

Patient Interview Guide

Study ID _____

Date:

Participant Name:

Time:

Name(s) of screener:

INTRODUCTION

Hello, my name is _____ and I work with Moffitt Cancer Center. We are conducting interviews with patients diagnosed with ovarian cancer. I would like to invite you to share your opinions about what you believe to be barriers to implementation of GC/GT for ovarian cancer patients and testing for at-risk relatives.

PURPOSE

We are seeking to identify barriers to implementation of GC/GT for ovarian cancer patients and cascade testing for at-risk relatives. The identification of barriers will be critical to the development of interventions to address this multifaceted problem and ultimately deliver high quality patient care as well as create opportunities to prevent cancer in at-risk relatives. We would like your help. Please feel free to provide honest opinions about your perceptions of barriers to the implementation of GC/GT for ovarian cancer patients.

The interview will take no more than 1 hour. In appreciation of your time, you will get a \$50 gift card at the end of our discussion. There are no right or wrong answers. We want to know what you really think, so please feel free to speak freely. We will audio record the discussion so we don't miss any of your comments. It is especially important that you speak clearly and loudly so that the digital recorder can pick up your voice.

Anything you say during this interview is confidential. We will not share your answers with anyone outside our research team. Also, your answers and comments will not be linked to your name or anything that might identify you. Additionally, your doctors will not know that you participated in this interview or see your responses. A final report will be prepared or published from these data but your name or anything that would identify you will not be used. We hope you feel comfortable to speak freely. We have to get through a certain number of questions and want to be sure to keep you only for the time that we promised. To make that happen, I may ask you to finish your thought or sentence and then move to another topic or question.

Do you have any questions about the study before we start? [Answer any questions]

Okay, let's get started.

Before we get started, I just want to provide you with a brief overview of some common terms we will be using during today's interview. You may or may have not heard these terms before.

- a. **Genetic Counseling**: Speaking with a genetic counselor regarding your genetic or inherited factors that may increase your risk of cancer (before you have had your blood drawn for testing).
- b. **Genetic Testing**: Giving a blood sample so that it can be analyzed to see if you carry a particular gene mutation that increases your risk of developing breast cancer.
- c. **Cascade testing** is when you do genetic testing for a patient with an ovarian cancer diagnosis. If that patient tests positive, then genetic counseling and testing is offered to blood relatives of the patient.

Do you have any questions about any of these terms?

[If yes, answer any questions]

[If no] **Great, let's get started!**

1. What are some of the things you have heard about **genetic counseling** prior to this study?
 - Probe: Where did you hear about **genetic counseling**?
2. Can you describe what a genetic counselor does?
3. What do you believe are some of the benefits of **genetic counseling**?
4. Did you ever personally receive a referral to a cancer genetic counselor?
 - If you **did not** receive one, do you wish you did? Why or why not?
 - If you **did** receive a referral:
 - Who provided this referral?
 - Did you or your doctor bring up the referral initially?
 - What reasons did your doctor give you for referring you for **genetic counseling**?
 - Did you attend a **genetic counseling** appointment? If so, can you tell me about your experience?
5. What would (or has) prevent(ed) you from receiving **genetic counseling**?
 - Probe: Cost, belief in effectiveness, fear, accuracy, etc.
 - Even if you have completed **genetic counseling**, what do you believe are reasons people may not complete it?
 - How do you think these reasons can be addressed for you or patients to complete?
6. Before today, what are some of the things you have heard about **genetic testing**?
 - What about **genetic testing** specific to the inherited gene for breast and ovarian cancer? These are also referred to as *BRCA1 & BRCA2 genes*.
 - Where did you hear about **genetic testing**?
7. What do you believe are some of the benefits of **genetic testing**?
8. Did any health care provider ever suggest a genetic test related to your cancer?
 - If yes, have you completed **genetic testing**?

- If not, would you be interested in learning more about **genetic testing**?
 - How did you feel about the quality of the information you received about **genetic testing**?

9. For patients who completed **genetic testing**:

- What prompted you to complete **testing**?
- Did you receive your test results?
 - If so, what did your test results reveal?
- Did you share test results with your family members?
 - Did you face any challenges in sharing this information with your family?
 - What resources would have been helpful to share this information with your family?

10. What would (or has) prevent(ed) you from receiving **genetic testing**?

- Probe: Cost, belief in effectiveness, fear, accuracy, etc.
- Even if you have completed **genetic testing**, what do you believe are reasons people may not complete it?
- How do you think these reasons can be addressed to make it easier for you or other patients to complete **genetic testing**?

11. Do you think **genetic testing** could have affected your ovarian cancer treatment?

- Probe: Why or why not?

12. Did any health care provider ever discuss whether any of your family members should have **genetic testing**?

- Have you discussed **genetic testing** with your family members?
- Did they receive **genetic testing**?

Okay now I need to ask you some questions about yourself. This will help us see if there are common characteristics among people we are interviewing.

1. What is your age?

2. What is your race?

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or other Pacific Islander

White

More than one race

Other

Please specify: _____

3. What is your ethnic identity?

Hispanic or Latino

Not Hispanic or Latino

4. Are you of Ashkenazi Jewish descent?

No

Yes

Maternal

Paternal

Both

5. How many years of school have you completed?

8 or less years

Some high school

High school graduate, or GED

Some college

College graduate or beyond

6. Do you have health care education or health care work experience?

No

Yes

Please specify: _____

7. What type of health insurance do you currently have?
- Private health insurance
 - Medicare
 - Medicaid
 - Military insurance
 - None
 - Prefer not to answer
 - Other
- Please specify: _____

Do you have any other questions or comments?

Okay, that concludes the interview. Thank you so much for your time!