

Cancer Research Network

Prophylactic Mastectomy Outcomes Study Survey

Notes for Potential Users

The survey on the following pages was used for the study described in the following publications:

- Geiger AM, Nekhlyudov L, Herrinton LJ, Rolnick S, Greene SM, West CN, Harris E, Elmore JG, Altschuler A, Fletcher SW, Emmons K. Quality of life after bilateral prophylactic mastectomy. *Ann Surg Oncol* (in press).
- Geiger AM, West CN, Nekhlyudov LN, Herrinton LJ, Liu AI, Altschuler A, Rolnick SJ, Harris EL, Greene SM, Elmore JG, Emmons K, Fletcher SW. Contentment with quality of life among breast cancer survivors with and without contralateral prophylactic mastectomy. *J Clin Oncol* 2006;24:1350-1356.
- Greene SM, Geiger AM, Harris E, Altschuler A, Nekhlyudov L, Barton M, Rolnick SJ, Fletcher S. Impact of IRB requirements on a multi-site Cancer Research Network study. *Ann Epidemiol* 2006;16:275-278.
- Nekhlyudov L, Bower M, Herrinton L, Altschuler A, Greene S, Rolnick C, Elmore J, Harris E, Liu IA, Emmons KM, Fletcher SW, Geiger AM. Women's decision-making roles regarding contralateral prophylactic mastectomy. *J Natl Cancer Inst Monogr* 2005;35:55-60.

We offer the survey for review by interested parties. We caution any potential users of any portions of the survey to consult the documentation of question sources at the end of this file to ensure appropriate use and attribution. Should any items developed or adapted by our group be used in another survey, we would appreciate citation of one or both of the first two publications listed above.

Any questions about the survey should be directed to Ann Geiger at ageiger@wfubmc.edu.

Living with Breast Cancer Risk: Survey of Experiences

We appreciate your taking time to participate in our research study by completing and returning this survey. Remember that completing this survey is voluntary. You may choose to skip questions that make you uncomfortable. Your participation in this study does not affect your medical care or coverage in any way. We will not share your specific answers with anyone else and no information identifying you will appear in study reports.

Please check or circle the one best answer to each of the following questions, unless instructed otherwise.

Your Health

1. In general, would you say your health is:

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very Good
- 5 Excellent

2. Has a doctor or other health care provider ever told you that you have: (check all that apply)

- 1 Cancer other than breast cancer
- 2 Depression or other psychological or mental condition
- 3 Diabetes
- 4 Hypertension/high blood pressure or heart disease
- 5 Osteoporosis
- 6 Overweight
- 9 Other, please specify: _____
- 0 None

Your Breast Cancer Experience and Thoughts

3. Have you ever been diagnosed with breast cancer including ductal carcinoma in situ (DCIS)?

- 0 No
- 1 Yes, please provide date of first diagnosis ____ / ____ / ____
- 8 Not sure

4. How would you describe your concern about developing breast cancer or, if you have had breast cancer, getting breast cancer again?

- 4 Very concerned
- 3 Concerned
- 2 Not very concerned
- 1 Not concerned at all

5. Below is a list of statements that describe reactions some women have to thinking about breast cancer. Each woman's experience is different so you may or may not have these concerns.

Please circle one number to indicate how frequently each comment about breast cancer was true for you during the past 30 days before you received this survey.

	FREQUENCY			
	Not at all	Rarely	Some-times	Often
a. I thought about breast cancer when I didn't expect to.	1	2	3	4
b. I had to keep myself from getting upset when I thought about breast cancer or was reminded of breast cancer.	1	2	3	4
c. I had dreams about breast cancer.	1	2	3	4
d. I avoided things that remind me of breast cancer.	1	2	3	4
e. I avoided conversations about breast cancer.	1	2	3	4
f. I was aware that I have a lot of feelings about breast cancer, but I didn't deal with them.	1	2	3	4
g. I tried not to think about breast cancer.	1	2	3	4

Your Life Right Now

6. Below is a list of statements that describe aspects of women's lives, including thoughts about your body and sexuality.

Please circle one number to indicate how true each statement has been for you during the past 30 days.

	FREQUENCY				
	Not At All	A Little Bit	Some-what	Quite A Bit	Very Much
a. I am able to enjoy life.	1	2	3	4	5
b. I am content with the quality of my life right now.	1	2	3	4	5
c. I feel self-conscious about my appearance.	1	2	3	4	5
d. I am happy with my current weight.	1	2	3	4	5
e. I am satisfied with my appearance when dressed.	1	2	3	4	5
f. I find it difficult to look at myself naked.	1	2	3	4	5
g. I am embarrassed for others to see my body.	1	2	3	4	5
h. I am able to feel like a woman.	1	2	3	4	5
i. I feel sexually attractive.	1	2	3	4	5
j. I am satisfied with my sex life.	1	2	3	4	5

7. Below is a list of statements that describe moods.

Please circle the number for each statement which best describes how often you felt or behaved this way <u>during the past 30 days</u> .	FREQUENCY			
	Rarely or None of the Time	Some or Little of the Time	Occasionally or a Moderate Amount of the Time	Most or All of the Time
a. I was bothered by things that usually don't bother me.	1	2	3	4
b. I did not feel like eating; my appetite was poor.	1	2	3	4
c. I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4
d. I felt that I was just as good as other people.	1	2	3	4
e. I had trouble keeping my mind on what I was doing.	1	2	3	4
f. I felt depressed.	1	2	3	4
g. I felt that everything I did was an effort.	1	2	3	4
h. I felt hopeful about the future.	1	2	3	4
i. I thought my life had been a failure.	1	2	3	4
j. I felt fearful.	1	2	3	4
k. My sleep was restless.	1	2	3	4
l. I was happy.	1	2	3	4
m. I talked less than usual.	1	2	3	4
n. I felt lonely.	1	2	3	4
o. People were unfriendly.	1	2	3	4
p. I enjoyed life.	1	2	3	4
q. I had crying spells.	1	2	3	4
r. I felt sad.	1	2	3	4
s. I felt that people disliked me.	1	2	3	4
t. I could not "get going."	1	2	3	4

A Few Details About You

8. What is your age?

___ ___ years

9. To what race/ethnic group do you belong? Please check all that apply.

- 1 Asian or Pacific Islander, please specify: _____
- 2 Black or African American
- 3 Hispanic/Latino, please specify: _____
- 4 Native American or Alaskan Native
- 5 White or Caucasian
- 9 Other, please specify: _____

10. What is the highest level of education you have completed?

- 1 Less than or some high school
- 2 High school or GED
- 3 Trade or technical school
- 4 Junior college, or some college
- 5 College graduate
- 6 Postgraduate work or degree

11. What is your current marital status?

- 1 Married
- 2 Living together but unmarried
- 3 Separated or divorced
- 4 Widowed
- 5 Single, never married

12. What is your current height?

___ feet ___ inches or ⁸⁸⁸ Not sure

13. What is your current weight?

_____ pounds or ⁸⁸⁸ Not sure

14. On what date did you complete this questionnaire?

___/___/___ (month/day/year)

If you **have** had one or both breasts surgically removed to **prevent** breast cancer, please continue with the questions below. Removal of a breast to treat cancer does not qualify.



If you **have not** had one or both breasts removed to **prevent** breast cancer, or have only had one or both breasts removed to **treat** breast cancer, please go to question 24 on the last page.



For Women who Have Had Surgery to Prevent Breast Cancer (Prophylactic Mastectomy)

Throughout this section we use the phrase **prophylactic mastectomy** to describe the removal of one or both breasts to prevent breast cancer.

15. Before your prophylactic mastectomy, how would you have described your concern about developing breast cancer?

- 4 Very concerned
- 3 Concerned
- 2 Not very concerned
- 1 Not concerned at all

16. What were your reasons for having a prophylactic mastectomy? Please check all that apply.

- 1 Uncomfortably large breasts
- 2 Concerns about appearance
- 3 Unclear mammogram results
- 4 Unclear pathology results
- 5 Breast cancer or ductal carcinoma in situ (DCIS) in one breast
- 6 Lobular carcinoma in situ (LCIS)
- 7 Fibrocystic breasts
- 8 Family history of breast cancer
- 9 Prevent breast cancer
- 0 Other, please specify: _____

17. At the time of your prophylactic mastectomy, what was your marital status?

- 1 Married
- 2 Living together but unmarried
- 3 Separated or divorced
- 4 Widowed
- 5 Single, never married


18. Which one statement best describes the decision about your prophylactic mastectomy?

- 1 I made the final decision to have surgery.
- 2 I made the final decision to have surgery after seriously considering my doctor's opinion.
- 3 My doctor and I shared responsibility for the final decision to have surgery.
- 4 My doctor made the final decision about my surgery, but seriously considered my opinion.
- 5 My doctor made the final decision about my surgery.

19. Thinking back to six months after your prophylactic mastectomy, how satisfied were you with your decision to have the surgery?

- 1 Very dissatisfied
- 2 Dissatisfied
- 3 Satisfied
- 4 Very satisfied

20. Did you have breast reconstruction after your prophylactic mastectomy? Breast reconstruction is a surgical procedure in which the breasts are recreated using implants or tissue from the body.

0 No. Please skip to question 21. 

- 1 Yes, done in a separate surgery after the prophylactic mastectomy
 - 2 Yes, done along with prophylactic mastectomy
- } Please continue with the next question (20a).

20a. How satisfied were you with the timing of your reconstruction relative to your prophylactic mastectomy?

- 1 Very dissatisfied
- 2 Dissatisfied
- 3 Satisfied
- 4 Very satisfied

20b. Have you had surgery to revise or repair your reconstruction?

- 0 No
- 1 Yes, one or two times
- 2 Yes, multiple times

21. All things considered, how satisfied are you with the medical care you received at the time of your prophylactic mastectomy?

- 1 Very dissatisfied
- 2 Dissatisfied
- 3 Satisfied
- 4 Very satisfied

22. Overall, how satisfied are you now with your decision to have prophylactic mastectomy?

- 1 Very dissatisfied
- 2 Dissatisfied
- 3 Satisfied
- 4 Very satisfied

23. What one thing do you wish you had known before your prophylactic mastectomy?

Final Questions for Everyone

24. Is there anything else you would like to share with us?

25. Please check here if you would like a copy of the results when available (approximately one year).

Thank you very much for completing the survey!

Please mail it to the coordinating center in the envelope we provided, or to:

[ADDRESS INFORMATION REMOVED]

Please refer to your cover letter for contact people who can answer questions about this study.

Cancer Research Network

Prophylactic Mastectomy Outcomes Study Survey

Documentation of Question Sources

Question #	Source
1	MOS SF-36 ¹
2	Created by our team
3	Used in prior survey ²
4, 15	Created by our team
5a-g	Revised Impact of Event Scale ³ (time reference modified from 7 to 30 days, number of statements reduced, some statements reworded)
6a,b,g	FACT-B ⁴ (question g modified)
6c,d,e	Hopwood ⁵ (questions on original instrument modified to statements)
6f	CARES ⁶ (modified to remove reference to breast cancer)
6h	FACT-B ⁴
6j	MOS ⁷
7a-t	CES-D ⁸
8–11	BRFSS ⁹ (modified for self-administration and to combine race/ethnicity into one question)
12-13	Used in prior survey ²
14, 16	Created by our team
17	BRFSS ⁹ (modified for retrospective use)
18	Degner and Sloan ¹⁰ (modified to pertain to prophylactic mastectomy surgery)
19, 21, 22	Used in prior survey ¹¹ (modified to pertain to prophylactic mastectomy surgery)
20a-b	Created by our team
21	Created by our team
23 – 25	Created by our team

¹Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Med Care* 1992;30:473-83.

²Geiger AM. Do Breast Cancer Risk Factors Vary by Dual Receptor Status? KPSC IRB #2134.

³Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. *Psychosom Med* 1979;41:209-18.

⁴Brady MJ, Cella DF, Mo F, Bonomi AE, Tulsky DS, Lloyd SR, Deasy S, Cobleigh M, Shiimoto G. Reliability and validity of the Functional Assessment of Cancer Therapy-Breast quality-of-life instrument. *J Clin Oncol* 1997;15:974-86.

⁵Hopwood P, Fletcher I, Lee A, Al Ghazal S. A body image scale for use with cancer patients. *Eur J Cancer* 2001;37:189-97.

⁶Ganz PA, Schag CA, Lee JJ, Sim MS. The CARES: a generic measure of health-related quality of life for patients with cancer. *Qual Life Res* 1992;1:19-29.

⁷Sherbourne CD. Social functioning: sexual problems measures. In: Stewart AL, Ware JE, eds. *Measuring functioning and well-being: the Medical Outcomes Study approach*. Durham, NC: Duke University Press, 1992:194-204.

⁸Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1977; 1: 385-401.

⁹Behavioral Risk Factor Surveillance System, 2000 Questionnaire. At <http://www.cdc.gov/brfss/>.

¹⁰Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol* 1992;45:941-50.

¹¹Geiger AM, Mullen ES, Sloman PA, Edgerton BW, Petitti DB. Evaluation of a breast cancer patient information and support program. *Eff Clin Pract* 2000;3:157-65. KPSC IRB #2126.