

Data and Biospecimen Use and Publications Committee

CANCER NAVIGATION SURVEY CODEBOOK

Updated November 2014

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Cancer Navigation Survey (CNS) data were collected from SCCS participants during May 2010 through January 2012. Participants who completed the first follow-up questionnaire in May, 2010 or later and indicated a cancer diagnosis were asked to complete the CNS questionnaire directly following completion of the follow-up survey. Additional participants were identified for the CNS survey only (i.e., not concurrent with the first follow-up survey) via identification of an incident cancer diagnosis in the state cancer registries.

Of participants reporting cancer during the first follow-up in May, 2010 or later, 78% continued on to complete the CNS. Of participants contacted de novo for completion of the CNS survey following cancer diagnosis from a state cancer registry, 23% chose to complete the survey.

The CNS was structured with a set of questions specific to either breast, prostate, lung, colorectal, or other cancers. Participants completed the questionnaire according to the type of cancer either self-reported or identified in the registry.

SCCS Participants	
e CNS	
N	
263	
105	
46	
195	
526	
1,135	

SECTION I. PATIENT RECOGNITION OF PROBLEM (A)

Variable Name	Question and Coding	Comments
CNSAge	Age at CNS interview	
	Numeric value (years) from 42 to 87	
CNSCancerType	What type of cancer?	
	B Breast	
	C Colorectal	
	L Lung	
	P Prostate	
	O Other multiple cancer types	
BrInitSympMedCare	What was the first thing that made you think you might have a problem?	Breast Cancer
	1 Problem with routine mammogram	Pathway
	2 Health problems or symptoms	
	3 Other	
	7777 Not applicable	
BrInitSympLump	Did you have a lump on one or both breasts?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrInitSympSwell	Did you have thickening or swelling of the breast?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrInitSympDischarge	Did you have nipple discharge?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrInitSympColor	Did you have a change in skin color?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrInitSympAppetite	Did you have a loss of appetite?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
BrInitSympWtLoss	Did you have an unexplained weight loss?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrInitSympLowEnergy	Did you have low energy (or you were feeling tired all the time)?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrInitSympOther	Did you have any other symptoms?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympMedCare	What was the first thing that made you think you might have a problem?	Colorectal Cancer
	1 Problem with colonoscopy or sigmoidoscopy	Pathway
	2 Health problems or symptoms	
	3 Other	
	7777 Not applicable	
CRCInitSympStomach	Did you have stomach or abdominal pain?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympBowel	Did you have changes in your bowel habits?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympBlood	Did you have blood in your stool?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympNausea	Did you have nausea or vomiting?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
CRCInitSympBloat	Did you have bloating or swelling of your belly?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympAppetite	Did you have a loss of appetite?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympWtLoss	Did you have an unexplained weight loss?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympLowEnergy	Did you have low energy (or you were feeling tired all the time)?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCInitSympOther	Did you have any other symptoms?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungInitSympMedCare	What was the first thing that made you think you might have a problem?	Lung Cancer
	1 Health problems or symptoms	Pathway
	2 Other	
	7777 Not applicable	
LungInitSympCough	Did you have a cough?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungInitSympBlood	Were you coughing up blood?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungInitSympBreath	Did you have difficulty breathing or getting enough air?	Lung Cancer
	0 No	Pathway
	1 Yes	,
	7777 Not applicable	

Variable Name	Question and Coding	Comments
LungInitSympPain	Did you have chest pain?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungInitSympAppetite	Did you have a loss of appetite?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungInitSympWtLoss	Did you have an unexplained weight loss	Lung Cancer
- , ,	0 No	Pathway
	1 Yes	·
	7777 Not applicable	
LungInitSympLowEnergy	Did you have low energy (or were you feeling tired all the time)?	Lung Cancer
- , ,	0 No	Pathway
	1 Yes	,
	7777 Not applicable	
LungInitSympOther	Did you have any other symptoms?	Lung Cancer
, .	0 No	Pathway
	1 Yes	·
	7777 Not applicable	
PrInitSympMedCare	What was the first thing that made you think you might have a problem?	Prostate Cancer
•	1 Problem with routine digital rectal exam	Pathway
	2 Problem with routine PSA blood test	,
	3 Health problems or symptoms	
	4 Other	
	7777 Not applicable	
PrInitSympLUTS	Did you have problems urinating or the need to urinate frequently?	Prostate Cancer
•	0 No	Pathway
	1 Yes	,
	7777 Not applicable	
PrInitSympBlood	Did you have blood in your urine?	Prostate Cancer
, , , , , , , , , , , , , , , , , , , ,	0 No	Pathway
	1 Yes	,
	7777 Not applicable	

Variable Name	Question and Coding	Comments
PrInitSympPain	Did you have back pain?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrInitSympAppetite	Did you have a loss of appetite?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrInitSympWtLoss	Did you have an unexplained weight loss?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrInitSympLowEnergy	Did you have low energy (or you were feeling tired all the time)?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrInitSympOther	Did you have any other symptoms?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
OtherInitSympMedCare	What was the first thing that made you think you might have a problem?	Other Cancer or
	1 Health problems or symptoms	Multiple Cancer
	2 Other	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherInitSympPain	Did you have pain?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherInitSympAppetite	Did you have a loss of appetite?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	

Variable Name	Question and Coding	Comments
OtherInitSympWtLoss	Did you have an unexplained weight loss?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherInitSympLowEnergy	Did you have low energy (or you were feeling tired all the time)?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherInitSympOther	Did you have any other symptoms?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
LengthSymptoms	How long were you having symptoms before your first doctor's visit about your problem?	
	Numeric value (days) from 1 to 11680	
MDPreDxType1	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	9999 Don't know	
MDPreDxTests1	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	9999 Don't know	
MDPreDxType2	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDPreDxTests2	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDPreDxType3	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	
MDPreDxTests3	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDPreDxType4	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	
MDPreDxTests4	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDPreDxType5	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	
MDPreDxTests5	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDPreDxType6	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreDxTests6	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDPreDxType7	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreDxTests7	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDPreDxType8	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreDxTests8	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDPreDxType9	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreDxTests9	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDPreDxType10	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreDxTests10	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
MDReferred	Were you referred to t his doctor by a different doctor?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDReferredType	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	

SECTION II. TESTING (B)

Variable Name	Question and Coding	Comments
TestLocChoice	Were you given a choice of the date and time when you could have your tests?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TestDateChoice	Were you given a choice of the date and time when you could have your tests?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
BrDxExam	Did you have a breast exam?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDxMammo	Did you have a mammogram?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDxImaging	Did you have an imaging scan?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDxBlood	Did you have a blood test?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDxBiopsy	Did you have a biopsy?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
BrDxOther	Did you have some other test?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDxNone	Did you not have any tests?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCDxFecOcc	Did you have a fecal occult blood test?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxSigmoidoscopy	Did you have a sigmoidoscopy?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxColonoscopy	Did you have a colonoscopy?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxBarium	Did you have a barium enema?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxImaging	Did you have an imaging scan?	Colorectal Cancer
- -	0 No	Pathway
	1 Yes	,
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
CRCDxBiopsy	Did you have a biopsy?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxOther	Did you have some other test?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxNone	Did you not have any tests?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxPolyps	Did the doctor find any polyps?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDxPolypsRemove	Did the doctor remove those polyps?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
LungDxPFT	Did you have a pulmonary function test?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDxSputum	Did you have a sputum test?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
LungDxBronchoscopy	Did you have a bronchoscopy?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDxBlood	Did you have a blood test?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDxImaging	Did you have an imaging scan?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDxBiopsy	Did you have a biopsy?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDxOther	Did you have some other test?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDxNone	Did you not have any tests?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDxPSA	Did you have a PSA blood test?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDxDRE	Did you have a digital rectal exam?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDxBoneScan	Did you have a bone scan?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
PrDxImaging	Did you have an imaging scan?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDxBiopsy	Did you have a biopsy?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDxOther	Did you have some other test?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDxNone	Did you not have any tests?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
OtherDxImaging	Did you have an imaging scan?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherDxBlood	Did you have a blood test?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherDxBiopsy	Did you have a biopsy?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherDxOther	Did you have some other test?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherDxNone	Did you not have any tests?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	

Variable Name	Question and Coding	Comments
MDExplWait	Did your doctor (or nurse) explain to you how long you would have to wait for your test	
	results?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDExplResult	Did your doctor (or nurse) explain to you what your test results meant?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDRecommend	Were there any tests or procedures that your doctor (or nurse) recommended that you did	
	not have?	
	0 No	
	1 Yes	
	9999 Don't know	
RefTestNotHelp	Did you not have the recommended tests because you did not think that the tests would	
	help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
RefTestInsurance	Did you not have the recommended tests because you had a problem with insurance	
	coverage or your ability to pay?	
	0 No	
	1 Yes	
	7777 Not applicable	
RefTestSick	Did you not have the recommended tests because you were too sick to have the tests?	
	0 No	
	1 Yes	
	7777 Not applicable	
RefTestAfraid	Did you not have the recommended tests because you were afraid or anxious about the	
	tests?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
RefTestAssistance	Did you not have the recommended tests because you did not have someone to help you	
	make the visit appointments or go with you?	
	0 No	
	1 Yes	
	7777 Not applicable	
RefTestConvenience	Did you not have the recommended tests because your visit appointment times were hard to	
	fit into your schedule?	
	0 No	
	1 Yes	
	7777 Not applicable	
RefTestTransport	Did you not have the recommended tests because you did not have a way to get there (you	
	did not have transportation)?	
	0 No	
	1 Yes	
	7777 Not applicable	
RefTestOther	Are there any other reasons why you did not have the recommended tests?	
	0 No	
	1 Yes	
	7777 Not applicable	

SECTION III. DIAGNOSIS (C)

Variable Name	Question and Coding	Comments
FirstMDToDx	Was this doctor the first doctor to tell you that you definitely had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
TimeApptToDx	How long was it between your first visit with this doctor about your problem and when you	
	were told you definitely had cancer?	
	1 Same day or one day	
	2 2-6 days	
	3 1-2 weeks	
	4 3-4 weeks	
	5 1-2 months	
	6 >2 months	
	9999 Don't know	
TimeApptToDxFeel	How did you feel about the amount of time between your first visit with this doctor about	
	your problem and when you were told you definitely had cancer?	
	1 Too short	
	2 About right	
	3 Too long	
	8888 Refused	
	9999 Don't know	
DxDelayApptCanceled	Were your visits canceled or postponed?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayApptWait	Were you kept waiting for more than 30 minutes?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
DxDelayMedRec	Did your first doctor not send your medical records to your new doctor?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayInsurance	Did you have problems with your insurance or your ability to pay?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayAssistance	Did you not have someone to help you make the visit appointments or go with you?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayConvenience	Were your visit appointment times hard to fit into your schedule?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayTransport	Did you not have a way to get to your doctor's office or did you not have transportation?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayTrust	Did you not trust your doctor or did not think your doctor could help you?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
DxDelayOther	Did you have another problem?	
•	0 No	
	1 Yes	
	8888 Refused	

Variable Name	Question and Coding	Comments
DxDelayNone	Did you have no problems?	
	0 No	
	1 Yes	
	8888 Refused	
DxDelayMainReason	Of these problems, which one was the biggest?	
	1 Your visits were canceled or postponed.	
	2 You were kept waiting for more than 30 minutes.	
	3 Your first doctor did not send your medical records to your new doctor.	
	4 You had problems with your insurance or your ability to pay.	
	5 You did not have someone to help you make the visit appointments or go with you.	
	6 Your visit appointment times were hard to fit into your schedule.	
	7 You did not have a way to get to your doctor's office or you did not have	
	transportation.	
	8 You did not trust your doctor or did not think your doctor could help you.	
	9 You had another problem.	
	7777 Not applicable	
	9999 Don't know	
MDDxExplainUnderstand	Overall, when you were being tested to see if you had cancer, how often did your doctors	
	explain things in a way you could understand?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	8888 Refused	
	9999 Don't know	
MDDxInformation	Overall, when you were being tested to see if you had cancer, how often did your doctors	
	give you as much information as you wanted?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	8888 Refused	
	9999 Don't know	

SECTION IV. TREATMENT DECISION-MAKING (D)

Variable Name	Question and Coding	Comments
MDOtherPreTx	Other than the doctors you have already told me about, did you talk to any new doctors	
	before getting any treatment for your cancer?	
	0 No	
	1 Yes	
	9999 Don't know	
MDPreTxType1	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	
MDPreTxTests1	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDPreTxType2	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
	9999 Don't know	
MDPreTxTests2	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDPreTxType3	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreTxTests3	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDPreTxType4	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreTxTests4	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDPreTxType5	Was this doctor a	
	1 Family doctor (also called a general practitioner)	
	2 Local community health center doctor (if both, select CHC doctor)	
	3 Specialist or hospital doctor	
	4 Emergency room doctor	
	5 Other	
	7777 Not applicable	
MDPreTxTests5	Did this doctor perform or order any tests to see if you had cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
MDDiscTxChoice	Did your doctors (or nurses) talk with you about the different kinds of treatment you could	
	have?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
BrDiscSurg	Did you talk about surgery for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscRad	Did you talk about radiation therapy for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscChemo	Did you talk about chemotherapy (by itself or with another therapy) for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscHormone	Did you talk about hormone therapy for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscOther	Did you talk about any other kinds of treatment for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscSurgLump	Did you talk about a lumpectomy for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscSurgMast	Did you talk about a mastectomy for your breast cancer?	Breast Cancer
<u> </u>	0 No	Pathway
	1 Yes	,
	7777 Not applicable	

Variable Name	Question and Coding	Comments
BrDiscSurgOther	Did you talk about any other kinds of surgery for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrDiscRadExternal	Did you talk about external radiation for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrDiscRadImp	Did you talk about radiation implants for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrDiscRadOther	Did you talk about any other kinds of radiation for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	·
	7777 Not applicable	
	9999 Don't know	
CRCDiscSurg	Did you talk about surgery for your colorectal cancer?	Colorectal Cancer
-	0 No	Pathway
	1 Yes	,
	7777 Not applicable	
	9999 Don't know	
CRCDiscRad	Did you talk about radiation therapy for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	•
	7777 Not applicable	
	9999 Don't know	
CRCDiscChemo	Did you talk about chemotherapy (by itself or with another therapy) for your colorectal	Colorectal Cancer
	cancer?	Pathway
	0 No	,
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
CRCDiscOther	Did you talk about other types of treatment for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDiscSurgColosIleos	Did you talk about colostomy or ileostomy for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDiscSurgColecIleec	Did you talk about colectomy or ileectomy for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDiscSurgOther	Did you talk about other types of surgery for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDiscRadExternal	Did you talk about external radiation therapy for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDiscRadImp	Did you talk about radiation implants for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCDiscRadOther	Did you talk about other radiation treatments for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
LungDiscSurg	Did you talk about surgery for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDiscRad	Did you talk about radiation therapy for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
ungDiscChemo	Did you talk about chemotherapy (by itself or with another therapy) for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungDiscOther	Did you talk about other treatments for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
.ungDiscSurgWedge	Did you talk about wedge resection for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
_ungDiscSurgLobe	Did you talk about lobectomy for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
.ungDiscSurgPneumo	Did you talk about pneumonectomy for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
.ungDiscSurgOther	Did you talk about another type of surgery for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
LungDiscRadExternal	Did you talk about external radiation for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
LungDiscRadImp	Did you talk about radiation implants for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
LungDiscRadOther	Did you talk about any other kinds of radiation?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PrDiscSurg	Did you talk about surgery for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDiscRad	Did you talk about radiation therapy for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDiscChemo	Did you talk about chemotherapy (by itself or with another therapy) for your prostate	Prostate Cancer
	cancer?	Pathway
	0 No	
	1 Yes	
	7777 Not applicable	
PrDiscCryo	Did you talk about cryotherapy for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDiscHormone	Did you talk about hormone therapy (including shots and pills) for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
PrDiscWait	Did you talk about no treatment for your prostate cancer at this time or "wait and see"?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDiscOther	Did you talk about any other kinds of treatment for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrDiscSurgProst	Did you talk about removal of your prostate for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PrDiscSurgTest	Did you talk about removal of your testicles for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PrDiscSurgOther	Did you talk about any other kinds of surgery for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PrDiscRadExternal	Did you talk about external radiation therapy for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PrDiscRadImp	Did you talk about radiation implants for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
PrDiscradOther	Did you talk about any other kinds of radiation for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
OtherDiscSurg	Did you talk about surgery for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherDiscRad	Did you talk about radiation therapy for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherDiscChemo	Did you talk about chemotherapy (by itself or with another therapy) for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherDiscHormone	Did you talk about hormone therapy (including shots and pills) for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherDiscOther	Did you talk about other treatments for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherDiscRadExternal	Did you talk about external radiation therapy for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
OtherDiscRadImp	Did you talk about radiation implants for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherDiscRadOther	Did you talk about any other radiation therapy for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
TxNotAvail	Were there any treatments that your doctors (or nurses) said you could not have?	
	0 No	
	1 Yes	
	9999 Don't know	
TxNotAvailMDExpl	Did they explain why you could not have other treatments?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TXNotAvailWontHelp	Did your doctors not think that treatment would help you (or the treatment was no	
	appropriate for you)?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxNotAvailIns	Did you have a problem with insurance coverage or your ability to pay?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxNotAvailSick	Were you too sick to have these treatments?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxNotAvailOther	Were there other reasons why these treatments were not available to you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDInfoPain	Did your doctors (or nurses) give you information about pain?	
	0 No	
	1 Yes	
	9999 Don't know	
MDInfoFatigue	Did your doctors (or nurses) give you information about fatigue?	
	0 No	
	1 Yes	
	9999 Don't know	
MDInfoAnxiety	Did your doctors (or nurses) give you information about anxiety?	
	0 No	
	1 Yes	
	9999 Don't know	
MDInfoFear	Did your doctors (or nurses) give you information about fear?	
	0 No	
	1 Yes	
	9999 Don't know	
MDInfoDepression	Did your doctors (or nurses) give you information about depression?	
	0 No	
	1 Yes	
	9999 Don't know	
MDInfoNutrition	Did your doctors (or nurses) give you information about nutrition?	
	0 No	
	1 Yes	
	9999 Don't know	
MDInfoNone	Did your doctors (or nurses) not give you any information about any of these?	
	0 No	
	1 Yes	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDInfoEnough	Did you get enough information?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDInfoMore	Would you have liked more information?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDInfoWanted	Would you have wanted them to give you this information?	
	0 No	
	1 Yes	
	7777 Not applicable	
BrMDInfoHotFlash	Did your doctors (or nurses) talk with you about hot flashes?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrMDInfoSwell	Did your doctors (or nurses) talk with you about swelling or lymphedema?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrMDInfoLibido	Did your doctors (or nurses) talk with you about loss of sexual libido?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrMDInfoNausea	Did your doctors (or nurses) talk with you about nausea and vomiting?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
BrMDInfoHairLoss	Did your doctors (or nurses) talk with you about hair loss?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrMDInfoWtLoss	Did your doctors (or nurses) talk with you about weight loss?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrMDInfoSEOther	Did your doctors (or nurses) talk with you about other physical side effects or late effects?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrMDInfoSENone	Did you not talk about any physical side effects or late effects?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoBM	Did your doctors (or nurses) talk with you about bowel movements?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoUrination	Did your doctors (or nurses) talk with you about urination?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoIntercourse	Did your doctors (or nurses) talk with you about sexual intercourse?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
CRCMDInfoNausea	Did your doctors (or nurses) talk with you about nausea or vomiting?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoHairLoss	Did your doctors (or nurses) talk with you about hair loss?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoWtLoss	Did your doctors (or nurses) talk with you about weight loss?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoSEOther	Did your doctors (or nurses) talk with you about other physical side effects or late effects?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCMDInfoSENone	Did you not talk about any physical side effects or late effects?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
LungMDInfoSputum	Did your doctors (or nurses) talk with you about increased sputum (or mucus) in your lungs?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungMDInfoThromb	Did your doctors (or nurses) talk with you about blood clots (or thrombosis)?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
LungMDInfoNausea	Did your doctors (or nurses) talk with you about nausea and vomiting?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungMDIngoHairLoss	Did your doctors (or nurses) talk with you about hair loss?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungMDInfoWtLoss	Did your doctors (or nurses) talk with you about weight loss?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungMDInfoSEOther	Did your doctors (or nurses) talk with you about other physical side effects of late effects?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungMDInfoSENone	Did you not talk about any physical side effects or late effects?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrMDInfoErection	Did your doctors (or nurses) talk with you about erections?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrMDInfoUrination	Did your doctors (or nurses) talk with you about urination?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrMDInfoBM	Did your doctors (or nurses) talk with you about bowel movements?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrMDInfoNausea	Did your doctors (or nurses) talk with you about nausea and vomiting?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
PrMDInfoHairLoss	Did your doctors (or nurses) talk with you about hair loss?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrMDInfoWtLoss	Did your doctors (or nurses) talk with you about weight loss?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrMDInfoSEOther	Did your doctors (or nurses) talk with you about any other physical side effects or late	Prostate Cancer
	effects?	Pathway
	0 No	
	1 Yes	
	7777 Not applicable	
PrMDInfoSENone	Did you not talk about any other physical side effects or late effects?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
OtherMDInfoNausea	Did your doctors (or nurses) talk with you about nausea and vomiting?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherMDInfoHairLoss	Did your doctors (or nurses) talk with you about hair loss?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
Other MDInfo WtLoss	Did your doctors (or nurses) talk with you about weight loss?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
OtherMDInfoBM	Did your doctors (or nurses) talk with you about bowel movements?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherMDInfoSEOther	Did your doctors (or nurses) talk with you about other physical side effects or late effects?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
OtherMDInfoSENone	Did you not talk about any physical side effects or late effects?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
	9999 Don't know	
MDInfoSEEnough	Did you get enough information about physical side effects or late effects?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDInfoSEMore	Would you have liked more information about physical side effects or late effects?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDInfoSEImportance	How important was the information about physical side effects and late effects when you	
	were deciding about your treatment?	
	1 Very important	
	2 Somewhat important	
	3 A little important	
	4 Not important	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDInfoSEWanted	Would you have wanted them to give you this information?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDInfoTxDecision	Looking back, if you had received this information, would your treatment decision have been	
	different?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxDecisionTime	How much time were you given to think about your treatment choices before the treatment	
	decision was made?	
	1 Same day	
	2 1-2 days	
	3 3-7 days	
	4 1-2 weeks	
	5 3-6 weeks	
	6 >6 weeks	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDecisionTimeOp	How did you feel about the amount of time you were given to think about your treatment	
	choices before the treatment decision was made?	
	1 Too short	
	2 About right	
	3 Too long	
	8888 Refused	
	9999 Don't know	
TxDecisionChange	Did the doctors (or nurses) tell you that you could change your mind about which treatment	
	to have?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxDecisionRole	Which of these statements best describes how you feel about your role in making decisions	
	for your cancer treatment?	
	1 My role was as big as I wanted.	
	2 My role was bigger than I wanted	
	3 I wish I had a bigger role.	
	8888 Refused	
	9999 Don't know	
TxDecisionFamily	In addition to you and your doctors (and nurses), did your family help to choose which	
	treatment plan you were going to have?	
	0 No	
	1 Yes	
	9999 Don't know	
TxDecisionFriends	In addition to you and your doctors (and nurses), did your friends help to choose which	
	treatment plan you were going to have?	
	0 No	
	1 Yes	
	9999 Don't know	
TxDecisionSpiritAdv	In addition to you and your doctors (and nurses), did your religious or spiritual advisor help	
	to choose which treatment plan you were going to have?	
	0 No	
	1 Yes	
	9999 Don't know	
TxDecisionOther	In addition to you and your doctors (and nurses), did some other person help to choose	
	which treatment plan you were going to have?	
	0 No	
	1 Yes	
	9999 Don't know	
TxDecisionNone	Did no one else help to choose your treatment plan?	
	0 No	
	1 Yes	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxDecisionConfid	How confident were you that the treatment decision made was the best one for you	?
	1 Fully confident	
	2 Confident, but with some doubts	
	3 Not confident	
	8888 Refused	
	9999 Don't know	

SECTION V. TREATMENT DELIVERY (E)

Variable Name	Question and Coding	Comments
TxRec	Have you had any treatments for your cancer?	
	0 No	
	1 Yes	
TimeDecToTx	How long was it from the time when your treatment decision was made until your first	
	doctor's visit related to your treatment?	
	1 The same day	
	2 1-2 days	
	3 3-7 days	
	4 1-2 weeks	
	5 3-6 weeks	
	6 >6 weeks	
	7777 Not applicable	
	9999 Don't know	
TimeDecToTxOp	How did you feel about the amount of time between your treatment decision was made and	
	your first doctor/s visit related to your treatment?	
	1 Too short	
	2 About right	
	3 Too long	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
BrTxSurg	Have you had surgery for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrTxRad	Have you had radiation therapy?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
BrTxChemo	Have you had chemotherapy (by itself or with another therapy)?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrTxHorm	Have you had hormone therapy (including shots and pills)?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrTxOther	Have you had any other treatment for your cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
BrTxSurgType	Did you have	Breast Cancer
	1 Lumpectomy	Pathway
	2 Mastectomy	
	3 Other	
	7777 Not applicable	
	9999 Don't know	
BrTxRadExternal	Did you have external radiation for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrTxRadImp	Did you have radiation implants for your breast cancer?	Breast Cancer
•	0 No	Pathway
	1 Yes	
	7777 Not applicable	
BrTxRadOther	Did you have some other type of radiation for your breast cancer?	Breast Cancer
	0 No	Pathway
	1 Yes	,
	7777 Not applicable	

Variable Name	Question and Coding	Comments
CRCTxSurg	Did you have surgery for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCTxRad	Did you have radiation therapy for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCTxChemo	Did you have chemotherapy (by itself or with another therapy) for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCTxOther	Did you have any other treatment for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
CRCSurgType	Did you have	Colorectal Cancer
	1 Colostomy or ileostomy	Pathway
	2 Colectomy or ileectomy	
	3 Other	
	7777 Not applicable	
	9999 Don't know	
CRCRadExternal	Did you have external radiation for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
CRCRadImp	Did you have radiation implants for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
CRCRadOther	Did you have any other type of radiation treatment for your colorectal cancer?	Colorectal Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
LungTxSurg	Did you have surgery for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungTxRad	Did you have radiation therapy for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungTxChemo	Did you have chemotherapy (by itself or with another therapy) for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungTxOther	Did you have any other type of treatment for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungTxSurgType	Did you have	Lung Cancer
	1 Wedge resection	Pathway
	2 Lobectomy	
	3 Pneumonectomy	
	4 Other	
	7777 Not applicable	
LungTxRadExternal	Did you have external radiation for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
LungTxRadImp	Did you have radiation implants for your lung cancer?	Lung Cancer
•	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
LungTxRadOther	Did you have any other type of radiation for your lung cancer?	Lung Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxSurg	Did you have surgery for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxRad	Did you have radiation therapy for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxChemo	Did you have chemotherapy (by itself or with another therapy) for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxCryo	Did you have cryotherapy for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxHormone	Did you have hormone therapy (including shots and pills) for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxWait	Did you have no treatment or "wait and see" for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxOther	Did you have some other type of treatment for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
PrTxSurgType	Did you have surgery to	Prostate Cancer
	1 Remove your prostate	Pathway
	2 Remove your testicles	
	3 Other	
	7777 Not applicable	
PrTxRadExternal	Did you have external radiation for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxRadImp	Did you have radiation implants for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
PrTxRadOther	Did you have some other type of radiation for your prostate cancer?	Prostate Cancer
	0 No	Pathway
	1 Yes	
	7777 Not applicable	
OtherTxSurg	Did you have surgery for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherTxRad	Did you have radiation therapy for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherTxChemo	Did you have chemotherapy (by itself or with another therapy) for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherTxHormone	Did you have hormone therapy (including shots and pills) for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	,

Variable Name	Question and Coding	Comments
OtherTxOtherType	Did you have some other type of treatment for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherTxRadExternal	Did you have external radiation for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherTxRadImp	Did you have radiation implants for your cancer?	Other Cancer or
·	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	
OtherTxRadOther	Did you have some other type of radiation for your cancer?	Other Cancer or
	0 No	Multiple Cancer
	1 Yes	Pathway
	7777 Not applicable	·
TxSurgAge1	At what age did you have your first cancer surgery?	
	Numeric value (years) from 40 to 84	
	7777 Not applicable	
	9999 Don't know	
TxSurgLoc1	Did you have any surgery at a different clinic or hospital?	
-	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
TxSurgAge2	At what age did you have your second cancer surgery?	
	Numeric value (years) from 42 to 77	
	7777 Not applicable	
	9999 Don't know	
TxSurgLoc2	Did you have any surgery at a different clinic or hospital?	
J	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxSurgAge3	At what age did you have your third cancer surgery?	
	Numeric value (years) from 50 to 56	
	7777 Not applicable	
TxSurgLoc3	Did you have any surgery at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxSurgAge4	At what age did you have your fourth cancer surgery?	
	Numeric value (years) from 59 to 59	
	7777 Not applicable	
TxSurgLoc4	Did you have any surgery at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxSurgAge5	At what age did you have your fifth cancer surgery?	
	Numeric value (years)	
	7777 Not applicable	
TxSurgLoc5	Did you have any surgery at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxRadAge1	At what age did you have your first cancer radiation treatment?	
	Numeric value (years) from 42 to 80	
	7777 Not applicable	
	9999 Don't know	
TxRadLoc1	Did you have any radiation at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxRadAge2	At what age did you have your second cancer radiation treatment?	
	Numeric value (years) from 44 to 72	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxRadLoc2	Did you have any radiation at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxRadAge3	At what age did you have your third cancer radiation treatment?	
	Numeric value (years) from 45 to 45	
	7777 Not applicable	
TxRadLoc3	Did you have any radiation at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxRadAge4	At what age did you have your fourth cancer radiation treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxRadLoc4	Did you have any radiation at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxRadAge5	At what age did you have your fifth cancer radiation treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxRadLoc5	Did you have any radiation at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxChemoAge1	At what age did you have your first cancer chemotherapy treatment?	
	Numeric value (years) from 42 to 83	
	7777 Not applicable	
	9999 Don't know	
TxChemoLoc1	Did you have any chemotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxChemoAge2	At what age did you have your second cancer chemotherapy treatment?	
	Numeric value (years) from 51 to 76	
	7777 Not applicable	
	9999 Don't know	
TxChemoLoc2	Did you have any chemotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxChemoAge3	At what age did you have your third cancer chemotherapy treatment?	
-	Numeric value (years) from 54 to 71	
	7777 Not applicable	
TxChemoLoc3	Did you have any chemotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxChemoAge4	At what age did you have your fourth cancer chemotherapy treatment?	
· ·	Numeric value (years) from 68 to 72	
	7777 Not applicable	
TxChemoLoc4	Did you have any chemotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxChemoAge5	At what age did you have your fifth cancer chemotherapy treatment?	
-	Numeric value (years) from 73 to 73	
	7777 Not applicable	
TxChemoLoc5	Did you have any chemotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxHormoneAge1	At what age did you have your first cancer hormone therapy treatment?	
Ŭ	Numeric value (years) from 40 to 78	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxHormoneLoc1	Did you have any hormone therapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxHormoneAge2	At what age did you have your second cancer hormone therapy treatment?	
	Numeric value (years) from 50 to 75	
	7777 Not applicable	
	9999 Don't know	
TxHormoneLoc2	Did you have any hormone therapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxHormoneAge3	At what age did you have your third cancer hormone therapy treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxHormoneLoc3	Did you have any hormone therapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxHormoneAge4	At what age did you have your fourth cancer hormone therapy treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxHormoneLoc4	Did you have any hormone therapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxHormoneAge5	At what age did you have your fifth cancer hormone therapy treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxHormoneLoc5	Did you have any hormone therapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
TxOtherAge1	At what age did you have your first other type of cancer treatment?	
	Numeric value (years) from 44 to 81	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxOtherLoc1	Did you have any other type of cancer treatment at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxOtherAge2	At what age did you have your second other type of cancer treatment?	
	Numeric value (years) from 57 to 67	
	7777 Not applicable	
TxOtherLoc2	Did you have any other type of cancer treatment at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxOtherAge3	At what age did you have your third other type of cancer treatment?	
	Numeric value (years) from 57 to 57	
	7777 Not applicable	
TxOtherLoc3	Did you have any other type of cancer treatment at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxOtherAge4	At what age did you have your fourth other type of cancer treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxOtherLoc4	Did you have any other type of cancer treatment at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxOtherAge5	At what age did you have your fifth other type of cancer treatment?	
	Numeric value (years)	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
TxOtherLoc5	Did you have any other type of cancer treatment at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxCryoAge1	At what age did you have your first cancer cryotherapy treatment?	
	Numeric value (years) from 53 to 76	
	7777 Not applicable	
TxCryoLoc1	Did you have any cryotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxCryoAge2	At what age did you have your second cancer cryotherapy treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxCryoLoc2	Did you have any cryotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxCryoAge3	At what age did you have your third cancer cryotherapy treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxCryoLoc3	Did you have any cryotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxCryoAge4	At what age did you have your fourth cancer cryotherapy treatment?	
	Numeric value (years)	
	7777 Not applicable	
TxCryoLoc4	Did you have any cryotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxCryoAge5	At what age did you have your fifth cancer cryotherapy treatment?	
	Numeric value (years)	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
TxCryoLoc5	Did you have any cryotherapy at a different clinic or hospital?	
	0 No	
	1 Yes	
	8888 Refused	
	9999 Don't know	
PostSurgPain	After your cancer surgery, did you have any pain?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgFatigue	After your cancer surgery, did you have any fatigue?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgNausea	After your cancer surgery, did you have any nausea and vomiting?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgSwell	After your cancer surgery, did you have any swelling (or lymphedema)?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgInfection	After your cancer surgery, did you have any infections related to the surgery?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgOtherProb	After your cancer surgery, did you have any other problems?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
PostSurgNoProb	After your cancer surgery, did you have no problems?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgHosp	Did your surgeon (or nurses) help you manage any symptoms or side effects you were having	
	while you were in the hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
PostSurgHospEnough	Was it enough help?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgHospMore	Did you need more help?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PostSurgHospWant	Would you have wanted them to help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
PostSurgHome	Did your surgeon (or nurses) talk with you about how you could manage any symptoms or	
	side effects at home after leaving the hospital?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
PostSurgHomeEnough	Was it enough information?	
	0 No	
	1 Yes	
	7777 Not applicable	
PostSurgHomeMore	Would you have liked more information?	
	0 No	
	1 Yes	
	7777 Not applicable	
PostSurgHomeWant	Would you have wanted them to give you this information?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxPain	When you were getting your treatment, did you have any pain?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxFatigue	When you were getting your treatment, did you have any fatigue?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxNausea	When you were getting your treatment, did you have any nausea or vomiting?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxWtLoss	When you were getting your treatment, did you have any weight loss?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxHairLoss	When you were getting your treatment, did you have any hair loss?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxUrination	When you were getting your treatment, did you have problems with urination?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxBM	When you were getting your treatment, did you have problems with your bowel	
	movements?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxIntercourse	When you were getting your treatment, did you have problems with sexual intercourse?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxOtherProb	When you were getting your treatment, did you have any other problems?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxNoProb	When you were getting your treatment, did you have no problems?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxHosp	Did your doctors (or nurses) help you manage any symptoms you were having while you	
	were being treated?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxHospEnough	Was it enough help?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxHospMore	Did you need more help?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxHospWant	Would you have wanted them to help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxHome	Did your doctors (or nurses) talk with you about how you could manage any symptoms or	
	side effects after your treatment is finished?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxHomeEnough	Was it enough information?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
TxHomeMore	Would you have liked more information?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxHomeWant	Would you have wanted them to give you this information?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxFinished	Have you finished getting all of your treatments for your cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
TxConcerns	How often did you feel like you could talk to your doctors (or nurses) about any concerns	
	related to your treatment?	
	1 Always	
	2 Most of the time	
	3 Some of the time	
	4 A little	
	5 Not at all	
	7777 Not applicable	
	9999 Don't know	
TxDelayApptCanceled	During the time you were getting treatment for your cancer, were your visits canceled or	
	postponed?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxDelayApptWait	During the time you were getting treatment for your cancer, were you kept waiting for more	
	than 30 minutes?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayMedRec	During the time you were getting treatment for your cancer, had your first doctor not sent	
	your medical records to your new doctor?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayInsurance	During the time you were getting treatment for your cancer, did you have problems with	
	your insurance of your ability to pay?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayAssistance	During the time you were getting treatment for your cancer, did you not have someone to	
	help you make the visit appointments or go with you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayConvenience	During the time you were getting treatment for your cancer, were your visit appointment	
	times hard to fit into your schedule?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
TxDelayTransport	During the time you were getting treatment for your cancer, did you not have a way to get to	
	your doctor's office or did you not have transportation?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayTrust	During the time you were getting treatment for your cancer, did you not trust your doctor or	
	did you not think your doctor could help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayOther	During the time you were getting treatment for your cancer, did you have another problem?	
	0 No	
	1 Yes	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
TxDelayMainReason	Of those problems, which one was the biggest? (Treatment problems that caused delays):	
	1 Your visits were canceled or postponed	
	2 You were kept waiting for more than 30 minutes	
	3 Your first doctor had not sent your medical records to your new doctor	
	4 You had problems with your insurance or your ability to pay	
	5 You did not have someone to help you make the visit appointments or go with you	
	6 Your visit appointment times were hard to fit into your schedule	
	7 You did not have a way to get to your doctor's office or you did not have	
	transportation	
	8 You did not trust your doctor or did not think your doctor could help you	
	9 You had another problem	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDRecommendFU	Did any of your doctors (or nurses) recommend follow-up visits and regular tests in case your	
	cancer comes back after finishing all of your treatment?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
RegScreen	Do you have regular tests to check for cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
RegScreenFreq	How often are you currently being tested for cancer?	
	1 1 time per month	
	2 4 times per year	
	3 3 times per year	
	4 2 times per year	
	5 1 time per year	
	6 <1 time per year	
	7777 Not applicable	
	9999 Don't know	
NoTxMDWontHelp	Did you have no treatment for your cancer because your doctors did not think that	
	treatment would help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoTxWontHelp	Did you have no treatment for your cancer because you did not think that treatment would	
	help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
NoTxInsurance	Did you have no treatment for your cancer because you had a problem with insurance	
	coverage or your ability to pay for the visit?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoTxSick	Did you have no treatment for your cancer because you were too sick to have treatment?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoTxAfrAnx	Did you have no treatment for your cancer because you were afraid or anxious about the	
	treatment?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoTxAssistance	Did you have no treatment for your cancer because you did not have someone to help you	
	make the visit appointments or go with you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoTxConvenience	Did you have no treatment for your cancer because your visit appointment times were hard	
	to fit into your schedule?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoTxTransport	Did you have no treatment for your cancer because you did hot have a way to get there or	
	you did not have transportation?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
NoTxOthReas	Were there any other reasons why you haven't had any treatment for your cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

SECTION VI. SUPPORT CARE (F)

Variable Name	Question and Coding	Comments
SuppServHomeCare	Have you had someone come to your home to help you with medical or self-care?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServMentalHealth	Have you seen a psychiatrist, psychologist, or mental health worker?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServSocialWork	Have you seen a social worker?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServPTOT	Have you seen a physical (or occupational) therapist?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServPainManagement	Have you seen a doctor or nurse to help with your pain?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServReligiousCounsel	Have you talked with a religious counselor such as a chaplain, minister, priest or rabbi	
	about your cancer?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServOther	Have you had some other support service?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServNone	Have you not had any support services?	
	0 No	
	1 Yes	
	9999 Don't know	

Variable Name	Question and Coding	Comments
MDArrSuppServDx	Did any of your doctors (or nurses) arrange these support services during the time when	
	your cancer was being tested?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MDArrSuppServTx	Did any of your doctors (or nurses) arrange these support services during the time when	
	your cancer was being treated?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedNotRec	Were there any support services that you feel you needed but did not receive?	
	0 No	
	1 Yes	
	9999 Don't know	
SuppServNeedHomeCare	Would you have liked to have someone come to your home to help you with medical or	
	self-care?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedMentalHealth	Would you have liked to see a psychiatrist, psychologist, or mental health worker?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedSocialWork	Would you have liked to see a social worker?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
SuppServNeedPTOT	Would you have liked to see a physical (or occupational) therapist?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedPainManagement	Would you have liked to see a doctor or nurse to help with your pain?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedReligiousCounsel	Would you have liked to talk to a religious counselor such as a chaplain, minister, priest or	
	rabbi about your cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedOther	Would you have liked some other support services?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedInsurance	Did you not receive the support services you felt you needed because you had a problem	
	with insurance coverage or your ability to pay for the support services?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedApptHelp	Did you not receive the support services you felt you needed because you did not have	
	someone to help you make the visit appointments or go with you?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
SuppServNeedConvenience	Did you not receive the support services you felt you needed because your visit	
	appointment times were hard to fit into your schedule?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedTransport	Did you not receive the support services you felt you needed because you did not have a	
	way to get there or you did not have transportation?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedSick	Did you not receive the support services you felt you needed because you were too sick to	
	get the support services?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedAfrAnx	Did you not receive the support services you felt you needed because you were afraid or	
	anxious about the support services?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
SuppServNeedOtherReas	Can you think of any other reasons why you did not receive the support services you felt	
	you needed?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
AltMed	Have you seen another kind of healer other than your regular doctors, such as an	
	acupuncturist, chiropractor, or herbalist to help you treat or relieve symptoms of your	
	cancer?	
	0 No	
	1 Yes	

Variable Name	Question and Coding	Comments
AltMedAware	Are your doctors (or nurses) aware that you are seeing other healers?	
	0 No	
	1 Yes	
	7777 Not applicable	

SECTION VII. QUALITY OF CARE (G)

Variable Name	Question and Coding	Comments
OncologistsN	Since you were told you definitely had cancer, how many different doctors have you seen	
	because of your cancer?	
	Numeric value 1-10	
	9999 Don't know	
QCareDx	Overall, how would you rate the quality of health care you received for the testing (or	
	diagnosis) of your cancer?	
	1 Excellent	
	2 Very good	
	3 Good	
	4 Fair	
	5 Poor	
	8888 Refused	
	9999 Don't know	
QCareTx	Overall, how would you rate the quality of health care you received for the treatment of	
	your cancer?	
	1 Excellent	
	2 Very good	
	3 Good	
	4 Fair	
	5 Poor	
	8888 Refused	
	9999 Don't know	
QCareRelative	Would you say that you received medical care that was better than, about the same as, or	
	worse than other patients with cancer?	
	1 Better	
	2 About the same	
	3 Worse	
	8888 Refused	
	9999 Don't know	
QCareAge	Do you think that the medical care you received was worse than other patients with cancer	
ŭ	because of your age?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
QCareGender	Do you think that the medical care you received was worse than other patients with cancer	
	because of your gender?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareRace	Do you think that the medical care you received was worse than other patients with cancer	
	because of your race or ethnic group?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareEducat	Do you think that the medical care you received was worse than other patients with cancer	
	because of your education level?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareHealthDis	Do you think that the medical care you received was worse than other patients with cancer	
	because of your health or disability?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareInsuranceType	Do you think that the medical care you received was worse than other patients with cancer	
	because of your type of insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareNoInsurance	Do you think that the medical care you received was worse than other patients with cancer	
	because of your lack of insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareIncome	Do you think that the medical care you received was worse than other patients with cancer	
	because of your level of income?	
	0 No	
	1 Yes	
	7777 Not applicable	

Variable Name	Question and Coding	Comments
QCareReligion	Do you think that the medical care you received was worse than other patients with cancer	
	because of your religion?	
	0 No	
	1 Yes	
	7777 Not applicable	
QCareOtherReas	Can you think of any other reasons why the medical care you received was worse than other	
	patients with cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDTrustToHelp	How often did you trust that your doctors (or nurses) were doing everything possible to help	
	you?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	5 Not applicable	
	8888 Refused	
	9999 Don't know	
KnowWhoToAsk	How often did you know who to ask when you had questions related to your cancer?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	5 Not applicable	
	8888 Refused	
	9999 Don't know	
EncourToAsk	How often did your doctors (or nurses) encourage you to ask all the cancer-related	
	questions you had?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	5 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
ProbQuickly	How often did you think that your cancer-related health problems were handled quickly	
	enough?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	5 Not applicable	
	8888 Refused	
	9999 Don't know	
MDWantedToSee	How often were you able to see the doctors or specialists you wanted to see for your	
	cancer?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	5 Not applicable	
	9999 Don't know	
MDTrustKnowledge	How often did your doctors (or nurses) seem to be aware of the tests and/or treatments for	
	your cancer that other doctors recommended or performed?	
	1 Always	
	2 Usually	
	3 Sometimes	
	4 Never	
	5 Not applicable	
	9999 Don't know	

SECTION VIII. QUALITY OF LIFE AND EMPLOYMENT (H)

Variable Name	Question and Coding	Comments
TxEffectProblem	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much have the physical side	
	effects and late effects of your cancer treatment been a problem for you?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
AfraidFutureTests	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much are you afraid of	
	future tests for cancer?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
AfraidRecurrence	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much are you afraid of your	
	cancer coming back?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
AfraidMetastasis	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much are you afraid of your	
	cancer spreading in your body?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
AfraidNewCancer	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much are you afraid of	
	getting a new cancer?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
InterfereFamily	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much has your cancer	
	interferred with your family life?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	

Variable Name	Question and Coding	Comments
InterfereSocial	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much has your cancer	
	intefered with your social activities?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
FinancialStrain	On a scale of 1 to 100, where 1 is not at all and 100 is a lot, how much has your cancer and	
	treatment caused financial problems?	
	Numeric value 1-100	
	8888 Refused	
	9999 Don't know	
EmployedDx	When you were diagnosed with your cancer, were you working for pay?	
	0 No	
	1 Yes	
EmployedCurr	Are you working for pay now?	
	0 No	
	1 Yes	
EmployedChange	As a result of your cancer, have you changed jobs or employers?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedLeave	As a result of your cancer, have you taken a leave of absence?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedQuit	As a result of your cancer, have you quit your job?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedFired	As a result of your cancer, have you been let go or fired?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
EmployedAbsent	As a result of your cancer, have you missed work?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedFewerHrs	As a result of your cancer, have you worked fewer hours?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedNotPromoted	As a result of your cancer, have you turned down a job or promotion?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedQuality	As a result of your cancer, have you felt that your work suffered?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedBadly	As a result of your cancer, have you felt your co-workers treated you badly?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedSupervisor	As a result of your cancer, have you felt your supervisor treated you badly?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
EmployedNoEffect	Did none of these happen as a result of your cancer?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

SECTION IX. HEALTH INSURANCE (I)

Variable Name	Question and Coding	Comments
InsuranceCNS	Do you currently have health insurance?	
	0 No	
	1 Yes	
MedicaidCNS	Do you have Medicaid?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MedicareCNS	Do you have Medicare?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
PrivateInsuranceCNS	Do you have private health insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
MilitaryInsuranceCNS	Do you have military insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
OtherInsuranceCNS	Do you have some other type of insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
NoInsuranceCurrReason	What is the one main reason why you do not have any health insurance?	
	1 You changed employers or lost your job.	
	2 Your family situation changed.	
	3 You lost or public program coverage.	
	4 Your employer does not offer insurance.	
	5 You can't afford insurance (or it is too expensive).	
	6 You don't believe in insurance.	
	7 You are not eligible for health insurance.	
	8 You do not need insurance.	
	9 Other	
	7777 Not applicable	
	9999 Don't know	
UsualSourceofCareCNS	How do you get health care most of the time?	
	1 A walk-in clinic (or community health center)	
	2 The emergency room	
	3 An alternative healer	
	4 Other	
	7777 Not applicable	
NoInsuranceEver	Between when you were first tested for cancer and today, was there ever a time when you	
	did not have health insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	
NoInsuranceDuration	For how many months did you not have health insurance?	
	Numeric value 1-2000	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
NoInsuranceEverReason	What was the one main reason why you did not have any health insurance?	
	1 You changed employers or lost your job.	
	2 Your family situation changed.	
	3 You lost your public program coverage.	
	4 Your employer did not offer insurance.	
	5 You couldn't afford it (or it was too expensive).	
	6 You didn't believe in insurance.	
	7 You were not eligible for health insurance.	
	8 You didn't need insurance.	
	9 Other	
	7777 Not applicable	
UsualSourceofCareUnins	During the time when you had no health insurance, how did you get health care most of time?	
	1 A walk-in clinic (or community health center)	
	2 The emergency room	
	3 An alternative healer	
	4 Other	
	7777 Not applicable	
	8888 Refused	
	9999 Don't know	
DxMedicaid	When you were being tested for cancer, did you have Medicaid?	
	0 No	
	1 Yes	
	9999 Don't know	
DxMedicare	When you were being tested for cancer, did you have Medicare?	
	0 No	
	1 Yes	
	9999 Don't know	
DxPrivateInsurance	When you were being tested for cancer, did you have private health insurance?	
	0 No	
	1 Yes	
	9999 Don't know	
DxMilitaryInsurance	When you were being tested for cancer, did you have military insurance?	
	0 No	
	1 Yes	
	9999 Don't know	

Variable Name	Question and Coding	Comments
DxOtherInsurance	When you were being tested for cancer, did you have some other kind of health insurance?	
	0 No	
	1 Yes	
	9999 Don't know	
ChangeInsuranceDxtoTx	Did your health insurance change between when you were being tested and when you were	
	being treated for your cancer?	
	0 No	
	1 Yes	
	9999 Don't know	
TxMedicaid	When you were being treated for cancer, did you have Medicaid?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxMedicare	When you were being treated for cancer, did you have Medicare?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxPrivateInsurance	When you were being treated for cancer, did you have private health insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxMilitaryInsurance	When you were being treated for cancer, did you have military insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
TxOtherInsurance	When you were being treated for cancer, did you have some other kind of health insurance?	
	0 No	
	1 Yes	
	7777 Not applicable	
ChangeInsuranceReason	Why did your insurance change?	
	1 Because of cancer	
	2 Other	
	7777 Not applicable	
	9999 Don't know	

Variable Name	Question and Coding	Comments
DxNoTestInsurance	When you were being tested to see if you had cancer, were there any tests your doctor (or	
	nurse) wanted you to get that you did not get because of problems with insurance or	
	because you could not afford them?	
	0 No	
	1 Yes	
	9999 Don't know	
TxNoTestInsurance	When you were being treated for your cancer, were there any treatments your doctor (or	
	nurse) wanted you to get that you did not get because of problems with insurance or	
	because you could not afford them?	
	0 No	
	1 Yes	
	9999 Don't know	
MDFinancialInfo	Did any of your doctors (or nurses) give you financial information on free or low-cost health	
	benefits or welfare?	
	0 No	
	1 Yes	
	9999 Don't know	
MDFinancialInfoDxorTx	Did you receive this information when you were being tested or treated?	
	1 Tested	
	2 Treated	
	3 Both	
	7777 Not applicable	
	9999 Don't know	
MDFinancialInfoHelp	Did this information help you?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDFinancialInfoUse	Did you apply for benefits?	
	0 No	
	1 Yes	
	7777 Not applicable	
MDFinancialInfoWant	Would you have wanted them to give you this information?	
	0 No	
	1 Yes	
	7777 Not applicable	
	9999 Don't know	