CBCS3 Follow Up #2 (18-Month) Telephone Survey/HP Form

Name: «FNAME» «LNAME»

DOB: «DOB»

Collected by (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 20 minutes. We'll also send you a check for Ten Dollars within 2 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 you met with our nurse, she reviewed your initial treatment. I'd like to go over that with you now in order to update your treatment information.

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.]

1. **Have you had any more procedures, such as biopsies, surgeries, or reconstruction, for breast cancer?** (READ ONLY IF ASKED: This would include: Sentinel Node Biopsy; Axillary Lymph Node Dissection; Mastectomy; Lumpectomy/breast conserving surgery; Reconstructive surgery; Excisional Biopsy; Fine needle aspiration; Core biopsy; Breast Reconstruction, recurrence or new tumor, or any other procedures.)

   1____ YES 2_____ NO (Go to pg. 4)

1st Surgical Procedure not listed on HP Report:

SCHEDULED or ACTUAL Surgical Procedure DATE:________________________________
(Circle "Scheduled" or "Actual" above)

Procedure type(s): ____

Facility Clinic Name/Address: ______________________________________

Doctor Name/Address: ____

Doctor Tel. ______________________________

(For actual procedure) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment (what was address)?

____

COMMENTS:

2nd Surgical Procedure not listed on HP Report:

Scheduled or Actual Surgical Procedure DATE:____
(Circle "Scheduled" or "Actual" above)

Procedure type(s): ____

Facility Clinic Name/Address:
____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual procedure) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment (what was address)?

____

COMMENTS:

3rd Surgical Procedure not listed on HP Report:

Scheduled or Actual Surgical Procedure DATE: ______________________________________
(Circle "Scheduled" or "Actual" above)

Procedure type(s): ____

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual procedure) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment (what was address)?

____

COMMENTS:

4th Surgical Procedure not listed on HP Report:

Scheduled or Actual Surgical Procedure DATE: ______________________________________
(Circle "Scheduled" or "Actual" above)

Procedure type(s): ____

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual procedure) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment (what was address)?

____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

5th Surgical Procedure not listed on HP Report:

Scheduled or Actual Surgical Procedure DATE: ______________________________________
(Circle "Scheduled" or "Actual" above)

Procedure type(s): ____

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual procedure) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment (what was address)?

____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

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

READ: Now I'm going to ask you about CHEMOTHERAPY. Chemotherapy is sometimes given prior to surgery, possibly after biopsy or a fine needle aspiration, to shrink the tumor prior to surgery. It 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 chemotherapy section of HP Report with participant. Verify dates of treatment and facility where treatment was given.)

2. **Have you had any (additional) chemotherapy, including appointments for consults, or are you scheduled to receive chemotherapy in the future?** 1____YES 2____NO (go to pg. 7)

1st 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: ________________________________

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___

If NO, where were you living/staying during this treatment?

____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)

COMMENTS:

2nd 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: _______________________________

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____

(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

3rd 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: _______________________________

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____

(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

4th 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: ________________________________

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____

(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

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

READ: 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 your breast cancer. I am NOT referring to imaging, such as mammograms, MRI or ultrasound. Instead, I am referring to radiation used to treat your breast cancer. (Review the radiation therapy section of HP Report with participant. Verify dates of treatment and facility where treatment was given.)

3. **Have you had any (additional) radiation treatments or consults or appointments about radiation, or are you scheduled to receive radiation in the future?** 1____YES 2____NO

1st 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

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____
(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

2nd 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

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____
(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

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

READ: Now I want to ask you about OTHER TREATMENTS you may have had.
[Review the Other Treatments/Visits listed on HP summary with participant.]

4. 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? 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

1st Visit/Other Treatment not listed on HP Report:
Scheduled or Actual Treatment/Visit Date: ____
(Circle "Scheduled" or "Actual" above)

Purpose of Visit: ____

Facility Clinic Name/Address: ____

Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

2nd Visit/Other Treatment not listed on HP summary:
Scheduled or Actual Treatment/Visit Date: ____
(Circle "Scheduled" or "Actual" above)

Purpose of visit: ____

Facility Clinic Name/Address: ____

(Ordering) Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?
____
(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

3rd Visit/Other Treatment not listed on HP Report:

Scheduled or Actual Treatment/Visit Date: ______________________________
(Circle "Scheduled" or "Actual" above)

Purpose of visit: ____

Facility Clinic Name/Address: ____

(Ordering) Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____

(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

4th Visit/Other Treatment not listed on HP Report:

Scheduled or Actual Treatment/Visit Date: ______________________________
(Circle "Scheduled" or "Actual" above)

Purpose of visit: ____

Facility Clinic Name/Address: ____

(Ordering) Doctor Name/Address: ____

Doctor Tel. ____

(For actual treatment:) **Were you living/staying at your current address at the time?** YES___ NO___
If NO, where were you living/staying during this treatment?

____

(ENTER IN CBCS DATABASE ADDRESS TAB w/dates of tx)
COMMENTS:

Additional treatments/visits? 1____ YES (Include additional page) 2____ NO

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:)				

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

(IF YES, RECORD SURGERIES/CHEMO/RADIATION INFO AND DATES OF TREATMENT IN QUESTIONS 1, 2, AND 3. NOTE IN COMMENTS: "TREATMENT IS FOR A 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

(IF YES, RECORD SURGERIES/CHEMO/RADIATION INFO AND DATES OF TREATMENT IN QUESTIONS 1, 2, AND 3. NOTE IN COMMENTS: "TREATMENT IS FOR A 2ND PRIMARY.")

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

1___YES 2___NO (Skip to Q. 9) 9___NA or Don't Know (Skip to Q. 9)

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): ____

____

(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 medical records releases 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 Fifteen Dollars ($15) when we receive the signed medical records releases.**

9. 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 14).

[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 (Skip to Q. 12) 9___Don't Know (Skip to Q.12)

11a. ___Gained: How much? ____ ______ ____ lbs**.**

11b. ____Lost: How much? _____ _____ _____ lbs**.**

12. Do you currently smoke? 1___YES
2___NO (Skip to Q. 13)
9___ NA or UNK (Skip to Q. 13)

12a. 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

13. Do you currently drink alcoholic beverages? 1 ___YES 2 ___NO 9 ___NA

(IF YES**) 13a. What type of alcoholic beverage or beverages do you usually drink? (check all that apply)**

a ______ Beer

b ______ Wine

c ______ Liquor

d ______ NA

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.

<u>Moderate</u> activities cause your heart rate and your breathing to go up just a little bit.

14. How many days per week do you do <u>moderate</u> physical activity for at least 10 minutes at a time?

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

<u>Vigorous</u> activities cause a large increase in your heart rate and breathing rate.

15. How many days per week do you do <u>vigorous</u> physical activity for at least 10 minutes at a time?

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

16a. What type of health insurance do you have now? (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

16b. 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. 17) 9___Not Answered or Unknown (Skip to Q. 17)

16c. 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

17. 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___Not answered or Unknown

18. Since your diagnosis, 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

19. Thinking back over the treatments you received for your breast cancer, did you begin or start any treatments for your breast cancer that you did not complete or finish? (Do not include interruptions in treatment here, only treatment that was started but never completed.)

Treatment (Review treatments based on answers to questions 1-4)	**Was treatment stopped (never finished)?** 1=YES 2=NO 9=NA (Not received)	**(If YES) Why was treatment stopped?** (Reason stopped) (Read list below and indicate all that apply) 1. Personal decision 2. Doctor decision 3. Financial 4. Transportation 5. Side effects 6. Religious 7. Recurrence 8. Other (Specify)
Surgeries		
Neoadjuvant Chemotherapy		
Adjuvant Chemotherapy		
Radiation		
Adjuvant Hormonal Therapy		
Adjuvant Herceptin		
Other: Specify		
Other: Specify		

Did you experience a delay in starting or obtaining any of your breast cancer treatments? (Do not include interruptions in treatment here, only treatment that was delayed before ever starting.)

Treatment (Review treatments based on answers to questions 1-4)	**Was the start of treatment delayed?** 1=YES 2=NO 9=NA (Not received)	**(If YES) Why was treatment delayed? (**Reason delayed) (Read list below and indicate all that apply) 1. Personal decision 2. Doctor decision 3. Financial 4. Transportation 5. Side effects 6. Religious 7. Recurrence 8. Other (Specify)
Surgeries		
Neoadjuvant Chemotherapy		
Adjuvant Chemotherapy		
Radiation		
Adjuvant Hormonal Therapy		
Adjuvant Herceptin		
Other: Specify		
Other: Specify		

21. You may remember during the nurse's home visit that as part of the interview, you answered a list of questions about quality of life and about any trouble you may be having with arm movement as a result of surgery. Since it's been about 18 months since the nurse's visit, we'd like to know if your answers to those questions have changed at all. We could mail these questions to you, along with a pre-paid envelope for you to return it, or, if you prefer, you can answer the questions over the phone. It will take another 15 to 20 minutes to complete this set of questions by phone, and just 10 minutes if you choose to complete them yourself at home. Either way, we'll send you an additional check for $12.00 for completing this set of questions.

Would you prefer that we send this last set of questions to you by mail, so you can answer the questions at your leisure and send them back to us? Or would you rather answer the survey questions over the phone?

_______ Does not want to complete this section

_______Complete by Mail (Indicate on Checklist below that Appendix A will be mailed to participant)

_______Complete by Phone now (Complete now – Use "Appendix A for use with Telephone Survey")

_______Complete by Phone later. If later, ask:

When would you like me to call you back to do the survey? ________________________________
(Determine good callback time/date, if possible)

CLOSING STATEMENT:

READ: Thank you for completing this follow-up questionnaire.

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.)

Medical records release forms? (with pre-paid return envelope)	**YES**	**NO**
Appendix/final set of questions? (with pre-paid return envelope)	**YES**	**NO**
Addl. check for $12 for completing Appendix on phone?	**YES**	**NO**
Other? ____	**YES**	**NO**

I'd like to remind you about a great breast cancer resource that may be of interest to you.

22. Do you have internet access? 1___YES 2___NO 9____ NA

23. Do you know about our study website? 1___YES 2___NO 9____NA

READ: The web address for the study is: http://cbcs.med.unc.edu. Or you can type "Carolina Breast Cancer Study" in the search/address box, and then select or click on "The Carolina Breast Cancer Study" from the list that appears.

21. Do you have any questions, before we end? 1___YES 2___NO

____

____

(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.)

READ: Just a reminder that we plan to contact you again in about nine months.

22. Is there a specific day of the week that's usually better for you? ______________________

23. What would be the best time to reach you? (circle one) Morning Afternoon Evening

Specific request: ____
(ENTER best day/time in CBCS)

VERIFY CONTACT INFO, OTHER CONTACTS:
Before we finish, please let me double-check your address and phone number. (Review info printed on call log.)

Is this the correct contact information for you? 1___YES 2___NO
(If incorrect, ENTER correct info below and make corrections on call log and in CBCS database)

____

____

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)

24. What is your preferred method of contact?

(Check all that apply)

1_____MAIL
2_____TELEPHONE
3_____E-MAIL
4_____NO PREFERENCE
5_____OTHER: ________________________

We'll be calling again in nine months or so. In case we can't reach you then, 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?
1___YES 2___NO

(If Yes) First contact:

Name: ____ Relationship: ________________________

Address: ____

Phone number(s): ____

E-Mail address: ____
(ENTER new contact info in CBCS)

Is there another person you'd like to leave as another contact, in case we are unable to reach you?
1___YES 2___NO

(If Yes) Second contact:

Name: ____ Relationship: ________________________

Address: ____

Phone number(s): ____

E-mail address: ____
(ENTER new contact info in CBCS)

READ: 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 wish you all the best.

Interview Call End time: ___ ___ : ___ ___ am / pm

NOTES:

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