

**Carolina Breast Cancer Study
Questionnaire Coding
(Phase 3)**

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 (in alphabetical order):

01 U.S.	57 Guatemala	81 Romania
52 Brazil	29 Guyana	30 Scotland
40 Argentina	76 Haiti	78 Somalia
80 Australia	23 Holland	51 South Africa
35 Austria	41 Hungary	24 South Korea
73 Barbados	11 India	05 Soviet Union / Russia
64 Belgium	61 Indonesia	13 Sri Lanka
06 Bermuda	42 Iran	79 Sudan
70 Bosnia	36 Ireland	15 Switzerland
52 Brazil	75 Israel	62 Sweden
02 Canada	32 Italy	10 Taiwan
43 Central America/ Panama Canal zone	27 Jamaica	63 Trinidad and Tobago
69 Chile	19 Japan	07 Turkey
37 China	77 Kenya	53 Ukraine
25 Colombia	71 Laos	[31] United Kingdom – DO NOT USE, CODE AS 08 Great Britain)
34 Croatia	56 Lebanon	49 Uzbekistan
22 Cuba	65 Liberia	46 Virgin Islands (Both UK and US)
33 Czech Republic	67 Liechtenstein	44 Venezuela
72 Democratic Republic of Congo	60 Lithuania	84 Vietnam
48 Ecuador	03 Mexico	14 West Africa
74 El Salvador	82 Moldova	16 West Indies
39 Egypt	59 Morocco	09 Yugoslavia
21 Ethiopia	18 New Zealand	54 Zimbabwe
28 European Countries, NOS	47 Nigeria	
20 France	38 North Korea	
04 Germany	12 Norway	
58 Ghana	45 Pakistan	
08 Great Britain	66 Panama	
68 Greece	83 Paraguay	
50 Guam	55 Peru	
	26 Philippines	
	17 Poland	
		99 Unknown

B4, B7, B9, D3, D34 (Body Part only). 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
210 Anal cancer	269 Gastrointestinal Tract	140 Pharynx
181 Appendix	763 Groin/Pelvis, NOS	384 Pleura (NOS)/Most mesothelioma
761 Axilla	039 Gum	619 Prostate
767 Back/Torso	764 Arm/Hand	633 Rhabdomyosarcoma (soft tissue)
814 Basal Cell	380 Heart	003 Sarcoma, NOS
240 Biliary Duct	760 Head/Face	764 Shoulder
679 Bladder	965 Hodgkin's disease (Hodgkin's Lymphoma)	319 Sinus
419 Bone	446 Kaposi's Sarcoma	449 Skin (Non-melanoma, Squamous Cell, or NOS)
421 Bone marrow	649 Kidney	849 Skin (Melanoma)
260 Bowel	765 Knee	179 Small Intestine
719 Brain	329 Larynx/Throat	422 Spleen
509 Breast (incl. invasive & CIS)	429 Leg connective tissue	720 Spinal Cord
209 Carcinoid (Carcinoid Syndrome)	420 Leukemia (Blood)	412 Spine
539 Cervix	009 Lip	807 Squamous cell, NOS
761 Chest	220 Liver	169 Stomach
189 Colon/Rectum	349 Lung	629 Testis
442 Ear	778 Lymphosarcoma	Throat—see larynx
759 Endocrine Gland (pituitary)	779 Lymphoma (Lymph Node)	379 Thymus
559 Endometrium/Uterus	410 Maxilla/Jaw	739 Thyroid
321 Epiglottis	069 Mouth/Oral	029 Tongue
159 Esophagus	421 Myeloma	099 Tonsil/Adenoid
400 Ewing's Sarcoma	950 Neuroblastoma	689 Urinary System
699 Eye	760 Neck/Nose	Uterus—see endometrium
441 Eyelid	569 Ovary	320 Vocal Cords
492 Fatty tissue - hip		519 Vulva/Vagina
519 Female Genitalia (external)		809 Unknown primary site per doctor e.g. AIDS related cancer

B10, B11. Other relatives**CODE UP TO 3 RESPONSES**

DO NOT include male relatives in the "other relatives" question.

- | | |
|--|---|
| 99 Don't Know | 15 Great Grandmother (related on both sides) |
| 01 Cousin (first) (Maternal) | 16 Great Grandmother (unknown) |
| 02 Cousin (first) (Paternal) | 17 Other (Maternal) |
| 03 Cousin (first) (related on both sides) | 18 Other (Paternal) |
| 04 Cousin (first) (unknown) | 19 Other (related on both sides) |
| [05] Niece (Maternal) not used in Phase 3 | 20 Other (unknown) |
| [06] Niece (Paternal) not used in Phase 3 | 21 Multiple (Maternal) |
| [07] Nieces (Both) not used in Phase 3 | 22 Multiple (Paternal) |
| [08] Niece (unknown) not used in Phase 3 | 23 Multiple (related on both sides) |
| 09 Great Aunt (Maternal) | 24 Multiple (unknown) |
| 10 Great Aunt (Paternal) | [25] Uncle (Paternal) not used in Phase 3 |
| 11 Great Aunt (related on both sides) | [26] Great Uncle (Paternal) not used in Phase 3 |
| 12 Great Aunt (unknown) | [27] Cousin – not used in Phase 3 |
| 13 Great Grandmother (Maternal) | [28] Cousin (Maternal) – should be 01. Do Not Use |
| 14 Great Grandmother (Paternal) | [29] 2 nd Cousin (Paternal) – should be 18. DNU |
| | [30] 2 nd Cousin (Maternal) – should be 17. DNU |
| | [31] Uncle (Maternal) – not used in Phase 3 |
| | [32] Nephew- brother's son not used in Phase 3 |
| | [33] Great Uncle (Maternal) - not used in Phase 3 |
| | [34] Great Great Aunt (Maternal) – should be 17. DNU |

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 (Dilation & Curettage)
- 07 Tamoxifen use
- 08 Due to hormone use / ERT
- 09 Mental trauma/stress/husband died
- 10 Endometrial ablation/uterine ablation (e.g. Novasure)
- 11 Provera use/Progestin/Norplant/Mirena/IUD
- 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
- 16 Unknown shot (injection)
- 17 Zoladex injections
- 18 Oral Contraceptives (Birth Control Pills)
- 19 Intrauterine adhesion/Asherman's Syndrome/synechiae
- 20 Pregnancy, then chemo—never had another period
- 21 Athletic training
- 22 Hyperthyroidism
- 23 Zometa and Zoladex injections
- 24 Lupron
- 25 No periods since last pregnancy
- 26 Double uterus
- 27 Implanon implant
- 28 Birth Control followed by HRT

C12a. Other pregnancy outcomes**CODE ONE RESPONSE**

- 99 Don't Know
- 01 Twin Pregnancy: One miscarried, One live birth
- 02 Pregnancy ended due to hysterectomy
- 03 Multiple stillbirths
- 04 Multiple: one stillbirth; one live birth
- 05 Missed abortion
- 06 Therapeutic abortion (IUD pregnancy)
- [07] Molar Pregnancy – **[DO NOT USE, not counted as a pregnancy]**

C14k. Other reason for not breastfeeding

CODE UP TO 2 RESPONSES

(Separated by Topic—Numerical order on pg. 6)

999 Don't Know

Reasons because of Mother:

- 002 Had to return to work / school / other activity
- 003 Too sore following childbirth
- 004 Breast infection/mastitis
- 007 Lack of educational support
- 009 It was painful
- 013 Had difficulty pumping
- [014] Didn't want to – **[DO NOT USE, C13 should be marked "No"]**
- 016 Had inverted nipples
- 017 Not comfortable breast feeding
- 018 Was a smoker
- 023 Difficulty breast feeding
- 025 Patient wasn't getting enough to eat / had a bad diet
- 027 Breast was tender/sore
- 028 Diagnosed with breast cancer (getting treatment) during pregnancy/while breast feeding
- 031 Mother was large breasted and afraid baby would suffocate / though it could be problematic
- 032 Mother consuming medication or substance (alcohol) that made it unsafe to breastfeed
- 037 Mother was a survivor of domestic violence, didn't want to put baby in danger/harm's way
- 038 Patient/mother was in hospital
- 041 No place to breastfeed at school
- 042 Afraid no one would be there to help/support her
- 043 Had to leave the country / Unable to breastfeed while traveling
- 044 Participant was self conscious
- 045 Breast engorgement
- 047 Didn't like breast feeding
- 050 Not enough breast tissue/breast hypoplasia
- 051 Participant was emotionally stressed
- 052 Milk Fever / Mastitis
- 055 Bleeding/bloody nipples
- 057 Husband passed away
- 059 Pregnant w/ another child
- 064 Participant did not have nipples
- 066 Participant had cysts removed from breasts in past

Reasons because of Baby:

- 006 Baby not interested, not compliant
- 008 2nd baby's medical issues
- 010 Low birth weight, premature
- 011 Baby had an infection
- 012 Baby not thriving
- 015 Baby had difficult time breast feeding
- 019 Baby in hospital for medical issues and unable to start/finish breastfeeding

- 021 Baby had colic
- 024 Baby in too much pain to breast feed
- 026 Baby wasn't satisfied/wanted to feed frequently
- 029 Baby was jaundiced
- 030 Baby had allergic reactions to milk
- 033 Baby had health problems
- 035 Baby wouldn't latch on
- 048 Sibling jealousy made it difficult / has other children
- 053 Baby's teeth came in / Baby was biting
- 054 Baby was already big and healthy

Reasons because of Milk Production/Education:

- 001 Lack of education on how to maintain milk production
- 005 Milk did not come in
- 020 Milk production stopped/milk dried up
- 022 Not enough milk *after 2nd pregnancy*
- 034 Participant thought she didn't have enough milk/ thought she didn't produce enough milk/
thought breast too small
- 036 Milk too thin
- 039 Milk not good, milk "was blue"
- 040 Produced too much milk
- 046 Reduced milk flow *due to scar tissue from surgery*
- 049 Bloody Milk
- 056 Dr. advised not to breast feed
- 058 Clogged Milk Ducts
- 063 Participant had a multiple birth
- 065 Participant thought formula was healthier for babies

C14k. Cont'd (In numerical order)

- | | |
|--|--|
| 999 Don't Know | 025 Patient wasn't getting enough to eat / had a bad diet |
| 001 Lack of education on how to maintain milk production | 026 Baby wasn't satisfied/wanted to feed frequently |
| 002 Had to return to work / school / other activity | 027 Breast was tender |
| 003 Too sore following childbirth | 028 Diagnosed with breast cancer during pregnancy/while breast feeding |
| 004 Breast infection | 029 Baby was jaundiced |
| 005 Milk did not come in | 030 Baby had allergic reactions to milk |
| 006 Baby not interested, not compliant | 031 Mother was large breasted and afraid baby would suffocate / though it could be problematic |
| 007 Lack of educational support | 032 Mother consuming medication or substance (alcohol) that made it unsafe to breastfeed |
| 008 2 nd baby's medical issues | 033 Baby had health problems |
| 009 It was painful | 034 Participant thought she didn't have enough milk /thought breasts were too small |
| 010 Low birth weight, premature | 035 Baby wouldn't latch on |
| 011 Baby had an infection | 036 Milk too thin |
| 012 Baby not thriving | 037 Survivor of domestic violence, didn't want to put baby in danger/harm's way |
| 013 Had difficulty pumping | 038 Patient/mother was in hospital |
| [014] Didn't want to [Contradicts Question] DO NOT USE | 039 Milk not good, "was blue" |
| 015 Baby had difficult time breast feeding | 040 Produced too much milk |
| 016 Had inverted nipples | 041 No place to breastfeed at school |
| 017 Not comfortable breast feeding | 042 Afraid no one would be there to help/support her |
| 018 Was a smoker | 043 Had to leave the country |
| 019 Baby in hospital for medical issues and unable to finish breastfeeding | 044 Participant was self conscious |
| 020 Milk production stopped/milk dried up | 045 Breast engorgement |
| 021 Baby had colic | 046 Reduced milk flow due to scar tissue from surgery |
| 022 Not enough milk <i>after 2nd pregnancy</i> | |
| 023 Difficulty breast feeding | |
| 024 Baby in too much pain to breast feed | |

- | | |
|---|---|
| 047 Didn't like breast feeding | 060 She thought she couldn't due to previous injury to breast |
| 048 Sibling jealousy made it difficult / has other children | 061 Mother was impatient |
| 049 Bloody Milk | 062 Eczema / skin condition on breast |
| 050 Not enough breast tissue/breast hypoplasia | 063 Participant had a multiple birth |
| 051 Participant was emotionally stressed | 064 Participant did not have nipples |
| 052 Milk Fever / Mastitis | 065 Participant thought formula was healthier for babies |
| 053 Baby's teeth came in | 066 Participant had cysts removed from breasts in past |
| 054 Baby was already big and healthy | |
| 055 Bleeding/bloody nipples | |
| 056 Dr. advised not to breast feed | |
| 057 Husband passed away | |
| 058 Clogged Milk Ducts | |
| 059 Pregnant w/ another child | |

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

[099] Don't Know (Phase 2) **DON'T USE**
 999 Don't Know (Use in Phase 3)

- 001 Insulin dependent diabetes mellitus (IDDM), Juvenile Onset, Type I
- 002 Non-insulin dependent diabetes mellitus (NIDDM), Adult Onset, Type II
- 003 Gestational diabetes
- 004 Adult onset - but requires insulin
- 005 Adult onset, NOS
- 006 Pre-diabetes / Borderline diabetic ~~–treated by MD~~
- 007 Drug induced, temporary (steroid)
- 008 Glucose intolerance
- 009 Diabetes insipidus
- 010 Diabetes mellitus, NOS
- 011 Elevated blood sugar
- 012 High blood sugar
- [013] Uterine fibroids -- **this should be reported in D1e. DO NOT USE**

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

[099] Don't Know (Phase 2) **DON'T USE**
 999 Don't Know (Use in Phase 3)

- | | |
|---|---|
| 001 Polycystic ovaries (cysts)/Stein-Leventhal Syn. | 017 Rupturing ovaries |
| 002 Fibroid cysts on ovaries/fibrocystic | 018 Ovarian cancer |
| 003 Benign tumor | 019 Oophorectomy due to tubal pregnancy |
| 004 Enlarged ovary | 020 Oophorectomy due to endometriosis |
| 005 Cyst, NOS / Polyp | 021 Mass from egg that did not pass/growth |
| 006 Short fertility time | 022 Dysmenorrhea - painful periods |
| 007 Ruptured Cyst | [023] Endometriosis on ovary – code as 09 DO NOT USE |
| 008 Dermoid cyst | 024 “Blocked ovary” |
| 009 Endometrioma on ovary/Endometriosis | 025 Malignant tumor |
| 010 Scarring | 026 Oophorectomy, NOS |
| 011 Irregular ovulation (problem w/ovulation) | 027 Ovulated but was not releasing an egg |
| 012 Fibroid tumor | [028] Oophorectomy due to endometriosis – code as 020 DO NOT USE |
| 013 Infection | 029 “Mass” was detected/ “growths” |
| 014 Tumor, NOS | [030] “Infection” – code as 013 DO NOT USE |
| 015 Abscess on ovary | 031 “Corrupted ovary” |
| 016 Adhesions | 032 “Floating” ovaries |
| | [033] Ruptured cysts – code as 07 DO NOT USE |

- 034 "Cocoon around ovaries"
- 035 Twisted or tilted ovary/torsion
- 036 Painful Ovaries
- 037 Bled a lot
- 038 Under production of hormones
- 039 Complications of appendicitis
- 040 Oophorectomy due to cyst
- 041 Chocolate cyst
- 042 "Something ruptured"
- 043 "Hidden" ovary
- 044 Premature ovarian failure (POF)
- 045 Endometriosis and twisted ovaries

- 046 Luteoma/Luteal Granuloma
- 047 Cysts and hysterectomy
- 048 Oophorectomy for cyst(s) and dysplasia
- 049 Mass - Dysplasia
- 050 Endometriosis and cyst(s)
- 051 Oophorectomy due to infection
- 052 Pelvic Inflammatory Disease
- 053 Cysts removed; fibroid tumors
- 054 Amenorrhea
- 055 Calcification in ovary
- 056 Increased blood in ovary

D1c. Thyroid Condition

CODE ONE RESPONSE

[099] Don't Know (Phase 2) DON'T USE
 999 Don't Know (Use in Phase 3)

- 001 Hypothyroidism
- 002 Hyperthyroidism
- 003 Goiter (enlarged thyroid)
- 004 Hashimoto's disease
- 005 Grave's disease
- 006 Lump on Thyroid/tumor
- 007 Multiple Conditions
- 008 Thyroid Cancer
- 009 Thyroiditis
- 010 Thyroidectomy
- 011 Swollen thyroid
- 012 Nodule(s) / "spots on thyroid" / cyst(s)
- 013 Thyroid storm
- 014 Combination hypo/hyperthyroid
- 015 Fluid on thyroid
- 016 Borderline condition
- 017 Overactive
- 018 "Took synthroid"/taking synthroid now

- 019 Parathyroid nodule / tumor
- 020 Wilson's syndrome
- 021 Infected thyroid
- 022 Hashimoto's and thyroid nodule
- 023 Partial thyroidectomy
- 024 Hypothyroidism and thyroid cancer
- 025 "Secondary thyroid cancer"
- 026 Enlarged thyroid
- [027] Thyroid removed- **code as 010**
Thyroidectomy DON'T USE
- 028 Multinodular Goiter
- 029 Partial thyroidectomy and hyperthyroidism
- 030 "Multiple growths"
- 031 Hyperthyroid & Thyroid goiter
- 032 "Thyroid Disease" (NOS)
- 033 Partial Thyroidectomy & Hypothyroidism
- 034 Goiter and Thyroidectomy
- 035 Thyroidectomy and hypothyroidism
- 036 Thyrotoxicosis
- 037 Thyroid stones

D1d. Problem with blood pressure

CODE ONE RESPONSE

- 999 Don't Know
- 001 High blood pressure (hypertension)
- 002 Low blood pressure (hypotension)
- 003 Muscle grew around renal artery, had renal angioplasty
- 004 Pulmonary hypertension
- 005 Neurocardiac syncope
- 006 Prehypertension / Borderline high blood pressure
- 007 Preeclampsia (high blood pressure during pregnancy)

D1e. Other serious problems**CODE ONE RESPONSE**

Starting on Dec 9, 2009, code multiple serious problems with "888" and assign "88" to age.

Single health problems (listed alphabetically): **Numerical order on pg. 12

999	Don't Know	268	Burns (3rd degree)
188	Abnormal Pap Test	223	Bursitis
155	Abscess on brain	082	Bypass surgery (double, triple, or quadruple)
084	Acid reflux	338	Cardiac arrest
212	Acoustic neuroma	090	Cardiac blockage/cardiac stent placed
010	Addison's disease	177	Cardiomegaly (enlarged heart)
113	Adult respiratory distress syndrome (ARDS)	204	Carotid Artery Stenosis
257	Allergy/Allergies	217	Carpal Tunnel Syndrome (CTS)
234	Alpha 1-antitrypsin Deficiency (A1AD)	271	Cataracts
298	Aorta surgery	070	Celiac disease
026	Anemia	206	Cellulitis
161	Aneurysm (Brain)	292	Cervical compression fracture
065	Aneurysm, NOS	042	Cervical dysplasia
211	Angioplasty / Coronary artery stent	303	Chairi decompression
389	Ankylosing spondylitis	259	Chemical allergy
285	Antiphospholipid Syndrome	331	Charcot-Marie-Tooth disease
072	Anxiety attacks	176	Chest pain/Angina
229	Aortic stenosis	390	Cholestatoma
096	Appendectomy / Appendicitis	018	Cholesterol problem / High cholesterol
278	Arteriovenous Malformation (AVM)	312	Chronic bronchitis
009	Arthritis	344	Chronic diarrhea / Rectal incontinence
003	Asthma	014	Chronic fatigue
324	Asthmatic Bronchitis	215	Chronic inflammation of the skin
189	Atherosclerosis/Coronary Artery Disease	127	Chronic kidney infection
290	Attention deficit hyperactivity disorder (ADHD)	016	Chronic migraine headache
039	Atrial Fibrillation	195	Chronic Obstructive Pulmonary Disease (COPD)
132	Avascular necrosis	386	Chronic pain (NOS)
203	Back Problems/surgery, (NOS) / back pain	124	Cirrhosis
035	Back ruptured disc/Herniated disc/Slipped disc	326	Cluster headaches
391	Barrett's disease	359	Cochlear implant
128	Bell's Palsy Stroke	094	Colitis
232	Bicornuate uterus	346	Colon resection
135	Bipolar/manic depressive disorder	301	Colon polyps
382	Bladder retention	228	Congenital leg/hip deformities
221	Bladder surgery	383	Congenital lung disease
269	Blindness	129	Congestive heart failure
097	Blood clots	095	Connective tissue disorder
333	Body tremors	101	Crohn's Disease/Inflammatory Bowel Disease
230	Bone fracture/dislocation	307	Crushed cervical disc
185	Bone Spur (Osteophyte)	252	Cystitis
136	Brain tumor, benign	381	Deaf (right ear)
237	Breast implants	170	Deep Vein Thrombosis
318	Breast reduction surgery	168	Degenerative Disc Disease
074	Bullous Pemphigoid (auto-immune dermatitis)	192	Degenerative Joint Disease (DJD)
		005	Depression

157	Depression with psychotic features	387	Heartburn / pyrosis
216	Dermatomyositis	046	Heart disease, NOS / Heart Problem
193	Dermoid Tumor	205	Heart murmur
283	Deatched Retina	248	Heart palpitations
100	Dextrocardia	296	Heart valve damage
227	Diabetic Neuropathy	207	Heart valve replacement
263	Diphtheria	182	Heart valve stenosis (HVS) (NOS)
220	Diverticulosis / Diverticulitis	305	Heat stroke
311	Double vagina, uterus & cervix	258	Heel surgery
376	Double vision	356	Hematoma from hysterectomy
270	Drug abuse	394	Hematuria
083	Eczema	133	Hepatitis (A,B, C, or any combination of)
017	Emphysema	063	Hernia
323	Endocardectomy	202	Herpes
075	Endometriosis	018	High cholesterol / cholesterol problem
013	Epilepsy	194	High triglycerides
320	Erythema nodosum	225	Hip replacement
064	Esophageal strictures	363	Histoplasmosis
200	Eye Injury (NOS)	149	HIV positive
023	Factor V deficiency	115	HPV
385	Factor X1	371	Hyperkalemia
246	Failed renal transplant	027	Hyperparathyroidism
184	Familial Adenomatous Polyposis (FAP)	377	Hypersensitivity pneumonitis
345	Familial polyposis	374	Hypertensive crisis
261	Fanconi aplastic anemia	233	Hypoglycemia
235	Fertility Issues	395	Idiopathic thrombocytopenic purpura (ITP)
030	Fibroid, NOS	276	IGG immune deficiency
006	Fibromyalgia	238	Infection (TB type, but not TB)
334	Fluid retention in legs/peripheral edema	328	Inflammatory arthritis
199	Food Allergy	267	Inoperable tumor (optic nerve)
360	Foot (right) reattached	231	Insomnia
291	Fracture Lumbar Spine	260	Interstitial cystitis
366	Fusion of vertebrate	213	Intracranial surgery
297	Gall bladder problems, NOS / Cholecystitis	380	Intussusception of colon
021	Gall bladder surgery / removal (Cholecystectomy)	111	Irregular heartbeat (cardiac arrhythmia)/Tachycardia
123	Gallstones	164	Irritable Bowel Syndrome (IBS)
242	Gangrenous bowel	116	Juvenile Polyposis Coli (JPC)
335	Gastrectomy (partial)	028	Kidney Failure/Renal failure/Dialysis
055	Gastric bypass for morbid obesity	012	Kidney problems/infections
174	Gastritis	336	Kidney removal (nephrectomy)
143	Gastroesophageal reflux disease (GERD)	011	Kidney stones
355	Gastroparesis w/ colectomy	388	Kienbock's disease
181	Glaucoma	108	Knee (torn meniscus)
353	Gonorrhea	060	Knee replacements
175	Gout	265	Laryngeal spasm
393	Guillain-Barré	329	Leaking blood vessels
343	Gunshot wound	361	Leg Amputation (below knee)
208	Head injury, (NOS)	378	Legionnaires' disease
219	Hearing Impairment	304	Leiomyomatosis
033	Heart attack/Myocardial infarction	118	Limb weakness / weakness on 1 side
255	Heart Block	322	Lipodermatosclerosis
		308	Lipoma

134	Liver, general issues	224	Peritonitis
262	Low adrenal levels	196	Pernicious Anemia
247	Low platelet count / Thrombocytopenia	317	Parotid tumor – noncancerous
313	Lung Nodule	397	Pilonidal cyst surgery
284	Lung Problem, NOS	286	Pinched nerve
148	Lupus	015	Pituitary adenoma
191	Lyme Disease	399	Pituitary gland removed
281	Lymphedema	078	Pneumonia
342	Macular Hemorrhage	162	Pneumothorax
077	Major auto accident with multiple injuries	273	Polio paralysis
241	Mechanical bowel obstruction	327	Polycystic kidney disease
398	Mastoiditis	264	Polycythemia
251	Meniere's disease	347	Polymyalgia rheumatica
325	Meningioma	321	Polyp in eye
020	Meningitis	121	Poor vision
332	Mental retardation	373	Post-traumatic stress disorder
300	Metabolic syndrome	226	Potassium deficiency
114	Migraines / Occular migraines	249	Pre-cancerous cells - cervix
171	Mitral Valve Prolapse (MVP)	288	Pre-cancerous cell, NOS
183	Molar pregnancy/Hydatidiform mole	186	Pre-cancerous cells - skin
348	Monoclonal Gammopathy of undetermined significance (MGUS)	187	Pre-cancerous cells - uterus
379	Mononucleosis	[66]	Preeclampsia – Capture in D1 d. as 007, DO NOT USE
081	MRSA (methicillin-resistant Staphylococcus aureus)	316	Premature Ventricular Contractions (PVC, VPC, VPB)
364	MTHFR (blood disorder)	256	Prolapsed bladder
362	Multifocal choroiditis	266	Pseudo brain tumor
152	Multiple sclerosis	277	Psoriasis
117	Muscle problems (spasms, weakness, etc)	282	Pulmonary atresia
209	Myomectomy	112	Pulmonary embolus
337	Narcolepsy	243	Pulmonary fibrosis pneumonia
173	Neurological Problems	[007]	Pulmonary hypertension - Reported in D1d. DO NOT USE
384	Non TB mycobacterium	169	Pulmonary Sarcoidosis
250	Numbness in extremities	392	Put in heart defibrillator
159	Oculodentodigital dysplasia (ODDD)	120	Raynaud's Syndrome
172	Open Heart Surgery	275	Removed shoulder implant
067	Osteoarthritis/DJD	[245]	Renal failure / dialysis – Code as 028 DO NOT USE
036	Osteopenia	370	Restless Leg syndrome
001	Osteoporosis	038	Retinopathy
375	Otosclerosis	130	Rheumatic fever
372	Overactive bladder	048	Rheumatoid arthritis
179	Overweight/Obese/Weight Issues	178	Rod-Cone Dystrophy
043	Pancreas didn't form correctly	131	Ruptured appendix/bowel
158	Pancreatitis	295	Salivary / Parotid gland removal
160	Panic disorder	004	Sarcoidosis
358	Parathyroid tumor removed	369	Schizophrenia
357	Parkinson's disease	163	Sciatica / Sciatic nerve damage
306	Perforated colon during colonoscopy	218	Scleroderma
354	Pericarditis	041	Scoliosis
299	Peripheral neuropathy	239	Seizure – psychogenic/NOS
349	Peripheral Vascular Disease (PVD, PAD, PAOD)	309	Septoplasty
289	Peritoneal tumor, benign	197	Shingles
		368	Shoulder dislocation / Broken shoulder

274	Shoulder silicone implant		code as 319 Torn rotator cuff
293	Sinus infection / Sinusitis	166	Transverse myelitis
214	Sinus surgery	367	Trauma from accident
144	Sjogren 's syndrome	254	Trigeminal neuralgia
079	Sleep apnea	082	Triple bypass - [See Bypass surgery]
106	Slow heart rhythm requiring defibrillator	280	Tuberculosis
167	Small fiber neuropathy	352	Tumor ^{behind-ear} (benign)
294	Small lungs	330	Tumor behind pancreas
302	Sojourners syndrome	315	Tumor on adrenal gland
025	Spinal cord injury	198	Tumor / Large Tumor (NOS)
061	Spinal Stenosis	047	Ulcerative colitis
032	Stroke	153	Urinary tract infection(s)
210	Stomach problems, (NOS)	034	Uterine fibroids/tumor/hysterectomy
240	Stomach ulcer	287	Uterine polyps
341	Stromal tumor in stomach (benign) / Gastrointestinal Stromal Tumor	272	Uveitis
396	Subdural hematoma	201	Valvular Insufficiency (Leaky Heart Valve)
057	Swollen joints	180	Varicose Veins
126	Syncope	110	Ventricular septal defect (VSD)
365	Synovial cyst (removed)	222	Vertigo
111	Tachycardia - [See Irregular heartbeat]	244	Vitamin B12 deficiency
310	Tendon repaired in ankle	236	Vitiligo
165	Tendonitis	119	Von Willebrand disease
279	Thalassemia	190	Wolff-Parkinson-White Syndrome (WPW)
122	Tonsillectomy	253	Zenker's diverticulum
319	Torn rotator cuff – arm		
[340]	Torn rotator cuff surgery – DO NO USE,		

**D1e. cont'd [Combination health problem] – DO NOT USE THESE CODES!
Starting on Dec 9, 2009, code multiple serious problems with "888" and
assign "88" to age.**

002	pneumothorax, heart attack and stroke	058	Seizures, left leg weakness leaving patient wheelchair bound
008	rheumatoid arthritis and sciatica	059	Sarcoidosis, high cholesterol
019	transverse myelitis and small fiber neuropathy	062	Dermoid tumor, endometriosis
022	Asthma & colon polyps	068	Arthritis, osteoporosis
024	Asthma & acid reflux	069	Cholecystitis, appendicitis
029	Rheumatoid arthritis, fibromyalgia	071	Hepatitis A & B, asthma
031	Fibromyalgia, chronic fatigue, pituitary adenoma, chronic migraine headache	073	Rheumatic fever, congestive heart failure
037	Irritable bowel syndrome, chronic tendonitis	076	High cholesterol, sensitive liver
040	Multiple sclerosis, rheumatoid arthritis, back, disc problems, neurological problems	080	High cholesterol, heart disease
044	HPV & pulmonary sarcoidosis	085	Abdominal hernia, knee replacement, sleep apnea
045	Rheumatoid arthritis, pulmonary embolus	086	Heart murmur, deep vein thrombosis, stroke
049	Open heart surgery, colon polyps	087	Sleep apnea, gastric bypass, osteoarthritis, morbid obesity
050	Gall bladder removal, hernia surgery	088	Acid reflux, DJD, scoliosis, anemia
051	Myocardial infarction, uterine fibroids, ruptured discs	089	Heart Attack, 2 stents, and brain tumor (benign)
052	Reynaud's syndrome, asthma	091	Kidney problems and Bell's Palsy Stroke
053	Tonsillectomy, uterine fibroids, gallstones	092	High cholesterol, high triglycerides
054	Heart valve issues & sarcoidosis	093	Osteoporosis, migraines
056	High cholesterol, decreased vision due to diabetes, syncope	098	Adult respiratory distress syndrome, pneumonia, migraines

099	Von Willebrand disease, endometriosis, deep vein thrombosis, MRSA	140	Bullous Pemphigoid, avascular necrosis
102	Heart disease, cirrhosis, atrial fibrillation	141	Triple bypass surgery, ruptured appendix/bowel
103	Multiple sclerosis, high cholesterol	142	Sarcoidosis, degenerative disc disease
104	Chrohn's Disease, colitis	145	Parathyroid condition, asthma, osteoporosis
105	Gallstones, hernias	146	Depression, epilepsy
107	Uterine fibroids, pre-cancerous cells, hysterectomy	147	Depression, anxiety
109	Mitral valve prolapse (MVP), irregular heartbeat	150	Thyroid goiter, HPV
[125]	Morbid obesity, gastric bypass — DO NOT USE CODE AS 055	151	Sick sinus syndrome, gastric bypass, hernia repair
137	Fibromyalgia, muscle spasms and weakness	154	Fibromyalgia, asthma
138	Ulcerative colitis, high cholesterol	156	Severe cellulitis, knee replacement, abdominal hernia, kidney stone
139	Knee replacement, arthritis		

D1e. Other serious problems cont'd (In numerical order)

Starting on Dec 9, 2009, code multiple serious problems with "888" and assign "88" to age.

999	Don't Know	036	Osteopenia
001	Osteoporosis	037	Don't Use
002	Don't Use	038	Retinopathy
003	Asthma	039	Atrial Fibrillation
004	Sarcoidosis	040	Don't Use
005	Depression	041	Scoliosis
006	Fibromyalgia	042	Cervical dysplasia
[007]	pulmonary hypertension—reported in D1d. DON'T USE	043	Pancreas didn't form correctly
008	Don't Use	044	Don't Use
009	Arthritis	045	Don't Use
010	Addison's disease	046	Heart disease, NOS
011	Kidney stones	047	Ulcerative colitis
012	Kidney problems	048	Rheumatoid arthritis
013	Epilepsy	049	Don't Use
014	Chronic fatigue	050	Don't Use
015	Pituitary adenoma	051	Don't Use
016	Chronic migraine headache	052	Don't Use
017	Emphysema	053	Don't Use
018	High cholesterol	054	Don't Use
019	Don't Use	055	Gastric bypass for morbid obesity
020	Meningitis	056	Don't Use
021	Gall bladder removal	057	Swollen joints
022	Don't Use	058	Don't Use
023	Factor V deficiency	059	Don't Use
024	Don't Use	060	Knee replacements
025	Spinal cord injury	061	Spinal Stenosis
026	Anemia	062	Don't Use
027	Hyperparathyroidism	063	Hernia
028	Kidney Failure/Renal failure/Dialysis	064	Esophageal strictures
029	Don't Use	065	Aneurism, NOS
030	Fibroid, NOS	066	Preeclampsia
031	Don't Use	067	Osteoarthritis
032	Stroke	068	Don't Use
033	Heart attack/Myocardial infarction	069	Don't Use
034	Uterine fibroids/tumor/hysterectomy	070	Celiac disease
035	Back ruptured disc/Herniated disc/Slipped disc	071	Don't Use
		072	Anxiety attacks
		073	Don't Use

- 074 Bullous Pemphigoid (auto-immune dermatitis)
- 075 Endometriosis
- 076 **Don't Use**
- 077 Major auto accident with multiple injuries
- 078 Pneumonia
- 079 Sleep apnea
- 080 **Don't Use**
- 081 MRSA (methicillin-resistant Staphylococcus aureus)
- 082 Triple bypass
- 083 Eczema
- 084 Acid reflux
- 085 **Don't Use**
- 086 **Don't Use**
- 087 **Don't Use**
- 088 **Don't Use**
- 089 **Don't Use**
- 090 Cardiac blockage/Cardiac stent placed
- 091 **Don't Use**
- 092 **Don't Use**
- 093 **Don't Use**
- 094 Colitis
- 095 Connective tissue disorder
- 096 Appendectomy / Appendicitis
- 097 Blood clots in legs and carotid artery
- 098 **Don't Use**
- 099 **Don't Use**
- 100 Dextrocardia
- 101 Crohn's disease/Inflammatory bowel disease
- 102 **Don't Use**
- 103 **Don't Use**
- 104 **Don't Use**
- 105 **Don't Use**
- 106 Slow heart rhythm requiring defibrillator
- 107 **Don't Use**
- 108 Knee (torn meniscus)
- 109 **Don't Use**
- 110 Ventricular septal defect (VSD)
- 111 Irregular heartbeat (Cardiac arrhythmia)
- 112 Pulmonary embolus
- 113 Adult respiratory distress syndrome (ARDS)
- 114 Migraines/Ocular migraines
- 115 HPV
- 116 Juvenile polyposis coli (JPC)
- 117 Muscle problems
- 118 Limb weakness / Weakness on 1 side
- 119 Von Willebrand disease
- 120 Raynaud's Syndrome
- 121 Poor vision
- 122 Tonsillectomy
- 123 Gallstones
- 124 Cirrhosis
- [125] Morbid obesity, Gastric bypass – **DO NOT USE, CODE AS 055**
- 126 Syncope
- 127 Chronic kidney infection
- 128 Bell's Palsy stroke
- 129 Congestive heart failure
- 130 Rheumatic fever
- 131 Ruptured appendix and bowel
- 132 Avascular necrosis
- 133 Hepatitis (A or B or C, or any combination of)
- 134 Liver, general issues
- 135 Bipolar/manic depressive disorder
- 136 Brain tumor, benign
- 137 **Don't Use**
- 138 **Don't Use**
- 139 **Don't Use**
- 140 **Don't Use**
- 141 **Don't Use**
- 142 **Don't Use**
- 143 Gastroesophageal reflux disease (GERD)
- 144 Sjogren 's syndrome
- 145 **Don't Use**
- 146 **Don't Use**
- 147 **Don't Use**
- 148 Lupus
- 149 HIV positive
- 150 **Don't Use**
- 151 **Don't Use**
- 152 Multiple sclerosis
- 153 Urinary tract infection(s)
- 154 **Don't Use**
- 155 Abscess on brain
- 156 **Don't Use**
- 157 Depression with psychotic features
- 158 Pancreatitis
- 159 Oculodentodigital dysplasia (ODDD)
- 160 Panic disorder
- 161 Aneurysm (Brain)
- 162 Penumothorax
- 163 Sciatica / Sciatic nerve damage
- 164 Irritable bowel syndrome
- 165 Tendonitis
- 166 Transverse myelitis
- 167 Small fiber neuropathy
- 168 Degenerative disc disease
- 169 Pulmonary sarcoidosis
- 170 Deep vein thrombosis
- 171 Mitral valve prolapse (MVP)
- 172 Open heart surgery
- 173 Neurological problems
- 174 Gastritis
- 175 Gout
- 176 Chest pain/Angina
- 177 Cardiomegaly (enlarged heart)
- 178 Rod-Cone Dystrophy
- 179 Overweight/Obese/Weight Issues
- 180 Varicose veins
- 181 Glaucoma
- 182 Heart valve stenosis (HVS) (NOS)
- 183 Molar pregnancy/Hydatidiform mole
- 184 Familial adenomatous polyposis
- 185 Bone spur (Osteophyte)
- 186 Pre-cancerous cells - skin
- 187 Pre-cancerous cells - uterus

188	Abnormal pap test	246	Failed renal transplant
189	Atherosclerosis	247	Low platelet count / Thrombocytopenia
190	Wolff-Parkinson-White Syndrome (WPW)	248	Heart palpitations
191	Lyme disease	249	Pre-cancerous cells - cervix
192	Degenerative joint disease (DJD)	250	Numbness in extremities
193	Dermoid tumor	251	Meniere's disease
194	High triglycerides	252	Cystitis
195	Chronic obstructive pulmonary disease (COPD)	253	Zenker's diverticulum
196	Pernicious anemia	254	Trigeminal neuralgia
197	Shingles	255	Heart block
198	Tumor / Large Tumor, (NOS)	256	Prolapsed bladder
199	Food allergy	257	Allergy/Allergies
200	Eye injury (NOS)	258	Heel surgery
201	Valvular insufficiency (Leaky heart valves)	259	Chemical allergy
202	Herpes	260	Interstitial cystitis
203	Back problem(s)/surgery, (NOS)/back pain	261	Fanconi aplastic anemia
204	Carotid artery stenosis	262	Low adrenal levels
205	Heart murmur	263	Diphtheria
206	Cellulitis	264	Polycythemia
207	Heart valve replacement	265	Laryngeal spasm
208	Head injury	266	Pseudo brain tumor
209	Myomectomy	267	Inoperable tumor (optic nerve)
210	Stomach problems, (NOS)	268	Burns (3rd degree)
211	Angioplasty / Coronary artery stent	269	Blindness
212	Acoustic neuroma	270	Drug abuse
213	Intracranial surgery	271	Cataracts
214	Sinus surgery	272	Uveitis
215	Chronic inflammation of skin	273	Polio paralysis
216	Dermatomyositis	274	Shoulder silicone implant
217	Carpal tunnel syndrome (CTS)	275	Removed shoulder implant
218	Scleroderma	276	IGG immune deficiency
219	Hearing impairment	277	Psoriasis
220	Diverticulosis / Diverticulitis	278	Arteriovenous malformation (AVM)
221	Bladder surgery	279	Thalassemia
222	Vertigo	280	Tuberculosis
223	Bursitis	281	Lymphedema
224	Peritonitis	282	Pulmonary atresia
225	Hip replacement	283	Detached retina
226	Potassium deficiency	284	Lung problem, NOS
227	Diabetic neuropathy	285	Antiphospholipid syndrome
228	Congenital leg/hip deformities	286	Pinched nerve
229	Aortic stenosis	287	Uterine polyps
230	Bone fracture/dislocation	288	Pre-cancerous cell, NOS
231	Insomnia	289	Peritoneal tumor, benign
232	Bicornuate uterus	290	Attention deficit hyperactivity disorder (ADHD)
233	Hypoglemia	291	Fracture lumbar spine
234	Alpha 1-antitrypsin Deficiency (A1AD)	292	Cervical compression fracture
235	Fertility Issues (Infertility)	293	Sinus infection / Sinusitis
236	Vitiligo	294	Small lungs
237	Breast implants	295	Salivary / Parotid gland removal
238	Infection (TB type, but not TB)	296	Heart valve damage
239	Seizure – psychogenic/NOS	297	Gall bladder problems, NOS / Cholecystitis
240	Stomach ulcer	298	Aorta surgery
241	Mechanical bowel obstruction	299	Peripheral neuropathy
242	Gangrenous bowel	300	Metabolic syndrome
243	Pulmonary fibrosis pneumonia	301	Colon polyps
244	Vitamin B12 deficiency	302	Sojourners syndrome
[245]	Renal failure / dialysis [DO NOT USE, see 028 Kidney failure]	303	Chairi decompression
		304	Leiomyomatosis

- 305 Heat stroke
- 306 Perforated colon during colonoscopy
- 307 Crushed cervical disc
- 308 Lipoma
- 309 Septoplasty
- 310 Tendon repaired in ankle
- 311 Double vagina, uterus & cervix
- 312 Chronic bronchitis
- 313 Lung nodule
- 314 Nerve injury to foot
- 315 Tumor on adrenal gland
- 316 Premature ventricular contractions (PVC, VPC, VPB)
- 317 Parotid tumor – noncancerous
- 318 Breast reduction surgery
- 319 Torn rotator cuff – arm
- 320 Erythema nodosum
- 321 Polyp in eye
- 322 Lipodermatosclerosis
- 323 Endocardectomy
- 324 Asthmatic Bronchitis
- 325 Meningioma
- 326 Cluster headaches
- 327 Polycystic kidney disease
- 328 Inflammatory arthritis
- 329 Leaking blood vessels
- 330 Tumor behind pancreas
- 331 Charcot-Marie-Tooth disease
- 332 Mental retardation
- 333 Body tremors
- 334 Fluid retention in legs/peripheral edema
- 335 Gastrectomy (partial)
- 336 Kidney removal (nephrectomy)
- 337 Narcolepsy
- 338 Cardiac arres
- 339 **NOT USED**
- [340] Torn rotator cuff surgery – **DO NOT USE, code as 319 Torn rotator cuff**
- 341 Stromal tumor in stomach (benign) /
Gastrointestinal stromal tumor
- 342 Macular hemorrhage
- 343 Gunshot wound
- 344 Chronic diarrhea / Rectal incontinence
- 345 Familial polyposis
- 346 Colon resection
- 347 Polymyalgia rheumatica
- 348 Monoclonal gammopathy of undetermined
significance (MGUS)
- 349 Peripheral vascular disease (PVD, PAD,
PAOD)
- [350] Parathyroid produces too much calcium –
**DO NOT USE, code as 027
Hyperparathyroidism**
- 351 Vitamin D deficiency
- 352 Tumor ^{behind ear} (benign)
- 353 Gonorrhea
- 354 Pericarditis
- 355 Gastroparesis w/ colectomy
- 356 Hematoma from hysterectomy
- 357 Parkinson's disease
- 358 Parathyroid tumor removed
- 359 Cochlear implant
- 360 Foot (right) reattached
- 361 Leg Amputation (below knee)
- 362 Multifocal choroiditis
- 363 Histoplasmosis
- 364 MTHFR (blood disorder)
- 365 Synovial cyst (removed)
- 366 Fusion of vertebrate
- 367 Trauma from accident
- 368 Shoulder dislocation/broken shoulder
- 369 Schizophrenia
- 370 Restless leg syndrome
- 371 Hyperkalemia
- 372 Overactive bladder
- 373 Post-traumatic stress disorder
- 374 Hypertensive crisis
- 375 Otosclerosis
- 376 Double vision
- 377 Hypersensitivity pneumonitis
- 378 Legionnaires' disease
- 379 Mononucleosis
- 380 Intussusception of colon
- 381 Deaf (right ear)
- 382 Bladder retention
- 383 Congenital lung disease
- 384 Non tuberculosis mycobacterium
- 385 Factor X1
- 386 Chronic pain (NOS)
- 387 Heartburn/pyrosis
- 388 Kienbock's disease
- 389 Ankylosing spondylitis
- 390 Cholestatoma
- 391 Barrett's disease
- 392 Put in heart defibrillator
- 393 Guillain-Barré
- 394 Hematuria
- 395 Idiopathic thrombocytopenic purpura (ITP)
- 396 Subdural hematoma
- 397 Pilonidal cyst surgery
- 398 Mastoiditis
- 399 Pituitary gland removed

D3a. Other cancer: see type of cancer on page 3.**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	042 Breast felt different
002 Swelling/redness/rash	043 Enlarged axillary lymph node
003 Breast drainage/ Breast leakage	044 MRI
004 Soreness/sensitivity/discomfort	045 Child bumped into it
005 Thickening	046 Cat jumped on her
006 Edema	047 "Breast felt heavy"
007 Inverted nipple	048 Participant found lump under her arm
008 Mammogram (not routine)	049 Spot looked like an insect bite
009 Pain/ dull achy	050 Participant had arm-and-leg pain from pathological fractures caused by bone metastasis
010 Lump resembling a boil	051 Found a lump & had pain in breast
011 Blood from nipple	052 Breast was warmed with an inverted nipple
012 Biopsy	053 Breast reduction surgery
013 Enlarged nipple	054 Retracted nipple
014 Other individual found lump	055 Increased breast size/change in size
015 Indentation(s)/ skin symptoms	056 Participant denies having breast cancer
016 Asymmetry	057 Hard/red Spot
017 "liver pain"	058 Pinhole in nipple
018 Lumps followed / Lumps monitored / calcification	059 Abscess/boil/sore/blister/ulcer
019 Dimpling/wrinkling/puckering	060 CT Scan, (NOS)
020 Discoloration	061 Prophylactic mastectomy
021 Discharge from nipple (not blood)	062 Hernia repair
022 Had surgery for infection	063 Benign Tumor removed from cervical spine
023 Back pain	064 Pre-existing lump changed
024 Nipple irritation	065 Prayer
025 She could see it	066 "Something was wrong"
026 Small bumps, itching	067 Change in shape
027 Ultrasound	068 Lymphedema in arm/trunk
028 Car accident – diagnostic tests run	069 Misdiagnosed mastitis
029 CT scan for chest pain while coughing	070 X-Ray
030 Acute, intermittent breast pain	071 Skin numbness
031 Hard bump from fall	072 Swollen breasts and palpable lymph nodes under arm
032 CT scan for blood clot	073 Breast felt hard/firm
033 Trauma	074 Arms swollen and lump in neck
035 Pain and thickening of skin	075 Found during hospital stay (NOS)
036 Bleeding and pain in left nipple	076 Surgery (NOS)
037 Blood in bra	077 Irritation and skin dimpling
038 Warm breast	078 Pain in breast bone/sternum
039 PET scan	079 Breast specific gamma imaging (BSGI)
040 "Something didn't feel right in the left armpit"/Left arm pain/Armpit pain	080 Abdominal pain checkup
041 Paget's disease of the breast	

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

D7a. Breast condition (not cancer)**CODE UP TO 4 CONDITIONS**

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

999 Don't know (Use in Phase 3)

- | | |
|---|---|
| 001 Benign tumor, cyst, fibrocystic disease
(Phyllode's tumor) fibroadenoma / negative
biopsy | 032 Oil cyst (post traumatic) |
| 002 Thickening | 033 Boils |
| 003 "Spot", discoloring, skin condition/mole | 034 Fluid in breast |
| 004 Microcalcifications | 035 Sarcoidosis |
| 005 Mastitis / breast infection / breast abscess | 036 Pocket |
| 006 Lump/Growth/tumor NOS | 037 Blood from nipple/ducts |
| 007 Clogged milk duct/swollen milk duct/milk
cyst/galactocele / enlarged milk ducts | 038 Itchy rash / rash |
| 008 Galactorrhea | 039 Varicose veins in breast |
| 009 Calcium deposits/Calcification | 040 Atypical hyperplasia |
| 010 Breast felt hot | 041 Dysplasia / Atypical cells / Precancerous
tissue |
| 011 Inflammation of scar tissue/scar tissue | 042 Mass of blood / hematoma / hemangioma |
| 012 Discharge/Clear fluid draining/cyst drained
(fluid-filled) / Cyst aspiration / nipple
discharge | 043 Milk gland (3 rd breast) |
| 013 Enlarged lymph node | [044] Lumpy breast - should be 006 DON'T
USE |
| 014 Scarred tissue | 045 "Milk on breast" at birth, was surgically
removed |
| 015 Growth or knot after injury/Knot, NOS | 046 Benign duct epithelium |
| 016 Abnormal mammogram finding/spot on
Mammogram / abnormal scan finding | 047 Follicular adenoma |
| 017 Breast abscess/infected tissue | 048 "Abnormal breast biopsy" |
| 018 "Cords" in breast | 049 "Bleeding tumor" |
| 019 Breast trauma/injury NOS | 050 Cellulitis |
| 020 Calcified milk duct | 051 Lobular carcinoma in situ (LCIS)/Lobular
neoplasia |
| 021 Lymph adenoma | 052 Painful condition treated with antibiotic |
| 022 "Fatty" tumor / fatty tissue | 053 Sharp / general pains |
| 023 Density / abnormal density on mammogram | 054 Thrombosis vein |
| 024 Inflammation of breast / edema due to
inflammation | 055 Burn injury |
| 025 Inverted nipple | 056 Cluster cysts |
| 026 Papilloma | 057 Angiofibroma |
| 027 Glandular breast | 058 Nipple bitten off |
| 028 Nodules | 059 Infected milk ducts |
| 029 Sensitivity/Soreness | 060 Lactiferous duct fistula |
| 030 "A place they watched" | 070 Swollen breasts with palpable nodes |
| 031 Aging condition | 071 Dry and scaly nipple |
| | 072 Shingles |
| | 073 Phlebitis of breasts |
| | 074 Benign skin changes (NOS) |

D19. Why chest X-rays

CODE ONE RESPONSE

Note: pre-operative/hospital admission/operative follow-up should be reported in category "C".

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

999 Don't know (Use in Phase 3)

030 Before having children

047 Research study

064 Breast Implants

065 To donate blood

ADD new codes

101 Car accident

[102] Surgical pre-op **(should be in "C") DON'T USE**

103 Patient request

104 TB screening

105 Poland requires yearly radiographs of chest

106 Required at discharge from military

D32. Body parts checked by CAT Scan

CODE ONE RESPONSE

99 Don't know

01 Ankle

02 Back/spine

03 Neck/throat

04 Kidneys and bladder

05 Knee

06 Back and shoulder

07 Shoulder

08 Knee and back

09 Neck and back/spine

10 Hips and shoulder

11 Kidneys

12 Hip

13 Back and legs

14 Neck and knee

15 Leg(s)

16 Thyroid

17 Back and hip and shoulder

18 Back and spine and hips

19 Neck and shoulders

20 Throat and arm

21 Arm/Hand

22 Left side

23 Foot

24 Knee and arm

25 Back and hip and right torso

26 Back and Hips

27 Legs and unknown second site

28 Neck and arm

29 Back and unknown site

30 Leg and arm(s)

31 Hip and knee

D34 (1st column) Diseases treated with radiation**CODE UP TO 3 DISEASES****(The diseases are listed in alphabetical order)**

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

999 Don't know (Use in Phase 3)

003 Acne
 039 Allergic reaction
 062 Anal Cancer
 012 Birthmark/mole
 025 Blood clot
 001 Cancer
 032 Cardiomyopathy
 058 Chemical burn
 021 Chest cold
 053 Choroidal Melanoma
 051 Coronary artery disease
 022 Cyst
 044 Ear infections
 014 Eczema
 056 Endometriosis
 005 Enlarged Thymus
 019 Exposed blood vessel
 031 Eye infection
 030 Fungus
 050 Furunculosis (Boils)
 024 Goiter
 045 Granuloma
 027 Grave's disease
 054 Heart surgery complication
 046 Hemangioma
 042 Histoplasmosis
 037 Hodgkin's Lymphoma / Hodgkin's disease
 017 Hook worm
 002 Hyperthyroidism
 048 Hypofunctioning thyroid nodule ("cold nodule")

009 Hypothyroidism
 041 Infertility
 010 Keloids
 028 Kidney ailments (NOS)
 035 Laryngitis
 055 Lumbar lipoma
 006 Lungs (spot on lungs)
 061 Melanoma
 052 Mesothelioma
 038 Multiple myeloma
 011 Myasthenia Gravis
 047 Non-Hodgkin's Lymphoma
 059 Papillary Carcinoma
 026 Parathyroid adenoma
 018 Plantar warts/any warts
 007 Pleurisy
 033 Pneumonia
 057 Psoriasis
 020 Pulled ligament
 029 Rash
 034 Rheumatoid Arthritis
 004 Rheumatic fever
 060 Sluggish gallbladder
 049 Thymus gland
 023 Thyroid problem/NOS
 040 To rule out tuberculosis
 008 Tonsillitis/Enlarged Tonsils & Adenoids/Strep Throat
 013 Tuberculosis
 016 Tumor/growth (not cancer)/lump/keloid
 043 Uterine blister
 036 Uterine bleeding (excess)
 015 Vaginal rash

D34 (2nd column) Body part treated with radiation: See sites of cancer on page 3.

E10. Type of birth control patch

999 Unknown

001 Ortho-Evra

E15. Type of hormone injections or implants

999 Unknown

001 Depo Provera

002 Mirena

003 Norplant

004 Lunelle

005 Depo Provera & Norplant

006 Depo Provera & Mirena

007 Lupron

008 Depo Provera & Mirena & Implanon

009 Norplant and Implanon

010 Implanon

011 Norplant and Mirena

*Do not add codes for hormone medications; consult with Mary Beth first.***NOTE: if hormone dose is unknown, write 999 in the dose field. For combination drugs with unknown dosage, write 999 in the first dosage field and leave the second one blank.****E22a. Combination estrogen/progesterone pill****999 Unknown****Activella**

001 Unknown Dose

014 1.0 mg/0.5 mg

018 0.5 mg/.1 mg

Angeliq

016 0.5mg/1.0mg

FemHRT

002 2.5 mcg/ 0.5 mg

003 5 mcg/ 1 mg

020 FemHRT, unknown dose

Kliogest

004 2/1 mg

Kliovance

005 1/0.5 mg

Mimvey

021 1.0/0.5 mg

Nuvelle

006 2 mg/ 75 mcg

Ortho-Prefest

007 1/0.09 mg

017 Unknown dose

Premelle

015 Unknown dose

Premphase

008 0.625/5 mg

019 Unknown dose

Prempro

009 0.3/1.5 mg

010 0.625/2.5 mg

011 0.625/5 mg

012 0.45/1.5 mg

013 Unknown dose

E22b. Premarin or other estrogen pills**999 Unknown pill****Amnestrogen**

041 0.3 mg
042 0.625 mg
043 1.25 mg
044 2.5 mg

Cenestin

045 0.3 mg
046 0.45 mg
047 0.625 mg
048 0.9 mg
049 1.25 mg

Diethylstilbestrol (DES)

050 0.1 mg
051 0.25 mg
052 0.5 mg
003 1 mg
015 5 mg
034 Unknown dose

Enjuvia

053 0.3 mg
054 0.45 mg
109 0.625mg
055 1.25 mg
108 Unknown dose

Estinyl

017 0.02 mg
018 0.05 mg
016 0.5 mg

Estrace (Estradiol)

032 0.5 mg
014 1 mg
020 2 mg
028 Unknown dose

Estratab

024 0.3 mg
023 0.625 mg
021 1.25 mg
022 2.5 mg
033 Unknown dose

Estratest

029 0.625/1.25 mg
030 1.25/2.5 mg
031 Unknown dose

Estrocon

056 0.625 mg
057 1.25 mg

Estrofem

058 2 mg

Estrogenmtest HS

111 0.625mg/
1.25mg

Estropipate

059 0.75 mg
060 1.5 mg
061 3 mg

Estrovis

026 100 mcg

Ethinyl Estradiol

062 10 mcg

Evex

063 0.625 mg
064 1.25 mg
065 2.5 mg

Femogen

066 0.625 mg
067 1.25 mg
068 2.5 mg

Femtrace

069 0.45 mg
070 0.9 mg
071 1.8 mg

Formatrix

072 Unknown dose

Gynetone

073 0.02 mg
074 0.04 mg

Gynodiol

075 1 mg
076 1.5 mg

Hormonin

077 Unknown dose

Mediatric

078 Unknown dose

Menest

011 0.3 mg
010 0.625 mg
012 1.25 mg
009 2.5 mg
036 Unknown dose

Menrium

079 **5-2**, 5/0.2 mg
080 **5-4**, 5/0.4 mg
081 **10-4**, 10/0.4 mg

Milprem

082 0.45/200 mg
083 0.45/400 mg

PMB

084 0.45/200 mg
085 0.45/400 mg

Ogen

005 0.625 mg
004 1.25 mg
006 2.5 mg
086 6 mg
027 Unknown dose

Ortho-Est

002 0.625 mg
087 0.75 mg
008 1.25 mg
088 1.5 mg
110 Unknown dose

Ovestin

089 2 mg

Premarin

019 0.3 mg
090 0.45 mg
007 0.625 mg
001 0.9 mg
025 1.25 mg
013 2.5 mg
107 Unknown dose

Premarin w/ methyl.

091 0.625/5 mg
092 1.25/ 10 mg

Progynova

093 2 mg

SK-Estrogen

094 0.3 mg
095 0.625 mg
096 1.25 mg
097 2.5 mg

Tace

098 12 mg
099 25 mg
100 72 mg
035 unknown dose

Vallestril

101 3 mg
102 20 mg

Zeste

103 0.625 mg
104 1.25 mg
105 2.5 mg

Zeste w/ methyl.

106 2.5/unk mg

E22c, e, f. Progestins**999 Unknown pill****Amen**

012 10 mg

Aygestin

023 2.5 mg

010 5 mg

021 10 mg

022 Unknown dose

Currtab

008 10 mg

Cycrin

004 2.5 mg

005 5 mg

006 10 mg

015 Unknown dose

Gynorest

031 5 mg

032 10 mg

Medroxyprogesterone

020 2.5 mg

026 5 mg

007 10 mg

019 Unknown dose

Megace

033 20 mg

Microgest

034 100 mg

035 200 mg

Namenda

036 10 mg

Norethindrone

039 2 mg

Norlutate

011 5 mg

024 Unknown dose

Norlutin

009 5 mg

Prometrium

025 100 mg

037 200 mg

Provera

001 2.5 mg

002 5 mg

003 10 mg

014 Unknown dose

E22d. Estrogen Patches**999 Unknown patch****Alora**

001 0.025 mg

002 0.05 mg

003 0.065 mg

004 0.075 mg

005 0.1 mg

035 Unknown dose

Climara

006 0.025 mg

007 0.0375 mg

008 0.05 mg

009 0.06 mg

010 0.075 mg

011 0.1 mg

033 Unknown dose

Climara Pro

012 0.045/0.015 mg

Combipatch

013 0.05/0.14 mg

014 0.05/0.25 mg

040 Unknown dose

Esclim

037 Unknown dose

015 0.05 mg

016 0.1 mg

Estraderm

017 0.05 mg

018 0.1 mg

039 Unknown dose

Estradiol

019 0.025 mg

020 0.0375 mg

021 0.05 mg

022 0.06 mg

023 0.075 mg

024 0.1 mg

036 Unknown dose

Progynova

025 50 mcg

Vivelle

026 0.05 mg

027 0.1 mg

034 Unknown dose

Vivelle dot

028 0.025 mg

029 0.0375 mg

030 0.05 mg

031 0.075 mg

032 0.1 mg

038 Unknown dose

E22g. Other hormones

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

Do not code use of Tamoxifen, Raloxifene, Arimidex, Aromasin, and Femara. These should be reported in E20.

- 99 Don't Know
- 01 Halotestin
- 02 Lupron
- 03 Male Hormone (NOS)
- 04 Danazol/Danocrine
- 05 DES injection / DES
- 06 Clomid
- 07 ** NA **
- 08 ** NA **
- 09 Testosterone, unknown dose
- 10 Progesterone vaginal suppositories
- 11 HCG injections
- 12 Femring/Estrogen Vaginal Ring/Estring/Estradiol Vaginal Ring
- 13 Bio-identical estrogen/progesterone cream
- 14 Menotropin medications (Menopur, Menogon, Pergonal)
- 15 Bio-identical Testosterone cream
- 16 Estrogen Vaginal Suppositories (Vagifem)
- [17] Estrogen Vaginal Ring DO NOT USE, Code as 12 - Femring/Estrogen Vaginal Ring/Estring/Estradiol Vaginal Ring**
- 18 Bio-identical estrogen/progesterone sublingual tablets
- 19 **NOT USED**
- 20 Progestin Injection for fertility
- 21 Fertility pill
- 22 Follicle Stimulating Hormone injection (FSH)
- 23 Progesterone Injections
- 24 Divigel (Topical gel)

F6, F9, F12, F15 Type of moderate/vigorous physical activity**CODE UP TO 3 ACTIVITIES**

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

999 Don't Know (use in Phase 3)

001 Walking / treadmill	030 Cleaning homes for work
002 Aerobics, exercise class, work out on exercise equipment, Gym.	031 Training dogs / playing with pets
003 Bicycling / stationary bicycle	032 Waitressing / walking a lot for work.
004 Gardening, yard work	033 Pilates
005 Stair climbing/stair stepper	034 Moving furniture
006 Golf	035 Carrying/chopping wood, bricks
007 Tennis / racquetball	036 Painting
008 Other games/sports	037 Carrying heavy objects/up stairs
009 Work around the home/Housework	038 Caring for someone/pushing husband in wheelchair & helping him with personal care
010 Running/jogging	039 Occupational therapy
011 Swimming	040 Badminton
012 Dancing/Zumba	041 Washing car/working on car/boat
013 Horseback riding/grooming; Mule riding	042 Cleaning stalls
014 Geriatric exercise	043 Caring for horses
015 Stretching and Toning exercises/ Floor exercises	044 Sit-ups, abs workout
016 Physical Therapy / Rehabilitation	045 Shopping
017 Water aerobics/Water activity, (NOS)	046 Cooking/Canning
018 Weight lifting	047 Choir director
019 Busy lifestyle	048 Hula hoop
020 Rollerblades/skates	049 Fishing
021 Hiking	050 Sailing
022 Play catch/softball	051 Basketball
023 Child care	052 Rock Climbing
024 Martial arts	053 Roofing/Construction/Remodeling/Home Improvement/Decorating
025 Yoga	054 Sexual Activity/Sex
026 Bowling	055 Trampoline exercises
027 Jumps rope	056 Water Skiing
028 Cardio-workout, NOS	057 Rafting/Kayaking/Canoeing
029 Resistance training / strengthening exercises	058 Exergaming
	059 Farm work
	060 Kickball

G2-G4. These are TEXT ONLY (no codes needed), up to **60 characters**.

Shorten or edit as necessary to fit 60 characters or less, make sure the words are legible.

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

G10, G11. Other work you do most (since/prior diagnosis) CODE ONE RESPONSE*(Codes should be in sync with FU#2 App A. - A101)*

999 Don't know	014 Driving
001 Climbing on ladder and moving equipment	015 Restaurant duties
002 Lifting patients/children	016 Running
003 Stooping for cleaning	017 Pushing / pulling / reaching
004 Heavy lifting	018 Nurse / caregiver duties
005 Housekeeping	019 Talking
006 Swimming	020 Work with hands and arms (NOS)
007 Dancing	021 Travel
008 Playing with children	022 Cooking
009 Computer work	023 Yardwork/gardening
010 Volunteer	024 Ultrasound Technician (right hand scanning)
011 Writing	025 Very Active (NOS)
012 Exercising/Fitness	026 Administrative/Clerical duties
013 Climbing stairs	027 Light weight labor
	028 Teaching

H2. Other Racial/Ethnic Groups**CODE ONE RESPONSE**

99 Don't Know
02 Multi-racial / mixed race
03 Spanish/Hispanic/Latino
[04] Asian/Pacific Islander - DON'T USE, Code as "04" Asian/Pacific Islander
[05] Indian - DON'T USE, Code as "04" Asian/Pacific Islander
[07] Latino – DON'T USE, Code as "03" Spanish/Hispanic/Latino
[08] Columbian – DON'T USE, Code as "03" Spanish/Hispanic/Latino
09 Jamaican
10 Arab/Arab-Berber
[11] East Indian DON'T USE, Code as "04" Asian/Pacific Islander

H7, H8, H9 Other Occupational Categories**CODE ONE RESPONSE EACH**

Sometimes, a woman reports a job title which should have been classified in one of the occupation categories. If you have a question about whether to place a job/occupation to a category, consult the list titled "1990 Occupational Classification System" located in the binder or on-line.

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

99 Don't Know
01 Marriage lasted only a short while
02 Self-employed/Business Owner
03 Military
04 Professional Athlete
05 Government worker
[06] Tour guide – should be #2 (service worker or laborer) DON'T USE
[07] Food service – should be #2 (service worker or laborer) DON'T USE
[08] Medical assistant – should be #2 (service worker or laborer) DON'T USE
[09] Clergy, minister – should be #5 (professional, etc.) DON'T USE
[10] Meat plant worker – should be #2 (service worker or laborer) DON'T USE
11 Student
12 Military chef
[13] Trophy maker / Engraver – should be #3 (craftworker, etc.) DON'T USE
14 Farm worker and clerical worker
[15] Interior designer – should be #5 (professional, etc.) DON'T USE

- 16 On disability / Retired due to medical problems
- [17] Farmworker and service worker/ laborer – **should be #1 (Farmer, farm worker) DON'T USE**
- 18 Housewife/Househusband
- [19] Taxi driver – **should be #2 (service worker or laborer) DON'T USE**
- [20] Security guard – **should be #2 (service worker or laborer) DON'T USE**
- [21] Landscaper – **should be #2 (service worker or laborer) DON'T USE**
- [22] Tobacco buyer – **should be #5 (professional, etc.) DON'T USE**
- [23] Certified Nursing Assistant (CNA) – **should be #2 (service worker or laborer) DON'T USE**
- [24] Truck Driver – **should be #2 (service worker or laborer) DON'T USE**
- [25] Independent Contractor, business owner – **should be #5 (professional, etc) DON'T USE**
- [26] Accounting clerk – **should be #4 (clerical worker, etc) DON'T USE**
Accountant – should be #5 (professional, etc) DON'T USE
- [27] Logger – **should be #1 (farmer, farm worker) DON'T USE**
- 28 Farm worker and factory worker

I6 Other Health Care Provider

CODE ONE RESPONSE

- 99 Don't know
- 01 Clinic, not health dept/Student Services Clinic
- 02 Physician's assistant
- 03 Nurse practitioner
- 04 Physician outreach
- 05 Veteran's administration
- 06 Chiropractor
- 07 Acupuncturist, Reiki Master, Psychotherapist
- 08 Dentist
- 09 Podiatrist
- 10 Ophthalmologist/Optometrst
- 11 Physical Therapist
- 12 Psychologist
- 13 Periodontist
- 14 Military Physician
- 15 Midwife

I17 Hospital Name and Location of Clinical Trial

CODE ONE RESPONSE

- 99 Don't know
- 01 Carolinas Medical Center (Blumenthal Cancer Center), Charlotte, NC (& Mecklenburg Medical Group)
- 02 Pitt County Hospital (ECU/Leo Jenkins Cancer Center), Greenville, NC
- 03 Kinston Medical Specialists, Kinston, NC
- 04 Clinic in Jacksonville, NC
- 05 Rex Hospital (Rex Cancer Center), Raleigh, NC
- 06 Southeastern Medical Oncology Center, Goldsboro, NC
- 07 Roanoke-Chowan Hospital, Ahoskie, NC
- 08 High Point Regional Hospital (High Point Cancer Center), High Point, NC
- 09 Wake Forest University Baptist Medical Center, Winston-Salem, NC
- 10 Southeastern Medical Oncology Center, Wilson, NC
- 11 UNC Hospital, Chapel Hill, NC
- 12 Marion L Shepard Cancer Center, Washington, NC
- 13 Moffitt Cancer Center, Tampa, FL
- 14 First Health Moore Regional (Pinehurst Medical Center), Pinehurst, NC
- 15 Waverly Hematology-Oncology, Cary, NC
- 16 Duke University, Durham, NC
- 17 Physician's East, Greenville, NC
- 18 Forsyth Memorial Hospital (Derrick L. Davis Forsyth Regional Cancer Center), Winston-Salem, NC
- 19 Emerywood Hematology-Oncology, High Point, NC

- 20 Wilmington Health Assoc. Oncology, Wilmington, NC
- 21 Total Cancer Care, Unknown, FL
- 22 Winston-Salem Health Care Internal Medicine, Winston-Salem, NC
- 23 Alamance Regional Medical Center, Burlington, NC
- 24 Carolinas Medical Center-Northeast (Northeast Medical Center), Concord, NC
- 25 Hanover Medical Specialists, Wilmington, NC
- 26 Piedmont Hematology Oncology, Winston Salem, NC
- 27 Duke Raleigh Hospital, Raleigh, NC
- 28 Wake Radiology, Cary, NC
- 29 Cancer Centers of North Carolina—Cary Office, Cary, NC
- 30 Cancer Centers of North Carolina—Raleigh Office, Raleigh, NC
- 31 Annie Penn Cancer center – Reidsville, NC
- 32 Moses H. Cone Memorial Hospital (Regional Cancer Center) – Greensboro, NC
- 33 UNC Greensboro – Greensboro, NC
- 34 New Hanover Regional Medical Center/Zimmer Cancer Center – Wilmington, NC
- 35 Johnston Cancer Center – Smithfield, NC
- 36 Presbyterian Hospital – Charlotte, NC
- 37 Cape Fear Valley Cancer Center – Fayetteville, NC
- 38 Wayne Memorial Hospital – Greensboro, NC
- 39 Eastern North Carolina Medical Group – Rocky Mount Office, Rocky Mount, NC
- 40 Piedmont Hematology Oncology - Kernersville, NC
- 41 Southeastern Medical Oncology – Rocky Mount, NC
- 42 Coastal Carolina Radiology Oncology – Wilmington, NC
- 43 South Atlantic Radiation Oncology – Supply, NC
- 44 Matthews Hemotology Oncology Associates – Matthews, NC
- 45 Levine Cancer Institute – Charlotte, NC

J3d. Who diagnosed your lymphedema?

(Codes should be in sync with FU#2 App A. – A3d)

CODE ONE RESPONSE

99 Don't know

- 01 Self
- 02 Cancer center staff / Clinic staff
- [03] Nurse practitioner—**should be option “b” for “nurse” DON’T USE**
- [04] Surgeon—**should be option “a” for “medical doctor” DON’T USE**
- [05] Nurse Navigator—**should be option “b” for “nurse” DON’T USE**

- 06 Lymphedema specialist
- 07 Physician's Assistant
- 08 Occupational Therapist
- [09] Plastic Surgeon—**should be option “a” for “medical doctor” DON’T USE**
- 10 Imaging test
- 11 Resource / patient Navigator (social worker)

J7h. Other people you talked with about your breast cancer **CODE ONE RESPONSE**
(Codes should be in sync with FU#2 App A. – A7)

- 99 Don't know
- 01 Navigator
- 02 Clients at work
- 03 Good friend
- 04 Parents at school where she works
- 05 Hospital worker / medical team
- 06 Support group
- 07 People that I meet/Strangers
- 08 Therapist / Mental health counselor
- 09 Another breast cancer survivor / person with breast cancer
- 10 "Anyone who will listen"
- 11 People at the cancer center
- 12 Prayer partners / church members / Bible study / Praise dance
- 13 Doctor's office staff
- 14 Internet blog/online communication
- 15 Students / classmates
- 16 Doctors
- 17 Patients
- 18 Father of child(ren)
- 19 Sponsor (AA)
- 20 Writing and blogging
- 21 Management of apartment complex
- 22 Employer(s)
- 23 Case Manager / Social worker (Health insurance, etc)
- 24 Participant denies having breast cancer
- 25 Sara/Nicole/CBCS Recruiter
- 26 Sorority sisters
- 27 Bingo players
- 28 Pray/Talk to God/A higher being
- 29 Prefers not to talk about her cancer
- 30 Women in general
- 31 Facebook/Twitter/Social Media
- 32 Public speech
- 33 Customers
- 34 Landlord
- 35 Exercise instructor
- 36 Non-Profit organizations / charitable organizations / Patient Advocates
- 37 Children's teachers
- 38 Attorneys
- 39 Community members
- 40 Swim team
- 41 Ex-husband
- 42 Newspaper / print media
- 43 Supervisor
- 44 Myself

K1. Comments**CODE UP TO 3 COMMENTS**

These comments have been classified into different categories, hopefully, the codes will be easier to find.

Comments about the survey/study***General Comments***

- 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 and cures of breast cancer/ Glad to see this research being done / Any information is valuable
- 017 Wanted more money
- 031 Some questions need refinement
- 034 Interested in knowing results
- 042 Participant wished she knew more about survey beforehand, so she could have prepared
- 044 Survey was thorough/ covered everything
- 051 Frustrated about figuring out amounts & frequencies / questions about amounts are vague
- 056 Difficult to recall X years ago / difficult to remember accurately
- 065 Thyroid questions were good and relevant to her
- 071 Concerned with the reliability/ accuracy of her responses to diet questions / alcohol use
- 078 Concern about confidentiality
- 085 The life events section was important
- 088 Wondered how this study will help/ very harmless/ hope it helps someone
- 089 Concern about mix-up of lab samples
- 099 Surprised to get letter
- 118 Wondered why questions only X years back/ Questions from earlier years are important
- 138 Ask if people are lesbian--does partner question include same sex?
- 139 Thought questions were relevant
- 143 Questions were difficult to answer
- 147 Questions on birth control pills should be asked differently
- 157 Questions should be more general
- 183 Wonders how studies are designed and how they work/ why she was chosen
- 188 It would be nice if you took referrals for participants
- [194] Very interesting – **should be 064 DON'T USE**
- [195] Pleasant interview – **should be 064 DON'T USE**
- 198 Why me?
- 200 Didn't like question about weight
- 234 Glad we were realistic about time it takes to complete survey / **Glad we conduct interviews at home**
- 235 Answered DASH questionnaire differently due to recent surgery
- 245 Survey made her think about how breast cancer changed her life
- 248 Interesting how answers could vary depending on interview date vs. diagnosis date
- 251 Participant glad that she's in NC
- 281 Loved the CBCS DVD
- 288 Certain question(s) should not be asked
- 294 QOL response affected by breast cancer related symptoms and issues

Complaint: no questions were asked or need more questions of the followings:

- 045 No questions about social activities/organization that a person is involved in
- 046 No asbestos questions, concerned about occupation exposure
- 054 More questions about exposure to radiation
- 055 More questions on surgery and treatment and side effects of surgery or treatment
- 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, diet, and nutrition
- 067 More questions on family history (Great Aunts had mastectomy), more genetic inquiry
- 068 More questions regarding sexual history
- 075 More medical history questions needed
- 083 More questions about family related stressors/ more comprehensive assessment of stress

- 096 Surprised we didn't inquire about water system
- 106 Support helps recovery/ more questions on support
- 114 More questions on menstrual history/ female problems
- 117 More questions about specific exercises
- 125 No questions about being breast fed as an infant
- 132 Emotional aspect was not addressed
- 133 Happy that questions were not too probing
- 136 More questions about medications, vitamins and herbs that women take
- 140 No chemo treatment questions
- 149 No questions about blood pressure
- 156 Surprised did not ask about parents' health / both had TB
- 158 Rural vs. Urban should be studied
- 167 No questions on electric blankets
- 168 More questions on environment
- 169 More questions about culture
- 173 Expected questions about previous surgeries
- 175 Surprised didn't ask about any prescription meds. taken routinely vs. specific meds
- 187 Need more questions on farms and pesticides (living adjacent to a farm, specific crops) and household use of insecticides
- 190 Would like a study on effects of chemo on decreased sex life
- 192 Should ask about alternative treatments received (eg. Hypothermia treatment).
- 202 Should ask about abnormalities that are not usually mentioned as symptoms
- 203 Should ask about conditions that overlap the symptoms (auto-immune diseases)
- 205 Has pain in breast from lymph node dissection/concerned this wasn't captured on DASH/QOL
- 209 Thinks QOL section should ask about past 14 days or more
- 210 QOL section confusing
- 211 Thinks it's cruel to ask questions about hair care to patients with hair loss due to chemo
- 215 Survey was hard
- 216 Interview was more in depth than participant thought it would be (in general or specific question)
- 218 A lot of reading (especially consent)
- 228 In section J7, should include "Survivor"
- 231 Thinks QOL has some "crazy questions"/ "stupid questions"
- 233 QOL should focus on amount of time to do activities
- 237 Survey too involved/took too long/too many questions
- 238 QOL section didn't adequately address some issues
- 246 Survey not thorough enough
- 249 Participant didn't like wording of survey, could be offensive/disheartening (ex. "illness")
- 254 More questions on Breast Cancer education
- 262 More questions regarding how diagnosis affects pt.'s job/how they make a living
- 263 More questions on impact of treatment costs
- 277 More psychological questions

Concerned/Worried/Wondered about the following (in alphabetical order):

(Could be related to breast cancer or some other general concerns)

- 236 Allergy shots/immunotherapy
- 123 Bras (can't get one to fit)
- 111 Breast - wonders if large breasted women have increased risk
- 015 Breast implants/ No questions about breast implants
- 082 Breast pain
- 013 Breast trauma
- 019 Caffeine, coffee consumption
- 001 Cancer clusters, Increase in cancer needs to be investigated
- 025 Cancer in pets
- 010 Chemical exposures, NOS/ environmental exposure/ preservatives in food / contaminated water
- 028 Chemical exposure at work/work history
- 240 Child(ren) - Worried about who will take care them if she died, (NOS)
- 166 Common factors between self and mother (mom has breast cancer)

- 026 Computer exposure
- 148 DES - Mother took DES during pregnancy / Participant exposed to DES
- 007 Detection or treatment of cancer/ unnecessary surgery
- 181 Deodorants
- 179 Depression
- 087 Diet pills / drastic weight fluctuations in last 5 years
- 119 Dietary factors
- 122 Dental health (poor)
- 137 Dominant side and where breast cancer develops
- 043 Drug use
- 120 EMF exposure / cell phone exposure
- 006 Estrogen / Hormone use
- 011 Family history
- 061 Fat consumption
- 159 Father was exposed to chemicals after she was conceived
- 208 Fertility drugs playing a role in breast cancer
- 047 Foods prepared in microwave
- 008 Food/water/ meat consumption / alcohol consumption
- 155 Fumes from tobacco companies
- 086 Gender roles (i.e. women as breadwinner)
- 006 Hormone / Estrogen use
- 206 Inflammation - Excessive inflammation
- 241 Insurance companies – Worried/hesitant to answer questions that insurance companies may find
- 016 Lactation/ passing down breast cancer susceptibility via breast feeding / milk not drying up for 1 year post-pregnancy
- 250 Latex allergy as problem for blood draw/treatment
- 135 Mammogram experiences/ Concerned about accuracy of mammograms / Should do ultrasound also
- 022 Marijuana use
- 014 Medication use
- 264 Menopausal symptoms (hot flashes, etc.)
- 201 Mercury exposure
- 062 Occupation concern, (poor ventilation), NOS
- 009 Other medical conditions' relationship to breast cancer
- 193 Paget's Disease: concerns regarding nipple ring & Paget's disease
- 023 Physical abuse from parent and husband
- 041 Physical activity / swimming
- 207 Pregnancy - difficult or "at risk" pregnancies / difficulties after pregnancies
- 227 Pregnancy - breast cancer incidence during pregnancy
- 033 Quality of life (how QOL affects breast cancer)
- 115 Radiation exposure / worked in a lab / thermogram exposure
- 080 Radium exposure
- 214 Recurrence, worries about it
- 049 Role of lifestyle in causing cancer / whether someone at age 50 could change
- 021 Sexual activity
- 196 Side effects of treatment/concerned about how she is feeling
- 171 Sleeping on the side of waterbed with heating element
- 199 Sleep issues
- 032 Smoking
- 116 Smoking - second hand smoke exposures
- 012 Stress
- 024 Where she lived
- 110 Women today get more illnesses than they did years ago
- 028 Work history / Chemical exposure at work
- 027 X-rays

Current / past health problems

- 030 Having biopsy soon
- 050 Has asthma

- 057 Had tubes tied early in life
- 058 Losing hair is the most stressful event (treatment is stressful)
- 063 Past diagnosis of anorexia & amenorrhea
- 077 Had cervical dysplasia/ positive pap, other vaginal symptoms
- 079 Has anemia
- 098 Arm was injured during breast cancer surgery
- 134 Lost first kidney in 1969, secondary complications of pregnancy
- 146 Has felt twinges in affected breast for years
- 150 Experiencing pain from car accident / Damaged chest and sternum in a car accident
- 152 Developed irregular heart beat after first chemo treatment
- 153 Developed vaginal bleeding after taking tamoxifen for two days
- 163 Diagnosed with Lupus / SLE
- 189 Rheumatic fever
- 204 Had difficulty getting pregnant
- 217 Patient was very tired before diagnosis or wasn't eating properly
- 224 Participant has problems with hands due to carpal tunnel syndrome
- 265 Participant notes stage/subtype of breast cancer
- 270 Previous/recent physical injury
- 291 Pinched nerve requiring physical therapy and some loss of motion, prior to breast cancer
- 297 Cancer metastasized

Comments about doctors/medical system:

- 038 Not enough concern about women's health problems by male doctors/ intimidated by doctor/ doctors didn't listen / Doctor not thorough/ felt like a number / bad ER experience
- 040 Thought her doctors were kind, considerate / care has been excellent / UNC has a super breast clinic
- 052 Medical system not honest with her
- 076 Doctor should have provided her with more options / should have provided more information
- 081 More money should be spent in research/Important to continue research
- 128 All women with breast cancer should get MRI or CS / screening
- 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
- 177 Would like to have been instructed on more exercises following surgery
- 197 Recommend better/more screening methods
- 247 Had a positive treatment experience, hopes other women have the same / Positive doctors and nurse experience
- 256 Does not like how doctor placed port, painful and difficult to access
- 257 Varying care for patients at different facilities
- 267 Doctors do a poor job communicating/felt she had to be her own advocate / should be better communication between doctors and patients
- 271 Participant was informed that mammograms cause cancer so she stopped having them
- 279 Questions/Plans to get prophylactic mastectomy
- 280 Participant found lump but didn't have insurance and was too young to get mammogram / hard to get care when having no insurance.

What might be related to breast cancer:

- 066 Migraines & fibromyalgia caused stress and may play a role in breast cancer
- 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
- 180 Sprayed dye on silk flowers in an enclosed area for 8 years
- 186 Thinks having lots of uterine fibroids causes breast cancer
- 191 Exposed to bad and toxic chemicals for 12 years.
- 212 Feels she had a predisposition to breast cancer because she is BRCA1/BRCA2 positive
- 220 Worked near world trade center, worried about air quality
- 236 Allergy shots/immunotherapy

Other comments:

- 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 and cures of breast cancer/ Glad to see this research being done / Any information is valuable should ask about other types of cancer
- 017 Wanted more money
- 018 Never thought at high risk / No history
- 020 Has recently begun exercising, exercise helps
- 029 Wondered about next generation's risk
- 031 Some questions need refinement
- 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
- 039 Participant notes she is Jewish/ Greek
- 042 Participant wished she knew more about survey beforehand, so she could have prepared
- 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
- 051 Frustrated about figuring out amounts & frequencies / questions about amounts are vague
- 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 X years ago / difficult to remember accurately
- 059 Didn't ask about other cancers in family/ volunteered more info on family history of cancer
- 060 More questions regarding current health status, diet, and nutrition
- 064 Enjoy time with interviewer/ glad she could help/ nice interview/ very interesting/ positive questionnaire and interview / very informative / very professional /very fulfilling
- 065 Thyroid questions were good and relevant to her
- 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 or therapies for breast cancer / more research into other treatments or therapies
- 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
- 078 Concern about confidentiality
- 083 More questions about family related stressors/ more comprehensive assessment of stress
- 106 Support helps recovery/ more questions on support
- 114 More questions on menstrual history/ female problems
- 117 More questions about specific exercises
- 125 No questions about being breast fed as an infant
- 132 Emotional aspect was not addressed
- 133 Happy that questions were not too probing
- 136 More questions about medications, vitamins and herbs that women take
- 140 No chemo treatment questions
- 149 No questions about blood pressure
- 156 Surprised did not ask about parents' health / both had TB
- 158 Rural vs. Urban should be studied
- 167 No questions on electric blankets
- 168 More questions on environment
- 169 More questions about culture
- 173 Expected questions about previous surgeries
- 175 Surprised didn't ask about any prescription meds. taken routinely vs. specific meds
- 187 Need more questions on farms and pesticides (living adjacent to a farm, specific crops) and household use of insecticides
- 190 Would like a study on effects of chemo on decreased sex life

- 192 Should ask about alternative treatments received (eg. Hypothermia treatment).
 085 The life events section was important
 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
 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
 099 Surprised to get letter
 101 Believes in early detection and getting mammograms
 102 Wishes there soon would be a cure for all cancers
 104 Mother was also interviewed (as a case)
 105 Insurance is dealing with medical bills
 112 Something to do with breast development
 113 Participated in RCT, may have received placebo
 118 Wondered why questions only X years back/ Questions from earlier years are important
 121 First diagnosis was CIS, but she had breast cancer, NOS
 124 Participant notes that she is confused
 126 Notes that father was devoted cancer researcher
 127 Notes family history of alcoholism
 129 Adopted, concerned about family history
 131 Illness has helped participant become more focused / had spiritual and/or mental growth
 138 Ask if people are lesbian--does partner question include same sex?
 139 Thought questions were relevant
 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)/BC takes you for a loop
 147 Questions on birth control pills should be asked differently
 154 Thinks women should get on with their lives after mastectomy / don't let it get you down
 157 Questions should be more general
 162 Mom's family is from NC
 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 / how long it has been there before detection
 170 Has lots of diabetes in her family
 172 Doesn't believe that her cigarette smoking caused her breast cancer
 174 If I had it again, would have lumpectomy
 176 Wondered if chemo had anything to do with developing diabetes
 178 I think my immune system is affected by my lack of sleep
 183 Wonders how studies are designed and how they work/ why she was chosen
 184 Feels women should be more informed about BC prevention & detection/Particularly in AA Women
 185 Thought if I ever got cancer it would be colon cancer
 188 It would be nice if you took referrals for participants
 213 Thinks treatment can be worse than disease/don't wish chemo on anyone/or disease on anyone
 219 Asked how to get genetic testing covered by insurance
 221 "God will heal her"
 222 "You didn't eat the cookies I baked"
 223 Needs financial assistance
 225 Participant did not want to finish QOL
 226 Participant was upset that she did not get the consents ahead of time
 229 Surprised by how sick she has been since her diagnosis
 230 "I have accepted my health/God bless me"
 232 God has a reason for what has happened to her/God helping her through journey

- [239] Needs financial assistance—**DO NOT USE**, SHOULD BE 223
 242 Said she trusted interview – invited her back any time
 243 Did Interview for daughters/Didn't want to do survey, but did it for daughters/daughters (NOS)
 244 Wants to put breast cancer behind her
 252 "This has been a journey"/Taking it one day at a time/It's hard/harder than thought it would be / not satisfied with life right now
 253 Breast cancer was only a mild life disruption / Glad the way things turned out
 255 Participant helps other breast cancer survivors / wants to help others
 258 "There are things worse than death"
 259 Participant is agnostic
 260 BC Resources are important, women should use available resources
 268 Survey brought back memories of childhood/when she was younger
 269 Participants may postpone treatment to have more children
 282 "I feel good" / Participant feels good / positive outlook on life
 283 Speaks poor English / needed translator for questions
 284 Having difficulty empathizing with other women with breast cancer
 285 Participant writing a book
 286 Has not had breast surgery yet
 287 Took birth control pills for extended period/everyday to avoid menstruation
 289 Participant works in medical field / familiar with cancer and cancer treatments
 290 No one cares / no one asks how she's feeling
 292 Regretting treatment option / patient wishes they chose a different treatment option
 293 Nurses need a raise! / doing a great job!
 295 Participant lived near power plant
 296 Always had healthy lifestyle to avoid other illnesses/diseases

Numerical Order

- 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 and cures of breast cancer/ Glad to see this research being done / Any information is valuable should ask about other types of cancers
 006 Estrogen / Hormone use
 007 Detection or treatment of cancer/ unnecessary surgery
 008 Food/water/ meat consumption / alcohol consumption
 009 Other medical conditions' relationship to breast cancer
 010 Chemical exposures, NOS/ environmental exposure/ preservatives in food / contaminated water
 011 Family history
 012 Stress
 013 Breast trauma
 014 Medication use
 015 Breast implants/ No questions about breast implants
 016 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 Caffeine, coffee consumption
 020 Has recently begun exercising, exercise helps
 021 Sexual activity
 022 Marijuana use
 023 Physical abuse from parent and husband
 024 Where she lived
 025 Cancer in pets
 026 Computer exposure
 027 X-rays
 028 Work history / Chemical exposure at work
 029 Wondered about next generation's risk

- 030 Having biopsy soon
- 031 Some questions need refinement
- 032 Smoking
- 033 Quality of life (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/ felt like a number / bad ER experience
- 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 Physical activity / swimming
- 042 Participant wished she knew more about survey beforehand, so she could have prepared
- 043 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 Foods prepared in microwave
- 048 (skipped?)
- 049 Role of lifestyle in causing cancer / whether someone at age 50 could change
- 050 Has asthma
- 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 X years ago / difficult to remember accurately
- 057 Had tubes tied early in life
- 058 Losing hair is the most stressful event (treatment is stressful)
- 061 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 /very fulfilling
- 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 or therapies for breast cancer / more research into other treatments or therapies
- 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 / should have provided more information
- 077 Had cervical dysplasia/ positive pap, other vaginal symptoms
- 078 Concern about confidentiality
- 079 Has anemia
- 080 Radium exposure
- 081 More money should be spent in research/Important to continue research
- 082 Breast pain
- 083 More questions about family related stressors/ more comprehensive assessment of stress
- 084 (skipped?)
- 085 The life events section was important

- 086 Gender roles (i.e. women as breadwinner)
- 087 Diet pills / drastic weight fluctuations in last 5 years
- 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
- 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 (skipped?)
- 101 Believes in early detection and getting mammograms
- 102 Wishes there soon would be a cure for all cancers
- 103 (skipped?)
- 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 (skipped?)
- 110 Women today get more illnesses than they did years ago
- 111 Breast - wonders if large breasted women have increased risk
- 112 Something to do with breast development
- 113 Participated in RCT, may have received placebo
- 114 More questions on menstrual history/ female problems
- 115 Radiation exposure / worked in a lab / thermogram exposure
- 116 Smoking - second hand smoke exposures
- 117 More questions about specific exercises
- 118 Wondered why questions only X years back/ Questions from earlier years are important
- 119 Dietary factors
- 120 EMF exposure / cell phone exposure
- 121 First diagnosis was CIS, but she had breast cancer, NOS
- 122 Dental health (poor)
- 123 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 (skipped?)
- 131 Illness has helped participant become more focused / had spiritual and/or mental growth
- 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 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)/BC takes you for a loop

- 146 Has felt twinges in affected breast for years
- 147 Questions on birth control pills should be asked differently
- 148 DES - Mother took DES during pregnancy / Participant exposed to DES
- 149 No questions about blood pressure
- 150 Experiencing pain from car accident / Damaged chest and sternum in a car accident
- 151 (skipped?)
- 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
- 155 Fumes from tobacco companies
- 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 / how long it has been there before detection
- 166 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 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 Depression / mental turmoil
- 180 Sprayed dye on silk flowers in an enclosed area for 8 years
- 181 Deodorants
- 182 (skipped?)
- 183 Wonders how studies are designed and how they work/ why she was chosen
- 184 Feels women should be more informed about BC prevention & detection/Particularly in AA Women
- 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 took referrals for participants
- 189 Rheumatic fever
- 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).
- 193 Concerns regarding nipple ring & Paget's disease
- [194] Very interesting – **should be 064 DON'T USE**
- [195] Pleasant interview– **should be 064 DON'T USE**
- 196 Concerned about side effects of treatment/concerned about how she is feeling
- 197 Recommend better/more screening methods
- 198 Why me?
- 199 Sleep issues
- 200 Didn't like question about weight
- 201 Concerned about mercury exposure

- 202 Should ask about abnormalities that are not usually mentioned as symptoms
 203 Should ask about conditions that overlap the symptoms (auto-immune diseases)
 204 Had difficulty getting pregnant
 205 Has pain in breast from lymph node dissection/concerned this wasn't captured on DASH/QOL
 206 Concerned about excessive inflammation
 207 Concerned about difficult or "at risk" pregnancies
 208 Fertility drugs playing a role in breast cancer
 209 Thinks QOL section should ask about past 14 days or more
 210 QOL section confusing
 211 Thinks it's cruel to ask questions about hair care to patients with hair loss due to chemo
 212 Feels she had a predisposition to breast cancer because she is BRCA1/BRCA2 positive
 213 Thinks treatment can be worse than disease/don't wish chemo on anyone/or disease on anyone
 214 Recurrence, worries about it
 215 Survey was hard
 216 Interview was more in depth than participant thought it would be
 217 Patient was very tired before diagnosis and wasn't eating properly
 218 A lot of reading (especially consent)
 219 Asked how to get genetic testing covered by insurance
 220 Worked near World Trade Center, worried about air quality
 221 "God will heal her"
 222 "You didn't eat the cookies I baked"
 223 Needs financial assistance
 224 Participant has problems with hands due to carpal tunnel syndrome
 225 Participant did not want to finish QOL
 226 Participant was upset that she did not get the consents ahead of time
 227 Pregnancy – breast cancer incidence during pregnancy
 228 In section J7, should include "Survivor"
 229 Surprised by how sick she has been since her diagnosis
 230 "I have accepted my health/God bless me"
 231 Thinks QOL has some "crazy questions"/ "stupid questions"
 232 God has a reason for what has happened to her
 233 QOL should focus on amount of time to do activities
 234 Glad we were realistic about time it takes to complete survey / Glad we conduct interviews at their homes
 235 Answered DASH questionnaire differently due to recent surgery
 236 Concerned about allergy shots/immunotherapy's relationship to breast cancer
 237 Survey too involved/took too long/too many questions
 238 QOL section didn't adequately address some issues
 [239] Needs financial assistance—**DO NOT USE, SHOULD BE 223**
 240 Child(ren) - Worried about who will take care them if she died
 241 Insurance companies – Worried/hesitant to answer questions that insurance companies may find
 242 Said she trusted interview – invited her back any time
 243 Participant didn't want to do interview, but agreed to do it for her daughters/daughters (NOS)
 244 Wants to put breast cancer behind her
 245 Survey made her think about how breast cancer changed her life
 246 Survey not thorough enough
 247 Had a positive treatment experience, hopes other women have the same
 248 Interesting how answers could vary depending on interview date vs. diagnosis date
 249 Participant didn't like wording of survey, could be offensive/disheartening (ex. "illness")
 250 Latex allergy as problem for blood draw/treatment
 251 Participant glad that she's in NC
 252 "This has been a journey"/Taking it one day at a time/It's hard/harder than thought it would be / not satisfied with life right now
 253 Breast cancer was only a mild life disruption / Glad the way things turned out
 254 More questions on breast cancer education
 255 Participant helps other breast cancer survivors / wants to help others
 256 Does not like how doctor placed port, painful and difficult to access

- 257 Varying care for patients at different facilities
- 258 "There are things worse than death"
- 259 Participant is agnostic
- 260 BC resources are important, women should use available resources
- 261 QOL responses affected by Non-BC related symptoms/issues
- 262 More questions regarding how diagnosis affects pt.'s job/how they make a living
- 263 More questions on impact of treatment costs
- 264 Menopausal symptoms (hot flashes, etc.)
- 265 Participant notes stage/subtype of breast cancer
- 266 Physical therapy helps, particularly on affected side
- 267 Doctors do a poor job communicating/felt she had to be her own advocate / Should be better communication between doctors and patients
- 268 Survey brought back memories of childhood/when she was younger
- 269 Participants may postpone treatment to have more children
- 270 Previous physical injury
- 271 Participant was informed that mammograms cause cancer so she stopped having them
- 272 CBCS Nurse Interviewer was 'better' than interviewer from a different study
- 273 Referred to Brenda McCants / Advocacy team
- 274 Family/friends helping her through BC
- 275 Hard to pull off a sweater
- 276 Worried about BPA/"Bad plastics"
- 277 More psychological questions
- 278 Still attractive and still a woman after BC/Chemo/Has self confidence
- 279 Questions/Plans to get prophylactic mastectomy
- 280 Participant found lump but didn't have insurance and was too young to get mammogram / hard to get care when having no insurance.
- 281 Loved the CBCS DVD
- 282 "I feel good" / Participant feels good / positive outlook on life
- 283 Speaks poor English / needed translator for questions
- 284 Having difficulty empathizing with other women with breast cancer
- 285 Participant writing a book
- 286 Has not had breast surgery yet
- 287 Took birth control pills for extended period/everyday to avoid menstruation
- 288 Certain question(s) should not be asked
- 289 Participant works in medical field / familiar with cancer and cancer treatments
- 290 No one cares / no one asks how she's feeling
- 291 Pinched nerve requiring physical therapy and some loss of motion, prior to breast cancer
- 292 Regretting treatment option / patient wishes they chose a different treatment option
- 293 Nurses need a raise! / doing a great job!
- 294 QOL response affected by breast cancer related symptoms and issues
- 295 Participant lived near power plant
- 296 Always had healthy lifestyle to avoid other illnesses/diseases
- 297 Cancer metastasized
- 298 Study helped her feel more comfortable talking about breast cancer
- 299 Has taken Xyrem for narcolepsy for 10 years
- 300 Participant unaware there were different types of breast cancer
- 301 Would like more information on in vitro fertilization for younger cancer patients
- 302 Breast Cancer has been more emotional than physical
- 303 Scared and initially thought was going to die and did not want to be around people

L4. Modifications to anthropometric measures:**CODE ONE RESPONSE**

- [099] Unknown (phase 2) DON'T USE
- 999 Unknown (Use in Phase 3)
- 001 Over pantyhose
- 002 Over clothes/pants
- 003 Tape measure held in place
- 004 Patient unable to stand/in wheel chair, or due to other physical problem
- 005 Height and weight done at clinic visit with clinic nurse
- 006 Girdle on

- 007 Participant refused (weight)
- 008 Shoes on / Flip flops on
- 009 Pregnant
- 010 Height and weight gotten from medical records
- 011 Participant gave measurement
- 012 Participant had cast on leg
- 013 Participant wore shoes and was measured over pants
- 014 ~~Weighed on carpet~~—Measurement(s) taken on carpet
- 015 Hip and waist not measured due to swelling of area following surgical/treatment procedure
- 016 Measurements taken over corset
- [017] Over thick skirt--(THIS SHOULD BE CODE 002) DON'T USE**
- 018 Some measurements not taken--bilateral amputee/had prostheses
- 019 Wearing vest support
- 020 Survey done in location where measurements not appropriate
- [021] Abdomen swollen from surgery--(THIS SHOULD BE CODE 015) DON'T USE**
- 022 CBCS nurse did measurements with different scale/instruments
- 023 Over thin robe
- 024 Hip measurement taken over abdominal bandage from surgery
- 025 Best estimate, tape too short / used two tapes
- 026 Participant refused waist/hip measurement
- 027 Participant had protruding hernia
- 028 Participant refused waist/hip measurement and weight
- 029 Participant had prostheses, measurements still taken
- 030 Weighed on scale at job
- 031 Weight done at dialysis center on center scales / Used MD's scale / Weight taken on scale other than CBCS's
- 032 Information obtained over phone
- 033 Weight higher than scale could measure
- 034 Nurse's scale incorrect
- 035 Participant had difficulty getting out of bed
- 036 Participant only wanted one measurement done
- 037 Participant's weight measured with shoes & brace; self-reported height
- 038 Height and weight self-reported; refused waist/hip measurements
- 039 Height self-reported; hips weren't measured; waist measured while pt seated
- 040 Height and weight self-reported; waist and hip measurements not taken due to patient being in a wheelchair/sick/could not stand
- [041] Participant unable to stand long enough to get heights and weight measurements--(THIS SHOULD BE CODED 004) DON'T USE**
- 042 Height and weight self-reported; waist and hip done while patient lying down
- 043 Waist and hip measurements obtained from someone other than CBCS nurse
- 044 Height self-reported; weight, waist, hip measurements done by nurse
- 045 Height and weight self-reported; waist and hip measurements not done because location not appropriate
- 046 Height and weight self-reported
- 047 Participant refused all measurements (height, weight, waist, hip)
- 048 Waist measurements taken over bandage
- 049 Measurement(s) self reported from recent doctor's appointment
- 050 Weight self reported
- 051 Height self-reported, weight measured, waist and hips not taken
- 052 Participant used own scale

M1. Where was the Interview

CODE ONE RESPONSE

[099] Unknown (Phase 2) DON'T USE

999 Unknown (Use in Phase 3)

001 Lineberger/CBCS office

002 Raleigh Internal Medicine

003 Alamance Hospital

004 Rex Radiation Oncology/Rex Cancer

- | | |
|--|--|
| Center/hospital | 037 Interviewer's home |
| 005 Heritage Hospital in Tarboro | 038 Church |
| [006] Workplace (should be 41) DON'T USE | 039 Store |
| 007 VA Hospital | 040 Hanes Hall at Duke |
| 008 Wayne Memorial Hospital | 041 Participant's office/workplace |
| 009 Pinehurst Clinic | 042 Clinic NOS / Cancer center NOS |
| 010 Bertie Memorial | 043 Assisted living setting |
| 011 UNC Oncology Clinic/Gravelly | 044 DUMC / Lennox Baker |
| 012 Rest Home | 045 Laundromat |
| 013 Nash General Hospital | 046 Phone Interview |
| 014 Adult Day Care Center / Children's day care center | 047 In a car |
| 015 Health Dept. | 048 Funeral home |
| 016 Hotel Room | 049 Dialysis center |
| 017 Lenoir Community Hospital | 050 UNC hospital |
| 018 Hotel Lobby | 051 Boyce - Willis clinic |
| 019 ECU/Leo Jenkins Cancer Center | 052 Conference room / hospital conference room |
| 020 Duke Cancer Control Center, Erwin Sq. | 053 Employment security office |
| 021 Women's Prison | 054 Rad/Onc craven hospital |
| 022 Half-way house (post prison) | 055 Museum of Art |
| 023 Duke Oncology Clinic/ Duke hospital | 056 Presbyterian Hospital |
| 024 Daughter's home / family member's home | 057 Zimmer Cancer Center / New Hanover Regional Medical Center |
| 025 Beaufort Hospital | 058 Attorney's office |
| 026 Central Carolina Cancer Center | 059 Patient's home and telephone |
| 027 Neighbor's House / friend's house | 060 Hope Lodge |
| 028 Moore Regional Hospital | 061 Participant's spouse's workplace |
| 029 Restaurant | 062 Urban Ministries |
| 030 Doctor's office | 063 Rest Area |
| 031 Morehead City hospital | 064 Park |
| 032 Bank | 065 Participant's significant other's home |
| 033 Rex medical library | 066 Club house (of residence) |
| 034 Greenville Pitt Memorial Hospital | 067 Community Center |
| 035 Hospital | 068 Parking lot |
| 036 Library | |

M3. 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 Disruptive children
- 06 Participant was late
- 07 Participant was guarded
- 08 Participant in pain and groggy / participant ill but answered anyways

M4. Quality of Responses

CODE ONE RESPONSE

- 01 Some responses provided by daughter
- 02 Majority responses provided by daughter
- 03 Difficulty answering questions due to language barrier
- 04 Participant very evasive
- [05] Participant not feeling well – **DO NOT USE, CODE UNDER M5 “021 Ill/not feeling well”**
- [06] Participant sometimes angry/sarcastic - **DO NOT USE, CODE UNDER M5 “023 Participant very suspicious/angry”**

M5. The Respondent:**CODE UP TO 3 RESPONSES**

- 001 Had trouble with medical history
- 002 Had trouble with hormones, medications
- 003 Had trouble with family history
- 004 Had trouble with pesticide information
- 005 Had trouble with menopause information
- 006 Had trouble with ages
- 007 Had trouble with occupational history
- 008 Had trouble with menstrual history
- 009 Had trouble with fruit and vegetable questions
- 010 Had trouble with smoking questions
- 011 Needed frequent prompting
- 012 Generally reliable, but some recall problems
- 013 Had trouble with alcohol questions
- 014 Did not want to answer question / Refused to recall
- 015 Many questions answered by daughter/ mother / family member
- 016 Participant said she had multiple personality disorder
- 017 Legally blind, everything read to participant
- 018 Apparent psychological problems
- 019 Unable to read
- 020 Difficulty hearing
- 021 Ill, not feeling well
- 022 Kept changing her answers
- 023 Participant very suspicious/ angry
- 024 Confused about questions
- 025 Did not understand English well, husband helped, someone helped with language
- 026 S/P stroke (CVA)
- 027 Tired / fatigued / seemed sleepy/ falling asleep
- 028 Nervous/anxious/hesitant
- 029 Very vague re: children / not specific
- 030 Talked a lot
- 031 Stopped school in elementary grades, low schooling
- 032 Family helped some
- 033 Participant was sarcastic at times and refused to answer
- 034 Participant was drinking
- 035 Participant was emotional
- 036 Participant doesn't know mom/dad or the family history
- 037 Participant was hesitant and uncomfortable with financial history
- 038 Participant was difficult to interview
- 039 Participant was texting during interview
- 040 Could not focus/concentrate

M6. Reasons for unsatisfactory information**CODE UP TO 3 RESPONSES**

- 001 Poor memory in general, just couldn't remember
- 002 Just couldn't remember certain information/dates / "Chemo brain"
- 003 Difficulty remembering events from long ago
- 004 Had a history of a stroke/ speech affected/ memory affected
- 005 Was very tired, sleepy due to pain meds/Chemo
- 006 Had trouble concentrating
- 007 Was concerned that she was unable to give specific enough information
- 008 Had trouble calculating amounts
- 009 Didn't seem to understand questions
- 010 Had trouble remembering due to medication use
- 011 Poor memory because of age
- 012 Low educational level
- 013 Had trouble remembering due to accident/head injury
- 014 Mentally retarded

- 015 Participant had been drinking
- 016 Participant was paranoid, ~~but answers seemed reliable~~
- 017 Didn't like probing, got angry
- 018 Participant can not read
- 019 Participant relied on information from relatives (phone calls, in person, etc)
- 020 Vague answers
- 021 Participant was suspicious
- 022 Blind
- 023 Family members frustrated
- 024 Seemed to want to "please" interviewer
- 025 Participant said she had Alzheimer's
- 026 Said these were tricky questions
- 028 Said she has bipolar disorder
- 029 Seemed to feel bad
- 030 Was walking during interview
- 031 Seemed depressed
- 032 Wanted to critique questionnaire
- 033 Very talkative / changed subject / off topic
- 034 Was in a hurry
- 035 Was interrupted / distracted by child(ren)
- 036 Doesn't know biologic family
- 037 Was afraid to answer financial questions/didn't answer financial questions
- 038 Had trouble with specifics
- 039 Participant had poor vision
- 040 Participant seemed a bit angry when nurse offered to help
- 041 Participant in a lot of pain by end of interview
- 042 Participant needed to change some answers after husband left the room due to secrets she didn't want him to know about/Clearly distracted by husband
- 043 Had to whisper at the time, son was in adjacent room
- 044 Didn't have much contact with parents/family
- 045 Participant hard of hearing
- 046 Phone distractions
- 047 Had issues answering QOL section due to health problems unrelated to her breast surgery that affected her physical activity
- 048 Difficulty understanding questions/Language Barrier
- 049 Participant denied having B.C.
- 050 Participant unsure of some answers due to emotional trauma
- 051 Participant was sarcastic
- 052 Slow to answer / Hesitant to answer / Seccrative
- 053 Participant angry her check arrived late
- 054 Participant acted strange with someone else around (e.g husband)
- 055 Participant refused to answer questions
- 056 Participant and family member/survey helper argued over answers
- 057 Participant reported contradictory information

M7. QOL completed by

CODE ONE RESPONSE

- 01 Husband helped
- 02 Mother helped
- 03 Daughter in law completed/helped
- 04 Not completed/too ill to complete
- 05 Daughter helped/translated
- 06 Participant denies having B.C., did not fill out QOL
- 07 Participant did most on own, but finished w/nurse assistance via phone
- 08 Refused to answer questions