

Carolina Breast Cancer Study Questionnaire Coding (Phase I)

Place of birth (Question B2) City: No coding

County:

999 Don't Know	025 Craven	051 Johnston	077 Richmond
888 Non-NC County	026 Cumberland	052 Jones	078 Robeson
001 Alamance	027 Currituck	053 Lee	079 Rockingham
002 Alexander	028 Dare	054 Lenoir	080 Rowan
003 Alleghany	029 Davidson	055 Lincoln	081 Rutherford
004 Anson	030 Davie	056 McDowell	082 Sampson
005 Ashe	031 Duplin	057 Macon	083 Scotland
006 Avery	032 Durham	058 Madison	084 Stanly
007 Beaufort	033 Edgecomb	059 Martin	085 Stokes
008 Bertie	034 Forsyth	060 Mecklenburg	086 Surry
009 Bladen	035 Franklin	061 Mitchell	087 Swain
010 Brunswick	036 Gaston	062 Montgomery	088 Transylvania
011 Buncombe	037 Gates	063 Moore	089 Tyrrell
012 Burke	038 Graham	064 Nash	090 Union
013 Cabarrus	039 Granville	065 New Hanover	091 Vance
014 Caldwell	040 Greene	066 Northampton	092 Wake
015 Camden	041 Guilford	067 Onslow	093 Warren
016 Carteret	042 Halifax	068 Orange	094 Washington
017 Caswell	043 Harnett	069 Pamlico	095 Watauga
018 Catawba	044 Haywood	070 Pasquotank	096 Wayne
019 Chatham	045 Henderson	071 Pender	097 Wilkes
020 Cherokee	046 Hertford	072 Perquimans	098 Wilson
021 Chowan	047 Hoke	073 Person	099 Yadkin
022 Clay	048 Hyde	074 Pitt	100 Yancy
023 Cleveland	049 Iredell	075 Polk	
024 Columbus	050 Jackson	076 Randolph	

State:

99 Don't Know	13 Illinois	27 Nebraska	41 South Dakota
88 Not US	14 Indiana	28 Nevada	42 Tennessee
01 Alabama	15 Iowa	29 New Hampshire	43 Texas
02 Alaska	16 Kansas	30 New Jersey	44 Utah
03 Arizona	17 Kentucky	31 New Mexico	45 Vermont
04 Arkansas	18 Louisiana	32 New York	46 Virginia
05 California	19 Maine	33 North Carolina	47 Washington
06 Colorado	20 Maryland	34 North Dakota	48 West Virginia
07 Connecticut	21 Massachusetts	35 Ohio	49 Wisconsin
08 Delaware	22 Michigan	36 Oklahoma	50 Wyoming
09 Florida	23 Minnesota	37 Oregon	51 Washington DC
10 Georgia	24 Mississippi	38 Pennsylvania	
11 Hawaii	25 Missouri	39 Rhode Island	
12 Idaho	26 Montana	40 South Carolina	

Country:

01 U.S.	07 Turkey	13 Sri Lanka	19 Japan
02 Canada	08 Great Britain	14 West Africa	20 France
03 Mexico	09 Yugoslavia	15 Switzerland	21 Ethiopia
04 Germany	10 Taiwan	16 West Indies	22 Cuba
05 Soviet Union	11 India	17 Poland	23 Holland
06 Bermuda	12 Norway	18 New Zealand	24 South Korea
			25 Colombia
			26 Philippines

Type of Cancer (Questions B4, B7, B8, and E5)

(These codes are topography codes from ICD-O, 2nd edition. Exception: Code for melanoma is made up)

999 Don't Know	239 Gallbladder	079 Parotid Gland
762 Abdomen (NOS)	760 Head/Face	609 Penis
761 Axilla	446 Kaposi Sarcoma	140 Pharynx
767 Back	649 Kidney	619 Prostate
240 Biliary Duct	329 Larynx/Throat	764 Shoulder
679 Bladder	420 Leukemia (Blood)	449 Skin (Non-melanoma or NOS)
419 Bone	009 Lip	849 Skin (Melanoma)
719 Brain	220 Liver	169 Stomach
509 Breast	349 Lung	629 Testis
539 Cervix	779 Lymphoma (Lymph Node)	379 Thymus
761 Chest	069 Mouth	739 Thyroid
189 Colon/Rectum	421 Myeloma	099 Tonsil/Adenoid
559 Endometrium/Uterus	950 Neuroblastoma	319 Sinus
159 Esophagus	760 Neck	412 Spine
699 Eye	569 Ovary	320 Vocal Cords
579 Female Genital Organs	259 Pancreas	
765 Foot (NOS)		410 Maxilla/Jaw

B11. and B12. Other relatives

99 Don't Know	13 Great Grandmother (Maternal)
01 Cousin (Maternal)	14 Great Grandmother (Paternal)
02 Cousin (Paternal)	15 Great Grandmother (Both)
03 Cousin (Both)	16 Great Grandmother (unknown)
04 Cousin (unknown)	17 Other (Maternal)
05 Niece (Maternal)	18 Other (Paternal)
06 Niece (Paternal)	19 Other (Both)
07 Nieces (Both)	20 Other (unknown)
08 Niece (unknown)	21 Multiple (Maternal)
09 Great Aunt (Maternal)	22 Multiple (Paternal)
10 Great Aunt (Paternal)	23 Multiple (Both)
11 Great Aunt (Both)	24 Multiple (unknown)
12 Great Aunt (unknown)	25 _____

C11. Other reasons for period stopping

- 99 Don't Know
- 01 Due to medication use
- 02 "Pituitary gland in shock" after traumatic birth
- 03 Sickle Cell Anemia
- 04 Period stopped when OC's discontinued, then started chemo
- 05 Periods stopped when tumor diagnosed
- 06 D & C
- 07 Tamoxifen use
- 08 Due to hormone use
- 09 mental trauma/stress
- 10 endometrial ablation

C15. Other pregnancy outcomes

- 99 Don't Know
- 01 Twin Pregnancy: One miscarried, One livebirth
- 02 Pregnancy ended due to hysterectomy
- 03 Multiple stillbirths
- 04 Multiple: one stillbirth, one livebirth

C18. Other fertility problems

- | | |
|-------------------------------------|---|
| 99 Don't Know | 07 Physical Weakness |
| 01 Obesity | 08 Diabetes |
| 02 Pituitary gland problems | 09 Anemia |
| 03 Hormones | 10 Body temperature at time of ovulation |
| 04 Timing of intercourse | 11 No infertility problems, but egg donor |
| 05 Age | 12 Menstrual cycle problems |
| 06 Complications related to IUD use | 13 problems with medications |
| | 14 polycystic ovaries |

C20. Medications to help get pregnant

- | | |
|---|---|
| 99 Don't Know | 08 Danazol, Danocrine |
| 01 Clomid, Clomiphene, Serophene | 09 Spironolactone, Aldactone |
| 02 Pergonal, Menotropins | 10 Prednisone, Dexamethasone, Decadron |
| 03 Bromocriptine, Parlodel | 11 Lupron, Leuprolide, Gonadotropin Releasing Hormone (GnRH) Agonists |
| 04 Chorionic gonadotropin, HCG, Profasi HP, Pregnyl, A.P.L. | 12 Follutein |
| 05 Medroxyprogesterone, Provera, Depo-Provera | 13 Pro-ception |
| 06 Urofollitropin, Metrodin | 14 _____ |
| 07 Synarel, Nafarelin | 15 _____ |
| | 16 _____ |

D21. b, d, f, and g. Progestins

- 99 Don't Know
- 01 Medroxyprogesterone, Provera, Amen, Cycrin
- 02 Norethindrone, Norlutin, Norlutate, Aygestin
- 03 Progesterone suppositories
- 04 Megestrol (Megace)
- 05 Progesterone injections
- 06 Prempro _____
- 07 _____

D21. c. Other estrogens

- 99 Don't Know
- 01 Ogen, Estropipate, Orthoest
- 02 Estrace, Estradiol
- 03 Estratabs, Esterified Estrogens, Menrium, Menest
- 04 Diethylstilbestrol, DES
- 05 Estrovis, Quinestrol
- 06 TACE, Chlorotrianisene
- 07 Estratest
- 08 _____
- 09 _____

D21. h Other hormones

- 99 Don't Know
- 01 Halotestin
- 02 Lupron
- 03 Male Hormone (NOS)
- 04 Danazol/Danocrine
- 05 _____
- 06 _____

E3. Type of Diabetes

- 99 Don't Know
- 01 Insulin dependent diabetes mellitus (IDDM), Juvenile Onset, Type I
- 02 Non-insulin dependent diabetes mellitus (NIDDM), Adult Onset, Type II
- 03 Gestational diabetes
- 04 Adult onset - but requires insulin
- 05 _____
- 06 _____

Thyroid Condition

- 99 Don't Know
- 01 Hypothyroidism
- 02 Hyperthyroidism
- 03 Goiter (enlarged thyroid)
- 04 Hashimoto's disease
- 05 Grave's disease
- 06 Lump on Thyroid
- 07 Multiple Conditions
- 08 Thyroid Cancer
- 09 Thyroiditis
- 10 Thyreidectomy, reason unknown

E4. Benign tumors, cysts, or growths

- | | |
|--|-----------------------------------|
| 99 Don't Know | 20 Liver |
| 01 Breast-benign tumor, cyst, fibrocystic disease | 21 Lymph nodes |
| 02 Ovary-cyst, benign tumor | 22 Bone tumor |
| 03 Uterus-fibroids, benign tumor, or cyst | 23 Adrenal Gland Tumor |
| 04 Thyroid | 24 Hip Knot |
| 05 Colon-polyps | 25 Ganglion |
| 06 Skin-sebaceous cysts, other skin growths | 26 Brain Tumor/ cyst/ head nodule |
| 07 Vulva-benign tumor | 27 Sub-urethral cyst |
| 08 Teratoma | 28 Axilla Tumor |
| 09 Cyst - Parotid Gland | 29 Cyst in nose |
| 10 Cervix - tumor, cyst, abnormal pap smear (if treated) | 30 Nodule in neck |
| 11 Mouth - cysts or tumors | 31 Arm tumor |
| 12 Abdominal cyst or tumor, internal (NOS) | 32 Bowen's tumor |
| 13 Throat - tumors or cysts | 33 Pituitary tumor |
| 14 Neuroma | 34 Salivary gland |
| 15 Cystocele-bladder | 35 Rectum |
| 16 Fallopian tube tumor | 36 Eye cyst |
| 17 Endometriosis | 37 Sarcoid tumor lung |
| 18 Vagina | 38 Female oenital organs (nos) |
| 19 Pilonidal cyst (hairy cyst) | 39 Kidney |
| | 40 Stomach |

E6. How breast cancer was found

- 99 Don't Know
- 01 Husband/Partner
- 02 Other Healthcare Professional
- 03 During other medical examination (not breast exam)
- 04 Sonogram
- 05 _____

E16. Diseases treated with radiation

- | | |
|---|------------------------------|
| 99 Don't Know | 09 Hypothyroidism |
| 01 Cancer | 10 Keloids |
| 02 Hyperthyroidism | 11 Myasthenia Gravis |
| 03 Acne | 12 Birthmark/mole |
| 04 Rheumatic Fever | 13 Tuberculosis |
| 05 Enlarged Thymus | 14 Eczema |
| 06 Spot on Lungs | 15 Vaginal rash |
| 07 Pleuresy | 16 Tumor/growth (not cancer) |
| 08 Tonsilitis/Enlarged Tonsils &
Adenoids/Strep Throat | 17 Hook worm |
| | 18 Planters warts |
| | 19 Exposed blood vessel |

Body part treated with radiation
Use same codes as for cancer sites

F7. Type of physical activity (Code up to 3 activities)

- 99 Don't Know
- 01 Walking
- 02 Aerobics, exercise class, work out on exercise equipment
- 03 Bicycling
- 04 Gardening, yard work
- 05 Stair climbing
- 06 Golf
- 07 Tennis
- 08 Other games/sports
- 09 Work around the home
- 10 Running/jogging
- 11 Swimming
- 12 Dancing
- 13 Horseback riding
- 14 Geriatric exercise
- 15 Stretching and Toning exercises
- 16 Physical Therapy
- 17 Water aerobics_____
- 18 _____

F23. Smoking Duration/ F26 & F28 use same coding scheme

Write in 0 as code if participant smoked at least 100 cigarettes in her lifetime, but smoked regularly for less than 1 year.

G16. Other pesticide jobs

- 99 Don't Know
- 01 Dipping animals in pesticides
- 02 Handling products treated with pesticides
- 03 Laboratory synthesis of pesticides
- 04 Did toxicity studies
- 05 Secretary

G20. Did you treat it yourself? Write in 03 as code if participant sometimes did it herself.**H2. Other Racial/Ethnic Groups**

- 99 Don't Know
- 01 African-American
- 02 Multi-racial
- 03 Spanish/Hispanic
- 04 Italian
- 05 Indian

H5-7 Other Occupational Categories

- 99 Don't Know
- 01 Marriage lasted only a short while
- 02 Self-employed
- 03 Military
- 04 Professional Athlete
- 05 Government worker
- 06 _____

I2. Code up to 5 causes

- | | |
|--|--------------------------------------|
| 01 Hormone exposure (OC's HRT) | 32 Lifestyle |
| 02 Not having children/late child birth | 33 No self-examinations or physicals |
| 03 Abortion | 34 Sun exposure |
| 04 Genes/heredity | 35 Vitamin Deficiency |
| 05 Foods we eat, preservatives/chemicals in food, diet | 36 Promiscuity/Sexual Practices |
| 06 Something in water | 37 Wearing bras |
| 07 Tobacco | 38 Electrolysis for facial hair |
| 08 Pesticides | 39 Related to other cancers |
| 09 Radiation/Magnetic fields | 40 Hysterectomy |
| 10 Trauma to breast | 41 Fluctuations in Weight |
| 11 Stress | 42 Poor health habits |
| 12 Environment/chemicals in the environment | 43 Mammograms |
| 13 Asbestos | 44 Egg donor program |
| 14 Medications | 45 X-rays |
| 15 Alcohol | 46 Size of breast |
| 16 Obesity | 47 Pregnancy related |
| 17 Fair skin | 48 Age |
| 18 Body Type | 49 Occupation |
| 19 Benign breast disease | 50 Prosthesis (Breast) |
| 20 Lack of exercise | 51 Computers |
| 21 Exposure to other cancer patients | 52 Viruses that stay in the body |
| 22 Problem in protein metabolism/Chemical imbalance | 53 The way you treat people |
| 23 Immune system deficiency | 54 Clogged milk ducts |
| 24 The devil/ungodlike actions | 55 Pets |
| 25 Something in blood | 56 Bee stings |
| 26 Breastfeeding | 57 (Sorry) men |
| 27 Electrocardiogram | 58 Sorrow/Depression |
| 28 Menopause | 59 Destiny |
| 29 "a cell went crazy" | 60 Hormonal imbalance |
| 30 Early Menstruation | 61 Physical street/heavy lifting |
| 31 Personality | 62 Physical abuse (being beaten) |
| | 63 Mother took DES |

I3. Code up to 3 comments

- 01 Cancer clusters, Increase in cancer needs to be investigated
- 02 Questions too personal
- 03 Questions were reasonable
- 04 Some questions' relevance to breast cancer is unclear
- 05 Would like to help out in search for causes of breast cancer/
Glad to see this research being done
- 06 Worried about hormone use
- 07 Concern about detection or treatment of cancer
- 08 Concerns about food/water
- 09 Wondered about other medical conditions' relationship to breast cancer
- 10 Wondered about other chemical exposures/ environmental exposure
- 11 Concern about family history
- 12 Concern about stress
- 13 Concern about breast trauma
- 14 Concern about medication use
- 15 Concern about breast implants
- 16 Concern about lactation
- 17 Wanted more money
- 18 Never thought at high risk
- 19 Concern about caffeine
- 20 Has recently begun exercising
- 21 Wondered about associations with sexual activity
- 22 Concerned about marijuana use
- 23 Concerned about physical abuse from parent and husband
- 24 Where she lived is more relevant than type of community
- 25 Concerned about cancer in pets
- 26 Concern about computer exposure
- 27 Concern about X-rays
- 28 Concern about work history
- 29 Wondered about next generation's risk
- 30 Having biopsy soon
- 31 Some questions need refinement
- 32 Concern about smoking
- 33 Wondered how QOL affects breast cancer
- 34 Interested in knowing results
- 35 Both adoptive parents had cancer (adoptive mom-breast)
- 36 Southern women not assessed, examined well
- 37 Thought she might have cancer, but chose to shut it out, ignore it
- 38 Not enough concern about women's health problems by male doctors
- 39 Participant notes she is Jewish
- 40 Thought her doctors were kind, considerate
- 41 Concern about physical activity
- 42 Participant wished she knew more about survey beforehand, so she could have prepared

J1. Where was the Interview

- | | |
|---------------------------------|--|
| 01 Trailer 48/CBCS | 18 Hotel Lobby |
| 02 Raleigh Internal Medicine | 19 ECU/Leo Jenkins Cancer Center |
| 03 Alamance Hospital | 20 Duke Cancer Control Center, Erwin Sq. |
| 04 Rex Radiation Oncology | 21 Women's Prison |
| 05 Heritage Hospital in Tarboro | 22 Half-way house (post prison) |
| 06 Workplace | 23 Duke Oncology Clinic |
| 07 VA Hospital | 24 Daughter's home |
| 08 Wayne Memorial Hospital | 25 Beaufort Hospital |
| 09 Pinehurst Clinic | 26 Central Carolina Cancer Center |
| 10 Bertie Memorial | 27 Neighbor's House |
| 11 UNC Oncology Clinic | 28 Moore Regional Hospital |
| 12 Rest Home | 29 Restaurant |
| 13 Nash General Hospital | 30 Doctor's office |
| 14 Adult Day Care Center | 31 Morehead City hospital |
| 15 Health Dept. | 32 Bank |
| 16 Hotel Room | |
| 17 Lenoir Community Hospital | 99 unknown |

J3. Respondent's cooperation

- 01 Belligerent
- 02 Respondent ill -- answers given by spouse
- 03 _____
- 04 _____

J4. Quality of Responses

- 01 Some responses provided by daughter
- 02 _____
- 03 _____
- 04 _____

J5. The Respondent

- 01 Had trouble with medical history
- 02 Had trouble with hormones, medications
- 03 Had trouble with family history
- 04 Had trouble with pesticide information
- 05 Had trouble with menopause information
- 06 Had trouble with ages
- 07 Had trouble with occupational history
- 08 Had trouble with menstrual history
- 09 Had trouble with fruit and vegetable questions
- 10 Had trouble with smoking questions
- 11 Needed frequent prompting
- 12 Generally reliable, but some recall problems
- 13 Had trouble with alcohol questions
- 14 Refused to recall
- 15 Many questions answered by daughter
- 16 Participant said she had multiple personality disorder
- 17 Legally blind, everything read to participant
- 18 Apparent psychological problems
- 19 Unable to read
- 20 Difficulty hearing
- 21 Ill, not feeling well

J6. Reasons for unsatisfactory information

- 01 Poor memory in general, just couldn't remember
- 02 Just couldn't remember certain information
- 03 Difficulty remembering events from long ago
- 04 Had a history of a stroke
- 05 Was very tired
- 06 Had trouble concentrating
- 07 Was concerned that she was unable to give specific enough information
- 08 Had trouble calculating amounts
- 09 Didn't seem to understand questions
- 10 Had trouble remembering due to medication use
- 11 Poor memory because of age
- 12 Low educational level
- 13 Had trouble remembering due to accident/head injury
- 14 Mentally retarded
- 15 Participant had been drinking

AN6B:

- 01 Over pantyhose
- 02 Over clothes/pants
- 03 Tape measure held in place
- 04 Patient unable to stand/in wheel chair
- 05 Height and weight done at clinic visit with clinic nurse
- 06 Girdle on
- 07 Participant refused (weight)
- 08 Shoes on
- 09 Pregnant
- 10 Height and weight gotten from medical records
- 11 Participant gave measurement
- 12 Participant had cast on leg
- 13 Participant wore shoes and was measured over pants
- 14 Weighed on carpet
- 15 Hip and waist not measured due to swelling of area following surgical/treatment procedure
- 16 measurements taken over corset
- 17 (over thick skirt--NOTE--THIS SHOULD BE CODE 2)
- 18 Some measurements not taken--bilateral amputee
- 19 Wearing vest support
- 20 Survey done in location where measurements not appropriate
- 21 (Abdomen swollen from surgery--NOTE--THIS SHOULD BE CODE 15)
- 22 CBCS nurse did measurements with different scale/instruments