

NORTH CAROLINA COLON CANCER STUDY

University of North Carolina
Chapel Hill, North Carolina

Participant Questionnaire

STUDY ID

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DATE OF INTERVIEW

		/			/		
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MM/DD/YY

A. Background Characteristics

Time began: ____ : ____ : ____

Since many people have never been in an interview exactly like this one, let me start by telling you a little bit about how it works. I am going to read you a set of questions exactly as they are worded so that everybody in the study will be answering the same questions. You will be asked to answer two kinds of questions. In some cases you will answer in your own words, and I will write down your answers word for word. For other questions you will be given a list of choices and asked to pick the one that fits best. If at any time during the interview you are not clear about what is wanted, please ask me. Also try to answer the questions as accurately and completely as possible. Take as much time as you need.

I would like to begin with some questions about your background

1. How old were you on your last birthday? _____ years
2. What is your date of birth? ____ / ____ / ____
month day year
3. Are you presently married, living as married, widowed, separated, divorced, or have you never married?

MARRIED.....	1
LIVING AS MARRIED.....	2
WIDOWED.....	3
SEPARATED.....	4
DIVORCED.....	5
NEVER MARRIED.....	6
4. What is the highest grade in school or year of college that you completed?

NONE.....	00			
ELEMENTARY/MIDDLE ...01	02	03	04	
	05	06	07	08
HIGH SCHOOL.....09	10	11	12	
COLLEGE.....13	14	15	16	
GRADUATE SCHOOL ...	17+			
5. Do you consider yourself:

White, not Hispanic.....	1
White, Hispanic.....	2
Black, not Hispanic.....	3
Black, Hispanic.....	4
Other (Specify _____).....	5
6. What language do you usually speak at home?

ENGLISH.....	1
SPANISH.....	2
SOMETHING ELSE.....	3
7. Sex of respondent [do not ask - enter sex]

MALE.....	1
FEMALE.....	2
8. During your lifetime, have you smoked at least 100 cigarettes?

YES.....	1
NO.....	GOTO QUES 10 ◀ 2

 - a. Were you currently smoking at the time you learned of your colon problem? (TIME OF DIAGNOSIS)

YES.....	1
NO.....	2
 - b. On average, how many cigarettes did you smoke per day during the entire time that you smoked?

10 CIGARETTES OR FEWER.....	1
11-20.....	2
21-40.....	3
MORE THAN 40.....	4
DON'T KNOW.....	8
9. What is the total number of years you smoked cigarettes? _____
(Remember to subtract years you did not smoke) years

10. Did you use any of the following other tobacco products on a regular basis for six months or longer?
(*may choose more than one*)
- | | YES | NO |
|--------------------------|-----|----|
| a. pipe | 1 | 2 |
| b. cigars..... | 1 | 2 |
| c. cigarillos..... | 1 | 2 |
| d. chewing tobacco | 1 | 2 |
| e. snuff..... | 1 | 2 |

11. Do you currently have a North Carolina Driver's License or ID card?
- | | |
|-----------|---|
| YES | 1 |
| NO | 2 |

Now I would like to ask you about your (husband/wife/partner) [*GOTO QUES 15 IF NEVER MARRIED*].

12. What is the highest grade in school or year of college that your (husband/wife/partner) completed?
- | | | | | |
|---------------------|-----|----|----|----|
| NONE | | | | 00 |
| ELEMENTARY | 01 | 02 | 03 | 04 |
| | 05 | 06 | 07 | 08 |
| HIGH SCHOOL | 09 | 10 | 11 | 12 |
| COLLEGE | 13 | 14 | 15 | 16 |
| GRADUATE SCHOOL ... | 17+ | | | |

13. During (his/her) adult life, what has your (husband/wife/partner) been doing most?
- | | | | | |
|--|--|--|--|---|
| Working | | | | 1 |
| Keeping house..... | | | | 2 |
| Not working because of a permanent disability..... | | | | 3 |
| Something else (specify below) | | | | 4 |
- GOTO QUES 15 ←

14. What (is/was) your (husband/wife/partner)'s job or your usual paid occupation, that is, the job that (he/she) held for the longest time or spent the most time doing?

[Job title/description] _____

The next questions are about people who currently live in your household.

15. How many people altogether live in your household, including yourself, children or others? _____
 [IF CURRENTLY INSTITUTIONALIZED, CODE '96' ← number
 IF LIVING ALONE OR CODE '96', GOTO QUES 18]

16. Are you currently living with.... (*Code "yes" or "no" for each item*)
- | | YES | NO |
|--|-----|----|
| a. Your spouse (<i>ask only if currently married</i>)? | 1 | 2 |
| b. Your children or grandchildren? | 1 | 2 |
| c. Other relatives?..... | 1 | 2 |
| d. Friends?..... | 1 | 2 |
| e. Anyone else? (<i>specify below</i>) | 1 | 2 |

17. How many in your current household are children ages 17 or less?.....
 number

18. Just before your recent illness, did you live alone? YES → (How long?) _____ years..... 1
 NO..... 2
 INSTITUTIONALIZED JUST BEFORE ILLNESS..... 3

B. Medical History

1. Has a doctor ever told you that you had a condition called familial polyposis, or Gardner's syndrome?
 - YES 1
 - NO..... 2
 - DON'T KNOW 8
2. Before your recent illness did you ever have a polyp removed from your large bowel?
 - YES 1
 - NO..... 2
 - DON'T KNOW 8
3. Has a doctor ever told you that you had ulcerative colitis?.....
 - YES 1
 - NO..... 2
 - DON'T KNOW 8

If YES → How old were you when you were first told that you had ulcerative colitis?
4. Has a doctor ever told you that you had Crohn's disease?.....
 - YES 1
 - NO..... 2
 - DON'T KNOW 8

If YES → How old were you when you were first told that you had Crohn's disease?.....
5. Did you ever have radiation treatments to your abdomen or pelvis?
 - YES 1
 - NO..... 2
 - DON'T KNOW 8

If YES → How old were you when you had radiation treatments?
6. Has a doctor ever told you that you had:

	YES	NO
a. diabetes	1	2
b. arthritis (including rheumatoid arthritis)	1	2
c. hypertension (high blood pressure).....	1	2
d. depression.....	1	2
e. heart attack or heart problems	1	2
f. asthma/chronic obstructive pulmonary disease (COPD)/chronic bronchitis	1	2
7. Have you ever had cancer?
 - YES 1
 - NO..... 2
 - DON'T KNOW 8

GOTO QUES 8 ←

First cancer _____		Another cancer? _____		Another cancer? _____			
Code number ____		Code number ____		Code number ____			
Age at first cancer _____		Age at second cancer _____		Age at third cancer _____			
01. colon/rectum	02. lung	03. breast	04. prostate	05. bladder	06. brain	07. cervix	08. kidney
09. leukemia/lymphoma	10. oral	11. ovary	12. pancreas	13. stomach	14. uterus	98. other	99. unknwn

8. Have you ever had any of the following operations?

Operation		Age at operation	Operation		Age at operation
gallbladder removed	YES1→	_____ age	hemorrhoids	YES..... 1→	_____ age
	NO.....2			NO..... 2	
	DK.....8			DK..... 8	
appendix	YES1→	_____ age	(WOMEN) tubal ligation	YES..... 1→	_____ age
	NO.....2			NO..... 2	
	DK.....8			DK..... 8	
tonsils	YES1→	_____ age	hysterectomy	YES..... 1→	_____ age
	NO.....2			NO..... 2	
	DK.....8			DK..... 8	
hernia repair	YES1→	_____ age	ovaries removed	YES..... 1→	_____ age
	NO.....2			NO..... 2	
	DK.....8			DK..... 8	

C. Occupation

1. During your adult life, what was your job or your usual paid occupation, that is, the job that you held for the longest time or that you spent the most time doing?

[Job title] _____

IF DID NOT WORK FOR AT LEAST SIX MONTHS, CHECK HERE →
AND SKIP TO QUES 9

2. What were your main activities or duties in this job? _____

3. In what kind of business or industry did you do this job? What did your part of the company make or do, or specialize in?

a. Business/Industry: _____

b. How many years did you work as a [JOB TITLE] in [BUSINESS INDUSTRY]? _____
years

4. What was your second-longest job or paid occupation? [IF NONE, ENTER "NONE" AND → GOTO QUES 9]

[Job title] _____

5. What were your main activities or duties in this job? _____

6. In what kind of business or industry did you do this job? What did your part of the company make or do, or specialize in?

a. Business/Industry: _____

b. How many years did you work as a [JOB TITLE] in [BUSINESS INDUSTRY]? _____
years

9. During your entire life, have you ever <u>lived</u> on a farm? (a farm is any place that raises crops or livestock and <u>sells them</u> to earn money)	YES 1→ NO 2 DON'T KNOW.... 8	How old were you when you first lived on a farm? _____ years old	For how many years did you live on any farm? _____ years
10. (During your entire life) have you ever <u>worked</u> on a farm other than those you lived on?	YES 1→ NO 2 DON'T KNOW.... 8	How old were you when you first worked on a farm? _____ years old	For how many years did you work on any farm? _____ years
11. (During your entire life) have you ever <u>lived or worked</u> on a <u>dairy farm</u> ?	YES 1→ NO 2 DON'T KNOW.... 8	How old were you when you first lived or worked on a dairy farm? _____ years old	For how many years did you live or work on a dairy farm? _____ years

D. Analgesic medications

We are now interested in obtaining information on certain medications that you may have taken during the **five years prior to your diagnosis**. These include medicines that you have obtained anywhere including a doctor's prescription, a hospital or neighborhood clinic, pharmacy, supermarket, store, friends, neighbors and relatives. During the **five years prior to your diagnosis** did you ever take any of the following prescription medications, for headache, backache, arthritis, bursitis, rheumatism, joint pain, injury, accident, operation, migraine, sinus trouble or (women) menstrual cramps or other reasons?

PRESCRIPTION Name of drug [SHOW CARD D1]	Used during 5 years prior to diagnosis?	At any time during the 5 years prior to your diagnosis did you take this medicine...	How many times per day or week?	In total, for how many weeks, months or years did you take MEDICINE ?		Did you use MEDICINE in year prior to diagnosis?
1. Aspirin with codeine; Percodan; Lortab; Roxiprin; Synalgos	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
2. Naprosyn, Anaprox <i>(naproxen)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
3. Voltaren, cataflam <i>(diclofenac)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
4. Motrin (prescription); Rufen <i>(ibuprofen)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
5. Feldene <i>(piroxicam)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
6. Ansaid <i>(flurbiprofen)</i> Orudis <i>(ketoprofen)</i> Dolobid <i>(diflunisal)</i> Tolectin <i>(tolmetin)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
7. Relafen <i>(nabumetone)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
8. Meclomen, Ponstel <i>(meclofenamate)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
9. Clinoril <i>(sulindac)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
10. Indocin <i>(indomethacin)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
11. Daypro <i>(oxaprozin)</i> Lodine <i>(etodolac)</i> Toradol <i>(ketorolac)</i>	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	
12. Fiorinal; Fortabs; Idenal; Axotal	YES.....1→ NO.....2 DK8	regularly (3 days or more/wk) 1→ occasionally (1 day or more/mo)..... 2 rarely/seldom (<1/mo)..... 3	Day ...1 Wk.....2 #	Wk..... 1 Mo..... 2 Yr..... 3	YES..... 1 NO..... 2 DK..... 8	

During the **five years prior to your diagnosis** did you ever take any of the following over-the-counter medications for any of the same or similar reasons?

OVER-THE-COUNTER Name of drug [SHOW CARD D2]	Used during 5 years prior to diagnosis??	At any time during the 5 years prior to your diagnosis did you take this medicine ...	How many times per day or week?	In total, for how many weeks, months or years did you take MEDICINE ?			Did you use MEDICINE in year prior to diagnosis?
13. Aspirin (generic or brand name), e.g. Anacin, Bayer, Empirin, Norwich Vanquish	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
14. Buffered aspirin (any brand, e.g., Ascriptin, Bufferin, Ecotrin)	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
15. BC, Goodys, or Stanback powders or tablets	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
16. Excedrin, Equagesic	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
17. Comtrex, Dristan, Allerest, Dimetapp, Drixoral, Sinarrest	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
18. Alka Seltzer or Bromoseltzer	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
19. Advil, Nuprin, Motrin IB, Midol IB (<i>ibuprofen</i>)	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
20. Tylenol, Datril, aspirin-free pain formula, aspirin-free Excedrin, or acetaminophen	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
21. Aleve, Anaprox (<i>naproxen</i>)	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	
22. Orudis KT, Actron (<i>ketoprofen</i>)	YES.....1→ NO.....2 DK.....8	regularly (3 days or more/wk)1→ occasionally (1 day or more/mo)2 rarely/seldom (<1/mo)3	Day1 Wk.....2 #	#	Wk1 Mo2 Yr3	YES..... 1 NO.....2 DK.....8	

23. Were you ever told by a doctor that you should avoid taking aspirin or medicines such as Motrin or Advil?

YES..... 1
No GOTO SECT E ← 2

IF YES: What medicine(s) were you told to avoid? _____

24. About how many years ago were you told to avoid this medicine? years

25. Why were you told to avoid this medicine? _____

E. Bowel habits and laxatives [NOTE: Questions refer to time PRIOR to diagnosis]

How many bowel movements did you have each week? number

Were you ever bothered by constipation as an adult? YES..... 1
 NO 2

Did you ever take laxatives, fiber, natural remedies, stool softeners, suppositories, oils (such as mineral oil) or enemas to help you move your bowels? These include medicines that you might have obtained anywhere including a doctor's prescription, a hospital or neighborhood clinic, pharmacy, supermarket, store, friends, neighbors and relatives.

YES..... 1
 NO GOTO NEXT PAGE ← 2

Please look at the list of laxatives and tell me about any you have used more than 10 times in your lifetime
 [SHOW CARD E]..... If used laxatives, but not more than 10 times, check here → and GOTO SECT F

Name of medicine [SHOW CARD E]	Code	How old were you when you started using [MEDICINE]?	About how often did you take this medication?				In total, for how many weeks, months or years did you take [MEDICINE]?	
			#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
1. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
2. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
3. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
4. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
5. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
6. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
7. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
8. _____	code	age	#	Day 1 Week 2 Month 3 Year 4	#	Weeks..... 1 Months 2 Years..... 3		
If more than 8 medicines, add additional page(s) and check here → <input type="checkbox"/>								

F. Physical activity

I would now like to ask you a series of questions about your level of physical activity in the **year before your illness** and **10 years ago**. For the questions about activity 10 years ago, try to recall where you were living, who you were living with and what sort of work you were doing. For these questions give your best estimate.

OCCUPATIONAL

The first questions have to do with work inside or outside the home for pay.	In the year before your recent illness	Ten years ago
1. During a typical week , how many days per week did you work inside or outside the home for pay?	_____ days	_____ days
2. On a typical day that you worked inside or outside the home for pay, how many hours per day did you work?	_____ hours	_____ hours

WORKDAY: OCCUPATIONAL *[leave section blank if did not work for pay]*

3. On work days, how many work hours were spent in: [SHOW CARD F1] <i>[total should add to the total hours worked]</i>	Year before illness	Ten years ago
a. Very hard activity (METS = 10)		
b. Hard activity (METS = 7)		
c. Moderate activity (METS = 4)		
d. Light activity (METS = 1.5)		

WORKDAY: NON-OCCUPATIONAL *[leave section blank if did not work for pay]*

4. On work days, when you were not at work, how many non-work hours were spent in: [SHOW CARDS F2A-C] <i>[total should add to the total hours not at work]</i>	Year before illness	Ten years ago
a. Sleeping, relaxing, self care (METS = 1)		
b. Very hard activity (METS = 10)		
c. Hard activity (METS = 7)		
d. Moderate activity (METS = 4)		
e. Light activity (METS = 1.5) <i>[by subtraction]</i>		

NONWORK/WEEKEND

5. On usual 24 hour non-work or weekend days, about how many hours do you spend in the following activities? [SHOW CARDS F2A-C] <i>[total should add to 24 hours]</i>	Year before illness	Ten years ago
a. Sleeping, relaxing, self care (METS = 1)		
b. Very hard activity (METS = 10)		
c. Hard activity (METS = 7)		
d. Moderate activity (METS = 4)		
e. Light activity (METS = 1.5) <i>[by subtraction]</i>		

G. Sources of care

Now I'd like you to think back to the time before you first became aware of the recent problems with your colon. These questions are about the places you usually went when you were sick or when you needed advice about your health.

1. Did you ever have a general checkup or examination, not counting exams made during a visit for an illness?

YES.....	1
NO.....	2

 - a. What was the date of your last check up? (*month/year*) Date: ___ ___/___ ___

2. During the 12 months before you became sick, did you have a health problem which you would have liked to have seen a doctor about but did not for some reason?

YES.....	1
NO.....	2

3. Just before your recent illness, was there a particular clinic health center, doctor's office or other place to which you would go if something were bothering you?

YES.....	1
NO.....	GOTO SECT H ← 2

4. What kind of place is that?

Hospital emergency room	1
Public health center or community clinic.....	2
A doctor's office or group practice.....	3
Some other place (SPECIFY BELOW).....	8

5. Did you usually see a particular doctor or medical person there, or did you usually see different doctors or medical personnel on each visit?

PARTICULAR DOCTOR/MEDICAL PERSON	1
DIFFERENT DOCTORS/MEDICAL PERSONNEL	GOTO SECT H ← 2

6. What is the name of the particular doctor or medical person that you usually saw?
 Name of doctor: _____

H. Diagnosis history

Now I'd like to ask you about your recent illness, that is, the problem with your colon.

I'm going to read you a list of symptoms that some people with colon problems report having. Please tell me if you had any of the following symptoms before you first saw a doctor about your problems.

a. Did you have:		b. At the time, how worried were you about this? (SHOW CARD H)	c. At the time, were you worried because you thought it might be a symptom of a serious illness?	d. What illness did you think it might be?
1. Blood in your stools or dark stools?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
2. Pain in your lower abdomen	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
3. Problems with constipation?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
4. Change in the type or size of stool, that is, pebble sized or ribbon-shaped stools?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
5. Diarrhea, that is watery stools?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
6. Nausea or vomiting?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
7. An unexplained weight loss?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
8. Loss of appetite?	YES 1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____
9. Any other symptoms? (SPECIFY BELOW) _____ _____	YES.....1→ NO.....2	Not worried at all 1 A little worried..... 2→ Quite worried 3→ Extremely worried..... 4→	Yes 1→ No.....2	_____ _____

....

10. Did you go to see a doctor or medical person because of (this/these) symptoms, or was your problem first discovered during a medical visit for some other reason?

- VISIT BECAUSE OF SYMPTOMS 1
- OTHER ILLNESS..... 2
- ROUTINE CHECK UP..... 3
- SPECIAL SCREENING (SPECIFY) _____ 4
- OTHER (SPECIFY) _____ 5

11. What was the date of the visit? (*Hand respondent calendar card*) / /
month year
 DON'T know D

12. About how long was it between the very first time you noticed (this/any of these) symptoms and the time you actually went to see a doctor, nurse practitioner, or some other medical person

- DAYS 1
- WEEKS 2
- MONTHS 3
- # DON'T KNOW..... D

13. Would you say that it was less than three weeks or three weeks or more?

- LESS THAN 3 WEEKS GOTO QUES 16 ← 1
- THREE WEEKS OR MORE 2
- DON'T KNOW 8

14. What was the main reason that you waited until then to make this visit?

- COULDN'T GET APPOINTMENT..... 1
- COST TOO MUCH..... 2
- DID NOT HAVE TIME 3
- THOUGHT PROBLEM WOULD GO AWAY..... 4
- THOUGHT PROBLEM NOT SERIOUS 5
- FEAR OF DOCTORS OR HOSPITALS 6
- FEAR OF BAD NEWS..... 7
- OTHER (SPECIFY) _____ 8
- DON'T KNOW GOTO QUES 16 ← 9

15. Were there any other reasons why you waited (may select more than one)?

- NO OTHER REASONS..... 0
- COULDN'T GET APPOINTMENT..... 1
- COST TOO MUCH..... 2
- DID NOT HAVE TIME 3
- THOUGHT PROBLEM WOULD GO AWAY..... 4
- THOUGHT PROBLEM NOT SERIOUS 5
- FEAR OF DOCTORS OR HOSPITALS 6
- FEAR OF BAD NEWS..... 7
- OTHER (SPECIFY) _____ 8
- DON'T KNOW 9

16. Where did you go for this very first medical visit related to your problem?

What was the name of the doctor or place? _____

17. To what kind of place did you go:

- HOSPITAL EMERGENCY ROOM..... 1
 - PUBLIC HEALTH CENTER OR COMMUNITY CLINIC 2
 - A DOCTOR'S OFFICE OR GROUP PRACTICE..... 3
 - SOME OTHER PLACE (SPECIFY BELOW) 8
-

18. What kind of medical person did you see? Was it:

- A general/family practitioner 1
- An internist..... 2
- Another specialist such as a
gastroenterologist or oncologist 3
- A surgeon..... 4
- A medical person who was not a
medical doctor, such as a chiropractor,
a nurse practitioner, or a lab tech..... 5
- Someone else (specify)..... 6
- Doctor, type unknown..... 7
- Don't know 8

19. Can you tell me how many visits you made about your medical problem, up to the time that you went into the hospital for surgery?

NUMBER OF VISITS _____

DON'T KNOWD

20. What is the name and address of the place that you are currently receiving treatment for the problem with your colon?

NAME: _____

ADDRESS: _____

I. Screening history

The following questions concern a number of medical exams and tests. Do <u>not</u> include the tests that were used to discover your colon cancer.		When was the last one? (mon/yr)
During the past <u>ten</u> years before you developed your colon problem, how many times did you have...?		
1. A general physical checkup even though you were not feeling ill (not for an illness or condition for which you were being treated)?	Times.....	___ / ___
2. A routine dental checkup?	Times.....	___ / ___
3. A routine eye exam?	Times.....	___ / ___
4. [MEN] A PSA (prostate cancer blood) test?	Times.....	___ / ___
5. [WOMEN] A PAP test?	Times.....	___ / ___
6. [WOMEN] A breast exam by a doctor?	Times.....	___ / ___
7. [WOMEN] A mammogram, that is, an x-ray of your breast?	Times.....	___ / ___
<i>[During the ten years before you developed your colon problem, how many times did you have:]</i>		
8. A rectal examination, that is, a finger examination of your rectum?	Times.....	___ / ___
9. A proctoscopic (procto) or flexible sigmoidoscopy examination, that is, an examination of your rectum with a lighted tube? [do not include exam that discovered cancer] Was this last done for screening or for some problem?	Times..... for screening.....1 for a problem2 (PROBLEM:.....)	___ / ___
10. A barium enema x-ray, that is an examination where barium was injected into your rectum and x-rays taken? [do not include exam that discovered cancer] Was this last done for screening or for some problem?	Times..... for screening..... 1 for a problem2 (PROBLEM:.....)	___ / ___
11. A colonoscopy examination, that is an examination in which a long flexible tube is inserted to examine the entire colon generally after cleaning out the bowels with laxatives or enemas. [do not include exam that discovered cancer] Was this last done for screening or for some problem?	Times..... for screening..... 1 for a problem2 (PROBLEM:.....)	___ / ___
12. A test to look for blood in your stools, such as a Hemoccult® test [do not include exam that discovered cancer] Was this last done for screening or for some problem?	Times..... for screening..... 1 for a problem 2 (PROBLEM:.....)	___ / ___

13. During the year before developing your colon problem did you receive a notice from your doctor that it was time for a routine check-up of any kind, not including dental and eye exams?

- YES..... 1
NO 2

14. (WOMEN) During the past ten years how often did you examine your own breasts for lumps or other unusual conditions? Would you say:

- At least once a month..... 1
Once every 2 months 2
Several times a year..... 3
Once or twice a year 4
Less than once a year 5
Never..... 9

J. Health Status

The following 12 questions ask for your views about your health. If you are unsure about how to answer a question, please give the best answer you can.

1. In general would you say your health is:
- | | |
|-----------------|---|
| Excellent | 1 |
| Very good..... | 2 |
| Good | 3 |
| Fair..... | 4 |
| Poor | 5 |

The following questions are about activities you might do during a typical day:

2. Does your health now limit you in **moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf, and, if so, how much?
- | | |
|-----------------------------|---|
| Yes, limited a lot..... | 1 |
| Yes, a little limited | 2 |
| No, not limited at all..... | 3 |
3. Does your health now limit you in **climbing several flights of stairs**, and, if so, how much?
- | | |
|-----------------------------|---|
| Yes, limited a lot..... | 1 |
| Yes, a little limited | 2 |
| No, not limited at all..... | 3 |

The next few questions are about your **work or other regular daily activities** during the past 4 weeks.

4. During the past 4 weeks, have you **accomplished less** than you would like as a result of your physical health?
- | | |
|----------|---|
| Yes..... | 1 |
| No..... | 2 |
5. During the past 4 weeks, were you **limited** in the kind of work or other activities as a result of your physical health?
- | | |
|----------|---|
| Yes..... | 1 |
| No..... | 2 |
6. During the past 4 weeks, have you **accomplished less** than you would like as a result of any emotional problems (such as feeling depressed or anxious)?
- | | |
|----------|---|
| Yes..... | 1 |
| No..... | 2 |
7. During the past 4 weeks, would you say you didn't do work or other activities **as carefully** as usual as a result of any emotional problems (such as feeling depressed or anxious)?
- | | |
|----------|---|
| Yes..... | 1 |
| No..... | 2 |
8. During the past 4 weeks, how much did **pain interfere** with your normal work (including both work outside the home and housework)?
- | | |
|-------------------|---|
| Not at all..... | 1 |
| A little bit..... | 2 |
| Moderately..... | 3 |
| Quite a bit..... | 4 |
| Extremely..... | 5 |

These next questions are about **how you feel** and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks ... [SHOW CARD J]

9. Have you felt calm and peaceful? [SHOW CARD J]
- | | |
|-----------------------------|---|
| All of the time | 1 |
| Most of the time | 2 |
| A good bit of the time..... | 3 |
| Some of the time | 4 |
| A little of the time..... | 5 |
| None of the time..... | 6 |

[How much of the time during the past 4 weeks ...]

10. Did you have a lot of energy? [SHOW CARD J]
- | | |
|------------------------------|---|
| All of the time | 1 |
| Most of the time | 2 |
| A good bit of the time | 3 |
| Some of the time | 4 |
| A little of the time..... | 5 |
| None of the time..... | 6 |
11. Have you felt downhearted and blue? [SHOW CARD J]
- | | |
|------------------------------|---|
| All of the time | 1 |
| Most of the time | 2 |
| A good bit of the time | 3 |
| Some of the time | 4 |
| A little of the time..... | 5 |
| None of the time..... | 6 |
12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? [SHOW CARD J12]
- | | |
|---------------------------|---|
| All of the time | 1 |
| Most of the time | 2 |
| Some of the time | 3 |
| A little of the time..... | 4 |
| None of the time..... | 5 |

K. Social support [NOTE: ALL QUESTIONS REFER PERIOD BEFORE ILLNESS]

1. Before your illness did you have a family member or friend to whom you could talk about your health?
- | | |
|----------|---|
| YES..... | 1 |
| NO | 2 |
2. Before your illness did you have anyone else to whom you could talk about your health?
- | | |
|----------|---|
| YES..... | 1 |
| NO | 2 |
3. Before your illness did you feel that you would have liked (someone/someone else) to talk to about your health?
- | | |
|----------|---|
| YES..... | 1 |
| NO | 2 |
4. Before your illness did you have a family member or friend to whom you could talk about your personal problems?
- | | |
|----------|---|
| YES..... | 1 |
| NO | 2 |
5. Before your illness did you have anyone else to whom you could talk about your personal problems?
- | | |
|----------|---|
| YES..... | 1 |
| NO | 2 |
6. Before your illness did you feel that you would have liked (someone/someone else) to talk to about your personal problems?
- | | |
|----------|---|
| YES..... | 1 |
| NO | 2 |
7. Before your illness, how many close friends did you have? These are people you felt at ease with, or could talk to about a private matter, or could call on for help.
- | | |
|------------------|---|
| NONE | 1 |
| 1 OR 2..... | 2 |
| 3 TO 5 | 3 |
| 6 TO 9 | 4 |
| 10 OR MORE | 5 |

8. Before your illness, how many relatives did you have that you felt close to?

NONE GOTO QUES 10 ← 1
 1 OR 2..... 2
 3 TO 5..... 3
 6 TO 9..... 4
 10 OR MORE 5

9. How many of these friends or relatives did you see at least once a month?

NONE 1
 1 OR 2..... 2
 3 TO 5..... 3
 6 TO 9..... 4
 10 OR MORE 5

10. Before your illness, did you belong to any of these kinds of groups? YES NO

a. A social or recreational group? 1 2
 b. A labor union, commercial group, professional organization? 1 2
 c. Church group? 1 2
 d. A group concerned with children (PTA, Boy Scouts, Girl Scouts)? 1 2
 e. A group concerned with community betterment, charity, or service? 1 2
 f. Any other group? Describe _____ 1 2

11. [*Before illness*] Did you attend church or other place of worship? YES 1 NO..... 2

How often? _____ #

DAYS 1
 WEEKS 2
 MONTHS 3
 DON'T KNOW D

12. In the year before your recent illness when you needed some extra help, could you count on anyone to help with daily tasks like grocery shopping, house cleaning, cooking, telephoning, giving you a ride?

YES 1
 NO..... 2
 I DIDN'T NEED HELP 3
 REFUSED..... 4
 DON'T KNOW..... 8

GOTO QUES 15 ←

13. In the past year, who was most helpful with these daily tasks?
 You may mention one or two people

MENTIONED: YES NO

a. SPOUSE? 1 2
 b. DAUGHTER? 1 2
 c. SON? 1 2
 d. SIBLING? 1 2
 e. OTHER RELATIVE? 1 2
 f. NEIGHBORS? 1 2
 g. CO-WORKERS? 1 2
 h. CHURCH MEMBERS? 1 2
 i. CLUB MEMBERS? 1 2
 j. PROFESSIONALS? 1 2
 k. ANY FRIENDS NOT INCLUDED IN THESE CATEGORIES? 1 2
 l. NO ONE? 1 2

14. In the year before your recent illness could you have used more help with daily tasks than you received? Would you say.....

A lot 1
 Some 2
 A little..... 3
 None at all (received sufficient help)..... 4
 Refused 7
 Don't know 8

15. In the year before your recent illness, could you count on anyone to provide you with emotional support? (talking over problems or helping you make a difficult decision)

- | | | |
|----------------|--------------------------|---|
| | YES | 1 |
| | NO..... | 2 |
| GOTO QUES 18 ← | I DIDN'T NEED HELP | 3 |
| | REFUSED..... | 4 |
| | DON'T KNOW..... | 8 |

16. In the year before your recent illness, who was most helpful in providing you with emotional support?

	<u>MENTIONED:</u>		YES	NO
a. SPOUSE?	1	2		
b. DAUGHTER?	1	2		
c. SON?	1	2		
d. SIBLING?	1	2		
e. OTHER RELATIVE?	1	2		
f. NEIGHBORS?	1	2		
g. CO-WORKERS?	1	2		
h. CHURCH MEMBERS?	1	2		
i. CLUB MEMBERS?	1	2		
j. PROFESSIONALS?	1	2		
k. ANY FRIENDS NOT INCLUDED IN THESE CATEGORIES?	1	2		
l. NO ONE?	1	2		

17. [*In year before*] Could you have used more emotional support than you received. Would you say...

- | | |
|---|---|
| A lot..... | 1 |
| Some..... | 2 |
| A little..... | 3 |
| No, none (received sufficient support)..... | 4 |
| Refused | 7 |
| Don't know | 8 |

18. In the year before your recent illness, when you needed some extra help financially, could you count on anyone to help you, that is, by paying any bills, housing costs, hospital visits, or providing you with food or clothes?

- | | |
|---------------------------------------|---|
| YES..... | 1 |
| No | 2 |
| OFFERED HELP BUT WOULDN'T ACCEPT..... | 3 |
| I DIDN'T NEED HELP | 4 |
| REFUSED..... | 7 |
| DON'T KNOW..... | 8 |

L. Health insurance coverage

I have just a few more questions and we'll be finished.

The following questions are about health insurance you had before your recent illness.

Which of the following types of health insurance did you have? (Yes or No for each)		YES	NO
IF ANY ARE 'YES', OBTAIN DATE BEGAN IN QUESTION 9	1. Part A Medicare (pays for hospitalization)?	1	2
	2. Part B Medicare (pays for doctors' bills)?	1	2
	3. CHAMPUS/CHAMPVA *?	1	2
	4. Medicaid/other public assistance/welfare-type program?	1	2
	5. Private health insurance/HMO for any part of hospital bills?	1	2
	6. Private health insurance/HMO for any part of doctors/surgeons bills? .. 1	2	
	7. Insurance which pays only for certain illnesses such as stroke or cancer?	1	2
	8. "Extra cash" policies that pay cash only if you go into the hospital?	1	2

*NOTE: CHAMPUS covers both active duty and retired career military personnel, their dependents and survivors;
CHAMPVA covers disabled veterans their dependents and survivors

[IF COVERED BY MEDICARE, MEDICAID, OR CHAMPUS/CHAMPVA, ASK QUESTION 9]

9. If you were covered by Medicare/Medicaid/Champus, when did coverage begin? _____/_____
(MONTH/YEAR)

[IF ALL OF THE ABOVE HEALTH INSURANCE QUESTIONS ARE ANSWERED "NO", ASK QUESTION 10]

10. If you had no health insurance, were you able to receive free health care from a doctor, hospital, clinic or health center?

YES..... 1
NO 2

M. Transportation and family income

1. Before you were diagnosed with cancer, did you own a car?

YES.....	1
NO.....	2

2. How did you usually get to your primary care doctor or clinic?

DROVE MYSELF.....	1
A FRIEND DROVE ME	2
SOMEONE IN MY FAMILY DROVE ME	3
TAXI.....	4
OTHER.....	5
DON'T KNOW.....	8

3. How long did it take you to get to your primary care doctor or clinic?

LESS THAN 15 MINUTES	1
15-30 MINUTES.....	2
30-60 MINUTES.....	3
MORE THAN ONE HOUR BUT LESS THAN 2 HOURS	4
TWO OR MORE HOURS	5
DON'T KNOW.....	8

4. About how many miles away was the clinic or primary care doctor's office? _____

miles

5. Would you please look at this card and tell me which NUMBER represents your family's total income before taxes for the past calendar year, including salaries, wages, social security, welfare, and other income? (*SHOW CARD M*)

INCOME CATEGORY [RANGE: 01-13]	_____
REFUSED.....	97
DON'T KNOW.....	98

6. How many persons were supported by this income during the past calendar year? _____

number

N. Water Use

1. I would like to ask you a series of questions about your use of water in the **year prior to your diagnosis**.

TYPE OF FOOD	NEVER or less than once per month	1-3 per month	1 per week	2-4 per week	5-6 per week	1 per day	2-3 per day	4 per day	5+ per day
A. Hot Beverages Made with Water									
Coffee (including brewed iced coffee)									
Tea (including brewed iced tea)									
Other hot drinks, e.g. hot chocolate, Postum, Bovril									
Soups									
B. Cold Beverages Made with Water									
Orange juice made from frozen concentrate									
Other juices or drinks made from frozen concentrate									
Drinks made from powdered milk or drink crystals, e.g. Kool-Aid, iced tea									
Other drinks mixed with water, e.g. scotch and water									
C. Water									
Tap Water									
Bottled Water									

2. During the **year prior to diagnosis**, when you made hot beverages with water, what was your usual source of water?

Tap Water..... 1
Bottled Water..... 2

3. During the **year prior to diagnosis**, when you made cold beverages with water, what was your usual source of water?

Tap Water..... 1
Bottled Water..... 2

4. You have given us a picture of your tap water use during the year prior to your recent illness. How would you describe your tap water consumption **10 years ago** compared to this?

Less 1
Same 2
More 3

5. You have given us a picture of your bottled water use during the year prior to your recent illness. How would you describe your consumption of bottled water **10 years ago** compared to this?

- Less 1
- Same 2
- More 3

6.During the **year prior to diagnosis**, how often did you take a shower at home?

- Day 1
 - Week 2
- _____ #

7.During the **year prior to diagnosis**, how often did you take a bath at home?

- Day 1
 - Week 2
- _____ #

8.During the **year prior to diagnosis**, how often did you swim indoors during cold months?

- Day 1
 - Week 2
 - Month 3
- _____ #

9.During the **year prior to diagnosis**, how often did you swim indoors during warm months?

- Day 1
 - Week 2
 - Month 3
- _____ #

10.During the **year prior to diagnosis**, how often did you swim in an outdoor pool during the warm months?

- Day 1
 - Week 2
 - Month 3
- _____ #

CLOSING

That completes the interview. You have been very helpful and I truly appreciate your time and cooperation.

Do you have any questions for me?

7. TIME ENDED: ____ : ____

P. Interviewer Evaluation

- | | |
|--|--|
| 1. Where was the interview conducted? | respondent's home..... 1
nursing home..... 2
hospital..... 3
health department..... 4
somewhere else..... 5 |
| 2. Respondent's cooperation was: | very good 1
good..... 2
fair..... 3
poor..... 4
unknown..... 8 |
| 3. The overall quality of this interview is: | high qualityGOTO QUES 5 ← 1
generally reliable..... 2
questionable..... 3
unsatisfactory 4
unknown..... 8 |
| 4. The MAIN reason for unsatisfactory or questionable quality of information was because the respondent: | did not want to be more specific..... 1
did not understand or speak English well..... 2
was bored or uninterested..... 3
was upset, angry, or emotionally unstable 4
had poor hearing or speech..... 5
was confused or distracted by frequent interruptions 6
was physically ill 7
other..... 8 |
| 5. Were third parties present? | spouse 1
other(s) 2
spouse and other(s) 3
no one else present 4 |
| 6. Information provided by: | subject exclusively..... 1
proxy 2
subject and proxy (SPECIFY BELOW) 3
_____ |
| 7. Interviewer initials _____ | |

Comments

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O. Body Size Measurements

Usual Weight	1 year ago	5 years ago	at age 18
What was your usual weight [TIME PERIOD] ago? [WOMEN -- do not include weight during pregnancy]	____ lbs. DON'T KNOW..... .D REFUSEDR	____ lbs. DON'T KNOW..... .D REFUSED..... .R	____ lbs. DON'T KNOWD REFUSEDR

Max/Min since age 18	maximum weight	minimum weight
What was your [maximum/minimum] weight (the [most/least] you ever weighed since you were age 18) and how old were you then? [WOMEN -- do not include weight during pregnancy]	____ lbs. DON'T KNOW..... .D REFUSEDR ____ age at maximum weight	____ lbs. DON'T KNOW..... .D REFUSED..... .R ____ age at minimum weight

Interviewer's Measurements	Respondent's reported measurement (if respondent refuses to be measured)
ENTER MEASURED HEIGHT TO NEAREST QUARTER INCH:	Can you tell me your height? (NEAREST QUARTER INCH)
____ feet ____ inches CAN'T MEASURE.. C CAN'T MEASURE.... .C REFUSEDR REFUSEDR	____ feet ____ inches DON'T KNOWD DON'T KNOW..... .D REFUSEDR REFUSED..... .R
ENTER MEASURED WEIGHT TO NEAREST POUND:	Can you tell me your weight? (NEAREST POUND)
____ lbs CAN'T WEIGHC REFUSEDR	____ lbs DON'T KNOWD REFUSED..... .R

Enter circumference measurements to the nearest millimeter.	Reading #1	Reading #2	Reading #3 (If measurements #1 and #2 differ by more than 10 mm), remeasure
waist circumference →	____ mm CAN'T MEASUREC REFUSED..... .R	____ mm CAN'T MEASURE... .C RSPEFUSEDR	____ mm CAN'T MEASUREC REFUSED..... .R
hip circumference →	____ mm CAN'T MEASUREC REFUSED..... .R	____ mm CAN'T MEASURE... .C REFUSEDR	____ mm CAN'T MEASUREC REFUSED..... .R