

CORE QUESTIONS TO MEASURE COLORECTAL CANCER SCREENING BEHAVIORS

General Comments

Standardization of measures of colorectal cancer screening behaviors (CRCS) is desirable because it will facilitate comparison of results across studies. Our long-term objective is to create a resource of measures with known reliability and validity across multiple settings and populations. Investigators are encouraged to use these questions in their research studies of colorectal cancer screening and to conduct studies to assess the reliability and validity of the questions in different subgroups of the population. For example, in studies of repeat screening when respondents are surveyed periodically, reliability or consistency in reporting dates or time intervals for the respondent's most recent test can be evaluated. Validation studies can be done when data are collected from more than one source, e.g., self-report and medical record. We also encourage researchers to share their findings with the research community by publishing the results in peer-reviewed journals.

Projects with unique needs may have to adapt questions or formats for a particular population or setting, but even then are encouraged to select or develop items that maximize comparability with the questions recommended here. Investigators who translate the questions likewise are encouraged to share their work and to provide a description of the process used to develop a translated version, e.g., back translation.

Questions were developed and refined through an iterative process by a working group sponsored by the Division of Cancer Control and Population Sciences (DCCPS) of the National Cancer Institute (NCI). Most of the questions were based on national surveys such as the National Health Interview Survey (NHIS) Cancer Control Module or on existing survey instruments provided by investigators who were conducting behavioral intervention studies of colorectal cancer screening.

Cognitive testing was done on these questions in 2002 during development of the NCI Health Information Trends Survey (HINTS). Some of these questions are included on HINTS 2002-2003.

Comments on the Survey

In the attached table, we provide information on the wording of the question and response categories, source where applicable, and comments on rationale.

We attempted to create questions that could be used in mail (M), telephone (T), and face-to-face surveys (F). However, in some instances data collection strategies differ for different modalities. For example, in T and F surveys a general strategy is to be brief and to ask a series of questions with skip patterns to get at specifics. This strategy does not work as well in M surveys because skip patterns may confuse respondents. In T or F interviews, it is feasible to use a hierarchical strategy for obtaining responses whereby an interviewer asks for the most precise answer first (e.g., month/year of a screening test) and then moves to less precise response options if a respondent cannot remember (e.g., “a year ago or less; more than 1 year but not more than 2 years, etc.”). This option would be difficult to format and would be space consuming in M surveys.

Descriptions of the colorectal cancer screening tests highlight characteristics that distinguish or differentiate them from each other. Thus, we did not describe every characteristic of each test but described those characteristics that differentiate them and that are likely to be remembered by a respondent.

Investigators may want to include a response option for “refused” in T and F surveys.

We did not include skip patterns.

Name and Affiliation of Work Group Members

Dennis J. Ahnen, M.D.
Denver Department of Veterans Affairs Medical Center and
University of Colorado School of Medicine and
Denver VA Medical Center
Denver, CO

Roshan Bastani, Ph.D.
School of Public Health and
Jonsson Comprehensive Cancer Center
University of California Los Angeles
Los Angeles, CA

Sherri Sheinfeld Gorin, Ph.D.
Joseph L. Mailman School of Public Health
Columbia University
New York, NY

Carrie Klabunde, Ph.D.
Division of Cancer Control and Population Sciences
National Cancer Institute
Bethesda, MD

Margaret T. Mandelson, Ph.D.
Group Health Cooperative Center for Health Studies
Seattle, WA

Helen Meissner, Ph.D.
Division of Cancer Control and Population Sciences
National Cancer Institute
Bethesda, MD

Marion Nadel, Ph.D.
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
Atlanta, GA

Sally W. Vernon, Ph.D., Work Group Chair
University of Texas-Houston School of Public Health and
Center of Health Promotion and Prevention Research
Houston, TX

Jane Zapka, Sc.D.
University of Massachusetts Medical School
Worcester, MA and
Medical University of South Carolina, Charleston, SC

CORE CRCS Questions

| Stool blood test or Fecal Occult Blood Test (FOBT) | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| The following questions are about the stool blood test, also known as a fecal occult blood test, a test to check for colon cancer. It is done at home using a set of 3 cards to determine whether the stool contains blood. You smear a sample of your fecal matter or stool on a card from 3 separate bowel movements and return the cards to be tested. | | |
| Question | Source | Comments |
| <p>Before this test was described, had you ever heard of a fecal occult or stool blood test?</p> <ul style="list-style-type: none"> • Yes • No • Not sure/don't know | Composite | <p>Not asked on the 2000 NHIS. Asked on HINTS.</p> <p>In cognitive testing about half of the 13 participants were more familiar with the phrase “fecal occult blood test” and the other half with “stool blood test”. Thus, we recommend including both in the description of the test and in the first question to orient the respondent.</p> |
| <p>If “yes” to “ever heard”:</p> <p>Have you ever done a stool blood test using a “home” test kit?</p> <ul style="list-style-type: none"> • Yes • No • Not sure/don't know | NHIS modified | <p>Modifications from the NHIS stem:</p> <ul style="list-style-type: none"> • Verb change from “to have” to “to do” because a person performs the test him/herself • “blood stool test” to “stool blood test” to correspond with conventional usage <p>Same response options as the NHIS. Asked on HINTS.</p> |
| <p>If “yes” to “ever had”:</p> <p>How many home stool blood tests have you done in the last 5 years?</p> <ul style="list-style-type: none"> • ____ (number from 1-5) • Not sure/don't know | NHIS modified | <p>NHIS limit is past 3 years. Asking about the past 5 years provides a greater opportunity to establish a pattern of screening. In cognitive testing, respondents had some difficulty with this question, but they seemed able to give an approximation.</p> |
| <p>When did you do your most recent home stool blood test?</p> <ul style="list-style-type: none"> • A year ago or less • More than 1 but not more than 2 years ago • More than 2 but not more than 5 years ago • More than 5 years ago • Not sure/don't know | NHIS modified | <p>We recommend that only persons who report having a FOBT test within the past two years be asked a follow-up question on month/year of the most recent test. Respondents in the cognitive testing had some difficulty remembering the date of this test if they had it more than two years ago.</p> <p>Response format is similar to the NHIS, but we collapsed some of the categories. Asked on HINTS.</p> |

| Question | Source | Comments |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>If you did your most recent test within the past year, what was the month and year? Month_____/Year_____</p> | Composite | <p>NHIS uses a hierarchical strategy to determine “recency”. First, respondents are asked for month/year. If unable to answer, they are asked for “days, weeks, months, years”.</p> <p>In cognitive testing, it was more difficult for respondents to recall month/year for FOBT than for SIG or COL; however, most were able to provide an estimate. In T and F surveys, interviewers could probe with follow-up questions, but this could not be done in M surveys.</p> <p>For intervention studies with prospective measurement, we recommend asking the month/year because it permits more precise estimation of the intervention effect, e.g., time-to-event analysis. Recall may be more accurate because the interval is usually one year or less.</p> |
| <p>Why did you do your most recent home stool blood test?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don’t know | Composite | <p>The purpose of this question is to distinguish between screening and diagnostic tests. Therefore, we did not include response options such as family history of CRC that are on the NHIS.</p> <p>We included “follow-up for an abnormal test”. Although follow-up FOBT is not standard of care for a positive FOBT, it sometimes occurs in practice.</p> |
| <p>Prompt for T and F surveys: “You said that your most recent test was [insert time frame]”</p> <p>When did you do the home stool blood test before your most recent one?</p> <ul style="list-style-type: none"> • None before the most recent • A year ago or less* • More than 1 but not more than 2 years before • More than 2 years before • Not sure/don’t know | Composite | <p>For T and F, it may be helpful to prompt respondents by repeating when they said they had their most recent test. In the prompt, we recommend using the broader response options rather than the month/year.</p> <p>Not asked on the 2000 NHIS.</p> <p>*This category will pertain only to a small number of respondents who may have been asked to repeat a positive FOBT within the same year.</p> |
| <p>Why did you have that home stool blood test?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don’t know | | Not asked on the 2000 NHIS or on HINTS. |

Sigmoidoscopy (SIG) and Colonoscopy (COL)

The following questions are about sigmoidoscopy and colonoscopy, two other tests to check for colon cancer. Both tests examine the colon using a narrow, lighted tube that is inserted in the rectum. Sigmoidoscopy only examines the lower part of the colon while colonoscopy examines the entire colon.

| With the sigmoidoscopy (SIG): | | With the colonoscopy (COL): |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • You are awake. • You are able to drive yourself home. • You are able to resume your normal activities. | | <ul style="list-style-type: none"> • You are given medicine through a needle in your arm to make you sleepy. • You need someone to drive you home. • You may need to take the rest of the day off from your usual activities. |
| Question | Source | Comments |
| See description above. | Composite | <p>We chose to describe these tests together because they are often confused; however, a separate series of questions is asked for each test. Because COL is described last, it may be helpful in T and F surveys to prompt respondents after the description by stating: “Now I am going to ask you about sigmoidoscopy.”</p> <p>We limited the descriptions to characteristics that differentiate the 2 tests. Several gastroenterologists recommended not describing the prep because it may be similar for both tests, and it is changing. We also omitted features that were unlikely to be salient to the respondent, e.g., time it took to do the test, who did the test, how far the tube was inserted.</p> <p>In cognitive testing, respondents were asked to repeat the descriptions of the tests after they were read aloud by the interviewer. All respondents were able to repeat most characteristics of the tests.</p> |
| <p>Before these tests were described, had you ever heard of SIG?</p> <ul style="list-style-type: none"> • Yes • No • Not sure/don’t know | | <p>The NHIS groups SIG, COL, and PROCTO. No description of the tests is provided unless a respondent asks for one or appears unsure what they are.</p> <p>On HINTS, a brief description of each test is read before the question is asked.</p> |
| <p>If “yes” to “ever heard”:</p> <p>Have you ever had a SIG?</p> <ul style="list-style-type: none"> • Yes • No • Not sure/don’t know | | <p>The NHIS groups SIG, COL, and PROCTO. Later in the question sequence, the respondent is asked: “What was this most recent exam called: a SIG, COL, PROCTO, or something else?”</p> <p>On HINTS, SIG and COL are asked about together, but a respondent may answer “yes” or “no” for each test. However, follow-up questions are asked only for the most recent test, i.e., either SIG or COL.</p> |

| Question | Source | Comments |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>If “yes” to “ever had”:</p> <p>How many SIG exams have you had in the last 10 years?</p> <ul style="list-style-type: none"> • 1 • 2 • > 2 • Not sure/don’t know | <p>NHIS modified</p> | |
| <p>Was your most recent SIG:</p> <ul style="list-style-type: none"> • A year ago or less • More than 1 but not more than 5 years ago • More than 5 but not more than 10 years ago • More than 10 years ago • Not sure/don’t know | | |
| <p>What was the month and year of your most recent SIG?</p> <p>Month _____ /Year _____</p> | | <p>Unlike FOBT, we did not limit the time frame to “past two years” for this question because the interval for compliance with guidelines is longer for SIG.</p> <p>In cognitive testing, respondents seemed able to remember the dates for this test.</p> <p>For intervention studies with prospective measurement, we recommend asking the month/year because it permits more precise estimation of the intervention effect, e.g., time-to-event analysis.</p> |
| <p>Why did you have your most recent SIG?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don’t know | | <p>The purpose of this question is to distinguish between screening and diagnostic tests. Therefore, we did not include response options such as family history of CRC that are on the NHIS.</p> |

| Question | Source | Comments |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|------------------------------------------------|
| <p>Prompt for T and F surveys: “You said that your most recent test was [insert time frame]”</p> <p>When did you have the SIG before your most recent one?</p> <ul style="list-style-type: none"> • None before the most recent • More than 1 but not more than 5 years before • More than 5 years before • Not sure/don’t know | | |
| <p>Why did you have that SIG?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don’t know | | <p>Not asked on the 2000 NHIS or on HINTS.</p> |

Colonoscopy (COL)

In T and F surveys, the interviewer may wish to repeat the description of colonoscopy. In M surveys, a respondent can refer back to the description. A lead-in for T and F might be: “Now I will ask you about colonoscopy, a test that uses a long tube and examines the entire colon.”

| With the colonoscopy (COL): | | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • You are given medicine through a needle in your arm to make you sleepy. • You need someone to drive you home. • You may need to take the rest of the day off from your usual activities. | | |
| Question | Source | Comments |
| Before these tests were described, had you ever heard of COL? <ul style="list-style-type: none"> • Yes • No • Not sure/don't know | | The NHIS groups SIG, COL, and PROCTO. No description of the tests is provided unless a respondent asks for one or appears unsure what they are. On HINTS, a brief description of each test is read before the question is asked. |
| If “yes” to “ever heard”: Have you ever had a COL? <ul style="list-style-type: none"> • Yes • No • Not sure/don't know | | The NHIS groups SIG, COL, and PROCTO. Later in the question sequence, the respondent is asked: “What was this most recent exam called: a SIG, COL, PROCTO, or something else?” On HINTS, SIG and COL are asked about together, but a respondent may answer “yes” or “no” for each test. However, follow-up questions are asked only for the most recent test, i.e., either SIG or COL. |
| If “yes” to “ever had”: How many COL exams have you had in the last 10 years? <ul style="list-style-type: none"> • 1 • 2 • > 2 • Not sure/don't know | NHIS modified | |
| Was your most recent COL: <ul style="list-style-type: none"> • A year ago or less • More than 1 but not more than 5 years ago • More than 5 but not more than 10 years ago • More than 10 years ago • Not sure/don't know | | |

| Question | Source | Comments |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>What was the month and year of your most recent COL? Month_____ /Year_____</p> | | <p>Unlike FOBT, we did not limit the time frame to “past two years” for this question because the interval for compliance with guidelines is longer for COL.</p> <p>In cognitive testing, respondents seemed able to remember the dates for this test.</p> <p>For intervention studies with prospective measurement, we recommend asking the month/year because it permits more precise estimation of the intervention effect, e.g., time-to-event analysis.</p> |
| <p>Why did you have your most recent COL?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don’t know | <p>NHIS modified</p> | <p>The purpose of this question is to distinguish between screening and diagnostic tests. Therefore, we did not include response options such as family history of CRC that are on the NHIS.</p> |
| <p>Prompt for T and F surveys: “You said that your most recent test was [insert time frame]”</p> <p>When did you have the COL before your most recent one?</p> <ul style="list-style-type: none"> • None before the most recent • More than 1 but not more than 2 years before • More than 2 years before • Not sure/don’t know | | |
| <p>Why did you have that COL?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don’t know | | <p>Not asked on the 2000 NHIS or on HINTS.</p> |

Barium Enema

Barium enema, or a lower GI series, is another test to check for colon cancer. X-rays are taken of the colon after barium or barium and air are given by enema. The day before the test you are asked to drink a lot of liquids and to take laxatives. No solid food is permitted.

| Question | Source | Comments |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Before this test was described, had you ever heard of barium enema or lower GI series?</p> <ul style="list-style-type: none"> • Yes • No • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |
| <p>If "yes" to "ever heard":</p> <p>Have you ever had a barium enema?</p> <ul style="list-style-type: none"> • Yes • No • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |
| <p>If "yes" to "ever had":</p> <p>How many barium enemas have you had in the last 10 years?</p> <ul style="list-style-type: none"> • 1 • 2 • > 2 • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |
| <p>Was your most recent exam:</p> <ul style="list-style-type: none"> • A year ago or less • More than 1 but not more than 5 years ago • More than 5 but not more than 10 years ago • More than 10 years ago • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |
| <p>What was the month and year of your most recent barium enema? Month _____ /Year _____</p> | | <p>Not asked on the 2000 NHIS or on HINTS.</p> <p>Unlike FOBT, we did not limit the time frame to "past two years" for this question because the interval for compliance with guidelines is longer for barium enema.</p> <p>In cognitive testing, respondents seemed able to remember the dates for this test.</p> |

| Question | Source | Comments |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|-----------------------------------------|
| <p>Why did you have your most recent barium enema?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |
| <p>Prompt for T and F surveys: "You said that your most recent test was [insert time frame]"</p> <p>When did you have the barium enema before your most recent one?</p> <ul style="list-style-type: none"> • None before the most recent • More than 1 but not more than 5 years before • More than 5 years before • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |
| <p>Why did you have that barium enema?</p> <ul style="list-style-type: none"> • Part of a routine exam or check-up • Because of a symptom or health problem • Follow-up of an earlier abnormal test • Not sure/don't know | | Not asked on the 2000 NHIS or on HINTS. |