

Breast Density Awareness
September, 2012

Q1. About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.

- Within the past year (anytime less than 12 months ago)1
- Within the past 2 years (1 year but less than 2 years ago)2
- Within the past 5 years (2 years but less than 5 years ago)3
- 5 or more years ago.....4

Q2. What kind of place do you USUALLY go to when you need routine or preventive care, such as a physical examination or check-up?

- Clinic or health center1
- Doctor's office or HMO.....2
- Hospital emergency room3
- Hospital outpatient department4
- [TEXT BOX]**Some other place, please specify:5
- I do not get routine or preventive care.....6

Q3. We are interested in learning what women like you generally think makes women more or less likely to develop breast cancer. This is not a test. We are just interested in what you think.

Please indicate whether you think that the following factors influence the likelihood of a woman getting breast cancer at some point in her life. Please rate each as: does not put you at increased risk, puts you at a small increased risk, or puts you at a large increased risk.

Does not put you at increased risk	Puts you at a small increased risk	Puts you at a large increased risk
1	2	3

- a. Having a mom, sister or daughter who has been diagnosed with breast cancer
- b. Having an aunt, niece, grandmother or half-sister who has been diagnosed with breast cancer
- c. Being overweight
- d. A diet rich in fruits and vegetables
- e. Not exercising or not being active
- f. Drinking alcohol in excess
- g. Drinking alcohol in moderation
- h. Being a smoker
- i. Having breasts that are mostly fat on a mammogram
- j. Having had a breast biopsy (or piece of tissue removed in the breast) in the past
- k. Having first menstrual period after the age of 15
- l. Having children
- m. Having the first child after age 30
- n. Breastfeeding
- o. Using oral contraception ("the pill")
- p. Onset of menopause at a later age
- q. Having breasts that are mostly dense on a mammogram
- r. Use of hormone therapy for postmenopausal symptoms
- s. Having a BRCA1 or BRCA2 gene mutation
- t. Using antiperspirant/talc powder under your arms
- u. Experience injury/trauma to the breast (enough to cause a bruise)

Q4. How old were you when you had your first menstrual period?

7-11 years old.....	1
12-13 years old.....	2
14 years or older.....	3
Don't know.....	4

Q5. Have your menstrual periods stopped permanently (not including pregnancy)?

No.....	1
Not sure, periods less frequent.....	2
Yes.....	3

[IF Q5 = 3]

Q5A. Why did your menstrual periods stop?

Periods stopped naturally.....	1
My uterus and both ovaries were surgically removed (hysterectomy and bilateral oophorectomy).....	2
My uterus was removed but I still have at least one ovary.....	3

[IF Q5 = 3]

Q5B. At what age did your periods stop?

[NUMBER BOX] Years

[CHECK BOX] Don't know

Q6. Have you ever been pregnant?

No.....	1
Yes.....	2

[IF Q6 = 2]

Q6A. How many times were you pregnant? (Please include all stillbirths, miscarriages, ectopic pregnancies, tubal pregnancies, induced abortions, and current pregnancies, if applicable)

[NUMBER BOX] Number of times pregnant

[IF Q6 = 2]

Q6B. How many of these pregnancies resulted in the live birth of a child? (count the birth of twins as 1)

[NUMBER BOX] Number of pregnancies

[IF Q6B >= 1]

Q6C. How old were you when your first child was born?

Less than 20 years old.....	1
20-24 years old.....	2
25-29 years old.....	3
30 years or older.....	4
Don't know.....	5

Q7. Have you ever used birth control pills/oral contraception ("the pill") for contraceptive purposes?

No.....	1
Yes, currently taking.....	2
Yes, in the past.....	3

Q8. Have you ever taken hormone replacement therapy other than birth control pills (e.g., estrogen, estrogen/progesterone combination)?

No.....	1
Yes, currently taking.....	2
Yes, in the past.....	3

Q9. Have you been tested for a BRCA1 or BRCA2 genetic mutation?
No1
Yes2

[IF Q9 = 2]

Q9A. Do you have a genetic mutation in one of these genes?
Yes1
No2
Don't know3

Q10. A mammogram is an x-ray of each breast to look for breast cancer. Have you ever had a mammogram?
No1
Yes2

[IF Q10 = 2]

Q10A. How old were you when you had your first mammogram?
Less than 40 years old1
40-44 years old2
45-49 years old3
50-54 years old4
55-59 years old5
60 years or older6
Don't know7

[IF Q10 = 2]

Q10B. When was your last (most recent) mammogram
Within the past year1
Between one and two years ago2
Between two and five years ago3
More than five years ago4
Don't remember5

[IF Q10 = 2]

Q10C. How many total mammograms do you think you've had in your lifetime?
11
2-42
5-93
10 or more4

[IF Q10 = 2]

Q10D. Have you ever been called back for additional tests after any mammogram?
No1
Yes2

[IF Q10D = 2]

Q10DI. How often have you been called back for additional tests?
Only once1
Occasionally2
Most of the times that I have had a
mammogram3
Every time that I have had a mammogram4

[IF Q10 = 2]

Q10E. Have you ever had a breast biopsy?
No1
Yes2

[IF Q10E = 2]

Q10E1. How many breast biopsies have you had?

- 11
- 22
- 33
- 4 or more4

[IF Q10 = 2]

Q10F. Where did you have your most recent mammogram?

- Hospital setting (radiology department)1
- Free-standing imaging center.....2
- Specialty Breast Clinic (that offers only breast care and mammograms)3
- Mobile mammography unit4
- [TEXT BOX]**Other, please specify:.....5

[IF Q10 = 2] [MULTIPLE RESPONSES ALLOWED]

Q10G. Thinking again about your most recent mammogram, how were your results given to you?

- 1. Letter
- 2. Telephone call
- 3. Meeting with doctor
- 4. **[TEXT BOX]**Other, please specify:

Q11. Including yourself, has anyone in your family been diagnosed with breast cancer?

- No1
- Yes2

[IF Q11 = 2] [MULTIPLE RESPONSES ALLOWED]

Q11A. Who was this?

- 1. Self
- 2. Mother
- 3. Grandmother
- 4. Aunt
- 5. Sister
- 6. Daughter
- 7. Niece
- 8. **[TEXT BOX]**Other, please specify:

[IF Q11A = 1]

Q11AI. At what age were you first diagnosed with breast cancer?

Age: **[NUMBER BOX]**

[IF Q11A = 2]

Q11AI2. At what age was your mother first diagnosed with breast cancer?

Age: **[NUMBER BOX]**

[IF ANY Q11A_3 TO Q11A_8 = 1; ASK FOR EACH SELECTION MADE IN Q11A]

Q11AII. How many **[IF Q11A = 3:of your grandmothers/IF Q11A = 4:of your aunts/IF Q11A = 5:of your sisters/IF Q11A = 6:of your daughters/IF Q11A = 7:of your nieces/IF Q11A = 8:others/IF Q11A = 8 AND TEXT ENTERED:others ("INSERT TEXT ENTERED IN Q11A_8")]** have been diagnosed with breast cancer?

[IF ANY Q11A_3 TO Q11A_8 = 1; ASK FOR EACH SELECTION MADE IN Q11A, HAVE Q11AIII FOLLOW Q11AII]

Q11AIII. How old was **[IF Q11A = 3:your grandmother/IF Q11A = 4: your aunt/IF Q11A = 5: your sister/IF Q11A = 6: your daughter/IF Q11A = 7: your niece/IF Q11A = 8:this other person/IF Q11A = 8**

AND TEXT ENTERED:this other person (“**INSERT TEXT ENTERED IN Q11A_8**”) when she was diagnosed with breast cancer? **[IF Q11AII > 1 OR Q11AII IS REFUSED:**If you have more than one **[IF Q11A = 3:grandmother/IF Q11A = 4:aunt/IF Q11A = 5:sister/IF Q11A = 6:daughter/IF Q11A = 7:niece/IF Q11A = 8:other person]**, what was the earliest age that **[IF Q11A = 3: your grandmother/IF Q11A = 4: your aunt/IF Q11A = 5: your sister/IF Q11A = 6: your daughter/IF Q11A = 7:your niece/IF Q11A = 8: this other person]** was diagnosed with breast cancer?]

Age: **[NUMBER BOX]**

Q12. Including yourself, has anyone in your family been diagnosed with ovarian cancer?

No1
Yes2

[IF Q12 = 2] [MULTIPLE RESPONSES ALLOWED]

Q12A. Who was this?

1. Self
2. Mother
3. Grandmother
4. Aunt
5. Sister
6. Daughter
7. Niece
8. **[TEXT BOX]**Other, please specify:

[IF Q12A = 1]

Q12AI. At what age were you first diagnosed with ovarian cancer?

Age: **[NUMBER BOX]**

[IF Q12A = 2]

Q12AI. At what age was your mother first diagnosed with ovarian cancer?

Age: **[NUMBER BOX]**

[IF ANY Q12A_3 TO Q12A_8 = 1; ASK FOR EACH SELECTION MADE IN Q12A]

Q12AII. How many **[IF Q12A = 3:of your grandmothers/IF Q12A = 4:of your aunts/IF Q12A = 5:of your sisters/IF Q12A = 6:of your daughters/IF Q12A = 7:of your nieces/IF Q12A = 8:others/IF Q12A = 8 AND TEXT ENTERED:**others (“**INSERT TEXT ENTERED IN Q12A_8**”) have been diagnosed with ovarian cancer?

[IF Q12A_3 TO Q12A_8 = 1; ASK FOR EACH SELECTION MADE IN Q12A, HAVE Q12AIII FOLLOW Q12AII]

Q12AIII. How old was **[IF Q12A = 3:your grandmother/IF Q12A = 4:your aunt/IF Q12A = 5:your sister/IF Q12A = 6:your daughter/IF Q12A = 7:your niece/IF Q12A = 8:this other person/IF Q12A = 8 AND TEXT ENTERED:**this other person (“**INSERT TEXT ENTERED IN Q12A_8**”) when she was diagnosed with ovarian cancer? **[IF Q12AII > 1 OR Q12AII IS REFUSED:**If you have more than one **[IF Q12A = 3:grandmother/IF Q12A = 4:aunt/IF Q12A = 5:sister/IF Q12A = 6:daughter/IF Q12A = 7:niece/IF Q12A = 8:other person]**, what was the earliest age that **[IF Q12A = 3:your grandmother/IF Q12A = 4:your aunt/IF Q12A = 5:your sister/IF Q12A = 6:your daughter/IF Q12A = 7:your niece/IF Q12A = 8:this other person]** was diagnosed with ovarian cancer?]

Age: **[NUMBER BOX]**

Q13. Have you ever heard of something called breast density?

No1
Yes2
Not sure3

[IF Q13 = 2]

Q14. Have you ever discussed your own breast density with a health care provider?
No1
Yes2

[IF Q14 = 2]

Q14A. What led to your discussion about breast density?
I asked my health care provider about my breast density1
My health care provider brought up the topic of density with me2
[TEXT BOX]Something else, please specify:3

[IF Q14 = 2]

Q14B. Do you have dense breasts?
No.....1
Yes2

[IF Q14B = 2] [MULTIPLE RESPONSES ALLOWED]

Q14BI. Who was it that told you that you have dense breasts?
1. The health care provider who ordered my mammogram
2. A radiologist who read my mammogram/my mammogram report
3. An imaging/x-ray technician
4. **[TEXT BOX]**Someone else, please specify:

[IF Q14B = 2]

Q14BII. Do you know your breast density category or percentage?
Yes1
No2
Not sure/Don't remember3

[IF Q13 = 2]

Q15. Have you heard about breast density from sources other than a health care provider?
No.....1
Yes2

[IF Q15 = 2] [MULTIPLE RESPONSES ALLOWED]

Q15A. From what other sources have you heard about breast density?
1. Book, magazine, newspaper
2. Radio or television
3. Internet
4. A friend or family member
5. **[TEXT BOX]**Some other source, please specify:

Q16. If a woman has dense breasts, what impact does this have on the ability of a mammogram to correctly detect cancer?

Dense breasts make it easier to see cancer on a mammogram1
Dense breasts do not impact the ability to see cancer on a mammogram2
Dense breasts make it more difficult to see cancer on a mammogram3
I don't know4

Q17. If you were told that the chance of your mammogram finding a cancer if one was present was no better than a flip of a coin (50% chance), how likely would you be to get mammograms in the future?

Very likely1
Somewhat likely2
Not at all likely3

Q18. Again, imagine that the chance of your mammogram finding a cancer was no better than a flip of a coin. Would you want to have an additional screening test of the breast that may find cancers not seen on the mammogram if it improved the chance of finding cancer?

- Yes, only if there was no additional cost to me.....1
- Yes, even if there was a small cost to me (like a co-pay)2
- Yes, even if there was a large cost to me3
- No4

[INSERT NO BACK]

Q19. Doctors and scientists agree that having dense breasts increases the risk of breast cancer and makes it harder to see cancer on a mammogram. But they do not agree at this time on whether women with dense breasts benefit from having additional types of breast imaging tests in addition to regular mammograms. And, at this time, there is no treatment to reduce your breast density. Would you still want to know if you have dense breasts?

- Yes1
- No2
- Unsure/No opinion3

Q20. Please indicate the extent of your agreement or disagreement with the following statements. Knowing my breast density does/would make me feel:

Strongly agree	Agree	Disagree	Strongly disagree
1	2	3	4

- a. Anxious (uneasy, worried, nervous)
- b. Informed to make decisions regarding my breast health
- c. Confused about what to do regarding my breast health

Q21. It is a federal law that all mammography centers must notify women of their mammogram interpretation by letter. Do you think that the letter should include information about your breast density?

- Yes1
- No2
- Unsure/No opinion3

[STANDARD KN QUESTIONS]

Q1. In general, would you say your physical health is...

- Excellent1
- Very good2
- Good.....3
- Fair4
- Poor5

Q43. Below is a list of the different kinds of health plans or health insurance people have, including those provided by the government. Please indicate whether or not you are currently covered by each type of insurance or not.

	Covered	Not covered	Not sure

- Health insurance through your or someone else's employer or union
- Medicare, a government plan that pays health care bills for people aged 65 or older and for some disabled people
- Medicaid or any other state medical assistance plan for those with lower incomes
- Health insurance that you bought directly
- Health insurance from some other source