

CBCS3 Follow Up #10 (10-year) Telephone Call Log

Name: «FNAME» «LNAME»	AGE: «SUBJECT_CURRENT_AGE»
Address: «ADDR1» «ADDR2» «CITY» «STATE» «ZIP»	In-home interview date: «NURSE_VISIT_DATE» Eligibility date: «CCR_FIRST_ELIG_DATE»
1st Phone #: «PHONE1»	DOB: «DOB»
2nd Phone #: «PHONE2»	Email: «EMAIL_ADDR»

COMMENTS: «SUBJECT_ADDR_COMMENTS»; «SUBJECT_COMMENTS»

ADDRESS HISTORY: (Obtain 2-year address history and enter in address tab in CBCS database for FU#10.)

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 YES: **When did you begin living at this address?** _____, _____
(Month) (Year)

(Calculate number of years at current address)

So, you've been living at this address continuously for about ____ years?

(If LESS THAN 2 years at current address, Go to C)

If NO:

B. Correct Street address: _____

Correct City, State, Zip: _____

When did you begin living at this address? _____, _____
(Month) (Year)

(Calculate number of years at current address)

So, you've been living at this address continuously for about ____ years?

(If LESS THAN 2 years at current address, Go to C)

C. What was your previous address?

1st Previous street address: _____

City, State, Zip: _____

When did you live at this address? FROM: _____, _____
(Month) (Year)

TO: _____, _____
(Month) (Year)

If LESS THAN 2 years (total at above addresses), obtain 2 year address history on separate sheet of paper and transfer to Address History tab in database after interview is completed.

READ: Thanks! Okay, let's get started. (Return to Follow-up #10 Telephone survey, p. 3)

Name: «FNAME» «LNAME»	AGE: «SUBJECT_CURRENT_AGE»
Address: «ADDR1» «ADDR2» «CITY» «STATE» «ZIP»	In-home interview date: «NURSE_VISIT_DATE» Eligibility date: «CCR_FIRST_ELIG_DATE»
1st Phone #: «PHONE1»	DOB: «DOB»
2nd Phone #: «PHONE2»	Email: «EMAIL_ADDR»

COMMENTS: «SUBJECT_ADDR_COMMENTS»; «SUBJECT_COMMENTS»

Call #	Initials	Date	Time	Contact Method	*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			
13.			____:____ AM / PM			
14.			____:____ AM / PM			

*Results: NA=No Ans.; NH=Not Home; LVM=Left Voice Mail; CB=Call Back; R=Refused; NFC=No Further Contact; CC=Call Completed

NOTES:

CBCS3 Follow Up #10 (10-Year) Telephone Survey

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 your breast cancer experience. All of the information you share with me today will be kept confidential, and it should only take about 20 minutes. You do not have to answer any questions that you don't want to answer. Just let me know if you want to skip a particular question and we'll move on to the next question. We'll also send you payment 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 begin, please let me double-check your address and phone number.** (Review/update address and telephone contact info printed on call log.)

READ: The last time we talked, we reviewed your breast cancer treatment history. I'd like to go over that with you now in order to update your treatment information. (See HP sheet. Review for information about previous recurrences/2nd primaries. Note whether addl. Med. Recs. are still needed from previous contacts.)

1. Since we last spoke (or within the last 2 years), have you had a (or another) **recurrence** 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. 2) 9 ___ NA or Don't Know (Skip to Q. 2)

1a. When was the recurrence? _____

1b. In what part of your body? _____

1c. 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: _____

Please tell me about any surgical procedures you have had for this recurrence.

1st Surgical Procedure for recurrence:

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

Procedure type(s): _____

Facility/Clinic Name/Address: _____

Medical Provider Name/Address: _____

COMMENTS: _____

Did you have another surgical procedure for the recurrence, or do you have any procedures scheduled? Y N

2nd Surgical Procedure for recurrence

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

Procedure type(s): _____

Facility/Clinic Name/Address: _____

Medical Provider Name/Address: _____

COMMENTS: _____

1d. Have you received any treatment(s) for the recurrence? 1___YES 2___NO (skip to Q.2)

1st Treatment/Procedure type(s) for recurrence: _____

1st Treatment or Procedure start date: _____

Is treatment completed or ongoing or stopped?

1___COMPLETED 2___ONGOING 3___STOPPED BEFORE IT WAS COMPLETED

If completed or stopped: COMPLETION/STOP DATE: _____

Medical Provider Name: _____

MD/Facility/Clinic Name: _____

Address: _____

City: _____ State: _____ Zip: _____

COMMENTS: _____

2nd Treatment/Procedure type(s) for recurrence: _____

2nd Treatment or Procedure start date: _____

Is treatment completed or ongoing or stopped?

1___COMPLETED 2___ONGOING 3___STOPPED BEFORE IT WAS COMPLETED

If completed or stopped: COMPLETION/STOP DATE: _____

Medical Provider Name: _____

MD/Facility/Clinic Name: _____

Address: _____

City: _____ State: _____ Zip: _____

COMMENTS: _____

2. **Since we last spoke** (or within the last 2 years), have you been diagnosed with a (or another) **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. 3) 9___NA or Don't Know (Skip to Q. 3)

2a. When were you diagnosed with the new breast tumor? _____

2b. Was it in the same breast or the other breast? _____

2c. 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: _____

Please tell me about any surgical procedures you have had for this new tumor.

1st Surgical Procedure for new breast primary:

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

Procedure type(s): _____

Facility/Clinic Name/Address: _____

Medical Provider Name/Address: _____

COMMENTS: _____

Did you have another surgical procedure for the new tumor, or do you have any procedures scheduled? Y N

2nd Surgical Procedure for new breast primary:

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

Procedure type(s): _____

Facility/Clinic Name/Address: _____

Medical Provider Name/Address: _____

COMMENTS: _____

2d. Have you received any treatment for the new tumor? 1___ YES 2___ NO (skip to Q.3)

1st Treatment/Procedure type(s) for new tumor: _____

1st Treatment or Procedure start date: _____

Is treatment completed or ongoing or stopped?

1___ COMPLETED 2___ ONGOING 3___ STOPPED BEFORE IT WAS COMPLETED

If completed or stopped: COMPLETION/STOP DATE: _____

Medical Provider Name: _____

MD/Facility/Clinic Name: _____

Address: _____

City: _____ State: _____ Zip: _____

COMMENTS: _____

2nd Treatment/Procedure type(s) for new tumor: _____

2nd Treatment or Procedure start date: _____

Is treatment completed or ongoing or stopped?

1___COMPLETED 2___ONGOING 3___STOPPED BEFORE IT WAS COMPLETED

If completed or stopped: COMPLETION/STOP DATE: _____

Medical Provider Name: _____

MD/Facility/Clinic Name: _____

Address: _____

City: _____ State: _____ Zip: _____

COMMENTS: _____

3. (If YES to Q. 1- recurrence or Q. 2 - new breast primary). With your permission, we may want to request copies of your medical records from the Medical Providers and hospitals you mentioned and request samples of the diagnostic surgeries or procedures for your (recurrence or new breast primary) to compare with the tissue we have from your original diagnosis. We'd like to mail the consent forms to you along with a pre-paid business reply envelope. If you sign the forms and mail them, we'll send you an additional payment for **\$15**. It's okay if you choose not to give us permission to get copies of your medical records - you can still participate in the study.

May I send the consent forms to you for your signature? 1___YES 2___NO

(If **YES**, circle YES on checklist (last page of survey) next to "Medical Records/Tumor block consents.")

4. In the past two years, have you been told by a Medical Provider that you had cancer in a place other than your breasts? (If possible, verify that this is for a new cancer, and not for a recurrence or metastasis. If recur or metastasis, record treatment info in questions 1-2.)

1___YES 2___NO (Skip to Q. 6a) 9___NA or Don't Know (Skip to Q. 6a)

5.	a. What type of cancer did you have?	b. What year was this cancer diagnosed?
1 st Diagnosis		
2 nd Diagnosis		
3 rd Diagnosis		

(9999 if don't know)

(Data Entry Note: If other cancer is reported, please record type and date in a FU#10 HP tab. Update to "MR not needed.")

6a. (Review HP Form with participant and provide an update with latest treatment information.)

Since the last time we spoke, 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 follow-ups, treatment or surgery related to breast cancer? This may include follow-up office visits with your surgeon or plastic surgeon, oncologist or Medical Provider, radiation oncologist, primary care physician, including procedures or treatments for your initial diagnosis.

1 ___ YES 2 ___ NO (If NO Skip to Q. 7)

1st New Visit/other Treatment or Procedure not previously 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 Medical Provider address a specific health issue or problem you were having? ___ Routine Visit ___ Problem

(Specify, if problem): _____

Treatment for: ___ Initial Diagnosis ___ Recurrence ___ New Primary

Facility/Clinic Name/Address: _____

(Ordering) Medical Provider Name/Address: _____

Medical Provider/Facility Tel. _____

COMMENTS: _____

6b. Have you had any additional cancer related visits, treatments or procedures not already mentioned?

1 ___ YES 2 ___ NO (If NO Skip to Q. 7)

2nd New Visit/other Treatment or Procedure not previously 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 Medical Provider address a specific health issue or problem you were having? ___ Routine Visit ___ Problem

(Specify, if problem): _____

Treatment for: ___ Initial Diagnosis ___ Recurrence ___ New Primary

Facility/Clinic Name/Address: _____

(Ordering) Medical Provider Name/Address: _____

Medical Provider/Facility Tel. _____

COMMENTS: _____

6c. Have you had any additional cancer-related visits, treatments or procedures not already mentioned?

1 ___ YES 2 ___ NO (If NO Skip to Q. 7)

3rd New Visit/other Treatment or Procedure not previously 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 Medical Provider address a specific health issue or problem you were having? ___ Routine Visit ___ Problem

(Specify, if problem): _____

Treatment for: ___ Initial Diagnosis ___ Recurrence ___ New Primary

Facility/Clinic Name/Address: _____

(Ordering) Medical Provider Name/Address: _____

Medical Provider/Facility Tel. _____

COMMENTS: _____

7. **(If YES to new visits/treatments/procedures for breast cancer).** With your permission, we may want to request copies of your medical records from the Medical Providers and hospitals you mentioned. We'd like to mail the consent forms to you along with a pre-paid business reply envelope. If you sign the forms and mail them, we'll send you payment for **\$15**. It's okay if you choose not to give us permission to get copies of your medical records - you can still participate in the study.

May I send the consent forms to you for your signature? 1 ___ YES 2 ___ NO

(If **YES**, circle YES on checklist (last page of survey) next to "Medical Records consents only.")

(Note: Prior Questions 7 and 8 are now Questions 4 and 5).

READ: Now I'd like to ask you about any new medical conditions other than cancer that you may have had **for the first time in the past two years**. (Note: Answers re: health conditions from FU6, FU7, and FU9 are included in folder.)

8. **In the past two years**, have you been told by a Medical Provider or other health professional that you have a new medical condition?

1 ___ YES 2 ___ NO (Skip to Q. 10) 9 ___ NA or Don't Know (Skip to Q. 10)

IF YES: 9a. What medical condition were you diagnosed with? (If they don't know what a medical condition is, read list: dementia, arthritis, asthma COPD, diabetes, HIV/AIDs, hypertension, kidney failure, cirrhosis or liver disease, osteoporosis, inflammatory bowel disease, ulcer, anxiety, depression, bipolar disorder, schizophrenia, congestive heart failure, angina/chest pain, heart attack, high cholesterol, stroke, blood clots in leg or lungs, thyroid problem), neuropathy, or any other condition?	b. What year was this condition diagnosed?	c. Do you currently take any prescription medications for this condition?
1st new medical condition: (describe)	(DK: 9999)	1 ___ Yes 2 ___ No
2nd new medical condition: (describe)	(DK: 9999)	1 ___ Yes 2 ___ No
3 rd new medical condition: (describe)	(DK: 9999)	1 ___ Yes 2 ___ No
4 th new medical condition: (describe)	(DK: 9999)	1 ___ Yes 2 ___ No

READ: Next, I want to ask some questions about any breast cancer screening or testing you may have had.

10. There are many breast imaging tests that may be used for breast cancer screening. Which tests did you receive for breast cancer screening within the **past 2 years?** (*Read options, check all that apply.*)

- a _____ Mammography (digital mammography)
- b _____ 3D mammography (digital breast tomosynthesis)
- c _____ Mammography, but don't know what type
- d _____ Breast MRI (magnetic resonance imaging)
- e _____ Breast ultrasound
- f _____ Other. _____
- g _____ No cancer screening

11. How often do you get a screening test(s) (mammogram, MRI, ultrasound) for breast cancer? (*Check one*)

- 1 _____ About every year
- 2 _____ About every two years
- 3 _____ About every three years
- 4 _____ I do not get screened on a regular basis
- 9 _____ NA (i.e. mastectomy) or Don't Know

12. Approximately how much time has passed since your last screening mammogram?
(Check one)

- 1 _____ Less than 1 year
- 2 _____ Between 1 and 2 years
- 3 _____ More than 2 years
- 9 _____ NA or Don't Know

13. Since the last time we spoke have you ever had a biopsy to diagnose or rule out a breast cancer?

- 1 _____ YES
- 2 _____ NO
- 9 _____ NA or Don't Know

14. Has a Medical Provider or other health professional ever recommended or referred you to get genetic counseling because of your family history of cancer?

- 1 _____ YES
- 2 _____ NO
- 9 _____ NA or Don't Know

15. Have you ever received genetic counseling because of your family history of cancer?

- 1 _____ YES
- 2 _____ NO
- 9 _____ NA or Don't Know

16. Did you receive genetic counseling as part of your care related to this breast cancer?

- 1 _____ YES
- 2 _____ NO
- 9 _____ NA or Don't Know

17. Has any member of your family, who you are related to by blood, ever received genetic counseling related to cancer?

- 1 _____ YES
- 2 _____ NO
- 9 _____ NA or Don't Know

READ: BRCA1 and BRCA2 are genes in a person's DNA that are associated with the risk of breast and ovarian cancer. There are genetic tests for mutations in BRCA1 and BRCA2, requiring a blood sample, saliva sample, or cheek swab, that can provide information about your risk for these cancers. For the next question we are only interested in tests performed by your health care provider and for diagnostic purposes. Please EXCLUDE any over the counter genetic test kits (e.g. 23andMe, Ancestry.com, etc)

18. Have you ever had a BRCA1 or BRCA2 genetic test or BRCA analysis?

- 1 _____ No-I did not have a BRCA1 or BRCA2 genetic test or analysis (Skip to Q.19)
- 2 _____ Yes, before primary breast cancer diagnosis
- 3 _____ Yes, after primary breast cancer diagnosis
- 9 _____ NA or Don't know (Skip to Q.19)

IF YES:

18a. Did the results of your BRCA1 or BRCA2 test indicate that you carry a mutation that would put you at increased risk for cancer?

- 1 _____ No, they did not indicate a mutation
 2 _____ Yes, only BRCA1
 3 _____ Yes, only BRCA2
 4 _____ Yes, BRCA1 and BRCA2
 5 _____ Inconclusive result
 9 _____ NA or Don't Know

READ: Sometimes Medical Providers order a genomic test that analyzes the activity of a group of genes that can affect how a breast cancer is likely to behave and respond to treatment. These tests can also help your Medical Provider determine the risk of your cancer coming back (recurring). Oncotype Dx, Paik-2, and Breast Cancer Index (BCI) are some of the names of these tests.

19. Has your Medical Provider ever ordered a genomic test to determine how your cancer or tumor will respond to treatment, or help determine your risk of recurrence?

- 1 _____ YES 2 _____ NO (Skip to Q. 21) 9 _____ NA or Don't Know

20. Did you complete the ordered genomic test?

- 1 _____ YES 2 _____ NO 9 _____ NA or Don't Know

READ: Now we are going to talk about Hormone therapy which is a form of systemic therapy—a way of administering drugs so they travel throughout the body, rather than being delivered directly to the cancer—that works to add, block or remove hormones from the body to slow or stop the growth of cancer cells.

Hormone therapy can also be used to treat cancer that has come back after treatment or that has spread to other parts of the body. Examples of hormone therapy drugs include: Tamoxifen, Femara/Letrozole, Aromasin/Exemestane, Arimidex/Anastrozole.

21. Since your breast cancer diagnosis, have you ever taken hormonal therapy pills to help keep your breast cancer from coming back?

- 1 _____ YES
 2 _____ NO → (Skip to Q.29)

22. At this time, are you taking hormonal therapy pills?

- 1 _____ Yes
 2 _____ No → 22a. What age did you stop? _____

23. Have you ever missed taking your hormone therapy pills?

- 1 _____ Yes
 2 _____ No → (Skip to Q. 29)

READ: The next five items list reasons why someone might miss taking hormone therapy pills. We will ask how often each statement has been true for you **during the last year** that you took (or have been taking) hormone therapy pills. Please respond with **often true**, **sometimes true** or **practically never true**

<i>(Circle one number per line)</i>		Often true for you	Sometimes true for you	Practically never true for you
24.	The pills are too expensive.	1	2	3
25.	You just forget to take them.	1	2	3
26.	You don't get around to refilling the prescription.	1	2	3
27.	The side effects of these pills are too hard to deal with.	1	2	3
28.	Taking medication for a long time is not healthy	1	2	3

29. Do you currently suffer from any of the following long-term side effects as a result of your surgeries or treatment for breast cancer? *(Read options, check all that apply)*

- a _____ Cardiac or heart problems
- b _____ Fatigue
- c _____ Memory Loss
- d _____ Bone pain
- e _____ Swelling of the arm or hand, also called Lymphedema
- f _____ Neuropathy or nerve pain, numbness or tingling

FOR CALLER/DATA ENTRY ONLY:
_____ None to all Q29a-f

READ: Next, I want to ask some questions about your **lifestyle**.

30. How much do you currently weigh? _____ lbs. (enter 888 if don't know or NA)

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

- 1 _____ YES 2 _____ NO (Skip to Q. 32) 9 _____ Don't Know (Skip to Q. 32)

31a. _____ Gained: How much? _____ lbs.

31b. _____ Lost: How much? _____ lbs.

32. Have you ever smoked cigarettes?

- 1 _____ YES 2 _____ NO (Skip to Q. 33) 9 _____ NA or Don't Know (Skip to Q. 33)

32a. Do you currently smoke cigarettes?

- 1 _____ YES 2 _____ NO (Skip to Q. 33) 9 _____ NA or Don't Know (Skip to Q. 33)

32b. 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

33. Do you currently drink alcoholic beverages?

- 1 _____ YES 2 _____ NO (Skip to Q. 34) 9 _____ NA or Don't Know (Skip to Q. 34)

33a. 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 "000" 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.

34. 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)

35. 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)

36. 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

37. In the past two years, was there a time when you did not have any health insurance?

1 ___ YES 2 ___ NO (Skip to Q. 38) 9 ___ NA or Don't Know (Skip to Q. 38)

37a. Combining all of the times that you were without coverage **in the past two years**, 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

38. In the past two years, was there ever a time that you wanted to see a Medical Provider, but could not because of financial issues?

1 ___ YES 2 ___ NO 9 ___ NA or Don't Know

39. In the past two years, was there ever a time that you wanted to see a Medical Provider, but could not, because of transportation issues?

1 ___ YES 2 ___ NO 9 ___ NA or Don't Know

40. Are you currently working for pay? This includes full-time or part-time paid work, as well as self-employment.

1 ___ YES 2 ___ NO

41. At any time since your breast cancer diagnosis, have you left a job due to breast cancer?

2 ___ NO

1 ___ YES → **41a.** If yes, why? (Read options, check all that apply)

a ___ I retired early

b ___ I was laid off or fired

c ___ I stopped working because my job was too physically demanding

d ___ I stopped working because my job was too mentally demanding

e ___ Other - *Please specify:* _____

42. Have concerns about health insurance kept you in a job since having breast cancer?

1 ___ YES 2 ___ NO

43. What is your present marital status?

1 ___ I have never married or lived as married

2 ___ I am married, or living as married

3 ___ I am widowed

4 ___ I am separated, divorced, or no longer living as married

9 ___ I prefer not to answer

44. Last year, what was your total family income range, before taxes?

- 0 _____ Less than \$5,000
- 1 _____ \$5,000 to \$10,000
- 2 _____ \$10,001 to \$15,000
- 3 _____ \$15,001 to \$20,000
- 4 _____ \$20,001 to \$30,000
- 5 _____ \$30,001 to \$50,000
- 6 _____ \$50,001 to \$100,000
- 7 _____ More than \$100,000
- 8 _____ Don't know
- 9 _____ Prefer not to answer

45. How many people are supported by this income? (This includes anyone you are supporting, not just for tax purposes; please indicate 1 for yourself)

_____ People

READ: Because we are living in unprecedented times and understand that COVID19 may have many impacts we have added six questions to the original interview. We greatly appreciate your response to these questions to help us assess the effects of this pandemic.

C1. Have you ever had COVID19?

- 1 ____ Yes, I was tested and confirmed to have COVID19
- 2 ____ Yes, I was never tested for COVID19 but I think I had COVID19
- 3 ____ No, I was tested for COVID19 but the test was negative
- 4 ____ No, I was not tested for COVID19 and do not ever think I had COVID19
- 9 ____ I don't know

C2. Has anyone whom you live with ever had COVID19?

- 1 ____ Yes, they were tested and confirmed to have COVID19
- 2 ____ Yes, they were never tested for COVID19 but I think they had COVID19
- 3 ____ No, they were tested for COVID19 but the test was negative
- 4 ____ No, they were not tested for COVID19 and do not ever think they had COVID19
- 8 ____ Not Applicable – Lives Alone
- 9 ____ I don't know

C3. Has anyone whom you have regular contact with ever had COVID19?

- 1 ___ Yes, they were tested and confirmed to have COVID19
- 2 ___ Yes, they were never tested for COVID19 but I think they had COVID19
- 3 ___ No, they were tested for COVID19 but the test was negative
- 4 ___ No, they were not tested for COVID19 and do not ever think they had COVID19
- 9 ___ I don't know

C4. On a scale of 1-10 (with 1 = not at all and 10 = a lot) how harmful has the COVID19 pandemic been to your economic status?

1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C5. On a scale of 1-10 (with 1 = not at all, and 10 = a lot) how has the COVID19 pandemic affected your job status?

1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C6. On a scale from 1-10 (with 1 = not at all and 10 = a lot), how much has the COVID 19 pandemic affected your emotional or mental health status?

1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

READ: Thank you for answering the questions in this survey.

46. You may remember that as part of some prior follow ups, we mailed you a survey with questions about health-related matters important for women with breast cancer. We would like to send out three short surveys following our interview today. If you complete them and mail them back, we'll send you an additional payment for **\$25**. We'll include a pre-paid envelope to mail them back to us.

May we send these surveys to you? 1 ___ YES 2 ___ NO
 (If **YES**, circle YES on checklist (last page of survey) next to "Mail-in (AppC/CaSUN/PAM 13) surveys")

47. We want to let you know that we so appreciate the time and energy you have given over the past ten years. As we continue to study the experiences of long-term breast cancer survivors, would you be willing to be contacted in future follow-ups? **(If NO, skip to ENDING.)**

YES MAYBE/I'M NOT SURE NO

IF YES, COMPLETE CONSENT ADDENDUM

Read: The last thing I need to do is to 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: Must include a signed copy of consent addendum in mailing – Circle YES in checklist box on last page of survey YES on checklist (last page of survey) next to “Consent Addendum”)

OTHER CONTACTS

(Review Q.48 If Consent Addendum indicates YES to contacting other contacts. If NO, Go to Q.49.)

48. 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 database if needed).**

1 ___ YES 2 ___ NO (Go to Q. 30)

(If Yes) 1st contact:

Name: _____ Relationship: _____

Address: _____

Phone number(s): _____ E-mail address: _____

Is there a 2nd contact?

Name: _____ Relationship: _____

Address: _____

Phone number(s): _____ E-mail address: _____

49. Do you have any questions or comments, before we end? 1 ___ YES 2 ___ NO

(Answer general questions about the study only. For medical questions, refer them to their MD.)

ENDING: That's it! Thank you for completing this call. You should be receiving a mailing from us within 4 weeks, including a gift card for **\$10** to thank you for taking the time to complete this follow up call with us.

CHECKLIST FOR MAILING (REVIEW WITH STUDY PARTICIPANT)

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

Consent Addendum (1 copy "FOR YOUR RECORDS")	YES	NO
Mail-in (AppC/CaSUN/PAM13) surveys (w/pre-paid envelope)	YES	NO
Medical records consents only (no block consents) (2 copies)	YES	NO
Medical records/Tumor block consents (2 copies)	YES	NO
New consent form for additional tissue specimen (2 copies)	YES	NO
Other? _____	YES	NO

With your help we have added to our understanding about lifestyle, treatment, and other factors affecting breast cancer outcomes. A huge thanks to you for making this study possible. 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: October 26, 2018

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

Principal Investigator: Melissa Troester, PhD, Dept. of Epidemiology (919) 966-7424; troester@unc.edu

Study Contact: Heather Tipaldos, Project Manager (919) 966-9438; email heather_tipaldos@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 contact information that is available publicly on the internet, such as Yahoo 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

