ORIGINAL ARTICLE

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# Colorectal Cancer Screening in Massachusetts: Measuring Compliance with Current Guidelines

CONTEXT. Professional organizations have published guidelines for colorectal cancer screening. Defining which patients are currently, or should be, screened is an important clinical and public health issue.

OBJECTIVE. To document the prevalence of colorectal cancer screening and profile the tests patients have had.

DESIGN/POPULATION. A random-digit telephone survey of Massachusetts adults, 50 years of age and older.

OUTCOME MEASURES. Percentage of persons ever and currently tested by fecal occult blood tests, flexible sigmoidoscopy, barium enema, colonoscopy, or some combination of these tests.

RESULTS. Sixty-five percent of those contacted agreed to the telephone interview. Approximately 29% of the 1119 respondents had never had any currently accepted test, including 10% who reported having only a fecal occult blood test done in a provider's office and 19% who reported having no tests. At least 51% were currently tested by one or more tests for screening, diagnosis, or both. Another 10% were possibly current by colonoscopy or barium enema, both of which can be ordered for screening but are more commonly used to evaluate a problem, such as rectal bleeding, or for surveillance after identification of a polyp or other abnormality. An additional 11% had been tested at some point but were not current according to guidelines.

CONCLUSIONS. Accurate assessment of rates of colorectal cancer screening is complex because of the multiple acceptable screening methods, the fact that patients may be tested for screening or diagnostic purposes, and the lack of adequate systems for tracking such testing. For accurate measurement, all methods must be assessed regardless of whether tests were ordered for screening, diagnosis, or surveillance.

Colorectal cancer is the second leading cause of cancer death in the United States; more than 134,000 new cases and over 56,000 deaths occur annually.[1] For many years, the Guide to Clinical Preventive Services[2] recommended testing for all persons at least 50 years of age with annual fecal occult blood testing, sigmoidoscopy (periodicity unspecified), or both. A more recent guideline has been published and widely disseminated with the endorsement of the American Gastroenterological Association and the Agency for Healthcare Research and Quality.[3] The five currently recognized options for colorectal cancer screening are presented in Table 1.

Although screening for colorectal cancer reduces mortality,[4–6] it is underutilized. Compliance rates in eligible populations are approximately 20% for fecal occult blood tests in the past year and 30% for flexible sigmoidoscopy in the past 5 years.[7, 8] Medicare and most managed care payers now cover colorectal cancer screening.[9]

*Edited by John D. Birkmeyer, MD*

See related editorial on pages 39-41.

*This paper is available at ecp.acponline.org.*

TABLE 1

Recommendations for Colorectal Cancer Screening among Asymptomatic People ≥50 Years of Age*

| |
|---|
| **Fecal occult blood testing annually *or*** |
| **Flexible sigmoidoscopy every 5 years *or*** |
| **Fecal occult blood testing annually and flexible sigmoidoscopy every 5 years *or*** |
| **Colonoscopy every 10 years *or*** |
| **Barium enema every 5 to 10 years** |

**Established by the Expert Panel of the Agency for Healthcare Research and Quality and adopted and published by the American Gastroenterological Association, 1997.* [3]

Several factors may contribute to low screening rates. These include 1) lack of physician knowledge regarding guidelines, 2) lack of physician acceptance of guidelines, 3) many guidelines with inconsistent recommendations, 4) multiple options for screening, and 5) lack of patient understanding of colorectal cancer and options for screening. The availability of several acceptable screening options for colorectal cancer makes screening more difficult for clinicians (who must understand the performance characteristics of each test and explain them to patients) and complicates measurements by which patients are currently screened. This is particularly relevant because managed care organizations and the National Committee on Quality Assurance are developing measures to assess compliance with colorectal cancer screening.[10]

Although many studies have examined physician and plan performance for other preventive services, notably mammography and immunization,[11] far less is understood about population prevalence or performance measures related to colorectal cancer screening. This study investigates the screening status of a random sample of adults according to the Preventive Services Guidelines as well as the American Gastroenterological Association Guidelines and documents the proportion of adults that is considered "currently screened" by diagnostic tests. We also explore the relationship of selected personal characteristics to screening status and explore reasons that patients are screened or not screened.

## Methods

### Patient Population and Survey Methods

A random-digit telephone survey, using the Kish method,[12] was conducted in spring and summer 1998 in Massachusetts. In addition, a minority oversample of black and Hispanic residents and a male oversample were drawn from a sample pool generated from the five largest urban areas. Each sampled number was called up to 10 times to determine whether it was a residential number. Once this was determined, households were screened to identify eligible respondents. Eligible participants were Massachusetts residents who had a working home telephone number, were at least 50 years of age, were cognitively able, and had no personal history of colorectal cancer. To calculate a response rate, we had to assume the eligibility rate among nonrespondents on the basis of the 19% eligibility rate among respondents. The final sample of 1119 respondents therefore reflects a consent rate of 63% for all residences that were eligible or assumed to be eligible (Figure 1).

### Study Variables and Analysis

To measure screening prevalence, we used a series of self-reported items that asked participants whether they had ever had a fecal occult blood test, sigmoidoscopy, colonoscopy, or barium enema. Participants were also asked about the timing of their most recent sigmoidoscopy and fecal occult blood test, as well as whether the fecal occult blood test was done at home or in a physician's office.

To create a summary variable, "current colorectal cancer testing," we considered a participant currently tested if the fecal occult blood test was done at home within the past year, if sigmoidoscopy was performed within the past 5 years, if colonoscopy or barium enema was done within the past 10 years, or if some combination of these tests was performed within the recommended interval. Participants who were tested outside of these guidelines, who reported only having a test for stool occult blood in a physician's office, or who reported never having been tested were considered "not currently tested." A single stool sample for occult blood obtained in the office is not a currently acceptable practice (Table 1).

To code whether testing was done for screening or diagnostic purposes, we used open-ended questions about the reasons for having each test. We considered "current" sigmoidoscopies, colonoscopies, or barium enemas to be diagnostic if the participant reported having symptoms. Persons were considered to be "current" with screening if the tests were performed for other reasons, including age, family history of colorectal cancer or polyps, personal history of polyps, history of another type of cancer, fear of cancer, peace of mind, doctor recommendation, as part of preparation for surgery, or as a follow-up to a previous test that was classified as current. Participants who were not "current" were asked to explain why they had not been tested.

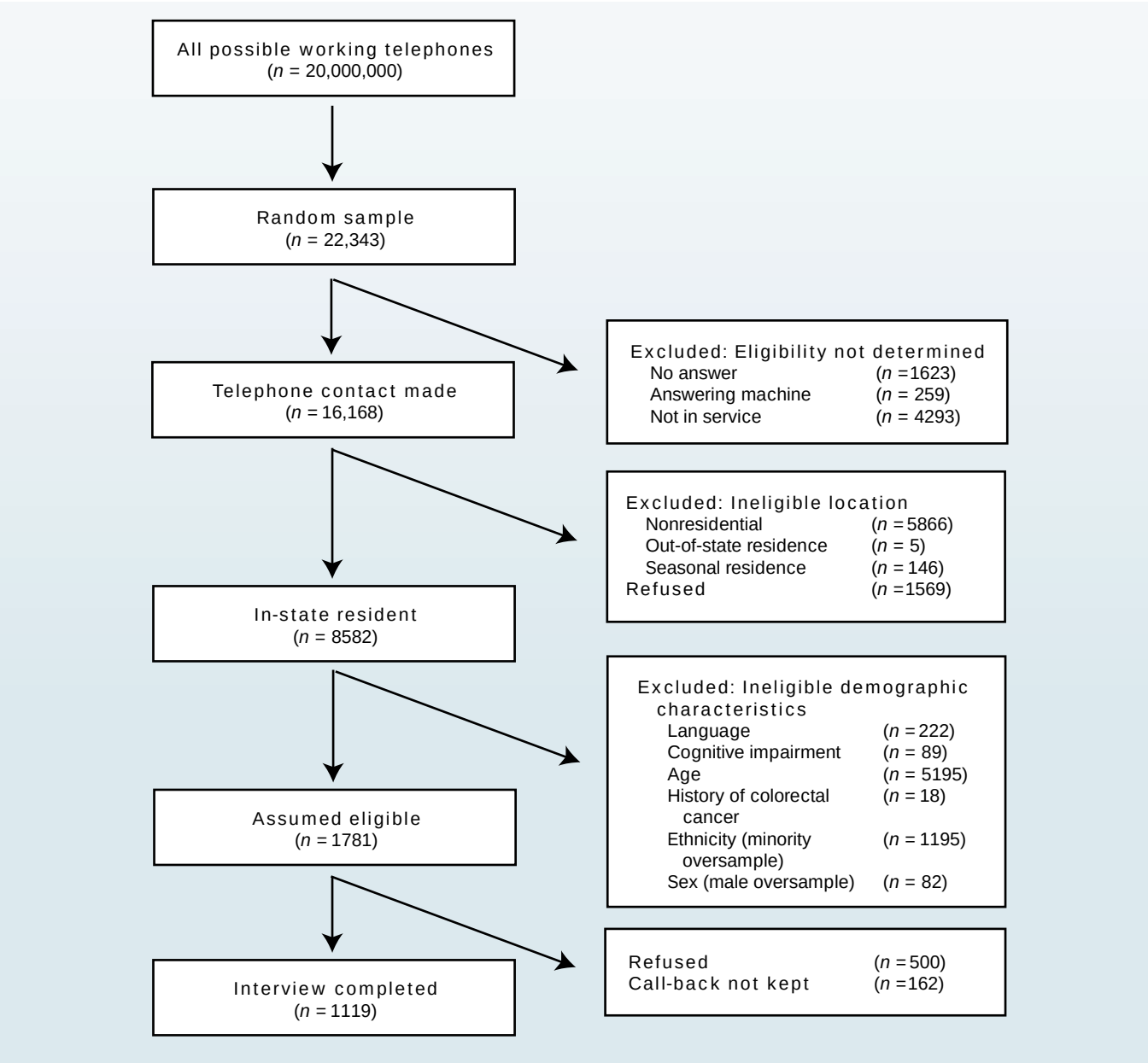


**FIGURE 1. Sample selection for telephone survey.**

In addition to survey items about screening, information was obtained on availability of insurance coverage. Categories were HMO, non-HMO, Medicare HMO, Medicare non-HMO, Medicaid or other insurance, and no insurance coverage. Additional measures included age, sex, ethnicity, education, employment, income, marital status, and family history of colorectal cancer.

### Statistical Analysis

Analyses included frequency distributions and cross-tabulations with chi-square testing. We used SUDAAN statistical software (Research Triangle Institute, Research Triangle Park, North Carolina) for weighted survey data.[13] All reported findings were weighted to the Massachusetts population values by education, sex, and ethnicity.

## Results

The characteristics of the survey sample are presented in Table 2. The sample was predominantly white, and a majority (61%) were not employed. More than 96% of respondents had some kind of medical insurance or entitlement.

TABLE 2

Characteristics of the Survey Sample ($n$ = 1119)

| VARIABLE | PROPORTION OF THE SAMPLE | PROPORTION CURRENTLY SCREENED |
|---|---|---|
| **All respondents** | **100%** | **51%** |
| **Age** | | |
| **50 to 64 yr** | **51%** | **48%** |
| **65 to 74 yr** | **29%** | **55%** |
| **≥75 yr** | **20%** | **54%** |
| **Sex** | | |
| **Male** | **43%** | **49%** |
| **Female** | **57%** | **52%** |
| **Employment** | | |
| **Not employed** | **61%** | **52%** |
| **<37 hr/wk** | **11%** | **59%** |
| **≥37 hr/wk** | **28%** | **45%** |
| **Education** | | |
| **Not a high school graduate** | **33%** | **52%** |
| **High school graduate** | **34%** | **48%** |
| **Post high school** | **17%** | **52%** |
| **≥ College graduate** | **16%** | **55%** |
| **Income** | | |
| **≤$10,000** | **13%** | **47%** |
| **$10,001–$25,000** | **25%** | **52%** |
| **$25,001–$50,000** | **23%** | **47%** |
| **>$50,000** | **25%** | **54%** |
| **Declined to answer** | **14%** | **55%** |
| **Ethnicity** | | |
| **White (non-Hispanic)** | **91%** | **51%** |
| **Black (non-Hispanic)** | **3%** | **65%** |
| **Hispanic** | **5%** | **47%** |
| **Other** | **1%** | **63%** |
| **Marital status** | | |
| **Married** | **54%** | **51%** |
| **Widowed** | **24%** | **51%** |
| **Divorced** | **13%** | **52%** |
| **Other** | **10%** | **50%** |
| **Family history of colorectal cancer** | | |
| **Yes** | **11%** | **62%** |
| **No** | **89%** | **49%** |
| **Insurance** | | |
| **Private, non-HMO** | **12%** | **48%** |
| **Private, HMO** | **29%** | **48%** |
| **Medicare, non-HMO** | **26%** | **51%** |
| **Medicare, HMO** | **20%** | **63%** |
| **Medicaid/other** | **9%** | **47%** |
| **Uninsured** | **4%** | **31%** |

## Screening Status

We first examined respondents' experience with all screening tests. Fifty-three percent reported that they had performed a fecal occult blood test at home. Thirty-six percent reported having had a sigmoidoscopy, 20% a colonoscopy, and 31% a barium enema. In addition, approximately 10% reported having a stool blood test in

a physician's office only and 19% reported never having any of the tests. Thus, 29% of respondents had never had any accepted test for colorectal cancer.

We also determined the number of patients who had ever had combinations of tests, and when data were available, we considered how recently the last screening was performed. Figure 2 describes the distribution of the colorectal cancer tests and the proportion of participants considered currently tested, according to guidelines. Approximately 51% of respondents were currently tested (i.e., had had ≥1 test for screening, diagnostic reasons, or both). Twenty-one percent had had at least one test but were not current, including the 10% who reported having only a fecal occult blood test in a physician's office. The survey did not ask patients to report the date of a colonoscopy or barium enema. We conservatively categorized patients who reported having these tests as "possibly current" because colonoscopy and barium enema have a long duration of effectiveness. Some persons reported "current" sigmoidoscopy and fecal occult blood tests and reported that colonoscopy or barium enema was done as follow-up to those tests. These persons were classified as current.

### Factors Related to Screening

We explored the relationship among the characteristics of the study population (Table 2) and testing status. We alternatively defined screened as "currently screened"

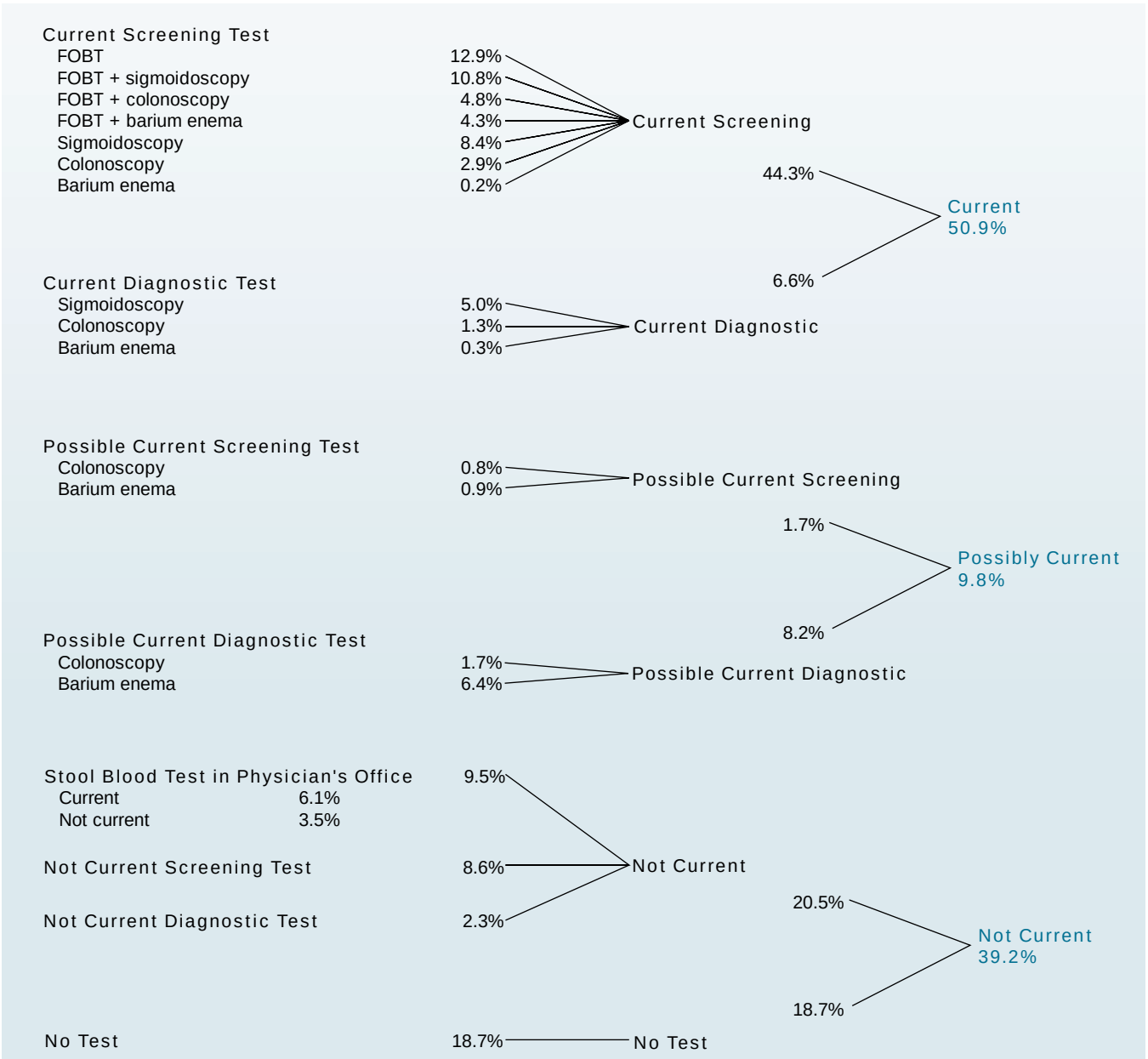


**FIGURE 2. Respondent screening or testing status (*n* = 1119).** FOBT = fecal occult blood test.

with and without the "possibly current" group. Sex, education, income, and marital status were not significantly associated with adherence to colorectal cancer screening regardless of the classification of the "possibly current" respondents. People who worked full time (>37 h/wk) were marginally less likely to be "currently screened" when "possibly current" persons were excluded (45% compared with 59% who worked < 37 hours per week and 52% who were not employed; $P = 0.06$). Ethnicity was of borderline significance when "possibly current" persons were included ($P = 0.06$). Age was significantly related when the "possibly current" persons were included (data not shown); 68% of those 65 to 74 years of age were "current" compared with 56% of those 50 to 64 years of age and 63% of those who were at least 75 years of age. No statistically significant association was found between age and screening status if "possibly current" persons were excluded. Insurance type was of only borderline significance when "possibly current" people were excluded ($P = 0.09$). Only 31% of uninsured persons were screened, while 63% of Medicare HMO members were "current." When "possibly current" people were included ($P = 0.03$), screening was less common among uninsured persons (36.8%) and was more common among HMO Medicare members (71.8%) than among elderly Medicare non-HMO members (63.8%).

Of all the personal variables, family history of colorectal cancer was the most consistently related to screening in several analyses (Table 3). Those with a family history were more likely to be currently tested than those without (62% vs. 49%; $P = 0.03$) and were much more likely to have ever had a colonoscopy (36% vs. 18%; $P = 0.002$) and a barium enema (43% vs. 29%; $P = 0.02$).

## Discussion

Our findings show that more attention must be paid to evaluation of colorectal cancer screening and to improvement of screening compliance. In this random sample of adults in Massachusetts, 28% had never had any of the recommended screening tests for colorectal cancer. Forty-six percent had a current fecal occult blood test, sigmoidoscopy, or both and were therefore current according to the Preventive Services Guidelines. According to a nationwide survey performed by the Centers for Disease Control and Prevention (CDC) in 1997,[7] 41% reported having either a fecal occult blood test or sigmoidoscopy and 10% reported having both within the recommended interval. We found that 35% of participants had received either a fecal occult blood test or flexible sigmoidoscopy and that 11% had received both tests. However, in the 1997 CDC report, 20% reported having a fecal occult blood test in the previous year and 30% reported having a flexible sigmoidoscopy in the preceding 5 years, compared with 33% and 24%, respectively, in our study. This may reflect an increased emphasis on fecal occult blood testing in the past few years.

We asked whether participants had ever had a colonoscopy or a barium enema, and 20% and 30%, respectively, reported that they had. As the prevalence of fecal occult blood testing and sigmoidoscopy screening increases, so will the prevalence of colonoscopy, which is the most frequently ordered follow-up test performed after an abnormal result on sigmoidoscopy or fecal occult blood tests. In future studies of screening prevalence, it will be important to document the dates of all tests to estimate the prevalence of "current testing." This is par-

TABLE 3
Relation between Colorectal Cancer Screening and Family History of Colorectal Cancer

| VARIABLE | TOTAL ($n$=1115)* | FAMILY HISTORY ($n$=125) | NO FAMILY HISTORY ($n$=990) | $P$ VALUE† |
|---|---|---|---|---|
| **Ever had a sigmoidoscopy** | **36%** | **40%** | **35%** | **>0.2** |
| **Ever had a colonoscopy** | **20%** | **36%** | **18%** | **0.002** |
| **Ever had a barium enema** | **31%** | **43%** | **29%** | **0.02** |
| **Ever had a fecal occult blood test** | **53%** | **59%** | **52%** | **>0.2** |
| **Currently tested** | **51%** | **62%** | **49%** | **0.03** |
| **Currently and possibly currently tested** | **61%** | **74%** | **59%** | **0.004** |

**Four responses were missing data for family history.*
*†For comparison of persons with and without a family history of colorectal cancer.*

ticularly true for persons with a family history, for whom screening and surveillance behavior is likely to differ.[14]

Our results clearly reinforce the important role of family history in colorectal cancer screening. Such history may increase the frequency and strength of clinicians' colorectal cancer screening recommendations and improve patient adherence. Physician recommendations for colorectal cancer screening tests may be extremely important in the diffusion of colorectal cancer screening among all adults older than 50 years of age because 75% of cases occur in people without a family history.[15]

A substantial proportion of the population (19%) has never been screened for colorectal cancer, and 10% are screened by only a stool blood test performed in a clinician's office. While recent information suggests that testing stool for occult blood at the time of the digital rectal examination does not increase the number of false-positive results or the cost per case of cancer detected,[16] the sensitivity of fecal occult blood testing increases with the number of samples per stool and the number of stools sampled.[3] Thus, if screening prevalence indicators are constructed with patient survey data, it would be useful to know the proportion that had "never been screened" or had received only a stool blood test in the office.

Appropriate documentation of screening status is further complicated because although guidelines are available for follow-up of patients in whom colonic adenomas are detected and removed, many clinicians do not accept them.[3, 17] In particular, a great deal of controversy surrounds the follow-up of patients with small tubular adenomas.[18, 19] Most patients lack knowledge about the type of polyps found (e.g., adenomas vs. hyperplastic, size and pathology of polyps). Given this, and limitations in accurate recall of dates of testing (particularly over extended periods), effective recommendations will require more questioning and documentation by primary care providers responsible for their patients' clinical preventive services. Clearly, screening tests and follow-up must be tailored to individual patients.[20] Factors to consider include not only previous tests and findings but also a family history of cancer and adenomas (including age of onset in first-degree relatives) and comorbid medical conditions. This decision making requires thoughtful history taking, good documentation, clear and participatory patient education, and a system of surveillance. This situation underscores the need for thoughtful design of data management systems that document and cue physicians about screening and surveillance needs.

Our study was limited by its modest response rate (65%). It is conceivable that persons who were willing to take such a survey on "health screening" were more likely to be connected with the health care system and to have been screened for colorectal cancer. In addition, our findings are from one state and may not be generalizable to other states or geographic regions. Surveys also reflect some degree of questionable validity because of errors in self-report; in our study, errors in recall of the time period in which a test was performed were also possible.[21, 22] However, some studies have found that patient reports are reasonably accurate. This is particularly relevant in view of the lack of complete data in medical records because tests are likely to be given by many different providers over extended periods. We observed some confusion in the type of test that the person had experienced (sigmoidoscopy vs. colonoscopy). Respondents (and patients) need to be provided with descriptions of tests to aid recall. In addition, social desirability bias regarding accurately reporting of adherence to fecal occult blood testing may have been present. Another limitation of self-report data is the questionable validity of the patient's report of the reason a test was done. For example, a sigmoidoscopy could have been done because the physician recommended it to evaluate a change in bowel habits. The respondent could have reported the reason as "my doctor recommended it," "done as a follow-up to another test," or both. This distinction, however, may be of limited importance in defining currently "tested" status.

Even with these limitations, our data have implications for designing performance measures for colorectal cancer screening. Careful thought about performance measures is important because their influence on physician behavior and patient choice is increasing (the performance measures in the Health Plan Employer Data and Information Set are one example).[10, 23] Issues to consider for colorectal cancer screening include the relatively long recommended interval for endoscopic screening tests (5 years for sigmoidoscopy and 10 years for colonoscopy).[3] As noted earlier, people can change providers and health plans and see specialists or several providers. For these reasons, the use of medical records to determine performance rates may be problematic and may cause dependence on patient report.

Our study has important implications for the design of electronic medical records and quality management systems used by individual practices, integrated delivery systems, and managed care organizations. Multiple options are available for colorectal cancer screening, some with screening intervals of up to 10 years. These factors must be incorporated into tracking systems for preventive care. Consider, for instance, a 60-year-old woman who is hospitalized for evaluation of abdominal pain and has a colonoscopy that does not detect any significant mucosal lesions. This patient is then effectively "up to date" for colorectal cancer screening for the next 10 years, and her primary care provider might choose not to recommend a fecal occult blood test or flexible sigmoidoscopy. In an ideal world, the reminder system of the office-based elec-

tronic medical record would receive a message about this colonoscopy and its results that might allow the clinician to "deactivate" further reminders about colorectal cancer screening for the next 10 years.

In conclusion, measurement of adherence to colorectal cancer screening guidelines is a moderately complex task. It will become increasingly important for medical practices to devote more thought and effort to the development of guidelines, methods to measure compliance, and reminder systems for colorectal cancer screening.

## Take-Home Points

- **Because there are several acceptable strategies for colorectal cancer screening, assessing adherence to guidelines is complex.**
- **We surveyed a random sample of Massachusetts residents at least 50 years of age and assessed the prevalence of colorectal cancer screening by fecal occult blood testing, flexible sigmoidoscopy, colonoscopy, and barium enema.**
- **Overall, 51% and 10% of survey respondents were current or possibly current, respectively, with colorectal cancer screening guidelines.**
- **Family history of colorectal cancer was an important determinant of screening participation.**
- **Patients may be up to date for colorectal cancer screening even if their last test was done for diagnostic rather than screening purposes.**


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