Form: 56 Vers: 01 ID#: SIS

Special Survey for Women with Breast Cancer

Version 1

Today's Date: ☐☐ / ☐☐ / 20☐☐
MONTH DAY YEAR

This special survey asks questions about your experiences with breast cancer and how this diagnosis has affected your life. The Centers for Disease Control and Prevention (CDC) and the National Institute of Environmental Health Sciences (NIEHS) have partnered to conduct this survey.

Your continued participation in the Sister Study is completely voluntary and greatly appreciated. Some questions may be personal or sensitive. All of your answers will be kept confidential. However, if you are not comfortable answering a question, please feel free to skip it and go to the next one.

Please mark the category that best describes your response. Try not to let your response to one question influence your responses to other questions. Answer according to your own feelings, rather than how you think most people would answer.

DIAGNOSIS, TREATMENT, AND FOLLOW-UP FOR BREAST CANCER

The following questions are about your breast cancer diagnosis, treatment, and follow-up care.

1. Thinking back to when you were first diagnosed with breast cancer, how did you first know that something was wrong? *(Please mark only one answer.)*

- ☐ Felt a lump by accident
- ☐ Felt a lump through a self-examination
- ☐ Spouse or partner felt a lump
- ☐ Doctor or nurse felt a lump
- ☐ Breast did not look normal
- ☐ Felt an unusual sensation, like pain or tenderness
- ☐ Experienced bleeding or discharge from nipples
- ☐ Routine mammogram
- ☐ Other, please specify:

2. How much time was there between when you first knew that something was wrong and when your breast cancer was diagnosed?

- ☐ Less than a month
- ☐ 1 to 2 months
- ☐ 3 to 6 months
- ☐ 7 to 12 months
- ☐ Over a year

3. During the time you were being treated for breast cancer, what type of health insurance coverage, if any, did you have? *(Please mark all that apply.)*

- ☐ A plan through my employer or union
- ☐ A plan through someone else's employer or union
- ☐ A plan that you or someone else buys on your own
- ☐ Medicare
- ☐ Medicaid
- ☐ Military, Tri-Care, CHAMPUS, or the VA
- ☐ Some other government program
- ☐ Got insurance from somewhere else
- ☐ **NOT** covered by insurance
- ☐ Don't know

4. During the time you were being treated for cancer, were you covered by health insurance the entire time, or were there any times during your cancer treatment when you did not have any health coverage?

- ☐ Not covered by health insurance any of the time
- ☐ Don't know

} **GO TO THE NEXT PAGE, QUESTION 5**

- ☐ Covered by health insurance the entire time
- ☐ Covered by health insurance part of the time

4a. Did you ever reach the maximum amount your health insurance would pay for your breast cancer treatment?

- ☐ Yes
- ☐ No
- ☐ Don't know

5. Clinical trials are research studies that involve people. They are designed to test the safety and effectiveness of new treatments and to compare new treatments with standard care. Often, patients in clinical trials are not told what treatment they received until the trial is over.

Were you ever offered or did you seek out participation in a clinical trial as part of your breast cancer treatment?

- ☐ No → **GO TO QUESTION 6**
- ☐ Yes

5a. Did you participate in a clinical trial as a part of your cancer treatment?

- ☐ Yes
- ☐ Don't know

} **GO TO QUESTION 6**

- ☐ No

5b. What was the main reason you did not enter the clinical trials you were offered?

- ☐ I did not meet the eligibility criteria
- ☐ I refused the treatment protocol
- ☐ I wanted to be treated elsewhere or by a different doctor
- ☐ Other, please specify:

6. Did your doctor recommend radiation therapy to treat your breast cancer?

- ☐ No → **GO TO THE NEXT PAGE, QUESTION 7**
- ☐ Yes

6a. Did you receive the total number of radiation treatments that your doctor believed were necessary?

- ☐ Yes
- ☐ Don't know

} **GO TO THE NEXT PAGE, QUESTION 7**

- ☐ No

6b. Were any of the following reasons why you did not get all of the radiation treatments that your doctor recommended? *(Please mark all that apply.)*

- ☐ Side effects or other medical reasons
- ☐ Treatments not working
- ☐ Cost or problems with insurance
- ☐ Trouble getting to treatment appointments
- ☐ Treatment took too much time
- ☐ I was missing or would miss too much work
- ☐ Couldn't get child or adult care
- ☐ I didn't think I needed it or wasn't sure why I needed it
- ☐ Other, please specify:

7. Did your doctor recommend chemotherapy to treat your breast cancer?

- ☐ No → **GO TO THE NEXT PAGE, QUESTION 8**
- ☐ Yes

7a. Did you receive the total number of chemotherapy treatments that your doctor believed were necessary?

- ☐ Yes
- ☐ Don't know

} **GO TO THE NEXT PAGE, QUESTION 8**

- ☐ No

7b. Were any of the following reasons why you did not get all of the chemotherapy treatments that your doctor recommended? *(Please mark all that apply.)*

- ☐ Side effects or other medical reasons
- ☐ Treatments not working
- ☐ Cost or problems with insurance
- ☐ Trouble getting to treatment appointments
- ☐ Treatment took too much time
- ☐ I was missing or would miss too much work
- ☐ Couldn't get child or adult care
- ☐ I didn't think I needed it or wasn't sure why I needed it
- ☐ Other, please specify:

8. Did your doctor prescribe hormonal therapies, like tamoxifen (also called Nolvadex), Arimidex (anastrozole), Aromasin (exemestane), or Femara (letrozole) for your breast cancer?

- ☐ No
- ☐ Don't know

} **GO TO THE NEXT PAGE, QUESTION 9**

- ☐ Yes

8a. When did you start taking them?

- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ 3-4 years ago
- ☐ 5 or more years ago

8b. Are you currently taking these pills for your breast cancer?

- ☐ Don't know
- ☐ Yes

} **GO TO QUESTION 8d**

- ☐ No

8c. Why are you no longer taking these pills for your breast cancer? *(Please mark all that apply.)*

- ☐ I never started taking them
- ☐ I took them for the full amount of time my doctor recommended
- ☐ My doctor switched me to a different type of treatment for my breast cancer
- ☐ Because of side effects or another medical reason
- ☐ Treatments not working
- ☐ I chose to stop
- ☐ Other

8d. How often do you or did you take these pills for your breast cancer exactly as prescribed?

- ☐ Always
- ☐ Most of the time

} **GO TO THE NEXT PAGE, QUESTION 9**

- ☐ Sometimes
- ☐ Rarely
- ☐ Never

8e. Why haven't you always taken your medications as prescribed? *(Please mark all that apply.)*

- ☐ Forgetfulness
- ☐ Feeling better or didn't think I needed them
- ☐ Wasn't told enough about them
- ☐ Side effects or other medical reasons
- ☐ Cost or problems with insurance coverage
- ☐ Prescription ran out or forgot to refill
- ☐ Other reasons

9. Did you receive any of the following additional treatments for your breast cancer? *(Please mark all that apply.)*

- ☐ Surgery to remove the tumor
- ☐ Bone marrow or stem cell transplant
- ☐ Herceptin, also called trastuzumab
- ☐ Did not receive additional treatment
- ☐ Other, please specify:

  [ ]
- ☐ Don't know

10. Have you ever had a mastectomy?

- ☐ No → **GO TO PAGE 8, QUESTION 12**
- ☐ Yes

10a. Which breasts did you have removed? *(Please mark all that apply and answer follow-up questions.)*

	☐ Left Breast	☐ Right Breast
b. Was this mastectomy to treat or prevent breast cancer?	☐ Breast cancer treatment ☐ Breast cancer prevention	☐ Breast cancer treatment ☐ Breast cancer prevention
c. When did you have this mastectomy?	☐☐ / ☐☐☐☐ MONTH YEAR	☐☐ / ☐☐☐☐ MONTH YEAR
d. What type of mastectomy did you have?	☐ Simple ☐ Partial ☐ Subcutaneous or nipple-sparing	☐ Simple ☐ Partial ☐ Subcutaneous or nipple-sparing
e. How satisfied are you with the decision to have this mastectomy?	☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied ☐ Somewhat dissatisfied ☐ Very dissatisfied	☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied ☐ Somewhat dissatisfied ☐ Very dissatisfied
f. If you were to make this decision again, would you still choose to have this mastectomy?	☐ Definitely yes ☐ Probably yes ☐ Unsure ☐ Probably not ☐ Definitely not	☐ Definitely yes ☐ Probably yes ☐ Unsure ☐ Probably not ☐ Definitely not
g. Did you experience any of the following complications during or after surgery? *(Please mark all that apply.)*	☐ Blood loss requiring a blood transfusion ☐ Hematoma or serious bruising ☐ Capsular contracture—scarring and hardening of the breast ☐ Implant rupture ☐ Seroma—fluid accumulation under the breast ☐ Flap necrosis ☐ Infection at the surgical site → **GO TO g1**	☐ Blood loss requiring a blood transfusion ☐ Hematoma or serious bruising ☐ Capsular contracture—scarring and hardening of the breast ☐ Implant rupture ☐ Seroma—fluid accumulation under the breast ☐ Flap necrosis ☐ Infection at the surgical site → **GO TO g1**
g1. If you experienced any infection, was it...	☐ within 30 days of surgery, ☐ a month to a year after surgery, ☐ a year or more after surgery, or ☐ you don't remember?	☐ within 30 days of surgery, ☐ a month to a year after surgery, ☐ a year or more after surgery, or ☐ you don't remember?

11. Did you undergo breast reconstruction?

- ☐ No → **GO TO QUESTION 12**
- ☐ Yes

11a. Which breasts did you have reconstructed? *(Please mark all that apply and answer follow-up questions.)*

		☐ Left Breast	☐ Right Breast
b.	Did you undergo immediate or delayed breast construction?	☐ Immediate ☐ Delayed or two-stage	☐ Immediate ☐ Delayed or two-stage
c.	Did you undergo implant (alloplastic) or living tissue (autologous – that is, TRAM or flap) reconstruction? *(Please mark all that apply.)*	☐ Implant or alloplastic c1. Was it... ☐ Silicone ☐ Saline ☐ Living tissue or autologous c2. Was it... ☐ TRAM ☐ Other flap	☐ Implant or alloplastic c1. Was it... ☐ Silicone ☐ Saline ☐ Living tissue or autologous c2. Was it... ☐ TRAM ☐ Other flap
d.	As part of breast reconstruction, did you undergo any of the following procedures? *(Please mark all that apply.)*	☐ Nipple or areola reconstruction ☐ Breast reduction (reduced size) ☐ Breast lift ☐ Breast augmentation (increased size) ☐ None	☐ Nipple or areola reconstruction ☐ Breast reduction (reduced size) ☐ Breast lift ☐ Breast augmentation (increased size) ☐ None
e.	How satisfied are you with your breast reconstruction?	☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied ☐ Somewhat dissatisfied ☐ Very dissatisfied	☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied ☐ Somewhat dissatisfied ☐ Very dissatisfied

12. How long ago was your most recent surgery, chemotherapy, or radiation treatment related to your breast cancer diagnosis? Please do **not** include hormonal medications like tamoxifen, Nolvadex, Aromasin, Arimidex, or Femara.

- ☐ Currently receiving treatment
- ☐ Less than 12 months ago
- ☐ At least 1 year ago, but less than 3 years ago
- ☐ At least 3 years ago, but less than 5 years ago
- ☐ At least 5 years ago, but less than 10 years ago
- ☐ More than 10 years ago

13. Overall, how satisfied are you with how well your medical team met your medical needs related to your cancer diagnosis and treatment?

- ☐ Very satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Very dissatisfied

14. How much does each of the following statements apply to you?

	Not at all	A little bit	Somewhat	Quite a bit	Very Much
a. I have had a hard time understanding what the doctors tell me about my cancer treatments.	☐	☐	☐	☐	☐
b. Before starting cancer treatment, I was well informed by my doctors and nurses about possible side effects of treatment.	☐	☐	☐	☐	☐
c. I received adequate support from my doctors and other health professionals in coping with side effects of my treatment.	☐	☐	☐	☐	☐
d. I received adequate support from my family and friends in coping with side effects of my treatment.	☐	☐	☐	☐	☐
e. I was well informed by my doctors and other health professionals about how much my cancer treatment would cost me.	☐	☐	☐	☐	☐
f. I received adequate information from my health care team about financial support options I could explore.	☐	☐	☐	☐	☐

15. At the completion of your cancer treatments, did your doctor give you a single written document summarizing **all** the treatments you actually received?

- ☐ No
- ☐ Don't know
- ☐ Yes

16. Have you **ever** received advice from a doctor, nurse, or other health care professional about where you should return or who you should see for routine cancer check-ups after completing treatment for cancer?

- ☐ No
- ☐ Don't know

} **GO TO QUESTION 17**

- ☐ Yes

16a. Was this information given to you as part of a written or electronic survivorship care plan? Please do not include appointment cards or reminders.

- ☐ No
- ☐ Don't know
- ☐ Yes

16b. Which doctors were you told to follow up with for your post-treatment cancer check-ups? *(Please mark all that apply.)*

- ☐ Primary care provider
- ☐ Breast surgeon
- ☐ Oncologist
- ☐ Other

17. To the best of your knowledge, are you now free of cancer?

- ☐ No
- ☐ Don't know
- ☐ Yes

18. In the last 12 months, has a doctor or other health professional told you that your breast cancer had come back or moved to another part of your body, such as your bones or other organs?

- ☐ No
- ☐ Yes

19. In the last 12 months, has a doctor or other health professional told you that you had a second or new cancer in a different location? Please do not include breast cancer that had spread to another part of your body.

- ☐ No
- ☐ Yes

20. Have you had both your ovaries removed?

- ☐ No
- ☐ Don't know
- ☐ Yes, before I was diagnosed with breast cancer

} **GO TO QUESTION 21**

- ☐ Yes, after I was diagnosed with breast cancer

20a. When did you have this surgery?

☐☐ / 2 0 ☐☐
MONTH YEAR

20b. Some women have their ovaries removed as part of breast cancer treatment to reduce exposure to natural hormones. Others have the surgery to prevent developing ovarian cancer — also called a preventive oophorectomy. Was your surgery done...

- ☐ as part of the treatment,
- ☐ to prevent ovarian cancer,
- ☐ both,
- ☐ for other reasons, or
- ☐ you don't know?

21. What type of doctor provides the **majority** of your health care? We want to know which type of doctor you see most often for illness or regular health care, for example, annual exams or physicals, treatment of colds, and so forth.

- ☐ Cancer surgeon
- ☐ Family practitioner
- ☐ Urgent care or walk-in
- ☐ Gynecologist
- ☐ General surgeon
- ☐ Gynecologic oncologist
- ☐ Internist or internal medicine doctor
- ☐ Plastic surgeon, reconstructive surgeon
- ☐ Medical oncologist
- ☐ Radiation oncologist
- ☐ Other

22. About how long has it been since you last visited a doctor for a routine check-up? A routine check-up is a general physical exam, not an exam for a specific injury, illness, or condition.

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

23. Currently, what type of health insurance coverage, if any, do you have? *(Please mark all that apply.)*

- ☐ A plan through your employer or union
- ☐ A plan through someone else's employer or union
- ☐ A plan that you or someone else buys on your own
- ☐ Medicare
- ☐ Medicaid
- ☐ Military, Tri-Care, CHAMPUS, or the VA
- ☐ Some other government program
- ☐ Get insurance from somewhere else
- ☐ **NOT** covered by insurance
- ☐ Don't know

MEDICAL TESTS

The following questions are about medical visits and tests you may, or may not, have received.

	Never	Less than 1 year ago	1-2 years ago	More than 2 years ago but less than 5 years ago	5 or more years ago	Don't know
24. When was the last time you had an echocardiogram — an ultrasound of the heart to look at the heart muscle and heart valves — or MUGA scan?	☐	☐	☐	☐	☐	☐
25. When was the last time you had a test to measure your bone strength or bone mineral density, such as a DEXA or quantitative CT scan?	☐	☐	☐	☐	☐	☐

26. **PLEASE CHECK IF:**

- ☐ You have had a double mastectomy or have had **both** breasts surgically removed. → **GO TO PAGE 14, QUESTION 31**
- ☐ You have **not** had a double mastectomy or still have **some or all** breast tissue. → **CONTINUE**

27. When did you have your most recent mammogram?

- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago
- ☐ Don't know

28. When did you have your most recent breast ultrasound?

- ☐ Never
- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago
- ☐ Don't know

29. A breast MRI, or magnetic resonance image, shows what is inside the breast, like a mammogram, but does not require squeezing the breast. Before getting a breast MRI, you are given a dye through a needle in the arm. During the test, you lie on your stomach and the bed moves into a tunnel-shaped machine.

When did you have your most recent breast MRI?

- ☐ Never had a breast MRI
- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago
- ☐ Don't know

30. A breast exam is when the breasts are felt by a doctor or other health professional to check for lumps or other signs of breast cancer.

When did you have your most recent breast exam done by a doctor or other health professional?

- ☐ Less than 6 months ago
- ☐ 6-12 months ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago
- ☐ Don't know

31. When did you have your most recent Pap test?

- ☐ Have never had a Pap test
- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago
- ☐ Not needed because I have had a hysterectomy with removal of the cervix
- ☐ Don't know

32. A blood stool test is a test that may use a special kit at home to determine whether your stool contains blood. It is also called a fecal occult blood test or FOBT.

Have you ever had a blood stool test using a home kit?

- ☐ No
- ☐ Don't know

} **GO TO QUESTION 33**

- ☐ Yes

32a. When did you have your last blood stool test using a home kit?

- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago
- ☐ Don't know

33. During a sigmoidoscopy, a flexible tube is inserted into the rectum to look for problems. A colonoscopy is similar, but uses a longer tube, and most people are given medication to relax or sedate them.

Have you ever had either a sigmoidoscopy or a colonoscopy?

- ☐ No
- ☐ Don't know

} **GO TO NEXT PAGE, QUESTION 34**

- ☐ Yes

33a. Was your most recent exam a sigmoidoscopy or a colonoscopy?

- ☐ Sigmoidoscopy
- ☐ Colonoscopy
- ☐ Don't know or not sure

33b. When did you have the most recent sigmoidoscopy or colonoscopy?

- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago, but less than 10 years ago
- ☐ More than 10 years ago
- ☐ Don't know

34. CA-125, also called cancer antigen 125, is a substance that may be found in the blood of patients with certain types of cancer, including ovarian cancer. A blood test is done to look for CA-125.

Since being diagnosed with breast cancer, have you had a blood test to check for CA-125?

- ☐ No
- ☐ Don't know
- ☐ Yes

LIFESTYLE

The following questions are about activities that you may, or may not, be doing. Please remember to answer as honestly as possible.

35. How often do you do each of the following compared to before you were diagnosed with breast cancer?	More often	About as often	Less often	Didn't do before and don't do now	Don't know
a. Exercise	☐	☐	☐	☐	☐
b. Participate in run or walk breast cancer awareness events	☐	☐	☐	☐	☐
c. Eat healthy foods	☐	☐	☐	☐	☐
d. Buy organic fruits and vegetables	☐	☐	☐	☐	☐
e. Drink alcoholic beverages	☐	☐	☐	☐	☐

35. How often do you do each of the following compared to before you were diagnosed with breast cancer?	More often	About as often	Less often	Didn't do before and don't do now	Don't know
f. Smoke cigarettes or use tobacco products	☐	☐	☐	☐	☐
g. Take vitamins or supplements	☐	☐	☐	☐	☐
h. Spend time with family and friends	☐	☐	☐	☐	☐
i. Make efforts to maintain a healthy body weight	☐	☐	☐	☐	☐
j. Buy hormone free meats or poultry	☐	☐	☐	☐	☐
k. Use make-up or other cosmetic products	☐	☐	☐	☐	☐
l. Use perfumes	☐	☐	☐	☐	☐
m. Get manicures or pedicures	☐	☐	☐	☐	☐
n. Avoid cosmetics and beauty products — including shampoos and deodorants — containing certain chemicals	☐	☐	☐	☐	☐
o. Use pesticides in the home for pest control	☐	☐	☐	☐	☐
p. Use herbicides or pesticides in the garden	☐	☐	☐	☐	☐
q. Color or dye your hair	☐	☐	☐	☐	☐
r. Use non-prescription natural hormone products	☐	☐	☐	☐	☐
s. Use Teflon or other non-stick pans or cookware	☐	☐	☐	☐	☐
t. Avoid second hand smoke or other people's tobacco smoke	☐	☐	☐	☐	☐
u. Use plastic containers to store or heat food or beverages	☐	☐	☐	☐	☐
v. Get enough sleep	☐	☐	☐	☐	☐
w. Avoid foods with chemical additives	☐	☐	☐	☐	☐

During the **past 7 days**, on how many days did you...		a. How much time did you usually spend doing these physical activities on one of those days?
36. do **vigorous** physical activities? These take hard physical effort and make you breathe much harder than normal, for example running or swimming at a fast pace. Think only about activities that you did for at least 10 minutes at a time.	☐ # DAYS **OR** ☐ No vigorous physical activity →	☐☐ HOURS **PER DAY** *(up to 24)* **AND** ☐☐ MINUTES **PER DAY** *(up to 59)* ☐ Not sure
37. do **moderate** physical activities? These take moderate physical effort and make you breathe somewhat harder than normal, for example dancing or doing yard work. Think only about those physical activities that you did for at least 10 minutes at a time. Do not include walking.	☐ # DAYS **OR** ☐ No moderate physical activity →	☐☐ HOURS **PER DAY** *(up to 24)* **AND** ☐☐ MINUTES **PER DAY** *(up to 59)* ☐ Not sure
38. **walk** for at least 10 minutes at a time? This includes walking at work and at home, walking to travel from place to place, and any other walking you might do solely for recreation, sport, exercise, or leisure.	☐ # DAYS **OR** ☐ No walking for at least 10 minutes →	☐☐ HOURS **PER DAY** *(up to 24)* **AND** ☐☐ MINUTES **PER DAY** *(up to 59)* ☐ Not sure

During the **past 7 days**, how much time did you...	
39. usually spend **sitting** on a **weekday**? This includes sitting while at work, at home, while doing course work, and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.	☐☐ HOURS **PER DAY** *(up to 24)* **AND** ☐☐ MINUTES **PER DAY** *(up to 59)* ☐ Not sure
40. usually spend **standing** on a **weekday**? This includes standing while at work, at home, and during leisure time.	☐☐ HOURS **PER DAY** *(up to 24)* **AND** ☐☐ MINUTES **PER DAY** *(up to 59)* ☐ Not sure

41. How similar was your level of activity this past week to your usual level of activity?

- ☐ Less than usual
- ☐ About the same
- ☐ More than usual

42. How strongly do you agree or disagree with each of the following statements about exercising regularly? Exercising...	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
a. is very difficult or tiring.	☐	☐	☐	☐	☐
b. is painful.	☐	☐	☐	☐	☐
c. is inconvenient or difficult to arrange.	☐	☐	☐	☐	☐

43. What was your weight, in pounds, when you were first diagnosed with breast cancer?

☐☐☐ POUNDS **OR** ☐ Don't know or don't remember

44. What is your current weight, in pounds?

☐☐☐ POUNDS

45. Since being diagnosed with breast cancer, have you tried to...	No	Yes
a. lose weight?	☐	☐
b. maintain your weight?	☐	☐
c. gain weight?	☐	☐

46. What is your current height? Please round to the nearest inch.

☐ FEET ☐☐ INCHES

47. When you were first diagnosed with breast cancer, did you smoke cigarettes?

- ☐ Not at all
- ☐ Some days
- ☐ Every day

48. Do you smoke cigarettes now?

- ☐ Not at all ⟶ **GO TO QUESTION 49**
- ☐ Some days
- ☐ Every day

48a. Have you ever stopped smoking for one day or longer because you were trying to quit?

- ☐ No
- ☐ Yes

49. For the following questions, one alcoholic beverage is considered to be a 12-ounce beer, a 5-ounce glass of wine, or a drink with one shot of liquor.

Over the past 30 days, on how many days did you have at least one drink of any alcoholic beverage, such as beer, wine, a malt beverage, or liquor?

- ☐ 0 days ⟶ **GO TO THE NEXT PAGE, QUESTION 50**
- ☐ 1 or more days

49a. Over the past 30 days, on how many days did you have one or more drinks?

☐☐
OF DAYS

49b. Over the past 30 days, on the days when you drank, about how many drinks did you have, on average?

☐☐
OF DRINKS

50. How often do you...	Always	Most of the time	Some-times	Rarely	Never	Don't know or not sure
a. include fruits and vegetables in meals and for snacks?	☐	☐	☐	☐	☐	☐
b. avoid eating food with saturated or trans-fats?	☐	☐	☐	☐	☐	☐
c. eat whole grains, such as brown rice or whole grain bread?	☐	☐	☐	☐	☐	☐
d. eat processed or refined grains such as white rice or white bread?	☐	☐	☐	☐	☐	☐
e. eat processed meats such as hot dogs or deli meats?	☐	☐	☐	☐	☐	☐
f. eat fish, poultry or beans?	☐	☐	☐	☐	☐	☐
g. eat beef, pork, or lamb?	☐	☐	☐	☐	☐	☐
h. eat fruits and vegetables of a variety of different colors, for example red, orange, yellow, and green?	☐	☐	☐	☐	☐	☐
i. select meat, poultry, dry beans, milk, and milk products that are lean, low-fat, or fat-free?	☐	☐	☐	☐	☐	☐
j. eat fatty foods?	☐	☐	☐	☐	☐	☐

51. Eating a healthy diet...	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
a. means that I'm limited to eating foods that I don't like.	☐	☐	☐	☐	☐
b. takes too much effort.	☐	☐	☐	☐	☐
c. costs too much money.	☐	☐	☐	☐	☐

PERSONAL MEDICAL HISTORY

The following questions are about conditions or symptoms you may have experienced. Please read each item carefully.

52. Currently, are you receiving treatment or taking medications for any of the following medical conditions?	No	Yes
a. Hypertension or high blood pressure	☐	☐
b. Diabetes, including borderline diabetes, but not including during pregnancy	☐	☐
c. Stomach or intestinal problems, such as Crohn's disease, ulcers, or inflammatory bowel disease	☐	☐
d. High cholesterol	☐	☐
e. Arthritis	☐	☐
f. Asthma, emphysema, or chronic obstructive pulmonary disease — also called COPD	☐	☐
g. Depression, feeling sad or blue	☐	☐
h. Anxiety or nervousness	☐	☐
i. Kidney problems or failure	☐	☐
j. Chronic liver condition	☐	☐
k. Other, please specify:	☐	☐

53. Lymphedema is an abnormal buildup of fluid that causes swelling, most often in the arms or legs. The condition develops when lymph vessels or lymph nodes are missing, impaired, damaged, or removed. Lymphedema can sometimes develop in an arm after surgery for breast cancer.

Since your breast cancer diagnosis, has a doctor or any other health professional told you that you have lymphedema?

☐ No
☐ Don't know
} **GO TO PAGE 23, QUESTION 57**

☐ Yes

54. To help treat or manage your lymphedema have you used or done any of the following?	No	Yes
a. Physical or massage therapy	☐	☐
b. Laser therapy	☐	☐
c. Compression bandages or garments	☐	☐
d. Prescription drugs or medications	☐	☐
e. Pneumatic pumps	☐	☐
f. Exercise or weight lifting	☐	☐
g. Alternative treatments like acupuncture or herbal supplements	☐	☐

55. How much has having lymphedema interfered with your ability to...	Not at all	A little	Quite a bit	Very much
a. perform tasks with the affected limbs?	☐	☐	☐	☐
b. lift or carry heavy objects, like a filled bucket or shopping bags?	☐	☐	☐	☐
c. sleep comfortably?	☐	☐	☐	☐
d. walk for more than 10 minutes?	☐	☐	☐	☐
e. participate in your hobbies or leisure activities?	☐	☐	☐	☐
f. wear the clothes of your choice?	☐	☐	☐	☐
g. do usual household activities?	☐	☐	☐	☐
h. work, either at home or place of employment?	☐	☐	☐	☐

56. Has your health insurance covered any of the medical visits, treatments or medications your doctors recommended to treat or manage your lymphedema?

- ☐ Yes, covered all
- ☐ Yes, covered some
- ☐ No, not covered
- ☐ Don't have health insurance
- ☐ No treatment

57. Neuropathy is pain, numbness, or discomfort caused by damage to the nerves that bring signals to and from the brain and spinal cord to other — or peripheral — parts of the body, such as the hands and feet. Women with breast cancer can sometimes develop neuropathy after completing treatment. Since your breast cancer diagnosis, has a doctor or any other health professional told you that you have neuropathy?

☐ No
☐ Don't know
} **GO TO THE NEXT PAGE, QUESTION 61**

☐ Yes
☐ Diagnosed before breast cancer

58. To help treat your neuropathy, have you used any of the following?	No	Yes
a. Pain relievers	☐	☐
b. Prescription drugs or medications	☐	☐
c. Electric nerve stimulation	☐	☐
d. Alternative treatments like acupuncture or herbal supplements	☐	☐

59. How much has having neuropathy interfered with your ability to...	Not at all	A little	Quite a bit	Very much
a. get dressed, such as trouble with buttons, zippers, putting on jewelry, and the like?	☐	☐	☐	☐
b. walk for more than 10 minutes?	☐	☐	☐	☐
c. pick up or hold onto objects?	☐	☐	☐	☐
d. work, either at home or a place of employment?	☐	☐	☐	☐
e. participate in your hobbies or leisure activities?	☐	☐	☐	☐
f. sleep comfortably?	☐	☐	☐	☐
g. do usual household activities?	☐	☐	☐	☐
h. lift or carry heavy objects, like a filled bucket or shopping bags?	☐	☐	☐	☐

60. Has your health insurance covered any of the medical visits, treatments or medications your doctors recommended to treat or manage your neuropathy?

- ☐ Yes, covered all
- ☐ Yes, covered some
- ☐ No, not covered
- ☐ Don't have health insurance
- ☐ No treatment

61. Heart disease is a broad term that includes congestive heart failure, cardiomyopathy or weak heart muscle, myocardial infarction or heart attack, arrhythmia or irregular heartbeat, coronary heart disease, stiff or leaking heart valves, or other heart problems that you see a cardiologist for on a regular basis. Heart disease does not include hypertension or high blood pressure or high cholesterol.

Since your breast cancer diagnosis, has a doctor or other health professional told you that you had heart disease?

- ☐ No
- ☐ Diagnosed before breast cancer
- ☐ Don't know

} **GO TO THE NEXT PAGE, QUESTION 62**

- ☐ Yes

61a. How long after your breast cancer were you diagnosed?

- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago

61b. Has your health insurance covered any of the medical visits, treatments, or medications your doctors recommended to treat or manage your heart disease?

- ☐ Yes, covered all
- ☐ Yes, covered some
- ☐ No, not covered
- ☐ Don't have health insurance
- ☐ No treatment

62. Since your breast cancer diagnosis, have you been told by a doctor or other health professional that you had osteoporosis?

- ☐ No
- ☐ Diagnosed before breast cancer
- ☐ Don't know

} **GO TO QUESTION 63**

- ☐ Yes

62a. How long after your breast cancer were you diagnosed?

- ☐ Less than a year ago
- ☐ More than 1 year ago, but less than 2 years ago
- ☐ More than 2 years ago, but less than 3 years ago
- ☐ More than 3 years ago, but less than 5 years ago
- ☐ More than 5 years ago

62b. Has your health insurance covered any of the medical visits, treatments or medications your doctors recommended to treat or manage your osteoporosis?

- ☐ Yes, covered all
- ☐ Yes, covered some
- ☐ No, not covered
- ☐ Don't have health insurance
- ☐ No treatment

63. Do you take any prescription drugs to prevent or treat osteoporosis?

- ☐ No
- ☐ Yes

64. Since you were first diagnosed with breast cancer, have you taken hormone replacement therapy, for example, estrogen or progesterone?

- ☐ No, never
- ☐ Yes, but not in the last month
- ☐ Yes, I have taken hormones in the last month
- ☐ Don't know

65. Have you been experiencing any problems in your thinking, memory, or attention **since** being diagnosed with and treated for breast cancer?

- ☐ Not at all ⟶ **GO TO THE PAGE 28, QUESTION 66**
- ☐ A little
- ☐ Quite a bit
- ☐ Very much

65a. In the past 12 months, have you experienced any of the following?

	No	Yes
1. Trouble concentrating or focusing	☐	☐
2. Trouble with short-term memory, like trouble remembering new information, simple instructions or a phone number	☐	☐
3. Having a hard time remembering or recalling words during a conversation	☐	☐
4. Having a hard time organizing daily tasks	☐	☐
5. Having difficulty multitasking	☐	☐
6. Other, please specify:	☐	☐

65b. When did you **first** start to notice these symptoms?

- ☐ Before being diagnosed with breast cancer
- ☐ During breast cancer treatment
- ☐ Less than 6 months after treatment ended
- ☐ More than 6 months after treatment ended

65c. In the past 12 months, have these symptoms...

- ☐ improved a lot,
- ☐ improved a little,
- ☐ stayed the same,
- ☐ gotten a little worse, or
- ☐ gotten a lot worse?

65d. Have you spoken to any of your doctors about these symptoms?

- ☐ No
- ☐ Yes

65e. Because of these symptoms, have you received or used any of the following?

	No	Yes
1. Psychological testing	☐	☐
2. Behavioral therapy	☐	☐
3. Prescription drugs or medications	☐	☐
4. Alternative treatments like herbal supplements, acupuncture, etc.	☐	☐

65f. How much have these symptoms interfered with your ability to...

	Not at all	A little	Quite a bit	Very Much	Not applicable
1. do your job?	☐	☐	☐	☐	☐
2. do the things you enjoy?	☐	☐	☐	☐	☐
3. work on a computer?	☐	☐	☐	☐	☐
4. read a book?	☐	☐	☐	☐	☐
5. do a puzzle?	☐	☐	☐	☐	☐
6. do usual household activities?	☐	☐	☐	☐	☐
7. do the things you routinely do?	☐	☐	☐	☐	☐
8. spend time with family and friends?	☐	☐	☐	☐	☐

65g. Has your health insurance covered any of the medical visits, treatments or medications your doctors recommended to treat these symptoms?

- ☐ Yes, covered all
- ☐ Yes, covered some
- ☐ No, not covered
- ☐ Don't have health insurance
- ☐ No treatment

66. At the time when you were first diagnosed with breast cancer, how many babies in all had you given birth to?

☐☐
OF BABIES

67. Before you were first diagnosed with breast cancer, had you gone through menopause or had you had your uterus or both of your ovaries removed?

- ☐ No ⟶ **CONTINUE**
- ☐ Yes ⟶ **GO TO PAGE 33, QUESTION 81**

68. At the time of your diagnosis with breast cancer, were you pregnant or breastfeeding?

- ☐ No
- ☐ Yes

69. At the time of your first diagnosis with breast cancer, had you had your tubes tied?

- ☐ No ⟶ **CONTINUE**
- ☐ Yes ⟶ **GO TO PAGE 33, QUESTION 81**

70. **Before you first received treatment** for breast cancer, how concerned were you that your cancer treatment could cause infertility?

- ☐ Not at all concerned
- ☐ A little concerned
- ☐ Somewhat concerned
- ☐ Very concerned

71. **Before your breast cancer diagnosis**, did you think you wanted to get pregnant at some point in the future?

- ☐ No
- ☐ Yes

72. **After you were diagnosed**, did you change your mind about trying to have children in the future?

- ☐ No
- ☐ Yes

73. Did you ever have a discussion with a health care provider about the effect your treatment could have on your future fertility or ability to have children?

☐ No →

73a. Would you have liked to have had this discussion with your provider?

- ☐ No
- ☐ Yes

} **GO TO THE NEXT PAGE, QUESTION 74**

☐ Yes →

73b. Who first brought up this topic?

- ☐ My doctor or health care provider
- ☐ I did

73c. When did these discussions take place? *(Please mark all that apply.)*

- ☐ Before starting chemotherapy
- ☐ During chemotherapy
- ☐ After completing chemotherapy
- ☐ Before starting hormone therapy, like tamoxifen
- ☐ During hormone therapy
- ☐ After completing hormone therapy

73d. With which of your medical providers did you have these conversations? *(Please mark all that apply.)*

- ☐ Medical oncologist
- ☐ Surgeon
- ☐ Radiation oncologist
- ☐ Primary care doctor
- ☐ Nurse or nurse practitioner
- ☐ Other

74. Before starting cancer treatment, did you know that some cancer treatments could affect a woman's fertility?

☐ No → **GO TO THE NEXT PAGE, QUESTION 75**

☐ Yes

Did concerns about fertility affect your treatment decisions in any of the following ways? Because of my concerns about my future fertility, I chose...	No	Yes	Not Applicable
74a. not to have radiation.	☐	☐	☐
74b. one regimen of radiation over another.	☐	☐	☐
74c. not to have chemotherapy.	☐	☐	☐
74d. one regimen of chemotherapy over another.	☐	☐	☐
74e. not to take tamoxifen or other hormonal medication.	☐	☐	☐
74f. to take tamoxifen or other hormonal medication for a shorter amount of time than recommended.	☐	☐	☐
74g. another option. Please specify:	☐	☐	☐

75. Before you began treatment, or during treatment, did you take any additional steps to lessen your chances of becoming infertile as a result of your cancer treatment?

☐ No →

75a. Why did you decide against steps to preserve your fertility?
(Please mark all that apply.)

- ☐ Did not wish to have children after cancer treatment
- ☐ Did not know there were any options
- ☐ It was too expensive
- ☐ Health insurance didn't cover it
- ☐ I wanted to start cancer treatment right away
- ☐ Fertility treatment options were overwhelming or invasive
- ☐ Was afraid it would affect my breast cancer or the treatment
- ☐ Decided to try to get pregnant at that time
- ☐ Decided to adopt in the future
- ☐ Decided to use egg or embryo donation in the future
- ☐ Concerned about passing on a disease
- ☐ Did not like available options

GO TO THE NEXT PAGE, QUESTION 76

☐ Yes →

75b. What steps have you taken?
(Please mark all that apply.)

- ☐ Cryopreservation or freezing of embryos or fertilized eggs
- ☐ Cryopreservation or freezing of unfertilized eggs
- ☐ Cryopreservation or freezing of ovarian tissue — that is, a piece of the ovary or the whole ovary
- ☐ GnRH agonist — for example, Lupron or Zoladex shots — for ovarian suppression during chemo
- ☐ Oral contraceptive pills or OCPs during chemo
- ☐ Not sure
- ☐ Other, please specify:

		No	Yes
76.	Because of your breast cancer diagnosis, have you consulted with a fertility specialist?	☐	☐
77.	Since being diagnosed, have you had any infertility treatments?	☐	☐
78a.	Since being diagnosed, have you adopted a child?	☐	☐
78b.	Since being diagnosed, have you legally fostered or taken in a child?	☐	☐

79. Did your menstrual periods stop either during or after the time of your breast cancer treatment?

☐ No → **GO TO THE NEXT PAGE, QUESTION 81**

☐ Yes

79a. What month and year did your menstrual periods first stop or how old were you when your menstrual periods first stopped? Please provide your best estimate if you cannot remember.

☐☐ / 20☐☐ **OR** ☐☐

MONTH YEAR AGE

79b. Did you later go back to having regular menstrual periods?

☐ No → **GO TO THE NEXT PAGE, QUESTION 82**

☐ Yes

79c. What month and year did your menstrual periods begin again?

☐☐ / 20☐☐

MONTH YEAR

80. What is your current menstrual status?

☐ I have had a period in the last 12 months.

☐ My periods stopped on their own (naturally).

☐ My periods stopped on their own but I began taking hormone replacement therapy before my periods fully stopped.

☐ My periods stopped after my uterus or ovaries were removed.

☐ My periods stopped due to treatment for a second cancer.

☐ My periods stopped because I am taking the kind of birth control pills that make me not have periods.

☐ My periods stopped for some other reason, please describe:

81. What month and year did you have your last menstrual period or how old were you when you had your last menstrual period? Please provide your best estimate if you cannot remember.

☐☐ / ☐☐☐☐ MONTH YEAR **OR** ☐☐ AGE

GENETIC COUNSELING AND TESTING

82. Before you were diagnosed with breast cancer, had you ever talked to your doctor about your family history of breast or ovarian cancer and what it might mean for your own health and cancer risk?

- ☐ No
- ☐ Yes

Genetic counseling involves an in-depth discussion with a trained genetic counselor or doctor about your family's health history.

83. Has a doctor or other health professional ever recommended or referred you for genetic counseling for breast or ovarian cancer?

- ☐ No
- ☐ Yes

84. Have you ever received genetic counseling for breast or ovarian cancer risk?

- ☐ No → **GO TO THE NEXT PAGE, QUESTION 85**
- ☐ Yes

84a. When did you receive genetic counseling? *(Please mark all that apply.)*

- ☐ Before I was diagnosed
- ☐ At the same time I was diagnosed
- ☐ After I was diagnosed

84b. From whom did you receive genetic counseling? *(Please mark all that apply.)*

- ☐ My regular or primary care doctor
- ☐ A nurse
- ☐ A genetic counselor
- ☐ My cancer doctor or oncologist
- ☐ Other
- ☐ Don't know

84c. Did a health care professional recommend that you receive genetic testing?

- ☐ No
- ☐ Yes

85. As far as you know, have any of your blood relatives received genetic counseling for breast or ovarian cancer risk?

- ☐ No
- ☐ Yes

BRCA1 and BRCA2 are genes in a person's DNA that are associated with the risk of breast and ovarian cancer. There are genetic tests for mutations in BRCA1 and BRCA2, requiring a blood sample, saliva sample, or cheek swab, that can provide information about your risk for these cancers.

86. Have you ever had a BRCA1 or BRCA2 genetic test or BRCA analysis?

☐ No →

86a. Why haven't you received genetic testing? *(Please mark all that apply.)*

- ☐ I didn't know about it
- ☐ I didn't want to
- ☐ Too expensive
- ☐ My friends or family didn't think I needed it
- ☐ I was afraid of the result
- ☐ Someone else in family was tested
- ☐ My doctor never brought it up
- ☐ Insurance wouldn't cover it
- ☐ My doctor didn't think I needed it
- ☐ I was afraid it would affect my health insurance coverage
- ☐ I would rather not know
- ☐ Other reasons

GO TO THE NEXT PAGE, QUESTION 87

☐ Yes →

86b. Did the results of your BRCA1 or BRCA2 test indicate that you carry a mutation that would put you at increased risk for cancer?

- ☐ No
- ☐ Don't know
- ☐ Yes
- ☐ Inconclusive result

87. Some studies show that BRCA1 and BRCA2 are more common in persons of Ashkenazi **Jewish** descent. Most people of Ashkenazi Jewish descent can trace their ancestry to Eastern Europe.

Are you of Ashkenazi Jewish descent?

- ☐ No
- ☐ Don't know
- ☐ Yes

88. As far as you know, have any of your blood relatives received a BRCA1 or BRCA2 genetic test?

- ☐ No ⟶ **GO TO QUESTION 89**
- ☐ Yes

88a. Did the result of any of your blood relatives' BRCA1 or BRCA2 tests indicate that they were a mutation carrier or have an increased risk for cancer?

- ☐ No
- ☐ Yes
- ☐ Inconclusive result
- ☐ Don't know

Please choose the best response for each of the following.

89. Compared to most women your age, what would you say are your chances of developing...	Much lower	Lower	About the same	Higher	Much higher
a. breast cancer again?	☐	☐	☐	☐	☐
b. ovarian cancer in your lifetime?	☐	☐	☐	☐	☐
c. another type of cancer in your lifetime?	☐	☐	☐	☐	☐

Please choose the best response for each of the following.

90. During the past month how often did you...	Never	Rarely	Sometimes	Often	All the time
a. worry about **getting breast cancer again?**	☐	☐	☐	☐	☐
b. have thoughts about **getting breast cancer again** that affected your mood?	☐	☐	☐	☐	☐
c. worry about **getting ovarian cancer?**	☐	☐	☐	☐	☐
d. worry about **getting another cancer?**	☐	☐	☐	☐	☐

EMPLOYMENT AND FINANCES

These questions are about your experiences with work during your breast cancer diagnosis, treatment, and recovery, if you were employed. There are also questions about the cost and financial impact your breast cancer may have had.

91. At the time of your breast cancer diagnosis, were you employed for pay at a job or business?

- ☐ No, unemployed
- ☐ No, retired
- ☐ No, on disability

} **GO TO PAGE 38, QUESTION 104**

- ☐ Yes, full time
- ☐ Yes, part time
- ☐ Other

91a. Did you take at least a week of leave or time off from work for any of your cancer treatment and recovery?

- ☐ No → **GO TO QUESTION 92**
- ☐ Yes

91b. What kind of time off or leave did your job provide during your treatment and recovery? *(Please mark all that apply, if your experience was mixed.)*

- ☐ Paid sick leave
- ☐ Other paid time off
- ☐ There was no provision for time off and I had to quit working
- ☐ Unpaid sick leave
- ☐ Family Medical Leave Act
- ☐ Other

92. Did you share information about your breast cancer diagnosis with your supervisor or any of your co-workers?

- ☐ No
- ☐ Yes
- ☐ Not Applicable

93. After your treatment and recovery, did you continue working for pay?

☐ No ⟶

93a. After treatment and recovery, did you...?
(Please mark all that apply.)

- ☐ retire,
- ☐ go on disability,
- ☐ quit working,
- ☐ lose your job or get fired, or
- ☐ other? Please specify:

GO TO PAGE 38, QUESTION 104

☐ Yes ⟶ **CONTINUE**

94. Did you continue working at the same job you had when you were diagnosed?

- ☐ No
- ☐ Yes

95. When you returned to work after treatment and recovery, did you typically work...

- ☐ the same number of hours,
- ☐ fewer hours, or
- ☐ more hours?

96. Did your job status, position, duties, or responsibilities change because of your cancer diagnosis, treatment, or related side effects?

- ☐ No
- ☐ Yes

97. Have you ever felt that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to...	No	Yes	Not Applicable	Don't know
a. perform any physical tasks required by your job?	☐	☐	☐	☐
b. perform any mental tasks required by your job?	☐	☐	☐	☐
c. perform any social tasks required by your job?	☐	☐	☐	☐

	No	Yes	Don't know
98. Did you ever feel that, because of your cancer, its treatment, or its lasting effects, you were less productive at work?	☐	☐	☐
99. Did you ever worry that, because of your cancer, its treatment, or its lasting effects, you might be forced to retire or quit work before you normally would have?	☐	☐	☐
100. Because of your breast cancer, did you stay at a job in part because you were concerned about losing your health insurance?	☐	☐	☐
101. Have you ever had to quit a job or decided to retire early because of your cancer, its treatment, or its lasting effects?	☐	☐	☐
102. Have you ever been let go, laid off, or fired from a job because of your cancer, its treatment, or its lasting effects?	☐	☐	☐
103. Have you experienced discrimination in your workplace resulting from your cancer diagnosis, treatment, and its lasting effects?	☐	☐	☐

104. Currently, are you employed for pay at a job or business?

- ☐ No, unemployed
- ☐ No, retired
- ☐ No, on disability
- ☐ Other

} **GO TO THE NEXT PAGE, QUESTION 105**

- ☐ Yes, full time
- ☐ Yes, part time

Please indicate to what extent each of the following applies to you.

	Not at all	A little	A fair amount	A lot	Very much
104a. I have difficulty speaking with my boss about my breast cancer.	☐	☐	☐	☐	☐
104b. I have difficulty talking to the people I work with about my breast cancer.	☐	☐	☐	☐	☐
104c. I have difficulty telling my employer that I cannot do something because of my breast cancer.	☐	☐	☐	☐	☐
104d. I am worried about being fired because of my breast cancer.	☐	☐	☐	☐	☐

105. To what degree has cancer caused financial problems for you and your family?

- ☐ A lot
- ☐ Some
- ☐ A little
- ☐ Not at all

		No	Yes
106.	Have you experienced financial problems or difficulties in paying for your cancer drugs or treatment?	☐	☐
107.	Have you or has someone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of treatment?	☐	☐
108.	Have you or your family ever had to file for bankruptcy because of your cancer, its treatment, or the lasting effects of treatment?	☐	☐

GENERAL HEALTH AND WELL-BEING

The questions in this section ask very generally about your overall health and emotions. Please read the instructions to each question carefully, as many ask you to think about certain periods of time.

Please select one response for each of the following questions.

109.	In general...	Excellent	Very good	Good	Fair	Poor
a.	would you say your health is...	☐	☐	☐	☐	☐
b.	would you say your quality of life is...	☐	☐	☐	☐	☐
c.	how would you rate your physical health?	☐	☐	☐	☐	☐
d.	how would you rate your satisfaction with your social activities and relationships?	☐	☐	☐	☐	☐
e.	how would you rate how well you carry out your usual social activities and roles? This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.	☐	☐	☐	☐	☐

110. To what extent are you able to carry out your everyday physical activities, such as walking, climbing stairs, carrying groceries, or moving a chair?

- ☐ Completely
- ☐ Mostly
- ☐ Moderately
- ☐ A little
- ☐ Not at all

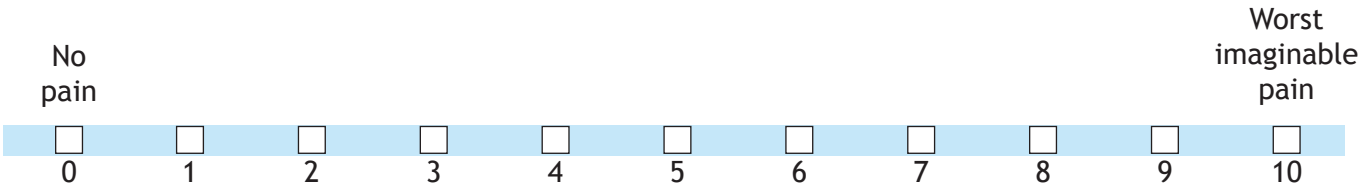
111. In the **past 7 days**, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

112. In the **past 7 days**, how would you rate your fatigue on average?

- ☐ None
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Extremely severe

113. In the **past 7 days**, how would you rate your pain on average?



114. Below is a list of some of the ways you may have felt or behaved. During the **past 7 days**, how often did you feel or act this way?

	Rarely or none of the time	A little of the time	A moderate amount of the time	Most or all of the time
a. I was bothered by things that usually don't bother me.	☐	☐	☐	☐
b. I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
c. I felt depressed.	☐	☐	☐	☐
d. I felt that everything I did was an effort.	☐	☐	☐	☐
e. I felt hopeful about the future.	☐	☐	☐	☐
f. I felt fearful.	☐	☐	☐	☐
g. My sleep was restless.	☐	☐	☐	☐
h. I was happy.	☐	☐	☐	☐
i. I felt lonely.	☐	☐	☐	☐
j. I could not "get going."	☐	☐	☐	☐

115. Over the past 7 days...	Never	Rarely	Sometimes	Often	Always
a. how often did you feel tired?	☐	☐	☐	☐	☐
b. how often did you experience extreme exhaustion?	☐	☐	☐	☐	☐
c. how often did you run out of energy?	☐	☐	☐	☐	☐
d. how often did your fatigue limit you at work, including work at home?	☐	☐	☐	☐	☐
e. how often were you too tired to think clearly?	☐	☐	☐	☐	☐
f. how often were you too tired to take a shower?	☐	☐	☐	☐	☐
g. how often did you have enough energy to exercise strenuously?	☐	☐	☐	☐	☐

116.	How much does this currently apply to you?	Not at all	A little	A fair amount	Much	Very much
a.	I have frequent pain.	☐	☐	☐	☐	☐
b.	I have chronic pain from scars, surgery or other breast cancer treatment.	☐	☐	☐	☐	☐
c.	I have pain that is not controlled by pain medication.	☐	☐	☐	☐	☐

117.	Did you ever participate in any of the following to help you cope with your breast cancer?	No	Yes
a.	Support group	☐	☐
b.	Professional counseling	☐	☐
c.	Talk to religious leaders or members of your spiritual community	☐	☐
d.	Talk to doctors, nurses, or other health professionals	☐	☐
e.	Talk to family	☐	☐
f.	Talk to friends	☐	☐
g.	Yoga	☐	☐
h.	Meditation	☐	☐
i.	Stress reduction or management techniques	☐	☐
j.	Other, please specify:	☐	☐

FAMILY, RELATIONSHIPS, AND INTIMACY

118. Did you or do you provide care for parents, children, grandchildren, or someone who was ill or disabled during any of the following periods of your life? *(Please mark all that apply.)*

- ☐ In the year before you were diagnosed with breast cancer
- ☐ While you were receiving care for breast cancer
- ☐ Currently

119.	Thinking back to **when you were diagnosed with and being treated for breast cancer**, did you have someone you relied on to...	No	Yes	Not Applicable
a.	remind or help you take medications?	☐	☐	☐
b.	help you cook meals?	☐	☐	☐
c.	help complete household chores?	☐	☐	☐
d.	run errands?	☐	☐	☐
e.	provide transportation?	☐	☐	☐
f.	help take care of your children?	☐	☐	☐
g.	help with your caregiving responsibilities, like having someone take care of sick friend or relative that you normally care for?	☐	☐	☐
h.	go to doctors' appointments?	☐	☐	☐
i.	complete work responsibilities?	☐	☐	☐
j.	help take care of important duties or responsibilities, for example, pay bills?	☐	☐	☐
k.	confide in or talk to about how you were feeling or doing?	☐	☐	☐
l.	provide comfort or support in a time of need?	☐	☐	☐
m.	share your worries or fears with?	☐	☐	☐

120.	How much do you agree or disagree with each of the following?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a.	I am worried that my family members have cancer causing genes.	☐	☐	☐	☐	☐
b.	My family members have a much higher chance of developing cancer than most people.	☐	☐	☐	☐	☐

121. Do you have any children?

☐ No → **GO TO THE NEXT PAGE, QUESTION 123**

☐ Yes

121a. When you were first diagnosed with breast cancer, did you talk to your children about your diagnosis and treatment and how it would impact the family?

☐ No

☐ Yes

☐ Not applicable

121b. Have you ever talked with a doctor or health professional about your children's chances of getting cancer?

- ☐ No
- ☐ Yes
- ☐ Not applicable

121c. Do you have at least one biological daughter?

- ☐ No → **GO TO QUESTION 123**
- ☐ Yes

122a. Have you ever talked to your daughter(s) about your family history of breast cancer?

- ☐ No
- ☐ Yes
- ☐ Not applicable

122b. Have you ever talked to your daughter(s) about things she could do to help prevent breast cancer?

- ☐ No
- ☐ Yes
- ☐ Not applicable

122c. Have you ever been concerned about your daughter's breast cancer risk because of your or your family's history of breast cancer?

- ☐ No
- ☐ Yes

The following questions are about your spouse or partner and your intimate relationships.

123. At the time you were diagnosed with breast cancer, were you married, living with someone as married, or in a significant relationship?

- ☐ No
- ☐ Yes

124. Have you ever had a romantic relationship end because of your breast cancer?

- ☐ No
- ☐ Yes

125. Are you currently married, living with someone as married, or in a significant relationship?

☐ No →

126. Given your life as it is now, how much do you agree or disagree with each of the following?	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship.	☐	☐	☐	☐	☐
b. I wonder how to tell a potential spouse or partner that I have had cancer.	☐	☐	☐	☐	☐

GO TO THE NEXT PAGE, QUESTION 128

☐ Yes →

127. How much do you agree or disagree with each of the following?	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. I am open and willing to discuss my cancer with my spouse or partner.	☐	☐	☐	☐	☐
b. My spouse or partner is open and willing to discuss my cancer with me.	☐	☐	☐	☐	☐
c. Having had breast cancer has improved my relationship with my spouse or partner.	☐	☐	☐	☐	☐
d. Having had breast cancer has put a strain on my relationship with my spouse or partner.	☐	☐	☐	☐	☐
e. My spouse or partner and I have difficulty talking about my breast cancer and what might happen in the future.	☐	☐	☐	☐	☐

THOUGHTS ABOUT AND EXPERIENCES WITH BREAST CANCER

128. How much do you agree or disagree with each of the following?	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. I think the doctors should have done a better job treating my cancer.	☐	☐	☐	☐	☐
b. Now that my initial treatment has ended I feel like my cancer doctors are not interested in my well being.	☐	☐	☐	☐	☐
c. I am concerned that my energy has not returned to what it was before I had cancer.	☐	☐	☐	☐	☐
d. I am bothered that my body cannot do what it could before having had cancer.	☐	☐	☐	☐	☐
e. Having had cancer has made me take better care of myself or my health.	☐	☐	☐	☐	☐
f. Having had cancer makes me feel uncertain about my health.	☐	☐	☐	☐	☐
g. I feel a sense of pride or accomplishment from surviving cancer.	☐	☐	☐	☐	☐
h. I feel guilty for somehow being responsible for getting cancer.	☐	☐	☐	☐	☐
i. Having had cancer has been the most difficult experience of my life.	☐	☐	☐	☐	☐
j. Having had cancer turned into a reason to make changes in my life.	☐	☐	☐	☐	☐
k. I have felt self-conscious about my appearance.	☐	☐	☐	☐	☐
l. I have felt less feminine as a result of having had breast cancer.	☐	☐	☐	☐	☐
m. I am satisfied with the appearance of my breasts.	☐	☐	☐	☐	☐
n. Since having had breast cancer treatment, my body seems less whole.	☐	☐	☐	☐	☐
o. I feel less sexually attractive as a result of having had breast cancer.	☐	☐	☐	☐	☐
p. I feel satisfied with my sex life.	☐	☐	☐	☐	☐
q. Uncertainty about my future affects my ability to make plans.	☐	☐	☐	☐	☐
r. Having cancer has affected my retirement plans.	☐	☐	☐	☐	☐

Please check to see that all questions are answered.

Thank you for completing this questionnaire and for your continued participation in the Sister Study.

Please mail this form to us at the address below.
A postage-paid envelope is provided.

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