

**CBCS3 Follow Up #6 (66-month) Telephone Call Log**

|   |  |
|---|--|
| Name: «FNAME» «LNAME»                             | AGE: «SUBJECT_CURRENT_AGE»   |
| Address : «ADDR1» «ADDR2»<br>«CITY» «STATE» «ZIP» | In-home interview date: «NURSE_VISIT_DATE»<br>Interviewing Nurse: «NURSE_NAME» |
| 1st Phone #: «PHONE1»                             | DOB: «DOB»   |
| 2nd Phone #: «PHONE2»                             | Email: «EMAIL_ADDR»  |

**COMMENTS:** «SUBJECT\_ADDR\_COMMENTS»; «SUBJECT\_COMMENTS»

**ADDRESS HISTORY:** (Obtain 3-year address history and enter in address tab in CBCS database.)

**READ: Please let me double-check your address and phone number.** (Review address and telephone contact info printed above. Make telephone corrections above. If tel. and address incorrect, please ask participant to provide age or birthday (month and day only) to confirm correct identity. Do not provide DOB to them!)

**A. Is this the correct contact information for you?** 1\_\_YES 2\_\_NO

If **NO**:

Correct Street address: \_\_\_\_\_

Correct City, State, Zip: \_\_\_\_\_

**B. When did you begin living at this address?** \_\_\_\_\_, \_\_\_\_\_  
(Month) (Year)

(Calculate number of years at current address)

**C. So, you've been living at this address continuously, including during any treatments for breast cancer, for about \_\_\_\_ years?**

**D. (If LESS THAN 3 years at current address, or if living elsewhere during treatment):**

**What was your previous address (or the address where you stayed during treatments)?**

1<sup>st</sup> Previous street address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

**E. When did you live at this address?** FROM: \_\_\_\_\_, \_\_\_\_\_  
(Month) (Year)  
TO: \_\_\_\_\_, \_\_\_\_\_  
(Month) (Year)

If LESS THAN 3 years (total at both addresses), obtain 3 year address history on separate sheet of paper.

**READ:** Thanks! Okay, let's get started. (Return to Follow-up Telephone survey, p. 1)

|   |  |
|---|--|
| Name: «FNAME» «LNAME»                             | AGE: «SUBJECT_CURRENT_AGE»   |
| Address : «ADDR1» «ADDR2»<br>«CITY» «STATE» «ZIP» | In-home interview date: «NURSE_VISIT_DATE»<br>Interviewing Nurse: «NURSE_NAME» |
| 1st Phone #: «PHONE1»                             | DOB: «DOB»   |
| 2nd Phone #: «PHONE2»                             | Email: «EMAIL_ADDR»  |

**COMMENTS:** «SUBJECT\_ADDR COMMENTS»; «SUBJECT COMMENTS»

| Call # | Initials | Date | Time               | *Result | Comments |
|--------|----------|------|--------------------|---------|----------|
| 1.     |          |      | ____:____<br>AM/PM |         |          |
| 2.     |          |      | ____:____<br>AM/PM |         |          |
| 3.     |          |      | ____:____<br>AM/PM |         |          |
| 4.     |          |      | ____:____<br>AM/PM |         |          |
| 5.     |          |      | ____:____<br>AM/PM |         |          |
| 6.     |          |      | ____:____<br>AM/PM |         |          |
| 7.     |          |      | ____:____<br>AM/PM |         |          |
| 8.     |          |      | ____:____<br>AM/PM |         |          |
| 9.     |          |      | ____:____<br>AM/PM |         |          |
| 10.    |          |      | ____:____<br>AM/PM |         |          |
| 11.    |          |      | ____:____<br>AM/PM |         |          |
| 12.    |          |      | ____:____<br>AM/PM |         |          |

\*Results: NA=No Answer; B=Busy, NH=Not Home; VM=Voice Mail/Ans. Machine; CB=Call Back Later;  
R=Refused Further Participation; CC=Call Completed  
NOTES:

**CBCS3 Follow Up #6 (66-Month) Telephone Survey/HP Form**

|                                       |   |
|---------------------------------------|---|
| Name: «FNAME» «LNAME»                 | Collected by (your initials):               |
| DOB: «DOB» AGE: «SUBJECT_CURRENT_AGE» | Date collected: ___ ___ / ___ ___ / ___ ___ |
| Date of Elig: «CCR_FIRST_ELIG_DATE»   | Start time: ___ ___ : ___ ___ am / pm       |

**READ:** Thank you for agreeing to talk with me about the treatments you received for breast cancer. All of the information you share with me today will be kept confidential, and it should only take about 15 to 20 minutes. We'll also send you a check for **\$10** within 4 weeks of completing this call. Do you have any questions before we begin?

**VERIFY PARTICIPANT'S ADDRESS/CONTACT INFO: READ:** Before we get started, please let me double-check your address and phone number. (Review/update address history info printed on **call log**.)

**(Okay, let's get started!)** How are you doing? How is your general health? (Don't record answer, take notes if needed)

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**READ:** The last time we talked, we reviewed your breast cancer treatment. I'd like to go over that with you now in order to update your treatment information. (See HP sheet)

**1.** First, I'd like to review any **SURGERY, BIOPSY, or RECONSTRUCTION** procedures you've had since we last talked to you. (Review the surgery/biopsy sections (actual and scheduled procedures) listed on Subject Health Professional Information (HP) report. Verify tx dates and facility.)

Have you had any more procedures, such as biopsies, surgeries, or reconstruction, for breast cancer? This would include: surgical procedures for initial diagnosis, recurrence, a new breast cancer, or another cancer.

1 \_\_\_ YES 2 \_\_\_ NO (Skip to Q. 2)

|  |
|--|
| <p><b>1<sup>st</sup> Surgical Procedure not listed on HP Report</b></p> <p><b>SCHEDULED</b> or <b>ACTUAL</b> Surgical Procedure DATE: _____<br/> <small>(Circle "Scheduled" or "Actual" above)</small></p> <p>Treatment for: ___ Initial Diagnosis ___ Recurrence ___ New Breast Primary ___ Other Cancer</p> <p>Procedure type(s): _____</p> <p>Facility/Clinic Name/Address: _____</p> <p>Doctor Name/Address: _____</p> <p>COMMENTS: _____</p> <p>_____</p> |
|--|

**2<sup>nd</sup> Surgical Procedure not listed on HP Report**

**SCHEDULED** or **ACTUAL** Surgical Procedure DATE: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Treatment for: \_\_\_ Initial Diagnosis \_\_\_ Recurrence \_\_\_ New Breast Primary \_\_\_ Other Cancer

Procedure type(s): \_\_\_\_\_

Facility/Clinic Name/Address: \_\_\_\_\_

Doctor Name/Address: \_\_\_\_\_

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_

**3<sup>rd</sup> Surgical Procedure not listed on HP Report**

**SCHEDULED** or **ACTUAL** Surgical Procedure DATE: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Treatment for: \_\_\_ Initial Diagnosis \_\_\_ Recurrence \_\_\_ New Breast Primary \_\_\_ Other Cancer

Procedure type(s): \_\_\_\_\_

Facility/Clinic Name/Address: \_\_\_\_\_

Doctor Name/Address: \_\_\_\_\_

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_

Additional surgical procedures? 1 \_\_\_ YES (Include additional page) 2 \_\_\_ NO

**2.** Now I'm going to ask you about **CHEMOTHERAPY**. Chemotherapy is sometimes given after surgery to destroy leftover (microscopic) cells that may remain after tumor removal by surgery, to prevent a possible recurrence. (Review the chemo section of HP Report with participant. Verify treatment dates and facility.)

Have you had any (additional) chemotherapy treatments or consults or appointments, or are you scheduled for a consult or to receive chemotherapy in the future? This would include treatments for your initial diagnosis, recurrence, or new breast cancer, or another cancer. 1 \_\_\_ YES 2 \_\_\_ NO (skip to Q. 3)

**1<sup>st</sup> Chemo Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Chemo Treatment START DATE: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Is treatment completed or ongoing or stopped? 1\_\_\_COMPLETED 2\_\_\_ONGOING  
3\_\_\_STOPPED

Expected or Actual Chemo Treatment END DATE: \_\_\_\_\_

Treatment for: \_\_\_Initial Diagnosis \_\_\_Recurrence \_\_\_New Breast Primary \_\_\_Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

Doctor Name/Address: \_\_\_\_\_

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_

**2<sup>nd</sup> Chemo Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Chemo Treatment START DATE: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Is treatment completed or ongoing or stopped? 1\_\_\_COMPLETED 2\_\_\_ONGOING  
3\_\_\_STOPPED

Expected or Actual Chemo Treatment END DATE: \_\_\_\_\_

Treatment for: \_\_\_Initial Diagnosis \_\_\_Recurrence \_\_\_New Breast Primary \_\_\_Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

Doctor Name/Address: \_\_\_\_\_

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_

Additional chemotherapy? 1\_\_\_ YES (Include additional page) 2\_\_\_ NO

**3.** Now I'm going to ask you about **RADIATION THERAPY**. Radiation therapy is when a machine is used to send a radiation beam to treat cancer. I am NOT referring to imaging, such as mammograms, MRI or ultrasound. Instead, I am referring to radiation used to treat your cancer. (Review the radiation therapy section of HP Report with participant. Verify treatment dates and facility.)

Have you had any (additional) radiation treatments or consults or appointments about radiation, or are you scheduled to receive radiation in the future? This would include: radiation treatments for your initial diagnosis, recurrence, or another cancer. 1\_\_\_YES 2\_\_\_NO (skip to Q. 4)

**1<sup>st</sup> Radiation Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Radiation Treatment START DATE: \_\_\_\_\_  
 (Circle "Scheduled" or "Actual" above)

Expected or Actual Radiation Treatment END DATE: \_\_\_\_\_

Is treatment completed or ongoing or stopped? 1\_\_\_COMPLETED 2\_\_\_ONGOING  
 3\_\_\_STOPPED

Treatment for: \_\_\_Initial Diagnosis \_\_\_Recurrence \_\_\_New Breast Primary \_\_\_Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

Doctor Name/Address: \_\_\_\_\_

COMMENTS: \_\_\_\_\_

\_\_\_\_\_

**2<sup>nd</sup> Radiation Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Radiation Treatment START DATE: \_\_\_\_\_  
 (Circle "Scheduled" or "Actual" above)

Expected or Actual Radiation Treatment END DATE: \_\_\_\_\_

Is treatment completed or ongoing or stopped? 1\_\_\_COMPLETED 2\_\_\_ONGOING  
 3\_\_\_STOPPED

Treatment for: \_\_\_Initial Diagnosis \_\_\_Recurrence \_\_\_New Breast Primary \_\_\_Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

Doctor Name/Address: \_\_\_\_\_

COMMENTS: \_\_\_\_\_

\_\_\_\_\_

Additional radiation? 1 \_\_\_ YES (Include additional page) 2 \_\_\_ NO

**4. Now I want to ask you about OTHER TREATMENTS you may have had. (Review the Other Treatments/Visits listed on HP summary with participant.)**

Are there any other health care providers (physician, clinic, hospital, etc.) who treated you or followed up with you, or whom you are scheduled to see, for treatment or surgery related to breast cancer or another type of cancer? This may include follow-up office visits with your surgeon or plastic surgeon, oncologist or doctor, radiation oncologist, primary care physician, or being treated for lymphedema or other side effects, or taking tamoxifen, hormones, herceptin, avastin, or alternative and complementary therapy, or any other treatments, but **not** mammograms or chest x-rays. (Alternative and complementary therapy examples: acupuncture, massage therapy, herbal supplements) 1\_\_\_YES 2\_\_\_NO (go to Q.5)

**1<sup>st</sup> Visit/Other Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Treatment/Visit Date: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Purpose of Visit: \_\_\_\_\_

If Follow-up or annual visit, ask: Was this a routine follow-up, or did the doctor address a specific health issue or problem you were having?      \_\_\_ Routine Visit    \_\_\_ Problem

(Specify, if problem): \_\_\_\_\_

Treatment for:    \_\_\_ Initial Diagnosis    \_\_\_ Recurrence    \_\_\_ New Breast Primary    \_\_\_ Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

(Ordering) Doctor Name/Address: \_\_\_\_\_

Doctor/Facility Tel. \_\_\_\_\_

COMMENTS: \_\_\_\_\_

\_\_\_\_\_

**2<sup>nd</sup> Visit/Other Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Treatment/Visit Date: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Purpose of Visit: \_\_\_\_\_

If Follow-up or annual visit, ask: Was this a routine follow-up, or did the doctor address a specific health issue or problem you were having?      \_\_\_ Routine Visit    \_\_\_ Problem

(Specify, if problem): \_\_\_\_\_

Treatment for:    \_\_\_ Initial Diagnosis    \_\_\_ Recurrence    \_\_\_ New Breast Primary    \_\_\_ Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

(Ordering) Doctor Name/Address: \_\_\_\_\_

Doctor/Facility Tel. \_\_\_\_\_

COMMENTS: \_\_\_\_\_

\_\_\_\_\_

**3<sup>rd</sup> Visit/Other Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Treatment/Visit Date: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Purpose of Visit: \_\_\_\_\_

If Follow-up or annual visit, ask: Was this a routine follow-up, or did the doctor address a specific health issue or problem you were having?      \_\_\_ Routine Visit    \_\_\_ Problem

(Specify, if problem): \_\_\_\_\_

Treatment for:    \_\_\_ Initial Diagnosis    \_\_\_ Recurrence    \_\_\_ New Breast Primary    \_\_\_ Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

(Ordering) Doctor Name/Address: \_\_\_\_\_

Doctor/Facility Tel. \_\_\_\_\_

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_

**4<sup>th</sup> Visit/Other Treatment not listed on HP Report**

**SCHEDULED** or **ACTUAL** Treatment/Visit Date: \_\_\_\_\_  
(Circle "Scheduled" or "Actual" above)

Purpose of Visit: \_\_\_\_\_

If Follow-up or annual visit, ask: Was this a routine follow-up, or did the doctor address a specific health issue or problem you were having?      \_\_\_ Routine Visit    \_\_\_ Problem

(Specify, if problem): \_\_\_\_\_

Treatment for:    \_\_\_ Initial Diagnosis    \_\_\_ Recurrence    \_\_\_ New Breast Primary    \_\_\_ Other Cancer

Facility/Clinic Name/Address: \_\_\_\_\_

(Ordering) Doctor Name/Address: \_\_\_\_\_

Doctor/Facility Tel. \_\_\_\_\_

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_

Additional other treatments/visits? 1 \_\_\_ YES (Include additional page) 2 \_\_\_ NO



5. Have you suffered from any of the following long-term side effects as a result of your surgeries or treatment for breast cancer? By long-term we mean side effects that you still have now.

| Description (Read list and mark "X" in appropriate box) | YES | NO | DON'T KNOW |
|---|-----|----|------------|
| a. SWELLING of the ARM or HAND, also called LYMPHEDEMA  |     |    |            |
| b. NUMBNESS, also called NEUROPATHY                     |     |    |            |
| c. CARDIAC OR HEART PROBLEMS                            |     |    |            |
| d. FATIGUE  |     |    |            |
| e. MEMORY LOSS  |     |    |            |
| f. OTHER (Describe:)                                    |     |    |            |

6. Have you had any recurrences of your breast cancer? This means the breast cancer has come back in the same place or it has spread from the original tumor to another part of your body.

1\_\_\_ YES                      2\_\_\_ NO (Skip to Q. 7)                      9\_\_\_ NA or Don't Know (Skip to Q. 7)

6a. When was the recurrence? \_\_\_\_\_

6b. In what part of your body? \_\_\_\_\_

6c. Have you received any treatment for the recurrence?    1\_\_\_ YES                      2\_\_\_ NO

6d. How were you diagnosed? (Read options, check all that apply)

- a. \_\_\_ Blood test
- b. \_\_\_ Biopsy or surgery
- c. \_\_\_ Imaging (ultrasound, pet scan, cat scan, x-ray)
- d. \_\_\_ Other: \_\_\_\_\_

(If Yes to 6c (treatment), Record treatments/visits/dates in Q. 1 thru 4. Circle "RECURRENCE.")

7. Have you been diagnosed with a new breast tumor? This means you had a new breast tumor in a new area on the same breast or in the other breast—some people call this a second primary.

1\_\_\_ YES                      2\_\_\_ NO (Skip to Q. 8)                      9\_\_\_ NA or Don't Know (Skip to Q. 8)

7a. When were you diagnosed with the new breast tumor? \_\_\_\_\_

7b. Was it in the same breast or the other breast? \_\_\_\_\_

7c. Have you received any treatment for the new tumor? 1\_\_\_ YES                      2\_\_\_ NO

7d. How were you diagnosed? (Read options, check all that apply)

- a. \_\_\_ Blood test
- b. \_\_\_ Biopsy or surgery
- c. \_\_\_ Imaging (ultrasound, pet scan, cat scan, x-ray)
- d. \_\_\_ Other: \_\_\_\_\_

**(If YES to 7c (treatments), Record any treatments/visits/dates in Questions 1 thru 4. Circle "NEW BREAST PRIMARY.")**

8. (If new treatment is indicated in questions 1-7): We want to request copies of your medical records from the doctors and hospitals you mentioned. We'd like to mail the consent form and medical records release forms to you along with a pre-paid business reply envelope. If you sign and mail them back, we'll send you an additional check for \$15.

May I send the forms to you for your signature? 1\_\_YES 2\_\_NO

8a. (if YES to 6 (recurrence) or 7 (new breast primary): With your permission, we want to request samples of the diagnostic surgeries or procedures for your (recurrence or new breast cancer) to compare with the tissue we have from your original diagnosis. We'd like to mail the consent form and tumor block release form to you along with a pre-paid business reply envelope. If you sign and mail it back, we'll send you an additional check for \$15.

May I send the **tumor block release** to you for your signature? 1\_\_\_YES                      2\_\_\_NO  
(Circle YES or NO in check boxes (last page of survey) next to Consent form for 2<sup>nd</sup> breast primary/ Recurrence data collection, Medical Records releases and Tumor Block Release form)

9. **Since your breast cancer diagnosis**, have you been told by a doctor that you had cancer in a place other than your breasts?

1\_\_\_ YES                      2\_\_\_ NO (skip to Q. 10)                      9\_\_\_ NA or Don't Know (skip to Q. 10)

| 9.                        | a. What type of cancer did you have? | b. How old were you when this cancer was diagnosed? |
|---------------------------|--------------------------------------|---|
| 1 <sup>st</sup> Diagnosis |                                      | ___ ___ Age<br>(Enter 99 if don't know)             |
| 2 <sup>nd</sup> Diagnosis |                                      | ___ ___ Age<br>(Enter 99 if don't know)             |
| 3 <sup>rd</sup> Diagnosis |                                      | ___ ___ Age<br>(Enter 99 if don't know)             |

**If YES, go back to #4 and enter treatment info for other cancer(s).**

Additional cancers? 1\_\_\_ YES (Include additional page)                      2\_\_\_ NO

**[Transition statement]** Now we've got some questions about your general health, physical activity and recent life experiences, Okay?

**10.** How much do you currently weigh? \_\_\_\_\_ lbs. (enter 888 if don't know or NA)

**11.** Have you gained or lost more than 5 pounds in the past two years?

1\_\_\_YES            2\_\_\_NO (Skip to Q. 13)            9\_\_\_Don't Know (Skip to Q.12)

**11a.** \_\_\_Gained: How much? \_\_\_\_\_ lbs.

**11b.** \_\_\_Lost: How much? \_\_\_\_\_ lbs.

**READ:** Next I will be asking you some questions about any medical conditions you may have. If you answer that you have been diagnosed with any of these medical conditions, I will then ask you if you have taken medications for these conditions.

| Have you <u>EVER</u> been told by a doctor or other health professional that you had any of the following conditions? | a. Answer:                             | b. What year was this condition diagnosed? | c. Do you currently take any prescription medications for this condition? |
|---|--|--|---|
| <b>12.</b> Alzheimer's disease  | 1 ___Yes →<br>2 ___No<br>9 ___DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>13.</b> Arthritis  | 1 ___Yes →<br>2 ___No<br>9 ___DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>14.</b> Asthma   | 1 ___Yes →<br>2 ___No<br>9 ___DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>15.</b> Chronic obstructive pulmonary disease (COPD), emphysema, or chronic bronchitis                             | 1 ___Yes →<br>2 ___No<br>9 ___DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>16.</b> Diabetes (do not include diabetes during pregnancy)  | 1 ___Yes →<br>2 ___No<br>9 ___DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |

| Have you <u>EVER</u> been told by a doctor or other health professional that you had any of the following conditions? | a. Answer:                                | b. What year was this condition diagnosed? | c. Do you currently take any prescription medications for this condition? |
|---|---|--|---|
| <b>17.</b> HIV/AIDS   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>18.</b> Hypertension   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>19.</b> Weak or failing kidneys - do not include kidney stones, bladder infections, or incontinence                | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>20.</b> Liver conditions, for example cirrhosis of the liver, chronic liver disease                                | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>21.</b> Osteoporosis   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>22.</b> Inflammatory bowel disease, such as Crohn's Disease/Ulcerative Colitis                                     | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>23.</b> Ulcer - stomach, duodenal or peptic ulcer  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>24.</b> Anxiety  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |

| Have you <u>EVER</u> been told by a doctor or other health professional that you had any of the following conditions? | a. Answer:                                | b. What year was this condition diagnosed? | c. Do you currently take any prescription medications for this condition? |
|---|---|--|---|
| <b>25.</b> Depression   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>26.</b> Bipolar Disorder   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>27.</b> Schizophrenia  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>28.</b> Congestive heart failure   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>29.</b> Angina/chest pain  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>30.</b> Heart attack/<br>myocardial infarction   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>31.</b> High cholesterol   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>32.</b> Stroke   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>33.</b> Blood clot in a leg or deep vein thrombosis  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |

| Have you <u>EVER</u> been told by a doctor or other health professional that you had any of the following conditions? | a. Answer:                                | b. What year was this condition diagnosed? | c. Do you currently take any prescription medications for this condition? |
|---|---|--|---|
| <b>34.</b> Blood clot in your lungs or a pulmonary embolus  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>35.</b> Problem with your thyroid  | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>36.</b> Any other serious condition? Specify:<br>_____   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |
| <b>37.</b> Any other serious condition? Specify:<br>_____   | 1 ___ Yes →<br>2 ___ No<br>9 ___ DK or NA | _____<br>(DK: 9999)                        | 1 ___ Yes<br>2 ___ No   |

**38.** Overall, how many different prescription medications do you currently take?    \_\_\_ \_\_\_

Thank you for completing the general health section. Next, I want to ask some questions about your lifestyle.

**39.** Do you currently smoke? 1\_\_\_YES    2\_\_\_NO (Skip to Q. 40)    9\_\_\_ NA or UNK (Skip to Q. 40)

**39a.** On average, how many cigarettes do you smoke per day? (20 cigs/pk)

- 1 \_\_\_ More than 2 packs
- 2 \_\_\_ >1½ to 2 packs
- 3 \_\_\_ >1 to 1½ pack
- 4 \_\_\_ ½ to 1 pack
- 5 \_\_\_ Less than ½ pack
- 6 \_\_\_ Once in a while, not every day
- 9 \_\_\_ NA

**40.** Do you currently drink alcoholic beverages?

- 1 \_\_\_ YES
- 2 \_\_\_ NO (Skip to Q. 41)
- 9 \_\_\_ NA (Skip to Q. 41)

**40a.** On average, how many drinks containing alcohol do you have each **week**? By one drink, we mean, for example, a 12 ounce can or glass of beer or cooler, a 5 ounce glass of wine, or a drink containing 1 shot of liquor.

\_\_\_\_\_ drinks per week  
(Enter "00" if less than 1 drink per week)

**READ:** Now I am going to ask you a few questions about your physical activity since we last spoke to you. I am going to ask about moderate and vigorous physical activity.

**41. Moderate activities cause your heart rate and your breathing to go up just a little bit.**

How many days per week do you do moderate physical activity for at least 10 minutes at a time?

\_\_\_\_ Days per week (enter 9 for Not Answered or Unknown)

**42. Vigorous activities cause a large increase in your heart rate and breathing rate.**

How many days per week do you do vigorous physical activity for at least 10 minutes at a time?

\_\_\_\_ Days per week (enter 9 for Not Answered or Unknown)

**43a. What type of health insurance do you have now? (Read options, check all that apply)**

- a \_\_\_\_ None
- b \_\_\_\_ Private health insurance purchased on your own or by your husband or partner
- c \_\_\_\_ Private health insurance from your employer or workplace or that of your husband or partner
- d \_\_\_\_ Medicaid
- e \_\_\_\_ Medicare
- f \_\_\_\_ Any other insurance that covers part of your medical bills
- g \_\_\_\_ Not Answered or Unknown

**43b. Since your diagnosis of breast cancer, was there a time when you did not have any health insurance?**

1\_\_YES      2\_\_NO (Skip to Q. 44)      9\_\_NA or Unknown (Skip to Q. 44)

**43c. Combining all of the times that you were without coverage since your diagnosis, what was the total amount of time that you did not have health insurance? (ENTER years and months, enter 00 if none, enter 99 if Unknown)**

\_\_\_\_ Years      \_\_\_\_ Months

**44. Since your diagnosis of breast cancer, was there ever a time that you wanted to see a doctor, but could not because of financial issues?**

1\_\_YES      2\_\_NO      9\_\_NA or Unknown

**45. Since your diagnosis of breast cancer, was there ever a time that you wanted to see a doctor, but could not, because of transportation issues?**

1\_\_YES      2\_\_NO      9\_\_NA or Unknown

**READ:** It is important for us to learn as much as possible about a history of breast cancer in your family, particularly your mother, sisters and daughters. For those who have had breast cancer, we would like to know when the cancer was diagnosed and how old they were at the time. We are interested in living and deceased members of your family, but only if they are full-blood relatives.

**46.** Has your mother ever been diagnosed with breast cancer?

1\_\_\_ YES      2\_\_\_ NO (Skip to Q. 48)      9\_\_\_ DK (Skip to Q.48)

|            |                                    |  |                                    |                                   |                           |
|------------|------------------------------------|--|------------------------------------|-----------------------------------|---------------------------|
| <b>47.</b> | a. What year was your mother born? | b. What year was she first diagnosed with breast cancer? | c. How old was she when diagnosed? | d. Is your mother still living?   | e. What year did she die? |
|            | _____                              | _____  | _____                              | 1___ Yes<br>2___ No<br>9___ NA/DK | _____                     |

**READ:** Now, let's discuss your sisters.

**48.** How many full sisters do you have? Do not include step-sisters or adopted sisters.

\_\_\_ \_\_\_ IF NONE, Skip to Q. 50.

**48a.** How many of your full sisters have been diagnosed with breast cancer?

\_\_\_ \_\_\_ IF NONE, Skip to Q. 50.

**READ:** I'd like to ask you a few questions about your sisters who had breast cancer.

| <b>49. What is your sister's first name?</b><br><small>(NOTE: WILL NOT BE ENTERED INTO DATABASE)</small> | <b>a. What year was she born?</b> | <b>b. What year was she first diagnosed with breast cancer?</b> | <b>c. How old was she when diagnosed?</b> | <b>d. Is [NAME] still living?</b> | <b>e. (If died) What year did she die?</b> |
|--|-----------------------------------|---|---|-----------------------------------|--|
| 1 <sup>st</sup> sister w/breast ca:<br>_____   | _____                             | _____   | _____                                     | 1___ Yes<br>2___ No<br>9___ DK/NA | _____                                      |
| 2 <sup>nd</sup> sister w/breast ca:<br>_____   | _____                             | _____   | _____                                     | 1___ Yes<br>2___ No<br>9___ DK/NA | _____                                      |
| 3 <sup>rd</sup> sister w/breast ca:<br>_____   | _____                             | _____   | _____                                     | 1___ Yes<br>2___ No<br>9___ DK/NA | _____                                      |

IF MORE THAN 3 SISTERS W/BREAST CANCER CHECK HERE \_\_\_ AND ADD ADDITIONAL PAGE.

**READ:** Now, let's discuss your daughters.

**50.** How many full daughters do you have? Do not include step-daughters or adopted daughters.

\_\_\_ \_\_\_ IF NONE, Skip to Q. 52.

**50a.** How many of your daughters have been diagnosed with breast cancer?

\_\_\_ \_\_\_ IF NONE, Skip to Q. 52.



**READ:** I'd like to ask you a few questions about your daughters who had breast cancer.

| 51. What is your daughter's first name?<br>(NOTE: WILL NOT BE ENTERED INTO DATABASE) | a. What year was she born? | b. What year was she first diagnosed with breast cancer? | c. How old was she when diagnosed? | d. Is [NAME] still living?     | e. (If died) What year did she die? |
|--|----------------------------|--|------------------------------------|--------------------------------|-------------------------------------|
| 1 <sup>st</sup> daughter w/breast ca:<br>_____                                       | _____                      | _____  | _____                              | 1__ Yes<br>2__ No<br>9__ DK/NA | _____                               |
| 2 <sup>nd</sup> daughter w/breast ca:<br>_____                                       | _____                      | _____  | _____                              | 1__ Yes<br>2__ No<br>9__ DK/NA | _____                               |
| 3 <sup>rd</sup> daughter w/breast ca:<br>_____                                       | _____                      | _____  | _____                              | 1__ Yes<br>2__ No<br>9__ DK/NA | _____                               |

**IF MORE THAN 3 DAUGHTERS W/BREAST CANCER CHECK HERE \_\_\_\_ AND ADD ADDITIONAL PAGE.**

**52.** (NEW QUESTION 9/2017) You may remember that as part of your second follow up at about 18 months after your in-home interview, we mailed you a survey with questions about quality of life and other health-related matters that women with breast cancer have reported are important. Since it's been about 4 years since you completed that survey, we would like to send you a similar survey. If you complete it and mail it back, we'll send you an additional check for **\$25**. We'll include a pre-paid envelope to mail it back to us.

**May we send this survey to you?**    1\_\_ YES    2\_\_ NO

(If **YES**, circle YES on checklist (last page of survey) next to "Mail-in (Appendix B) survey")

**53.** We would like your permission to contact you again in another year or so, just to see how you're doing. Is that okay with you?

1\_\_ YES    2\_\_ NO    (If **NO**, Skip to Q. 55; update database "May Contact" field to "NO")

(If NO, note comments/reason: \_\_\_\_\_ )  
(If **NO**, please remember to update Event 106, FU#7 Reminder Letter from "Scheduled" to "Cancelled-No further contact")

**CONSENT ADDENDUM**

**Read:** The last thing I need to do is read a short consent addendum to you.

**(READ CONSENT ADDENDUM VERBATIM, CHECK APPROPRIATE ANSWERS, SIGN/DATE FORM. It is fine to summarize or explain the options on the consent addendum AFTER reading the entire form to the participant.)**

(Note: We will include a copy of consent addendum in mailing to participant – Circle YES in checklist box on last page of survey.)

**OTHER CONTACTS**

**(If Consent Addendum indicates YES to contacting other contacts – If NO, Go to Q. 55.)**

**54. VERIFY OTHER CONTACT INFO: READ:** In case we can't reach you, is there a name and phone number you can give us for a friend or relative who may be able to help us find you? (**VERIFY OTHER CONTACT INFO from printouts, update if needed**). 1\_\_YES 2\_\_NO (Go to Q. 55)

**(If Yes) 1<sup>st</sup> contact:**

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number(s): \_\_\_\_\_ E-Mail address: \_\_\_\_\_

**Is there a 2<sup>nd</sup> contact?**

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

Phone number(s): \_\_\_\_\_ E-mail address: \_\_\_\_\_

**(ENTER all new contact info in CBCS)**

**55.** Do you have any questions or comments, before we end? 1\_\_YES 2\_\_NO  
(Answer general questions only. For medical questions, refer to their MD, or tell them the researchers can get back to them.)

**VERIFY ADDRESS INFO (if not done at beginning of interview).**

**Before we finish, please let me double-check your address and phone number.** (VERY IMPORTANT!! Review last address printed on call log, and update with any additional addresses for the past three years.)

**READ:** That's it for questions! Thank you for completing this call.

| <b>CHECK LIST FOR MAILING (REVIEW WITH STUDY PARTICIPANT)</b>  |            |           |
|--|------------|-----------|
| <b>READ: OK. You should be receiving a mailing from us shortly, including a check for \$10 to thank you for taking the time to complete this follow up call with us.</b> |            |           |
| (If YES to any other items below, please mention that they will be in the mailing, as well.)   |            |           |
| <b>(added 9/2017) Mail-in (Appendix B) survey (w/pre-paid envelope)</b>  | <b>YES</b> | <b>NO</b> |
| <b>Medical records release forms (w/pre-paid envelope)</b>   | <b>YES</b> | <b>NO</b> |
| <b>Consent Addendum (Marked "FOR YOUR RECORDS")</b>  | <b>YES</b> | <b>NO</b> |
| <b>Consent form for 2<sup>nd</sup> breast primary/recurrence data collection</b>   | <b>YES</b> | <b>NO</b> |
| <b>Tumor block release form (w/pre-paid envelope)</b>  | <b>YES</b> | <b>NO</b> |
| <b>Other? _____</b>  | <b>YES</b> | <b>NO</b> |
| (Describe)   |            |           |

**ENDING:** Thank you so much for all your help with the Carolina Breast Cancer Study. Please contact us anytime, we always look forward to speaking with you. Our toll-free number is 1-866-927-6920, and my name is \_\_\_\_\_. On behalf of the Carolina Breast Cancer Study, we wish you all the best.

**Interview Call End time:** \_\_\_\_ : \_\_\_\_ am / pm

**NOTES:** \_\_\_\_\_

**University of North Carolina-Chapel Hill  
Consent to Participate in a Research Study**

**Addendum to provide additional information to subject after original consent**

**IRB Study #92-0410**

**Consent Form Version Date:** November 30, 2017

**Title of Study:** LCCC 9204: Population-Based Molecular Epidemiology of Breast Cancer: “The Carolina Breast Cancer Study”

**Principal Investigator:** Andy Olshan, PhD, Dept. of Epidemiology (919) 966-7424; andy\_olshan@unc.edu

**Study Contact:** Mary Beth Bell, Project Manager (919) 966-9438; email mbell@unc.edu

The following information should be read as an addition to the original Consent Form that you read and signed at the beginning of the study. Unless specifically stated otherwise in the following paragraphs, all information contained in that original Consent Form is still true and remains in effect. Your participation continues to be voluntary. You may refuse to participate, or may withdraw your consent to participate at any time, for any reason. A copy of this consent addendum will be provided to you by mail.

**New or additional information**

**Consent Addendum**

In the event we are unable to reach you for future contact at the telephone number, address, or email on file for you, we may attempt to find updated contact information for you by calling the people you have provided as “other contacts.” We may also contact the health care providers that we have on file for you to ask for updated contact information. We may also try to find updated information that is available publicly on the internet, such as Facebook or Google.

We will always maintain your privacy and confidentiality during any contact attempts. We will say only that we are trying to reach you about a UNC health study. We will ask to speak with you directly. If you are no longer affiliated with that number, we will request your updated contact information. We will never identify the Carolina Breast Cancer Study by name or indicate that you are enrolled in the Carolina Breast Cancer Study. We will never mail any study materials to an address other than the one you, your other contacts, your physician, or the post office provides to us.

**Subject’s Agreement:**

The information contained in the consent addendum has been read to me, and I may contact the study personnel listed on this consent addendum if I have any questions or concerns. If necessary, in order to obtain updated contact information for me in the future, I voluntarily allow study staff to contact:

My “other contacts:”            \_\_\_ **YES**            \_\_\_ **NO**

My health care providers:    \_\_\_ **YES**            \_\_\_ **NO**

My place of work:                \_\_\_ **YES**            \_\_\_ **NO**

\_\_\_\_\_  
**Signature of Staff Person Reading Consent Addendum**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**<<FNAME>> <<LNAME>>**

**Printed Name of Research Subject**

