



Published in final edited form as:

*J Cancer Educ.* 2010 September ; 25(3): 431–436. doi:10.1007/s13187-010-0068-z.

## African American's Self-Report Patterns Using the National Cancer Institute Colorectal Cancer Screening Questionnaire

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### Abstract

Abstract Studies that examine colorectal cancer screening (CRCS) behaviors and correlates rely on self-reports of screening status. Self-reports of CRCS may be more biased than other self-reported cancer screening because of multiple screening options, tests may be offered in combination, and screening schedules differ for each test. The National Cancer Institute (NCI) sponsored the development of a core set of questions to measure self-reported CRCS that are consistent with current guidelines, the NCI Colorectal Cancer Screening questionnaire (NCI CRCS). Several studies support the validity and reliability of this measure; however, none of the existing studies have described African American (AA) responses to items that might be important to clinical decision making and research related to screening adherence. This paper addresses the limited descriptions of AA response patterns to items that comprise the NCI CRCS. The NCI CRCS was administered to 439 AAs 50 to 75 years, participating in the baseline survey of a Center for Excellence in Cancer Communication CRC study. The survey measured self-reported CRCS, factors associated with screening, and response patterns to items that might affect estimates of screening and screening adherence. AA participants reported on CRCS, the test used, and time interval since last screening. Except for queries related to month and year of screening, few participants reported uncertainty in response to items. Two thirds of participants reported receiving CRCS; however, less than half of participants were adherent to guidelines. Less than half reported healthcare provider recommendations to screen. AA participants responded to items on the NCI CRCS as developed. Until new strategies or items are available, interval since last screening appears to be the most appropriate item to estimate AA self-reported CRCS adherence. Strategies are needed to increase physician recommendation to screen.

## Keywords

African American responses; Colorectal cancer screening; National Cancer Institute

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## Introduction

Although there has been progress in reducing the burden of cancer in the U.S [1], disparities persist [1–3]. Disparities are particularly evident in colorectal cancer (CRC), which is the third most common cancer and cause of cancer-related death of African American (AA) in the U.S. [4]. CRC disparity may be partially attributable to differences in AA screening utilization, which has been linked to later stage CRC diagnosis among African Americans [4–6]. Regular screening facilitates earlier detection, lowers mortality [1–3], and may reduce incidence through detection and removal of pre-cancerous polyps [7,8]. Current guidelines recommend that men and women, ages 50 to 75, screen via one of three methods: an annual fecal occult blood test (FOBT), a sigmoidoscopy (Sig), a combination of annual FOBT and Sig every 5 years, or a colonoscopy (Col) every 7 to 10 years [9].

Most studies that examine CRC screening behaviors and correlates rely on self-reported screening status. While self-reported data are likely the most cost effective strategy for obtaining data on population screening behaviors [10] and sometimes the only data available, studies have suggested that these reports are subject to over-reporting bias [11]. Self-reported CRC screening is more complicated than many other self-reported cancer screening behaviors because there are multiple options, the tests may be offered in combination, and the screening intervals required for adherence are different for each [1]. Recent studies have suggested that questionnaire design can reduce reporting bias [11].

Recognizing these issues, the National Cancer Institute (NCI) developed the NCI Colorectal Cancer Screening questionnaire (NCI CRCS), a core set of questions to measure self-reported CRC screening that are consistent with current guidelines [9]. There are now several studies that support the validity and reliability of this measure of self-reported CRC [12–16]. While several studies have specifically reported the number of AAs included in reliability and validation studies [12,14,16], not all studies have analyzed and reported reliability and validity data for AAs. Bastani et al. noted the difficulties in conducting a validation study that included AA participants. Of the 204 AAs in the original follow-up sample, only 17 were in the validation sample. Vernon et al. reported a sample that included 226 AAs randomized to three survey administration conditions. However, data on reliability and validity were not reported by race. Partin et al. reported on the sensitivity, specificity, reports to record ratio, and concordance for 85 AAs included in a validation sample. There were no statistically significant differences for AAs and non-AAs on validity measures using this questionnaire. While these data are important, participant reactions and response patterns are also important. Without a large sample, it is difficult to know whether participants will provide the information necessary to assess adherence to CRC screening. Despite positive findings, none of the studies reporting on administration of the NCI CRCS have described AA responses to individual items that might be important to clinical decision-making and research, as it relates to screening adherence.

This paper addresses the limited descriptions of AA response patterns to items that comprise the NCI CRCS. Data from the baseline survey of a Center for Excellence in Cancer Communication CRC study are used to examine (1) AA self-reported CRC screening, screening method, and factors associated with screening and (2) AA response patterns to items that might affect estimates of screening adherence using items from the NCI CRCS.

## Methods

### Sample

Data for this study were obtained as part of a larger study, the Elimika Project. Study recruitment took place from September 2006 to May 2008. Sample participants were 771 AAs, between the ages of 45 and 75 years, U.S. born, and residents of the St. Louis Standard Metropolitan Statistical Areas (SMSA) identified for recruitment. There were 386 (180 males, 206 females) and 385 (180 males, 205 females) participants in the treatment groups, respectively. Exclusion criteria included previous diagnosis of CRC and difficulty reading and/or comprehending health literature.

### Procedure

The Saint Louis University Institutional Review Board approved this study and the consent procedures used. Participants were recruited from residences on randomly selected census blocks in urban and suburban segments of the St. Louis SMSA. To facilitate this community recruitment strategy, only census tracts that were at least 70% AA were included. Once census blocks were selected, trained recruiters randomized participants to receive one of two types of gender-specific, culturally targeted CRC prevention-related publications. A random numbers table was used to determine which residence would be approached first.

Individuals answering their door received the project description and were queried to determine eligibility. Recruiters documented refusals, ineligibility, and participation. Only one participant per household was permitted. Due to low enrollment of males, the sampling strategy was modified to first ask the person answering the door to identify whether the household included an eligible male and included a group recruitment strategy beginning in July 2007. Group recruitment locations included churches, fraternal organizations, nursing homes, and health fairs. Sites were randomly assigned to one of the two experimental conditions.

All recruited individuals were screened for literacy (an eighth grade reading level was required), and eligibility was confirmed. Individuals who agreed to participate reviewed and signed the consent form, a demographic form and baseline survey. The demographic survey took 5 to 10 min, and the baseline survey took approximately 45 to 60 min. After completion of the baseline survey, the first CRC prevention-related publication was distributed. Participants received a follow-up telephone interview 2 weeks later; a second publication, 8 weeks later; followed by a telephone interview at 2 weeks, with the process repeated a third time. Participants received \$15 gift certificates at the completion of each contact. Only data reported in the baseline survey is analyzed in this paper.

### Measures

Self-reported data included sex, highest level of education completed, income, insurance status, marital status, and employment status, as well as CRC screening history for FOBT, Sig, and Col using the NCI CRCS [10]. Information was also obtained on diet, family history, healthcare contact, CRC knowledge, benefits, barriers, and other sociocultural attitudes, but findings are not reported in this paper.

### Dependent Measures

The self-reported CRC screening items administered on the baseline survey were adapted from the NCI CRCS questionnaire. The survey used in this study omitted NCI CRCS items that queried whether a barium enema was the screening test obtained, items that queried how many times a participant had received a particular screening, and the reason for any screening that was obtained. NCI CRCS items included: whether participants ever had a screening test to see if their colon was healthy and whether participants had ever received a FOBT, Sig, or Col. A

description of each screening test was provided. Response options were “yes”, “no”, or “don't know”. Participants who responded “yes” were asked to select a time range for their most recent test. Response choices for FOBT and Sig were “A year ago or less”, “More than 1 year, but not more than 2 years ago”, “More than 2 years, but not more than 5 years ago”, “More than 5 years ago”, and “Don't know”. Choices for answering “yes” to Col were “A year ago or less”, “More than 1 year, but not more than 5 years ago”, “More than 5 years, but not more than 10 years ago”, “More than 10 years ago”, and “Don't know”. In addition to selecting a time range for their most recent test, participants answering “yes” to a screening test were also asked to report the month and year of their most recent test. Validity and reliability have been established in studies of largely non-ethnic populations [12–16].

### Independent Measures

Measures to assess factors influencing screening behaviors included recommendation for CRC screening, personal history of disease, and demographic characteristics. Recommendation for CRC screening was measured by asking the participants whether they had been advised within the last year by a healthcare provider to have a CRC screening test. Participants were also asked about their personal history of chronic disease, including cancer, diabetes, hypertension, and heart disease.

Demographic variables included sex, insurance status, highest education level completed, employment status, income, and marital status. Participants' insurance status was measured by asking how they paid for healthcare during the past 12 months. Participants were asked to report their age on their last birthday and their highest level of school completed. Response options for education included “some high school or less”, “high school graduate or GED”, “some college”, or “a least college degree”. Employment status was measured as a dichotomous variable (yes/no) in response to a query of current employment status, with the option to specify type of employment. Participants were asked to report an income range for the previous year in categories including <\$20,000, \$20,000 to <\$40,000, and ≥\$40,000. Participants reported their marital status as single, married or living with a partner, divorced or separated, or widowed.

## Results

### Data Analysis

All analyses were conducted on participants who were 50 years of age and older ( $n=439$ ). This decision was based on US Preventive Task Force and American Cancer Society guidelines that recommend screening at 50 years of age and older. Screening for those outside of this age range requires physician advocacy. Descriptive statistics were generated to describe the demographic characteristics of the sample and proportions and  $t$  tests were used to identify differences in demographic reporting by sex. Logistic regression models were used to identify the associations between screening status and insurance status, as well as provider recommendation. Stratified analyses using chi-square tests were conducted to identify the differences in associations by sex.

### Sample Characteristics

The demographic characteristics of the sample by sex are presented in Table 1. The mean age was about 56 years for both men and women. Approximately, half were employed ( $n=97$ ; 48.3% and  $n=114$ ; 49.1%, respectively). Nearly half of the men ( $n=90$ ; 47.9%) reported earning an income of \$40,000 a year or greater, whereas slightly more than one third of women reported earnings in this income bracket ( $n=75$ ; 34.6%). An overwhelming majority reported having insurance, with more women being insured ( $n=206$ ; 89.6%) than men ( $n=157$ ; 80.5%). More than half of the men ( $n=111$ ; 54.7%) reported being currently married or living with a partner

compared to only 28.2% ( $n=66$ ) of the women. Educational attainment was nearly the same for both groups except having attended some college. More women reported having attended some college ( $n=107$ ; 45.9%) than men ( $n=70$ ; 34.8%). Among men and women, more participants reported having a personal history of chronic disease ( $n=138$ ; 71.1% and  $n=175$ ; 74.8%, respectively).

### Responses to National Cancer Institute Colorectal Cancer Screening Questionnaire

Almost two thirds of both men and women reported having screened for CRC using at least one of the screening tests (FOBT, Sig, or Col). Screening rates for FOBT were similar for men and women (38% and 37%, respectively). About 25% reported having had a Sig, making it the least reported test obtained. Col was the most commonly reported test among both men and women (about 49% and 69%, respectively). This was the only test for which there was a significant difference in self-reported screening, with 20% more women reporting having one.

We gained information on the reliability of responding by comparing the percentage of participants who answered yes to the item, “Have you ever had a screening test to see if your colon is healthy” to those who reported receiving screening via one or more of the three modalities described. The majority (84.5%,  $n=366$ ) who indicated that they had screened for a healthy colon also indicated screening via one of three modalities. The remaining participants (8.3%, 6.7%, and .5% respectively) answered no, had missing data, or had a combination of no or not sure responses to each modality.

Overall, 3.8% of the participants were unsure of their CRC screening status. More men were unsure of being screened than women (5.0% and 2.6%, respectively). Only 1.8% of men and 1.1% of women were unsure if they had received a FOBT. Many more respondents were unsure if they had received a Sig as compared to FOBT, with men reporting more uncertainty (11.4% vs. 5.4%). Similarly, more men were unsure of receiving Col (7.2% vs. 0.4%).

An advantage of the NCI CRCS is the ability to obtain data on screening month and year or time interval since last screening to determine adherence. Females were more able than males to specify a time interval since their most recent screening for FOBT (92.6% vs. 80.5%), Sig (81.5% vs. 64.1%), and Col (99.2% vs. 83.0%). Col had the highest recalled screening date (month and year), as well as time interval since last screening, followed by FOBT and Sig, respectively. This trend exists for both male and females. Of those reporting having a specific screening test, more male participants were unsure of the year of their most recent test for all tests; FOBT (47.0% vs. 35.3%), Sig (50.0% vs. 38.3%), and Col (39.2% vs. 17.6%).

Of the participants in this study reporting any CRC screening, only 63.8% provided self-reported data that indicate that they were adherent to guidelines (58.9% men and 67.5% women). Adherence to screening was greatest for Col. Adherence rates for Sig and FOBT were similar. However, participant reports of FOBT can be categorized using strict or liberal criteria. Strict criterion classifies only those who report CRC screening by FOBT in the last year as adherent. A more liberal approach to CRC screening adherence by FOBT takes into account insurance requirements and scheduling concerns and classifies self-reported screening completed “more than 1 year, but not more than 2 years ago” as adherent. As expected, when assessed using the liberal criterion, more participants were categorized as adherent for FOBT.

Insurance status was the only significant predictor of screening status in the two models. Those who were insured were 2.73 [1.65, 4.51] times more likely to have undergone CRC screening. Insured men were more likely to have screened for CRC (3.63 [1.76, 7.51]) than women (2.09 [1.02, 4.30]), but results were not significant. Less than half of AA men and women, 50 years of age and older, reported receiving a healthcare provider's recommendation to screen. Overall, those who received a healthcare provider recommendation to screen for CRC were 1.14 [0.75,

1.73] times more likely to have been screened; however, this association was not significant. When stratified by gender, a healthcare provider recommendation increased the likelihood of men being screened (1.56 [0.78, 3.12]), but was unrelated to screening among women (0.95 [0.56, 1.61]); again, associations were not significant.

## Discussion

The current study examines the responses of a large sample of AAs, 50 years and older, to a self-reported measure designed to produce valid, reliable, and comparable data across studies. Consistent with data indicating the validity of the NCI CRCS for AAs, these data suggest reasonable and consistent responses to items designed to assess self-reported screening behavior. Participants who indicated any screening, ever answered affirmatively to screening via a specific test. Fewer than 5% indicated that they were unsure of their screening status, although certainty varied when specific screening tests were queried. Participants reported the greatest certainty for screening via FOBT and the least certainty for screening via Sig. Variations in response by screening test have been found in reliability and validity studies [12–14,16].

In general, uncertainty was highest for the scope tests. This could be due to several factors or combination of factors, such as requirements for test preparation, invasiveness of the test, and screening frequency. First, memory effects due to the time between Sig and Col screenings may affect screening certainty. However, one might expect greater uncertainty for Col if this explanation were correct due to longer screening intervals. Alternatively, participants may have lacked sufficient knowledge of their procedures to distinguish between Sig and Col, with the description of sedation serving as a strong cue to Col screening [15]. Finally, Col may be more familiar to participants due to media coverage [12].

These data suggest that the best strategy for collecting the information on screening intervals necessary to establish AA CRC screening adherence are through queries of time intervals rather than queries of the month and year of screening. Self-reported month and year of screening were of greater concern, with as many as 50% of male participants unable to provide a month and year of Sig. Patterns were similar for Col. Sex differences in the ability to report screening dates and time intervals may reflect true subgroup differences; however, Partin et al. [16] noted that findings related to a variety of subgroup differences have been inconsistent across studies.

The use of the NCI CRCS permitted an assessment of AA adherence to screening guidelines. Importantly, when adherence is considered, AA self-reported screening rates fall dramatically, with only 42.3% of participants reporting adherence to guidelines. Adherence varied by screening test reported, with the greatest adherence to Col and poorest for Sig and FOBT. Over-reporting of screening behavior has been noted in previous studies [13,16] and may result in even lower adherence rates.

Consistent with previous studies, insurance status was related to CRC screening [17], while physician recommendation to screen, previously noted as an important factor in CRCS [17], was not significantly associated with participant's screening behavior in this study. Of greater concern, although over 80% of the sample was covered by insurance, less than 50% of AA participants reported receiving a recommendation to screen. Our data do not provide information on this deficit in provider recommendation, but physician reminder systems and incentives could be powerful interventions to increase screening and adherence, perhaps in conjunction with studies of efforts to assist in the establishment of healthcare homes.

## Limitations

The limitations of this study are related to both the sample and the measure. While larger and more diverse, this sample is not representative of AAs in the region or the nation. In addition, it is difficult to know all of the ways that the changes in the sampling strategy may have affected the final sample. However, the samples' size and participants' diverse education and income address a gap in the current literature. This study provides data on AAs response to a reliable and validated measure that suggests the appropriateness of its use. The measure, itself, may create response uncertainty because the measure does not describe newer chemical stool tests, such as the FIT, or virtual colonoscopy. In addition, due to the length of the assessment, the description of the double contrast barium enema and items assessing knowledge of CRC screening guidelines were omitted. Thus, the impact of screening knowledge is unknown, and participants who did not report receiving a specific CRC screening test may have been unable to do so because items and descriptions related to the screening test that they received were not provided. However, current US Preventive Services Task Force recommendations do not recommend the tests that were omitted [9]. This study also omitted the NCI CRCS item that asked participants to indicate the reason for physician CRCS referral. While the number of AAs who reported a physician recommendation to obtain screening was small, some proportion of these recommendations is likely to have been diagnostic rather than screening referrals.

## Implications and Directions for Future Research

While there might be some increased utility to including descriptions and items for additional CRC screening tests, current data suggest that AA participants respond well to items on the NCI CRCS as developed. Responses provide important data on screening and adherence that can be monitored to assist in efforts to address disparities in CRC incidence and mortality. Future studies should test the relative effectiveness of reminder systems and incentives in increasing healthcare provider recommendations for CRC screening among AAs as a strategy to reduce health disparities. In addition, lingering participant confusion about CRC screening tests suggests the need to improve patient education efforts. An educated, health-literate client can ask a physician whether they are eligible or should be screened, while those who lack knowledge cannot.

## Acknowledgments

**Supported by** National Cancer Institute: Centers of Excellence in Cancer Communication Research (CECCR) (CA-P50-95815) Community Networks Program for the Elimination of Cancer Disparities (PECaD) (5-U01-CA114594).

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Table 1

Demographic characteristics of participants by sex ( $n=439$ )

Characteristic	Sex		<i>p</i> value		
	Male ( $n=204$ )			Female ( $n=235$ )	
	Number	Percent		Number	Percent
Age <sup>b</sup>		55.8	56	0.000	
Currently employed					
No	104	51.7	118	50.9	0.466
Yes	97	48.3	114	49.1	
Income					
<\$20,000	60	31.9	74	31.4	0.000
\$20,000–<\$40,000	38	20.2	68	31.3	
≥\$40,000	90	47.9	75	34.6	
Insurance coverage					
No	38	19.5	24	10.4	0.006
Yes	157	80.5	206	89.6	
Marital status					
Single	47	23.2	56	3.9	0.000
Married or living with a partner	111	54.7	66	28.2	
Divorced or separated	33	16.3	80	34.2	
Widowed	12	5.9	32	13.7	
Educational level					
Some high school or less	24	11.9	17	7.3	0.075
High school graduate or GED	51	25.4	48	20.6	
Some college	70	34.8	107	45.9	
At least college degree	56	27.9	61	26.2	
Personal history of chronic disease <sup>a</sup>					
No	56	28.9	59	25.2	0.230
Yes	138	71.1	175	74.8	

<sup>a</sup>Hypertension, diabetes, heart disease, or cancer<sup>b</sup>Mean values reported