

The next several questions ask about conditions involving your breasts.

D4. Now I am going to ask you some questions about your diagnosis of breast cancer.

(Read the following, as well: "We want to know how your breast condition was first detected. This is different from how it was diagnosed. I'd like you to tell me how you first found out that something was not right about your breast." Probe: Ask if she went to the doctor for a specific breast problem or if the doctor found something out of the blue.)

a. How was your breast cancer first detected?

1 ____ You found a lump. P3D4A

2 ____ Your spouse or partner found a lump.

3 ____ A routine mammogram showed something suspicious.

4 ____ Doctor or nurse found a lump.

5 ____ Ultrasound exam

6 ____ Other, specify: P3D4B (3 digit code)

9 ____ NA

b. What was the date?

P3D4C / P3D4D ____

Month Year

D5. At the time of your diagnosis of breast cancer, did you have any of the following symptoms?

Pain or discomfort in your breast?	P3D5A	1 ____ Yes	2 ____ No	9 ____ NA
Discharge from the nipple?	P3D5B	1 ____ Yes	2 ____ No	9 ____ NA
Change in the skin of the breast?	P3D5C	1 ____ Yes	2 ____ No	9 ____ NA
Any other symptoms?	P3D5D	1 ____ Yes	2 ____ No	9 ____ NA
<div style="text-align: right;"> ↳ Specify: <u>P3D5E , P3D5F</u> (3 digit code) </div>				

Mammography and level of health care

The next few questions are about mammograms. As you probably know, a mammogram is an X-ray of the breast that is taken by a machine that presses against the breast while the picture is being taken.

D8. Have you ever had a mammogram?

- 1 ☐ Yes P3D8
 2 ☐ No -----> SKIP TO D12
 9 ☐ NA

D9. How old were you when you had your first mammogram?

P3D9 Age (enter 99 if don't know)

Now I will be asking about the mammograms you had at different ages.

D10.	Before Age 40	Between 40 and 50	Age 50 or older
How many mammograms did you have?	<u>P3D10A</u> (Enter 00 for no mammograms in this age period.)	<u>P3D10B</u> (Enter 00 for no mammograms in this age period. Enter 98 for not that old yet.)	<u>P3D10C</u> (Enter 00 for no mammograms in this age period. Enter 98 for not that old yet.)

Now I would like to ask you about your most recent mammograms.

D11. In the past TWO years, how many mammograms have you had? P3D11 (Number)

D12. During the TWO years prior to your diagnosis of breast cancer, how many times did you visit a physician for any reason?

- P3D12
 1 ☐ Never
 2 ☐ Once
 3 ☐ Twice
 4 ☐ Three or more times
 9 ☐ NA

D13. During the TWO years prior to your diagnosis of breast cancer, how many times did a physician or other health care professional conduct a breast exam on you ?

- P3D13
 1 ☐ Never
 2 ☐ Once
 3 ☐ Twice
 4 ☐ Three or more times
 9 ☐ NA

- D14.** During the TWO years prior to your diagnosis of breast cancer, did you do a breast exam on yourself?
By this we mean, did you feel your own breasts to look for lumps or other changes?

P3D14A

- 1 ☐ Yes ----->
2 ☐ No
9 ☐ NA

How often did you conduct a breast exam on yourself?

- 1 ☐ Less than once a year
2 ☐ About once or twice a year
3 ☐ Every 2 to 3 months
4 ☐ About once a month
5 ☐ More often than once a month
9 ☐ NA P3D14B

D4a. How detected breast condition (other)
CODE ONE RESPONSE

[099] Don't know (Phase 2) DON'T USE

999 Don't know (Use in Phase 3)

001 Nipple looked different
002 Swelling/redness/rash
003 Breast drainage/ Breast leakage
004 Soreness/sensitivity/discomfort
005 Thickening
006 Edema
007 Inverted nipple
008 Mammogram (not routine)
009 Pain/ dull achy
010 Lump resembling a boil
011 Blood from nipple
012 Biopsy
013 Enlarged nipple
014 Other individual found lump
015 Indentation(s)/ skin symptoms
016 Asymmetry
017 "liver pain"
018 Lumps followed / Lumps monitored /
calcification
019 Dimpling/wrinkling/puckering
020 Discoloration
021 Discharge from nipple (not blood)
022 Had surgery for infection
023 Back pain
024 Nipple irritation
025 She could see it
026 Small bumps, itching
027 Ultrasound
028 Car accident – diagnostic tests run
029 CT scan for chest pain while coughing
030 Acute, intermittent breast pain
031 Hard bump from fall
032 CT scan for blood clot
033 Trauma
035 Pain and thickening of skin
036 Bleeding and pain in left nipple
037 Blood in bra
038 Warm breast
039 PET scan
040 "Something didn't feel right in the left
armpit"/Left arm pain/Armpit pain
041 Paget's disease of the breast

042 Breast felt different
043 Enlarged axillary lymph node
044 MRI
045 Child bumped into it
046 Cat jumped on her
047 "Breast felt heavy"
048 Participant found lump under her arm
049 Spot looked like an insect bite
050 Participant had ~~arm-and-leg~~ pain from
pathological fractures caused by bone
metastasis
051 Found a lump & had pain in breast
052 Breast was warmed with an inverted nipple
053 Breast reduction surgery
054 Retracted nipple
055 Increased breast size/change in size
056 Participant denies having breast cancer
057 Hard/red Spot
058 Pinhole in nipple
059 Abscess/boil/sore/blister/ulcer
060 CT Scan, (NOS)
061 Prophylactic mastectomy
062 Hernia repair
063 Benign Tumor removed from cervical spine
064 Pre-existing lump changed
065 Prayer
066 "Something was wrong"
067 Change in shape
068 Lymphodema in arm/trunk
069 Misdiagnosed mastitis
070 X-Ray
071 Skin numbness
072 Swollen breasts and palpable lymph nodes
under arm
073 Breast felt hard/firm
074 Arms swollen and lump in neck
075 Found during hospital stay (NOS)
076 Surgery (NOS)
077 Irritation and skin dimpling
078 Pain in breast bone/sternum
079 Breast specific gamma imaging (BSGI)
080 Abdominal pain checkup

CODE UP TO 2 RESPONSES**D5. Other symptoms at time of diagnosis**

[099] Don't know (Phase 2) DON'T USE

999 Don't know (Use in Phase 3)

Nipple:

001 Nipple looked different/looked uneven/came off / shriveled areola

005 Itchy nipples/itching

013 Inverted nipple/retracted nipple

038 Growth from nipple

051 Nipple was dry/cracked

052 Nipple was dimpling

053 Nipple tenderness &/or discharge

059 Nipple felt different/texture different

069 Nipple changed in size

071 Nipple changed position

081 Tingling sensation in nipple

Problems in chest/neck area, pain in unaffected breast:

014 Stiffening in arms

017 Chest pains

018 Pain in rib below breast / above breast / hardness under arm

020 Knot under arm/lymph nodes enlarged

022 Back/arm pain, papilloma, mass

030 Soreness in underarm area/"pulling" under arm

034 Soreness in neck area

041 lump in other breast/lump found in breast/s ~~pain in other breast~~

044 Pain in unaffected breast

066 Pain radiating to shoulder / pain in shoulder

067 Swollen underarm

073 Shortness of breath

083 Pain in sternum

Problems in affected breast: shape/size changed, felt different, discharge, etc.:

002 Swelling and redness

006 Breast felt "tight" or tender/soreness

008 Cyst

009 Increased in size/change in size (due to swelling, etc)

010 Sensitive

011 Shape changed

012 Indented line across breast

019 Edema of breast

021 Bleeding

023 Discharge from breast/foul smelling

025 Breast got firm/hard

026 Bumps / pebbles

027 Burning sensation/warm/hot to touch

028 "twinges" / stinging / felt like electricity go through breast

029 Pressing - like feeling/breast needed to be rubbed

031 Asymmetry

032 Dimple on breast

033 "funny feeling" / felt something wasn't right/felt different

035 Color darkened / discoloration

036 Thickening

037 Heaviness of affected area

039 Inflammation

040 Open sore

045 Itching and/or burning beneath the skin

054 "Pinching"

056 Skin toughened / Breast was dry and rough feeling

- 057 Visually see knot under skin / “Could see lump sticking out under skin”
- 060 Tenderness with period
- 061 Episodic redness
- 062 Rash
- 063 Mole fell off
- 068 Redness
- [064] Breast felt heavy—**DO NOT USE, code as “037 Heaviness of affected area”**
- 065 Cellulitis
- 070 Pain/discomfort (NOS)
- 078 Pulling sensation

Other problems:

- 003 Fatigue / weakness / tiredness
- 004 Fever/cold symptoms
- 007 Low sex drive
- 015 Food cravings (esp. starch, sweet)
- 016 Nosebleeds
- 024 Weight loss
- 042 Frequent vaginal infections
- 043 Lots of indigestion
- 046 Hot flashes
- 047 Itching, NOS
- 048 Bruising, NOS
- 049 General feeling of not being well
- 050 Change in vision
- 055 “Aware something was there the whole time”
- 058 Prominent veins
- 072 Small, red raised bump
- 074 Anxiety
- 075 Nauseous / Nausea
- 076 Skin Numbness
- 077 Enlarging palpable mass
- 079 Skin issues/changes (NOS)
- 080 Hair loss (in general)
- 082 Hair became dry
- 084 Fatigued + dry hair
- 085 Heat intolerance