

# **ATTACHMENT F**

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*Data Collection Instrument:  
Follow-Up Questionnaire*

Public reporting burden of this collection of information is estimated to average 15 minutes per response, 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)

**[8.6 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 am calling on behalf of the Centers for Disease Control and Prevention (CDC) and Henry Ford Health System. We spoke with you about a year ago and I'm following up with you now to ask a few additional questions. If you remember, we are working to conduct a health research study about women's knowledge about cancer, their experiences with cancer in their family and worries they may have about cancer.

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

As I mentioned, we are working with researchers at Henry Ford Health System and we spoke with you about a year ago. At that time, 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. We conduct a lot of research for the federal government, including CDC. We are the same research firm that conducted the initial survey in which you participated a year ago.>

**[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.]**

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

**[CONSENT]**

If you recall, this is a research study about what women know and think about cancer. Today, we will ask you questions about your personal cancer history, your family cancer history, and your thoughts about your own risk of cancer. Taking part in this survey will take about 15 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 wish to finish the survey, it will not change the care you get at Henry Ford Health System. If you complete the full interview today, you will be sent a \$10 gift card for your time.

You will not directly benefit from answering our questions. But the data we collect during this interview 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. We are in the process of applying for a Certificate of Confidentiality. This means that anything you tell us will not have to be given out to anyone, 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 to 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 when we write reports or papers.

If you have concerns about the study or how it is being carried out, you may contact <study coordinator for Macro> at <phone number>. 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-XXX-XXXX. Tell them you are calling about CDC protocol # XXXX. 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-XXXX.

Before I ask these questions, I would like to get your verbal consent to participate in this interview. Would you like to participate?

[If NO: Thank you for your time. If you change your mind, please call <phone number>]

[If YES: I will confirm that you are willing to answer the questions in this survey and will document your verbal consent. Do you have any questions for me before we start the survey? {ANSWER ANY QUESTIONS}]

### **[8.3 Grade Level, Flesch Kincaid Readability Formula]**

#### **[PERSONAL CANCER HISTORY]**

**I'm going to start by asking you some questions about your medical history.**

1. Has a health care professional told you that you had cancer since you participated in the last survey?  
 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?
- BRAIN TUMOR
  - BREAST
  - COLON OR COLORECTAL
  - ENDOMETRIAL
  - KIDNEY
  - LEUKEMIA/LYMPHOMA
  - LIVER
  - LUNG
  - OVARIAN **[IF DIAGNOSED WITH OVARIAN CANCER, SKIP TO QUESTION #8]**
  - SARCOMA
  - SKIN
  - THYROID
  
  - OTHER **[Record Response]** \_\_\_\_\_
  - DON'T KNOW
  - REFUSED

**[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.**

2. 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
3. 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

**[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
4. 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 7]</b>	1	2	3	4	5	8	9
5. 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
6. 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

7. Since you participated in the last survey, have you talked to a healthcare professional about screening for ovarian cancer?
- YES
  - NO
  - DON'T KNOW
  - REFUSED

**[SCREENING BEHAVIOR]**

The next questions are about your experiences with getting tested or screened for ovarian cancer. By screening, I am referring to when a health care professional checks to see if you have a disease when you are not showing any signs or experiencing any symptoms.

8. 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.
- 8a. Have you ever heard of a CA-125 test?
- Yes
  - NO **[Skip to Question 10]**

- 8b. Have you had a blood test to check for CA-125 since you participated in the previous telephone survey?
- YES
  - NO **[Skip to Question 9]**
  - DON'T KNOW **[Skip to Question 9]**
  - REFUSED **[Skip to Question 9]**
- 8c. In what month and year did you have your last CA 125 test?
- Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec  
2007 2008
- DON'T KNOW
  - REFUSED
- 8d. 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
- 8e. I am going to read you a series of reasons why a person would 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.
- 8e1. Was it because of symptoms you were having such as bloating, pain or abnormal bleeding?
- YES
  - NO
  - DON'T KNOW
  - REFUSED
- 8e2. Was it to check on problems you were having such as fibroids or ovarian cyst?
- YES
  - NO
  - DON'T KNOW
  - REFUSED
- 8e3. Was it because of your family history of cancer?
- YES
  - NO
  - DON'T KNOW
  - REFUSED

8e4. Was it part of a routine physical exam or screening exam?

- YES
- NO
- DON'T KNOW
- REFUSED

8e5. Was it because of a suggestion made by a family member or friend?

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

8e6. Was it for another reason?

- YES **[If yes, ask what reason.]**
- NO
- DON'T KNOW
- REFUSED

9. Are you planning to get **[CATI PROGRAM: "a" or "another"]** CA-125 blood test?

- YES
- NO
- DON'T KNOW
- REFUSED

10. 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 had a transvaginal ultrasound examination since you participated in the previous telephone survey?

- YES
- NO **[Skip to Question 11]**
- DON'T KNOW **[Skip to Question 11]**
- REFUSED **[Skip to Question 11]**

10a. In what month and year did you have your last transvaginal ultrasound examination?

- Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec  
2007 2008
- DON'T KNOW
  - REFUSED

10b. 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

10c. I am going to read you a series of reasons why a person would have a transvaginal ultrasound examination. 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.

10c1. Was it as part of an examination during pregnancy?

- YES
- NO
- DON'T KNOW
- REFUSED

10c2. Was it because of a family history of cancer?

- YES
- NO
- DON'T KNOW
- REFUSED

10c3. Was it to check on symptoms such as abnormal bleeding or pain?

- YES
- NO
- DON'T KNOW
- REFUSED

10c4. Was it to check on problems such as fibroids, ovarian cyst or endometriosis?

- YES
- NO
- DON'T KNOW
- REFUSED

10c5. Was it part of a routine physical exam or screening exam?

- YES
- NO
- DON'T KNOW
- REFUSED



10c6. Was it because of a suggestion made by a family member or friend?

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

10c7. Was it for another reason?

- YES **[If yes, ask what reason.]**
- NO
- DON'T KNOW
- REFUSED

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

- YES
- NO
- DON'T KNOW
- REFUSED

### **[FAMILY CANCER HISTORY]**

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

12. When you were previously interviewed for this study, you told me that you **[CATI PROGRAM “had a \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_” or “did not have any female relatives”]** who had been diagnosed with breast or ovarian cancer. Since that time, have you learned of **[CATI PROGRAM “any other” or “any”]** females relatives on either your mother’s or father’s side of the family who had breast or ovarian cancer?

- YES
- NO **[Skip to Closing Statements]**
- DON'T KNOW **[Skip to Closing Statements]**
- REFUSED **[Skip to Closing Statements]**

12a. Who was that? [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 \_\_\_\_\_]**
- DON'T KNOW
- REFUSED

12b. Were any of these female relatives diagnosed with breast or ovarian cancer since you participated in the last survey?

- YES
- NO
- DON'T KNOW
- REFUSED

13. 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

**[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 \$10.00 gift card. Could you please verify your mailing address for me? [RECORD MAILING ADDRESS]  
Your gift card should be mailed to you within 3-4 weeks.

Thank you again.

