

**“What You Need To Know About™ Breast Cancer”
Booklet In-Depth Interviews**

Attachment 14A: Interview Guide

Attachment 14B: Screener

Attachment 14A: Interview Guide

“What You Need To Know About™ Breast Cancer” Booklet IDIs (Year 5, Tasks B2.4 & B2.5)

2011

Interviewer Identification			
Name of interviewer _____			
Date of interview _____			
Interview start time _____		Interview end time _____	
Interviewee Identification			
Name of interviewee _____			
Interview mode (circle one): In-person Web Conference Phone only			

OMB #: 0925-0046-14.3
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I. Introduction (5 minutes)

Hi, this is _____ from the Academy for Educational Development or AED. AED is a nonprofit organization working across the U.S. and globally to improve education and health programs. AED was contracted by the National Cancer Institute (NCI) to conduct this study. Also on the phone with me is _____ from AED. S/he will be taking notes today, so we can accurately capture your feedback.

First of all, we would like to thank you for your interest in taking part in this research study and for being here with us today. As you already know, our interview today will focus on your

thoughts and opinions about the *What You Need to Know About™ Breast Cancer* booklet. The interview will last no more than 1 hour.

Before we continue, I wanted to confirm if this is still a convenient time for you to participate in this interview.

[IF NO, ASK: "What would be a more convenient time for me to call back?" ...Confirm saying, "Ok, we will call you back at (time) on (day, date)."]

(IF YES, BEGIN THE INTERVIEW.)

Did you receive a copy of the booklet in the mail?

(IF NO, SCHEDULE A CALL-BACK AT A LATER DATE):

Did you have time to read the booklet?

(IF NO, SCHEDULE A CALL-BACK AT A LATER DATE)

Thank you for having taken the time to review the booklet. This booklet is part of NCI's *What You Need to Know* series, which currently includes 23 English-language booklets about different cancer types, 9 of which have also been translated to Spanish. NCI has been publishing the *What You Need to Know* series since 1978. The content of each booklet in the series is updated on a regular basis. As part of the next revision of the *What You Need to Know About™ Breast Cancer* booklet, NCI is interested in gathering feedback from individuals diagnosed with breast cancer to identify opportunities to improve the booklet to better meet the needs of patients, as well as inform NCI's future research and efforts in this area. That is what brings us here today...

The feedback you provide today will be kept secure to the extent permitted by law. The findings will be reported to the NCI in a summary form and no names or other identifying information will be used. With your permission, we would like to audiotape today's interview. The recording will only be used to aid us at AED in writing our report of the findings. Do I have your permission to record our discussion today? If so, I will turn on the recorder now.

[If participant agrees – and has signed a consent form – proceed with taping the interview. If participant is uncomfortable or unsure, proceed without taping.]

I also would like to remind you that you can stop the interview at any time or choose not to answer any particular question without any penalty. There may be questions that I will ask that you may not be able to answer or feel comfortable answering. That is OK. Please just let me know if you are unable to answer a question and we will move on to the next question. Because we have a limited amount of time there will also be points in the interview where I may move the discussion to another question. If there is time in the end, we can always revisit a topic.

[If NCI representative(s) will be listening say the following:] _____ from the NCI are listening to our interview today on the phone [or from the room next door]. She/they will be

listening in to let me know if I have covered everything I need to ask during the interview or if she/they have any follow up questions she/they would like me to ask you in order to learn more about your opinions, thoughts and perspectives on the topics we are discussing today. To protect your privacy, I will only use your first name today. If you prefer for the representative(s) from the NCI to not listen in, please let me know.

Do you have any questions for me before we get started? **[Address any questions]**

Let's get started then...

Before we actually talk about the booklet, I would like to ask you a few questions about your experience with cancer. Again, please feel free to let me know if you prefer not to answer any particular question I ask.

[NOTE: Throughout the interview—and whenever appropriate—probe participants to think back to the time soon or right after they were diagnosed]

II. Warm-Up/Background (5 minutes)

1. How long ago were you diagnosed with breast cancer?
2. What stage was the cancer at the time that you were diagnosed?
3. Have you undergone any type of treatment? If so, what type? How long ago did you undergo this treatment(s)? Have you completed treatment?

III. Information Needs & Information-Seeking Post Diagnosis (5 minutes)

1. Thinking back to when you were first diagnosed, what kinds of questions did you have?
2. Looking back at it now, is there anything else you wish you had known at that time?
3. What resources did you use to get the information you needed after you were diagnosed?
 - a. Probe: Did you use any print materials, such as books, brochures, pamphlets? If so, can you share some examples of materials you used? What type of information did they have? What organizations were they from?
 - b. Probe: Did you search for any information online? If so, what website or websites did you use? Was there any difference in the type of information you looked for online versus in print or from your health providers?
 - c. Probe: What other resources, if any, did you use?

IV. Reactions to the booklet (40 minutes)

Now I'd like to go through the patient information booklet you received in the mail. This booklet is the current version that is available to the public. As I mentioned before, this booklet is in the process of being revised. I'm interested in hearing about your impressions of the booklet (e.g., what you liked or didn't like) and how you think it could be better or more useful.

I know you also received a few separate pages that are a prototype of what the new booklet might look like. For now, let's focus on talking about the content in the current version. Later on in the interview we will take a few minutes to talk about the prototype for the new layout or look of the booklet.

A. General Impressions (15 minutes)

Let's start by talking about your overall impressions of the booklet.

1. BEFORE you even opened the booklet and read it, what were your reactions to it?
 - a. Probe: If I had never seen a copy of the booklet, how would you describe it to me?
 - b. Before you opened the booklet and read it— in other words, based on the information on the cover, its title—what type of information were you expecting to find in this booklet? Who did you think this booklet was intended for?
2. AFTER you read the booklet, what were your overall reactions?
 - a. Probe: What sections did you first go to when you began reading the book?
 - b. Probe: Did it meet the expectations you said you had about its content before you had opened it and read it?
3. Is there anything about the booklet that you particularly liked?
 - a. Probe: If YES, what did you like about it? Why?
 - b. Probe: If NO, why do you think that is the case?
4. Is there anything you particular disliked or that bothered or offended you?
 - a. Probe: If yes, what? Why?
5. What do you think about the size and length of the booklet?
 - a. Probe: Do you think is too long? Too short? Just right? Why?
 - b. Probe: What do you think of the 5" x 8" size of the booklet?

6. What words would you use to describe the tone of the booklet to me? Do you think the tone is appropriate? Or do you think it needs to be changed in any way?
7. Do you think the images and illustrations on the booklet are helpful? Why or why not?
 - a. Probe: How, if in any way, could the medical illustrations of the breasts and lymph nodes (for example, on pg.3 and pg. 23) be improved?
 - b. Probe: Do you prefer photos or drawings? (go to pg.11) Would you prefer to see photos or drawings of female patients with their physicians?
8. On a scale of 1-10, where 1 is “not at all useful” and 10 is “extremely useful”, how useful do you think this booklet would have been in answering the kinds of questions you had initially, in the time soon after your diagnosis?
 - a. Probe: Why did you give it that rating? What, if anything, would have made you give it a higher rating?
9. What do you see as the main purpose of the booklet? How well would you say it accomplishes its purpose? Why?

While the *What You Need to Know About™ Breast Cancer* booklet may serve as an information resource for breast cancer patients in general, it was particularly developed by the NCI as a resource for recently diagnosed breast cancer patients. So, as we continue the interview, I would like to ask you to keep this in mind in your responses and feedback. In other words, as we continue, I would particularly like to hear your thoughts and opinions, based on your own personal experiences, about how this booklet meets or could better meet or address the information needs of breast cancer patients soon after their diagnosis.

Let's continue then...

B. Clarity and Organization (5 minutes)

I would now like to ask you a few questions to get your opinion related to the organization and the clarity of the information in the booklet.

1. Is there anything in the booklet that was unclear, confusing or not explained well enough? If yes, what? Why?
2. On a scale of 1-10 where 1 is not at all clear and 10 is crystal clear, how clearly written or easy to understand was this booklet?
 - a. Probe: Why did you give it that rating? What, if anything, would have made you give it a higher rating?

3. How well explained were the more difficult terms and concepts in the booklet? (For example, terms and concepts like “targeted therapy” and “lymph node”)
4. What do you think about the organization of the booklet?
 - a. Probe: Is the booklet laid out in a logical order?
 - b. Probe: Is the information easy to find? For example, if you had a question about hormone therapy, would you know where to find it?
 - c. Probe: Is there anything you would change about the way in which the booklet is organized? Anything you would not like to see changed?

C. Specific Reactions to the Content of the Booklet (15 minutes)

Let's go through and discuss some specific sections of the booklet so you can tell me your thoughts about each of these sections and the comments you might have jotted down as you read through the booklet. Given that we have limited time today, let's focus on any general thoughts or comments you may have. If you marked any suggestions for very specific edits—such as changing a word or the wording of a sentence— please keep in mind that once the interview is over you can send us the booklet with all the comments and suggestions you marked on it; that way NCI can look at the notes or edits you jotted down even if we don't have a chance to talk about all of them today.

[If in their response to Q1 and Q2 of this part of the interview participant mentions any of the following sections—Treatment, Questions for Doctor (text boxes), Dictionary and/or NCI Publications, make sure to also address the probes included below on Q3 for each of those sections. If they don't come up in their response to Q1 and Q2, make sure to still address the sections and probes included in Q3 before moving on to the next part of the interview.]

Let's go to the table of contents at the beginning of the booklet. ***[Confirm they are on the table of contents page then continue.]*** Let me start by asking you....

1. What particular section or sections in the booklet do you consider to be the most useful? ***[For those 1+ years since diagnosis OR past treatment phase, also say:]*** In other words, thinking back to the time soon after your diagnosis, what section(s) would have been the most useful to you at that time?

[For the sections they mention, discuss the general probes that follow. Try to probe section by section, as time allows.]

- a. Probe: Why do you think that section(s) would have been [would be] useful to you? Is there any specific information within that section(s) that makes it particularly useful?
- b. Probe: Is there anything you think needs to be changed? If so, what? How do you think it needs to be changed?

- c. Probe: Is there anything you particularly liked about that section(s) that you would not like to see changed? If so, what?
 - d. Probe: Are there any thoughts or comments you would like to share about this section(s)—for example, perhaps something you jotted down on the booklet as you were reading it?
2. Do you have any thoughts about other sections in the booklet that you would like to share—perhaps something you would like to see changed, or something that you liked that you would NOT want to see changed?
 3. Before we move on, let me ask you a few more questions about some particular sections that we have not discussed yet...

[Discuss with the participant questions below that have not been addressed so far in the interview for each of the sections below]

- **Treatment** section (pg. 19)
 - a. Probe: What was your overall reaction to this section? Anything you particularly liked or disliked about it? Anything you would change about it or that you would not want to see changed?
 - b. Probe: ***[If still in treatment]*** Would the information included in this section be helpful to you in making treatment-related decisions? Why or why not? ***[If already past treatment phase]*** Would the information in this section be helpful to you in making treatment-related decisions after you were diagnosed? Why or why not?
 - c. Probe: Do you think the information included about each treatment option is clear?
 - d. Probe: Is the amount of information included in this section about each treatment appropriate? Is it enough? Too much? Too little?
 - e. Probe: How could the treatment section be improved? Is there any information that you think is missing in this section? Is there any information that should be taken out? If so, what should be added/excluded? Why?
 - f. Probe: Is there information you would have liked immediately following diagnosis to inform treatment options that is not included here? ***[For those still undergoing treatment]*** Is there any information you would want to have seen in the booklet to help inform your treatment options?
- **Questions for Doctor—Text Boxes** (pgs. 21, 26, 29 and 35 in Treatment Section)
 - a. Probe: On pages 21, 26, 29 and 35 there is a text box with treatment-related questions for patients to ask their doctor. What did you think of these text boxes?
 - b. How helpful do you think you would have found these questions when you were first diagnosed? Why?
 - c. Are there any important questions missing? If so, which ones? Why?
 - d. Are there any questions here that you would leave out? If so, which ones? Why?

- **Dictionary** (pg. 48)
 - a. Probe: What was your overall reaction to this section? Anything you particularly liked or disliked about it? Anything you would change about it or that you would not want to see changed?
 - b. Probe: Are the definitions provided for each of the terms clear and easy to understand? If no, which term(s) is not clearly defined?
 - c. Probe: Are the terms included in the dictionary appropriate? Why or why not? If not, what are some examples of terms that may not need to be included in the dictionary?
 - d. Probe: Are there other terms used in the booklet that you think should have been defined and included in the dictionary? Which ones?

- **National Cancer Institute Publications** (pg. 48)
 - a. Probe: How clear is it to the reader how to get copies of other available NCI publications?

Let's now go back again to the table of contents at the beginning of the booklet. ***[Confirm they are on the table of contents page then continue.]***

4. Now that we have had a chance to discuss different sections in the booklet, is there any section or particular information in the booklet that you think should be taken out? If so, what? Why?
 - a. Probe: Do you think the "risk factors" section is appropriate for this booklet or should it be removed? Why or why not? What about the "symptoms" and "detection and diagnosis" sections?

5. Does the booklet give enough information? Did the booklet capture everything a recently diagnosed breast cancer patient would need and want to know?
 - a. Probe: [If NO] What questions about breast cancer are not answered?
 - b. Probe: [If NO] Can you suggest any other pieces of information that we haven't talked about that would improve this booklet? Is there information or content that you would like to see added to the booklet that is not already there? If yes, what? Why?

D. Reactions to the Layout and Design (5 minutes)

1. How does the layout and design in the current printed booklet compare to that of the prototype pages? Which one do you like best? Why?

2. Looking in more detail at each layout and design (the one from the current booklet and the one from the prototype), what are some of the specific things you liked most about each one? What do you like least about each one?

3. Now, let's focus on the prototype. Of those things you mentioned you did not like much about its layout and design, do you have any suggestions on how these may be improved?
 - a. Probe: Would you keep it as it is in the current version instead? Or do you have other suggestions for how to change it?
4. It is likely that this prototype will undergo more revisions before the new version of the booklet is printed. Is there anything about this prototype that you would not want to see changed? If so, what? Why?

V. Wrap-up/Closing (5 minutes)

1. If your doctor provided you with a thin NCI brochure on breast cancer rather than a booklet of this size and you were told to go to the NCI website for more information, would you go to the website? Why or why not?
2. Do you have any other comments regarding the booklet or any other topics we discussed that you would like to share with us today?

Thank you for your time today. The information you provided will be very helpful to NCI as they move forward to better meet the informational needs of individuals diagnosed with breast cancer. If you can, we encourage you to send back to AED the booklet that you reviewed with any comments, edits or suggestions you marked on it. Before you send it, feel free to go back to the booklet and add any additional comments or suggestions you may have thought about during the interview today.

Well, once again, thank you very much for your time and participation. Have a nice day/evening.

**National Cancer Institute
2011**

**Attachment 14B: Screener for IDI task:
“What You Need To Know About™ Breast Cancer” Booklet
(Year 5, Tasks B2.4 & B2.5)**

Recruit **24 breast cancer patients/survivors:**

- 12 of whom were diagnosed with breast cancer within less than 1 year.
- 12 of whom were diagnosed with breast cancer within the last 1 to 3 years.

Approximately half (5 to 6) of the participants in each group of 12 should have been diagnosed at an earlier stage (Stage 0, Stage I and Stage II), while the remaining half (5 to 6) should have been diagnosed at a later stage (Stage III and Stage IV).

Only female breast cancer patients should be recruited.

PROSPECTIVE PARTICIPANT SCREENER

Hello, I'm _____ from [agency name]. I'm calling today on behalf of the National Cancer Institute, or NCI. Thank you for contacting us to express interest in participating in a research study the NCI is conducting about a breast cancer booklet they have developed. Through this research study, NCI wants to explore whether there are ways in which the booklet may be improved to better meet the needs of breast cancer patients. This research study will also help NCI gain a better understanding of the cancer-information needs of breast cancer patients after their diagnosis in order to inform NCI's future research and efforts in this area.

I need to ask you just a few questions to determine whether I can invite you to participate in an interview. My questions today will only take a few minutes. Some of the questions are about your personal experiences with cancer. Your responses will be kept secure to the extent permitted by law. We are not selling any product or service. Everyone who is eligible and participates will be paid \$75 as a thank you for your time.

May I continue with my questions?

1. I understand that you currently have or have had breast cancer? Is that correct?

Yes _____
Stop>> No _____

2. How many months or years ago were you diagnosed with breast cancer?
_____ [RECORD MONTHS/YEARS SINCE DIAGNOSIS]

Less than 1 year _____
1-3 years _____
Stop>> More than 3 years _____

3. What was the stage of the breast cancer when you were diagnosed?

Stop>> Stage 0 _____
Stage I _____
Stage II _____
Stage III _____
Stage IV _____

4. Have you read the booklet "What You Need to Know About Breast Cancer", which is a publication from the National Cancer Institute?

Yes _____
No _____
Not sure _____

5. Have you ever read any other publications (e.g., booklets, pamphlets) from the National Cancer Institute?

Yes _____
No _____
Not sure _____

We are almost done. Now we would just like to ask you a few demographic questions.

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

Less than high school _____
High school diploma/GED _____
Some college _____
College degree _____
Graduate degree _____

7. Please identify which of the following ranges matches your income?

- Under \$35,000 _____
\$35,000 - \$50,000 _____
\$50,000 - \$75,000 _____
Over \$75,000 _____

8. What is your age?

____|____| [RECORD AGE]

- Under 30 _____
30 - 60 _____
Over 60 _____

9. Which of the following best describes your race (may choose one or more)?

- American Indian or Alaska Native _____
Asian _____
Black or African American _____
Native Hawaiian or Other Pacific Islander _____
Caucasian/White _____

10. Do you consider yourself Hispanic or Latino?

- Yes _____
No _____

****STOP LANGUAGE:**

Thank you very much for your time. The NCI greatly appreciates your interest in taking part of this research study.

In order to gain feedback from patients with a range of experiences and circumstances, NCI would like to include in this study participants that have been diagnosed within different time frames (e.g., some who have been diagnosed very recently and others for which a longer period has passed since diagnoses) as well as patients that were diagnosed at different cancer stages (e.g., Stage I, Stage II). As of today, we have recruited all of the persons with a similar experience as yours [SAY, for example: diagnosed within the last 1-3 years OR diagnosed at a Stage II] that can be included in this study. Therefore, at this time, we would like to hold on scheduling your participation. However, because there is always the possibility that someone who has already been recruited may need to cancel their participation, we would like to keep

you on our list of persons interested in participating in order to contact you in the near future if someone else cancels their participation. Would that be okay with you?

NCI would still like to send you a free copy of the breast cancer booklet in case you would like to use it for your own reference or share with others. Would you be interested in receiving a copy of the booklet? [If “yes”, ask for a mailing address].

Once again, thank you for your time and interest. Have a good day/evening.

INVITE TO INTERVIEW:

Thank you for answering my questions. As I mentioned this study is being conducted on behalf of the National Cancer Institute.

In order for us to learn from your opinions, thoughts, and experience firsthand, I would like to invite you to participate in a one-on-one interview. The interview will last about sixty minutes and it can be done either in-person, by phone or through web conference. Given that during the interview you will be discussing your thoughts about different parts of the booklets and it is possible you or the interviewer may want to point to different sections in the booklet, we encourage participants to complete the interview either in-person or through web conference. However, if your preference is to participate by phone, we understand and can accommodate for that. The in-person interviews would be conducted either at NCI's offices in Rockville, MD or in AED's office near Dupont Circle, in Washington DC. AED is a non-profit research agency that has been contracted by NCI to conduct this study. The web conference would be done using both the phone and the computer; participants that select this option would need to have a reliable high-speed Internet connection. The way the web conference would work is that in addition to being on the phone with the interviewer, the participant would also log in on a website (e.g., Go-to-Meeting) that would allow them to see the computer screen of the interviewer; on the screen, the participant would be able to see an electronic copy of the booklet so that during the interview they or the interviewer will have the ability to point to different parts of the booklet with their computer mouse. During the web conference the interviewer and participant would not be able to see each other; there will be no web cameras involved.

How would you like to participate in this interview?

[RECORD INTERVIEW MODE: _____]

You will be mailed a copy of the booklet to review before the interview. Along with it, you will also receive some guidelines or instructions for reviewing the booklet. You will be asked to spend about 1 hour reviewing the booklet before the interview. In addition, the packet you receive in the mail will include the [Say, as appropriate: directions of where you will need to go OR the phone number OR computer and online log-in information] for the interview. [Only say if participate is being interviewed remotely: You will also be mailed a consent form that you will need to sign and return, either by mail, fax or e-mail, before the interview.]

*As a token of appreciation for your time you will receive a **[\$75 Visa Gift Card]** once the interview is completed. Can we schedule your participation?*

We would like to schedule the interview on a day and time that is most convenient for you. Beginning on [DAY- allow at least 10 day for mailing materials and review time], when would be a convenient time for you to participate in the interview?

INTERVIEW DATE: _____ INTERVIEW TIME: _____

NAME: _____

EMAIL *** _____

PHONE: (DAY) _____

(EVE) _____

(FAX) _____

(CELL) _____

MAILING ADDRESS: _____

Additional Notes

Prior to concluding call with scheduled participant:

- Remember to get their mailing address to where they would like the booklet/review instructions sent.
- If participating remotely, please confirm if the incentive gift card that will be mailed to them after the interview should be mailed to the same address they provided for mailing the booklet packet (Note that all gift cards will need to be sent to an address where someone will be available to sign for the packet).
- If participating in-person, make sure to confirm which location they would prefer to go to for the interview (Rockville location or DC location)