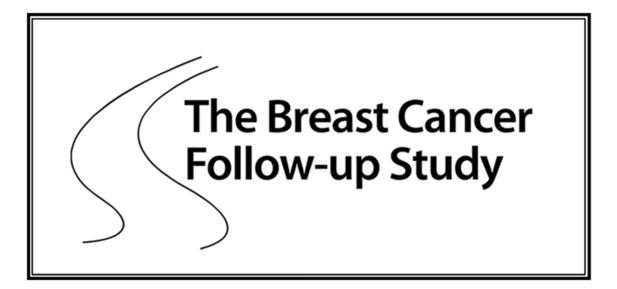


STUDY I.D. #\_\_\_\_\_



Conducted by:

### University of Southern California Keck School of Medicine

Return to: Dr. Ann Hamilton Breast Cancer Follow-up Study USC/Norris Comprehensive Cancer Center 1441 Eastlake Ave, Rm 3427A, MC9175 Los Angeles, CA 90089-9175

Questions? Please call 323.865.0687

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 Southern California and University of Michigan.

### Breast Cancer Follow-up Study

# 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. <b>Example:</b> 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.				
•	<b>Example:</b> • Other (please specify) <u>my friend who is a doctor</u> Mark only <b>one</b> response for each question, <u>unless</u> 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. In general would you say your <u>current</u> health is:

○ Excellent ○ Very Good ○ Good ○ Fair ○ Poor

A2. Please indicate below whether you have ever been told by a doctor that you had any of the following health conditions. If you answer 'Yes' please indicate how much it has bothered you in the past month.

a.	Chronic bronchitis o	or emphysema	?			
	⊙Yes →	How much h	as this bothe	red you in t	he <u>past month</u>	?
		O Not at all	O A little	O Some	O Moderately	O A lot
b.	Heart disease such	as coronary a	rtery disease	or congest	ive heart failure	<del>?</del> ?
	⊙Yes →	How much h	as this bothe	red you in t	he <u>past month</u>	?
		O Not at all	O A little	O Some	O Moderately	O A lot
C.	Cancer except skin O No	cancer and bro	east cancer?			
	⊙Yes	How much has this bothered you in the past month?				
		O Not at all	O A little	O Some	O Moderately	O A lot
d.	Diabetes?					
	⊙Yes →	How much h	as this bothe	red you in t	he <u>past month</u>	?
		O Not at all	O A little	O Some	O Moderately	O A lot



#### Please mark the response (Yes or No) that indicates if you have ever been told by a doctor that you had any of the following health conditions...

e.	e. Gastrointestinal problems such as irritable bowel syndrome, ulcerative colitis, or Crohn's disease?					
	⊖ No					
	⊙Yes —→	How much h	nas this both	ered you in	the past month	<u>ı</u> ?
		0	0	0	0	0
		Not at all	A little	Some	Moderately	A lot
f.	High blood pressu	ıre?				
	⊖ No					
	⊙Yes →	How much h	nas this both	ered you in	the past month	<u>ı</u> ?
				0	O Madawatah	
		Not at all	A little	Some	Moderately	A lot
g.	Stroke?					
			aa thia hath		the next menth	.0
				o	the past month	0
		Not at all	A little	Some	Moderately	A lot
h.	Arthritis?					
	⊖ No					
	⊙Yes —→	How much h	nas this both	ered you in	the past month	<u>ı</u> ?
		0	0	0	0	0
		Not at all	A little	Some	Moderately	A lot
i.	Depression?					
	⊙Yes —→			-	the past month	
		O Not at all	O A little	O Some	O Moderately	O A lot
j.	Chronic low back				y	
1.		pun.				
	⊖ No					0
	⊙Yes →			_	the past month	_
		O Not at all	O A little	O Some	O Moderately	O A lot



A3. How much has your breast cancer bothered you in the past month?

0	0	0	0	0
Not at all	A little	Some	Moderately	A lot

A4. How concerned are you about your breast cancer at this time?

0	0	0	0	0
Not at all	A little	Somewhat	Moderately	Very

- A5. Have you been admitted to the hospital overnight in the past 12 months?O Yes O No
- A6. Have you had another episode of breast cancer since you were first diagnosed and treated?

O No

○ Yes → a. When? \_\_\_\_\_/ \_\_\_\_\_ month year

- b. Where was the cancer found? \_\_\_\_\_
- c. What treatment(s) did you receive? Please mark ALL that apply.
  - Lumpectomy
  - Mastectomy
  - O Radiation Treatment
  - Chemotherapy
  - Breast reconstruction



### **Section B: Taking Medicine**

# Please mark the ONE response below that indicates how much you agree with the following statements.

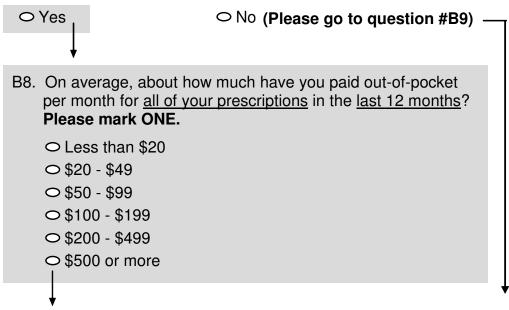
B1.	Medicines do n	nore good thai	n harm.		
	0	0	0	0	0
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
B2.	Doctors someti	me prescribe	medicine(s) when t	they don't ne	eed to.
	0	0	0	0	0
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
B3.	It is best to avo	id taking med	icine, if possible.		
	0	0	0	0	0
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
B4.	Sometimes it's ok not to take the medicine(s) your doctor prescribes.				
	0	0	0	0	0
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
B5.	When it comes	to my health,	I would rather an e	expert just te	ell me what to do.
	0	0	0	0	0
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

- B6. How many different kinds of prescription medication have you taken in the <u>past</u> <u>week</u>? **Please mark ONE.** 
  - 00 01

  - 02
  - 03
  - O 4 or more



B7. Do you regularly take any prescription medicine?



- B9. Which type of doctor has been most involved in directing your follow-up care for your breast cancer in the past 12 months? **Please mark ONE.** 
  - O Primary care doctor or family doctor
  - Gynecologist
  - Medical oncologist
  - O Breast surgeon
  - O Other (please specify)
- B10. How long have you been seeing this doctor? Please mark ONE.
  - O Less than a year
  - 1 2 years
  - O More than 2 years



#### Thinking about this same individual doctor, how often does this doctor...

B11. ...listen carefully to you?

	O Never	O Occasionally	O Some of the time	O Usually	O All the time
B12.	explain th	nings in a way that y	ou can under	stand?	
	O Never	O Occasionally	O Some of the time	O Usually	O All the time
B13.	spend er	nough time with you	?		
	O Never	O Occasionally	O Some of the time	O Usually	O All the time

# Please mark the response that indicates how much you agree with the following statements.

B14. I completely trust this doctor's judgment about my medical care.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

B15. This doctor would always tell me the truth about my health, even if there was bad news.

O	O	O	O	O
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

B16. I am able to tell my doctor how I feel, even if they disagree with me.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

#### Thinking about this doctor's medical practice:

B17. When you go to this medical practice, how often do you see the same doctor?

0	0	0	0	0
Never	Occasionally	Some of the time	Usually	All the time



### **Section C: Other Treatments**

C1.Have you taken any of the following hormonal breast cancer medicines <u>in the past</u> <u>week</u>: Raloxifene (Evista); Exemestane (Aromasin); Letrozole (Femara);Tamoxifen (Nolvadex); Anastrazole (Arimidex)?

⊖ Yes		) (Please go to q	uestion #C11, p	og 9.)		
	the response(s) belo r medicine(s) you too			-		
	<ul> <li>Raloxifene (Evista)</li> <li>Exemestane (Aromasin)</li> </ul>					
○ Letrozole	· · · · · · · · · · · · · · · · · · ·					
○ Tamoxifer	· · · · · ·					
○ Anastrazo	le (Arimidex)					
•	questions, please ma vith the <u>hormonal bre</u>	•				
C3. How often do	o you forget to take y	our medicine?				
0	0	0	0	0		
Never	A little	Sometimes	Quite a bit	A lot		
C4. How often ar	e you careless abou	t taking your med	dicine?			
O Never	O A little	O Sometimes	O Quite a bit	O A lot		
INEVE	A IIIIe	Sometimes	Quite à bit	A IOL		
C5. When you ar	e feeling better, how	/ often do you sto	p taking your me	edicine?		
O		O				
Never	A little	Sometimes	Quite a bit	A lot		
C6. If you feel wo	orse when you take y	our medicine, ho	w often do you s	stop taking it?		
0	0	0	0	0		
Never	A little	Sometimes	Quite a bit	A lot		
	bes the cost of your ling to take it?	hormonal breast o	cancer medicine	keep you		
0	0	0	0	0		
Never	A little	Sometimes	Quite a bit	A lot		

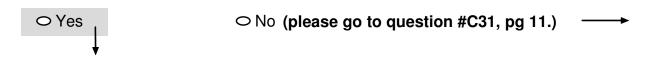
C8. On average, about how much have you paid out-of-pocket per month for your <u>hormonal breast cancer</u> medicine in the last 12 months? **Please mark ONE.** 

- O Less than \$20
- ○\$20 \$39
- **O** \$40 \$99
- ○\$100 \$199
- \$200 or more
- C9. Please mark the response(s) below that indicate <u>any additional</u> hormonal breast cancer medicine(s) you have taken <u>since you were diagnosed</u> with breast cancer. **Please mark ALL that apply.** 
  - Raloxifene (Evista)
  - O Exemestane (Aromasin)
  - O Letrozole (Femara)
  - Tamoxifen (Nolvadex)
  - O Anastrazole (Arimidex)
  - O I have not taken any other hormonal breast cancer medicine.
- C10. What is the total combined time that you have been on any of these medicines (both current and past medicine)? **Please mark ONE.** 
  - O Less than 1 year.
  - O Between 1 and 2 years.
  - 2 years or more.

Please go to question #D1, pg 11.



C11. Have you <u>ever taken</u> any of the following hormonal breast cancer medicine such as Raloxifene (Evista), Exemestane (Aromasin), Letrozole (Femara), Tamoxifen (Nolvadex), or Anastrazole (Arimidex)?



C12. Please mark the response(s) below that indicate which of the following hormonal breast cancer medicine(s) you've taken <u>at any time</u>. **Please mark ALL that apply.** 

• Raloxifene (Evista)

- O Exemestane (Aromasin)
- O Letrozole (Femara)
- Tamoxifen (Nolvadex)
- O Anastrazole (Arimidex)
- C13. How long were you on this (these) medicine(s)? If you are not sure, please take your best guess. **Please mark ONE.** 
  - Less than 1 year.
  - O Between 1 and 2 years.

○ 2 years or more.

C14. How long has it been since you've taken hormonal breast cancer medicine? **Please mark ONE.** 

O Less than 1 month

O 1 month or more

- C15. Mark the ONE response that best matches your experience with your hormonal breast cancer medicine.
  - I have stopped taking it for good.
  - I have stopped taking it for now.

#### Please continue on next page.



# By marking Yes or No, please indicate which factors were important in the decision to stop taking your hormonal breast cancer medicine.

C16. My doctor told me to stop	⊖ Yes	⊖ No					
C17. I stopped for medical reasons	⊖ Yes	⊖ No					
C18. I stopped because of insurance reasons	3. I stopped because of insurance reasons O Yes O						
C19. I wasn't sure if it was helping	9. I wasn't sure if it was helping O Yes O No						
C20. I stopped because of the side effects.	⊖ Yes	⊖ No					
C21. I kept forgetting to take it	⊖ Yes	O No					
C22. I thought I'd taken it long enough	⊖ Yes	O No					
C23. I was worried about the risks	⊖ Yes	O No					
C24. It was too expensive	⊖ Yes	O No					
C25. I wanted to move on from the cancer	⊖ Yes	O No					
C26. I dislike being on medication.	. OYes	O No					
C27. I completed the recommended course of treatment	⊖ Yes	O No					
C28. Other reason (please explain)							
C29. How likely are you to start taking your hormonal breas	t cancer medi	cine again?					
0 0 0	0	0					
Not at all likely A little likely Somewhat likely C	uite likely	Very likely					
C30. How likely would you be to start taking your hormonal your doctor urged you to? <b>Please mark ONE.</b>	breast cancer	r medicine if					
o o o	0	0					
Not at all likely A little likely Somewhat likely C	uite likely	Very likely					
Please skip C31 and go to question #D1, pg 11 (next page).							



- C31. If you have <u>never</u> taken any hormonal breast cancer medicine please mark the reason(s) below that explain why. **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.
  - My doctor recommended it but I chose not to.
  - I was worried about side effects.
  - It was too expensive.
  - Other (please explain) \_\_\_\_\_\_

### **Section D: Other Surgical Treatment Options**

D1. Since your breast cancer diagnosis have you been told that breast reconstruction is an option for women who have a mastectomy?

⊙Yes ○No

D2. Have you been told that you can have breast reconstruction at a later time (after your mastectomy surgery)?

⊙Yes ○No

D3. Have you been told that your insurance should cover most of the cost of breast reconstruction?

⊙Yes ○No

D4. Since your diagnosis, have you <u>wanted</u> to talk to a plastic surgeon about breast reconstruction?

⊙ Yes ○ No

D5. Have you talked to a plastic surgeon about breast reconstruction?

⊙Yes ○No



# Please mark the ONE response that most closely matches how much you agree or disagree with the following statements.

D6. I wanted to talk more to a plastic surgeon about breast reconstruction.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

D7. I wanted to talk more to other women who have had breast reconstruction.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

D8. I am satisfied with my decision about whether or not to have breast reconstruction.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

D9. I regret the choice that I made of whether or not to have breast reconstruction.

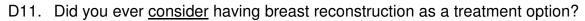
0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

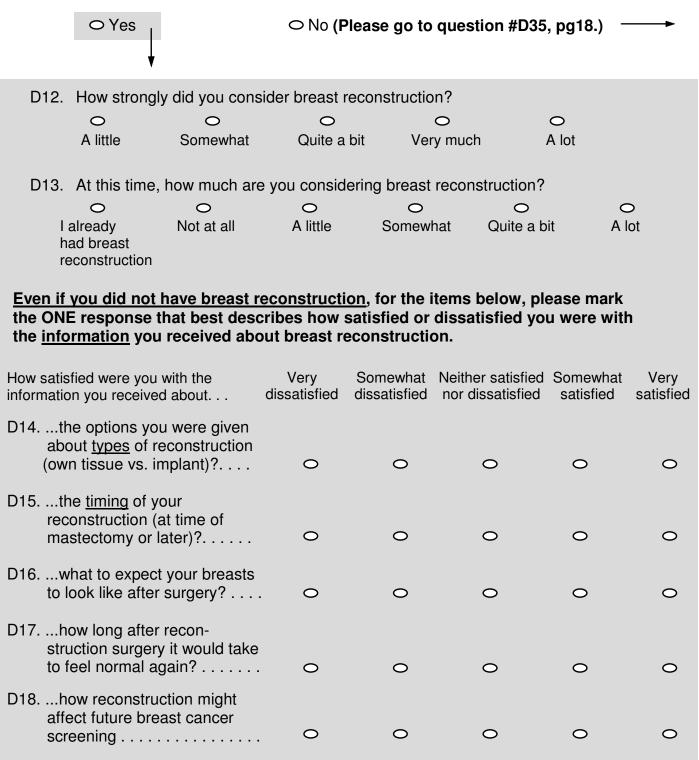
D10. I am satisfied that I was adequately informed about the issues important to breast reconstruction.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree



### **Deciding about Breast Reconstruction**

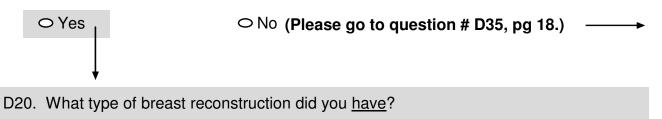




#### Please continue on next page.

### **Surgical Experiences**

D19. Have you had breast reconstruction?



- a TRAM flap (uses your own tissue from the abdomen)
- O a latissimus dorsi flap (uses your own tissue from the back)
- a saline implant
- O a silicone implant
- O Other (please explain)

The following questions are about your breast reconstruction surgery. **Please mark the ONE response that best describes your situation.** 

How <u>satisfied or dissatisfied</u> have you been with:	Very dissatisfied	A little dissatisfied	Neither satisfied nor dissatisfied	A little satisfied	Very satisfied
D21. The overall results of yo reconstruction?	$\sim$	0	0	0	0
D22. The timing of your recorn struction (at the time of your mastectomy or late	0	0	0	0	0
D23. The size of your reconstructed breasts?.		0	0	0	0



	s <u>atisfied or dissatisfied</u> you been with:	Very dissatisfied	A little dissatisfied	Neither satisfied nor dissatisfied	A little satisfied	Very satisfied
D24.	How natural your recon- structed breast(s) looks?	··· O	0	0	0	0
D25.	How your reconstructed breasts feel to touch?	0	0	0	0	0
D26.	How closely matched yo breasts are to each othe	$\sim$	0	0	0	0

Please mark the ONE response that indicates how much you agree or disagree with each statement:

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
D27.	I would encourage other women in my situation to have breast reconstruction	0	0	0	0	0
D28.	The complications from the breast reconstruction make me regret having it		0	0	0	0
D29.	Having this surgery change my life for the better		0	0	0	0
D30.	The outcome matched my expectations	0	0	0	0	0
D31.	I wish I had not had breast reconstruction	0	0	0	0	0



D32. Did your breast reconstruction start <u>at a later time</u> than your mastectomy surgery or did it start <u>at the same time</u> as your mastectomy?

0	It <u>started at a later</u> my mastectomy su		<ul> <li>It started at the same time as my mastectomy.</li> <li>(Please go to question #E1, pg 20.)</li> </ul>			
D33	<ol> <li>How much did the breast reconstruct</li> </ol>		ies contribute to yo	ur decision to delay	,	
Mee	dical Factors					
a.	I needed to hav	ve radiation thera	ару.			
	O Not at all	O A little	O Somewhat	O Quite a bit	O A lot	
b.	I needed to hav	e chemotherap	у.			
	O Not at all	O A little	O Somewhat	O Quite a bit	O A lot	
C.	I had other heal	Ith issues that k	ept me from having	reconstruction.		
	O Not at all	O A little	O Somewhat	O Quite a bit	O A lot	
d.	My doctor told r	ne I should wait	t.			
	O Not at all	O A little	O Somewhat	O Quite a bit	O A lot	
e.	I had trouble fin	iding a surgeon	to perform the surg	jery.		
	O Not at all	O A little	O Somewhat	O Quite a bit	O A lot	
f.	I tried to have re with surgery.	econstruction at	the time of my mas	stectomy but had pr	oblems	
	O Not at all	O A little	O Somewhat	O Quite a bit	O A lot	



How much did the following issues contribute to your decision to delay breast reconstruction?

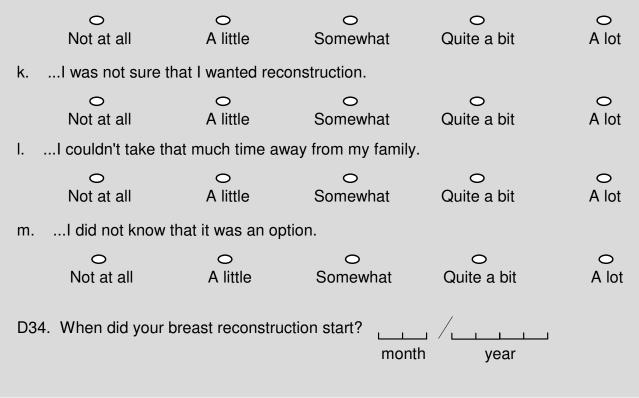
#### **Financial Factors**

... My insurance did not cover it. g. 0 0 0 0 0 Not at all A little Quite a bit Somewhat A lot ...I couldn't find a surgeon who took my insurance. h. 0 0 0 0 0 Not at all A little Somewhat Quite a bit A lot ...I couldn't take that much time off from work. i. 0 0 0 0 0 A little Not at all Somewhat Quite a bit A lot

How much did the following issues contribute to your decision to delay breast reconstruction?

#### **Personal Factors**

j. ...I was focused on treating the breast cancer.



Please go to Question #E1, pg 20.



### If You Have Not Had Breast Reconstruction

D35. How much have the following issues contributed to your decision not to have breast reconstruction?

#### **Personal Factors**

a. I did not want additional surgery.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

b. I am afraid of implants.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

c. It is not important to me.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

d. I did not know that it was still an option.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

e. I couldn't take that much time away from my family.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

#### **Medical Factors**

f. I tried to have reconstruction but was not able to complete it because of complications.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

g. I had other health issues that did not make me a candidate for reconstruction.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot



h. I was concerned that breast reconstruction would interfere with the detection of a cancer recurrence.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

i. I was concerned about the possible complications of reconstruction.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

j. I had trouble finding a surgeon to perform the surgery.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

k. My doctor did not recommend reconstruction.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

#### **Financial Factors**

I. My insurance would not cover it.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

m. I couldn't find a surgeon who accepts my insurance.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot

n. I couldn't take that much time off from work.

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	A lot



### **Section E: Medical Tests**

We would like to ask you about an MRI (magnetic resonance imaging test).

An 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.

- E1. Did you have an MRI when you were first diagnosed with breast cancer?
  - Yes○ No○ I don't know
- E2. Have you had an MRI <u>since you completed your surgical treatment</u> for breast cancer?
  - ⊖ Yes
  - O No
  - I don't know

The following questions refer to "genetic testing for cancer risk." That is, a blood test to look for gene mutations or changes, to see if women and their families have a greater risk of developing breast cancer in the future.

- E3. Did a genetic counselor, doctor, or other health professional <u>talk with</u> you about having a genetic test for breast cancer risk?
  - Yes○ No○ I don't know
- E4. How much did you want to have a genetic test for breast cancer risk?

0	0	0	0	0
Not at all	A little	Somewhat	Quite a bit	Very much



E5. Have you ever had a genetic test for breast cancer risk?

⊙ No →	<ul> <li>a. <u>Why didn't you get a genetic test for breast cancer risk?</u></li> <li>Please mark ALL that apply.</li> <li>My doctor didn't recommend it.</li> <li>I didn't want it.</li> <li>My family didn't want me to get it.</li> <li>It was too expensive.</li> <li>Other (please explain)</li> </ul>
⊙ Yes →	<ul> <li>a. <u>Why did you get tested?</u> Please mark ALL that apply.</li> <li>My doctor thought I should get tested.</li> <li>I wanted more information about my own health.</li> <li>I wanted more information for my family members.</li> <li>My family wanted me to be tested.</li> <li>Other (please explain)</li> </ul>
	<ul> <li>b. What was the result? Please mark ONE.</li> <li>I did not have any mutations in the gene tests.</li> <li>I had a mutation in a gene that increases the risk of breast cancer.</li> <li>A gene mutation was found but not one that has been shown to increase the risk of breast cancer.</li> <li>I don't know.</li> <li>Other (please explain)</li></ul>

O I don't know if I had a genetic test for breast cancer.

E6. <u>Since your breast cancer diagnosis</u>, has a family member had a genetic test to determine if they carry a gene mutation (or change) for breast cancer?

O Yes

O No

○ I don't know



### **Section F: Information and Support**

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

# For each item below, please mark the ONE response (Yes or No) that best describes your experience.

F1. Since you were diagnosed with breast cancer, have you received <u>enough</u> information from your doctor(s) or their staff about. . .

a.	 hormone therapy (such as Tamoxifen or Arimidex)?	⊖ Yes	⊖ No
b.	 life style changes such as nutrition, exercise and/or stress management.	⊖ Yes	⊖ No
c.	 the effects of alcohol consumption on breast cancer risk	⊖ Yes	⊖ No
d.	 the effects of breast cancer and treatment on sexual functioning?	⊖ Yes	⊖ No
e.	 the effects of having breast cancer on one's relationship with their spouse or partner?	⊖ Yes	⊖ No
f.	 what to do about feelings of anxiety or depression?	⊖ Yes	⊖ No
g.	 information about long term effects of breast cancer treatment	⊖ Yes	⊖ No
h.	 risk of breast cancer recurrence	⊖ Yes	O No
i.	 risk of getting other cancers	⊖ Yes	⊖ No
j.	 genetic testing for breast cancer.	⊖ Yes	⊖ No
k.	 other (please explain)		



- F2. Do you ever go on-line to use the Internet?
  - O No
  - - ⊖ Home
    - O Work
    - Some other place (please specify)
    - b. How often do you go on-line to use the Internet?
      - $\ensuremath{\mathbb{O}}$  Less than once a day
      - O Daily
      - O Several times a day



F3. We would like to know how much <u>emotional support</u> you have received from different people since you were diagnosed with breast cancer.

How much emotional support have you received from	None	A little	Some	Quite a bit	A lot
ayour health care provider(s)?	0	0	0	0	0
bother women with breast cancer?	. 0	0	0	0	0
cfriends?	. 0	0	0	0	0
dco-workers?	0	0	0	0	0
emembers of your religious community?	0	0	0	0	0
ffamily members (not including a spouse or partner)?	. 0	0	0	0	0

F4. Have you wanted <u>more emotional support</u> from any of the following people since you were diagnosed with breast cancer?

a.	health care provider(s)?	⊖ Yes	O No
b.	other women with breast cancer?	⊖ Yes	O No
c.	friends?	⊖ Yes	O No
d.	co-workers?	⊖ Yes	O No
e.	members of your religious community?	⊖ Yes	O No
f.	family members (not including a spouse or partner)?	⊖ Yes	⊖ No
g.	Other (please specify)		



#### F5. Do you have a husband or partner?

○ Yes								
Since your diagnosis with breast cancer, how important has it been for your husband/partner to								
F6keep working	g in order to keep th	neir healt	h insurance					
O Not at all important	O A little important	Some	D ewhat ortant	O Very important		O Extremely mportant		
F7get a new jol	o in order to get he	alth insu	rance.					
0	0	C	5	0		0		
Not at all important	A little important		ewhat ortant	Very importar		Extremely mportant		
F8increase thei	r work hours in orde	er to cov	er your med	ical exper	nses.			
0	0	Ċ	>	0		0		
Not at all important	A little important		ewhat ortant	Very importar		Extremely mportant		
F9. For the items b satisfied you an husband or par	re with various as		-			w		
	U	Very Insatisfied	Slightly I Unsatisfied	Neutral	Slightly Satisfied	Very Satisfied		
acommunication	and openness	0	0	0	0	0		
bresolving conflic	cts and arguments	0	0	0	0	0		
csexual satisfact	ion	0	0	0	0	0		
dsharing duties a chores	and household	0	0	0	0	0		
eintimacy and clo	oseness	0	0	0	0	0		
foverall satisfact relationship	tion with your	0	0	0	0	0		

# F10. How much emotional support have you received from your husband/partner since you were diagnosed with breast cancer?

0	0	0	0	0
None	A little	Some	Quite a bit	A lot



### Section G: How You are Feeling

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 <u>during the past 7 days</u>.

	Physical Well-Being	Not at all	A little bit	Some- what	Quite a bit	Very much
G1.	I have a lack of energy	0	0	0	0	0
G2.	I have nausea	0	0	0	0	0
G3.	Because of my physical condition, I have trouble meeting the needs of my family	0	0	0	0	0
G4.	I have pain	0	0	0	0	0
G5.	I am bothered by side effects of treatment.	0	0	0	0	0
G6.	l feel ill	0	0	0	0	0
G7.	I am forced to spend time in bed	0	0	0	0	0



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

<u>Se</u>	ocial/Family Well-Being	Not at all	A little bit	Some- what	Quite a bit	Very much
G8.	I feel close to my friends	0	0	0	0	0
G9.	l get emotional support from my family	0	0	0	0	0
G10.	I get support from my friends	0	0	0	0	0
G11.	My family has accepted my illness	0	0	0	0	0
G12.	I am satisfied with family communication about my illness	0	0	0	0	0
G13.	I feel close to my partner (or the person who is my main support.)	0	0	0	0	0

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

Emotional Well-Being	Not at all	A little bit	Some- what	Quite a bit	Very much
G14. I feel sad	0	0	0	0	0
G15. I am satisfied with how I am coping with my illness.	0	0	0	0	0
G16. I am losing hope in the fight against my illness		0	0	0	0
G17. I feel nervous	. 0	0	0	0	0
G18. I worry about dying	. 0	0	0	0	0
G19. I worry that my condition will get worse	. 0	0	0	0	0



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

<u> </u>	Functional Well-Being	Not at all	A little bit	Some- what	Quite a bit	Very much
G20.	I am able to work (include work at home)	0	0	0	0	0
G21.	My work (include work at home) is fulfilling.	0	0	0	0	0
G22.	I am able to enjoy life	0	0	0	0	0
G23.	I have accepted my illness	0	0	0	0	0
G24.	I am sleeping well	0	0	0	0	0
G25.	I am enjoying the things I usually do for fun	0	0	0	0	0
G26.	I am content with the quality of my life right now.	0	0	0	0	0

### In the past 7 days, how satisfied have you been with:

		Not at all	A little bit	Some- what	Quite a bit	Very much
G27.	How you look in the mirror <u>clothed</u> ?	0	0	0	0	0
G28.	The shape of your breast(s) when you are wearing a bra?	0	0	0	0	0
G29.	The shape of your breast(s) when you are <u>not</u> wearing a bra?	0	0	0	0	0
G30.	How normal you feel in your clothes?.	0	0	0	0	0
G31.	How comfortably your bras fit?	0	0	0	0	0
G32.	The softness of your breast(s)?	0	0	0	0	0
G33.	How you look in the mirror <u>unclothed</u> ?	0	0	0	0	0



## If you <u>have not</u> had a breast cancer recurrence please answer the following questions. (If you have had a recurrence, please go to question #H1, pg 30.)

G34. How likely do you think it is that your breast cancer will recur?

0	0	0	0	0
Not at all	A little	Somewhat	Quite	Very

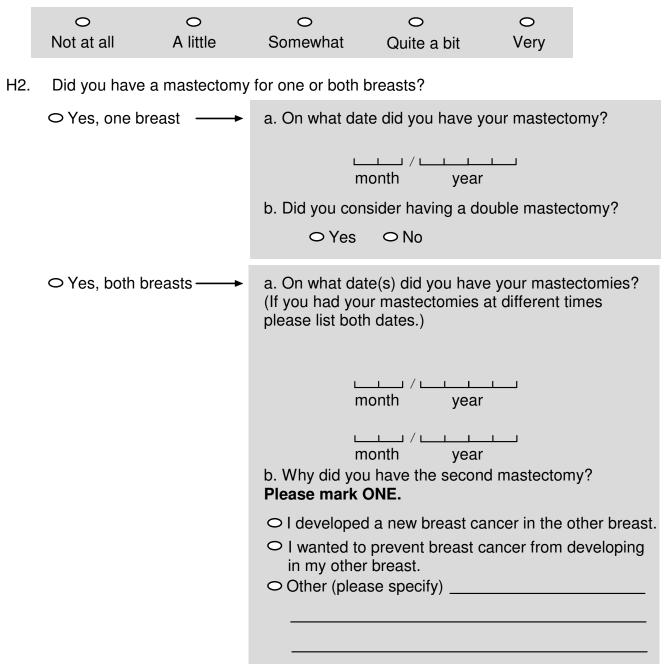
# G35. Please mark the response below that indicates how true each statement is for you.

	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	0	0	0	0	0
b. I worry that breast cancer may occur in my other breast	0	0	0	0	0
c. I worry that breast cancer will spread to other parts of my body	0	0	0	0	0



#### **Section H: Treatment and Decision Making**

H1. When you were first diagnosed with breast cancer, how strongly did you consider having a mastectomy <u>on your unaffected breast</u>?



○ No, I did not have a mastectomy

- H3. What was your bra cup size before your breast surgery?
  - OA OD
  - OB ODD
  - OC Other (please specify)



# 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. . .

H4. ... I would make a different decision about what type of surgery to have (that is whether to have a lumpectomy or mastectomy.)

0	0	0	0	0
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

H5. ... I would choose a different surgeon to perform my surgery.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H6. ... I would take more time to make decisions about my treatment.

0	0	0	0	0
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

H7. ... I would consult more doctors about my treatment before making a decision.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

H8. ... I would do everything the same.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree



### Section I: Spirituality and Religion

# For each item below, please mark the ONE response that most closely matches your experience.

I1. Religion is important in my day-to-day life.

0	0	0	0	0
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

I2. Prayer has helped me cope during times of serious illness.

0	0	0	0	0
None of	A little bit	Some of	A good bit	All of
the time	of the time	the time	of the time	the time

I3. I enjoy attending religious functions held by my religious or spiritual group.

0	0	0	0	0
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

I4. Suffering in silence makes me stronger.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I5. I know someone in my religious or spiritual community that I can turn to.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I6. I rely on people who share my spiritual or religious beliefs for support.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

I7. One's life and death follows a plan from God.

0	0	0	0	0
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree



I8. Suffering in silence helps me avoid becoming a burden to others.

0	0	0	0	0
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

I9. I seek out people in my spiritual or religious community when I need help.

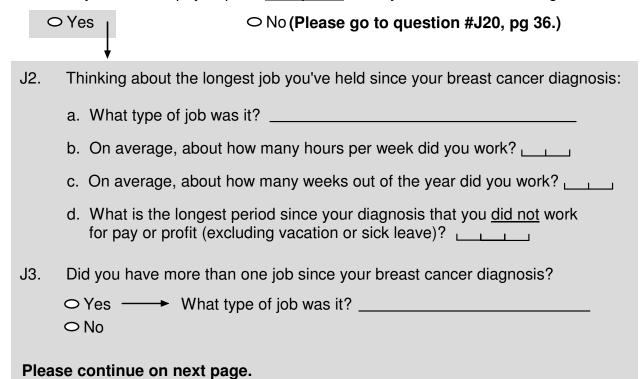
0	0	0	0	0
None of	A little bit	Some of	A good bit	All of
the time	of the time	the time	of the time	the time

I10. I believe God protects me from harm.

0	0	0	0	0
Strongly	Disagree	Neither agree	Agree	Strongly
disagree		nor disagree		agree

### Section J: Home and Work

J1. Did you work for pay or profit <u>at any time</u> since your breast cancer diagnosis?





The following questions are about your experience working for pay or profit <u>at anytime</u> since your diagnosis, <u>even if you do not work for pay now</u>. For each statement below, please mark the ONE response that indicates how true each statement is for you.

How important has it been to . . .

. .

J4.	avoid changing jobs because you were worried about losing your health insurance?					
	0	0	0	0	Ċ	S
	Not at all	A little	Somewhat	Very		emely
	important	important	important	important	impo	ortant
J5.	keep work	ing in order to keep	your health insura	ance?		
	0	0	0	0	Ċ	C
	Not at all	A little	Somewhat	Very	Extre	emely
	important	important	important	important	impo	ortant
J6.	get a new	job in order to get h	ealth insurance?			
	0	0	0	0	Ċ	C
	Not at all	A little	Somewhat	Very	Extre	emely
	important	important	important	important	impo	ortant
Pleas	e answer Yes	s or No to each of	the following stat	tements.		
J7.		ease my work hours ed medical expense		•	⊖ Yes	⊖ No
J8.		ease my work hours h issues			⊖ Yes	⊖ No
J9.	I was denied	job opportunities b	ecause I had brea	st cancer	⊖ Yes	⊖ No
J10.		en a welcome sour	• •		⊖ Yes	⊖ No
J11.		for a new job if I co			⊖ Yes	⊖ No
Plea	se continue d	on next page.				



### J12. Are you currently working for pay or profit?

ΟYe	○ Yes				
J13.	Are you self e	employed for your	main job? O	Yes ON0	
J14.	How satisfied	l are you with your	current job?		
	O Not at all satisfied	O A little satisfied	O Somewhat satisfied	O Quite satisfied	O Very satisfied
J15.	How satisfied	l are you with your	salary, or the amo	unt you are paid f	or your job?
	O Not at all satisfied	A little satisfied	O Somewhat satisfied	O Quite satisfied	O Very satisfied
J16.	How satisfied responsibilitie		ability to balance y	vour job(s) with yo	our other
	O Not at all satisfied	O A little satisfied	O Somewhat satisfied	O Quite satisfied	O Very satisfied
J17.	How importa	nt is it to you that y	ou continue to wor	k?	
	O Not at all important	O A little important	O Somewhat important	O Quite important	O Very important
J18.	How many ho	ours are you expec	ted to work in total	, in a typical 7-da	y week?
	۔۔۔۔۔ hour	S			
J19.	Please mark	the ONE stateme	ent below that bes	t describes how	you feel.
		ied with the numbe e to work more hou	er of hours I work p urs per week.	er week.	

 $\ensuremath{{\scriptsize \bigcirc}}$  I would like to work fewer hours per week.

Please go to J23, page 37.

## 

### If you do not work for pay or profit:

J20. How long has it been since you have worked for pay or profit?

1 - 6 months
7 - 12 months
1 - 2 years
more than 2 years but less than 5 years
5 years or more
I've never worked for pay or profit.

#### J21. How important is it to you that you work?

0	0	0	0	0
Not at all important	A little important	Somewhat important	Quite important	Very important

J22. Are you currently looking for a job? O Yes O No

Please continue on next page.



J23. Since your breast cancer diagnosis, are you worse off regarding:

- a. ... Health insurance? O No ⊖ Yes How much is this due to your breast cancer and treatment? 0 0 0 0 0 Not at all A little Somewhat Quite a bit Very much b. ... Employment status? O No ○ Yes How much is this due to your breast cancer and treatment? 0 0 0 0 0 Not at all A little Somewhat Quite a bit Very much c. ... Financial status? O No ○ Yes How much is this due to your breast cancer and treatment? 0 0 0 0 0 Not at all A little Somewhat Quite a bit Very much
- J24. How much have you paid out-of-pocket for medical expenses related to your breast cancer (including co-payments, hospital bills, and medication costs)? **Please mark ONE.** 
  - less than \$500
    \$500 \$2000
    \$2001 \$5000
    \$5001 \$10,000
    more than \$10,000

J25. How did you pay for these out-of-pocket expenses? Please mark ALL that apply.

- I used my income and/or savings.
- I borrowed money from family or friends.
- I borrowed money against my house.
- O I left some of my medical bills unpaid.
- I increased my credit card debt.
- O Other (please specify)



J26. Do you currently have debt from your breast cancer treatment?

⊙ Yes ○ No

# J27. Thinking about the <u>last 12 months</u>, please answer yes or no to each of the following statements.

Because of the cost, did you have to...

ago without medication?	⊖ Yes	O No
btake less than the fully prescribed amount of a prescription?	⊖ Yes	O No
cmiss a doctor's appointment?	⊖ Yes	O No
dmiss a mammogram?	⊖ Yes	O No

J28. What type of medical insurance <u>do you have now</u>? **Please mark ALL that apply.** 

○ None

- Insurance provided through my employer or union (including HMO)
- Insurance provided to my spouse through his employer or union (including HMO)
- O Insurance that I purchased myself
- Medicaid (Medi-Cal) or other state provided insurance.
- O Medicare/government insurance
- O Other (please specify)
- J29. In addition to you, who else in your household is covered by your medical insurance <u>now</u>? **Please mark ONE.** 
  - O I don't have medical insurance.

○ Me alone

- My spouse and me
- My spouse, children and me



# J30. In the <u>last 12 months</u>, have the costs of your prescription medicine(s) been... **Please mark ONE.**

- O ... completely covered by health insurance?
- O ... mostly covered by health insurance?
- O ... partially covered by health insurance?
- O ... not covered at all by health insurance?

#### J31. Please answer yes or no to each of the following statements.

Since your breast cancer diagnosis, <u>because of your own personal medical</u> <u>expenses</u> (including co-payments, hospital bills, medication costs and insurance premiums) have you or someone in your household. . .

a.	gone without health insurance?	⊖ Yes	O No
b.	$\dots$ had your utilities turned off because the bill was not paid? $\dots$	⊖ Yes	O No
C.	had to move out of your house or apartment because you could not afford to stay there?	⊖ Yes	O No



### Section K: Language Preferences

K1. Do you speak Spanish?

○ Yes, I speak Spanish.

No, I don't speak Spanish.
 (Please go to question #L1, next page.) —

K2. In general, what language(s) do you read and speak?					
	Only English	O English better than Spanish	O Both equally	O Spanish better than English	O Only Spanish
K3.	What langua	age do you usually sp	eak at home?		
	O Only English	O More English than Spanish	O Both equally	O More Spanish than English	O Only Spanish
K4.	In what lang	uage do you usually	think?		
	O Only English	O More English than Spanish	O Both equally	O More Spanish than English	O Only Spanish
K5.	What langua	age do you usually sp	eak with your f	riends?	
	O Only English	O More English than Spanish	O Both equally	O More Spanish than English	O Only Spanish



### Section L: A Few More Questions About You

L1. Please indicate how many of your <u>first degree</u> relatives have been diagnosed with the cancers listed below.

Please include only blood relatives who are: parents, brothers, sisters, children.

	<u>No</u> first degree relatives	<u>1</u> first degree relative	<u>2 or more</u> first degree relatives
a. Breast cancer	0	0	0
b. Ovarian cancer	0	0	0
c. Colon cancer	0	0	0
d. Gastric (stomach) cancer	0	0	0
e. Prostate cancer	0	0	0

L2. At the time of your cancer diagnosis, how many children did you have under the age of 18 living at home?

- L3. What is your current marital status? Please mark ONE.
  - O Married O Separated
  - O Widowed O Never Married
  - O Divorced O Living with your partner
- L4. How would you describe yourself? **Please mark ALL that apply.** 
  - I work full time. I am a homemaker.
  - O I work part time. O I am a student.
  - I am unemployed. I am disabled (unable to work).
  - O I am retired.
- L5. About how much do you weigh?

pounds or kilograms



L6. What is the total yearly income of your entire household, before tax deductions, from all sources? **Please mark ONE.** 

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

L7. How many people are supported by the total income for your household <u>including</u> <u>yourself</u>? **Please mark ONE.** 

1 (just you)
2
3
4 or more

L8. Did anyone help you fill out this survey?

○ No ○ Yes

L9. Today's date is: \_\_\_\_ / \_\_\_ / \_\_\_\_ month day year

Thank you very much for filling out this survey! Your answers are <u>very</u> important to us.

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

Dr. Ann Hamilton Breast Cancer Follow-up Study USC/Norris Comprehensive Cancer Center 1441 Eastlake Ave, Rm 3427A, MC9175 Los Angeles, CA 90089-9175

If you have any questions, please call Jennifer Zelaya at 323.865.0687