

**CBCS3 Follow Up #4 (38-month) Telephone Call Log**

Name: <<FNAME>> <<LNAME>>	AGE: <<SUBJECT_CURRENT_AGE>>
Address : <<ADDR1>> <<ADDR2>> <<CITY>> <<STATE>> <<ZIP>>	In-home interview date: <<NURSE_VISIT_DATE>> Interviewing Nurse: <<NURSE_NAME>>
1st Phone #: <<PHONE1>>	DOB: <<DOB>>
2nd Phone #: <<PHONE2>>	Date of Dx: <<CCR_FIRST_ELIG_DATE>>

**COMMENTS:** <<SUBJECT\_ADDR\_COMMENTS>>; <<SUBJECT\_COMMENTS>>

**READ: Please let me double-check your address and phone number.** (Review address and telephone contact info printed above. Make telephone corrections above.)

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

If NO:

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

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

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

NOTE: If LESS THAN 2 years at current address, or if living elsewhere during treatment,  
**READ: What was your previous address (or the address where you stayed during treatments)?**

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

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

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

NOTE: If LESS THAN 2 years at current address, or if living elsewhere during treatment,  
**READ: What was your previous address (or the address where you stayed during treatments)?**

2<sup>nd</sup> Previous street address: \_\_\_\_\_

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

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

**Return to Follow-up survey, p. 12. READ "ENDING" to participant, enter interview end time.**

Name: «FNAME» «LNAME»	AGE: «SUBJECT_CURRENT_AGE»
Address : «ADDR1» «ADDR2» «CITY» «STATE» «ZIP»	In-home interview date: «NURSE_VISIT_DATE» 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.			____:____ AM/PM		
2.			____:____ AM/PM		
3.			____:____ AM/PM		
4.			____:____ AM/PM		
5.			____:____ AM/PM		
6.			____:____ AM/PM		
7.			____:____ AM/PM		
8.			____:____ AM/PM		
9.			____:____ AM/PM		
10.			____:____ AM/PM		
11.			____:____ AM/PM		
12.			____:____ 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 #4 (38-Month) Telephone Survey/HP Form**

Name: <<FNAME>> <<LNAME>>	AGE: <<SUBJECT_CURRENT_AGE>>
DOB: <<DOB>>	Collected by (your initials):
In-home interview date: <<NURSE_VISIT_DATE>>	Date collected: ___ / ___ / ___
Date of Dx: <<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 10 to 15 minutes. We'll also send you a check for \$10 within 3 weeks of completing this call. Do you have any questions before we begin?

**READ: How are you doing? How is your general health?** [Don't need to record answer, just take notes if necessary] \_\_\_\_\_

**READ:** When we last spoke, we reviewed your treatment information, and we sent you an updated copy of your treatment summary with the last newsletter. I'd like to go over that information with you now in order to update our files.

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 dates of treatment and facility where treatment was given.)

Have you had any more procedures, such as biopsies, surgeries, or reconstruction, for breast cancer or for another cancer? This would include procedures for your initial diagnosis, a recurrence, a new breast cancer, or another cancer.                    1 \_\_\_ YES                    2 \_\_\_ NO (Go to pg. 3)

**1<sup>st</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

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

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

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

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

**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

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

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 before surgery to shrink the tumor or 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 dates of treatment and facility.)

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

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

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

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

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

**3<sup>rd</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

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 dates of treatment and facility where treatment was given.)

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 (Go 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: \_\_\_\_\_

Was treatment stopped before it was completed? 1\_\_\_COMPLETED 2\_\_\_ONGOING 3\_\_\_STOPPED

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

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: \_\_\_\_\_

Was treatment stopped before it was completed? 1\_\_COMPLETED 2\_\_ONGOING 3\_\_STOPPED

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

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

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

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

**3<sup>rd</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: \_\_\_\_\_

Was treatment stopped before it was completed? 1\_\_COMPLETED 2\_\_ONGOING 3\_\_STOPPED

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

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 cancer? This may include follow-up office visits with your surgeon or plastic surgeon, oncologist, 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

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

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

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

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

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

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

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

**Thanks for reviewing your treatment information with me.**

**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	CODE
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:)				

\*NOTE: IF "YES" TO SIDE EFFECTS in a, b, or c ABOVE, ASK:

**HAVE YOU DISCUSSED ANY OF THESE SIDE EFFECTS WITH A DOCTOR?    \_\_\_ YES    \_\_\_ NO**

If "**YES**", GO BACK TO QUESTION 4 AND RECORD MD INFO, CHECKING "PURPOSE OF VISIT: PROBLEM" AND SPECIFY WHICH SIDE EFFECTS ABOVE WERE DISCUSSED WITH THIS MD. RECORD ADDITIONAL MD'S AS NEEDED TO CAPTURE WHICH MD'S MAY HAVE SIDE EFFECT RECORDS.



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. Are you currently enrolled in a clinical trial or research study for the treatment of breast cancer?

1\_\_\_ YES                      2\_\_\_ NO                      9\_\_\_ NA or Don't Know

**IF YES:**

8a. What is the name (or number) and location of the clinical trial or research study you are taking part in? (Trial Name or Number, if known):

\_\_\_\_\_

(Hospital name and location): \_\_\_\_\_

\_\_\_\_\_

**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. 9e)      9\_\_\_ NA or Don't Know (Skip to Q. 9c)

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 (Enter 99 if don't know)
2 <sup>nd</sup> Diagnosis	_____	___ ___ Age (Enter 99 if don't know)
3 <sup>rd</sup> Diagnosis	_____	___ ___ Age (Enter 99 if don't know)

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

**READ:** (If new treatment is indicated in questions 1-8) We would like to request copies of your medical records from the doctors and hospitals you mentioned. I would like to mail the HIPAA and medical records release forms to you along with a pre-paid business reply envelope. If you mail them back in the envelope we send, there's no postage required, and we'll send you another check for **\$15** when we receive the signed medical records releases.

**9c.** May I send the releases to you for your signature? 1\_\_\_YES      2\_\_\_NO  
(If Yes, circle **YES** next to Med. Records release forms on checklist on page 12).

**9d. (if YES to 6 (recurrence) or 7 (new breast primary) or 9 (other cancer)).** 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

(If YES, circle YES on checklist (last page of survey) next to Tumor Block Release form)

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

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

**11.** Have you gained or lost more than 5 pounds since we last talked to you?

1\_\_\_ YES      2\_\_\_ NO      9\_\_\_ Don't Know

**IF YES:**

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

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

**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.

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

**12.** 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)

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

**13.** 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)

**14a.** 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

**14b.** In the past 2 years, was there a time when you did not have any health insurance?

1\_\_YES      2\_\_NO (Skip to Q. 15)      9\_\_Not Answered or Unknown (Skip to Q. 15)

**14c.** Combining all of the times that you were without coverage **in the past 2 years**, what was the total amount of time that you did not have health insurance? (ENTER years and months, enter 0/00 if none, enter 9/99 if Unknown. Note: total should not be greater than 2 years, 00 months)

\_\_\_\_ Years      \_\_\_\_ Months

**15.** In the past 2 years, was there ever a time that you wanted to see a doctor, but could not because of financial issues?

1\_\_YES      2\_\_NO      9\_\_Not answered or Unknown

**16.** In the past 2 years, was there ever a time that you wanted to see a doctor, but could not, because of transportation issues?

1\_\_YES      2\_\_NO      9\_\_ Not answered or Unknown

**17.** Do you have any questions, before we end? 1\_\_YES      2\_\_NO

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(Please try to answer **general** questions only. Do not dispense medical advice! If the question is treatment related or medical, or if you don't know the answer to a general question, offer to research the question and let them know someone will contact them with an answer.)

18. At this time, we plan to contact you again in about a year or so, just to see how you're doing. Is that okay with you?

1\_\_YES      2\_\_NO (If NO, skip to p.12, Verify Address Info, for mailing of check. ALSO UPDATE CBCS DATABASE "MAY CONTACT" FIELD TO "NO.")

(If NO, note comments/reason: \_\_\_\_\_ )  
(If NO, please remember to update Event 92, FU#5 Packet from "Scheduled" to "Cancelled-No further contact")

Do you have an e-mail address that we can use to contact you? 1\_\_YES    2\_\_NO

E-mail address: \_\_\_\_\_  
(Enter e-mail address in CBCS database)

What is your preferred method of contact?

- (Check all that apply, enter in Outcomes tab)
- a\_\_\_\_MAIL
- b\_\_\_\_TELEPHONE
- c\_\_\_\_E-MAIL
- d\_\_\_\_NO PREFERENCE
- e\_\_\_\_OTHER: (f)\_\_\_\_\_

**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, last page of survey)

**OTHER CONTACTS (If Consent Addendum indicates YES to contacting other contacts – If NO, Go to Verify Address 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

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

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

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

Phone number(s): \_\_\_\_\_ E-Mail address: \_\_\_\_\_  
(ENTER new contact info in CBCS)

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

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

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

Phone number(s): \_\_\_\_\_ E-mail address: \_\_\_\_\_  
(ENTER new contact info in CBCS)**VERIFY ADDRESS INFO (if not verified at start 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 two years.)

**CLOSING STATEMENT:**

**READ:** Thank you for completing this follow-up questionnaire. (GO to next page)

## CHECKLIST

### CHECK LIST FOR MAILING (REVIEW WITH STUDY PARTICIPANT)

**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.**

(If YES to any other items below, please mention that they will be in the mailing, as well as business reply envelope.)

<b>New consent form for additional tumor specimens (2 copies)</b>	<b>YES</b>	<b>NO</b>
<b>HIPAA and Medical records release forms? (2 copies)</b>	<b>YES</b>	<b>NO</b>
<b>Tumor Block Release form? (2 copies)</b>	<b>YES</b>	<b>NO</b>
<b>Consent Addendum (1 copy "FOR YOUR RECORDS")</b>	<b>YES</b>	<b>NO</b>
<b>Other? _____</b>	<b>YES</b>	<b>NO</b>

(Describe)

**ENDING:** Please remember that you can contact us anytime and that we always look forward to speaking with you. Our toll-free number is 1-866-927-6920, and again, my name is \_\_\_\_\_. On behalf of everyone at the Carolina Breast Cancer Study, we thank you for your participation and 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 9, 2015

**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, indicating your place of employment or membership in a club or organization. If we do, we may attempt to reach you at that location by telephone only.

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**

Organizations or club memberships publicly listed on my Facebook or elsewhere:    \_\_\_ **YES**            \_\_\_ **NO**

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

\_\_\_\_\_  
Date

\_\_\_\_\_  
«FNAME» «LNAME»

**Printed Name of Research Subject**

