

CASE Follow-up Telephone Interview

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CA. DIAGNOSIS AND TREATMENT OF BREAST CANCER

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RE-ORDERED - START AT CA12b

CA12b. Breast tumors usually start 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 tumors have both ductal and lobular features. A few tumors start in other breast 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 or layer of cells in the breast where it started. This does not mean it has spread past the breast, although it might have.

PRESS '1' TO CONTINUE 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 invasive and in-situ 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 a non-invasive cancer, often it is not considered breast cancer at all. Instead, doctors think of it as an indicator of increased risk of getting breast cancer in the future.

PRESS '1' TO CONTINUE 1
GO TO CA0

CA0. The following questions about breast conditions and breast diseases are about being diagnosed with breast cancer, DCIS, LCIS, Paget's disease or phyllodes tumors. You reported that you were diagnosed with one of these breast conditions. Is that correct?

YES..... [CA1]..... 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]

CA1. OMITTED

[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 one of these breast conditions? 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]

|_|_|
AGE

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

GO TO CA12

CA2A. Moved - see below
CA2B. Moved - see below
CA2C. Omitted
CA3. Moved - See below
CA4. Omitted
CA4a. Omitted
CA5. Omitted
CA5a. Omitted
CA6. Moved - see below
CA7. Omitted
CA7b. Omitted
CA8. Moved - see below
CA9. Omitted
CA9b. Omitted
CA9c. Omitted
CA10. Omitted
CA11. Omitted

CA12. Was the breast condition in your left breast only,
right breast only, or both breasts?

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

ALL GO TO CA13

CA12a. Moved - see below
CA12b. Moved - see above
CA12c. Moved - see above

CA13. Was your breast condition described as
invasive - infiltrating - only,
non-invasive -in situ - only, or
both invasive and non-invasive?

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

CA14. Did your disease start the in ducts,
lobules, or someplace else?

DUCTS [CA3]..... 1
LOBULES [CA3]..... 1

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

SOMEPLACE ELSE[CA14a] 1
REF [CA3]..... 7
DK..... [CA3]..... 8

MARK ALL THAT APPLY

CA14a. Please specify where your disease started.

PLEASE SPECIFY: [CA3]

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

YES.....[CA6]..... 1
NO[CA6]..... 2
NOT APPLICABLE (DCIS OR LCIS)
.....[CA6]..... 3
REF[CA6]..... 7
DK.....[CA6]..... 8

CA6. At the time of your diagnosis and treatment, had the disease spread to a different part of your body other than the original breast or nearby lymph nodes? That is, had it metastasized?

YES.....[CA12a] 1
NO[CA12a] 2
NOT APPLICABLE (DCIS OR LCIS)
.....[CA12a] 3
REF[CA12a] 7
DK.....[CA12a] 8

RE-ORDERED

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

What was the stage of your breast condition?

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

0 [CA16] 01
1 [CA16] 02
2 [CA16] 03
2a [CA16] 04
2b [CA16] 05
3 [CA16] 06
3a [CA16] 07
3b [CA16] 08
3c [CA16] 09
4 [CA16] 10
REF [CA16] 97
DK..... [CA16] 98

CA15. Omitted

CA15A. Omitted

CA15B. Omitted

CA15C. Omitted

CA16. Breast diseases are usually tested to determine if they respond to hormones like estrogen -- estrogen receptor positive or ER positive -- and progesterone --progesterone receptor positive or PR positive.

Was your tumor ER positive, borderline or ER negative?

ER POSITIVE 1
BORDERLINE2
ER NEGATIVE 3
TEST NOT DONE.. 4
REF 7
DK..... 8

CA17. Was your tumor PR positive, borderline, or PR negative?

PR POSITIVE . [CA18A] 1
BORDERLINE [CA18A]..... 2
PR NEGATIVE [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 3
TEST NOT DONE.. 4
REF 7
DK..... 8

CA18. Omitted

CA18A. Breast conditions are sometimes also tested for a marker called HER2 or HER2NEU. Was your disease HER2 positive?

YES..... [CA20] 1
NO [CA20] 2
REF [CA20] 7
DK..... [CA20] 8

CA19. Moved - see below

CA20. Have you had surgery, not counting a biopsy, to remove the diseased breast tissue?

YES..... [CA21r] 1
NO [CA25] 2
REF [CA25] 7
DK..... [CA25] 8

CA21a. Omitted

CA21b. Omitted

CA22a. Omitted

CA22b. Omitted

CA23a. Omitted

CA23b. Omitted

CA21r. For your **right** breast, have you had a lumpectomy or partial removal of breast, a mastectomy, or breast reconstruction

LUMPECTOMY OR PARTIAL
REMOVAL OF BREAST 1
MASTECTOMY..... 1
BREAST RECONSTRUCTION 1
NONE 1
REF 7
DK..... 8

MARK ALL THAT APPLY

CA21l. For your **left** breast, have you had a lumpectomy or partial removal of breast, a mastectomy, or breast reconstruction

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

MARK ALL THAT APPLY

[EDIT CHECK: IF CA20 = 1 AND CA21r = NONE and CA21l = NONE - VERIFY AND CORRECT]

CA24. Moved - see below
CA24a. Moved - see below
CA24b. Moved - see below

CA25. Have you had chemotherapy for this breast condition?	YES..... [CA48]	1
	NO [CA48]	2
	REF [CA48]	7
	DK..... [CA48]	8

CA48. Have you had radiation therapy for this breast condition?	YES..... [CA56]	1
	NO [CA56]	2
	REF [CA56]	7
	DK..... [CA56]	8

CA56. Have you had a bone marrow or stem cell transplant for this breast condition?	YES.....	1
	NO	2
	REF	7
	DK.....	8

[ASK CA57 ONLY IF CA25 OR CA48 = YES]

CA57. Did side effects from chemotherapy or radiation therapy for this breast condition prevent you from getting all of the treatment that was initially planned?	YES.....	1
	NO	2
	REF	7
	DK.....	8

[ASK CA58 ONLY IF CA25 OR CA48 = YES]

CA58. Were you hospitalized due to side effects from chemotherapy or radiation therapy for this breast condition?	YES..... [CA33]	1
	NO [CA33]	2
	REF [CA33]	7
	DK..... [CA33]	8

CA25A. Omitted
CA25B. Omitted
CA26. Omitted
CA26a. Omitted
CA27. Omitted
CA28. Omitted
CA29. Omitted
CA30. Moved - see below
CA31. Omitted
CA32. Omitted

CA33. Have you taken any of the following medications as part of your treatment?	YES..... [CA38]	1
	NO [CA38]	2
	REF [CA38]	7
	DK..... [CA38]	8

Tamoxifen or Raloxifene, such as Nolvadex or Evista?

CA34. Omitted
CA35. Omitted
CA36. Omitted

CA37. Omitted

CA38. (Have you taken any of the following medications as part of your breast cancer treatment?)	YES..... [CA43] 1
	NO [CA43] 2
	REF [CA43] 7
Aromatase inhibitor or AI such as Arimidex, Aromasin, or Femara?	DK..... [CA43] 8

CA39. Omitted

CA40. Omitted

CA41. Omitted

CA42. Omitted

CA43. (Have you taken any of the following medications as part of your breast cancer treatment?)	YES..... [CA52B] 1
	NO [CA52B] 2
	REF [CA52B] 7
Targeted therapy for HER2 such as Herceptin or TYKERB?	DK..... [CA52B] 8

CA44. Omitted

CA45. Omitted

CA46. Omitted

CA47. Omitted

CA48. Moved - see above

CA49. Omitted

CA50. Omitted

CA51. Omitted

CA52. Omitted

CA52A. Omitted

[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 treatment and follow-up?	YES..... 1
	NO [CA24] 2
	REF [CA24] 7
[AFTER FIRST ITERATION] Did you participate in another clinical trial or are you participating in another clinical trial in connection with your treatment and follow-up?	DK..... [CA24] 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?
MARK ALL THAT APPLY

Chemotherapy drug [CA24] 1
Chemotherapy dose or
frequency..... [CA24] 1
Symptom management or
prevention..... [CA24] 1
Radiation therapy [CA24] 1
Hormonal treatment ... [CA24] 1
Surgical treatment [CA24] 1
REF [CA24] 7
DK..... [CA24] 8

CA52E. Omitted

CA52F. Omitted

[END REPEATING RECORD]

CA53. Omitted

CA54. Omitted

CA55. Omitted

RE-ORDERED

CA24. Think back to when you were first diagnosed with this breast condition and before you started any treatment for your breast condition. Were you still having regular menstrual periods at that time?

YES..... [CA30] 1
NO [CA8]..... 2
REF [CA8]..... 7
DK..... [CA8]..... 8

CA30. Did your menstrual periods stop permanently because of your treatment?

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

CA8. Please keep in mind that these questions are about being diagnosed with breast cancer, DCIS, LCIS, Paget's disease or phyllodes tumors. After your first diagnosis of breast disease, were you diagnosed with a second breast disease - either in the same breast or the other breast?

YES..... [CS1A] 1
NO [CA24a] 2
REF [CA24a] 7
DK..... [CA24a] 8

CS1. Omitted

[ASK CS1A IF CA8 = YES:]

[CHECK ANSWER TO CS1A AGAINST DOB]

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

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

IF YEAR PROVIDED, GO TO CS56

[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 CS56]

--	--

AGE

CS56. What was the second breast condition?

MARK ALL THAT APPLY

Invasive breast cancer 1
Ductal carcinoma in-situ, DCIS 1
Lobular carcinoma in-situ, LCIS 1
Other, please specify: 1

REF 7

DK..... 8

GO TO CA24a

CA24a. Have you had both your ovaries removed?

No, I still have one or both of my ovaries

..... [CA2A] 1

Yes, I had both ovaries removed before the diagnosis of this breast condition

..... [CA2A] 2

Yes, I had both ovaries or my last ovary removed after the diagnosis of this breast condition

..... 3

REF [CA2A] 7

DK..... [CA2A] 8

[ASK CA24B ONLY IF CA24a = 3]

CA24b. What was the month and year when you had your last ovary removed?

|_|_|
MONTH

|_|_|_|_|
YEAR

[CA24c]

[ASK CA24C ONLY IF CA24a = 3]

CA24c. Some women have their ovaries removed as part of breast cancer treatment to reduce exposure to natural hormones. Others have the surgery to prevent ovarian cancer -- also called a preventive oophorectomy.

Why were your ovaries removed?

As part of treatment for breast cancer, DCIS or LCIS

..... [CA2A] 1

To prevent ovarian cancer

..... [CA2A] 2

For both treatment and prevention

..... [CA2A] 3

For other reasons, please specify: . 4

..... [CA2A]

REF [CA2A] 7

DK..... [CA2A] 8

CA2A. Sometimes there is a delay between when a woman first notices a lump, or a mammogram shows an abnormality, and the diagnosis of the breast condition. How much time went by between when you first realized there was a problem and when you were told what the diagnosis was?

Less than 1 month [CA59] 1
 1 month or more [CA2A1] 2
 REF [CA59] 7
 DK..... [CA59] 8

[ASK CA2A1 ONLY IF CA2A = 2]
 CA2A1. How many months?

|_|_| MONTHS ... [CA59]01-99

CA59. How was your breast condition **first** discovered?

MARK ONLY ONE RESPONSE

It was first discovered by me or by my partner ... [CA60] 1

It was found during a routine mammogram or other breast cancer screening such as an MRI or ultrasound ... [CA59A] 2

It was discovered by a physician or other health care provider
 [CA60] 3

It was found during an unrelated medical procedure such as an x-ray for pneumonia or a bone scan
 [CA60] 4

REF [CA60] 7
 DK..... [CA60] 8

[ASK CA59A ONLY IF CA59 = 2]
 CA59A. When was this test?

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

CA60. Did you receive genetic counseling as part of your care related to this breast condition?

YES..... 1
 NO 2
 REF 7
 DK..... 8

CA61. 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.

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

No, I did not have a BRCA1 or BRCA2 genetic test or BRCA analysis

..... [CA2B] 1

Yes, before the diagnosis of his breast condition [CA61A]..... 2

Yes, after the diagnosis of his breast condition

..... [CA61A] 3

REF [CA2B] 7

DK..... [CA2B] 8

[ASK CA61A ONLY IF CA61 = 2 OR 3]

CA61A. Did the results of your BRCA1 or BRCA2 test indicate that you carry a mutation that would put you at increased risk for cancer?

MARK ALL THAT APPLY

No, they did not indicate
mutation..... 1
Yes, BRCA1 1
Yes, BRCA2 1
Inconclusive result 1
REF 7
DK..... 8

GO TO CA2B

CA2B. During the time you were being evaluated for this breast condition, 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 any of the medical treatment your doctors recommended?

YES.....[CA62a] 1
NO[CA62a] 2
REF[CA62a] 7
DK.....[CA62a] 8

CS2A-CS55. Omitted

CA62a. In general, would you say your health is...

Excellent 1
Very good 2
Good..... 3
Fair 4
or Poor? 5
REF 7
DK..... 8

CA62b. In general, would you say your quality of life is...

Excellent 1
Very good 2
Good..... 3
Fair 4
or Poor? 5
REF 7
DK..... 8

CA62c. In general, how would you rate your physical health?

Excellent 1
Very good 2
Good..... 3
Fair 4
or Poor 5
REF 7
DK..... 8

CA62d. In general, how would you rate your satisfaction
with your social activities
and relationships?

Excellent 1
Very good 2
Good 3
Fair 4
or Poor 5
REF 7
DK 8

CA62e. In general, how would you rate how well you carry
out your usual social activities and roles? This
includes activities at home, at work and in your
community, and responsibilities as a parent, child,
spouse, employee, friend, etc.

Excellent 1
Very good 2
Good 3
Fair 4
or Poor 5
REF 7
DK 8

CA63. To what extent are you able to carry out your
everyday physical activities such as walking,
climbing stairs, carrying groceries, or moving a
chair?

Completely 1
Mostly 2
Moderately 3
A little 4
or Not at all 5
REF 7
DK 8

CA64. In the past 7 days, how often have you been
bothered by emotional problems such as feeling
anxious, depressed, or irritable?

Never 1
Rarely 2
Sometimes 3
Often 4
or Always 5
REF 7
DK 8

CA65. In the past 7 days, how would you rate your
fatigue on average?

None 1
Mild 2
Moderate 3
Severe 4
or Extremely severe 5
REF 7
DK 8

CA66. In the past 7 days, how would you rate your pain
on average? Please rate on a scale where zero is
no pain and ten is the worst imaginable pain.

|__|__|
00 - 10
REF 97
DK 98

GO TO MRINTRO1