

MAMMOGRAM SURVEY

Thank you for participating in the Long Term Follow-Up Study. As the sister of an individual who survived a serious childhood illness such as cancer, your responses provide valuable information in the fight against such diseases.

For questions about completing this questionnaire, please call 1-800-775-2167. Please use the envelope that was enclosed with this form and mail your completed survey to:

LONG-TERM FOLLOW-UP STUDY
MAYO MAIL CODE 715
420 DELAWARE ST SE
MINNEAPOLIS MN 55455-9940

The following questions ask about your history of having mammograms of the breasts. Because different tests are used at different times, a definition of each test is provided to help you answer the questions.

MAMMOGRAM - an x-ray is taken of each breast separately by a machine that flattens or squeezes each breast.

Routine mammogram - a mammogram that is done for check-up purposes only. This type of mammogram is done for a woman who has not had symptoms or breast problems at the time of the routine mammogram.

Diagnostic mammogram - a mammogram that is done to evaluate a breast problem, such as a lump or pain in the breast.

1. Have you EVER HAD any type of mammogram?

Yes No Don't know

Skip to Question 14

2. About how old were you when you had your first mammogram?

years old

Don't know / don't remember

3. Have you ever had a ROUTINE MAMMOGRAM for check-up purposes only? (You did not have any symptoms or breast problems at the time of the routine mammogram.)

Yes No Don't know

Skip to Question 5

4. How often do you go for a ROUTINE MAMMOGRAM?

Every 6 months Every 3-5 years
 Every year Less often than every 5 years
 Every 2 years Never/only had 1 or 2

5. How many MAMMOGRAMS (ROUTINE or DIAGNOSTIC) have you had in the LAST 4 years?

1 More than 4
 2 Don't know / don't remember
 3
 4

The following five questions are about your two most recent **MAMMOGRAMS** (ROUTINE OR DIAGNOSTIC)

6. When did you have your MOST RECENT mammogram? Was it:

Less than 1 year ago 5 or more years ago
 1-2 years ago Never
 3-4 years ago

7. What was the MAIN reason you had this mammogram? (*Please check only one*)

Part of a routine physical exam/screening test
 Because of a specific breast problem

Please! Do not mark below this line

EDIT	CODE
------	------

0418605475

8. Which of the following sources paid for some or all of the cost of this mammogram? **(Mark all that apply)**

- Private health insurance
- Medicare
- Medicaid
- Free clinic
- Other source

Please specify:

9. When did you have your NEXT MOST RECENT mammogram (before the one in question 8)? Was it:

- Less than 1 year ago
- 1-2 years ago
- 3-4 years ago
- 5 or more years ago
- Have only had 1 mammogram

Skip to Question 11

10. What was the MAIN reason you had this NEXT MOST RECENT mammogram? **(Please check only one)**

- Part of a routine physical exam/screening test
- Because of a specific breast problem

11. Have you EVER had a mammogram where the results were not normal?

- Yes
- No
- Don't know

Skip to Question 14

12. Because of these results, what additional tests or surgery did you have? **(Mark all that apply)**

- None
- Another mammogram
- Ultrasound of the breast
- MRI of the breast
- Clinical breast exam by a doctor
- Needle biopsy (needle inserted into a breast lump)
- Tumor or lump was removed (lumpectomy)
- Breast removed / mastectomy

13. Did the surgery or additional tests indicate that you had cancer?

- Yes
- No
- Don't know

14. Have you ever had an operation or a biopsy to remove a lump from your breast that was found to be BENIGN OR NONCANCEROUS?

- Yes
- No
- Don't know

Skip to Question 16

15. How many of these operations have you had?

- operations
- Don't know

If you have had a mammogram in the past two years, skip to Question 17, on page 3.

16. If you HAVE NOT HAD a mammogram in the LAST TWO YEARS, what are the MOST IMPORTANT reasons?

(Please RANK the 3 most important reasons: 1 = most important, 2 = second most important, and 3 = third most important)

- No reason/never thought of it
- Didn't need it/didn't know I needed this type of test
- Doctor didn't order it/didn't say I needed it
- Haven't had any problems
- Put it off/didn't get around to it
- Too expensive/no insurance/cost
- Too painful, unpleasant, or embarrassing
- I'm too young
- Don't have a doctor
- Other reason:

17. When do you plan to have a mammogram in the future?

- Within the next 6 months
- In 6 months to 1 year
- In 1-2 years
- In 3-4 years
- In 5 or more years
- When my doctor recommends
- When I have a symptom
- Not planning to have one
- Don't know

18. In the PAST YEAR has a doctor or other health professional RECOMMENDED that you have a mammogram?

- Yes
- No
- Don't know

19. When did you have your MOST RECENT breast exam by a doctor or other health professional to check for lumps or other signs of breast cancer? Was it:

- Less than 1 year ago
- 1-2 years ago
- 3-4 years ago
- 5 or more years ago
- Never

20. Do you perform breast self-exams?

- No
- Yes, every month, always
- Yes, every month, but skip sometimes
- Yes, every so often

21. How old were you when you had your first menstrual period?

- 12 or younger
- 13
- 14
- 15 or older
- Not sure
- Never started my period

22. Have your menstrual periods stopped permanently? (**mark one**)

- No
- Yes, natural menopause
- Yes, following a surgical procedure
- Yes, following radiation or chemotherapy
- Yes, don't know cause
- Not sure

IF NO or NOT SURE, when was the first day of your last period?

		/			/				
M	M		D	D		Y	Y	Y	Y

IF YES, what was your age at your last period? years old

23. Are you currently taking a birth control pill or hormone replacement therapy, for example, Premarin, Prempro?

- Yes
- No
- I am not sure

Name of medication:

24. Are you currently taking anti-estrogen medicine, for example, Nolvadex (tamoxifen), or Evista (Raloxifene)?

- Yes
- No
- I am not sure

Name of medication:

Reason you were taking this medication:

25. Have you ever given birth?

- No
- Yes

How old were you when your first child was born? years old

26. When did you have your MOST RECENT Pap smear (test for cancer of the cervix)?

- Less than 1 year ago 5 or more years ago
 1-2 years ago Never
 3-4 years ago

HEALTH CARE

1. What is your current height? (to the nearest inch)

feet	inches	

2. What is your current weight? (to the nearest pound)

pounds			

3. Which of the following describes the area where you live?

- Rural Urban Suburban

4. For your non-emergency care, do you have a primary care physician or a place you go for medical care?

- No Yes

5. When you were growing up, did your mother go to a doctor for routine physical examinations? *(please mark only one)*

- Never Every year
 Rarely Don't know
 Some of the time

6. Does/did your mother get ROUTINE mammograms? *(please mark only one)*

- Never Every year
 Rarely Don't know
 Some of the time

7. Have any blood relatives been diagnosed with breast cancer?

- | Mother | Sister(s) | Daughter(s) |
|-----------------------------------|------------------------------------|------------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> No | <input type="checkbox"/> No |
| <input type="checkbox"/> Yes | <input type="checkbox"/> One | <input type="checkbox"/> One |
| <input type="checkbox"/> Not sure | <input type="checkbox"/> 2 or more | <input type="checkbox"/> 2 or more |
| | <input type="checkbox"/> Not sure | <input type="checkbox"/> Not sure |

The following questions ask about your views on mammograms.

		1	2	3	4	5
	Strongly disagree					
	Disagree					
	Don't agree or disagree					
	Agree					
	Strongly agree					
1. If I have a breast exam from a doctor or nurse, I don't need to have a mammogram.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Those people who are close to me will benefit if I have a mammogram.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Mammograms have a high chance of leading to breast surgery that is not needed.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would be more likely to have a mammogram if my doctor told me how important it was.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Having a mammogram every year or two will give me a feeling of control over my health.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Once you have a couple of mammograms that are normal, you don't need to have any more for a few years.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Regular mammograms give you peace of mind about your health.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Mammograms are necessary even when there is no history of breast problems in a family.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. If a mammogram finds something, then whatever is there will be too far along to do anything about it anyway.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Mammograms are most helpful when you have one every year or two.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I would probably not have a mammogram if my doctor seemed to doubt that I really needed one.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. If I eat a healthy diet, I will lower my risk of getting cancer far enough that I probably do not need to have a mammogram		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I would probably not have a mammogram unless I had some breast symptoms or discomfort.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please! Do not mark below this line

The next few questions ask your views about your health care. There are no right or wrong answers - please answer how you feel.

	Extremely				
	Quite a bit				
	Moderately				
	A little bit				
	Not at all				
	1	2	3	4	5
1. Some people are very concerned about their health, while others are not as concerned. How concerned are you about your own health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Some people are very interested in going to the doctor for a general physical exam to check on their health, while others are not as interested. How interested are you about going to a doctor for "routine medical check-ups"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you ever feel uncertain about your future health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you ever worry about being called a complainer or a hypochondriac?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you ever worry that a problem with your health will be discovered if you go to a doctor for a routine check-up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you ever worry about getting cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue on Page 6

The statements below describe beliefs that some people have about the risk of getting breast cancer. For each one, please mark the box that best describes what you think about the statement.

- | | False | True | Not sure |
|---|--------------------------|--------------------------|--------------------------|
| 1. I think I am more likely to get breast cancer than other people I know. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. It is very likely that I will get breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I may get other things, but I don't think I'll get breast cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I don't have to worry about getting breast cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am too young to get breast cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. A lump in the breast is nearly always a sign of breast cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

The average lifetime risk for breast cancer for women is 1 in 9, or 11 percent. We are interested in what you think about your own breast cancer risk.

7. How would you estimate your own chance of getting breast cancer in the future?
- Much more than the average woman Less than the average woman
- More than the average woman Much less than the average woman
- Same as the average woman

8. On a scale from 0 to 100 percent, what do you think your chance is of developing breast cancer in your lifetime?

percent

9. From which of the following sources have you obtained information about your level of risk for breast cancer?
(mark all that apply)

- Friends and/or relatives Your primary care doctor
- Newspapers and/or magazines Internet
- Television Other; please specify:

10. Cancer chemoprevention research studies are being conducted to identify medicines (for example, finasteride, aspirin, calcium, tamoxifen, etc.) to prevent breast, colon, and other cancers. Have you ever participated in a cancer chemoprevention study?

- Yes → *What is the name of the medication(s) tested?*
- No
- I don't know/don't remember

IF NO, would you consider taking part in a cancer chemoprevention study? Yes No

Please! Do not mark below this line

We are interested in how people respond when they confront stressful experiences. By "stressful" we mean situations that are difficult or troubling to you, either because they upset you or because it takes a lot of effort to deal with them. There are many ways to deal with stress. We would like you to indicate what you generally do, feel, and think when you experience stressful situations. Obviously, different experiences may bring out different responses, but please think about what you *usually* do when you are under a lot of stress.

	I usually do this a lot			
	I usually do this a medium amount			
	I usually do this a little bit			
	I usually don't do this at all			
	1	2	3	4
1. I turn to work or other substitute activities to take my mind off things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I concentrate my efforts on doing something about it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I say to myself "this isn't real."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I admit to myself that I can't deal with it, and quit trying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I get used to the idea that it happened.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I daydream about things other than this.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I make a plan of action.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I accept that this has happened and that it can't be changed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I just give up trying to reach my goal.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I take additional action to try to get rid of the problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I refuse to believe that it has happened.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I sleep more than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I try to come up with a strategy about what to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I give up the attempt to get what I want.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I think about how I might best handle the problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I pretend that it hasn't really happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I go to movies or watch TV, to think about it less.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I accept the reality of the fact that it happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I take direct action to get around the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I reduce the amount of effort I'm putting into solving the problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I learn to live with it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I think hard about what steps to take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I act as though it hasn't even happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I do what has to be done, one step at a time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please! Do not mark below this line

Each item below is a statement about your health with which you may agree or disagree. For each item please mark the box that best describes how much you agree or disagree with that statement.

This is a measure of your personal beliefs; there are no right or wrong answers.

	Strongly disagree					
	Moderately disagree		Slightly disagree		Slightly agree	
	Moderately agree		Slightly agree		Strongly agree	
	1	2	3	4	5	6
1. If I get sick, it is my own behavior which determines how soon I get well again	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. No matter what I do, if I am going to get sick, I will get sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Having regular contact with my physician is the best way for me to avoid illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Most things that affect my health happen to me by accident.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Whenever I don't feel well, I should consult a medically trained professional.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I am in control of my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My family has a lot to do with my becoming sick or staying healthy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. When I get sick, I am to blame.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Luck plays a big part in determining how soon I will recover from an illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Health professionals control my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My good health is largely a matter of good fortune	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. The main thing that affects my health is what I myself do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. If I take care of myself, I can avoid illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. No matter what I do, I'm likely to get sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. If it's meant to be, I will stay healthy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. If I take the right actions, I can stay healthy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Regarding my health, I can only do what my doctor tells me to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

We welcome your comments:

THANK YOU!

Please include this form in the envelope provided and mail to:
LONG-TERM FOLLOW-UP STUDY
MAYO MAIL CODE 715
420 DELAWARE ST SE
MINNEAPOLIS MN 55455-9940

Please! Do not mark below this line