

Section B: Diagnosis and Testing of Your Cancer

Genetic Testing for Cancer Risk

Genetic testing for cancer risk – often called BRCA tests or multi-gene panel tests – looks for gene mutations or changes to see if women and their families have a greater risk of developing breast cancer in the future.

B15. Genetic tests for breast cancer risk are ordered by a doctor or genetic counselor and can be done with either a blood test or a saliva test where you rinse your mouth with mouthwash and spit into a tube.

Have you **ever** had a blood or saliva genetic test for breast cancer risk that was ordered by a doctor or genetic counselor?

Yes

No

Don't know

B15a. Why haven't you had a genetic test for breast cancer risk?

Please mark ALL that apply.

- I plan to have a genetic test in the future
- I don't know if I've had a genetic test
- My doctor didn't recommend it
- I didn't want it
- My family didn't want me to get it
- It was too expensive
- I was afraid I would lose my insurance or have to pay more for insurance
- I was afraid of discrimination
- Other (please explain): _____

Please go to B22 "Tumor Tests" on page 7

B16. Why did you get a genetic test? **Please mark ALL that apply.**

- My doctor thought I should
- My family wanted me to be tested
- I wanted to get more information about my own health
- I wanted to get more information for my family members
- Because of my family history
- To help me decide about my treatment
- Other (please explain): _____

Please continue to B17 at the top of the next page

If you have NOT had a genetic test for breast cancer risk, please skip this page and go to B22 →

B17. When did you have the genetic test?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Before I was diagnosed with breast cancer	After I was diagnosed but before I had surgery	After I had surgery to treat my breast cancer

B18. What was the result of the genetic test? **Please mark ONE.**

- I did not have any mutations in the gene tests
- I had a mutation in the BRCA1 or BRCA2 gene that increases the risk of breast cancer
- I had a mutation in another gene (not BRCA1 or BRCA2) that increases the risk of breast cancer
- A gene change was found, but not one that has been shown to increase the risk of breast cancer (sometimes called a “variant of uncertain significance”)
- I don’t know the results
- Other (please explain): -----

B21. Did the genetic test results influence your decision about whether or not to have **both breasts** removed?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was <u>never</u> interested in having both breasts removed	Made me <u>much less</u> interested	Made me <u>less</u> interested	Did not influence my decision	Made me <u>more</u> interested	Made me <u>much more</u> interested

Section C: Your Treatments

Surgery

C2. What was the first surgery that you had to remove your breast cancer after the biopsy test?

- I did not have any surgery after the biopsy
- I had a mastectomy (removal of the entire breast)
- I had a lumpectomy (removal of the cancer and some surrounding tissue)

Please go to C3 at the top of the next page

a. Did you have a second lumpectomy to remove more breast tissue from the same breast?

- Yes – I had another lumpectomy to remove more breast tissue from the same breast
- No – I only had one lumpectomy

b. Did you have a mastectomy later, on the same breast?

- Yes – I had a mastectomy after my lumpectomy
- No – I did not have a mastectomy

c. How strongly did your doctor recommend that you have a mastectomy after your initial lumpectomy?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Very strongly | Strongly | Moderately | Weakly | Not at all |

d. How strongly did you request to have a mastectomy after your initial lumpectomy?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Very strongly | Strongly | Moderately | Weakly | Not at all |

Please continue to C3 on the next page

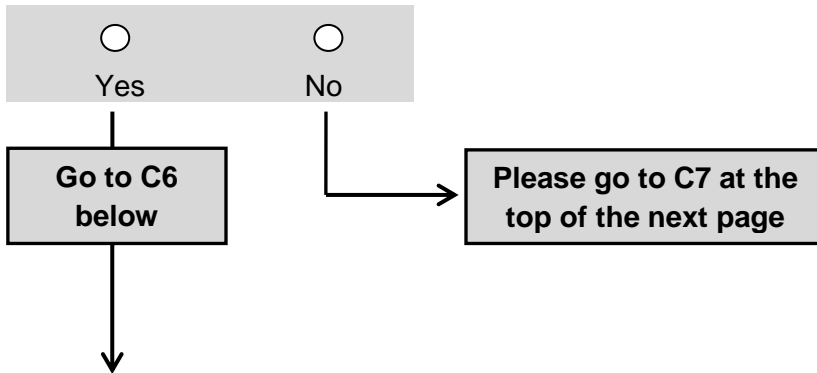
C3. What kind of mastectomy did you have?

- I did not have a mastectomy
- Mastectomy only – no reconstruction
- Mastectomy with reconstruction and I kept my own nipple, called a nipple sparing or nipple saving mastectomy
- Mastectomy with reconstruction and my original nipple was removed

C4. What type of breast reconstruction did you have?

- I have not had any breast reconstruction surgery
- A DIEP flap, TRAM flap, or latissimus dorsi flap (uses your own tissue from the abdomen or back)
- An implant (silicone or saline)
- Other (please explain): _____

C5. Did you have a mastectomy on **both breasts**?



C6. How important were the following factors in your decision to have a mastectomy on **both breasts**?

	Not at all important	A little important	Somewhat important	Quite important	Very important
a. My age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Having a family history of breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Wanting both breasts to match after reconstruction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section D: Decision Making

D1. **In general**, please tell us how often you have these thoughts and feelings when you make decisions.

	Never	Rarely	Sometimes	Often	Always
a. I worry about making a bad decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I struggle to decide what the right decision is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I get angry at myself when I have made a bad decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I worry a lot about the outcomes of my decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D2. When making decisions about **how to treat my breast cancer**...

	Not at all	A little	Somewhat	Quite a bit	A lot
a. I weighed the pros and cons of all the treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I feel like I really thought through all the issues important to the treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I talked with others – family or friends – before making treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I talked with other breast cancer patients before making treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I spent time thinking about all of the treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D3. When making decisions about **how to treat my breast cancer**...

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I would like to have had more information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I would like to have participated more	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I am satisfied with the amount of time I had	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I am satisfied with the amount of involvement I had from family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D4. **When decisions were being made about your treatments**, how important was it to you that your treatments...

	Not at all important	A little important	Somewhat important	Quite important	Very important
a. Reduced the need for more surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Allowed you to avoid side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Allowed you to avoid exposure to radiation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Required fewer trips back and forth for treatment visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Did not make you feel bad about your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Kept you from worrying about the cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Allowed you to feel feminine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Were the most extensive possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Were the least extensive possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Allowed you to keep your original breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Were what your partner/family wanted you to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Were what your doctor wanted you to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. Were the same treatments that other women you know have received	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. Were the newest, most advanced treatments available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o. Had the shortest recovery time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p. Gave you peace of mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q. Allowed you to avoid having follow-up mammograms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
r. Did not require you to spend a lot of your own money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
s. Had a lower possibility of complications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
t. Allowed you to continue to care for your home and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
u. Allowed you to continue to work for pay	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D5. At the time that decisions were being made about your treatments, how much do you feel that your preferences were considered?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	Slightly	Moderately	Very much	Completely

Surgery decisions

D6. When did you make a decision about your initial surgical treatment?

- Before my first visit with a surgeon
- After my first visit with a surgeon
- After two or more visits

D7. Did you see a second surgeon for an opinion about your surgery treatment options?

Yes
↳

a. Did that second surgeon perform your breast surgery?

- Yes
- No

No

D8. How strongly did the surgeons you consulted for breast cancer recommend one option over the other for your initial surgery?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly recommended <u>lumpectomy</u>	Weakly recommended <u>lumpectomy</u>	Did not recommend one surgery option over the other	Weakly recommended <u>mastectomy</u>	Strongly recommended <u>mastectomy</u>

D9. How strongly did you consider having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very strongly	Strongly	Moderately	Weakly	Not at all

D10. When you discussed treatment options with your surgeon, was the idea of having a mastectomy on both breasts ever discussed? **Please mark ONE.**

- No, it was never discussed
- Yes, and I was the first to bring it up
- Yes, and my surgeon was the first to bring it up
- Yes, and another person I brought to my clinic visit was the first to bring it up

D11. How much time did you spend talking with the surgeons you consulted for breast cancer about having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No time at all	A little bit of time	Some time	Quite a lot of time	All of the time (it was the only option we talked about)

D12. How strongly did the surgeons you consulted for breast cancer recommend having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly recommended it	Weakly recommended it	Did not make a recommendation – left it up to me	Weakly recommended <u>against</u> it	Strongly recommended <u>against</u> it

D13. How much did the surgeons you consulted for breast cancer oppose your interest in having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	A little bit	Somewhat	Quite a bit	Very much	I did not have any interest in having a mastectomy on both breasts

D14. My surgeons told me that having a mastectomy on my “other” breast – the breast without cancer – would:

	Yes	No	Not discussed
a. Give me a better chance of surviving the breast cancer I already have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Reduce the chances of the breast cancer I already have coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Reduce the chances of developing a new cancer in my “other” breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Improve the cosmetic outcome of my surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Make my recovery from the surgery take longer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section J – Family History of Cancer

To help us better understand your family history, please answer the following question to tell us if any of your blood relatives have had breast cancer and how old they were at the time of their breast cancer diagnosis.

J1. Has your mother ever been diagnosed with breast cancer?

- Yes, my mother was diagnosed with breast cancer before age 50
- Yes, my mother was diagnosed with breast cancer at or after age 50
- No
- Don't know

Sisters

J2. How many sisters do you have? 0 1 2 3 4 or more

J3. How many of your sisters have been diagnosed with breast cancer? 0 1 2 3 4 or more

J4. Have any of your sisters been diagnosed with breast cancer before age 50? Yes No Don't know

Daughters

J5. How many daughters do you have? 0 1 2 3 4 or more

J6. How many of your daughters have been diagnosed with breast cancer? 0 1 2 3 4 or more

J7. Have any of your daughters been diagnosed with breast cancer before age 50? Yes No Don't know

J8. Although it is uncommon, men can also get breast cancer. Has a man in your family (blood relative) ever been diagnosed with breast cancer?

Yes

No

Don't know

J9. Have any of your parents, brothers, sisters, or biological (blood related) children ever been diagnosed with any of the cancers below? **Please mark ALL that apply.**

- | | | | | |
|-----------------------------------------|--------------------------------------|------------------------------------------------|---------------------------------------------|-------------------------------------------------|
| <input type="radio"/> Ovarian cancer | <input type="radio"/> Uterine cancer | <input type="radio"/> Prostate cancer | <input type="radio"/> Colon cancer | <input type="radio"/> Stomach (gastric) cancer |
| <input type="radio"/> Pancreatic cancer | <input type="radio"/> Brain cancer | <input type="radio"/> Sarcoma (muscle or bone) | <input type="radio"/> Ocular melanoma (eye) | <input type="radio"/> Cutaneous melanoma (skin) |
| <input type="radio"/> Leukemia (blood) | <input type="radio"/> None of these | | | |

Section K: Home and Work

K5. **At the time of your breast cancer diagnosis**, what was the total yearly income of your entire household, before taxes, from all sources – including child support, alimony, disability, social security, and unemployment?

- | | |
|-----------------------------------------|-----------------------------------------|
| <input type="radio"/> Less than \$5,000 | <input type="radio"/> \$40,000-\$59,999 |
| <input type="radio"/> \$5,000-\$9,999 | <input type="radio"/> \$60,000-\$89,999 |
| <input type="radio"/> \$10,000-\$19,999 | <input type="radio"/> \$90,000 or more |
| <input type="radio"/> \$20,000-\$29,999 | <input type="radio"/> Don't know |
| <input type="radio"/> \$30,000-\$39,999 | |

Current Status

K21. Which of the following best describes your **current** employment status? **Please mark ALL that apply.**

- | | |
|----------------------------------------------------------------------|-----------------------------------------------------|
| <input type="radio"/> Employed full-time | <input type="radio"/> Retired |
| <input type="radio"/> Employed part-time | <input type="radio"/> Student |
| <input type="radio"/> Unemployed and looking for work | <input type="radio"/> Homemaker |
| <input type="radio"/> Temporarily laid off or on sick or other leave | <input type="radio"/> Other (please explain): _____ |
| <input type="radio"/> Disabled | _____ |

K22. Please tell us about your medical insurance right before you were diagnosed with breast cancer as well as your medical insurance at the present time. **Please mark ALL that apply in both columns.**

What type of medical insurance...

	Did you have right before your breast cancer diagnosis?	Do you currently have?
a. None	<input type="radio"/>	<input type="radio"/>
b. Insurance provided through my current or former employer or union (including HMO)	<input type="radio"/>	<input type="radio"/>
c. Insurance provided to another family member (e.g., spouse) through their current or former employer or union (including HMO)	<input type="radio"/>	<input type="radio"/>
d. Insurance purchased directly from an insurance company (by you or another family member)	<input type="radio"/>	<input type="radio"/>
e. Insurance purchased from an exchange (sometimes called "Obamacare" or the Affordable Care Act)	<input type="radio"/>	<input type="radio"/>
f. Medicaid or other state provided insurance	<input type="radio"/>	<input type="radio"/>

g. Medicare/government insurance	<input type="radio"/>	<input type="radio"/>
h. Veterans Affairs (VA, including those who have ever used or enrolled for VA health care)	<input type="radio"/>	<input type="radio"/>
i. Other (please explain): _____	<input type="radio"/>	<input type="radio"/>

Section M: A Few More Questions

M1. Today's date is: _____ / _____ / _____
 month day year

M2. About how tall are you? _____ feet _____ inches or _____ meters

M3. **At the time of your breast cancer diagnosis**, about how much did you weigh?

_____ pounds or _____ kilograms

M4. **Before your breast surgery**, what was your bra cup size?

- A D
- B DD
- C Other (please explain): _____

M5. **In the 12 months before your diagnosis with breast cancer**, what was your experience with your menstrual periods?

- I had no menstrual periods in the 12 months before my breast cancer diagnosis
- I had regular (or the usual timing of) menstrual periods in the 12 months before my breast cancer diagnosis
- I had a change in the timing of menstrual periods in the 12 months before my breast cancer diagnosis

M6. **In the 12 months before your breast cancer diagnosis**, did you experience hot flashes or night sweats at any time – even once?

 Yes No

M7. What is your birth date? _____ / _____ / _____
month day year

M8. **When you were diagnosed with breast cancer**, what was your marital status?

- Married
- Living with partner
- Divorced
- Widowed
- Separated
- Never married

M9. What is the highest level of education you have completed?

- No high school
- Some college or technical school
- Some high school
- College graduate (Bachelor's degree)
- High school graduate or G.E.D.
- Graduate degree or higher

M10. Are you of Hispanic, Latino, or Spanish origin?

- Yes, Mexican, Mexican-American, or Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin (please explain): _____
- No

M11. Are you of Jewish descent?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

M12. For how many years have you lived in the United States? _____ years

M13. In what country were you born? _____

- Don't know

M14. In what country was your mother born? -----

Don't know

M15. In what country was your father born? -----

Don't know

M16. Which of the following best describes your race? **Please mark ALL that apply.**

White

Chinese

Black or African-American

Filipino

American Indian or Alaska Native

Japanese

Native Hawaiian or other Pacific Islander

Korean

Asian Indian

Vietnamese

Other Asian (please explain): -----

Other Race (please explain): -----