

**Carolina Breast Cancer Study
Questionnaire Coding
(Phase 2)**

B2. Place of Birth (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 Allegheny	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	52 Puerto Rico
11 Hawaii	25 Missouri	39 Rhode Island	
12 Idaho	26 Montana	40 South Carolina	

Country:

01 U.S.	17 Poland	33 Czech Republic
02 Canada	18 New Zealand	34 Croatia
03 Mexico	19 Japan	35 Austria
04 Germany	20 France	36 Ireland
05 Soviet Union / Russia	21 Ethiopia	37 China
06 Bermuda	22 Cuba	38 North Korea
07 Turkey	23 Holland	39 Egypt
08 Great Britain	24 South Korea	40 Argentina
09 Yugoslavia	25 Colombia	41 Hungary
10 Taiwan	26 Philippines	42 Iran
11 India	27 Jamaica	43 Central America/ Panama Canal zone
12 Norway	28 European Countries, NOS	44 Venezuela
13 Sri Lanka	29 Guyana	
14 West Africa	30 Scotland	
15 Switzerland	31 United Kingdom (08)	99 Unknown
16 West Indies	32 Italy	

B4, B7, B9, D3, D31. Type of Cancer

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

999 Don't Know per interviewee	579 Female Genital Organs & Reproductive Organs	259 Pancreas
762 Abdomen (NOS)	765 Foot (NOS)/Leg (NOS)	079 Parotid Gland
749 Adrenal Gland (NOS)	239 Gallbladder	609 Penis
181 Appendix	763 Groin/Pelvis, NOS	140 Pharynx
761 Axilla	039 Gum	619 Prostate
767 Back/Torso	764 Arm/Hand	003 Sarcoma, NOS
814 Basal Cell	380 Heart	764 Shoulder
240 Biliary Duct	760 Head/Face	319 Sinus
679 Bladder	965 Hodgkin's disease	449 Skin (Non-melanoma or NOS)
419 Bone	446 Kaposi's Sarcoma	849 Skin (Melanoma)
421 Bone marrow	649 Kidney	179 Small Intestine
260 Bowel	765 Knee	422 Spleen
719 Brain	329 Larynx/Throat	720 Spinal Cord
509 Breast (incl. invasive & CIS)	429 Leg connective tissue	412 Spine
539 Cervix	420 Leukemia (Blood)	807 Squamous cell, NOS
761 Chest	009 Lip	169 Stomach
189 Colon/Rectum	220 Liver	629 Testis
442 Ear	349 Lung	Throat—see larynx
759 Endocrine Gland (pituitary)	778 Lymphosarcoma	379 Thymus
559 Endometrium/Uterus	779 Lymphoma (Lymph Node)	739 Thyroid
321 Epiglottis	410 Maxilla/Jaw	029 Tongue
159 Esophagus	069 Mouth/Oral	099 Tonsil/Adenoid
400 Ewing's Sarcoma	421 Myeloma	689 Urinary System
699 Eye	950 Neuroblastoma	320 Vocal Cords
441 Eyelid	760 Neck/Nose	519 Vulva/Vagina
492 Fatty tissue - hip	569 Ovary	
519 Female Genitalia (external)		809 Unknown primary site per doctor e.g. AIDS related cancer
		633 Rhabdomyosarcoma

B10, B11. Male relative, other relatives**CODE UP TO 3 RESPONSES**

- | | |
|---------------------------------|--|
| 99 Don't Know | 15 Great Grandmother (Both) |
| 01 Cousin (first) (Maternal) | 16 Great Grandmother (unknown) |
| 02 Cousin (first) (Paternal) | 17 Other (Maternal) |
| 03 Cousin (first) (Both) | 18 Other (Paternal) |
| 04 Cousin (first) (unknown) | 19 Other (Both) |
| 05 Niece (Maternal) | 20 Other (unknown) |
| 06 Niece (Paternal) | 21 Multiple (Maternal) |
| 07 Nieces (Both) | 22 Multiple (Paternal) |
| 08 Niece (unknown) | 23 Multiple (Both) |
| 09 Great Aunt (Maternal) | 24 Multiple (unknown) |
| 10 Great Aunt (Paternal) | 25 Uncle (Paternal) |
| 11 Great Aunt (Both) | 26 Great Uncle (Paternal) |
| 12 Great Aunt (unknown) | 27 Cousin |
| 13 Great Grandmother (Maternal) | 28 Cousin (maternal) – should be 01 |
| 14 Great Grandmother (Paternal) | 29 2 nd Cousin (paternal) – should be 18 |
| | 30 2 nd Cousin (maternal) – should be 17 |
| | 31 uncle (maternal) |
| | 32 Nephew- brother's son |

C10. Other reasons for period stopping**CODE ONE RESPONSE**

- 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/hormone discontinuation
- 05 Periods stopped when tumor diagnosed
- 06 D & C
- 07 Tamoxifen use
- 08 Due to hormone use / ERT
- 09 Mental trauma/stress/husband died
- 10 Endometrial ablation
- 11 Provera use/Progestin
- 12 Prolonged steroid use
- 13 Medical procedure/Surgery (other than removal of uterus or ovaries)
- 14 Became irregular & spotting before estrogen (HRT)
- 15 Depo Provera

C12. Other pregnancy outcomes**CODE ONE RESPONSE**

- 99 Don't Know
- 01 Twin Pregnancy: One miscarried, One livebirth
- 02 Pregnancy ended due to hysterectomy
- 03 Multiple stillbirths
- 05 Missed abortion
- 06 Therapeutic abortion (IUD pregnancy)

C15. Other fertility problems**CODE ONE RESPONSE**

99 Don't Know	25 Ovulation Problems
01 Obesity	26 Low Sperm Count
02 Pituitary gland problems	27 Miscarriages
03 Hormones	28 "built close" - unable to conceive baby through birth canal
04 Timing of intercourse	29 "A narrow tube" / damage to tubes / blocked tubes / tubal adhesions
05 Age	30 "Female Problem"
06 Complications related to IUD use	31 Tendency for ectopic pregnancy
07 Physical Weakness	32 Low hormone levels
08 Diabetes	33 "Trying too hard"
09 Anemia	34 Anovulatory cycles
10 Body temperature at time of ovulation	35 Allergy to sperm/ "problem with her that was killing the sperm"
11 No infertility problems, but egg donor	36 Infection
12 Menstrual cycle problems	37 Female organs not developed well
13 problems with medications	38 Endometriosis
14 polycystic ovaries / Ovarian Cysts	39 Fibroid on womb
15 Birth control pills (take longer)	40 Grief
16 Thyroid problems	41 Heavy bleeding
17 Mental problem	42 Adhesions
18 Tipped uterus	43 Tear during previous pregnancy
19 Cyst in uterus	44 Problems with egg fertilization
20 Ovulate early	
21 Lazy sperm/sperm have low mobility	
22 Stress	
23 Sclerocystic ovaries	
24 Scar Tissue	44

D1a. Type of Diabetes**CODE ONE RESPONSE**

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	09 Diabetes insipidus
05 Adult onset, NOS	10 Diabetes mellitus, NOS
06 Borderline diabetic - treated by MD	11 Elevated blood sugar, resolved on own
07 Drug induced, temporary (steroid)	12
08 Glucose intolerance	13

D1b. Problems with ovaries**CODE ONE RESPONSE**

99 Don't Know	22 Dysmenorrhea - painful periods
01 Polycystic ovaries (cysts)/Stein-Leventhal Syn.	23 Endometriosis on ovary – same as 09
02 Fibroid cysts on ovaries/fibrocystic	24 “blocked ovary”
03 Benign tumor	25 Malignant tumor
04 Enlarged ovary	26 Oophorectomy, NOS
05 Cyst, NOS / Polyp	27 Ovulated but was not releasing an egg
06 Short fertility time	28 Partial oophorectomy due to endometriosis
07 Ruptured Cyst	29 “Mass” was detected/ “growths”
08 Dermoid cyst	30 “infection”
09 Endometrioma on ovary/Endometriosis	31 “corrupted ovary”
10 Scarring	32 “Floating” ovaries
11 Irregular ovulation (problem w/ovulation)	33 Ruptured cysts - should be 07
12 Fibroid tumor	34 “cocoon around ovaries”
13 Infection	35 Twisted or tilted ovary
14 Tumor, NOS	36 Painful Ovaries
15 Abscess on ovary	37 Bled a lot
16 Adhesions	38 Under production of hormones
17 Rupturing ovaries	39 Complications of appendicitis
18 Ovarian cancer	40 Oophrectomy due to cyst
19 Oophorectomy due to tubal pregnancy	41 Chocolate cyst
20 Oophorectomy due to endometriosis	42
21 Mass from egg that did not pass/growth	

D1c. Thyroid Condition**CODE ONE RESPONSE**

99 Don't Know	14 Combination hypo/hyperthyroid
01 Hypothyroidism	15 Fluid on thyroid
02 Hyperthyroidism	16 Borderline condition
03 Goiter (enlarged thyroid)	17 Overactive
04 Hashimoto's disease	18 “Took synthroid”/taking synthroid now
05 Grave's disease	19 Parathyroid nodule
06 Lump on Thyroid/tumor	20 Wilson's syndrome
07 Multiple Conditions	21 Infected thyroid
08 Thyroid Cancer	22
09 Thyroiditis	23
10 Thyroidectomy, reason unknown	24
11 Swollen thyroid	
12 Nodule	
13 Thyroid storm	

D3. Other cancer: see type of cancer on page 2.**D4. Other types of breast cancer (“Inflammatory” is invasive breast cancer) CODE ONE RESPONSE**

(01 - 03 have been dropped)

04 Bilateral breast cancer	12 multi-focal calcifications in duct
05 Paget's disease, NOS	13 bad milk duct
06 “breast cancer in zero stage”	14 Not cancer
07 “bad tissue”	15 Non invasive pre cancer
08 intraductal	16 Stage I cancer
09 spot (on mammogram)/ lesion	17 possible invasive
10 non-invasive breast cancer	18
11 microcalcifications / calcium deposits	

D5. How detected breast condition (other)**CODE ONE RESPONSE**

- | | |
|--|---|
| 01 Nipple looked different | 15 Indentation(s)/ skin symptoms |
| 02 Swelling & redness | 16 Asymmetry |
| 03 Breast drainage | 17 "liver pain" |
| 04 Soreness/sensitivity | 18 Lumps followed / Lumps monitored/calcification |
| 05 Thickening | 19 Dimpling |
| 06 Edema | 20 Discoloration |
| 07 Inverted nipple | 21 Discharge from nipple (not blood) |
| 08 Mammogram (not routine) because of pain/flu | 22 Had surgery for infection |
| 09 Pain/ dull achy | 23 Back pain |
| 10 Lump resembling a boil | 24 Nipple irritation |
| 11 Blood from nipple | 25 She could see it |
| 12 Biopsy | 26 Small bumps, itching |
| 13 Enlarged nipple | 27 Ultrasound |
| 14 Other individual found lump | 28 |

D6. Other symptoms at time of diagnosis**CODE UP TO 2 RESPONSES**

- | | |
|---|---|
| 01 Nipple looked different/looked uneven/came off | 24 Weight loss |
| 02 Swelling & redness | 25 Breast got firm/hard |
| 03 Fatigue /weakness | 26 Bumps |
| 04 Fever/cold symptoms | 27 Burning sensation/warm |
| 05 Itchy nipples/itching | 28 "twinges" / stinging / felt like electricity go through breast |
| 06 Breast felt "tight" or tender/soreness | 29 Pressing - like feeling/breast needed to be rubbed |
| 07 Low sex drive | 30 Soreness in underarm area/"pulling" under arm |
| 08 Cyst | 31 Asymmetry |
| 09 Increased in size/change in size | 32 Dimple on breast |
| 10 Sensitive | 33 "funny feeling" / felt something wasn't right/felt different |
| 11 Shape changed | 34 Soreness in neck area |
| 12 Indented line across breast | 35 Color darkened / discoloration |
| 13 Inverted nipple | 36 Thickening |
| 14 Stiffening in arms | 37 Heaviness of affected area |
| 15 Food cravings (esp starch, sweet) | 38 Growth from nipple |
| 16 Nosebleeds | 39 Inflammation |
| 17 Chest pains | 40 Open sore |
| 18 Pain in rib below breast / above breast | 41 lump in other breast/pain in other breast |
| 19 Edema of breast | 42 Frequent vaginal infections |
| 20 Knot under arm/lymph nodes enlarged | 43 Lots of indigestion |
| 21 Bleeding | 44 Pain in unaffected breast |
| 22 Back/arm pain, papilloma, mass | |
| 23 Discharge from breast/foul smelling | |

D8. Breast condition (not cancer)**CODE UP TO 4 CONDITIONS**

- | | |
|---|--|
| 01 Benign tumor, cyst, fibrocystic disease
(Phyllode's tumor) fibroidadenoma | 23 Density / abnormal density on mammogram |
| 02 Thickening | 24 Inflammation of breast / edema due to
inflammation |
| 03 "Spot", discoloring, skin condition/mole | 25 Inverted nipple |
| 04 Microcalcifications | 26 Papilloma |
| 05 Mastitis | 27 Glandula breast |
| 06 Lump/Growth/tumor NOS | 28 Nodules |
| 07 Clogged milk duct/swollen milk duct | 29 Sensitivity |
| 08 Galactorrhea | 30 "A place they watched" |
| 09 Calcium deposits | 31 Aging condition |
| 10 Breast felt hot | 32 Oil cyst (post traumatic) |
| 11 Inflammation of scar tissue/scar tissue | 33 Boils |
| 12 Discharge/Clear fluid draining | 34 Fluid in breast |
| 13 Enlarged lymph node | 35 Sarcoidosis |
| 14 Scarred tissue | 36 Pocket |
| 15 Growth or knot after injury/Knot, NOS | 37 Blood from nipple |
| 16 Abnormal mammogram finding/spot on
mammogram | 38 Itchy rash |
| 17 Breast abscess/infected tissue | 39 Varicose veins in breast |
| 18 "Cords" in breast | 40 Atypical hyperplasia |
| 19 Breast trauma/injury NOS | 41 Dysplasia/atypical cells |
| 20 Calcified milk duct | 42 Mass of blood / hemotoma |
| 21 Lymph adenoma | 43 Milk gland (3 rd breast) |
| 22 "Fatty" tumor / fatty tissue | 44 |
| | 45 |

D21. Why chest X-rays**CODE UP TO 2 RESPONSES**

- | | |
|---|--|
| 01 Routine preoperative/pre-surgical/hospital admission/operative follow-up | 38 Infection |
| 02 TB screening /+ TB / family had TB | 39 Pulled muscle in chest |
| 03 Diagnosis for sarcoidosis | 40 Cancer screening/diagnosis |
| 04 Anxiety attacks | 41 Cancer follow-up |
| 05 Evaluating chest pain | 42 Chest congestion |
| 06 COPD (Chronic obstructive pulmonary disease) | 43 Arthritis |
| 07 Trauma/accident, examine for broken bones | 44 Embolism/Thrombosis |
| 08 Routine physical / Routine screening | 45 Pleurisy |
| 09 Colds / Flu/ | 46 Fainting spell |
| 10 Asthma / Allergies | 47 Research study |
| 11 Bronchitis | 48 Secondary to Crohn's disease |
| 12 School requirement | 49 Swallowed object |
| 13 Employer requirement | 50 Allergic reaction |
| 14 Pneumonia | 51 Rheumatic fever / Rheumatic heart disease |
| 15 Heart condition / cardiac problems | 52 Unexplained weight loss |
| 16 Lung related condition / spot on lung /collapsed lung | 53 Inflammation |
| 17 Indigestion/ gastritis | 54 Evaluate back pain or problem |
| 18 Evaluating bone pain (in neck, shoulder, back) | 55 CVA (stroke) |
| 19 Pregnancy follow-up | 56 Hodgkins disease |
| 20 Smoked | 57 Leuffler's syndrome |
| 21 Evaluating muscle pain | 58 Sarcoidosis - should be 03 |
| 22 Tiredness | 59 Esophageal reflux |
| 23 High blood pressure | 60 Inflamed cartilage (chondritis) |
| 24 Emphysema | 61 Cyst |
| 25 Diagnostic, NOS | 62 Follow up for Histoplasmosis |
| 26 Evaluate cough / wheezing | 63 Burning breast / Breast condition |
| 27 Travel | 64 Breast Implants |
| 28 Required for adoption/foster care | 65 To donate blood |
| 29 Insurance requirement | 66 Pneumothorax |
| 30 Before having children | 67 Chest mass |
| 31 Aneurysm | 68 Bleeding ulcers |
| 32 Respiratory illness | 69 Polio |
| 33 Difficulty breathing / shortness of breath | 70 Gallbladder problems |
| 34 Scoliosis | 71 Chronic sinus problems |
| 35 Liver problems | 72 Laryngeal spasms |
| 36 Hernia | 73 Seizures |
| 37 Kidney ailments / kidney stones | 74 Lupus |
| | 99 Don't know |

D31a. Diseases treated with radiation

- 99 Don't Know
- 01 Cancer
- 02 Hyperthyroidism
- 03 Acne
- 04 Rheumatic Fever
- 05 Enlarged Thymus
- 06 Spot on Lungs
- 07 Pleurisy
- 08 Tonsillitis/Enlarged Tonsils & Adenoids/Strep Throat
- 09 Hypothyroidism
- 10 Keloids
- 11 Myasthenia Gravis
- 12 Birthmark/mole
- 13 Tuberculosis
- 14 Eczema
- 15 Vaginal rash
- 16 Tumor/growth (not cancer)/lump/keloid
- 17 Hook worm
- 18 Plantar warts/any warts
- 19 Exposed blood vessel
- 20 Pulled ligament
- 21 Chest cold
- 22 Cyst

CODE UP TO 3 DISEASES

- 23 Thyroid problem/NOS
- 24 Goiter
- 25 Blood clot
- 26 Parathyroid adenoma
- 27 Grave's disease
- 28 Kidney ailments (NOS)
- 29 Rash
- 30 Fungus
- 31 Eye infection
- 32 Cardiomyopathy
- 33 Pneumonia
- 34 Rheumatoid Arthritis
- 35 Laryngitis
- 36 Excess uterine bleeding
- 37 Hodgkins disease
- 38 Multiple myeloma
- 39 Allergic reaction to a deodorant
- 40 To rule out TB
- 41 Infertility
- 42 Histoplasmosis
- 43 Uterine blister
- 44 Ear infections
- 45 Granuloma
- 46
- 47

D31b. Body part treated with radiation: See sites of cancer on page 2.

(Note: Codes for hormone use are different from Phase I)

Do not add codes for medications; consult with Susan first.

E11 a. Conjugated estrogens (Premarin goes in this blank ONLY)**Possible doses**

- 01 Premarin 0.9 mg
- 07 Premarin 0.625 mg
- 13 Premarin 2.5 mg
- 19 Premarin 0.3 mg
- 25 Premarin 1.25 mg

E11 c. Estrogens (esterified or otherwise)**DO NOT USE CODES 01, 07, 13, 19, 25. THESE WERE PREVIOUSLY USED FOR PREMARIN**

99 Don't Know	21 Estratab 1.25 mg
02 Ortho-Est 0.625 mg	22 Estratab 2.5 mg
03 DES 1 mg	23 Estratab 0.625 mg
04 Ogen 1.25 mg	24 Estratab 0.3 mg
05 Ogen 0.625 mg	26 Estrovis 100 mcg
06 Ogen .2.5 mg	27 Ogen, NOS dose
08 Ortho-Est 1.25 mg	28 *Estrace, NOS dose
09 Menest 2.5 mg	29 Estratest HS .625mg
10 Menest 0.625 mg	30 Estratest 1.25 mg
11 Menest 0.3 mg	31 Estratest Unknown dose
12 Menest 1.25 mg	32 *Estrace 0.5 mg
14 *Estrace 1 mg (Estradiol 1mg)	33 Estratab NOS dose
15 DES 5 mg	34 DES, NOS dose
16 Estinyl 0.5 mg	35 Tace unknown dose
17 Estinyl 0.02 mg	36 Menest, NOS dose
18 Estinly 0.05 mg	37 Triest 2.5mg
20 *Estrace 2 mg (Estradiol 2mg)	

NOTE: If hormone dose is unknown, write 9999999 (7 9's) in the dose blank.***ESTRACE --> ONLY POSSIBLE DOSES ARE 0.5 mg, 1 mg and 2 mg. ALL OTHER DOSES SHOULD BE CODED AS UNKNOWN (# 28).**

E11 b, f, d, g . Progestins

- 99 Don't Know
- 01 Provera 2.5 mg
- 02 Provera 5 mg
- 03 Provera 10 mg
- 04 Cycrin 2.5 mg
- 05 Cycrin 5 mg
- 06 Cycrin 10 mg
- 07 Medroxy-progesterone 10 mg
- 08 Curretab 10 mg
- 09 Norlutin 5 mg
- 10 Aygestin 5 mg
- 11 Norlutate 5 mg
- 12 Amen 10 mg
- 13 Prempro, unknown dose
(SEE NOTE BELOW FOR CORRECT CODING)
- 14 Provera, unknown dose
- 15 Cycrin, unknown dose
- 16 **Premphase (see below)
- 17 Cycrin, unknown dose
- 18 Prempro. 2.5 mg (DO NOT USE! SEE BELOW)
- 19 Medroxy progesterone, NOS dose
- 20 Medroxy progesterone, 2.5 mg
- 21 Aygestin, 10 mg
- 22 Aygestin, unknown dose
- 23 Aygestin, 2.5 mg
- 24 Novlutate, unknown dose 25.
- 25 Prometruim, 100 mg
- 26 Medroxyprogesterone 5mg

E11 h. Other hormones (Coders define, no need to consult with Susan for this one)

Do not code Bellaspas, hormone injections (except DES), or creams.

- 99 Don't Know
- 01 Halotestin
- 02 Lupron
- 03 Male Hormone (NOS)
- 04 Danazol/Danocrine
- 05 DES injection / DES
- 06 Clomid
- 07 Evista / Raloxifene Unknown dose
- 08 Evista 60 mg
- 09 Testosterone, unknown dose

*** NOTE: Prempro** is a combination: conjugated estrogen (Premarin) + Progesterone.
 When Prempro is listed, both rows **E11. a** and **b** should be filled out.
 E11. a is the estrogen component, E11. b is the progesterone component.
 Age first use, age last use, duration, etc., is the same because Prempro is a single pill.

* Code Prempro as E11.a ---> .625 mg “everyday” for how taken
 E11.b. ---> code 13 2.5 mg “everyday” for how taken

** Code Premphase as E11. a ---> 0.625 mg “everyday” for how taken
 E11. b ---> code 16 5mg “>= 14 days” for how taken

Triest/Prog:

Code similar to Prempro:

Triestrogen 2.5mg in E11c

Progesterone 100mg in El1c

Do not add codes for E13; consult with Susan first

E13. Drug code--antidepressants

** Do not code Alprazolam, Ambien, Ativan, Benzodiazepine, Buspar, Centrax, Clonazepam, Clorazepate, Klonopin, Delmace, Depakot, Diazepam, Librax, Lorazepam, Meprobamate, Risperdal, Temazepam, Tranxene, Valium, Xanax.

999 Unknown name / unknown dose

Amitriptyline

043 100 mg
044 50 mg
045 10 mg
050 25 mg
092 unknown dose
110 150 mg

Anafranil

064 25 mg
065 50 mg
098 unknown dose

Asendin

007 25 mg
019 50 mg
081 unknown dose

Celexa

116 20 mg
121 unknown dose

Desipramine

001 10 mg
002 25 mg
003 50 mg
004 100 mg
005 150 mg
079 unknown dose

Desyrel

023 50 mg
024 150 mg
085 unknown dose
112 100 mg

Doxepin

069 10 mg
070 25 mg
071 50 mg
102 unknown dose
115 75 mg

Effexor

013 25 mg
014 37.5 mg
015 50 mg
016 75 mg
017 100 mg
083 unknown dose
Revised 11/08/2006

Elavil

032 75 mg
033 100 mg
034 150 mg
035 50 mg
036 25 mg
046 10 mg
088 unknown dose

Etrafon

105 unknown dose

Imipramine

049 25 mg
055 10 mg
056 50 mg
096 unknown dose

Lithium

123 300 mg
106 900 mg
108 unknown dose

Ludiomil

025 75 mg
031 25 mg
037 50 mg
087 unknown dose

Luvox

041 100 mg
042 50 mg
091 unknown dose
(doesn't come in 300 mg)

Nardil

038 15 mg
089 unknown dose

Norpramin

020 150 mg
021 25 mg
022 100 mg
026 75 mg
027 50 mg
028 10 mg
084 unknown dose

Nortriptyline

067 10 mg
068 25 mg
104 75 mg
101 unknown dose

Pamelor

061 50 mg
062 10 mg
063 25 mg
097 unknown dose
114 75 mg

Parnate

051 10 mg
095 unknown dose

Paxil (Parocetene)

111 10mg
039 20 mg
040 30 mg
090 unknown dose

Prozac

066 20 mg
072 10 mg
122 40 mg
100 unknown dose

Remeron

117 45 mg
118 30 mg
119 15 mg
120 unknown dose

Serzone

006 250 mg
011 100 mg
012 200 mg
018 150 mg
080 unknown dose

Sinequan

073 10 mg
074 25 mg
075 100 mg
076 75 mg
077 50 mg
078 150 mg
103 unknown dose

Trazodone

008 50 mg
009 100 mg
010 150 mg
082 unknown dose

Triavil

107 4-50
109 unknown dose

Tofranil

047 25 mg
048 10 mg
054 50 mg
057 PM, 150 mg
058 PM, 75 mg
059 PM, 100 mg
060 PM, 125 mg
093 unknown dose

Wellbutrin (no 150 mg -- code as 094)

052 100 mg
053 75 mg
094 unknown dose

Zoloft

124 25 mg
029 50 mg
030 100 mg
086 unknown dose

Zyban

113 150 mg

E15. Drug codes--Prescription pain relievers

**** DO NOT code these medications: Carisoprodol, Cortisone injections, Cyclobenzaprine HCL, Darvocet, Darvon, Dexamethasone, Dicyclomine, Endocet, Flexeril, Hydrocod APAP, Hydrocodone, Lortabs, Midrin, Oxycodone APAP, Parafon Forte, Percocet, Plaquenil, Propacet, Propact, Propoxyphene, Propoxz-n-apap, Roaxin, Roxilox, Skelaxin, Talwin, Tylenol #2, Tylenol #3, Ultram, Veetids, Vicoden.**

999 Unknown name / unknown dose

Arthrotec 088 75 mg	Feldene 037 20 mg 038 10 mg 066 unknown dose	020 600 mg 021 800 mg 022 400 mg 059 unknown dose	052 unknown dose 083 750 mg 087 1000 mg
Anaprox 031 DS, 550 mg, 500 mg 032 275 mg 063 unknown dose	Fiorinal 098 unknown dose	Naprelan 077 500 mg 079 375 mg	Salsalate 076 750 mg
Ansaid 006 50 mg 012 100 mg 053 unknown dose	Fenoprofen 081 600 mg	Naprosyn 008 EC, 375 mg 009 EC, 500 mg 011 500 mg 017 375 mg 055 unknown dose 084 250 mg	Sulindrac 026 200 mg 027 150 mg 061 unknown dose
Cataflam 080 50 mg	Flurbiprofen 089 unknown dose	Naproxen 010 500 mg 016 375 mg 018 250 mg 056 unknown dose 075 550 mg	Tolectin 013 200 mg 019 600 mg 025 DS, 400 mg 057 unknown dose
Celebrex 091 100 mg 092 200mg 094 unknown	Ibuprofen 001 400 mg 002 600 mg 003 800 mg 086 1600 mg 050 unknown dose	Toradol 007 10 mg 054 unknown dose	Vicoprofen 101 7.5/200 mg
Choline Mag T 093 750mg	Indocin 039 SR, 75 mg 040 50 mg 041 25 mg 067 unknown dose	Orudis 043 50 mg 044 75 mg 045 25 mg 069 unknown dose	Vioxx 095 12.5 mg 096 unknown dose 097 25mg
Clinoril 028 200 mg 029 150 mg 062 unknown dose	Indomethacin 042 50 mg 048 25 mg 068 unknown dose 090 75 mg	Oruvail 082 200mg	Voltaren 023 75 mg 024 25 mg 030 50 mg 060 unknown dose 078 100 mg 100 Unknown drug 100mg
DayPro (Oxaprozin) 004 600 mg 051 unknown dose	Lodine 035 400 mg 036 300 mg 073 500 mg 065 unknown dose	Piroxicam 046 10 mg 047 20 mg 070 unknown dose	
Diclofenac 085 75 mg	Ketoprofen 099 unknown dose	Ponstel 049 250 mg 071 unknown dose 072 Monogesic dose	
Diflunisal 014 250 mg 015 500 mg 058 unknown dose	Methocarbamol /ASA 074 unknown dose	Relafen 005 500 mg	
Disalcid 033 750 mg 034 500 mg 064 unknown dose	Motrin		

E13b. Other condition (for antidepressants)**CODE UP TO 2 CONDITIONS**

14 General aches including: muscle pain, breast pain, leg pain, arm pain, sore throat, joint pain, toothache

- | | |
|---------------------------------------|--|
| 02 Ovarian cyst | 29 Phobic d/o |
| 03 To help sleep | 30 Allergies / Hives / Itching |
| 05 Fever | 31 Obsessive-compulsive disorder (OCD) |
| 06 Blood thinner | 32 Migraine headaches |
| 11 Stomach | 33 Dealing with child's death |
| 13 Inflammation | 34 Relaxant |
| 15 Post operatively | 35 PMS |
| 16 Heart disease/head problems | 36 "Tired all the time" |
| 17 Cold symptoms | 37 Kidney stone |
| 18 Pain disorder | 38 Irritable Bowel Syndrome |
| 19 Back pain | 39 Hot flashes / Menopause mood swings |
| 20 Panic disorder | 40 Post injury |
| 21 Fibromyalgia | 41 Restless leg syndrome |
| 22 Appetite suppressant | 42 Eye problem |
| 23 Neuropathy | 43 High blood pressure |
| 24 Chronic fatigue syndrome / fatigue | 44 Multiple Sclerosis |
| 25 Bipolar d/o (manic depression) | 45 PMS |
| 26 Diabetes | 46 Chronic boils |
| 27 Quit smoking | 47 Lupus |
| 28 Shingles | |

E15b, E17 b. Other condition (for general prescription & OTC drugs)**CODE UP TO 2 CONDS**

14 General aches including: muscle pain, breast pain, leg pain, feet pain, knee pain, arm pain, shoulder pain, sore throat, joint pain, toothache, bone pain, endometrium pain, lip pain, neck pain, hip pain, elbow pain, sinus pain, chest pain, ear pain, repetitive motion pain, heelspur, sciatica, broken bone, bone spur, jaw pain, cancer pain, fever aches, pulled muscle, stiffness, rib pain.

- | | |
|--|---|
| 02 Ovarian cyst | 47 Nerve problems |
| 03 To help sleep / rest | 48 Pregnancy |
| 05 Fever | 49 Heartburn, esophageal reflux / nausea |
| 06 Blood thinner | 50 Bronchitis |
| 11 Stomach | 51 Raynaud's disease |
| 13 Inflammation | 52 Respiratory illness |
| 14 General aches | 53 Post polio syndrome |
| 15 Post operatively
(do not use "other" code, has own category) | 54 Migraines |
| 16 Heart disease/heart problems/heart | 55 Connective tissue disorder |
| 17 Cold symptoms/Flu symptoms | 56 Fascitis / condition of plantar fascia |
| 19 Preventive/Good for you | 57 Accident / Injury / Broken bone |
| 20 Fibromyalgia | 58 Chemotherapy |
| 21 Light stroke | 59 Relaxant/tension/stressed out |
| 24 Arthritis/ Tendonitis
(do not code here under "other", has its own category) | 60 Swelling |
| 27 Neuromas | 61 Radiation treatment pain |
| 29 Poor circulation/phlebitis | 62 Lupus/SLE |
| 30 Infection | 63 Heel spurs (should be 14) |
| 31 Muscle spasms/cramps | 64 Diabetes |
| 35 Cyst, NOS | 65 Rheumatic fever |
| 36 Allergy | 66 Pancreatitis |
| 37 Tubal pregnancy / pregnancy pain | 67 Thyroid problem |
| 38 Kidney stones | 68 Sarcoidosis |
| 39 Polymyalgia rheumatica | 69 General tiredness |
| 40 Shingles | 70 Prevent bruises |
| 41 Lung condition (pleurisy) | 71 Blood pressure |
| 42 Birth of child | 72 Spider bite |
| 43 Foot fungus | 73 Restless leg syndrome |
| 44 Hernia, NOS location | 74 PMS |
| 45 Carpal tunnel syndrome | 75 Diverticulitis |
| 46 Stress | 76 Liver problems |
| | 77 |

Do not add codes for E17; consult with Susan first

E17. Drug codes--nonprescription pain relievers

**** Note: Do not code Percegesic**

01 Actron	16 Motrin
02 Advil	17 Nuprin
03 Aleve (Naproxen)	18 Orudis
04 Anacin	19 Tylenol, Regular (325 mg)
05 Ascriptin	20 Tylenol, Extra Strength (500 mg)
06 Aspirin, generic (ASA)	21 Vanquish
07 Bayer aspirin	22 Baby Aspirin
08 BC powder	23 Tylenol PM
09 Bufferin	24 Extra strength Bufferin/Arthritis strength Bufferin
10 Doan's pills	25 Excedrin, Extra
11 Ecotrin	26 Acetaminophen
12 Excedrin, Regular	27 Tylenol Extended relief (650 mg)
13 Goody's	28
14 Ibuprofen, Regular	99 Unknown
15 Ibuprofen, Extra Strength	

F6. Type of physical activity

CODE UP TO 3 ACTIVITIES

99 Don't Know	16 Physical Therapy
01 Walking / treadmill	17 Water aerobics
02 Aerobics, exercise class, work out on exercise equipment, Gym.	18 Weight lifting
03 Bicycling	19 Busy lifestyle
04 Gardening, yard work	20 Rollerblades/skates
05 Stair climbing	21 Hiking
06 Golf	22 Play catch
07 Tennis / racquetball	23 Child care
08 Other games/sports	24 Martial arts
09 Work around the home	25 Yoga
10 Running/jogging	26 Bowling
11 Swimming	27 Jumps rope
12 Dancing	28 Cardio-workout, NOS
13 Horseback riding/grooming	29 Resistance training / strengthening exercises
14 Geriatric exercise	30 Cleaning homes for work
15 Stretching and Toning exercises/ Floor exercises	31 Training dogs
	32 Waitressing / walking a lot for work.

F13a. If 'OR' is written down, use the following hierarchy and keep one response only

1. drumsticks;
2. wings;
3. breasts.

G2, G3. These are TEXT ONLY (no codes needed), up to **60 characters**.

Shorten or edit as necessary to fit 60 characters or less.

Only **ONE career** should be listed, and up to **THREE businesses/industries (G4)** for the ONE career.

H2. Other stressful events**CODE UP TO 3 EVENTS**

Codes A-T correspond to events listed in questions H1a-t on pages 40-42 of survey.

Health (Participant)

- 01 Breast cancer/ breast condition/mastectomy
- 17 Operation / surgery (including dental), dental work/ for breast cancer
- 23 Depression / mental problems / being lonely / nervous breakdown/ nerves
- 25 Participant diagnosis of cancer (not breast cancer) / benign growth other than cancer
- 37 Cancer scare
- 39 Chronic health conditions – participants (e.g. arthritis, hypertension , shingles, other cancer)
- 40 Acute health conditions – participants (e.g. heart attack, broken bone, stroke) / Accident NOS
- 41 Miscarriage / abortion
- 43 Hospitalization
- 44 Participant in drug/alcohol rehab/alcoholism
- 87 Trying to quit smoking
- 96 Attempted suicide
- AI Biopsy
- AV Infertility
- AX Radiation therapy
- H Got married**
- I Had a divorce or break-up with a spouse or partner**
- K Had a baby or adopt a child**

Health (Family)

- 04 Family member with psychological problems/senile
- 10 Family members on drugs/alcohol
- 11 Children w/breast disease; sister / granddaughter
- 12 Daughter w/high risk pregnancy or miscarriage / daughter pregnancy / abortion, NOS / family member premature baby
- 13 Family member in major accident/trauma
- 14 Chronic health condition – family member/disabilities
- 15 Acute health condition – family member
- A Spouse or partner had a serious illness**
- B Spouse or partnet died**
- C Children, parents or siblings had a serious illness**
- D Either of the parents died**
- E Any children died**
- F Close family members or friends died or had a serious illness**

Husband/Spouse/Signif. Other

- 26 Dealing/communicating w/partner or ex-partner/his family
- 45 Husband in military went to war
- 46 Broken engagement / marriage problems / break-up / infidelity / husband became impotent / husband remarried
- 47 Spouse ran for public office
- 48 Spouse infidelity
- 49 Spouse's ex-wife
- 50 Moving in with partner
- 51 Long distance marriage
- AF (was 105) Problem with ex-husband / father of children
- N Spouse/partner lost job or retired**
- O Spouse/partner threatened with a lay-off**

Other Family Issues

- 02 Problem with grandchild/family problems NOS/ Taking care of elders / illness / nursing home
- 07 Family stress due to illness, step children
- 21 Relative / child in prison
- 22 Child(ren) with bad crowd / raising children or teenagers / raising grandchildren / children moved back home / children left home / went into military / empty nest syndrome
- 27 Mourning for a family member or members / death of grandchildren
- 29 Family member as victim of crime or abuse
- 30 Loss of child or grandchild due to divorce / children's response to divorce / loss of visiting rights
- 31 Interaction w/biological family / reunion w/children given up for adoption
- 32 Parent admitted to nursing home / retirement community
- 33 Children having problems in school / getting job / entering college / NOS / in high school / starting kindergarten
- 63 Family member moving in or out / family member moving/ arrested, on trail
- 64 Family legal/custody problems/estate issues
- 65 Worry about children / family
- 66 Child's wedding /marriage/remarriage in family
- 71 Family member marriage problems
- 73 Son with baby out-of-wedlock / daughter got pregnant while in school
- 74 Problems with son-in-law or daughter-in-law
- 75 Family member changed job / loss of job
- 76 Being a single parent / being head of household
- 77 Problem with mother-in-law or father-in-law
- 78 Child with mental or physical disability
- AB (was 101) Loss of support from family/loss of control
- AG (was 106) Tension with family member
- AL (was 111) Foster parenting issues
- AM (was 112) Long distance family relationships
- AS Son tried to commit suicide
- AT Two sons decided to convert to Islam / change of faith
- AU Son's financial problems
- AW Daughter's problems
- AY Son missing
- AZ Not knowing dad but suspecting who he was
- BA Parents' financial problems
- J Family member of friend had a divorce or break-up**
- L Any of the children had a baby or adopt a child**
- M Major conflict with children or grandchildren**
- P Close family members or friends lost their job or retired**
- Q A Cherished pet died**
- S Physically abused or threatened with a weapon by family member or friend**
- T Verbally abused or threatened with harm by a family member or friend**

Friends/Neighbors

- 18 Abusive neighbor / living in bad neighborhood
- 19 Issues w/friends / helping friends / maintaining friendships
- 20 Disturbing neighbor / neighbor's dog
- AA (was 100) Dealing/communicating with friend

Job

- 03 Stress on the job, new job, job transfer, quit job, going back to work, finding a job, presentation for job/ salary change
- 52 Spouse's job
- 53 Selling family business / business failure / business finance / business expansion / starting new business
- 83 Contemplating retirement
- 92 Harassment at workplace / personnel conflict

Money/Finance

- 08 Filed bankruptcy
- 14 Couldn't go on vacation (due to finances)
- AN (was 113) Husband bought car / major purchase
- BB Preparing income taxes
- G Had major problem with money**

Home

- 09 Moving related events / relocation / selling home / buying home / building home / losing home / remodeling home / homeless / bad deal on home

Church

- 72 Lost her church / lost position at church
- AC (was 102) Dealing with church-related events, discord

Daily Living / Other

- 06 Witnessed violent acts
- 24 Legal action (sued or being sued)
- 36 Pet's health / adopted a pet / pet NOS
- 38 Daily living / juggling roles as wife, mother, job, busy lifestyle/ lifestyle changes
- 42 Problem w/car / losing a car / very long commute in car / driving/ transportation
- 61 School stress / going back to college / grad school
- 62 Going to prison
- 82 Holidays
- 88 Decision making alone (spouse died) , living alone
- 89 Learning to ride a motorcycle
- 91 Immigration to U.S.
- 97 Writing a book
- 99 Don't know
- AD (was 103) Continued mourning after death >5 years ago
- AE (was 104) Anticipating doing this interview
- AH (was 107) Taking bar exam / PhD
- AK (was 110) Concern with invasion of privacy, being stalked
- AO Fight
- AP Falsely accused of something
- AQ Conflict with landlord
- AR Living out in the country/ farm
- R Experience any major accidents, disasters, robberies, or similar events**

ADD CODES HERE:

- BE Coordinating a fundraising event
- BF Dispute over family land
- BG Memories of verbal/physical abuse
- BH Went into military reserve
- BI Taking an airline flight
- BJ trying to qualify for disability
- BK can't read adequately

I2. Other Racial/Ethnic Groups**CODE ONE RESPONSE**

- 99 Don't Know
- 01 African-American (**deleted**)
- 02 Multi-racial
- 03 Spanish/Hispanic
- 04 Italian (**deleted**)
- 05 Indian (**deleted**)
- 06 Asian/ Pacific Islander (**This is already coded in I2 as choice #4**)

I7, I8, I9 Other Occupational Categories**CODE ONE RESPONSE EACH**

(Refer to the 1990 Occupational Classification System enclosed in the binder)

- 99 Don't Know
- 01 Marriage lasted only a short while
- 02 Self-employed
- 03 Military
- 04 Professional Athlete
- 05 Government worker
- 06 Tour guide – **should be #2 (service worker or laborer)**
- 07 Food service – **should be #2 (service worker or laborer)**
- 08 Medical assistant – **should be #2 (service worker or laborer)**
- 09 Clergy, minister – **should be #5 (professional, etc.)**
- 10 Meat plant worker – **should be #2 (service worker or laborer)**
- 11 Student
- 12 Military chef
- 13 Trophy maker / Engraver – **should be #3 (craftsworker, etc.)**
- 14 Farm worker and clerical worker
- 15 Interior designer – **should be #5 (professional, etc.)**
- 16 On disability
- 17 Farmworker and service worker/ laborer (should be #1 for I8)
- 18 Housewife

J0a. Type of Surgery**CODE ONE RESPONSE**

- 01 Intraductal mastectomy
- 02 Partial mastectomy
- 03 Bilateral mastectomy
- 04 Mastectomy - prophylactic (Both or one breast)
- 05 Lymph nodes removed with biopsy
- 06 Quadectomy
- 07 Modified radical mastectomy (this should be answer #2 (mastectomy))
- 08 Excisional Biopsy
- 08 Reconstruction
- 09 Bilateral lumpectomy

J2. Causes of breast cancer (3-digit code)**CODE UP TO 5 CAUSES**

- | | |
|---|---|
| 001 Hormone exposure (OC's, HRT) | 049 Occupation |
| 002 Not having children/late child birth | 050 Prosthesis (Breast) / augmentation |
| 003 Abortion | 051 Computers |
| 004 Genes/heredity/predisposition/family history | 052 Viruses that stay in the body/ bacteria in the body |
| 005 Foods we eat, preservatives/chemicals/hormones in food, diet, fatty foods | 053 The way you treat people |
| 006 Something in water/ water quality / chlorine in water | 054 Clogged milk ducts |
| 007 Tobacco (smoke, additives in cigarettes) | 055 Pets |
| 008 Pesticides/ chemical use | 056 Bee stings |
| 009 Radiation/Magnetic fields | 057 (Sorry) men |
| 010 Trauma to breast | 058 Sorrow/Depression/ hopelessness/ emotions / hiding emotions/ tragedy/ fear |
| 011 Stress | 059 Destiny/ chance |
| 012 Environment/chemicals in the environment/ pollution | 060 Hormonal imbalance/ "it's hormonal" |
| 013 Asbestos | 061 Physical stress/heavy lifting /straining |
| 014 Medications | 062 Physical abuse (being beaten) |
| 015 Alcohol | 063 Mother took DES / took DES herself |
| 016 Obesity | 064 Alterations in DNA / Mutations |
| 017 Fair skin | 065 Having babies at young age |
| 018 Body Type | 066 Early menopause |
| 019 Benign breast disease/ fibrocystic breasts/ cysts | 067 Breast cancer as outcome from 1 ^o disease |
| 020 Lack of exercise (or exercise related) | 068 Too many hormone being produced |
| 021 Exposure to other cancer patients | 069 Hard work/ job stress |
| 022 Problem in protein metabolism/Chemical imbalance | 070 Not breastfeeding/ medication to stop milk production/ no milk production / long time before milk stopped |
| 023 Immune system deficiency | 071 Deodorant w/ talcum/ deodorant |
| 024 The devil/un-godlike actions | 072 Cancer is contagious |
| 025 Something in blood/ blood type | 073 Exposure to lead base paint |
| 026 Breastfeeding | 074 Caffeine |
| 027 Electrocardiogram | 075 Chemical/ drugs/PCP/marijuana |
| 028 Menopause / lack of estrogen | 076 Fertility drugs |
| 029 "A cell went crazy"/ wild cell/ abnormal cell growth | 077 Air we breathe |
| 030 Early Menstruation | 078 Injury/ bruising to breast |
| 031 Personality / Type A personality / psychology of the person | 079 Anger |
| 032 Lifestyle | 080 Long menstrual periods / menstrual periods NOS |
| 033 No self-examinations, physicals or other screening | 081 Artificial implant |
| 034 Sun exposure | 082 Not going to doctor / no yearly check-ups |
| 035 Vitamin Deficiency | 083 Secondhand smoke |
| 036 Promiscuity/Sexual Practices | 084 No real reason women get breast cancer/ bad luck |
| 037 Wearing bras / Padded bras / constrictive bras | 085 Imbalance in the body |
| 038 Electrolysis for facial hair | 086 Clothes |
| 039 Related to other cancers | 087 Physical complications |
| 040 Hysterectomy | 088 Thyroid related conditions |
| 041 Fluctuations in Weight | 089 Lack of education |
| 042 Poor health habits | 090 Cosmetics/ lotions / hairspray |
| 043 Mammograms | 091 Poor rest, insomnia |
| 044 Egg donor program | 092 Predisposition/ susceptibility |
| 045 X-rays | 093 Malfunction in the body a long time ago |
| 046 Size of breast | 094 Damage done from abscess |
| 047 Pregnancy related | 095 Overall, not taking care of your body / overall the way you live |
| 048 Age | 096 Cells attack each other |
| | 097 Stored resentment - problems not cleared within self |

J2. Causes of breast cancer (3-digit code)

098 Calcium deposits
 099 Religious/ spiritual reference
 100 "Bumps"/ lumps
 101 Chemical exposure from working/ living on a farm
 102 Inhaling household cleaning sprays
 103 Sexual stimulation
 104 Meat consumption
 105 An accumulation of breast conditions, in mastitis
 106 "Something that's allowed to happen to us"
 107 Cysts (should be 019)
 108 "Matter of who has cell", related to cell function/ mutations of cells/ cell division mutation
 109 Born with it, but not heredity
 110 Environmental estrogens
 111 Carried a (heavy) handbag
 112 Sleeping on stomach
 113 Dust on plants
 114 Case did not think she was "a candidate for cancer"
 115 Diet pills
 116 Farming tobacco
 117 Cooking with aluminum pots
 118 Bad health care
 119 Working in an old building/building materials
 120 Electric and gas stoves
 121 Living in an area where cancer is prevalent

122 Amount of personal power over environment
 123 What you think / attitudes
 124 Miscarriages
 125 Lack of support to breast / not wearing bra
 126 Coke / Soda
 127 Psoriasis
 128 Seat belts
 129 Exposure to carcinogens / toxins/ chemicals/dyes
 130 Microwaves
 131 Exposure to fluoroscopy
 132 Anxiety
 133 Multifactorial
 134 Things in the soil
 135 Causes are unknown
 136 Family history (**should be 004**)
 137 Pneumonia /respiratory illness
 138 Not getting medication to dry up milk after childbirth
 139 Condoms
 140 White sugar is a carcinogen
 141 Cotton dust at workplace
 142 Proximity to military bases
 143 Shingles
 144 Lack of love
 145 Taking megavitamins
 146 Not keeping breast
 147 Abuse of breast
 148
 149
 150

CODE UP TO 5 CAUSES

J3. Comments (3-digit code)**CODE UP TO 3 COMMENTS**

- 001 Cancer clusters, Increase in cancer needs to be investigated
- 002 Questions too personal
- 003 Questions were reasonable
- 004 Some questions' relevance to breast cancer is unclear
- 005 Would like to help out in search for causes of breast cancer/ Glad to see this research being done / Any information is valuable
- 006 Worried about hormone use
- 007 Concern about detection or treatment of cancer/ unnecessary surgery
- 008 Concerns about food/water/ meat consumption / alcohol consumption
- 009 Wondered about other medical conditions' relationship to breast cancer
- 010 Wondered about other chemical exposures/ environmental exposure/ preservatives in food
- 011 Concern about family history
- 012 Concern about stress
- 013 Concern about breast trauma
- 014 Concern about medication use
- 015 Concern about breast implants/ No questions about breast implants
- 016 Concern about lactation/ passing down breast cancer susceptibility via breast feeding / milk not drying up for 1 year post-pregnancy
- 017 Wanted more money
- 018 Never thought at high risk / No history
- 019 Concern about caffeine, coffee consumption
- 020 Has recently begun exercising, exercise helps
- 021 Wondered about associations with sexual activity
- 022 Concerned about marijuana use
- 023 Concerned about physical abuse from parent and husband
- 024 Where she lived is more relevant than type of community, worried about where she lived
- 025 Concerned about cancer in pets
- 026 Concern about computer exposure
- 027 Concern about X-rays
- 028 Concern about work history / Chemical exposure at work
- 029 Wondered about next generation's risk
- 030 Having biopsy soon
- 031 Some questions need refinement
- 032 Concern about smoking
- 033 Wondered how QOL affects breast cancer
- 034 Interested in knowing results
- 035 Both adoptive parents had cancer (adoptive mom-breast) / Neighbors she lived with now have cancer – 1 breast and 1 unknown
- 036 Southern women not assessed, examined well
- 037 Thought she might have cancer, but chose to shut it out, ignore it
- 038 Not enough concern about women's health problems by male doctors/ intimidated by doctor/ doctors didn't listen / Doctor not thorough
- 039 Participant notes she is Jewish/ Greek
- 040 Thought her doctors were kind, considerate / care has been excellent / UNC has a super breast clinic
- 041 Concern about physical activity / swimming
- 042 Participant wished she knew more about survey beforehand, so she could have prepared
- 043 Wondered about drug use
- 044 Survey was thorough/ covered everything
- 045 No questions about social activities/organization that a person is involved in
- 046 No asbestos questions, concerned about occupation exposure
- 047 Concerned about foods prepared in microwave
- 048 Distant relatives had cancer / Family history of breast cancer
- 049 Question role of lifestyle in causing cancer and whether someone at age 50 could change
- 050 Has asthma

J3. Comments (3-digit code)**CODE UP TO 3 COMMENTS**

- 051 Frustrated about figuring out amounts & frequencies / questions about amounts are vague
- 052 Medical system not honest with her
- 053 Thought religion/faith is relevant
- 054 More questions about exposure to radiation
- 055 More questions on surgery and treatment and side effects of surgery or treatment
- 056 Difficult to recall 5 years ago / difficult to remember accurately
- 057 Had tubes tied early in life
- 058 Losing hair is the most stressful event (treatment is stressful)
- 059 Didn't ask about other cancers in family/ volunteered more info on family history of cancer / should ask about other types of cancer
- 060 More questions regarding current health status and current diet
- 061 Concern about fat consumption
- 062 Occupation concern, (poor ventilation), NOS
- 063 Past diagnosis of anorexia & amenorrhea
- 064 Enjoy time with interviewer/ glad she could help/ nice interview/ very interesting/ positive questionnaire and interview / very informative / very professional
- 065 Thyroid questions were good and relevant to her
- 066 Migraines & fibromyalgia caused stress and may play a role in breast cancer
- 067 More questions on family history (Great Aunts had mastectomy), more genetic inquiry
- 068 More questions regarding sexual history
- 069 Interested in pathogenesis of breast cancer - how breast cancer metastasizes
- 070 Interested in herbal therapies, other alternative treatment for breast cancer
- 071 Concerned with the reliability/ accuracy of her responses to diet questions / alcohol use
- 072 Why most women don't get breast cancer on the left side? / Would like to know how many women get breast cancer on left side vs. right side
- 073 I have lots of friends with cancer
- 074 I always knew I would get breast cancer
- 075 More medical history questions needed
- 076 Doctor should have provided her with more options
- 077 Had cervical dysplasia/ positive pap, other vaginal symptoms
- 078 Concern about confidentiality
- 079 Has anemia
- 080 Concern about radium exposure
- 081 More money should be spent in research
- 082 Concern about breast pain
- 083 More questions about family related stressors/ more comprehensive assessment of stress
- 084 Thought questionnaire was thorough (this is the same as 044)
- 085 The life events section was important
- 086 Concern about gender roles (i.e. women as breadwinner)
- 087 Drastic weight fluctuations in last 5 years / concern about diet pills
- 088 Wondered how this study will help/ very harmless/ hope it helps someone
- 089 Concern about mix-up of lab samples
- 090 States trying to live a healthy life
- 091 Participant very suspicious
- 092 Questions about African-American women
- 093 Relaxation and recreation is important
- 094 Thought stress questions should have focused on 1 year prior to diagnosis/ 5 years prior
- 095 Need to keep a positive outlook
- 096 Surprised we didn't inquire about water system
- 097 Found out certain food/drink increases estrogen levels
- 098 Arm was injured during breast cancer surgery
- 099 Surprised to get letter
- 100 Disappointed that there won't be any follow-up / Follow-up would be good
- 101 Believes in early detection and getting mammograms

J3. Comments (3-digit code)**CODE UP TO 3 COMMENTS**

- 102 Wishes there soon would be a cure for all cancers
- 103 If anything is found I want to know (wants results) (should be 034)
- 104 Mother was also interviewed (as a case)
- 105 Insurance is dealing with medical bills
- 106 Support helps recovery/ more questions on support
- 107 Feels that inverted nipple is a breast cancer risk factor
- 108 Feels that poor self image (i.e. mind/ body/ spirit) related to cancer
- 109 Feels that sexual practices and sexual identity have an impact on cancer (this should be 021)
- 110 Concern that women today get more illnesses than they did years ago
- 111 Wonders if large breasted women have increased risk
- 112 Something to do with breast development (thelarche)
- 113 Participated in RCT, may have received placebo
- 114 Concerned about menstrual characteristics (i.e. cycle irregularity) / need more questions on menstrual history/ female problems
- 115 Concerned about radiation exposure, worked in a lab
- 116 Concern about 2nd hand smoke exposures
- 117 More questions about specific exercises
- 118 Wondered why questions only 5 years back/ Questions from earlier years are important
- 119 Wondered about other dietary factors
- 120 EMF exposure
- 121 First diagnosis was CIS, but she had breast cancer, NOS
- 122 Concerned with poor dental health
- 123 Concern about bras (can't get one to fit)
- 124 Participant notes that she is confused
- 125 No questions about being breast fed as an infant
- 126 Notes that father was devoted cancer researcher
- 127 Notes family history of alcoholism
- 128 All women with breast cancer should get MRI or CS / screening
- 129 Adopted, concerned about family history
- 130 Concerned about estrogen use (this should be 006)
- 131 Illness has helped participant become more focused
- 132 Emotional aspect was not addressed
- 133 Happy that questions were not too probing
- 134 Lost first kidney in 1969, secondary complications of pregnancy
- 135 Mammogram experiences/ Concerned about accuracy of mammograms / Should do ultrasound also
- 136 More questions about medications, vitamins and herbs that women take
- 137 Wondered about correlation between dominant side and where breast cancer develops
- 138 Ask if people are lesbian--does partner question include same sex?
- 139 Thought questions were relevant
- 140 No chemo treatment questions
- 141 Biggest fear is getting breast cancer
- 142 Lived on Long Island
- 143 Questions were difficult to answer
- 144 Lived in Germany
- 145 It was a shock (to get Breast cancer)
- 146 Has felt twinges in affected breast for years
- 147 Questions on birth control pills should be asked differently
- 148 Mother took DES during pregnancy / Participant exposed to DES
- 149 No questions about blood pressure
- 150 Damaged chest and sternum in a car accident
- 151 Questions about diet should be less specific
- 152 Developed irregular heart beat after first chemo treatment
- 153 Developed vaginal bleeding after taking tamoxifen for two days
- 154 Thinks women should get on with their lives after mastectomy / don't let it get you down

J3. Comments (3-digit code)**CODE UP TO 3 COMMENTS**

- 155 Fumes from tobacco companies were bad where she grew up in Richmond, VA
- 156 Surprised did not ask about parents' health / both had TB
- 157 Questions should be more general
- 158 Rural vs. Urban should be studied
- 159 Father was exposed to chemicals after she was conceived
- 160 Need more physical therapy following mastectomy / Need longer hospital stay after mastectomy
- 161 Doctors should be more inclined to do biopsies rather than waiting to repeat various tests
- 162 Mom's family is from NC
- 163 Diagnosed with Lupus / SLE
- 164 Used to stay in fog a lot as a child
- 165 Interested to know where my breast cancer came from / what caused it/ suspicious of certain things
- 166 Concerned about common factors between self and mother (mom has breast cancer)
- 167 No questions on electric blankets
- 168 More questions on environment
- 169 More questions about culture
- 170 Has lots of diabetes in her family
- 171 Concerned about sleeping on the side of waterbed with heating element
- 172 Doesn't believe that her cigarette smoking caused her breast cancer
- 173 Expected questions about previous surgeries
- 174 If I had it again, would have lumpectomy
- 175 Surprised didn't ask about any prescription meds. taken routinely vs. specific meds.
- 176 Wondered if chemo had anything to do with developing diabetes
- 177 Would like to have been instructed on more exercises following surgery
- 178 I think my immune system is affected by my lack of sleep
- 179 I spent a lot of time in depression
- 180 Sprayed dye on silk flowers in an enclosed area for 8 years
- 181 Concerned about deodorants causing breast cancer
- 182 Age categories for alcohol should be narrower / 10 years or less than 25, 25-49, 50+
- 183 Wonders how studies are designed and how they work/ why she was chosen
- 184 Feels women should be more informed about BC, can't always feel lumps
- 185 Thought if I ever got cancer it would be colon cancer
- 186 Thinks having lots of uterine fibroids causes breast cancer
- 187 Need more questions on farms and pesticides (living adjacent to a farm, specific crops) and household use of insecticides
- 188 It would be nice if you too referrals for participants
- 189 At age 13 had rheumatic fever and was in bed for year
- 190 Would like a study on effects of chemo on decreased sex life.
- 191 Exposed to bad and toxic chemicals for 12 years.
- 192 Should ask about alternative treatments received (eg. Hypothermia treatment)

K1. Where was the Interview**CODE ONE RESPONSE**

01 Lineberger/CBCS	29 Restaurant
02 Raleigh Internal Medicine	30 Doctor's office
03 Alamance Hospital	31 Morehead City hospital
04 Rex Radiation Oncology/Rex Cancer Center/hospital	32 Bank
05 Heritage Hospital in Tarboro	33 Rex medical library
06 Workplace (use 41)	34 Greenville Pitt Memorial Hospital
07 VA Hospital	35 Hospital
08 Wayne Memorial Hospital	36 Library
09 Pinehurst Clinic	37 Interviewer's home
10 Bertie Memorial	38 Church
11 UNC Oncology Clinic /Gravelly	39 Store
12 Rest Home	40 Hanes Hall at Duke
13 Nash General Hospital	41 Participant's office/workplace
14 Adult Day Care Center / Children's day care center	42 Clinic NOS / Cancer center NOS
15 Health Dept.	43 Assisted living setting
16 Hotel Room	44 DUMC / Lennox Baker
17 Lenoir Community Hospital	45 Laundromat
18 Hotel Lobby	46 Phone Interview
19 ECU/Leo Jenkins Cancer Center	47 In a car
20 Duke Cancer Control Center, Erwin Sq.	48 Funeral home
21 Women's Prison	49 Dialysis center
22 Half-way house (post prison)	50 UNC hospital
23 Duke Oncology Clinic/ Duke hospital	51 Boyce - Willis clinic
24 Daughter's home / family member's home	52 Conference room / hospital conference room
25 Beaufort Hospital	53 Employment security office
26 Central Carolina Cancer Center	54 Rad/Onc craven hospital
27 Neighbor's House / friend's house	55 Museum of Art
28 Moore Regional Hospital	56
	99 unknown

K3. Respondent's cooperation**CODE ONE RESPONSE**

- 01 Belligerent/ hostile
- 02 Respondent ill -- answers given by spouse
- 03 Respondent ill/had a stroke - answers given by daughter
- 04 Refused to answer several questions
- 05

K4. Quality of Responses**CODE ONE RESPONSE**

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

K5. The Respondent:**CODE UP TO 3 RESPONSES**

- 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/ mother / family member
- 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
- 22 Kept changing her answers
- 23 Participant very suspicious/ angry
- 24 Confused about questions
- 25 Did not understand English well, husband helped, someone helped with language
- 26 S/P stroke (CVA)
- 27 Seemed sleepy/ falling asleep
- 28 Nervous/ anxious
- 29 Very vague re: children / not specific
- 30 Talked a lot
- 31 Stopped school in elementary grades, low schooling
- 32

K6. Reasons for unsatisfactory information**CODE UP TO 3 RESPONSES**

- 01 Poor memory in general, just couldn't remember
- 02 Just couldn't remember certain information / dates
- 03 Difficulty remembering events from long ago
- 04 Had a history of a stroke/ speech affected/ memory affected
- 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
- 16 Participant was paranoid, but answers seemed reliable
- 17 Didn't like probing, got angry
- 18 Participant can not read
- 19 Participant relied on information from relatives (via phone calls)
- 20 Vague answers
- 21 Participant was suspicious
- 22 Blind
- 23 Family members frustrated
- 24 Seemed to want to "please" interviewer
- 25 Participant said she had Alzheimer's
- 26 Said these were tricky questions
- 28 Said she has bipolar disorder
- 29 Seemed to feel bad
- 30 Was walking during interview
- 31 Seemed depressed
- 32 Wanted to critique questionnaire
- 33 Very talkative
- 34 Was in a hurry

AN6B:**CODE ONE RESPONSE**

- 01 Over pantyhose
- 02 Over clothes/pants
- 03 Tape measure held in place
- 04 Patient unable to stand/in wheel chair, or due to other physical problem
- 05 Height and weight done at clinic visit with clinic nurse
- 06 Girdle on
- 07 Participant refused (weight)
- 08 Shoes on / Flip flops 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/had prostheses
- 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
- 23 Over thin robe
- 24 Hip measurement taken over abdominal bandage from surgery
- 25 Best estimate, tape too short / used two tapes
- 26 Participant refused waist/hip measurement
- 27 Participant had protruding hernia
- 28 Participant refused waist/hip measurement and weight
- 29 Participant had prostheses, measurements still taken
- 30 Weighed on scale at job
- 31 Weight done at dialysis center on center scales / Used MD's scale / Weight taken on scale other than CBCS's
- 32 Information obtained over phone
- 33 Weight higher than scale could measure
- 34 Nurse's scale incorrect
- 35
- 36
- 37
- 99 Not specified