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A Study of Women's Experiences with Treatment for Breast Cancer

Conducted by:

**University of Southern California
Keck School of Medicine**

**Return to: Breast Cancer Treatment Study
Parkview Medical Building PMB-A201
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Questions? Please call 323.442.2712

This study is funded by a grant from the National Institutes of Health and has been approved by the Institutional Review Boards of University of Michigan and University of Southern California.



Study of Women's Experiences with Treatment for Breast Cancer

This is a study about how treatment decisions are made for women when they are diagnosed with breast cancer and what women think about the quality of their health care experiences. Thank you for agreeing to be part of this study. Your answers are very important to us. Any information you provide is strictly confidential and will not be shared with anyone outside of the study. Your answers will be combined with those of everyone else in the study so no one individual can be identified. There are no right or wrong answers so please give the answers that best describe your situation.

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).
- Please fill in the oval next to your answer completely using blue or black ink.
Example: Fill in ovals completely, like this: Yes
Not like this: No Or this: No
- Please follow any instructions that direct you to the next question.
Example: No (Please go to question C13)
- If you mark an answer with a line after it, please write the specific information on the line.
Example: Other (please specify) *my friend who is a doctor*
- Mark only **one** response for each question, **unless** other instructions are given (e.g. Please mark **ALL** that apply).
- As much as possible, please try to answer all of the questions in one sitting.



Section A: Your Health

A1. How would you rate your current health?

Poor Fair Good Very Good Excellent

A2. Before you were told you have breast cancer, would you say your health was:

Poor Fair Good Very Good Excellent

A3. Before you were told you have breast cancer, had you ever been told by a doctor that you had any of the following health conditions?

a. Chronic bronchitis or emphysema Yes No

b. Heart disease such as coronary artery disease or congestive heart failure Yes No

c. Cancer, excluding skin cancer and breast cancer Yes No

d. Diabetes Yes No

e. High blood pressure Yes No

f. Stroke Yes No

g. Arthritis Yes No



Section B: Diagnosis and Treatment

- 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 found a lump.
 - My husband/partner found a lump.
 - I noticed other breast symptoms such as pain, inflammation or nipple discharge.
 - Other (please explain) _____

- B2. How much time passed between when a problem with your breast was first noticed and your breast cancer was diagnosed with a biopsy test (a procedure where tissue or cells are taken from the breast to test for cancer)?
- less than a month
 - 1 - 3 months
 - 4 - 6 months
 - more than 6 months
- B3. How much time passed between when your breast cancer was first diagnosed with a biopsy test and you had surgery for your breast cancer?
- less than a month
 - 1 - 3 months
 - 4 - 6 months
 - more than 6 months
 - I haven't had additional surgery after the biopsy.



Two different types of biopsies can be done to diagnose breast cancer. Some women have both. We would like to know which type you had.

B4. What type of biopsy (or biopsies) did you have to diagnose your breast cancer?

Please mark ALL that apply.

A **needle biopsy** (when a needle is used to take tissue or cells from the breast to test for cancer).

An **excisional biopsy** (when a surgeon cuts out some breast tissue to examine it for cancer).

Other (please explain) _____

B5. On which breast did you have the biopsy (or biopsies)?

Right

Left

Both

B6. What is the name of the doctor who did the biopsy (or biopsies)? _____

B7. Where is this doctor located?

Name of hospital and/or clinic: _____

City: _____

B8. Did you have to go back to the doctor more than one time to have a biopsy done?

No

Yes → How many times? _____



Section C: Your Surgical Treatment

The next group of questions asks about discussions you may have had with any surgeon about treating your breast cancer.

C1. Was a family member or friend with you at any time when you were discussing surgical treatment options with any surgeon?

- No
- Yes

C2. Which procedure (that is, a lumpectomy or mastectomy) did the first surgeon that you talked to recommend?

- The surgeon did not recommend one procedure over the other.
- The surgeon recommended a lumpectomy.
(The removal of the cancer and some surrounding tissue)
- The surgeon recommended a mastectomy.
(The removal of the entire breast)



a. What reason did he/she give for recommending a mastectomy? **Please mark ALL that apply.**

- The lump in my breast was too big to have a lumpectomy.
- My breast was too small to have a lumpectomy.
- The cancer had spread to too many places in the breast.
- The initial surgery did not get all of the cancer.
- I'm not able to have radiation.
- Other (please explain)

C3. Did the first surgeon that you talked to perform your lumpectomy or mastectomy?

No

Yes → a. What is his/her name? _____

b. What is the name of the hospital where you had your surgery?



C4. Please indicate which factors below describe how the first surgeon was selected.

a. I was referred by another doctor.	<input type="radio"/> Yes <input type="radio"/> No
b. I was referred by my health plan.	<input type="radio"/> Yes <input type="radio"/> No
c. I selected the surgeon because of his/her reputation.	<input type="radio"/> Yes <input type="radio"/> No
d. I selected the surgeon because of the reputation of his/her hospital.	<input type="radio"/> Yes <input type="radio"/> No
e. I selected the surgeon because he/she practiced close to my home.	<input type="radio"/> Yes <input type="radio"/> No
f. I already knew this surgeon.	<input type="radio"/> Yes <input type="radio"/> No
g. Other (please explain) _____	

C5. Before your surgery, did you talk with a second surgeon about surgical treatment options for your breast cancer (that is, whether to have a lumpectomy or mastectomy)?

Yes

No (please go to question C11, page 8) →



C6. Why did you decide to consult with a second surgeon? **Please mark ALL that apply.**

- I wanted to know more about breast cancer treatment options.
- I wanted to get a second opinion about my treatment options.
- I wasn't certain that I wanted to be treated by the first surgeon.
- Other (please explain) _____

C7. Please indicate which factors below describe how the second surgeon was selected.

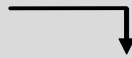
- a. I was referred by another doctor. Yes No
- b. I was referred by my health plan. Yes No
- c. I selected the surgeon because of his/her reputation. Yes No
- d. I selected the surgeon because of the reputation of his/her hospital. Yes No
- e. I selected the surgeon because he/she practiced close to my home. Yes No
- f. I already knew this surgeon. Yes No
- g. Other (please explain) _____

Please continue on next page, Question C8.



C8. Which procedure (that is, a lumpectomy or mastectomy) did the second surgeon recommend?

- The surgeon did not recommend one procedure over the other.
- The surgeon recommended a lumpectomy.
- The surgeon recommended a mastectomy.



a. What reason did he/she give for recommending a mastectomy? **Please mark ALL that apply.**

- The lump in my breast was too big to have a lumpectomy.
- My breast was too small to have a lumpectomy.
- The cancer had spread to too many places in the breast.
- The initial surgery did not get all of the cancer.
- I'm not able to have radiation.
- Other (please explain)

C9. Did the second surgeon perform your lumpectomy or mastectomy?

No

Yes → a. What is his/her name? _____

b. What is the name of the hospital where you had your surgery?

c. Why did you have this surgeon perform your surgery?

C10. Did you consult with any other surgeons?

Yes

No

Please continue on next page, Question C11.



Before your surgery, did any surgeon or their staff...

C11. ...explain that women who have a mastectomy usually do not need radiation therapy?	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> I don't remember
C12. ...explain that if you have a lumpectomy you might need more surgery to remove remaining breast cancer.	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> I don't remember
C13. ...explain that the chance of breast cancer coming back in the area of the surgery may differ depending on which surgical treatment you receive?	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> I don't remember
C14. ...explain that there are different types of breast reconstruction such as breast implants or using your own tissue to create a new breast?	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> I don't remember
C15. ...explain that breast reconstruction can be done either at the same time that a mastectomy is done or later?	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> I don't remember

C16. What other types of doctors did you consult with before your surgery?

- A radiation oncologist (a doctor who specializes in radiation treatment).
- A medical oncologist (a doctor who specializes in chemotherapy).
- A plastic surgeon (a doctor who performs breast reconstruction).
- I didn't consult with any other doctor before my surgery.
- Other (please explain)



C17. How much did your surgeon (that is, the one who performed your surgery) participate in the decision about whether to have radiation?

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

C18. How much did your surgeon participate in the decision about whether to have chemotherapy?

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

C19. How much did your surgeon participate in the decision about whether to have breast reconstruction?

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

C20. How much did a medical oncologist (or chemotherapy doctor) participate in treatment decisions for your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I did not see this type of doctor.	Not at all	A little	Somewhat	Quite a bit	Very much

C21. How much did a radiation oncologist participate in treatment decisions for your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I did not see this type of doctor.	Not at all	A little	Somewhat	Quite a bit	Very much

C22. How much did a plastic surgeon participate in the decision about whether to have breast reconstruction?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I did not see this type of doctor.	Not at all	A little	Somewhat	Quite a bit	Very much



Section D: Questions About Your Treatments

Surgery

D1. What was the first surgery that you had to remove your breast cancer after the biopsy test?

I had a lumpectomy (removal of the cancer and some surrounding tissue).

I had a mastectomy (removal of the entire breast).
(please go to question D4) →

I did not have any surgery after the biopsy.
(please go to question D4) →

D2. Did you have to have a second lumpectomy to remove more breast tissue from the same breast?

No, I only had one lumpectomy.

Yes, I had to have another lumpectomy to remove more breast tissue.

D3. Did you have to have a mastectomy, later, on the same breast?

No, I did not have to have a mastectomy.

Yes, I had to have a mastectomy after my lumpectomy.



Radiation Therapy

D4. Did you or are you going to have radiation therapy to treat your breast cancer?

Yes → a. What is the name of the doctor who treated you or is going to treat you?

b. Where did you go or are you going to have your radiation treatments?

Name of hospital and/or clinic: _____

City: _____

c. How many weeks of radiation treatments did you or are you going to have?

1 week

2 - 4 weeks

5 weeks or more

Other (please specify) _____

d. Did you have ALL of the radiation treatments that your doctor told you to have?

No

Yes

I'm still receiving treatment.

I'm going to start treatment.

e. Was your radiation treatment delayed for any reason?

No

Yes → Why? _____

No → a. 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)



Chemotherapy

Chemotherapy is a treatment where women receive medicine by an intravenous tube to destroy cancer cells.

D5. Did you or are you going to have chemotherapy to treat your breast cancer?

Yes → a. What is the name of the doctor who treated you or is going to treat you?

b. Where did you go or are you going to have your chemotherapy treatments?

Name of hospital and/or clinic: _____

City: _____

c. Did you have ALL of the chemotherapy treatments that your doctor told you to have?

No

Yes

I'm still receiving treatment.

I'm going to start treatment.

d. Were any of your chemotherapy treatments delayed for any reason?

No

Yes → Why? _____

No → a. Why didn't you, or don't you plan to, have chemotherapy?

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 didn't want to lose my hair.

I was worried about the cost.

It would have been too much of a burden on me or my family.

Other (please explain)



Breast Reconstruction

D6. Have you had breast reconstruction?

- Yes → a. What type of procedure did you have?
 - Breast implants or tissue expanders.
 - Breast reconstruction that uses your own tissue.
- b. Did you have breast reconstruction surgery at the same time as your mastectomy or later?
 - At the same time as my mastectomy.
 - I had it done later.
- c. Why did you decide to have breast reconstruction?

d. Are you satisfied with the results?

- Yes
- No → Why not? _____

No → a. Why haven't you had breast reconstruction?

Please mark ALL that apply.

- I had a lumpectomy.
- I'm planning to have it later.
- I'm still considering it.
- I didn't know how or where to get it.
- I was worried about the cost.
- I didn't want more surgery.
- It is not important to me to create a new breast.
- I'm afraid of implants.
- Other (please explain)



Section E: Getting the Medical Care You Needed

We want to know about the experience you had when you went to see your doctor(s) for your breast cancer. **For each item below please mark the ONE response that best describes how much of a problem it was.**

E1. *When you were being treated for breast cancer, how much of a problem was. . .*

	Not a problem	Somewhat of a problem	A big problem
a. ...finding doctor(s) to treat your breast cancer after it was diagnosed. . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...the amount of money you paid for visits to your doctor(s).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...the amount of money you paid for treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...the amount of money you paid for medications.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...getting an appointment with your doctor(s) when you had a problem. . . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...waiting to see your doctor(s) once you arrived for your appointments. . . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...getting to speak to your doctor(s) or their staff by phone when you had a question.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...getting to your doctor's office.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...scheduling your surgery at a time that was convenient for you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



When you were being treated for breast cancer:

- E2. How often did you have problems understanding information about your breast cancer or your treatment because of difficulty with written information?

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

- E3. How often did you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read written information from the hospital or clinic?

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

- E4. How often did you have problems filling out medical forms by yourself?

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

For each of the items below please mark the ONE response that best describes your opinion:

- E5. I am satisfied that I was adequately informed about the issues important to the decision about what kind of surgery to have.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

- E6. I am satisfied with the decision about what kind of surgery to have.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

- E7. I wish I had given more consideration to other surgical treatment options.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree



E8. I would like to have had more information when the decision about surgery was made.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

E9. I would like to have participated more in making the decision about what kind of surgery to have.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

E10. My level of participation in making the decision about what kind of surgery to have was more than I wanted.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree



Section F: Coordinating Your Care

We would like to learn about the help you received during your breast cancer treatment. **Please mark the response that best describes your experience.**

F1. How often did your surgeon(s) or their staff help you with referrals to other 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

F2. How often did you know who to ask when you had questions about breast cancer or your treatment?

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

F3. How often were you given confusing or contradictory information about breast cancer or your treatment?

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

F4. How often did you know what the next step in your treatment would be?

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

F5. How often did your doctor(s) have the medical information they needed to make decisions about your breast cancer treatment?

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

F6. Overall, 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



Section G: Information and Support

When women are diagnosed with breast cancer, they receive different types of information from their doctor(s) about diagnosis and treatment.

G1. For each item below, please mark the ONE response that best describes your experience.

The information I received from my doctor(s) or their staff about...

	Not at all useful	A little useful	Somewhat useful	Very useful	Extremely useful	Did not get
a. ...how to manage side effects of radiation was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...how to manage side effects of chemotherapy was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...hormone therapy (such as Tamoxifen or Arimidex) was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...alternative or holistic treatments was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...nutrition and/or diet was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...the effects of breast cancer and treatment on sexual functioning was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...the effects of having breast cancer on one's relationship with their spouse or partner was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...how to manage recovery after surgery was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...feelings of anxiety or depression was	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. ...Other (please explain)	<hr/> <hr/>					



G2. *Would you have liked more information from your doctor(s) or their staff about...*

a. ...the surgical treatment options such as lumpectomy or mastectomy?	<input type="radio"/> Yes	<input type="radio"/> No
b. ...how likely breast cancer is to come back once it's been treated?	<input type="radio"/> Yes	<input type="radio"/> No
c. ...different types of breast reconstruction?	<input type="radio"/> Yes	<input type="radio"/> No
d. ...how to manage side effects of radiation treatment?	<input type="radio"/> Yes	<input type="radio"/> No
e. ...how to manage side effects of chemotherapy treatment?	<input type="radio"/> Yes	<input type="radio"/> No
f. ...hormone therapy (such as Tamoxifen or Arimidex)?	<input type="radio"/> Yes	<input type="radio"/> No
g. ...alternative or holistic treatments?	<input type="radio"/> Yes	<input type="radio"/> No
h. ...nutrition and/or diet?	<input type="radio"/> Yes	<input type="radio"/> No
i. ...the effects of breast cancer and treatment on sexual functioning?	<input type="radio"/> Yes	<input type="radio"/> No
j. ...the effects of having breast cancer on one's relationship with their spouse or partner?	<input type="radio"/> Yes	<input type="radio"/> No
k. ...how to manage recovery after surgery?	<input type="radio"/> Yes	<input type="radio"/> No
l. ...what to do about feelings of anxiety or depression?	<input type="radio"/> Yes	<input type="radio"/> No
m. ...other (please explain)		
<hr/>		
<hr/>		



G3. Did any of your doctor(s) or their staff make arrangements for you to talk to women with breast cancer, or go to a support group for women with breast cancer?

- No
- Yes

G4. Did you talk to any women with breast cancer?

Please mark ALL that apply.

- No, I didn't talk to women with breast cancer.
 - Yes, patients who my doctor referred me to.
 - Yes, a breast cancer support group.
 - Yes, a family member who has had breast cancer.
 - Yes, a friend or neighbor who has had breast cancer.
 - Other (please specify)
-

G5. What was your experience talking to other women with breast cancer?

Please mark ALL that apply.

- I didn't talk to women with breast cancer.
 - Talking to other women helped me make treatment decisions.
 - Talking to other women helped me emotionally.
 - Talking to other women made me doubt my treatment decisions.
 - Talking to other women helped me know what to expect.
 - Talking to other women made me scared or anxious about treatment.
 - Talking to other women helped me cope with the challenges and side effects of treatment.
 - Talking to other women made me wonder why I didn't get the same treatments they had.
 - Other (please explain)
-
-

G6. Would you have liked more contact with other women with breast cancer?

- No
- Yes
- I'm not sure.



Section H: Decision Making

We are interested in learning about your experiences when decisions were being made about treatment for your breast cancer.

H1. Which of the following statements best describes how the decision was made about which surgical treatment to have for your breast cancer (that is, whether to have a lumpectomy or mastectomy.) **Please mark ONE.**

- My surgeon(s) made the decision with little input from me.
- My surgeon(s) made the decision but seriously considered my opinion.
- My surgeon(s) and I made the decision together.
- I made the decision after seriously considering my surgeon(s) opinion.
- I made the decision with little input from my surgeon(s).

H2. We would like to know how you feel about how this decision was made (that is, the decision about whether to have a mastectomy or lumpectomy). **Please mark the ONE statement that best describes how you feel.**

- I wish my surgeon(s) had been more involved in making this decision.
- My level of involvement in this decision was right for me.
- I wish I had been more involved in making this decision.

H3. How important was your husband's or partner's opinion in the decision about which surgical treatment to have for your breast cancer?

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

H4. How important was the opinion of another family member in the decision about which surgical treatment to have for your breast cancer?

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

H5. How important was a friend's opinion in the decision about which surgical treatment to have for your breast cancer?

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



H6. For each item below, please mark ONE.

When decisions were being made about your surgery, how important was it that the type of surgery you had. . .

	Not at all important	Somewhat important	Very important
a. ...would keep you from worrying about the cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...would allow you to avoid the possibility of a second surgery to remove more cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...would not make you feel bad about your body, like it was disfigured	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...would not interfere with your sex life in the long term	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...would allow you to avoid exposing yourself to radiation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...would allow you to avoid going back and forth to radiation treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...would allow you to feel feminine . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...would reduce the chances of the cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Please mark the response below that most closely matches how much you agree or disagree with the following statements:

If I had it to do over. . .

H7. . . . I would make a different decision about what type of surgery to have (that is whether to have a lumpectomy or mastectomy.)

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H8. . . . I would choose a different surgeon to perform my surgery.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H9. . . . I would take more time to make decisions about my treatment.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H10. . . . I would make decisions about my treatment more quickly.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H11. . . . I would consult more doctors about my treatment before making a decision.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H12. . . . I would do everything the same.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree



Section I: Home and Work

Now we'd like to ask some questions about your work and family life before and after you were diagnosed with breast cancer.

I1. Before you were diagnosed with breast cancer, did you work for pay?

Yes

No (please go to question I9, page 26) →



I2. What type of work was this?

I3. On average, about how many hours per week did you work before your diagnosis?

 hours

I4. 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.

I5. Which of the following was available to you through your work?

Please mark ALL that apply.

- Medical insurance
- Paid sick leave
- Disability benefits
- Flexible work schedule
- None of the above
- Other (please explain) _____

I6. Did you work for pay during any of your breast cancer treatment?

- Yes
- No

Please continue on next page, Question I7.



17. As a result of your breast cancer or its treatment did you have any of the following experiences?

- a. I arranged to work fewer hours Yes No
- b. I changed jobs within the company Yes No
- c. I took time off. Yes No
- d. I quit my job. Yes No
- e. I lost my job Yes No
- f. I had trouble doing my job well Yes No
- g. I decided to keep my job to keep my health insurance. Yes No
- h. Other (please explain)

18. Please indicate if your employer did any of the things below to help you when you were being treated for breast cancer.
(If you did not have an employer, please mark 'Does not apply'.)

My employer...

- a. ... developed a plan with me so I could take the necessary time off Yes No Does not apply
- b. ... allowed me flexibility in my schedule so I could get treatments Yes No Does not apply
- c. ... paid me for sick days Yes No Does not apply
- d. ... didn't do anything to help Yes No Does not apply
- e. Other (please explain)

Please continue on next page, Question I9.



I9. As a result of breast cancer or its treatment:

- a. Have you lost family income? Yes No Does not apply
- b. Have household chores been left undone? Yes No Does not apply
- c. Has your husband or partner missed work? Yes No Does not apply
- d. Has your husband or partner had trouble doing his/her job well? Yes No Does not apply
- e. Have your children missed school? Yes No Does not apply
- f. Have your children had trouble in school? Yes No Does not apply
- g. Do you worry about keeping your job? Yes No Does not apply
- h. Do you worry about getting a new job in the future? Yes No Does not apply

I10. We'd like to learn about how your illness has affected your finances.

Please mark ALL of the responses below that apply to you and/or your family.

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

- I had to use savings.
- I could not make payments on credit cards or other bills.
- I cut down on spending for food and/or clothes.
- I cut down on spending for health care for other family members.
- I cut down on spending for activities for the children.
- I cut down on recreational activities such as going out for dinner or to the movies.
- I cut down on purchasing household items.
- I cut down on expenses in general.
- My illness has had no impact on my finances.
- Other (please explain)

I11. How much do you worry about current or future financial problems as a result of your breast cancer and treatments?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <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 |

I12. Are you currently working for pay? Yes No



Section J: Experiences with Symptoms

The next questions ask about symptoms you may have had recently or when you were being treated for breast cancer. **Please indicate how much you experienced these symptoms when you were being treated for breast cancer.**

	<i>During your treatment for breast cancer. . .</i>	Not at all	A little bit	Some-what	Quite a bit	Very much
J1.	...have you had pain or swelling in the arm?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J2.	...have you had pain or swelling in the affected breast?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J3.	...have you had skin problems on or near the area of your breast where you had your surgery?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J4.	...have you experienced any hot flashes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J5.	...have you experienced any vaginal dryness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J6.	...have you been more tired than usual? .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J7.	...Other (please specify) _____					
J8.	Do you think that your doctor(s) and their staff did everything they could to help you manage your symptoms?	<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



Section K: How You Have Been Feeling Recently

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

<u>Physical Well-Being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
K1. I have a lack of energy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K2. I have nausea.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K3. Because of my physical condition, I have trouble meeting the needs of my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K4. I have pain.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K5. I am bothered by side effects of treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K6. I feel ill.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K7. I am forced to spend time in bed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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

<u>Social/Family Well-Being</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
K8.	I feel close to my friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K9.	I get emotional support from my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K10.	I get support from my friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K11.	My family has accepted my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K12.	I am satisfied with family communication about my illness. . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K13.	I feel close to my partner (or the person who is my main support).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p><i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this oval <input type="radio"/> and go to the next section (question K15).</i></p>						
K14.	I am satisfied with my sex life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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

<u>Emotional Well-Being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
K15. I feel sad.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K16. I am satisfied with how I am coping with my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K17. I am losing hope in the fight against my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K18. I feel nervous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K19. I worry about dying.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K20. I worry that my condition will get worse.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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

<u>Functional Well-Being</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
K21. I am able to work (include work at home).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K22. My work (include work at home) is fulfilling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K23. I am able to enjoy life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K24. I have accepted my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K25. I am sleeping well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K26. I am enjoying the things I usually do for fun.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K27. I am content with the quality of my life right now.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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

<u>Additional Concerns</u>	Not at all	A little bit	Some-what	Quite a bit	Very much
K28. I have been short of breath.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K29. I am self-conscious about the way I dress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K30. One or both of my arms are swollen or tender.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K31. I feel sexually attractive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K32. I am bothered by hair loss.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K33. I worry that other members of my family might someday get the same illness I have.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K34. I worry about the effect of stress on my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K35. I am bothered by a change in weight.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K36. I am able to feel like a woman.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K37. I have certain parts of my body where I experience significant pain.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



K38. Please mark the response below that indicates how true each statement is for you.

	Not at all	A little bit	Some-what	Quite a bit	Very much
a. I worry about my breast cancer coming back in the same breast. . . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I worry that breast cancer may occur in my other breast.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I worry that breast cancer will spread to other parts of my body. . .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section L: Language Preferences

L1. Do you speak Spanish?

Yes, I speak Spanish.

No, I don't speak Spanish.

(please go to Question M1, page 35) →

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

- Only English
 English better than Spanish
 Both equally
 Spanish better than English
 Only Spanish

L3. What language do you usually speak at home?

- Only English
 More English than Spanish
 Both equally
 More Spanish than English
 Only Spanish

L4. In what language do you usually think?

- Only English
 More English than Spanish
 Both equally
 More Spanish than English
 Only Spanish

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

- Only English
 More English than Spanish
 Both equally
 More Spanish than English
 Only Spanish

L6. In general, when talking to health care providers such as doctors and nurses, what language do you prefer to use?

- Only English
 More English than Spanish
 Both equally
 More Spanish than English
 Only Spanish

Please continue on next page, Question L7.



L7. When you met with your surgeon to discuss your breast cancer treatment, who helped translate what the doctor was saying? **Please mark ALL that apply.**

- I did not need help translating.
- My husband/partner
- My child or another family member
- Someone from the doctor's office
- My doctor spoke Spanish.
- Other (please specify)

L8. Did you get as much help with translation as you needed?

- I didn't need help.
- No
- Yes

L9. Which of the following sources were available to you in Spanish?

Please mark ALL that apply.

- Pamphlets about breast cancer and breast cancer treatments
- Consent forms
- Insurance forms
- Appointment slips
- Other (please specify) _____
- No written information was available in Spanish.
- I don't know.

L10. Was there anything that you wanted in Spanish that was not available to you in Spanish? (please list)

Please continue on next page, Question M1.



Section M: A Few More Questions About You

- M1. Which of the following members of your family had been diagnosed with breast cancer at the time of your recent breast cancer diagnosis? **(Please include only family members who are related by blood.)**
Please mark ALL that apply.
- Mother
 - Sister
 - Daughter
 - Grandmother
 - Aunt
 - No family members had been diagnosed with breast cancer.
- M2. Please indicate which item below best describes your experience with your menstrual period 12 months prior to your diagnosis with breast cancer.
- I had no menstrual periods in the 12 months prior to my breast cancer diagnosis.
 - I had regular (or the usual timing of) menstrual periods in the 12 months prior to my breast cancer diagnosis.
 - I had a change in the timing of menstrual periods in the 12 months prior to my breast cancer diagnosis.
- M3. Did you experience hot flashes or night sweats at any time during the 12 months prior to your breast cancer diagnosis?
- Yes
 - No
- M4. What is your birth date: month/day/year? / /
- M5. About how tall are you? feet inches or . meters
- M6. About how much did you weigh at the time of your breast cancer diagnosis?
 pounds or kilograms
- M7. On average, how many cigarettes did you smoke a day at the time of your breast cancer diagnosis?
- None, I didn't smoke.
 - less than one pack a day
 - about one pack a day
 - more than one pack a day



- M8. What is the highest level of education you have completed?
- Grade School or less
 - Some College or Technical School
 - Some High School
 - College Graduate (Bachelor's Degree)
 - High School Graduate or G.E.D.
 - Graduate Degree

M9. When you were diagnosed with breast cancer, what was your marital status?
Please mark ONE.

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

M10. Are you Hispanic/Latina?

- Yes
- No

M11. Which of the following best describes your race? **Please mark ALL that apply.**

- White
- Black, African-American or Negro
- American Indian or Alaska Native
- Asian or Pacific Islander
- Some other race (Please specify) _____

M12. In what country were you born? _____

- I don't know.

M13. How many years total have you lived in the U.S.?

- _____ years
- I have lived in the U.S. my entire life.
- I don't know.

M14. In what country was your mother born? _____

- I don't know.

M15. In what country was your father born? _____

- I don't know.



M16. When you were diagnosed with breast cancer, what type of medical insurance did you have? **Please mark ALL that apply.**

- No insurance
- Employer provided insurance
- Self purchased insurance
- Spouse's insurance
- Medi-Cal or state provided insurance
- Medicare
- Other _____

M17. When you were diagnosed with breast cancer, which of the following choices best described your work situation? **Please mark ALL that apply.**

- I worked full-time.
- I worked part-time.
- I worked occasionally.
- I was a homemaker.
- I was a student.
- I was unemployed.
- I was disabled (unable to work).
- I was retired.
- I don't remember.

M18. When you were diagnosed with breast cancer, what was the total yearly income of your entire household, before tax deductions, from all sources?

- less than \$10,000
- \$10,000 - \$19,999
- \$20,000 - \$29,999
- \$30,000 - \$39,999
- \$40,000 - \$49,999
- \$50,000 - \$59,999
- \$60,000 - \$69,999
- \$70,000 - \$89,000
- \$90,000 or more
- I don't know.

M19. When you were diagnosed with breast cancer, how many people were supported by the total income for your household including yourself?

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



M20. Can you describe the most important thing that would have improved your experience when you were being treated for breast cancer?

M21. Is there any way we could improve this questionnaire?

M22. Did anyone help you fill out this questionnaire?

- No
- Yes

M23. Today's date is: / /
 month day year

**Thank you very much for filling out this survey!
Your answers are very important to us.**

Please return the survey in the envelope provided or mail to:

**Breast Cancer Treatment Study
Parkview Medical Building PMB-A201
1420 San Pablo Street
Los Angeles, CA 90089-9047**

If you have any questions, please call Alma Acosta-Pegueros at (323) 442-2712.