

CBCS3 Follow Up #1 (Nine 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) from original health professionals (HP) form. 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 aspirate; Core biopsy; Breast Reconstruction, recurrence or new tumor, or any other procedures.)

1 ___ YES

2 ___ NO

1st Surgical Procedure not listed on HP summary:

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 summary:

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 summary:

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 summary:

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 summary:

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 form with participant. Verify dates of treatment and facility where treatment was given.)

- 2. Have you had any (additional) chemotherapy, including consults or office visits to discuss treatments, or are you scheduled to receive chemotherapy in the future?**
1___YES 2___NO

1st Chemo Treatment not listed on HP summary:

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 REASON 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 summary:

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 REASON 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 summary:

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 REASON 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 summary:

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 REASON 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 form with participant. Verify dates of treatment and facility where treatment was given.)

3. Have you had any (additional) radiation treatments or consults or office visits about radiation, or are you scheduled to receive radiation in the future? 1 ___ YES 2 ___ NO

1st Radiation Treatment not listed on HP summary:
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 ___ NO, WAS COMPLETED 2 ___ STOPPED
REASON 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 summary:
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 ___ NO, WAS COMPLETED 2 ___ STOPPED
REASON 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 or Office Visits 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/Treatment not listed on HP summary:
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/Treatment not listed on HP summary:
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:

3rd Visit/Treatment not listed on HP summary:

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:

4th Visit/Treatment not listed on HP summary:

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:

Additional treatments/visits? 1___ YES (Include additional page)

2___ NO

Thanks for reviewing your treatment information with me.

(No Question 5)

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 (Go to 7) 8___ Don't Know (Go to 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 (Go to 8) 8___ Don't Know (Go to 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 (Go to 9) 8___Don't Know (Go to 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 them 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 consents.**

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 13).

[Transition statement] Now we've got just a few questions about your general health 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 (Go to 12) 8 ___ Don't Know (Go to 12)

11a. ___ Gained: How much? _____ lbs. (enter 888 if don't know)

11b. ___ Lost: How much? _____ lbs. (enter 888 if don't know)

12. Do you currently smoke? 1 ___ YES 2 ___ NO (Go to 13) 9 ___ NA (Go to 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.

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

14. 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 NA)

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

15. 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 NA)

16. 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 ____ NA

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

(Does specimen kit need to be mailed - Check yield in DB?) 1____YES 2____NO (Go to 18)

17. After your in-home interview, we discovered that the specimen the nurse collected did not contain enough material for the lab to analyze. With your permission, I'd like to ask you to have your doctor draw 2 tubes of blood at your next doctor's appointment and send it to us. I can send you a mailing kit with all the materials your doctor will need to draw the sample and send it back to us. The study will pay for all costs associated with the blood collection. You would just need to take the kit with you to your next appointment. We'll call your doctor and make all the arrangements.

17a. May I send you a kit? 1__YES 2__NO

(If Yes, circle YES next to Specimen Kit on Checklist on page 13)

(If YES:) **When is your next doctor's appointment?** _____

Doctor/Clinic name and address: _____

Doctor's tel. _____

(IF NO to 17a:) **Would you be willing to do a mouth rinse? You may have done one when the nurse came to your house. I can send you a mouth rinse kit with all the materials you will need to collect the sample yourself, right in your own home, and send it back to us.**

17b. May I send you a mouth rinse kit? 1__YES 2__NO

(If Yes, circle YES next to Mouth Rinse Kit on Checklist on page 13.)

READ: Before we end this call, I'd like to tell you about two great breast cancer resources that may be of interest to you.

18. Do you have internet access? 1__YES 2__NO 9__NA

19. 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.

20, (Question 20 deleted 2/4/2010 – Breast Cancer Resource Directory now hand-delivered)

21. Before we end, do you have any questions? 1__YES 2__NO 9__NA

(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.)

CHECK LIST FOR MAILING (REVIEW WITH STUDY PARTICIPANT)

READ: OK. You should be receiving a mailing from us shortly, including a check for Ten Dollars to thank you for your time today.

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

Medical records release forms? YES NO
(with treatment summary and pre-paid return envelope)

Specimen Kit? YES NO

Mouth Rinse Kit? YES NO

Other? _____

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)

ADDITIONAL QUESTIONS TO 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, make corrections on call log)

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)

We'll be calling again in 9 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?

First contact:

Name: _____ Relationship: _____

Address: _____

Phone number: _____

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?

Second contact:

Name: _____ Relationship: _____

Address: _____

Phone number: _____

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:
