

# **ATTACHMENT E**

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*Data Collection*

*Instrument: Baseline*

*Questionnaire*

Public reporting burden of this collection of information is estimated to average 5 minutes per response for the eligibility screener and 35 minutes per response for the baseline survey, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX)

**[7.9 Grade Level, Flesch-Kincaid Readability Formula]**

**[CALL INTRODUCTION]**

Hello, may I speak with <first and last name of potential participant>? My name is <name>, and I'm calling on behalf of the Centers for Disease Control and Prevention (CDC) and Henry Ford Health System. Researchers at Henry Ford and the CDC are working together on a study about what women know and think about cancer, their experiences with cancer in their family, worries they may have about cancer, and their own risk of cancer.

**<If caller asks how you got their number:**

As I mentioned, we are working with researchers at Henry Ford Health System. You were randomly selected from patients who have been seen in the past at one of the Henry Ford Health System locations.>

**<If caller asks about who is conducting the interview:**

I'm calling from ORC Macro, a national health research and consulting firm, on behalf of the CDC. We conduct a lot of research for the federal government, including CDC.>

We would like to ask you a few questions to see if you qualify to participate in the study. These initial questions should take only about 5 minutes. You then may be selected to participate in the full study. Any information we gather during this study will be treated in a confidential manner unless otherwise required by law. Would you have time to answer the initial questions now?

Yes  No **[If no, stop interview]**

[IF YES, PROCEED. IF NO, THANK HER FOR HER TIME.]

[IF INTERESTED, BUT NOT AVAILABLE RIGHT NOW, FIND OUT WHEN SHE COULD BE REACHED AGAIN.]

Do you have any questions or concerns before we start? [Record]

**May we begin?**

**[AGE CHECK]**

**First I need to ask you in what month and year you were born?**

Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec

1 9 0 0

1 1

2 2

3 3

4 4

5 5

6 6

7 7

8

9

\_\_\_ DON'T KNOW [Terminate Call]

\_\_\_ REFUSED [Terminate Call]

**[CATI PROGRAM – Terminate call if later than 1976.]**

**[If born later than 1976]**

Thank you for your interest in our survey. Unfortunately, we are only able to include women who are at least 30 years of age. We appreciate your time. **[TERMINATE CALL]**

**[SCREENING]**

**Now I need to ask you some questions about your medical history.**

1. Has a health care professional ever told you that you had cancer?

\_\_\_ YES

\_\_\_ NO **[Skip to Question 2]**

\_\_\_ DON'T KNOW **[Skip to Question 2]**

\_\_\_ REFUSED **[Skip to Question 2]**

1a. What type of cancer was that?

**[RECORD UP TO 3]**

\_\_\_ BRAIN TUMOR

\_\_\_ BREAST

\_\_\_ COLON OR COLORECTAL

\_\_\_ ENDOMETRIAL

\_\_\_ KIDNEY

\_\_\_ LEUKEMIA/LYMPHOMA

\_\_\_ LIVER

\_\_\_ LUNG

\_\_\_ OVARIAN **\*\*[Go to TERMINATION TEXT]**

\_\_\_ SARCOMA

\_\_\_ SKIN

\_\_\_ THYROID

\_\_\_ OTHER [Record Response] \_\_\_\_\_

\_\_\_ DON'T KNOW **\*\*[Go to TERMINATION TEXT]**

\_\_\_ REFUSED **\*\*[Go to TERMINATION TEXT]**

**Ask the following question ONLY if participants identify a breast cancer diagnosis in Question 1a above.**

**1a1. At what age or in what year were you first told that you had breast cancer?**

- AGE [Record age] \_\_\_\_\_
- YEAR
- DON'T KNOW
- REFUSED

2. Have you ever had both your ovaries removed?

- YES **\*\*[Go to TERMINATION TEXT]**
- NO
- DON'T KNOW
- REFUSED

3. Has your mother, sister (including half-sister), daughter, aunt or grandmother had breast cancer? Not an adopted relative or relatives related by marriage only.

- YES
- NO
- DON'T KNOW
- REFUSED**\*\*[Go to TERMINATION TEXT]**

3a. [If "yes"] Which of these family members has had breast cancer?

3a1. So just to confirm, you have **[CATI PROGRAM: \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_]** with breast cancer. Is that correct?

4. Has your mother, sister (including half-sister), daughter, aunt or grandmother had ovarian cancer? Not an adopted relative or relatives related by marriage only.

- YES
- NO
- DON'T KNOW
- REFUSED**\*\*[Go to TERMINATION TEXT]**

4a. [If "yes"] Which of these family members has had ovarian cancer?

**\*\*[TERMINATION TEXT]**

Thank you for answering my questions. Based on your responses, we are finished with the interview. For this study we are including random samples of women over the age of 30 who have no personal history of ovarian cancer, or who have not had surgery to remove both ovaries. I appreciate your time! Do you have any questions for me?

[IF THE PARTICIPANTS ASKS ABOUT THE INCENTIVE LET THEM KNOW THAT ONLY WOMEN WHO QUALIFY FOR AND COMPLETE THE FULL QUESTIONNAIRE WILL RECEIVE THE INCENTIVE.]

**[STOP]**

**\*\*[CONTINUING TEXT]**

Thank you for answering my questions. You qualify for participation in our study. Do you have any questions before we begin? [ANSWER ANY QUESTIONS.]

**[7.9 Grade Level, Flesch-Kincaid Readability Formula]**

**[CONSENT]**

First, I would like to tell you more about this research study. As I said before, this is a study about what women know and think about cancer. We will ask you questions about cancer in your family, your thoughts about cancer, and about your own risk of cancer. In total, we will speak with about 2,000 women. Taking part in this survey will take about 35 minutes. You can choose whether to be in the study or not.

There is very little risk to you in taking part in the study. You may not feel like talking about your experiences with cancer. If I ask any questions you do not want to answer, tell me and I will skip them. You may change your mind about taking part in the survey and stop at any time. If you do not want to finish the survey, it will not change the care you get at Henry Ford Health System. If you complete the full survey today, you will be sent a fifteen dollar gift card for your time.

You will not directly benefit from answering our questions. But the data we collect during this survey will help us learn how women make decisions about their health. The information from this study also will help CDC find out who is tested for cancer and why. It will give doctors information on how best to discuss cancer testing with their patients.

This call may be reviewed to check on my work, but what you say will be kept private. To protect the privacy of all women in the study, we are in the process of applying for a Certificate of Confidentiality for this study. This assures that all answers that you give will be kept private. Anything you tell us will not have to be given to anyone else, even if a court orders us to do so, unless you say it's okay. But under the law, we must report to the state suspected cases of child abuse or if you tell us that you are planning to cause serious harm to yourself or others. Your answers to questions will be kept separate from your name or other personal information. Only study staff will be able to see that information. We will never use your name in any report. We will always combine your answers with answers from other women in the survey when we write reports or papers.

I may ask you to let us contact you again in about one year to ask some of the same questions. Taking part in the study now does not mean that you have to let us contact you in the future. If you allow us to call you again, it would take about fifteen minutes and you would receive a ten dollar gift card.

If you have concerns about the study or how it is being carried out, you may contact Gretchen Simmons at 404-321-3211, Extension 2220. If you have questions about your rights as a participant in this study, you may call the office of CDC's Deputy Associate Director for Science at 1-800-548-8814. Tell them you are calling about CDC protocol #4908. Someone will return your call as soon as possible. You may also call the Office of Research Administration at Henry Ford Hospital at 1-313-916-4444.

Before I ask these questions, I would like to get your verbal consent to participate in this study.

Thank you for your time. If you change your mind, please call 550-555-5555.

I will confirm that you are willing to answer the questions in this survey and will note your verbal consent. Do you have any questions for me before we start the survey?

**[7.5 Grade Level, Flesch Kincaid Readability Formula]**

**[MAIN QUESTIONNAIRE]**

**COPING**

**In the next section, I am going to ask about how you typically react to events or unexpected problems. I will read several different scenarios, and then I will read a number of possible responses to the situation described. I want you to imagine yourself in each situation, and I would like you to tell me all of the responses that would apply to you and how you would respond.**

5. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Indicate all of the statements that might apply by saying “yes” or “no” for each one.

	Yes	No	Don't Know	Refused
a. I would ask the dentist exactly what work was going to be done.	1	2	8	9
b. I would take a tranquilizer or have a drink before going.	1	2	8	9
c. I would try to think about pleasant memories.	1	2	8	9
d. I would want the dentist to tell me when I would feel pain.	1	2	8	9
e. I would try to sleep.	1	2	8	9
f. I would watch all the dentist's movements and listen for the sound of the drill.	1	2	8	9
g. I would watch the flow of water from my mouth to see if it contained blood.	1	2	8	9
h. I would do mental puzzles in my mind.	1	2	8	9

6. Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off based on evaluations of your work. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Indicate all of the statements that might apply to you by saying “yes” or “no” for each one.

	Yes	No	Don't Know	Refused
a. I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	2	8	9
b. I would review the list of duties for my	1	2	8	9

present job and try to figure out if I had fulfilled them all.				
c. I would go to the movies to take my mind off things.	1	2	8	9
d. I would try to remember any arguments or disagreements I might have had that would have resulted in the supervisor having a lower opinion of me.	1	2	8	9
e. I would push all thoughts of being laid off out of my mind.	1	2	8	9
f. I would tell my family that I'd rather not discuss my chances of being laid off.	1	2	8	9
g. I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	2	8	9
h. I would continue doing my work as if nothing special was happening.	1	2	8	9

***ANXIETY***

**I am going to read a few statements people have used to describe themselves. For each statement I would like you to tell me how much you feel that way right now, at this moment. Your choices are: “not at all,” “somewhat,” “moderately,” or “very much.” There are no right or wrong answers. Do not spend too much time on any one statement but give the answer that seems to describe best your feelings at this moment.**

	Not at All	Somewhat	Moderately	Very Much	Don't Know	Refused
7. I feel calm.	1	2	3	4	8	9
8. I am tense.	1	2	3	4	8	9
9. I feel upset.	1	2	3	4	8	9
10. I am relaxed.	1	2	3	4	8	9
11. I feel confident.	1	2	3	4	8	9
12. I am worried.	1	2	3	4	8	9

**OK, now that you have answered the questions about how you feel right now, I want you to respond to the same statements, but about how you generally or usually feel. I will read each statement, and you tell me how much you generally feel this way. Again, your choices are: “not at all,” “somewhat,” “moderately,” or “very much.”**

	Not at All	Somewhat	Moderately	Very Much	Don't Know	Refused
13. I feel calm.	1	2	3	4	8	9
14. I am tense.	1	2	3	4	8	9
15. I feel upset.	1	2	3	4	8	9
16. I am relaxed.	1	2	3	4	8	9
17. I feel confident.	1	2	3	4	8	9
18. I am worried.	1	2	3	4	8	9

**PERCEIVED RISK**

**For the next 2 items I will read statements about the possibility of getting ovarian cancer. Please tell me how you would rate your chances.**

19. Compared to most women your age, what would you say your chances are for developing ovarian cancer in the next 10 years? Would you say they are...

- Much lower
- Lower
- About the same
- Higher
- Much higher
- DON'T KNOW
- REFUSED

20. How likely is it that you will develop ovarian cancer in your lifetime? Would you say it is...

- Not at all likely
- A little likely
- Very likely, or
- Extremely likely
- DON'T KNOW
- REFUSED

Now think about the health histories of your own family members.

21. Have you ever talked with a healthcare professional about your family history of cancer?

- YES
- NO
- DON'T KNOW
- REFUSED

22. Do you believe that your **own** family medical history *increases, decreases, or has no effect on your personal* risk for developing ovarian cancer?

- INCREASES
- DECREASES
- HAS NO EFFECT
- DON'T KNOW
- REFUSED

23. Please tell me how much you agree or disagree with the following statement. "Getting ovarian cancer would be a very serious problem." Would you say you...

- Strongly Agree
- Agree
- Disagree, Or
- Strongly Disagree
- DON'T KNOW
- REFUSED



24. Please tell me how much you agree or disagree with the next statement. “There is a lot I can do to prevent ovarian cancer.” Do you...

- Strongly Agree
- Agree
- Disagree, Or
- Strongly Disagree
- DON'T KNOW
- REFUSED

**WORRY**

The next few questions ask about your thoughts of ovarian cancer during the past month. Please respond whether you have had these thoughts “never,” “rarely,” “sometimes,” “a lot,” or “all the time.”

	Never	Rarely	Sometimes	A Lot	All the Time	DON'T KNOW	REFUSED
25. During the past month, how often have you thought about your own chances of developing ovarian cancer? Would you say... <b>[If “never”, skip to Question 28]</b>	1	2	3	4	5	8	9
26. During the past month, how often have thoughts about your chances of getting ovarian cancer affected your mood? Would you say...	1	2	3	4	5	8	9
27. During the past month, how often have thoughts about your chances of getting ovarian cancer affected your ability to perform your daily activities? Would you say...	1	2	3	4	5	8	9

## ***FAMILY CANCER HISTORY***

**If participant responded in Questions 3 and 4 that they had some family history of breast or ovarian cancer continue, else skip to Question 29.**

**I would like to learn more about cancer in your family.**

28. Earlier, when I asked about cancer in your family, you said that you had at least one blood-related relative who had been diagnosed with breast or ovarian cancer. Which female relatives, on either your mother's or father's side of the family, ever had breast or ovarian cancer? Anyone else?

**[Check all that apply]**

- GRANDMOTHER [probe for number of grandmothers \_\_\_\_\_]
- AUNT [probe for number of aunts \_\_\_\_\_]
- MOTHER
- SISTER [probe for number of sisters \_\_\_\_\_]
- DAUGHTER [probe for number of daughters \_\_\_\_\_]
- OTHER [specify \_\_\_\_\_]
- NONE [If no **female** relatives, skip to Question 29.]
- DON'T KNOW [Skip to Question 29]
- REFUSED [Skip to Question 29]

**INTERVIEWER: Based on total responses to 28, circle the appropriate relationship variables in TABLES 1 and 2 and proceed with questioning for each relative listed, up to 9**

**Table 1**  
**Ovarian & Breast Cancer in GRANDMOTHERS and AUNTS**

<b>Relationship</b> [CIRCLE UP TO 9] G=Grandmother A=Aunt	Was your [G or A] on your father's or mother's side? *	Did your [G or A] have breast cancer?	[If "Yes" to breast cancer] If you know, did your ___ have cancer in one or both breasts?	[If "Yes" to breast cancer] If you know, at about what age was your ___ first diagnosed with breast cancer?	Did your [G or A] have ovarian cancer?	[If "Yes" to ovarian cancer] If you know, at about what age was your ___ first diagnosed with ovarian cancer?
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused
G A	Father	Yes	One	RECORD AGE	Yes	RECORD AGE
	Mother	No	Both	Don't know	No	Don't know
	Don't know	Don't know	Don't know	Refused	Don't know	Refused
	Refused	Refused	Refused	Refused	Refused	Refused

\* If participant says 2 (both) grandmothers had breast or ovarian cancer, first ask about one and then the other (e.g., "First, let's talk about your grandmother on your mother's side of your family....")

**Table 2**

**Ovarian & Breast Cancer in MOTHERS, SISTERS, DAUGHTERS & OTHER**

Relationship [CIRCLE UP TO 9]  M=Mother S=Sister D=Daughter O=Other	Did your _____ have breast cancer?	[If "Yes" to breast cancer] If you know, did your _____ have cancer in one or both breasts?	[If "Yes" to breast cancer] If you know, at about what age was your _____ first diagnosed with breast cancer?	Did your _____ have ovarian cancer?	[If "Yes" to ovarian cancer] If you know, at about what age was your _____ first diagnosed with ovarian cancer?
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused
M S D O (O=_____)	Yes No Don't know Refused	One Both Don't know Refused	RECORD AGE Don't know Refused	Yes No Don't know Refused	RECORD AGE Don't know Refused

29. Men can sometimes get breast cancer, although it is extremely rare. Have any of your male family members ever been diagnosed with breast cancer? By family members, I mean a blood relative like your father, brother (including half-brother), grandfather, uncle, or son?

- YES
- NO [Skip to Question 30]
- DON'T KNOW [Skip to Question 30]
- REFUSED [Skip to Question 30]

29a. Who was it?

- GRANDFATHER [If yes, number of grandfathers \_\_\_\_\_ and if only one, Mother's side or Father's side]
- FATHER
- UNCLE [If yes, number of uncles \_\_\_\_\_ and how many on mother's side and how many on father's side]
- BROTHER [If yes, number of brothers \_\_\_\_\_]
- SON [If yes, number of sons \_\_\_\_\_]
- DON'T KNOW
- REFUSED

30. Now I'd like to ask about other cancers in your family. Please think about your blood relatives such as your mother or father, grandparents, aunts or uncles, sisters or brothers, or children. Other than breast or ovarian cancer, have any of your blood relatives ever been told by a doctor or other health care professional that they had cancer?

- YES
- NO [Skip to Question 31]
- DON'T KNOW [Skip to Question 31]
- REFUSED [Skip to Question 31]

30a.

Who was that? (Relationship to Self)	Was that relative on your mother's or father's side?	What type of cancer did they have?	At what age were they diagnosed?
---	---	---------------------------------------	-------------------------------------

31. Genetic counseling involves a discussion with a health care professional about your family's history of cancer. Have you ever been referred by a doctor or another health care professional for genetic counseling for cancer risk?

- YES
- NO
- DON'T KNOW
- REFUSED

32. Has **anyone else** in your family been referred by a doctor or another health care professional for genetic counseling for cancer risk?

- YES
- NO
- DON'T KNOW
- REFUSED

33. There is a blood test called BRCA1 or BRCA2 that is a genetic test used to see if a person is at risk for getting breast or ovarian cancer based on changes in their genes (DNA). It does not determine if you have cancer or will definitely get cancer, but it can provide information about your risk of getting cancer. Have you ever had a BRCA1 or BRCA2 test?

- YES
- NO [**Skip to Question 34**]
- DON'T KNOW [**Skip to Question 34**]
- REFUSED [**Skip to Question 34**]

33a. Did the test results show that you have an increased risk for getting cancer?

- YES
- NO
- DON'T KNOW
- REFUSED

34. Has **anyone else** in your family ever had a BRCA1 or BRCA2 test to assess their risk for getting cancer?

- YES
- NO [**Skip to Question 35**]
- DON'T KNOW [**Skip to Question 35**]
- REFUSED [**Skip to Question 35**]

34a. If you know, did the test results show that your other family members have an increased risk for getting cancer?

- YES
- NO
- DON'T KNOW
- REFUSED

**CLOSENESS**

The next few questions ask about your relationship with relatives and close friends who have had cancer.

- 35. Have you ever had a close friend who was diagnosed with cancer?
  - YES [how many friends? \_\_\_\_\_]
  - NO [If also “No,” “Don’t know,” or “Refused” for Question 28-30, Skip to next section – Screening Questions.]
  - DON’T KNOW [If also “No,” “Don’t know,” or “Refused” for Question 28-30, Skip to next section – Screening Questions.]
  - REFUSED [If also “No,” “Don’t know,” or “Refused” for Question 28-30, Skip to next section – Screening Questions.]

<b>CATI PROGRAM: Tally responses</b>	
A. Number of relatives with cancer (Q28 + Q29 + Q30)	_____
B. Number of close friends with cancer (Q35)	_____
<b>C. Total (A+B)</b>	_____ → <b>If the total is:</b>
	None (0).....Skip to Question 49
	Exactly 1.....Go to Question 36
	More than 1.....Skip to Question 37

- 36. Did your [CATI PROGRAM “relative” or “friend”] who had cancer die from the disease?
  - YES [Skip to Question 37b]
  - NO [Skip to Question 38, use present tense]
  - DON’T KNOW [Skip to Question 38, use present tense]
  - REFUSED [Skip to Question 38, use present tense]
  
- 37. Of your [CATI PROGRAM “relatives” or “close friends”] who had cancer, to whom would you say you feel closest?  
[Enter response \_\_\_\_\_.]
  - 37a. Is your [Response to Question 37] still living?
    - YES [Skip to Question 38, use present tense]
    - NO
    - DON’T KNOW
    - REFUSED

37b. In what year did your **[Response to Question 37]** die?

**[CIRCLE]**

1 9 0 0

2 0 1 1

2 2

3 3

4 4

5 5

6 6

7 7

8 8

9 9

\_\_\_ DON'T KNOW

\_\_\_ REFUSED

37c. How old was **[CATI PROGRAM: he/she]** at the time?

0 0

1 1

2 2

3 3

4 4

5 5

6 6

7 7

8 8

9 9

\_\_\_ DON'T KNOW

\_\_\_ REFUSED

37d. How old were you at the time of **[CATI PROGRAM: his/her]** death?

0 0

1 1

2 2

3 3

4 4

5 5

6 6

7 7

8 8

9 9

\_\_\_ DON'T KNOW

\_\_\_ REFUSED



- 37e. Did your **[Response to Question 37]** die from cancer or from another cause?  
 \_\_\_ Cancer  
 \_\_\_ Another Cause  
 \_\_\_ DON'T KNOW  
 \_\_\_ REFUSED

**CLOSENESS**

**For the next few questions, I will read each statement, and you tell me what best describes your relationship and your experiences with your [Response to Question 37].**

- |   |                           |                             |                                 |            |         |
|---|---------------------------|-----------------------------|---------------------------------|------------|---------|
| 38. How close <b>[CATI PROGRAM “was” or “is”]</b> your relationship with your <b>[Response to Question 37]</b> ? Would you say....  | <b>Not close</b>          | <b>Somewhat close</b>       | <b>Very close</b>               | Don't Know | Refused |
| 39. How much time did you spend with your <b>[Response to Question 37]</b> before <b>[CATI PROGRAM “he/she”]</b> became ill from cancer? Would you say....  | <b>No time</b>            | <b>Some time</b>            | <b>A lot of time</b>            | Don't Know | Refused |
| 40. How much time <b>[CATI PROGRAM “did you spend” or “have you spent”]</b> with your <b>[Response to Question 37]</b> during his/her illness?  | <b>No time</b>            | <b>Some time</b>            | <b>A lot of time</b>            | Don't Know | Refused |
| 41. How much negative change <b>[CATI PROGRAM “did you witness” or “have you witnessed”]</b> in your <b>[Response to Question 37]</b> 's quality of life or daily living after he/she became ill?     | <b>No negative change</b> | <b>Some negative change</b> | <b>A lot of negative change</b> | Don't Know | Refused |
| 42. How often <b>[CATI PROGRAM “did” or “do”]</b> you talk with your <b>[Response to Question 37]</b> about the cancer?   | <b>Never</b>              | <b>Sometimes</b>            | <b>Very often</b>               | Don't Know | Refused |
| 43. How much do you believe you resemble your <b>[Response to Question 37]</b> physically?  | <b>Not at all</b>         | <b>Somewhat</b>             | <b>A lot</b>                    | Don't Know | Refused |
| 44. How much do you believe you resemble your <b>[Response to Question 37]</b> in terms of personality?   | <b>Not at all</b>         | <b>Somewhat</b>             | <b>A lot</b>                    | Don't Know | Refused |
| 45. How much has your <b>[Response to Question 37]</b> 's experience with cancer affected you?  | <b>Not at all</b>         | <b>Somewhat</b>             | <b>A lot</b>                    | Don't Know | Refused |
| 46. How often do you think about your <b>[Response to Question 37]</b> 's experience with cancer?   | <b>Never</b>              | <b>Sometimes</b>            | <b>Very often</b>               | Don't Know | Refused |
| 47. How much time have you spent talking with friends or family members about any concerns you had about your <b>[Response to Question 37]</b> 's experience with cancer?                             | <b>No time</b>            | <b>Some time</b>            | <b>A lot of time</b>            | Don't Know | Refused |
| 48. No one knows exactly why some people get cancer and others don't, but we do know that certain environments, family histories, and personal habits can increase a person's risk of getting cancer. |                           |                             |                                 |            |         |

48a. What do you think might have caused your **[Response to Question 37]** to get cancer? **[OPEN-ENDED]** Anything else? **[CODE UP TO 3]**

- FAMILY HISTORY/GENES
- UNHEALTHY DIET
- SMOKING
- SECONDHAND SMOKE
- OLDER AGE
- ALCOHOL/DRINKING
- CAFFEINE
- MEDICATIONS/ESTROGEN THERAPY
- SUN BATHING/TANNING
- OVERWEIGHT/OVEREATING/LITTLE EXERCISE
- NOT GOING TO THE DOCTOR
- POOR GENERAL HEALTH
- ENVIRONMENTAL FACTORS-GENERAL, PESTICIDES, RADIATION
- PERSONALITY TRAITS
- STRESS
- BAD LUCK/CHANCE
- FATE/GOD'S WILL
- OTHER (RECORD UP TO 3) \_\_\_\_\_
- NOTHING
- NO/DON'T KNOW
- REFUSED

48b. For you personally, what do you think might increase your own chances of getting cancer? **[OPEN-ENDED]** Anything else? **[CODE UP TO 3]**

- FAMILY HISTORY/GENES
- UNHEALTHY DIET
- SMOKING
- SECONDHAND SMOKE
- OLDER AGE
- ALCOHOL/DRINKING
- CAFFEINE
- MEDICATIONS/ESTROGEN THERAPY
- SUN BATHING/TANNING
- OVERWEIGHT/OVEREATING/LITTLE EXERCISE
- NOT GOING TO THE DOCTOR
- POOR GENERAL HEALTH
- ENVIRONMENTAL FACTORS-GENERAL, PESTICIDES, RADIATION
- PERSONALITY TRAITS
- STRESS
- BAD LUCK/CHANCE
- FATE/GOD'S WILL
- OTHER (RECORD UP TO 3) \_\_\_\_\_
- NOTHING
- NO/DON'T KNOW
- REFUSED

**SCREENING BEHAVIOR**

The next questions are about your experiences with getting tested or screened for various kinds of cancer. This is when a health care professional checks to see if you have a disease when you are not showing any signs or experiencing any symptoms.

49. A fecal occult blood test is a test kit that you receive from a health care professional to screen for colon or rectal cancer. At home, you put a small piece of stool on a test card. You do this for three bowel movements in a row. Then you return the test cards to the doctor or lab. The stool samples are checked for blood. Have you had a fecal occult blood test?

- YES
- NO, NEVER [**Skip to Question 50**]
- DON'T KNOW [**Skip to Question 50**]
- REFUSED [**Skip to Question 50**]

49a. When was your most recent fecal occult blood test? Was it...

- Within The Past Year,
- Between 1 And 2 Years Ago, Or
- More Than 2 Years Ago?
- DON'T KNOW
- REFUSED

50. A colonoscopy is another method used to test for colon cancer. A tube is inserted in the rectum to view the bowel for signs of cancer or other health problems. In this exam, the **entire colon** is checked. Sedation or pain medication usually **is required**. Have you had a colonoscopy?

- YES
- NO, NEVER [**Skip to Question 51**]
- DON'T KNOW [**Skip to Question 51**]
- REFUSED [**Skip to Question 51**]

50a. When was your most recent colonoscopy? Was it...

- Within The Past Year,
- Within The Past 1-5 Years,
- Within The Past 6-10 Years, Or
- More Than 10 Years Ago?
- DON'T KNOW
- REFUSED

51. A flexible sigmoidoscopy is another method used to test for colon cancer. A tube is inserted in the rectum to view the bowel for signs of cancer or other health problems. In this exam, the **last part of the colon** is checked. Sedation or pain medication is usually **not required**. Have you had a sigmoidoscopy?

- YES
- NO, NEVER [**Skip to Question 52**]
- DON'T KNOW [**Skip to Question 52**]
- REFUSED [**Skip to Question 52**]

51a. When was your most recent sigmoidoscopy? Was it...

- Within The Past Year,
- Within The Past 1-3 Years,
- Within The Past 4-5 Years, Or
- More Than 5 Years Ago?
- DON'T KNOW
- REFUSED

52. A mammogram is an x-ray of each breast to look for early signs of breast cancer. Have you had a mammogram?

- YES
- NO, NEVER [**Skip to Question 53**]
- DON'T KNOW [**Skip to Question 53**]
- REFUSED [**Skip to Question 53**]

52a. When was your most recent mammogram? Was it...

- Within The Past Year,
- Between 1 And 2 Years Ago, Or
- More Than 2 Years Ago?
- DON'T KNOW
- REFUSED

53. A clinical breast exam is when a health care professional feels your breasts for lumps. Have you had a clinical breast exam?

- YES
- NO, NEVER [**Skip to Question 54**]
- DON'T KNOW [**Skip to Question 54**]
- REFUSED [**Skip to Question 54**]

53a. When was your most recent clinical breast exam? Was it...

- Within the past year,
- Between 1 and 2 years ago, or
- More than 2 years ago?
- DON'T KNOW
- REFUSED

54. Have you ever had a pap smear test to test for cervical cancer?  
[**READ IF NECESSARY:** A Pap smear is a routine test for women in which a health care professional examines the cervix, takes a cell sample from the cervix with a small stick or brush and sends it to the lab.]

- YES
- NO, NEVER [**Skip to Question 55**]
- DON'T KNOW [**Skip to Question 55**]
- REFUSED [**Skip to Question 55**]

54a. When was your most recent pap smear test? Was it...

- Within The Past Year,
- Between 1 And 3 Years Ago, Or
- More Than 3 Years Ago?
- DON'T KNOW
- REFUSED

55. A CA-125 test is a blood test used to find some types of cancer, especially ovarian cancer. This test is sometimes recommended as a screening test for women with a strong family history of ovarian cancer or women with a hereditary genetic risk for ovarian cancer.

55a. Have you ever heard of a CA-125 blood test?

- YES
- NO [**Skip to Question 58**]

56. Have you ever had a blood test to check for CA-125?

- YES
- NO [**Skip to Question 57**]
- DON'T KNOW [**Skip to Question 57**]
- REFUSED [**Skip to Question 57**]

56a. Was that:

- Within the past year
- 1-2 years ago, or [**Skip to Question 56b**]
- More than 2 years ago? [**Skip to Question 56b**]
- DON'T KNOW [**Skip to Question 56b**]
- REFUSED [**Skip to Question 56b**]

56a1. What month did you have your CA-125 test within the past year?  
Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec

- DON'T KNOW
- REFUSED

56b. Was having the test a result of your request, a healthcare professional's suggestion, or both your request and a healthcare professional's suggestion?

- My request
- Healthcare professional's suggestion
- Both: my request & professional's suggestion
- Other [EXPLAIN]
- DON'T KNOW
- REFUSED

56c. I am going to read you a series of reasons why a person might have a CA-125 blood test. For each one, I would like you to tell me whether or not it was the reason you had a CA-125 blood test. You may answer 'yes' to more than one reason.

56c1. Was it because of symptoms you were having such as bloating, pain or abnormal bleeding?

- YES
- NO
- DON'T KNOW
- REFUSED

56c2. Was it to check on problems you were having such as fibroids or ovarian cyst?

- YES
- NO
- DON'T KNOW
- REFUSED

56c3. Was it because of your family history of cancer?

- YES
- NO
- DON'T KNOW
- REFUSED

56c4. Was it part of a routine physical exam or screening exam?

- YES
- NO
- DON'T KNOW
- REFUSED

56c5. Was it because of a suggestion made by a family member or friend?

- YES Which family member (or friend) \_\_\_\_\_?
- NO
- DON'T KNOW
- REFUSED

- 56c6. Was it for another reason?  
 YES **[If yes, ask what reason.]**  
 NO  
 DON'T KNOW  
 REFUSED

57. Are you planning to get **[CATI PROGRAM: “a” or “another”]** CA-125 blood test?  
 YES  
 NO  
 DON'T KNOW  
 REFUSED

58. During a transvaginal ultrasound a probe is placed into the vagina and is used to produce a picture of the uterus and ovaries. Doctors examine the picture for changes or abnormal areas. Have you ever had a transvaginal ultrasound examination?  
 YES  
 NO **[Skip to Question 59]**  
 DON'T KNOW **[Skip to Question 59]**  
 REFUSED **[Skip to Question 59]**

- 58a. Was that:  
 Within the past year  
 1-2 years ago, or **[Skip to Question 58b]**  
 More than 2 years ago? **[Skip to Question 58b]**  
 DON'T KNOW **[Skip to Question 58b]**  
 REFUSED **[Skip to Question 58b]**

- 58a1. What month did you have your transvaginal ultrasound examination within the past year?  
Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec  
 DON'T KNOW  
 REFUSED

- 58b. Was having the test a result of your request, a healthcare professional's suggestion, or both your request and a healthcare professional's suggestion?  
 My request  
 Healthcare professional's suggestion  
 Both my request and healthcare professional's suggestion  
 Other, please specify \_\_\_\_\_  
 DON'T KNOW  
 REFUSED

- 58c. I am going to read you a series of reasons why a person might have a transvaginal ultrasound examination. For each one, I would like you to tell me whether or not it was the reason you had a transvaginal ultrasound. You may answer 'yes' to more than one reason.

- 58c1. Was it as part of an examination during pregnancy?  
 YES  
 NO  
 DON'T KNOW  
 REFUSED
- 58c2. Was it because of a family history of cancer?  
 YES  
 NO  
 DON'T KNOW  
 REFUSED
- 58c3. Was it to check on symptoms such as abnormal bleeding or pain?  
 YES  
 NO  
 DON'T KNOW  
 REFUSED
- 58c4. Was it to check on problems such as fibroids, ovarian cyst or endometriosis?  
 YES  
 NO  
 DON'T KNOW  
 REFUSED
- 58c5. Was it because of a suggestion by a family member or friend?  
 YES Which family member (or friend) \_\_\_\_\_?  
 NO  
 DON'T KNOW  
 REFUSED
- 58c6. Was it part of a routine physical exam or screening exam?  
 YES  
 NO  
 DON'T KNOW  
 REFUSED
- 58c7. Was it for another reason?  
 YES [If yes, ask what reason.]  
 NO  
 DON'T KNOW  
 REFUSED



59. Are you planning to get [CATI PROGRAM: “a” or “another”] transvaginal ultrasound?

- YES
- NO
- DON'T KNOW
- REFUSED

60. Have you ever given birth?

- YES [How many children? \_\_\_\_\_]
- NO
- DON'T KNOW
- REFUSED

61. Endometriosis is a condition in which the lining of the uterus grows outside of the uterus and causes abdominal or pelvic pain. Have you ever been told by a health care professional that you have endometriosis?

- YES
- NO
- DON'T KNOW
- REFUSED

62. A hysterectomy is an operation to remove the uterus (womb). Have you had a hysterectomy?

- YES
- NO
- DON'T KNOW
- REFUSED

### **DEMOGRAPHICS**

**And now some questions about your general background.**

63. Are you Hispanic or Latino?

- YES
- NO
- DON'T KNOW
- REFUSED

64. Which one or more of the following would you say is your race?

**[Record UP TO 3 responses, if necessary]**

- American Indian, Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other **[Record Response]** \_\_\_\_\_
- DON'T KNOW
- REFUSED

65. Having a Jewish heritage may affect your risk for breast and ovarian cancer. Do you have any Jewish ancestors?

- YES
- NO
- DON'T KNOW
- REFUSED
- OTHER [**Record Response**] \_\_\_\_\_

66. What is your marital status, are you currently...?

- Married
- Separated
- Divorced
- Single, never married
- Living with a significant other or partner, or
- Widowed
- DON'T KNOW
- REFUSED

67. Was there a time in the past year when you needed to see a health care professional but could not because of the cost?

- YES
- NO
- DON'T KNOW
- REFUSED

68. What is the highest grade or year of school you completed?

**[Read only if necessary:]**

- Never attended school or only attended kindergarten
- Grades 1 through 8 (Elementary)
- Grades 9 through 11 (Some high school)
- Grade 12 or GED (High school graduate)
- College 1 year to 3 years (Some college or technical school)
- College 4 years or more (e.g., college graduate, bachelor's, BA, BS)
- Graduate degree (e.g., master's, doctorate, MD, JD, PhD)
- DON'T KNOW
- REFUSED

69. I'm going to read you some ranges for income. Please stop me when I reach your income range. Is your annual household income from all sources...?

**[If respondent refuses at ANY income level, code "Refused."]**

**[Read until she stops you:]**

- \$25,000 or less
- More than \$25,000 but less than \$35,000
- More than \$35,000 but less than \$50,000
- More than \$50,000 but less than \$75,000
- More than \$75,000
- DON'T KNOW
- REFUSED

70. How many people, including you, were supported by this income during this past calendar year?

- PERSON/PEOPLE
- DON'T KNOW
- REFUSED

### **KNOWLEDGE**

**The following questions are about ovarian cancer. Please tell me whether you think these statements are "true," "false," or that you don't know.**

71. Women never experience symptoms of ovarian cancer.

- TRUE
- FALSE
- DON'T KNOW
- REFUSED

72. Ovarian cancer causes more deaths than breast cancer.

- TRUE
- FALSE
- DON'T KNOW
- REFUSED

73. I am going to read you some things that may increase, decrease or have no effect on a woman's chances of getting ovarian cancer. If you are not sure, you can say you don't know. Do you think that **[CATI PROGRAM: FIRST ITEM]** increases, decreases, or has no effect on a woman's chances of getting ovarian cancer? How about **[CATI PROGRAM: SECOND ITEM, etc.]**?

**CIRCLE:**

**I=Increase D=Decrease**  
**NE=No effect DK=don't know**

- |   |   |   |    |    |
|---|---|---|----|----|
| a. being hit in the abdomen                               | I | D | NE | DK |
| b. having one or more close relatives with ovarian cancer | I | D | NE | DK |
| c. giving birth   | I | D | NE | DK |
| d. having had breast, endometrial, or colon cancer        | I | D | NE | DK |
| e. getting older  | I | D | NE | DK |
| f. having many sexual partners                            | I | D | NE | DK |
| g. taking oral contraceptives                             | I | D | NE | DK |

***INCLUDE CLOSING STATEMENTS/REMARKS***

Those are all of the questions that we have today—thanks for your time and thoughtful responses. And thank you for helping us to learn about ways to understand women’s risk and worry about ovarian cancer.

We talked about several types of screening during this interview. Age and family history are some factors that help determine the need for some of these screening methods. Any questions you may have about your need for any of the screening tests we discussed today should be discussed with your doctor. You can also find more information about cancer at the website for the Centers for Disease Control and Prevention at [www.cdc.gov/cancer/](http://www.cdc.gov/cancer/).

Do you have any questions for me regarding this survey? **[ANSWER ANY QUESTIONS]**

I’d like to make sure I have your correct mailing address so we can send you the \$15.00 gift card. Could you please verify your mailing address for me? **[RECORD MAILING ADDRESS]** Your gift card, along with a thank you letter, should be mailed to you within 3-4 weeks.

As I stated in the beginning of our call, we would like to contact you again in about one year to ask you a few additional questions—this would be a brief call that would take no more than 15 minutes of your time. As I mentioned earlier, if you participate in the follow-up interview you will receive a \$10 gift card. Giving us permission now to contact you again, does not mean you have to participate in the follow-up study. Are you willing to let us call you again to invite you to participate in the study? **[RECORD RESPONSE]**

**[IF NO, THANK THEM FOR PARTICIPATING TODAY AND CONFIRM THAT WE WILL NOT CALL THEM BACK IN ONE YEAR FOR THE FOLLOW-UP INTERVIEW.]**

**[IF YES]:**

We would like to send you a reminder letter about one month prior to when we call you for the follow-up interview. Can we mail the reminder letter to you at the same address to which we will mail your \$15 gift card in 3-4 weeks from now? **[IF NOT, ASK IF THERE IS ANOTHER ADDRESS TO WHICH THE REMINDER LETTER CAN BE MAILED.]**

In addition, since people often move within the span of a year, we would like to get the name of one or two other people who would likely know where we could reach you. Many people give

their mother's or sister's name. Others give the name of a very close friend. Is there someone who would be a good person for us to contact in case we cannot reach you at this phone number?

If yes, what is their name? Would you spell that for me?

**NAME:**

And what is their relationship to you?

**RELATIONSHIP:**

Where would we contact him/her?

**ADDRESS:**

**CITY:**

**STATE:**

**ZIPCODE:**

Is there a phone number?

**PHONE NUMBER:**

Finally, we have a toll-free number you can call at any time during the next year if you would like to update us with new contact information if you move or change your telephone number. The toll-free number is 1-800-XXX-XXXX. Since this number is only used for this study, you can leave your contact information on the voicemail if nobody is available to answer the phone when you call. If you prefer you can leave your name and telephone number and someone can call you back.

Do you have any final questions before we conclude for today?

**[ANSWER ANY QUESTIONS.]**

Thank you again.

