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CONTRACTING ORGANIZATION: O a e & ^ i A i ^ c ^ } a } A Q • c i c a ^ A - O a a [ i } a e  
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# REPORT DOCUMENTATION PAGE

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<b>13. SUPPLEMENTARY NOTES</b>					
<b>14. ABSTRACT</b> During this reporting period, we completed analysis and reported on the qualitative focus group and one-on-one interviews, finalized the survey and cognitive guide for testing the survey in the cognitive phase, completed translation of the survey and cognitive guide documents into Spanish, Chinese and Tagalog, and completed 36 total cognitive interviews with breast cancer survivors from 7 racial/ethnic groups. Because of the complexities of issues that were identified in the qualitative analysis, we decided to include more survey items than originally intended to be tested in the cognitive phase and, to reduce participant fatigue, we split the cognitive survey guide into two interviews, with the goal of testing each overall section of the survey on 3 participants. We conducted a thorough analysis of the aggregate cognitive data, tested revisions to problematic questions on remaining cognitive participants, further revised, and ultimately finalized the survey instrument. We have developed training materials and protocol for the final, epidemiologic, study phase.					
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## INTRODUCTION

The objective of this study is to measure the prevalence and impacts of discrimination at the institutional- and individual- level to identify the underlying factors contributing to disparities in breast cancer diagnosis, treatment, and quality of life. The specific aims are to: 1) develop a survey tool tailored towards cancer patients for assessing discrimination in health care settings; 2) quantify the prevalence of individual- and contextual-level discrimination across racial/ethnic groups; and 3) assess the effects of individual- and contextual-level discrimination on disparities in: a) late stage diagnosis, b) cancer treatment (including breast conserving surgery (BCS) and adjuvant radiation), and c) quality of life (QOL). This study comprises two components: developmental (Aim 1) and application (Aims 2-3). The developmental component used qualitative research to develop an instrument tailored for breast cancer patients. Because tools have not been developed for cancer patients nor for different races/ethnicities, we conducted focus groups and qualitative (one-on-one) interviews to discern relevant discrimination topics. The topics, together with existing instruments, were used to develop an instrument to be cognitive-tested in a small sample of patients. We will then conduct a pilot test, including a reliability test-retest, of select instrument items and field methodology to optimize its reliability. In the application component, we will conduct a cross-sectional epidemiologic study using a multilevel approach by incorporating individual- and neighborhood-level information including: 1) previously collected geographic information systems (GIS) data about the social and built environment; and 2) telephone interviews with a population-based cohort of breast cancer patients.

## BODY

The original Statement of Work for the first three years of the study is as follows:

- Task 1* Obtain IRB approvals, design and obtain approvals on focus group and qualitative interview instruments, translate and back-translate instruments, develop study tracking system and training materials, Months 1-6
- Prepare and submit IRB applications for DOD and NCCC.
  - Apply for cancer registry data from the Greater Bay Area Cancer Registry (GBACR).
  - Develop MS Access tracking system.
  - Develop interviewer training manual.
  - Translate, back-translate, convene meeting(s) to decenter instruments.
  - Hire staff.
  - Obtain first case listing data from the GBACR, download into tracking system.
  - Organize community advisory committee meeting to introduce study and obtain feedback about general research strategy.
- Deliverables: IRB approvals, finalized instruments for focus group and qualitative interviews, community advisory committee feedback
- Task 2* Conduct focus group and qualitative interviews, Months 7-12
- Select breast cancer patients for contacting regarding focus group and qualitative interviews.
  - Recruit breast cancer patients for fulfilling the numbers of required focus group and qualitative participants for each racial/ethnic group.
  - Conduct focus group and qualitative interviews.
  - Transcribe interviews.
- Deliverables: completed focus group and qualitative interviews, transcripts of completed interviews
- Task 3* Conduct qualitative data analysis, design epidemiologic survey instrument, Months 13-18
- Code the transcribed interviews.
  - Conduct thematic-driven qualitative data analysis.
  - Design epidemiologic survey instrument.
  - Translate epidemiologic survey instrument.
  - Develop and obtain IRB approval for recruitment materials and procedures for cognitive interviews.
- Deliverables: completed qualitative data analysis, epidemiologic survey instrument and recruitment materials for cognitive interviews

- Task 4* Conduct cognitive interviews, revise epidemiologic survey instrument as necessary, Months 19-21
- a. Select breast cancer patients for contacting regarding cognitive interviews.
  - b. Recruit breast cancer patients for fulfilling the numbers of required cognitive interviews for each racial/ethnic group.
  - c. Conduct cognitive interviews.
  - d. Convene study staff meetings to discuss results from cognitive interviews and to revise instrument as necessary.

Deliverables: completed cognitive interviews, refined epidemiologic survey instrument based on cognitive testing

- Task 5* Conduct pilot testing, revise epidemiologic survey instrument as necessary, Months 22-24
- a. Select breast cancer patients for contacting regarding pilot test interviews.
  - b. Recruit breast cancer patients for fulfilling the numbers of required pilot test interviews for each racial/ethnic group.
  - c. Conduct pilot test interviews.
  - d. Conduct reliability test-retest interview.
  - e. Conduct data analysis.
  - f. Convene study staff meeting to discuss results from pilot test interviews and to revise instrument as necessary.
  - g. Convene community advisory committee to review study instrument and field recruitment methods and obtain advice regarding appropriateness, relevance, and feasibility.

Deliverables: completed pilot test interviews, refined epidemiologic survey instrument and field methods based on pilot testing, community advisory committee feedback

- Task 6* Conduct epidemiologic interviews, GIS analysis to create neighborhood variables, Months 25-40
- a. Select breast cancer patients for contacting regarding epidemiologic interviews.
  - b. Recruit breast cancer patients for the epidemiologic interviews.
  - c. Conduct epidemiologic interviews.
  - d. Design data entry system in MS Access.
  - e. Edit questionnaire, conduct double data entry.
  - f. Conduct quarterly, interim data analysis to look for unusual data patterns.
  - g. Clean and prepare epidemiologic interview data for analysis.
  - h. Conduct GIS analysis to create study-specific neighborhood measures and merge to interview dataset.
  - i. Create statistical program to conduct multilevel modeling analysis.
  - j. Conduct test-runs of multilevel modeling analysis.

Deliverables: completed epidemiologic interviews, epidemiologic analytic dataset, multilevel modeling analysis program

### *Progress*

To date, we have completed tasks 1 through 4 outlined in the Statement of Work. As mentioned in previous annual reports, transcription, translation and analysis of the qualitative data took longer than expected. In addition, IRB approvals continue to be time consuming, especially due to State of California furloughing during the past reporting period. As mentioned in our annual report of July 2010, our initial look at the qualitative data indicated to us that simply adapting existing discrimination survey items, particularly in the medical or health care setting, would be inadequate, given that breast cancer patients did not explicitly identify discrimination. At the same time, further analysis of the qualitative data revealed that participants did experience subtle forms of medical discrimination. For example, one Filipina participant described having to insist on receiving a breast biopsy secondary to a nipple abnormality and normal mammograms. It took a full 5 years before she was able to get the needle aspiration. However, when asked whether she thought she was treated unfairly because of her race, ethnicity, education, etc., she said she did not think so—that she was just unlucky to have consulted with the wrong doctors. Our analyses indicated that our survey instrument would need to include items that

would allow us to capture this type of information in many, more subtle and objective ways—not just by asking about medical discrimination explicitly.

Over the past reporting period, we successfully completed Task 4, the cognitive component. The primary objective of the cognitive component was to identify problem areas in the survey items and to revise accordingly and test further. We had developed several strategies and survey items to measure both everyday and medical discrimination. We then split the survey into 2 separate versions of a cognitive instrument, with all discrimination items being covered in both versions. The cognitive instruments incorporated a set of specific questions following each survey question or set of survey questions, to assess participants' understanding of the item. Specific cognitive questions included: what did the participant understand the question(s) to mean, if the categories were adequate, if the question was offensive, if it was difficult to do the necessary calculations or estimations in their heads, etc. We also systematically collected feedback from the interviewers about the ease in wording of the survey items, the perceived ease with which respondents answered, concerns about the accuracy of variable measurement, and cultural appropriateness. A team of three researchers coded participant responses to probed questions, highlighting problems in eight specific areas: reading, instructions, clarity, assumptions, knowledge/memory, sensitivity/bias, response category, and translation/cultural issues based on the Q-Bank codes. These three reviewers then met and triangulated information obtained from cognitive testing and interviewer feedback. We then refined/modified survey items for a second round of cognitive testing. We will be reporting our experience and the value of cognitive testing in a separate process manuscript.

As reported in the July 2010 annual report, we described the secondary qualitative data analysis being led by Dr. Janet Shim (UCSF) to explore the emerging concept of cultural health capital in our qualitative data. Dr. Shim continues to actively analyze the data. We had developed, de novo, a set of survey items to measure cultural health capital, but these items did not perform well in cognitive testing, so are not being included in the epidemiologic survey. However, we have subsequently submitted additional grant applications that aim to explore cultural health capital in further depth and to develop and test survey questions that will measure this concept in multi-ethnic cancer patient populations.

Secondary to issues in hiring, training, and retaining qualified Tagalog interviewers, we were unable to test the Tagalog version of the survey instrument. However, our experience with cognitive testing demographic survey items (some of which are in the final version of the EBCC survey) in Tagalog in another project enabled us to identify translation issues unique to this language and population. As a result, the Tagalog translation of the final survey instrument has undergone a rigorous process of translation, back-translation, input from outside Tagalog-language consultants, and further refinement. We are confident that the final Tagalog version of the survey instrument will perform similarly to the other-language versions.

Due to time constraints, we have integrated Task 5, the pilot test component, with Task 6, the epidemiologic component. Thus, the test-retest will be conducted among a sample of participants in the epidemiologic component. At this time, we have received conditional IRB approval of the English epidemiologic phase instruments. We are in the process of translating these instruments, and developing the interviewer training materials. Training of interviewers will take place in August. To make up for the study delays, we plan to increase our interviewers' levels of effort during the epidemiologic phase and we expect that we will be able to complete the epidemiologic interviews in a considerably shorter amount of time than originally outlined in the Statement of Work. In addition, we have already assembled the institutional and contextual data, which are tasks outlined in Task 6 of the Statement of Work. We expect to conduct preliminary analyses of the epidemiologic data as they are being collected. The remaining tasks will be completed within the approved no-cost extension period.

## KEY RESEARCH ACCOMPLISHMENTS

- Translated epidemiologic survey instrument in three languages (Spanish, Chinese, and Tagalog)
- Successfully conducted cognitive interviews with 36 participants from among 10 racial/ethnic groups in 4 different languages (3 Cantonese, 3 Mandarin, 6 Spanish, 24 English). Implemented an Interviewer Rating System to systematically obtain feedback from interviewers regarding survey questions and ease of administration.
- Analyzed cognitive testing data using two independent coders and incorporated findings into revision of epidemiologic survey instrument. Completed expert review of epidemiologic survey leveraging the expertise of our Community Advisory Board and clinician collaborators.
- Presented qualitative and cognitive findings at the NCI Science of Discrimination conference, and will be presenting findings at the 2011 Era of Hope meeting.
- Manuscript reporting on qualitative results is selected to be among a few to be further selected for inclusion in a special theme issue on discrimination for the American Journal of Public Health.
- Three additional manuscripts are currently under preparation, including manuscripts reporting on: 1) qualitative results on social support, social burden, and social networks; 2) qualitative results on cultural health capital; and 3) commentary paper on the benefits of integrating mixed-methods research in epidemiologic studies.
- Developed survey modules for measuring medical discrimination.
- Begun to assemble secondary, contextual data on neighborhoods and institutions.
- Submitted additional grant applications to leverage infrastructure developed through this study, including using the cases to be recruited as part of the epidemiologic phase for a future case-control study (notified about funding through the California Breast Cancer Research Program); incorporating a medical records abstraction component for assessing adherence to clinical practice guidelines; and conducting formative research to better understand the formation and dynamics of social networks and to develop survey tools to measure social networks among breast cancer survivors.

## REPORTABLE OUTCOMES

- Our cognitive analyses revealed important findings that were used to further refine the epidemiologic survey instrument. For the medical discrimination module, several questions were deleted from the survey because they were found to be conceptually ambiguous and yielded a large proportion of “don’t know” responses during testing. These questions were intended to capture the extent to which women perceived that medical discrimination occurred when a patient’s physician is of a different racial/ethnic background or of the same racial/ethnic background (“How often do you think a patient is treated unfairly by his or her doctor when they are of different racial or ethnic backgrounds?” and “How often do you think a patient is treated unfairly by his or her doctor when they are of the same racial or ethnic background?”). However, we found that questions that ask about hypothetical knowledge of other people’s experiences when interacting with their health care provider were difficult to answer. We also found that asking women to identify the main reason as to why they felt they were treated unfairly was problematic, as women found it too difficult to choose one main reason. For this module, we also dropped the items on internalized racism as the cognitive interviews indicated that these questions were too biased/sensitive (e.g., “Have you ever considered getting your hair straightened?”) or were too ambiguous (e.g., “Have you considered getting eyelid surgery to make your eyes bigger [surgery that creates double folds in the eyelids]?”) and requires further improvement and testing prior to fielding.
- Through review by experts/advisors, we also implemented a number of revisions. For example, in terms of response options for reporting frequency of discrimination experiences, we found that women preferred to answer with vague quantifiers (e.g., “never, rarely, sometimes, often”) than with actual counts (e.g., 0, 1 time, 2-3 times, 4 times) that were previously used in standardized instruments.
- Cognitive testing also revealed translation and cultural equivalency issues for key terms in the discrimination module, such as “respect,” “courtesy,” “threatened,” and “harassed.” These translation issues were found to be more problematic in Chinese and were identified for further revision by our translation staff. We also found that the framing of the questions and transition language were critical to improving survey performance. Many respondents reported frustration with questions they perceived not to be directly related to their breast cancer diagnosis and treatment. These include questions about

general and medical discrimination, coping/stress management, and neighborhood characteristics. To address these concerns, we incorporated transition and framing language that explained the general purpose of particular sets of questions to improve survey flow and ease respondent concerns.

- Findings from the cognitive interviews relevant to other (non-discrimination) domains resulted in modifications to the survey items on treatment, out-of-pocket costs, cultural health capital, and immigration-related stress. For example, with respect to the out-of-pocket question, cognitive interviewing helped us to identify questions that were overly complex and place a large burden on the respondent. We were able to then break it down into simpler questions, which resulted in more accurate responses with less respondent burden. We also learned from the cognitive interview process how to modify survey items, such as the survey items on immigrant stress, that were originally designed for self-administration to be more feasibly administered by an interviewer over the phone.
- Appendix B includes the epidemiologic survey that will be administered in the epidemiologic phase of the study.

## **CONCLUSIONS**

The developmental phase of the study has been successfully completed after substantial vetting of the epidemiologic survey instrument through rigorous cognitive testing, feedback from interviewers, and review by our Community Advisory Committee. This process has been critical to the development of a comprehensive survey instrument to measure self-reported medical discrimination across multi-ethnic populations.

## **REFERENCES**

None.

## **APPENDICES**

Next page.

### Appendix A:

Study Focus Group, Qualitative and Cognitive interview outcomes and response rates by ethnic group and interview type

Interview type / Outcome	Numbers of subjects by race/ethnicity							TOTAL
	White	Chinese	African American	Hispanic	Filipina	Japanese	Other	
<b>Focus group</b>								
Invitation letter sent	50	87	46	52	61	33	n/a	329
Ineligible	7	2	1	14	16	7	n/a	47
Refused	15	29	3	14	31	11	n/a	103
Participated	6	11*	6	5	3	6**	n/a	37**
Lost to follow up	5	-	-	10	9	1	n/a	25
Not needed***	12	23	7	7	-	8	n/a	57
Not reached****	5	22	29	2	2	1	n/a	61
Response rate, % (of contacted and eligible)	28.6%	27.5%	66.7%	26.3%	8.8%	31.3%	n/a	25.9%
<b>Qualitative (one-on-one) interview</b>								
Invitation letter sent	20	45	18	18	20	19	21	161
Ineligible	2	4	-	5	1	1	7	20
Refused	4	19	1	6	5	11	4	50
Participated	3	6+	3	3	3	3	5++	26
Lost to follow up	1	3	-	1	-	1	1	7
Not needed***	10	6	6	3	2	2	-	29
Not reached****	-	7	8	-	9	1	4	29
Response rate, % (of contacted and eligible)	42.9%	24.0%	75.0%	33.3%	37.5%	21.4%	55.6%	34.2%
<b>Cognitive interview</b>								
Invitation letter sent	39	21	16	20	32	25	48	200
Ineligible	8	-	3	2	1	-	6	20
Refused+++	8	2	5	5	5	12	17	54
Participated	6	6	6	6	2	6	4++++	36
Lost to follow up	4	1	2	1	-	4	13	25
Not needed***	1	2	-	3	2	1	2	11
Not reached****	12	10	-	3	22	3	4	54
Response rate, % (of contacted and eligible)	42.9%	75.0%	54.5%	54.5%	28.6%	33.3%	19.0%	40.0%

\* 2 focus groups; 6 participants in Mandarin focus group and 5 participants in Cantonese focus group.

\*\* Note that total number of Japanese participants was erroneously reflected in previous Focus Group numbers. 6 Japanese survivors participated in the Focus Group with a total of 37 participating across all r/e groups.

\*\*\* Hold/Not needed = participants who were contacted but not needed for the focus group, qualitative, or cognitive interviews because the goal for number of participants was reached, or participants who could not participate in these phases but agreed to be contacted for later phases; these women will be re-contacted for subsequent phases of the study.

\*\*\*\* Not reached = participants who had not been reached by the time we reached our goal numbers or ended recruitment for the focus group, qualitative, or cognitive interviews, but who are not necessarily lost to follow up or whose addresses still need to be traced.

+ 3 Mandarin; 3 Cantonese

++ 2 Discovered ineligible after interviewing.

+++ Includes MD Refusals

++++ 1 American Indian, 1 Asian Indian, 1 Fiji Islander, 1 Tongan

Appendix B  
Epidemiologic Survey

## EQUALITY IN BREAST CANCER CARE

### Epidemiologic Survey

07/19/2011

DATE: \_\_\_\_\_

TIME START: \_\_\_\_\_

STUDY ID: \_\_\_\_\_

TIME END: \_\_\_\_\_

INTERVIEWER: \_\_\_\_\_

➤ GENERAL INSTRUCTIONS TO INTERVIEWER:

*IT IS EXTREMELY IMPORTANT TO READ EACH QUESTION VERBATIM. All participants need to hear each question in the exact same way in order for us to ensure that the responses they provide are not biased.*

*Read all **BOLD black** type. The questions are in **BOLD black** type, as well as some instructions and introductions to various sections. Do not read choices that are in ALL CAPS. The choice "I don't know" is indicated by "D/K," and if the participant refuses to answer a question, select "REF" or "REFUSED." You are not to give "D/K" as an answer choice, but if, after probing, the participant says that they do not know, you would then circle that choice. **Instructions that begin with BLUE BOLD fonts indicate that there are optional, additional explanations or probes you can read to the participant—they are not required to be read. The fonts in red are instructions to guide you to the next question or skip pattern.** Instructions in **yellow text boxes** indicate you need to either enter an answer response on the Reference Sheet, or check the Reference Sheet response for skip pattern. If there are no skip pattern instructions, proceed to the next question.*

➤ READ THESE INSTRUCTIONS TO PARTICIPANT:

**Thank you again for agreeing to participate in the Equality in Breast Cancer Care or "EBCC" study.**

**During this interview, we will be asking you a variety of questions, some will be specific to your breast cancer treatment and others will be broader questions about your life experiences. You may skip any questions that you do not feel comfortable answering. You may also stop answering questions at any time. You can decide not to participate simply by telling me that you do not want to answer any questions at all.**

**We appreciate your time and effort in helping us with this research study.**

SECTION 1: INTRODUCTION (INTRO)

INTRO1. **Do you have any questions before we begin?**

- 1 Yes → *Address participant's questions as applicable, and then go to **INTRO2***
- 2 No → *Go to **INTRO2***

INTRO2. **May I start with the questions?**

- 1 Yes → *Begin Survey*
- 2 No → *Comments regarding refusal:*

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**SECTION 2: GENERAL QUESTIONS (G)**

We would like to gather some basic information about you.

G1. What is your date of birth? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 Month Day Year

G2. Are you Latina or Hispanic?  
 (Circle one)

- 1. Yes → **GO TO G3**
- 2. No → **GO TO G4**
- 88. REFUSED
- 99. D/K

If Yes, check box here and on Reference Sheet box G2.	
---	--

G3. Please look at Show Card #1. What is your Latina or Hispanic ancestry or origin? You may choose all that apply. (Circle all that apply)

- |                       |  |
|-----------------------|--|
| 1. Argentinean        | 13. Paraguayan                           |
| 2. Bolivian           | 14. Panamanian                           |
| 3. Chicana            | 15. Peruvian                             |
| 4. Chilean            | 16. Puerto Rican                         |
| 5. Costa Rican        | 17. Salvadoran                           |
| 6. Cuban              | 18. Spanish-American (from Spain)        |
| 7. Ecuadorean         | 19. Uruguayan                            |
| 8. Guatemalan         | 20. Venezuela                            |
| 9. Honduran           | 87. Other Latina (please specify): _____ |
| 10. Mexican American  |  |
| 11. Mexican/ Mexicana | 88. REFUSED                              |
| 12. Nicaraguan        | 99. D/K                                  |

If more than one response selected, check box here and on Reference Sheet box G3.	
---	--

G4. Please look at Show Card #2. Which of the races/ethnicities would you use to describe yourself? You may choose all that apply.  
 (Circle all that apply)

- 1. American Indian or Alaskan Native
- 2. Asian
- 3. Black/African-American
- 4. Native Hawaiian
- 5. Other Pacific Islander
- 6. White
- 87. Other (please specify): \_\_\_\_\_
- 88. REFUSED
- 99. D/K

Circle responses here and on Reference Sheet item G4.
---

If more than one response selected, check box here and on Reference Sheet box G4.	
---	--

SECTION 2: GENERAL QUESTIONS (G)

G5. **[If R is American Indian or Alaska Native]** Please look at Show Card #3. Which of the listed tribes is your tribal heritage? You may choose all that apply. (Circle all that apply)

- |               |                                   |
|---------------|-----------------------------------|
| 1. Athabascan | 11. Navajo                        |
| 2. Cahuilla   | 12. Pomo                          |
| 3. Cherokee   | 13. Pueblo                        |
| 4. Choctaw    | 14. Sioux                         |
| 5. Chumash    | 15. Tlingit                       |
| 6. Karuk      | 16. Yurok                         |
| 7. Kumeyaay   | 87. Other tribe (please specify): |
| 8. Luiseno    | _____                             |
| 9. Maidu      | 88. REFUSED                       |
| 10. Miwok     | 99. D/K                           |

If more than one response selected, check box here and Reference Sheet box G5.

G6. **[If R is American Indian or Alaska Native]** – Are you enrolled in a state or federally recognized tribe? (Circle one)

- 1. Yes → **GO TO G7**
- 2. No → Check Reference Page response to item **G4**, **GO TO appropriate ethnic group question (if more apply), based on response to G4.**
- 88. REFUSED
- 99. D/K

G7. Please look at Show Card #3. In which of the listed tribes are you enrolled? (Circle all that apply)

- |               |                                   |
|---------------|-----------------------------------|
| 1. Athabascan | 11. Navajo                        |
| 2. Cahuilla   | 12. Pomo                          |
| 3. Cherokee   | 13. Pueblo                        |
| 4. Choctaw    | 14. Sioux                         |
| 5. Chumash    | 15. Tlingit                       |
| 6. Karuk      | 16. Yurok                         |
| 7. Kumeyaay   | 87. Other tribe (please specify): |
| 8. Luiseno    | _____                             |
| 9. Maidu      | 88. REFUSED                       |
| 10. Miwok     | 99. D/K                           |

SECTION 2: GENERAL QUESTIONS (G)

G8. **[If R is Asian]** – Please look at Show Card #4. Which of the listed ethnic groups best describe you (such as Chinese, Filipina)? You may choose all that apply.  
(Circle all that apply)

- |                           |   |
|---------------------------|---|
| 1. Bangladeshi            | 11. Laotian                             |
| 2. Burmese                | 12. Malaysian                           |
| 3. Cambodian (Kampuchean) | 13. Pakistani                           |
| 4. Chinese                | 14. Sri Lankan                          |
| 5. Filipina               | 15. Taiwanese                           |
| 6. Hmong                  | 16. Thai                                |
| 7. Indian (India)         | 17. Vietnamese                          |
| 8. Indonesian             | 87. Other Asian (please specify): _____ |
| 9. Japanese               | 88. REFUSED                             |
| 10. Korean                | 99. D/K                                 |

If more than one response selected, check box here and on Reference Sheet box G8.

G9. **[If R is Pacific Islander]** – Please look at Show Card #5. Which of the listed ethnic groups best describe you (such as Samoan, Tongan)? You may choose all that apply. (Circle all that apply)

- |  |
|--|
| 1. Fijian  |
| 2. Guamanian/Chamorro                              |
| 3. Samoan  |
| 4. Tongan  |
| 87. Other Pacific Islander (please specify): _____ |
| 88. REFUSED  |
| 99. D/K  |

If more than one response selected, check box here and on Reference Sheet box G9.

SECTION 2: GENERAL QUESTIONS (G)

G10. **[If R is White]** – Please look at Show Card #6. Which of the listed ethnic groups best describe you? You may choose all that apply. (Circle all that apply)

1. Arab Middle Eastern
2. Non-Arab Middle Eastern
3. English
4. Eastern European
5. French
6. German
7. Irish
8. Italian
9. Russian
10. Scandinavian
11. Mixed European descent
87. Other (please specify): \_\_\_\_\_
88. REFUSED
99. D/K

If more than one response selected, check box here and on Reference Sheet box G10.	
--	--

G11. **[If R is Black/African-American]** – Please look at Show Card #7. Which of the listed ethnic groups best describe you? You may choose all that apply. (Circle all that apply)

1. African American
2. Cape Verdean
3. Ethiopian
4. Ghanaian
5. Nigerian
6. Somali
7. Jamaican
8. Haitian
9. Brazilian
85. Other African (please specify): \_\_\_\_\_
86. Other West Indian/Caribbean (please specify): \_\_\_\_\_
87. Other Central/South American (please specify): \_\_\_\_\_
88. REFUSED
99. D/K

If more than one response selected, check box here and on Reference Sheet box G11.	
--	--

➤ **Check Reference Sheet boxes G2 – G11. If any boxes checked, GO TO G12. If all boxes blank, GO TO G14, page 8.**

G12. Do you identify with any one race or ethnic group in particular? (Circle one)

1. Yes → **GO TO G13**
  2. No
  88. REFUSED
  99. D/K
- } **GO TO G14, page 8.**

SECTION 2: GENERAL QUESTIONS (G)

G13. Please look at Show Card #8. Which of the listed racial or ethnic groups do you most identify with? Please choose only one. (Circle one)

- |                                     |  |
|-------------------------------------|--|
| 1. African American/ Black          | 46. Nigerian   |
| 2. American Indian or Alaska Native | 47. Pakistani  |
| 3. Arab Middle Eastern              | 48. Panamanian                                       |
| 4. Non-Arab Middle Eastern          | 49. Paraguayan                                       |
| 5. Argentinean                      | 50. Peruvian   |
| 6. Asian                            | 51. Puerto Rican                                     |
| 7. Bangladeshi                      | 52. Russian  |
| 8. Bolivian                         | 53. Salvadoran                                       |
| 9. Brazilian                        | 54. Samoan   |
| 10. Burmese                         | 55. Scandinavian                                     |
| 11. Cambodian (Kampuchean)          | 56. Somali   |
| 12. Cape Verdean                    | 57. Spanish-American (from Spain)                    |
| 13. Chicana                         | 58. Sri Lankan                                       |
| 14. Chilean                         | 59. Taiwanese  |
| 15. Chinese                         | 60. Thai   |
| 16. Columbian                       | 61. Tongan   |
| 17. Costa Rican                     | 62. Uruguayan  |
| 18. Cuban                           | 63. Vietnamese                                       |
| 19. Eastern European                | 64. White  |
| 20. Ecuadoran                       | 81. Other African (specify):<br>_____                |
| 21. English                         | 82. Other Asian (specify):<br>_____                  |
| 22. Ethiopian                       | 83. Other Central/South American (specify):<br>_____ |
| 23. Fijian                          | 84. Other Latina (specify):<br>_____                 |
| 24. Filipina                        | 85. Other Pacific Islander (specify):<br>_____       |
| 25. French                          | 86. Other West Indian/Caribbean (specify):<br>_____  |
| 26. German                          | 87. Other (specify):<br>_____                        |
| 27. Ghanaian                        | 88. REFUSED  |
| 28. Guamanian/Chamorro              | 89. D/K  |
| 29. Guatemalan                      |  |
| 30. Haitian                         |  |
| 31. Hmong                           |  |
| 32. Honduran                        |  |
| 33. Indian (India)                  |  |
| 34. Indonesian                      |  |
| 35. Irish                           |  |
| 36. Italian                         |  |
| 37. Jamaican                        |  |
| 38. Japanese                        |  |
| 39. Korean                          |  |
| 40. Laotian                         |  |
| 41. Malaysian                       |  |
| 42. Mexican/Mexicana                |  |
| 43. Mixed European descent          |  |
| 44. Native Hawaiian                 |  |
| 45. Nicaraguan                      |  |

SECTION 2: GENERAL QUESTIONS (G)

G14. In what country were you born?

\_\_\_\_\_



If born outside  
the US, check  
box here and on  
Reference Sheet  
item G14.

**SECTION 3: DIAGNOSIS AND TREATMENT (T)**

The next section will focus on questions about your breast cancer diagnosis and treatment.

T1. **Have you had a recurrence of your breast cancer since your breast cancer diagnosis in [dxyr:\_\_\_\_\_]?**

*(Circle one)*

1. Yes
2. No
88. REFUSED
99. D/K

T2. **What was your marital or relationship status at the time of your breast cancer diagnosis?**

*(Read responses and circle one)*

1. Legally married or registered domestic partner
2. Separated
3. Divorced
4. Widowed
5. Living with a partner to whom you are not married
6. In a relationship but not living with partner
7. Single
87. Other (please specify) \_\_\_\_\_
88. REFUSED
99. D/K

SECTION 4: HEALTH INSURANCE (H)

T3. Which of the following best describes your current marital or relationship status?

(Read responses and circle one)

1. Legally married or registered domestic partner
2. Separated
3. Divorced
4. Widowed
5. Living with a partner to whom you are not married
6. In a relationship but not living with partner
7. Single
87. Other (please specify) \_\_\_\_\_
88. REFUSED
99. D/K

T4. At the time of your breast cancer diagnosis, what was your bra size?

(Write in number and letter: Ex. 36A)

\_\_\_\_\_

- 88 REFUSED
- 99 D/K

T5. Did you have surgery for your breast cancer? By surgery we mean a procedure in which breast tissue was removed.

(Circle one)

1. Yes → **Go to T7**
2. No → **Go to T6**
88. REFUSED } **Go to T13, page 13**
99. D/K }

SECTION 4: HEALTH INSURANCE (H)

T6. Please respond 'Yes' or 'No' if any of the following were reasons why you did not have surgery:

(Read each reason and circle 'Y' or 'N' for each)

**Was it because...**

- |   |   |   |
|---|---|---|
| 1. You did not feel it was necessary. ....                      | Y | N |
| 2. You have not had surgery, but are considering doing so. .... | Y | N |
| 3. You didn't want to have surgery. ....                        | Y | N |
| 4. Your doctor did not recommend it. ....                       | Y | N |

**Was it because...**

- |  |   |   |
|--|---|---|
| 5. Of your age. ....                       | Y | N |
| 6. Of side effects. ....                   | Y | N |
| 7. Of financial or insurance reasons. .... | Y | N |

**Are there any other reasons why you did not have surgery that I have not yet mentioned?**

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

Go to T13  
page 13

T7. Did you have a lumpectomy or lumpectomies?

(Probe: surgery to remove the lump from your breast?)

(Circle one)

- 1. Yes → How many lumpectomies did you have? \_\_\_\_\_
- 2. No
- 88. REFUSED
- 99. D/K

T8. Did you have an axillary or sentinel node dissection?

(Probe: surgery to remove lymph nodes from your armpit?)

(Circle one)

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

SECTION 4: HEALTH INSURANCE (H)

T9. **Did you have a mastectomy?**  
(**Probe:** surgery to remove your entire breast?)

(Circle one)

- 1. Yes → **Which breast?** (Circle one)    Left    Right    Both
  - 2. No
  - 88. REFUSED
  - 99. D/K
- } **Go to T13, page 13**

T10. **Was breast reconstruction offered as an option to be done at the same time as your mastectomy?**  
(**Provide definition as needed:** Breast reconstruction is surgery to rebuild your breast(s) with some type of tissue or implant. Reconstruction can be done at the time of mastectomy or any time later.)

(Circle one)

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

T11. **Did you have breast reconstruction?**

(Circle one)

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

SECTION 4: HEALTH INSURANCE (H)

**T12. Did you end up getting a mastectomy for any of the following reasons?**

*(Read each reason and circle 'Y' or 'N' for each)*

**Was it because...**

- 1. You did not want to go through radiation treatment ..... Y N
- 2. You could not (or did not want to) travel everyday to receive radiation treatments..... Y N
- 3. You believed that someone who gets a mastectomy has a better chance of surviving breast cancer than someone who gets a lumpectomy ..... Y N
- 4. You did not want to worry about a recurrence ..... Y N

**Are there any other reasons why you ended up getting a mastectomy that I have not yet mentioned?**

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

		Yes	No	REF	D/K
T13.	<b>Did your doctor recommend radiation treatment? (Circle one)</b>	1	2	88	99
T14.	<b>Did you receive radiation treatment? (Circle one)</b>	1	2	88	99

*Check Reference Sheet, page 2, item T13 and T14 for skip pattern instructions*

**T15. Did you stop receiving radiation before completing the recommended number of treatments?**

*(Circle one)*

- 1. Yes → **Go to T16**
  - 2. No
  - 88. REFUSED
  - 99. D/K
- } **Go to T19, page 15**

SECTION 4: HEALTH INSURANCE (H)

T16. Did you end up completing the recommended number of radiation treatments?

(Circle one)

- 1. Yes → **Go to T19**
  - 2. No → **Go to T17**
  - 88. REFUSED
  - 99. D/K
- } **Go to T19, page 15**

T17. Please respond 'Yes' or 'No' if any of the following were reasons why you did not complete radiation:

(Read each reason and circle 'Y' or 'N' for each)

**Was it because...**

- 1. Of side effects ..... Y      N
- 2. Of transportation problems ..... Y      N
- 3. Of financial or insurance reasons..... Y      N

**Was it because...**

- 4. You did not feel it was necessary to continue ..... Y      N
- 5. You did not want to commit to the length of time required to complete treatment..... Y      N
- 6. You were worried about your fertility ..... Y      N

} **Go to T19, page 15**

**Are there any other reasons why you did not complete radiation treatment that I have not yet mentioned?**

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

SECTION 4: HEALTH INSURANCE (H)

T18. Please respond 'Yes' or 'No' if any of the following were reasons why you did not have radiation:

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

- 1. Of financial or insurance reasons ..... Y      N
- 2. Of transportation problems ..... Y      N

Was it because...

- 3. You were worried about side effects ..... Y      N
- 4. You did not feel it was necessary ..... Y      N
- 5. You did not want to commit to the length of time required for treatment. Y      N
- 6. You were worried it would affect your fertility ..... Y      N

Are there any other reasons why you did not receive radiation treatment that I have not yet mentioned?

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

		Yes	No	REF	D/K
T19.	<b>Did your doctor recommend chemotherapy?</b> (Circle one)	1	2	88	99
T20.	<b>Did you receive chemotherapy?</b> (Circle one)	1	2	88	99

*Check Reference Sheet, page 3, item T19 and T20 for skip pattern instructions*

SECTION 4: HEALTH INSURANCE (H)

T21. **Did you stop receiving chemotherapy before completing the recommended number of treatments?**

(Circle one)

Yes → **Go to T22**

No  
REFUSED  
D/K

} **Go to T25, page 17**

T22. **Did you end up completing the recommended number of chemotherapy treatments?**

(Circle one)

Yes → **Go to T25**

No → **Go to T23**

REFUSED  
D/K

} **Go to T25, page 17**

T23. **Please respond 'Yes' or 'No' if any of the following were reasons why you did not complete chemotherapy:**

(Read each reason and circle 'Y' or 'N' for each)

**Was it because...**

- |  |   |   |
|--|---|---|
| 1. Of side effects.....                    | Y | N |
| 2. Of transportation problems.....         | Y | N |
| 3. Of financial or insurance reasons ..... | Y | N |

**Was it because...**

- |  |   |   |
|--|---|---|
| 4. You did not feel it was necessary to continue.....                                    | Y | N |
| 5. You did not want to commit to the length of time required to complete treatment ..... | Y | N |
| 6. You were worried about your fertility.....  | Y | N |

} **Go to T25, page 17**

**Are there any other reasons why you did not complete chemotherapy that I have not yet mentioned?**

87. Other reason (specify) \_\_\_\_\_
87. Other reason (specify) \_\_\_\_\_
88. REFUSED
99. D/K

SECTION 4: HEALTH INSURANCE (H)

T24. Please respond 'Yes' or 'No' if any of the following were reasons why you did not have chemotherapy:

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

- 1. Of financial or insurance reasons ..... Y      N
- 2. Of transportation problems ..... Y      N

Was it because...

- 3. You were worried about side effects..... Y      N
- 4. You did not feel it was necessary ..... Y      N
- 5. You did not want to commit to the length of time  
required for treatment ..... Y      N
- 6. You were worried it would affect your fertility..... Y      N

Are there any other reasons why you did not receive chemotherapy treatment that I have not yet mentioned?

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

	Yes	No	REF	D/K
T25. Did your doctor recommend Tamoxifen, Arimidex, or some other type of hormone treatment for your breast cancer? ( <i>Probe:</i> The kind of medication that you take for 5 years?) ( <i>Circle one</i> )	1	2	88	99
T26. Did you take Tamoxifen, Arimidex, or some other type of hormone treatment for your breast cancer?  ( <i>Circle one</i> )	1	2	88	99

*Check Reference Sheet, page 4, item T25 and T26 for skip pattern instructions*

T27. Was there any time you stopped taking hormone treatment?

(Circle one)

- 1. Yes → **Go to T28**
  - 2. No
  - 88. REFUSED
  - 99. D/K
- } **Go to T32, page 20**

T28. Are you still taking hormone treatment?

(Circle one)

- 1. Yes → **Go to T29**
  - 2. No → **Go to T30**
  - 88. REFUSED
  - 99. D/K
- } **Go to T32, page 20**

T29. Please respond 'Yes' or 'No' if any of the following were reasons why you had temporarily stopped taking hormone treatment:

(Read each reason and circle 'Y' or 'N' for each)

**Was it because...**

- 1. Of side effects ..... Y N
- 2. Of financial or insurance reasons ..... Y N

**Was it because...**

- 3. You did not feel it was necessary to continue ..... Y N
- 4. Your doctor recommended you **stop** temporarily..... Y N
- 5. You were worried it would affect your fertility ..... Y N

**Are there any other reasons why you temporarily stopped taking hormone therapy that I have not yet mentioned?**

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

} **Go to T32, page 20**

SECTION 4: HEALTH INSURANCE (H)

T30. Please respond 'Yes' or 'No' if any of the following were reasons why you stopped taking hormone treatment:

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

- 1. Of side effects ..... Y N
- 2. Of financial or insurance reasons ..... Y N

Was it because...

- 3. You did not feel it was necessary to continue ..... Y N
- 4. Your doctor recommended you **stop** taking it..... Y N
- 5. You finished treatment..... Y N
- 6. You were worried it would affect your fertility ..... Y N

Go to T32,  
page 20

Are there any other reasons why you are no longer taking hormone therapy that I have not yet mentioned?

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

T31. Please respond 'Yes' or 'No' if any of the following were reasons why you did not take hormone treatment:

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

- 1. Of financial or insurance reasons..... Y N

Was it because...

- 2. You did not feel it was necessary ..... Y N
- 3. You were worried about side effects ..... Y N
- 4. You were worried it would affect your fertility..... Y N

Are there any other reasons why you did not take hormone therapy that I have not yet mentioned?

- 87. Other reason (specify) \_\_\_\_\_
- 87. Other reason (specify) \_\_\_\_\_
- 88. REFUSED
- 99. D/K

SECTION 4: HEALTH INSURANCE (H)

T32. Which of the following best describes the role your **DOCTORS** played when making decisions about your treatment? Was the final treatment decision:

*(Read responses and circle one)*

1. Made on your own
2. Made after hearing your doctor's input.
3. Made together with your doctor(s).
4. Made by your doctor(s) after hearing your input.
5. Made by your doctor(s) on their own with little input from you.
77. N/A (ex. Family made decision)
88. REFUSED
99. D/K

T33. Did you seek traditional methods or alternative healing to help with the cancer or side effects from treatment? For example, did you use Chinese or Eastern medicine, vitamins or herbal supplements, massage, yoga, acupuncture, etc?

*(Circle one)*

1. Yes
2. No
88. REFUSED
99. D/K

T34. Did you seek spiritual healing such as talking to individuals in your church, praying, meditating, etc?

*(Circle one)*

1. Yes
2. No
88. REFUSED
99. D/K

**SECTION 4: HEALTH INSURANCE (H)**

H1. **Did you have health insurance at the time of your breast cancer diagnosis?**

*(Circle one)*

- 1. Yes → **Go to H5**
- 2. No → **Go to H4**
- 88. REFUSED } **Go to H5**
- 99. D/K }

H2. **Did you get health insurance after you learned of your breast cancer diagnosis?**

*(Circle one)*

- 1. Yes → **Go to H5**
- 2. No → **Go to H4**
- 88. REFUSED } **Go to H5**
- 99. D/K }

H3. **You said that you had no health insurance from any source for your breast cancer diagnosis and treatment. Is that correct?**

*(Circle one)*

- 1. Yes → **Go to H5**
- 2. No → **Go to H4**
- 88. REFUSED } **Go to H5**
- 99. D/K }

Circle response here and enter response number in Reference Sheet, page 5, item H3.

SECTION 4: HEALTH INSURANCE (H)

H4. Please look at Show Card #9. What kind of health insurance or health care coverage did you have/get?

(Circle all that apply)

1. Health insurance through my job or my husband's/wife's/partner's job (such as Blue Cross, HealthNet, Kaiser, etc.)
2. Individual health insurance not provided by my job or my husband's/wife's/partner's job (such as Blue Cross, HealthNet, Kaiser, etc.)
3. Medicare Part A and/or Part B
4. Medicare Part D prescription drug coverage (Medicare drug card)
5. Extra insurance for Medicare (Medi-Gap)
6. Medi-Cal
7. Other government health program (county or state)
8. Military health care (such as TRICARE, VA, CHAMP-VA)
9. Indian Health Service
10. Single-service plan (such as dental, vision, prescriptions)
87. Other: \_\_\_\_\_
88. REFUSED
99. D/K

Circle response(s) here and enter response number(s) in Reference Sheet, page 5, item H4.

H5. Did you have any out-of-pocket costs for fertility treatments because of your breast cancer diagnosis? By out-of-pocket, we mean costs that you paid for yourself.

(Circle one)

1. Yes → **Go to H6**
  2. No
  88. REFUSED
  99. D/K
- } **Go to H7**

H6. How much would you estimate your out-of-pocket costs were for these treatments? Your best estimate is fine.

SECTION 4: HEALTH INSURANCE (H)

H7. Now I'd like you to think about how much money you spent out-of-pocket on breast cancer-related medical care WITHIN THE FIRST YEAR OF YOUR DIAGNOSIS. Again, your best estimate is fine.

*[If needed, you can offer the definition for out-of-pocket costs: Include only payments that YOU made, not total bills or charges. Include copayments and deductibles, but do not include health insurance premiums. Do not include health care costs that you were reimbursed for later.]*

Did you have any out-of-pocket costs for:	If Yes: How much did you pay out-of-pocket?	No	Didn't rec'v this tx	REF	D/K
a. Did you have any out-of-pocket costs for consultations, including any second opinions?	1 \$ _____	2	77	88	99
b. Did you have any out-of-pocket costs for tests, such as blood tests, genetic tests or imaging?	1 \$ _____	2	77	88	99
c. Did you have any out-of-pocket costs for surgeries?	1 \$ _____	2	77	88	99
d. chemotherapy?	1 \$ _____	2	77	88	99
e. radiation?	1 \$ _____	2	77	88	99
f. hormonal therapy?	1 \$ _____	2	77	88	99
g. any other prescription drugs?	1 \$ _____	2	77	88	99
h. any alternative therapies like herbs, Chinese medicine, supplements, and massages?	1 \$ _____	2	77	88	99
i. any OTHER out-of-pocket costs related to your breast cancer care not mentioned already? [After the amount is given, ask:] Please specify what costs you included. _____	1 \$ _____	2	77	88	99

**Section 5: PATIENT-PROVIDER COMMUNICATION (P)**

Now we are going to move on to the next Section which is about your doctors and other healthcare providers.

**P1 With which of the following types of doctors did you discuss your breast cancer treatment?**

*(Read each doctor type and circle one response for each)*

	Yes	No	REF	D/K
a. <b>Internist/Primary care doctor</b>	1	2	88	99
a1. <b>[If Yes] Is your internist/primary care doctor male or female?</b>	M F			
b. <b>Surgeon</b>	1	2	88	99
b1. <b>[If Yes] Is your surgeon male or female?</b>	M F			
c. <b>Plastic Surgeon</b>	1	2	88	99
c1. <b>[If Yes] Is your plastic surgeon male or female?</b>	M F			
d. <b>Oncologist (doctor who treats cancer with drugs)</b>	1	2	88	99
d1. <b>[If Yes] Is your oncologist male or female?</b>	M F			
e. <b>Radiation oncologist (radiation doctor)</b>	1	2	88	99
e1. <b>[If Yes] Is your radiation oncologist male or female?</b>	M F			
<b>Are there any other types of doctors that I have not yet mentioned with whom you spoke with about your treatment options?</b>				
f. <b>Other MD (specify) _____</b>	1	2	88	99
f1. <b>Is your [Other MD] male or female?</b>	M F			
g. <b>Other MD (specify) _____</b>	1	2	88	99
g1. <b>Is your [Other MD] male or female?</b>	M F			

Circle responses here and also circle doctor types in Reference Sheet, page 5, item P1.

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

P2. How difficult was it for you to reach your [doctor type] when you wanted to? This includes by phone, in-person, or e-mail.	Not at all difficult	Some-what difficult	Very difficult	Refused	Don't Know
a. Internist/Primary care doctor	1	2	3	88	99
b. Surgeon	1	2	3	88	99
c. Plastic Surgeon	1	2	3	88	99
d. Oncologist	1	2	3	88	99
e. Radiation Oncologist	1	2	3	88	99
f. Other MD: _____	1	2	3	88	99
g. Other MD: _____	1	2	3	88	99

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

P3. How difficult was it for you to understand your [doctor type]?	Not at all difficult	Somewhat difficult	Very difficult	REF	Don't Know	P4. Was this because you and your [doctor type] spoke different languages?	Yes	No	REF	Don't Know
a. Internist/ Primary care doctor	1	2	3	88	99	→ if '2' or '3': Was this because you and your internist/ primary care doctor spoke different languages?	1	2	88	99
b. Surgeon	1	2	3	88	99	→ if '2' or '3': Was this because you and your surgeon spoke different languages?	1	2	88	99
c. Plastic Surgeon	1	2	3	88	99	→ if '2' or '3': Was this because you and your plastic surgeon spoke different languages?	1	2	88	99
d. Oncologist	1	2	3	88	99	→ if '2' or '3': Was this because you and your oncologist spoke different languages?	1	2	88	99
e. Radiation Oncologist	1	2	3	88	99	→ if '2' or '3': Was this because you and your radiation oncologist spoke different languages?	1	2	88	99
f. Other MD specify: _____	1	2	3	88	99	→ if '2' or '3': Was this because you and your [doctor type] spoke different languages?	1	2	88	99
g. Other MD specify: _____	1	2	3	88	99	→ if '2' or '3': Was this because you and your [doctor type] spoke different languages?	1	2	88	99

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

P5. **Did someone else help you understand your doctor(s)?**

*(Circle one)*

- 1. Yes → *Go to P6*
  - 2. No
  - 88. REFUSED
  - 99. D/K
- } *Go to P7*

P6. **Please look at Show Card # 10. Who was the main person who helped you understand your doctor(s)?**

*(Circle one)*

- 1. Your husband or partner
- 2. Another family member over age 18
- 3. A family member under age 18
- 4. A friend over age 18
- 5. A friend under age 18
- 6. A non-medical office staff person
- 7. A medical staff person, including nurses or doctors
- 8. A professional interpreter
- 9. A telephone interpreter service
- 87. Someone else (specify)  
\_\_\_\_\_
- 88. REFUSED
- 99. D/K

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

Check Reference Page item P1. Ask P7 only about doctors listed in P1.

P7. Please look at Show Card #11. Which of the listed racial/ethnic categories would you use to describe your [doctor type]?

*(Circle all that apply)*

a. Internist/Primary Care doctor

- 1 White
- 2 Latino or Hispanic
- 3 Black or African American
- 4 Asian (specify): \_\_\_\_\_
- 5 American Indian or Alaskan Native
- 6 Native Hawaiian or Other Pacific Islander
- 87 Other (specify): \_\_\_\_\_
- 88 REFUSED
- 99 D/K

b. Surgeon

- 1 White
- 2 Latino or Hispanic
- 3 Black or African American
- 4 Asian (specify): \_\_\_\_\_
- 5 American Indian or Alaskan Native
- 6 Native Hawaiian or Other Pacific Islander
- 87 Other (specify): \_\_\_\_\_
- 88 REFUSED
- 99 D/K

c. Plastic Surgeon

- 1 White
- 2 Latino or Hispanic
- 3 Black or African American
- 4 Asian (specify): \_\_\_\_\_
- 5 American Indian or Alaskan Native
- 6 Native Hawaiian or Other Pacific Islander
- 87 Other (specify): \_\_\_\_\_
- 88 REFUSED
- 99 D/K

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

P7(cont.)

d. **Oncologist**

- 1 White
- 2 Latino or Hispanic
- 3 Black or African American
- 4 Asian (specify): \_\_\_\_\_
- 5 American Indian or Alaskan Native
- 6 Native Hawaiian or Other Pacific Islander
- 87 Other (specify): \_\_\_\_\_
- 88 REFUSED
- 99 D/K

e. **Radiation Oncologist**

- 1 White
- 2 Latino or Hispanic
- 3 Black or African American
- 4 Asian (specify): \_\_\_\_\_
- 5 American Indian or Alaskan Native
- 6 Native Hawaiian or Other Pacific Islander
- 87 Other (specify): \_\_\_\_\_
- 88 REFUSED
- 99 D/K

f. **Other MD (specify \_\_\_\_\_)**

- 1 White
- 2 Latino or Hispanic
- 3 Black or African American
- 4 Asian (specify): \_\_\_\_\_
- 5 American Indian or Alaskan Native
- 6 Native Hawaiian or Other Pacific Islander
- 87 Other (specify): \_\_\_\_\_
- 88 REFUSED
- 99 D/K

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

P8. **If you could choose, would you prefer to be treated by doctors of your own racial/ethnic group, another racial/ethnic group, or do you NOT have a preference?**

*(Circle one)*

- 1. Your own racial/ethnic group → *Go to P9*
  - 2. Another racial/ethnic group
  - 3. No preference
  - 88. REFUSED
  - 99. D/K
- } *Go to P10*

P9. **Why would you prefer to have a doctor who is of the same race/ethnicity as you? Is it because:**

*(Read each reason and circle 'Y' or 'N' for each)*

- 1 She or he would understand your disease better than others  
(that is, the type of cancer you have, your biology or physiology) .....Y N
- 2 She or he would be able to speak your language. ....Y N
- 3 She or he would understand your cultural beliefs. ....Y N
- 4 She or he would be able to relate to you better. ....Y N
- 5 You feel you would be more involved in making decisions about your  
care .....Y N
- 6 Other: please specify \_\_\_\_\_
- 88 REFUSED
- 99 D/K

SECTION 5: PATIENT-PROVIDER COMMUNICATION (P)

P10. Now I would like you to think about all of your care that you had for your breast cancer.

(Read each question and circle one response for each)

	Always	Usually	Sometimes	Never	Refused	D/K
a. How often did your doctors carefully listen to you? <i>READ "Would you say Always, Usually, Sometimes, Never" after the first 2 questions and then as necessary.</i>	1	2	3	4	88	99
b. How often did your doctors encourage you to ask questions?	1	2	3	4	88	99
c. How often were your nurses helpful to you?	1	2	3	4	88	99
d. How often did you think that problems were handled quickly enough?	1	2	3	4	88	99
e. How often did the doctors, nurses, and other medical staff seem to work well together as a team?	1	2	3	4	88	99
f. How often did you know whom to ask when you had any questions?	1	2	3	4	88	99

P11. OVERALL, on a scale of 1 to 10 where 1 is the worst health care possible and 10 is the best health care possible, what number would you use to rate the breast cancer care you have received ?

(Write down number)

88 REFUSED  
99 D/K

**Section 6: MEDICAL DISCRIMINATION**

There have been many stories about people experiencing unfair treatment for many reasons by their health care team (including doctors, nurses, office staff and technicians).

- M1. While getting medical care for breast cancer, did you feel you were treated unfairly by having any of the following things happen to you?

(Read each question and circle one response for each)

HOW OFTEN...	Never	Rarely	Sometimes	Often	REFUSED	D/K
a. were you treated with less respect than other people <i>READ "Would you say Never, Rarely, Sometimes, or Often" after the first 2 questions and then as necessary.</i>	1	2	3	4	88	99
b. did you receive poorer service than others	1	2	3	4	88	99
c. did someone from your health care team act as if he or she thinks you are not smart	1	2	3	4	88	99
d. did someone from your health care team act as if he or she is better than you	1	2	3	4	88	99
e. did you feel like someone was not listening to what you were saying	1	2	3	4	88	99
f. did someone make inappropriate comments to you or about you	1	2	3	4	88	99
g. did you have to wait longer than other people to be seen by your health care team	1	2	3	4	88	99
h. did you feel that you were denied a test or treatment	1	2	3	4	88	99
i. did you feel that you had to insist on receiving a test or treatment	1	2	3	4	88	99

If ANY "2," "3," or "4" Go to M2

If ALL "1," "88," or "99" Go to M3

SECTION 6: MEDICAL DISCRIMINATION (M)

M2. Please see Show Card #12. I will read through each option. Please tell me which of these may be the reasons why you were treated unfairly while getting medical care for breast cancer?

(Read each reason and circle one response for each)

Was it because of...	Yes	No	Refused	D/K
a. Your health insurance (or lack of)	1	2	88	99
b. The way you speak English	1	2	88	99
c. Your birthplace	1	2	88	99
d. Your gender	1	2	88	99
e. Your race/ethnicity	1	2	88	99
f. Your age	1	2	88	99
g. Your religion	1	2	88	99
h. Your height or weight	1	2	88	99
i. Your skin color	1	2	88	99
j. Your sexual orientation	1	2	88	99
k. Your education	1	2	88	99
l. How much money you have	1	2	88	99
m. A physical disability	1	2	88	99
n. Your appearance on a given day	1	2	88	99
Other: o. please specify _____	1	2	88	99

SECTION 6: MEDICAL DISCRIMINATION (M)

**Now, I would like you to think about medical care in general, not just care related to your breast cancer.**

**M3. In general, how concerned are you that you may be treated unfairly *because of your race/ethnicity* when seeking medical care?**

*(Read responses and circle one)*

- 1 Not at all concerned
- 2 A little concerned
- 3 Somewhat concerned
- 4 Extremely concerned
- 88 REFUSED
- 99 D/K

**M4. In general, how concerned are you that people of your same race/ethnicity may be treated unfairly *because of their race/ethnicity* when seeking medical care? This could include a family member, friend, or someone you do not know personally.**

*(Read responses and circle one)*

- 1 Not at all concerned
- 2 A little concerned
- 3 Somewhat concerned
- 4 Extremely concerned
- 88 REFUSED
- 99 D/K

SECTION 6: MEDICAL DISCRIMINATION (M)

M5. For this next set of questions, please indicate whether you think these statements are True or False.

*(Read each statement and circle one response for each)*

	True	False	REF	D/K
a. Patients have sometimes been deceived or misled at hospitals.	1	2	88	99
b. Hospitals often want to know more about your personal affairs or business than they really need to know.	1	2	88	99
c. Hospitals have sometimes done harmful experiments on patients without their knowledge.	1	2	88	99
d. Hospitals give the best care to people with the most money.	1	2	88	99
e. Hospitals will treat you differently depending on what insurance you have.	1	2	88	99

SECTION 6: MEDICAL DISCRIMINATION (M)

M6. For the next items, please tell me how much you agree with each one.

(Read and circle one response for each item)

	Strongly Agree	Agree	Disagree	Strongly Disagree	REF	D/K
a. In general, you find it difficult to trust doctors. <i>READ "Would you say Strongly Agree, Agree, Disagree, or Strongly Disagree" after the first 2 questions and then as necessary.</i>	1	2	3	4	88	99
b. In general, you find it difficult to trust nurses.	1	2	3	4	88	99
c. Your doctor has made references to your race/ethnicity or skin color when it did not seem important.	1	2	3	4	88	99
d. You trust your doctor's advice because you were treated at a very prestigious/well-known medical facility.	1	2	3	4	88	99
e. <i>Check Reference sheet responses for items H3 and H4. If H3 = 1 OR if H4 = 3, 4, 6, or 7 (no other numbers circled), ask:</i> Because of your insurance status, you are happy to receive any medical treatment you can get.	1	2	3	4	88	99

M7. How often have you felt that you were treated badly or unfairly because of your race or ethnicity while getting breast cancer care?

(Read responses and circle one)

- 1. Never
- 2. Rarely
- 3. Sometimes
- 4. Often
- 88. Refused
- 99. Don't Know

**Section 7: SOCIAL SUPPORT, STRESS, COPING**

These next questions focus on your support networks within the FIRST YEAR of your breast cancer diagnosis.

S1.

<i>(Read each reason and circle one response for each item)</i>	None	1 or 2	3 to 5	6 to 9	10 or more	REF	D/K
a. How many close relatives did you have? (By close we mean people you felt at ease with, could talk to about private matters, and could call on for help)	0	1	2	3	4	88	99
b. How many close friends did you have (who were not relatives)?	0	1	2	3	4	88	99

*If 1 – 4 circled for either question,  
Go to S2*

*If BOTH questions "0," "88," or "99"  
Go to S3*

S2. How many of these friends and/or family members did you see or talk to at least once a month?

*(Read responses and circle one)*

- 0. None
- 1. 1 or 2
- 2. 3 to 5
- 3. 6 to 9
- 4. 10 or more
- 88. REFUSED
- 99. D/K

SECTION 7: SOCIAL SUPPORT (S)

S3. Did you belong to any of these kinds of groups:

(Read each group and circle one response for each item)

	Yes	No	REF	D/K
a. A social or recreational group	1	2	88	99
b. A labor union, commercial group, or professional association	1	2	88	99
c. A church or temple group	1	2	88	99
d. A group concerned with children	1	2	88	99
e. A group concerned with community betterment, charity or service	1	2	88	99
f. Any other group: please specify _____	1	2	88	99

S4. Still thinking about the first year within your diagnosis, did you have any close friends who were ever diagnosed with breast cancer?

(Circle one)

- 1. Yes → Go to S5
  - 2. No
  - 88. REFUSED
  - 99. D/K
- } Go to S6

S5. Did you meet any of these people as a result of you both having breast cancer?

(Circle one)

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

SECTION 7: SOCIAL SUPPORT (S)

**S6. Within the first year of your diagnosis, did you know of any family members who were ever diagnosed with breast cancer?**

*(Circle one)*

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

**S7. Still thinking about the first year within your diagnosis, was it helpful to you to share your breast cancer experience with people in general?**

*(Circle one)*

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

SECTION 7: SOCIAL SUPPORT (S)

S8. Did you ever attend any of the following support group meetings for cancer patients <u>within the first year of your diagnosis?</u>	Yes	No	REF	D/K	S9. In general, how helpful did you find this support group?	Very helpful	Somewhat helpful	Not at all helpful	REF	D/K
a. a support group at your church?	1	2	88	99	[If YES:] a. In general, how helpful did you find this support group?	1	2	3	88	99
b. a support group at your hospital or clinic?	1	2 ↓	88	99	[If YES:] b. In general, how helpful did you find this support group?	1	2	3	88	99
<p>S8bx: [If NO to item b:]  <b>What was the main reason why you did not attend?</b>  <i>(Read and circle one)</i></p> <ol style="list-style-type: none"> <li>1. Too busy to attend</li> <li>2. Other obligations (such as work or job, child or dependent care)</li> <li>3. Didn't think it would be useful</li> <li>4. Too difficult to travel to support group location</li> <li>5. Could not find a support group</li> <li>6. Didn't feel comfortable sharing your experience with people you don't know</li> <li>87. Other, specify: _____</li> <li>88 REFUSED</li> <li>99 D/K</li> </ol>										
Are there any other types of cancer support groups I have not yet mentioned that you attended?	Yes	No	REF	D/K		Very helpful	Somewhat helpful	Not at all helpful	REF	D/K
c. Other support group (specify): _____	1	2	88	99	[If YES:] In general, how helpful did you find this support group?	1	2	3	88	99
d. Other support group (specify): _____	1	2	88	99	[If YES:] In general, how helpful did you find this support group?	1	2	3	88	99

SECTION 7: SOCIAL SUPPORT (S)

S10. These next questions focus on support you may have received within the first year of your breast cancer diagnosis.

(Read each statement and circle one response for each)

How much of the time did you have...	All of the time	Most of the time	Some of the time	A little bit of the time	None of the time	REF	D/K
<p>a. someone you could count on to listen to you when you needed to talk?</p> <p><i>READ "Would you say All of the time, Most of the time, Some of the time, A little bit of the time, None of the time" after the first 2 questions and then as necessary.</i></p>	1	2	3	4	5	88	99
b. someone to give you information to help you understand a situation?	1	2	3	4	5	88	99
c. someone to share your most private worries and fears with?	1	2	3	4	5	88	99
d. someone to help you if you were confined to bed?	1	2	3	4	5	88	99
e. someone to take you to the doctor if you needed it?	1	2	3	4	5	88	99
f. someone to prepare your meals if you were unable to do it yourself?	1	2	3	4	5	88	99
g. someone to help with daily chores if you were sick?	1	2	3	4	5	88	99

## SECTION 7: SOCIAL SUPPORT (S)

S11. The next questions ask about the overall stress you felt within the first year of your breast cancer diagnosis.

(Read each statement and circle one response for each)

<i>Within the first year of your breast cancer diagnosis, how often...</i>	Never	Almost Never	Sometimes	Fairly Often	Very Often	REF	D/K
a. were you upset because of something that happened unexpectedly? <i>READ "Would you say Never, Almost Never, Sometimes, Fairly Often, or Very Often" after the first 2 questions and then as necessary.</i>	0	1	2	3	4	88	99
b. did you feel that you were unable to control the important things in your life?	0	1	2	3	4	88	99
c. did you feel "stressed"?	0	1	2	3	4	88	99
d. did you feel confident about your ability to handle your personal problems?	0	1	2	3	4	88	99
e. did you feel that things were going your way?	0	1	2	3	4	88	99
f. did you feel that you could not cope with all the things that you had to do?	0	1	2	3	4	88	99
g. were you able to control irritations in your life?	0	1	2	3	4	88	99
h. did you feel that you were on top of things?	0	1	2	3	4	88	99
i. were you angered because of things that were outside of your control?	0	1	2	3	4	88	99
j. did you feel difficulties were piling up so high that you could not overcome them?	0	1	2	3	4	88	99

SECTION 8: QUALITY OF LIFE (Q)

**Section 8: QUALITY OF LIFE (Q)**

**Q1: For the next section, please think about your general health over the past 4 weeks.**

*(Read each statement and circle one response for each)*

	Excellent	Very Good	Good	Fair	Poor	REF	D/K
<p>a. In general, over the past 4 weeks, would you say your health was:</p> <p><i>READ "Excellent, Very Good, Good, Fair, or Poor" after the first 2 questions and then as necessary.</i></p>	1	2	3	4	5	88	99
<p>b. In general, over the past 4 weeks, would you say your quality of life was:</p>	1	2	3	4	5	88	99
<p>c. In general, over the past 4 weeks, how would you rate your physical health?</p>	1	2	3	4	5	88	99
<p>d. In general, [over the past 4 weeks], how would you rate your mental health, including your mood and your ability to think?</p>	1	2	3	4	5	88	99
<p>e. In general, [over the past 4 weeks], how would you rate your satisfaction with your social activities and relationship?</p>	1	2	3	4	5	88	99
<p>f. In general, [over the past 4 weeks], please rate how well you carried out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)</p>	1	2	3	4	5	88	99

SECTION 8: QUALITY OF LIFE (Q)

Q2. **Still thinking about the past 4 weeks, to what extent were you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**

*(Read responses and circle one)*

1. Completely
2. Mostly
3. Moderately
4. A Little
5. Not at all
88. REFUSED
99. D/K

Q3. **OVER THE PAST 4 WEEKS how often were you bothered by emotional problems such as feeling anxious, depressed, or irritable?**

*(Read responses and circle one)*

1. Never
2. Rarely
3. Sometimes
4. Often
5. Always
88. REFUSED
99. D/K

Q4. **OVER THE PAST 4 WEEKS how would you rate your fatigue on average?**

*(Read responses and circle one)*

1. None
2. Mild
3. Moderate
4. Severe
5. Very Severe
88. REFUSED
99. D/K

SECTION 8: QUALITY OF LIFE (Q)

Q5. On a scale of 1 to 10, **OVER THE PAST 4 WEEKS**, how would you rate your pain on average? Zero is no pain and 10 is the worst pain imaginable.

(Circle one)

0 1 2 3 4 5 6 7 8 9 10  
 No pain Worst Pain Imaginable

Q6: For each statement please tell me how true each one is for you.

(Read each statement and circle one response for each)

<u>OVER THE PAST 4 WEEKS...</u>	Not at all	A little bit	Somewhat	Quite a bit	Very Much	REF	D/K
a. You were self-conscious about the way you dress <i>READ "Would you say Not at all, A little bit, Somewhat, Quite a bit, or Very Much" after the first 2 questions and then as necessary.</i>	1	2	3	4	5	88	99
b. One or both of your arms were swollen or tender	1	2	3	4	5	88	99
c. You felt sexually attractive	1	2	3	4	5	88	99
d. You were bothered by a change in weight	1	2	3	4	5	88	99
e. You were bothered by side effects from treatment (such as insomnia, hot flashes, joint pain, etc.).	1	2	3	4	5	88	99
f. You worried about the risk of cancer in other family members	1	2	3	4	5	88	99

SECTION 8: QUALITY OF LIFE (Q)

**Q7. Now I'd like you to think about the future. Next year, at this time, would you predict that your overall health will be better, about the same, or worse?**

*(Circle one)*

- 1 Better
- 2 About the same
- 3 Worse
- 88 REFUSED
- 99 D/K

***[Go to Next Page]***

SECTION 8: QUALITY OF LIFE (Q)

Thinking about how your breast cancer diagnosis has affected you, please rate how true these statements were for you before your breast cancer diagnosis and again now, since your breast cancer diagnosis.

Q8. You are comfortable with who you are:

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. How true was this <u>before</u> your breast cancer diagnosis? <i>READ "Would you say Not at all, A little bit, Somewhat, Quite a bit or Very Much" after the first 2 questions and then as necessary.</i>	1	2	3	4	5	88	99
b. How true is this now <u>since</u> your breast cancer diagnosis?	1	2	3	4	5	88	99

Q9. You realize who your real friends are:

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. How true was this <u>before</u> your breast cancer diagnosis?	1	2	3	4	5	88	99
b. How true is this now <u>since</u> your breast cancer diagnosis?	1	2	3	4	5	88	99

Q10. You can adjust to things you cannot change:

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. How true was this <u>before</u> your breast cancer diagnosis?	1	2	3	4	5	88	99
b. How true is this now <u>since</u> your breast cancer diagnosis?	1	2	3	4	5	88	99

Q11. Your life is meaningful:

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. How true was this <u>before</u> your breast cancer diagnosis?	1	2	3	4	5	88	99
b. How true is this now <u>since</u> your breast cancer diagnosis?	1	2	3	4	5	88	99

SECTION 8: QUALITY OF LIFE (Q)

**Q12. Please see Show Card #13. The next series of questions are about other medical conditions you may have had besides breast cancer.**

**Some of these medical terms may sound unfamiliar to you. Generally if people have not heard of these, this usually means that they do not have this medical condition.**

*(If R answers yes to any of the items below, then ask about treatment and limitation of activities.)*

					In what year were you first diagnosed with this condition?	Are you under treatment for your condition?				Are any of your regular activities currently limited because of your condition?			
	Yes	No	N/A	D/K	Year	Yes	No	N/A	D/K	Yes	No	N/A	D/K
a. Have you ever had a heart attack? <sup>1</sup>	1	2	77	99		1	2	77	99	1	2	77	99
b. Have you ever been treated for heart failure? (You may have been short of breath and the doctor may have told you that you had fluid in your lungs or that your heart was not pumping well.) <sup>2</sup>	1	2	77	99		1	2	77	99	1	2	77	99
c. Have you had an operation to unclog or bypass the arteries in your legs? <sup>3</sup>	1	2	77	99		1	2	77	99	1	2	77	99
d. Have you had a stroke, cerebrovascular accident, blood clot or bleeding in the brain, or transient ischemic attack (TIA)?	1	2	77	99		1	2	77	99	1	2	77	99
e. Have you ever had angina, also called angina pectoris?	1	2	77	99		1	2	77	99	1	2	77	99
f. Do you have coronary heart disease?	1	2	77	99		1	2	77	99	1	2	77	99

<sup>1</sup> Myocardial infarction

<sup>2</sup> Congestive heart failure

<sup>3</sup> Peripheral vascular disease

SECTION 8: QUALITY OF LIFE (Q)

					In what year were you first diagnosed with this condition?	Are you under treatment for your condition?				Are any of your regular activities currently limited because of your condition?			
	Yes	No	N/A	D/K	Year	Yes	No	N/A	D/K	Yes	No	N/A	D/K
g. Do you have hypertension, also called high blood pressure?	1	2	77	99		1	2	77	99	1	2	77	99
h. Do you have asthma?	1	2	77	99		1	2	77	99	1	2	77	99
i. Do you have emphysema, chronic bronchitis, or chronic obstructive lung disease? <sup>4</sup>	1	2	77	99		1	2	77	99	1	2	77	99
j. Do you have stomach ulcers, or peptic ulcer disease? <sup>5</sup>	1	2	77	99		1	2	77	99	1	2	77	99
jx. [If yes] Has this condition been diagnosed by endoscopy?	1	2	77	99									
k. Do you have diabetes (high blood sugar)?	1	2	77	99		1	2	77	99	1	2	77	99
l. Have you ever had poor kidney function (blood tests show high creatinine)? <sup>6</sup>	1	2	77	99		1	2	77	99	1	2	77	99

<sup>4</sup> Chronic obstructive pulmonary disease (participant is considered to have pulmonary disease if she takes medications regularly (without flare-ups) or only for flare-ups)

<sup>5</sup> Ulcer disease

<sup>6</sup> Renal

SECTION 8: QUALITY OF LIFE (Q)

					In what year were you first diagnosed with this condition?	Are you under treatment for your condition?				Are any of your regular activities currently limited because of your condition?			
	Yes	No	N/A	D/K	Year	Yes	No	N/A	D/K	Yes	No	N/A	D/K
m. Do you have rheumatoid arthritis? <sup>7</sup>	1	2	77	99		1	2	77	99	1	2	77	99
n. Do you have hepatitis, cirrhosis, or serious liver damage?	1	2	77	99		1	2	77	99	1	2	77	99
o. Have you been diagnosed with another cancer? If yes, please specify: _____; <i>If Yes, go to a. below.; If No, go to p</i>	1	2	77	99		1	2	77	99	1	2	77	99
a. Has the cancer spread, or metastasized to other parts of your body?	1	2	77	99									
p. Have you been diagnosed with any other health problem? <i>[If yes]</i> Specify: _____	1	2	77	99		1	2	77	99	1	2	77	99

<sup>7</sup> Connective tissue disease

**Section 9: DISCRIMINATION (D)**

These next questions are not directly about your breast cancer experiences, but about other experiences you may have had in general. These are also important for understanding why women may have different breast cancer experiences.

D1. First, I would like you to think about situations where you have been treated unfairly over your entire lifetime.

(Read and circle one response for each)

Over your entire lifetime, how often....	Never	Rarely	Sometimes	Often	REF	D/K
a. have you been treated unfairly at school? <i>READ "Would you say Never, Rarely, Sometimes or Often" after the first 2 questions and then as necessary.</i>	1	2	3	4	88	99
b. have you been treated unfairly when getting hired or getting a job?	1	2	3	4	88	99
c. have you been treated unfairly at work?	1	2	3	4	88	99
d. have you been treated unfairly when getting housing?	1	2	3	4	88	99
e. have you been treated unfairly when getting medical care?	1	2	3	4	88	99
f. have you been treated unfairly when getting credit, bank loans, or a mortgage?	1	2	3	4	88	99
g. have you been treated unfairly when seeking legal services related to immigration?	1	2	3	4	88	99
h. have you been treated unfairly from the police or in the courts?	1	2	3	4	88	99

If ANY "2," "3," or "4" Go to D2

If ALL "1," "88," or "99" Go to D3

SECTION 9: DISCRIMINATION (D)

D2. Please see Show Card #12. I will read through each option. Please tell me which of these may be the reasons why you were treated unfairly over your lifetime?

(Read and circle one response for each)

Was it because of...	Yes	No	REF	D/K
a. Your health insurance (or lack of)	1	2	88	99
b. The way you speak English	1	2	88	99
c. Your birthplace	1	2	88	99
d. Your gender	1	2	88	99
e. Your race/ethnicity	1	2	88	99
f. Your age	1	2	88	99
g. Your religion	1	2	88	99
h. Your height or weight	1	2	88	99
i. Your skin color	1	2	88	99
j. Your sexual orientation	1	2	88	99
k. Your education	1	2	88	99
l. How much money you have	1	2	88	99
m. A physical disability	1	2	88	99
n. Your appearance on a given day	1	2	88	99
o. Other: please specify _____	1	2	88	99

SECTION 9: DISCRIMINATION (D)

D3. **How stressful has this/have these experience(s) of unfair treatment usually been for you?**

*(Read responses and circle one)*

1. Not at all stressful
2. A little stressful
3. Somewhat stressful
4. Extremely stressful
88. REFUSED
99. D/K

***[Go to next page]***

SECTION 9: DISCRIMINATION (D)

Now I am going to ask you about unfair treatment in your everyday life.

D4. **Over the past 12 months, how often have any of the following things happened to you in your day-to-day life?**

*(Read and circle one response for each)*

Over the past 12 months, how often....	Never	Rarely	Sometimes	Often	REF	D/K
a. have you been treated with less respect than other people? <i>READ "Would you say Never, Rarely, Sometimes or Often" after the first 2 questions and then as necessary.</i>	1	2	3	4	88	99
b. have you received poorer service than other people at restaurants or stores?	1	2	3	4	88	99
c. have people acted as if they think you are not smart?	1	2	3	4	88	99
d. have people acted as if they are afraid of you?	1	2	3	4	88	99
e. have people acted as if they think you are dishonest?	1	2	3	4	88	99
f. have people acted as if they're better than you?	1	2	3	4	88	99
g. have you been called names or were insulted?	1	2	3	4	88	99
h. have you been threatened or harassed?	1	2	3	4	88	99
i. have you been followed around in stores?	1	2	3	4	88	99

Box A

If **2 or more "2"**  
check box A

Box B

If **ANY "3," or "4,"**  
check box B

Box C

If **ALL "88," or "99"**  
check box C

SECTION 9: DISCRIMINATION (D)

Check Boxes **A**, **B**, and **C**, page 54.

If Box **A** OR Box **B** checked, Go to **D5**.

If Box **C** checked, determine why **Refused** or **D/K** for all, then Go to **D8**, page 57.

If **No Boxes** checked, Go to **D8**, page 57.

- D5. Please see Show Card #12. I will read through each option. Please tell me which of these may be the reasons why you were treated unfairly over the past 12 months?

(Read and circle one response for each)

Was it because of...	Yes	No	Refused	D/K
a. Your health insurance (or lack of it)	1	2	88	99
b. The way you speak English	1	2	88	99
c. Your birthplace	1	2	88	99
d. Your gender	1	2	88	99
e. Your race/ethnicity	1	2	88	99
f. Your age	1	2	88	99
g. Your religion	1	2	88	99
h. Your height or weight	1	2	88	99
i. Your skin color	1	2	88	99
j. Your sexual orientation	1	2	88	99
k. Your education	1	2	88	99
l. How much money you have	1	2	88	99
m. A physical disability	1	2	88	99
n. Your appearance on a given day	1	2	88	99
o. Other: please specify _____	1	2	88	99

SECTION 9: DISCRIMINATION (D)

D6. **How stressful has this/have these experience(s) of unfair treatment usually been for you?**

*(Read responses and circle one)*

- 1. Not at all stressful
- 2. A little stressful
- 3. Somewhat stressful
- 4. Extremely stressful
- 88. REFUSED
- 99. D/K

D7. **How did you respond to this/these experience(s)? Did you:**

*(Read and circle one response for each)*

	Yes	No	N/A	REF	D/K
a. try to do something about it	1	2	77	88	99
b. accept it as a fact of life	1	2	77	88	99
c. work harder to prove them wrong	1	2	77	88	99
d. believe that you brought it on yourself	1	2	77	88	99
e. talk to someone about how you were feeling	1	2	77	88	99
f. express anger or get mad	1	2	77	88	99
g. pray about the situation	1	2	77	88	99

SECTION 9: DISCRIMINATION (D)

**D8. Over the past 12 months how often have you felt that you were treated badly or unfairly because of your race or ethnicity?**

*(Read responses and circle one)*

- 1. Never
- 2. Rarely
- 3. Sometimes
- 4. Often
- 88. REFUSED
- 99. D/K

***[Go to next page]***

SECTION 9: DISCRIMINATION (D)

D9. I will now ask you some questions about how you see yourself. Please tell me how much you agree with each statement.

(Read and circle one response for each)

	Strongly Agree	Agree	Disagree	Strongly Disagree	REF	D/K
a. You've always felt that you could make of your life pretty much what you wanted to make of it. <i>READ "Would you say Strongly Agree, Agree, Disagree, or Strongly Disagree" after the first 2 questions and then as necessary.</i>	1	2	3	4	88	99
b. Once you make up your mind to do something, you stay with it until the job is completely done.	1	2	3	4	88	99
c. You like doing things that other people thought could not be done.	1	2	3	4	88	99
d. When things don't go the way you want them to, that just makes you work even harder.	1	2	3	4	88	99
e. Sometimes, you feel that if anything is going to be done right, you have to do it yourself.	1	2	3	4	88	99
f. It's not always easy, but you manage to find a way to do the things you really need to get done.	1	2	3	4	88	99
g. Very seldom have you been disappointed by the results of your hard work.	1	2	3	4	88	99
h. You feel you are the kind of individual who stands up for what she believes in, regardless of the consequences.	1	2	3	4	88	99
i. In the past, even when things got really tough, you never lost sight of your goals.	1	2	3	4	88	99
j. It's important for you to be able to do things the way you want to do them rather than the way other people want you to do them.	1	2	3	4	88	99
k. You don't let your personal feelings get in the way of doing a job.	1	2	3	4	88	99
l. Hard work has really helped you to get ahead in life.	1	2	3	4	88	99

SECTION 10: NEIGHBORHOOD (N)

**Section 10: NEIGHBORHOOD (N)**

We would like to know about the area you live in. The following questions are about your current neighborhood.

N1. In what year did you first move to your current address? \_\_\_\_\_  
*year*

N2. The next questions are about your neighbors:

*(Read and circle one response for each)*

	Often	Sometimes	Rarely	Never	REF	D/K
a. How often do you see neighbors talking outside in the yard, on the street, at the corner park, etc?	1	2	3	4	88	99
b. How often do neighbors watch out for each other, such as calling if they see a problem?	1	2	3	4	88	99

	A lot	Some	A Few	None	REF	D/K
c. How many neighbors do you know by name?	1	2	3	4	88	99
d. How many neighbors do you have a friendly talk with at least once a week?	1	2	3	4	88	99
e. How many neighbors could you call on for assistance in doing something around your home or yard or to "borrow a cup of sugar " or some other small favor?	1	2	3	4	88	99

**Section 11: EDUCATION, OCCUPATION, AND INCOME (E)**

The next section will focus on your education and occupation.

E1. Please look at Show Card #14. What is the HIGHEST level of school you have completed or the highest degree you have received?

*(Circle one)*

1. Never attended/kindergarten only
2. 1st grade
3. 2nd grade
4. 3rd grade
5. 4th grade
6. 5th grade
7. 6th grade
8. 7th grade
9. 8th grade
10. 9th grade
11. 10th grade
12. 11th grade
13. 12th grade, High School Graduate
14. 12<sup>th</sup> grade, did not graduate
15. GED or took a test to graduate
16. Some college, no degree
17. Associate degree (such as AA, AS, ABA)
18. Bachelor's degree (such as BA, BS, BBA)
19. Master's degree (such as MA, MS, MBA)
20. Professional degree (such as MD, DDS, JD)
21. Doctoral degree (such as PhD, EdD)
88. REFUSED
99. D/K

SECTION 11: EDUCATION, OCCUPATION AND INCOME (E)

**E2. Please look at Show Card #15. Which of the following best describes what you currently do?**

*(Circle One)*

1. Currently working full-time
2. Currently working part-time
3. Unemployed or looking for work
4. Retired
5. On disability permanently
6. On disability for a period of time (on sick leave or maternity leave or disability leave for other reasons)
7. Keeping house/homemaker
8. Student
9. Volunteer/work without pay
87. Other, specify: \_\_\_\_\_
88. REFUSED
99. D/K

**E3. We would like to know about your usual occupation. This would be the longest held job that best describes the kind of work you do (did):**

*(Read below questions and enter responses)*

a. **In what kind of business or industry do (did) you work?**

\_\_\_\_\_  
**(For example:** health care, banking, education, manufacturing, retail)

b. **What kind of work do (did) you do or what was your job title?**

\_\_\_\_\_  
**(For example:** registered nurse, personnel manager, supervisor of order department, machine operator.)

SECTION 11: EDUCATION, OCCUPATION AND INCOME (E)

**E4. How many people are currently living in your household, including yourself?**

*(Write in number and follow skip pattern instructions)*

1. Number of people \_\_\_\_\_ *If "1" Go to E5, otherwise go to 2-4 below*
2. Of these people, how many are children? \_\_\_\_\_
3. Of these people, how many are adults? \_\_\_\_\_
4. Of the adults, how many bring income into the household? \_\_\_\_\_
88. REFUSED } **GO TO E5**
99. D/K }

**E5. Which of the following best describes the home where you live. Is it...?**

*(Read responses and circle one)*

1. Owned or being bought by you (or someone in the household)?
2. Rented for money?
3. Occupied without payment of money or rent?
4. Other (specify) \_\_\_\_\_
88. REFUSED
99. D/K

SECTION 11: EDUCATION, OCCUPATION AND INCOME (E)

**E6. Please look at Show Card #16. Which of these categories best describes your total combined family income for the past 12 months? This should include income (before taxes) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), and so on.**

*(Circle one)*

1. \$24,000 or less
2. \$25,000 through \$35,000
3. \$36,000 through \$45,000
4. \$46,000 through \$55,000
5. \$56,000 through \$65,000
6. \$66,000 through \$75,000
7. \$76,000 through \$99,000
8. \$100,000 through \$149,000
9. \$150,000 through \$199,000
10. \$200,000 or more
88. REFUSED
99. D/K

**SECTION 12: IMMIGRATION (I)**

The following questions are about your family's background/ancestry.

11. In what state or country was:

	STATE	COUNTRY
a. Your biological father born?	_____	_____
b. Your father's mother (your grandmother) born?	_____	_____
c. Your father's father (your grandfather) born?	_____	_____
d. Your biological mother born?	_____	_____
e. Your mother's mother (your grandmother) born?	_____	_____
f. Your mother's father (your grandfather) born?	_____	_____

Check Reference Sheet, page 1, item **G14**.

↓  
If **not** checked, **Go to I4, page 66**.

If checked, **continue below**.

Now we would like to know about your background.

12. How old were you when you first came to this country to live?

\_\_\_\_\_ years old

88 REFUSED

99 D/K

SECTION 12: IMMIGRATION (I)

13. The following are a list of reasons that people give for coming to the United States. Please tell us how important each one of these reasons was for you and/or your family to come to the US.

(Read responses and circle one response for each item)

	Not important	Somewhat important	Very important	N/A	REF	D/K
a. To find employment or a job <i>READ "How important was this? Not Important, Somewhat Important, or Very Important" after the first 2 questions and then as necessary.</i>	1	2	3	77	88	99
b. To improve your life or that of your family and look for better opportunities	1	2	3	77	88	99
c. To join other family members already living in the US	1	2	3	77	88	99
d. Because of the political situation in your country of origin	1	2	3	77	88	99
e. Because you (or your family) were mistreated for political reasons	1	2	3	77	88	99
f. For medical care	1	2	3	77	88	99
g. To get a better education	1	2	3	77	88	99
h. Because of marital or family problems	1	2	3	77	88	99

SECTION 12: IMMIGRATION (I)

14. We would like to know about which languages you speak and prefer.

What languages do you speak at home?

\_\_\_\_\_ →

If non-English language only, check box here and also on Reference Sheet, page 5, item 14.

15. What languages did you speak while growing up?

\_\_\_\_\_ → *If more than one language Go to a. below:*

a. Which language did you speak the most?

\_\_\_\_\_

Check responses to items 14 and 15 above:

→ If only "ENGLISH" → Check Reference sheet, page 1, item G14.

↓  
If not checked, Go to End of survey page 71.

If checked, Go to I10, page 69.

→ Else (if other language[s] listed) → Go to I6, page 67.

SECTION 12: IMMIGRATION (I)

16. The next few questions are about speaking English.

(Read responses and circle one response for each item)

	Not at all well	Poorly	OK	Well	Very well	REF	D/K
a. How well do you speak English? <i>READ "Not at all well, Poorly, OK, Well, Very well" after the first 2 questions and then as necessary.</i>	1	2	3	4	5	88	99
b. How well do you understand spoken English?	1	2	3	4	5	88	99
c. How well do you read English?	1	2	3	4	5	88	99
d. How well do you write English?	1	2	3	4	5	88	99

17. Please tell me how often you experience difficulties in the following areas **BECAUSE** of your ability to speak and understand English?

(Read responses and circle one response for each item)

How often do you experience difficulties when....	Never	Sometimes	Often	Very often	N/A	REF	D/K
a. you are at work? <i>READ "Never, Sometimes, Often, Very Often" after the first 2 questions and then as necessary.</i>	1	2	3	4	77	88	99
b. you try to understand official documents, such as tax forms?	1	2	3	4	77	88	99
c. you go shopping and have to talk to a sales clerk?	1	2	3	4	77	88	99

Check Reference sheet, page 5, item **I4**:

If checked → Go to **I8**, page 68.

If **not** checked → Check Reference sheet, page 1, item **G14**.

↓

If checked, Go to **I10**, page 69.

If **not** checked, Go to **End of Survey**, page 71.

SECTION 12: IMMIGRATION (I)

18. Does anyone in your household speak English?

(Circle one)

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

19. Does anyone in your household read English?

(Circle one)

- 1. Yes
- 2. No
- 88. REFUSED
- 99. D/K

Check Reference sheet item, page 1, item **G14**.



If checked, **Go to I10, page 69.**

If **not** checked, **Go to End of Survey, page 71.**

SECTION 12: IMMIGRATION (I)

110. Next, I would like to ask about your current level of stress [or stress you feel] about living in the US. Please remember that any information you provide will be kept confidential.

(Read responses and circle one response for each item)

You feel that living in the US is stressful:	Never	Sometimes	Often	Very often	N/A	REF	D/K
a. because you lack the opportunity to visit your country of origin. <i>READ "Would you say Never, Sometimes, Often, or Very Often" after the first 2 questions and then as necessary.</i>	1	2	3	4	77	88	99
b. because you are living away from your family, relatives, and friends.	1	2	3	4	77	88	99
c. because you are unable to do the things you used to enjoy when you were in your country of origin.	1	2	3	4	77	88	99
d. because you are mistreated by others of your ethnic group.	1	2	3	4	77	88	99
e. because you have or had a job that is below your experience and qualifications.	1	2	3	4	77	88	99
f. because you are treated as an outsider by other Americans.	1	2	3	4	77	88	99
g. because you have few, if any, opportunities to participate in American politics.	1	2	3	4	77	88	99
h. because you are constantly reminded of your minority status.	1	2	3	4	77	88	99
i. because you are disappointed that your standard of living is not what you had hoped for when you first came to the US.	1	2	3	4	77	88	99

Continued next page

SECTION 12: IMMIGRATION (I)

110 Continued:

<b>You feel that living in the US is stressful:</b>	Never	Sometimes	Often	Very often	N/A	REF	D/K
<b>o. because you have to depend on others for understanding how to access support services that you need.</b>	1	2	3	4	77	88	99
<b>p. because you don't understand the healthcare system here in the U.S.</b>	1	2	3	4	77	88	99
<b>q. because you feel you have heavy responsibilities for BOTH your family here in the U.S. as well as family in your country of origin.</b>	1	2	3	4	77	88	99
<b>r. because you worry about losing ties to your parents' culture.</b>	1	2	3	4	77	88	99
<b>s. because you feel you are obligated to take care of your parents in their old age.</b>	1	2	3	4	77	88	99

111. Finally, my last few questions are about some immigration experiences you may have had.

(Read questions and circle one response for each item)

	Yes	No	N/A	REF	D/K
<b>a. Do you feel guilty for leaving family or friends in your country of origin?</b>	1	0	77	88	99
<b>b. Have you been questioned about your legal status?</b>	1	0	77	88	99
<b>c. Do you think you will be deported if you go to a social or government agency, regardless of your legal status?</b>	1	0	77	88	99
<b>d. Do you avoid seeking health services due to fear of immigration officials, regardless of your legal status?</b>	1	0	77	88	99

**END OF SURVEY**

That concludes the interview. Thank you so much for taking the time to answer our questions.

C1. **[If participant has been identified as a 10% retest participant]:** In order to make sure we are getting the most accurate data, we will be re-contacting participants in about two weeks to ask just a few of the same questions I have just asked you. May I call you in two weeks to conduct a very short interview – about 15 minutes – asking a few of the same questions we went over today?

- 1 Yes → Proceed to schedule convenient time for re-test below.
- 2 No → Comments regarding refusal: \_\_\_\_\_ → Go to C2

RETEST DATE: \_\_\_\_\_

TIME: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_

} → Go to C2

C2. Our study team may be involved with future studies that aim to better understand women’s breast cancer experiences. Would you be interested in being contacted by us again to learn about potential opportunities to participate in future studies? If you say “yes,” this does not mean you are consenting to participate in future studies, just that you are allowing us to inform you about them.

- 1 Yes → Go to C3, next page
- 2 No → Comments regarding refusal: \_\_\_\_\_ → Go to Thank you, next page.

SECTION 13: CONCLUSION (C)

C3. **I would like to confirm your best contact information.** *(Confirm address and telephone information. If any new information, or additional phone numbers, indicate below).*

*PARTICIPANT'S Current Contact Information (if different from Assignment Sheet):*

Name	Phone Number(s) (    )    - (    )    -
Street Address	City, State, Zip
Email address	



**Would you also be able to provide the contact information of one or two people who might help us locate you in case you move?**

*Contact information for people who might help us locate participant:*

Name #1	Phone Number(s) (    )    - (    )    -
Street Address	City, State, Zip

Name #2	Phone Number(s) (    )    - (    )    -
Street Address	City, State, Zip

→ **THANK YOU: We are very grateful for your input and participation in this research. Thank you so much for taking the time to speak with me.**