



Individualized Cancer Care

A study examining women's breast cancer treatment experiences and decision making

Conducted by: Keck School of Medicine at the University of Southern California, Emory University, and the University of Michigan

This study is funded by a grant from the National Cancer Institute and has been approved by the Institutional Review Boards of Emory University, the University of Southern California, and the University of Michigan.

General Instructions

PLEASE READ THESE INSTRUCTIONS CAREFULLY

- Answer each question as best you can. Please do not leave any blank. However, if you feel that you do not wish to answer a question, please write 'skip' next to it and continue on to the next question.

- Put an **x** or fill in the circle ● next to your answer.

Example: Yes or Yes

- Please erase or cross your answer out completely if you want to change your answer.

Example: ~~Yes~~

- Mark only one response for each question unless other instructions are given, such as "**Mark ALL that apply**".

- Please follow any instructions or arrows that direct you to the next question.

Example: No \longrightarrow **Please go to F9 on the next page.**

- If you mark an answer with a line after it, please write the specific information on the line.

Example: Other (please explain): *It was less than one week.*

Please be reminded that your responses to this survey are confidential and will not be shared with your doctors.

Section A: How Are You Doing?

In general...	Excellent	Very good	Good	Fair	Poor
A1. Would you say your health is ...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A2. Would you say your quality of life is ...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A3. How would you rate your physical health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A4. How would you rate your mental health, including your mood and your ability to think?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A5. How would you rate your satisfaction with your social activities and relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Excellent	Very good	Good	Fair	Poor
A6. In general , please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Completely	Mostly	Moderately	A little	Not at all
A7. To what extent are you able to carry out your everyday physical activities, such as walking, climbing stairs, carrying groceries, or moving a chair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Often	Always
A8. In the past 7 days , how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

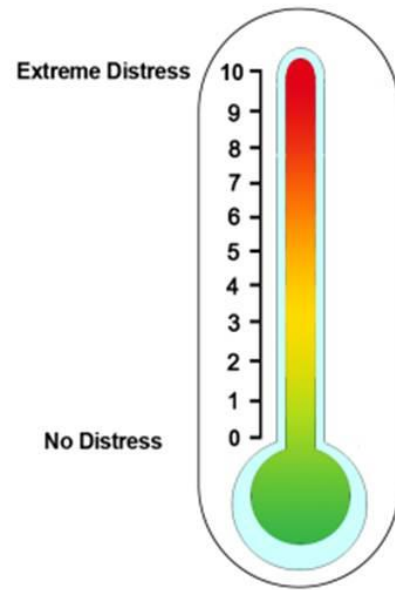
	None	Mild	Moderate	Severe	Very severe
A9. How would you rate your fatigue on average ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No pain									Worst imaginable pain
A10. How would you rate your pain on average ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A11. How are you doing overall?

Please look at the thermometer to the right and write in the number from 0-10 on the line below that best describes how much distress you have been experiencing **in the past 7 days, including today:**

_____ (0-10)



A12. Please tell us whether you have ever been told by a doctor that you had any of the following health conditions:

Yes	No	
<input type="radio"/>	<input type="radio"/>	a. Chronic bronchitis or emphysema
<input type="radio"/>	<input type="radio"/>	b. Heart disease, such as coronary artery disease or congestive heart failure
<input type="radio"/>	<input type="radio"/>	c. Diabetes
<input type="radio"/>	<input type="radio"/>	d. Blood clots in the legs or the lung
<input type="radio"/>	<input type="radio"/>	e. Connective tissue disease, such as lupus or scleroderma
<input type="radio"/>	<input type="radio"/>	f. Stroke
<input type="radio"/>	<input type="radio"/>	g. Depression
<input type="radio"/>	<input type="radio"/>	h. High cholesterol
<input type="radio"/>	<input type="radio"/>	i. High blood pressure or hypertension

Section B: Diagnosis and Testing of Your Cancer

B1. How was a problem with your breast first discovered? **Please mark ONE.**

- The breast cancer was first detected on a routine mammogram
- A doctor or nurse found a lump during a breast exam
- I or my husband/partner found a lump
- I noticed other breast symptoms such as pain, skin change, redness or nipple discharge
- Other (please explain): _____

B2. What was the date when you were first diagnosed with breast cancer? _____ / _____
month year

B3. How did you first find out that you had breast cancer? **Please mark ONE.**

- Radiology doctor who did my biopsy told me
- My primary care doctor told me
- My surgeon called and told me before my first visit with him/her
- My surgeon told me during my first visit with him/her
- A nurse told me before my first visit with a surgeon
- Other (please explain): _____

Next, please tell us about the tests you received to evaluate your breast cancer.

Biopsy

B4. A biopsy is a procedure where tissue or cells are taken from the breast to test for cancer. On which breast did you have a biopsy to diagnose your cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Left	Right	Both

B5. When you first had your biopsy or biopsies that found the cancer, were you told you had cancer in **both breasts**?

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

B6. One type of biopsy is a needle biopsy. It uses a hollow needle inserted in the breast with local numbing medicine to remove a small amount of tissue from your breast. Sometimes a special imaging machine is used to locate the right tissue to remove.

Before a breast operation, was a needle biopsy used to diagnose your breast cancer?

<input type="radio"/> Yes	<input type="radio"/> No
---------------------------	--------------------------

Breast MRI

Next, we would like to ask you about a **Breast MRI (magnetic resonance imaging test)**. A Breast MRI is a scan in which a patient lies down and is placed inside a machine that uses a powerful magnet to take pictures of the breast. The machine is very noisy. Patients are asked before the test about any metal in the body.

B7. How involved were you in deciding whether or not to have a Breast MRI to evaluate the extent of your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

B8. **After diagnosis**, did you have a Breast MRI to evaluate the extent of your breast cancer?

- Yes →
- No
- Don't know

B8a. Did the results of the Breast MRI change your decision about what type of surgery to have for your breast cancer?

- Yes No Don't know

Other Imaging Tests

B9. How involved were you in deciding whether or not you had other imaging tests – such as CT scans or bone scans – to find out if cancer had spread to other places in your body?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

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.

B10. Did a doctor or other health professional talk with you about having a genetic test for breast cancer risk?

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

B11. Did you have a counseling session with a genetic counseling expert – that is, an appointment where the whole discussion is about genetic risk for breast cancer?

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

B12. How much did you want to have a genetic test to tell you the risk of you or your family developing new cancers in the future?

<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

B13. Has a family member ever had a genetic test to determine if they carry a gene mutation (or change) for breast cancer?

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

B14. Does any member of your family have a gene mutation that increases the risk of breast cancer?

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

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?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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.**

- | | |
|------------------------------------------------------------------------------|------------------------------------------------------------|
| <input type="radio"/> My doctor thought I should | <input type="radio"/> Because of my family history |
| <input type="radio"/> My family wanted me to be tested | <input type="radio"/> To help me decide about my treatment |
| <input type="radio"/> I wanted to get more information about my own health | <input type="radio"/> Other (please explain): _____ |
| <input type="radio"/> I wanted to get more information for my family members | _____ |

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): _____

B19. Which provider ordered your genetic test? **Please mark ONE.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgeon	Medical oncologist	Primary care provider	Genetic counselor	Other (please explain:) _____	Don’t know

B20. Which provider(s) discussed the genetic test results with you? **Please mark ALL that apply.**

- Surgeon
- Medical oncologist
- Primary care provider
- Genetic counselor
- Other (please explain): _____
- Don’t know
- N/A – I don’t have results yet

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 interested</u> 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

Tumor Tests

Some patients have their cancer tumor sent for additional testing. Examples of this type of test are **Oncotype DX[®]** and **Mammaprint/Symphony[®]**.



B22. How involved were you in deciding whether or not to have the Oncotype DX or Mammaprint/Symphony test to find out whether you would benefit from chemotherapy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

B23. Was your cancer tumor sent for the Oncotype DX or Mammaprint/Symphony test?

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

↓

→ Please go to C1 at the top of the next page

B24. What were the results of the Oncotype DX or Mammaprint test for your tumor?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low risk	Intermediate risk	High risk	I don't remember

B25. How helpful was the Oncotype DX or Mammaprint test in making a decision about whether or not to get **chemotherapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

B26. Did the Oncotype DX or Mammaprint test change your mind about whether or not to get **chemotherapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made me <u>much less</u> interested in chemotherapy	Made me <u>less</u> interested in chemotherapy	Did not change my mind	Made me <u>more</u> interested in chemotherapy	Made me <u>much more</u> interested in chemotherapy

B27. How helpful was the Oncotype DX or Mammaprint test in making a decision about whether or not to get **radiation therapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

B28. Did the Oncotype DX or Mammaprint test change your mind about whether or not to get **radiation therapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made me <u>much less</u> interested in radiation therapy	Made me <u>less</u> interested in radiation therapy	Did not change my mind	Made me <u>more</u> interested in radiation therapy	Made me <u>much more</u> interested in radiation therapy

Please continue to C1 on the next page

Section C: Your Treatments

C1. **Before your surgery**, did you consult with any of these providers about your treatment decisions?

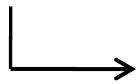
Yes	No	
<input type="radio"/>	<input type="radio"/>	a. Radiation oncologist (a doctor who specializes in radiation treatment)
<input type="radio"/>	<input type="radio"/>	b. Medical oncologist (a doctor who specializes in chemotherapy)
<input type="radio"/>	<input type="radio"/>	c. Plastic surgeon (a doctor who performs breast reconstruction)
<input type="radio"/>	<input type="radio"/>	d. Primary care provider (a doctor, physician assistant, or nurse practitioner who sees you for common problems or standard checkups)
<input type="radio"/>	<input type="radio"/>	e. Genetic counselor (someone who reviews your family history and explains the purpose and results of genetic tests)
<input type="radio"/>	<input type="radio"/>	f. Navigator (often a nurse, someone who helps you with your treatment schedule, test results, or who gives you and your family information about breast cancer)

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?

Very strongly Strongly Moderately Weakly Not at all

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

Very strongly Strongly Moderately Weakly Not at all

Please continue to C3 on the next page

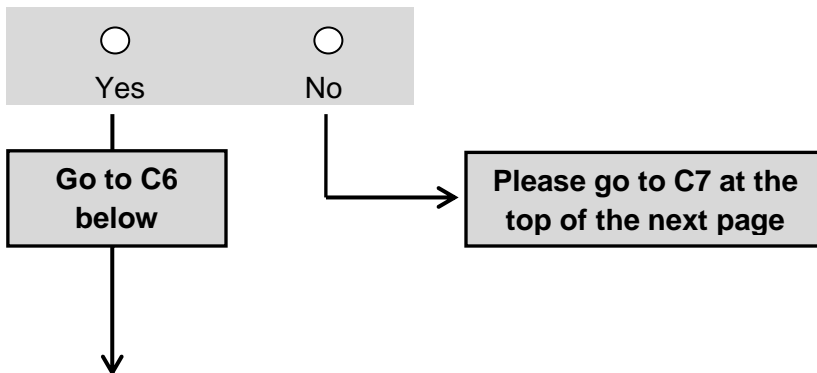
C3. What kind of mastectomy did you have?

- 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**?



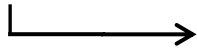
C6. How important were the following factors in your decision to have a mastectomy on **both breasts**?

	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"/>

Please continue to C7 on the next page

C7. Breast cancer sometimes spreads to the lymph nodes under the armpit. Which of the following best describes what was done to the lymph nodes under your armpit? **Please mark ONE.**

- I did not have any lymph nodes removed
- I had a sentinel node biopsy ONLY – where a radioactive material or blue dye was injected into the breast and only one or a few lymph nodes in the armpit were removed
- I had a complete axillary dissection – where all or most of the lymph nodes were removed



A. How were all or most of the lymph nodes removed? **Please mark ONE.**

- I had a needle biopsy before my surgery that showed cancer in the lymph nodes under the armpit, so all of the lymph nodes were taken out later during my surgery
- I had a single operation in which my sentinel nodes were tested and found to have cancer, so all of the lymph nodes were taken out at that time
- I had a single operation in which all of my lymph nodes were removed – no needle biopsy or sentinel node testing was done
- My sentinel nodes were found to have cancer during a first operation, so I had a second, separate operation to remove all of the lymph nodes
- I'm not sure how the lymph nodes were removed

- I don't know

Radiation Therapy

Please answer the following questions even if you did not have radiation therapy

C8. **At the time of your breast cancer diagnosis**, how much time did it or would it have taken you to get from your home to the nearest radiation treatment facility?

<input type="radio"/> Less than 15 minutes	<input type="radio"/> 31 to 60 minutes	<input type="radio"/> I don't know
<input type="radio"/> 15 to 30 minutes	<input type="radio"/> More than 60 minutes	

C9. Did any doctor tell you that radiation treatment...

	Yes	No	Don't remember
a. Usually involves daily trips to an outpatient facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Can be completed in 3-4 weeks or less	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer the following questions even if you did not have radiation therapy

In the past, radiation treatment has almost always involved five or six weeks of daily treatment (Mondays-Fridays) to the *whole breast*. Recently, doctors have started to sometimes use shorter courses of treatment.

C10. Did any doctor tell you that a shorter course of radiation (3-4 weeks or less) was an option for you?

Yes No

One kind of short course radiation treatment lasts **3-4 weeks** and treats the **whole breast**. (This is called “hypofractionated whole breast radiation”.)

C11. Did any doctor tell you that this kind of shorter course of radiation (**3-4 weeks**) to the **whole breast**...

	Yes	No	Don't remember
a. Works as well as 5-6 weeks to the whole breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Is still being studied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. May lead to a worse cosmetic result	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Another option for a short course of radiation lasts **1 week or less** and treats only **part of the breast**. (This is called “accelerated partial breast irradiation” or PBI.)

C12. Did any doctor tell you that this kind of short courses of radiation (**1 week or less**) to **part of the breast**...

	Yes	No	Don't remember
a. Works as well as 5-6 weeks to the whole breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Is still being studied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. May lead to a worse cosmetic result	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C13. **When deciding about radiation therapy**, how much did the treatment length (in other words, the number of weeks of visits for radiation) influence your decision?

Not at all A little Somewhat Quite a bit A lot

C14. Did you or are you going to have radiation therapy to treat your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes – I am finished with radiation therapy	Yes – I am still having radiation therapy	Yes – I plan to have radiation therapy but haven't started yet	No

Please go to C15 below

Please go to C14a

C14a. Why didn't you, or don't you, plan to have radiation therapy?
Please mark ALL that apply.

- My doctor(s) did not discuss it with me
- My doctor(s) said I didn't need it
- My doctor(s) left it up to me and I chose not to
- I was worried about side effects or complications
- I was worried about the cost
- It would have been too much of a burden on me or my family
- Other (please explain): _____

Please go to C18 on the next page

C15. How many total weeks of radiation treatments are planned?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1 week	2-4 weeks	5 weeks	6 or more weeks

C16. How was, or will, your radiation treatment be given? **Please mark ALL that apply.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using beams from outside my body	Using a balloon placed inside my breast	Using needles placed into my breast	I don't know how my radiation treatment was, or will be, given

C17. Which of the following areas were, or will be, treated with radiation? **Please mark ALL that apply.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My whole breast	Only the part of the breast where my tumor was	The chest wall, after my mastectomy	The lymph node areas

Please continue to C18 on the next page

Chemotherapy

C18. Chemotherapy is a treatment where medicine is given into a vein to try to kill any cancer cells in the body that may remain after surgery.

Did you or are you going to have chemotherapy to treat your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes – I am finished with chemotherapy	Yes – I am still getting chemotherapy	Yes – I plan to get chemotherapy but haven't started yet	No

C19. When did you, or will you, have your first dose of chemotherapy?

- Before I had my surgery (lumpectomy or mastectomy)
- After I had my surgery
- N/A – I will not receive any chemotherapy

Hormonal Therapy

C20. Hormonal therapy helps block estrogen from getting to cancer cells that may remain in the body. Hormonal therapy is sometimes called “anti-estrogen therapy” or “endocrine therapy.” Examples include **tamoxifen**, **anastrozole** or Arimidex, **letrozole** or Femara, and **exemestane** or Aromasin.

Have you or are you going to be taking any of these medications? **Please mark ONE.**

- Yes, I currently take one of these medications
- Yes, I plan to take one of these medications in the future but haven't started yet
- Yes, I took one of these medications before but no longer take it
- No, I am not taking any of these medications right now and I am unsure whether or not I should start
- No, I have no plans to take any of these medications

Side Effects During Treatment

C21. **In the past 7 days**, I have been bothered by side effects of treatment.

<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

C22. During treatment – **including surgery, radiation, and chemotherapy** – please tell us how severe each of these side effects was at its worst.

At its worst, what was the severity of your...

	None	Mild	Moderate	Severe	Very severe
a. Nausea and vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Loose or watery stools or diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Constipation or hard stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Arm swelling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Breast skin irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Feelings of sadness or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C23. Next, we would like to know if you got help from your health care team to deal with any side effects of treatment – even one time. **Please mark ALL that apply on each row.**

	I did not have or seek help for this problem	I called or emailed for help	I discussed it at a routine clinic visit	I went for an <u>unscheduled</u> clinic visit	I went to the emergency room or hospital
a. Nausea and vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Loose or watery stools or diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Constipation or hard stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Arm swelling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Breast skin irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Feelings of sadness or anxiety	<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"/>

Chemotherapy decisions

A medical oncologist is a doctor that specializes in discussing and giving chemotherapy and hormonal therapy, when needed, to women with breast cancer.

D15. Did you see a medical oncologist to talk about whether or not to receive chemotherapy?

<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Don't know
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D16. How strongly did the first medical oncologist you consulted recommend chemotherapy?

<input type="radio"/> Very strongly recommended it	<input type="radio"/> Weakly recommended it	<input type="radio"/> Left it up to me	<input type="radio"/> Weakly recommended <u>against</u> it	<input type="radio"/> Very strongly recommended <u>against</u> it	<input type="radio"/> I did not consult with a medical oncologist
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Section E: How You Feel About Your Decisions

Please tell us how you feel about the decisions that were made for your breast cancer treatment. If your doctor did not offer you the test or treatment that is listed, please mark N/A for "Not applicable."

E1. Please rate the amount of information you had when the following decisions were made:

	Not enough		Just right		Too much	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E2. I received enough information about the following topics:

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
a. The effects of breast cancer and treatment on sexual functioning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. The impact of treatment on ability to work inside or outside the home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The effects of having breast cancer on my relationships with family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The risk of my breast cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. How to deal with feelings of anxiety or depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E3. How **satisfied** are you with the decision about...

	Not at all satisfied	A little satisfied	Somewhat satisfied	Quite satisfied	Totally satisfied	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section F: Questions about Breast Cancer

Please answer the following questions about the tests and treatments for breast cancer.

F1. Which treatment gives women a better chance of surviving breast cancer?

- Lumpectomy with radiation
- Mastectomy
- There is no difference between these two treatment options
- Don't know

F2. On average, which treatment results in a higher chance of the cancer coming back anywhere in the body after being treated?

- Lumpectomy with radiation
- Mastectomy
- There is no difference between these two treatment options
- Don't know

F3. Does removing the “**other**” **breast** – the breast without cancer – improve survival for ...

	Yes	No	Don't know
a. All women with breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Women with a strong family history of breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Women with a genetic mutation that increases cancer risk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

F4. If any breast cancer cells are found under the arm, do all lymph nodes under the arm need to be removed?

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

F5. Does removing all the lymph nodes under your arm increase the risk of arm swelling?

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

F6. Is it possible that your breast cancer will spread to other parts of your body?

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

G2. Thinking about the family and friends who helped you with your treatment decisions, how often did one of these people...

	Never	Rarely	Sometimes	Often	Very often
a. Attend doctor appointments with you where decisions about your treatment plan were discussed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Take notes for you during a doctor's appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Talk to you about your treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Share information with you from <u>other sources</u> about your treatment options (for example, from the internet or from talking with others)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section H: Communicating with Your Doctors

	None of the time	A little of the time	Some of the time	Quite a bit of the time	All of the time
H1. When it came to getting treatment for breast cancer, I preferred to be told what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H2. When it came to getting treatment for breast cancer, I wanted <u>my doctor</u> to tell me what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H3. I preferred to make my <u>own</u> decisions about my treatments for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H4. For the next set of questions, please think about the surgeon who was most involved in your surgery.

I feel that my surgeon...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Understood how I saw things with respect to my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Listened to how I would like to handle my breast cancer treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Encouraged me to ask questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H5. How often did your surgeons or their staff help you with referrals to other cancer doctors for treatments such as radiation or chemotherapy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Usually	Always

H6. These next questions are about the medical oncologist who was most involved in the decision about whether or not you had or plan to have chemotherapy.

**If you did not see a medical oncologist,
please go to H7 below**

I feel that my medical oncologist...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Understood how I saw things with respect to my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Listened to how I would like to handle my breast cancer treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Encouraged me to ask questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These next questions are about your primary care provider - the health care provider that you see for general illnesses or routine checkups.

H7. How long have you been seeing your current primary care provider?

<input type="radio"/> Less than 6 months	<input type="radio"/> 6 – 11 months	<input type="radio"/> 1 – 2 years	<input type="radio"/> More than 2 years	<input type="radio"/> I don't currently have a primary care provider
---------------------------------------------	----------------------------------------	--------------------------------------	--------------------------------------------	-------------------------------------------------------------------------

H8. **Since your breast cancer diagnosis**, how many times have you seen your current primary care provider?

<input type="radio"/> I haven't seen my primary care provider since my diagnosis	<input type="radio"/> 1 time	<input type="radio"/> 2 times	<input type="radio"/> 3 or more times
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H9. **In general**, I feel that my current primary care provider...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Understands how I see things with respect to my medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Listens to how I would like to handle things regarding my medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Encourages me to ask questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H10. Please read each statement and **mark ONE response on each row.**

	Never	Rarely	Sometimes	Often	Always
a. When you have a new health problem, do you go to your primary care provider before going somewhere else?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Does your primary care provider know what problems are most important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. After going to the specialist or special service for breast cancer, did your primary care provider talk with you about what happened at the visit?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H11. How much did your primary care provider participate in your breast cancer treatment decisions?

<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	A lot

H12. **In the past 6 months**, how often did your primary care provider seem informed and up-to-date about the care you got from your breast cancer doctors?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Always

H13. **After your initial cancer treatment is finished**, which doctor would you prefer to see for each of the following?

	Prefer primary care provider	Prefer cancer doctors	Either one is fine	Prefer to see both
a. Follow-up for breast cancer (mammograms)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Screening for other cancers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. General preventive care such as vaccinations or check-ups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Treatment of my ongoing or future medical problems such as diabetes or heart disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Physical symptoms such as pain, fatigue, or lymphedema	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Emotional problems such as depression or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Reassuring me about my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H14. During your breast cancer care, how satisfied were you with how your doctors worked together?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all satisfied	A little satisfied	Somewhat satisfied	Very satisfied	Extremely satisfied

H15. How frequently has one of your cancer doctors (not your primary care provider) done any of the following?

	Never	Rarely	Sometimes	Often	A lot
a. Written a prescription for a problem other than your breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Given you a referral to another specialist for something <u>not related to your breast cancer</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Ordered a test for something other than your breast cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section I: Your Thoughts and Feelings

The questions below are important to help us better understand how women like you feel towards the end of treatment and the beginning of the recovery period. Please answer these questions the best way you can.

I1. For the question below, please write in a number from 0% to 100% where...

0% = you think there is absolutely no chance that your breast cancer will come back in the breast or the area around it in the next 10 years, and

100% = you think it is absolutely certain that your breast cancer will come back in the breast or the area around it in the next 10 years

After receiving all the planned treatments, what do you think is the chance that your cancer will come back in the breast or the area around it within 10 years?

% (0 to 100)

I2. After receiving all of the planned treatments, do you consider the chance of your cancer coming back in the breast or the area around it to be:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very low	Low	Moderate	High	Very high

13. Next, we would like to ask you for your opinion on the chances of your cancer spreading to other parts of your body. For the question below, please write in a number from 0% to 100% where...

0% = you think there is absolutely no chance that your breast cancer will spread to other parts of your body in the next 10 years, and

100% = you think it is absolutely certain that your breast cancer will spread to other parts of your body in the next 10 years

After receiving all the planned treatments, what do you think is the chance that your cancer will spread to other parts of your body within 10 years?

% (0 to 100)

↳ I3a. Why did you pick this number?

14. After receiving all the planned treatments, do you consider the chance of your cancer spreading to other parts of your body to be:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very low	Low	Moderate	High	Very high

15. How much did your doctors discuss with you the chance of your cancer coming back?

<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	A lot

16. When your doctors discussed the chance of your cancer coming back, did they use...

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only words (For example, "small chance")	Only numbers (For example, "8% chance")	Both words and numbers	My doctors did not discuss the risk with me

17. Compared to other women with similar breast cancer and treatment, how likely do you think it is that your breast cancer will come back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Much less likely	Less likely	About the same	More likely	Much more likely

18. **In the past month**, how often have you worried about your cancer coming back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Almost never	Rarely	Sometimes	Often	Almost always

19. **During the past month**, how often has worrying about your cancer coming back...

	Almost never	Rarely	Sometimes	Often	Almost always
a. Made you feel upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Made it difficult for you to carry out your usual daily activities at home or at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Made you feel distant from family and friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. When you see your cancer doctors for follow-up care, how often do they ask if you are worried about your breast cancer coming back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Almost never	Rarely	Sometimes	Often	Almost always

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 | | | |

J10. Has your spouse or partner ever been diagnosed with any type of cancer?

Yes No I don't have a spouse or partner

Section K: Home and Work

Before Your Breast Cancer Diagnosis

K1. **Before you were diagnosed with breast cancer**, did you work for pay? Yes No

K2. **Before you were diagnosed with breast cancer**, what was your 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 | _____ |

K3. On average, about how many hours per week did you work **before your diagnosis**? _____ hours per week

K4. **At the time of your breast cancer diagnosis**, which of the following was available to you through your employer? **Please mark ALL that apply.**

- I did not work for pay at the time of my diagnosis with breast cancer
- Paid sick leave
- Disability benefits
- Flexible work schedule
- None of the above
- Other (please explain): _____

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?

- Less than \$5,000
- \$5,000-\$9,999
- \$10,000-\$19,999
- \$20,000-\$29,999
- \$30,000-\$39,999
- \$40,000-\$59,999
- \$60,000-\$89,999
- \$90,000 or more
- Don't know

K6. **At the time of your breast cancer diagnosis**, how many people were supported by the total income for your household, including yourself?

- 1 (just you)
- 2 people
- 3 people
- 4 or more people

During Your Treatment for Breast Cancer

K7. Did you work for pay during **any** of your breast cancer treatment? Yes No

K8. About how many days of work have you missed because of your breast cancer or its treatment?

- I haven't missed any work
- Less than a week
- 7 – 14 days
- 15 – 30 days
- More than a month
- I stopped working all together

K9. Since your breast cancer diagnosis, how much money (income) have you lost due to time off from work?

- \$0
- \$1 to \$500
- \$501 to \$2,000
- \$2,001 to \$5,000
- \$5,001 to \$10,000
- More than \$10,000

K10. How much have you paid out-of-pocket for medical expenses related to your breast cancer (including co-payments, hospital bills, and medication costs)?

- \$0
- \$1 to \$500
- \$501 to \$2,000
- \$2,001 to \$5,000
- \$5,001 to \$10,000
- More than \$10,000

K11. How much money have you spent over and above your normal budget due to out-of-pocket non-medical expenses related to your breast cancer (such as supplies like wigs, bras, or bandages; travel; child or elder care; and complementary or alternative medicine)?

- \$0
- \$1 to \$500
- \$501 to \$2,000
- \$2,001 to \$5,000
- \$5,001 to \$10,000
- More than \$10,000

K12. Do you currently have debt (for example, unpaid bills, credit card balance, bank loans, or borrowing money from family or friends) from your breast cancer treatment?

- | | |
|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> |
| Yes | No |

K13. Due to the financial impact of having breast cancer...

- | Yes | No | |
|-----------------------|-----------------------|----------------------------------------------------------------------------------------|
| <input type="radio"/> | <input type="radio"/> | a. I had to use savings |
| <input type="radio"/> | <input type="radio"/> | b. I could not make payments on credit cards or other bills |
| <input type="radio"/> | <input type="radio"/> | c. I cut down on spending for food |
| <input type="radio"/> | <input type="radio"/> | d. I had my utilities turned off because the bill was not paid |
| <input type="radio"/> | <input type="radio"/> | e. I had to move out of my house or apartment because I could not afford to stay there |
| <input type="radio"/> | <input type="radio"/> | f. Other (please explain): _____ |

Since your breast cancer diagnosis, are you worse off regarding...

K14. Employment status?

No

Yes → a. How much is this due to your breast cancer and treatment?

Not at all A little Somewhat Quite a bit Very much

K15. Financial status?

No

Yes → a. How much is this due to your breast cancer and treatment?

Not at all A little Somewhat Quite a bit Very much

K16. How much do you worry about current or future financial problems as a result of your breast cancer and treatments?

Not at all A little Somewhat Quite a bit A lot

K17. How much did you want to talk to your health care providers about the impact of having breast cancer on your employment or finances?

Not at all A little Somewhat Quite a bit A lot

K18. **During your breast cancer experience**, how much did you discuss the impact of having breast cancer on your employment or finances with each of the following people?

	Not at all	A little bit	Somewhat	Quite a bit	A lot
a. Cancer doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Social worker or other professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Primary care doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

K19. How much did your cancer doctors and their staff help you in dealing with the impact of having breast cancer on your employment or finances?

Not at all A little Somewhat Quite a bit A lot

Current Status

K20. Are you **currently** working for pay?

<input type="radio"/>	<input type="radio"/>
Yes	No

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...

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"/>

K23. In the **last 12 months**, have the costs of your prescription medicine(s) been covered by health insurance?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Completely covered	Mostly covered	Partly covered	Not covered at all	I have not taken any prescription medicine in the past 12 months

Section L: Language and Other Preferences

L1. What language do you primarily speak? **Please mark ONE.**

- English Mandarin Cantonese Korean
 Spanish Vietnamese Japanese Other (please explain): _____

L2. In general, what language(s) do you read and speak?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	English better than any other language	Both equally	Another language better than English	Only another language

L3. What language do you usually speak at home?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	More English than any other language	Both equally	Another language more than English	Only another language

L4. In what language do you usually think?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	More English than any other language	Both equally	Another language more than English	Only another language

L5. What language do you usually speak with your friends?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Only English	More English than any other language	Both equally	Another language more than English	Only another language

L6. Please circle the **ONE** number on each line that best describes your thoughts and feelings.

All things considered, I feel that I...

	1	2	3	4	5	6	7	8	9	10
a.	Am lucky in life						Am unlucky in life			
b.	Almost never worry						Almost always worry			
c.	Am very optimistic about life						Am very pessimistic about life			

L7. How much do you agree with each of the items below?

	Not at all	A little bit	Somewhat	Quite a bit	A lot
a. Through my faith in God, I can stay healthy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I rely on God to keep me in good health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Prayer is the most important thing I do to stay healthy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

L8. How often do you have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Always

L9. How often do you find numerical information to be useful?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Very often

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): _____

M11. Are you of Jewish descent?

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

Section N: Your Doctors

N1. We want to learn from doctors about better ways to communicate with patients and their families about treatment decisions. The information you provide below will help us contact the doctors who treat patients with breast cancer. The doctors may be surveyed about their treatment practices. Importantly, your answers will never be shared with any doctors and your personal information including your name will never be used in any communication.

a. **Surgeon** who performed your first lumpectomy or mastectomy:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

b. **Medical oncologist** who talked to you about or delivered chemotherapy or hormonal therapy:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

c. **Clinic or hospital** where you received most of your chemotherapy:

Name of clinic or hospital: _____

Street address: _____ City: _____

d. **Radiation oncologist** who talked to you about or delivered radiation therapy:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

e. **Plastic surgeon or breast surgeon** who performed your breast reconstruction:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

f. **Primary Care Provider** (or family doctor) who sees you for general illnesses or routine checkups:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

Please continue to the next page

