



The Sister Study Special Survey



Instructions:

- Please use **DARK BLUE OR BLACK BALLPOINT PEN.**
- Do not write comments on the form.
- Please keep this questionnaire clean, flat, and dry.
- Do not fold or tear any of the pages.

Fill in the bubbles COMPLETELY for each of the questions in this form.

Like this: ● Not like this: ⊗ ✓

If you must change an answer, please mark a single horizontal line through it and bubble in the correct answer completely.

Like this: ● YES — Not like this: ⊗ YES

Please write responses without touching the sides of the boxes.

Like this:

1	2	3	4	5	6	7	8	9	0
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This is a one-time survey that asks questions about your experiences having a sister who had breast cancer and your beliefs about breast cancer. The survey is being done as a partnership between the Centers for Disease Control and Prevention (CDC) and the National Institute of Environmental Health Sciences.

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, just skip it and go on 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. Don't take too long thinking over your replies; your immediate reaction will probably be more accurate than a long, thought-out response.

If you have more than one sister who had breast cancer, please think only about **one sister** in particular while answering these questions.

Please write the name or initials of that sister here:

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Public reporting burden for this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0522). Do not return the completed form to this address.

*U.S. Department of Health and Human Services
National Institutes of Health / National Institute of Environmental Health Sciences
Centers for Disease Control and Prevention / Division of Cancer Prevention and Control*



Today's Date:

/ / 20
(month) (day) (year)

1. Have you ever been diagnosed with breast cancer?

- Yes ► **STOP! There are no further questions. Thank you!**
- No ► **Please continue with question 2.**

2. Have you talked with your doctor about what your family history of breast cancer might mean for your own health and cancer risk?

No ► **Go to question 4**

- Yes, we've talked about this a little
- Yes, we've talked about this in depth

	Yes	No
3. Has a doctor or other health professional ever told you that you have...		
a. a higher chance of getting breast cancer than other women your age?	<input type="radio"/>	<input type="radio"/>
b. a higher chance of getting ovarian cancer than other women your age?	<input type="radio"/>	<input type="radio"/>

4. How satisfied are you with the level of communication you have had with your doctor about your family's history of cancer and your own cancer risk?

- Very satisfied
- Satisfied
- Neither
- Dissatisfied
- Very dissatisfied

Genetic counseling involves a discussion with a trained genetic counselor about your family's health history.

5. Has a doctor or other health professional ever recommended or referred you to get genetic counseling because of your family history of cancer?

- Yes
- No



6. Have you ever received genetic counseling because of your family history of cancer?

- Yes
- No

7. Has any member of your family, who you are related to by blood, ever received genetic counseling related to cancer?

- Yes
- No
- Don't know

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 or saliva sample, that can provide information about your risk for these cancers.

8. Have you ever had a BRCA1 or BRCA2 genetic test?

Yes

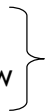


9. Did your BRCA1 or BRCA2 test result indicate an increased risk for cancer?

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

No

Don't know



Go to question 10

10. Has any member of your family, who you are related to by blood, ever had a BRCA1 or BRCA2 genetic test?

Yes

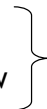


11. Did any of those family members have a BRCA1 or BRCA2 test result that indicated an increased risk for cancer?

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

No

Don't know



Go to question 12



A breast self-exam is a method of examining the appearance and feel of your breasts for suspicious lumps or changes.

Please choose the best response for each of the following.

12. Do you perform breast self-exams on a regular basis?

Yes ▶

13. Approximately how often do you perform a breast self-exam?

- Weekly
- Monthly
- Every couple of months
- Every 6 months
- Yearly

No ▶ **Go to question 14**

14. Have you ever been taught how to give yourself a breast self-exam?

- Yes
- No

15. Have you ever gone to your doctor because you felt a lump during a breast self-exam?

- Yes
- No

A breast MRI, or magnetic resonance image, shows the inside of 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 MRI procedure, you lie on your stomach and the bed moves into a tunnel-shaped machine.

16. Have you ever had a breast MRI?

Yes ▶

17. What was the reason for your **most recent** breast MRI? (Mark all that apply.)

- I had an abnormal mammogram
- I had a lump or other breast problem
- My healthcare provider told me I was high risk
- My family history of breast cancer
- I have dense breasts
- I requested it
- Other, specify:
- Don't know

- No
- Don't know

▶ **Go to question 18**



The next sets of questions are about your experiences with breast cancer in your family. They ask about relationships, experiences, and discussions among family members about breast cancer.

18. Is the sister you previously named still living?

Yes ► **Go to question 22**

No ►

19. Did she die from breast cancer or another cause?

- Breast cancer
- Another cause
- Don't know

20. How old was she when she died?

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AGE

21. How old were you at the time of her death?

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AGE

Please choose the best response for each of the following.

22. How close is (was) your relationship with this sister?

- Not close
- A little close
- Close
- Very close

23. How much...	Not at all	Very little	Somewhat	Very much
a. do you believe you resemble(d) this sister physically?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. do you believe you resemble(d) this sister in terms of personality?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. has this sister's breast cancer affected how you think about your own health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



24. Please choose the best response for each of the following. How often...	Never	Rarely	Sometimes	Often
a. did you spend time talking with this sister before she was diagnosed with breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. do you (did you) spend time talking with this sister during her breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. do you (did you) help take care of this sister during her breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. do you (did you) accompany this sister to her doctor's appointments and treatments related to her breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. do you (did you) talk with this sister about her breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. do you think about this sister's experience with breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. do you (did you) spend time talking with friends or family members about your concerns about this sister's breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Do you have at least one daughter?

No ► **Go to question 28**

Yes ►

26. Have you ever...	Yes	No
a. talked to your daughter(s) about your family history of breast cancer?	<input type="radio"/>	<input type="radio"/>
b. talked to your daughter(s) about things she could do to help prevent breast cancer?	<input type="radio"/>	<input type="radio"/>
c. been concerned about your daughter's breast cancer risk because of your family history of breast cancer?	<input type="radio"/>	<input type="radio"/>

27. How much do you agree or disagree with the following statement? I have all the information I need to talk to my daughter(s) about breast cancer.	<input type="radio"/> Strongly disagree <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Strongly agree
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The next few questions measure your beliefs about breast cancer and the impact of having a breast cancer in your family.

28. Please choose the best response for each of the following. Compared to most women your age, what would you say your chances are for developing...	Much lower	Lower	About the same	Higher	Much higher
a. breast cancer in your lifetime?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ovarian cancer in your lifetime?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



29. How much do you agree or disagree with the following statements?	Strongly disagree	Disagree	Agree	Strongly agree
a. There's not much I can do to lower my chances of getting breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. My family history of breast cancer makes me try to live a healthier lifestyle.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I have someone I trust that I can talk to about my concerns about developing breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Getting breast cancer would be a very serious problem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I think about breast cancer more than most diseases.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Getting breast cancer is often in the back of my mind.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. I am often bothered by thoughts or worry about my chances of getting breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. There's not much I can do to lower my chances of getting ovarian cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Getting ovarian cancer would be a very serious problem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. I am often bothered by thoughts or worry about my chances of getting ovarian cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Routine mammograms are likely to do more harm than good.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Medical care is likely to do more harm than good.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. For each of the following statements, choose whether you believe it would generally increase, have no effect on, or decrease a woman's chances of developing breast cancer.	Increase	No effect	Decrease	Don't know
a. Exercising for 30 to 60 minutes most days of the week.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Eating a low-fat diet.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Eating more servings of fruits and vegetables per day.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Gaining weight after menopause.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Drinking one glass of red wine per day.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Drinking more than one alcoholic beverage per day.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Being exposed to chemicals or toxins in the environment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Using hormone replacement therapy after menopause.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



30. For each of the following statements, choose whether you believe it would generally increase, have no effect on, or decrease a woman's chances of developing breast cancer.	Increase	No effect	Decrease	Don't know
i. Using oral contraceptives (birth control).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. A blow or other injury to the breast.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. A stressful life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. A history of breast cancer on her mother's side of the family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. A history of breast cancer on her father's side of the family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. A history of ovarian cancer on her mother's side of the family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o. A history of ovarian cancer on her father's side of the family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. Since your sister's diagnosis with breast cancer, do you participate in any of the following more often, about as often, or less often than you did before she was diagnosed?	More often	About as often	Less often	Didn't do before and don't do now
a. Exercise regularly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Eat healthy foods.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Drink alcoholic beverages.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Smoke cigarettes or use tobacco products.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Take vitamins or supplements.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Get regular health check-ups.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Perform breast self-exams.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Get regular mammograms.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Get regular breast ultrasounds.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Get regular breast MRIs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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.

The Sister Study, 1009 Slater Road, Suite 120, Durham, NC 27703
 phone: 1-877-4SISTER (1-877-474-7837); email: update@sisterstudy.org

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