

## CASE Follow-up Telephone Interview

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#### CA. DIAGNOSIS AND TREATMENT OF BREAST CANCER

## CA. DIAGNOSIS AND TREATMENT OF BREAST CANCER

CA0. You reported that you were diagnosed with breast cancer. Is that correct?

YES.....	1
NO ..... [CA0A].....	2
REF ..... [CA0A].....	7
DK..... [CA0A].....	8

[ASK CA0A IF CA0 IS NOT YES:]

CA0A. Please describe your diagnosis so that we can correct our records.

SPECIFY: \_\_\_\_\_  
[END]

[VERIFY DATE OF DIAGNOSIS, IF PROVIDED.]

[CHECK ANSWER TO CA1a AGAINST DOB]

CA1a. What is the month and year you were told that you definitely had breast cancer? Usually this is at the time of the diagnostic biopsy or surgery

|\_|\_|\_|    |\_|\_|\_|\_|  
MONTH        YEAR  
IF YEAR PROVIDED, GO TO CA12

R PREVIOUSLY REPORTED DIAGNOSIS IN [FILL MONTH / FILL YEAR]

[ASK CA2 ONLY IF CA1a YEAR = DK]

[CHECK ANSWER TO CA2 AGAINST DOB]

CA2. How old were you at the time of this diagnosis?

|\_|\_|  
AGE  
GO TO CA12

CA12. Was the cancer in your left breast, right breast, or both left and right breasts?

LEFT BREAST .....	1
RIGHT BREAST.....	2
BOTH LEFT AND RIGHT BREASTS ...	3
REF .....	7
DK.....	8

CA12a. Doctors evaluate a woman's breast cancer in part by determining how large the tumor is and how far it's spread. This is called staging and is often used to guide treatment decisions.

0 .....	01
1 .....	02
2 .....	03
2a .....	04
2b .....	05
3 .....	06
3a .....	07
3b .....	08
3c .....	09
4 .....	10
REF .....	97
DK.....	98

At the time of your diagnosis, what was the stage of your breast cancer?

INTERVIEWER: IF R HAD MORE THAN ONE TUMOR WITH DIFFERENT STAGES, SELECT THE HIGHEST VALUE.

CA12b. Breast cancer usually starts in either the milk ducts or the lobules - milk producing glands. If it starts in the ducts it is called **ductal**. If it starts in the lobules it is called **lobular**. Some breast cancers can have features of both ductal and lobular cancer. A few tumors start in other tissues.

Breast cancer is usually described as **invasive** - sometimes called infiltrating - or **non-invasive** - sometimes called in-situ.

**Invasive cancer** is cancer that has spread beyond the exact place in the breast where it started. This does not mean it has spread past the breast, although it might have.

PRESS '1' TO CONITNUE ..... 1

CA12c. **Non-invasive or in-situ cancer** is a tumor that has not spread beyond the milk ducts or lobules where it started into any surrounding breast tissue. Sometimes a cancer can have both features.

**In-situ or non-invasive ductal cancer (ductal carcinoma in-situ - DCIS)** is sometimes described as early stage cancer or pre-invasive cancer.

**In-situ or non-invasive lobular cancer (lobular carcinoma in-situ - LCIS)** is also called lobular neoplasia. While it is sometimes considered as a non-invasive cancer, often it is not considered cancer at all. Instead, doctors think of it as a marker of increased risk for getting breast cancer in the future.

PRESS '1' TO CONITNUE ..... 1

CA13. Was your cancer described as invasive - sometimes called infiltrating - or non-invasive - sometimes called in situ?

INVASIVE (INFILTRATING) ..... 1  
NON-INVASIVE (IN SITU) ..... 2  
BOTH ..... 3  
REF ..... 7  
DK..... 8

CA14. Did your cancer start the in ducts (ductal), lobules (lobular) or someplace else?

PROBE: DUCTS - ALSO DUCTAL, DUCTAL CANCER, DUCTAL CARCINOMA IN-SITU, OR DCIS  
LOBULES - ALSO LOBULAR, LOBULAR CANCER  
LOBULAR CARCINOMA IN-SITU, OR LCIS

DUCTS ..... [CA3]..... 1  
LOBULES ..... [CA3]..... 2  
BOTH ..... [CA3]..... 3  
OTHER..... [CA3]..... 4  
REF ..... [CA3]..... 7  
DK..... [CA3]..... 8

CA3. At the time of your diagnosis, had the cancer spread to your lymph nodes? That is, were you told you had positive nodes?

YES..... [CA6]..... 1  
NO ..... [CA6]..... 2  
REF ..... [CA6]..... 7  
DK..... [CA6]..... 8

CA6. At the time of your breast cancer diagnosis, had the breast cancer spread to a different part of your body other than the breast or lymph nodes? That is, had it metastasized?	YES..... [CA16] ..... 1 NO ..... [CA16] ..... 2 REF ..... [CA16] ..... 7 DK..... [CA16] ..... 8
CA16. Breast cancers are usually tested to determine if they respond to hormones like estrogen -- this is called estrogen receptor or ER positive -- and progesterone - this is called progesterone receptor or PR positive. Was your tumor ER positive, ER negative or borderline? <i>[In the data collected by hard copy this question could be blank.]</i>	ER POSITIVE ..... 1 ER NEGATIVE ..... 2 BORDERLINE / MARGINAL..... 3 TEST NOT DONE.. ..... 4 REF ..... 7 DK..... 8
CA17. Was your tumor PR positive, PR negative or borderline? <i>[In the data collected by hard copy this question could be blank.]</i>	PR POSITIVE . [CA18A] ..... 1 PR NEGATIVE [CA18A] ..... 2 BORDERLINE / MARGINAL [CA18A] . 3 TEST NOT DONE[CA18A] ..... 4 REF ..... 7 DK..... 8
[ASK CA17a IF CA16 AND CA17 = DK OR REF] CA17a. Were you told your tumor was hormone receptor positive, hormone receptor negative or borderline?	HORMONE RECEPTOR POSITIVE ..... 1 HORMONE RECEPTOR NEGATIVE.... 2 BORDERLINE / MARGINAL..... 3 TEST NOT DONE.. ..... 4 REF ..... 7 DK..... 8
CA18A. Breast cancers are sometimes also tested for a marker called HER2 or HER2NEU. Was your cancer HER2 (HER2NEU) positive?	YES..... [CA20] ..... 1 NO ..... [CA20] ..... 2 REF ..... [CA20] ..... 7 DK..... [CA20] ..... 8
CA20. Have you had surgery, not counting a biopsy, to remove the breast cancer?	YES..... [CA21r] ..... 1 NO ..... [CA25]..... 2 REF ..... [CA25]..... 7 DK..... [CA25]..... 8
CA21r. For your <b>right</b> breast, have you had a lumpectomy or partial removal of breast, a mastectomy, or breast reconstruction  MARK ALL THAT APPLY	LUMPECTOMY OR PARTIAL REMOVAL OF BREAST ..... 1 MASTECTOMY..... 2 BREAST RECONSTRUCTION ..... 3 NONE ..... 4 REF ..... 7 DK..... 8

CA21I. For your left breast, have you had  
a lumpectomy or partial removal of breast,  
a mastectomy, or breast reconstruction

MARK ALL THAT APPLY

LUMPECTOMY OR PARTIAL  
REMOVAL OF BREAST ....[CA25] 1  
MASTECTOMY.....[CA25] 2  
BREAST RECONSTRUCTION .[CA25] 3  
NONE .....[CA25] 4  
REF .....[CA25] 7  
DK.....[CA25] 8

[EDIT CHECK: IF CA20 = 1 AND CA21r = NONE and CA21I = NONE - VERIFY AND CORRECT]

CA25. Have you had chemotherapy for this breast  
cancer?

YES..... [CA48] ..... 1  
NO ..... [CA48] ..... 2  
REF ..... [CA48] ..... 7  
DK..... [CA48] ..... 8

CA48. Have you had radiation therapy for this breast cancer?

YES..... [CA33] ..... 1  
NO ..... [CA33] ..... 2  
REF ..... [CA33] ..... 7  
DK..... [CA33] ..... 8

CA33. Have you taken any of the following medications  
as part of your breast cancer treatment?

Tamoxifen, Evista, or Raloxifene

YES..... [CA38] ..... 1  
NO ..... [CA38] ..... 2  
REF ..... [CA38] ..... 7  
DK..... [CA38] ..... 8

CA38. (Have you taken any of the following medications  
as part of your breast cancer treatment?)

Arimidex

YES..... [CA43] ..... 1  
NO ..... [CA43] ..... 2  
REF ..... [CA43] ..... 7  
DK..... [CA43] ..... 8

CA43. (Have you taken any of the following medications  
as part of your breast cancer treatment?)

Herceptin or TYKERB?

YES..... [CA52B] ..... 1  
NO ..... [CA52B] ..... 2  
REF ..... [CA52B] ..... 7  
DK..... [CA52B] ..... 8

[BEGIN REPEATING RECORD]

[FOR EACH TRIAL R WAS IN]

CA52B. Did you participate in a clinical trial or are you  
participating in a clinical trial in connection with your  
breast cancer treatment and follow-up?

[AFTER FIRST ITERATION] Did you participate in  
another clinical trial or are you participating in  
another clinical trial in connection with your  
breast cancer treatment and follow-up?

YES..... ..... 1  
NO ..... [CA8]..... 2  
REF ..... [CA8]..... 7  
DK..... [CA8]..... 8

[ASK CA52C-CA52D IF CA52B = YES:]

CA52C. What was the name or number of the trial, the sponsor and/or the specific medicine  
or treatment being studied, if known?

[RECORD VERBATIM:] \_\_\_\_\_

CA52D. What was being tested?  
CHECK ALL THAT APPLY

Chemotherapy drug ..... [CA8] ..... 1  
Chemotherapy dose or  
frequency..... [CA8] ..... 2  
Symptom management or  
prevention..... [CA8] ..... 3  
Radiation therapy ..... [CA8] ..... 4  
Hormonal treatment .... [CA8] ..... 5  
Surgical treatment ..... [CA8] ..... 6  
REF ..... [CA8] ..... 7  
DK..... [CA8] ..... 8

[END REPEATING RECORD]

CA8. Since the time *of* your first breast cancer  
diagnosis, have you been diagnosed with a second  
breast cancer - either in the same breast or the  
other breast?

YES..... [CS1A] ..... 1  
NO ..... [CA24] ..... 2  
REF ..... [CA24] ..... 7  
DK..... [CA24] ..... 8

[ASK CS1A IF CA8 = YES:]

[CHECK ANSWER TO CS1A AGAINST DOB]

CS1A. In what month and year was this other cancer  
diagnosed?

|\_|\_| | |\_|\_|\_|\_|\_|  
MONTH YEAR

IF YEAR PROVIDED, GO TO CA24

[ASK CS2 ONLY IF CS1A YEAR = DK]

[CHECK ANSWER TO CS2 AGAINST DOB]

CS2. How old were you at the time of this diagnosis?  
[GO TO CA24]

|\_|\_|  
AGE

CA24. Were you having regular menstrual periods at the  
time you were first diagnosed with breast cancer  
and before you started treatment?

YES..... [CA30] ..... 1  
NO ..... [CA24a] ..... 2  
REF ..... [CA24a] ..... 7  
DK..... [CA24a] ..... 8

CA30. Did your menstrual periods stop permanently after  
the time of your breast cancer treatment?

YES..... [CA24a] ..... 1  
NO ..... [CA24a] ..... 2  
REF ..... [CA24a] ..... 7  
DK..... [CA24a] ..... 8

CA24a. Have you had both your ovaries removed since  
being diagnosed with breast cancer?

YES..... ..... 1  
NO ..... [CA2A] ..... 2  
REF ..... [CA2A] ..... 7  
DK..... [CA2A] ..... 8

[ASK C24B ONLY IF CA24a = 1]

CA24b. What month and year did you have both  
ovaries removed?

|\_|\_| | |\_|\_|\_|\_|\_|  
MONTH YEAR [CA2A]

- CA2A. Sometimes there is a delay between when a woman first notices a lump, or a mammogram shows an abnormality, and the final diagnosis of breast cancer. How much time went by between when you first realized there was a problem and when you were told the diagnosis was breast cancer?
- < 1 MONTH – DIAGNOSED VERY CLOSE TO INITIAL IDENTIFICATION ..... 00
- |\_\_|\_\_| MONTHS
- CA2B. During the time you were being evaluated for breast cancer, did you have any form of health care coverage, including health insurance, pre-paid plans such as HMOs, or government plans such as Medicare or Medicaid?
- YES..... [CA19] ..... 1  
 NO ..... [CA19] ..... 2  
 REF ..... [CA19] ..... 7  
 DK..... [CA19] ..... 8
- CA19. When you were undergoing diagnosis and treatment, did concern about the cost keep you from receiving medical treatment your doctors recommended?
- YES..... [MRIntro1] ..... 1  
 NO ..... [MRIntro1] ..... 2  
 REF ..... [MRIntro1] ..... 7  
 DK..... [MRIntro1] ..... 8