

PROMOTING INFORMED DECISION MAKING ABOUT MAMMOGRAPHY

24-Month Follow-up Survey

I'll be asking you questions about your health and health practices.

Mammography History

First, I'd like to ask you about mammograms.

1.1 Since we last spoke on <LastSurvey>, have you had a mammogram?

1=Yes 2=No 7=Refused 8=Don't Know

If 1.1= Yes → 1.2a
No, Refused, Don't Know → 1.4a

1.2a In what month and year was your most recent mammogram?

Month _____	Day <u>1</u> _____	Year _____
Est _____	Est <u>X</u> _____	Est _____
Seas: Spr Sum Fall Win		Real _____
Real _____		

REF=Refused DNK=Don't Know

1.2b Did you have this mammogram at a Blue Cross and Blue Shield network provider facility?

1=Yes 2=No 7=Refused 8=Don't Know

1.3a Did you have another mammogram since <LastSurvey>?

1=Yes 2=No 7=Refused 8=Don't Know

If 1.3a= Yes → 1.3b
No, Refused, Don't Know → 1.4a

1.3b In what month and year did you have it?

Month _____	Day <u>1</u> _____	Year _____
Est _____	Est <u>X</u> _____	Est _____
Seas: Spr Sum Fall Win		Real _____
Real _____		

REF=Refused

DNK=Don't Know

1.3c Did you have this mammogram at a Blue Cross and Blue Shield network provider facility?

1=Yes 2=No 7=Refused 8=Don't Know

A breast biopsy refers to the surgical removal of a sample of breast tissue for the purpose of determining the absence or presence of cancer. This is not an aspiration where a needle is inserted into the breast to remove fluid.

1.4a Since we last spoke on <LastSurvey>, how many benign (non-cancer) breast biopsies have you had? *(Do not read choices. Verify this DOES NOT include biopsies prior to date of last survey.)*

- 1. 1
- 2. 2
- 3. 3
- 4. 4 or more
- 5. None – cancer was found
- 6. Have not had a breast biopsy since we last spoke

7=Refused

8=Don't Know

If 1.4a= 1,2,3,4, Refused, Don't Know → 1.4b

5 → If had breast cancer, do not stop interview. Ask sections 6, 7, 13, 14, 15, and 16.

6 → Skip to question 2.1 or 2.2

1.4b Were you ever told that this biopsy/these biopsies showed atypical hyperplasia?
*(A benign (non-cancer) condition in which breast tissue has certain abnormal features.)
(Verify this DOES NOT include biopsies prior to date of their last survey.)*

1=Yes 2=No 7=Refused 8=Don't Know

1.4c In what month and year did you have this biopsy/these biopsies?

Biopsy 1:

Month _____(1-12) 97=REF 98=DNK

Year 1997 1998 1999 2000
9997=REF 9998=DNK

Biopsy 2:

Month _____(1-12) 97=REF 98=DNK

Year 1997 1998 1999 2000
9997=REF 9998=DNK

Biopsy 3:

Month _____(1-12) 97=REF 98=DNK

Year 1997 1998 1999 2000
9997=REF 9998=DNK

Biopsy 4:

Month _____(1-12) 97=REF 98=DNK

Year 1997 1998 1999 2000
9997=REF 9998=DNK

Intentions

Please mention: "Within a year" includes the time now until 12 months from now.

For women in 50's:

2.1 Which of the following best describes you? Are you...

(Read choices 1-3 only)

1. Thinking about having a mammogram within a year
2. Definitely planning on having a mammogram within a year
3. Not thinking about having a mammogram within a year
4. Depends on your doctor's recommendation/Whatever your doctor says
5. Only have a mammogram if you have symptoms

7=Refused

8=Don't Know

Please mention: "Within 1-2 years" includes the time now until 24 months from now.

For women in 40's:

2.2 Which of the following best describes you? Are you...

(Read choices 1-3 only)

1. Thinking about having a mammogram within 1-2 years
2. Definitely planning on having a mammogram within 1-2 years
3. Not thinking about having a mammogram within 1-2 years
4. Depends on your doctor's recommendation/Whatever your doctor says
5. Only have a mammogram if you have symptoms

7=Refused

8=Don't Know

QUESTIONS 2.3A & 2.3B - ONLY for women who had a mammogram since last survey:

2.3a Since we last spoke on <LastSurvey>, have you had an abnormal mammogram, or a mammogram that required a follow-up procedure, but turned out **not** to be cancer? (*Verify it DOES NOT include mammograms prior to date of last survey.*)

1=Yes

2=No

7=Refused

8=Don't Know

If 2.3a= Yes → 2.3b

No, Refused, Don't Know → 2.4

2.3b In what month and year did you have this abnormal mammogram(s)?

Abnormal 1:

Month _____ (1-12) 97=REF 98=DNK

Year 1997 1998 1999 2000
9997=REF 9998=DNK

Abnormal 2:

Month _____ (1-12) 97=REF 98=DNK

Year 1997 1998 1999 2000
9997=REF 9998=DNK

2.3c How upsetting was having an abnormal mammogram? Would you say:

1. Not at all upsetting
2. Slightly upsetting
3. Somewhat upsetting
4. Very upsetting
5. Extremely upsetting

7=Refused

8=Don't Know

2.4 Do you have an appointment for a mammogram?

1=Yes

2=No

7=Refused

8=Don't Know

For women in 50's

- 2.5 On a scale from 0 to 10, where 0=definitely will NOT get a mammogram and 10 =definitely WILL get a mammogram, how likely is it that you will get a mammogram in the next 12 months, that is, in about one year?

_____ (Specify a number and not a range)

97=Refused

98=Don't Know

For women in 40's

- 2.6 On a scale from 0 to 10, where 0=definitely will NOT get a mammogram and 10 =definitely WILL get a mammogram, how likely is it that you will get a mammogram in the next 24 months, that is, in about 2 years?

_____ (Specify a number and not a range)

97=Refused

98=Don't Know

**(For all women who have ever had a mammogram:
If EVERMAM=YES Or
EVERMAM=NO,REF or DNK and Q 1.1=1)**

- 2.7 On a scale from 0 to 100, where 0=no pain and 100=Pain as bad as you can imagine, please rate the pain you felt during your last mammogram by choosing a number that best describes it.

_____ (Specify a number and not a range)

997=Refused

998=Don't Know

A clinical breast exam, or CBE, is when the breasts are checked for lumps by a doctor or nurse.

- 2.8 Since we last spoke on <LastSurvey>, have you had your breasts examined by a doctor, nurse or other health care provider?

1=Yes

2=No

7=Refused

8=Don't Know

Provider Info.

I'm now going to ask you a few questions about your health care provider.

- 3.1 **Since we last spoke on <LastSurvey>, has a doctor or health care provider recommended that you have a mammogram?**

1=Yes 2=No 7=Refused 8=Don't Know

- 3.2 **Since we last spoke on <LastSurvey>, have you raised any questions or concerns about breast cancer screening with a doctor, nurse or health care provider?**

1=Yes 2=No 7=Refused 8=Don't Know

- 3.3 **What is the specialty of the health care provider you see regularly for women's health exams like breast exams and pap smears?**

1. General Internist
2. Family Physician/General Practitioner
3. Obstetrician/Gynecologist
4. Nurse Practitioner

6. Other? _____ (Please specify) 7=Refused 8=Don't Know

- 3.4 **Is this person a man or woman?**

1. Male
2. Female

7=Refused 8=Don't Know

- 3.5 **About how old is he/she (*use gender from 3.4*)? Would you say:**

1. Under age 50
2. Between 50 and 65
3. Over age 65

7=Refused 8=Don't Know

3.6 How long have you been seeing him/her (*use gender from 3.4*)?

1. Less than 6 months
2. 6-12 months
3. 13-36 months (more than 1, but less than 3 years)
4. More than 36 months (more than 3 years)

7=Refused

8=Don't Know

Barriers

4.1 Women give many reasons for not getting mammograms. We are interested in learning more about those reasons.

(Probe if needed. Do not read choices. Select up to 3 in the order mentioned. If other, please specify.)

Are there any particular reasons or concerns that have kept you from having a mammogram, or could keep you from having a mammogram in the future?

1. Afraid of finding breast cancer
2. Afraid of losing breast
3. Afraid of losing hair
4. Anxiety (general/nervous)
5. Care-giving duties interfere (too much to do)
6. Concerned about radiation
7. Confusion regarding guidelines
8. Cost
9. Current illness
10. Didn't get around to it
11. Dislike specific doctor (provider)
12. Doctor (provider) does CBE (clinical breast exam)
13. Doctor (provider) never recommended it
14. Does own SBE (self-breast exam)
15. Doesn't know purpose of mammograms
16. Doesn't know who needs mammograms
17. Doesn't like to go to doctors unless really sick
18. Doesn't think she'll get breast cancer
19. Doesn't want to know
20. "Don't fix what ain't broke"
21. Embarrassed about CBE (clinical breast exam)
22. Embarrassed about mammogram
23. Facility hours are limited
24. Family history of breast cancer worries her
25. Forgot appointment
26. Has symptoms or is having problems with breast(s)
27. Knows nothing about mammograms
28. Looking for trouble
29. Mastectomy (single)
30. Never thought about it
31. No family history
32. No doctor (provider)
33. No symptoms or problems with breast(s)
34. Not interested
35. Not necessary due to age (too old or too young)
36. One past mammogram is enough
37. Pain/Discomfort from mammogram
38. Questions accuracy of mammograms
39. Questions effectiveness of mammograms
40. Questions quality of mammograms
41. Radiology facility (environment)
42. Social/Emotional problems
43. Time limited (not enough time)
44. Transportation problems
45. Uncomfortable asking for referral
46. Worried about abnormal result
47. Worried about having a mammogram
48. Radiology facility (personnel)
49. Not necessary (general)
50. Forgot to schedule an appointment
51. Mammograms cause cancer
52. Puts faith in God
53. Only have when doctor (provider) recommends
54. Breast size
55. Inconvenient location of mammography facility
56. Difficulty making appointment
57. Doctor follows different guidelines
58. Pregnant or breastfeeding

95=No barriers

96=Other?

97=Refused

98=Don't Know

Facilitators

- 5.1 What is the main reason(s) you might want to get a mammogram?
*(Probe if needed. Do not read choices. Select up to 3 in the order mentioned.
If other, please specify.)*

1. Your provider recommended it
2. To feel more at ease
3. To find out if you have breast cancer
4. Precautionary measure (to be on the safe side, make sure things are okay, have/had cancer or family history of cancer(not breast), because of age)
5. Has a family history of breast cancer
6. No reason(s)
7. At high risk for some other reason(s)
8. To keep from getting breast cancer
9. Knows/Knew someone with breast cancer (not including blood relative)
10. For sake of family/friends

96=Other?

97=Refused

98=Don't Know

Family History of Breast Cancer

The next questions are about whether or not any of your close blood relatives have been diagnosed with breast cancer. This includes your mother and full or half-sisters only. Do not include step-sisters or adopted family members.

*If variable: **MOTHER=1 GO TO 6.2a**
 MOTHER=2,7,8 GO TO 6.1a*

6.1a **Since we last spoke on <LastSurvey>, was your mother told by a doctor that she had breast cancer?**

1=Yes 2=No 7=Refused 8=Don't Know

*If 6.1a= Yes → 6.1b
 No, Refused, Don't Know → 6.2a*

6.1b How old was your mother when she was first diagnosed with breast cancer? Was she:

1. < 50 years of age
2. ≥ 50 years of age

7=Refused 8=Don't Know

*If variable: **SISNUM=0, 97, 98 GO TO 7.1**
 0<SISNUM<97 and SISNUM=SISBCNUM GO TO 7.1
 0<SISNUM<97 and SISNUM>SISBCNUM GOTO 6.2a*

6.2a **Since we last spoke on <LastSurvey>, (was/were any of) your sister(s) told by a doctor that (she/they) had breast cancer?**

1=Yes 2=No 7=Refused 8=Don't Know

*If 6.2a= Yes → 6.2b
 No, Refused, Don't Know → 7.1*

6.2b Since we last spoke on <LastSurvey>, how many of your sisters were told by a doctor that they had breast cancer?

97=Refused

98=Don't Know

6.2c How old was your sister when she was first diagnosed with breast cancer?

1. < 50 years of age

2. ≥ 50 years of age

7=Refused

8=Don't Know

If she had 2 sisters diagnosed since date of last survey:

6.2d How old was your other sister when she was first diagnosed with breast cancer?

1. < 50 years of age

2. ≥ 50 years of age

7=Refused

8=Don't Know

If she had 3 sisters date of last survey:

6.2e How old was your other sister when she was first diagnosed with breast cancer?

1. < 50 years of age

2. ≥ 50 years of age

7=Refused

8=Don't Know

If she had any other sisters diagnosed since date of last, please continue asking the above questions.

PLEASE CONFIRM THAT THEY ARE ONLY GIVING US INFORMATION ON RELATIVES SINCE DATE OF LAST SURVEY.

Medical History

7.1a How often do you get your periods?

1. You have regular monthly periods
2. Your periods are irregular (Prompt: You skip months)
3. Your period was 12 or more months ago
4. You've had no periods since you had a hysterectomy

7=Refused

8=Don't Know

7.1b Which of the following best describes you?

1. There is no indication that you are near menopause
2. You think you may be close to or in the beginning stages of menopause but you're not sure
3. You have begun menopause
4. You have been through menopause

6. Other? _____ (*please specify*)

7=Refused

8=Don't Know

If 7.1b = 4 → 7.1c

1,2,3,6,7,8 → 7.1d

7.1c How old were you when you went through menopause?

_____ years of age (*Please specify an age and not a range*)

997=Refuse

998=Don't Know

7.1d Have you stopped getting your menstrual periods?

(Other than for pregnancy)

1=Yes

2=No

3=HRT

7=Refused

8=Don't Know

If 7.1d = Yes → 7.1f

No, N/A, Refused, Don't Know → 7.2a

HRT → 7.1e

Interviewer response if respondent expresses concern with questions 7.1a and 7.1d:

We apologize for having to ask this question again. We are only trying to get the most up to date and accurate information by validating some of the more important questions by asking them in different ways.

7.1e At what age did you start using hormone replacement therapy (HRT)?

_____ *(Please give a specific age and not a range)*

97=Refused

98=Don't Know

Go to 7.2a and select Yes.

7.1f How old were you when you stopped getting your menstrual periods?
(Do not read choices)

1. < 30 years of age
2. 30-34 years of age
3. 35-39 years of age
4. 40-44 years of age
5. 45-49 years of age
6. 50-54 years of age
7. Age 55 or older

97=Refused

98=Don't Know

Interviewer response if respondent expresses concern with questions 7.1c and 7.1f:

Question 7.1c refers to your age when you actually finished going through all the changes related to menopause. Question 7.1f refers specifically to your age when you had your last period.

If she said her menstrual period is induced by HRT in 7.1d, do not ask 7.2a. Circle 1=Yes and then go to 7.2b.

Menopause, often called the change of life, occurs when a woman's ovaries stop making estrogen and progesterone. Hormone replacement therapy is estrogen and progesterone that is given to menopausal women in the form of pills, patch or cream.

If asked: The following are a list of drugs used for HRT: (See attached)

7.2a Have you ever used hormone replacement therapy?

1=Yes 2=No 7=Refused 8=Don't Know

If 7.2a= Yes → 7.2b

No, Refused, Don't Know → 7.2c

7.2b Are you now using hormone replacement therapy?

1=Yes 2=No 7=Refused 8=Don't Know

If 7.2b= Yes → 7.3

No, Refused, Don't Know → 7.2c

7.2c Have you thought about using hormone replacement therapy?

1=Yes 2=No 7=Refused 8=Don't Know

The Pap Smear is a test in which the cervix or mouth of the womb is scraped lightly for a sample and then examined to see if any cancer cells are present.

7.3 How long ago did you have your last Pap Smear?
(Read choices if necessary)

1. Never had a pap test
2. Within the last 12 months (≤ 1 year ago)
3. 13-24 months ago (>1 but ≤ 2 years ago)
4. ≥ 25 months ago (>2 years ago)

7=Refused 8=Don't Know

7.4 Have you had a hysterectomy?

1=Yes

2=No

7=Refuse

8=Don't Know

7.5a Have you had your ovaries removed?

1=Yes

2=No

7=Refused

8=Don't Know

If 7.5a= Yes → 7.5b

No, Refused, Don't Know → 7.6a

7.5b Did you have one ovary or both ovaries removed?

1=One

2=Both

7=Refused

8=Don't Know

7.5c What year did you have your ovary(ies) removed?

_____ Year

9997=Refused

9998=Don't Know

The next questions are about your smoking history.

7.6a Do you now smoke?

1=Yes

2=No

7=Refused

8=Don't Know

If 7.6a= Yes → 7.6b

No, Refused, Don't Know →

IF VARIABLE SMOKE=1 then ask 7.6e.

IF VARIABLE SMOKE=2,7,8 then go to 7.7a.

7.6b How many cigarettes do you smoke on a typical day?

_____ *(Specify number and not a range)*

97=Refused

98=Don't Know

7.6c Are you seriously considering stopping smoking within the next 6 months?

1=Yes

2=No

7=Refused

8=Don't Know

If 7.6c= Yes → 7.6d

No, Refused, Don't Know → 7.7

7.6d Are you planning to stop smoking within the next 30 days?

1=Yes

2=No

7=Refused

8=Don't Know

Go to 7.7a

7.6e When did you quit? (*Date must be after the last survey*)

_____ Month _____ Year

Month: 97=Refused

Year: 9997=Refused

98=Don't Know

9998=Don't Know

7.7a Do you exercise or participate in an active physical sport, such as walking, jogging or bicycling?

1=Yes

2=No

7=Refused

8=Don't Know

If 7.7a= Yes → 7.7b

No, Refused, Don't Know → 7.8

7.7b On average, how many times per week do you exercise?

_____ times (*Specify a number and not a range. Code less than once a week as 0*)

97=Refused

98=Don't Know

7.8 How often do you have a preventive dental exam? (*a check-up when you have no problems or symptoms*)

1. Twice a year or more
2. Once a year
3. Every 2-4 years
4. Seldom or never

7=Refused

8=Don't Know

7.9 Do you use a sunscreen product to protect you from the sun? Would you say:
(*it does count if it's in make-up*)

1. Yes, all year long
2. Yes, but only seasonally
3. Rarely or Never

7=Refused

8=Don't Know

7.10 How would you describe your current health?
Would you say it is...

1. Excellent
2. Good
3. Fair
4. Poor

7=Refused

8=Don't Know

Misperceptions/Risks

Now I would like to ask you a few questions about the risks for breast cancer and the benefits of mammography. Please bear with us. Some of the questions seem repetitive, but they are very important to this project.

8.1 For which age group do you think mammography is more effective in reducing deaths from breast cancer? Would you say it is more effective for:

1. Women aged 40-49
2. Women aged 50-65
3. Age makes no difference

7=Refused

8=Don't Know

8.2 Who do you think is more likely to get breast cancer? Is it:

1. Women aged 40-49
2. Women aged 50-65
3. Women over age 65
4. Age makes no difference

7=Refused

8=Don't Know

I will now be asking you for your opinions about your chances of getting breast cancer in the next 10 years and in your lifetime.

8.3a How likely are you to get breast cancer in the next 10 years?
Would you say:

1. Very unlikely
2. Unlikely
3. 50-50 chance
4. Likely
5. Very likely

7=Refused

8=Don't Know

If 8.3a= 3 → 8.3b

Else → 8.4

8.3b What do you mean by that?

8.4 On a scale from 0 to 100 where 0 = certain not to happen, and 100 = certain to happen, how likely are you to get breast cancer in the next 10 years?

_____ *(Specify a number and not a range)*

997=Refused

998=Don't Know

8.5a How likely are you to get breast cancer in your lifetime?
Would you say:

1. Very unlikely
2. Unlikely
3. 50-50 chance
4. Likely
5. Very likely

7=Refused

8=Don't Know

If 8.5a = 3 → 8.5b

Else → 8.5c

8.5b What do you mean by that?

8.5c In the previous question, you said that your risk of getting breast cancer in your lifetime was *<insert response from 8.5a>*. What things did you think about that led you to choose that answer?

(Do not read choices. Probe as needed. You may circle up to 3 in the order mentioned.)

- | | |
|-------------------------------------------------------|-----------------------------------------------------------|
| 1. Do/Did drink Alcohol | 2. Do not(or never) drink Alcohol |
| 3. Do use/Have used Birth control pills | 4. Do not use/Have not used Birth control pills |
| 5. Has/Had breast injury (bruising, etc.) | 6. Has not had Breast injury (bruising, etc.) |
| 7. Do/Did Breastfeed | 8. Do not/Did not Breastfeed |
| 9. Do consume Caffeine | 10. Do not consume caffeine |
| 11. Do get regular Clinical breast exams (CBE) | 12. Do not get regular Clinical breast exams (CBE) |
| 13. Do Eat right (good diet) | 14. Do not Eat right (bad diet) |
| 15. Do Exercise regularly | 16. Do not Exercise regularly |
| 17. Do have Family history of breast cancer | 18. Do not have Family history of breast cancer |
| 19. Do have Family history of other cancers | 20. Do not have Family history of other cancers |
| 21. Do have good Health | 22. Do not have good Health |
| 23. Do use/Have used HRT | 24. Do not use/Have not used HRT |
| 25. Do use/Have used Infertility drugs | 26. Do not use/Have not used Infertility drugs |
| 27. Do get regular Mammograms | 28. Do not get regular Mammograms |
| 29. Am Overweight | 30. Am not Overweight |
| 31. Do have Personal history of breast cancer | 32. Do not have Personal history of breast cancer |
| 33. Do have Personal history of other cancers | 34. Do not have Personal history of other cancers |
| 35. Am Sexually active | 36. Am not Sexually active |
| 37. Do/Did Smoke | 38. Do not(or never) Smoke |
| 39. Do experience Stress | 40. Do not experience Stress |
| 41. Has/Had Symptoms(pain/lump/cyst, etc.) | 42. Has not had Symptoms (pain/lump/cyst, etc.) |
| 43. My Age (younger) | 44. My Age (older) |
| 45. Age at menarche (younger) | 46. Age at menopause (older) |
| 47. Attitude (negative) | 48. Attitude (positive) |
| 49. Based on what Doctor told me | 50. Doctor hasn't told me |
| 51. Environmental factors | |
| 52. Faith in God | |
| 53. No faith in God | |
| 54. Numerous mammograms | |
| 55. None/Few mammograms | |
| 56. Parity issue - age at childbirth (younger) | |
| 57. Parity issue - age at childbirth (older) | |
| 58. Parity issue - not having children | |
| 59. Relative's age at diagnosis of cancer (younger) | |
| 60. Relative's age at diagnosis of cancer (older) | |
| 61. Has had abnormal mammogram(s) | |
| 62. Has not had abnormal mammogram(s) | |

96=Other _____(Please specify)

97=Refused

98=Don't Know

(If > 1 choice was listed in 8.5c, go to 8.5d. Else go to 8.6.)

8.5d Which of the following reasons you just gave me is your main reason? Is it *<repeat choices from 8.5c>*?

- | | |
|-------------------------------------------------------|-----------------------------------------------------------|
| 1. Do/Did drink Alcohol | 2. Do not(or never) drink Alcohol |
| 3. Do use/Have used Birth control pills | 4. Do not use/Have not used Birth control pills |
| 5. Has/Had breast injury (bruising, etc.) | 6. Has not had Breast injury (bruising, etc.) |
| 7. Do/Did Breastfeed | 8. Do not/Did not Breastfeed |
| 9. Do consume Caffeine | 10. Do not consume caffeine |
| 11. Do get regular Clinical breast exams (CBE) | 12. Do not get regular Clinical breast exams (CBE) |
| 13. Do Eat right (good diet) | 14. Do not Eat right (bad diet) |
| 15. Do Exercise regularly | 16. Do not Exercise regularly |
| 17. Do have Family history of breast cancer | 18. Do not have Family history of breast cancer |
| 19. Do have Family history of other cancers | 20. Do not have Family history of other cancers |
| 21. Do have good Health | 22. Do not have good Health |
| 23. Do use/Have used HRT | 24. Do not use/Have not used HRT |
| 25. Do use/Have used Infertility drugs | 26. Do not use/Have not used Infertility drugs |
| 27. Do get regular Mammograms | 28. Do not get regular Mammograms |
| 29. Am Overweight | 30. Am not Overweight |
| 31. Do have Personal history of breast cancer | 32. Do not have Personal history of breast cancer |
| 33. Do have Personal history of other cancers | 34. Do not have Personal history of other cancers |
| 35. Am Sexually active | 36. Am not Sexually active |
| 37. Do/Did Smoke | 38. Do not(or never) Smoke |
| 39. Do experience Stress | 40. Do not experience Stress |
| 41. Has/Had Symptoms(pain/lump/cyst, etc.) | 42. Has not had Symptoms (pain/lump/cyst, etc.) |
| 43. My Age (younger) | 44. My Age (older) |
| 45. Age at menarche (younger) | 46. Age at menopause (older) |
| 47. Attitude (negative) | 48. Attitude (positive) |
| 49. Based on what Doctor told me | 50. Doctor hasn't told me |
| 51. Environmental factors | |
| 52. Faith in God | |
| 53. No faith in God | |
| 54. Numerous mammograms | |
| 55. None/Few mammograms | |
| 56. Parity issue - age at childbirth (younger) | |
| 57. Parity issue - age at childbirth (older) | |
| 58. Parity issue - not having children | |
| 59. Relative's age at diagnosis of cancer (younger) | |
| 60. Relative's age at diagnosis of cancer (older) | |
| 61. Has had abnormal mammogram(s) | |
| 62. Has not had abnormal mammogram(s) | |

96=Other _____(Please specify)

97=Refused

98=Don't Know

- 8.6 On a scale from 0 to 100 where 0 = certain not to happen, and 100 = certain to happen, how likely are you to get breast cancer in your lifetime?

_____ *(Specify a number and not a range)*

997=Refused

998=Don't Know

For the next two questions, I want you to think about your chances of getting breast cancer compared to other women your age within the next 10 years and in your lifetime.

- 8.7 Compared to other women your age, how likely are you to get breast cancer in the next 10 years? Would you say:

1. Much below average
2. Below average
3. Same average risk as other women your age
4. Above average
5. Much above average

7=Refused

8=Don't Know

- 8.8 Compared to other women your age, how likely are you to get breast cancer in your lifetime? Would you say:

1. Much below average
2. Below average
3. Same average risk as other women your age
4. Above average
5. Much above average

7=Refused

8=Don't Know

- 8.9 How worried are you about getting breast cancer in the next 10 years? Are you:

1. Not at all worried
2. Slightly worried
3. Somewhat worried
4. Worried
5. Very worried

7=Refused

8=Don't Know

8.10 If a woman your age does not have any breast problems or symptoms, how often should she get a mammogram? (***Do not read choices***)

1. More than once a year
2. Every year
3. Every 1-2 years
4. Every 2 years
5. Greater than every two years
6. Only when she has a problem/symptom
7. When a doctor says so
8. Never

96=Other?

97=Refused

98=Don't Know

Decisional Balance

For the next set of questions we are interested in your feelings about breast cancer and mammography. I'm going to read you some statements. Please tell me if you agree, disagree or if you are undecided.

- 9.1 Your family will benefit if you have a mammogram.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused 8=Don't Know

- 9.2 Mammograms often lead to breast surgery that is not needed.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused 8=Don't Know

- 9.3 You would be more likely to go for a mammogram if your doctor told you it is important for you. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused 8=Don't Know

- 9.4 Having mammograms causes a lot of worry or anxiety about breast cancer.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused 8=Don't Know

9.5 Having mammograms every year or two would give you a feeling of control over your health. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.6 Once you have a couple of mammograms that are normal, you don't need to have any more for a few years. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.7 Mammograms **are** needed for women your age. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.8 Having mammograms every year or two would give you peace of mind about your health. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.9 Women your age need mammograms even when they have no family history of breast cancer. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.10 Assuming your current insurance coverage and financial status, the cost of a mammogram would cause you to hesitate about getting one. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.11 There is so much different information about how often women should have mammograms that you are confused. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.12 The pain caused by having a mammogram is bad enough to make you put off getting one. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.13 Mammograms aren't perfect but it's better to have them just to be on the safe side.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.14 If breast cancer is found early by a mammogram, a woman might be able to have surgery that would save her breast. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.15 Mammograms save the lives of women your age.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.16 You would be worried that a mammogram would show that you **had** cancer when, in fact, you **did not**. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.17 You would be worried that a mammogram would show that you **did not** have cancer when, in fact, you **did**. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.18 If you've never had breast problems, you don't need to have a mammogram. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.19 You are torn between getting and not getting a mammogram in the next year (*age 50's*) or in the next year or two (*age 40's*). Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.20 You understand the benefits and limitations of mammography for women your age. Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.21 Most of the women you know get regular mammograms.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

9.22 The hassle of getting a mammogram might keep you from having one.
Do you agree, disagree, or are you undecided?

1. Agree
2. Undecided
3. Disagree

7=Refused

8=Don't Know

Decision Making

10.1 Do you have enough information to make the decision whether to get mammograms?

1=Yes

2=No

7=Refused

8=Don't Know

10.2 Women get information about breast cancer from many sources. I am going to read you a list of ways you could get information about breast cancer, how to prevent it and find it early. For each one, please tell me whether you might like to get information that way, assuming it was free. After you've told me yes or no for each one, I'll ask which one would be your first choice. But, for now, please just tell me, would you want to get breast cancer information:

a. From a personal computer -- either by Email or the Internet?

1=Yes

2=No

7=Refused

8=Don't Know

If 10.2a=1 → 10.2a1

Else → 10.2b

a1. Is there an internet health site you especially like?

1=Yes

2=No

7=Refused

8=Don't Know

If 10.2a1=1 → 10.2a2

Else → 10.2b

a2. Which one? _____

b. Watching a video cassette that was mailed to your home?

1=Yes

2=No

7=Refused

8=Don't Know

c. Listening to an audio cassette that was mailed to your home?

1=Yes

2=No

7=Refused

8=Don't Know

d. Reading brief personalized printed materials created especially for you and mailed to your home?

1=Yes

2=No

7=Refused

8=Don't Know

e. Using an interactive computer CD-Rom program that would let you select which information you wanted to get?

1=Yes

2=No

7=Refused

8=Don't Know

f. Receiving a telephone call from a trained health professional who could talk with you and answer your questions?

1=Yes

2=No

7=Refused

8=Don't Know

g. Any other way you'd like to get information about breast cancer?
(Specify: _____)

1=Yes

2=No

7=Refused

8=Don't Know

(If > 1 response = YES in 10.2a-g, go to 10.3. Else go to 11.1.)

10.3 Thinking about the answers you just gave me, which of the ways of receiving information do you prefer the most? (*Only options they answered YES to should appear. If only one YES, skip to 11.1*)
(*Check only one option. If needed, add: "If you had to choose just one, what would it be?"*)

1. Access by computer (Email or internet)
2. Video cassette mailed to home
3. Audio cassette mailed to home
4. Personalized printed materials mailed to home
5. Interactive CD-Rom
6. Discussion with a trained health professional by telephone
7. Other (Specify: _____)

97=Refused

98=Don't Know

Patient Satisfaction with Health Decisions

The following questions are about the decision you have made to have or not have mammograms since we last spoke on <date of last survey>. Please answer the questions based on the way you feel right now.

(*PLEASE NOTE: If the participant insists that she really didn't make a decision and that these questions do not apply, you may skip this section by selecting response #6.*)

11.1 You are satisfied that you are adequately informed about issues important to your decision. Do you:

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree
6. NOT APPLICABLE OR DID NOT MAKE A DECISION

7=Refused

8=Don't Know

11.2 The decision you made was the best decision possible for you personally.

Do you:

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree
6. NOT APPLICABLE OR DID NOT MAKE A DECISION

7=Refused

8=Don't Know

11.3 You are satisfied that your decision was consistent with your personal values and beliefs.

Do you:

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree
6. NOT APPLICABLE OR DID NOT MAKE A DECISION

7=Refused

8=Don't Know

11.4 You expect to successfully carry out or continue to carry out the decision you made.

Do you:

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree
6. NOT APPLICABLE OR DID NOT MAKE A DECISION

7=Refused

8=Don't Know

11.5 You are satisfied that this was your decision to make.

Do you:

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree
6. NOT APPLICABLE OR DID NOT MAKE A DECISION

7=Refused

8=Don't Know

11.6 You are satisfied with your decision.

Do you:

1. Strongly Agree
2. Agree
3. Neither Agree nor Disagree
4. Disagree
5. Strongly Disagree
6. NOT APPLICABLE OR DID NOT MAKE A DECISION

7=Refused

8=Don't Know

Intervention Assessment

(For those in StudyGrp=2 and 3 ONLY with NEWSLETTER=YES)

The next few questions are about the personalized newsletter we sent you last year. The newsletter was 4-8 pages long. It was called “Personally Relevant Information about Screening Mammography” and had your name on the cover. It contained articles such as an update on your breast cancer risk, answers to your questions about mammography, an article about breast cancer and family history, and an article about Tamoxifen, a drug used for breast cancer prevention among high risk women.

12.1 How much of the newsletter would you say you read? ***(Read only first three choices)***

1. None
2. A little or some
3. Most or all
4. Do not remember receiving newsletter

7=Refused

8=Don't Know

If 12.1= 1 → 12.3

2,3 → 12.2

4,7,8 → 12.11a

12.2 Did you read the newsletter:

1. As soon as you received it, or did you
2. Put it aside and read it later

7=Refused

8=Don't Know

12.3 Would you say that you:

1. Kept the newsletter for a while, or
2. Discarded the newsletter soon after receiving it

7=Refused

8=Don't Know

If 12.1=1 → 12.11a

Else → 12.4

I'm going to ask you some specific questions about the newsletter. You may have received other materials or calls related to the project; but, please think about only the newsletter when answering these questions.

12.4 Did the newsletter contain information that seemed to be especially for you?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

12.5 Did the information in the newsletter help you decide whether to get regular mammograms? *(Read first 4 responses.)*

1. Yes
2. No
3. Not sure
4. Already getting regular mammograms

7=Refused

8=Don't Know

12.6 Did the information in the newsletter help you think about the benefits of getting regular mammograms? *(Read first 4 responses.)*

1. Yes
2. No
3. Not sure
4. Already knew the benefits

7=Refused

8=Don't Know

12.7 Did the information in the newsletter help you think about the limitations of getting regular mammograms? *(Read first 4 responses.)*

1. Yes
2. No
3. Not sure
4. Already knew the limitations

7=Refused

8=Don't Know

12.8 Did the information in the newsletter help you overcome any reasons you may have had for not getting mammograms? *(Read first 4 responses.)*

1. Yes
2. No
3. Not sure
4. Do not have any reasons not to get mammograms

7=Refused

8=Don't Know

12.9 In general, was the information in the newsletter useful to you?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

12.10 Did you give the newsletter to anyone else to read?

1=Yes

2=No

7=Refused

8=Don't Know

(If GAILEST=NO, skip to 12.15 if applicable)

As part of the PRISM project, we gave you an estimate of your personal chance of getting breast cancer in the next 10 years based on a mathematical model called the GAIL model.

12.11a Do you think that number was a good estimate of your breast cancer risk?

1=Yes

2=No

7=Refused

8=Don't Know

If 12.11a= Yes, No → 12.11b

Else → 12.12

12.11b Why or why not?

- 12.12 What was the number that you were given as an estimate of your breast cancer risk? (*Note: Women are allowed to look at their materials if they have it, but do not ask them to do this. If women don't know or are uncertain, please use the following probe:*
Please give me your best guess if you are uncertain or do not recall.)

_____ (*Please enter a number and not a range. Record to one decimal place.*)

997=Refused 998=Don't Know

- 12.13 Was the estimate of your chance of getting breast cancer:

1. Higher than you expected
2. About what you expected
3. Lower than you expected

7=Refused 8=Don't Know

- 12.14 Assuming that your health care organization could send you personalized materials similar to those we sent you on breast cancer and mammography for an additional charge, how much would you be willing to pay for these materials per year? Please stop me when I reach the **highest** amount you would be willing to pay per year. (*Read choices 1-4 only*)
(*Note: If the participant asks "what materials?", say, the booklet that was mailed the first year and newsletter that was mailed this year.*)

1. \$1 - \$5
2. \$6 - \$10
3. \$11 - \$15
4. More than \$15
5. Would not be willing to pay any money

7=Refuse 8=Don't Know

(For those in StudyGrp=3 ONLY with COUNSELING=YES:)

Next, I'd like to ask you some questions about the telephone call you received last year from Ms. Linda James to discuss your newsletter.

- 12.15 Do you remember getting a call from Ms. James to discuss the newsletter?

1=Yes 2=No 7=Refused 8=Don't Know

If 12.15= Yes → 12.16

No, Refused, Don't Know → 12.26

I'd like to get your reactions to the call with Ms. James. Thinking about the call separate from the newsletter, please answer yes, no or not sure to the following questions.

12.16 Did the call help you decide whether to get regular mammograms?
(Read first 4 responses.)

1. Yes
2. No
3. Not sure
4. Already getting regular mammograms

7=Refused

8=Don't Know

12.17 Did the call help you think about the benefits of getting regular mammograms?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

12.18 Did the call help you think about the limitations of getting regular mammograms?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

12.19 Did the call help you overcome any reasons you may have had for not getting mammograms? *(Read first 4 responses.)*

1. Yes
2. No
3. Not sure
4. Do not have any reasons not to get mammograms

7=Refused

8=Don't Know

12.20 In general, was the discussion with Ms. James useful to you?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

12.21 Did the call raise any new concerns for you about breast cancer and mammography?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

12.22 Did the call make you feel worried about breast cancer or mammography?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

Now, please think about the call in addition to the newsletter that you received.

12.23 Did the call make the information in the newsletter more clear?

(Read first 4 responses.)

1. Yes
2. No
3. Not sure
4. Was already clear

7=Refused

8=Don't Know

12.24a Would you say that the call was:

1. A helpful addition to the newsletter
2. Or, not a helpful addition to the newsletter

7=Refused

8=Don't Know

If 12.24a = 2 → 12.24b
1, 7, 8 → 12.25

12.24b Why was the call not helpful?

(Read first 4 responses.)

1. Because you had already decided whether to have regular mammograms?
2. Because you already understood the information in the newsletter?
3. Or, some other reason (specify: _____)
4. Dislike being called at home

7=Refused

8=Don't Know

12.25 If you could choose, would you have gotten:

(Read first 4 responses.)

1. The newsletter only
2. The call only
3. Both the newsletter and the call
4. Neither the newsletter nor the call

7=Refused

8=Don't Know

- 12.26 Assuming that your health care organization could send you personalized materials similar to those we sent you along with telephone calls from a health advisor like Ms. James for an additional charge, how much would you be willing to pay for these services **per year**? Please stop me when I reach the **highest** amount you would be willing to pay **per year**.

(Read choices 1-4 only)

(Note: If the participant asks “what materials?”, say, the booklet that was mailed the first year and newsletter that was mailed this year.)

1. \$1 - \$5
2. \$6 - \$10
3. \$11 - \$15
4. More than \$15
5. Would not be willing to pay any money

7=Refuse

8=Don't Know

- 12.27 During your participation in the PRISM project, you received approximately 3 ***(if Studygrp=1 or 2)*** / 5 ***(if Studygrp=3)*** telephone calls over the past 3 years. Was this:

1. Not enough
2. Too much
3. Just right

7=Refuse

8=Don't Know

- 12.28 Do you think that Blue Cross and Blue Shield should continue calling women about getting regular mammograms?

1. Yes
2. No
3. Not sure

7=Refused

8=Don't Know

Depression

Now, I would like to ask you a few questions about how you have been feeling within the last week. (Do not read number of days unless needed)

13.1 During the last week, how often...

a. Were you bothered by things that usually don't bother you? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

b. Did you have trouble keeping your mind on what you were doing? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

c. Were you feeling depressed? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

d. Did you feel that everything you did was an effort? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

e. Did you feel hopeful about the future? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

f. Did you feel fearful? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

g. Did you feel your sleep was restless? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

h. Did you feel happy? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

i. Did you feel lonely? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

j. Could you not get 'going'? Would you say:

1. Rarely or none of the time (*< 1 day*)
2. Some or little of the time (*1-2 days*)
3. Occasionally or a moderate amount of the time (*3-4 days*)
4. Most or all of the time (*5-7 days*)

7=Refused

8=Don't Know

Health Care Organization

I'm now going to ask you a few questions about your health care coverage and where you get your healthcare.

14.1 Are you currently a member of Blue Cross and Blue Shield of North Carolina?

1=Yes

2=No

7=Refused

8=Don't Know

14.2 Does your health plan pay for routine mammograms?

1=Yes

2=No

7=Refused

8=Don't Know

14.3a What type(s) of health insurance coverage do you have?

(Read choices if necessary. Select all that apply)

Commercial

1. Traditional (Indemnity, Comprehensive, Major Med, Fee for Service)
2. Managed Care (HMO, PCP, PPO, POS/MedPoint)

Non-Commercial

3. Medicare
4. Medicaid

5. None 6=Other? 7=Refused 8=Don't Know

If 14.3a=5 → 15.1a

1,2,3,4, Refused, Don't Know → 14.3b

14.3b ***(If BCBS member: 14.1=1)***

If you have an insurance carrier other than BCBS, what is the name(s)?

(If only has BCBS, please specify NONE.)

(If non-BCBS member: 14.1=2,7,8)

What is the name of your insurance carrier(s)?

14.3c Does your insurance require a co-payment for a mammogram?

If needed: Probe: the insurance you currently use/will use to obtain your mammograms

1=Yes 2=No 7=Refused 8=Don't Know

If 14.3c=Yes → 14.3d

No, Refused, Don't Know → 15.1a

14.3d How much is your co-payment for a mammogram?

_____ *(Specify dollar amount)*

997=Refused

998=Don't Know

Demographics

Now I would like to take a moment to update our records.

15.1a Do you still live at (*read current address*)?

1=Yes

2=No

7=Refused

8=Don't Know

If 15.1a=Yes → 15.2a

No, Refused, Don't Know → 15.1b

15.1b What is your current address?

Street address _____

Apt #/PO Box _____

City _____ State _____ Zip _____

16.1 Comments:

Total interview time: _____ minutes