

Final: 11-25-97

NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM

***FOCUS GROUP RESEARCH:
ATTITUDES REGARDING MAMMOGRAPHY RE-SCREENING***

MODERATOR DISCUSSION GUIDE OUTLINE

- I. Background and Introductions (10 minutes)
- II. Attitudes/Practices/Experiences re Health Care in General (10 minutes)
(Please note: A portion of Section II may be cut if the start time of a group is delayed for unforeseen reasons. This will help to retain time for other key topics.)
- III. General Understanding of Purpose of/Recommended Frequency for CBEs and Mammograms (10 minutes)
 - A. Purpose of CBEs and Mammograms
 - B. Frequency
 - C. Breast Cancer
 - D. Other Breast Health Problems

(Please note: Discussion about how often CBEs and mammograms are recommended has been moved to this section of the guide.)
- IV. Experiences with Breast Exams and Mammograms (25 minutes)
 - A. Reasons for Getting Last/Next to Last Breast Exam/Mammogram
 - B. Timing and Logistics
 - C. Breast Exam Experience
 - D. Mammogram Experience
 - E. Concerns/Questions About Breast Exam/Mammogram
- V. Response to Results of Mammogram (15 minutes)
 - A. Obtaining Results
 - B. Response to Results and Recommendation About Follow-Up Mammogram

(Please note: Section V.B. incorporates discussion about how women made decisions about having/not having another mammogram.)
- VI. Summary of Ideas and Suggestions (10 minutes)
- VII. Closing and Departure (10 minutes)

TOTAL TIME: 90 minutes

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MODERATOR DISCUSSION GUIDE

Please note: As with all moderator discussion guides, this document is a *GUIDE* only; not a script from which the moderator will read questions verbatim. It is important for observers to be aware that the moderator will adapt the wording of the questions and the order in which they are introduced according to what emerges as most suitable for each group of women, the specific dynamics of each group, and comments from the participants. Please note also that all text in this document that is not printed in bold is information for the moderator or observers only; e.g., the Objectives stated for each section. Thus, this information may contain words or references -- e.g., "NBCCEDP" or "screening" -- that will not be used by the moderator in discussion with the participants.

Target Audiences:

Women who received mammograms from an NBCCEDP site...

1. With *negative benign* result; then returned for follow-up within recommended 12-24 months.
2. With *negative benign* result; but *did not* return within recommended 12-24 months for follow-up mammogram.
3. With *probably benign* result; then returned for follow-up mammogram within recommended 3-6 months.*
4. With *probably benign* result; but *did not* return for follow-up screening within recommended 3-6 months.*

*Women in these groups may not be aware that their result was not negative or benign despite conscientious efforts to notify them. The moderator will not refer to her own awareness of the women's status.

1. BACKGROUND AND INTRODUCTIONS (about 10 minutes)

Objective: Put participants at ease by explaining the purpose of and procedures for the group and by facilitating introductions to help participants become comfortable with each other and the moderator.

The moderator will:

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Thank participants for attending.

Introduce herself.

Explain that the purpose of the discussion is to hear about experiences with and feelings about different aspects of health care, particularly experiences with breast exams and mammograms. The moderator will point out that everyone has in common the fact that they have had at least one mammogram, but will not mention knowing the initial negative/probably benign outcome or that participants have/have not returned within the recommended timeframe for follow-up screening.

Emphasize that there are no right or wrong answers and that everyone should feel free to talk about their opinions honestly.

Stress that names will not be used in any report about the discussion.

Explain the presence and purpose of recording device and observers.

Facilitate participants' self-introductions.

[Note: To help the women feel more at ease about speaking in a group, the moderator usually asks them to tell something about themselves during the introductions. This gives participants an opportunity to hear themselves speak and address an "easy" topic before the formal discussion of more difficult topics begins. Usually, the moderator will say something like "tell us about your family" or "tell us about some of the things that keep you busy these days." Questions about family and lifestyle have research value for this study, as they provide context for the women's comments throughout the discussion. It is also important to be concerned about posing a warm-up question that is easy for participants to answer and cannot be construed as having a "right" or "wrong" answer. Otherwise, the warm-up can intensify, rather than alleviate, discomfort about the group setting.]

II. *ATTITUDES/PRACTICES/EXPERIENCES RE HEALTH CARE IN GENERAL***
(10 minutes)**

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Objective: Explore how often women see a doctor and for what reasons. This will enable the research team to learn about differences between attitudes and behavior vis a vis health care in general and breast health specifically.

You know that the main thing we will be talking about will be your experiences and feelings about the breast exam and mammograms you have had. But first, I'd like to hear a little bit about *other things* you might go to see a doctor or nurse for. Sometimes, women tell me they go to a doctor or nurse fairly often; others tell me they do not go very often.

What would you say is usual for you?

***HOW OFTEN* do you go to a doctor or nurse for yourself (rather than for your children, parents, or other person)?**

***WHAT KINDS OF THINGS* have you gone to a doctor for in the last year or so?**

The moderator will probe to determine whether women go for symptoms only, preventive care, some combination of these, or other reasons.

***WHERE* do you go for health care? (e.g., doctor, clinic, hospital, etc.)**

What about different kinds of *TESTS* that you can get during a visit. Are there any tests you have had in the last year? Such as...

If group has begun on time, the moderator will explore briefly participants' responses to determine more about attitudes and beliefs toward tests they mention. Potential topics for exploration include:

***Age* when first obtained various tests;**

***Reasons* for going;**

Understanding of test(s)' purpose(s);

***Frequency* of obtaining test(s);**

***Experiences (positive and negative)* with different tests (e.g., *results, comfort/discomfort*)**

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Similarly, if time permits and response to open-ended question is limited, the moderator may try to stimulate further discussion by mentioning examples such as gynecological check-up, Pap, clinical breast exams (CBEs) and mammogram.

The moderator will focus the discussion during this portion of the group more on tests *other than mammograms* although it is expected that the women will begin to talk about mammograms during this portion of the discussion.

III. GENERAL UNDERSTANDING OF PURPOSE OF/RECOMMENDED FREQUENCY FOR CBEs and MAMMOGRAMS (10 minutes)

Objective: Learn what women understand about mammography and the extent to which they believe and trust that it is a valuable screening tool for early detection of breast cancer.

[Note: The moderator will adjust wording throughout the discussion to fit with what participants have/have not already brought up.]

A. PURPOSE OF CBES AND MAMMOGRAMS:

Some of you have already mentioned your experiences with breast exams and mammograms. Everyone here has had at least one breast exam by a doctor or nurse and at least one mammogram. Let's talk about what these tests are for.

For example, what is the doctor or nurse looking for when she or he examines your breasts?

Now let's talk about the mammogram. First of all, what is a mammogram?
(If no one answers, the moderator will tell women that it is an X-ray of the breast.)

And in your own words, how would you describe what it is for?

Now I am going to read a statement that I would like to get your reactions to:

“STUDIES HAVE SHOWN THAT MAMMOGRAMS ARE THE BEST WAY TO FIND BREAST CANCER EARLY WHEN IT IS EASIEST TO TREAT.”

When you hear that statement, what thoughts come to mind?

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**For example, do you believe this is true? Why/why not?
What else have you heard?**

B. FREQUENCY:

What have you heard about *HOW OFTEN* we are supposed to go for breast exams and mammograms?

How often do you think *YOU* should go?

Is the recommendation about how often we are supposed to go different for different women?

C. BREAST CANCER:

Has anyone ever known someone with breast cancer?

For example, have you -- or someone in your family or among your friends -- ever had breast cancer?

If yes, the moderator will briefly explore participants' experiences. Note: It is important to give women this opportunity to speak about personal experience with cancer. However, no one will be pressed to talk about it if they do not wish to.

D. OTHER BREAST HEALTH PROBLEMS:

Has anyone had an experience with *other* breast problems such as pain, swelling, nipple discharge, or what the doctor might have called fibrocystic disease?

IV. EXPERIENCES WITH BREAST EXAMS AND MAMMOGRAMS (25 minutes)

Objective: Obtain information about the factors that promote or discourage women from obtaining breast exams/mammogram.

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A. REASON(S) FOR GETTING LAST/ “NEXT-TO-LAST” BREAST EXAM/MAMMOGRAM OF INTEREST:

Note: For women who have *NOT* been re-screened, the focus of interest is on the *last* mammogram. For women who have been re-screened, the focus is on the *next-to-last* mammogram, results of which included the recommendation to be re-screened within a specific timeframe. Wording for the following questions will be adjusted when date information about participants’ mammograms is available, possibly just before the groups begin.

Now I would like you to think back to:

For delayed or no re-screening group...

Your LAST breast exam and mammogram.

OR for re-screened group...

The breast exam and mammogram that you had (timeframe).

What was the main reason you decided to go?

The moderator will probe factors that influenced the decision to go for the mammogram of interest to this study. For example, the following may be explored:

Was it because a doctor or nurse recommended it?

Because a friend or family member said to?

A combination of these?

Other things? (Such as...)

B. TIMING AND LOGISTICS:

B1. WHEN

Do you remember *HOW LONG AGO* it was?

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(This will not be asked in groups where the timeframe has already been discussed.)

B2. WHERE

Where did you call to make an appointment? Why there?

B3. RESPONSE TO STAFF

**Were the people you talked to friendly? Helpful?
Did you wish they had been different in any way?**

**Did you have any questions for them when you called?
How did they handle your questions?**

B4. CONVENIENCE

Was it easy or difficult to get an appointment that was *convenient* for you to go for the breast exam and mammogram?

***How long* was it from the time you called until you could get an appointment?**

**Tell me about how you were able to *keep your appointment*.
For example, if you care for a parent or children, did you have to make other arrangements for them? Or, did you...
Take the bus/several buses, arrange for ride/etc.?
Take time off from work? How much time?**

B5. COMPANIONSHIP

Did anyone go with you? Did you wish someone had?

B6. COST

**How much did it *COST* you if there was a charge? What about other things you had to pay for, like transportation to get to the appointment?
For babysitting or taking time off from work?
Anything else that you had to pay for yourself?**

C. BREAST EXAM EXPERIENCE

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(Note: Mammograms are discussed separately below.)

Let's talk about the breast exam first. Then we'll talk about the mammogram. If a friend of yours had never had a *breast exam* and asked you to tell her about it, how would you describe what happens and what it is like?

(If not mentioned...) **Was there any discomfort of any kind while the doctor or nurse examined your breasts? (If yes...) How would you describe that part of the exam?** (Moderator will encourage as much discussion as possible about pain.)

Did you have any other concerns or questions that you wanted to ask about the exam? Such as...

Is there anything you wish they would do differently? Such as...

D. MAMMOGRAM EXPERIENCE

Now let's talk about the mammogram part. Suppose your friend had never had a *mammogram*, let's talk what kinds of things you would tell her about what that's like.

(If not mentioned...) **Was there any discomfort of any kind during the mammogram? (If yes...) How would you describe it?**

Were you told ahead of time that the mammogram could be uncomfortable? Were you given any advice about how to reduce the discomfort next time? (Note: Questions about the influence of discomfort on obtaining future mammograms will be posed later.)

Is there anything you wish they would do differently? Such as...

E. CONCERNS/QUESTIONS ABOUT BREAST EXAM/MAMMOGRAM

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Did you have any other concerns or questions that you wanted to ask about the breast exam and/or the mammogram?

Did you feel that you could talk about your concerns or questions during your visit? Why/why not?

V. RESPONSE TO RESULTS OF MAMMOGRAM (15 minutes)

Objective: Profile awareness of and response to mammogram results and to the recommendations to return for a follow-up mammogram within a particular timeframe.

A. OBTAINING RESULTS

Did you get the results of your mammogram?

Some women may not know their results and/or that the results included a recommendation for re-screening within a particular timeframe.

If all women in the group DID obtain results, the moderator will go to the next page now to proceed where indicated with questions for women who DID obtain results.

FOR WOMEN WHO SAY THEY DID NOT OBTAIN RESULTS:

Do you have any ideas about why you *did not* get the results?

Were you surprised that you did not get results?

Did you think about calling to find out? Why/why not?

Note: The moderator will probe gently to learn what women who did not obtain results reveal about efforts, if any, to obtain results. Potential probes:

Sometimes, women say that the real reason they do not call for results is that they are *AFRAID* to find out. Did you feel that way?

Were there any *OTHER REASONS* that you did not call?

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***IF ALL WOMEN IN THE GROUP SAY THEY DID NOT OBTAIN RESULTS,
MODERATOR WILL SKIP TO PAGE 12 NOW.***

If there are women who say THEY DID RECEIVE RESULTS, the moderator will continue with the following questions for them.

FOR WOMEN WHO SAY THEY DID RECEIVE RESULTS:

How did you hear about the results of your mammogram? How soon?

Were the results in writing?

How would you describe in your own words what the results were?

Was there anything confusing or hard to understand about the results?

Did you ask any questions about the results? (If yes, moderator will explore.)

Were there any recommendations along with the results?

(Following response to open-ended question...) **Was there a recommendation to return for another mammogram in the future?** (To those who say yes, the moderator will ask...)

What was the recommendation?

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**B. RESPONSE TO RESULTS AND RECOMMENDATION ABOUT FOLLOW-UP
MAMMOGRAM**

*Note: Women in two of the groups **did not** return in the recommended timeframe. These women may or may not know the results of their last mammogram and/or may not know that the results included a recommendation for re-screening. In the other two groups, participants **did return** in the recommended timeframe, but that may or may not have been because it was recommended with the results of their last mammogram. The moderator will take ample time to explore women's responses fully to obtain as much information as possible about what discouraged women from going/motivated them to go.*

Who has been back for another mammogram since the one we have been talking about?

*If EVERYONE in the group says she has been back, the moderator will skip to **PAGE 14** now to proceed.*

TO THOSE WHO SAY THEY HAVE NOT BEEN BACK:

I know there are many different reasons that women may not go back even when it is recommended. Please tell me about why you have not been back.

Following responses to this open-ended request, the moderator will promote further discussion with some questions similar to the following. The moderator will probe gently to help assure that the women do not feel that they are being criticized in any way for not going back. The moderator will also adjust wording to fit appropriately with what women might have said about not calling for results if they did not obtain them.

Sometimes, women *DO NOT REALIZE THEY SHOULD GO BACK*. Was that true for anyone?

Some women say that the real reason they do not go back is that they are *AFRAID* to. Did you feel that way?

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Was there something about *THE EXPERIENCE YOU HAD BEFORE* that has made it hard to go back?

Were you concerned about it being hard to get a *CONVENIENT APPOINTMENT* (because of transportation, family care issues, job, etc.)?

Were there any *PROBLEMS WITH THE WAY STAFF TREATED YOU DURING SCHEDULING* last time?

Was there *DISCOMFORT OR PAIN* during the breast exam or mammogram? (Again, moderator will encourage as much discussion as possible about pain.)

Or *EMBARRASSMENT* during the exam or mammogram?

Did you have any worries about *COST*?

Did you know you could get another low cost mammogram?

Did other demands on your time make it hard to go back?

IF THERE ARE WOMEN in the group WHO HAVE BEEN BACK, the moderator will continue on the next page with questions for them.

If there are NO WOMEN in the group WHO SAY THEY HAVE BEEN BACK, the moderator will SKIP to PAGE 15 to proceed with questions in Section VI.

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TO THOSE WHO SAY THEY HAVE BEEN BACK:

1. WHEN did you go back?

HOW LONG after you got the results of your last mammogram was that?

2. Tell me about WHY you decided to return?

The moderator will explore responses as much as possible to determine what motivated women to be re-screened. Following responses to the open-ended question, the moderator will probe further if needed to determine if women returned:

**Because it was recommended after the last time;
Because of a friend or relative urging her to;
For other reasons; or
For a combination of reasons (and if so, which ones.)**

**3. Was there ANYTHING DIFFERENT ABOUT THE LAST BREAST EXAM and mammogram you had from the time before that?
For example:**

**Getting a convenient appointment;
The way the staff treated you;
The exam or mammogram itself; etc.**

**Did you have any questions this time that you had not had before?
Did you feel like you could ask your questions?
Did you get information that was helpful?**

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VI. SUMMARY OF IDEAS AND SUGGESTIONS (10 minutes)

Objective: Obtain ideas and suggestions from women about what would help women get recommended breast exams and mammograms.

Moderator will adjust wording for the different groups.

We have talked about different things that have helped you or discouraged you from getting the breast exams and mammograms that are recommended. We're just about out of time now, so I have just a few more things to talk about:

FOR WOMEN WHO HAVE NOT BEEN RE-SCREENED:

What do you think are the main reasons that women *DO NOT* go?

Is there anything someone could have told you or helped you with to convince **YOU to go back?**

Think of your friends and female relatives over age 50. If you had one minute to share information with one of them about going to get a breast exam and mammogram, what would you say after our discussion today?

If there are NO women in the group who have been re-screened, the moderator will SKIP to the NEXT PAGE now.

FOR WOMEN WHO HAVE BEEN RE-SCREENED:

I'd like you to think of your friends and female relatives over age 50. If you had one minute to share information with someone of them about going to get a breast exam and mammogram, what would you say?

If she was not sure whether she should go back, what would you say to *convince* her to go?

And finally, what do you think are the main reasons that women *DO NOT* go? What would make it easier for you to go as often as recommended?

VII. CLOSING AND DEPARTURE (10 minutes)

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Objective: Obtain wrap-up advice from participants, thank them for attending, and provide opportunity for them to take print information and/or speak with a NBCCEDP expert who will be available.

I am going to step out of the room to check on your money, and I will be gone for just a minute. While I am gone, I would like you to think about any questions or concerns you have about breast exams and mammograms because I have invited someone who knows a lot about this to come back with me. She will be happy to answer anything you might like to know. [Depending on the dynamics of the group, the moderator may invite women to write down their questions or concerns so that the representative can address them without women having to identify themselves with their questions.]

While out of the room, the moderator will check with observers to determine if they have any crucial follow-up questions. Upon returning to the participants, the moderator will:

Pose observers' brief follow-up questions.

Signal for the NBCCEDP representative to join the group and introduce her. This person should thank the participants and invite them to pose questions or concerns - or - if time is short, indicate that she will remain for people to talk with afterward. She or the moderator may offer print information for participants to take home with them.

The moderator will then thank participants again and provide departure instructions.

TOTAL TIME: @ 90 minutes (tight)