINGS 9 DK/REF → SIBLINGS | Q 1 1 2 9 |

| 1ST CANCER | 2ND CANCER | 3RD CANCER | 4TH CANCER | |
|--|--|--|--|--|
| Q_NEWS1_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] | Q_NEWS1_CA2_ | Q_NEWS1_CA3_ | Q_NEWS1_CA4_T | |
| Q_NEWS1_CA1_A What was [HIS/HER] age when (S/HE) was diagnosed? [ENTER AGE @ DX _____] [DON'T KNOW/REFUSED = 999] | Q_NEWS1_CA2_A | Q_NEWS1_CA3_A | Q_NEWS1_CA4_A | |
| Q_NEWS1_CA1_W What year was (S/HE) diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ 9 [DON'T KNOW/REFUSED] | Q_NEWS1_CA2_W | Q_NEWS1_CA3_W | Q_NEWS1_CA4_W | |
| Q_NEWS1_CA2 [Has/had] this [sister/ brother] been diagnosed with another kind of cancer? 1 YES → Q_NEWS1_CA2_T 2 NO → Q_NEWS2_VS 9 DK/REF → Q_NEWS2_VS | Q_NEWS1_CA3 1 YES → Q_NEWS1_CA3_T 2 NO → Q_NEWS2_VS 9 DK/REF → Q_NEWS2_VS | Q_NEWS1_CA4 1 YES → Q_NEWS1_CA4_T 2 NO → Q_NEWS2_VS 9 DK/REF → Q_NEWS2_VS | Q_NEWS1_CA5 1 YES → Q_NEWS1_CA5_T 2 NO → Q_NEWS2_VS 9 DK/REF → Q_NEWS2_VS | |

| CANCER TYPES | | |
|-----------------------------------|--|----------------------------|
| 10 <u>ABDOMINAL</u> | 21 <u>ESOPHAGEAL</u> | 33 <u>RECTAL</u> |
| 11 <u>[RETIRED CODE]</u> | 46 <u>GALL BLADDER</u> | 34 <u>SKIN-BASAL OR SC</u> |
| 44 <u>APPENDIX</u> | 47 <u>GASTROESOPHAGEAL</u> | 49 <u>SMALL INTESTINE</u> |
| 45 <u>BILIARY DUCT</u> | 48 <u>HEPATO-BILIARY</u> | 35 <u>SPINAL</u> |
| 12 <u>BLADDER</u> | 22 <u>INTESTINAL, NOS</u> | 36 <u>[RETIRED CODE]</u> |
| 13 <u>BLOOD</u> | 23 <u>KIDNEY</u> | 37 <u>STOMACH (GASTR</u> |
| 14 <u>BONE</u> | 24 <u>LEUKEMIA (ACUTE, CHRONIC, OTHER)</u> | 38 <u>TESTICULAR</u> |
| 15 <u>BRAIN</u> | 25 <u>LIVER</u> | 39 <u>THROAT</u> |
| 16 <u>BREAST</u> | 26 <u>LUNG</u> | 40 <u>THYROID</u> |
| 17 <u>CERVICAL</u> | 27 <u>LYMPHOMA, HODGKINS</u> | 50 <u>URETER</u> |
| 18 <u>COLON (LARGE INTESTINE)</u> | 28 <u>MELANOMA</u> | 41 <u>UTERINE</u> |
| 19 <u>COLORECTAL</u> | 29 <u>NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC)</u> | 42 <u>OTHER (SPECIFY):</u> |
| 20 <u>ENDOMETRIAL</u> | 30 <u>OVARIAN</u> | 43 <u>[RETIRED CODE]</u> |
| | 31 <u>PANCREATIC</u> | 99 <u>DON'T KNOW/REF</u> |
| | 32 <u>PROSTATE</u> | |

CHILDREN VITAL STATUS

Q_CHILD At the time of your first interview, you reported having:

- [] NO CHILDREN [→ GO TO OTHER RELATIVES]; [IF REPORTS HAVING CHILDREN → GO
- [] LIVING SONS (LIST NAMES) AND
- [] LIVING DAUGHTERS (LIST NAMES)
- [] SONS NOT LIVING AT THE TIME OF YOUR FIRST INTERVIEW (LIST NAMES) AND
- [] DAUGHTERS NOT LIVING AT THE TIME OF YOUR FIRST INTERVIEW (LIST NAMES)

| 1 ST CHILD | 2 ND CHILD | |
|--|---|--|
| Q_C1_VS [IF LIVING CHILDREN @ B/L=0 → GO TO Q_C1_CA] [IF LIVING CHILDREN @ B/L=1] Is your [son/daughter] [NAME] still living? [IF LIVING CHILDREN @ B/L>1] Starting with your oldest child [NAME], is (S/HE) still living? 1 YES [→ GO TO Q_C1_CA] 2 NO 9 DON'T KNOW/REFUSED [→ GO TO Q_C1_CA] | Q_C2_VS [FOR SUBSEQUENT CHILDREN LIVING AT BASELINE] Continuing with your next oldest child [NAME], is (S/HE) still living? 1 YES →Q_C1_CA 2 NO 9 DK/REF →Q_C1_CA | |
| Q_C1_D_W [IF NO] When did (S/HE) die? 1 [ENTER YEAR OF DEATH] ___ ___ ___ or 2 [ENTER AGE AT DEATH] ___ or 3 [ENTER YEARS SINCE DEATH] ___ 9 DON'T KNOW/REFUSED | Q_C2_D_W | |
| Q_C1_DEC_L In what city and state (and country if outside US) did (S/HE) die? [ENTER CITY] _____ [ENTER STATE] _____ [ENTER COUNTRY IF NOT USA] _____ [DON'T KNOW/REFUSED = BLANK] | Q_C2_DEC_L | |
| Q_C1_CA1 [IF CONTINUING FROM ABOVE] Has (S/HE) ever diagnosed with cancer? [IF CONTINUING WITH CHILDREN DECEASED @ B/L] Had your son/daughter [NAME] ever been diagnosed with cancer? 1 YES 2 NO/NOT THAT I'M AWARE OF [→ GO TO NEXT SIBLING]; IF NO MORE SIBLINGS [→ GO TO Q_S_NEW1] 9 DON'T KNOW/REFUSED [→ GO TO NEXT SIBLING]; IF NO MORE SIBLINGS [→ GO TO Q_S_NEW1] | Q_C2_CA1 1 YES 2 NO → NEXT SIB; [IF NO MORE SIBS → Q_S_NEW1] 9 DK/REF →NEXT SIB; [IF NO MORE SIBS → Q_S_NEW1] | |

| 1 ST CANCER | 2 ND CANCER | 3 RD CANCER | 4 TH CANCER |
|---|--|--|---|
| Q_C1_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] | Q_C1_CA2_T | Q_C1_CA3_T | Q_C1_CA4_T |
| Q_C1_CA1_A What was [HIS/HER] age when (S/HE) was diagnosed? [ENTER AGE @ DX _____] [DON'T KNOW/REFUSED = 999] | Q_C1_CA2_A | Q_C1_CA3_A | Q_C1_CA4_A |
| Q_C1_CA1_W What year was (S/HE) diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ or 9 [DON'T KNOW/REFUSED] | Q_C1_CA2_W | Q_C1_CA3_W | Q_C1_CA4_W |
| Q_C1_CA2 Has/had this [SON/DAUGHTER] been diagnosed with another kind of cancer? 1 YES → Q_C1_CA2_T 2 NO → Q_C2_VS 9 DON'T KNOW/REF → Q_C2_VS | Q_C1_CA3 1 YES → Q_C1_CA3_T 2 NO → Q_C2_VS 9 DK/REF → Q_C2_VS | Q_C1_CA4 1 YES → Q_C1_CA4_T 2 NO → Q_C2_VS 9 DK/REF → Q_C2_VS | Q_C1_CA5 1 YES → Q_C1_C2 2 NO → Q_C2_VS 9 DK/REF → Q_C2_VS |

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- Deleted: [
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| CANCER TYPES | | |
|----------------------------|---|---------------------|
| 10 ABDOMINAL | 21 ESOPHAGEAL | 33 RECTAL |
| 11 [RETIRED CODE] | 46 GALL BLADDER | 34 SKIN-BASAL OR SC |
| 44 APPENDIX | 47 GASTROESOPHAGEAL | 49 SMALL INTESTINI |
| 45 BILIARY DUCT | 48 HEPATO-BILIARY | 35 SPINAL |
| 12 BLADDER | 22 INTESTINAL, NOS | 36 [RETIRED CODE] |
| 13 BLOOD | 23 KIDNEY | 37 STOMACH (GASTR |
| 14 BONE | 24 LEUKEMIA (ACUTE, CHRONIC, OTHER) | 38 TESTICULAR |
| 15 BRAIN | 25 LIVER | 39 THROAT |
| 16 BREAST | 26 LUNG | 40 THYROID |
| 17 CERVICAL | 27 LYMPHOMA, HODGKINS | 50 URETER |
| 18 COLON (LARGE INTESTINE) | 28 MELANOMA | 41 UTERINE |
| 19 COLORECTAL | 29 NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC) | 42 OTHER (SPECIFY): |
| 20 ENDOMETRIAL | 30 OVARIAN | 43 [RETIRED CODE] |
| | 31 PANCREATIC | 99 DON'T KNOW/REF |
| | 32 PROSTATE | |

Q_NEWC Do you have any other biological children that we have not covered?
 1 YES
 2 NO → GO TO Q_REL_CA
 9 DON'T KNOW/REFUSED → GO TO Q_REL_CA

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- Deleted:]
- Deleted: [
- Deleted:]

Q_NEWC_N [IF YES] *How many sons and daughters?*
 [ENTER NUMBER OF SONS] _____
 [ENTER NUMBER OF DAUGHTERS] _____
 [DON'T KNOW/REFUSED, ENTER 99]

| 1 ST NEW CHILD | 2 ND NEW CHILD |
|---|---|
| Q_NEWC1_VS [FOR FIRST NEW CHILD] Starting with your oldest child, is this a son or daughter? 1 SON 2 DAUGHTER 9 DON'T KNOW/REFUSED [→OTHER RELATIVES] Q_NEWC1_NM What is [his/her] name? [TRY TO OBTAIN FIRST & LAST NAME] [FILL IN NAME] _____ [DON'T KNOW/REFUSED = BLANK] | Q_NEWC2_VS [FOR SUBSEQUENT SIBLINGS] Continuing with your next oldest child, is this a son or daughter? |
| Q_NEWC1_BD When was (S/HE) born? 1 [ENTER MONTH] _____ [DON'T KNOW/REF MONTH= 99] [ENTER DAY] _____ [DON'T KNOW/REF DAY= 99] [ENTER YEAR] _____ [DON'T KNOW/REF YR= 9999] <i>or</i> 2 [ENTER CURRENT AGE] _____ 9 DON'T KNOW/REFUSED | Q_NEWC2_BD |
| Q_NEWC1_VS Is (S/HE) still living? 1 YES [→Q_S_CA1] 2 NO 9 DON'T KNOW/REFUSED [→Q_S_CA1] | Q_NEWC2_VS 1 YES [→Q_S_CA1] 2 NO 9 DK/REF [→Q_S_CA1] |
| Q_NEWC1_D_W [IF NO] When did (S/HE) die? 1 [ENTER YEAR OF DEATH] _____ <i>or</i> 2 [ENTER AGE AT DEATH] _____ <i>or</i> 3 [ENTER YEARS SINCE DEATH] _____ 9 DON'T KNOW/REFUSED | Q_NEWC2_D_W |
| Q_NEWC1_D_L In what city and state (and country if outside US) did (S/HE) die? [ENTER CITY] _____ [ENTER STATE] _____ [ENTER COUNTRY IF NOT USA] _____ [DON'T KNOW/REFUSED = BLANK] | Q_NEWC2_D_L |
| Q_NEWC1_CA1 Was (S/HE) ever diagnosed with cancer? 1 YES 2 NO/NOT THAT I'M AWARE OF [→SIBLINGS] 9 DON'T KNOW/REFUSED [→SIBLINGS] | Q_NEWC2_CA1 1 YES 2 NO [→ SIBLINGS] 9 DK/REF [→ SIBLINGS] |

| 1 ST CANCER | 2 ND CANCER | 3 RD CANCER | 4 TH CAN |
|--|---|---|---|
| Q_NEWC1_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] _____ | Q_NEWC1_CA2_T | Q_NEWC1_CA3_T | Q_NEWC1_CA4 |
| Q_NEWC1_CA1_A What was (HIS/HER) age when (S/HE) was diagnosed? [ENTER AGE @ DX _____] [DON'T KNOW/REFUSED = 999] | Q_NEWC1_CA2_A | Q_NEWC1_CA3_A | Q_NEWC1_CA4 |
| Q_NEWC1_CA1_W What year was (S/HE) diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ 9 [DON'T KNOW/REFUSED] | Q_NEWC1_CA2_W | Q_NEWC1_CA3_W | Q_NEWC1_CA4 |
| Q_NEWC1_CA2 Has/had this [SON/DAUGHTER] been diagnosed with another kind of cancer? 1 YES → Q_NEWC1_CA2_T 2 NO → Q_NEWC2_VS 9 DK/REF → Q_NEWC2_VS | Q_NEWC1_CA3 | Q_NEWC1_CA4 | Q_NEWC1_CA5 |
| | 1 YES → Q_NEWC1_CA3_T 2 NO → Q_NEWC2_VS 9 DK/REF → Q_NEWC2_VS | 1 YES → Q_NEWC1_CA4_T 2 NO → Q_NEWC2_VS 9 DK/REF → Q_NEWC2_VS | 1 YES → Q_NEWC1_CA5_T 2 NO → Q_NEWC2_VS 9 DK/REF → Q_NEWC2_VS |

| CANCER TYPES | | |
|----------------------------|---|---------------------|
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| 44 APPENDIX | 47 GASTROESOPHAGEAL | 49 SMALL INTESTINE |
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| 12 BLADDER | 22 INTESTINAL NOS | 36 [RETIRED CODE] |
| 13 BLOOD | 23 KIDNEY | 37 STOMACH (GASTR) |
| 14 BONE | 24 LEUKEMIA (ACUTE, CHRONIC, OTHER) | 38 TESTICULAR |
| 15 BRAIN | 25 LIVER | 39 THROAT |
| 16 BREAST | 26 LUNG | 40 THYROID |
| 17 CERVICAL | 27 LYMPHOMA, HODGKINS | 50 URETER |
| 18 COLON (LARGE INTESTINE) | 28 MELANOMA | 41 UTERINE |
| 19 COLORECTAL | 29 NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC) | 42 OTHER (SPECIFY): |
| 20 ENDOMETRIAL | 30 OVARIAN | 43 [RETIRED CODE] |
| | 31 PANCREATIC | 99 DON'T KNOW/REF |
| | 32 PROSTATE | |

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| 1ST OTHER RELATIVE DIAGNOSED WITH CANCER | 2ND OTHER RELATIVE |
|--|--|
| Q_REL1_CA1 Have any of your other relatives ever been diagnosed with cancer? 1 YES 2 NO/NOT THAT I'M AWARE OF [→ GO TO SECTION 5] 9 DON'T KNOW/REFUSED [→ GO TO SECTION 5] | Q_REL2_CA1 [FOR SUBSEQUENT RELATIVES] Have any other relatives been diagnosed with cancer? 1 YES 2 NO → SECTION 5 9 DK/REF → SECTION 5 |
| Q_REL1_C1_NM [IF YES] Who was the relative affected? [RECORD AS SPECIFIC AS POSSIBLE, I.E., PATERNAL UNCLE [FIRST NAME LAST NAME], MATERNAL AUNT [FIRST NAME LAST NAME] [FILL IN NAME] DON'T KNOW/REFUSED = BLANK | Q_REL2_C1_NM |

| 1ST CANCER | 2ND CANCER | 3RD CANCER | 4TH CANCER |
|--|--|--|--|
| Q_REL1_CA1_T [IF YES] What type of cancer was it? [ENTER CODE] _____ | Q_REL1_CA2_T | Q_REL1_CA3_T | Q_REL1_CA4_T |
| Q_REL1_CA1_A What was [HIS/HER] age when [S/HE] was diagnosed? [ENTER AGE @ DX] _____ [DON'T KNOW/REFUSED = 999] | Q_REL1_CA2_A | Q_REL1_CA3_A | Q_REL1_CA4_A |
| Q_REL1_CA1_W In what year was (S/HE) diagnosed? 1 [YEAR @ DX] _____ or 2 [YEARS SINCE DX] _____ 9 [DON'T KNOW/REFUSED] | Q_REL1_CA2_W | Q_REL1_CA3_W | Q_REL1_CA4_W |
| Q_REL1_CA2 Has/had this relative been diagnosed with another kind of cancer? 1 YES → Q_REL1_CA2_T 2 NO → Q_REL2_VS 9 DK/REF → Q_REL2_VS | Q_REL1_CA3 1 YES → Q_REL1_CA3_T 2 NO → Q_REL2_VS 9 DK/REF → Q_REL2_VS | Q_REL1_CA4 1 YES → Q_REL1_CA4_T 2 NO → Q_REL2_VS 9 DK/REF → Q_REL2_VS | Q_REL1_CA5 1 YES → Q_REL1_CA5_T 2 NO → Q_REL2_VS 9 DK/REF → Q_REL2_VS |

| <u>CANCER TYPES</u> | | |
|-----------------------------------|--|----------------------------|
| 10 <u>ABDOMINAL</u> | 21 <u>ESOPHAGEAL</u> | 33 <u>RECTAL</u> |
| 11 <u>[RETIRED CODE]</u> | 46 <u>GALL BLADDER</u> | 34 <u>SKIN-BASAL OR SC</u> |
| 44 <u>APPENDIX</u> | 47 <u>GASTROESOPHAGEAL</u> | 49 <u>SMALL INTESTINE</u> |
| 45 <u>BILIARY DUCT</u> | 48 <u>HEPATO-BILIARY</u> | 35 <u>SPINAL</u> |
| 12 <u>BLADDER</u> | 22 <u>INTESTINAL, NOS</u> | 36 <u>[RETIRED CODE]</u> |
| 13 <u>BLOOD</u> | 23 <u>KIDNEY</u> | 37 <u>STOMACH (GASTR)</u> |
| 14 <u>BONE</u> | 24 <u>LEUKEMIA (ACUTE, CHRONIC, OTHER)</u> | 38 <u>TESTICULAR</u> |
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| 16 <u>BREAST</u> | 26 <u>LUNG</u> | 40 <u>THYROID</u> |
| 17 <u>CERVICAL</u> | 27 <u>LYMPHOMA, HODGKINS</u> | 50 <u>URETER</u> |
| 18 <u>COLON (LARGE INTESTINE)</u> | 28 <u>MELANOMA</u> | 41 <u>UTERINE</u> |
| 19 <u>COLORECTAL</u> | 29 <u>NON-HODGKINS LYMPHOMA (LYMPH, LYMPHATIC)</u> | 42 <u>OTHER (SPECIFY):</u> |
| 20 <u>ENDOMETRIAL</u> | 30 <u>OVARIAN</u> | 43 <u>[RETIRED CODE]</u> |
| | 31 <u>PANCREATIC</u> | 99 <u>DON'T KNOW/REF</u> |
| | 32 <u>PROSTATE</u> | |

SECTION 5: BEHAVIORAL/GENETIC TESTING

The next 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.

- Q_RISK [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 MUCH LOWER
 2 SOMEWHAT LOWER
 3 THE SAME
 4 SOMEWHAT HIGHER
 5 MUCH HIGHER
 9 [DON'T KNOW DON'T INCLUDE ON SELF-COMPLETED (MAILED) SURVEYS]

- Q_TEST **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 YES
 2 NO
 9 DON'T KNOW/REFUSED

- Q_SF1 **In general would you say your health is** [READ CHOICES]
 1 EXCELLENT
 2 VERY GOOD
 3 GOOD
 4 FAIR
 5 POOR
 9 DON'T KNOW/REFUSED [DON'T READ]

I am going to read a list of activities you might do during a typical day. I want to know if your health now limits you in these activities.

| | YES, LIMITED A LOT | YES, LIMITED A LITTLE | NO, NOT LIMITED AT ALL | DON'T KNOW/ REFUSED |
|--|-----------------------------|-----------------------------|------------------------------|-----------------------------|
| Q_SF2 Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. Would you say [READ CHOICES EXCEPT DON'T KNOW/REFUSED] | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _9 |
| Q_SF3 Climbing several flights of stairs. Would you say [READ CHOICES EXCEPT DON'T KNOW/REFUSED] | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _9 |

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 your physical health? As a result of your physical health ...

| | ALL OF THE TIME | MOST OF THE TIME | SOME OF THE TIME | A LITTLE OF THE TIME | NONE OF THE TIME | DON'T KNOW/ REFUSED |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF4 ...have you accomplished less than you would like? Would you say [READ CHOICES EXCEPT DON'TKNOW/REFUSED] | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |

| | ALL OF THE TIME | MOST OF THE TIME | SOME OF THE TIME | A LITTLE OF THE TIME | NONE OF THE TIME | DON'T KNOW/ REFUSED |
|--|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF5 ...were you limited in the kind of work or other activities. Would you say [READ CHOICES EXCEPT DON'T KNOW/ REFUSED] | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |

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 emotional problems (such as feeling depressed or anxious). As a result of your emotional problems...

| | ALL OF THE TIME | MOST OF THE TIME | SOME OF THE TIME | A LITTLE OF THE TIME | NONE OF THE TIME | DON'T KNOW/ REFUSED |
|--|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF6 ...have you accomplished less than you would like. Would you say [READ CHOICES EXCEPT DON'T KNOW/ REFUSED] | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |

| | | | | | | |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF7 ...did you do work or other activities less carefully than usual. Would you say [READ CHOICES EXCEPT DON'T KNOW/ REFUSED] | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|

| | | | | | | |
|---|--|--|--|--|--|--|
| Q_SF8 During the past 4 weeks, how much did pain interfere with your normal work, including both work outside the home and housework? Would you say [READ CHOICES] | | | | | | |
| 1 NOT AT ALL | | | | | | |
| 2 A LITTLE BIT | | | | | | |
| 3 MODERATELY | | | | | | |
| 4 QUITE A BIT | | | | | | |
| 5 EXTREMELY | | | | | | |
| 9 DON'T KNOW/REFUSED | | | | | | |

These questions are about how you feel and how things have been with you during the past 4 weeks. How much of the time during the past 4 weeks...

| | ALL OF THE TIME | MOST OF THE TIME | SOME OF THE TIME | A LITTLE OF THE TIME | NONE OF THE TIME | DON'T KNOW/ REFUSED |
|--|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF9 ...have you felt calm and peaceful? Would you say [READ CHOICES EXCEPT DON'T KNOW/ REFUSED]... | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |

| | | | | | | |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF10 ...did you have a lot of energy? Would you say [READ CHOICES EXCEPT DON'T KNOW/ REFUSED].... | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|

| | | | | | | |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF11 ...have you felt downhearted and depressed [READ CHOICES EXCEPT DON'T KNOW/ REFUSED].... | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|

| | ALL OF THE TIME | MOST OF THE TIME | SOME OF THE TIME | A LITTLE OF THE TIME | NONE OF THE TIME | DON'T KNOW/ REFUSED |
|---|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Q_SF12 <i>...has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)</i> [READ CHOICES EXCEPT DON'T KNOW/ REFUSED]... | <input type="checkbox"/> _0 | <input type="checkbox"/> _1 | <input type="checkbox"/> _2 | <input type="checkbox"/> _3 | <input type="checkbox"/> _4 | <input type="checkbox"/> _9 |

(Q_STUDIES_FU)

Q_STUDIES **Have you ever participated in any other genetic or family-based cancer studies, other than this study?**

- 1 YES → Specify: (Q_STUDIES_TXT) _____
- 2 NO
- 9 DON'T KNOW/REFUSED

SECTION 6: CONTACT INFORMATION [NOT TRANSMITTED TO UCI]

Q_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?***

Q_CONTACTFN [IF YES] [ENTER FIRST NAME] _____

Q_CONTACTLN [ENTER LAST NAME] _____

Q_CONTACTREL [ENTER RELATIONSHIP TO R] _____

Q_CONTACTSTR [ENTER STREET ADDRESS] _____

Q_CONTACTCTY [ENTER CITY] _____

Q_CONTACTST [ENTER STATE] _____

Q_CONTACTCO [ENTER COUNTRY IF NOT USA] _____

Q_CONTACTZIP [ENTER ZIP] _____ - _____

Q_CONTACTPH1 [ENTER PHONE] (_____) _____ - _____

Q_CONTACTPH2 [ENTER PHONE] (_____) _____ - _____