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<b>13. ABSTRACT (Maximum 200 Words)</b>  This project aims to gain a better understanding of the implications of genetic testing for breast-ovarian cancer susceptibility. The primary goal is to evaluate the impact of BRCA1/B RCA2 mutation testing on long term psychosocial (quality of life, distress, social functioning) and prevention/surveillance (mammography, CA125, transvaginal ultrasound, prophylactic mastectomy, prophylactic oophorectomy and chemoprevention) outcomes. To accomplish this we will measure outcomes within a group of women who received BRCA1/BRCA2 test results at least four years ago. We will divide our sample based upon their personal cancer history - evaluating cancer survivors with different measures compared to unaffected individuals. For both survivors and unaffected individuals we will recruit separate comparison samples of women who have never received BRCA1/BRCA2 testing. To date, we have submitted a protocol and received IRB approval from Georgetown University, have submitted a protocol and are awaiting approval from the DOD, have developed our measurement and data management systems and are prepared to begin accrual upon receipt of human subjects approval from the DOD.				
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## INTRODUCTION

Genetic testing for breast-ovarian cancer susceptibility has the potential to reduce breast and ovarian cancer mortality among high risk women. However, there has been ongoing concern regarding the quality of life implications of learning one's mutation status. To date, there have been no studies to evaluate the long-term psychosocial and behavioral impact of receiving clinical BRCA1/2 test results. Several studies have examined these outcomes in the short-term. Although preliminary evidence suggests that the receipt of a positive BRCA1/2 test result does not lead to increased short-term distress, it is clear that women who receive positive test results do report more distress than those who receive negative test results. It is not clear, however, whether this distress has long-term implications. It is possible that distress could decline over time as the individual adapts to her positive test result and ongoing risk. Alternatively, the modestly elevated distress reported in the short-term could be evidence of chronic stress. Ongoing stress has been shown to adversely impact health behaviors and health outcomes. Given the risk status of this population, it is particularly important to better understand the long-term distress levels and the role of distress in adoption of recommended breast and ovarian cancer risk reduction and early detection behavior. To date, there have been no studies to examine these issues.

One of the main potential benefits of BRCA1/BRCA2 testing is to motivate carriers to take behavioral action to reduce their risk of breast and ovarian cancer mortality. However, we do not yet know whether carriers actually engage in such actions. Preliminary evidence suggests that a relatively small proportion of carriers obtain prophylactic surgery in the year following testing. The proportion of carriers who utilize chemopreventive agents such as tamoxifen remains unknown. The few studies to examine screening utilization in the year following disclosure found sub-optimal rates of screening among positives. In fact, rates of mammography have not been found to increase following a positive mutation test. Although mutation carriers did report higher rates of mammography, this difference was due to appropriate decreases in screening among younger noncarriers. In terms of ovarian cancer screening, rates of CA-125 and transvaginal ultrasound do increase among carriers in the year following testing. However, overall ovarian cancer screening rates remain below 30%. To date, there have been no studies to evaluate the long-term cancer prevention and screening behaviors of this population. If genetic testing is to fulfill its promise of reducing mortality among individuals from hereditary cancer families, behavioral change must follow the receipt of a positive test result. The first step to addressing this question is to evaluate the behavior of individuals in the years following testing. If individuals remain non-adherent to prevention and screening guidelines, it is particularly important to understand why and to identify early predictors of behavioral non-adherence in this vulnerable population. We will evaluate the role of distress/quality of life as a potential predictor of adverse behavioral outcomes.

The primary goal of this project is to evaluate long term psychosocial (quality of life, distress, social functioning) and prevention/surveillance (mammography, CA125, transvaginal ultrasound, prophylactic mastectomy, prophylactic oophorectomy and chemoprevention) outcomes. To accomplish this we will measure outcomes within a group of women who received BRCA1/BRCA2 test results at least four years ago. We will divide our sample based upon their personal cancer history – evaluating cancer survivors with different measures compared to unaffected individuals. For both survivors and unaffected individuals we will recruit separate comparison samples of women who have never received BRCA1/BRCA2 testing.

Until we better understand the long-term outcomes of BRCA1/2 testing, it is unlikely that such testing will fulfill its promise to reduce breast and ovarian cancer mortality. By evaluating the impact of testing, appropriate intervention strategies can be developed so that individuals at-risk for distress or non-adherence could be targeted for early intervention and/or ongoing support. This research could

provide information necessary to make decisions about how and where to allocate scarce counseling resources and to tailor health promotion efforts to individual needs. Genetic testing for breast-ovarian cancer susceptibility is becoming more widely available to the general population. Prior to its routine use, we should make sure that we fully understand its long-term implications.

## **BODY**

We have listed each of the tasks from our Statement of Work, and the associated accomplishments.

*Task 1.* Finalize accrual procedures and measures to be included (months 1-6).

a. Meet with CARE program staff to confirm the procedures for patient recontact.

We have completed this task and have generated a list of CARE participants who are eligible for recontact for this study. As soon as final DOD IRB approval is received, we can immediately begin to enroll these individuals.

b. Finalize recruitment letters for each of the study cohorts.

These letters have been completed and are included in the attached Appendix.

c. Finalize the telephone questionnaires to be administered to each cohort.

These interviews have been completed and we are awaiting final DOD IRB approval to begin pilot testing and finalizing these surveys.

d. Develop interview database.

Preliminary interview database has been developed. This database will be beta tested upon receipt of approval to begin interviewing.

e. Develop subject tracking system using Access database.

A preliminary tracking system has been developed and tested. This tracking system will be tested, modified and finalized upon approval to begin interviewing and collection of initial data.

f. Develop CATI system for telephone interviewing and data entry.

CATI system has been developed based upon our current surveys. This system will be modified as needed when data collection begins.

g. Review computer databases of each cohort to determine procedures for participants recruitment and eligibility.

Done.

*Task 2.* Conduct participant accrual (months 4-48).

Unfortunately we have not yet received approval from the Department of Defense IRB to begin participant accrual. We have an approved and active protocol at Georgetown University (IRB #03-304). We submitted our initial DOD human subjects protocol on 1/13/03. We followed up with Teri Donner on 2/24/03 and were told that the review was ongoing and we could expect to hear something shortly. After not hearing anything for several months we sent an e-mail on 8/18/03. In response to this e-mail we were told that our protocol was reassigned to Diana Weld and that we should have a review shortly. After not receiving a review for another several months, we e-mailed again on 1/7/04. This e-mail was followed by a phone call and another e-mail on 4/3/04. We learned at this time that

our protocol had again been reassigned to Christie Stewart. We were informed that we would have a review within a few days. On 5/7/04 we checked again and were told that the review was forthcoming. After a final e-mail at the beginning of June, we finally received a preliminary review on 6/8/04. We responded to this review of 7/22/04 and are currently awaiting word on our revisions. As soon as the protocol is approved by the DOD IRB, we will make any needed modifications to the Georgetown IRB and upon approval begin recruiting.

Despite the delay of over a year, we should still be able to complete the study accrual within the timeline originally outlined. We have compiled patient lists and hired the staff needed to complete the interviews in a timely fashion.

*Task 3. Preliminary Data Analyses (months 24-33)*

We will begin preliminary data analyses in Year 3 as originally scheduled.

*Task 4. Final analysis and manuscript preparation (months 34-48).*

Our final analyses will be delayed by approximately four to six months and will begin in month 38-40. Manuscript preparation will now begin in month 42 and continue to month 48. Of course these timelines depend upon timely review of the revised protocol by the DOD.

## **KEY RESEARCH ACCOMPLISHMENTS**

Our accomplishments to date center on our completion of all preliminary work in anticipation of final approval by the DOD to commence human subjects accrual.

## **REPORTABLE OUTCOMES**

To date we have no reportable outcomes.

## **CONCLUSIONS**

This project seeks to gain a better understanding of the long-term psychosocial and behavioral implications of undergoing genetic counseling and testing for breast-ovarian cancer susceptibility. Since the start of the study, we have prepared all of our data collection and data management tools, hired our study staff, begun regular meetings, and compiled lists of participants to be contacted for participation. However, due to delays on the part of the Department of Defense Human Subjects review, we have been unable to commence study accrual and interviewing. We are fully prepared to begin accrual within weeks of receiving final approval from the DOD. It is our hope that approval can be obtained by Sept 1, 2004 – so that participant interviews can begin by Oct 1, 2004. If this timeline is met, we will be able to meet all of our study accrual goals.

## **REFERENCES**

None

**APPENDICES**

- A. Study Personnel Listing.....p. X
- C. Study Questionnaires.....p. 13



## **APPENDIX A: Current Salaried Study Personnel**

Marc D. Schwartz, Ph.D.	Principal Investigator
Beth N. Peshkin, M.S.	Co-Investigator
Kathryn L. Taylor, Ph.D.	Co-Investigator
Claudine Isaacs, M.D.	Co-Investigator
Lauren DeEcheandia, B.S.	Project Director
Clinton Finch, B.S.	Data Manager/Programmer
Sarah Rogers, M.A.	Data Specialist
Shibao Feng, Ph.D.	Biostatistician

## **Appendix B: Study Surveys**

Referral ID# \_\_\_\_\_

Interviewer: \_\_\_\_\_

Date \_\_\_\_\_

### TELEPHONE INTERVIEW -- Survivor Cohort and Comparison Groups

- The first few questions are about your family history of cancer. Here we are only talking about blood relatives.

	breca age	bilateral?	ovca age	alive?
<b>Was your mother ever diagnosed with breast or ovarian cancer?</b>				
Mother				
<b>Do you have any sisters? NO YES If Yes, how many? _____</b>				
Sister #1				
Sister #2				
Sister #3				
<b>Do you have any daughters? NO YES If Yes, how many? _____</b>				
Daughter #1				
Daughter #2				
Daughter #3				
<b>Does/Did your mother have any sisters? NO YES If Yes, how many? _____</b>				
Maternal Aunt #1				
Maternal Aunt #2				
Maternal Aunt #3				
<b>Does/Did your father have any sisters? NO YES If Yes, how many? _____</b>				
Paternal Aunt #1				
Paternal Aunt #2				
Paternal Aunt #3				
<b>Was your [maternal/paternal] grandmother ever diagnosed with breast or ovarian cancer?</b>				
Maternal Grandmother				

Paternal Grandmother				
<b>Do you have any other female relatives affected with breast or ovarian cancer?</b>				
NO YES If Yes, how many? _____				
brca age bilateral? ovca age alive?				
Relationship:				
Relationship:				
Relationship:				
<b>Do you have any male relatives affected with breast cancer?</b>				
NO YES If Yes, how many? _____				
brca age bilateral? alive?				
Relationship:				
Relationship:				
Relationship:				
<b>Do you have any male relatives diagnosed with prostate cancer?</b>				
NO YES If Yes, how many? _____				
age@dx alive?				
Relationship:				
Relationship:				
Relationship:				
<b>Do you have any Jewish ancestors from Central or Eastern Europe?</b>				
NO YES				
Is your mother of Ashkenazi Jewish descent? NO YES UNKNOWN				
Is your father of Ashkenazi Jewish descent? NO YES UNKNOWN				

2. Were you yourself ever diagnosed with breast cancer?

Yes..... 1 How old were you at first diagnosis? \_\_\_ Was it bilateral? \_\_\_

Were you ever diagnosed a second time? Yes.....1

No.....2 **Go To Question**

2a

If yes: How old were you at the second diagnosis? \_\_\_

Was it a recurrence or a new primary? \_\_\_\_\_

Was it in the same or opposite breast? \_\_\_\_\_

No..... 2 **Go To Question 2a**

2a. Have you ever had any other type of cancer?

Yes..... 1

No..... 2 **GO TO: QUESTION 2b if patient diagnosed with breast cancer  
QUESTION 3 if patient has no cancer history**

What type of cancer?

- Ovarian .....
- Colon .....
- Endometrium .....
- Cervical .....
- Lung... .....
- Melanoma.....
- Other.. .....

How old were you at first diagnosis? \_\_\_\_ Was it bilateral? \_\_\_\_

Age at diagnosis \_\_\_\_

Age at diagnosis \_\_\_\_

Age at diagnosis \_\_\_\_

Age at diagnosis \_\_\_\_

Age at diagnosis \_\_\_\_

Age at diagnosis \_\_\_\_

Type of cancer \_\_\_\_\_

2b. Did you have radiation therapy?

Yes..... 1

No..... 2 **Go To Question 2d**

2c. Are you still undergoing radiation?

Yes..... 1

No..... 2

2d. Did you have chemotherapy?

Yes..... 1

No..... 2 **Go To Question 3**

2e. Are you still undergoing chemotherapy ?

Yes..... 1

No..... 2

The next questions are about your medical history.

3. Have you ever had a breast biopsy?

Yes..... 1

No..... 2 **Go to Question 5**

3a. What was the result?

Atypical hyperplasia.....1

Hyperplasia.....2

Neither (i.e., calcification, benign, fibrocystic).....3

Malignant.....4

Don't know.....9

4. How many breast biopsies have you had? \_\_\_\_\_ Biopsies
5. How old were you when you had your first menstrual period? \_\_\_\_\_ years old
6. Are you still menstruating?

Yes..... 1      **Go to Question 7**  
 No..... 2

6a. How old were you when you had your last period?  
 \_\_\_\_\_ years old      \_\_\_\_\_ don't know

6b. Why did your periods stop?  
 Natural menopause (change of life)..... 1  
 Hysterectomy..... 2  
 Took medication that stopped periods..... 3  
 Other..... 4

7. Have you ever used oral contraceptives; that is, birth control pills?

Yes..... 1  
 No.....2      **Go to Question 8**  
 Don't know..... 9      **Go to Question 8**

7a. What was the total number of months or years that you used oral contraceptives?

\_\_\_\_\_ months or years      \_\_\_\_\_ don't know

7b. How many of these months or years of use occurred before you ever gave birth - (IF SUBJECT SAYS NEVER GAVE BIRTH, ANSWER IS SAME AS 7a).

\_\_\_\_\_ months or years      \_\_\_\_\_ don't know

8. Have you ever been pregnant?

Yes..... 1  
 No..... 2      **Go to Question 12**

9. How many pregnancies have you had? \_\_\_\_\_ Pregnancies

Don't know..... 9

10. Have you ever given birth?

Yes..... 1      **Go to Question 11**  
 No..... 2      **Go to Question 12**

11. How old were you when you had your first child? \_\_\_\_\_ years old

12. Have you taken Tamoxifen – a hormone to treat breast cancer that is being reviewed as a means of preventing breast cancer? (or subject may know this as Novaldex)?

Yes ..... 1 If yes, what is the total number of months/years that you were taking it? \_\_\_\_\_ months/years

No ..... 2 **GO TO Q13**

12a. Are you currently taking Tamoxifen?

Yes..... 1  
No ..... 2

12b. Did you begin taking tamoxifen following your receipt of BRCA1/2 test results?

Yes..... 1  
No..... 2

13. Have you taken raloxifene – a hormone used to treat osteoporosis and is being reviewed as a means of preventing breast cancer? (or subject may know this as Evista)

Yes ..... 1 If yes, what is the total number of months/years that you were taking it? \_\_\_\_\_ months/years

No ..... 2 **GO TO Q14**

13a. Are you currently taking raloxifene?

Yes..... 1  
No ..... 2

**13b. Did you begin taking raloxifene following the receipt of your BRCA1/2 test result?**

**Yes..... 1  
No..... 2**

14. The next set of questions are about some of the stressors that you may have experienced related to your history of breast cancer and your risk for future cancer. Over the past couple of weeks, how much stress have you experienced regarding <item>? Would you say that <read statement> has been..... <read options>

a. your risk of developing cancer [again]

- Not at all stressful..... 1
- A little bit stressful..... 2
- Moderately stressful..... 3
- Very stressful..... 4

b. decisions about things you can do to reduce cancer risks (i.e., prophylactic surgery)

- Not at all stressful..... 1
- A little bit stressful..... 2
- Moderately stressful..... 3
- Very stressful..... 4

c. decisions about cancer screening (i.e., mammography, breast self-examinations)

- Not at all stressful..... 1
- A little bit stressful..... 2
- Moderately stressful..... 3
- Very stressful..... 4

15a. How confident are you that you can cope with your risk of developing cancer [again] ?

- Not at all confident..... 1
- Somewhat confident..... 2
- Moderately confident..... 3
- Very confident.....4

b. How confident are you that you have made good decisions about your cancer prevention?

- Not at all confident..... 1
- Somewhat confident..... 2
- Moderately confident..... 3
- Very confident .....4

c. How confident are you that you have made good decisions about your screening options?

- Not at all confident..... 1
- Somewhat confident..... 2
- Moderately confident..... 3
- Very confident.....4



16a. In your opinion, how likely is it that you will develop breast cancer again, would you say..  
**READ LIST]**

- Not at all likely..... 1
- A little bit likely..... 2
- Somewhat likely.....3
- Very likely.....4
- Definitely..... 5

16b. On a scale from 0 to 100 where 0 means that you definitely won't get breast cancer again and 100 means that you definitely will get breast cancer again, how likely would you say you are to develop breast cancer again \_\_\_\_\_

The next questions are about your attitudes and opinions about ovarian cancer.

17a. In your opinion, how likely is it that you will develop ovarian cancer, would you say.. **[READ LIST]**

- Not at all likely..... 1
- A little bit likely..... 2
- Somewhat likely.....3
- Very likely..... 4
- Definitely..... 5

17b. On a scale from 0 to 100 where 0 means that you definitely won't get ovarian cancer and 100 means that you definitely will get ovarian cancer, how likely would you say you are to develop ovarian cancer?  
 \_\_\_\_\_

18. Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
In the last month, how often have you felt that things were going your way?	0	1	2	3	4
In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

19. I'm going to read a list of comments made by some people who have had cancer. Please tell me how frequently these comments were true for you during the past seven days. [READ STATEMENT] Would you say this occurred...not at all, rarely, sometimes, or often?

	Not at All	Rarely	Some- times	Often
a. I thought about it when I didn't mean to.....	0.....	1.....	3.....	5
b. I avoided letting myself get upset when I thought about it or was reminded of it.....	0.....	1.....	3.....	5
c. I had tried to remove it from memory.....	0.....	1.....	3.....	5
d. I had trouble falling asleep or staying sleep, because of pictures or thoughts about it that came into my mind.....	0.....	1.....	3.....	5
e. I had waves of strong feelings about it.....	0.....	1.....	3.....	5
f. I had dreams about it.....	0.....	1.....	3.....	5
g. I stayed away from reminders of it.....	0.....	1.....	3.....	5
h. I felt as if it hadn't happened or it wasn't real.....	0.....	1.....	3.....	5
i. I tried not to talk about it.....	0.....	1.....	3.....	5
j. Pictures about it popped into my mind.....	0.....	1.....	3.....	5
k. Other things kept making me think about it.....	0.....	1.....	3.....	5
l. I was aware that I still had a lot of feelings about it, but I didn't deal with them.....	0.....	1.....	3.....	5
m. I tried not to think about it.....	0.....	1.....	3.....	5
n. Any reminder brought back feelings about it.....	0.....	1.....	3.....	5
o. My feelings about it were kind of numb.....	0.....	1.....	3.....	5

20. Now I am going to read a list of problems and complaints that people sometimes have. Please tell me how much discomfort that problem has caused you in the last two weeks.

	Not at All	Slightly	Mod- erately	Extremely
a. Nervousness or shakiness inside .....	1	2	3	4
b. Thoughts of ending your life .....	1	2	3	4
c. Suddenly scared for no reason .....	1	2	3	4
d. Feeling lonely.....	1	2	3	4
e. Feeling fearful.....	1	2	3	4
f. Feeling blue .....	1	2	3	4
g. Feeling not interested in things.....	1	2	3	4
h. Feeling tense or keyed up.....	1	2	3	4
i. Spells of terror or panic.....	1	2	3	4
j. Feeling hopeless about the future .....	1	2	3	4
k. Feeling so restless you couldn't sit still.....	1	2	3	4
l. Feeling of worthlessness.....	1	2	3	4

21a. In general, would you say your health is: \_\_\_\_\_ Excellent \_\_\_\_\_ Very good \_\_\_\_\_ Good \_\_\_\_\_ Fair \_\_\_\_\_ Poor  
(1) (2) (3) (4) (5)

The following items are about activities you might do during a typical day.

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
b. Does your health now limit you in terms of moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Does your health limit you in terms of climbing several flights of stairs	1	2	3

d. During the past 4 weeks, have any problems with your physical health resulted in your accomplishing less than you would like  
Yes (1) No (0)

e. During the past 4 weeks, have any problems with your physical health limited you in the kind of work or other activities that you do  
Yes (1) No (0)

f. During the past 4 weeks, have any emotional problems such as depression or anxiety resulted in your accomplishing less than you would like

Yes (1)                      No (0)

g. During the past 4 weeks, have any emotional problems resulted in your not being able to do your work or other activities as carefully as usual

Yes (1)                      No (0)

h. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? [READ LIST]

Not at all	A little bit	Moderately	Quite a bit	Extremely
(0)	(1)	(2)	(3)	(4)

These next three questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks. . .

	All of the Time	Most of the Time	A Good Bit	Some of the Time	Little of the Time	None of the Time
i. Have you felt calm and peaceful?	1	2	3	4	5	6
j. Did you have a lot of energy?	1	2	3	4	5	6
k. Have you felt downhearted and blue?	1	2	3	4	5	6

l. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? [READ LIST]

All of the time     Most of the time     Some of the time     A little of the time     None of the time

22. Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

**PHYSICAL WELL-BEING**

G  
P1  
G  
P2  
G  
P3  
G  
P4  
G  
P5  
G  
P6  
G  
P7

		Not at all	A little bit	Some- what	Quite a bit	Very much
	I have a lack of energy	0	1	2	3	4
	I have nausea.....	0	1	2	3	4
	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
	I have pain.....	0	1	2	3	4
	I am bothered by side effects of treatment.....	0	1	2	3	4
	I feel ill.....	0	1	2	3	4
	I am forced to spend time in bed.....	0	1	2	3	4

**SOCIAL/FAMILY WELL-BEING**

G  
S1  
G  
S2  
G  
S3  
G  
S4  
G  
S5  
G  
S6

		Not at all	A little bit	Some- what	Quite a bit	Very much
	I feel close to my friends.....	0	1	2	3	4
	I get emotional support from my family.....	0	1	2	3	4
	I get support from my friends.....	0	1	2	3	4
	My family has accepted my illness.....	0	1	2	3	4
	I am satisfied with family communication about my illness.....	0	1	2	3	4
	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4

Q  
1

Regardless of your current level of sexual activity, please

*I am satisfied with my sex life* 0

1      2      3      4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

**EMOTIONAL WELL-BEING**

Not at all    A little bit    Some-what    Quite a bit    Very much

G  
E1

I feel sad

0      1      2      3      4

G  
E2

*I am satisfied with how I am coping with my illness*

0      1      2      3      4

G  
E3

I am losing hope in the fight against my illness.....

0      1      2      3      4

G  
E4

I feel nervous.....

0      1      2      3      4

G  
E5

I worry about dying.....

0      1      2      3      4

G

I worry that my condition will get worse .....

0      1      2      3      4

**FUNCTIONAL WELL-BEING**

Not at all    A little bit    Some-what    Quite a bit    Very much

G  
F1

I am able to work (include work at home).....

0      1      2      3      4

G  
F2

My work (include work at home) is fulfilling.....

0      1      2      3      4

G  
F3

I am able to enjoy life .....

0      1      2      3      4

G  
F4

I have accepted my illness.....

0      1      2      3      4

G  
F5

I am sleeping well .....

0      1      2      3      4

G  
F6  
G

I am enjoying the things I usually do for fun ..... 0 1 2 3 4

I am content with the quality of my life right now..... 0 1 2 3 4

23. Each item below describes a way in which different people respond to situations. On a scale from 1 (I haven't been doing this at all) to 4 (I've been doing this a lot), rate how often you have used these strategies in the past month to cope with your past breast cancer and your risk for developing another cancer.

- a. I've been concentrating my efforts on doing something about the situation I'm in. ... 1 2 3 4
- b. I've been trying to come up with a strategy about what to do..... 1 2 3 4
- c. I've been trying to see it in a different light, to make it seem more positive..... 1 2 3 4
- d. I've been accepting the reality of the fact that it happened..... 1 2 3 4
- d. I've been making jokes about it..... 1 2 3 4
- e. I've been trying to find comfort in my religious or spiritual beliefs..... 1 2 3 4
- f. I've been getting emotional support from others..... 1 2 3 4
- g. I've been trying to get advice or help from other people about what to do..... 1 2 3 4
- h. I've been turning to work or other activities to take my mind off things. .... 1 2 3 4
- i. I've been saying to myself "this isn't real."..... 1 2 3 4
- j. I've been saying things to let my unpleasant feelings escape..... 1 2 3 4
- k. I've been using alcohol or other drugs to make myself feel better. .... 1 2 3 4
- l. I've been giving up trying to deal with it..... 1 2 3 4
- m. I've been criticizing myself..... 1 2 3 4
- n. I've been taking action to try to make the situation better..... 1 2 3 4
- o. I've been thinking hard about what steps to take..... 1 2 3 4
- 4
- p. I've been looking for something good in what is happening..... 1 2 3 4
- q. I've been learning to live with it..... 1 2 3 4
- r. I've been making fun of the situation. .... 1 2 3 4
- s. I've been praying or meditating..... 1 2 3 4
- t. I've been getting comfort and understanding from someone..... 1 2 3 4
- u. I've been getting help or advice from other people..... 1 2 3 4
- v. I've been doing something to think about it less, such as going  
to the movies, watching TV, reading, daydreaming, sleeping, or shopping..... 1 2 3 4
- w. I've been refusing to believe that it has happened..... 1 2 3 4
- x. I've been expressing my negative feelings..... 1 2 3 4
- y. I've been using alcohol or other drugs to help me get through it..... 1 2 3 4

- z. I've been giving up the attempt to cope..... 1 2 3 4
- aa. I've been blaming myself for things that happened..... 1 2 3 4

24. Patients in the Survivor Cohort (i.e., have received genetic counseling) answer Q. 24 others go to Q. 25.

Now, thinking about the decision you made to learn your BRCA1/2 status, please listen to the following comments some people make about that decision. Please indicate how strongly you agree or disagree with these comments, using this scale: [don't read the numbers, only the descriptors].

- 1=strongly agree
- 2=agree
- 3=neither agree nor disagree
- 4=disagree
- 5=strongly disagree

- a. I am satisfied that I was adequately informed about the issues important to my decision about genetic testing.
- b. The decision I made about genetic testing was the best decision possible for me personally.
- c. I am satisfied that my decision about genetic testing was consistent with my personal values.
- d. I am satisfied that this was my decision to make.
- e. I am satisfied with my decision about genetic testing.

The next few questions are about your cancer screening practices and medical decision making?

25a. Have you ever had a fecal occult blood test? *(also known as an FOBT. This test detects blood in the stool and is a screening test for colon cancer).*

Yes .....1      Date of last FOBT: month \_\_\_\_\_ year \_\_\_\_\_

No .....2

25b Have you ever had a colonoscopy or flexible sigmoidoscopy?

Yes .....1      Date of last colonoscopy: month \_\_\_\_\_ year \_\_\_\_\_

  Date of last sigmoidoscopy: month \_\_\_\_\_ year \_\_\_\_\_

No .....2

26. Have you ever had surgery to remove your breast(s)?

Yes..... 1      **Go to Q26a**

No..... 2      **Women Go to Q27,**



26a. Did you have surgery to remove one or both breasts?

One..... 1 Date: \_\_\_\_\_ / \_\_\_\_\_ **Go to Q26b**  
month year

Both..... 2 Date first breast removed: \_\_\_\_\_ / \_\_\_\_\_  
month year  
Date second breast removed: \_\_\_\_\_ / \_\_\_\_\_ **Go to Q26c**  
month year

26b. Was it for prevention or cancer treatment?

Prevention..... 1 **Go to Question 27**  
Cancer Treatment..... 2 **Go to Question 27**  
Other \_\_\_\_\_ 3 **Go to Question 27**

26c. Was it for (READ LIST)?

Cancer treatment on both sides..... 1 **Go to Question 28**  
Cancer treatment on one side and prevention on the other side..... 2 **Go to Question 28**  
Prevention of cancer on both sides..... 3 **Go to Question 28**

27. Are you considering having any (additional) breast surgery?

Yes .....1  
No.....2 (**go to Question 28**)

27b. What (additional) breast surgery are you considering (READ LIST)

Preventive removal of one breast .....1  
Preventive removal of both breasts (Bilateral mastectomy).....2  
Other..... \_\_\_\_\_ .....3

28. How many times did you examine your own breast(s) in the past 3 months? \_\_\_\_\_ Times

29. Have you ever had a mammogram?

Yes..... 1  
No..... 2 **Go to Question 30**

29a. How old were you when you had your first mammogram?

\_\_\_\_\_ years old

29b. When was your last mammogram? \_\_\_\_\_ / \_\_\_\_\_  
month year

30. When was your last breast exam by a doctor or nurse? \_\_\_\_\_ / \_\_\_\_\_  
month year



34b. Pelvic ultrasound for screening purposes, not pregnancy. **Pelvic ultrasound** (sound waves are projected onto the abdomen and an image is displayed -- your bladder has to be full).

- Yes.....1 **Go to Question 34c.**
- No.....2 **Go to Question 34d.**
- Don't know or never heard of it.....9 **Go to Question 34d.**

34c. When was the last time you had this? \_\_\_\_\_ /  
month year

34d. Transvaginal ultrasound for screening purposes, not pregnancy. **Transvaginal ultrasound** (a probe is inserted into the vagina to image the ovaries -- your bladder does not have to be full).

- Yes.....1 **Go to Question 34e.**
- No.....2 **Go to Question 35**
- Don't know or never heard of it.....9 **Go to Question 35**

34e. When was the last time you had this? \_\_\_\_\_ /  
month year

34f. Did this test include Doppler flow color imaging?

- Yes.....1
- No.....2
- Don't know or never heard of it.....9

**The last questions are about your background.**

35. What is the date of your birth? \_\_\_\_\_ / \_\_\_\_\_ /  
month day year

36. What is your race or ethnic background? **[READ LIST]**

- Black or African American..... 1
- Caribbean or West Indian..... 2
- White/non-Hispanic..... 3
- Hispanic..... 4
- Asian or Pacific Islander..... 5
- Native American..... 6
- Other... \_\_\_\_\_ ..... 9
- Spanish or Hispanic..... 8

37. How many years of school have you completed? **[READ LIST]**

- 8 or less years..... 1
- Some high school..... 2
- High school graduate, or GED..... 3
- Some college..... 4
- College graduate or beyond..... 5

38. What is your religious background? **[DO NOT READ LIST]**

- Catholic.....1
- Protestant.....2
- Jewish.....3
- Atheist/None.....4
- Other \_\_\_\_\_.....5

39. Are you currently employed for salary or wages? **[READ LIST]**

- Not employed.....1
- Full-time employed.....2
- Part-time employed.....3
- Retired.....4

40. What was your household income before taxes last year? **[READ LIST]**

- less than \$20,000.....1
- \$20,001 - \$35,000.....2
- \$35,001 - \$50,000.....3
- \$50,001 - \$75,000.....4
- greater than \$75,000.....5

41. Do you have health insurance?

- Yes.....1
- No.....2

What type? **[READ LIST]**

- Fee for service (such as Blue Cross/Blue Shield)..... 1
- Health Maintenance Organization, HMO or other prepaid plan..... 2
- PPO or Point of Service..... 3
- Military/Champus..... 4
- Medicaid..... 5
- Medicare..... 6
- Other \_\_\_\_\_..... 9

Referral ID# \_\_\_\_\_

Interviewer: \_\_\_\_\_

Date \_\_\_\_\_

### TELEPHONE INTERVIEW -- Unaffected Cohort

1. The first few questions are about your family history of cancer. Here we are only talking about blood relatives.

	brea age	bilateral?	ovca age	aiive?
<b>Was your mother ever diagnosed with breast or ovarian cancer?</b>				
Mother				
<b>Do you have any sisters?</b>		NO	YES	If Yes, how many? _____
Sister #1				
Sister #2				
Sister #3				
<b>Do you have any daughters?</b>		NO	YES	If Yes, how many? _____
Daughter #1				
Daughter #2				
Daughter #3				
<b>Does/Did your mother have any sisters?</b>				
		NO	YES	If Yes, how many? _____
Maternal Aunt #1				
Maternal Aunt #2				
Maternal Aunt #3				
<b>Does/Did your father have any sisters?</b>				
		NO	YES	If Yes, how many? _____
Paternal Aunt #1				
Paternal Aunt #2				
Paternal Aunt #3				
<b>Was your [maternal/paternal] grandmother ever diagnosed with breast or ovarian cancer?</b>				
Maternal Grandmother				

Paternal Grandmother				
<b>Do you have any other female relatives affected with breast or ovarian cancer?</b>				
NO YES If Yes, how many? _____				
brca age bilateral? ovca age alive?				
Relationship:				
Relationship:				
Relationship:				
<b>Do you have any male relatives affected with breast cancer?</b>				
NO YES If Yes, how many? _____				
brca age bilateral? alive?				
Relationship:				
Relationship:				
Relationship:				
<b>Do you have any male relatives diagnosed with prostate cancer?</b>				
NO YES If Yes, how many? _____				
age@dx alive?				
Relationship:				
Relationship:				
Relationship:				
<b>Do you have any Jewish ancestors from Central or Eastern Europe?</b>				
NO YES				
Is your mother of Ashkenazi Jewish descent?	NO	YES	UNKNOWN	
Is your father of Ashkenazi Jewish descent?	NO	YES	UNKNOWN	

2. Were you yourself ever diagnosed with breast cancer?

Yes..... [Switch to Survivor Cohort Interview]

No..... [Go to 2a]

2a. Have you ever had any other type of cancer?

Yes..... 1 [Switch to Survivor Cohort Interview]

No..... 2 **GO TO: QUESTION 3**

The next questions are about your medical history.

3. Have you ever had a breast biopsy?

- Yes..... 1
- No..... 2      **Go to Question 5**

3a. What was the result?

- Atypical hyperplasia.....1
- Hyperplasia.....2
- Neither (i.e., calcification, benign, fibrocystic).....3
- Malignant.....4
- Don't know.....9

4. How many breast biopsies have you had?      \_\_\_\_\_ Biopsies

5. How old were you when you had your first menstrual period?      \_\_\_\_\_ years old

6. Are you still menstruating?

- Yes..... 1      **Go to Question 7**
- No..... 2

6a. How old were you when you had your last period?

\_\_\_\_\_ years old      \_\_\_\_\_ don't know

6b. Why did your periods stop?

- Natural menopause (change of life)..... 1
- Hysterectomy..... 2
- Took medication that stopped periods..... 3
- Other \_\_\_\_\_..... 4

7. Have you ever used oral contraceptives; that is, birth control pills?

- Yes..... 1
- No.....2      **Go to Question 8**
- Don't know..... 9      **Go to Question 8**

7a. What was the total number of months or years that you used oral contraceptives?

\_\_\_\_\_ months or years      \_\_\_\_\_ don't know

7b. How many of these months or years of use occurred before you ever gave birth - (IF SUBJECT SAYS NEVER GAVE BIRTH, ANSWER IS SAME AS 7a).

\_\_\_\_ months or years      \_\_\_\_ don't know

8. Have you ever been pregnant?

Yes..... 1  
No..... 2      **Go to Question 12**

9. How many pregnancies have you had?      \_\_\_\_ Pregnancies

Don't know..... 9

10. Have you ever given birth?

Yes..... 1      **Go to Question 11**  
No..... 2      **Go to Question 12**

11. How old were you when you had your first child?      \_\_\_\_ years old

12. Have you taken Tamoxifen – a hormone that is sometimes used in healthy women as a means of preventing breast cancer? (or subject may know this as Novaldex)?

Yes ..... 1      If yes, what is the total number of months/years that you were/are taking it? \_\_\_\_\_ months/years

No ..... 2      **GO TO Q13**

12a. Did you begin taking tamoxifen following your receipt of BRCA1/2 test results?

Yes..... 1  
No..... 2

13. Have you taken raloxifene – a hormone used to treat osteoporosis and is being reviewed as a means of preventing breast cancer? (or subject may know this as Evista)

Yes ..... 1      If yes, what is the total number of months/years that you were/are taking it? \_\_\_\_\_ months/years

No ..... 2      **GO TO Q14**

13a. Did you begin taking raloxifene following the receipt of your BRCA1/2 test result?

Yes..... 1  
No..... 2



14. The next set of questions are about some of the stressors that you may have experienced related to your family history of breast cancer and your own risk for cancer. Over the past couple of weeks, how much stress have you experienced regarding <item>? Would you say that <read statement> has been..... <read options>

a. your risk of developing cancer

- Not at all stressful..... 1
- A little bit stressful..... 2
- Moderately stressful..... 3
- Very stressful..... 4

b. decisions about things you can do to reduce cancer risks (i.e., prophylactic surgery)

- Not at all stressful..... 1
- A little bit stressful..... 2
- Moderately stressful..... 3
- Very stressful..... 4

c. decisions about cancer screening (i.e., mammography, breast self-examinations)

- Not at all stressful..... 1
- A little bit stressful..... 2
- Moderately stressful..... 3
- Very stressful..... 4

15a. How confident are you that you can cope with your risk of developing cancer?

- Not at all confident..... 1
- Somewhat confident..... 2
- Moderately confident..... 3
- Very confident..... 4

b. How confident are you that you have made good decisions about your cancer prevention?

- Not at all confident..... 1
- Somewhat confident..... 2
- Moderately confident..... 3
- Very confident..... 4

c. How confident are you that you have made good decisions about your screening options?

- Not at all confident..... 1
- Somewhat confident..... 2
- Moderately confident..... 3
- Very confident..... 4

16a. In your opinion, how likely is it that you will develop breast cancer, would you say.. **READ LIST]**

- Not at all likely..... 1
- A little bit likely..... 2
- Somewhat likely.....3
- Very likely.....4
- Definitely..... 5

16b. On a scale from 0 to 100 where 0 means that you definitely won't get breast cancer and 100 means that you definitely will get breast cancer, how likely would you say you are to develop breast cancer

---

The next questions are about your attitudes and opinions about ovarian cancer.

17a. In your opinion, how likely is it that you will develop ovarian cancer, would you say.. **[READ LIST]**

- Not at all likely..... 1
- A little bit likely..... 2
- Somewhat likely.....3
- Very likely..... 4
- Definitely..... 5

17b. On a scale from 0 to 100 where 0 means that you definitely won't get ovarian cancer and 100 means that you definitely will get ovarian cancer, how likely would you say you are to develop ovarian cancer?

---

18. Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
In the last month, how often have you felt that things were going your way?	0	1	2	3	4
In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

19. I'm going to read a list of comments made by some people who have a family history of breast cancer. Please tell me how frequently these comments were true for you during the past seven days. [READ STATEMENT] Would you say this occurred...not at all, rarely, sometimes, or often?

	Not at All	Rarely	Some- times	Often
a. I thought about it when I didn't mean to.....	0.....	1.....	3.....	5
b. I avoided letting myself get upset when I thought about it or was reminded of it.....	0.....	1.....	3.....	5
c. I had tried to remove it from memory.....	0.....	1.....	3.....	5
d. I had trouble falling asleep or staying sleep, because of pictures or thoughts about it that came into my mind.....	0.....	1.....	3.....	5
e. I had waves of strong feelings about it.....	0.....	1.....	3.....	5
f. I had dreams about it.....	0.....	1.....	3.....	5
g. I stayed away from reminders of it.....	0.....	1.....	3.....	5
h. I felt as if it hadn't happened or it wasn't real.....	0.....	1.....	3.....	5
i. I tried not to talk about it.....	0.....	1.....	3.....	5
j. Pictures about it popped into my mind.....	0.....	1.....	3.....	5
m. Other things kept making me think about it.....	0.....	1.....	3.....	5
n. I was aware that I still had a lot of feelings about it, but I didn't deal with them.....	0.....	1.....	3.....	5
m. I tried not to think about it.....	0.....	1.....	3.....	5
n. Any reminder brought back feelings about it.....	0.....	1.....	3.....	5
o. My feelings about it were kind of numb.....	0.....	1.....	3.....	5

20. Now I am going to read a list of problems and complaints that people sometimes have. Please tell me how much discomfort that problem has caused you in the last two weeks.

	Not at All	Slightly	Mod- erately	Extremely
a. Nervousness or shakiness inside .....	1	2	3	4
b. Thoughts of ending your life .....	1	2	3	4
c. Suddenly scared for no reason .....	1	2	3	4
d. Feeling lonely.....	1	2	3	4
e. Feeling fearful .....	1	2	3	4
f. Feeling blue .....	1	2	3	4
g. Feeling not interested in things.....	1	2	3	4
h. Feeling tense or keyed up.....	1	2	3	4
i. Spells of terror or panic.....	1	2	3	4
j. Feeling hopeless about the future .....	1	2	3	4
k. Feeling so restless you couldn't sit still.....	1	2	3	4
l. Feeling of worthlessness.....	1	2	3	4

SF36

21. Now I would like to ask you some questions about your views of your health. This information will help us to understand how you feel and how well you are able to do your usual activities.

a- In general, would you say your health is:

1. Excellent     2. Very good     3. Good     4. Fair     5. Poor

b- Compared to ONE YEAR AGO, how would you rate your health in general NOW?

1. MUCH BETTER than one year ago.  
 2. Somewhat BETTER now than one year ago.  
 3. About the SAME as one year ago.  
 4. Somewhat WORSE now than one year ago.  
 5. MUCH WORSE now than one year ago.

c- The following items are about activities you might do during a typical day. **Does your health now limit you in these activities? If so, how much?**

Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
i) <b>Vigorous activities</b> , such as running, lifting heavy objects, participating in strenuous sports?	1	2	3
ii) <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?	1	2	3
iii) Lifting or carrying groceries?	1	2	3
iv) Climbing <b>several flights</b> of stairs?	1	2	3
v) Climbing <b>one flight</b> of stairs?	1	2	3
vi) Bending, kneeling or stooping?	1	2	3
vii) Walking <b>more than a mile</b> ?	1	2	3
viii) Walking <b>several blocks</b> ?	1	2	3
ix) Walking <b>one block</b> ?	1	2	3
x) Bathing or dressing yourself?	1	2	3

d- During the **past 4 weeks**, have you had any of the following problems with your work or other regular activities *as a result of your physical health?*

	Yes	No
i) Cut down on the <b>amount of time</b> you spent on work or other activities?	Yes	No
ii) <b>Accomplished less</b> than you would like?	Yes	No
iii) Were limited in the <b>kind</b> of work or other activities?	Yes	No
iv) Had <b>difficulty</b> performing the work or other activities (for example it took extra effort)?	Yes	No

e. 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)?

	Yes	No
i) Cut down on the <b>amount of time</b> you spent on work or other activities?	Yes	No
ii) <b>Accomplished less</b> than you would like?	Yes	No
iii) Didn't do work or other activities as <b>carefully</b> as usual?	Yes	No

f. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

1. Not at all     2. Slightly     3. Moderately     4. Quite a bit     5. Extremely

g. How much **bodily pain** have you had during the **past 4 weeks**?

1. None    2. Very mild    3. Mild    4. Moderate    5. Severe    6. Very severe

h. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

i. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 week ...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of pep?	1	2	3	4	5	6
b) Have you been a very nervous person?	1	2	3	4	5	6
c) Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d) Have you felt calm and peaceful?	1	2	3	4	5	6
e) Did you have a lot of energy?	1	2	3	4	5	6
f) Have you felt downhearted and blue?	1	2	3	4	5	6
g) Do you feel worn out?	1	2	3	4	5	6
h) Have you been a happy person?	1	2	3	4	5	6
i) Did you feel tired?	1	2	3	4	5	6

j. During the past 4 weeks, how much of the time has your **physical health** or **emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

1. All of the time  
 2. Most of the time.  
 3. Some of the time  
 4. A little of the time.  
 5. None of the time.

k. How **TRUE** or **FALSE** is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a) I seem to get sick a little easier than other people?	1	2	3	4	5
b) I am as healthy as anybody I know?	1	2	3	4	5
c) I expect my health to get worse?	1	2	3	4	5
health is excellent?	1	2	3	4	5

22. Each item below describes a way in which different people respond to situations. On a scale from 1 (I haven't been doing this at all) to 4 (I've been doing this a lot), rate how often you have used these strategies in the past month to cope with your risk for developing cancer.

a. I've been concentrating my efforts on doing something about the situation I'm in. ...	1	2	3	4
b. I've been trying to come up with a strategy about what to do.....	1	2	3	4
aa. I've been trying to see it in a different light, to make it seem more positive.....	1	2	3	4
d. I've been accepting the reality of the fact that it happened.....	1	2	3	4
bb. I've been making jokes about it.....	1	2	3	4
cc. I've been trying to find comfort in my religious or spiritual beliefs.....	1	2	3	4
dd. I've been getting emotional support from others.....	1	2	3	4
ee. I've been trying to get advice or help from other people about what to do.....	1	2	3	4
ff. I've been turning to work or other activities to take my mind off things. ....	1	2	3	4
gg. I've been saying to myself "this isn't real." .....	1	2	3	4
hh. I've been saying things to let my unpleasant feelings escape.....	1	2	3	4
ii. I've been using alcohol or other drugs to make myself feel better. ....	1	2	3	4
jj. I've been giving up trying to deal with it.....	1	2	3	4
kk. I've been criticizing myself.....	1	2	3	4
ll. I've been taking action to try to make the situation better.....	1	2	3	4
mm. I've been thinking hard about what steps to take.....	1	2	3	4
nn. I've been looking for something good in what is happening.....	1	2	3	4
oo. I've been learning to live with it.....	1	2	3	4
pp. I've been making fun of the situation. ....	1	2	3	4
qq. I've been praying or meditating.....	1	2	3	4
rr. I've been getting comfort and understanding from someone.....	1	2	3	4
ss. I've been getting help or advice from other people.....	1	2	3	4
tt. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping.....	1	2	3	4
uu. I've been refusing to believe that it has happened.....	1	2	3	4
vv. I've been expressing my negative feelings.....	1	2	3	4
ww. I've been using alcohol or other drugs to help me get through it.....	1	2	3	4
xx. I've been giving up the attempt to cope.....	1	2	3	4
aa. I've been blaming myself for things that happened.....	1	2	3	4





25b. Was it for prevention or cancer treatment?

- Prevention..... 1      **Go to Question 26**
- Cancer Treatment..... 2      **Go to Question 26**
- Other \_\_\_\_\_ 3      **Go to Question 26**

25c. Was it for (READ LIST)?

- Cancer treatment on both sides..... 1      **Go to Question 27**
- Cancer treatment on one side and prevention on the other side..... 2      **Go to Question 27**
- Prevention of cancer on both sides..... 3      **Go to Question 27**

26. Are you considering having any (additional) breast surgery?

- Yes .....1
- No.....2 (go to Question 27)

26b. What (additional) breast surgery are you considering (READ LIST)

- Preventive removal of one breast .....1
- Preventive removal of both breasts (Bilateral mastectomy).....2
- Other.....3

27. How many times did you examine your own breast(s) in the past 3 months? \_\_\_\_\_ Times

28. Have you ever had a mammogram?

- Yes..... 1
- No..... 2      **Go to Question 29**

28a. How old were you when you had your first mammogram?

\_\_\_\_\_ years old

28b. When was your last mammogram? \_\_\_\_\_ /  
month      year

29. When was your last breast exam by a doctor or nurse? \_\_\_\_\_ /  
month      year

30. Have you had your uterus removed?

- Yes..... 1      What age? \_\_\_\_\_ What was the reason? \_\_\_\_\_
- No.....2

31. Have you had your ovaries removed?

- Yes..... 1      Date: \_\_\_\_\_ /  
month      year
- No.....2      **Go to Question 32**

31a. Was it one ovary or both?

One.....1  
Both.....2

31b. Did you have your ovary (ovaries) removed for (READ LIST)?

The treatment of ovarian cancer ..... 1  
The treatment of breast cancer ..... 2  
Prevention..... 3  
A medical reason aside from cancer  
treatment?..... 4 Please specify \_\_\_\_\_

*IF BOTH OVARIES REMOVED, GO TO QUESTION 34*

32. Are you considering having your ovaries removed for prevention?

Yes.....1  
No.....2

33. Have you had any of the following tests to screen for ovarian cancer?

33a. CA-125 (a blood test)

Yes.....1  
No.....2  
Don't know or never heard of it.....9

When was the last time you had this? \_\_\_\_\_ /  
month year

33b. Pelvic ultrasound for screening purposes, not pregnancy. **Pelvic ultrasound** (sound waves are projected onto the abdomen and an image is displayed -- your bladder has to be full).

Yes.....1 **Go to Question 33c.**  
No.....2 **Go to Question 33d.**  
Don't know or never heard of it.....9 **Go to Question 33d.**

33c. When was the last time you had this? \_\_\_\_\_ /  
month year

33d. Transvaginal ultrasound for screening purposes, not pregnancy. **Transvaginal ultrasound** (a probe is inserted into the vagina to image the ovaries -- your bladder does not have to be full).

- |                                      |   |                            |
|--------------------------------------|---|----------------------------|
| Yes.....                             | 1 | <b>Go to Question 33e.</b> |
| No.....                              | 2 | <b>Go to Question 34</b>   |
| Don't know or never heard of it..... | 9 | <b>Go to Question 34</b>   |

33e. When was the last time you had this? \_\_\_\_\_ /  
month                      year

33f. Did this test include Doppler flow color imaging?

- |                                      |   |
|--------------------------------------|---|
| Yes.....                             | 1 |
| No.....                              | 2 |
| Don't know or never heard of it..... | 9 |

**The last questions are about your background.**

34. What is the date of your birth? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
month      day      year

35. What is your race or ethnic background? **[READ LIST]**

- |                                |   |
|--------------------------------|---|
| Black or African American..... | 1 |
| Caribbean or West Indian.....  | 2 |
| White/non-Hispanic.....        | 3 |
| Hispanic.....                  | 4 |
| Asian or Pacific Islander..... | 5 |
| Native American.....           | 6 |
| Other... _____.....            | 9 |
| Spanish or Hispanic.....       | 8 |

36. How many years of school have you completed? **[READ LIST]**

- |                                   |   |
|-----------------------------------|---|
| 8 or less years.....              | 1 |
| Some high school.....             | 2 |
| High school graduate, or GED..... | 3 |
| Some college.....                 | 4 |
| College graduate or beyond.....   | 5 |

37. What is your religious background? **[DO NOT READ LIST]**

- |                   |   |
|-------------------|---|
| Catholic.....     | 1 |
| Protestant.....   | 2 |
| Jewish.....       | 3 |
| Atheist/None..... | 4 |
| Other _____.....  | 5 |

38. Are you currently employed for salary or wages? **[READ LIST]**

- Not employed.....1
- Full-time employed.....2
- Part-time employed.....3
- Retired.....4

39. What was your household income before taxes last year? **[READ LIST]**

- less than \$20,000.....1
- \$20,001 - \$35,000.....2
- \$35,001 - \$50,000.....3
- \$50,001 - \$75,000.....4
- greater than \$75,000.....5

40. Do you have health insurance?

- Yes.....1
- No.....2

What type? **[READ LIST]**

- Fee for service (such as Blue Cross/Blue Shield)..... 1
- Health Maintenance Organization, HMO or other prepaid plan..... 2
- PPO or Point of Service..... 3
- Military/Champus..... 4
- Medicaid..... 5
- Medicare..... 6
- Other \_\_\_\_\_..... 9